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The continual journey : parents' spirituality after the death of a child from terminal illness

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The Continual Journey: Parents'
Spirituality After the Death of a
Child from Terminal Illness

ABSTRACT

This study sought to better understand bereaved parents' spirituality following the death

of a child due to terminal illness. While previous research has looked at the role of spirituality

following the death of a child, study populations have been predominantly female, Caucasian,

and Christian. A goal of this study was to explore this issue among a more diverse population, in

terms of religion, gender and ethnicity.

The researcher met with and provided recruitment flyers to representatives of interfaith

organizations, parent support groups, and local hospices. Additional recruitment included a

snowball method utilizing acquaintances and colleagues of the researcher. Eleven individuals,

including eight women and three men, participated in face-to-face, telephone, or Skype audio-

recorded interviews. Participant modal age range was 61-70, with an average of 13 years having

passed since their loss. The semi-structured interview elicited participants' conceptualization of

spirituality and their perceptions regarding the role that spirituality played in their lives, how

their spirituality changed, how their family made use of spirituality, and how spirituality

impacted significant relationships after their child's death.

Findings indicate the centrality of spirituality as a tool for coping with the loss of a child,

the enduring nature of a parents' bereavement, and the diverse nature of supportive relationships

that change after the death of a child. In addition to pointing to challenges in recruiting a

religiously and ethnically diverse sample, study findings highlight for care professionals the potential benefits of incorporating spirituality into therapeutic interventions for bereaved parents.

THE CONTINUAL JOURNEY: PARENTS' SPIRITUALITY AFTER THE DEATH OF

A CHILD FROM TERMINAL ILLNESS

A project based upon an independent investigation,
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for the degree of Master of Social Work.

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CHAPTER I

Introduction

The death of a child is an unnatural and devastating event which can have a profound impact upon surviving family members as they adjust to an altered existence without their loved one. Since adults are expected to outlive their children, the devastation of a child's death is greatly felt by a child's surviving parents. After the loss of a child, parents may experience an existential impasse, questioning the validity and nature of the world. In order to make sense of this event, parents may turn to, or away from their religion or spirituality. For some, spirituality may be a way of grounding in reality as it can provide a framework for meaning making as well as an avenue for coping with loss. For others, spirituality and religion may become the source of great anger and anguish, therefore weakening its influence in the lives of the bereaved. Spirituality remains an important force in the United States, with 84 percent of Americans identifying as religious (Gallup Inc., 2011). Despite the prevalence of faith in the United States, a country founded on Judeo-Christian principles, religion and spirituality are subjects frequently avoided by practitioners (Golsworthy & Coyle, 2001) who are often responsible for the care and support of grieving families.

According to the United States Census Bureau one person dies every 12 seconds (U.S. Census Bureau, 2013). If each person's death impacts five people alone, more than 10 million people in the United States grieve the loss of a loved one each year (Walsh, 2012, p.1). The grief after a child's death is great no matter the cause, yet some research has shown that parents whose

child has died from a terminal illness experience greater challenges coping with their loss than those whose children die of suicide, homicide, or an accident (Matthews & Marwitt, 2004). Terminal illness impacts individuals and families in a unique way for they must cope with the challenge of anticipatory grief, knowing that their loved one will not survive their illness. Despite a 60 percent reduction in the overall risk of mortality in the past 75 years due to advances in treatment and care (Hoyert, 2012), millions are still impacted every year by life limiting diagnoses that will not only change their lives but forever mark the lives of their loved ones.

Using a grief theory conceptual lens, the current study explored the way in which bereaved parents' spirituality changed after the death of a child due to terminal illness. As the majority of prior research on bereaved parents and their relationship with spirituality has been carried out with a predominantly Christian, Caucasian, and female population, this study attempted to recruit a more diverse sample in terms of religion, gender, and ethnicity.

By understanding the function and nature of individuals' spirituality following overwhelming loss, social workers and other care professionals will know better how to target their services and provide helpful interventions for grieving parents. Findings from this study will help religious and parental support groups, as well as those in caring professions to better understand aspects of bereavement and spirituality, and the ways in which support can be offered to bereaved parents. This topic is especially relevant to the social work community as this profession is often responsible for providing emotional support to parents dealing with this traumatic and unanticipated alteration in life cycle, whether in a community, inpatient, or outpatient setting.

CHAPTER II

Literature Review

The purpose of the current study is to explore how relationship with spirituality among a diverse group of parents is impacted following the death of a child due to a terminal illness. The intent of this review is twofold: to gain an understanding of the complexities of parents' spirituality, and to add to our knowledge of grief theory and its contribution to the discussion of loss and bereavement. .Review of the literature is presented in the following five sections: 1) Definitions of key terminology: parents, loss, bereavement, grief and spirituality; 2) Historical overview and discussion of grief theory; 3) Unique aspects of parental grief; 4) Spirituality as a coping strategy in bereavement; and 5) Limitations in the extant research: gender, ethnicity, and faith.

Definitions

In order to gain a better understanding of bereaved parents' relationship with spirituality, it is important to first provide working definitions of parents, loss, bereavement, grief, and spirituality.

Notions of family. In the past traditional families were seen as having two married heterosexual parents. However, family definitions have changed significantly in the last fifty years as the rates of co-habitation, non-marital child rearing, (Holtzman, 2011) and divorce (Cherlin, 1992) have increased, and same-sex marriage legislation has been introduced in multiple states. Although adoption rates have decreased by 5% from 2000 to 2008, many

children are adopted each year, with 135,813 children adopted in 2008 (Child Welfare Information Gateway, 2011). Because of these trends, individual and societal conceptualizations of "parent" have changed significantly. Therefore, in this report parents are defined as those who have an "emotional attachment" to their child and "who fill the parental role, regardless of the adult's gender or genetic relatedness to the child" (Holzman, 2011, p. 619).

Loss, bereavement, and grief. Therese Rando (1993) clarifies the complexities of the difference in definition between loss, bereavement, and grief. Rando defines loss as either a physical or psychological loss, meaning that the loss can be of something tangible or a symbolic loss (Rando, 1993). Bereavement is defined as the state of having suffered either or both of these losses. Grief is "the process of experiencing the psychological, behavioral, social, and physical reactions to the perception of loss" (1993, p.22). According to Rando, grief is not static, but, rather, impacts individuals for a lifetime; it is a natural reaction to a loss and is dependent upon the unique individual experiencing the loss (1993).

Spirituality. Findings from previous study indicate that there are multiple ways in which people define spirituality (Mattis, 2000). Some believe spirituality to have its roots in Judeo-Christian tradition (Bradshaw, 1994; Pattinson, 2001) while others argue that there is a second type of secularized spirituality (McSherry & Cash, 2004). In an analysis of the changing definition of spirituality, researchers have argued that a universal definition of spirituality is not possible, as it is dependent upon one's worldview; providing a global definition runs the risk of cheapening the term and rendering it meaningless (McSherry & Cash, 2004). Within the context of this study, spirituality will be defined as, "a personal search for meaning and purpose in life, which may or may not be related to religion" which is "self-chosen" and "motivate[s] individuals to achieve their optimal being . . . and [gain] the ability to transcend beyond the infirmities of

existence" (Tanyi, 2002, p.506). Therefore, within the context of this study a broad definition of spirituality will be used.

Grief Theory

The topic of grief has been a continuous area of intrigue throughout generations. Different scholars have examined its varied facets, changing our conceptualization of grief. The academic literature on grief theory is vast and the conceptualization of grief has changed significantly since its earliest roots, dating back to: Burton's 1651 publication of *The Anatomy of Melancholy*; Darwin's publication on emotional expression in 1872; and later to Freud's seminal work *Mourning and Melancholia* in 1917, placing grief in a pathological and psychoanalytic framework (Granek, 2010).

Granek (2010) argues that Helene Deutsch made significant contributions to grief literature, laying a framework for researchers' conceptualization of grief after first bringing the subject into psychological discussions. Deutsch claimed there was no course that grief always followed but that it was necessary to complete (Deutsch, 1937 as cited in Granek, 2010). Melanie Klein expanded upon previous literature and challenged previous conceptions of grief, stating that grief is a process and period for potential growth rather than something pathological that needed to be fixed (Klein, 1940 as cited in Granek, 2010).

In her discussion of Bowlby's work on attachment theory, Stroebe (2002) points to that author's groundbreaking work highlighting the importance of conceptualizations of attachment and the negative impact of separation within the context of grief literature (Bowlby, 1980 as cited in Stroebe, 2002). Granek (2010) makes further note of the contributions Bowlby's work focusing on the psychodynamic aspects of grief and Parkes' empirical and scientific perspectives on bereavement (Bowlby, 1973 & 1980 and Parkes, 1994 as cited in Granek, 2010). According

to Granek (2010), Parkes' work focused more on the deprived individual while Bowlby's interest centered on the deprived child. Although both authors examined attachment and bereavement, Stroebe credits Parkes for being the first who noted the impact separation can have on an individual. In her discussion of the importance of Parkes' work, Stroebe goes on to state, "Death is the most extreme form of relationship deprivation that a person can experience" (Stroebe, 2002 p.132).

The negative impact of separation, previously the subject of study by Bowlby, became the core of Elizabeth Kubler-Ross' five-stage grief model. The stages in this model include: denial, anger, bargaining, depression, and acceptance (Kubler-Ross, 1964). According to Kubler-Ross, denial of a loved one's death is the first phase entered by the grieving individual. It is a protective phase of shock in which an individual experiences a period of disbelief and may ask questions as to why and how an event took place. Gradually, an understanding of the death sinks in, and the grieving individual is able to begin to cope with the loss of their loved one. The individual who is left behind often feels anger towards the person who has died, the self, and care professionals. Anger is the expressed and menacing emotion that often covers up other feelings associated with loss (Kubler-Ross, 1964). Bargaining is an attempt at a temporary truce in which the bereaved individual tries to reinstate reality as what it once was. Often, this stage is associated with feelings of guilt for what could have been done differently (Kubler-Ross, 1964). Depression follows, resulting in feelings of deep sadness and loss of desire to do anything. Acceptance is the final phase in which the bereaved individual accepts the present reality that their loved one is physically gone (Kubler-Ross, 1964). Kubler-Ross notes that if individuals have been angry with God, this is the phase in which their anger ceases. A longitudinal study on the stage grief theory found that each grieving indicator, as described by Kubler-Ross, peaked at

its predicted time (Maciejewski, Zhang, Block, & Prigerson, 2007). This study found that acceptance was ever increasing with time from loss, and disbelief ever decreasing; yearning, anger and depression peaked at approximately six months from the time of loss (Maciejewski et al., 2007).

Not all agree with the five-stage theory as proposed by Kubler-Ross. Wortman and Silver (1989) disproved the necessity of individuals experiencing a period of depression (as cited in Maciejewski et al., 2007, p.716). In addition, Holland and Neimeyer (2010) studied stage theory with an ethnically diverse population and found little support for its central tenets. In their study, overall sense making was found to be a stronger predictor of grief indicators of anger, disbelief and depression, than length of time since loss (Holland & Neimeyer, 2010). Additionally, there was some evidence of an "anniversary reaction", or period of heightened distress around the anniversary of a loved one's death (Holland & Neimeyer, 2010), not consistent with stage grief theory.

Stroebe, Gergen, Gergen & Stroebe (1992) wrote that a modernist paradigm takes the perspective that to support one's need for success and progress, the goal of grief is to eventually return the individual to a normal level of functioning; therefore any behavior that is not in accordance with this paradigm is pathological (1992 as cited in Granek, 2010, p.48). Hogan and Schmidt (2002) developed and tested their own theory, "Grief to Personal Growth"—an attempt to debunk the general belief that an individual must return to a normal phase of acceptance of loss. These authors posit, instead, that an individual might experience a "changed self identity and worldview" (2002, p.620). The phases of Grief to Personal Growth model consist of despair, detachment, intrusivity, social support, and personal growth (Hogan & Schmidt, 2002). Hogan and Schmidt (2002) found that detachment from others was a common theme in the

grieving process of the bereaved parent and that parents who had lost their child would often experience interpersonal and intrapersonal crises. Detachment as a coping strategy can have a negative impact on a couple's relationship, especially if the two grieve in different ways. However, findings from this study show that during a period of introspection and individual seclusion, social support sought by the individual or offered by others can aid in the bereaved individual's achievement of personal growth by helping them to process their experience (Hogan & Schmidt, 2002).

In modern American culture, grief is often considered a "private crisis of individuals" that "hovers dangerously close to psychopathology" without consideration for the way in which grief may be an interrelationship (Shapiro, 1994, p.6). Grief that is not addressed can have a negative emotional impact that can permeate through generations (Gajdos, 2002). Grief has a profound influence not only on the individual, but also on the family and community at large.

Cultural Conceptualizations of Grief

Numerous ethnographies have studied the way in which different cultures and communities grieve the loss of a loved one, but few have addressed parental bereavement within a cultural context (Cacciatore, 2009). Studies have found universal acceptance of the notion that there is a deep pain associated with loss that is experienced by all who grieve (Cowles, 1996); however, the effect of loss on the individual may be dependent upon social context (Cacciatore, 2009; Rosenblatt, Walsh, & Jackson, 1976) which, in turn, impacts individual coping behavior.

In the United States, differing ethnic and cultural backgrounds, as well as varying familial and individual belief systems, influence patterns of coping with death. Previous research has found that religious practices and beliefs are important for African American (Janowiak, 1995) and Asian Indian American Hindu populations (Gupta, 2011) in helping

individuals make meaning of their loss and understand their current life. Others have found that differing cultures evidence greater reliance on previous generations; for example, Native American communities rely on ancestral prayer as a means of coping with loss (Cacciatore, 2009) and Japanese communities share the belief that their loved one will join ancestors in a community (Klass, 2001). Grief has been conceptualized as a process that is greater than an individual's pain, with the importance of social support and connection to others being central to African American (Janowiak, 1995) and Japanese (Klass, 2001) conceptualizations of grief.

There has been some comparative research looking at the grief experience of different ethnicities and cultures within the United States. One study found that Mexican American college students evidenced more intense grief reaction than Anglo-American college students following the death of a close relationship; findings indicated significantly higher scores on somatization and loss of control scales among the Mexican American students (Oltjenbruns, 1998). Another study examining differences in grief reaction between African Americans and Caucasian Americans found more complicated grief among African Americans, extending beyond the nuclear family (Laurie & Neimeyer, 2008). African Americans in this study also maintained a stronger connection with the deceased, felt a greater sense of support in their grief, and were less likely to seek professional support than Caucasian Americans (Laurie & Neimeyer, 2008). Within the context of grief theory, there are few studies which examine the way in which Americans from different racial and ethnic backgrounds grieve the loss of a loved one (Laurie & Neimeyer, 2008), and more specifically, the loss of a child. Cacciatore (2009) argues for the importance of understanding an individual's culture, especially after the death of a child, so that caregivers might better know how to support parents in grief.

A Parent's Grief

The grief a parent experiences when a child is diagnosed with a terminal illness and after the child's death is profound. In a study comparing bereavement patterns, Saunders (1980) found significantly higher intensities of grief among those who survive the death of a child as compared with the death of a lover, or a parent. Matthews and Marwitt (2004) studied the impact that different types of loss had on bereaved parents' worldviews. Their study found that parents who lost a child due to terminal illness experience greater challenges coping with their loss than those who lose their children due to suicide, homicide, or an accident (2004).

Previous literature has found that the grief process parents face is complicated (Rando, 1993), non-linear (Arnold & Gemma, 2008), and enduring (2008). The death of a child is especially troubling, as parents are reminded of their loss as each would-be developmental milestone for their child passes (Fletcher, 2010; Shapiro, 1994). In a study comparing bereaved to non-bereaved parents, findings indicated that bereaved parents had more depressive symptomology, poorer wellbeing, higher incidence of cardiovascular problems, and more frequent marital deregulation than non-bereaved parents (Rogers, Floyd, Seltzer, Greenberg & Hong, 2008). In addition, parents of children with cancer have more distress (Noll et al., 1995), and anxiety (Labbe, 1996) than parents who do not have children with terminal illness. Families of children who have terminal illness also report having more negative impacts on their psychological and physical health (Fletcher, 2010), and report less family cohesion than families without a terminally ill child (Labbe, 1996).

Parents have multiple reactions to their child's terminal illness, and must cope with their grief throughout diagnosis, treatment, and eventual death of their loved one. Parental grief throughout the life cycle is often associated with a number of emotions including: guilt, remorse,

sorrow, regret, and shame (Arnold & Gemma, 2008), anger, hostility, and despair (Sidmore, 2000). This complex array of emotions plays out in numerous contexts for bereaved parents. More specifically, parents of children dying of terminal illness are often placed in a caregiving role that, at the end of their child's life, often leaves them feeling the unique and painful experience of survivor's guilt (Shapiro, 1994). Parents who are very involved with their child at the end of life and identify as a caregiver may feel a sense of emptiness at the time of their child's death as their role is no longer needed, and they may struggle to find ways to fill time that previously would have been devoted to caretaking for their child (Price, Jordan, Prior, & Parkes, 2011).

Because of the intense range of emotions and deep pain experienced by parents, some feel as though a metaphor better captures their deep pain. Arnold and Gemma (2008) found that there were a number of different metaphors used by parents in their study including: an erupting volcano, a well to which one descends, and a tree without a limb. The most common response made by 75% of participants described grief as, "an empty or hollow space inside" (p. 664).

Parents struggle with the intensity of their feelings and try to find ways to remedy their painful feelings and experiences. One study found that parents engage in a number of activities to cope with these feelings including: 1) remembering a linking object that connects to deceased child; 2) emphasizing more the importance of religious ideas and devotion; 3) remembering and recalling times when they were happy; and 4) identifying with, and taking in a part of their child (Klass, 2001). Other studies found that parents continue to rely on their need to 'do' in order to aid and support their family after their child's death (Price et al., 2011). These actions often take the form of piloting, protecting, providing and preserving (2011). Parents depend on their ability to pilot a chaotic situation after their child's death by helping their family to navigate and control

the chaotic situation. Parents have a desire to protect their child from the pain of their illness when they are alive and also from their eventual death; their inability to do so makes them feel incompetent (Price et al., 2011; Shapiro, 1994). If parents were not present at the time of their child's death they might feel guilty that they were unable to provide for their child when they were most in need (Price et al., 2011). Finally, parents often feel as if preserving the parental role in grief is a way to promote some normalcy and predictability in one's life after the death of a child (Price et al., 2011).

Not only do parents feel the devastating pain associated with the loss of a child as individuals, they also feel this loss as a couple, as a family, and as a part of a community. A partner or spouse may further complicate parental grief as individuals within a couple often grieve and cope with loss differently. Previous research has found that women experience higher levels of grief than men, and are more likely to display such grief in an overt way, and with higher intensity, than their male counterparts (Rando, 1993; Sidmore, 2000; Smart, 1993). After a child's death, parents often cope differently with the loss of their child by providing for their family in different ways. Mothers tend to focus on providing for their family's emotional and physical needs, while fathers tend to focus on maintaining their status as a financial provider for the family (Price et al., 2011). These differences in coping patterns and methods of grief may cause great strain and misunderstandings within a marital relationship (Shapiro, 1994).

Strain on a parental relationship can, in turn, have negative impacts throughout the family system. One study found that when there was marital disharmony and social adversity within a family, a child's self-esteem and self-concept might suffer (Overholser & Fritz, 1990). In a study examining the relationship between adjustment to cancer and psychosocial outcome, parents who reported high levels of emotional strain were more likely to express anger and have

more negative emotional outbursts that may be a result of a lack of emotional closeness within a family (1991).

After a family loses a child, each family member must therefore work to reconstruct themselves as well as their family structure. Often a family undergoes an intense emotional reaction or "shock wave" after such an event, becoming a different organism (Bowen, 1976). The shock wave can have a more profound effect when the death is of a significant family member, or if the surviving parent had an especially close relationship with the child (1976). This can be a period of great turmoil within a family if the emotional equilibrium is unbalanced and family members are closed off from each other (1976).

Friends of bereaved parents may react differently to the death of a child, which, in turn, may have an impact upon the support they provide to the bereaved parent. A case study examining the way in which a social network provides support to a bereaved parent after the death of a child found that social closeness had a significant impact on reactions to and means of support in grief (Hass & Walter, 2007). More specifically, weak ties provided theological information to the bereaved parent they may not have considered, and strong ties provided more comfort to bereaved parents in discussing theological and emotional questions because of closeness (2007). The death of a child impacts bereaved parents individually, within a parental partnership, family, and also within other relationships and friendships outside the family. Often parents find spirituality or religious practices to be helpful in this pursuit (Shapiro, 1994).

Spirituality and Coping with the Loss

An individual's relationship with spirituality is often greatly impacted by a traumatic event. Previous research has found that individuals diagnosed with Post Traumatic Stress Disorder (PTSD) are more likely to experience a change in religiosity—forming either a stronger

or weaker religious bond—than the general population (Falsetti, Resick & Davis, 2003). Over time, religious strain mediates PTSD symptoms and can lead to poorer health outcomes for those with great religious distress (Harris et al., 2012).

Not all outcomes for trauma survivors are negative; many experience a period of posttraumatic growth (PTG). PTG is related to an individual's relationship with spirituality and consists of the following components: spiritual change, coping challenges, and existential reevaluation (Harris et al., 2010). In a study of religious strain and stress symptomology, findings show that when individuals used calm and focused prayer, greater PTG was experienced, with the exception of individuals who had survived an interpersonal trauma, such as the death of a loved one (2010). Researchers believe survivors of interpersonal trauma may have a greater challenge using social support from a higher power and their religious community, therefore making religion a less effective coping strategy for this population (2010).

Previous research has found that parents use spirituality in a number of different ways following the death of a child: to maintain a connection to their loved one (Sormanti & August, 1997); to make meaning of their loss (Barrera et al., 2009; Lichtenthal, Currier, Neimeyer & Keesee, 2010); and as a tool to cope with their child's death (Arnold, Gemma & Cushman, 2005; Pargamant, Ano & Wacholtz, 2005). One study found that the intensity of a parent's grief was inversely related to their ability to make meaning of their child's death (Keesee, Currier & Neimeyer, 2008). Other research has found that parents who are able to make meaning of their loss are more likely to have a changed perspective on life, placing greater importance on family and the wellbeing of others (Barrera et al., 2009).

In their review of the literature through a search of the PsychINFO and PsychARTICLES databases, Ungureanu and Sandberg (2010) uncovered a large number of studies supporting the

finding of differences between individuals, as well as within couples, in coping strategies utilized during a period of bereavement, especially with regards to use of spirituality. Gender differences were apparent, with women more likely than men to use religion as a means of coping with the loss of a child (2010). Findings from this study also indicated that prayer plays a significant role in a couple's conflict resolution while serving to strengthen the couple's mutuality and support in their grief (2010).

Sormanti and August (1997) found that the death of a child resulted in parents adopting a stronger religious belief, while other researchers have found that an individual's belief system is not always capable of withstanding the trauma of losing a loved one, and an individual experiencing such loss may subsequently undergo a period of religious struggle or doubt (Wortmann & Park, 2009). Although a majority of parents in the study made use of spirituality as a means to cope, others relied more on beliefs in science and fate to explain the death of their children (Barrera et al., 2009).

Not only are parents impacted by the loss of a child, but teenagers who lose a loved one also undergo a period of bereavement that alters their relationship with spirituality. Most often, this change in teenagers' spirituality is a means of maintaining a connection with their deceased loved one (Cait, 2004). In a study of the adolescent bereavement process, teens that had lost a sibling reported a change in their spiritual growth due to having gained a new perspective on themselves, others, a higher power, life and death, as well as a new relationship with their deceased sibling (Batten & Oltjenburns, 1999). Similar to the literature on parent's relationship with spirituality, some adolescents in this study reported an increased comfort in faith, while others reported a loss of faith and deep anger with God (1999). Similarly, women who had lost a parent in their teenage years described great spiritual change with regards to the type and

strength of their relationship with spirituality. These women experienced a range of different types of relationship to their spirituality after the death of a parent: a push-pull relationship; a move from detachment to connection; a strengthening of belief; and, a relationship that changed from non-religious to self-centered spirituality (Cait, 2004).

Limitations of Prior Research

Researchers who study bereaved parents have noted the lack of diversity in study populations as a limitation, citing samples that are primarily female (Keesee et al., 2008; Lichtenthal et al., 2010), Caucasian (Barrera et al., 2009; Keesee et al., 2008), and Christian (Burke, Neimeyer, & Elacqua, 2012). Multiple researchers cite the need for more diverse samples in future research on bereaved parents (Arnold, Gemma, & Cushman, 2005; Sormani & August, 1997). For example, the study sample in Arnold et al.'s (2005) study of the ongoing nature of parental grief was 99% White and 97% female. An additional study, the goal of which was to better understand a parent's spiritual needs during a child's death and bereavement, had a sample of 33 participants, 20 of whom were mothers; 55% of the participants were White, and 85% spiritually affiliated as Christian (Meert, Thurston & Briller, 2005). Although Janowiak's (1995) study of cultural patterns in African American bereavement focused on an underrepresented population within the literature, all participants were female and Christian.

Because previous study samples have been limited in diversity, much has yet to be explored about the use of religion and its transformative effect on the lives of the bereaved among a more diverse population. It would be important to explore the ways in which a diverse group—more representative of males, people of color, and non-Christian faiths—differs with regard to their relationship with spirituality after the loss of a child due to terminal illness.

CHAPTER III

Methods

Study Design and Sampling

This qualitative exploratory study sought to answer the question: How does a parents'
grieving process after the death of one's child from terminal illness affect their relationship with
spirituality? Sub-questions of interest included: How does the death of a child impact one's
spirituality, family relationships, and relationships outside the family? What are the similarities
and differences in spirituality following the loss of a child among religiously and ethnically
diverse populations? This study was conducted through personal interviews of parents who have
lost a child to terminal illness. It was exploratory in design to allow the stories of the
participants to emerge.

A non-probability purposive sampling technique was used to recruit a sample of parents
who had lost a child to terminal illness at least two years prior to the recruitment period.
Inclusion criteria for participation in the current study were that individuals must be 18 years and
older and have lost a child from a terminal illness more than two years ago. Based on the work
of Meert et al. (2005), a two-year time frame was selected to avoid a parent's earliest and most
traumatic part of grief. Recruitment announcements, as well as the interview itself, were in
English. Parents whose child had died from another cause other than terminal illness, or who
had lost a child within the past two years, were not eligible to participate in this study.

An effort was made to reach out to a religiously diverse population in a large northeastern city and surrounding community. Previous studies on bereavement have used focus groups (Janowiak, 1995), open-ended interview (Burke, Niemeyer, McDevitt-Murphy, Ippolito, & Roberts, 2011), online surveys (Lichtenthal et al., 2010) or mailed surveys (Sormanti & August, 1997) as methods of data collection. Participants in prior research on this topic have been predominantly female, Caucasian, and Christian. Because of this, an effort was made to recruit a sample representative of diverse faith communities including Christian, Jewish, Muslim, Buddhist, Hindu, and Church of Christ Scientist. Efforts were also made to ensure as diverse a sample as possible in terms of age, gender, and ethnicity.

The researcher first sent e-mails (Appendix A) or made phone calls (Appendix B) to interfaith organizations and parental support groups in a large metropolitan area on the east coast to inform organization leaders of the nature of the project, and ask if they would willingly allow the researcher to recruit within their community. Compassionate Friends and Community Metropolitan Ministries expressed interest after the researcher's preliminary informal outreach efforts. These organizations permitted the researcher to follow up with leadership to pursue recruitment of members following approval of the study by Smith College School for Social Work (SCSSW) Human Subjects Review (HSR) Committee.

Within one week of receipt of HSR Committee approval (Appendix C), the researcher contacted the organization leaders to meet and discuss a feasible plan for recruitment within the organization. The researcher also answered any questions the organizational leadership had about the nature of the study. At this time, the researcher provided the organizations' representatives with the interview questions. The researcher provided a recruitment flyer (Appendix D) by hard copy or e-mail, depending on what best suited the organization. The

organization representatives then distributed these flyers among the membership for purposes of recruitment. The researcher also indicated her availability to present at an organizational meeting if that was the preferred method of recruitment. As fewer than six participants were recruited within the first two weeks using these methods the researcher then expanded recruitment efforts. The researcher obtained approval from SCSSW HSR Committee (Appendix E) to allow recruitment efforts to include snowball methods through acquaintances and colleagues of the researcher, as well as among community advocacy programs. Data collection methods were also amended to allow telephone or Skype interviews, in addition to the original plan of in-person interviews. After implementing these recruitment methods, the researcher obtained approval from a hospice (Appendix F) and from the SCSSW HSR Committee (Appendix G) to locate her research in that agency.

Individuals who learned about the study from a posting, organizational representative, community or organizational meeting, or from an acquaintance, all contacted the researcher directly by telephone or email to express their interest in participating. If more than one parent of the same child wished to participate, each was interviewed separately. The researcher clarified the eligibility criteria of each participant; if the criteria were met, the researcher then scheduled a mutually beneficial time and location. Participants were also given the option to choose whether they preferred to be interviewed in person, on the telephone, or on Skype. In-person interviews were conducted in public locations such as coffee shops and libraries where the interviewee felt comfortable and conversation could be held in private. Two participants stated they would prefer to be interviewed in their home due to great discomfort with an interview in a public setting.

Data Collection

At the time of the scheduled interview, those participants interviewed in person (n = 5) were asked to read and sign an informed consent (Appendix H) indicating their agreement to participate in the study. Those that elected to carry out a telephone (n = 3) or Skype (n = 3) interview were e-mailed a copy of the informed consent form with a request to review the form and indicate their agreement to participate in an email to the researcher, prior to scheduling an interview. These participants were later contacted by the researcher and requested to send a signed copy of the Informed Consent Form by regular mail, in keeping with the methods approved by the Smith College School of Social Work Human Subjects Review Committee. A list of local and national resources for support (Appendix I) was attached to the Informed Consent Form should participants desire to obtain support at any time following the completion of the interview that was dependent upon participant's location.

The interview (Appendix J) consisted of six demographic questions followed by five open-ended questions. Demographic data collected included: gender, age, race/ethnicity, religion/spirituality, marital status, and number of years since death of child. Open-ended questions asked about participant spirituality after the loss of their child. The first question, "What does spirituality mean to you?" created a point of entry in conversation and helped in the development of rapport between researcher and interviewee, essential for eliciting participant in-depth thoughts in a challenging area. Additional questions such as, "Thinking about your bereavement process following your loss, how would you describe the role, if any, that spirituality has played in this process?" and "How and in what ways has your spirituality impacted significant relationships outside the family?" followed. The researcher used probing questing with the purpose of enhancing the content of the discussion. All interviews were audio-

recorded. The interview process did not exceed 45 minutes in consideration of the difficulty of the interview topic.

Steps were taken to ensure reliability and validity of the current study. In order to make the personal interviews as consistently as possible, all interviews were carried out in a structured format in which all participants were asked the same questions, given the same time frame for the interview, and allowed to clarify any areas of confusion with the researcher. The researcher also asked the same probing questions to elicit more information to further strengthen the interviewee's narrative, and ensure validity.

Steps to protect participant confidentiality. Due to the small number of participants in this study, confidentiality was crucial in order to maintain ethical standards. In order to safeguard participant's confidentiality, precautions were taken with regard to e-mail contact between the researcher and participants. All e-mails sent to the researcher were addressed to a password safe account, only known by the researcher.

In order to safeguard participant responses, all identifying information was removed from the data.   Participants were informed through the Informed Consent form (Appendix H) that only the researcher would listen to and transcribe the recorded interview in order to ensure their privacy.   Letters of consent were not connected with transcribed interviews. Each participant was given a number in place of their name in all transcription materials in order to protect the identity of participants. Transcripts of the interview were shared with a research advisor only after all identifying information had been removed. The Informed Consent form explained that all data would be presented in the aggregate without reference to identifying information and that any identifying information derived from illustrative quotations has been disguised or removed. Further, participants were informed that all data, audiotapes, and consent forms would be kept

secure in a locked cabinet for three years as required by Federal regulations, after which time they would be destroyed or kept secure as long as they are needed.

Sample Characteristics

In total, 11 bereaved parents, including two couples, participated in the current study. The sample was majority female (n=8), Christian or Catholic (n=10), and White (n=11). All participants spoke English. Age range, rather than exact age was collected, with ages ranging from over 40 to over 80, with a modal age range of 61-70. Years since the death of their child ranged from 3 to 22 years, with an average of 13 years. Sample characteristics will be addressed in greater detail in the following chapter.

Data Analysis

This researcher transcribed the recorded interviews and transcripts were used as the basis of analysis. An open-coding method was used as an approach to analysis. The researcher identified code categories and themes that arose in participant narratives. This approach sought to minimize omissions and biases, giving each sentence of the participant's response due weight. The researcher discussed categories with her advisor on multiple occasions to minimize subjectivity and ensure the accuracy of the coding technique.

To analyze the data, the researcher went through the content of each interview text line-by-line, and wrote summary ideas in the margins of the transcript. This process was carried out repeatedly until no new ideas were written in the margins. The researcher then took note of relevant and repeating themes across participants. Salient themes were then compiled and presented, with attention paid to patterns of similarity and difference among and between participants.

The computer program Excel was used for statistical analysis of demographic data through descriptive and frequency statistics.

CHAPTER IV

Findings

This study explores bereaved parents' spirituality after the death of a child due to a terminal illness. The sample of 11 participants was recruited through outreach to a hospice, a local chapter of a national bereaved parent support organization, and by snowball technique beginning with acquaintances of colleagues and friends of the researcher. This chapter will first present demographic and descriptive information regarding the sample, including gender, age range, religion, marital status, and number of years since death of child. Secondly, this chapter will present the themes generated through qualitative analysis of the transcribed interview data. Five themes emerged within the broad areas of the meaning of spirituality for participants, the use of spirituality in their personal lives, and the impact of their child's death on familial and social relationships. These themes include: "defining spirituality," "shifts in spirituality," "role of spirituality," "role of God," and "relationships with others." Within each theme, several sub-themes emerged. Themes and corresponding sub-themes are shown in Table 1, below, and will be discussed in greater detail, with illustrative quotes used throughout.

Table 1

Categories and themes

Shifts in Spirituality
     Enduring Nature of Grief
     Strengthened Faith
     Faith as Constant
     Changed View of God
     Changed View of Prayer
     Life Story

Role of Spirituality
     Connection with God and Child
     Comfort of Tradition
     Call to be Better People

Role of God
     God as Protector
     God as Holder
     God as Challenger
     God as Helper

Relationships with Others
     Friends and Family
     Strangers
     Religious Institutions
     Spiritual Leaders
     Isolation

Sample Characteristics

     Of the 11 participants, 8 (73%) identified as female and the remaining 3 identified as

male. All of the participants identified as White or Caucasian. Three participants (27%)

identified their religion or spirituality as Christian, six (55%) identified as Catholic or Roman

Catholic, one (9%) identified as Jewish, and one (9%) identified as being raised Catholic but

currently not adhering to a religious doctrine. Of the eight women interviewed, five (63%) were

married, two were divorced (25%), and one was widowed (13%). Of the three men interviewed,

all reported being currently married. Two couples were interviewed, both couples being over the

age of 60. Participants' age ranged from over 40 to over 80 years, with a modal age range (n=6)

between 61-70 years. The length of time since the death of their child ranged from 3 to 22 years, with the mean of 13 years and a median of 12 years.

Of the 11 participants, 6 were an acquaintance of a friend or colleague of the researcher; 3 were recruited from Compassionate Friends, and two were recruited by a hospice. The method of data collection was dependent upon geographic location with five (45%) of the interviews conducted in person, three (27%) by telephone, and three (27%) using Skype.

Table 2

Demographic Characteristics

Gender	Male	3
	Female	8
Age	Total Range	41-80+
	Mode Range	61-70
Race/Ethnicity	White	11
Religion/Spirituality	Roman Catholic	7
	Christian	3
	Jewish	1
Marital Status	Married	8
	Divorced	2
	Widowed	1
Years Since Child's Death	Total Range:	3-22
	Mean number of years	13
	Median number of years	12
Recruitment source	Compassionate Friends	3
	Acquaintance of Friend/Colleague	6
	Hospice	2
Data collection method	In Person	5
	Telephone	3
	Skype	3

Defining Spirituality

In response to the two-part question, "What does spirituality mean to you? What comes to mind when you hear the word spirituality?" there were a range of responses with some common themes. Five participants expressed some version of spirituality as the recognition of a supreme being; one of these participants described a "higher force" and another stated that it was a "power outside of yourself."

Another theme was the view of spirituality as a way of connecting. Six participants expressed this view. Of these, four mentioned that it was a way of connecting with God. One participant mentioned, "I don't know what else to say. I mean just daily living and a connection to God." One participant expressed that spirituality was a way of connecting with herself when she said, "… being connected with that piece of ourselves and growing that part of ourselves that moves forward in the world and hopefully impacts it in a good way." Three of these participants stated that spirituality was a way of connecting with their deceased child; one of these participants stated that spirituality gives her, "a sense of peace and contentment and the belief that I will be reunited with [child's name] again." Two participants stated that spirituality was a way of connecting with a community, and for one participant it meant, "connecting with other people in other parts of the world through prayer and through study." Two participants expressed a view of spirituality as a means of connecting with ancestors and one stated that it was a way of connecting with future progeny. One participant depicted these two forms of connection when he stated, "It also is communicating with grandparents, great-grandparents, people that you have never met before; children, grandchildren, great-grandchildren that you will never get to meet either."

Even though all participants were able to provide a definition for spirituality, some participants stated that they found it a challenging concept to define. One participant stated it gave her a general sense of peace; another stated that it is a combination of, "faith on the one hand and something very new age-y." Other participants described spirituality as a belief in something more than the material world. Finally, one participant shared not only what spirituality meant in her life but also its purpose in bettering her life, stating, "The more in touch with [spirituality] that I can be personally, the richer my life."

Shifts in Spirituality

In response to being asked about whether they had experienced a change in their spirituality since the death of their child, most participants (n=6) stated that their spirituality had strengthened as a result of their child's death. Others stated it had not changed (n=3), while the remaining 2 participants described a shift in their spirituality apart from strengthening. Six themes emerged from the discussion of shifts in spirituality which will be examined in detail. These are: "enduring nature of grief," "strengthened faith," "faith as constant," "changed view of God," "changed view of prayer," and "life story."

Enduring nature of grief. When asked about spirituality after their child's death, multiple participants noted the enduring nature of their grief and their deep pain. One participant described her pain as,

> You just have a broken heart. It is just not going to heal. I have 10
>
> grandchildren, I have six great grandchildren, I have plenty of love in my life,
>
> but I am functioning on no heart—a broken heart.

Another participant spoke to the pain and said, "you really go into a black hole." Yet another participant stated,

I have a [child's name] shaped hole in my heart. And as I have tried to

explain to people, grief is like this huge canyon. It is this huge canyon, you

can't jump across it, you can't climb down and get up the other side—you can't go

around it. It is this huge huge bottomless crater. In the beginning it has these really really

really sharp edges, and if you get too close to the edge you are going to get cut. As you

learn to live with the grief, as I call it, as you learn to live with the big black hole, as you

learn to drag the big black hole with you. The edges get duller, and it is not as heavy to

pull along. But it is still there.

Strengthened faith. The most common response to how participants' spirituality had

changed since the death of their child was that spiritual belief had strengthened and become a

more important component of life. For example, one female participant stated, "I would have to

say it has only gotten stronger" and another participant stated:

It has become more important. When things are going your way, you're your

life is perfect and you have everything . . . you don't need God as much . . .

there is no such thing as an atheist who is in a foxhole.

When asked about her spirituality after the death of her daughter, another participant stated:

Of course it deepened my husband and my faith because we had to lean on

God so much, and we were trying to be strong for our children and trying to

be strong for each other and still needing to go through that grieving . . . I

had to lean on God in a very personal and immediate way.

One participant reflected on his changed spirituality and attributed much of his "contentment"

with his spirituality to his daughter:

In a very odd way I think sometimes [child's name]'s death was a present to me by

giving me this . . . I wouldn't be at this level of contentment if she wouldn't have died.

It sounds like a horrible thing to say, obviously I wish that she wouldn't have died and

wouldn't have gotten sick, but it is a legacy that she leaves for me.

Three participants noted that after the death of their child they had a stronger belief in the

hereafter and in being reunited with their child, which they attributed to their strengthened

spirituality. One female participant stated,

When you are down on earth and things have fallen apart in so many ways,

you look for reassurance in the hereafter . . . it is easier to get through those

things if you believe that there is an eternity, and if you are a good person

you will be rewarded after you die.

Many of the participants who believed in a hereafter took comfort from knowing that

they would be reunited with their child. One mother stated that spirituality plays more of a role

in her day-to-day life, as she now relies on a deeper belief in reuniting with her son, "and that is

what will get me through the day, or the second. It is not day by day, it is second by second

trying to get by."

Faith as constant. Not all participants described a strengthening of faith; some

expressed that they had not experienced a change as faith had been a constant throughout their

life. One participant stated she did not have a change in her spirituality for, "we made it a

practice of going to church . . . I mean we still go to church and we did before." Another

participant spoke in this way about her spiritual life, "It has always been unusually strong," and

described how she went to church five days a week growing up and found faith-based

institutions to attend for high school and college. Another participant shared a similar

background of being raised in faith, stating, "I don't see how it could be more important because my faith has always been central. Being raised in the home that I was raised in—it has always been the cornerstone of my life."

Changed view of God. Three participants noted that after the death of their child that they had a changed view or conception of God as being more mysterious and differing from any prior conceptualization. One participant described the transformation of belief after the death of her son in the following way:

> I think a big part of that [change] is that I don't feel some relationships with
> a human identifying God as much . . . now it feels like whatever creator
> force, divine spiritual being is out there is more ethereal and completely out
> of any paradigm that we have on this earth, so impossible to define what we
> know but definitely out there.

Two other participants described their new understanding of God to be that of a "mystery." In discussing the shifts in spirituality since his son's death and in his older age, one participant stated:

> It is very clear to me that I know very few answers . . . we live with it
> better if we are willing to admit that it is a mystery . . . that is a huge change
> from the faith that knew everything.

Another participant also endorsed the concept of a mysterious God, stating:

> After [child's name] died I realized that I do feel differently about God . . .
> there is a lot more unknown. I became more accepting and acknowledgeable
> about mystery . . . now I feel like I just put more in this little box of mystery
> . . . [God is] more of a mystery with a capital 'M'.

Changed view of prayer. Some participants noted a shift in their spirituality in the form

of a changed view of prayer. One participant stated that his perspectives on prayer had changed,

and that too often [people treat], "… God like a Santa Clause in the sky, we tell him what we

want and we expect him to give it to us." He went on to explain that his prayers, "were all self

centered prayer until I lost [child's name]," and now his prayer is more focused on being, "the

pencil in God's hand." Another participant agreed there had been a marked change in her

orientation to prayer, from feeling that it could make a difference to, following her son's death,

thinking, "*que sera sera*, what will be will be. I don't feel that I have control anymore."

Life story. Participants' explanations of spiritual shift differed somewhat depending

upon number of years since the death of their child. Participants who had lost their child

between 10-12 years prior to the interview noted that there was a waxing and waning

relationship with spirituality, or one in which the importance of spirituality changed somewhat

throughout their grieving process. One mother described the change in her spirituality as a

"curve", with her spirituality experienced as very strong immediately following her son's death,

and then, after three years finding her spirituality in a "trough" before it started to increase again

in the recent years leading up to the 10-year anniversary of her son's death. This mother stated

that she has a desire to return to the level of spirituality she experienced closer to the death of her

son. She stated,

> I think a big change is that I am trying to tap into that spirituality more
>
> through mindfulness practices, through meditation, breathing, being more in
>
> the moment which is something that we totally were when [child's name]
>
> was sick because we had no other choice, and that is a really good way to
>
> live.

Another participant described a similar process where,

> When [child's name] died we did *kaddish* every day. You have to go to the
>
> synagogue twice a day and there are three prayers . . . that is a very intense
>
> year . . . after that I kind of slumped and stopped going to synagogue for a
>
> little bit. But then after that I just felt very very comfortable in the
>
> synagogue.

Participants who had lost their child more than 10-12 years ago situated their spirituality following their child's death within the context of a greater life narrative, describing how their spirituality had changed their view of life. One father stated,

> As the years go on you talk about it more spiritually. For me you have the
>
> phenomenal pain for a long long time, but eventually it turns to more of a joy
>
> in the sense that you remember her life.

This participant reflected on the slow process of being able to find joy and, "a sense of celebrating her life" when he stated, "faith is a big part of that process" in being able to shift from his sadness and pain.

One participant placed the death of their child in the context of other deaths in their lives. Another participant stated, "I don't fear death, I welcome it . . . I have so many people waiting for me." This participant's sister had died when she was younger and she had a lot of anger towards God, whereas, after the death of her daughter, she "realize[d] that there is a reason for everything and we shouldn't question." Having a reason for things gave her a sense of peace, and a new appreciation of beauty around her for, "I look at things so much differently than I ever did before. I enjoy life. I live in the moment . . . it is a nice place to be." She went on to

explain that her spirituality has changed "for the better. I don't question and I don't dwell on what 'coulda shoulda woulda' . . . that's just a waste of time and energy."

Another participant explained that her spirituality had steadily grown since toddlerhood. She described an awareness of people's spirituality that, "lives within us all," her sense that people become disconnected from their spirituality throughout challenges in life, and that the death of her son was one such challenge that called her to reexamine this internal sense of spirituality.

Role of Spirituality

Participants described the different roles spirituality plays within their life. Some participants noted that spirituality played a role in providing the connection between themselves and God or child, others noted the importance of the comfort or tradition of their spirituality, while a few felt as though their spirituality called them to become better people.

Connection with God and child. Two participants noted their use of spirituality as a way to connect with God and their child through "signs." One participant mentioned that she continues to receive multiple signs from her daughter in her everyday life in the form of dimes, rainbows, butterflies, ladybugs, dragonflies, cardinals, sunrises, and sunsets. Another woman told a story of a young boy she met on vacation who would not leave her side and who had the same name as her son, and expressed feeling that it was a sign from her son.

Another participant described having a special connection with her dog at the time of her son's death and told of the odd occurrences that had followed directly on his death:

> Literally at the moment of his death she started whimpering, which really
>
> made me feel as if, and I think my husband too, who is much more of a—not
>
> believing that there is anything else, that there is something else out there,

but for her to have felt some sense of loss and leaving . . . that was a very

powerful thing for us.

She went on to describe how there were a lot of "little things that happened after his death" such as when three of her son's favorite things happened in succession, and when glitter in a snow globe settled into the shape of a heart.

Comfort of tradition. Some participants experienced the role of spirituality in their life as a source of comfort or tradition that is closely tied with their religious faith or practice. One participant expressed feeling great comfort in knowing that her son was a "comet child", or someone who:

. . . go[es] through our lives like a comet, they are there and gone in a short

 moment but they are so special that they leave a lifetime impact not only on

their families but on people that meet them when they were young.

This conceptualization helped to calm her in the belief that this was her son's role in life. Other participants took comfort in religious practices and teachings. One participant stated he found great comfort in the Catholic Church, and that there were answers that were taught before he knew the questions to ask. Two of the male participants noted the comfort of having prayer, rituals, and traditions to which they could return. Despite differences in their faith backgrounds, both men found comfort in the traditions of their religious practices. One stated:

The rage and the sorrow and the grief, everything mellowed out when I was

in the synagogue, listening to the prayers that I listened to when I was a kid

that I know have been around for thousands of years.

The other male participant noted how comforting prayer has been throughout his life, including prayers to God as well as to a "network of saints" available to adherents of the Catholic Church.

Three participants questioned how it was possible for someone to go through the loss of a child without the comfort and support of faith. Without faith, one participant said, "I would have closed up, just shriveled up and died . . . the pain was so severe and intense I had to have something to fall back on." One participant believed spirituality was crucial in her healing process, stating, "I think you need faith, spirituality - something to cling to."

The idea of faith as something to "cling to" or to "fall back on" was one that was especially healing for these bereaved parents. One participant noted, "If you have no faith you can't draw on faith . . . I believe so much in people building a basis of faith. It might not be death, but there are tremendous setbacks in life, and if you can pull on that faith and live it, it is really key."

Call to be better people. Some participants believed their child's death to be a call for them to become a better person. One individual stated:

I am a better person now because of what happened to [child's name] . . . it

has brought me closer to Christianity and more in tune with self-

improvement . . . reaching out to more people who have lost children, people

who have suffered.

Another participant explained that after the death of his son, "I was broken in a healthy way, not broken and trampled down, but broken so that my ego was broken, so that I no longer approach life—at least I try to approach life daily." He went on to explain that while he experienced the death of his son as a loss, he felt strengthened in some way:

I think if we accept losses, regardless of what kind they are, that they

strengthen us. They are part of the refining power that are talked about in

the scriptures, the struggles are meant to refine us and make us more pure.

These participants described the importance they placed on standing strong rather than breaking under the pain and suffering, and using grief as a tool for self-improvement. In this vein, one participant alluded to a quote she attributed to Emily Dickinson, saying, "We never know how great we are until we are called to rise."

Role of God

In their discussion of spirituality after the death of their child, participants discussed the multiple roles that God played and continues to play in their grief process. Although participants did not necessarily employ this terminology, the following emerged as recurring themes with regard to the role of God: God as Protector, God as Holder, God as Challenger and God as Helper.

God as protector. A few participants voiced their conception of God as a protector, or as being responsible for the care and safety of their loved one. One participant noted, "I was relieved that God took her home . . . I was relieved that she was out of her suffering . . . I thanked God for that." Another stated, "You need to have a stronger faith in [heaven] because you need to feel that the person is safe with God."

God as holder. Some participants voiced their conceptualization of the role of God as holder, or container for their anger, blame, and pain. One participant described experiencing this feeling coming after having "railed at God":

> I got this feeling, and it was almost tangible, just this 'lay it all on me because
> you can't handle this and I can and that is what I am here for' . . . holding
> onto it until I was ready to take it on myself.

Another participant described that with the help of God she was able to direct her, "anger towards sin . . . instead of at anybody else."

God as challenger. Others believed that God had conferred upon them the death of their child as a way to challenge them. One participant stated that her spirituality, "has gotten stronger. It has tested me more . . . I passed the test. I had to. If I didn't I would have lost my mind." Another participant openly discussed the anger that she often feels towards God. "[Child's name] is mine! And [I] have a tug of war [with God]. You gave him to me! You know you don't take a gift back!" Another participant explained that she felt as if she had been chosen to be her son's mother and that his death was a part of God's plan; this participant conceptualized her child's death as a challenge and prayed to God that, "it would make me a better person."

God as helper. Many participants expressed a conception of God in the role of helper, specifically in helping them meet the challenges they faced with the death of their child. One participant stated that the death of his daughter was a "challenge" that his wife and children faced, and that it was God's role, "to help us . . . get through life." He also stated, "When you get hit with this grief you look to a higher power to help you . . . overcome this tremendous hurt." He stated that God was a tremendous support and, "When it came to [child's name] we made all the efforts that we could . . . we had to leave the results to God." Another participant explained that she thanks God and said, "We make very clear at this point that we are as far as we are in our grief walk because of our relationship with God." She went on to explain, ". . . the Lord has helped us through the entire process of her diagnosis, her treatment, and her death." When asked about her reliance on group support, this participant responded, "I have always felt as though God was my support group" and, therefore, did not feel as though grief support groups were needed. Others felt that they had a direct connection in talking with God. One participant stated, "I get great comfort in talking with God, knowing that he listens to me."

Relationships with Others

Participants were asked about how their relationships with others had changed after the death of their child. A number of different themes emerged, including: changed relationships with friends and family; changed relationships with strangers; changed relationships with one's religious institution and spiritual leaders; and an increased sense of isolation.

Friends and family. In response to a question about the ways in which their spirituality had impacted significant relationships, a number of participants commented on changes in their relationships with friends and family. Participants described a number of changes, including: closeness with others who are spiritual; reconnection with family and friends; and closeness with others who had suffered loss. Three female participants described gravitating towards relationships with others who shared their religious beliefs. One woman stated, "I go to church more. I like to spend more time with people who feel the same way that I do." Another participant who indicated that she found it helpful to connect with friends who affirm her belief stated:

> I think I tend to go to people that I know are more spiritual versus I don't go to somebody who doesn't believe . . . that helps knowing other people and knowing people are going through the same thing.

Yet another participant stated that she felt that spirituality gave her the strength to discuss her bereavement with a small group of friends.

A few participants discussed the ability to reconnect with family and friends. One participant found solace in forming a relationship with others from her church who shared their grief of a lost loved one; because of this, she was able reconnect with her religious community. Two participants talked about the "overwhelming" amount of support they received when their

child died. One participant discussed the multiple supports available from childhood friends, adult friends, and neighbors. Another participant stated that he found it, "very comforting" that there so many had supported him during his daughter's funeral. Still another participant stated that an important component of faith, beyond having a belief in something, is [having], "somebody you can share that all with."

The death of a child served not only to help participants reconnect with others, but also served to forge relationships with those who had had a similar loss. For one participant, "It established a connection with my older sister who lost her child." For these participants, friends and family members served as an important source of support and connection in the grieving process.

Strangers. In addition to changes in their relationships with family and friends, changes also occurred in participants' relationships with strangers. Speaking of the occasions when he met new individuals in his travels, one participant stated:

I don't remember a time where successes connected me with another

person or the group I was talking to, but when I would mention the things

that I learned from my children that I didn't want to learn such as the loss of

[child's name] and the brokenness of that . . . that is where the connections were made . .

. bereavements are what helped build bridges and helped make

connections between people.

One woman discussed the way that journaling online and sharing her story with others had enlightened her to a connection with many that she didn't realize had existed:

I have received many e-mails from people that we don't know telling me

 that because of [child's name]'s journey and our entire family's journey, that

they have either come to Christ, they didn't know him before, or they have

renewed their faith or their prayer life has deepened or any of those things.

Other participants noted that, even more than the transformation of their connection with

others, strangers' relationship to spirituality served to strengthen their own faith. One participant

who works at a religious job explained about his interaction with others, "You watch other

people in faith and it supports your faith."

Religious institutions. A few participants found that their relationship with their

religious institution changed after the death of their child. Some became more involved with

their existing faith community or religious institution, while others found new faith communities.

One participant found purpose in answering the call of a priest for an acolyte position in the

church:

> I volunteered right away. I told him how I remember in the second week
>
> how important that was . . . to be able to serve made a whole bunch of sense,
>
> it gave me a sense of being able to further the connection with something
>
> that I had always believed in deeply.

Other participants left their prior faith communities. One participant stated, "We ended

up changing churches because our faith outgrew our church," while another participant stated,

"With regards to religious institutions, I have definitely pulled away." Another participant stated

that he had distanced himself from his religious community because after his daughter's death he

had become a more "serious person" and felt "really out of place. Everything just seemed so

silly." He stated it had become more challenging to remain a member of that community and he

had therefore found a more religious community in which, "God is a very big part of their lives

as opposed to the other communities. That fits with me better now." In discussing the challenge

involved in attending church, another participant stated, "It is the church where he was buried. Like if they play the same song or something, that is difficult."

Spiritual leaders. Participants had many reactions to the way in which their relationship with spiritual leaders had shifted after the death of a child. Some felt as though their religious or spiritual leader had been a source of support and that their relationship strengthened, while others felt their bond with their religious leader had been broken.

One participant noted how helpful the parish priest had been in relating with the family on a "spiritual and personal level" after the death of their daughter, and that they had felt comforted in conversations with the priest, stating, "[Child's name] was with God and we could rest assured that she was fine." Another found new comfort after the death of her son in going to see a medium, taking solace in knowing "[he] is out there." Yet another participant felt that her priest was an integral part in the process of her daughter's illness stating, "[the priest] really made a connection with her before she got sick. It was almost like he was part of the family dealing with someone being sick."

Not all felt comforted by religious leaders or spiritual people. One participant stated:

I did get mad at my rabbi for a number of years since he didn't come . . . I had

a couple of very very deep deep conversations with a Lutheran minister . . . I

wish I would have had a rabbi to have those discussions with but he wasn't

there.

Isolation. Instead of greater connection with others, some participants voiced experiencing a new feeling of isolation from others, including those with whom there had previously been a valued connection. One participant reflected on his role in his synagogue, family, and other group situations, comparing it to the experience of a newly sober alcoholic:

There is no room for that person in their group anymore, either their family

or their group of friends. That is what I think happened to a large degree

with the people that I hung around with too. Because you really just see

things—you become sadder.

This participant stated that he felt removed from the life that he had known before. Another

participant described a similar feeling, expressing not wanting to attend church because of what

she perceived as others' expectations regarding her healing process. She described that her

husband had a different way of grieving, finding church engagement supportive, and how

challenging this was for her. She explained that she does not have anyone to talk with about her

grief and that, "It is a lonely process . . . it is lonely right from the beginning of the hard part. It

doesn't—like grief that begins to soften, loneliness doesn't, it is always there."

Within the current study, participants expressed many facets of the way in which

spirituality had impacted their life after the death of their child from a terminal illness, including

shifts in spirituality, role of spirituality, role of God, or relationship with others; regardless of the

particular focus of their experience, all participants spoke of the influence of spirituality on their

life. Findings from the current study will be examined more closely in the following chapter

with emphasis on implications for social work practice and areas for future research.

CHAPTER V

Discussion

The goal of the present study was to better understand bereaved parents' spirituality after the death of a child from a terminal illness; it was hoped that a more diverse sample of participants could be recruited to participate, given the relative absence of diversity in studies on this topic to date. Participants were asked to reflect upon their spirituality after the death of their child. Salient findings from the current study will be discussed through the lens of grief theory, with attention to implications for social work practice and research.

Centrality of Spirituality as a Tool in Coping

Findings from the current study indicate that bereaved parents rely on spirituality to address their enduring sorrow which changes over the course of their lifetime journey in grief. Although, due to the nature of the study question, those who chose to participate may have been individuals for whom spirituality was an organizing principle in their lives, all participants voiced that spirituality was critical in their ability to cope following the loss of their child. These findings expand upon prior studies of posttraumatic growth (Harris et al., 2010), as the current study indicates that bereaved parents who have lost a child due to terminal illness experience either a strengthening of their spirituality or a continuation of its central role in their life.

Enduring Nature of Bereavement

This study recruited an older sample which is significant within the context of prior research on spirituality and grief theory. Prior studies of spirituality have found that an

individuals' spirituality changes throughout the life course with marked differences between age groups including 18 to 35, 35 to 49, 50 to 64, and more than 64 years of age (Moberg, 1999 as cited in Moberg, 2008). The fact that the modal age group in this sample was 61-70 years is of interest in light of studies that have shown that individuals in their mid-50s to mid-70s experience a significant increase in spirituality (Wink & Dillon, 2002).

Findings from the current study support previous research on the continuing nature of parent's grief throughout life and the desire on the part of the bereaved parent to maintain a connection with their loved one. This study supports findings that a parent's grief, although enduring, is also specific to the individual's experience of their child's death (Arnold & Gemma, 2008). Findings from the current study indicate that spirituality can be used both as a way to cope with perpetual grief, and as a way to maintain a connection to one's child.

Changing Relationships with Others

Perhaps one of the most important findings from the current study was the diverse nature of supportive relationships with others experienced by bereaved parents after the death of a child. The current study found that bereaved parents utilize many different types of relationships— some spiritual and some not—and that parents' choice of these connections, as well as their importance and type of relationship, may shift as time goes on and as they progress in their grieving process.

This finding has important implications for social work practice in that bereaved parents' willingness to relate to those in the caring profession may change with regards to their grieving process. Different therapeutic approaches might also be more beneficial at a particular point in an individual's grieving process, and it is important for those in the social work profession to know how their role as therapist might grow and change with time. It is also important for those

in the caring profession to help individuals explore their own social network of support, as connection with others can be a crucial component in bereaved parents' grieving process. Individuals in the current study who felt isolated conveyed a deep desire to share in their sorrow with another. It is therefore important for those in the helping profession to be aware of the changing relationships experienced by bereaved parents so as to better be able to support them.

Study Limitations

Several limitations of this study must be considered in a discussion of salient findings. These include: methods of data collection, sample bias, and the method of data analysis.

The current study collected qualitative data which is subjective in nature. In carrying out the analysis, the researcher, alone, coded the data; therefore, themes and findings may have been skewed to those that appeared relevant to the researcher. Despite precautions, having only one researcher limited the reliability of the study as there were no other reviewer findings with which to compare, and thus better ensure, the credibility of the coding scheme. In addition, the researcher and participant created a unique relationship based on manifest and latent similarities and differences that may have had a direct impact upon the way the interview was conducted and the responses given. This relationship should be considered in the examination of findings to the extent that it might have had an impact on the topics a participant discussed during the interview.

The sample may have been somewhat biased towards individuals for whom religion or spirituality is already a salient theme in their lives. Also, despite efforts to recruit among community-based organizations with a diverse membership, the final sample was predominantly female, Christian and older—a demographic profile consistent with that of samples from previous studies which have lacked diversity in gender, race/ethnicity, and religion. Locating potential participants and identifying recruitment sources for the current study was a challenge as

not all bereaved parents who have lost a child to terminal illness actively engage in either a religious community or with parent grief support groups. In addition, not all parents who have lost a child are willing to participate in an in-person interview. Therefore, it is possible that the sample consisted of parents who were more likely have a strong spiritual life and more interested in sharing thoughts about a difficult life experience with another. In addition, this is a small (N=11) convenience sample, which limits the current study's generalizability. One cannot generalize these results to all bereaved parents as not all avenues of individuals' spiritual experience are represented here. It is important that future studies include parents who may have turned away from spirituality in their grief.

Not only is qualitative research at its base a subjective process, but the researcher's own bias could have influenced the data analysis from the current study. The researcher is a young, white, female, social work student, who was raised in the Episcopal church, currently does not attend religious services but identifies with being a spiritual person. The researcher is not a mother, but has lost a family member from a terminal illness. Any combination of these factors may have influenced the lens through which the researcher analyzed interview data. The researcher could have inadvertently highlighted aspects that seemed either similar to or different from the researcher's perspective, or missed information conveyed by the participant.

Despite limitations posed by the method of data collection, the bias of the sample, and the method of data analysis, findings from this study inform professional practice in the field of social work and other helping professions.

Implications for Social Work Practice

Salient findings from the current study can influence the way that social workers and those in the caring profession serve those who have lost a child due to terminal illness.

The finding that spirituality is a central component in bereaved parents' coping process is significant when approaching and supporting a parent who has lost a child. It is important to know that spirituality can be an important force in the lives of some bereaved parents. Caring professionals should therefore consider ways in which they might be able to engage bereaved parents, who demonstrate an interest, in a discussion of their use of spirituality; likewise, professionals can also consider the potential benefits to such parents of referral to services or other resources that provide this orientation or focus in work. In 1999 a physician, Christina Puchalski, developed a spirituality assessment tool called Faith, Importance and Influence, Community, and Address (FICA), and incorporated it into her medical interview (Puchalski, 1999 as cited in Walsh, 2012). This tool, which is easily accessible online, can be used by social workers and other care providers in a multitude of different settings and could provide an entry point into such discussions. Importantly, although there may be a desire on the part of bereaved parents to explore their spirituality as it relates to the death of their child, findings also indicate that individuals for whom spirituality is an important source of support may also seek out and make use of services in which spirituality is not necessarily a component or major focus.

It is also important for social work professionals to remember the enduring nature of bereavement. Findings from the current study have shown that some feel isolated in their continual grief for they have no one with whom to express their pain. No matter how many years have passed since the death of one's child it is important that social workers and those in caring professions enter into discussions with parents about their bereavement process. Based on these findings, it may be that for those in the older age group, spirituality and approaches that incorporate the use of spirituality can be a supportive intervention and may be especially helpful

for older adults who may be motivated to share with others their experience of spirituality and grief.

Social workers must also be cognizant of the way in which bereaved parents' relationships to others may shift and change after the death of a child. Providing parents psychoeducational services aimed at enhancing their knowledge of this phenomenon, and normalizing this process before the death of the child, may be helpful for parents so that they are more informed about what to expect. It is also important for social workers to be aware of the changes in relationships that a bereaved parent conveys so that the social worker can provide the best support and recommend different types of support at different points during the grieving process.

Implications for Social Work Research

Despite the important information that these study findings provide, there is still much that remains to be explored about bereaved parents' spirituality after the death of a child.

Future studies should attempt to recruit parents who are younger, male, identify their race as other than White, and ascribe to a faith other than Christianity. The experience carrying out this study was consistent with findings that bereaved parents—including a diverse population—present a challenge for recruitment for social work research. Future studies should attempt to learn the extent to which improved recruitment methods will address this challenge, taking into account inherent barriers to participation for bereaved parents, as well as differences in orientation to research participation based on religious practices, age, gender, the nature of the child's death, or other mediating factors.

Future research should focus on spirituality in bereavement among parents younger than age 50 who may not be experiencing a strengthening of faith that often comes with age. Future

studies should also explore differences among bereaved parents in comfort level discussing the death of their child, by age and years since a child's death. As well, research could look at factors that may be associated with seeking help from services like Compassionate Friends and/or maintaining contact with the child's health care provider, including length of time since the child's death. Future research should also explore whether or not bereaved parents are more or less likely to experience the "acceptance" stage, as explicated in the grief theory model, based on their use of spirituality as a means of support or as a way of coping with loss.

Future studies should add to our understanding of bereaved parents' relationships with others, including the timeline of shifting relationships, predictable changes in types, roles, or importance of supporting relationships throughout the grieving process, and the unique reliance on relationships that characterize this population. The nature of the child's death as a factor in patterns of relationships among bereaved parents constitutes another area of recommended study. In addition to social relationships, future research should examine bereaved parents' spiritual trajectory, adding to the profession's understanding of grief reactions and informing services and therapeutic interventions to better meet the needs of bereaved parents.

Conclusion

Findings from this study indicate that there are many bereaved parents who use spirituality in their grieving process long after the death of their child from terminal illness. Despite limitations in the current study, major findings regarding the centrality of spirituality in coping, the enduring nature of bereavement, and the changing relationships experienced by bereaved parents will help to inform social work practice and research. Continued efforts to incorporate spirituality into a supportive grief process should be made by those who not only work with but provide support for in any capacity to those who have lost a child.

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Appendix A

Initial Recruitment E-mail to Organization/Community of Interest

[Name of leader of organization],

My name is Ellen Patterson and I am graduate student at Smith College School for Social Work.

I am in the process of recruiting participants for a research project for a master's thesis. The goal of the study is to better understand bereaved parents' spirituality after the death of a child from a terminal illness. I seek to explore how the grieving process resulting from death of a child from terminal illness affects their parents' spirituality. I want to learn more about how bereaved parents use spirituality, in hopes that such knowledge will inform care providers so that bereaved parents might be better supported by professionals and caring communities.

At this time I am asking if you would consider permitting me to recruit participants for my project from your organization. I will be contacting you within the week to learn of your interest in the project, and to talk with you about the best method of informing members of your community about my research study. I am able to provide a flyer **(**that **can** be posted in a communal area or included in a newsletter**)**, and/or present information about my study in person at a meeting. If you have any questions about the project or would like to meet in person, please do not hesitate to contact me. I do appreciate you taking the time to consider my project, and I look forward to connecting with you this week.

Thank you.

Ellen Patterson
Smith College School for Social Work
ecpatter@smith.edu

Phone Script Transcript

Hello. Is *[name of organization leader]* available?

My name is Ellen Patterson and I am a graduate student in my final year at Smith College School for Social Work, and am working on my Master's thesis.

How are you doing today?

I am calling you today because of your involvement with _____ community. My research is exploratory in nature. My goal is to better understand bereaved parents' spirituality after the loss of a child due to terminal illness. I am calling to ask you if I might be able to recruit for my study within your community.

[If wonder what study entails]
Participation in this study is entirely voluntary and will involve a personal interview with me. The interview will last no longer than 45 minutes and will take place at a time and location that is convenient for the interviewee, and in a space that is also private. If anyone in your community expresses interest in participating, they can contact me. Once eligibility for the study has been established and an interview scheduled, they will be asked to sign an informed consent form.   Participant's responses will be confidential, and they are free to end the interview at any time.

[If wonder about advertisement]
I would like to advertise at *[name of organization]* for my study. I want to make sure that I advertise for the study in a way that you are comfortable with. I can provide a flyer advertising the study and could also be present for an organization meeting to answer any questions. What sounds best for *[name of organization]*?

[If does not want to have anyone participate]
I understand your hesitation to have someone who you don't know talk about something that is so sensitive with members of your community. I would be willing to meet with staff, members of your organization and/or interested individuals to answer any questions, either in person, on the phone or by e-mail.   I can also assure you that I have received approval from Smith College to conduct this study, and will provide the names and contact information of support resources in the area should participants wish to access these at any point before, during, or after the interview.
[If still not interested]
I appreciate you taking the time to speak with me today. Have a good afternoon.

Appendix C

Human Subjects Review Approval

SMITH COLLEGE

February 3, 2013

Ellen Patterson

Dear Ellen,

Thank you for making all the requested changes to your Human Subjects Review application. Your project is now approved by the Human Subjects Review Committee.

Please note the following requirements:

Consent Forms: All subjects should be given a copy of the consent form.

Maintaining Data: You must retain all data and other documents for at least three (3) years past completion of the research activity.

In addition, these requirements may also be applicable:

Amendments: If you wish to change any aspect of the study (such as design, procedures, consent forms or subject population), please submit these changes to the Committee.

Renewal: You are required to apply for renewal of approval every year for as long as the study is active.

Completion: You are required to notify the Chair of the Human Subjects Review Committee when your study is completed (data collection finished). This requirement is met by completion of the thesis project during the Third Summer.

Good luck with your project.

Sincerely,

Marsha Kline Pruett, M.S., Ph.D., M.S.L.
Acting Chair, Human Subjects Review Committee

CC: Beth Lewis, Research Advisor

Recruitment Flyer Distributed, E-mailed, or Posted in Organizations

Research Study:
Spirituality after the Death of a Child
Smith College School for Social Work
MSW Thesis

The purpose of the current study is to **explore bereaved parents' spirituality after the loss of a child from terminal illness**.

Who is eligible?
Parents who have **lost a child from a terminal illness more than 2 years ago**

What will you be asked to do?
Audio-recorded, **in-person interview** with researcher lasting **no more than one hour**

This is a volunteer study, and those who choose to participate in this study will not be financially compensated.

If you have any questions or are interested in participating, please contact:
Ellen Patterson at ecpatter@smith.edu.

Appendix E

Amended Recruitment Approval

SMITH COLLEGE

School for Social Work
Smith College
Northampton, Massachusetts 01063
T (413) 585-7950   F (413) 585-7994

March 6, 2013

Ellen Patterson
82 Willet Street
Quincy, MA 02170

Dear Ellen,

I have reviewed your amendment and it looks fine. This amendment to your study is therefore approved. Thank you and best of luck with your project.

Sincerely,

Marsha Kline Pruett, M.S., Ph.D., M.S.L.
Acting Chair, Human Subjects Review Committee

CC: Beth Lewis, Research Advisor

Appendix F

Approval for Agency Recruitment

HOSPICE
of the NORTH SHORE
& GREATER BOSTON

North Shore
75 Sylvan Street
Suite B-102
Danvers, MA 01923
p 978.774.7566
f 978.774.8700
www.hns.org

Greater Boston
70 Walnut Street
Suite 301
Wellesley, MA 02481
p 978.774.7566
f 978.774.8700
www.hns.org

Kaplan Family
Hospice House
78 Liberty Street
Danvers, MA 01923
p 978.774.7566
f 978.774.4589
www.hns.org

Bertolon Center
for Grief & Healing
78 Liberty Street
Danvers, MA 01923
p 978.774.5100
f 978.646.9587
www.griefandhealing.org

March 4th 2013

Smith College
School for Social Work
Lilly Hall
Northampton, MA 01063

To Whom It May Concern,

Hospice of the North Shore and Greater Boston (HNSGB) gives permission for Ellen Patterson to locate her research in this agency. We do not have a Human Subjects Review Board and therefore, request that Smith College School for Social Work's (SSW) Human Subject Review Committee (HSR) perform a review of the research proposed by Ellen. HNS will abide by the standards related to the protection of all participants in the research approved by SSW HSR Committee.

On behalf of the HNSGB Ethics Committee,

Rona Tyndall
Spiritual Care Coordinator

Linda Reedy
Social Work Coordinator

Appendix G

Human Subjects Review Agency Approval

SMITH COLLEGE

School for Social Work
Smith College
Northampton, Massachusetts 01063
T (413) 585-7950   F (413) 585-7994

March 15, 2013

Ellen Patterson

Dear Ellen,

The Human Subjects Review Committee has approved your plan to recruit at the Hospice of the North Shore and Greater Boston.

Please note the following requirements:

Consent Forms: All subjects should be given a copy of the consent form.

Maintaining Data: You must retain all data and other documents for at least three (3) years past completion of the research activity.

In addition, these requirements may also be applicable:

Amendments: If you wish to change any aspect of the study (such as design, procedures, consent forms or subject population), please submit these changes to the Committee.

Renewal: You are required to apply for renewal of approval every year for as long as the study is active.

Completion: You are required to notify the Chair of the Human Subjects Review Committee when your study is completed (data collection finished). This requirement is met by completion of the thesis project during the Third Summer.

Good luck with your project.

Sincerely,

Marsha Kline Pruett, M.S., Ph.D., M.S.L.
Acting Chair, Human Subjects Review Committee

CC: Beth Lewis, Research Advisor

Appendix H

Informed Consent Form

Dear Participant,

My name is Ellen Patterson, and I am a graduate student pursuing my Masters in Social Work at Smith College. I am conducting a research study of which the goal is to explore bereaved parents' spirituality following the death of a child due to terminal illness. This study is for my master's level thesis, and will be used for academic purposes of presentation and publication.

Participation involves individual interview with the researcher that will be audiotaped and last no longer than 45 minutes. The researcher will transcribe the interview. Participants must be 18 years or older, and have lost a child more than two years ago due to terminal illness.

Discussions of bereavement and spirituality are sensitive topics, and participants may experience feelings of discomfort during the interview process. Attached to this letter is a list of referral resources in the area for additional support. This interview will provide participants an opportunity to explore their own feelings about bereavement and spirituality, in a way that may not have been previously addressed. Findings from this study **may** also help religious and parental support groups, as well as those in caring professions better understand aspects of bereavement and spirituality, and the ways in which support can be offered to bereaved parents. Compensation will not be provided for participation in this study.

Every possible measure will be taken to maintain confidentiality. Your responses will be kept separate from your name and other identifying information. Demographic information will only be used to describe the sample. The researcher will be the only individual who will listen to the interview unless a translator is needed, in which case the translator will first sign a confidentiality pledge stating they will not share information pertaining to current study. Transcripts of the interview will be shared with a research advisor, but with identifying information removed or disguised. Data in professional publications or presentations will be presented in the aggregate without reference to identifying information. Data, audiotapes, and consent forms will be kept secure in a locked cabinet for three years as required by Federal regulations, after which they will be destroyed or kept secure as long as they are needed.

Participation in this study is voluntary. You may withdraw from this study at any time up to March 31st 2013 and you may refuse to answer ant question. If you so choose to withdraw from the study all materials pertaining to you will be destroyed. If you have not withdrawn from the study by April 1st, 2013, your answers will be a permanent part of this study If you have any questions or concerns about your rights or any aspects of the study, please e-mail me at (ecpatter@smith.edu) or the Chair of the Smith College School for Social Work Human Subjects Review Committee at (413) 585-7974.

BY SIGNING BELOW YOU ARE INDICATING THAT YOU HAVE READ AND UNDERSTAND THE ABOVE INFORMATION AND THAT YOU HAVE HAD THE OPPORTUNITY TO ASK QUESTIONS ABOUT THE STUDY, YOUR PARTICIPATION, AND YOUR RIGHTS, AND THAT YOU AGREE TO PARTICIPATE IN THE PERSENT STUDY.

Thank you for your participation in this study.

_____
_____

Participant Signature   Date
_____
_____
Researcher Signature   Date

Appendix I

Community Resources: Massachusetts

The Compassionate Friends-http://www.compassionatefriends.org/home.aspx
MA Chapters in: Boston (617)288-8068, Concord/Needham (781)444-1091, Harwich (774) 722-9827, Holliston/Milford (508)473-4239, North Adams (413) 664-9661, Springfield (413)687-1073 or (413)533-1959, Swampscott (781)639-2544, Worcester (508) 845-1462, Buzzards Bay (508) 717-5088), Dudley (508 248-7144, Hingham (781) 749-3401 or (781) 337-8649, Newburyport (978) 697-1349, North Reading (781)938-5562, Stoughton (330)237-8068, Westminster (978) 786-5014

Bereaved Parents of the USA- Sturbridge MA Chapter: 508-764-6170, http://www.bereavedparentsusa.org/BP_Ch_Massachusetts.htm

The Children's Room- Arlington, MA: http://childrensroom.org (781) 641-0012

Children's Hospital Boston: individual, family and group support
http://www.childrenshospital.org/

Supportive websites

http://www.lossofachild.org/

http://www.griefhaven.org/index-firstpage.shtml

http://www.hellogrief.org/resources/massachusetts/

http://www.dana-farber.org/Adult-Care/Treatment-and-Support/Patient-and-Family-Support/Bereavement-Support.aspx

http://www.dougy.org/grief-support-programs/search-results/44b539c11c700a15527ba564739807cb/

Community Resources

The Compassionate Friends-http://www.compassionatefriends.org/home.aspx
MN Chapters: Minneapolis/Golden Valley (763)542-8528, Apple Valley 651)683-9236, St Paul/Maplewood (507)351-4042 & (651)528-6073, Rockford (763)843-8685, Hudson (651)429-6604, Monticello (763)295-3610, Hutchinson (320)833-2300, Owatonna (507)455-1636, Clear Lake (715) 263-2739, New Ulm (507) 359-2737, Rochester (507) 289-8203 & (651) 923-4922.

Healing Quilt: offers comfort and support to families who have lost a child within the Children's Hospitals and Clinics system. Contact (612) 813-7346.

Center For Grief: offers many support groups for those who have lost an infant, child, sibling, or friend. If interested contact (651) 241-6206.

Children's Hospital Minneapolis: individual, family and group support
http://www.childrensmn.org/patientfamily/family-services-a-resources/bereavement-services/bereavement-support-groups

Supportive websites

http://www.lossofachild.org/

http://www.griefhaven.org/index-firstpage.shtml

http://www.hellogrief.org/resources/massachusetts/

http://www.dana-farber.org/Adult-Care/Treatment-and-Support/Patient-and-Family-Support/Bereavement-Support.aspx

http://www.dougy.org/grief-support-programs/search-results/44b539c11c700a15527ba564739807cb/

http://www.centering.org/

http://www.dougy.org/

Appendix J

Interview Guide

Descriptive Questions:

Gender: Male   Female   Transgender   Other

Age: 18-30   31-40   41-50   51-60   61-70   71-80   81-90   >90

Race/ethnicity: American Indian or Alaska Native
                     Asian
                     Black or African American
                     Hispanic or Latino
                     Native Hawaiian or other Pacific Islander
                     White
                     Other

Religion/spirituality: _____

Marital status: Single   Married   Widowed   Divorced   Civil Union
                     Unmarried partner   Cohabitating

 Number of years since death of child: _____

Open-Ended Questions:

1) What does spirituality mean to you? What comes to mind when you think of spirituality?

2) Thinking about your bereavement process following your loss, how would you describe the role, if any, that spirituality has played in this process?
    Probing Question:
        - Did you find that it was a source of support or not? In what ways?

3) Have you found that your relationship, or lack thereof, with spirituality has changed since your loss?
    Probing Questions:
        - Have you found that you think differently about spirituality?
        - Is it more or less important?
        - Does spirituality play more of a role in your life?
        - Did your relationship with spirituality change? In what ways?

4) Tell me about how your family made use of spirituality following your loss.
    Probing Questions:
        - Do you share your spirituality with other family members? If so, with whom, in what ways?

- Does your family openly discuss ways in which spirituality has or has not been helpful in understanding/coping with the loss?
- Do your family members share their feelings about spirituality and loss?

5) How and in what ways has your relationship, or lack of relationship, with spirituality impacted significant relationships outside the family?
   Probing Questions:
   - How has your spirituality impacted significant relationships with friends? Religious institutions? Group support?
   - Is your relationship with spirituality now a component with others outside the family? Was it before your loss?