

EXPLORING MOTHERS' EXPERIENCES OVER TIME
FOLLOWING DEATH OF THEIR YOUNG CHILD FROM CANCER:
IMPLICATIONS FOR PRACTICE

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Abstract

This qualitative research study provides an in-depth exploration of a sample of bereaved mothers' experiences over time following the death of their young child from cancer ten or more years ago. Eight mothers completed semi-structured interviews containing questions about their bereavement experience over time. Through a grounded theory analysis of the data eight major themes emerged consistently across subjects. In interpreting these major themes three overarching themes or meta themes have been identified. These meta themes encompass different yet overlapping aspects of the adaptation to the bereavement process: (a) the phenomenological: losing a child is a transformative experience; (b) the structural: child loss is unique among losses; and (c) the theoretical: the nature of continuing bonds and its grounding in attachment theory. Clinical implications for working with bereaved mothers are discussed.

Keywords: Child loss, grief, bereavement

Dedication

Dedicated to my children,

Jessica, Brian, Evan,

Alex, Lauren & Jason

who each hold a special place in my heart

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Chapter I

Introduction

Children are not supposed to die. The death of a child is a senseless injustice.

A child's death—whether expected or unexpected, regardless of age and cause—is incomprehensible (Arnold & Gemma, 1994).

Each year, over 50,000 U.S. children die (U.S. National Center for Health Statistics, 2009), with cancer being the leading cause of death by disease among U.S. children between infancy and age 15 (National Cancer Institute, 2011). Although death is a natural and universal experience that touches everyone at some point during the life cycle, the death of a child and the grief process that follows differs from other grief in a number of ways. Clinical observations and empirical investigations are making it increasingly clear that parental bereavement cannot be adequately understood in terms of the general conceptualizations that are held for grief and mourning (Arnold & Gemma, 1994; 2008; Knapp, 2005; Rando, 1986).

There is a body of research that has shown parental bereavement to be associated with more intense and prolonged grief with longer lasting difficulties than other types of bereavement (Kamm & Vandenberg, 2001; Klass & Marwit, 1988; Knapp, 1987, 2005; Rando, 1986, 1983; Rogers, Floyd, Seltzer, Greenberg & Hong, 2008; Schwab, 1992; Shapiro, 1994). In her landmark study comparing adult bereavement following the death of a parent, spouse, or child, Sanders (1979-1980) found significantly higher intensities of grief among those surviving the death of a child. Sanders also reported that there were no significant differences between the grief of parents whose child died after a lengthy illness versus a sudden and

unexpected death. In a similar study comparing bereavement phenomena in recently bereaved spouses, adult children and parents, Middleton, Raphael, Burnett and Marinek's (1998), findings support the hypothesis that intensity of grief for parents who had lost a child was higher than for widows/widowers, who in turn have more intense reactions than adult children losing a parent.

Song, Floyd, Seltzer, Greenberg and Hong (2010), examined the long-term effects of a child's death on bereaved parents' health related quality of life and found that even for parents whose child died on average of two decades earlier there was a significant and measurable negative impact on their well-being as they approached old age. Similarly, Rogers et al. (2008) examined the long-term effects of the death of a child on parents' adjustment in midlife. On average 18.05 years since the time of death bereaved parents reported more depressive symptoms, poorer well-being, and more health problems and were more likely to have experienced a depressive episode and marital disruption than were comparison parents. In a 12–15 year follow-up of 26 parents who lost a child to sudden infant death, Dyregrov and Dyregrov (1999) reported that most parents still considered the death of the child to affect their daily life but few parents were at risk of psychological complications at the time of follow-up.

Regardless of the years since death, the age of the child at the time of death, and the cause of the child's death, research has shown that parental bereavement has no clear endpoint, with many bereaved parents grieving the loss of their deceased children for the rest of their lives (Arnold & Gemma, 2008; Knapp, 2005; Rando, 1983; Woodgate, 2006). Arnold, Gemma and Cushman's (2005) study of bereaved

parents, with 24.4 mean years since death of their child, offers empirical support for the notion of grief as ongoing in the life of a parent whose child had died, regardless of age of the child and circumstances of the death.

Parental grief is best appreciated as grief over a lifetime (Arnold & Gemma, 2008; Buckle & Fleming, 2011; Keesee, Currier, & Neimeyer, 2008; Klass, 2001); a process that evolves but never ends. It is important to note that the associated processes and outcomes that are frequently experienced as an ongoing and lifelong basis include those that are positive and life transforming (Arnold & Gemma, 2008; Riley, LaMontagne, Hepworth & Murphy, 2007). Many mothers report changes they regard as positive, or at least adaptive in some way, to have resulted from their struggle with grief (Calhoun, Tedeschi, Cann & Hanks, 2010; Gerrish, Steed & Neimeyer, 2010; Talbot, 2002). Calhoun and Tedeschi (1998, 2004) have used the term posttraumatic growth (PTG) to describe positive changes that can accompany the struggle with extreme adversity.

Tedeschi and Calhoun (2004) note that “posttraumatic growth is most likely a consequence of attempts at psychological survival” (p. 5). Forever changed by the trauma, one cannot revert back to pre-trauma levels of functioning; however, some individuals may surpass former levels of functioning and experience transformation in their lives. They argue that PTG is typically reported in three broad domains of identity: personal (e.g., increased personal strength); relational (e.g., greater intimacy with others); and spiritual (e.g., increased appreciation of life and changed priorities for living). However, Tedeschi and Calhoun (2004) caution that post-traumatic

growth is not a cure and that distress may continue despite the amount of post-traumatic growth.

Rationale for Study

Health professionals have a critical role in supporting bereaved parents and rely on models of grief to inform and guide their practice. Although grief theories have evolved over time, research shows that many therapists maintain old models of grief (Breen, 2011) that are not helpful and can even be harmful to the bereaved. As the subject of bereavement continues to become a part of mainstream psychology, it is becoming clear that many of the assumptions made about grief need to be reevaluated (Wortman & Silver, 1989, 2001). Models and concepts which earlier in the history of psychotherapy were accepted without question are now being challenged and tested empirically (Archer, 1999), leading to new understandings of the grieving process (Bonanno & Kaltman, 1999; Wortman & Silver, 2001).

The grief work hypothesis, based on Freud's (1917) ideas, has been accepted by the majority of those working in the area of bereavement and grief (Rubin, Malkinson, & Witztum, 2012). The central ideas of grief work in the professional and lay literature include the following: distress or depression is inevitable following a loss; distress is necessary, and failure to experience distress is indicative of pathology; the importance of working through the loss; the expectation of recovery and reaching a state of resolution; and the necessity of breaking the attachment bond with the deceased loved one. However, Wortman and Silver (1989, 2001) found no empirical support of the grief work perspective leading many to question its effectiveness (Bonanno & Kaltman, 1999). For example, more recently researchers

have highlighted the important role played by maintaining a continued sense of attachment with the deceased (Klass, Silverman, & Wortman, 1996) and conclude that maintaining continuing psychological and emotional bonds with the deceased is not necessarily an indication of problematic grieving.

Yet despite the emergence of an empirical and theoretical critique of the grief work hypothesis (e.g., Bonanno & Kaltman, 1999; Currier, Holland, Coleman & Neimeyer, 2008; Klass, Silverman & Nickman, 1996; Stroebe, Schut & Stroebe, 2005; Wortman & Boerner, 2010), older models continue to shape the understandings of grief presented in university curricula and post-university training across multiple disciplines (Barcklay, Wyatt, Shore, Finlay, Grande, & Todd, 2003; Dickinson, 2007; Maciejewski, Zhang, Block & Prigerson, 2007; Zisook & Shear, 2009). Furthermore, cursory attention is given to loss and bereavement during training (Rubin, Malinson & Witztum, 2012). There is no required graduate course on bereavement and less than a fifth of students in the health professions are offered a full course on death, the rest are typically provided death-related content in a few lectures (Wass, 2004). As loss and bereavement are a ubiquitous and central part of human existence Rubin et al. (2012) argue that all clinicians should be required to have basic competence in this aspect of the human encounter.

There is a clear misalignment between contemporary grief research and grief counseling practices, and this disparity may influence the practice of grief counselors and other health care professionals and limit intervention effectiveness (Breen, 2011; Bridging Work Group, 2005). In addition, there is a paucity of research describing how those working with the bereaved understand grief and how they incorporate

these understandings into their practices. It is essential for therapists to examine assumptions made about the grieving process and in particular about the grief following the death of a child as this will have a great impact on the therapeutic alliance for patients reacting to the impact of loss in their lives. Child loss is particularly misunderstood as many of the *normal* features of parental grief are the very features accentuated in those labeled with prolonged or chronic grief. Grief models need to be reworked to account for a parent's normal grief response and to recognize parental bereavement as a special type of grief with its vast expanse of normal bereavement behavior (Arnold & Gemma, 1994).

Although the death of a child is a traumatic event whose affects may last a lifetime, research on parental bereavement is more limited than might be expected (Rogers, et al., 2008). There are studies that examine longer term outcomes of child loss; however, most research assesses the functioning of bereaved parents for only a brief period during the early phase of bereavement. Such studies are primarily quantitative and assess health related quality of life. There is a lack of qualitative research examining parents' experience in therapy and their retrospective grief experience over time. Furthermore, the majority of the empirical work has concentrated on perinatal loss, and sudden or violent death. Cause of death (i.e., anticipated or sudden; accidental, intentional, or illness-related) has been found to influence bereavement outcomes (Christ, Bonanno, Malkinson, & Rubin, 2003; Miles & Demi, 1992).

Literature pertaining to families who have experienced the loss of a child to cancer, specifically, remains limited (Barrera et al., 2009; Russo & Wong, 2005).

When the death is caused by cancer, parents are exposed not only to their own loss, but also to the prolonged physical and emotional suffering of the child. The possibility of anticipatory grief has important implications for parents and families bereaved from cancer (Christ, Bonanno, Malkinson & Rubin, 2003). In their study comparing bereaved mothers and mothers of children with cancer, Bortz, Malkinson and Krulik (2013), observed that the mother-child relationship became closer following the child's cancer diagnosis. These and other factors may create distinct post-bereavement challenges (Bortz et al., 2013; Kreicbergs, Valdimarsdóttir, Ónelo, Hentzer, & Steineck, 2004; McCathy et al. 2010).

Rando (1983) evaluated the grief and bereavement experiences of 54 parents whose children died from cancer during the previous two months to three years. She found that anticipating a child's death ameliorated the intensity and duration of parental grief if a child died within 18 months to 2 years from the time of diagnosis. However, when the child's diagnosis was more than 18 months to two years from time of death the intensity and duration of their grief and bereavement exceeded that of parents whose children died either suddenly or after a briefer time frame. This finding is in contrast to previous research that has asserted that a mother's more extensive participation during a child's hospitalization facilitates her anticipatory grief and subsequent adjustment following the death. Rando posits that when an illness lasts too long the stress of the experience works against adequate preparation for the death by the parents. The long duration of the illness may lessen the coping abilities of the parents after the death.

Another possibility is that parents' increased involvement with a child's medical care needs that exceeds 18 months to two years before an anticipated death is associated with the denial of the possibility of a child's death. This is especially true when the child survives the illness against statistical odds for an extended period of time. Therefore, although the loss experience of these parents would be classified in previous research as anticipated in nature, these parents were not prepared for when or how their children died, and said their child's death, which had been a "possibility" for years, was sudden in nature (Barrerra et al., 2009).

In addition, Rando (1983) reported that parents who were highly involved in the care of their dying children showed prolonged rumination about the deceased child, and were often unable to emotionally or physically tend to other responsibilities and family members following the death of the child. Grieving under these circumstances may or may not have unique characteristics that need to be examined prospectively. Thus, for theoretical and practical purposes, the bereavement processes of parents who have lost a child to cancer warrant special attention (Barrera et al. 2009).

Statement of Purpose

The purpose of this research is to explore the experiences and needs of mothers whose young child died from cancer ten or more years ago. The proposed study aims to develop a deeper understanding of some of the key themes of the longer term sequelae of child loss and to offer those working with this population a better understanding of how mothers cope with loss and how they develop constructive methods for continuing their lives. Exploring and understanding the experiences of

mother's whose child died from cancer is an essential task to provide accurate information to clinicians working with this population. An ultimate goal of this study is to integrate the knowledge gained from its findings into clinical practice and to offer best practices for those working with this vulnerable population.

Research Questions

In order to contribute to the knowledge base and understanding of maternal bereavement following the death of a young child from cancer the following research questions guided this qualitative inquiry:

1. What are the subjective experiences of mothers whose young child died from cancer?
2. What are the psychological consequences of losing a child to cancer?
3. What are the implications of the mothers' perspective for theory and clinical practice?

The open-endedness of the researcher's questions allowed the participants to contribute as much detailed information as they desired while allowing the researcher to ask follow up or probing questions based on participant responses to previous questions.

Chapter II

Literature Review

The Evolution to our Current Understanding of Grief and Mourning

Modernity has brought with it a myriad of changes to our experience of terminal illness and dying, and in turn, to our perceptions and attitudes towards grief and mourning. A comprehensive review of the existing grief literature will provide a framework for understanding contemporary grief theories. For most of the 20th century the purpose of grief has been defined as the breaking of an attachment. However, contemporary grief theories or the “new wave” of thinking about the grief process have shifted to more of a relational perspective than an individual orientation to grief that focuses on the complexity of human relationships and the connectedness of individuals to those living and to those who have died. Fundamental to the new psychoanalytic model of mourning, is “the need to preserve attachment to the lost person and the importance of securing a sense of meaningful relationship, which transcends loss” (Hagman, 2001, p. 22). A transformation and internal reconstruction of the attachment to the deceased person is emphasized and rather than breaking bonds the nature of the relationship to the deceased and how it affects the bereaved may be at the heart of the mourning experience.

Following a brief discussion on the taboo nature of death and by association to grief and mourning, early grief theories are analyzed and explored within the historical context that they unfolded. Although many of the earlier theories overlap in their emphasis and conclusions, each model contributes to or complements the overall understanding of the complex bereavement process. Their legacies, both positive and

negative are highlighted. Where traditional models are not always based on empirically sound evidence and do not capture the complexity of the bereaved's experience more contemporary models are an attempt to integrate theories with an eye towards understanding the depth of emotions, the complexity and diversity of grief experiences, as well as the way in which bereavement is socially and culturally constructed. Contemporary grief theorists recognize the importance of an integration of grief theories. It is only through an understanding of the complex interactions of systems that an understanding of grief that is more reflective of actual grief experience becomes possible.

Definition of Terms

Although the terms grief, mourning, and bereavement are often used interchangeably in the grief and bereavement literature, they are different processes within the death and dying experience. Bereavement is defined as the objective situation of an individual who has recently experienced the loss of a significant other through that person's death. Bereavement is the cause of both mourning and grief. Grief is the consequence of a psychological trauma. It is an individual's complex reaction to the loss of a loved person that involves the emotional response to loss, with accompanying psychological and physiological reactions. It is the individual's internal experience. Mourning, in contrast, is the external expression of one's grief and encompasses the ways in which grief is expressed. Stroebe and Stroebe (1987) have explained that the behaviors and rituals of mourning are shaped by the practices of each culture with culture providing the guidelines for the expected behaviors of the bereaved individuals. Societal expectations of grief impact the experience of

bereavement (Costa, Hall, & Stewart, 2007). Thus a person may experience extremely painful grief, but because of a need to appear stoic, many not mourn.

Taboo Nature of Grief

Historically there has been a taboo surrounding the open discussion of death and the associated grief and mourning processes. Gilbert (2006) states, “Even while death makes, history makes death, makes and remakes it as it has been continually renamed from age to age and place to place” (p. 105). Contemporary changes include the transformation of attitudes and beliefs about death from invisibility to visibility. In his research on the American experience of death, David Moller, a sociologist, approached the American Cancer Society for permission to include the organization’s materials about death, grief and mourning. The Society’s reaction was, “Absolutely not. In no way do we want to be associated with a book on death. We want to emphasize the positive aspects of cancer only” (Gilbert, 2006, p. 106). This demonstrates the 20th century reaction to death as an unmentionable unnatural subject.

Similarly, British anthropologist Geoffery Gorer (1965) addressed our American culture’s discomfort with bereavement and ban on openness to the grieving process. He likened our taboo surrounding the topic to the prudery toward sexuality in the preceding century. He stated that the societal attitude suggested “sensible, rational men and women can keep their mourning under complete control by strength of will or character so that it need be given no public expression, and indulged, if at all, in private (p. 111). Clive Seale (1988) adds that our modern society is “death denying.” Tony Walter (1991) explains that our western society has abandoned public mourning

rituals and as a culture we are unprepared and ill-equipped to support individuals who are in the bereavement process.

Earlier and more primitive societies embraced death and grieving as an integral part of the social fabric; however, as western societies have moved toward secularization and medicalization of terminal care and death, death as a taboo topic has become the cultural norm. In our contemporary society Elizabeth Kubler-Ross (1975) observed that death most frequently occurs in a hospital, a hospice or a nursing home, away from family and friends, hidden from children. This process toward medicalization has moved our society to keeping dying and death out of sight of family and friends. Philippe Aries (1974), a French historian, points to the displacement of the site of death where “one no longer died at home in the bosom of one’s family but in the hospital alone” (p. 87). Also, with extended life expectancies death has become less of an everyday reality. Stephenson (1985) explained that we have become a “death-free” generation and that “statistically, a family can reasonably expect that a death will not occur within it for twenty years” (p. 32).

Funeral rites in the 20th century have also undergone dramatic changes. As recently as the 1950s, families prepared the deceased’s body for the burial, opened the home for the wake and display of the body. Extended family, friends, neighbors, and the community participated in the process with visits, thoughts and gifts of consolation. As family and friends visiting the grieving family members, they provided a strong psychosocial network to provide emotional support to the bereaved. Today the body is quickly removed to a funeral home, where it is prepared for burial out-of-sight of the grieving family and friends. Funerals are quick and the bereaved,

often by well-meaning family and friends, are encouraged not to dwell on sad thoughts in an attempt to get them to rejoin life and to regain the previous pattern and routine of their lives.

As the American culture has embraced an individualistic approach to our lives, a more private view and experience of death is encouraged; whereas, the collectivist outlook of other cultures holds a view of death as part of a traditional communal belief system (Archer, 1999). In the collectivist society individuals view themselves as part of a whole, motivated and supported by the norms and duties of the group. With an emphasis on connectedness of people and obligations to others, the death of a community member sends emotional ripples throughout the total group with the death experienced more deeply and personally by each member of the community.

Through his personal experience with death, Geoffrey Gorer (1965) came to realize that society's taboo surrounding death, dying and bereavement exacerbate the process, contributing to the emotional difficulty of living through this emotional crisis. He recalled his feelings after his father's death when he was a ten-year-old boy, "In an attempt to convey the desolation I was feeling I said to Miss Russell that I did not think I should ever be able to enjoy flowers again; at which she reprimanded me, telling me not to be morbid" (p. 3). After experiencing the loss of his brother, Gorer became aware of society's lack of social rituals to support a grieving individual, and felt this societal reality prolonged his mourning. When he declined several invitations to cocktail parties while he was grieving he experienced harsh, non-supportive reactions by his friends:

The people who invited me responded to this statement with shocked embarrassment, as if I had voiced some appalling obscenity. Indeed, I got the impression that, had I stated that the invitation clashed with some esoteric debauchery I had arranged, I would have had understanding and jocular encouragement; as it was the people whose invitations I had refused, educated and sophisticated though they were, mumbled and hurried away. They clearly no longer had any guidance from ritual as to the way to treat a self-confessed mourner, and, I suspect, they were frightened lest I give way to my grief and involve them in a distasteful upsurge of emotion (p. 14).

Similarly, Arnold and Gemma (1994) state that there is a social pressure against the prolonged and public expression of personal grief:

One is expected to wipe away any sign of acute mourning, to reduce and cover intense emotion, and to regain control – as though to deny the very existence of one's loss. When a child dies, this urgency to wipe away is more exaggerated. The social pressure toward denial of loss becomes pressure to deny one's pain, sorrow, and loneliness and therefore finally to deny the very existence of this precious and loved child (p. 26).

Contemporary researchers of death and bereavement have suggested that progress is being made in lessening the taboo of the subject of death with attempts to change the patterns of hiding and ignoring this ubiquitous human experience.

However, the reality of the American society as a death denying society has been acutely experienced by many experiencing grief and bereavement. Haig (1990) observed that there currently is an explosion of self-help books focusing on coping

with death and dying, a proliferation of bereavement support groups, and a noticeable increase in research and scholarly publications in the area of death and dying. One explanation for this is provided by the griever themselves. Within this individualistic society, with community no longer offering the needed psychosocial support and understanding, resources, including self-help books, support groups, on-line resources and grief counseling are attempts to fill the void and are often initiated by the bereaved themselves. Once an individual is personally faced with death, he/she suddenly finds him/herself forced into the arena of death and grief with no escape or ability to continue the death denying cultural norm. On an experiential level the griever is acutely aware of the lack of social support during the phases of bereavement and an intense emotional disconnect between the societal messages and beliefs about what he/she should be experiencing and the reality of the actual grieving process.

This “awakening” or “aha” personal experience has been the motivational impetus for many authors who have found themselves compelled to begin research about death, dying and the grieving process and to become groundbreakers as each writes on this “taboo” topic. Esther Schor (1994) was sparked by her mother’s diagnosis of breast cancer at the age of 42. Her confrontation with death and her personal mourning inspired her to write *Bearing the dead: The British culture of mourning from Enlightenment to Victoria*. Sandra Gilbert (2006) wrote *Death’s door* in response to the grief after the sudden death of her husband. Austin Kutsher (1969) spearheaded the writing of *Death and bereavement* after his young wife’s death caused by cancer.

As the subject of bereavement becomes more a part of mainstream psychology, researchers have alerted us that many of the assumptions about grief need to be reevaluated. Many assumptions that were accepted without question are being tested empirically, leading to new understandings of the grieving process (Bonanno & Kaltman, 1999; Wortman & Silver, 1989, 2001). When there is incongruence between the bereaved's reactions and others' expectations of an understood or acceptable grieving process, grief can become problematic and complicated. With our culture's death and dying taboo many individuals have developed an unrealistic perspective on a normal grief response. As a result, the griever holds assumptions about how one should handle the grieving process and when grief does not follow a predictable path, the grieving individual may judge him/herself harshly with concerns about underlying psychological problems and psychopathology. Strobe, Gergen, Gergen, and Stroebe (1996), contemporary researchers of the grieving process, emphasize, "to the extent that the professional view of proper mourning becomes accepted as normal, then previous orientations become irrelevant—if not deviant" (p, 18).

Mourning and Melancholia

Throughout the centuries, poets, artists and composers have recognized grief as a central component of the human condition. However, Sigmund Freud (1917) was the first to bring grief into the sciences by addressing the psychological process of grieving in his classic paper, *Mourning and melancholia*, in which he highlights the commonalities between grief and depression. Freud's primary focus was on the pathological state of melancholia, only using mourning as a tool for comparison for a

standard of the normal affect associated with bereavement. Freud asserts that although melancholia gives the appearance of grief it is brought on by psychological rather than real, object loss or disappointment. Furthermore, in melancholia there is the presence of a marked lowering of self-regard: “the self-reproaches are reproaches against a loved object which have shifted away from it onto the patient’s ego” (p. 248). Thus, the ego internalizes the lost person, “the shadow of the object falls upon the ego” (p. 249), and both ego and object fall under the harsh judgment of a critical agency (a concept later developed into the super-ego). By contrast, Freud asserts that in normal mourning there is no process of identification and internalization, but rather a gradual withdrawal of libido from the lost person. Once this task is completed the libido is “free” to be invested elsewhere.

Freud asserts that although mourning involves “grave departures from the normal attitude to life, it never occurs to us to regard it as a pathological condition and to refer it to medical treatment” (p. 243). In spite of the severe symptoms associated with grief, Freud’s perspective was that the psychological experience could be easily explained:

Reality-testing has shown that the loved object no longer exists, and it proceeds to demand that all libido shall be withdrawn from its attachments to that object. This demand arouses understandable opposition—it is a matter of general observation that people never willingly abandon a libidinal position, not even, indeed, when a substitute is already beckoning to them. This opposition can be so intense that a turning away from reality takes place and a clinging to the object through the medium of a hallucinatory wishful

psychosis. Normally, respect for reality gains the day. Nevertheless its orders cannot be obeyed at once. They are carried out bit by bit, at great expense of time and cathectic energy, and in the meantime the existence of the lost object is psychically prolonged. Each single one of the memories and expectations in which the libido is bound to the object is brought up and hypercathected, and detachment of the libido is accomplished in respect of it. Why this compromise by which the command of reality is carried out piecemeal should be so extraordinarily painful is not at all easy to explain in terms of economics. It is remarkable that this painful unpleasure is taken as a matter of course by us. The fact is, however, that when the work of mourning is completed the ego becomes free and uninhibited again (p. 244).

Freud conceptualized that individuals cathect libido, or infuse psychic energy, onto a love object over the course of life, a connection that is “strengthened by a thousand links.” When a love object dies the task of grief is the decathexis or detachment of libido from the original love object so that libido is available for investment in a new object. Thus grieving involves a process of hypercathecting and then decathecting the internal image of the lost object (Fraley & Shaver, 1999). Once the ego is freed from the attachment to the deceased the bereaved can make a psychologically healthy and successful readjustment to life. Freud (1915) explains his economic theory of libido as follows:

We possess, as it seems, a certain amount of capacity for love—what we call libido—which in the earliest stages of development is directed towards our own ego. Later, though still at a very early time, this libido is diverted from

the ego on to objects, which are thus in a sense taken into our ego. If the objects are destroyed or if they are lost to us, our capacity for love (our libido) is once more liberated; and it can then either take other objects instead or can temporarily return to the ego (p. 81).

Freud suggests that if identification and internalization with the lost object is present, normal mourning is transformed into pathological mourning. Freud viewed ongoing emotional relationships with the deceased as pathological. Thus, for Freud melancholia, or pathological grief, represents a refusal to relinquish the love object by maintaining emotional connection to the deceased.

However, Freud's own experiences with grief suggest a very different psychological experience that appears to contradict his theoretical conceptualization that one must gradually withdraw libidinal energy from the love-object if adaptation to loss is to occur. Silverman and Klass (1996) point out how Freud's personal experience with grief did not support his theoretic model of grief. They state that "after important deaths, Freud seemed unable to find new attachments and unable to find a sense of transcendent connection that he seemed to think necessary if his bond with the deceased were to be continued" (p. 6). Similarly, Shapiro (2001) writes, "Freud's enduring attachments to his deceased daughter and grandson eloquently testify to the need for alternative models" (p. 304).

Several of Freud's' personal letters offer a wealth of information regarding the losses he experienced through death, how he coped with them and how he empathized with others during their losses (Dozios, 2000). In the winter of 1920 Freud experienced the death of his daughter Sophie. In personal letters he writes that he

experienced her death as a “serious narcissistic injury (E.L. Freud, 1961, p. 328).

Three years later he grieved the death of his grandson, Sophie’s son, who died at the age of four. At that time he wrote:

I find the loss very hard to bear. I don’t think I have experienced such grief...I work out of sheer necessity; fundamentally everything has lost its meaning to me. To me, this child has taken the place of all my children and all my grandchildren and since then I don’t care for any of my grandchildren. I can find no joy in life (E.L. Freud (Ed.), 1961, p. 344).

Several years later, in a personal letter of condolence to his friend and colleague Ludwig Binswanger, who had recently experienced the loss of his son, in a letter dated nine years after Sophia’s death, Freud wrote:

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

Freud’s idea that one gradually withdraws libido from the love-object and that “time will heal” seem to be disconfirmed by his own experience. Freud’s personal accounts suggest that at a deep and emotional level he understood that to de-invest one’s libidinal energy from the deceased loved one was an unnatural and unwanted accomplishment. Rather, Freud may have valued ongoing emotional connection with the deceased. One can wonder what differing trajectory might have

occurred had subsequent theories been developed from Freud's more personal reflections that speak about connection rather than letting go. This may have been one of the reasons that he later altered his views on mourning and melancholia.

In the *Ego and the id*, Freud (1923) wrote about the important function that identification plays in grief. He suggests that "it is through identification with the deceased that aspects of the person who has died come to reside, unconsciously, in the self. Taking in and identifying with aspects of those who have died is what makes mourning bearable and even transformative" (Berzoff, 2011, p. 263). It appears that Freud recognized that the withdrawal of the libido that attaches one person to another can take place only when the lost person has been "reinstated" within the ego: "By taking flight into the ego love escapes extinction" (Freud, 1917, p. 257).

By asserting that the tendency to internalize lost love-objects is a normal part of dealing with loss and not specific to depression, Freud rejects his original theory (Dozios, 2000). However, Freud's subsequent thoughts about mourning and the identification as a result of object loss do not receive the attention they deserve and the notion that one has to withdraw libidinal energy from the deceased for a "normal" grief process has persisted.

Freud's account of the loss and depression experienced during the grieving process in *Mourning and melancholia* remains a landmark contribution to our understanding of the psychodynamics of this universal experience. Freud's evocative description of the slow, painful image-by-image process of confrontation with the reality of loss has been echoed by other writers, including the bereaved themselves (Shapiro, 2001). Although contemporary researchers have identified flaws and

limitations in Freud's seminal work (Wortman & Silver, 1989, 2001) the idea of unconscious activity, central to his perspective on mourning, is essential in explaining the existence of such phenomena as intense preoccupation with the deceased and recurring dreams of the deceased. Bradbury (2001) stresses that Freud's insights about ambivalence during the mourning process and identification with a lost object continues to have significant impact on our contemporary views of normal and pathological grief. Similarly, Stroebe and Strobe (1987) identify Freud's psychoanalytical process of "working through" grief as a continuing influence in our current theories for understanding the grief experience and for helping the bereaved. Freud's invaluable contribution that grieving is a normal adaptation to loss, and that grieving requires hard work, "grief work," remains a foundation for our continued understanding of bereavement. Lindeman (1944), Bowlby (1969), and Parkes (1970), pioneers in grief studies used Freud's theoretical model as the foundation for their work.

Symptomatology of Grief

The first systematic study of grief was conducted in 1944 by psychiatrist Eric Lindemann following the tragic Coconut Grove fire in Boston, Massachusetts, in which he interviewed one hundred surviving family members. Lindemann's experience demonstrated to him that "acute grief is a definite syndrome with psychological and somatic symptomatology" (p. 155). He states that "the picture shown by persons in acute grief is remarkably uniform" (p. 141). Contemporary scholars of grief and bereavement have described Lindemann's observation and

description of grief as one of the classic contributions to the understanding of this emotionally challenging life crisis (Parkes, 1970).

Lindemann described the phenomenology of grief as follows:

Sensation of somatic distress occurring in waves lasting from twenty minutes to an hour at a time, a feeling of tightness in the throat, choking with shortness of breath, need for sighing, and an empty feeling in the abdomen, lack of muscular power, and an intense subjective distress described as tension or mental pain. The patient soon learns that these waves of discomfort can be precipitated by visits, by mentioning the deceased, and by receiving sympathy. There is a tendency to avoid the syndrome at any cost, to refuse visits lest they should precipitate the reaction, and to keep deliberately from thought all references to the deceased....the sensorium is generally somewhat altered. There is commonly a slight sense of unreality, a feeling of increased emotional distance from other people (sometimes they appear shadowy or small), and there is intense preoccupation with the image of the deceased....another strong preoccupation is with feelings of guilt. The bereaved searches the time before the death for evidence of failure to do right by the lost one. He accuses himself of negligence and exaggerates minor omissions....In addition, there is often disconcerting loss of warmth in relationship to other people, a tendency to respond with irritability and anger, a wish not to be bothered by others at a time when friends and relatives make a special effort to keep up friendly relationships. These feelings of hostility, surprising and quite inexplicable to the patients, disturbed them and again

were often taken as signs of approaching insanity. Great efforts are made to handle them, and the result is often a formalized, stiff manner of social interaction (pp. 141-143).

In the following passage Lindemann captures with insightful precision, the angst and pain of the newly bereaved as he struggles through the weight of another day:

The activity throughout the day of the severely bereaved person shows remarkable changes. There is no retardation of action and speech; quite the contrary, there is a push of speech, especially when talking about the deceased. There is restlessness, inability to sit still, moving about in an aimless fashion, continually searching for something to do. There is however, at the same time, a painful lack of capacity to initiate and maintain organized patterns of activity. What is done is done with lack of zest, as though one were going through the motion. The bereaved clings to the daily routine of prescribed activities; but these activities do not proceed in the automatic, self-sustaining fashion which characterized normal work but have to be carried on with effort, as though each fragment of the activity became a special task. The bereaved is surprised to find how large a part of his customary activity was done in some meaningful relationship to the deceased and has now lost its significance (p. 143).

We continue to value this profile of grief presented by Lindemann and find consistency with our current understanding of the symptomatology of grief and mourning. However, similar to Freud's conceptualization, Lindemann presented a time limited frame for regaining psychological equilibrium that appears to be

unrealistic and incongruent with current research. Lindemann concluded that eight to ten sessions of grief work within a four to six week time period was an expected course of the psychotherapy process in “uncomplicated and undistorted grief reaction” (p. 144). Lindemann outlined the psychological tasks that were central to the resolution of bereavement and grief. These tasks included: accepted the pain of the bereavement, reviewing the relationship with the deceased, becoming acquainted with alternations in modes of emotional reaction, accepting the surprising changes in feelings especially the overflow of hostility, expressing sorrow and the sense of loss, finding an acceptable formulation of a future relationship with the deceased, verbalizing feelings of guilt and finding others who can be used as primary support for the acquisition of new patterns of behavior.

The accomplishment of these tasks in the eight to ten sessions described by Lindemann appears to be an overly optimistic and unrealistic therapeutic model. However, it is essential to consider the context of his research, which facilitates an understanding of the limitations of Lindemann’s seminal bereavement and grief research. After the tragic fire, his goal was to help the psychologically and emotionally injured survivors to regain functioning in their lives. His work can be credited as the origin of crisis intervention within the therapeutic context. As the hospital was not equipped to handle the large number of patients injured by the fire, his objective was to aid patients in the re-owning of their strengths and re-entering life with new resources. Perhaps his research more accurately describes the four to six week hospitalization phase of recovery. During this phase of adjustment the patient who immediately after the fire was not capable of coping nor able to function in life

now is able to return home, reenter his/her life, begin to function again and simultaneously manage the grieving process.

With Lindemann's ground breaking work in 1944, it is surprising that the psychological study of grief and bereavement did not receive further attention until the mid-1960s when Elizabeth Kubler-Ross began her project of learning about this process from her dying patients and John Bowlby began studying young children's reaction to temporary loss of mother.

Stages of Grief

In her extensive work with dying patients, psychiatrist Elizabeth Kubler-Ross (1969) observed similar stages that dying patients tended to pass through in coping with and understanding death which she outlined in her popular book, *On death and dying*. Although this model was first used with people who were sick and dying, it was soon realized that individuals followed the same psychological sequence in trying to cope with the loss of a loved one and her phases were soon borrowed by the larger grief community as a tool for describing the grief process. The stages observed by Kubler-Ross, which have become popularly known as the "five stage model of grief," are denial, anger, bargaining, depression and acceptance.

For Kubler-Ross the first stage of denial is a means of protecting oneself from the shock of the loss and a means of keeping the emotional pain at a distance. For a limited period of time denial can be a valuable defense mechanism. Samuel Clemens (a.k.a. Mark Twain) described this defense mechanism poignantly in his autobiography. In the following passage, written ten years after the death of his

daughter, he expresses his amazement at the shock he experienced upon receiving the news of her death:

It is one of the mysteries of our nature that a man, all unprepared, can receive a thunder-stroke like that and live. There is but one reasonable explanation of it. The intellect is stunned by the shock and but gropingly gathers the meaning of the words. The power to realize their full import is mercifully wanting. The mind has a dumb sense of vast loss—that is all. It will take mind and memory months and possibly years to gather together the details and thus learn and know the whole extent of the loss (Neider, 1959, p. 438).

Similarly Anne Morrow Lindbergh writes: “Contrary to the general assumption, the first days of grief are not the worst. The immediate reaction is usually shock and numbing disbelief. One has undergone an amputation” (Lindbergh, 1973, p. 212-213).

The next of Kubler-Ross’ stages is anger. As one begins to understand the reality of the death, an emotional turmoil may be stirred up that manifests itself as anger. Anger is an unavoidable part of the grief process and has been reported by sociologists and anthropologists as a common and frequent aspect of grief. Bowlby (1980) stated that there can be no doubt that “in normal mourning anger expressed towards one target or another is the rule” (p. 29). The bereaved may feel outraged at the unfairness of the loss and may even feel anger towards the person who died for abandoning them. Anger and ingratitude towards those offering comfort is also seen. Bowlby (1980) argued that the griever is looking to others for help—help to regain the person lost. Therefore, “the comforter who takes no side in the conflict between a

striving for reunion and an acceptance of loss, may be of greater value to the bereaved” (p. 92). However, a comforter “who seems to be in favor of acceptance of the loss is as keenly resented as if he had been the agent of it” (p. 92). This is more than the griever’s emotional state can bear.

The role of anger in the grieving process continues to be highly misunderstood. It is often viewed by others as startling, out of place and irrational. Yet when anger is allowed to be openly expressed it can relieve some of the emotional pressure that is an invariable part of grief.

Following the anger stage is the bargaining stage. It is during this phase that people often beg their “higher power” to reverse the loss in exchange for their improved behavior or significant life change. It is a form of emotional negotiation to enable the griever to feel a sense of control.

As the reality of the loss begins to set in, so does the realization that bargaining and anger will not be able to reverse the loss. Grievers may experience feelings of hopelessness in their inability to change the events and a sense of depression sets in. During this phase people often blame themselves for the loss, wishing they had done things differently, often believing that their actions have contributed to the loss. Guilt is a common emotion during the grieving process.

Finally the phase of acceptance is reached. It is during this phase that the individual, having processed all the emotional pain and upheaval, and having accepted the loss as final, can now reinvest in life and plan for the future.

Kubler-Ross’ work was revolutionary, challenging previous theories and practices of death and bereavement. Most importantly, she opened dialogue on a topic

that had been avoided and suppressed. Her work was quickly popularized and was highly regarded by caregivers, the dying and the bereaved. There are, however several limitations to the use of Kubler-Ross' model for those grieving the loss of a loved one. As her work was done primarily with dying patients, generalizing her findings to bereavement does not fully capture the depth of grief work. In fact, applying her model to those who are grieving the loss of someone, versus anticipating their own death, represents a significant departure from the clinical data, and sample, supporting her model. Additionally, many people have misinterpreted her stages as being absolute and linear. It is often forgotten that Kubler-Ross never viewed these phases as linear. Rather, she maintained that "these mechanisms will last for different periods of time and will replace each other or exist at times side-by-side" (Kubler-Ross, 1969, p. 35).

Shuchter and Zisook (1993) remind us that "grief is not a linear process with concrete boundaries but rather, a composite of overlapping fluid phases that vary from person to person. Therefore, stages are meant to be general guidelines only and do not prescribe where an individual 'ought' to be in the grieving process" (p. 23). The potential danger in viewing the stages as linear is that the bereaved will compare their reactions to the "norms," and may then feel that they are not grieving "right." Furthermore, any rigid paradigm does not take into account such factors as type of loss, gender, age and culture. Yet, Kubler Ross' work has been a springboard to a more comprehensive description of bereavement (Cook & Dworkin, 1992), and has strongly influenced the common understanding of grief in our society,

Attachment and Loss

While studying the mental health of young children's response to temporary loss of mother (or permanent mother substitute), John Bowlby, a British psychiatrist, began the formulation of an attachment theory. Bowlby observed that human beings have a tendency to make strong attachment out of a need for security and safety (not simply a need gratifying object as Freud postulated), and when that attachment is threatened or severed, a strong emotional reaction follows (Bowlby, 1969). This emotional reaction, or "attachment behavior," has been defined as "seeking and maintaining proximity to another individual" p. 241).

Bowlby (1969) observed that attachments first begin between child and parent and then continue between adult and adult. Throughout human development, continual attachments to others are formed that "play a vital role in the life of man from the cradle to the grave" (p. 256). Bowlby maintained that if there are attachments then there is inevitable grief. By understanding the nature of the bond that ties a child to his mother we can better understand why loss causes us so much pain (Bowlby, 1980).

Bowlby (1969) hypothesized that grief is an expression of separation anxiety and loss. In *Grief and mourning in infancy and early childhood*, Bowlby (1960), pointed to the "striking similarities between the responses of young children following loss of mother and the responses of bereaved adults (Bowlby, 1980, p. 255) and views attachment behavior in adults to be a 'straightforward continuation of attachment behavior in childhood' (p. 255). Bowlby (1969) stated, "the responses to be seen in infants and young children to loss of mother are, at the descriptive level,

substantially the same as those to be observed when the older child or adult loses a loved figure...the underlying processes are probably similar, both, it was contended required the same description, namely mourning” (p. 317). Additionally, Bowlby stated that an early loss sets up a dispositional pattern of response to all subsequent losses throughout one’s life.

Bowlby (1980) further stressed that there are universal circumstances that will lead an adult’s attachment behavior to become more readily elicited: “In sickness and calamity, adults often become demanding of others; in conditions of sudden danger or disaster a person will almost certainly seek proximity to another known and trusted person. In such circumstances an increase of attachment behavior is recognized by all as natural” (p. 255-256).

Viewing this from an evolutionary perspective can shed more light as to the function of the attachment system. Throughout the course of evolution, instinct develops around the premise that attachment losses are retrievable. Therefore, in an attempt to reinstate the lost relationship the most powerful forms of attachment behavior are activated. Behavioral responses making up the grieving process can be viewed as pro-survival mechanisms geared towards restoring the lost bonds. This instinctual behavior has survival value as it keeps the child in close proximity to the mother for protection from predators. However, in the case of death a permanent loss has occurred and the biological function of assuring proximity to the attachment figure becomes dysfunctional. Yet, if the “urge to recover and scold are automatic responses built into the organism, it follows that they will come into action in response to any and every loss and without discriminating between those that are

really retrievable and those, statistically rare, that are not” (Bowlby, 1979, p. 53). Subsequently, the bereaved wrestle between two opposing impulses: activated attachment behavior and the need to survive without the loved one. With the many studies conducted on primates in this area (i.e. Lorenz, 1963; Tinbergen, 1951; Harlow & Harlow, 1965), it is now well documented that separation and loss give rise to “many forms of emotional distress and personality disturbance (Bowlby, 1979, p. 328) among all social living creatures.

Bowlby’s studies on the nature of attachment behavior and its role in human life have illuminated the many forms of distress including anxiety, anger, depression and emotional detachment that separation and loss give rise to. Focusing on the biological responses to separation and loss rather than the psychological aspects of grief, Bowlby was the first to offer a functional interpretation of aspects of grief such as searching for the lost person, the feeling of the presence of the deceased, or anger about having been deserted (Stroebe & Stroebe, 1987). Bowlby’s research has played a significant role in guiding contemporary bereavement research, for understanding grief and grieving and, for helping to pave the way for subsequent bereavement research (Stroebe & Schut, 2001). Stroebe (2002) asserts that “...attachment theory is the most powerful theoretical force in contemporary bereavement research...” (p. 127).

Dimensions of Grief

Colin Murray Parkes (1970) began a longitudinal study of 22 London widows’ psychological reactions to bereavement. His study confirmed Bowlby’s belief that grief is a process not a state and that transition from one phase to another is

seldom distinct with features from one phase of grief often persisting into the next. In collaboration with Bowlby, he went on to develop four dimensions of the mourning process: shock and numbness, yearning and searching, disorganization and despair and reorganization.

Parkes' first phase of grief is shock and numbness. As the shock and numbness begins to dissipate and the reality of the loss starts setting in, the yearning and searching phase begins. Bowlby and Parkes found that "the most characteristic feature of grief is not prolonged depression but acute and episodic "pangs"" (Parkes, 1972, p. 39). A pang of grief, or pining is an intense yearning for the dead person. Parkes (1970) and Parkes and Prigerson (2010) suggest that the pining or yearning that constitutes separation anxiety is the characteristic feature of the pang of grief. At such a time the lost person is strongly missed and the survivor sobs or cries aloud for him or her. Parkes defines pining as a "persistent and obtrusive wish for the person who is gone, a preoccupation with thoughts that can only give pain" (Parkes, 1972, p. 40). A preoccupation with the deceased can include memories of the deceased voice or touch, and clear visualization of the deceased as he appeared when alive. Several of the widows in Parkes' study recounted experiencing a visualization of their deceased husband in their usual place in the room. Others spoke of their memories being so intense as to amount to a perception.

As to why we would experience such a useless and unpleasant emotion, Parkes (1972) explained that pining is the "subjective and emotional component of the urge to search for a lost object" (p. 40). It is common for the bereaved to feel drawn toward places that are in some way connected to the bereaved. One woman explained

how she could only leave her home for a short time before she felt the strong need to return home—the place her husband died. As Parkes explained, “the commonest means of mitigating the pain of grieving comprises the maintenance of a feeling or impression that the bereaved person is nearby although they may not be seen or heard” (Parkes, 1972, p. 72).

Although the mind and heart have a sense that the object of the search is no longer available, instinctively we still search for the lost object. Author Pearl Buck, shortly after the death of her husband, described her undeniable urge to search for him: “...was he still hovering about the house at, the essence of himself, and were I there would I perceive his presence?...I fought off the mighty yearning to go in search of him wherever he was. For surely he was looking for me, too. We were ill at ease, always when apart. But where are the pathways?”

Parkes (1979) stated that without the presence of pining and preoccupation with thoughts of the deceased “grief cannot truly be said to have occurred and when present it is a sure sign that a person is grieving” (p. 72). There is no clear end-point to yearning, and one can experience pangs of grief many years after a loss.

Anger is another component frequently evident during this phase. It can be aroused by those held responsible for the loss as well as by frustrations at fruitless searching (Bowlby, 1980). From an evolutionary perspective anger is both usual and useful when separation is only temporary. It helps in overcoming obstacles to finding the lost person and once reunited with the lost person, by reproaching whoever was responsible for the separation making it less likely that it will happen again. Since irretrievable loss is statistically rare it is not taken into account by evolutionary

forces. Therefore, anger can be “seen as an intelligible constituent of the urgent though fruitless effort a bereaved person is making to restore the bond that has been severed” (Bowlby, 1980, p. 91).

During the next phase, disorganization and despair, “there is painful repetitious recollection of the loss experience, which is the equivalent of worry work and must occur if the loss is to be fully accepted as irrevocable” (Parkes, 1979, p. 77).

Only if the bereaved

can tolerate the pining, the more or less conscious searching, the seemingly endless examination of how and why the loss occurred, and anger at anyone who might have been responsible, not sparing even the dead person, can he come gradually to recognize and accept that the loss is in truth permanent and that his life must be shaped anew. In this way only does it seem possible for him fully to register that his old patterns of behavior have become redundant and have therefore to be dismantled (Bowlby, 1980, p. 93).

In *A grief observed* (1961), C.S. Lewis reflects on his experience of bereavement following the untimely death of his wife from cancer:

I think I am beginning to understand why grief feels like suspense. It comes from the frustration of so many impulses that had become habitual. Thought after thought, feeling after feeling, action after action, had H for their object. Now their target is gone. I keep on, through habit, fitting an arrow to the string; then I remember and I have to lay the bow down. So many roads lead through to H. I set out on one of them. But now there's an impassable frontier-post across it. So many roads once; now so many cul-de-sacs (p. 47).

Finally, the phase of reorganization in which “there is the attempt to make sense of the loss, to fit it into one’s set of assumptions about the world (one’s ‘assumptive world’) or to modify those assumptions if need be” (Parkes, 1979, p. 77). Parkes (1972) understood that grief “is a process of realization, of making psychologically real an external event which is not desired and for which coping plans do not exist.”

Parkes developed a description of the phases of grief and is responsible for extending concepts of attachment theory to empirical research within the area of bereavement (Stroebe & Schut, 2001) and beginning a sounder empirical basis for describing grief (Archer, 1999). Parkes’ greatest contributions can be attributed to the fact that he began the arduous task of investigating variables that affect the nature and course of grief (Archer, 1999).

Tasks of Grieving

In *Grief counseling & grief therapy*, William Worden (1982, 2009) was the first to suggest how to have a therapeutic conversation with a bereaved person. He suggests that there are four tasks of mourning that are necessary for the bereaved to accomplish if equilibrium is to be reestablished and for the process of mourning to be completed. Since mourning is a process and not a state, and following Freud’s example of “grief work,” Worden’s tasks are not passive, rather they require effort and is consistent with the reality most griever report (Stroebe & Schut, 2001).

Worden picks up where Kubler-Ross left off, with acceptance being the first task the bereaved must accomplish. In this task we hear echoes of Freud’s influence in that the bereaved are required to defer to the “reality of the loss.” It is only after

one accepts the loss that true grieving can begin. Once the finality of the loss is accepted, the next task is to work through the pain of grief. Gradually and over time the deep sadness of grief must be accepted. The focus of this task is not on working through or resolving the pain, but rather on enduring the pain and sadness.

Preoccupations with the deceased along with daily reminders of the deceased serve to heighten emotional pain, making this an extremely difficult task to complete.

Commonly felt emotions and experiences during this task (which is similar to Parkes' phase of protest and yearning), include sadness, anger, guilt, anxiety, regret, social withdrawal, insomnia, transient auditory and visual hallucinations of the dead person, restlessness and searching behavior. Society either encourages or condones expressions of grief and completion of this task can be made more difficult when the griever is not given permission by society to openly grieve.

The third of Worden's tasks is to adjust to an environment in which the deceased is missing, a task that is subjective to the bereaved. The realization of what exactly has been lost and the changes that result in one's life as a result of the loss is not always clear and may not be fully realized for years.

Worden's fourth task has had an evolution. In 1982 in the first edition of his book the fourth task is to withdraw emotional energy from the deceased and reinvest it in another relationship. In this way he was embracing the Freudian idea of withdrawal of energy in order to form new relationships. In 1991 in the second edition of his book the fourth task is to emotionally relocate the deceased and move on with life. Finally in 2009 and congruent with the newer understandings of bereavement the fourth task is to find an enduring connection with the deceased in the

midst of embarking on a new life. The change Worden made allows for the possibility of a continued relationship with the deceased in the emotional lives of the bereaved as opposed to withdrawing emotional energy which rings of Freud's notion of hypercathexis (detaching libidinal energy from the diseased loved one).

Stroebe and Schut (2001) suggest additional tasks that need to be performed such as working toward acceptance of the changed world, not just the reality of the loss. The subjective environment itself needs to be reconstructed. Additionally, they point out that bereaved people work toward developing new roles, identities, and relationships, not just relocating the deceased and "moving on."

Again it is important to note that not all griever undertake these tasks and not in a linear order. However, Stroebe and Schut (2001) suggest that completion of the work associated with each task should facilitate adaptation. Yet there is an implicit "time" dimension in this formulation that suggest different coping tasks are appropriate at different durations of bereavement. Although Stroebe & Schut (2001) argue that this may be useful in making predictions about adaptive coping, putting times and durations into expected grieving processes can leave the bereaved feeling like they are not grieving "right."

Continuing Bonds

In their research and clinical interviews with families who had experienced a significant death, Klass, Silverman and Nickman (1996), editors of *Continuing bonds: New understandings of grief*, realized that they were observing a phenomenon that could not be explained by existing models of grief.

Rather than observing a stage of disengagement, which we were educated to expect, but rather, we were observing people altering and then continuing their relationships to the lost or dead person. Remaining connected seemed to facilitate both adults and children's ability to cope with the loss and the accompanying changes in their lives. These "connections" provided solace, comfort and support, and eased the transition from the past to the future... We also observed that there was little social validation for the relationship people reported with the deceased or absent person (p. xviii).

This led them to propose a new model of grief based on the mourner's continuing bonds with the deceased. The continuing bonds model "challenges the idea that the purpose of grief is to sever the bonds with the deceased in order for the survivor to be free to make new attachments and to construct a new identity" (p. 22). Rather their research suggests that "resolution of grief involves continuing bonds that survivor's maintain with the deceased and that these continuing bonds can be a healthy part of the survivor's ongoing life" (p. 22). Klass et al., propose "that rather than emphasizing letting go, the emphasis should be on negotiating and renegotiating the meaning of the loss over time. While the death is permanent and unchanging the process is not" (p. 19).

Bowlby (1973) was the first to introduce the concept of internalized models and suggested that it is through internalized models of the external world that attachments are maintained. In using the idea of internal models to explain attachment, Bowlby has opened the door to other issues of internalization of relationships and was the first to draw attention to the inner representation of

significant others in the survivor's psychic world. These representations may continue to play an important role in the survivors' psychic life. Bowlby argued that "failure to recognize that a continuing sense of the dead person's presence, either as a constant communion or in some specific and appropriate location, is a common feature of healthy mourning has led to much confused theorizing" (p. 100).

Bowlby (1973) maintained the high prevalence of a continuing sense of the dead person and its compatibility with a favorable outcome gave no support to Freud's hypothesis that for grief to be successfully resolved one had to detach memories and hopes from the dead. He further states that, "the resolution of grief is not to sever bonds but to establish a changed bond with the dead person" (p. 399). Klass (1988) suggests that identification—or something like what Freud was trying to describe with the term identification—is an aspect of normal grief. This is in the Bowlby's group data but is not adequately accounted for in their theory.

Contemporary research continues to find that we don't detach from our loved ones after they die; rather we perceive them differently and continued emotional connection to the deceased may continue indefinitely. Therefore, rather than encouraging the bereaved to detach from their lost loved one, they must be helped to find an appropriate place for the dead in their emotional lives which will enable them to maintain an attachment while continuing to live effectively in the world. In this way the dead may be assessable in the present and even in the construction of a future (Klass, 1988).

In earlier periods in western societies continuing bonds with the deceased was common; a practice that remains well accepted outside of western cultures and is a far

more common pattern than is severing the bonds with the dead (Arnason, 2012; Bonanno & Kaltman, 1999; Klass et al., 1996; Klass & Walter, 2001). Schuchter & Zisook (1993) maintain that continuing bonds appears to be both universal and essential with several features of grief, especially those related to attachment behaviors, continuing years after a loss. Research appears to indicate that “some aspects of grief work may never end for a significant proportion of otherwise normal bereaved individuals,” with many maintaining “a timeless emotional involvement with the deceased and that this attachment often represents a healthy adaptation to the loss of a loved one” (p. 94).

The empirical reality is that people do not relinquish their ties to the deceased, nor do they let them go. Shuchter and Zisook (1993) describe the changed bond as a transformation or a shift “from what had been a relationship operating on several levels of actual, symbolic, internalized, and imagined relatedness to one in which the actual living and breathing relationship has been lost, but the other forms remain or may even develop in more elaborate forms” (p. 34). Attig (1996) asserts that “death does not end our caring or our loving but is compatible with our continuing and transforming our care and our love” (p. 170). By incorporating the deceased and what they cared about in their daily lives, the bereaved “re-interpret several aspects of (their) experiences as survivors, finding a way to love the deceased without their physical presence, helping this pain to carry less of a pervasive aspect in their lives” (p. 187).

With the understanding that we are psychologically incapable of relinquishing all of the bonds that are a part of our most intimate relationships, a revised definition

of “acceptance” is needed. This new definition must include the idea that the bereaved individual is “emotionally prepared to live with an altered relationship with the deceased which will be sustained by ongoing contact and communication, dreams, memories, and living legacies” (Schuchter & Zisook, 1987, p. 181). This is not to suggest that one is living in the past. Klass et al., (1996) point to the “paradox of letting go and remaining involved” (p. 351); the bond will shift and change over time. Shapiro (1996) states that, “grief is resolved through the creation of a loving growing relationship with the dead that recognizes the new psychological or spiritual (rather than corporeal) dimensions of the relationship” (p. 552).

Rather than using words such as recovery, resolution or closure, to refer to this process, Klass et al. (1986) use the term “accommodation” a concept they believe better captures the experience of the bereaved. Accommodation “does not disregard past relationships, but incorporates them into a larger whole. In this process, people seek to gain not only an understanding of the meaning of death, but a sense of the meaning of this now dead or absent person in their present lives (p. 19).” The varieties of the continuing relationship with the deceased has also been examined (Rubin & Shechory-Stahl, 2013-2013).

Arnason (2012) suggests that “presence” is the key word in the continuing bonds thesis in that it is the experiencing subject who experiences the presence of the deceased. He writes, “It is the continuing presence of the deceased in the lives of the living that calls for the idea of continuing bonds. It is the experience of the living of that presence which is the crucial point” (p. 66). Arnason asserts that “the continuing bonds thesis offers a markedly different perspective. It considers also the relations

between people but emphasizes the impact these relations have upon individual persons” (p. 66).

Meaning reconstruction

Robert Neimeyer (2001) argues that reconstructing a world of meaning is the central process in grieving and is an aspect of the grief experience that cannot be explained by existing theories of grief. Models of meaning reconstruction or meaning making have their roots in constructivist thought which views individuals as creating their own reality through the meanings they find within their lives. Constructivism posits an individual’s reality is organized through how he/she makes sense of his/her experiences, perceptions, and narratives (Neimeyer, 1999). Grief is a disruption of attachment that involves relearning the self and the world (reconstructing meaning).

We are meaning-seeking and meaning-making creatures. The death of a loved one can create a loss of meaning for living and the shattering of one’s fundamental assumptions about life (Janoff-Bulman, 1992). How we react to loss depends on the meaning we attribute to the loss and the meaning of life without the deceased. In order to move forward, we have to find a way of reconstructing our meaning systems in order to adapt to an altered set of realities. In *Man’s search for meaning* (1939), Victor Frankl writes: “Suffering ceases to be suffering in some way at the moment it finds meaning” (p. 179). Frankl argued that “man’s main concern is not to gain pleasure or to avoid pain, but rather to see a meaning in his life. That is why man is even ready to suffer, on the conditions, to be sure, that his suffering has a meaning” (p.179). When we are confronted with hopeless situation which we cannot change, we are challenged to change ourselves. Meaning must be discovered by each individual.

Finding meaning in loss is a complex and paradoxical process. Ross (1988) argues that the “response to the meaning of the death—and thus also the meaning of life—may affect the course of mourning. It is contended that for some bereaved individuals, the ongoing involvement with these issues of meaning may result in a deeper richer way of being in the world, despite the additional anxiety and discomfort that may accompany such intense searching” (p. 309). Harvey (1996), asserts that “the key to trying to transform losses into something that is positive is the hard work of the mind and spirit to give our losses meaning and to learn and to gain insights from them, and to impart to others something positive based on the experience” (p. 3). Attig (1996) maintains that we both discover and invent new meaning in the face of the loss.

Gillies & Neimeyer (2006) attribute three activities that are involved in meaning reconstruction: sense making (the process of finding or creating a sense of understanding regarding a loss), benefit finding (the creation of meaning structures that underscore positives resulting from a loss), and identity change (the positive or negative reconstruction of self). Sense making and benefit finding are two separate aspects reported by bereaved individuals which indicate how adaptation to loss can transform over time.

Research suggests that sense making and benefit finding may facilitate the process of growth or positive transformation in the wake of loss (Nolen-Hoeksema & Christopher, 2002). Additionally, research has shown that individuals who are successful in finding meaning do not put the issue aside and move on. Rather, they continue to search for meaning as intensely as those who search but have not found

meaning (Davis, Wortman, Lehman, & Silver, 2001). Meaning reconstruction also encompasses some different possibilities. It can incorporate the ways in which the deceased loved one might continue to be a part of the lives of the bereaved

Narrative Approach to Grief

Robert Neimeyer (2001) argues that the grieving process is one of reconstructing meaning in one's life that makes sense of the past and lays a foundation for the future. This process is accomplished through the telling and re-telling of the narrative of the shattering event of the death and serves as a means of facilitating the "reauthoring of the self in the wake of loss" (p. 175).

Narratives, or life stories, are stories that people use to make sense of their lives by telling a story that makes sense of their past and present experiences. Narrative therapy suggests that our lives are organized by the stories we tell ourselves and others. These stories give structure and meaning to our experiences. Each individual has a unique life story that proves him/her with an identity. Matthews & Marwit (2006) state that, "narrative provides a thread of continuity to one's experience, and a sense of coherence to one's evolving identity" (p. 9).

People are constantly revising their narrative in response to new experiences (Gilbert, 2002); our stories are fluid and may be revised to reflect new experiences and new meaning. Janoff-Bulman (1989) asserts that painful life experiences can disrupt one's self narrative and can shatter one's assumptive world. Bereavement often forces individuals to "restructure and rebuild previously held assumptions about the self and world" (Matthews & Marwit, 2006, p. 87). Narratives help people make

sense of this new world by allowing the individual to attribute meaning to his/her life by “reauthoring” it in a preferred direction (Ramanoff, 2001).

Parkes (1971) was the first to introduce the idea of an assumptive world into the area of bereavement. He describes our assumptive world as “our interpretation of the past and our expectation of the future, our plans and our prejudices” (p. 102). Janoff-Bulman (1989) took this idea further and explores what happens to a person’s “assumptive world” in the face of traumatic loss. She explores the question of how an individual copes with the shattering of his/her assumptive world. Matthews & Marwit (2006) write, “traumatic events violate our internal guides and shatter our fundamental assumptions about the world and ourselves—assumptions containing benevolence, meaning, and self-worth—which gives us a sense of immunity to such trauma” p.91). Although most of us are aware that bad things happen to people, we operate with the belief that it won’t happen to us. A traumatic loss “interrupts our understanding of the universe as well as our role in it, we struggle to make sense of a seemingly senseless event and construct a new and modified identity—one that incorporates the loss, and the over whelming feelings of grief that bereavement brings with it” (p. 91).

The re-authoring of one’s life story or narrative reconstruction is an attempt to make real what has happened and to understand it. Through the telling and re-telling of the story of the deceased as well as of the survivors, it enables the living to integrate the dead into their lives. Thus, the task of the griever is to “re-establish his/her constructions of the self and his/her world in light of the death” (Matthews & Marwit, 2006, p. 91). Attig (1996) states that the bereaved continues to love the

deceased, not as a fixed memory but as someone who has the power to move and motivate them. Attig proposes that the bereaved achieve this by re-telling and reviewing the stories shared, constantly reinterpreting the value and meaning they give.

Neimeyer (1999) suggests several narrative strategies for bereaved individuals struggling to reconstruct meaning following a loss: writing epitaphs, journaling, acknowledging how the deceased influenced their lives, and writing poetry to express the experience of grief. In the following passage one mother speaks of both her need and the benefit of telling and re-telling the story of her daughter's untimely death:

My daughter was a normal, healthy young lady, looking forward to becoming a teenager. Then, a strange sensation appeared in the muscle of her upper arm and everything changed! She waged the toughest battle of her life, but died of cancer in the middle of her thirteenth year. How does a mother cope with so tragic a loss? I told and retold the story. I talked about how we faced the chemo, the pain, and the fear together, about the fun we had, about the impact on our family, about the final days on the wish trip, about her death, about her friends, about the support of our faith community. I shared with all who would listen and, gradually, the story telling helped me to make sense of things, to cope with the gaping hole in my world, to find a new normal for myself, to move on. My daughter still lives—in eternity, in my memory, in the life I live as a result of having been her mom for those thirteen and a half years, and in the stories – hers, mine ours (Bosticoo & Thompson, 2005, p. 1).

Stories may also serve a cathartic function for individuals. Many bereaved individuals have indicated that talking and going over events helped get them through the effects of the loss. To quote one bereaved mother, “Each time I tell my story it occupies less space and grief in my soul” (Bosticco, & Thompson, 2005, p. 5). “Our stories inform our lives and our lives, in turn, are shaped by our stories. We need to create stories to make order of disorder and to find meaning in the meaningless” (Gilbert, 2002, p. 236).

Dual-Process Model

The Dual-Process Model (DPM) of grief distinguishes between the two major types of stressors associated with loss, loss-oriented versus restoration-oriented, and views the resolution of grief as being derived from the oscillation between these two processes (Stroebe & Henk, 2010; Stroebe & Schutt, 1999). Stroebe and Schut (2001) maintain that rather than being a new model the DPM is an attempt to integrate existing ideas. Incorporated into the DPM as its basic dimension is the tension between approach and avoidance (Archer, 1999), thus affirming that the griever benefits from dealing with both types of stressors concurrently or oscillating between them.

Loss-oriented stressors are the approach part of the DPM and are focused on confronting and processing the loss. While the bereaved focus on loss-oriented stressors they are more likely to engage in processing and expression of strong emotions related to loss. The focus of attachment theory on the nature of the lost relationship would be consistent with this (Stroebe & Schut, 2001). This “grief work” involves the need to face the grief, confronting stimuli and thoughts associated with

the loss, emotionally relocating the deceased and finding meaning in the loss. It incorporates rebuilding of assumptions about the presence of the lost person in one's life.

By contrast, restoration-oriented stressors are concerned with the secondary stressors that are an indirect consequence of the loss. It concerns the way in which the person copes with other daily aspects of his or her life both present and future organizations of their life. It may also serve as a distraction from and avoidance of grieving (Stroebe & Schut, 1999). Both processes require a rebuilding of aspects of one's life. Stroebe et al., (1999) state that "restoration incorporates the rebuilding of shattered assumptions about the world and one's own place in it, just as loss-orientation incorporates rebuilding of assumptions about the presence of the lost person in one's life" (p. 5).

The DPM challenges the grief work hypothesis belief that the only means of recovery from or resolution of grief is by confronting the thoughts and feelings about the loss (Archer, 1999). At times it may be necessary to actively avoid thoughts and feelings associated with the loss, to deny aspects of it and to distract oneself from loss-related thoughts (Stroebe & Schutt, 1999). Following this model, "avoidance and mitigation are seen not merely as defenses against psychological pain but as ways in which people are able to maintain essential activities and to restructure aspects of their lives" (Archer, 1999, p. 105).

At the core of the DPM is the argument that the oscillation of coping between the two types of stressors is "the single central process in adaptive grieving (Stroebe,

et al., 2005, p. 5). Empirical studies seem to indicate that too much confrontation or too much avoidance is detrimental to adaptation (Stroebe & Schut, 2001).

Although Stroebe and Schut (2001) have shown the benefits of oscillating between the two major stressors of the mourning process it is important to point out that for the bereaved there are few activities that are engaging enough to be a distraction from loss-related thoughts and emotions which are all encompassing and thus require a great effort if one is to be distracted from the influence of the loss. The establishment of a new relationship of the same type, such as remarriage, may be one situation that is a great enough distraction to help the process. This fits in with the DPM but would not help the process of resolution according to the grief work view (DeSpelder & Strickland, 2010).

Two-track Model

The Two-track model of coping with bereavement first proposed by Simon Shimshon Rubin (Rubin, 1981; Rubin et al., 2012), views bereavement as a function of two distinct yet inter-related processes: the bereaved's functioning and the bereaved's relationship to the deceased. The process of adaptation to bereavement is linked to the disruption in and the achievement of new levels of homeostatic function as well as the disruption in the relationship to the deceased which also requires reorganization. When considering bereavement from both functional and relational aspects the analysis of personality function can be separated from the object attachment aspects of the bereavement process (Rubin, Malkinson & Witztum, 2000).

The first process, which Rubin labels track-one, is concerned with the individual's level of functioning in daily activities. It is broken into nine sub-areas:

self-esteem, familial, interpersonal, somatic, depression, anxiety, meaning structure, psychiatric symptoms, and investment. The processes involved in this track are fundamentally similar to responses individual's experience when faced with situations of crisis, trauma, and stress. However, in situations of crisis, trauma and stress that do not involve the death a significant other, there is obviously no concern with the issue of the bond to the deceased and its meaning for recovery from loss. Therefore, the degree of change and difficulty regarding one's relationship to the deceased following loss are assessed in their own right in track-two as "a significant and independent feature of the outcome to mourning and loss" (Rubin, 1996, p. 216).

The nine sub areas of track-two, considers the quality of the ongoing relationship to the deceased and how it continues to affect the griever (Rubin, 1996). Notice that it is not whether there is an ongoing relationship with the deceased that is of interest, for that is a given, rather, Rubin argues, "it is the nature and place of that relationship in the inner and outer worlds of the survivors that deserve our attention" (p. 230).

From an object relations perspective, the internal representations of others, although based in reality, are also influenced by internal object schemata. It is these internal representations that affect the perceptions and interactions of the individual. However after the death of a significant person present and future interactions in the real world come to an end between the living and the deceased; further interaction with the deceased person and the living exists solely in the realm of the internal world of the bereaved. Additionally, the representation of the deceased in the world of the bereaved person affects their self-perception, affective functioning and psychological

well-being. In an effort to manage the internal equilibrium of the individual's self-image, memories and past relationship are being continually reworked at both conscious and unconscious levels.

In thinking about the terms “recovery “ and “resolution” which are often used with regards to bereavement, the Two-track model sees the term recovery as an adequate term when being used to assess the first track, that of functioning. However, along the second dimension of the continuing relationship to the deceased, the term resolution may be a more precise one. Indeed, labels such as “resolution” or “completion” of grief are deemed inappropriate (Stroebe, Hanson, Strobe, Schut, 2001). If recovery means returning to the former state or the pre-crisis state, then an individual affected by trauma may never recover. If an individual affected by trauma are expected to return to their pre-crisis state a paradox is immediately established for the one thing the individual affected by trauma frequently cannot do— that is, to return to how things were—neither in a practical or physical sense, nor in an emotional or psychological sense.

It is becoming clearer that bereaved individuals do not “recover,” “get over their loss” or “get back to normal” but rather adapt and adjust to the changed situation. They do not return to their pre-loss state. It is therefore important that researchers and clinicians understand that the coping tasks for the bereaved may not be to return to previous levels of functioning. Rather the goal may be to negotiate a meaningful life without the deceased. This may include important and enduring changes as a result of the loss. Rubin et al., (2000) emphasize that there are varying degrees of adjustment, coping and continued relationship to the representations of the

deceased “which can be neither fixed nor static” (p. 29). Therefore it is important to remember that both recovery and resolution range across the continuum.

Integrative Biopsychosocial Model

Individual reactions are clearly dependent on a myriad of factors including preexisting personality traits, developmental level of the bereaved, the nature of the relationship with the deceased, mode of death, perceived social support and previous and concurrent stressors. Although grief reactions share many similarities, each individual’s grief reaction is as personal as his/her fingerprint and “bears the individual’s own idiosyncratic stamp of personhood” (Harvey, 1996, p. 47). To limit explanations to those of a single discipline would not allow for the full understanding of the complex nature and experience of bereavement. It is only through an understanding of the interactions of the biological, psychological and social factors that a richer and deeper understanding of the grief process can be realized.

Rubin et al., (2000) stress that:

Individuals bereaved of a close relation are always products of a unique life track. To do even rudimentary justice to the complex of background variables involved, would require one to address characteristics of personal history, sex, age, culture, coping styles, personality traits, meaning structures, support systems, together with variation in physical and emotional situational variables. Each of these variables functions as an intervening variable that impacts upon the course of the bereavement response. The type of relationship to the deceased prior to death, the causes and circumstances surrounding the death, also influence the experience of loss and the type of mourning process

that an individual will experience along the way toward recovery from loss (p. 29).

Researchers propose adopting strategies that encourage the integration of discoveries rather than the proliferation of isolated findings and approaches. The beginnings of such an approach can be seen with the Two-track model and the Dual-process model. Shaver & Tancredy (2001) argue that rather than counter observations, researchers should work towards finding a way they all eventually can be incorporated into a single theoretical framework.

The Unique aspects of parental bereavement

Parenting is a permanent change in the individual. A person never gets over being a parent. Parental bereavement is also a permanent condition, for the death of a child is the death of a part of the self (Klass, 1988, p. 178).

The death of a child is traumatic for parents regardless of the cause of death. It is the violation of the natural expectations that parents can protect their children and that children will survive their parents which presents bereaved parents with one of the most difficult aspects in parental bereavement. Rando (1987) asserts that such violations contribute to this grief being the most severe and complicated ever to be documented. It is a grief that cannot be adequately understood nor responded to in terms of the general conceptualizations that are held for grief and mourning.

In *The year of magical thinking*, Joan Didion chronicles her grief after the sudden death of her husband. Two years later her daughter died. In an interview she states that the grief over the loss of her daughter “is a whole different level of

loss.....I recognize little things like that as being part of the process, but on the other hand, it's a whole different level of loss" (Van Meter, 2005).

Dennis Klass (1988), a researcher in the field of grief and bereavement, was asked to be the professional advisor to a chapter of Compassionate Friends, a self-help group for bereaved parents. Bringing knowledge and experience of the bereavement process he was, however, unprepared for what he experienced: "clearly here was a grief that had a different quality from what I had seen before" (p. xii).

This experience led him to begin an in-depth exploration of the dynamics of parental bereavement. Through the many interviews he conducted with mothers and fathers who lost a child from various causes and ages he observed that the death of a child creates two disequilibria: "First a disequilibrium between the self and the social world, for the death of a child radically changes the social environment in which the parent lives. Second there is a disequilibrium in the inner life of the parent, for the child who died was part of the parent's self" (Klass, 1988, p. 18). Klass argues that the resolution of parental bereavement is achieved when bereaved parents reach new equilibria in these two areas.

Each child has a unique place in the inner life and in the self organizing structure of the parent's own development. Shapiro (2001) observes that a lost child is mourned by a parent in a way that reflects aspects of the self invested in that particular child: "aspects of the self that were invested in the child are suddenly, abruptly, lost to the self and need to be reintegrated into the self or into new relationships" (p. 190). Shapiro suggests that grieving is a lifelong process of learning to manage and negotiate in life without this vital part of oneself, which cannot be

replaced. The raw wound may heal in some fashion, but the scar and emptiness of missing the child who is lost is forever present.

Klass (1988) asserts that the child is part of the psychic structure of the parent, and when a child dies the self itself needs to be redefined. A consistent theme expressed by bereaved parents is that something about themselves has changed. They are not the same person they were before their child died. Klass observed that as bereaved parents “reconstruct their model of the self, so too they reconstruct their way of interacting within the social environment” (Klass, 1988, p. 18). Klass asserts that a positive resolution to parental grief is not a return to how life was before.

Rather,

the changed social self and the internalized inner representation of the child are provisions for a new self that is different from the self the parent knew before the child died. The resolution of parental bereavement is not a return to the status quo ante. The resolution of parental grief is found in the development of a new self. The new self, with its new social interactions and its new sources of solace, learns to live in a world made forever poorer by the death of a child (p. 180).

Chapter III

Methods

Qualitative research methods were used in this study to explore the experience over time of mothers who had a young child die from cancer ten or more years ago. The research aims to develop a deeper understanding of key themes in the long term sequela of child loss. This chapter will discuss the use of qualitative methodology and its appropriateness for exploring sensitive phenomenological issues of maternal bereavement. Criteria for recruitment, the interview questions, data analysis procedure and ethical considerations will also be discussed.

Research Design

This study used qualitative research methods in order to obtain more in-depth and rich data to explore the experiences and needs of mothers who had a young child die from cancer ten or more years ago. Grounded theory is a specific method of qualitative research and the method used for analyzing the data. Grounded theory emerged in the 1960s as a result of Glaser and Strauss's sociological research study on dying hospital patients (Corbin & Strauss, 2008). Through their work they created a method that allowed the researcher to systematically generate theory "grounded" in empirical data (Chamaz, 2010; Glaser, 2011; Glaser & Strauss, 1967). Strauss and Corbin (1998) state that "the researcher begins with an area of study and allows the theory to emerge from the data" (p. 12).

Creswell (1998; 2007) defines qualitative research as an "inquiry process of understanding based on distinct methodological traditions of inquiry that explore a social or human problem. The researcher builds a complex, holistic picture, analyzes

words, reports detailed views of informants, and conducts the study in a natural setting” (p. 15). There is an emphasis on the subjective aspects of people’s behavior. Glaser (1992) insists that “the theory must respect and reveal the perspective of the subjects and not that of the researcher” (p. 17).

Corbin and Strauss (2008) assert that qualitative methodologies allow researchers to immerse themselves within the “inner experience of participants to determine how meanings are formed through and in culture” (p. 12). The use of a qualitative method for the collection of rich interview data makes possible a deeper understanding of the individual’s inner experience. These qualities make this method of study particularly conducive to investigations of parental bereavement, an inherently deep and highly sensitive “lived experience” (Padgett, 1998).

Without manipulating or controlling variables, an inductive approach to data analysis is used to produce theories, rather than an attempt to prove or disprove any particular hypotheses. Through a systematic analysis and synthesis of subjective, experimental data, theoretically based constructs can be generated. With its “idiographic outlook” (Issac & Michael, 1997, p. 218), qualitative inquiry is an appropriate method for discovering emerging categories, themes, and relationship that result from a particular phenomenon and is an appropriate research method for exploring sensitive phenomenological issues of maternal bereavement.

Neimeyer and Hogan (2001) suggest that applying qualitative research to the study of bereavement adds a greater understanding of the breadth and depths of the grieving process. They assert that qualitative approaches such as grounded theory and case study, “are better positioned to introduce novelty, scope and depth to the study of bereavement” (p. 113). Capturing and interpreting the narratives told by mothers in a natural and richly

detailed manner offers the most genuine source of information, and may lead to more accurate understandings of how professionals can best support bereaved mothers.

They further suggest that “if used creatively and critically, qualitative approaches can help suggest more trenchant theories of bereavement, which can then be tested and refined using more precise quantitative methods” (p. 113).

Participants

Inclusion criteria for the study required that participants be the mother of a young child who died from cancer, the child’s death must have occurred ten or more years ago and the child who died must have been between the ages of 4–13 at the time of their death.

Those excluded from the study included mothers who had a young child die of causes other than cancer; mothers whose child was not between the ages of 4–13 at time of their death; and mothers who had a child die less than ten years ago.

Measures

Two instruments were developed by the principal investigator as the primary method of data collection used in this grounded theory study. First, a brief demographic and basic information questionnaire (Appendix A) was formulated that asked each participant to provide the following information: current age, race/ethnicity, religion, education, profession, years married, age of child at diagnosis, age of child at time of death, name of illness, length of illness, number of other children at time of death, other children born after the death. Second, a semi-structured interview (Appendix B) consisting of a series of open-ended prompt questions was developed to encourage elaboration in response to the experience over time of having a child who died from cancer.

Procedure

Recruitment of Subjects. Participants were recruited through a network and convenience sample. Initially, the researcher contacted mothers known to the researcher who have experienced the loss of a child to cancer. These mothers were then asked if they knew of other mothers that they might recommend for the study (snowball sampling.) Interested participants were given the researcher's phone number and e-mail address. Interested participants contacted the researcher via e-mail. When eligibility was confirmed (child died of cancer and was between the ages of 4-13 and the loss occurred over 10 years ago), participants were sent a brief description of the study and an informed consent (Appendix C) which was signed and sent back to the principal investigator. Once the signed informed consent was received by the principal investigator participants were contacted via e-mail to schedule a convenient time for the interview.

Data Collection. Data were collected through the demographic questionnaire and semi-structured interviews. Interviews were conducted by phone or SKYPE with all participants being in their home in a place they determined to be comfortable and private. The interview began with a list of demographic questions (Appendix A) which included age, years married, illness child died from, age of child at time of death, other children at home at time of death, occupation, level of education and other children born after death and length of illness. This then flowed into the semi-structured interview (Appendix B). The interview was comprised of open-ended questions about participants experiences over time of having a young child die of cancer. The interviews were generally between one and half hours and two hours in

length. Participants were given the option to withdraw at any point in the study, but all eight completed the study protocol. No adverse effects were reported by any participants during or after the interview. Interviews were audio taped to contribute to the authenticity of the study. The principal investigator transcribed all the interviews. Each participant was assigned a pseudonym which was the only identification used on response materials. No identifying information was attached to the transcriptions or audiotapes. Consent forms were kept in a separate locked file from the interview data collected. All audio recordings, interview transcripts, and other data collected from the participants will be maintained in confidence by the investigator in a locked file cabinet for seven years after the completion of the study. After seven years, the principal investigator will destroy all research material.

Data Analysis. Grounded theory methodology was used to analyze the data (Charmaz, 2006; Glaser & Strauss, 1967; Richards & Morse, 2013; Silverman, 2010). Each interview was audio recorded and then transcribed verbatim. Each transcript was read one or more times to develop a sense of the overall context of the data. The interviews were then coded (or categorized) in three phases: open coding, axial coding, and selective coding.

The initial phase (open coding), entailed the generation of codes (or categories). Interviews were coded using a line-by-line level of analysis in which individual responses were coded into more concise statements, words or phrases. Through this process a series of categories, concepts or codes were developed which began to explain the phenomena that emerged from the data. Throughout the coding

process the researcher maintained notes or “memos” about the codes and comparisons and any other associations, thoughts, or ideas that came to mind.

The next phase (axial coding) entailed making connections between categories. Data was grouped and arranged on the basis of parallels and theoretical connections across transcripts. The researcher remained open to new findings as they emerged across all transcripts. This avoided forcing data into larger categories (Glaser, 1992).

The third phase (selective coding) represented the highest level of data abstraction and involved synthesizing and integrating the axial codes so that they could be incorporated into theory (Glaser & Strauss, 1967). The process of selective coding began when it became apparent that new and unique themes within the data were no longer emerging. During this phase the list of codes was considered in its entirety and the main themes that brought together the relationships and connections within the data were extrapolated.

Ethics of research with bereaved parents and rationale for time frame post loss

Examining the subjective experiences and perceived support needs of parents whose children have died is a very complicated and complex process. The sensitive nature of the issues being explored makes many researchers hesitant to request family participation in quantitative or qualitative research designs, especially during what may be an intensely painful period in their lives (Buckle, Dwyer, Corbin & Jackson, 2010; Dyregrov, 2004; Hynson, Aroni, Bauld & Sawyer, 2006).

Kreicbergs, Valdimarsdóttir, Steineck, and Henter (2004) proposed a nationwide postal questionnaire to Swedish parents who had lost a child due to cancer

between 1992 and 1997 and were denied approval by the local ethics committee. However, a pilot study to assess the harm and benefit of the questionnaire was approved with 95% of parents finding the pilot study valuable. Based on the results of the pilot study, (n=17), the ethics committee approved the main study and the researchers were allowed to proceed with their research which consisted of 129 questions about the child's care and death and five about the parents' perceptions of the study. Four hundred and twenty three (99%) parents found the investigation valuable, 285 (68%) were positively affected, and 123 (28%) were negatively affected (10 [2%] of whom, very much). Their findings suggest that most bereaved parents could perceive an inquiry about a child's death due to cancer as valuable four to nine years after their loss.

In a similar study by Dyregrov (2004), bereaved parents experience of research participation was evaluated to explore which methodologies cause least distress. The sample included parents who lost a child to various causes including suicide, Sudden Infant Death Syndrome (SIDS) and accidents. Although many experienced emotional pain before, during, and after the interview, the results show that 100% of the parents who participated in research about their grief and their deceased child found the experience to be "positive", very positive", none regretted participating and all found the experience helpful. Although painful to talk about the loss, most bereaved parents benefit from participation in such research and linked the positive experiences to being allowed to tell their complete story, the format of the interview, and a hope that they might help others. The study suggests that processes

of meaning reconstruction and increased awareness of the bereavement process were facilitated by the interviews.

In another study, Kreicbergs, Valdimarsdottir, Onelov, Henta and Steineck (2004), assessed an excess risk of anxiety, depression, low or moderate well-being or self-assessed quality of life four to nine years after losing a child to cancer. They found significant and measurable differences four to six years after bereavement. However, the intensity of certain grief related symptoms does diminish over time and seven to nine years after the loss psychological morbidity in bereaved parents decreased to levels similar to those among non-bereaved parents. It is for this reason that ten years post loss of their child will be participant inclusion criteria. Few studies focus on parent's retrospective of their early grief and their grief over time.

Chapter IV

Results

Thematic Analysis

The participants in this study were eight mothers who had a young child, between the ages of 4-13, die from cancer ten or more years ago. All participants were Caucasian and ranged in age from 45-66 years old. The death of their child took place between 10-36 years ago. Seven of the participants were married to the father of the child who died. One participant had separated from the father of the child who died before the child's diagnosis. All participants identified as Caucasian and identified as Baptist, Catholic, Christian, Orthodox Jewish, Jewish and Lutheran (see Table 1).

The mothers interviewed for this study spoke deeply and at length about their experience over time of having a young child die of cancer. In the course of data analysis, a number of themes common to participants emerged. These themes were grouped into eight major themes (see Table 2) according to their relevance and are discussed below under sub-headings of each theme. The narratives of the participants with direct quotations are provided to ground the process in the data.

Theme I: Grief is an individual and ongoing process that changes over time. All eight of the mothers interviewed expressed the idea that the experience of grief and the bereavement process are highly individual with each person and each situation being unique. Mothers caution about having expectations about how one should grieve since each person's grief is unique to them and the history they bring.

They expressed a need for their grief to be honored, not to be judged for how they grieve and not to be told they are “doing it wrong.”

A. The individual nature of grief.

P6: To grieve in your own way. Don't try to let anybody else tell you to get over this or not to tell anybody else. Oh it's been too much now, it's time for you to be over it. Only each person can work through it in their own way. They can be counseled you know, be guided but at the same time you gotta do what feels right for you.

P5: I don't think you can lump people together because everyone's experiences and support networks are different.

P8: Grief isn't...you can't really write about grief because each person experiences it differently.

P7: That everybody, well, everybody grieves differently. And you have to allow the person to grieve their own way.

P4: That everybody grieves differently. And what is very therapeutic for one person may be very harmful to another.

P1: What I went through was my experience and what someone else goes through might be totally totally different and then a third person may be the same thing I felt but maybe in a different order. And what it means is that you really have to, don't try to put everybody in a box. Nobody fits in the box in grieving.

B. Grief has no time line.

P1: I think some of the most important points is that there is no time line...You can't project to somebody a certain, a certain pattern. You can't say okay first you are gonna wanna kill yourself and then after that you will feel better but you still gonna feel like...

P5: You can't put a time frame on it and you can't put stages to it. You know like I remember, studying about the stages of grief when I took psychology class. You really can't...you know you never get over it. You learn to live with it and it takes years and years and years. And even then there are times you go back to a place that doesn't feel good, a place that is hard.

P4: I think some of the most important points is that there is no time line. So I think people feel a lot of pressure to be like, it's been two years and so enough it's done. That's it. There is no time line.

P3: Well, basically that to me it is not like a circle. To me it is more like a spiral. You start in the center and you go through those first stages really quickly, the bargaining and the anger and the depression and everything, and you can go through them pretty rapidly in my opinion. But then as time goes by the spiral tends to more go outward in my opinion and you may have depression for a long period of time and then you might decide that I'm going to go back into the bargaining like if I feel better I'll act better or something but then you might get angry again. You just have to give yourself a chance to go through all of it.... just give yourself time to go through it....and viewing the stages as linear, I think that is a misconception in my opinion. That, okay she's finished with her anger phase now she is going into this phase. It just doesn't work like that. I have always felt that the stages are not a linear line but everything I read about it seemed to indicate that it was. I was like, but that is not how mine went.

P2: ...there is no cut time. You can't say you can mourn for this and this amount of time and that's it. ...Each person has to work through their own feelings at their own pace and know that it is right for them.

C. *Grief changes the experience of time.* Time changes grief but grief also changes the experience of time. It is a bidirectional relationship that also changes ones perception of time.

1. Time is experienced as both long and short.

P4: I remember getting to a year and that is such a big anniversary and then I was so pissed off because I thought, geeze I've went a year, you know, I should get her back. I mean a year that's enough. So, I think that it's been in those funny ways that time is, both much longer and much shorter than I thought it would be.

P5: It was a really good day. That gave us the insight that we can have good days, you know. It does happen. But I think it took, a long time you know. Probably, in some respects it didn't take a long time, but in some respects it did take a long time. You know.

P5: I could say that now that I'm 12 years.

P7: ...for me now ten years out.

P8: ...the further the grief goes.

P3: I was keeping track of the day when she would actually be gone longer than she was here and that was a couple of years ago. You know, and to me that was a big deal.

2. *Time both stops and continues.* Mothers spoke of the difficulty in imagining their child at the age they would be now. While at the same time mothers are keenly aware of the age their child would be now. Mothers hold both representations of their child –as they were and how they might be. There is fluidity in mothers' use of past and present tense when speaking about their child. It is often the image of the child at the age they were when they died that is internalized yet the child continues to move forward in time as part of the mother; through the mother the child moves forward in time.

P7: We decorate her crypt....and it gets harder when she gets older because even though we still think of her, she loved Sponge Bob and she loved Elmo where would she be now? And it's kind of hard. I mean she's gonna be fifteen. How do you decorate for a fifteen year old? Do you decorate it as a five year old or do you decorate for a fifteen year old?

P4: When I think of her in my head. When I picture her and talk to her she is 7. In my real reality life I know that she would be 18 and she would be a college freshman and...she would be probably not even living here anymore. So I kind of probably more for me when I'm actually thinking about her when I'm happy about her or sad about her or anything I'm thinking you know of her as a 7-year-old. That's the actual concrete picture of her that I have.

P5: She would have just had her 24th birthday....I can't picture her in that way. I can try to, but that does hurt, that is hard. I haven't really thought about it consciously before....but at the same time I do have a sense of how she would be if she were here now. I told you we are very close with her close friends. I don't know. And I see how her sister's grown up, that kind of thing.

P7: I try and picture her at 15 rather than 4. And I can't do it. So I just. I still picture her as 4. With all the pictures we have around the house. Before she got sick again. And that's still her. The fact that she is gonna be 15 just blows my mind.

P8: Um, his birth....well actually it's funny. His birthday I feel a little sad on his birthday but his birthday at this point I feel kind of um, like, disconnected

from his birthday because it's been so long. I can't comprehend him at any age but 12. I can't move passed. In my mind he's in heaven. He's with Jesus and he's still 12. He's just gonna be forever 12. So his birthday is really kind of disconnected from the birthdays at this point. Other than the fact that I feel overwhelmed that like how could he be 21. And I'm like boy he's now 21.

P7: ...I'll see things and I'll smile. Like wouldn't that look cute on her? Of course I'm looking at something that would look cute on a five year old and she's actually fifteen.

D. *Early phases of grief are remembered with acuteness.* All the mothers have very clear memories of the death event and their early grief. Thoughts of dying so as to be released from the intensity of the pain were not uncommon.

1. A sense that the pain will last forever.

P4: I can remember you know just thinking I won't live for 5 years. Nobody can live with this much pain. You think I will either die or I will feel better because I can't do this, you know, for that long.

P1: At one point, okay I used to spend time asking G-d let me not wake up in the morning because it was so painful. And when I was driving I would imagine driving off the overpass or lying in the bathtub and slitting my wrists.

2. Shock and numbness. Shock and numbness is well known in the grief

literature. It emerged in the data in these ways:

P3: I was disbelieving that it happened. I thought G-d you made a mistake...I honestly thought it...there had been a mistake. Life was not supposed to do that.

P4: Those first days are such a blur of disbelief and pain and you know just their just blurry and weird.

P5: I remember going back to work after Rachel died...and I just remember, going back and just sitting at my desk and thinking what the heck just happen? You know what I mean, like, there was a surrealism to the whole thing in the beginning. Like now I'm back in the real world and how do you reconcile everything we just went through and people getting up and going to work every day.

P7: I was basically in shock when it first happened to the point that I don't remember a lot of it after she passed.

3. *Metaphors.* Each mother had a beautiful way of using metaphor to describe her internal experience.

P1: In the beginning the pain was very physical I remember I could feel it *inside me* it was *this horrible knife* that there were some nights that it just felt like I was *gonna implode*. The pain was just gonna overwhelm me and I think that in the beginning you get so overwhelmed by the pain.

P3: You kind of have to put the grief aside for a few hours because otherwise you *drown in it*. I probably did drown in it quite a bit in the beginning.

P3: ...there might be days when you are angry and there might be days when you are incredibly sad or depressed. But you have to just keep *plowing through it*.

P5: And I think the first year I was just....maybe even the first 2 years I was on *auto pilot*.

P4: I think....be very very gentle on yourself. Don't expect too much too soon. You know, you are *so bruised* and so vulnerable and people expect, some people, so much of you.

P8: One of the things I didn't do, like I tried to *fight the grief*. When it came at me. I'd try to, no I'm not gonna be depressed again... Scared that *I would sink* and be so depressed that I'd become suicidal...what would happen if the grief *would still hit* me and would actually *pull me under*.

P7: When I lost her it just hurt. It just hurt. There was like a *knot* in my stomach

P7: ...that big *huge hole* in your soul.

P6: It was *raw and harsh*

4. *Need to keep busy.*

P7: ...his boss, his wife would say, you know if you are not feeling good one day just call me. You don't have to come in. I said, those are the days that I'm gonna need to come in. I just need, I know I needed to keep myself busy. Cause if I would have sat, and I can do that now, sit down and start thinking about her I can just put myself right into a pity party.

P2: And I'd start crying but then you know it's—I had so much so many things to take my mind off of it. Like dealing with being a mother. It's...and then I was active in my kids school also.

P8: And if I pause to think about it then the sadness will come to me. So I just keep myself busy.

5. *Anger.*

P7: ...you are angry and you are not sure who to be angry at. You know, you can be angry at G-d. Which I was very angry. When she was going through everything. And you can be, you can't be angry at the doctor because he is doing everything he possibly can. So who do you push your anger too? It's tough.

6. *Denial.*

P7: Because I pushed a lot of my grief away. And tried to deny, pretend she was somewhere else, or she was next door.

P1: It just took me a very long time to get through the fact that he is not coming back.

E. All consuming—“maternal preoccupation”. All the mothers expressed that thinking about their child and feeling the loss was all consuming.

P3: Grief takes up a lot of your time, it really does. It is hard to think about doing other things when you are just feeling miserable because you are missing your child.

P4: You know I think the relationship with Sophia, initially after she died was still just as intense as the grief and everything. You know it's all swooped up together...If my attachment was as strong and intense—labor intensive—as it was in the very beginning, I would not be able to function in my life. Cause, that you know, it's all encompassing.

P2: I paid shiva (condolence) calls to other people. I felt how insensitive I must have been. I never realized how in the early phase it is all non-stop.... I just never imagined how all-consuming it could be... I felt, even though I had the other kids I had my other kids to take my mind but your mind really doesn't.

P1: When he first died I needed to validate his existence. I needed to validate that he was here. I used to wear a necklace with his picture on it. Anywhere I

would go, I just had to let people know, my son just died, it was—I had to let people know that he was here. It was like, always there.

F. *Grief never ends.*

P8: The grief is always with me. There is always an emptiness.

P7: I don't think that you can ever totally let go of the grief. It will never ever leave you.

P3: I don't like to use the word closure because it is never really closed.

P5: It's not like you work through it and then you are done. You know. Like I don't think I will ever be done. I just won't. You know. I will...I'll miss my daughter the rest of my life, you know. And it is a daily thing, you know. Some days now are a lot better than other days. But it's...it's always kind of there.

G. *Grief never ends...but it eases.*

1. *The passage of time influences grief.* The inherent process of grief that the passage of time influences emerged in the data in these ways:

P2: Each person is different. Your grieving process has to take time and it has to go through a certain process before you come back to real living without hang ups and you are always gonna remember and you are always gonna miss that child so don't think one day you are gonna wake up one day and say I'm a person, I can go on with my life, because that is part of your life now. This is always gonna be but you are not always going to be grieving. You are always gonna miss him or her you are always gonna love that child but you don't have to grieve constantly.

P3: ...not nearly as bad as before. And wave is really good because I often thought of grief like an ocean. When it first happened it was like being dropped from an airplane into an ocean, that there was a storm going on and the waves were really high and you felt that you were drowning, but it's a lot calmer now. It really is.

P4: We all know it continues forever but not in the same way. I've said it—it doesn't get lighter necessarily but I'm quite accustomed to the weight by this point.

P7: A lot of people say that it gets easier. And I don't feel that it gets easier like I said. I feel that it eases...Is the best way for me to explain it. 24/7 knot in your stomach like somebody's fist is in there. Now then it gets to like 12/7

then it goes to 10/7 and now I don't have the knot in my stomach. I will get it because I miss her, miss her terribly. And I could still...break down.

P4: No. I wouldn't say I worked through my grief because that would suggest an end. But I think that I've worked my grief to the point that I can live my life with happiness. Which I didn't think would be a possibility. So I wouldn't say I worked through it cause that... I reject the notion that I'll ever be completely through it but I've I've.....come to terms with it maybe, sort of.

P3: The memories are a lot more faded now. I don't constantly think about her the way I used to. Where you are thinking oh she is not getting to drive her first car or go on her first date or get married. I mean these mile stones; they don't hit you in the face as much as they did years ago.

P5: Sometimes I feel like my body knows. You know what I mean. Like you just, you are just off, even if I'm not thinking about it. It's just this...ehhhh....I don't know. Obviously, you know, we cope better now, as time has gone by.

P6: You're grief stricken but you have to go on. You have to deal eventually with the different stages of grief. Those kinds of things. And um, you know you go through those and it never it never goes away of course but it is true that the edges gets less raw or less rough as time goes on...over time it's not as hard a thing and not something that you cry every day...It is hard now it is gonna always be hard but it will get better...but you can live with that hole. It's I guess what I'm trying to say.

2. *Bad memories fade.* As time moves on mothers are able to think about their child without the bad memories flooding them.

P3: It used to be that I thought of her every single day but now I can go several days and I don't think about her and if I do think about her I can think about her with a smile.

P8: Sometimes I'll hear something, a certain song will come on the radio or especially the one grandson who has a lot of his mannerisms. He'll do something that will make me think of Andrew. Kind of makes me smile. I feel like he's still here.

P7: I try not to remember the bad times, like when she was so sick. She gave us so much joy and so much fun ah. She was a little, just....way beyond her years.

P6: I feel that the more you're out the longer it's been, the more you can try and remember the positive things. Take more of the good times and the

memories that you have that come to the surface more of the good things and the funny things and the special kinds of relationship things rather than the horrible parts of the death.

P5: It also took probably three to four years for more of the happy memories to be, you know, like, not only memories of her illness and death. In the beginning it was hard to get past those memories. To enjoy those other memories. You would have those other memories but it would hurt so bad because she's not here. I would say with time now we can have the happy memories even though it hurts that she is not here they can still be happy memories. That took, that took, a number of years.

3. Mothers learn how to manage their grief. It is the interplay of many factors that help move the grief along to a gentler place. Over time mothers learn how to manage their grief. There is an acceptance that the pain never goes away and mothers develop strategies to manage it. Mothers speak of the more active nature of coping and management strategies.

P3: You learn to cope. You learn what works. You learn....you learn what the hot spots are and you don't go there.

P1: I think part of the grieving process is learning how to live with the pain. How to accept that this pain is there and you can bury it inside and you can learn how to live with it. But I don't think—it's not like, okay, now it's over and the pain is totally gone because there are times when there can be like a little flash. It will hit you real strong. And have in mind, just accept that sometimes it will hit you and you know like not to get upset, not to feel like I'm slipping back. I know that when there is a bad time that there will be a good time after. I am gonna get back up after wards.

P8: I've learned to co-exist with my grief.

P5: I don't know if you really work through your grief. I mean I would phrase it more like you live through your grief. Or you live in spite of your grief. You learn to manage it... You learn to live with it and it takes years and years and years.

P7: That it's not gonna get better. You hate to say that. But it's not. You are always gonna have that big huge hole in your soul. Other than you learn to live with it... You just, you have to get, you have to deal with your new normal.

P7: You learn to live with your grief. You learn to live with that and your sadness. And nothing ever, it'll never ever be the same. It's just a new normal. Which is what everybody used to tell me. So no I'm not over my grief. I still have it. Who knows. Some days are worse than others. Some days are better than others.

P5: It's been a bunch of years, I mentally put it aside....You learn to manage it.

P8: For me now ten years out, it means accepting the days when I feel like crap.... I used to try to pretend that I was okay...but now I just go ahead and I just I try not to let myself go too deep in dealing with that. But I just go ahead and just accept that's how I feel....I've learned to kind of drift with the waves. You know. You just accept the fact that it is a hard day. And just know that it will be okay again.

P6: You do have this huge hole in your heart where that person dwelled. But it's but it still...but you can live with that hole. It's I guess what I'm trying to say...I guess that's where the good memories and the bad memories live in that hole that has been created by the death.

H. Grief changes over time – but some things don't change.

1. Child is always missed, child is always missing.

P7: When there are special events. Like my son graduating. He graduated and she would be going into the high school this year...and like when she would have had her communion. Like special things that would have been in her life, and her brother's life.

P7: Her best friend lives across the street. He is actually, she was August, he's October. So they were apart in school years but only two months apart in age. And he's, he's about, maybe like 5'10"-5'11". And he is only going into 9th grade. And I just see how he grows and I'm thinking and I wonder...

P3: ...like just missing her at main events, like weddings or something like that...even after 15 years the emotion is still there.

P4: Every once in a while I'm going through the closet and I'll see a piece of clothing I hadn't seen in a long time or a book or something that was very special and that makes me sad and....you know....missing her and the whole life that would have been for all of us.

P1: When I was at his best friend's wedding and I was so happy for my friend, and I was so happy for him and then I'm sitting there dancing and all of a sudden it's like a knife jumped into me. He is never gonna experience this.

P6: Sometimes even joy or seeing something that I know Patrick would like or you know, a lot of times we see something outside and we'll talk about how Patrick would love that. And tears will come knowing that he can't...

P7: But as far as I'm concerned I think I've grown a lot. But I've also missed a lot. I've missed a lot with her.

P7: I feel cheated. I feel ripped off. I feel you know, there is a lot of things I have feelings. And I just say our lives would be so much different if she was still here.

2. *Fear that child will be forgotten.* All mothers expressed the fear that their child will be forgotten.

P4: I think...I think the basic needs of having your child remembered. Having your child spoken about. They don't change. I mean I think that is a constant. I still need and crave people to mentioned Sophia, have Sophia's picture, you know. Have her wrapped up in you know, I don't expect them you know every breathe they take, but every once in a while it is lovely when somebody says, oh that reminded me of Sophia, or that was funny when she bla bla. You know. And I think, having your child forgotten is a huge fear for all of us. Like they didn't matter so I don't think that changes at all.

P5: But I would say, you know it is important to acknowledge, just to acknowledge the loss of the person. You know. Like a lot of people won't talk to me about Rachel. But other people will. And you know it's ah, you know, I don't want people to forget her, you know.

P8: It feels good to talk about him. It hurts but it feels good. Cause I don't want to, I don't want anyone to forget him . I don't want anyone to forget him.

P6: The needs of someone to speak your child's name and to reminisce with you about your child that really doesn't change.

P4: You need an acknowledgement, maybe a card on her birthday. You know that kind of thing that somebody still remembers your lovely child.

P7: My feeling is you need those friends or family members that will still allow you to talk about your child. That won't think "oh boy here she goes again." They don't give me that. They talk about her too. They'll remember something she did or said or I just...that is a big thing to me. I don't care if it's 30 years later. I still want to talk about my baby.

Theme II: Mothers have a need to maintain the attachment with their child. All

the mothers expressed a strong need to maintain a connection with their child.

Mothers find ways to feel connected to their child, to continue to love, honor, and value the life of their child and to make the child's presence known and felt in the lives of family and friends. Mothers gravitate to relationships, activities, things that facilitate and support their attachment and connection to their child.

A. Felt sense of child. All mothers expressed a felt sense that their child is a part of them.

P4: I always think of myself as the mother of two girls. She's just a part of me...I sort of feel like she's, she's part of me in a way in what I do and what I see....and I certainly think of her daily and you know, she is just sort of a constant presence...just sort of incorporated in me.

P4: Sophia is not consciously in every waking thought but she is with me as I move through my life whether I am thinking of her or not...Like I'm able to just move through my life....you know with her just sort of being a part of me.

P5: I don't know how you can ever really not have a relationship with your child...Obviously I don't have a relationship like I had with her when she was alive, because she is not here. But I still feel like she is a part of me and I still feel like she is a part of my family. I still sign her name to cards. Um, I usually put her name in a little heart at the end. You know - she is just a part of who I am.

P5: She continues to be a part of our family because she is a part of who we are. You know. I have three children not two children.

P7: She helps me. She helps me get through a lot of things. Just knowing that she's there. And you know you said how do you know she's there I'm not really sure I know how she's there. Other than I feel her. Yeah. I feel her and it's hard to explain.

P6: I continue to have a relationship with him because he is part of me...The attachment is still as strong as it ever was it's just that he is not here. I mean you could look at it in a way that Patrick has missed out on a lot of things my attitude is more that Patrick hasn't really missed out on anything because in my belief he's with us. And what we miss of course is being with him.

P7: I feel her in my heart. I don't know how else to say it.

B. Telling stories about child's life and death. As evidenced throughout the interviews as a whole mothers continue to have a need to talk about their child. They expressed this explicitly in the following ways:

P8: I talk about him to people. I like to tell people the story of that month that he passed away.... I talk about Andrew's life and death all the time.

P7:I love talking about her even if it makes me cry.

P7: I appreciate the talking – it's good.

P3: I appreciate getting the chance to talk about her.

P5: It's always hard to talk about it but at the same time I always like to talk about Rachel.

P4: Talking about it is good in all kinds of contexts.

P2: I talk to people about him all the time.

P7: And I could still break down. But the fact that people allow me to talk about her. Like last night we had a party across the street and we were talking about her. All the, she was just such a ray of sunshine in this neighborhood and everybody loved her. And she was funny. She was very funny. So I try and remember the positive things.

P3: On the list serve we just, well one of the things we say, just come talk to us...just to come tell us as much as you possibly can so that we can understand you and it's a chance to let them live their child again You know in a way vicariously they bring their child alive again in some ways again because new people are learning about their child. I feel like that is really important.

C. Mothers feel a need to do things for their child. All the mothers spoke about the need to continue mothering their child. The mothers spoke of the many active things they do that facilitates connection to their child.

P6: I do things like my passwords for all my different accounts are mostly variations on his birthday and his name and things like that. I mean that is

kind of a trivial kind of things but it is a way to stay connected. And um, you know we of course think of him daily.

P6: I said I was very active in this charity for some years after his death and I'm still connected to it. I'm a platelet donor. I've given platelets over probably close to 220 times now over the past 15 years and to me that is a huge connection. I didn't really understand until he needed them, in fact, what platelets were and why chemo therapy patients would need them. I just feel like it is something that I can do that because of him that I knew about and so I give sometimes when I've been referred for various reasons I give easily every two weeks I give platelets. I would never have done that if it hadn't been for his illness...but still keeping those kinds of things going to keep the child in your memory in an active kind of way.

P5: Just still feel close to her. You know. I miss her. I think about her. II don't know. I feel her in my heart. I don't know how else to say it. Some of that translates into you know we keep a lot of reminders of Rachel. We have her pictures. We have her things. We do things in her memory.

P3: I would say I still think about her a lot and I still do things in her memory.

P4: I mentioned that she was treated at St. Jude's hospital for several years we would do around her birthday every year, a party, a fundraiser, whatever, toy drive, for the hospital, we got away from that the last couple of years, But I'm training for a race, a fundraising run, also for the hospital so we do things to kind of remember the hospital, you know that helped her. And that helps me feel, you know, somewhat connected.

P1: The memorial library was very very small then so it was more that I used to take care of his grave. I would go there and clean it up and make it all nice and neat. And also like I played with his toys, I built up the Legos that he never built, He always wanted me to that go back and rebuild all those mother creations. Then as time went by it was more like I connected to him through the books. The library, it's like taking care of the library, seeing people use the library, seeing people enjoy the books, seeing my friends enjoy the books. That is my connection to him.

P7: I wanted to do something in her name to raise awareness to childhood cancer...and now what we do we raise money. We still do the fundraisers and we raise money to help the parents financially.

D. Fulfilling child's wishes, child's mission, internalizing child's good qualities.

P6: Patrick's illness brought to me things that I would never have been involved in otherwise.

P5: If I can go out of my way to be nice to someone or to help someone, not that I didn't do it before but you know. I just know that is how she was. You know. I want to emulate her good qualities if I can.

P1: When he very first died I had this burning desire that I had to make up for all the mitzvahs that he was missing. And now maybe it is just habit. I always feel like I'm doing mitzvahs for him.

P8: The second year on Andrew's birthday, I decided to start a toy drive. Cause one of the things - my son, planned his whole funeral... He didn't want them to bring any flowers. He said flowers were for girls. He wanted them to bring toys. And at the end of the funeral he wanted the toys to be taken to the hospital and given to other children. Not just cancer kids but all the kids in the hospital... So the second year I did the toy drive and I collected over 300 toys to take up to the hospital. The second year, the third year I did the toy drive and we collected over 1,500 toys.

P6: One of the things we had always loved to do together, Patrick and his father and I, and get all the siblings when they could was to travel to the mountains and do things there. And so about five or six years ago my husband just decided that he'd like to buy a place, a vacation home in the mountains and so we did and we bought a condominium in just about an hour and half from where we live. From there we go to a lot of other points of interest in the mountain area. And so that has been a great joy to us because we know that Patrick would have liked it and would go there.

E. Maintaining relationships that honor child's presence in mother's life.

P4: The things that you lose in a weird way, you lose the relationships with the people who were caring for your child, because those become very important in your life. The nurses, the hospice, the doctors, you know, it's all a giant part of your life which is gone. They know your child.

P7: I think actually her best friend was a boy who lived across the street. He actually still lives there. And I watch him growing, thinking. And they spent almost every day together for the first 4 years of their life. And I see him, and it keeps her alive to.

P6: Last night I was at camp, camp chemo camp for kids and their siblings. It was a place that he - he only got to go to camp one time - but he absolutely loved it. And he was, you know, just had the greatest time there and so I went back there every year as a connection.

P5: For a long time, for years now we've made treat bags that we take to the hospital. Before all her friends and her sister went off to college they would come over and do it with me.

P6: one of the things that might be of help is to make sure you keep in touch with people who, who were part of your, or enough of post part of your life that you can do those kinds of things. That you can realize that they are or at least hope that they are gonna bring up and of course you are not going to sit around waiting for them to do that but still at least have the connection where that can happen sometimes.

1. *Especially with the siblings.* All the mothers expressed the importance of making the child real and present for the child's siblings. These mothers found ways to actively make the child real for the child's siblings.

P1: I do things for him. It's like every day when I give Tzedakah I say "*elu neshmas*" (in memory of) and I say his name. My little girls when they give tzedakah they know. My daughter Sarah, is 6 years old and she knows to say, *Elu neshmos yossef Chaim Ben Meichoel Dovid Ha levi*, (in memory of Joey) that is what you say before you give tzedakah."

P2: All my kids know about Gabriel. All my kids that were born after him they all know about him. And every year for his anniversary I used to bring ices to the camp whichever one of my kids was in camp then. Give ices and so they all know and now I hear stories that my kids that were born afterwards are telling their kids about him. That they have an uncle in heaven.

P2: Also you can't make like a saint out of your child that died in your other children's eyes. Because then they will never live up to him or they will. It's just they won't be any connection at all.

P4: In bringing this other child into our family I have to keep Sophia a part of our home for her and so we talk about Sophia and what she's like and stories about her and how old she would be now and you know I think I feel a responsibility to my daughter now, my daughter's name is Scarlet, so I feel a responsibility to let Scarlet know her sister in some way.

P5: When, the first few years we had a tradition that I started, just the four of us. That every Friday when we had Shabbat dinner we would share memories of Rachel. And for me it was a way to you know, that everyone could talk about Rachel. And my kids could learn things they didn't know about her that Stephanie could share, that Matt didn't know about her because you know, he doesn't have any independent memories of her.

P8: ...and they were in the room when Andrew died. And they remember and it keeps Andrew fresh in their memories. I doubt they would have remembered this in the years later if we hadn't talked about it.

P6: So you know, that relationship with our daughters and their feelings about Patrick we talk about it some but like I say he is a part of all of our lives in the child that we adopted in the years you know, after his death she has a bond with him because she knew that he was...he was just a diehard fan of the big rivals. And the 17 year old has adopted that team so you know primarily because she knew Patrick ...And we talk about the fact that she and Patrick were alive at the same time. She was born in January of 90 I guess she was born in January of 96 and he died in December and they were alive together for that year so you know those kinds of things have evolved to.

F. Relationship is bi-directional. Mothers expressed the idea that the relationship with their child is bi-directional. All mothers have a sense of their child's presence and believe that their child affects them in the world.

P7: I talk to her all the time. Like I wish she could talk back...I'll just be driving in the car and say you know please watch over your brother. Wish I could see you today. Stuff like that.

P7: I feel her. I feel her with me...I believe that she is with me. She guides me sometimes...she pushes me. She helps me.

P2: ...someone I can count on now if I need an extra pull... when I have a problem with let's say one of my children. I say help me out here like, and usually he does. I mean it is G-d you pray to but you need sometimes connection you know, help you brother.

P8: When something funny happens like if a picture falls off the wall or something. You know, how those quirky things happen. The first thing we always will say - because Andrew was a jokester - like, alright Andrew - very funny. My mom has this clock that goes off when the sunlight hits it and birds sing. And one night it was night time, it was pitch black and the clock started singing - like for no reason at all the clock just started singing. We are like, "okay, I guess Andrew's here." If something happens at my mom's house or my daughter's house or here we'll call each other. And say, "well Andrew's over here I guess he left your house. He's over here because there is something mischievous happening." We all figure it was Andrew.

P1: I don't picture him really like in a physical body. It is more sort of like a thought. Because he is in the next world I mean, when we hit about five years he was firmly implanted in the next world. It's like, I don't know I just

envision him, up there learning *Torah*, whatever it is, whatever they do. I know they stay connected with us down here.

Theme III: Mothers make a conscious decision to live life. As mothers begin to accept their new normal, they make a conscious decision to go on living.

P1: Well for five years I had been so sad. Basically my life was black. I had these glasses on and everything was black. I'm tired of it. I don't want to be sad anymore. I want to be happy again. I think internally I just decided I'm sick of being depressed, I'm sick of being sad. And I worked on it and I think I reached one level, maybe it is like letting go, that holding on to him, to go around and say I had a son who died, letting go, and not having that need anymore because when I hit ten years also it was another I guess another milestone that... I just felt I felt, I don't know how to describe it. I felt more - I don't want to say at peace with it, but it is a part of my life. It's who I am and it's like it's not a black mark on me.

P6: You can choose to either work through it or let it control you. And you have to make that choice.

P5: I'm not sure the shift was about you know how I feel about her but it was more like at some point I felt like I could still have a life you know. Which was very hard to acknowledge that you can do. Even though you are doing it all the time. You know what I mean. It didn't feel like I was doing it. You know, it felt more like going through the motions in some ways even though I'm sure there was more substance to what I was doing.

P2: For your own self I'd rather be happy then crying and morbid all the time. And I know he is happy and he *sheps nachus* (gets joy) from us.

A. Often because of the other children.

P7: I have to admit that it was my son that kept me going. If it wasn't for him I don't know where I'd be. He deserved a functioning mother. In my eyes, he deserved a functioning mother. It wasn't fair that yes he lost his sister then he should lose his mother too? And I just couldn't have that and that is the only reason I went on and worked. I guess that is what they mean by work through your grief. So I pushed on and because of him. I got up every morning and I functioned because of him... Like people will say well you did have a choice. You had a choice you could have went underneath your bed. I didn't feel that I did have a choice. Because of my son. I did not have a choice.

P8: I was in and out of the hospital. I just... I wasn't in good shape. And then like six months to a year after he died I remember sitting in the van. We had a van then and watching my daughter practicing doing her cartwheels in our

front yard. And she had been trying to do cartwheels since she was about 11. And all of a sudden I looked at her and she was doing these perfect cartwheels. And I thought, wow I still have a child left and I've been completely neglecting her because of my own grief. And that's when I started pulling me together.

P2: I saw people in the hospital that were so bitter and I like my husband and I said we would never do this to our kids. You know I don't want them to grow up in a bitter house, in a sad house... You know you can't grieve all the time. You have to... kids need to be happy. Need to grow up feeling secure and not morbid. It is just not right for them. we tried to take them places and I would watch the kids on the merry-go-round and think I can't see him on the merry-go-round.

P5: I think in part because we had two younger kids we had to keep going and I remember thinking a lot those first couple years that my goals was to make sure that their lives weren't ruined. You know. I felt like my life was ruined but I didn't want my other kids lives to be ruined.

B. *To honor the memory of their child.* Mothers feel a maternal obligation to keep their child's memory alive and to live life in a way that honors their child.

Mothers need to make life mean something in order to honor their child's memory.

P4: I try to make it - and I like to think that I would do this if she were here - but I probably won't be as cognizant of it, but try to live my life in a way that would if not make her proud not make her embarrassed. I said I told her before she died when we all knew I would be okay. I didn't know how but I would be okay because I never wanted to blame any, you know, I would I be alright if Sophia hadn't died or I would live my life not well if Sophia hadn't died, that didn't seem fair to her. So I think that some choices I make are to honor her. Some choices I make you know I just wouldn't I wouldn't want to....blame anything that I did in my life that wasn't good enough on that experience. So I think , I don't live my life like 100% for her, I don't do everything that I do in her memory but I think that, i's a guide, that can guide me that you know I would want to live a life in which both of my children would be proud.

P4: I don't want Sophia's death to ruin me you know. I think that—and I actually sort of promised her that.

P1: There are certain things that I do and then afterwards I'll feel really bad about it. It's like I don't want to embarrass him or I think about something and then I'm like I'm not gonna do it because I'm gonna have to face him. I'm

gonna have to go to his grave on his *Yeirtzeit* and know that he knows what I did and it's like I don't know it makes me feel like smelly, dirty, or sullied.

P2: And I know he is happy and he *sheps nachus* from us. I just hope that when he comes back he doesn't look at me and say, "hey ma how can you do this, or do that?"

P1: Yeah, I told you it's a very spiritual one. It is more of like doing *mitzvahs* for him and then making him proud. It is in the back of my head. It's so funny because G-d is always watching, and yet that doesn't scare me as much as I don't want to embarrass Joey. Why and I more concerned about how he views me?

C. *Helping is healing.* The mothers expressed the wish to give over some of their hard earned lessons as a way of helping others. They said that helping is healing and is a way have keeping connected to their child. It is also a way of finding meaning and purpose in their child's life and death.

P4: I feel like, that touching back on the working through grief. I feel like any kind of thing I can do to help makes me, you know, it's an advantage to me. With the hospital or with hospice or with, Ronald McDonald house or all the fantastic things that we got help with. You know, sometimes I think that is very healing, to help a little.

P7: I think the connection just got stronger. And I think that has a lot to do with Emily's Foundation...Because she is always, I mean you figure we've done all these events and I always have pictures of her. We all have t-shirts...Emily's Foundation has really really helped me. It's helped me keep her alive.

P5: It helps to do something. So I guess we try to do things that honor Rachel's memory and the fact that she had such a warm heart and wanted to help other kids, help other people, we try to find things to do individually and as a family that you know, you know, that keep her....you know....Keep her in the front.

P7: It really helps me because it makes me feel good that I'm doing something.

P5: I have reached out to other people when I've learned they've lost a child.

P3: I'm still on the list. I'm one of the older members that's on there and we counsel other parents.

P2: The truth of the matter is that after I went through it I would in my own way I would counsel a lot of people and I would tell them exactly what to expect

Theme IV: Mothers' themes of guilt.

A. Guilt for not saving child. All mothers expressed the feeling that they should have been able to save their child. Some mothers feel guilty around diagnosis and treatment.

P5: She was my child and I should have been able to protect her and for whatever reason I couldn't protect her from this. And I know it sounds weird to say it because when I see other people go through stuff with their kids I am empathetic and would never think of pointing blame or that they should have blame or that they should feel that way so intellectually I know it doesn't make sense but emotionally I have a problem with that....For a long time after Rachel died I felt like it was my fault. I know it wasn't logical but I felt like it was my fault... I just felt like she was my world she was my responsibility, and I failed somehow. And part of me does still feel that way, because how could this have happened?

P8: But mostly, I have a lot of guilt. I feel guilty that he was, you know, that he wasn't diagnosed for the first 6 months. And you know doctors and therapists and family and friends all say it's not your fault but that guilt makes me ... Cause I often think that if my son had been diagnosed sooner, not six months later, maybe he would still be alive... I still feel guilty. I feel guilty that we waited 6 months.

P6: I feel like you know maybe the fact that I was a chemist and around a lot of chemicals or maybe he was exposed to something else in the environment or maybe he was born with a defect... I do worry sometimes that my life as a chemist may have exposed me to things that he shouldn't have been exposed to in the years. I also worry sometimes that...I mean this is kind of strange but he had a big stuffed lion and we had to have the lion cleaned one time, and it came back smelling of the cleaning material, you know, the cleaning solution and I took it and had it washed and got that stuff out but that particular chemical is a carcinogen. So I worry sometimes that maybe his exposure to that particular chemical could have caused him to have the illness that he had.

P2: For years I used to think at night should we have gone to this doctor should we have done this...

P7: I regret things too. I regret why I didn't push for an MRI in December when her hand started hurting. Maybe it wouldn't have invaded the spine. It gets to the point where you just can't do that. But you do, you still do.

B. Guilt if not keeping child's memory alive. All the mothers interviewed expressed feeling guilty if their attachment to their child is not being felt. They expressed feeling guilty if they are not thinking about their child. Mothers feel a responsibility to keep child's memory alive with others.

P4: I have some new friends, people who didn't know Sophia. Going this long of course, that are new. And I am....not very careful I talk about Sophia because that feels disloyal and too hard to just sort of dance around it.

P4: If I thought I was letting go that would feel disloyal to me.

P4: I almost felt at first like I had to, like I had to go to the cemetery. Like I had to you know. Or I wasn't, or I'd feel guilty, or like I wasn't doing my job.

P1: Well right after he died, I had this desire that I had to tell people I had this son, like he was here and now he's not. It's like I sort of wanted I had this need to let people know that this kid was here and that he's not.

P2: ...like at the beginning I would feel that at the beginning it wasn't right for me to have a good time or to enjoy myself I would feel, how could I? How could I enjoy myself? And have a good time when I lost a child.

C. Guilt for neglecting other children and concern for the long term effects on them. Seven of the mothers had other children at the time of their child's death and they all expressed a concern about the siblings. Several mothers expressed feeling guilty for not being emotionally present for their other children during their child's illness and after their death.

P7: Definitely they need to do something for the surviving siblings. Especially when they are younger. Because in fact I heard it said that they are the forgotten grievers.

P8: My daughter...Kimberly was thirteen when he died. I got off the bed and my daughter was holding, she was hugging to my mom her grandma, and she came running to me and.....I put my hand up to stop her. I put my hand up to

stop her. And I said no and I ran out of the room. And I feel like crap about that. I've apologized to her so many times. And she is like mom especially now that she's a mom. I think when she was 13 years she...I put her in counseling after Andrew died. I think she had a little bit of resentment because she understood why I wasn't around during the time that Andrew was sick. But for her that year that I was in and out of the hospital that I couldn't function that is the time that she had a hard time understanding why I wasn't there then. Like, what about me?

P5: And it hurts me deeply to know how much my younger son has missed out by not having a childhood with Rachel. And in some ways, and strangely his personality is more like Rachel's and he actually looks more like Rachel. Like when he was born we were like Oh My G-d, this is a boy version of Rachel...I just think now if she were here to be his big sister... It hurts when I think about how just not having her here as well as the changes in all of us for what we went through. You know, and it's probably changed him. He doesn't know it.

P1: When he very first died I pulled away from the kids because, giving love was too painful. I wasn't there. Love was too painful. Because when you open up your heart it just gets broken. I pulled away from the kids I couldn't...I stopped saying *shema* with them at night. There were certain rituals that I couldn't do anymore. I wouldn't read them stories any more. I just really pulled away. I put a big fence up. My oldest daughter went through her teenage years with a mother that was not there. I pulled away from the kids. It's taken a real effort now to push myself back to being there for them and enjoying them. Letting - taking that risk again. You know, not all kids die.

P2: My oldest daughter was four when he passed away and she would become hysterical, all of a sudden she would become hysterical. What's the matter? The ABC are dying. And I said what do I do? And I called my friend she is hysterical. I can't calm her down and we had spoken to a psychologist like does she need, should I send her somewhere or what. He said no, just hold her and hug her and reassure her that it is too soon. She is too young and too soon that she would need professional help. Just gave her a lot of loving thank-g-d and then in nursery school one day her teacher said to me one day, her teacher told me that she is telling the other kids.

P5: ...that also has fallen really hard on my daughter too, because she went from being the youngest in the family for 7 years, to having a baby brother to within two years losing her big sister and being the oldest. You know. And then seeing her parents be different. I mean Everything shifted, you know. And so that is why, I worry that most about her because she was still very young but there were all these huge changes in her life...but you know, it comes up, it's comes up over the years. Different things have come up. So there was a lot of stuff with her that we had to deal with.

P8: I'm the one that feels bad. I feel bad for you know, not comforting her when her brother died. I've never in my life felt that much pain. It was just more than I can bear. I I I just, I was not a good mom to her at that point.

P6: We found out later that she actually thought for years that her coming since she spoke no English or anything at the time that her coming is what had actually caused him to be sick. I mean she carried that around for a long time before we knew that she even thought that. So it's been a challenge to say the least.

Theme V: The impact of grief on relationships. All mothers reported that the experience of losing a child had a tremendous impact on their relationships with others, including spouse, family, and friends.

A. Some relationships are strengthened and some are lost. Not every relationship is going to survive. Some relationships are lost particularly lost because of betrayal.

P5: Some friends in the beginning I just had to back off from. You know, who kind of expected too soon for me to go back to being how I was. Which I'm never going to go back to being how I was... And then I had other friends who were just, and continue to be, rocks. They were there for me and there for my family. They don't necessarily say anything but I just know that they are there... They have just always been there no matter what. You know - anything. With some people I have gotten a lot closer with a number of people. Even when I don't see them for a while, just like, we have been through the best and worst of things together in our lives. I think losing Rachel was the first worst thing that we all went through together. You know. Obviously what they went through wasn't like what I went through but, you know, all these years later we are all very close.

P8: People who I thought would be there for me were not. And people that I didn't think would be there and understand were.

P4: Some friends who were not able to deal with the sadness and the grief are gone too so I think that's a real hard part of it - disappointing... That is always interesting - how that plays out. Boy that separates the wheat from the chaff. You don't know, and you don't, it's not always the people you think that will come through and be there for you and your friendship will continue. Because some people will just drop off because it is too hard. I think I had relationships that ended abruptly right around that time - the time that she died because I

think it's too hard for people and it's too scary and you become their worst case scenario and so you know that is not a good person to hang out with. Some family members and friends, it really made me see the good in them and how devoted that they are and good that they are. So I think in relationships it really is a defining moment in a friend or family relationship because you really sort of see how that person is in a crisis, how that person is if you need them. And some people and some people you really thought would be there are just not up to the task. So I think there were relationships that were certainly strengthened or continued to be strong and there were some that just dissolved. Just couldn't be around them.

P1: I was very lucky, most of my friends, they all let me grieve, they all said to me you have gone through the absolute worst thing. And they never tried to tell me you got to get over it. There were people who were not my friends, but just acquaintances, "okay, it's a year now, time to be happy now." It's like, F – you. But my good friends, they allowed me the grieving process. I did have one close friend who anytime I would mention something about him she would change the subject and after a while though, there was sort of like, she does now say things about him, so she has changed on her end there is still almost like a rift between us. There is a closeness that is gone. Because, I guess I wasn't getting emotionally what I needed from her so I let the friendship sort of die.

P7: I'm very fortunate in that respect. I'm on this bereavement site, so many people have lost their friendships. Their family members have pushed back. I have been sooo fortunate that my family - I wouldn't have been able to get through it without my family and friends. So I was very fortunate in the friends and family that I have. They've all been there for me.

1. *Relationship with spouse.* Of the eight mothers interviewed seven were married to the father of the child who died. Mothers reflected on the differences of how men and women grieve. Mothers also expressed feeling a special bond with their spouse, the only other person who shares this experience with them in a way that no one else can.

P1: He's the one that I want to be with. And that's strengthened the bond between us. And he was the one I could wake up in the middle of the night and just start crying and he would know why I was crying. You know, I just feel over the time we have gotten stronger. I mean we still have fights you know but I think that there is this connection...I guess like in a way he is a connection to him. A connection to Joey.

P2: One of the things my husband said to me he said, "I need you." And you know we tend to think as mothers it is just us and it's not - and men grieve completely differently than women. I mean, women are more emotional but it is just a difference...and in the hospital we saw people that were really being pulled apart. People that were getting divorced. And we just got closer I think.

P3: I think in some ways we have gotten a little bit closer because we both went through it. We grieved it differently so there wasn't that understanding but I think overall we both become stronger through it.

P3: Oh I think everything is affected by it but we know we are still together we didn't divorce or anything like that. Which happens to some families. You know. I...we felt like, we'd been through the worst of it together.

P4: Um, you know I think it has certainly evolved. It's not an easy thing on a relationship. And we continued to be married and have a good happy marriage but it's been, you know, it's hard. Because you grieve so differently and you are in differently places and I think our relationship now having gone through all of this, you know, we know more about each other than we would have.

P5: I think we are closer. Not that we weren't close. Um,.....but no one else has been through what we have been through. No one's survived what we had to survive. So we get each other. I mean our personalities are different. I mean the things I'm telling he would probably never discuss. I mean he is not.....as verbal that way. Analytical that way. I don't know how to explain it. But you know, he is quiet anyway. I'm definitely the more talkative one in the family but he you know, we just been there, I mean, he has always been there. We were there for each other.

P6: ...like I say we processed things somewhat different. Not really. I mean not in the sense that we have grown apart or anything like that. I guess we do have some differences and one of the things that binds us together is Thomas and his life and the fact that he was our child.

P7: ...after she passed away, we were okay but I really think it's because we let each other grieve the way we needed to grieve. Like he and I said that I'm gonna write a book because everybody says that 80, I think the hospital is 95% of or 90 it's really high, of parents who lose a child divorce...the percentage of parents that don't stay together after the loss of a child. And I think that the main reason is because they don't allow each other to grieve the way they need to grieve.

B. *Helpful and harmful comments and gestures.* Mothers had very clear

ideas about what they found helpful and harmful from others.

P8: I used to come down on myself. Like I should be doing better by now because that's what everyone tells me. You should be - you shouldn't do this... Do you think I'm feeling sad on purpose? Like do you think that I'm just, like I like to feel sad? You know. I know that he would not want, he would not have wanted me to feel suicidal. He would not have wanted me to feel sad. He would not. But all that does for someone to tell you that it actually makes you feel even crummier. Because then you are like, G-d no he wouldn't want me to feel sad. But I do feel sad. Now I'm feeling sadder because now I'm disappointing him.

P4: ... and I will tell you my favorite, the worse, but now it is my favorite. I was at the cemetery. It wasn't that long after she died, it was still cold outside. My husband was there and there was a family visiting a grave nearby and women kind of came over and said, you know, wanted to know what our situation was and I told her our daughter seven and died of cancer. And this women, G-d bless her, I'm sure she was trying, people don't know what to say. But I was so raw and weird, and she said, ah, she said something bad must have been going to happen to her and G-d saved her. My husband stepped in front of me because I was like rah! I'm like, really? Getting cancer at six? You really think we dodged the bullet on this one?

P4: Wow, wow, I think that is part of like, its self-preservation. Because I think it's the same thing when people say, you are so strong I couldn't have handled it, you know if it was me. And so its boy thank goodness I'm so strong. So I think people think well if I'm weak then maybe that won't happen to me I think that is sort of a self-preservation thing.

P8: Yes, people say things that they mean well I know that they mean well, but it's not like...one of the things when people say is you know G-d doesn't make any mistakes. I don't - I hate to hear that statement. I know they mean well. But it is not helpful thing to say. You know. Because grief and anger are kind of connected together. But I've learned in the beginning when someone would say that it would cause me to burst into tears and be extremely agitated, like what do you mean. So it wasn't a mistake to take my son from me? I wasn't a bad mom da da da. Now I look at it when they say that, I'm like, Okay, cause they don't know. They are not trying to hurt you they are trying to say something that they think will help you feel better. But really there is nothing that anyone can say to make a parent feel better that's lost their child. There's no words that you can say that is gonna make you, okay, that's good.

P8: That would be the one thing don't try to say anything. Just be there. But they would say I understand I lost my grandma last year. Your grandmother was 83 years old. I mean it's sad, but my son was 12. It's not the same comparison. A lot of people will try to compare that. But I think they are doing it because they just don't know what to say.

P7: ...they are in a better place. That is the worst thing I feel that you could say to a grieving parent. They are not in a better place. They might be in a pretty place They might even be in a beautiful place but they are not in a better place. A better place is in their parent's arms. Or a mother's arms. And people still say that. I think it's just something, it's not better. Don't say better. For a 90 year old that's sick. They will be in a better place. Not for a 4 year old.

P7: when people say you are so strong Cathy, you are so strong. You're so strong I could never do that. You know what fifteen years ago I didn't think I could do it either. I'm not strong. I did, I didn't think I had a choice.

P6: ...people will say I don't know how you've done it; I don't know how you've gotten through; it I don't know how you've, and you don't want to be harsh and uh and or anything but you sort of bite your tongue to not say, "well what choice do I have."

P8: And when somebody tells you that they understand it they don't. They don't. It's like. I've never been in a house fire. I can tell you what I would do if my house sets on fire. I know everything I'm supposed to do. Will I do it? I don't know. I've never been in a house fire. If you have not buried your child you can say oh if I buried my child, I'd feel sad for a while and then I'd put myself together and move on. But you don't know that.

P4: But I have pictures I talk about Sophia often with people just I think it's just, I try not to let that be real weird or awkward, you know, cause I think if I talk comfortably about her then other people will...People are so scared of doing the wrong thing and saying the wrong thing. You know, if I say happy birthday will that make her sad. Maybe she wasn't thinking about it. Yeah, right, I forgot. So, yeah, yes, it is her birthday, and yes I would like you to tell me happy birthday for her.

P7: You just got to be able to listen. And not talk over the person. Let them cry.

C. Seeking out and relying on various supports.

1. Community of friends, family and neighbors.

P7: My friends really stepped in and took over a lot of that and kids needed chauffeuring to like baseball practice of something like that they would step in and do it....We had a good support network.

P2: ...and a very good support system. My family, my friends. Friends that would call me. ..I had friends calling me all the time, you know, I'm here for

you. And I used to read things on the list serve, you know, I just kept saying how lucky I was that I had my family and my friends.

P6: But he was a well-loved kind of child and we were well loved in our community and people knew and followed it for two year and so we were blessed to have those kinds of connections and love and care of a lot of people.

2. *Professional support.* All eight mothers reached out to a mental health professional at various times during their grief process. Some mothers continue to seek out the help of therapists who listened, did not rush them in their grief or look to “fix” them, and viewed their experience as unique were found to be helpful.

P3: My husband’s insurance paid for six weeks so I went to a counselor and it really didn’t do anything for me. I did not connect with this woman at all... what she was saying to me wasn’t making a whole lot of sense to me at the time. It was kind of like I was getting a hurried up version of grief 101. ...instead of just letting me talk.

P4: She always did and she helped you know helped guide or say yeah I think that is a good idea or maybe try it this way or whatever. But yeah, I never felt like she would say you know you are doing it wrong or you need to do this. Or she would really listen and give instruction if needed but most of the time it was like yeah I think you should do that, I think that is a good - you know, you are in such a vulnerable weird place that having somebody say yeah that is a good idea, I think you should do that is important and valuable at that time I think. You just don’t know what to do.....it was mother’s day and I was just beside myself, what am I gonna do, what am I gonna do and I said, all I want to do is sit at the cemetery and cry. And she said, sounds good. Do it. You know and I was shocked because I thought she would be like, no you need to do this and that. That is what I did and I cried for an hour and went home and that felt right to me. You know. It felt just having somebody validate, yeah do that, sure. It was so important to me - helpful.

P5: I kind of felt like she had this - and it may just be the place I was in I don’t know. It just felt like she had this box for parental grief and that is where I was being placed...Like, you know I was just one of them. She was gonna treat me the way she dealt with anybody else who had grief issues. As opposed to seeing me as an individual and what I went through with my child.

P1: It felt like she wasn’t listening to me.

P8: But they don't try to tell me. They listen. They just kind of help me accept the feelings, and to know that it will pass... They never tried to tell me how I should think or feel. They just kind of helped me. They are the ones who taught me how to ride the grief. They never told me, oh you shouldn't feel sad.

P7: I tried personal one on one counseling, that just wasn't good for me. The one lady, you know what I didn't like she just sat there and she was on her computer the whole time like typing in what I was saying. I don't know. There was no personal connection.

P7: Right off the top said oh I'm gonna give you an appointment with the psychiatrist because I think you need some anti-depressants or anti-anxiety. And I think that just turned me off... Especially within the first year, all these psychologists wanted to put me on drugs. They kept saying you need an anti-depressant. You need this. I'm like no I can do this myself.

P7: I had gone to how many, probably only two. I don't remember the first one. The one lady, you know what I didn't like she just sat there and she was on her computer the while time like typing in what I was saying. I don't know. There was no personal and maybe it was my fault for not giving someone else another chance, which it probably was. Um, and I like you are asking these questions and I'm just continuing on, you know. And that is what I needed and she wasn't giving me that.

P6: But she was very good at sort of teaching me some things about just sort of directing me in different ways to honor my grief. Directing us in ways to let each other grieve because you know it's hard. It's just like I think probably friends see us and all want us to be better. With your spouse you just want them to feel better and your first instinct is to try to do something. Sometimes they just need to cry or be sad or grieve whatever. And so I think she was good at helping us understand everybody grieves differently everybody grieves at different times. Giving each other the latitude to grieve like we needed to without trying to jump in and change it or fix it or you know whatever. So she was very empathetic listener.

P4: She definitely respected her memory and the role she had in our life.

P5: I would want therapist to know that it's unlike anything else that you will ever experience. It is not like losing your parent or your sibling or losing a sibling or unless maybe if you lost a sibling when you were young like my daughter did.

3. *Connecting with other mothers who have been through the same.* All

mothers expressed the importance of making connections with others who have gone through a similar experience. They spoke of the value of support from people who had similar losses.

P1: And there are times when you feel something and you want to know is this normal. And I could call up a bereaved friend and ask her. Tell her that I'm feeling this and she can say, yeah, I went through that too. Or I can be in her group and everyone can share how they went through that same experience and it's like, okay I'm not crazy.

P3: Like I had joined the list on line and I found and it was a big outlet for me. Plus I read a lot so I read a lot of grief books and I found that to be helpful.

P4: I needed to see people, who were 1, 5, 10 years out. I needed to see people that had survived this. Because it didn't seem possible and that - I mean I was just hungry for it. I just thought I got to see some example of people who had survived this. That will help me know that I can too. If they can do it I can do it.

P4: I got really soon on this on line group... which was a message board e-mail group for people specifically, it was almost all women, but it could be women or men, whose child had died from cancer and so it was a lifeline for me. I could talk to these people and even though we were complete strangers and this was the only experience that we, you know, talk through in those early days, you know there were so many - I couldn't sleep in my bed for like a year because Sophia slept with us and I thought that was crazy and I would put this down and there would be five people who oh yeah, me too. I haven't been able to do that

P5: The people there were just wonderful. I mean obviously they had been through what I had been through already. And it was you know it just felt like there were people there who kind of...different from my family and friends, support group here, you know what I mean. They walked the path already, you know and they would be upfront about things that you couldn't talk to about with anybody else. Like what if anything do you put in the casket. I don't know. All sorts of weird stuff that no parent should have to think about.

P5: I think there is a certain level of comfort in just knowing that you are knowing that you are not the only parent that is broken this way. I remember when we were sitting *shiva* for Rachel that one of my closest friends bought a friend of hers who I had never met before who a number of years earlier, before my friend knew her, had lost a child...And I just remember she came

to *shiva* one night and she said I just wanted to come and hold your hand. And you know I had, I had hundred and fifty or more people in my house, You know. I couldn't even remember all the people who came to my house those days, But I remember this woman coming and holding my hand.

P8: That on line support group has been a life saver. Everyone on there has lost a child to cancer. So....they understand.

P7: Joined support group..... It was the best thing for me. It was a group. It was people talking. It was a great experience to be able to be with Mom's that just get it. That have heard, you know, have heard the words, "your child has cancer."... But just to be able to, you know, they get it. They understand those feelings, those words are, you don't have to explain that to anyone.

P7: ...a group of parents. So I went to that for six weeks. ...it was the best thing I could have ever done. ...it was the best thing for me. It was a group. It was people talking. Everybody had the majority of the people had lost a child to cancer...it helped me with you know, that it's okay to not go through her room. To leave her clothes there, Two, three, four years later, you know. Because there were some that were out further than me.

Theme VI: The Role of Faith and Spirituality. All mothers spoke of the role spirituality prior to and during their grief process.

A. Faith keeps mothers going and may guide how they grieve.

P3: In fact I don't know how parents do it who don't believe that because I would think that it's just such an empty feeling.

P2: I was so so sure that when he passed away that *Moshiach* (messiah) was coming immediately and had I known then what I know now I would not have been able to survive. If I were to know that 36 years later I'm still waiting for *Moshiach*.

P7: I have to believe that, I do believe that there is somebody up there with her. And I say prayers before I go to bed. My own little thing. I talk to G-d on my own.

P1: I felt like I was letting him go and do his thing in heaven. He is busy up there, with all these other holy *Nehomas* (souls). It's more like letting him go to do those things. You know what, it's the same thing when you kid - letting Goldie go and get married and it was like, this is what you spend your whole life working on. You want your kid to get married and start their own house and then the night before the wedding I sat and cried. And not because of Joey but because she was getting married. It was like, it was letting go of her and

you know that expression if you love something let it go - it was talking about the butterfly. And that is how I think of him, he is flying, he is soaring, and I was holding on to him, I wasn't letting him soar. Now I feel like he can soar and he can achieve these great heights and I'm not holding him back.

P2: G-d doesn't want a person to mourn overly. It's not good for the soul of the person that passed away. They don't, they are not at rest when we are down here mourning constantly.

P2: I have to tell you this story. One of my daughters, the one that was born when Gabriel was sick, her first child was a stillborn. It was full term...my grandchild. I was with my daughter in the hospital when she gave birth. They knew there was something wrong with the baby but they didn't know what...and then the baby was born and he wasn't breathing and they had a whole team of doctors trying to get him to start. They worked on him and worked on him and worked on him, and nothing nothing. They asked my daughter if she wanted to hold him and she said no. I'm there and my heart is breaking like anything and I'm crying (crying) and I took the baby, the nurse gave me the baby to hold and I held him and then I stayed with him. Um, they took him into the morgue and I stayed with him for quite a while...and I was telling him all the things that I wanted to tell to Gabriel (crying).

B. *Mothers' belief that they will see their child again.* All mothers expressed the belief in some form of after life in which they will see their child again.

P8: He's my child. I love him. I try to, I try to live right so someday I can see him again.

P7: I still believe in G-d. To me there's gotta be somebody up there taking care of my daughter. There's just gotta be somebody there. And I am gonna see her again. That kind of stuff I do believe.

P3: I'm okay if I don't think of her each day. I think, me personally I know I'm going to see her again. That is just my background. I'm a Christian and I believe that she will be there. So for me, that kind of that sustains me...In fact I don't know how parents do it who don't believe that because I would think that it's just such an empty feeling.

P2: The fact I know he is coming back. G-d willing it should be soon.

C. *Shifts in religious and spiritual belief systems.* Faith keeps mothers going but the grief also can change the faith. Some mothers reported an evolution of their spirituality and faith. Several mothers spoke of having to accommodate their

preexisting belief structure to allow for a definition of G-d that would allow this to happen.

P4: So you know I was pretty pissed about the whole thing. But my spiritual life has evolved and I think that if I wanted to have any spiritual life at all it had to. Because it didn't make any sense to me anymore. You know. And it didn't make any sense to me that this G-d would be like, and Sophia will die, and this one will, you know. And I read a lot of books and bad things happen to good people. And you know different things and have come to a sort of different relationship kind of much less micro managing G-d that I had imagined before. And just sort of a you know, just like my dad on earth loves me and wants the best for me, can't really change a whole lot, you know, kind of there to talk to if I need him, but isn't going to be able to you know, dissolve cancer if I need him to. So my religious life, my religious belief has evolved all though this.

P8: The first three or four years were really rough with me with G-d. I wanted nothing to do with him...when he first died I remember saying there is no G-d. There was no G-d. There just couldn't be a G-d to take a child from a parent.

P7: There is a lot of reasons why things have changed. I still believe in G-d. To me there's gotta be somebody up there taking care of my daughter. There's just gotta be somebody there. And I am gonna see her again. That kind of stuff I do believe. Um, and I have to believe that, I do, believe that there is somebody up there with her. Um, and I say prayers before I go to bed. My own little thing. I talk to G-d on my own. As far as the church, the Catholic church, really really let me down through this whole thing.nobody contacted us....and I'm very bitter about that...finally the priest did come down because it was out of guilt he came down to the hospital and proceeded to try and justify her dying. She will never know pain. She won't ever know anger. She won't ever know hurt. She will never...and I looked at him and I said then explain to me why her 8 year-old brother is going to be experiencing all those things at once. Like it...you don't justify a 4-year-old's death. Just don't do it.

P3: I think I have to say stronger. I mean I always, I always – if you had asked me before I ever had kids I would say sure, I believe I'm going to heaven and that will be the end of it. But now there is a purpose. It's like, you know, when my dad passed away over a year ago one of my first thoughts was, Darn, he gets to see Jennifer before I do.

Theme VII: Changes in self. All mothers spoke of changes they experienced in themselves. They expressed a sense of feeling different but could not always articulate fully what that felt experience was.

A. *Feeling different.*

P4: I think it changes you at the core. Your sort of soul is different, you know, having gone through that and seen that and...but I don't know if the people who know me on the outside would see it much.

P5: It hurts when I think about how not, just not having her here as well as the changes in all of us for what we went through.

P4: In some ways I think I'm a whole different person...but it's hard to put into words but that experience is completely transformative.

P5: It's like the world shifted on its axis. You know. And you just can't find your mooring, just, I don't know. It's um, it's just so hard to put into words. You know, like the whole foundation of my life had been altered. You know you are never the same.

P5: I'm a different person now but it is sort of hard to say.

P5: I'm never going to go back to being how I was.

P3: If they knew about Jennifer it's different. At first you want to continue talking about your child but there is really nothing new to say you know. You can talk about your living kids you know what the next grade that they went, when they start driving a car, when they went to college. Your child who is gone they, they, don't ever get those milestones so there is nothing really new to say about them. Now for people who have never heard about Jennifer and I've just met them since Jennifer passed away I don't always chose to share anything about my past with them. It depends upon um if I feel like they are gonna be around and they need to know more about me or something otherwise, they don't know anything *different* about me.

P5: Loosing Rachel was really like losing a big huge part of myself in my life. Like I feel like I'm a diminished person. Because of what happened with Rachel.

B. *More empathic.* Mothers reported feeling other's pain more deeply.

P3: I think I'm a lot more aware. I never really paid that close of attention to other people who had kids who were very seriously ill - people whose

children had died. I have a friend who lost a child shortly after childbirth and it – it didn't really hit me so much about her lose until after Jennifer had died and then I thought, "Oh this is how Cindy must have felt."

P4: ...but I just felt that mother's pain and her anguish and just knew exactly what she was going through and what she is going to go through. And I just hate it for her.

P8: There's a women that lives around here - she almost lost her daughter. Her daughter has Down syndrome and she had a stroke four months ago. She ended up in the hospital. They didn't know whether she would live or die. And she was keeping everyone posted on Facebook. I was obsessed. I couldn't stay off of facebook. I was like constantly praying for her and just like my heart just went out to the mother.

P2: More understanding of others.

P1: Once I lost him I knew what it means to lose something and I wanted that back so badly...Before he died..... I don't think I gave too much thought to other people's pain. And then after he died I was really selfish I used to think I am going through the absolute worse, nobody's suffering is close to what mine is. But one thing that I learned is everybody's suffering is as strong as my suffering was to me that's how strong their suffering is to them. And it's helped me to feel I guess more empathy towards people.

C. Different values.

P7: I definitely have different values as far as what is important. You know people get upset when their refrigerator breaks or their dishwasher breaks, you know and it's just you just have to put everything into perspective. And some times that is easier said than done... You know, and we have to just continue to remind ourselves what's important.

P5: On the one hand, you know, maybe I am a little more easy going. I'm not as uptight about school things and other things. But on the other hand, it can also translate into I can be impatient with stuff. You know what I mean. Like some things just feel too trivial to have to deal with.

P5: I think on the one hand I feel like I am a very different parent then I was. Before my son was born and I just had my girls and they were healthy. Like on the one hand, I think I'm more easy going and maybe easy going can sometimes be translated into, I hope it isn't, but lacksidasical. I just don't have the mental and emotional energy for some of the things that I had before. So, on the one hand, certainly I'm a more empathetic person.

P5: I'm very different in what I tolerate and don't tolerate. I don't have the same kind of energy I had before... I also have less tolerance for the petty things that come up. Sometimes I just let it roll. Like I don't even have the energy to let something bother me that maybe would have, that maybe would be an annoyance.

P6: Again you know the biggest thing is me being a little more aware hopefully of what is important in life versus the things that just are more trivial and probably the focus, you know. And in some cases maybe even trying to help other people see that too.

P4: I think in general though it grows you up in a way that you don't have time for a lot of BS from people. You just sort of don't have the emotional energy for that kind of thing.

P8: But one of the good things is I used to be really hard on my kids and stuff. I'm a neat freak. Everything in its place. And everything. I'm still a neat freak that's me. But I don't impose my neat freakiness on the kids anymore. Like I'll be like clean your room and then I'll just go in there because at the end of the day it's not what I'm remembered for. I don't remember how many times I told Andrew to clean his room. So I guess I. with some things it's like I don't sweat the small stuff anymore. Like little stuff that people do I'm just like, it's really not that big of a deal.

D. Living in the moment—value life more.

P1: Well before he got sick I was very focused on you know, I'm taking this class and they talk about how people go through life and you do all these steps, you are just trying to get to whatever the goal is like it's making a certain amount of money or whatever. And that is what I was doing. I was working 3 jobs, and the kids, I was raising the kids but I wasn't in the moment. You know what I'm saying? But now I have this hanging on my kitchen, it's my absolute favorite saying, it is the Baal Shem Tov saying, "and it's like so central. *"Where your thoughts are there you are all of you."* Meaning that if I'm right here now and I'm talking to you. When we *pray* and we face Eretz Yisroel (the land of Israel) and we think about the *Bait Hamikdosh* (temple) it's like we are there. When you ask me questions about Joey and about what happened I'm there. My kids are talking to me in the car and telling me about their day and I'm thinking about what I gotta cook for supper. I'm not there with my kids. My physical body is there but my brain is elsewhere and I'm trying really hard to focus in on being in the moment, you know being with the kids.

P6: I try like I said to cherish the moments then maybe I would have otherwise...you value life a lot more when you lose someone like a child. Particular someone young like that. You do have a better sense of how short

life really is and well, even though I may not be the best at it, I try to treasure each moment and try to have a balance of what is really important versus what you might think is important.

P4: But I think my parenting with Scarlet is a little different. And I think....not in the way that I would have thought. I thought I would be more careful and worried and all that. I think I'm sort of a shit happens, kind of now. And like - experience it - go do it, dance, go outside if it's raining, you know, and I tried so hard with Sophia, from the moment she was born, I was supper like organic mom, making baby food, doing all this, everything was so perfect and then she died. And so you know, with this one I'm just like, you know, ice-cream for breakfast, sure why not? It's sort of given me a more of a free reign feeling you know. We are gonna just experience it all, you know.

E. More vulnerable.

P2: Much more vulnerable Very vulnerable. I think anytime - you know when Gabriel started that his leg was a hurting him - one of my other kids would complain...doctor came right over to my house...to reassure me. But I also, my some of my children had gone to school in a different neighborhood and I changed the schools to be in my neighborhood. I just did not want them ...I needed them to be close to me...every time a child gets sick of mine or my grandchildren I am in a panic. To this day.

P4: I have an awareness of the fragility of all of it that I probably didn't before. Have a glimpse into the really really importance of enjoying the day and not maybe counting on maybe the next ten years or whatever. That is good and bad. I mean it is awful to sort of think, you know, that way, but that'sbut fundamentally, like day to day, kind of you know I work at the same job, I'm married to the same man. I'm you know, no. I haven't like day to day life probably I lead it the same but I just know stuff I wish I didn't know.

P8: ...even before Andrew's illness I was a very protective mom. But since Andrew's illness I am probably over protective of all the kids. I worry constantly that something might happen... But now I guess with the kids now they get sick, my daughter even calls me - kid has a fever we need to go to the pediatrician. If it is after hours we are going to the hospital. She'll say it's probably okay and I'll say no let's take him to the hospital.

Theme VIII: Changes in world view. Mothers spoke of living in a world where the natural order of life has been violated.

A. Living with a changed world.

P1: I also spend a lot of time searching, I didn't want to know why he died, I wanted to know why we all had to suffer. Why did I have to suffer? Why did my husband have to suffer? Why did my in-laws, why did the kids? It was more like trying to figure out all the suffering that we were going through.

P3: I'm a little more aware of other people that are going through issues with their children. I mean before Jennifer got sick I had three of the most perfect kids you could ever want... It was an eye-opener that something like that happens.

P7: Everybody used to tell me that it's not G-d's fault. And You know what I totally agree. G-d did not give her cancer. G-d did not have her relapse. But he could have given us the miracle.

P3: I was disbelieving that it happened. I thought G-d you made a mistake...I honestly thought it...there had been a mistake. Life was not supposed to do that.

P2: In the middle of doing something I would all of a sudden start crying at first I thought that if you believe in G-d and if you believe G-d is good, which he is even though we don't understand it, why should I feel, why should I cry, why should I feel this emptiness. But that is part of grieving. And it is part of life...

P5: We've known other families since us who have lost children, and, which, sometimes I can't even believe how many people we know, that have lost children since I lost Hannah. Cause I think that before, like growing up I don't ever remember this. I don't remember my parents or cousins or anyone knowing anyone that lost a child.

P4: I'm sure it has matured me or opened my eyes in certainly a way that I didn't realize before – that there was such suffering and death and illness. But it's also, kind of like when you have a baby and you suddenly....I don't know, you are everybody's mom, you have a baby and you figure that out and then you are like oh all these babies are just as precious. And so I think that just like that sort of opens your heart. The same thing is when you lose a child, you know, it's made me realize that mothers' all over the world who this happens to, whether it is illness or war, whatever horrible thing it is, it's the same thing you know and so I think that it makes, it opens your heart in a different way, you know, that this kind of horrible sadness goes on all the time and there are lots and lots of children in hospitals right now you know full of these babies that are sick and all these mothers and fathers going through the same thing so I think it opens your heart in that way. Just everybody going through the situation that I didn't really look at before. Hard to look at before.

B. Living with a lack of control.

P8: Yeah. I just become....I don't sweat the small stuff. I just, I look at all countries and the fighting and I'm like, I think that I just wish everybody would be... I keep thinking that Andrew was twelve years old, and he died. And I came to realize that life is not promised to us. You don't know how long you are gonna be here. I wish people would just enjoy life and not sweat the small stuff. Looking for something to argue about or get mad about. Just learn to move on.

P4: But I think probably in a more personal kind of.....honest, it's made... it's certainly made me I think we all going through that have a little post traumatic, you know stress, and it certainly made me where I don't think I would have before looked for the danger in, you know, like just, is this day gonna bring something scary. Is this day gonna bring a death. Like I just know how life can change. Like everything's fine, la la la and then everything is really bad all of a sudden so I guess that is just, showed me that. Maybe I didn't know that before I didn't realize it you know.

P6: ...a lot that I can do and there is a whole lot that I can't do and so I sort of have to let that go too.

P2: ...for years I used to think at night should we have gone to this doctor should we have done this, you know how you do it. I would have gone this route, it would have ended up the same way because things are ... you have your choices, but you have to make your choices but in the end everything is from G-d.

P4: When we got to St. Jude's they were pretty brutally clear, that this is what we will do of you want us to. It will end the same way no matter what we do. I- you know still didn't believe that and so we did treatment and prayed and did you know everything I could think about doing and she died exactly the time frame and the way they said you know, she would. You do what you can or what you think you can.

Chapter V

Discussion

This research study explored the experience over time of eight mothers who had a young child die of cancer ten or more years ago. Although each bereaved mother in this study had her own unique story that was complex and heartbreaking several prominent themes emerged consistently across subjects. In interpreting these major themes three overarching themes or meta themes have been identified (see Figure 1). These meta themes encompass different yet overlapping aspects of the adaptation to the bereavement process: (a) the phenomenological: losing a child is a transformative experience; (b) the structural: the loss of a child is unique among losses; and (c) the theoretical: the nature of continuing bonds and its grounding in attachment theory. Relevance in terms of training and provision of clinical services will be examined. A discussion of study limitations and suggestions for future research will conclude this chapter.

Interpreting the Data

Meta Theme I: Losing a child is a transformative experience. The collective stories emerging from the mothers in the present study suggest that the loss of a child was a transformative event for these mothers, one that required a redefinition of the self and a shift in world view. The mothers spoke of the challenges of integrating the loss of their child into their life narrative, trying to make sense of and find meaning in such a devastating event, the changes in the self, the revisions they have made in their assumptions about the world and the ways these impact their social and relational worlds.

The mothers in the present study spoke of a sense of knowing that they are different in some fundamental way. They conveyed a sense of knowing that the experience of losing their child has forever changed them at their very core. Klass (1986) writes that the child is part of the psychic structure of the parent, and when a child dies the self itself needs to be redefined. A consistent theme expressed by the mothers in this study is that something about themselves has changed and that they are not the same person they were before their child died.

The death of a child creates an existential wound that shatters assumptions that the world is a fair and just place, that is predictable and controllable (Janoff-Bulman, 1992). For the mothers in the present study the death of their child created a disconnect whereby the world could no longer be experienced the same as before. The mothers expressed the felt sense that they could not be in the world in the same way as they were before their child died. Klass (2013) asserts that when death cannot be assimilated into one's existing world view then the components of the world view must be accommodated to the new reality. Mothers seek some way to make sense of what has happened to their child and to themselves. They seek to understand why this event occurred and in the process they have to adjust their worldview to incorporate the event and find a way to make sense of it that will allow them to continue living in a world that no longer includes the living breathing presence of their child.

In Klass' (1988) study of 155 bereaved parents he observed that as parents reconstruct their model of the self they simultaneously reconstruct their way of interacting within the social environment. A positive resolution to parental grief is not a return to how life was before. Rather, "the changed social self and the internalized

inner representation of the child are provisions for a new self that is different from the self the parent knew before the child died” (p. 80). Klass asserts that, “the resolution of parental bereavement is not a return to the status quo ante. The resolution of parental grief is found in the development of a new self. The new self, with its new social interactions and its new sources of solace, learns to live in a world made forever poorer by the death of a child” (p. 180).

A. Narrative reconstruction. How do mothers incorporate the paradoxes of loss? Living with absence and presence? Living in past, present and future? Holding on while moving on? How do mothers incorporate the experience of grief that changes overtime? How does grief change the sense of time and how does time change the sense of grief? How do mothers imagine a future self?

The notion of a future self is best understood through the process of narrative reconstruction. Neimeyer (1999) asserts that it is through a process of meaning reconstruction that makes sense of the past and lays a foundation for the future. Niemeyer observes that though a process of meaning making we seek to review and revise the fundamental meanings by which we organize a sense of self. We seek to organize our relationships that have continuity and coherence from our past to our present, to our now changed future.

Niemeyer (1999, 2010) suggests that this process is accomplished through the telling and re-telling of the narrative of the shattering event of the death and serves as a means of facilitating the “reauthoring of the self in the wake of loss” (p. 175). Mothers are faced with a reconstruction of meaning as they must accept a new normal and invest in a world where a child can suffer and die. Grief unfolds as mothers live

with loss and without the dead child in a new transformed reality (Arnold & Gemma, 1994).

For the mothers in the present study constructing a narrative and sharing stories of the child's life and death remains an important part of the bereavement process. Mothers strive to access that story rather than to cut it off and discontinue it. They strive to carry that story forward and mingle it with their own.

These mothers shared well-constructed, coherent narratives of their bereavement experience including stories of their relationship with their child, their child's diagnosis and treatment, the death, early grief, present grief and how they continue to assimilate the experience into their present lives and into their future lives. These narratives explained their bereavement experience to others and themselves.

As these mothers shared their stories they were reworking and reintegrating aspects of their experience in their continuing evolving sense of self. Several mothers had "aha" moments during the process of telling their narratives to this researcher which will change how they view aspects of their experience as they move forward in their bereavement. Through the process of narrative reconstruction the mothers' narratives evolve, grow and change as they are incorporated and reincorporated into their life narrative.

The mothers in the present study spoke of a sense of knowing that they are different in some fundamental way. They conveyed a sense of knowing that this experience has forever changed them at their very core. How the changes begin to be incorporated into a new sense of self was not easily articulated by these mothers.

Although mothers have some inkling of how they were transformed and in what ways there remains something unknown and perhaps unknowable in the process. The unknowable part is a central theme that runs through the data; it is possible that we may never fully understand this process of the transformation of the self following the loss of one's child. There are some things that you can adapt to, learn, know and understand over a life time of living with the loss of a child. But there may be some things that are unknown and unknowable.

Meta Theme II. The nature of continuing bonds. All the mothers interviewed in the present study spoke of experiencing a strong emotional bond with their child who died. The data suggests that these mothers find solace in continued connection and attachment to their child who died. This supports the continuing bonds (Klass et al., 1996) conceptualization of grief and how the inner representation of the ongoing relationships with the deceased loved one sits comfortably with bereaved individuals.

The mothers in the present study spoke of experiencing their child as being a part of their past, present and future. These mothers found ways to incorporate their child into their life and to live in ways that give purpose to their child's life and death. All the mothers interviewed expressed the idea that their child remains an active and dynamic force in their lives. Far from letting go of connections to their child who died, grieving mothers adapt, grow, and change these connections as they move forward in bereavement.

Additionally, the mothers in the present study expressed the need to continue mothering their child who died. Klass (1988) asserts that "parenting is a permanent

change in the individual. A person never gets over being a parent. Parental bereavement is also a permanent condition, for the death of a child is the death of a part of the self” (Klass, 1988, p. 178). The child who was physiologically part of the mother remains emotionally part of the parent. Death ends the child’s life but it does not sever the bond between parent and child; “parenthood as a psychobiologic process ends only with the death of the parent” (Raphael, 1983, p. 185).

A. *Social recognition of continuing bonds.* An important component of the continuing bonds paradigm for bereaved mothers is that those in their social and relational world understand, recognize and honor the reality that their child remains an active and present part of their life. Klass (1996) examined the transformations, both internally and socially, that occur for bereaved parents as they come to terms with the death of their child. Klass asserts that the primary purpose of these transformations is the integration of the representations of the deceased into the psychic *and* social world of the bereaved parents. When the reality of the continuing relationships between parent and child is recognized socially, the parent is better able to adapt to the internalized representation of the child.

Indeed the mothers interviewed in the present study expressed feeling grateful, validated, relieved, pleased, and understood when others spoke about their child and when others recognized that they continue to be a mother to their child who died. It was vitally important to them that others recognize that their child continues to be a present and active force in their lives. Klass et al., (1996) write that “the end of grief is not severing the bond with the dead child, but integrating the child into the

parent's life and into the parent's social networks in a different way than when the child was alive" (p. 199).

B. The absence of presence and the presence of absence. Another important finding in the present study is the idea of absence of presence and the presence of absence (Goss & Klass, 2005). The mothers' use of past and present tense when speaking about their child speaks to the fluid and seamless way in which mothers live with physical absence but psychological presence. Living with the presence of absence is a different kind of awareness. The child's absence is always felt and that absence has a presence. It takes up space.

The mothers expressed the feeling that their child is always missed and that their child is always missing. Mothers are aware of those who are physically present and just as aware of those who are not physically present. Just as mothers remember the important things that happen for their children mothers cannot escape the awareness of the important things that have not happened for their children. Since time and experience does not stop the loss of one's child is continuously experienced and re-experienced, negotiated and re-negotiated (McCabe, 2003).

Rosenblatt (2000) explains the way in which parents continue their child's timelines filling in their empty track:

parents continue to be in contact with the child who died in that they keep track of the timeline the child would be on. In their narrative they might note when the child would have started school, begun dating, or taken driving lessons. That means, in a sense, that parents recurrently reach new losses; each event and achievement that the child does not reach is a new loss for the

parents. Another way to understand it is that parent and child are still connected in the present. Continuing to keep track of the child's timeline is a way of saying, "I have not given up on you; I still know what and who you would have been" (p. 134).

Mothers continue to hold on to their child in their mind and heart. The mothers in the present study spoke of having an awareness that their child is absent while simultaneously having a felt sense that their child is very present.

Meta Theme III. Child loss is unique among losses. The data from the present study supports the literature that recognizes parental grief of a child to be of a different kind with a different trajectory than other losses (Rando, 1996; Knapp, 2009; Klass, 1988). In his research with bereaved parents Klass (1988) writes "clearly here was a grief that had a different quality from what I had seen before" (p. xii).

Several researchers have argued for the inclusion of Prolonged Grief Disorder (PGD) in DSM-5 (Prigerson, Vanderwerker & Maciejewski (2008). Such an inclusion would place the concept of grief in the realm of pathology and runs the risk of pathologizing the normative grief response of parents who have lost a child. The key features of PGD being disbelief regarding the death; anger and bitterness over the death; intense yearning for the deceased with recurrent pangs of painful emotions; preoccupying thoughts of the deceased including intrusive thoughts related to the death. These key features usually last longer than 6 months, impeded and hamper daily life and work functions, and create a sense of hopelessness and isolation for the sufferer. Following this criteria the grief response of all the mothers in the present study would be considered pathological.

Several mothers spoke of their experience in therapy and feeling that their therapists did not understand and recognize the uniqueness of child loss and what they knew they were experiencing. These mothers said that it felt like their therapists were providing them with generic “grief 101.” Several mothers were prescribed antidepressants within weeks of their child’s death.

When that understanding is lacking mothers feel that their experience is being trivialized. This adds to mothers’ pain and frustration as they feel marginalized. Mothers feel understood and validated when their grief is recognized to be of a different quality. The data suggests that there is something existentially different about this type of loss. This concept emerged in all the responses in various forms across all the mothers

A. Grief over a lifetime. The present study supports Arnold and Gemma’s (2008) research findings that parental grief is best appreciated as grief over a lifetime. Klass (2013) asserts that “meaning reconstruction, reinvestment, and so on can co-exist with continuing sorrow” (p. 598). Consistent with this finding the mothers in the present study multitask:

they assimilate into their preexisting worldview, change their worldview, and evolve in their sense of sorrow. And they continue to do all three in their ongoing lives long after clinicians would say that they are done grieving. Most of us are seldom of one mind or psychic state, and bereaved people remain of many minds and states...It appears, then, that we can grow, that we can change, that we can still believe; and yet that we can still be not resigned to

the death. We can accept reality, but the reality can still remain ultimately unacceptable (p. 600-601).

The mothers in the present study expressed the need for people to recognize the fact that their child's life and death remain a part of their ongoing life forever. Mothers continue to hold on to their attachment to their child, they continue to grieve the loss of their child and they continue to figure out how to live in the world where their child no longer physically exists but is very much a part of their psychological life.

Balk's (2004) questioning of the appropriateness of the term "recovery" in relation to grief is particularly relevant to child loss. The often used word "recovery" in the bereavement literature did not match the experience of the mothers in the present study. The mothers in this study did not believe they would ever "recover" from the loss of their child and found the concept insensitive and not reflective of their experience. The mothers did not resonate with the idea that their grief would ever fully end nor did they think that was possible or desirable. The experience of these mothers fits better with Balk's understanding of a grief process trajectory that involves profound redefinition of one's sense of self so as to allow for eventual integration into a different version of life.

B. Shadow grief. As this study suggests, the conventional theories that look towards the resolution of grief are inadequate when applied to the death of a child. Peppers and Knapp (1980) coined the term "shadow grief" to describe the burden of grief that mothers of a child who died in infancy carry for the rest of their lives. Parents experience a painful awareness of the child's death that never completely goes away. While overtime bereaved parents function normally, shadow grief is

“characterized by a dull ache in the background of one’s feelings that remains fairly constant and that, under certain circumstances and on certain occasions, comes bubbling to the surface, sometimes in the form of tears, sometimes not, but always accompanied by a feeling of sadness and a mild sense of anxiety” (Knapp, 2005, p. 43).

Clinical Implications of the Study

The goal of this study was to contribute to what is known about the longer-term sequelae of the death of a young child from cancer and what the findings mean for the training of clinicians and the development of new treatment intervention models. The findings suggest that mothers who have had a young child die from cancer share some common concerns and challenges as they navigate and reconstruct a sense of self in a changed world. The following recommendations are made in recognition of this fact, with the goal of helping mental health professionals and other care providers better serve this population and their families. Many of the findings of this study have important implications for clinicians.

1. Death education and training are necessary for clinicians working with bereaved mothers. Clinicians must be familiar with the normative data about parental loss of a child so as not to misdiagnose or pathologize the unique but normative trajectory of those suffering the loss of a child. Clinicians must understand that grief is a process that cannot be rushed.

2. When providing treatment to bereaved mothers it is important for clinicians to focus on the individual experience of the mother rather than relying on grief theories. Bereaved mothers should be approached from a position of “not knowing”

rather than presumed understanding to allow for an understanding of each bereaved mothers unique experiences. Clinicians must keep in mind that the mother is the expert on what she is experiencing. Bereaved mothers yearn to have their experience understood and validated.

3. It is important for clinicians to understand how grief theories have shifted from more traditional stage theories of grief to more constructivist theories in order to conceptualize and make use of the most current and appropriate theories when working with bereaved mothers. A constructivist grief framework emphasizes the important role of meaning making throughout the grieving process. Central goals of a constructivist grief framework when working with bereaved mothers include: a) helping mothers find or create meaning in the death of their child and in their present life; b) exploring ongoing emotional attachment and relationship with their child and how this connection can offer solace; c) helping mothers to integrate their child's story into their ongoing life; d) encouraging the construction of meaning and the integration of meaning into a newly constructed life narrative; d) facilitating the construction of meaning on both an intrapersonal and interpersonal level; e) using the narrative approach as a guiding concept to facilitate the re-authoring of a newly constructed life narrative.

4. Another important area for clinicians working with this population to be aware of are the myths associated with the loss of a child. There is falsely accepted myth that couples cannot survive the loss of their child. This myth has become accepted as a piece of common knowledge when the reality is that it is false. The mothers in the present study spoke about this and the data suggests otherwise.

Although this myth has since been challenged (Compassionate Friends, 1999, 2006; Schwab, 1992) with no evidence for a higher divorce rate among bereaved parents, many clinicians, researchers and those in the general population continue to perpetuate this myth adding an undue burden on grieving couples. If clinicians have accepted this myth as truth then as they enter into a therapeutic relationship with bereaved mothers, fathers and families they may transmit this message in subtle and not so subtle ways bringing an undue burden on couples grieving the loss of their child.

5. Clinicians must have comfort sitting with ambiguity, with the unknown and the unknowable. They must have comfort sitting with the paradoxes of loss. For example, sitting comfortably with the fluidity with which mothers speak of their child in past, present and future terms. It is allowing for the possibility that joy and sorrow can co-exist. What it means for mothers to live with the absence of presence and the presence of absence. What it means to sit with mothers who have accepted the death of their child while simultaneously the death of their child remains completely unacceptable.

Suggestions for Further Research

The results of this exploratory study illustrate that mothers who had a young child die from cancer ten or more years ago share common thoughts, feelings and experiences. This was an open-ended hypothesis-generating study; further research is needed to gather more data about specific processes by which mothers adapt to the loss of their child. Future studies may, in part, focus upon developing and examining alternative intervention models created from phenomenological data. Ideally such

studies should utilize a mixed models methodology, including both quantitative, empirically based instruments and qualitative measures.

Additional study is needed to explore these findings across a wider sample, particularly focusing on those groups underrepresented in the present study. Examining how cultural and spiritual factors may both complicate and facilitate the grieving process is a particularly rich area of inquiry. Future studies that catch parents along the continuum of grief, as well as studies that assess attachment style and its meaning for those grieving the loss of a child are important as well. Another area of study might include how transitional objects and transitional phenomena can facilitate internalization of the lost person and its meaning for the bereaved. Studies that examine who is and who is not able to find something positive in loss, factors that predict difficulty in making meaning as well as the emotional consequences of finding meaning is another area in need of further research.

Limitations of the Study

The limitations of this study reflect the nature of qualitative research, focusing on phenomenological experiences with small samples. Study participants were not chosen at random and therefore the results from the study cannot be construed to represent the characteristics of the large population of bereaved mothers. Participants were at one time or another part of an online support group for mothers who lost a child to cancer and all participants responded to a request to be interviewed. Thus results may not be extrapolated to those who do not engage in such a support seeking endeavor.

Additionally, the sample size of this study was intentionally small to capture the richness of the stories in the qualitative analysis. However, the study's small sample size of eight participants means that statistical conclusions cannot be drawn to infer similar characteristics to the larger population of bereaved mothers.

An additional limitation of the study was the homogenous ethnicity of the sample, all members of whom described themselves as Caucasian. Thus, future research with a more diverse sample is needed. Studies that utilize cross-cultural samples are needed to better understand the ways in which bonds are retained in other cultures following loss of a child.

Conclusion

This qualitative research study provides an in-depth exploration of a sample of eight bereaved mothers' experiences over time following the death of their young child from cancer ten or more years ago. The study's aim was to extend and deepen current understanding of parental grief. Through a grounded theory analysis of the data three overlapping aspects of the adaptation to the bereavement process were identified: (a) the phenomenological: losing a child is a transformative experience; (b) the structural: child loss is unique among losses; and (c) the theoretical: the nature of continuing bonds.

This study expands and supports a constructivist grief framework that views parental grief as a continuing and evolving process. A process that includes an ongoing connection between a mother and her deceased child; a process that recognizes that mothers create and navigate a narrative that grows, changes and moves with mother as mother moves forward in time. It is not about closure. It is

about learning to live with ambiguity; learning to live with paradox; learning to live with the pain of the loss.

Education and training is an integral component for increasing the effectiveness of those who are supporting individuals experiencing loss and grief. Older stage-based paradigms continue to inform public policy and to dominate Western professional and lay expectations of bereavement. Understanding the multidimensional impact of bereavement has clear implications for research and clinical intervention. As bereaved mothers must re-learn to navigate their changed world and changed self, so too must professionals seek to have a better understanding of this profound experience. Such a commitment to understanding the nature of this grief will lead to examining and promoting new theories that are grounded in empirical evidence, which includes the phenomenological experience of bereaved mothers. Only through this professional, and perhaps even broader societal commitment, can the most effective support be offered to help bereaved parents navigate one of life's most emotionally challenging experiences.

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Table 1

Summary of Participant Demographics

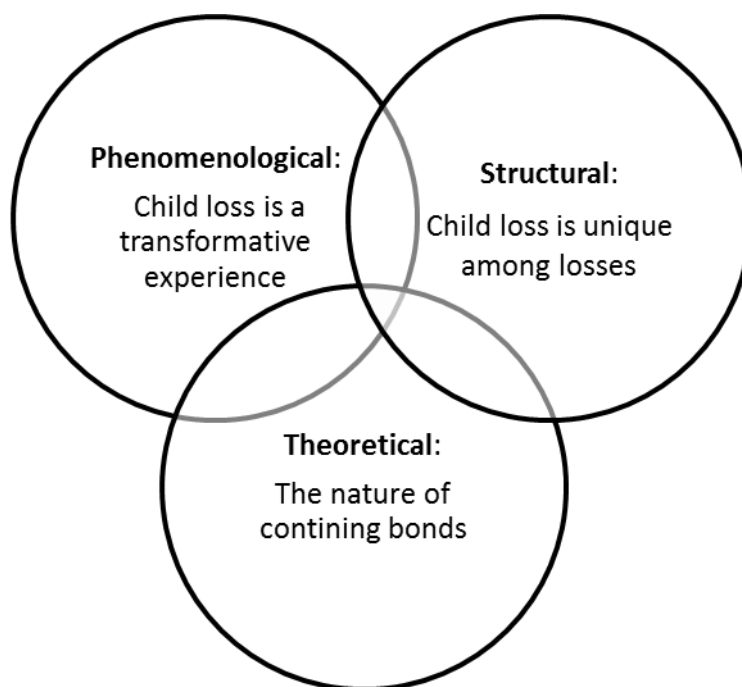
Participant	P1	P2	P3	P4	P5	P6	P7	P8
Age	46	62	50	49	53	66	49	46
Race/ Ethnicity	Caucasian	Caucasian	Caucasian	Caucasian	Caucasian	Caucasian	Caucasian	Caucasian
Education	AA	Some College	BA	BA	JD	MS	Some College	HS
Occupation	Elementary Teacher	House Wife	Purchas- ing	Dental Hygienist	Attorney	Chemist	Adminis- trator	Waitress
Religion	Jewish Orthodox	Jewish Orthodox	Christian	Baptist	Jewish	Lutheran	Catholic	Catholic
Years Married	25	46	32	23	26	27	21	Divorced (before diagnosis)
# of Children	7	13	3	2	3	5	2	2 and Custody of 2
Age of Child at Diagnosis	9 years	5 years	9 years	6 years	11 years	8 years	6.5 months	9 years
Years Since Child Died	12	36	15	12	12	17	10	10
Age of Child at Time of Death	13	6	13	7	13	8	5	13
Length of Illness	4 years	1 year	4 years	1 year	1 year	2 years	4 years	3.5 years
Type of Cancer	Leukemia	Leukemia	Colon	Brain Tumor	Bone	Ewing Sarcoma	Brain Tumor	Carci- noma
Age of Siblings at Time of Death	11, 9, 7, 5	1, 3, 5, 8, 9	14, 13	None	9, 5	17, 15, 7	8	13, Custody - 2, 4
# of Children Born after death	2	8	None	Adopted Infant	None	None	None	None

Table 2

List of Themes

<p>Theme I: Grief is an individual and ongoing process that changes over time</p> <ul style="list-style-type: none"> A. The individual nature of grief B. Grief has no time line C. Grief changes the experience of time. <ul style="list-style-type: none"> 1. Time is experienced as both longer and shorter 2. Time both stops and continues D. Early phases of grief are remembered with acuteness <ul style="list-style-type: none"> 1. A sense that the pain will last forever 2. Shock and numbness 3. Metaphors 4. Need to keep busy 5. Anger 6. Denial E. Maternal preoccupation – all consuming F. Grief never ends G. Grief never ends...but it eases <ul style="list-style-type: none"> 1. The passage of time influences grief 2. Bad memories fade 3. Mothers learn to manage their grief H. Grief changes over time – but some things don't change <ul style="list-style-type: none"> 1. Child is always missed, child is always missing 2. Fear that child will be forgotten <p>Theme II: Mothers continuing attachment to their child</p> <ul style="list-style-type: none"> A. Felt sense of child B. Telling stories about child's life, death and grief C. Mother's feel a need to do things for their child D. Fulfilling child's wishes, child's mission – internalizing child's good qualities E. Maintaining relationships that honors child's presence in mother's life <ul style="list-style-type: none"> 1. With siblings F. Relationship is bi-directional <p>Theme III: Mothers make a conscious decision to live life</p> <ul style="list-style-type: none"> A. Often because of the other children B. To honor the memory of their child C. Helping is healing 	<p>Theme IV: Themes of Guilt</p> <ul style="list-style-type: none"> A. Guilt for not saving child B. Guilt when not thinking of child C. Guilt for neglecting other children and concern for the long term effects on them. <p>Theme V: The Impact of grief on relationships</p> <ul style="list-style-type: none"> A. Some relationships are strengthened and some are lost <ul style="list-style-type: none"> 1. Relationship with spouse B. Helpful and harmful comments and gestures C. Seeking out and relying on various supports <ul style="list-style-type: none"> 1. Community of friends, family and neighbors 2. Professional support 3. Connecting with others who have been through the same <p>Theme VI: The role of faith and spirituality</p> <ul style="list-style-type: none"> A. Faith keeps mothers going and may guide how they grieve B. Mothers belief that they will see their child again C. Shifts in religious and spiritual belief systems <p>Theme VII: Changes in Self</p> <ul style="list-style-type: none"> A. Feeling different B. More empathic C. Change in values D. Value life more-Living in the moment E. More vulnerable <p>Theme VIII: Changes in world view</p> <ul style="list-style-type: none"> A. Living with a changed world B. Living with a lack of control
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Figure 1

Meta Themes

Appendix A
Demographic Interview

Age: _____

Racial/ethnic Background: _____

Religion: _____

Education: _____

Years married: _____

Years since child died: _____

Number of children: _____

Age of child at time of diagnosis: _____

Type of cancer: _____

Length of child's illness: _____

Age of child at time of death: _____

Number of children born after child's death: _____

Appendix B

Semi-Structured Interview

1. Can you tell me your child's story?
2. Could you tell me a little bit about your experience at the time of his/her death?
3. Have you heard the expression "working through your grief" and what would that mean to you?
4. Can you describe the ways in which you continue to be attached to him/her? How does that connection, internal relationship you have with him/her, how does that, affect you in your life today?
5. Could you tell me of some personal changes that you have experienced since he/she died?
6. Do you lead your life differently now because of his/her death?
7. How might you say your attachment to him/her is different or the same since he/she died? And different from the year he died, 5 years after he died, versus now?
8. Are there specific times that he/she comes to your mind?
9. How do you picture him/her in your mind's eye?
10. Thinking back, how has the lived experience been the same or different from what you may have imagined it was like to go through the grief process. (How were your expectations of what it was like to go through a grief process the same or different than what you experienced?)
11. Do you continue to have a relationship with your son/daughter? How has it changed or evolved over time? How might you explain the change in your attachment?
12. How does that connection, internal relationship you have with you child, how does that affect you in your life today?
13. Are there particular triggers that bring on the waves of grief? At this point in time different from early on?
14. I'd just like to check in now – what has it been like for you to speak about all this with me? How do you feel having gone into all of this?

15. Have you experienced changes in your world view since his illness and death?
16. Have you heard the expression “letting go” and what would that mean to you?
17. What has it been like in your relationship with others since your son’s death?
18. How has your relationship with your husband changed?
19. Did you seek therapy at all after losing your son?
At what point after his death did you seek therapy for yourself and what was that experience like for you?
20. What have you learned through your grief process that you would want therapists to know? Looking back now from your perspective now 11 years out, what do you think is most helpful for therapists to know about when working with newly bereaved mothers?
21. What can you offer someone in the early time after their child has died?
22. How might you describe the needs of bereaved mothers as time goes on five, ten and beyond years after the loss?
23. Do you think there is anything I left out? Anything you would want to tell me.

Appendix C

Informed Consent for Study Participants

Informed Consent Agreement

You are invited to participate in a research study. Before you agree to participate it is important that you know enough about this study in order to make an informed decision. If you have any questions about the nature of this study, please ask the principal investigator (PI). You should be satisfied with the answers you received from the PI before you agree to participate in this study.

Purpose of the Study

The purpose of the present study is to explore the experiences and needs of mother's whose young child died from cancer eight or more years ago with the goal of offering best practices for those helping bereaved mothers both in the early phase of bereavement and over time. Mothers will be asked to be reflective as to what was helpful, what was unhelpful, how the needs of bereaved mothers change over time, and their experiences in therapy.

The principal investigator (PI) is a doctoral student at the Graduate School of Applied and Professional Psychology at Rutgers University and is conducting this study as a fulfillment of dissertation and doctoral requirements. It is anticipated that 8-10 individuals will participate in this study. If you wish to be provided with the general results of this study, you should notify the PI, and this information will be shared with you at the completion of the study.

Study Procedures: You will be interviewed about your experiences over time since the death of your child. The interview will take about 2 hours.

Interviews will be audio taped in order to ensure accurate transcription and authenticity of the data obtained. Interviews will be transcribed and tapes will be destroyed after transcription. The PI will maintain any tape recordings, transcripts of interviews, or other data collected from you in confidence in a locked file cabinet. These materials will be destroyed at the end of the study.

Risks: The interview focuses on your experience over time since the death of your child. Research shows that most parents who participate in research regarding the loss of their child find it personally beneficial. However, if in reflecting on your experiences you experience discomfort or distress recalling painful memories or discussing matters of a personal nature, it is important you notify the PI immediately so that she can discuss these feelings with you and provide you with referrals to local counseling services if necessary. Note that the study will not pay for any counseling services recommended following participation in this study. In this event, you would assume all financial responsibility for such services.

Benefits: Your experience and knowledge have tremendous value in helping the field of bereavement, and in particular bereavement following loss of a child. The present research will contribute to the current literature on therapists' experiences working with bereaved mothers, enhance clinician's understanding of how best to support mother's following the loss of a child, and may be useful in guiding future graduate training programs interested in helping bereaved individuals.

Confidentiality: All records will be stored in locked files and will be kept confidential to the extent permitted by law. The data obtained from your interview will be stored on an electronic data file in the PI's password protected personal computer in order to keep it confidential.

The data will be available only to the research team and no identifying information will be disclosed. Audiotapes and other paper work will be assigned a case number. Your responses will be grouped with other participants' responses and analyzed collectively. All common identifying information will be disguised to protect your confidentiality. This will include changing your name and other demographic information (i.e. age, occupation).

Research Standards and Rights of Participants: Your participation in this research is VOLUNTARY. If you decide not to participate, or if you decide later to stop participating at any time during the interview, you will not lose any

benefits to which you are otherwise entitled. Also, if you refer other individuals for participation in this study, your name may be used as the referral source only with permission.

I understand that I may contact the investigator or the investigator's dissertation chairperson at any time at the addresses, telephone numbers or emails listed below if I have any questions, concerns or comments regarding my participation in this study.

Subject's Initials-

Melanie Karger, Psy.M. (Investigator)
Rutgers University
GSAPP
152 Frelinghuysen Rd
Piscataway, NJ 08854-8085
Telephone: 973.607.7068
Email: mkarger@eden.rutgers.edu

Monica Indart, Psy.D. (Chairperson)
Rutgers University
GSAPP
152 Frelinghuysen Rd
Piscataway, NJ 0885408085
Telephone: 848.445.3951
Email: mjmindart@yahoo.com

If you have any questions about your rights as a research subject, you may contact the IRB Administrator at Rutgers University at: Rutgers University, The State University of New Jersey
Institutional Review Board for the Protection of Human Subjects
Office of Research and Sponsored Programs
3 Rutgers Plaza
New Brunswick, NJ 08901-8559
Tel: 848.932.4058
Email: humansubjects@orsp.rutgers.edu

I have read and understood the contents of this consent form and have received a copy of it for my files. I consent to participate in this research project.

Participant Name (Print) _____

Participant Signature _____ Date _____

Investigator Signature _____ Date _____

Informed Consent Agreement Audiotape Addendum

You have already agreed to participate in a research study entitled *Exploring Mother's Experiences Overtime Following Death of Their Young Child from Cancer: Implications for Practice* conducted by Melanie Karger, Psy.M. This form requests your permission to allow the Principal Investigator (Melanie Karger) to make a sound recording (audiotape) of your interview as a part of this research study.

You do not have to agree to be recorded in order to participate in this study.

If you do agree to audio-taping, the recording(s) will be used for analysis by the primary investigator (Ms. Karger).

The recording(s) will be distinguished from one another by an identifying case number. Your name will not be used or linked in any way to the recording except through a case number held by the principal Investigator.

The recording(s) will be stored in a locked file cabinet by identifying number not by name or other information that might disclose your identity. The tapes will be retained until the project is completed and the dissertation has been successfully defended. It is expected that the tape will be destroyed within four years after your interviews.

Your signature on this form grants the Principal Investigator permission to record you during your participation in the above-referenced study. The investigator will not use the recording(s) for any other reason than that/those stated in the consent form without your written permission.

Participant Name (Print) _____

Participant Signature _____ Date _____

Investigator Signature _____ Date _____