

A MIXED METHOD STUDY OF CONTINUING BONDS: MAINTAINING CONNECTIONS

AFTER THE DEATH OF A CHILD

By

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Dedicated to my sister, Anissa,  
all other children who have lived with life-threatening illnesses  
and  
to all families who have experienced the loss of a child

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## CHAPTER I

### INTRODUCTION

Few experiences in a family's life have as profound an effect as the death of a child. The death of a child symbolizes the loss of a future for families (Davies et al., 2004). A child's death is unexpected in today's society, and families typically never "get over" the loss but try to cope by integrating the loss into their lives. Families engage in different coping strategies that result in new competencies and personal growth, or grief distress that can recur and persist for years after the child's death (Gerhardt, 2003). Miles and Crandall (1983) found that bereaved parents suggest positive outcomes following the death of their child including having stronger faith, being more compassionate and caring, and living life more fully; however, bereaved parents are at higher risk for negative consequences such as marital disruptions (Oliver, 1999), mental illnesses (Li, Laursen, Precht, Olsen, & Mortensen, 2005), and mortality (Li, Precht, Mortensen, & Olsen, 2003), including parental suicide attempts after the expected death of a child (Davies, 2006). Negative consequences for bereaved siblings include feeling guilty, depressed, lonely, frightened, angry, and avoidant, and some experience psychosomatic disorders or behavior problems (Davies, 2006; Kramer, 1984; Rosen, 1985; Silverman, Baker, Cait, & Boerner, 2003). On the other hand, Kramer (1984) found that siblings living with a leukemic child experienced increased sensitivity and empathy, enhanced personal maturation, and greater family cohesion. Similarly, Hogan and DeSantis (1994) report that bereaved adolescents perceive their family being closer together as a result of the stress of coping with their sibling's death. It is known that the death of a child has a profound impact on parents' and siblings' lives, but it is uncertain if



and how continuing bonds relate to coping strategies and grief symptoms in families who have experienced the loss of a child.

Emerging programs to support families faced with life-threatening conditions focus on palliative care. The concept of pediatric palliative care evolved from the hospice philosophy to meet gaps in care for seriously ill and dying patients (Himmelstein, Hilden, Boldt, & Weissman, 2004). Palliative care for infants, children, and adolescents strives to enhance the dignity of a child's life and to support the family's needs with empathy and culturally sensitive care (Strong, Feudtner, Carter, & Rushton, 2004). A team approach minimizes physical, psychological, and social distress while improving the quality of life for dying children and their families (World Health Organization [WHO], 1998). The Children's Project on Palliative/Hospice Services (ChiPPS) (2003) describes pediatric palliative care as a philosophy and program to deliver care to children with life-threatening conditions and their families. This care affirms life by assisting children and families in fulfilling their physical, psychological, social, and spiritual goals.

### **Purpose of the Study and Research Questions**

Little is known about how to help siblings and parents cope with the death of a child, and even less is known about how to help a child living with a life-threatening illness. Continuing bonds is a current phenomenon that needs to be studied to determine its relationship to coping strategies and grief symptoms in families of children with life-threatening illnesses. The overall purpose of the study is to explore continuing bonds in children living with advanced cancer, as well as continuing bonds in bereaved families who have lost a child to cancer. Secondary purposes of this study include examining associations among continuing bonds, coping strategies, and grief symptoms in bereaved parents and siblings who experienced the death of a

child from cancer. Research questions are 1) Based on bereaved parents' and siblings' perspectives, do children with cancer do or say things before they die to be remembered? 2) Do bereaved parents and siblings continue bonds with children who have died of cancer? 3) What is the relationship between continuing bonds and coping strategies? 4) What is the relationship between continuing bonds and grief symptoms?

### **Significance of Continuing Bonds**

The phenomenon of continuing bonds specifically related to pediatric palliative care is significant to society in general, healthcare, and the discipline, science, and practice of nursing. In the United States, over 53,000 children die and 500,000 cope with life-threatening conditions each year (Himmelstein et al., 2004; National Center for Health Statistics, 2003). According to the Centers for Disease Control and Prevention (2007), a total of 2,223 childhood cancer deaths occurred in the United States in 2004. Much research has been dedicated to studying quality of life and survivorship. However, the relationships among continuing bonds, coping strategies, and grief symptoms are understudied even though reports have shown that the death of a child is especially stressful, sometimes even causing significant negative consequences to the bereaved such as increased parent mortality, suicide, and myocardial infarction (Davies, 2006; Li et al., 2003; Li, Hansen, Mortensen, & Olsen, 2002). With improvements in child healthcare delivery leading to decreased mortality rates over the past few decades (Carter & Levetown, 2004), pediatric palliative care as a holistic approach is required for chronically ill children over longer periods of time. Trends suggest that children living with life-threatening conditions and their families are a significant and growing population and a compelling focus of study. Therefore, a comprehensive understanding of how to help these families is significant to society. Research is

needed to determine the relationships among continuing bonds, coping strategies, and grief symptoms for families of children with life-threatening illnesses.

Understanding continuing bonds related to pediatric palliative care is also significant to healthcare. Children's end-of-life care is a poorly understood phenomenon with only a limited number of studies focusing on continuing bonds and the needs of a child living with a life-threatening illness and his or her family (Himmelstein et al., 2004). The American Academy of Pediatrics (AAP) (2000) recommends increased research support to understand the healthcare needs of dying children. In 2003, ChiPPS identified the urgent need to complete research in this area as continued pediatric palliative practice based on adult data is inadequate to fully describe circumstances surrounding care of children with life-threatening conditions and their families. Despite increasing recognition of the needs of these children, continuing bond research remains in its infancy. Healthcare providers need a better understanding of continuing bonds to discern if children living with life-threatening illnesses can benefit from doing or saying things so that they will be remembered. Also, providers need to increase their knowledge about if and how parents and siblings maintain connections with the deceased and subsequent impact on coping strategies and grief symptoms. More research related to continuing bonds will allow healthcare providers to know if and how to provide continuing bond opportunities for children living with life-threatening illnesses and their families. Moreover, the study of continuing bonds is significant to healthcare to provide optimal care for this vulnerable population.

The National Institute of Nursing Research (NINR) has recognized the significance of continuing bonds to the nursing discipline, nursing science, and nursing practice. The NINR (2004) promotes research themes of the future, which include the primary theme to enhance the end-of-life experience for patients and their families. Henderson (1961) defines nursing as

assisting individuals in activities that contribute to health, its recovery, or to a peaceful death.

The American Nurses Association's (ANA) (2003) definition states, "Nursing is the protection, promotion, and optimization of health and abilities, prevention of illness and injury, alleviation of suffering through the diagnosis and treatment of human response, and advocacy in the care of individuals, families, communities, and populations" (p. 6). Continuing bonds research will provide the nursing discipline a better understanding of how to help children and families dealing with life-threatening illnesses. The practice of nursing will benefit from increased understanding of the body of knowledge related to continuing bonds. Exploration of this phenomenon is significant to nursing to improve care and enhance the life experience for these children and their families.

## CHAPTER II

### LITERATURE REVIEW AND THEORETICAL FRAMEWORK

To discuss literature and theory related to continuing bonds, key terms (pediatric palliative care, continuing bonds, coping strategies, and grief symptoms) will be defined. Theories related to continuing bonds will then be addressed, followed by a critical analysis of relevant methodological literature. Finally, research questions and hypotheses will be presented.

#### **Definition of Terms**

##### *Pediatric Palliative Care*

The concept of palliative care originally evolved from the hospice philosophy to meet gaps in care for seriously ill and dying patients (Himmelstein et al., 2004). In 1967, Dame Cicely Saunders founded the first modern hospice in the United Kingdom (Clark, 1998). Florence Wald, the Dean of Yale University, founded hospice care in the United States in 1974 (Hospice and Palliative Nurses Association, 2004). At that time, cancer served as the model disease in hospice development and palliative care services (Foley, 2000). During 1975, St. Luke's Hospice in New York was the first hospice in the United States incorporated into an existing medical center and included inpatient care, home care, clinic care, and bereavement counseling for families (St. Luke's Hospice/Palliative Care Program, 1973-1996). In 1982, the first children's hospice opened in England, launching the integrated model of pediatric palliative care that continues to the current model.

Palliative care received recognition as a specialty area after receiving its own definition published by the World Health Organization (WHO) in 1990. The work of the Children's International Project on Palliative/Hospice Services (History of ChiPPS, 2002) began in 1998 and involved a two-day meeting with 30 leaders in fields of pediatric hospice and palliative care. They identified strategies to address critical issues facing the field of pediatric palliative care. ChiPPS contributed to the field by developing a detailed description of pediatric palliative care:

Pediatric palliative care is both a philosophy of care and an organized program for delivering care to children with life-threatening conditions. This care focuses on enhancing quality of life for the child and family, minimizing suffering, optimizing functions, and providing opportunities for personal growth.... Therapies should take a holistic approach, assisting children and families in fulfilling their physical, psychological, social and spiritual goals while remaining sensitive to personal, cultural and religious values, beliefs and practices. Pediatric palliative care affirms life by supporting the child's and family's goals for the future and hopes for cure or life prolongation... (ChiPPS Newsletter #4, 2003, p. 1)

The goal of palliative care is to relieve suffering and to maximize patients' dignity and quality of life and death. Recent evidence suggests palliative care should begin at the time of diagnosis of a potentially life-threatening illness (Orloff, Quance, Perszyk, Flowers, & Veale, 2004). Palliative care is appropriate over the illness trajectory of a progressive, life-threatening illness and may be initiated in conjunction with curative treatment. A holistic family-centered model of pediatric palliative care encourages families' involvement in a mutually beneficial and supportive partnership (Gilmer, 2002). Specifically, in focusing on a holistic approach, four dimensions of pediatric palliative care emerge from the ChiPPS (2003) description: (a) physical, (b) psychological, (c) social, and (d) spiritual constructs.

The physical dimension of pediatric palliative care involves management of pain and symptoms and should be a cornerstone of care for children facing life-threatening illnesses (Himmelstein et al., 2004). Patients present with symptoms related to diagnosis, disease stage, and

therapeutic interventions (Carter & Levetown, 2004). Symptoms change in response to primary and palliative treatments and frequently require re-evaluating the child's condition and needs. Pharmacologic and nonpharmacologic treatments for pain, dyspnea, nausea and vomiting, drooling, and seizures are required (Himmelstein et al., 2004). Although the importance of providing timely management of pain and symptoms is well recognized, the literature indicates that such care is often lacking for pediatric patients.

A retrospective medical record review was completed for children ( $n=105$ ) who were hospitalized at Vanderbilt Children's Hospital at the time of their death (Carter et al., 2004). The chart review tool was useful in investigating three aspects of care: clinical management, family and child interdisciplinary support, and pain and symptom management. Pain medication was received by 90% of the children in the last 72 hours of life, and 55% received additional comfort care measures. Only 26% of children for whom life support was withheld or withdrawn received additional analgesia or sedative dosing at the time of such withdrawal. Pain, shortness of breath, and dyspnea were the most commonly occurring symptoms (24%) documented; however, descriptive documentation regarding pain control or other symptoms being routinely assessed and treated existed for only one-half of children. Overall, physician and nursing documentation of symptom assessment, treatment, and reassessment was inadequate. Carter et al. concluded that opportunities exist to enhance not only the documentation of end-of-life care, but also overall communication and deliberation. Enhanced pain and symptom management and the utilization of supportive, comprehensive, interdisciplinary, palliative care services need to be addressed for children living with life-threatening illnesses and their families.

Other studies also found inadequate pain and symptom control in children. Levetown (2004) presented a post-operative pain management survey showing just 12 out of 25 pediatric

patients had analgesics prescribed compared with all 18 adults who had analgesics prescribed. Twelve pediatric patients received 24 doses, and 18 adults received 671 doses. Levetown also presented a national survey of cancer centers in 1991 reporting only 30% of children receiving bone marrow aspirations received analgesics or sedation. Thirdly, Levetown reported on a retrospective study at Boston Children's Hospital in 2000 that found pediatric cancer patients reported inadequate pain control led to persistent suffering. Another study based on interviews of 68 family members of 44 deceased children found that pain management was a main concern for families who reported that pain control was often ineffective (Contro, Larson, Scofield, Sourkes, & Cohen, 2002). Finally, a retrospective, single-institution study of the parents of children who died of cancer reported that symptoms were more frequently reported by parents than physicians, the treatment of symptoms was often ineffective, and the majority of children suffered "a lot" (Wolfe et al., 2000). Wolfe et al.'s findings indicated the distressing symptoms experienced by children living with cancer were similar to those seen in adult patients with cancer.

In summary, the number of studies with children having life-threatening conditions is very small. Taken together, the findings of this limited number of studies indicate substantial gaps in the development of reliable, valid, and developmentally appropriate tools to measure physical symptoms and quality of life for children living with life-threatening illnesses.

The psychological dimension of pediatric palliative care centers on how the experience of life-threatening illness affects how the child feels about himself or herself (Carter & Levetown, 2004). Children have thoughts about death that often appear in their fantasies and in their play (Armstrong-Dailey & Zarbock, 2001). A child's concept of death is influenced by developmental level, maturation, and condition. Children living with life-threatening illnesses experience feelings of grief, loss, fear, and separation (Himmelstein et al., 2004). Expression of their fears and



concerns is thought to be necessary to decrease anxiety and reduce feelings of isolation and alienation. Dying children are often aware of the fatal prognosis even without being told (Kreicbergs, Valdimarsdottir, Onelov, Henter, & Steineck, 2004). Before children intellectually understand death, they respond to it emotionally (Armstrong-Dailey & Zarbock, 2001). Children of even very young ages are capable of talking about death and should be included in discussions of their illness and treatment at a developmentally appropriate level. Open and honest communication is essential, particularly in the face of uncertain outcomes (Gilmer, 2002). Children with life-threatening illnesses need reassurance that they are loved and cared for, and feeling included in tasks and decisions can bring comfort during a very confusing time (Armstrong-Dailey & Zarbock, 2001).

Kreicbergs et al. (2004) surveyed parents who lost a child to cancer and included questions asking if they had discussed death directly with their child and whether or not they regretted the decision. None of the parents who discussed death with their child reported having regrets, but 27% of the parents who did not talk with their child about death regretted not having done so. Most of these parents regretted not talking to their child about death because they later realized their child seemed to have been aware of his or her imminent death without being told. Although parents may not completely ever resolve their grief after the death of a child, regretful parents who did not talk with their child about death demonstrated higher rates of ongoing depression and anxiety compared with parents who openly communicated about death with their child. This study illustrates the intimate emotional experience of parents with a dying child. Ample evidence suggests that even very young children have an understanding that death exists, and that communication is even more important when the child appears to be aware of impending death. Although this study addresses the psychological aspects of pediatric palliative

care, it does not consider the experience of the child but focuses only on the emotional experience of the parent.

Two additional studies were found that address psychological aspects of care for children living with life-threatening illnesses. An exploratory, descriptive study by Davies et al. (1998) concentrated on experiences of mothers from five different countries who had a child die from cancer in the past six months. Mothers' reactions to the diagnosis, their management of end-stage illness, and the experiences of coping with bereavement were similar for all mothers. They reported shock, fear, and guilt in reaction to the life-threatening diagnosis and found it difficult to cope with grief after the child's death. However, this study also focused on the experience of mothers, not the experience of children. Another study by Andresen, Seecharan, and Toce (2004) compared nurses' and physicians' perceptions of the quality of care and events of death of children at an academic, tertiary care, faith-based children's hospital. Results from self-administered surveys following child deaths showed that there was good quality of care at the time of death for most patients. Once again, this study did not examine the experience of the child living with the life-threatening illness but focused on the provider's perception of quality of care.

In the psychological dimension of pediatric palliative care, few studies have focused on care of children living with life-threatening illnesses. Studies mostly center on experiences of family members and healthcare providers but not on the child's feelings and emotional experiences. Thus, there is a gap in understanding what children with life-threatening conditions are experiencing, and until that gap is closed, caregivers and parents will not have all the information that may be needed to better anticipate and respond to significant psychological challenges faced by children who are dying. Research related to the psychological dimension of

pediatric palliative care is minimal overall, and a significant gap exists related to research that focuses on the experience of the child.

The social dimension of pediatric palliative care involves the impact a life-threatening illness has on the child's interaction with others (Carter & Levetown, 2004) and involves communication, maintaining normal childhood activities, and resources for social support. Communication with children requires consideration of the child's developmental level to encourage expression of hopes, dreams, fears, and reflection (Himmelstein et al., 2004). An individual who is an effective communicator is emotionally available, candid, and open to children's questions. Communication may include oral communication, body language, drawing pictures, playing with stuffed animals, writing stories or letters, playing or writing music, and creating rituals. The healthcare team's role includes provision of social support and guidance to families with seriously ill children (Orloff et al., 2004).

Armstrong-Dailey and Zarbock (2001) believe that however seriously ill, the child should be encouraged to live, not just to exist. The child living with a life-threatening illness is still a child and needs to continue familiar life activities and interactions for as long as possible. Daily activities such as playing, going to school, being disciplined, being responsible, and spending time with friends and family serve as the very foundation of life, and these social interactions need to be supported to the extent possible (Himmelstein et al., 2004).

Investigators have conducted studies of social support for children with cancer provided by family, other children with life-threatening illnesses, healthy friends, and significant adults. From the perspective of family social support, a study by Rait and colleagues (1992) reported that adolescent cancer survivors showed lower levels of family cohesion than healthy adolescents and families. This could be related to some adolescent survivors adopting a "hyperindependent

attitude” after their treatment. In contrast, when adolescents with cancer experienced illness over a long period of time, family cohesiveness increased (Kvist, Rajantie, Kvist, & Siimes, 1991). In this study, parents reported the quality of their relationship with their sick child increased because the child with cancer needed more attention compared with their other children.

Social support for children living with life-threatening illnesses can also come from other children with life-threatening illnesses. Katz, Rubinstein, Hubert, and Blew (1988) examined the impact of summer camp on children with cancer and found that 18 children with cancer, ages 6 to 12 years, reported that physical and social activities increased during camp, and children’s self-engaged activities decreased after camp. Interaction of the children with their families also improved after camp, and positive changes were still present 4 weeks following the summer camp experience.

Healthy friends can also be a source of social support for children living with life-threatening illnesses. Nichols (1995) found that most teens with cancer are satisfied with support from their relatives, but not from their healthy friends and classmates. Nichols suggested that the healthy friends did not know how to support their adolescent friend with cancer. Although children and teens with cancer feel their healthy friends do not know how to support them, they still want to maintain relationships with them (Varni, Katz, Colegrove, & Dolgin, 1993). School attendance is difficult for the child living with a life-threatening illness, and attendance is typically lower even though the child wants to go to school. Decreased opportunities to interact with friends make it harder for children living with life-threatening illnesses to maintain friendships with other healthy children and derive social support from them.

Children living with life-threatening illnesses can also gain social support from significant adults. Medical staff, teachers, and youth workers can facilitate positive interaction

between adolescents with cancer and their parents and peers (Manne & Miller, 1998). Children and adolescents particularly feel that nurses can offer technical and humanistic support by providing a warm touch, by interacting in caring ways to make the child feel special, and by offering age-appropriate information (Hockenberry-Eaton & Minick, 1994). Support groups and programs, school re-entry programs, and social skills training programs are examples of strategies led by significant adults to promote social support for children living with life-threatening illnesses and their families.

In summary, although studies have examined aspects of the social dimensions of pediatric palliative care, several limitations emerge. First, the populations examined were limited mainly to adolescents. Second, participants were restricted to cancer diagnoses and varied in degree of illness severity. Third, much of the research in this area is not current. Thus, research is needed to better understand the social support needs of children of all ages with life-threatening conditions.

Last, the spiritual dimension of pediatric palliative care refers to how the child understands the meaning of an experience (Carter & Levetown, 2004). Spirituality comes into focus when an individual faces emotional stress, physical illness, or death (Smith & McSherry, 2004). Questions such as “Why is God doing this?” or “What is heaven like?” may be asked (Armstrong-Dailey & Zarbock, 2001). In childhood, spirituality is developmentally defined and can be experienced without any personal religious beliefs, values, and practices (Himmelstein et al., 2004). Spirituality is involved with a child’s approach to understanding life and includes concerns such as unconditional love, forgiveness, hope, safety, security, and legacy. Even very young children may need to engage in discussions related to what dying and the afterlife are like (Armstrong-Dailey & Zarbock, 2001).

Nurses can help families by providing a safe place where spiritual needs, uncertainty, and hope reside among healthcare providers and the recipients of their care (Gilmer, 2002). In the terminal phase of an illness, children of all ages must attend to unfinished business (Armstrong-Dailey & Zarbock, 2001). This may include delegating who will receive certain belongings after their death, writing letters, drawing pictures, taking a special trip, or talking with significant people. Children of all ages living with life-threatening illnesses want to know their life has made a difference, not only through their accomplishments, but also by touching others (Himmelstein et al., 2004). Spiritual assessment centers on understanding what is important to the child, understanding meaning of the child's life according to the child and his or her family, and the child's hopes and dreams for the future.

Limited studies relevant to spirituality were identified. A longitudinal study by Wink and Dillon (2003) concluded that high spirituality was positively related to well-being, but reported that spirituality does not stabilize and gain prominence until the second half of adulthood. Taylor's (2003) qualitative study found that adult cancer patients and their caregivers had spiritual needs such as creating meaning, finding purpose, giving and receiving love, and preparing for death. However, little is actually known about children's spirituality, and even less is known about the spiritual needs of children living with life-threatening illnesses (Davies, Brenner, Orloff, Sumner, & Worden, 2002). Though few in number, studies document that children living with life-threatening illnesses exhibit thoughts and feelings about prayer and God (Pehler, 1997; Wilson, 1994). Silber and Reilly (1985) reported that spiritual and religious issues increased directly with seriousness of illness in hospitalized adolescents.

Limitations of these studies include non-standardized measurement techniques, variations in the definition of spirituality, and inconsistent understanding of existence of spirituality in

children. Furthermore, although information related to spirituality in children living with life-threatening illnesses and their families can be identified and a few research studies were found across pediatric populations, there is a gap in the literature for research specifically related to spirituality in children living with life-threatening illnesses. Research to address spirituality in children living with life-threatening illnesses is necessary to enhance care for these children and their families.

Within the dimensions of pediatric palliative care emerges the concept of continuing bonds. At first glance, it appears the concept fits within the description of the spiritual dimension. A further look reveals the dimensions of pediatric palliative care relate to one another, therefore, continuing bonds impacts each dimension of pediatric palliative care. A significant need to address continuing bonds across the physical, psychological, social, and spiritual dimensions in children living with life-threatening illnesses and their families clearly relates to the principle of holistic care, which is inherent in the description of pediatric palliative care (ChiPPS, 2003).

### *Overview of Continuing Bonds*

The continuing bonds model developed in the 1990s and was perceived as an abnormal part of bereavement in the last century (Silverman & Klass, 1996). The idea of continuing bonds began with Freud's understanding that the primary goal of grieving was to cut bonds with the deceased so new attachments could form. However, Freud's personal experiences with grief did not always support his theoretic model. After important deaths in his life, Freud acknowledged his inability to find new attachments after such loss. On the ninth anniversary of his daughter's death, Freud wrote to his friend after hearing his son had died:

Although we know that after such a loss the acute state of mourning will subside, we also know we shall remain inconsolable and will never find a substitute. No matter what may fill the gap, even if it be filled completely, it nevertheless remains something else. And actually this is how it should be. It is the only way of perpetuating that love which we do not want to relinquish. (Freud, 1961, p. 239)

A couple of years after the death of Freud's grandson at age 4, colleagues reported "[Freud] had never been able to get fond of anyone since that misfortune, merely retaining his old attachments; he had found the blow quite unbearable, much more so than his own cancer" (Jones, 1957, p. 92).

Freud's theory dominated subsequent formulations of appropriate grieving behavior. His writings about his experiences with grief were not integrated into psychoanalytic thought. The post-Freud paradigm for understanding grief has maintained that connections with the deceased must be cut so new attachments can form. Historically, survivors have continued bonds with the deceased, but this insight has not been incorporated into new generations of theory and research.

Klass, Silverman, and Nickman (1996) were the first to examine the role of continuing bonds with the deceased in grief resolution as a part of scholarly and clinical work. The idea grew out of discussions in which the three researchers shared their findings in different research projects with families who had experienced a significant death of a child, spouse, or parent, as well as with families adopting a child. Both bereaved children and adults seemed to maintain connections with the deceased. Adoptees had parallel experiences by trying to maintain connections with a "fantasy" birth parent, even when they were adopted at birth. Older adoptees who had known their birth families also maintained internal connections.

The researchers' interviews with bereaved children revealed that they developed a set of memories, feelings, and actions to stay connected with the deceased. They seemed to continue the relationships rather than letting go. These relationships were maintained by dreaming, talking



to the deceased, believing the deceased was watching them, keeping belongings of the deceased, visiting the grave, and thinking about the deceased. The researchers found these connections developed over time and were not static.

As the researchers brought threads of their work together, new linkages became apparent. The new phenomenon was like having a baby. The baby is pushed out of the mother, but birth is not about letting go. It is about a change in the nature of the mother's connection with her infant. Delivering a baby does not break the bond but rather leads to a new set of relationships. Similarly, the bereaved change their relationships with the deceased. These ongoing connections and changes are the focus of this new understanding of grief called continuing bonds. Continuing bonds can be defined as a bereaved individual having an ongoing inner relationship with a deceased person (Field, Gal-Oz, & Bonanno, 2003). The concept of continuing bonds developed based on the reality of how Klass and his colleagues (1996) observed people experiencing and living their lives, rather than finding ways of verifying preconceived theories of how people should live. Klass et al. looked at their respective research findings and determined they were observing phenomena that could not be explained by available grief models that taught them to expect an observed stage of disengagement. They believed they were observing the bereaved alter and then continue their bond with the lost person. These connections provided comfort and served to ease the transition from the past to the future, and remaining connected seemed to facilitate coping strategies for both adults and children.

### *Overview of Coping Strategies*

Bereaved individuals use a variety of coping strategies in response to the stresses of losing a child. According to Compas, Champion, & Reeslund (2005), responses to stress include

two processes: 1) automatic, involuntary responses, and 2) coping. Automatic, involuntary responses to stress include involuntary engagement and involuntary disengagement. Involuntary engagement is described as automatic responses oriented toward a stressor, as opposed to involuntary disengagement that refers to uncontrolled behaviors focused away from the stressor. In contrast to these involuntary responses, coping includes strategies that are controlled, voluntary responses to stress.

Coping is defined as “conscious volitional efforts to regulate emotion, cognition, behavior, physiology, and the environment in response to stressful events or circumstances” (Compas, Connor-Smith, Saltzman, Thomsen, & Wadsworth, 2001, p. 6). Coping is further distinguished as voluntary engagement coping and voluntary disengagement coping (Compas et al., 2005). Voluntary engagement coping is described as dealing with the stressful situation or one’s emotions, including primary and secondary control coping. Primary control coping is a direct attempt to influence the stressor or one’s emotions as a stress response (i.e., problem solving, emotional expression, emotional regulation). Secondary control coping involves adapting to the stressor (i.e., acceptance, cognitive restructuring, positive thinking, distraction). Furthermore, voluntary disengagement coping is described as efforts to distance oneself from the stressor emotionally, cognitively, and physically (i.e., avoidance, denial, wishful thinking). Since coping is situation specific, positive outcomes are highest when primary control coping is used with controllable stressors (Compas et al., 2001). Secondary control coping may be particularly effective in response to uncontrollable events, such as the loss of a child. In contrast, it is difficult to find evidence that disengagement coping can be helpful.

Coping strategies include primary control coping, secondary control coping, and voluntary disengagement coping for the purposes of this study. These variables can be

operationalized by using the Responses to Stress Questionnaire (RSQ) (Connor-Smith, Compas, Wadsworth, Thomsen, & Saltzman, 2000). The instrument can be tailored to specific stressor domains such that a grief specific version can be used for bereaved individuals. The measure is factor-derived into five types of stress responses: primary control engagement, secondary control engagement, voluntary disengagement, involuntary engagement, and involuntary disengagement. The RSQ will operationalize coping strategies of bereaved parents and siblings (primary control coping, secondary control coping, and voluntary disengagement coping) necessary to examine associations among continuing bonds, coping strategies, and grief symptoms.

### *Overview of Grief Symptoms*

The loss of a child is one of the most stressful events possible, and grieving is a lifelong process (Himmelstein et al., 2004). According to Jacob (1993), grief is a normal, dynamic, individualized process encompassing physical, emotional, social, and spiritual aspects of individuals who lose someone significant, with possible positive and negative consequences. Grief symptoms include personal growth and grief distress. Parents typically never get over a child's death, but parents in uncomplicated grief learn to adjust and integrate the loss into their lives (Himmelstein et al., 2004). Generally, uncomplicated grief results in eventual signs of healing, such as resuming everyday function, deriving pleasure from life, and establishing new relationships. These individuals experience new capabilities and personal growth after an initial grieving period. Personal growth in children can be operationalized by using the Hogan Inventory of Bereavement (HIB), a self-report measure that produces a factor score for personal growth (Hogan & DeSantis, 1996b). Personal growth in adults can be operationalized by using the Hogan Grief Reaction Checklist (HGRC), a self-report measure assessing a variety of grief

symptoms, including a subscale score for personal growth (Hogan, Greenfield, & Schmidt, 2001).

On the other hand, negative consequences of grief include distress. Distress is a response to losses occurring from the journey of a life limiting illness, affecting both patients and their families (Lobb, Clayton, & Price, 2006). Although grief severity and duration varies for bereaved families, most show similar patterns of grief distress. Heightened symptoms of grief distress characterize complicated grief, a high risk for parents and siblings who experience the loss of a child (Himmelstein et al., 2004). Complicated grief deviates from the expected reaction for a given society or culture. This form of grief includes absent grief, delayed grief, and prolonged or unresolved grief. Absent grief includes the inhibition of typical grief expressions or denial of the loss and the associated feelings. Delayed grief occurs when a considerable amount of time occurs between the loss and the onset of grief reactions, from weeks to years. Prolonged grief is associated with persistent depression, loss preoccupation, yearning for the deceased, and social inhibition that does not transform over time. Grief distress can also be operationalized by utilizing the HIB for children and the HGRC for adults. The HIB produces a subscale score for grief (Hogan & DeSantis, 1996b), based on items which measure grief distress symptoms. The HGRC produces subscale scores for grief distress symptoms, including despair, panic behavior, blame and anger, detachment, and disorganization (Hogan et al., 2001).

### **Relevant Theoretical Frameworks**

Several theories are related to the phenomenon of continuing bonds, including Attachment Theory, Continuing Bonds Theory, and the Dual Process Model. These theoretical

approaches will be analyzed, including discussion of theoretical links between key concepts and synthesis of conceptual and theoretical knowledge.

### *Attachment Theory*

From an evolutionary perspective, attachment is conceived as a universal bias in infants to remain in the proximity of a protective caregiver (Sagi-Schwartz et al., 2003). J Bowlby (cited in Sonkin, 2005) defined attachment as the affective bond between an infant and a primary caregiver. According to Bowlby, Attachment Theory focuses on making and breaking relationships, bonds between children and their caregivers, and separation or loss of attachment figures (Sagi-Schwartz et al., 2003).

Bowlby, a postwar consultant to the World Health Organization, studied ill effects maternal deprivation had on homeless children (Silverman & Klass, 1996). Bowlby's Attachment Theory developed as a way of understanding these children, and its purpose was to keep the mother in close proximity. Attachment behaviors develop during infancy when survival requires being physically close to a primary caregiver (Bonanno & Kaltman, 1999). However, infants will protest and show distress if separated from their caregiver in order for the caregiver to return. Such attachment behaviors are considered part of human evolutionary inheritance, so theorists have extended the attachment model to include adulthood relations. Grief from the death of a loved one is a natural behavioral response that develops to foster closeness with and minimize separation from the object of attachment. It is thought to manifest as a protest response when bereaved individuals recognize the deceased cannot return. According to Bowlby, the purpose of grief is to sever the bond and attachment with the deceased (Silverman & Klass, 1996). Although Bowlby's later work in 1980 admits to observing continuing bonds with the

deceased, he did not revise his own theory about grief resolution. Therefore, followers of Attachment Theory continue to define grief resolution as severing bonds with the deceased.

### *Continuing Bonds Theory*

People never get over death of a loved one, but people are changed by the experience (Silverman & Klass, 1996). Part of that change includes an altered but continuing relationship with the deceased. Recently, an alternative theory of continuing bonds has been proposed (Klass et al., 1996), which is an outgrowth of Bowlby's Attachment Theory. This theory suggests that the bereaved engage in grief work to maintain a spiritual connection or ongoing attachment with the deceased to facilitate recovery. Bereaved individuals maintain a "sense of presence" with the deceased in the absence of physical contact (Silverman & Nickman, 1996). It is thought that a set of memories, feelings, and actions develop in the first years after the death to remain connected with the deceased (Klass et al., 1996). Connection strategies may include locating, experiencing, reaching out to, remembering, or keeping something that belonged to the deceased (Normand, Silverman, & Nickman, 1996; Silverman & Nickman, 1996). Rather than letting go, the meaning of loss over time is renegotiated and relationships are continued (Silverman & Klass, 1996). These connections allow survivors to hold the deceased in their memories via this inner representation, which can be a normal part of grief. The bond is not static and may take on new forms and change over time, but the connection remains. Although recent work has established that bereaved individuals maintain proximity to the deceased through continuing bonds (Field et al., 2003; Hogan & DeSantis, 1996a), literature fails to validate continuing bonds' association with coping strategies and grief symptoms.

### *Dual Process Model*

According to Stroebe and Schut (1999), previous theories about coping with bereavement have shortcomings, including a poor definition of “grief work,” and fail to represent the dynamic process characteristic of grieving. They proposed the Dual Process Model of coping with bereavement (DPM, see Figure 1), which developed as a stressor-specific analysis of the coping process, and is one of the few attempts to integrate the Continuing Bonds Theory within an established stress and coping framework (Stroebe, 2002). According to Stroebe and Schut (1999), the DPM identifies loss-oriented and restoration-oriented stressors. Loss-orientation refers to the death events and loss experience, and restoration-orientation refers to secondary stressors of day-to-day life that result from the death. The model suggests that adjustment to the loss includes confrontation and avoidance of both loss-stressors and restoration-stressors concurrently, a process known as oscillation. Healthy adaptation and coping involves balanced oscillation between the two stressors, alternating between positive and negative aspects of dealing with loss itself and secondary concurrent changes. On the other hand, individuals excessively absorbed in the death (e.g., rumination) or excessively avoidant (e.g., denial) may experience greater complications. The model was originally developed to examine coping in bereaved spouses, so the DPM has not been used to study children living with life-threatening illnesses, bereaved parents, and bereaved siblings.

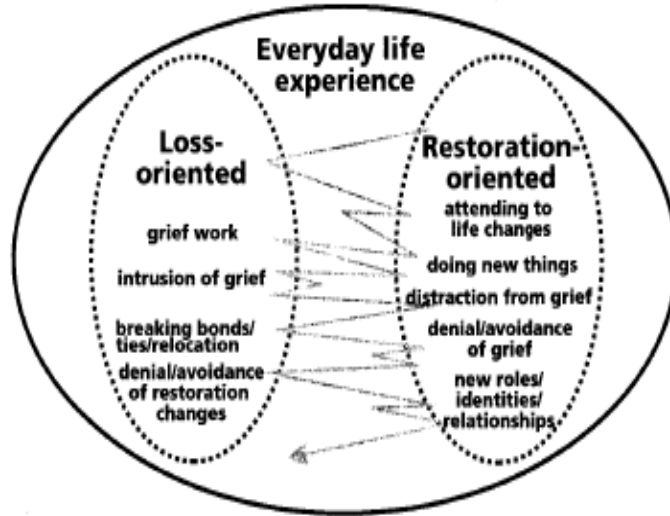


Figure 1. A Dual-Process Model of coping with bereavement (Stroebe & Schut, 1999)

Stroebe, Schut, and Stroebe (2005) applied the DPM to examine how continuing bonds affect coping and adjustment. They conclude no simple affirmative or nonaffirmative answer can be provided about whether or not bonds to the deceased should be broken or retained for adaptive coping in the bereaved. They state other variables, including nature of the relationship to the deceased and the bereaved individual's attachment style, determine whether or not bonds are continued and whether or not continued bonds are helpful or hurtful.

### *Conceptual Model*

Based on the DPM, Gerhardt (2003) provides a conceptual model related to coping with bereavement from the death of a child to guide the Parent-Sibling Bereavement Study. Variables in the model shown in Figure 2 will be discussed, including characteristics of the child's death; developmental level; grief work; grief symptoms; and parent, sibling, and family functioning.



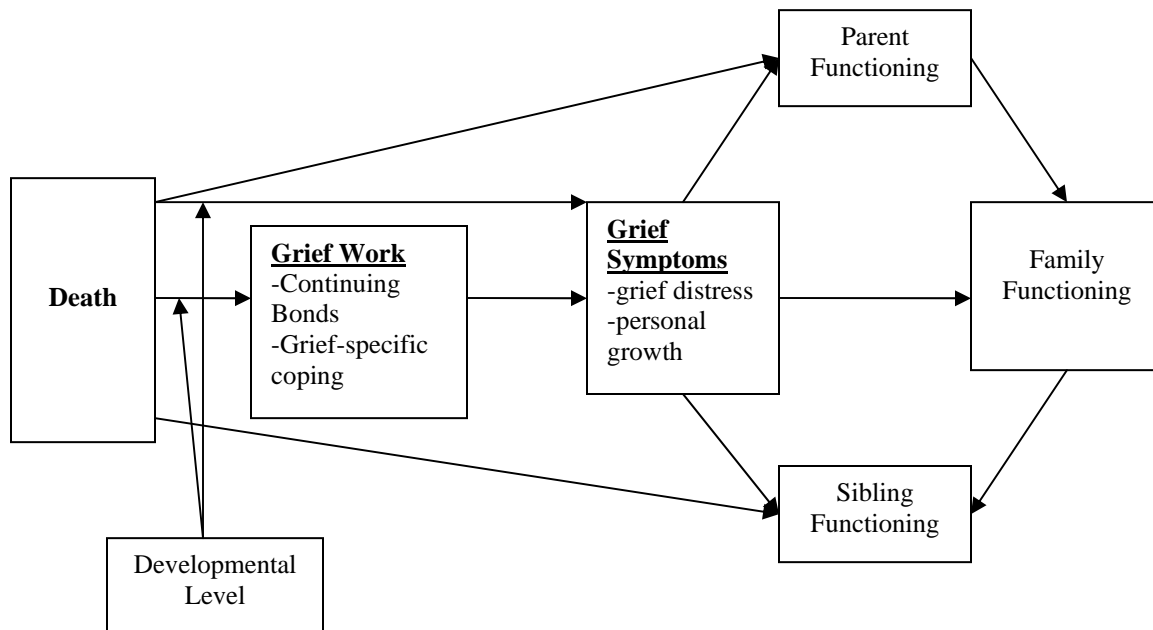


Figure 2. Conceptual model integrating Continuing Bonds Theory and stress and coping theory (Gerhardt, 2003)

Characteristics of the child’s death may be a risk factor for sibling and parent outcomes (Gerhardt, 2003). Length of illness, location of death (home vs. hospital), if the death was expected or not, time elapsed since death, and overall stressfulness of the death are all shown to be factors that can be associated with more severe grief reactions and distress. Also, evidence suggests that developmental level can influence adjustment to death, and that a sibling’s age and concept of death should be considered within this framework.

Grief work includes maintaining continuing bonds with the deceased and grief-specific coping strategies. Studies indicate that a greater degree of continuing bonds may be associated with higher grief-specific symptoms and more severe grief distress at 5 years postloss, but finer analysis shows it may be related to attempts to maintain more physical rather than spiritual connections (Field et al., 2003). However, these findings have been studied with adults only; the distinction between physical and spiritual connections and its impact on grief have not been

studied in bereaved children and adolescents. Maintaining such bonds with the deceased can be accomplished through a variety of coping strategies, including primary control engagement, secondary control engagement, and disengagement (Compas et al., 2005). Characteristics of the child's death and grief work both have direct effects on grief symptoms, including personal growth and grief distress as previously discussed. All of these factors are affected by the loss of a child and impact parent, sibling, and family functioning.

### *Theoretical Synthesis*

Synthesis of the Continuing Bonds Theory (Klass et al., 1996), the DPM (Stroebe et al., 2005), and Gerhardt's (2003) conceptual model reveals that bereaved individuals maintain connections with the deceased and that associations exist among continuing bonds, coping strategies, and grief symptoms. One assumption across these frameworks is that a connection exists between the bereaved and the deceased before the death in order for connections to be maintained. Although the Attachment Theory proposes that connections must be cut with the deceased, it is documented that Bowlby recognized late in his career that connections were being maintained (Silverman & Klass, 1996). However, his theory was never changed to reflect this finding. Based on theoretical synthesis across Continuing Bonds Theory, the DPM, and Gerhardt's framework, a conceptual model is proposed that depicts associations among continuing bonds, coping strategies, and grief symptoms as shown in Figure 3.

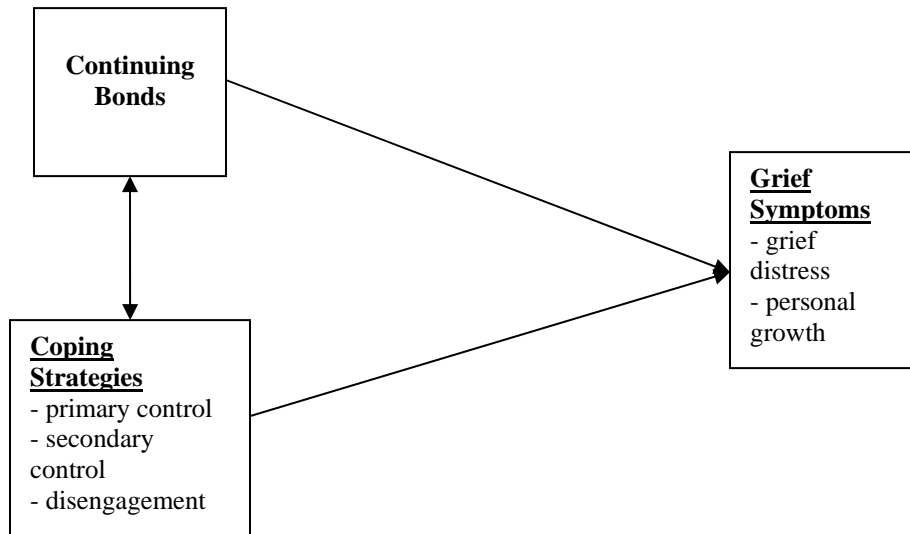


Figure 3. Conceptual model of continuing bonds based on theoretical synthesis

Weaknesses exist after synthesis of theoretical literature related to continuing bonds. Theoretical models do not incorporate children living with life-threatening illnesses. Concepts include continuing bonds, coping strategies, and grief symptoms after the death of a child, focusing on survivors. However, models do not include the possibility that continuing bonds may also be beneficial to ill children. Furthermore, it remains unknown whether or not children living with life-threatening illnesses do or say things before they die so that they will be remembered.

Also, confusion across theoretical literature exists related to continuing bonds, especially regarding the associations between continuing bonds, coping strategies, and grief symptoms. The conceptual model in Figure 3 depicts a noncausal relationship between continuing bonds and coping strategies, a direct effect of continuing bonds on grief symptoms, and a direct effect of coping strategies on grief symptoms. However, the literature is unclear regarding theoretical associations and does not provide evidence supporting positive or negative correlations. Furthermore, the literature does not differentiate between associations continuing bonds might

have with coping strategies (primary control, secondary control, and disengagement), grief distress, and personal growth. More research is necessary to gain a better understanding of continuing bonds and the associations with coping strategies and grief symptoms to better serve children living with life-threatening illnesses and their families.

### **Critical Analysis of Relevant Literature**

In addition to significant shifts in theory that have yet to be fully examined, recent reviews suggest that the design and methodological rigor of bereavement literature has lagged behind other areas of research (Dijkstra & Stroebe, 1998; Oliver, 1999). Methodological approaches specifically related to continuing bonds will be critically analyzed, and a synthesis of methodological knowledge will be presented.

#### *Identification of Articles*

A review of the literature, without limits placed on years included in the search, was conducted using CINAHL, Medline, OVID, and Pubmed. Combinations of keywords “child,” “life-threatening illness,” “death,” “palliative care,” “continuing bond,” “connection,” and “bereavement” were used. Several pediatric palliative care websites and books were used as supportive literature. The literature revealed a lack of published nursing research and little research in general by other disciplines related to continuing bonds. A total of 26 research articles from years 1989-2006 were selected.

### *Qualitative Research*

Fourteen qualitative research articles related to continuing bonds (Barrera et al., 2006; Chan et al., 2005; Davies, 2005; Davies et al., 1998; Doran & Hansen, 2006; Hogan & DeSantis, 1992; Hogan & DeSantis, 1994; Meert, Thurston, & Briller, 2005; Riches & Dawson, 1998; Sedney, 2002; Silverman, Baker, Cait, & Boerner, 2003; Silverman, Nickman, & Worden, 1992; Sormanti & August, 1997; Wilson, 2001). Sample sizes ranged from 10 to 157 bereaved participants including mothers, parents, siblings, children, families, family supports, or film characters who had experienced loss. Most studies focused on American individuals, although three studies specifically looked at individuals from other countries or cultures (Chan et al., 2005; Davies et al., 1998; Doran & Hansen, 2006). Nine studies focused on loss of a child (Barrera et al., 2006; Davies, 2005; Davies et al., 1998; Doran & Hansen, 2006; Meert et al., 2005; Riches & Dawson, 1998; Sedney, 2002; Sormanti & August, 1997; Wilson, 2001), two studies focused on loss of a sibling (Hogan & DeSantis, 1992; Hogan & DeSantis, 1994), two studies investigated parent loss (Silverman et al., 1992; Silverman et al., 2003), and one focused on loss of various family members (Chan et al., 2005). All studies took place within 6 years postloss and included interviews and one film review. Eight studies used the Continuing Bonds Theory (Barrera et al., 2006; Chan et al., 2005; Davies, 2005; Doran & Hansen, 2006; Riches & Dawson, 1998; Sedney, 2002; Silverman et al., 1992; Wilson, 2001), and other studies were guided by implied frameworks related to continuing connections (Sormanti & August, 1997), pediatric palliative care (Davies et al., 1998), bereavement (Hogan & DeSantis, 1992; Silverman et al., 2003), coping (Hogan & DeSantis, 1994), and spirituality (Meert et al., 2005). Similarities and differences across articles are presented.

All 14 qualitative studies provided evidence that bereaved individuals do maintain connections with the deceased after death. The majority of studies identified themes reflecting how bonds are maintained with the person who died (Chan et al., 2005; Davies, 2005; Doran & Hansen, 2006; Hogan & DeSantis, 1992; Meert et al., 2005; Sedney, 2002; Silverman et al., 1992; Sormanti & August, 1997; Wilson, 2001). Strategies included the following: visiting the gravesite, talking to the deceased, signs from the deceased, locating the deceased, experiencing the deceased, reaching out to the deceased, waking memories, keepsakes, dreams, storytelling, sense of presence, faith-based connections, proximity connections, ongoing rituals, and pictorial remembrances. Davies (2005) found that parents preserve memories and recollections of the life and death of their children who have died. Some parents even suggested maintaining a connection with their dead child was their main spiritual need (Meert et al., 2005). This need was met by maintaining a physical presence at the time of death, and after the death by memories, mementos, memorials, and altruistic acts. Families who lost a baby similarly reported that they participated in some type of activity to keep the baby alive in the family memory (Wilson, 2001). So, a common theme across qualitative studies with bereaved individuals is that connections and bonds were maintained after death.

Another similarity noted across qualitative literature is that all 14 studies used survivors as participants, and data collection occurred after the death of the child. Studies were framed around the potential benefit that continuing bonds may have for survivors. None of the qualitative literature included children living with life-threatening illnesses as part of the proposed conceptual models, and there was no mention of this possibility within the scope of continuing bonds or findings from these qualitative studies.

On the other hand, differences are noted across qualitative studies related to continuing bonds. One difference was various strategies used by the bereaved that facilitated continuing bonds and the type of bond or connection that was maintained. Some bonds were maintained via more physical means (e.g., keeping possessions) as opposed to more spiritual connections (e.g., reminiscing) (Field et al., 2003). Some reports suggested that bereaved individuals who shift to less physical bonds tend to report less distress. Barrera et al. (2006) found that bereaved parents continued relationships with deceased children through either evolving or static continuing bonds. Parents engaged in evolving continuing bonds adjusted to the physical disappearance of the child while keeping the child's memory alive through a spiritual bond. Parents engaged in static continuing bonds focused on the physical loss, maintained connections primarily through the child's possessions, and were unable to move on. However, Riches and Dawson (1998) studied 36 bereaved parents and found that photographs and other concrete artifacts appeared to help parents hold on to and reconstruct the memory of their child by reasserting parenthood, confirming the death, celebrating the child's life in establishing a biography, and constructing bereaved parenthood in facing the everyday world. More research is needed to determine the distinction between physical and spiritual bonds among bereaved parents and siblings.

Another significant difference between qualitative results is related to continuing bonds' impact on coping and adjustment. Sormanti and August (1997) found that 41 of 43 bereaved parents described continued connections with their child as positive and helpful in the healing process. Some mothers described memories of their babies as one of the most comforting things (Davies et al., 1998). Meert et al. (2005) found that parents who had lost a child felt a maintained relationship could create inner strength and personal motivation and bring good to others, and these things were all part of parents' recovery. On the other hand, Silverman et al. (2003) studied

bereaved children who had lost a parent; they identified a pattern of legacies that children maintained with their deceased parent that had potential to have negative impacts on these children. Also, some bereaved adolescents had compromised coping mechanisms because of their preoccupation with highly charged thoughts and feelings associated with images and memories surrounding the life and death of their sibling (Hogan & DeSantis, 1994). More research is needed to determine the relationships among continuing bonds, coping strategies, and grief symptoms.

### *Quantitative Research*

In addition to qualitative methodology, eight quantitative research studies were identified related to continuing bonds (Boelen, Stroebe, Schut, & Zijerveld, 2006; Carnelley, Wortman, Bolger, & Burke, 2006; Field et al., 2003; Field & Friedrichs, 2004; Field, Nichols, Holen, & Horowitz, 1999; Gamino, Sewell, & Easterling, 2000; Neimeyer, Baldwin, & Gillies, 2006; Russac, Steighner, & Canto, 2002). Sample sizes ranged from 30 to 768 individuals, mostly consisting of bereaved spouses and widows, and studies ranged from 3 months to 64 years postloss. Various theoretical models were used, including grief models (Gamino et al., 2000; Russac et al., 2002), Self-Regulation Theory (Carnelley et al., 2006), Attachment Theory (Field et al., 1999; Neimeyer et al., 2006; Russac et al., 2002), and Continuing Bonds Theory (Boelen et al., 2006; Field et al., 2003; Field & Friedrichs, 2004).

Across quantitative articles, differences were noted related to instruments used to draw conclusions related to continuing bonds. Two studies utilized the Continuing Bonds Scale (CBS), which measures continuing bonds as a single factor (Field et al., 2003; Neimeyer et al., 2006). Field and Friedrichs (2004) developed a 6-item Continuing Bond coping measure, while Boelen



et al. (2006) developed three questions to tap continuing bond manifestations of presence, possessions, and memories. Two studies used empty-chair monologue tasks (Field et al., 1999; Field et al., 2003). Other assessment measures were related to emotional recovery, including questions related to the nature and frequency of thoughts and memories of the deceased and continuing involvement with the deceased (Carnelley et al., 2006). Furthermore, researchers mostly examined associations with various grief and depression measures such as the Beck Depression Inventory (Field et al., 2003; Field & Friedrichs, 2004), Hogan Grief Reaction Checklist (Gamino et al., 2000), Inventory of Complicated Grief (Boelen et al., 2006; Neimeyer et al., 2006), Texas Revised Inventory of Grief (Field et al., 1999; Field et al., 2003), and Symptom Checklist (Boelen et al., 2006), as well as scales for griever status, similarities to deceased, and closeness of relationships to deceased (Russac et al., 2002).

Differences also were seen related to the impact of continuing bonds. It remains unclear whether or not continuing bonds have a negative or positive impact for bereaved individuals. Negative impacts of continuing bonds included more negative moods (Field & Friedrichs, 2004), higher grief symptom patterns, and expressions of greater helplessness (Field et al., 2003). On the other hand, there was support that continuing bonds can result in positive impacts, including less blame towards the deceased (Field & Friedrichs, 2004). Gamino et al. (2000) proposed that maintaining positive memories of the deceased as part of a continuing relationship was adaptive. Another study found that continued bonds facilitated positive mood in the deceased, but only at a later point in time after death (Field & Friedrichs, 2004). Carnelley et al. (2006) found that the extent to which continuing bonds may be beneficial may depend on whether the bereaved focuses on positive or negative aspects. Their recently bereaved respondents reported negative feelings after thinking or talking about their spouse between sometimes and rarely. However, the

recently bereaved and those bereaved for decades reported positive affects from memories and conversations with their spouse who died; however, the frequency did not change with time since loss. Frequency of thoughts that resulted in negative feelings decreased with time; they can take decades after the death to reach their lowest level. On the other hand, the frequency of thoughts that resulted in feeling happy did not decrease with time; as long as 20 years after the loss, respondents still thought about his or her spouse once every week or two and had a conversation about him or her about once a month. The positive thoughts may serve to continue a bond with the deceased. More research is necessary to determine the contextual nature surrounding continuing bonds that results in either a positive or negative impact for the bereaved.

Another study posited that the form of continuing attachment is what makes continuing bonds adaptive or not (Field et al., 1999). Bereaved spouses with a tendency to hang on to possessions or belongings showed greater distress in a monologue role play with the deceased and had significantly positive correlations with grief and helplessness. Hanging on to the deceased person's possessions for comfort was predictive of less decrease in grief-specific symptoms over time. A continued bond via possession items implied an avoidant form of coping used by those having difficulty handling the loss. In contrast, bereaved individuals who used memories for comfort indicated less distress during the monologue and showed significant negative correlations with helplessness and grief. A continued bond via memories suggested this type of continued attachment entailed greater acknowledgement and acceptance of the death. Boelen et al. (2006) also looked at different manifestations of continuing bonds, including presence, possessions, and memories; recovering memories predicted grief in bereaved individuals but not depression, and use of the deceased person's possessions weakly predicted both grief and depression. On the other hand, Neimeyer et al. (2006) suggested an interaction

between meaning-making and continuing bonds. They found that continuing bonds predicted greater levels of traumatic and separation distress in bereaved individuals, but only when the survivors were unable to make meaning of the loss. Further research is needed to determine the role of continuing bonds within bereavement adaptation.

Differences also were noted across quantitative literature related to continuing bond expressions to cope with death (Field & Friedrichs, 2004; Russac et al., 2002). Bereaved individuals reported expressions such as thinking of the deceased, doing activities that would have pleased the deceased, talking to the deceased, and preserving keepsakes of the deceased. However, research did not explain the impact of various types of continued bond expressions on coping strategies or grief symptoms. Hanging on to possessions may be a form of adaptive coping, but Field et al.'s (1999) results suggested that excessive reliance on them at 6 months postloss may have maladaptive consequences. Early after the death, bereaved individuals may tend to hang on to more concrete objects, and over time, the continued bond may change to abstract forms of bonds.

### *Mixed Method Research*

Four mixed method studies were identified that included both quantitative and qualitative methods (Arnold, Gemma, & Cushman, 2005; Herth, 1990; Miller, 1989; Silverman & Worden, 1992). Sample sizes ranged from 30 to 125 individuals. Studies focused on samples of bereaved parents (Arnold et al., 2005) and bereaved children who lost a parent (Silverman & Worden, 1992), while the other two studies explored samples of critically ill and terminally ill adults (Herth, 1990; Miller, 1989). Silverman and Worden (1992) used a conceptual model of adaptation to better understand social and family interactions. Arnold et al. (2005) followed the

lead of an integrated grief theory, while Miller (1989) and Herth (1990) used theoretical models of hope to guide their studies.

All four mixed method studies supported the beneficial nature of continuing bonds. Terminally ill adults in both studies reported that memories and family bonds serve to inspire and build hope (Herth, 1990; Miller, 1989). Similarly, Silverman and Worden (1992) studied 125 bereaved children's reactions after the death of a parent, and these children reported efforts to remain connected with the deceased. Arnold et al. (2005) explored the continuing nature of parental grief, finding that bereaved parents who reported their grief had ended were more likely to still feel strongly connected to their children. The study also suggested that continuing grief can be combined with positive, life-affirming feelings for bereaved parents. Although these four studies differed in the target population of terminally ill adults rather than bereaved children and parents, findings were similar to suggest significance in maintained connections between survivors and the deceased. More research is imperative to determine if continuing bonds could be beneficial to children living with life-threatening illnesses.

### *Methodological Synthesis*

Based on the methodological review, limited conclusions related to continuing bonds can be drawn about the impact of a child's death on surviving siblings and parents. Issues will be discussed, specifically related to theoretical frameworks, measurements, impact, and methodology related to continuing bonds.

Theoretical issues are noted across methodological literature. The Continuing Bonds Theory was included as a guiding framework in 11 out of 26 articles identified related to continuing bonds (Barrera et al., 2006; Boelen et al., 2006; Chan et al., 2005; Davies, 2005;

Doran & Hansen, 2006; Field et al., 2003; Field & Friedrichs, 2004; Riches & Dawson, 1998; Sedney, 2002; Silverman et al., 1992; Wilson, 2001). Other conceptual frameworks used related to pediatric palliative care, coping, bereavement, grief, spirituality, self-regulation, Attachment Theory, adaptation, and hope. This likely accounts for the various outcomes measured across studies. A consistent guiding framework and clear conceptual definitions and outcomes are necessary to advance the science related to continuing bonds.

Measurement issues related to various types of continuing bonds are noted across the methodological literature. Five studies specifically examined continuing bonds, yet various measures were used. Two studies used the CBS (Field et al., 2003; Neimeyer et al., 2006), while Field and Friedrichs (2004) used the Continuing Bond Coping measure. Boelen et al. (2006) developed three continuing bond questions related to presence, possessions, and memories, and Barrera et al. (2006) developed open-ended questions to explore continued relationships with deceased children. Empirical evidence related to how different types of bonds (e.g., physical and spiritual) affect outcomes and how different outcomes account for different types of correlations has yet to be determined. Few studies investigated factors associated with both adaptive and maladaptive outcomes among these families. Because the theory of continuing bonds is a recent development, there is relatively little quantitative data to describe associations between continuing bonds, coping strategies, and grief symptoms.

Third, studies examined continuing bonds as a potential benefit to bereaved individuals. All identified methodologies collected data after a death, except for two mixed method studies focusing on hope in terminally ill adults (Herth, 1990; Miller, 1989). However, one of the spiritual concerns of children is legacy (Gibbons, 2001). Legacies of children may include accomplishments, but also the difference that a child's life has made in the lives of those he or

she has touched. Children need and want to know that they will not be forgotten (Levetown, Liben, & Audet, 2004). For children whose death can be anticipated, efforts to create memories and confirm that they are loved and will be remembered are important. Children who face potential death as a result of a sudden illness (such as trauma, accidents, etc.) may need more innovative approaches to create memories such as making molds of their hand or taking pictures. The use of play, music, or art activities may create such legacies as lasting memories of times shared together (Thayer, 2001). Videos, writings, sculptures, or homemade crafts should also be encouraged as ways to capture a child's spirit. Individuals who care for dying children are in an ideal position to provide opportunities to foster such legacy-creating interventions. The research literature is silent in respect to understanding how continuing bonds can impact children living with life-threatening illnesses. Continuing bonds not only has the possibility of helping parents and siblings cope with the death of child, but may also help the child living with a life-threatening illness cope with the possibility of death. If the child were to also participate in expressions so they would know their bond would be continued in the case of their impending death, they might better be able to cope with living with a life-threatening illness, knowing they might leave behind a legacy that will be maintained.

There is a call for mixed method research related to continuing bonds. Only one mixed method study sampled bereaved children, and while mixed methods were used to address study aims, only qualitative methods explored continuing bonds (Silverman & Worden, 1992). Also, Arnold et al.'s (2005) mixed method study sampled bereaved parents; results associated with continuing bonds mainly stemmed from qualitative items related to the experience of grief versus quantitative items related to loss and grief. Furthermore, these mixed method studies did not specifically measure continuing bonds with quantitative methods, and no identified mixed

method studies used an interview combined with the Continuing Bonds Scale in bereaved parents and siblings who had experienced the loss of a child. A more comprehensive approach to understanding continuing bonds would include empirical knowledge combined with an in depth view of families' experiences via in depth open-ended questions.

Furthermore, across methodological studies, various informants, various time periods since death, various causes of death, and different forms of continuing bonds have been considered. Different measures have been used, and a variety of outcomes have been measured. There appears to be support for the hypothesis that bonds can be continued after an individual's death; however, how survivors continue bonds with deceased children, continuing bonds' impact on coping strategies and grief symptoms, and whether continuing bonds might be beneficial to children living with life-threatening illnesses remain unknown. This project addresses the gaps noted across theoretical and methodological approaches.

### **Research Purposes, Aims, Questions, and Hypotheses**

The overall purpose of the study is to explore continuing bonds in children living with advanced cancer, as well as continuing bonds in bereaved families who have lost a child to cancer. The secondary purpose of this study is to examine associations among continuing bonds, coping strategies, and grief symptoms in bereaved parents and siblings who experienced the death of a child from cancer. Study aims are to 1) examine if and how children with cancer do or say things before they die to be remembered, based on bereaved parents' and siblings' perspectives, 2) examine how bereaved parents and siblings maintain bonds with deceased children, 3) examine relationships among continuing bonds and coping strategies in bereaved parents and siblings, and 4) examine relationships among continuing bonds and grief symptoms

in bereaved parents and siblings. The research questions for this study are: 1) Based on bereaved parents' and siblings' perspectives, do children with cancer do or say things before they die to be remembered? 2) How do bereaved parents and siblings continue bonds with children who have died of cancer? 3) What is the relationship between continuing bonds and coping strategies? 4) What is the relationship between continuing bonds and grief symptoms? No hypotheses are presented for research questions 1 and 2 because of the qualitative nature of the questions. However, for research questions 3 and 4, hypotheses are 1a) continuing bonds will be positively correlated with primary and secondary control coping strategies in bereaved parents and siblings; 1b) continuing bonds will be negatively correlated with disengagement coping strategies in bereaved parents and siblings; 2a) continuing bonds will be positively correlated with positive growth outcomes in bereaved parents and siblings; and 2b) continuing bonds will be negatively correlated with grief distress in bereaved parents and siblings.

This research is paramount to begin filling the theoretical and methodological gaps currently seen across the body of knowledge related to continuing bonds within pediatric palliative care. The current study will advance the state of science related to continuing bonds and, most importantly, improve the lives of this significant and growing population.



## CHAPTER III

### METHODOLOGY

Mixed methodology allowed the researcher to explore continuing bonds in children living with advanced cancer and continuing bonds in bereaved families who have lost a child to cancer, as well as associations among continuing bonds, coping strategies, and grief symptoms in bereaved families. The mixed methods research design will be described, as well as the research setting. Details about the sample are included, including inclusion and exclusion criteria, recruitment methods, and strategies to ensure human subjects protection. Data collection procedures also will be explained, and instruments used to collect data will be described. Finally, analysis of qualitative and quantitative data will be presented.

#### **Research Design**

This study was a simultaneous mixed methods design with one data collection point and was part of an ongoing larger, multi-site Parent-Sibling Bereavement Study funded by the National Cancer Institute. This mixed method design used method triangulation, defined as the collection of different kinds of data to bring clarity to a single complex phenomenon (Liehr & Lobiondo-Wood, 2006). Incorporating both qualitative and quantitative methods to answer the research question allowed for development of a rich and fuller understanding of continuing bonds. Qualitative data were enriched by the addition of quantitative data collected simultaneously. Within this design, different data collection methods gathered information on different aspects of continuing bonds. The study included both qualitative and quantitative data

to provide additional insights and a comprehensive understanding of continuing bonds in ill children and bereaved parents and siblings of children who died of cancer.

### **Description of Research Setting**

The researcher assisted parents and children to complete a data assessment in their homes at a convenient time for them. Another research setting was acceptable if the family was not comfortable for researchers to come to their home, such as a public library or family meeting room.

### **Sample**

#### *Criteria for Sample Selection, Inclusion, and Exclusion*

Data collection sites included three children's hospitals in the southeastern United States, northeastern United States, and southeastern Canada. After Institutional Review Board approval at each data collection site, all children cared for at the three children's hospitals who died of cancer were identified by the pediatric hematology-oncology departments according to each hospital's cancer registries. The healthcare and research teams at each data collection site reviewed this list to determine if the family met criteria for a school-based project, part of the larger Parent-Sibling Bereavement Study. Eligible siblings 1) had a brother or sister who died from cancer between 3-12 months ago; 2) were 8-18 years old; 3) were fluent in English and had an English fluent parent; and 4) lived within 100 miles of the medical center. Adopted, half-siblings, and step-siblings were eligible if the parent reported that regular ongoing contact occurred between the sibling and the deceased child. Biological parents and step-parents living

outside the home also were eligible to participate if regular contact was maintained with the child. These criteria allowed for families to determine who was significant and knowledgeable of the deceased child and remaining sibling.

### *Methods for Subject Recruitment*

As part of the larger study, each deceased child's attending physician sent a letter to parents of siblings who met inclusion criteria between 3-12 months after the death. The letter stated that the family would be contacted soon regarding a study about sibling bereavement. A toll-free number with 24-hour voicemail was provided for families to leave their name if they did not wish to be contacted. Two weeks after the letter was mailed, the researcher phoned parents to describe and request permission to complete the school-based study. If there were more than one eligible sibling in the family, one child was randomly selected using a random number table.

After recruitment, home visits with bereaved families were scheduled. The researcher, along with project directors from the other two data collection sites, called families with a description of the home assessment according to a telephone script, seeking permission to come to the home to complete the consent form and home assessment.

### *Human Subjects Protection*

Informed consent was obtained from each participating parent at the beginning of the home visit, and assent was obtained from the child. Upon arrival to the family's home, the researcher provided parents a copy of the consent form and children a copy of the assent. The researcher reviewed the form aloud and answered any questions from the family. Parents provided informed consent, and children provided assent by signing the form. As families

disclosed protected health information relating to them and the deceased child, they were told that the study was a multi-site project and that their data would be shared with collaborating sites, including the data management center.

The researcher explained to parents and children that expected risks from the study might include feeling upset by answering certain questions about their loss. If any questions were upsetting, those items could be skipped, and breaks were encouraged during the visit at anytime. The project was described as being voluntary, and parents and children could stop at any time. The researcher had a background in pediatric nursing and, along with all research assistants, completed training related to the larger study and attended weekly interdisciplinary research team meetings to maximize sensitivity when working with bereaved families.

## **Data Collection Methods**

### *Procedures*

This project was part of the home-assessment phase of the larger study. Two researchers attended each home visit, one working with the sibling and one working with the parents. The larger study asked parents to complete a set of 14 questionnaires and asked children to complete a set of 11 questionnaires, both followed by a concluding interview. The visit took about 2.5 hours to complete for parents, and about 2 hours for children. Three questionnaires and two interview questions administered during the larger study made up this project. Measures were presented individually, and both primary caregivers in each family were encouraged to participate.

## *Instruments*

Bereaved children and parents individually completed the following measures with the help of the researcher:

### *Continuing Bonds Scale (CBS)*

The CBS was administered to bereaved parents and siblings 10 years and older (see Appendix A). This instrument measures different ways in which bereaved individuals maintain psychological connections to the deceased (Field et al., 2003). The scale consists of 20 items rated from 1 (not at all true) to 5 (very true). Items initially applied to bereaved spouses, but the larger study edited items to apply to bereaved parents and siblings. Items reflect various ties to the deceased, including memories, keeping possessions, sense of presence, identifying with the deceased, and reminiscing. Internal consistency for the CBS used with bereaved spouses was found to be .87 (Field et al., 2003), and scores in this study had an internal consistency of .93.

### *Responses to Stress Questionnaire (RSQ)*

The RSQ is a 57-item measure of context-specific stress and voluntary and involuntary response to stress, shown in Appendix B (Connor-Smith et al., 2000). Items are rated from 1 (not at all) to 4 (a lot) indicating the frequency of responses enacted by the individual. In this study, bereaved individuals 10 years of age and above completed a grief specific version. Five types of coping have been factor-derived: primary control engagement, secondary control engagement, voluntary disengagement, involuntary engagement, and involuntary disengagement (Connor-Smith et al., 2000). Previous studies by Connor-Smith et al. have demonstrated internal consistencies for the five factors ranging from .73 to .92 across three samples. In the current study, internal consistencies ranged from .79 (secondary control engagement) to .91 (involuntary engagement). Concurrent validity has been shown through correlations with another coping

measure, heart rate reactivity, and self and parent reports (Connor-Smith et al., 2000). The RSQ has been used previously with children exposed to chronic illness and other stresses.

#### *Hogan Grief Reaction Checklist (HGRC)*

The HGRC was used in this study to assess grief symptoms of bereaved parents (see Appendix C). This 61-item measure examines a variety of grief symptoms experienced by bereaved individuals (Hogan et al., 2001). Items are rated on a 5 point Likert scale from 1 (does not describe me at all) to 5 (describes me very well). Correlations between the HGRC and another grief measure, the Grief Experience Inventory, show concurrent validity (Gamino et al., 2000). If desired, the measure may be used to produce six factors assessing despair, panic behavior, blame and anger, detachment, disorganization, and personal growth. Alpha levels ranging from .79 to .90 have been shown for the six factors in previous literature (Hogan et al., 2001). Hogan et al. also demonstrated construct validity by measuring intercorrelations among the six factor scores. Statistically significant inverse relationships were demonstrated between personal growth and each of the other negative subscales. Data from the current study demonstrated inverse relationships between personal growth and each of the negative subscales; however, some of those correlations were very small and none were statistically significant. For this study, grief distress (49 items) and personal growth (12 items) scores were used. The grief distress score was calculated by summing the five negative subscores of despair, panic behavior, blame and anger, detachment, and disorganization. Similarly, previous studies summed the five negative subscores to give an index score called “grief misery,” which demonstrated solid concurrent validity (Gamino et al., 2000; Riley, LaMontagne, Hepworth, & Murphy, 2007). In the current study, the internal consistency value for the grief symptom score was .95, and the alpha value was .83 for the personal growth factor score.

### *Hogan Inventory of Bereavement (HIB)*

The HIB was used to assess grief symptoms for bereaved siblings 10 years and older in this study (see Appendix D). This measure is a 46-item self-report measure for grief symptoms rated for the past 2 weeks on a scale of 1 (does not describe me) to 5 (describes me very well) (Hogan & DeSantis, 1996b). It has been adapted for use with children and adolescents and produces two factor derived scales: grief distress (24 items) and personal growth (22 items). Previous studies depict internal consistencies of .91 for the grief subscale and .92 for personal growth (Ens & Bond, 2005). In the current study, the internal consistency alpha value for the grief factor was .89; for the personal growth factor score, the alpha value was .93. Ens and Bond (2005) found a positive, but not statistically significant, relationship between grief and personal growth ( $r = 0.12, p = .21$ ). A similar level of association and lack of statistical significance was found in the current study ( $r = .169, p = .291$ ).

### *Concluding Interview*

The researcher asked six open-ended questions at the conclusion of both parent and child interviews, as part of the larger study. Two of the six questions explored continuing bonds and were used for this project (see Attachment E). These discussions were audio-taped for later coding and stored with coded data in locked cabinets on site. Cassette tapes will be destroyed five years after the larger study's conclusion.

## **Data Analysis**

Data analysis addressed qualitative and quantitative data. Qualitative data included participants' responses to two open-ended questions. Qualitative data analysis began with data collection as the researcher conducted interviews, carefully "listening" to what was seen, heard,

and experienced to discover meaning. Interviews were transcribed verbatim by research assistants at each data collection site. Research assistants followed the same guidelines to transcribe interviews, and transcripts were double-checked for accuracy by the researcher and site project directors. Completed transcripts were uploaded to a secure digital drop box where the researcher accessed all transcribed interviews.

Content analysis explored how bereaved parents and siblings maintain bonds with deceased children, and if and how children with cancer do or say things before they die to be remembered. According to LoBiondo-Wood and Haber (2006), content analysis is defined as a research method used to analyze and accurately report combined subject responses. The purpose of this method is to provide knowledge, offer new insights, represent facts, and develop practical guides to action. Hickey and Kipping (1996) suggest that content analysis is a structured approach to analyzing data from open-ended questions. Furthermore, content analysis has been a popular data analysis method in past studies related to end-of-life care (Hsieh & Shannon, 2005). Content analysis of qualitative data in the current study included six main steps: 1) immersion, 2) manifest content analysis, 3) identifying preliminary categories, 4) latent content analysis, 5) category checks and reaching consensus, and 6) developing a formalized narrative description.

Immersion involved repeatedly reading the transcripts and gaining a sense of the data as a whole. The researcher highlighted words from transcripts that captured key thoughts and made notes of her first impressions in the margins. Beginning with 15 transcripts, she clustered similar ideas together within excerpted quotes, focusing on manifest content analysis; manifest content refers to what the text says and describes the visible, obvious components (Berg, 2004). Preliminary categories emerged, and suggestions developed for category names. Using email, the researcher then sent the suggested coding scheme and excerpted quotes to two experts in the



field of palliative care and qualitative research. Both experts' research programs focus on enhancing care of children with life-threatening conditions. These individuals demonstrate excellence in scholarship and research as recognized by colleagues at national and international levels. They continually disseminate knowledge from their programs of research and have extensive qualitative methodology experience. They each have sustained programs of research with external funding and make significant contributions to the field of pediatric palliative care.

The three researchers had conference calls every two to three weeks over a period of four months to discuss the rationale for emerging categories, enhancing dependability of data. At this stage, the first researcher re-examined data by recoding original transcripts, making any changes agreed upon during conference calls (e.g., editing category names, exploring new categories, combining categories, dividing categories into subcategories). Then the researcher added 15 new transcripts to the coding scheme, adding new codes when encountered data did not fit into an existing code. In contrast to manifest content analysis, the researcher refocused to latent content after analyzing 30 transcripts. Latent content refers to relationship and involves interpreting underlying meaning of the text (Berg, 2004).

Latent content analysis continued throughout the rest of data analysis. The researcher kept operational notes, or memos containing directions to oneself with questions, possible comparisons, and leads for follow up (Strauss & Corbin, 1990); these frequent memos tracked important thoughts and ideas about the data without assigning premature category labels. Memos also tracked the researcher's decision trail, enhancing reliability of the data. Rogue responses, those that did not seem to fit into any existing category, were identified as "other" and reconsidered each time transcripts were recoded.

The three researchers continued to have conference calls every two to three weeks to decrease the risk of inconsistency and to discuss various data interpretations, reducing the likelihood of bias and assumptions being made. Each conference call also included category checks. The second and third researcher noted any discrepancies within the coding from the first researcher. For example, the first researcher initially viewed visiting the cemetery as part of remembering the child through special locations. However, expert researchers viewed the cemetery as different from other locations, allocating the cemetery to one category and other locations to another. After discussing this discrepancy, all three researchers agreed that “visiting the cemetery” was one emerging theme, and “locations the child occupied when he or she was alive” was another. The three researchers repeated this analysis process until they all reached consensus and no new categories emerged. The first researcher then examined all data based on the final coding scheme.

Finally, the first researcher typed findings in narrative form, presenting each major category and including respondents’ quotes to augment conformability. Narrative form allowed the researcher to note a few coding discrepancies. These discrepancies were reallocated to appropriate categories and were discussed and agreed upon by the other two researchers. A formalized description of participants’ responses emerged from content analysis, addressing 1) if and how children with cancer do or say things before they die to be remembered, from survivors’ perspectives, and 2) how bereaved parents and siblings continue bonds with children who died from cancer.

Quantitative correlation techniques determine relationships between two or more variables, as well as strength and direction of the relationship (Munro, 2001). Therefore, the researcher chose correlational analyses to test hypotheses among continuing bonds, coping

strategies (primary control, secondary control, and disengagement), and grief symptoms (personal growth and grief distress). Figure 4 hypothesizes that correlations exist among continuing bonds, coping strategies, and grief symptoms. More specifically, this model predicted 1) positive correlations between continuing bonds and primary and secondary control engagement coping strategies; 2) negative correlations between continuing bonds and disengagement coping strategies; 3) positive correlations between continuing bonds and personal growth; and 4) negative correlations between continuing bonds and grief distress.

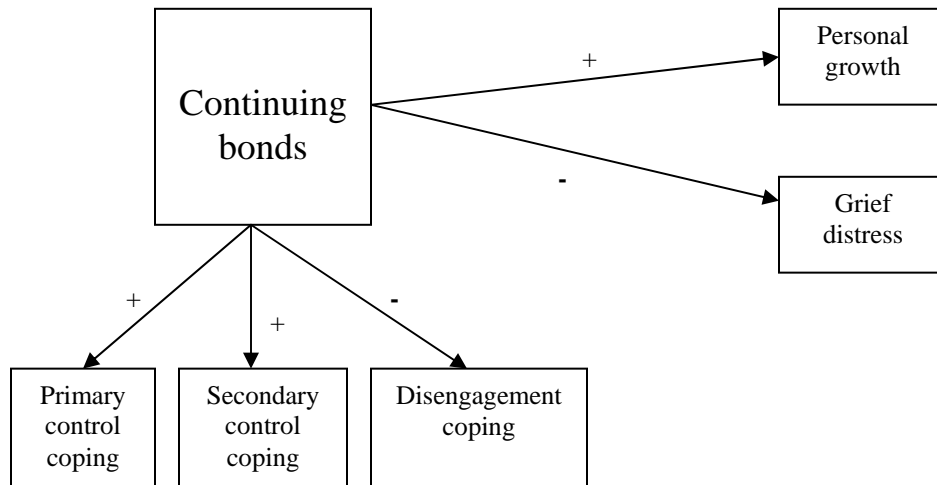


Figure 4. Correlational hypotheses

Quantitative data included participants' responses to the study questionnaires. Individual item responses and scored data files were obtained from the larger study's data management center. The researcher used SPSS to conduct the quantitative data analysis. Inspection of the score distributions revealed that some of the study variable data values were not distributed normally to the extent that parametric assumptions were not met. Thus, the researcher used

Spearman's rho correlation coefficients to assess associations among the questionnaire scores.

For bereaved parents, associations were examined between 1) CBS and RSQ scores, and 2) CBS and HGRC scores. For bereaved siblings, results were analyzed between 1) CBS and RSQ scores, and 2) CBS and HIB scores. If both mother and father participated from the same family, their responses were averaged together. Scoring programs for each measure allowed for minimal missing data. All tests of statistical significance used a maximum alpha level of .05.

Correlational analyses addressed the study's secondary purpose by examining relationships among continuing bonds, coping strategies, and grief symptoms in bereaved parents and siblings of children who died from cancer.

## CHAPTER IV

### FINDINGS

Participants included 107 bereaved parents and siblings who participated in the larger study. Forty-one families of children who died of cancer comprised the sample, with 18 families recruited from a children's hospital in the southeastern United States, 10 families recruited from a children's hospital in the northeastern United States, and 13 families recruited from a children's hospital in southeastern Canada. Data collected in families' homes were demographic information, responses to interview questions, and responses to questionnaires (CBS, HIB, HGRC, and RSQ). Sample characteristics and qualitative and quantitative findings will be presented.

#### **Participant Characteristics**

The researcher collected sample characteristics from bereaved parents who completed a demographic questionnaire and from deceased children's medical records. Participants represented 41 families and included 41 siblings, 28 fathers, and 38 mothers, with mostly White and Non-Hispanic individuals (see Table 1). Racial distributions of the sample reflect state and province distributions from the U.S. Census (2006) and Statistics Canada (2001). Fathers averaged 43.57 years old, mothers averaged 40.45 years old, and siblings averaged 12.64 years old. Deceased children averaged 11.38 years old, and their cancer illnesses averaged 33.9 months. Data collection occurred approximately one year after the death.

Table 1. Family Characteristics

Bereaved Parents		
	Mean (SD)	Range
Age in years		
• Father's	43.57 (7.72)	32-63
• Mother's	40.45 (7.82)	27-61
	<i>N</i>	%
Gender		
• Father (Male)	28	42.4
• Mother (Female)	38	57.6
Race		
<u>Father's</u>		
• White	22	81.5
• Black	2	7.4
• Asian	0	0.0
• Other	3	11.1
<u>Mother's</u>		
• White	29	76.3
• Black	5	13.2
• Asian	2	5.3
• Other	2	5.3
Ethnicity		
<u>Father's</u>		
• Non-Hispanic	24	92.3
• Hispanic	2	7.7
<u>Mother's</u>		
• Non-Hispanic	34	94.4
• Hispanic	2	5.6
Bereaved Siblings		
	Mean (SD)	Range
Age in years	12.54 (2.65)	8-18
	<i>N</i>	%
Gender		
• Male	16	39.0
• Female	25	61.0
Race		
• White	29	70.7
• Black	6	14.6
• Asian	2	4.9
• Other	4	9.8
Ethnicity		
• Non-Hispanic	39	95.1
• Hispanic	2	4.9

Table 1, continued

Deceased Children		
	Mean (SD)	Range
Age in years	11.38 (5.33)	0-21
Months from diagnosis to death	33.90 (28.63)	2-128
Months since death	12.61 (5.77)	6-35
	<i>N</i>	%
Gender		
• Male	22	53.7
• Female	19	46.3

### Qualitative Findings

The researcher collected qualitative data from bereaved parents and siblings responding to two open-ended questions (see Appendix E). Findings included ill children doing and saying things to be remembered, as well as survivors maintaining connections with deceased children.

#### *Ill Children Doing and Saying Things to be Remembered*

Children with advanced cancer did and said things before they died to be remembered. Four major themes emerged: 1) Some children living with cancer did and said things to be remembered, 2) some children living with cancer did not do or say things to be remembered, 3) survivors remembered qualities of deceased children, and 4) legacies resulted in inspiration for survivors and children living with advanced cancer. Each of these major themes will be presented.

## *Children Doing and Saying Things to be Remembered*

Some children living with advanced cancer did things to be remembered, including making crafts for others, willing things away, writing letters to loved ones, and giving special gifts. One father talked about what his ill child did so they would be connected:

One of the things...that she did for me was we went and got matching rings. She has hers, and I wear mine on the same finger.... It was just something that she did, you know for me. [The deceased child] wanted a little connection kinda thing. I assured her that one day I'll be with her again and see her again, and that will be a sure way that I could recognize her if we had matching kinda stuff.

The majority of children gave away things, such as personal belongings. "She told me that she wanted me to have her teddy. Her teddy bear, her favorite stuffed animal.... It was very important. I have it in my bedroom, on my bed." A sibling talked about the belongings his brother left for him:

He left his games behind. (Int: Do you think he left games behind in order to be remembered by...do you think it would be something that he would have liked to be remembered by?) Yeah, I think so.

Another sibling said her deceased sister gave her some personal belongings: "She gave me lots of stuff. She gave me like a bunch of old t-shirts because she loved t-shirts. Those are special." A mother told about her son giving away his personal belongings:

Did he will his stuff out? Yes he did...yes he willed his CDs and his tape player to (sister), his sister. His clothes, he wanted his cousin to go through his clothes and pick out his clothes that he wanted. Wanted them to have his clothes...there were some particular toys that needed to go to the cousins and you know that kind of stuff...he gave me a particular necklace that he wanted me to have, that was his, a cross one, and just different things like that.

Survivors also described how ill children, when they were alive, made special gifts for their loved ones:

Yeah, he did [made] a cement stone, like a stepping stone. And he put sign language 'I love you' and he put like 'sis' on the bottom.... He did it for my mom, my dad, my grandma, and good friends of his.



One child explicitly talked to her mom about giving away some personal belongings so others could remember her:

One thing that me and her did before she passed...we talked about her belongings. And each one of her nurses was to have a specific toy that she had. And she told me, she says, "Mommy, you have to give it to them after I am gone. And they have to know that I wanted them to have this to remember me."

Very few children explicitly said their intent was to be remembered, yet their actions implied that they wanted to be remembered. One child made crafts for others, but the mom did not perceive it was with intent to be remembered:

We never had like the one moment to talk about that. But so, she made these crafts...flowers out of paper. We have that as a token of her. (Int: So even though she didn't do it purposely to be remembered by...) No, no, no. But she just made it there (hospital) and she goes, "Okay, mommy, I thought you'd like one." Or when her aunts would come or her cousins, she actually made some for them, too. (Int: So she wasn't aware that she was passing, but she made things for everybody?) Yeah. Yeah.

Similarly, one sibling did not mention the ill sister doing or saying anything to be remembered, yet the sick child desired to be remembered: "She said, '...All that I care for is that you remember me and don't forget me.'" Some parents described ill children's fears of being forgotten: "One of her [deceased child] biggest fears was, 'What if (younger sibling) grows up and she doesn't remember that she had a big sister named (name of deceased child)?"

#### *Children Not Doing or Saying Things to be Remembered*

While many children living with advanced cancer did things to be remembered, other children did not because of their illness, age, or unexpected death. One sibling stated her sister "couldn't" do or say anything to be remembered. Another sibling shared about her brother's unexpected death:

We didn't know he was going to pass away so quickly. When my mom was talking to him about making a will or whatever, he said he wasn't ready for that. And she felt we could, that he could wait a little bit longer cause they thought he was gonna pass away at the end of the summer, but it ended up he sort of ended up passing away in the middle of

the summer. And so because it's so abrupt, he never actually told anybody, you know, about this and I want you to think of me when you look at this and that kind of stuff.

Some survivors perceived children with advanced cancer did not know they were dying, and therefore did not do or say anything to be remembered:

I don't think he knew that he'd be going. I don't think he realized. I don't think he ever really realized he was really sick. I mean, it was just always a part of going to the hospital. He never really asked why his whole life. Yeah...I don't think he really realized that he was sick or anything.

A father's child died suddenly, but he also did not want to discuss death with his child:

You know we never discussed these things with (deceased child)... We never talked about death and dying to him. And I didn't want to. It was, I didn't think it was appropriate.... I didn't want him to have those thoughts. I didn't want him to be scared. As it turned out, it happened suddenly, and maybe that was for a reason. I don't think he ever knew that this was gonna take his life.... I don't know that he ever thought about dying. I really can't say with confidence that he did.

Some ill children did not want to talk about death:

He didn't really want to say talk about his death at all. He didn't want to talk about it, he didn't want to think about it. He just wanted to get on with doing whatever he was going to do that day. And never really, you know, I would ask him if he wanted to talk about anything or if he had any questions or anything and he would always say "nope" and change the subject. So I mean certainly he is known for a lot of things, and I don't think he'd done them with the intention of being remembered, but that's how it evolved.

The father of the same child said, "(Deceased child) didn't really wanna talk about life without him living."

Other survivors claimed ill children did not need to do or say anything to be remembered:

"I think she was well aware of how deeply loved she was. So she didn't need to leave anything behind." Another mom said, "I asked her actually if there was anything that she wanted me to relay to anybody, and she said, 'nope' cause everybody knew it from her that she loved them.... She never wanted to be famous or anything, but she wanted to be remembered."

One sibling shared how his brother living with advanced cancer desired to do something to be remembered. However, he realized before his death that he had already left behind a legacy, so he did not have to do anything on purpose for others to remember him:

Before he died, he told me and his girlfriend and mom. He goes, “Before I die, I want to carry out a legacy or do something that nobody else has ever done.” Then, 2 weeks later he goes, “You know, I have carried out a legacy. I’ve been like a dad to (sibling), and I’ve treated him like one more than the real dad did.” And he goes, “I’ve already done what I needed to do.”

### *Survivors Remembering the Deceased Child*

Although most bereaved parents and siblings reported that children living with advanced cancer did not purposely do or say things to be remembered, survivors did remember qualities of deceased children, deceased children’s concern for family, and deceased children’s belief about afterlife.

*Qualities of deceased children.* Bereaved parents and siblings remembered qualities of deceased children. Some survivors shared these qualities explicitly, while others told snapshot stories to illustrate such qualities. Many respondents, especially bereaved parents, remembered qualities by explicitly expressing things about children’s characters. A father talked about the qualities of his deceased child who could not speak or communicate because of his age: “[He] touched a lot of lives in the hospital...and has had a positive outreach to others...reached people all around the world...even with unspoken words.” A mom valued qualities about her deceased child:

The main thing was just his attitude that he left with us.... Anytime you asked him how he was doing it was always “good.” So that was a big, positive thing for use just to see, just to see his attitude through the whole thing. But not really a special message or anything.

Others said their child was “really a great kid” or “such a funny kid,” and many shared their child had a “positive outlook” and was “full of hope.” One father remembered his son’s

inner-strength and courage: “Unintentional was, to me, his inner-strength. He faced it a lot better than I would have...a load of courage.”

Other survivors remembered qualities about deceased children, but rather than sharing these explicitly, they shared snapshot stories which depicted qualities of deceased children.

Stories captured pieces of who the children were:

There was a song.... It was the last thing she ever said and I remember...“Let me see your grill”...and it says “smile for me daddy.” Cause I got my gold (teeth)... So every time I hear that song I always think about her...music...that was her passion.... The last thing she said to me...she smiled and said, “Let me see your grill daddy.” That was the last thing she said to me before she stopped talking. She smiled to me and said that.

One mother remembered her son’s qualities through a story about his love for Dr. Pepper:

One time he was on the couch, this was before he, this was maybe a month, but he was not feeling well and he turned blue and we really thought he was gonna die right then. And we were talking, and he was asking if he was gonna die, and I said kinda looks like you are and whatever, so he was like, “Well, Mom,” this was his request (laughs), “Mom, so you think I can have some Dr. Pepper before I die?” Yep, so it was just kind of a funny thing. I mean he didn’t...it was you know almost a month I guess passed that time (until his death), but it was just funny because, anyway, he loved Dr. Pepper.

This mom told another story about her son’s requests related to his death. The story encapsulates part of the child’s qualities and character:

Yes, he had special requests. He did. As a matter of fact, he wanted to be buried underneath the tree in the backyard. We didn’t do that. He wanted to know if the hearse was gonna pick him up in a big car, and if it was, I suggested it was, he said, “Well, okay, well have them peel out for me cause I wanna peel out.” So they peeled out of the drive. Yeah, crazy stuff.

One sibling told a story about a sister:

Here’s one thing we can’t forget about her. (Name of deceased child) ate all the muffins. And...every time my mom opened the pan cabinet, and she saw the empty muffin pan, she always blamed it on me for eating all the muffins.

*Deceased children’s concern for family.* Not only did survivors remember qualities of deceased children, bereaved parents and siblings also remembered deceased children’s concern

for family. Many participants conveyed that deceased children needed to know their loved ones would be ok: “She needed to know that I was going to be ok.” A mother shared how her child told her it would be ok: “Momma it’s ok, it’s ok.” One parent said her child’s concern for her was really helpful: “He did ask me if I was going to be ok. So that was pretty helpful.”

Many survivors said their ill child told them, “I love you.” One mother remembered her child telling her, “You know I love you. I really love you. Don’t you ever forget that.” Similarly, a father said, “The night before he passed away...he just told me he loved me and goodnight, and that’s about the last, the real positive thought.” A sibling also shared, “She said she loved me, and then I had to sing this crazy song for her.”

Other bereaved family members said their children were only concerned for others, not themselves: “He was just concerned about us.” One mother expressed how her son prayed for everyone but himself:

He prayed a lot...asking for blessing from God. For everybody. But one thing is so weird that he never included himself in that. He says that I ask God to have mercy on you, and Mom and Dad and everybody in the family, in hospital, all the people who worked and everything, but he never asked anything for himself.

Likewise, a mother said her child always thought of others: “He always thought of someone else other than himself...always made the nurses laugh, always cutting up with them, made (doctor) laugh.” Another mother expressed how her child focused on her when she passed away:

I think she did something to be remembered. I think that in the end, I was holding her like this and her eyes should have been straight ahead because she had lost the ability to move her eyes. But her eyes were over at me. I think she was focused on me when she passed away. I believe that.

*Deceased children’s belief about afterlife.* A large number of survivors recounted deceased children’s belief about an afterlife. Many talked about children believing they would go to Heaven or be with Jesus after they died. A mother remembered her daughter’s view of the

afterlife: “Nine days before she died, she told me that she was going to go be with Jesus soon.... She said ‘God’s put peace in my heart.’” Another mother shared how her daughter’s belief about the afterlife was a message of peace and comfort:

She told me not to worry about it, that she was going to make it all right with her friend. She went to Care-a-Lot Heaven. And knew she was going and told me that I would be there to meet her at the spot when it was my time to go. So she knew she was going. And I’ll never forget that. Being able to know that she would not forget me. Because she would be waiting for me at the spot. Knowing that, I knew she was going to be fine.

Other parents found comfort in remembering children saying they were going to Heaven: “He told us that he was going to sleep and that he was going to Heaven. And that was great comfort.” Another mom said, “She was ready to go home and be with the Lord.” While some parents recalled their child’s belief about Heaven or Jesus, one mom said she is not worried because she knows her child is okay wherever she is:

I knew that she was really gone. She gave me a very big smile, so I know that wherever she is, she is okay and she was telling me that “Mom, its okay.” That’s why I’m not worried. I know she’s okay and I know she wanted to be okay with whatever or however.

Finally, a bereaved parent remembered a special message her son left for friends related to his certainty about life after death: “If I don’t come home, don’t feel sorry for me, be envious of me.”

### *Effects on the Ill Children and Survivors*

Outcomes from ill children doing and saying things to be remembered included both inspiration for the ill children and survivors.

*Inspiration for the ill children.* Ill children were inspired from their personal experience of living with cancer. Living with cancer inspired children to impact others’ lives. One mother expressed that her child “really made a strong impact on a lot of people, because of his strong faith and trust in God to be in control and do what He knows is best for everybody.” Another

bereaved parent said his daughter not only had a huge impact on others, but believed her cancer was worthwhile to lead others to the Lord:

I've never seen anyone that had an effect on so many people so young without any effort.... I mean...she said in her letter...she said, "...I'd like to be well but I am not. And if my sickness in any way causes someone to come to Lord, to get close to Lord, then it's worth it all...."

Cancer also inspired ill children to prepare themselves for death. This mostly included telling loved ones their wishes and asking where they would go if they died. One mom told how her ill daughter asked questions about dying:

We had our Pastor (name of pastor) come in and talk with her...because she had a few questions about dying. Spiritually, [the ill child asked], "Really, what happens now? I mean, you have to tell me the nitty gritty because we are getting down to this point." She was concerned [with] what was going to happen. So he [the pastor] just said, "...it's not like you're going to be laying down here waiting in darkness for God to come get you. It's more like Jesus will pick you up when you are still alive and hand you up." When she knew that...she was like, "Fine. I'm not afraid to die. I mean if that's how its going to be, I'm not afraid to die."

One child living with advanced cancer wanted a particular gift so she and her loved ones could all be angels. According to her mom, she said,

Mom I want you to buy this for me, you know, her, me, and (other friends) and all their friends because they're wings, it's like angel wings for a Christmas present for them so we can all be angels.

On the other hand, some ill children were inspired by cancer to prepare others for their death. One mom said her son said things that seemed like "intuitions" or "warning signs":

He said, "I won't be back".... And he's like, "But I won't have a chance to get macaroni and cheese again".... And he wanted me to sleep with him that night.... Maybe he knew.

A child said his or her ill sibling knew he was going to die:

He kept pushing us.... It comforted my mom a lot when he knew...when he told us, he knew he was gonna die. He told us to wear bright colors and not black....

*Inspiration for survivors.* Terminally ill children were inspired to live their lives differently because of their cancer. Survivors remembered ill children's advice for how to live life, usually from things that children said. Compared to previous triggers that resulted in comfort and staying connected with deceased children, ill children's advice inspired survivors for how to live life in the moment. One mother was inspired by her son's resolution:

As part of our New Year's ritual, we would make resolutions within our family, and for the last 2 years, his was to have a good laugh every day. So, of course, that has become the motto attached to (deceased child) with everybody. So he didn't say it with that intent. It was truly what he wanted to do, but it's become his legacy....

One ill brother left a message with his sibling about how to live life: "He was always telling me to work harder on things and do better." Another ill child told his sibling, "Give everything you have and everything." A mom found guidance through her son's message about complaining:

Somebody [my niece] was complaining. He looked at her and goes, "(Name of niece), I'm dying. Do you hear me complaining?" And, when I even think about complaining, I'll stop myself.

Many ill children's messages about how to live life were related to God. One father described his teenage son's special message to a crowd at school. From the pitcher's mound of the school baseball field, the ill child said, "Jesus died on the cross for our sins, and I thank God for that." One mom carried on her son's legacy. She said her ill son always had a special message: "His legacy he left was, 'Do you know God?' He did this to everybody that he ever met.... He would get the conversation around to God." At the end of her interview, the mom was asked if there was anything else she would like to share. She said, "Do you know God?"

### *Survivors Maintaining Connections with Deceased Children*

Bereaved parents and siblings maintained connections with children who died from cancer. Three major themes emerged: 1) Bereaved parents and siblings purposely chose triggers



to remember deceased children, 2) bereaved parents and siblings experienced nonpurposeful triggers that reminded them of deceased children, and 3) survivors experienced both comforting and discomforting effects from reminders of deceased children.

### *Purposeful Triggers*

Bereaved parents and siblings chose triggers that reminded them of deceased children. Choosing triggers was a purposeful, voluntary, and conscious action. Nine purposeful triggers were evident. Many survivors chose visual representations of deceased children, such as photographs; some kept ashes of deceased children. Bereaved parents and siblings also visited locations children occupied when they were alive or chose to be with deceased children's personal belongings. Others visited cemeteries and engaged in activities to honor the deceased children. Finally, most respondents chose to communicate with deceased children, think about deceased children, and do things the deceased children would have liked or chosen.

*Visual representations of deceased children.* Bereaved parents and siblings often chose visual representations to remind themselves of deceased children. A few survivors talked about shadowboxes and paintings, but the majority of visual representations included photographs, videos, and scrapbooks. Photographs were most commonly chosen by survivors. A father described his experience of voluntarily choosing to keep and look at pictures of his deceased child: "I think about him all the time and have pictures of him around and always stop to look at those.... I like being reminded of him. I like talking about him, I like, to me all of that keeps him more alive." Another parent shared similar thoughts of how she keeps her deceased child's picture in every room: "I do like to keep his picture, it's up in every room, [I] kind of still incorporate it that way."

Participants most often chose to keep photographs of deceased children, but some chose to keep videos. One mother said, “Her movies, her pictures. If I didn’t have that I think I would go crazy. I really would.” Another mom chose to watch videos to remember her deceased child:

Just occasionally we’ll listen to a video just to hear his voice. It is, because I’m worried that I’ll forget. It’s very difficult. But I do worry that I’ll forget what he sounded like...and, and what he looked like and smelled like. Those are things I think about a lot. And so then looking at the videos of him – not very often but just after weeks that are hard – it helps me remember just the little sound of his voice and his little, you know, like his...the way he said something, just his motions, just who he was.

In addition, visual representations included teddy bears, which were especially chosen by siblings. One sibling chose “a teddy bear with his picture on it.” However, another child chose the bear itself to represent the deceased sibling:

When he was in third grade and he didn’t go to any school, (the hospital) sent our classroom a big teddy bear to put in his seat for him, so we got to keep him. His name is (name of deceased child)...so, I talk to him sometimes and it feels just like I’m talking to (deceased child).

*Keeping ashes of deceased children.* While keeping visual representations allowed survivors to embrace memories of deceased children, bereaved parents and siblings maintained part of deceased children by keeping the children’s ashes. One mother shared how she holds her son and talks to him:

At first I’d come out here and get his ashes and take them out and sit – well, I was holding him in this chair and just sitting here and rock.... I don’t so much do that anymore, as often. I’ll walk by and kiss his little container thing and try to say goodnight to him every night when I go to bed.

Another mother talked about how maintaining the ashes allowed her family to keep part of the deceased child:

We planted a tree at my parents’ house and scattered some of his ashes out there. It’s kind of been made into a garden, so the kids get to go out there and decorate it, and you know, they can go out and talk to him if want or just visit.... We have his, he was cremated, so we have his ashes by the fireplace there. And so, that was important to (10 year old sibling) – I tried to explain what it meant to have his ashes. So he is, so we can keep him

here with us. (Ten year old sibling) thought that was kind of neat. And soon after the funeral, we had a tornado warning so we had to go downstairs, and he (10 year old sibling) was very insistent that we had to take (deceased child) down with us.

*Locations children occupied when they were alive.* In addition to survivors choosing to keep part of deceased children by holding on to ashes, many bereaved parents and siblings chose to visit specific locations deceased children occupied when they were alive, most commonly deceased children's rooms. Siblings especially chose children's rooms as reminders. One sibling said, "...when I want to go, when I want to think about him I go and hang out in his room, so that's what I do. Just think and look at his stuff." Another sibling chose to play in the deceased child's room: "Sometimes I just like walk into his room and play with my little brother. In his room. It kinda makes me remember him when he was in our house and stuff." Some siblings slept in deceased children's beds:

His room is right across from me.... (Int: Do you go in there?) Oh yeah. Yeah.... Even when he was alive, and now that he isn't alive I always sleep in his bed cause he has this really cool mattress. It's nice and comfy. Yeah, it's comfy and nice and warm.

Bereaved parents chose to keep deceased children's rooms intact as way to remember them. One parent described the child's room:

His room is still the way he left it. He managed to get connected with a lot of celebrity kinds of people...he has a lot of autographed stuff.... He just met a whole lot of people. So we've kept all that autographed stuff in his room just the way he had it and so forth.

For some parents, their homes served as reminders of deceased children. The houses held many memories since they lived there in the past: "As you can see that the house is just (name of deceased child) this, (name of deceased child) that."

Another mother explained how their family chose a familiar holiday location to remember their child: "We went on our holiday, we went to that place we had all decided, as a family last year that we would go to and had been there last summer as well...so we talked a lot

about (deceased child) while we were there.” Additionally, one father chose to hike on the same trails he and his child used to hike on together:

I have those times I like to get away. Go places that he and I went and enjoy time alone. And at that time I feel more with him.... But I like to hike and there was hikes that I go on and particular trails that he was with me, and I recall those and I, I stop and, you know it, it’s a time of meditation and reflection, and I feel close to him then.

*Being with deceased children’s personal belongings.* Bereaved family members also chose to be with deceased children’s personal belongings, including bedding, clothing, and toys. Siblings especially talked about holding on to toys that belonged to deceased children. One sibling stated, “I bought him a Thomas Train toy and now it’s up in my room. I keep it on my bed. I have some of his toys.” Another sibling shared, “Her bed’s right beside mine, and all of her stuffed animals are there.” Siblings “...sometimes sleep with one of her stuffed animals.” Another child stated, “...stuffed lamb...I gave him that.... He always slept with that, and my mom let me have it since I got it for him.” Parents also chose toys that belonged to deceased children. One mom said there were “...certain little toys that I would probably never get rid of....” A father talked about keeping one of his child’s toys: “He always liked Thomas. So I have one of his trains.”

Many survivors kept deceased children’s clothes and sometimes chose to wear them. A father said, “We keep her clothes very close to us.” Another sibling shared, “I use her stuff...like whatever she had that I can use. Cell phone or necklace. Her bracelet...sometimes clothes.” One mother talked about wearing her deceased child’s clothes: “I also use some of her clothes...I’ll wear her stuff.”

Family members also kept other personal belongings. A father talked about looking at his son’s car in the garage, as well as touching and feeling other belongings to remember him:

His car's in the garage that I look at, and you know, I even see him backing up and you know, on his way out to see his friends, you know, and wave, and nod, you know the ol' head nod. All of his goods, everything he has is still in his room and you know, we touch and feel those...just anything we can to remember.

Other personal belongings included dog tags. A sibling said he wears his brother's dog tags every day which say, "Rest in peace my brothers" and includes the deceased child's name and date of death: "...That's mostly how I remember him. I wear it everyday."

One mom specifically advised others to keep deceased children's personal belongings: "Choose to keep personal belongings, when you need to smell them or you need to remember." Sometimes, these personal belongings had varying meanings for survivors in the same family. Keeping personal belongings helped one mother, yet it did not help her surviving child, nor was it understood by her boyfriend:

I have two big crates of her stuff in there. Schoolbooks that she's written in, notes that she's written, her favorite coat...when she would lose her hair, the hat things she would wear, I mean just anything like that. Her pencils. Just every little belonging that I could keep, I kept. Having her belongings with me, it makes me feel much better. (Sibling) had a bad time with it for a while. She felt kind of weirded out almost by having (deceased child) around, but it makes me feel a whole lot better. I don't think (boyfriend) understands that, but I have to do it.

*Visiting cemeteries.* While many survivors chose being with children's personal belongings, some chose to visit cemeteries where deceased children were buried: "I go to the cemetery all the time. It helps." One parent visited the cemetery to keep a promise to her deceased child:

I try to go to the cemetery every week. That was my promise to him that on the first day that he passed away...I will come no matter what. I feel that he's there, but I still don't believe that he's there. But I just go there that, I don't, his soul is there or something that he knows that I'm still keeping my promise.

Similar to these weekly gravesite visits, another parent expressed, "I try to make regular visits to the gravesites."

Many bereaved parents and siblings talked to deceased children at the cemetery: “We go to the cemetery twice a week now. We talk to her there, we talk to her there.” A sibling shared the same experience: “I talk to (deceased child). Like I’ll go to his grave sometimes and talk to him.” A father said he talks to his child at the cemetery: “I go to the cemetery and sit down beside him and talk to him still.”

One mother shared a story about a particular visit to the cemetery. She talked about how she, her surviving child, and the dog visited the gravesite on the deceased child’s birthday. She said the dog went right to his grave:

It was like he [deceased child] was calling her [family dog], and she [family dog] went right there.... (Name of sibling) walked over and put the stuff out, put the card down. About that time, the wind blew and the card opened up and it started making music. He said, “(Name of deceased child) already opened his card, Mom.” And so, he knew we were there. He knew.

The cemetery was a place for connection. Not only did this family feel connected with the deceased child, but they perceived the deceased child connected with them through the wind.

In contrast, only a few participants purposely chose not to visit cemeteries. One mother did not think her deceased child was present there. “I don’t visit the, I don’t go to the cemetery very often...because I don’t think of him as being there. So that’s not something that I do.” A father said, “I don’t feel the need to go.... I think that cemeteries are kinda morbid.”

*Activities honoring deceased children.* Many bereaved parents and siblings chose special activities to honor deceased children, such as planning and participating in special events and projects. Some parents started foundations to keep their child’s memory alive: “[We] started a foundation...we’re trying to fund certain research projects...a way that we somewhat stay in touch or keep her memory alive.” Another parent said their foundation was a way to “continue her fight.”

Many activities involved bereaved families giving to the community, for the benefit of others, especially involving sports events. One bereaved family sponsored a soccer team in their child's memory. Another family funded a scholarship in memory of their deceased child: "She was a competitive swimmer...and so we're still doing that. We've got a fund for a scholarship in her name. And they're gonna name our spring swim meet after her."

Others created a website or ran marathons to remember deceased children. One mother chose to create a website from birthday money she received from her deceased child:

I made a website just a few days before his 12<sup>th</sup> birthday.... Last year for my birthday he gave me \$50 and he said, "Mommy, you can go buy anything you want".... I didn't know what to give him. Then I came across this website and it cost me \$50....

A father remembered his child while training for marathons:

I go out and exercise – I've run two marathons – and I do that for the training...buying an I-pod and putting it on and getting lost in the music and hearing the spoken Word and hearing Bible verses and all kinds of things. And I just think about him a lot during that....

Many bereaved families also chose memorial events, especially on deceased children's birthdays. A father worked on special projects to remember his child:

I work on some things...like we had a kind of memorial thing for him on the anniversary of his birthday.... Also, I've kind of been working on this little scrapbook project related to (name of deceased child) as well.

A sibling said the family held a "candlelight service one time in our backyard for him." One mother explained how sending up balloons allowed her to communicate to her deceased child: "I've done things like send up balloons to him with notes on them." Although most survivors chose activities after the death of their child, one mother shared an activity the family participated in together before the child died:

That is one of the paintings that we did...that's her hand (points to colorful little green and yellow painting of child's hand).... Before she passed away...we [the family and the ill child] put this together...to remember.

*Communicating to deceased children.* Communicating to deceased children was another means of remembering and connecting. This communication was through talking to deceased children, writing letters to deceased children, and praying with deceased children. Many bereaved fathers, mothers, and siblings chose to talk to deceased children. A mother said, “Whenever I need to talk to her, I do.” Another mother talked to her child every night, telling her child how proud she was:

I talk to her...every night when I finish praying.... I’m thankful for the gift I had...I’ll just say, “(Name of deceased child), I’m so sorry for what you had to go through, but mommy is so proud of you for what you had gone through.”

A sibling said, “I talk to her everyday.”

Some survivors talked silently to deceased children: “I also talk to her in my head.... I talk to her all the time.” An interviewer asked a sibling if he or she ever talked to the deceased child. A sibling responded, “Yeah.... In my head.” A father said,

I know, I prayed and prayed and prayed so often and felt a little betrayed, never bitter, I never lost my faith. I did for a while maybe stop praying as much, but when I talked and meditated in quiet it was always to (deceased child).... But I do speak with him. Maybe not aloud, vocally....

Other survivors talked out loud to deceased children: “I talk to her. I don’t necessarily know that she hears me but it makes me feel better to...just to say her name.” Another mother sought advice from her deceased child: “I just talk out and may say, ‘(Name of deceased child), what would you do...what do you think about this?’ ...maybe it’s on a good day or something I could do that.”

Some survivors chose to communicate to deceased children through prayer: “(I) pray, for him and with him.” Some siblings communicated to deceased children through writing. One sibling said, “I like write him letters sometimes,” and another sibling simply said, “I write to him.” Communicating to deceased children was a way for survivors to remember and stay in



touch, as stated by a mother: “We’re very in touch and yeah, talk with him constantly, dream about him, seek his guidance.”

*Thinking about deceased children.* Survivors also chose to think about deceased children as they were in the past by reminiscing memories: “We reminisce about him just like we were doing here...we just reminisce a lot.... I hope we’ll always do that. You know, because he’ll always be a part of our family.” Another said, “I like to think about her often. I think about the good things, the bad things and sometimes I laugh about the arguments we got into and so that might make me feel better.... I just, pretty much keeping her in my mind helps.”

Bereaved family members also thought about deceased children in the present by thinking of what the children would be doing now:

I think of what he might be doing, you know at this point in his life. He’d probably be preparing to get his learner’s permit...maybe asking questions. He had a subtle way of asking things that he was interested in.... I often think how, how would he be? I’m sure he’d be responsible, very, very responsible...you know, the possibilities, I guess.

Another survivor chose to think about the deceased child’s current spiritual existence:

I believe that her spirit or essence is on a different plain now. And through the help of elders, contact exists and that general spirit exists. It’s a learning process for me, but that positive energy that was my daughter still exists. (Int: And how would you say you kept in touch with her spirit?) By concentrating...I don’t keep in touch, I acknowledge and focus energy on that spirit.

*Doing things deceased children would have liked or chosen.* Survivors also chose to do things deceased children would have liked or chosen, such as listening to music, eating foods, and choosing room decorations. Bereaved mothers especially expressed this, illustrated by one mother who chose to play games and make foods that her deceased child liked:

And then we’ll play cards, that’s what (deceased child) used to like. She liked playing cards.... (Sibling will) go on the computer that she used to like to play, too. So you know, we’ll do events at home, like I’ll try to make stuff that she used to like and then we’ll eat in her honor.

One mother described how her other children chose the deceased child's favorite color: "Pink is her favorite color, and the boys...will color in pink or write in pink, or wear pink to remember her." Another mother gave away a lot of her deceased child's things because they knew that's what he wanted:

Right away, right away when he died, we got rid, not got rid of, but we gave away a lot of his things just because we knew that's what he wanted. He wanted his things to be used. He didn't want them to sit around and rot.... He wanted his clothes to go here and there, here and there, and books and different things that he had kind of, you know, "willed out" you know, so that was, that was good actually for him to have prepared us kind of in that way....

One mother maintained the same relationships her deceased child had:

There was a little boy in his class and his mom...I always keep tabs on (her boys) and what he's up to and he's kinda like (deceased child's) size right now, and so it's just kinda (deceased child's) class.... When that class graduates, I'll be there.

Finally, another mother collected pocket change with friends and put it in a room at the hospital, giving other families happiness and hope:

That's so something that (deceased child) would have done, so it makes me feel that I'm doing something that would make him happy.... On his birthday we had a lot of new toys and stuff...so on his birthday I took a day off and took them to the hospital...and he would have been so happy to do that.... So just stuff like that makes me feel like (deceased child) is in me doing it or something.

### *Nonpurposeful Triggers*

Contrary to purposely choosing triggers, some bereaved parents and siblings had nonpurposeful, involuntary, nonconscious triggers that reminded them of deceased children. Nonpurposeful triggers occurred unexpectedly to survivors. Although nonpurposeful triggers were reported by fewer survivors, they similarly served as reminders of deceased children. Examples included having dreams about deceased children, receiving signs or visits from deceased children, and feeling deceased children's presence. A father said, "I find myself maybe, maybe still kind of talking to him and those things, keeping him a part [of my life]." A mom

stated that she thinks about her deceased son, but rather than consciously choosing to think about him, she thinks of him in response to others' comments: "I still think about him when someone asks me how many children I have." Another mom was reading a book:

I remember one time laying in the bathtub, and I'm not thinking of nothing. There's nothing going on in my head, and all of a sudden it [the book] said, "Quit putting flowers at my grave, and you enjoy 'em." ...And that's exactly what she [deceased child] would say.... It's not you thought it, it's just like a thought in your head.... It just popped in your head.

Some survivors experienced unexpected signs and visits from deceased children. In one family, the mother said,

Every night when we go to bed, we feel her in the room. Sometimes we hear things. She messes with the baby's mobile in the bed all of the time. Our curtains move constantly.

The father expressed how the deceased child visited him as well:

I think she sends me signs a lot, and I have seen her. She has come and visited me and it's been a real changing experience for me. I definitely believe she is in a better place. You know, when you see a child, you know, go through the changes that she had, losing all her hair, swelling up with fluids and everything. And when she came to me she was her original self. She had the curly blonde hair and blue eyes. It was a good feeling to know that she's in a better place.

Furthermore, the sibling of that family talked about nonpurposeful triggers related to the senses:

I see her, and I can also, you know, smell her. She smells like cleanness. I can also, just taste...cause she loved cheese, and I can just taste it. Whenever I eat something that's cheesy I also remember her. It makes me feel closer to her. The whole experience of meeting her made me feel really close to her...and lucky to meet her. Yes, it makes me feel a whole lot better.

Another mom talked about a conversation she had with her surviving son, and she described an unexpected reminder of her child:

I told (sibling) one day, I said, you know, you are a strong little boy. And I said, you know, you have just...I have cried and cried, and you are just my little rock. And he said, "Mom, he's right here (mom stands up and puts her arm out like it's around shoulder of someone standing next to her)." Oh my gosh, [it] broke my heart.

Finally, many survivors had unexpected dreams about the children. One sibling said,

On my dad's side of the family, we have sort of spiritual connections...just events that will occur.... With my dreams, I dream about a scenario and then sometime later, I find myself in the same situation, like I've been here before, and I know exactly what's going to happen.... My [deceased] sister comes to visit me in dreams, and she tells me it's very real, very clear, so I just ask her something. I have no control over it, so whenever I get the dream, I feel very lucky. So, I ask the questions in the dream and get the answers, so I can share it with my whole family, and I ask her, "So, how are you? Are you safe? Are you scared?" [My deceased sister says], "No, I'm not scared. I stay with this woman, and we cook together." And then she [deceased sister] gives a vision to me in my head, so I can see it myself. So, she's living...with this black woman, and they're cooking together. They're at the stove, and I don't know what they're cooking. But, she looked very happy, and she also looked the same as how she looked when she was sick...but she didn't look like what she looked like when she just died.... I kept saying, "What does it look like? What does heaven look like?" She said, "Oh, it's just the same as...when you're on Earth. There's buildings, there's trees, there's roads. It's just that it's in a different place. You can't connect with people who live here on Earth, just in Heaven." So she showed me the vision...it looked exactly the same.

Although nonpurposeful reminders of deceased children were reported by fewer people, survivors had parallel outcomes from nonpurposeful and purposeful reminders of deceased children.

### *Effects on Survivors*

Outcomes from purposeful and nonpurposeful triggers included both comforting and discomforting effects on survivors. Bereaved parents and siblings also talked about the continuum of trigger effects.

*Comforting effects.* When triggers stimulated positive memories about and being with deceased children, comforting effects resulted, including soothing, comfort, making the bereaved person feel better, and sensing deceased children's presence. One parent said, "It makes me feel good when I start talking to her...it just makes me feel good...I pick up some of her toys, and then I told her about it, so it helps me." Some survivors conveyed how using deceased children's personal belongings helped them remember: "He gave me a couple of shirts...so I wear them to

help me remember.” Others desired continued contact with deceased children: “We want as much contact as possible with his past...having a son that I don’t have anymore, you, you cling to everything you have.”

Survivors also found comfort in having a sense of deceased children’s ongoing presence; the focus was on maintaining relationship with deceased children. Many survivors shared how reminders kept deceased children a part of the family and kept their memory alive: “He’ll always be a part of our family.” One mother found comfort in sensing her deceased child’s presence at the cemetery: “His soul is there or something.” A sibling sensed the deceased child’s presence after choosing to be with her personal belongings: “I slept with her clothes...I’d be thinking that it was me hugging her.” Another mother sensed her child’s ongoing presence in a toy robot: “That’s a piece of him I can leave up on the shelf and leave it there and not let nobody have a piece of it.” She also sensed his presence through looking at one of his sweaters: “It was his, and I can look at it, and I guess I don’t care how old I would ever get, I can look at it, and I can see him in this. I can see (deceased child), this is (deceased child)’s face right there.” Finally, some survivors talked about remaining connected and maintaining bonds with deceased children:

We [the family] always talk about (name of deceased child) and the past. (Name of deceased child) was a really outdoor kinda kid, so we had four-wheelers, and now all my sisters ride his four-wheelers, and that keeps the bond.

*Discomforting effects.* Although most people found comfort in purposeful and nonpurposeful memories, some found it difficult to be reminded of deceased children and found it difficult to choose reminders:

I have spent some time trying to write memories out.... I’ve actually not been too successful at that. I end up more journaling myself than I do writing. I sort of had hoped to look at photo albums and stuff and write some of the stories down along with the pictures, but I haven’t quite gotten to that.

Discomforting results occurred when reminders stimulated hurt and sadness. In these cases, survivors chose to avoid or disengage with purposeful triggers:

Her bedroom was very, very hard to go into at first, and I primarily didn't...it's been very hard going through a lot of her stuff.... I would be in there for 30 minutes or an hour and it was just overwhelming and staggering. I just had to get out.

Likewise, a father maintained keepsakes of his deceased child but avoids them by putting them out of sight: "We've got some keepsakes and such, but just kind of put them away, and nothing I see daily or anything like that."

Some survivors appreciated various reminders of their children, but also found such experiences difficult or challenging. One mother talked about her child being a competitive swimmer and said the spring swim meet was named after her. She said, "It will be good, but it will be kind of hard to deal with that, too."

*Continuum of effects.* Reminders resulted in survivors having comforting and discomforting feelings at the same time. One mom talked about the continuum of comforting and discomforting effects when choosing an activity her deceased child would have liked:

At home we made jewelry, and she loved to do that, and I've got the jewelry table set up in her bedroom. And I love to go in there and do that, but sometimes it just gets to the point where I have to leave.

Another mom similarly described the fluidity of trigger effects:

We've had lots of community stuff going on. So, to some degree we have felt that, and it's been great and there's a lot of people that want to do things in memory of (deceased child) and to remember (deceased child) and put things in place, but they're hard to go to, and you just feel like you're getting over one, and then something else pops up.... We were torn because we wanted him to be remembered, and we wanted to go to these events. But at the same time it was very difficult to go.

## Quantitative Findings

The researcher collected quantitative data from bereaved parents and siblings responses to questionnaires (CBS, HIB, HGRC, and RSQ). Although the researcher proposed examination of associations between continuing bonds and coping strategies on the RSQ, associations with involuntary responses to stress were added after similar findings emerged during qualitative interviews. Therefore, correlational analyses examined relationships between continuing bonds and responses to stress, as well as relationships between continuing bonds and grief symptoms.

### *Relationships Between Continuing Bonds and Responses to Stress*

Correlations assessing the relationships between continuing bonds and responses to stress are shown in Table 2. Within the sample of bereaved parents, the only statistically significant association was a positive correlation between continuing bonds and involuntary engagement ( $r = .325, p = .038$ ). In contrast, the relationship between continuing bonds and involuntary engagement was not statistically significant within the sample of bereaved siblings ( $r = .087, p = .635$ ). As noted in Table 2, however, within the sample of bereaved siblings, continuing bonds was also positively associated with primary control engagement ( $r = .415, p = .018$ ) and inversely associated with voluntary disengagement ( $r = -.367, p = .039$ ). None of the other associations with continuing bonds were statistically significant ( $p > .05$ ).

Table 2. Correlations Between Continuing Bonds and Responses to Stress

		Voluntary Responses to Stress (Coping Strategies)			Involuntary Responses to Stress	
		Primary control engagement	Secondary control engagement	Voluntary disengagement	Involuntary engagement	Involuntary disengagement
CBS (parents $N=41$ )						
•	Correlation coefficient	-.129	-.060	-.010	.325*	-.063
•	Sig. (2 tail)	.421	.708	.949	.038	.695
CBS (siblings $N=32$ )						
•	Correlation coefficient	.415*	-.074	-.367*	.087	.002
•	Sig. (2 tail)	.018	.688	.039	.635	.992

\*. Correlation is statistically significant at the 0.05 level.

#### *Relationships Between Continuing Bonds and Grief Symptoms*

Correlations assessing the relationships between continuing bonds and grief symptoms in bereaved parents and siblings are shown in Table 3. In bereaved parents, continuing bonds demonstrated a rather strong positive correlation with despair ( $r = .370, p = .017$ ); however, associations with personal growth ( $r = .044, p = .783$ ) and grief distress ( $r = .221, p = .165$ ) were negligible. On the other hand, within the sample of bereaved siblings, continuing bonds demonstrated even stronger positive correlations with both personal growth ( $r = .637, p < .001$ ) and grief distress ( $r = .521, p = .001$ ).



Table 3. Correlations Between Continuing Bonds and Grief Symptoms

	Personal Growth	<b>HGRC</b> Grief Distress
<b>CBS</b> (parents $N=41$ )		
• Correlation coefficient	.044	.221
• Sig. (2 tail)	.783	.165
	Personal Growth	<b>HIB</b> Grief Distress
<b>CBS</b> (siblings $N=40$ )		
• Correlation coefficient	.637**	.521**
• Sig. (2 tail)	< .001	.001

\*\* . Correlation is statistically significant at the 0.01 level

## CHAPTER V

### DISCUSSION

This study primarily explored continuing bonds in children with advanced cancer and their bereaved families. Secondly, the study examined associations among continuing bonds, coping strategies, and grief symptoms in bereaved parents and siblings who experienced the death of a child from cancer. The meaning of findings related to each research question will be discussed, as well as an overall synthesis. Significance of findings, as well as strengths and limitations of the study, will be presented. Furthermore, the researcher offers implications for nursing practice, education, research, and policy.

#### **Meaning of Findings Related to Research Questions**

The meaning of findings will be discussed as related to each of the four research questions presented in this study: 1) Based on bereaved parents' and siblings' perspectives, do children with cancer do or say things before they die to be remembered? 2) How do bereaved parents and siblings continue bonds with children who have died of cancer? 3) What is the relationship between continuing bonds and coping strategies? 4) What is the relationship between continuing bonds and grief symptoms?

#### *Ill Children Building Legacies*

While continuing bonds may be a coping strategy for bereaved parents and siblings who lost a child to cancer, qualitative findings suggest that creating legacy may be how ill children

take part in continuing bonds, and legacy may be a coping strategy for ill children living with cancer. Some ill children purposely did or said things to be remembered, resulting in inspiration to impact others' lives and prepare for their own deaths. These findings suggest that ill children may be using legacy-making as a secondary control engagement strategy to effectively cope with cancer. Secondary control engagement is defined as adapting to a stressor, using coping strategies such as acceptance, cognitive restructuring, positive thinking, and distraction (Compas et al., 2005). While legacy has received little attention in the literature, Alvarez (2005) spoke with a bereaved child about a tangible link left behind by her deceased mother. The child said, "Because memories can be there, and not be there," but the tangible link was "a permanent memory that will never erase" (p. 1). Alvarez suggests that a small but growing number of terminally ill parents are leaving behind tangible links for their children, such as videos, letters, cards, and gifts. One pilot study described an intervention, dignity therapy, as a "legacy-making exercise" for older adults with end-stage malignancies (Chochinov, Hack, Hassard, Kristjanson, McClement, & Harlos, 2005). Ill patients discussed issues that mattered most or that they most wanted remembered. A final transcription was provided back to them to bestow to a friend or family member. Findings showed increased sense of dignity, sense of purpose, sense of meaning, and will to live, while decreasing suffering and depressive symptoms. Perhaps a legacy-making intervention could provide similar benefits to terminally ill children.

Findings of the current study also suggest that the majority of participants perceived that children involuntarily built nontangible legacies that exist in survivors' memories: legacies of love, quality, belief, and inspiration. Such legacies positively inspired survivors to live differently. In addition to a possible coping strategy, legacy-making may be an involuntary automatic response of engagement from ill children oriented towards living with cancer. While

the current study suggests positive outcomes of inspiration from involuntary responses to stress, minimal evidence from previous literature suggests healthy outcomes from involuntary responses to stress, such as Connor-Smith et al.'s (2000) study which found strong associations between involuntary responses to stress and emotional-behavioral problems across three samples. This discrepancy warrants further study of positive outcomes within involuntary responses to stress.

While findings suggest that ill children respond to cancer through legacies, this understanding suggests that children living with advanced cancer are aware of their nearing death. Most bereaved parents in the current study sensed their child was aware of his or her impending death, although a small number of parents perceived their ill child was unaware. However, the ill children exemplified awareness of death through their actions and implied words, suggesting that children may communicate death awareness with actions before explicit communication can occur. Similarly, the AAP (2000) points out that children's hints to talk about death may be subtle. Kreichbergs et al. (2004) found 47% of parents sensed their child was aware of his or her imminent death, as compared to 13% of parents who did not sense this awareness. Spinetta, Rigler, and Karon (1973) note serious illness accelerates cognitive development:

To equate awareness of death with the ability to conceptualize it and express the concept in an adult manner denies the possibility of an awareness of death at a less cognitive level. If it is true that the perception of death can be engraved at some level that precedes a child's ability to talk about it, then a child might well understand that he is going to die long before he can say so. (p. 844)

#### *Bereaved Parents and Siblings Continuing Bonds*

Qualitative findings suggest that bereaved families continue bonds with deceased loved ones, consistent with the Continuing Bonds Theory (Klass et al., 1996) and previous studies (Chan et al., 2005; Davies, 2005; Davies et al., 1998; Doran & Hansen, 2006; Hogan &

DeSantis, 1992; Hogan & DeSantis, 1994; Meert et al., 2005; Riches & Dawson, 1998; Sedney, 2002; Silverman et al., 1992; Silverman et al. 2003; Sormanti & August, 1997; Wilson, 2001).

The purposeful and nonpurposeful nature of how survivors continued bonds with deceased children may be understood in relationship to Compas et al.'s (2005) model of coping. New knowledge from the current study adds that continuing bonds may be survivors' response to the stress of losing a child, including 1) coping and 2) automatic, involuntary responses. Bereaved parents purposely chose triggers to remind them of their deceased children, suggesting possible use of voluntary engagement coping, defined as dealing with the stressful situation or one's emotions (Compas et al., 2005). On the other hand, survivors experienced nonpurposeful reminders of deceased children, suggesting possible involuntary engagement, or involuntary responses oriented towards children's death (Compas et al., 2005).

In addition, continuing bonds resulted in comforting and discomforting effects for bereaved parents and siblings. Survivors mostly experienced comforting effects from both purposeful and nonpurposeful continuing bonds; this suggests that both voluntary coping and involuntary responses related to continuing bonds may be helpful for survivors. While previous evidence supports voluntary engagement coping as a healthy coping strategy associated with better psychological adjustment (Compas et al., 2001), minimal benefits from involuntary responses to stress have been noted. Again, Connor-Smith et al. (2000) found strong associations among involuntary responses to stress and emotional and behavioral problems across three samples, but findings of the current study suggest that involuntary responses (e.g., unexpected dreams/visits from deceased children) can be very helpful to survivors, resulting in comfort, soothing, and making the bereaved feel better. More research is needed among positive and negative outcomes related to involuntary responses to stress.

While survivors mostly experienced comforting effects from continuing bonds, discomforting effects also occurred. Bereaved family members alternated between purposely engaging continuing bonds when comforting effects occurred and purposely disengaging reminders when discomforting effects occurred. Survivors may be alternating between use of voluntary engagement and voluntary disengagement coping strategies. This alternation is similar to the oscillation process observed in the Dual Process Model, as individuals alternate between positive and negative aspects of dealing with loss and secondary changes (Stroebe & Schut, 1999). Overall, bereaved parents and siblings described continuing bonds as helpful voluntary and involuntary responses to losing a child from cancer.

#### *Continuing Bonds and Coping Strategies*

Quantitative evidence suggests statistically significant relationships between continuing bonds and coping strategies in bereaved siblings, yet not in bereaved parents. For siblings, strong direct associations between continuing bonds and primary control engagement suggest that bereaved children may be using coping strategies such as problem solving, emotional expressions, and emotional modulation. Perhaps continued bonds heighten bereaved children's sense of direct control over their emotions related to losing a brother or sister, considering primary control engagement is a coping strategy defined as having direct control over a stressor or one's emotional response to the stressor (Compas et al., 2005). Because coping is situation specific, outcomes are typically positive when primary control coping is used with controllable stressors (Compas et al., 2001). Secondary control coping may be more effective in response to uncontrollable events, such as the loss of a brother or sister, yet evidence from this study did not suggest that continuing bonds promoted siblings' use of secondary control coping.

In addition to continuing bonds revealing associations with primary control engagement coping, a strong inverse relationship between continuing bonds and voluntary disengagement occurred in bereaved siblings. As defined, voluntary disengagement coping strategies include avoidance, denial, and wishful thinking (Compas et al., 2005), and prior evidence suggests these are ineffective coping strategies (Compas et al., 2001). Overall, continuing bonds may promote primary control engagement coping strategies and minimize voluntary disengagement coping strategies in bereaved brothers and sisters. A better understanding about coping strategies used with the uncontrollable stressor of a child's death is needed.

Associations between continuing bonds and coping strategies differed for bereaved parents. Continuing bonds did not have statistically significant associations with primary control engagement, secondary control engagement, or voluntary disengagement coping strategies. Interestingly, continuing bonds in bereaved parents strongly associated with involuntary engagement, described as automatic responses oriented toward a stressor (Compas et al., 2005). Similarly, qualitative findings of this study suggest a positive relationship between continuing bonds and involuntary engagement as bereaved parents experienced nonpurposeful reminders of deceased children (e.g., having dreams about deceased children, receiving unexpected visits/signs from deceased children). Previous literature suggests that involuntary engagement (e.g., rumination) is not a healthy response to stress (Compas et al., 2001). In contrast, qualitative findings of this study suggest that bereaved parents found nonpurposeful reminders of their children, suggestive of involuntary engagement, to result in mostly comforting effects, including soothing and making the bereaved person feel better.

### *Continuing Bonds and Grief Symptoms*

Additional quantitative findings in the current study show continuing bonds did not strongly relate with personal growth or grief distress in bereaved parents. However, higher continuing bond scores directly associated with more despair, one particular grief distress symptom, in bereaved parents. Similarly, Field et al. (2003) found strong associations between continuing bonds and grief 5 years postloss for bereaved spouses and found weak correlations between continuing bonds and positive states of mind; Field et al. were not surprised by these findings, suggesting that stressors aside from the spouse's death likely had greater bearing on participants' psychological symptoms and positive state measure scores, where grief distress scores were likely more reflective of bereavement related stress. Findings of the current study differ from other studies that noted statistically significant associations between spontaneous positive memories of the deceased and personal growth in bereaved spouses (42.3%), parents (36.5%), children (11.8%), and others (9.4%) (Gamino et al., 2000). However, associations between continuing bonds and grief distress may be quite different among various types of loss compared to loss of a child.

On the other hand, significant positive correlations occurred between continuing bonds and personal growth, as well as grief distress, in bereaved children. Perhaps these dual associations indicate continuing bonds encourage bereaved siblings to be resilient survivors. Hogan and DeSantis (1996) discuss trajectories of grief distress and personal growth, including that resilient bereaved children experience turning points at their most intense points of grief. They realize they must begin to learn how to let go of the pain associated with grief distress and create a revised model of the world. Bereaved siblings reformulate a reality that includes ongoing attachments with their deceased brother or sister, leading to the process of personal



growth. Hogan and DeSantis state, “Ongoing attachment, then, is the silent variable that mediates the construct of grief and the construct of personal growth. While ongoing attachment becomes manifest when grief is at its most intense, it begins to emerge at the death of a brother or sister in the construct of personal growth” (p. 251). They conclude that ongoing attachments accelerate personal growth over time, yet grief will continue to reemerge during significant life events. Therefore, quantitative evidence in the current study similarly suggests that continuing bonds may encourage bereaved siblings to be resilient survivors. Since most siblings in the current study were interviewed approximately 1 year postloss, they have possibly come to turning points towards personal growth; however, maybe not enough time has passed to fully begin the process of lessening the intensity of grief distress. Perhaps continuing bonds will lower grief distress and accelerate the intensity of personal growth over time in these bereaved siblings.

#### *Overall Synthesis of Meaning of Findings*

Meanings of findings related to all four research questions were compared and contrasted with the previously proposed conceptual model of continuing bonds shown in Figure 3, which was based on theoretical synthesis of the Continuing Bonds Theory (Klass et al., 1996), the Dual Process Model (Stroebe & Schut, 1999), and Gerhardt’s (2003) conceptual framework. Findings of the current study suggest that legacy may be the concept linking ill children to the continuing bonds model, as ill children are participating in creating bonds with others, via legacies, that can continue in case of death. However, the previously proposed conceptual model of continuing bonds does not include children living with life-threatening illnesses but begins with the death of a child.

Considering that the overarching umbrella of pediatric palliative care begins with diagnosis of a life-threatening condition (Orloff et al., 2004), as well as suggestions from findings in the current study, perhaps the continuing bonds model should be expanded to include children living with life-threatening illnesses. In contrast to the current conceptual model in Figure 3, the expanded model of continuing bonds shown in Figure 5 begins with ill children diagnosed with cancer. As previously discussed, legacy may be an ill child's response to the uncontrollable stressor of a life-threatening condition such as cancer, including both coping strategies and automatic responses. After the death of a child, survivors may respond to the uncontrollable stressor of the death by continuing bonds with the deceased child. Since the researcher did not originally propose to examine associations between continuing bonds and involuntary responses to stress, the model in Figure 3 did not include automatic, involuntary responses to stress. However, findings of the current study suggest continuing bonds may be both a coping strategy and an automatic response to a child's death. Therefore, this new finding was also added to the expanded model of continuing bonds shown in Figure 5. More research is needed to better understand continuing bonds in children living with life-threatening illnesses and their families.

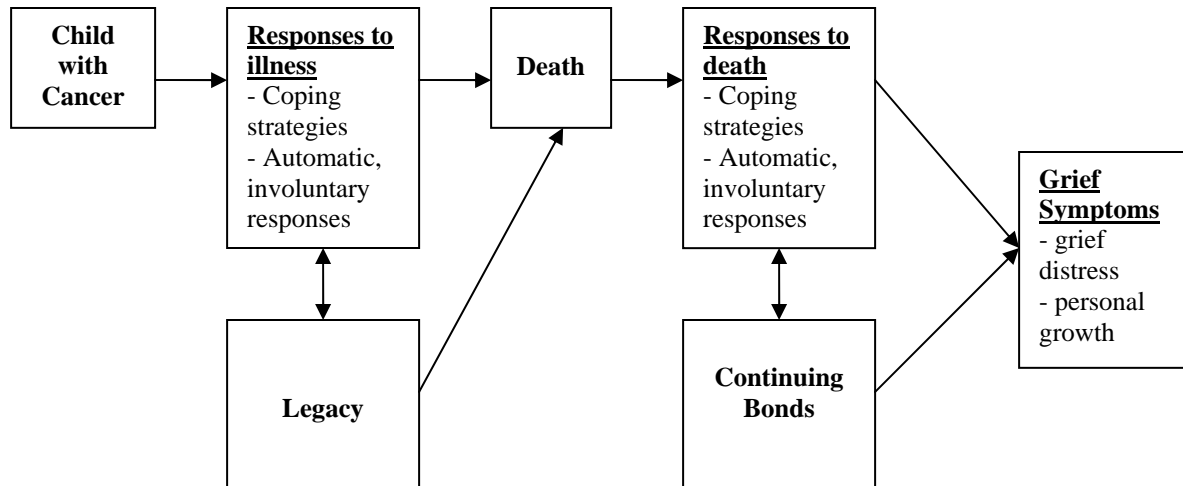


Figure 5. Proposed expanded model of continuing bonds

### Significance

Findings of this study significantly contribute to the current understanding of continuing bonds in bereaved parents and siblings. This better understanding introduces legacy as a possible response to life-threatening illness and continuing bonds as a possible response to loss. Legacy may be a coping strategy that can increase health and quality of life for children living with life-threatening illnesses, while decreasing negative consequences of suffering and distress for ill children. Continuing bonds may be a coping strategy that can increase health and quality of life for bereaved families, while decreasing negative consequences of mortality, marital disruptions, mental illnesses, and behavior problems for bereaved parents and siblings as noted in previous literature (Davies, 2006; Kramer, 1984; Li et al., 2003; Li et al., 2005; Oliver, 1999; Rosen, 1985; Silverman et al., 2003).

This study also introduced possible positive effects that legacy and continuing bonds may have as involuntary responses to life-threatening illness and death. This opens the door to future

research within this unexplored territory. A better understanding of these processes could also lead to improving the lives of children living with life-threatening illnesses and their families.

Additionally, new knowledge has been added in respect to potentially expanding the model of continuing bonds to not only incorporate involuntary responses to stress, but also how ill children can be part of the continuing bonds model through legacy. Legacy-making may be a novel approach to minimizing negative consequences, meeting needs, and improving quality of life for dying children within all dimensions of pediatric palliative care: physical, psychological, social, and spiritual. Furthermore, ill children creating legacy may increase the value of continuing bonds for bereaved families. “The value of a memento is in the meaning and memory attached to its creation” (Albrecht, Connolly, Ceronsky, & Landis, 2008, p. 5). Improving life of ill children may in turn improve lives of bereaved families as depicted in Figure 5. Findings from this study may help improve lives of children living with life-threatening illnesses and surviving family members.

### **Limitations**

The researcher notes limitations of this study related to the study sample, design, measurement, and analysis. First, families in complicated grief may have refused participation, causing findings to possibly be skewed towards families who are coping better with their grief. However, only 11 (14.3%) eligible families refused participation in the larger study; of these families, 9 (11.7%) actively and 2 (2.6%) passively refused. One must be careful not to transfer findings to bereaved families experiencing complicated grief. In addition, the composition of the participant sample limits application of findings to bereaved individuals within other cultures, and results cannot be generalized across all terminal conditions as this study targeted only

bereaved families who lost children to cancer. However, the sample was appropriate to address the research questions and aims of the current study.

Second, limitations exist related to the study design. One research question examined children living with advanced cancer, but retrospective findings consisted of bereaved parents' and siblings' perspectives. While family members likely knew their child very well, one must take caution to assume children living with cancer had the same perspectives as retrospective reflections from their bereaved parents and siblings. Even though this limitation is noted, the retrospective design was appropriate to address the research question related to ill children. Considering this research question was unexplored in previous literature, a retrospective design was warranted before prospective examination of such a vulnerable population of terminally ill children.

Third, the researcher notes measurement limitations. The 20-item CBS used in this study with bereaved parents and siblings has not been previously validated, and the 11-item version is only noted in two previous studies (Field et al., 2003; Neimeyer et al., 2006). The CBS also measures continuing bonds as a single factor, making quantitative examination of different types of bonds unfeasible. Also, the grief measures differed between parents and children, causing limitations in conclusions drawn from comparisons between grief symptoms in bereaved parents and siblings. However, the researcher chose reliable and valid measures appropriate for ages of targeted participants.

Finally, the researcher notes limitations of qualitative content analysis. Because of the limited nature of the qualitative data, analysis did not extend past content analysis. Qualitative data limited findings to generation of a conceptual description of continuing bonds, yet conceptualization, or theory generation, did not occur. However, this study was not designed for

grounded theory, and the state of the science related to continuing bonds called first for a description, which was successfully generated through content analysis. More research is needed to address such limitations related to the current state of science on continuing bonds.

### **Strengths**

While several limitations were noted, strengths of the current study unfold as well. First, the sample size of 107 bereaved individuals is large compared to previous qualitative and mixed method studies related to continuing bonds in which sample sizes ranged from 10 to 157 participants (Arnold et al., 2005; Barrera et al., 2006; Chan et al., 2005; Davies, 2005; Davies et al., 1998; Doran & Hansen, 2006; Herth, 1990; Hogan & DeSantis, 1992; Hogan & DeSantis, 1994; Meert et al., 2005; Miller, 1989; Riches & Dawson, 1998; Sedney, 2002; Silverman et al., 1992; Silverman et al., 2003; Silverman & Worden, 1992; Sormanti & August, 1997; Wilson, 2001). Second, data collection occurred across three sites in different geographical locations, increasing transferability of findings. Also, all data sites used comparable data collection protocols and participated in monthly conference calls to ensure stability of data over time, increasing dependability of findings. Third, high internal consistencies resulted across quantitative measures in the current study, increasing reliability of quantitative findings. Fourth, method and researcher triangulation enhanced scientific rigor of the study. Method triangulation incorporated different kinds of data to bring additional clarity to understanding the phenomenon of continuing bonds. Use of both qualitative and quantitative methods, using both questionnaires and interview questions, developed a richer and fuller understanding of continuing bonds. Additionally, researcher triangulation included three researchers analyzing and interpreting qualitative data, and a statistician assisted in quantitative analysis and verified results, increasing

rigor and trustworthiness of study results. Fifth, member checking increased credibility of qualitative findings. As part of the larger study, the researcher was able to go back to several bereaved families 1 year after data collection. This allowed the researcher to verify results with parents and siblings to ensure the findings actually reflected their perspectives.

Furthermore, peer debriefing increased credibility of the study. Peer debriefing included discussions about the analytic process, findings, and conclusions with other researchers in the field. Specifically, the researcher consulted with an expert in the area of continuing bonds. The expert has studied bereavement for over 30 years and edited a book describing the concept of continuing bonds (Klass et al., 1996). She is currently involved in a community-based program for grieving children, which provides support for children, teens, young adults, and families grieving a death. She is conducting research on the impact of the program on bereaved children, and continuing bonds is a significant piece of the program. Additionally, she is writing a new edition of a book related to bereavement in children. A dissertation enhancement award allowed the researcher to travel and meet with this expert, which provided additional depth to interpretation of findings and conclusions of this project.

### **Implications for Nursing**

Based on findings of this study, the researcher offers implications for nursing practice, education, and future research. In addition, the researcher speculates implications for future nursing policy.

### *Practice*

Nurses may benefit from assessing needs of ill children related to continuing bonds. Some ill children may want to purposely take part in continuing bonds via legacy building, and nurses may need to promote such legacy-making opportunities. Other ill children may not want or need to purposely create a legacy, but may need help to realize the legacies they have already created. “Everyone makes a difference in somebody’s life. Everyone. It’s just not everyone gets the chance to realize that difference in this life” (Stepanek, 2005, p. 2). Practicing nurses can facilitate appropriate legacy-making and/or realization opportunities for children living with terminal conditions.

### *Education*

Nurses are also in an ideal position to educate children living with life-threatening conditions. Ill children may benefit from learning how some survivors perceived that children living with advanced cancer purposely created legacies, and how other families perceived ill children’s nonpurposeful legacies of love, quality, belief, and inspiration. Nurses can also share with ill children how such legacies resulted in inspiration for the children living with cancer, as well as inspiration for survivors. If nurses educate children living with life-threatening illnesses, ill children might have the opportunity to use legacy-making as a strategy to cope with cancer.

Nurses can also educate families about ill children’s awareness of death. Parents especially need to know that ill children may have advanced understandings of death, and that children’s actions may speak of this awareness before explicit words occur. Such information could help families communicate about death with their ill child. Also, nurses can educate surviving family members about continuing bonds. Families may gain from learning how



previous survivors continued bonds with their deceased child and the related outcomes. Although more evidence is needed to determine what promotes continuing bonds as a healthy coping strategy, nurses can share what is currently known about continuing bonds and associations with coping strategies and grief symptoms.

With an interdisciplinary team approach being a critical attribute of pediatric palliative care (Foster, 2007), nurses can also promote interdisciplinary collaboration related to continuing bonds. Physicians, nurses, psychologists, child life specialists, social workers, and other healthcare providers have the joint goal to improve care for children with life-limited illnesses and their families. Not only is a team approach essential to meeting needs of dying children, but interdisciplinary collaboration is essential to better understand continuing bonds within pediatric palliative care. Furthermore, interdisciplinary education about continuing bonds among healthcare professionals is indicated, including both practicing healthcare professionals and students. Nurses can disseminate knowledge related to continuing bonds to help educate healthcare professionals on this significant phenomenon within terminally ill children and their families.

### *Research*

“The question of how humans both hold on and let go of those who have died is a worthwhile, and a grand problem in science. To a great extent, it still lies before us unsolved” (Klass, 2006, p. 857). Results of this study lead to implications and recommendations for future nursing research to continue making headway within the current scientific mysteries related to continuing bonds.

First, research is needed to improve quantitative measurement of continuing bonds. A factor analysis of the CBS would allow for quantitative examination of different types of continuing bonds. Better measures should be developed to examine purposeful and nonpurposeful aspects of continuing bonds, as well as comforting and discomfoting effects. Similarly, Klass (2006) recommended that empirical researchers develop better measures to study conscious and unconscious aspects of continuing bonds, as well as positive and negative consequences. Additionally, development of a legacy measure may allow for quantitative examination related to continuing bonds and children living with life-threatening conditions. The researcher speculates that this measure could be developed based on a prospective study designed to talk with terminally ill children about legacy.

Second, another potential area for future research pertains to the relationship between continuing bonds and spirituality. Even though interview questions did not ask about issues of spirituality, many adult participants referred to spirituality, and many ill children openly shared their spirituality and talked about God to others. When doing so, even forthrightly in situations of “normal” childhood play activities (e.g., during a baseball game), other children and adults responded with tolerance. Typically, children who speak out in such ways are criticized or ignored. Thus, further exploration of the relationship between terminal illness in children and spirituality is warranted. Given that little is known about this relationship, qualitative research approaches would be indicated.

Third, more research is needed to determine if the Continuing Bonds Theory should be expanded to include children living with life-threatening illnesses. Klass (2006) stated, “We are still looking for scholars...whose work will give us methods or theory that we can incorporate into ours” (p. 857). A grounded theory research design could add knowledge about possibly

incorporating terminally ill individuals into the existing theory, as well as develop a clear conceptual definition of legacy. Moreover, prospective studies are essential to explore ill children's points of view related to continuing bonds, specifically related to legacy-making. The infrequency of ill children intentionally building legacy may be related to lack of opportunity or lack of knowledge. While Chochinov et al.'s (2005) study shows promise that legacy-making can decrease suffering and distress for adults at the end of life, legacy-making has not yet been studied within pediatric populations. A study is being developed to prospectively explore legacy in children living with life-threatening illnesses. A better understanding of legacy is crucial to further develop healthy coping strategies and decrease negative consequences for dying children and their families.

### *Policy*

One can speculate how future research may influence implications for nursing policy. If future evidence suggests continuing bonds can be a positive coping strategy for children living with life-threatening illnesses as well as for bereaved families, future policies could address continuing bond opportunities for this population. If continuing bond interventions could decrease negative consequences for ill children and bereaved families, new policy related to continuing bonds could not only save healthcare dollars, but most notably improve services for this vulnerable population.

Continuing bonds research may have indications related to pediatric palliative care reimbursement policies. For example, 10% state budget reductions are currently proposed for the California Children's Services program, which provides specialty care to children with childhood cancers, as well as other life-threatening conditions (Children's Hospice and Palliative Care

Coalition, 2008). Reimbursement cuts would compromise access that children with life-threatening illnesses have to specialists and care. Research finding positive benefits from continuing bond services could prevent such barriers to pediatric palliative care, improving quality of care and access to service for this important population.

If future evidence supports that ill children participate in continuing bonds as a natural response to the uncontrollable stressor of a terminal illness, such findings might address policies related to new designations for Allowing a Natural Death (AND). In contrast to Do Not Resuscitate orders, an AND order is meant to ensure only comfort measures for individuals facing death (Meyer, 2008). When using the AND, healthcare providers acknowledge impending death of the patient and ensure that everything done for the patient will allow the dying process to occur with minimal discomfort. Perhaps continuing bonds play a role in contributing to a good death. More work is needed to determine how continuing bonds may influence implications for AND policies.

### **Conclusion**

We believe we can best reorient ourselves to this world's needy children by not viewing them as broken – for if we do, we will soon realize that we are unable to “fix” them all. Nor should we see each child or family as a “problem” needing to be solved – because we will not be able to solve them all. Rather, we should look at each child and family as affording an opportunity for us to provide service. (Carter & Levetown, 2004, p. xii)

This mixed method study explored how survivors continue bonds with deceased children, explored how dying children create legacies, and examined associations among continuing bonds, coping strategies, and grief symptoms in bereaved families who experienced the death of a child from cancer. Findings add new knowledge to the state of science related to pediatric palliative care, and specifically offer new insight related to continuing bonds and legacy. These

revolutionary phenomena demand further research to deliver optimal services to children living with life-threatening illnesses and their families.

Appendix A  
Continuing Bonds Scale

### Continuing Bonds Scale - Parent

	Not at all True	Slightly True	Moderately True	Considerably True	Very True
1. I seek out things to remind me of my child.	1	2	3	4	5
2. I keep things that belonged to or were closely associated with my child as a reminder of him/her.	1	2	3	4	5
3. I like to talk or reminisce with others about my child.	1	2	3	4	5
4. I have inner conversations with my child where I turn to him/her for comfort or advice.	1	2	3	4	5
5. Even though no longer physically here, my child continues to be a loving presence in my life.	1	2	3	4	5
6. I am aware of having taken on many of my child's habits, values, or interests.	1	2	3	4	5
7. I am aware of the positive influence of my child on who I am today.	1	2	3	4	5
8. I attempt to carry out my child's wishes.	1	2	3	4	5
9. I have many fond memories of my child that bring joy to me.	1	2	3	4	5
10. When making decisions, I imagine my child's viewpoint and use this as a guide in deciding what to do.	1	2	3	4	5
11. I experience my child as continuing to live through me.	1	2	3	4	5
12. I find ways to continue to include my child in the family or our activities.	1	2	3	4	5
13. I have comforting dreams of my child.	1	2	3	4	5
14. I visit the cemetery or memorial site to be close to my child.	1	2	3	4	5

	Not at all True	Slightly True	Moderately True	Considerably True	Very True
15. I often look at pictures of my child.	1	2	3	4	5
16. I remind myself that I will eventually see or be with my child again.	1	2	3	4	5
17. Even though no longer physically here, I have seen, heard, smelled, or touched my child.	1	2	3	4	5
18. I find comfort in being in my child's room or bed.	1	2	3	4	5
19. I find comfort in going places my child enjoyed or where s/he spent a lot of time.	1	2	3	4	5
20. It helps me to stay in touch with my child's friends.	1	2	3	4	5



### Continuing Bonds Scale - Child

	Not at all True	Slightly True	Moderately True	Considerably True	Very True
1. I look for things to remind me of my brother or sister.	1	2	3	4	5
2. I keep things that belonged to or were closely associated with my brother or sister as a reminder of him/her.	1	2	3	4	5
3. I like to talk or share memories with others about my brother or sister.	1	2	3	4	5
4. I talk to my brother or sister and turn to him/her for comfort or advice.	1	2	3	4	5
5. Even though no longer physically here, my brother or sister continues to be a loving presence in my life.	1	2	3	4	5
6. I am aware of having taken on many of my brother or sister's habits, values, or interests.	1	2	3	4	5
7. I am aware of the positive influence of my brother or sister on who I am today.	1	2	3	4	5
8. I attempt to carry out my brother or sister's wishes.	1	2	3	4	5
9. I have many fond memories of my brother or sister that bring joy to me.	1	2	3	4	5
10. When making decisions, I imagine what my brother or sister would do and use this as a guide in deciding what I should do.	1	2	3	4	5
11. I often think or feel that my brother or sister continues to live through me.	1	2	3	4	5
12. I find ways to continue to include my brother or sister in the family or our activities.	1	2	3	4	5

	Not at all True	Slightly True	Moderately True	Considerably True	Very True
13. I have comforting dreams of my brother or sister.	1	2	3	4	5
14. I visit the cemetery or memorial site to be close to my brother or sister.	1	2	3	4	5
15. I often look at pictures of my brother or sister.	1	2	3	4	5
16. I remind myself that I will eventually see or be with my brother or sister again.	1	2	3	4	5
17. Even though no longer physically here, I have seen, heard, smelled, or touched my brother or sister.	1	2	3	4	5
18. I find comfort in being in my brother or sister's room or bed.	1	2	3	4	5
19. I find comfort in going places my brother or sister enjoyed or where s/he spent a lot of time.	1	2	3	4	5
20. It helps me to stay in touch with my brother or sister's friends.	1	2	3	4	5

Appendix B  
Responses to Stress Questionnaire

**RESPONSES TO STRESS**

This is a list of things that parents who have lost a child sometimes find stressful or a problem to deal with. Please circle the number indicating how stressful the following things have been for you in the past year.

	Not at all	A little	Somewhat	Very
a. Missing the fun things we used to do as a family	1	2	3	4
b. Financial concerns	1	2	3	4
c. Concerns about how this loss is affecting or will affect my family	1	2	3	4
d. Concerns about getting back to work	1	2	3	4
e. Difficulty getting back into normal routine	1	2	3	4
f. Thinking about what my child would have been like in the future	1	2	3	4
g. Communicating with my surviving children about the illness/death	1	2	3	4
h. Not getting enough help or social support	1	2	3	4
i. Feeling unsure about how to talk to friends or family about my child	1	2	3	4
j. Regrets about decisions we made when my child was ill	1	2	3	4
k. Feeling pressure to put up a good "front" for my family and friends	1	2	3	4
l. Not being able to relieve my children's or my partner's grief	1	2	3	4
m. Other: _____	1	2	3	4

Below is a list of things that parents sometimes do, think, or feel when their child has died. Everyone copes in their own way – some parents do a lot of the things listed below, other parents just do or think a few of these things.

Think of all the stressful parts of having lost your child that you checked off above. For each item below, circle **one** number from 1 (not at all) to 4 (a lot) that shows **how much** you do or feel these things when you are trying to deal with the stressful aspects of the loss. Please let us know about everything you do, think, and feel, even if you don't think it helps make things better.

WHEN DEALING WITH THE STRESS OF MY CHILD'S DEATH:	How much do you do this?			
	Not at all	A little	Some	A lot
1. I try not to have any emotions.	1	2	3	4
2. I feel sick to my stomach or get headaches.	1	2	3	4
3. I try to think of different ways to deal with stress related to having lost my child. <b>Write one plan you thought of:</b> _____ _____	1	2	3	4
4. I don't feel any emotions at all, it's like I have no feelings.	1	2	3	4
5. I wish that I were stronger so that things would be different.	1	2	3	4
6. I keep remembering what has happened or can't stop thinking about my child's death.	1	2	3	4

WHEN DEALING WITH THE STRESS OF MY CHILD'S DEATH:

How much did you do this?  
Not at all A little Some A lot

- |  |  |   |   |   |   |  |                                     |                                  |  |  |                |
|--|--|---|---|---|---|--|-------------------------------------|----------------------------------|--|--|----------------|
| <p>7. I let someone or something know how I feel. <i>(remember to circle a number.)</i> →</p> <p><b>Check all you talked to:</b></p> <table border="0"> <tr> <td><input type="checkbox"/> Spouse/Partner</td> <td><input type="checkbox"/> Friend</td> <td><input type="checkbox"/> Physician</td> <td><input type="checkbox"/> Brother/Sister</td> <td><input type="checkbox"/> Clergy Member</td> </tr> <tr> <td><input type="checkbox"/> My children</td> <td><input type="checkbox"/> Parent</td> <td><input type="checkbox"/> Nurse</td> <td><input type="checkbox"/> Therapist/Counselor</td> <td><input type="checkbox"/> None of these</td> </tr> </table>   | <input type="checkbox"/> Spouse/Partner              | <input type="checkbox"/> Friend           | <input type="checkbox"/> Physician                    | <input type="checkbox"/> Brother/Sister             | <input type="checkbox"/> Clergy Member      | <input type="checkbox"/> My children       | <input type="checkbox"/> Parent     | <input type="checkbox"/> Nurse   | <input type="checkbox"/> Therapist/Counselor | <input type="checkbox"/> None of these | <p>1 2 3 4</p> |
| <input type="checkbox"/> Spouse/Partner  | <input type="checkbox"/> Friend                      | <input type="checkbox"/> Physician        | <input type="checkbox"/> Brother/Sister               | <input type="checkbox"/> Clergy Member              |   |  |                                     |                                  |  |  |                |
| <input type="checkbox"/> My children   | <input type="checkbox"/> Parent                      | <input type="checkbox"/> Nurse            | <input type="checkbox"/> Therapist/Counselor          | <input type="checkbox"/> None of these              |   |  |                                     |                                  |  |  |                |
| <p>8. I decide I'm okay the way I am, even though I'm not perfect.</p>   | <p>1 2 3 4</p>                                       |   |   |   |   |  |                                     |                                  |  |  |                |
| <p>9. When I'm around other people I act like my child's death never happened.</p>   | <p>1 2 3 4</p>                                       |   |   |   |   |  |                                     |                                  |  |  |                |
| <p>10. I just <b>have</b> to get away from everything when I am dealing with the stress of it.</p>   | <p>1 2 3 4</p>                                       |   |   |   |   |  |                                     |                                  |  |  |                |
| <p>11. I deal with the stress of having lost my child by wishing it would just go away, that everything would work itself out.</p>   | <p>1 2 3 4</p>                                       |   |   |   |   |  |                                     |                                  |  |  |                |
| <p>12. I get really jumpy.</p>   | <p>1 2 3 4</p>                                       |   |   |   |   |  |                                     |                                  |  |  |                |
| <p>13. I realize that I just have to live with things the way they are.</p>  | <p>1 2 3 4</p>                                       |   |   |   |   |  |                                     |                                  |  |  |                |
| <p>14. When I am dealing with the stress of having lost my child, I just <b>can't</b> be near anything that reminds me of what is happening.</p>   | <p>1 2 3 4</p>                                       |   |   |   |   |  |                                     |                                  |  |  |                |
| <p>15. I <b>try</b> not to think about it, to forget all about it.</p>   | <p>1 2 3 4</p>                                       |   |   |   |   |  |                                     |                                  |  |  |                |
| <p>16. I really don't know what I feel.</p>  | <p>1 2 3 4</p>                                       |   |   |   |   |  |                                     |                                  |  |  |                |
| <p>17. I ask other people or things for help or for ideas about how to make things better. <i>(remember to circle a number.)</i> →</p> <p><b>Check all you talked to:</b></p> <table border="0"> <tr> <td><input type="checkbox"/> Spouse/Partner</td> <td><input type="checkbox"/> Friend</td> <td><input type="checkbox"/> Physician</td> <td><input type="checkbox"/> Brother/Sister</td> <td><input type="checkbox"/> Clergy Member</td> </tr> <tr> <td><input type="checkbox"/> My children</td> <td><input type="checkbox"/> Parent</td> <td><input type="checkbox"/> Nurse</td> <td><input type="checkbox"/> Therapist/Counselor</td> <td><input type="checkbox"/> None of these</td> </tr> </table>  | <input type="checkbox"/> Spouse/Partner              | <input type="checkbox"/> Friend           | <input type="checkbox"/> Physician                    | <input type="checkbox"/> Brother/Sister             | <input type="checkbox"/> Clergy Member      | <input type="checkbox"/> My children       | <input type="checkbox"/> Parent     | <input type="checkbox"/> Nurse   | <input type="checkbox"/> Therapist/Counselor | <input type="checkbox"/> None of these | <p>1 2 3 4</p> |
| <input type="checkbox"/> Spouse/Partner  | <input type="checkbox"/> Friend                      | <input type="checkbox"/> Physician        | <input type="checkbox"/> Brother/Sister               | <input type="checkbox"/> Clergy Member              |   |  |                                     |                                  |  |  |                |
| <input type="checkbox"/> My children   | <input type="checkbox"/> Parent                      | <input type="checkbox"/> Nurse            | <input type="checkbox"/> Therapist/Counselor          | <input type="checkbox"/> None of these              |   |  |                                     |                                  |  |  |                |
| <p>18. When I am trying to sleep, I <b>can't stop</b> thinking about having lost my child or I have bad dreams about it.</p>   | <p>1 2 3 4</p>                                       |   |   |   |   |  |                                     |                                  |  |  |                |
| <p>19. I tell myself that I can get through this, or that I will be okay.</p>  | <p>1 2 3 4</p>                                       |   |   |   |   |  |                                     |                                  |  |  |                |
| <p>20. I let my feelings out. <i>(remember to circle a number.)</i> →</p> <p><b>I do this by: (Check all that you did.)</b></p> <table border="0"> <tr> <td><input type="checkbox"/> Writing in my journal/diary</td> <td><input type="checkbox"/> Drawing/painting</td> </tr> <tr> <td><input type="checkbox"/> Complaining to let off steam</td> <td><input type="checkbox"/> Being sarcastic/making fun</td> </tr> <tr> <td><input type="checkbox"/> Listening to music</td> <td><input type="checkbox"/> Punching a pillow</td> </tr> <tr> <td><input type="checkbox"/> Exercising</td> <td><input type="checkbox"/> Yelling</td> </tr> <tr> <td><input type="checkbox"/> Crying</td> <td><input type="checkbox"/> None of these</td> </tr> </table> | <input type="checkbox"/> Writing in my journal/diary | <input type="checkbox"/> Drawing/painting | <input type="checkbox"/> Complaining to let off steam | <input type="checkbox"/> Being sarcastic/making fun | <input type="checkbox"/> Listening to music | <input type="checkbox"/> Punching a pillow | <input type="checkbox"/> Exercising | <input type="checkbox"/> Yelling | <input type="checkbox"/> Crying              | <input type="checkbox"/> None of these | <p>1 2 3 4</p> |
| <input type="checkbox"/> Writing in my journal/diary   | <input type="checkbox"/> Drawing/painting            |   |   |   |   |  |                                     |                                  |  |  |                |
| <input type="checkbox"/> Complaining to let off steam  | <input type="checkbox"/> Being sarcastic/making fun  |   |   |   |   |  |                                     |                                  |  |  |                |
| <input type="checkbox"/> Listening to music  | <input type="checkbox"/> Punching a pillow           |   |   |   |   |  |                                     |                                  |  |  |                |
| <input type="checkbox"/> Exercising  | <input type="checkbox"/> Yelling                     |   |   |   |   |  |                                     |                                  |  |  |                |
| <input type="checkbox"/> Crying  | <input type="checkbox"/> None of these               |   |   |   |   |  |                                     |                                  |  |  |                |
| <p>21. I get help from other people or things when I'm trying to figure out how to deal with my feelings. <i>(remember to circle a number.)</i> →</p> <p><b>Check all that you went to:</b></p> <table border="0"> <tr> <td><input type="checkbox"/> Spouse/Partner</td> <td><input type="checkbox"/> Friend</td> <td><input type="checkbox"/> Physician</td> <td><input type="checkbox"/> Brother/Sister</td> <td><input type="checkbox"/> Clergy Member</td> </tr> <tr> <td><input type="checkbox"/> My children</td> <td><input type="checkbox"/> Parent</td> <td><input type="checkbox"/> Nurse</td> <td><input type="checkbox"/> Therapist/Counselor</td> <td><input type="checkbox"/> None of these</td> </tr> </table>                            | <input type="checkbox"/> Spouse/Partner              | <input type="checkbox"/> Friend           | <input type="checkbox"/> Physician                    | <input type="checkbox"/> Brother/Sister             | <input type="checkbox"/> Clergy Member      | <input type="checkbox"/> My children       | <input type="checkbox"/> Parent     | <input type="checkbox"/> Nurse   | <input type="checkbox"/> Therapist/Counselor | <input type="checkbox"/> None of these | <p>1 2 3 4</p> |
| <input type="checkbox"/> Spouse/Partner  | <input type="checkbox"/> Friend                      | <input type="checkbox"/> Physician        | <input type="checkbox"/> Brother/Sister               | <input type="checkbox"/> Clergy Member              |   |  |                                     |                                  |  |  |                |
| <input type="checkbox"/> My children   | <input type="checkbox"/> Parent                      | <input type="checkbox"/> Nurse            | <input type="checkbox"/> Therapist/Counselor          | <input type="checkbox"/> None of these              |   |  |                                     |                                  |  |  |                |
| <p>22. I <b>just can't</b> get myself to face the situation.</p>   | <p>1 2 3 4</p>                                       |   |   |   |   |  |                                     |                                  |  |  |                |
| <p>23. I wish that someone would just come and take away the stressful aspects of it.</p>  | <p>1 2 3 4</p>                                       |   |   |   |   |  |                                     |                                  |  |  |                |

**You're half done. Before you keep working, look back at the first page so you remember the aspects of your loss that have been stressful for you lately. Remember to answer the questions below thinking about these things.**

WHEN DEALING WITH THE STRESS OF MY CHILD'S DEATH:

How much did you do this?  
 Not at all   A little   Some   A lot  
 1   2   3   4

24. I do something to try to fix the stressful aspects of it.  
**Write one thing you did:** \_\_\_\_\_  
 \_\_\_\_\_
25. Thoughts about the stressful aspects just pop into my head. 1 2 3 4
26. When I am dealing with the stress, I feel it in my body.  
*(remember to circle a number.)* → 1 2 3 4  
**Check all that happen:**  
 My heart races                       My breathing speeds up                       None of these  
 I feel hot or sweaty                       My muscles get tight
27. I try to stay away from people and things that make me feel upset or remind me of having lost my child. 1 2 3 4
28. I don't feel like myself when I am dealing with it, it's like I am far away from everything. 1 2 3 4
29. I just take things as they are; I go with the flow. 1 2 3 4
30. I think about happy things to take my mind off it or how I'm feeling. 1 2 3 4
31. When something stressful happens related to having lost my child, I can't stop thinking about how I am feeling. 1 2 3 4
32. I get sympathy, understanding, or support from someone. *(remember to circle a number.)* → 1 2 3 4  
**Check all you went to:**  
 Spouse/Partner     Friend                       Physician                       Brother/Sister                       Clergy Member  
 My children                       Parent                       Nurse                       Therapist/Counselor                       None of these
33. When something stressful happens related to the loss, I can't always control what I do.  
*(remember to circle a number.)* → 1 2 3 4  
**Check all that happen:**  
 I can't stop eating                       I can't stop talking  
 I do dangerous things                       I have to keep fixing/checking things  
 None of these
34. I tell myself that things could be worse. 1 2 3 4
35. My mind just goes blank, I can't think at all. 1 2 3 4
36. I tell myself that it doesn't matter, that it isn't a big deal. 1 2 3 4
37. When I am faced with the stressful parts of having lost my child, right away I feel really:  
*(remember to circle a number.)* → 1 2 3 4  
**Check all that you feel:**  
 Angry                       Sad                       None of these  
 Worried/anxious                       Scared
38. It's really hard for me to concentrate or pay attention. 1 2 3 4
39. I think about the things I'm learning from having lost my child, or something good that will come from it. 1 2 3 4
40. After something stressful happens related to it, I can't stop thinking about what I did or said. 1 2 3 4

WHEN DEALING WITH THE STRESS OF MY CHILD'S DEATH:

How much did you do this?  
Not at all A little Some A lot

- |  | 1 | 2 | 3 | 4 |
|--|---|---|---|---|
| 42. When I'm dealing with it, I end up just lying around or sleeping a lot.  |   |   |   |   |
| 43. I keep my mind off it by:<br>(remember to circle a number.) →<br><b>Check all that you do:</b>   |   |   |   |   |
| <input type="checkbox"/> Exercising <input type="checkbox"/> Reading <input type="checkbox"/> Shopping<br><input type="checkbox"/> Doing a hobby <input type="checkbox"/> Watching TV <input type="checkbox"/> Listening to music <input type="checkbox"/> None of these | 1 | 2 | 3 | 4 |
| 44. When something stressful happens related to having lost my child, I get upset by things that don't usually bother me.  |   |   |   |   |
| 45. I do something to calm myself down when I'm dealing with the stress of it.<br>(remember to circle a number.) →<br><b>Check all that you do:</b>  |   |   |   |   |
| <input type="checkbox"/> Take deep breaths <input type="checkbox"/> Pray <input type="checkbox"/> Walk<br><input type="checkbox"/> Listen to music <input type="checkbox"/> Take a break <input type="checkbox"/> Meditate <input type="checkbox"/> None of these        | 1 | 2 | 3 | 4 |
| 46. I just freeze; I can't do anything.  |   |   |   |   |
| 47. When the stressful things happen, I sometimes act without thinking.  |   |   |   |   |
| 48. I keep my feelings under control when I have to, then let them out when they won't make things worse.  |   |   |   |   |
| 49. I can't seem to get around to doing things I'm supposed to do.   |   |   |   |   |
| 50. I tell myself that everything will be all right.   |   |   |   |   |
| 51. When something stressful happens related to the loss, I can't stop thinking about why this is happening.   |   |   |   |   |
| 52. I think of ways to laugh about it so that it won't seem so bad.  |   |   |   |   |
| 53. My thoughts start racing when I am faced with the stressful parts of having lost my child.   |   |   |   |   |
| 54. I imagine something really fun or exciting happening in my life.   |   |   |   |   |
| 55. When something stressful happens related to the loss, I can get so upset that I can't remember what happened or what I did.  |   |   |   |   |
| 56. I try to believe that it never happened.   |   |   |   |   |
| 57. When I am dealing with the stress of having lost my child, sometimes I can't control what I do or say.   |   |   |   |   |

### RESPONSES TO STRESS

This is a list of things about having lost a brother or sister that kids and teenagers sometimes find stressful or a problem to deal with. Please circle the number indicating how stressful the following things have been for you in the past year.

	Not at all	A little	Somewhat	Very
a. Missing the fun things I used to do with my family	1	2	3	4
b. Concerns about what happened to my brother/sister after he/she died	1	2	3	4
c. Feeling bad about times I did not get along with my brother/sister	1	2	3	4
d. Concerns that someone else in my family will die	1	2	3	4
e. Concerns about how my parents or other family members are feeling	1	2	3	4
f. Trying to help other people feel better since my brother/sister died	1	2	3	4
g. My parents not having much time to do things with me	1	2	3	4
h. Having a lot more chores or responsibilities at home than I used to have	1	2	3	4
i. Feeling like my friends or other people treat me differently	1	2	3	4
j. Feeling unsure about how to talk to my family or others about my brother/sister	1	2	3	4
k. Feeling pressure to put up a good "front" for my family and friends	1	2	3	4
l. Other: _____	1	2	3	4

Below is a list of things that kids and teenagers sometimes do, think, or feel when they are dealing with the death of a brother or sister. Everyone copes in their own way – some kids and teenagers do a lot of the things listed below, other people just do or think a few things.

**Think of all the stressful parts of having lost a brother or sister that you marked above.** For each item below, circle **one** number from 1 (not at all) to 4 (a lot) that shows **how much** you do or feel these things when you are trying to deal with these things. Please let us know about everything you do, think, and feel, even if you don't think it helps make things better.

WHEN DEALING WITH THE STRESS OF MY BROTHER OR SISTER'S DEATH:

	How much do you do this?			
	Not at all	A little	Some	A lot
1. I try not to have any emotions.	1	2	3	4
2. I feel sick to my stomach or get headaches.	1	2	3	4
3. I try to think of different ways to deal with stress related to having lost my brother or sister. <b>Write one plan you thought of:</b> _____ _____	1	2	3	4
4. I don't feel any emotions at all, it's like I have no feelings.	1	2	3	4
5. I wish that I were stronger and less sensitive so that things would be different.	1	2	3	4
6. I <b>keep remembering</b> what has happened or <b>can't stop thinking</b> about my brother or sister's death.	1	2	3	4



## WHEN DEALING WITH THE STRESS OF MY BROTHER OR SISTER'S DEATH:

How much did you do this?  
Not at all A little Some A lot

7. I let someone or something know how I feel. (*remember to circle a number.*) → 1 2 3 4  
**Check all that you talked to:**  
 Parent     Friend     Brother/Sister     Doctor or Nurse     None of These  
 Teacher     God     Pet     Stuffed Animal
8. I decide I'm okay the way I am, even though I'm not perfect. 1 2 3 4
9. When I'm around other people I act like my brother or sister's death never happened. 1 2 3 4
10. I just **have** to get away from everything when I am dealing with the stress of it. 1 2 3 4
11. I deal with having lost my brother or sister by just wishing it would go away, that everything would work itself out. 1 2 3 4
12. I get really jumpy. 1 2 3 4
13. I realize that I just have to live with things the way they are. 1 2 3 4
14. When I am dealing with the stress of having lost my brother or sister, I just **can't** be near anything that reminds me of what is happening. 1 2 3 4
15. I try not to think about it, to forget all about it. 1 2 3 4
16. I really don't know what I feel. 1 2 3 4
17. I ask other people or things for help or for ideas about how to make things better. (*remember to circle a number.*) → 1 2 3 4  
**Check all that you talked to:**  
 Parent     Friend     Brother/sister     Doctor or Nurse     None of These  
 Teacher     God     Pet     Stuffed Animal
18. When I am trying to sleep, I **can't stop** thinking about having lost my brother or sister, or I have bad dreams about it. 1 2 3 4
19. I tell myself that I can get through this, or that I will be okay. 1 2 3 4
20. I let my feelings out. (*remember to circle a number.*) → 1 2 3 4  
**I do this by: (Check all that you did.)**  
 Writing in my journal/diary     Drawing/painting  
 Complaining to let off steam     Being sarcastic/making fun  
 Listening to music     Punching a pillow  
 Exercising     Yelling  
 Crying     None of these
21. I get help from other people or things when I'm trying to figure out how to deal with my feelings about having lost my brother or sister. (*remember to circle a number.*) → 1 2 3 4  
**Check all that you went to:**  
 Parent     Friend     Brother/sister     Doctor or Nurse     None of these  
 Teacher     God     Pet     Stuffed Animal
22. I just **can't** get myself to face having lost my brother or sister. 1 2 3 4

**You're half done! Before you keep working, look back at the first page so you remember the things about losing a brother or sister that have been stressful for you lately. Remember to answer these questions thinking about those things.**

## WHEN DEALING WITH THE STRESS OF MY BROTHER OR SISTER'S DEATH:

How much did you do this?  
Not at all A little Some A lot

23. I wish that someone would just come and take away the stressful parts of having lost my brother or sister. 1 2 3 4
24. I do something to try to fix the stressful parts of it. 1 2 3 4  
**Write one thing you did:** \_\_\_\_\_  
\_\_\_\_\_
25. Thoughts about having lost my brother or sister just pop into my head. 1 2 3 4
26. When I am dealing with the stress of it, I feel it in my body. (*remember to circle a number.*) → 1 2 3 4  
**Check all that happen:**  
 My heart races       My breathing speeds up       None of these  
 I feel hot or sweaty       My muscles get tight
27. I try to stay away from people and things that make me feel upset or remind me of having lost my brother or sister. 1 2 3 4
28. I don't feel like myself when I am dealing with the stress of it; it's like I am far away from everything. 1 2 3 4
29. I just take things as they are; I go with the flow. 1 2 3 4
30. I think about happy things to take my mind off the stressful parts or how I'm feeling. 1 2 3 4
31. When the stressful parts of having lost a brother or sister happen, I can't stop thinking about how I am feeling. 1 2 3 4
32. I get sympathy, understanding, or support from someone. (*remember to circle a number.*) → 1 2 3 4  
**Check all that you went to:**  
 Parent       Friend       Brother/sister       Doctor or Nurse       None of these  
 Teacher       God       Pet       Stuffed Animal
33. When the stressful parts of it happen, I can't always control what I do. (*remember to circle a number.*) → 1 2 3 4  
**Check all that happen:**  
 I can't stop eating       I can't stop talking  
 I do dangerous things       I have to keep fixing/checking things  
 None of these
34. I tell myself that things could be worse. 1 2 3 4
35. My mind just goes blank when the stressful parts of it happen, I can't think at all. 1 2 3 4
36. I tell myself that it doesn't matter, that it isn't a big deal. 1 2 3 4
37. When I am faced with the stressful parts of having lost my brother or sister, right away I feel really: (*remember to circle a number.*) → 1 2 3 4  
**Check all that you feel.**  
 Angry       Sad       Scared       Worried/anxious       None of these
38. It's really hard for me to concentrate or pay attention. 1 2 3 4
39. I think about the things I'm learning from having lost my brother or sister or I think of something good that will come from it. 1 2 3 4

40. After something stressful happens related to my brother or sister's death,

## WHEN DEALING WITH THE STRESS OF MY BROTHER OR SISTER'S DEATH:

How much did you do this?  
Not at all A little Some A lot

	1	2	3	4
I can't stop thinking about what I did or said.				
41. I say to myself, "This isn't real."	1	2	3	4
42. When I'm dealing with it, I end up just lying around or sleeping a lot.	1	2	3	4
43. I keep my mind off it by: <i>(remember to circle a number.)</i> →	1	2	3	4
<b>Check all that you do:</b>				
<input type="checkbox"/> Exercising				
<input type="checkbox"/> Seeing friends				
<input type="checkbox"/> Watching TV				
<input type="checkbox"/> None of these				
<input type="checkbox"/> Playing video games				
<input type="checkbox"/> Doing a hobby				
<input type="checkbox"/> Listening to music				
44. When the stressful parts of having lost my brother or sister happen, I get upset by things that don't usually bother me.	1	2	3	4
45. I do something to calm myself down when I'm dealing with the stress of it. <i>(remember to circle a number.)</i> →	1	2	3	4
<b>Check all that you do:</b>				
<input type="checkbox"/> Take deep breaths				
<input type="checkbox"/> Pray				
<input type="checkbox"/> Walk				
<input type="checkbox"/> Listen to music				
<input type="checkbox"/> Take a break				
<input type="checkbox"/> Meditate				
<input type="checkbox"/> None of these				
46. I just freeze; I can't do anything.	1	2	3	4
47. When something stressful happens related to having lost my brother or sister, sometimes I act without thinking.	1	2	3	4
48. I keep my feelings under control when I have to, then let them out when they won't make things worse.	1	2	3	4
49. I can't seem to get around to doing things I'm supposed to do.	1	2	3	4
50. I tell myself that everything will be all right.	1	2	3	4
51. When something stressful happens related to it, I can't stop thinking about why this is happening to me.	1	2	3	4
52. I think of ways to laugh about it so that it won't seem so bad.	1	2	3	4
53. My thoughts start racing when I am faced with the stressful parts of having lost my brother or sister.	1	2	3	4
54. I imagine something really fun or exciting happening in my life.	1	2	3	4
55. When something stressful happens related to it, I get so upset that I can't remember what happened or what I did.	1	2	3	4
56. I try to believe that it never happened.	1	2	3	4
57. When I am dealing with having lost my brother or sister, sometimes I can't control what I do or say.	1	2	3	4

## Appendix C

### Hogan Grief Reaction Checklist

### HOGAN GRIEF REACTION CHECKLIST

*This questionnaire consists of a list of thoughts and feelings that you may have had **since** your child died. Please read each statement carefully, and choose the number that best describes the way you have been feeling during the **past two weeks, including today**. Circle the number beside the statement that best describes you. Please do not skip any items.*

	Does not describe me at all	Does not quite describe me	Describes me fairly well	Describes me well	Describes me very well
1. My hopes are shattered	1	2	3	4	5
2. I have learned to cope better with life	1	2	3	4	5
3. I have little control over my sadness	1	2	3	4	5
4. I worry excessively	1	2	3	4	5
5. I frequently feel bitter	1	2	3	4	5
6. I feel like I am in shock	1	2	3	4	5
7. Sometimes my heart beats faster than it normally does for no reason	1	2	3	4	5
8. I am resentful	1	2	3	4	5
9. I am preoccupied with feeling worthless	1	2	3	4	5
10. I feel as though I am a better person	1	2	3	4	5
11. I believe I should have died and he or she should have lived	1	2	3	4	5
12. I have a better outlook on life	1	2	3	4	5
13. I often have headaches	1	2	3	4	5
14. I feel a heaviness in my heart	1	2	3	4	5
15. I feel revengeful	1	2	3	4	5
16. I have burning in my stomach	1	2	3	4	5

	Does not describe me at all	Does not quite describe me	Describes me fairly well	Describes me well	Describes me very well
17. I want to die to be with him or her	1	2	3	4	5
18. I frequently have muscle tension	1	2	3	4	5
19. I have more compassion for others	1	2	3	4	5
20. I forget things easily, e.g. names, telephone numbers	1	2	3	4	5
21. I feel shaky	1	2	3	4	5
22. I am confused about who I am	1	2	3	4	5
23. I have lost my confidence	1	2	3	4	5
24. I am stronger because of the grief I have experienced	1	2	3	4	5
25. I don't believe I will ever be happy again	1	2	3	4	5
26. I have difficulty remembering things from the past	1	2	3	4	5
27. I frequently feel frightened	1	2	3	4	5
28. I feel unable to cope	1	2	3	4	5
29. I agonize over his or her death	1	2	3	4	5
30. I am a more forgiving person	1	2	3	4	5
31. I have panic attacks over nothing	1	2	3	4	5
32. I have difficulty concentrating	1	2	3	4	5
33. I feel like I am walking in my sleep	1	2	3	4	5

	Does not describe me at all	Does not quite describe me	Describes me fairly well	Describes me well	Describes me very well
34. I have shortness of breath	1	2	3	4	5
35. I avoid tenderness	1	2	3	4	5
36. I am more tolerant of myself	1	2	3	4	5
37. I have hostile feelings	1	2	3	4	5
38. I am experiencing periods of dizziness	1	2	3	4	5
39. I have difficulty learning new things	1	2	3	4	5
40. I have difficulty accepting the permanence of the death	1	2	3	4	5
41. I am more tolerant of others	1	2	3	4	5
42. I blame others	1	2	3	4	5
43. I feel like I don't know myself	1	2	3	4	5
44. I am frequently fatigued	1	2	3	4	5
45. I have hope for the future	1	2	3	4	5
46. I have difficulty with abstract thinking	1	2	3	4	5
47. I feel hopeless	1	2	3	4	5
48. I want to harm others	1	2	3	4	5
49. I have difficulty remembering new information	1	2	3	4	5
50. I feel sick more often	1	2	3	4	5
51. I reached a turning point where I began to let go of some of my grief	1	2	3	4	5
52. I often have back pain	1	2	3	4	5
53. I am afraid that I will lose control	1	2	3	4	5

Children's Friendship Study – G

ID # \_\_\_\_\_ - \_\_\_\_\_ - \_\_\_\_  
 Date \_\_\_\_\_  
 RA \_\_\_\_\_ T1 or T2

	Does not describe me at all	Does not quite describe me	Describes me fairly well	Describes me well	Describes me very well
54. I feel detached from others	1	2	3	4	5
55. I frequently cry	1	2	3	4	5
56. I startle easily	1	2	3	4	5
57. Tasks seem insurmountable	1	2	3	4	5
58. I get angry often	1	2	3	4	5
59. I ache with loneliness	1	2	3	4	5
60. I am having more good days than bad	1	2	3	4	5
61. I care more deeply for others	1	2	3	4	5



Appendix D

Hogan Inventory of Bereavement

**HOGAN INVENTORY OF BEREAVEMENT**  
 (Children's Form)

*This questionnaire consists of a list of thoughts and feelings that you may have had **since** your brother or sister died. Please read each statement carefully, and choose the number that best describes the way you have been feeling during the **past two weeks, including today**. Circle the number beside the statement that best describes you. Please do not skip any items.*

	Does not describe me at all	Does not quite describe me	Describes me fairly well	Describes me well	Describes me very well
1. I believe I will lose control when I think about him or her	1	2	3	4	5
2. I believe I am a better person	1	2	3	4	5
3. I have grown up faster than my friends	1	2	3	4	5
4. I get a sick feeling when I am having fun	1	2	3	4	5
5. I believe I am stronger because of the grief I have had to deal with	1	2	3	4	5
6. I have no control over my sadness	1	2	3	4	5
7. I have learned to deal better with my problems	1	2	3	4	5
8. I believe I am going crazy	1	2	3	4	5
9. My religion has become more important to me	1	2	3	4	5
10. I want to die to be with him or her	1	2	3	4	5
11. I can put up with others a lot better	1	2	3	4	5
12. I get a sick feeling when I am feeling happy	1	2	3	4	5
13. I have learned that all people die	1	2	3	4	5
14. I should have died and he or she should have lived	1	2	3	4	5

	Does not describe me at all	Does not quite describe me	Describes me fairly well	Describes me well	Describes me very well
15. I have changed my mind about what is important to me	1	2	3	4	5
16. I feel sad when I think about him or her	1	2	3	4	5
17. I have a better outlook on life	1	2	3	4	5
18. Family holidays such as Christmas are sad times for my family	1	2	3	4	5
19. I am more caring and nice to others	1	2	3	4	5
20. I believe I have little control over my life	1	2	3	4	5
21. I have learned to deal better with my life	1	2	3	4	5
22. I get all nervous and jumpy and scared for no reason	1	2	3	4	5
23. I can help others who are sad because somebody they love died	1	2	3	4	5
24. I do dangerous things to help me forget that he or she is dead	1	2	3	4	5
25. I care more for my family	1	2	3	4	5
26. I am afraid that more people I love will die	1	2	3	4	5
27. I try to be kinder to other people	1	2	3	4	5
28. I have nightmares about his or her death	1	2	3	4	5
29. I don't take people for granted	1	2	3	4	5
30. I worry about everything	1	2	3	4	5
31. I have a better imagination and can make-up things better	1	2	3	4	5

	Does not describe me at all	Does not quite describe me	Describes me fairly well	Describes me well	Describes me very well
32. I do not believe I will ever get over his or her death	1	2	3	4	5
33. I am more aware of others' feelings	1	2	3	4	5
34. I don't care what happens to me	1	2	3	4	5
35. I understand how other kids feel when someone they love dies	1	2	3	4	5
36. My family will always be incomplete	1	2	3	4	5
37. I am more understanding of others	1	2	3	4	5
38. I am often sick	1	2	3	4	5
39. I am less likely to get upset with myself	1	2	3	4	5
40. People don't know what I am going through	1	2	3	4	5
41. I don't think I will ever be happy again	1	2	3	4	5
42. I know how easy it is for life to be taken away	1	2	3	4	5
43. I can get help for my grief when I need it	1	2	3	4	5
44. I have trouble paying attention to my schoolwork and other things	1	2	3	4	5
45. I am afraid to get close to people	1	2	3	4	5
46. I do not sleep well at night	1	2	3	4	5

Appendix E  
Concluding Interview

**CONCLUDING GRIEF INTERVIEW - PARENT**

**"Thank you for all of the information you've shared today. I have just a few final questions, which are open-ended. You might need to think a little before you can answer them, so take a minute to think if you'd like."**

1. Some parents have told us that they stay in touch with their child who died by talking to them, keeping something special that belonged to them, or remembering them in some special way. Others haven't said much about this. What about you? What kinds of things do you do to remember or stay in touch with your child?

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2. Some parents have told us that their child did or said something before he/she died so that they would be remembered. Others haven't said much. What, if anything, did your child do or say so that he/she would be remembered?

*(Probe if needed: leaving a special message, giving you/sibling a gift or other belonging of theirs?)*

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**CONCLUDING GRIEF INTERVIEW - CHILD**

**"Thank you for all of the information you've shared today. I have just a few final questions, which are open-ended. You might need to think a little before you can answer them, so take a minute to think if you'd like."**

1. Some kids/teens have told us that they stay in touch with their brother/sister who died by talking to them, keeping something special that belonged to them, or remembering them in some special way. Others haven't said much about this. What about you? What kinds of things do you do to remember or stay in touch with your brother/sister?

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2. Some kids/teens have told us that their brother/sister did or said something before he/she died so that they would be remembered. Others haven't said much. What, if anything, did your brother/sister do or say so that he/she would be remembered?

*(Probe if needed: leaving a special message, giving you a gift or other belonging of theirs?)*

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