AN ABSTRACT OF THE DISSERTATION OF


Abstract approved:  

One of the most powerful and life-changing events that can occur in the life of a family is the death of a child. Researchers who have studied death and bereavement suggest that a child’s death has a dramatic impact on parents. However, little is known about the ways in which child loss influences a parent’s sense of identity and subsequent parental behavior. The purpose of this study was to explore how the life event of having a child die affects parents in their sense of identity and behavior as a mother or father. It was also to search for common patterns and themes in parental accounts of a child’s death that provide a better understanding of this topic. Individual mothers and fathers were interviewed and asked about their experience in losing a child, and how this experience shaped their feelings of identity and parental behavior in relation to both the deceased child and their other children. Nineteen mothers and fathers who had children die as a result of accidental causes or illness were interviewed. Interview transcripts were qualitatively analyzed for content. Findings were broken into four primary categories: (a) parental experience in the context of loss; (b) impact of a child’s death on parental
identity; (c) parental behavior in relation to the deceased child; and (d) parental behavior in relation to surviving children. The findings provided support to the idea that a child’s death has a significant impact on parental identity and a parent’s subsequent behavior. The findings demonstrated that how a child dies is a critical factor in how parents experience the loss. The findings related to parental identity show that parents struggle with their sense of competence, mourn the lost parent-child bond, and feel a loss of parental hopes for the future. The findings about parental behavior in relation to the deceased child suggest that connecting with and remembering the child in diverse ways are fundamental aspects of parental behavior after a child’s death. The findings also show that a child’s death shapes surviving parent-child relationships as parents mediate the loss experience for children, become more protective, and increase their parental efforts in behalf of children.
Parental Accounts of A Child’s Death:
Influences on Parental Identity and Behavior

by

Sean E. Brotherson

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Approved:

Redacted for Privacy
Co-Major Professor, representing Human Development and Family Studies

Redacted for Privacy
Co-Major Professor, representing Human Development and Family Studies

Redacted for Privacy
Chair of Department of Human Development and Family Sciences

Redacted for Privacy
Dean of Graduate School

I understand that my dissertation will become part of the permanent collection of Oregon State University libraries. My signature below authorizes release of my dissertation to any reader upon request.

Sean E. Brotherson, Author
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I dedicate this work to my brother Mark, who we loved and lost too soon; my parents
Karen and Jack, who have been heroic to me; and my wife, Kristen, my love.
CHAPTER I

INTRODUCTION

Each life's journey is a personal journey, one person's pathway through the events and changes which mark the developmental terrain of the mortal landscape. Some life events are commonly experienced, such as marriage, others may affect a person due to distinctive cultural or cohort experiences within a group or time period, and yet others are unique to both the unfolding pattern of individual development and personal experience (Baltes, Reese, & Lipsitt, 1980). The study of adult development focuses on the question of how individuals experience such events during adulthood and how transitions in adult life may be critical to an adult's sense of meaning and identity. In particular, much of developmental theory attempts to frame distinctive life experiences, periods, or transitions in adulthood that can affect an adult's sense of identity (Baltes, 1987; Duvall, 1962; Erikson, 1959, 1982; Levinson, 1978, 1990; Loevinger, 1976; Vaillant, 1977).

Developmental theorists like Erik Erikson (1950, 1959, 1982) have suggested that the formation of a coherent sense of individual identity is central in the journey of human development. Thus, as individuals continue the ongoing process of establishing a sense of identity, it is clear that certain events may significantly impact the formation of identity and its influence on their sense of personal meaning and subsequent behavior.

Life events that impact developmental experience are many and varied. The theory of identity development formulated by Erikson (1959, 1982) highlights a process
of dynamic stages and transitions that individuals move through which are associated with different periods of life maturity (age periods). As individuals move into young adulthood and middle adulthood, the primary developmental tasks associated with these stages of life development are developing *intimacy* with others and *generativity*, or caring for the next generation. In other words, working at and having some success in these "developmental tasks" becomes important at each stage of life for the maintenance of a strong, coherent sense of identity. Among the life events associated with these developmental tasks, becoming a parent and doing the hard work of parenting are suggested as being common to this experience for human beings, although not universal. For example, Erikson asserts, "Parenthood is, for most, the first, and for many, the prime generative encounter" (1964, p. 130). He thus suggests that a parent's relationship with a child can be critical to his or her individual sense of identity in adulthood. Since generativity, and specifically parenthood, represents a primary task of identity development for many individuals in Erikson's model of adulthood, any life event that alters or transforms the parental experience would then have significant implications for identity development.

The experience of being a parent is a lifelong career (Cowan & Cowan, 1992), and so may become a very strong component of one's individual identity. Stryker (1980, 1981) theorized that identity is framed within the role context and developed through repeated interaction with significant others, such that any person's self-concept is composed of multiple "identities." Of particular importance is the salience of an identity, or how prominent it is in one's self-concept (McCall & Simmons, 1978). The essence of
an identity is comprised of one's self-meaning in a role (LaRossa & Reitzes, 1993), and parenthood is generally a role which most parents invest with a great deal of personal meaning and significance (Cowan & Cowan, 1992). If an individual encounters a life event that threatens or dramatically impacts one's sense of parental identity, then both the individual and others may well experience important shifts in their emotions, attitudes, or behaviors related to parenting. Perhaps one of the most powerful life events in a family occurs when a family member dies, particularly if the event is unexpected (Holmes & Rahe, 1967; Holmes & Masuda, 1974). This potentiality suggests the question of how parents who lose a child shape the meaning of that experience and how this event influences the parent's sense of identity.

Neugarten (1979) has suggested that one critical type of experience may be a life event that occurs "off-time" in the life cycle rather than at an expected time, upsetting the expected trajectory of an individual's experience. Another perspective on this type of experience categorizes life events as normative and non-normative, with increased individual stress occurring as a result of non-normative experiences (Pearlin, 1975). Theorists who study death and bereavement have suggested that the loss of a family member, particularly a child, is such an "off-time" or "non-normative" event, and that this can have negative consequences for the survivors (Danish, Smyer, & Nowak, 1980). In fact, a child's death is recognized as being among the most difficult life events that a parent may encounter (Sanders, 1980). The importance of such an event for parents and their subsequent parental experience is punctuated by the recognition that any such
personal loss is "intrinsically linked to the disruption of a sense of personal identity" (DeGarmo & Kitson, 1996, p. 983; Parkes, 1986; Weigart & Hastings, 1977).

Recent theoretical work has focused on integrating identity and stress theory, providing a substantial theoretical context for understanding the impact of child loss on parental identity (Burke, 1991; Thoits, 1991). Thoits’ (1991) theory of identity relevance postulates that the more important an identity is to an individual, the more significant will be the impact of a stressor related to that identity. Additionally, a consequential life event will disrupt a person's sense of identity and necessitate reconstruction of its meaning (Burke, 1991). A child's death, then, is a powerful life event that may alter or transform one's parental identity and this impact will lead to both negative and positive influences on individual and family well-being (DeGarmo & Kitson, 1996). Due to the potentially significant influence that a child's death can have on a parent and the family system, research that examines how such a loss affects and changes parental identity and subsequent parental behavior can make a valuable contribution to our understanding.

In recent years a new body of literature has emerged that suggests life experiences are given meaning and linked to identity as individuals frame such experiences in a narrative context (Dollahite, Hawkins, & Brotherson, 1996; Day, 1991; Mair, 1988; Martin, Hagestad, & Dietrick, 1988; McAdams, 1985, 1993; Polkinghorne, 1988; Riessman, 1993; White & Epston, 1990). Bruner (1990) posits that individuals make sense of their experience primarily by presenting it in narrative form. Others assert that identity itself is formed and changed in a "life story," as individuals make meaning of life events and formulate stories that express their identity (MacIntyre, 1981; McAdams,
Widdershoven introduces the concept of "narrative identity," this being "the unity of a person's life as it is experienced and articulated in stories that express this experience" (1993, p. 7). Narratives thus reflect life experience and the interpretation of events, and so embrace the meanings embedded in the creation and re-creation of one's identity. Since narratives capture this important human process of developing an identity and re-shaping it through subsequent life experience, they may be an appropriate and potentially powerful vehicle for examining individual identity in specific contexts (Palus, 1993). This study will explore narrative accounts of parents' loss of a child to gain insight into how such a life event impacts parental identity and shapes subsequent parental behavior.

**Statement of the Problem**

The topics of death of a family member, bereavement, and grief have been studied for many years in the social and behavioral sciences. However, at present only a minimal amount of in-depth research using a qualitative approach has been conducted. While a number of studies have examined the experience of losing a family member by using qualitative methodologies (Carter, 1989; Farnsworth & Allen, 1996; Kessler, 1987), those that have limited the participant population to parents who have lost a child are few in number (Bernstein, 1997; Cook, 1983; Edelstein, 1984; Knapp, 1986; Miles & Perry, 1985). Additionally, these studies generally focused on the grief expression of the individual rather than how the event impacted a sense of parental meaning and identity. Since losing a child may significantly impact an individual's sense of parental identity
and their subsequent experience as a parent (Burke, 1991; Cleiren, 1993; Knapp, 1987), research which highlights this process can provide valuable understanding to parents, scholars, and practitioners.

The experience of child loss for parents has undergone much change over the last century. Whereas it may have been likely for nearly half of all parents to undergo a child's death a century ago, decreased child mortality rates make it much less likely today (Skolnick, 1991). Also, in American culture there is a tendency to avoid the topics of death and dying, and to associate death with almost devastating trauma for family members (Leming & Dickinson, 1994; Knapp, 1987). A child's death represents a major "off-time" event that has serious implications for a parent's subsequent development (Bowlby, 1980; Parkes & Weiss, 1983). Several important factors may influence how such an event impacts the parent, including expectedness of the event, culture, relationship with the deceased, gender, and type of death (Edmonds, 1993). Considering the importance of the parental identity to most parents (Cowan & Cowan, 1992), life events that threaten or disrupt that identity need to be explored and understood. Life events that prompt identity loss or transition in adulthood and the stories told about such transitions are clearly important. This study allows for exploration of the narratives shared by parents concerning the loss of a child and may provide new insight into how such an event does impact a parent's sense of identity.

Life experiences that may dramatically affect an individual's sense of identity influence not only the individual but others in their lives as well (Burke, 1991; Cleiren, 1993; Sanders, 1980). For parents, a child's death can impact their relationships with a
spouse, other children, their own parents, siblings, and others (Kalish, 1985; Knapp, 1987; Lehman, Lang, Wortman, & Sorenson, 1989; Owen, Fulton, & Markusen, 1982). During the ongoing process of identity transition that a child's death may trigger, parental behavior may be altered and re-shaped over time. Implications of such changes in parental behavior for the parent, spouse, or children should be addressed and explored. This study has been conceptualized in order to further research on how a child's death may impact parental behavior through examining parental accounts of child loss.

An important element of this research project also exists in the methodology being used. A qualitative approach to studying this topic by interviewing parents about child loss can fill a gap in the existing research. It also permits a focus on the personal, contextual nature of such an event. This allows for studying a sensitive topic in a way that emphasizes meaning, lowers personal barriers, and fosters a connection between researchers and participants (Farnsworth, 1996; Thompson, 1992). As one folklorist has commented, "It is as individual stories of individual, breathing human beings—not as dots on a chart of social norms—that they speak to us of our humanity" (Wilson, 1990, p. 7).

**Purposes of the Study**

The purposes of this study are (a) to search for common patterns and themes in the narratives that illustrate how parents express the impact of a child’s death on themselves and their parental behavior, (b) to develop a deeper and more comprehensive understanding of how a child’s death impacts a parent's sense of identity and their subsequent behavior, and (c) to utilize the findings in formulating theoretical concepts
regarding parental response to a child's death. It is hoped that the findings will also be helpful for use in educational and clinical settings. These purposes will be accomplished through collecting personal accounts shared by parents who have experienced a child's death and examining them for relevant findings. The research will be conducted with a heterogeneous sample of parents who have had children die in varying circumstances and at different ages. The study is intended primarily to be an interpretive effort that will generate new and more extensive knowledge of parents' experience of child loss and also connect this knowledge to a substantive theoretical framework.

Another purpose of this study is to conduct this research in a meaningful, personal context that allows for sensitivity and mutual understanding. Important elements to consider such as parental relationship with the child, type of death, age of the child, and the meaning system of the parents should be placed in such a context, in which parents' voices can be heard and appreciated (Farnsworth, 1996; Thompson, 1992). All of these elements and how they influence a parent's response to a child's death, as well as the manner in which the event affects a parent, are captured in the narratives told by parents about their experience. Indeed, genuinely appreciating and understanding such an experience requires hearing and interpreting such narratives, for "the meaning of life cannot be determined outside of the stories told about it" (Widdershoven, 1993, p. 2). This study will focus on parental narratives that can provide a window of insight into the traumatic occurrence of losing a child and help us to understand the particular factors that influence how such an event affects the parent over time.
Research Questions

The preparation of research questions for this study has been guided by a review of pertinent literature and feedback from colleagues and participants in the pilot study for this research. It has seemed important to ground the research questions in real-world experiences and issues arising from the context of parental loss of a child (Marshall & Rossman, 1989). The primary research question formulated for this study is: "How do fathers and mothers who experience a child's death describe its impact on their parental identity and subsequent parental behavior?" Other specific research questions intended to guide the research process include the following:

- What does the narrative told by a parent about the loss of a child reveal about how the parent has made meaning of the experience?
- What common elements or themes might be seen in the narratives told by parents about how a child's loss has influenced their sense of parental identity?
- What common elements or themes might be seen in the narratives told by parents about how a child's loss has influenced their subsequent parental behavior?
- How can parents be assisted in the experience of losing a child through the development and application of insights from other parents' narratives about their experience?

These questions as currently developed provide the framework for exploring parents' experiences of a child's death.

Summary

In the course of adulthood major life events may impact the developmental course, but of particular import is the influence of a child's death upon a parent (Bernstein, 1997; Knapp, 1987; Sanders, 1980). A parent's relationship with a child can
be critical to his or her sense of identity in adulthood, since it represents a critical context for the development of generativity (Erikson, 1959). Theorists have suggested that an individual's sense of identity is expressed within the stories that people formulate and use to frame their life experiences (McAdams, 1985; Palus, 1993). The potential significance of this study rests in its purpose to capture both the content and meaning of a child's death for parents through examining parental narratives. This can provide a framework for more fully understanding how this event influences parental identity and subsequent parental behavior, as well as generating insights that can assist those who work with bereaved parents. Additionally, the use of narrative accounts to collect information and gain increased understanding of this topic highlights the possibility of using diverse research approaches to study such sensitive issues.

This chapter introduced the topic of identity in adulthood and this study's focus on exploring the influence of a child's death on parental identity and subsequent parental behavior. The theoretical context for understanding this issue was reviewed and existing gaps in the research were suggested. The study's potential contribution, purposes, and guiding research questions were outlined so as to demonstrate how this study fits into the contemporary scholarship on parents' experience of a child's death.
CHAPTER II

LITERATURE REVIEW

This chapter provides an overview of the research literature on the experience of parents when a child dies. First, the significance of child loss as a life change event is described. Next, the context of parental bereavement when a child dies is addressed. Finally, a number of critical factors in the experience of a child's death, potential impacts on a parent's sense of identity, and the influence of this event on family relationships is reviewed.

The Significance of Child Loss

While most individuals undergo the changes that accompany physical growth, psychological maturation, and social interaction, at times during the life course dramatic changes may be initiated due to the impact of a powerful life event. Such events, sometimes called "life change events," represent pivotal occurrences that take place in a person's life and prompt high levels of stress, change, and adaptation. A variety of incidents including divorce, personal injury, retirement, pregnancy, and others can act as such life change events. Among the life change events considered to be most significant in a person's life is the death of a close family member, which may result in the highest levels of stress and change (Holmes & Rahe, 1967). A child's death, in particular, creates such a response in parents who face that particular challenge. The loss of a child often becomes a catalyst in the parent's life that leads to important shifts which change the

There is nearly universal agreement in research on loss and bereavement that the death of a child has a more severe impact on individuals, particularly parents, than any other type of loss (Bernstein, 1997; Edelstein, 1984; Farnsworth & Allen, 1996; Finkbeiner, 1996; Knapp, 1986; Rando, 1985; Sanders, 1980; Weiss, 1988). While some researchers have tended to combine all types of death among family members (spouse, child, sibling, etc.) as similar, there is substantive evidence that these are experienced differently by the survivors (Arnold & Gemma, 1994; Bowlby, 1980; Lehman, Lang, Wortman, & Sorenson, 1989; Rando, 1988). When compared to grieving spouses, children, or siblings, parents generally exhibit higher intensities of bereavement, greater physical distress, and more anger, guilt, and depression (Rando, 1985; Sanders, 1980; Videka-Sherman, 1987). The terminology used to describe the impact of a child's death draws a vivid picture of how this event is viewed in contemporary society. This experience has been variously depicted as: "an overwhelming assault on the individual"; "[the] ultimate human tragedy"; "shattering, unique among losses"; "an unbearable sorrow" (Bernstein, 1997; Knapp, 1986; Rando, 1985; Sanders, 1989). The poet Emily Dickinson captured a parent's grief poignantly when she wrote, "This is the hour of lead." A child's death severs the strong bond that characterizes most parent-child relationships, perhaps the most powerful among human relationships, and plunges the parent into a maelstrom of guilt, anger, confusion, and mourning for the lost child. This is truly a life
change event of immense proportions, such that "one life [is] ended and another life is indelibly changed" (Bernstein, 1997, p. xiv).

The experience of a child's death in the family has changed considerably during the twentieth century in North America. In today's society such a death is regarded as "unnatural and untimely, reversing the expected order of life events" (Wheeler, 1994, p. 261). It seems to undercut the projected flow of time and family continuity in which parents die first. However, this view of a child's death has evolved partially due to the dramatic declines in mortality in American families during the twentieth century, which have resulted in a greatly diminished rate of child loss in families and increased longevity for parents (Uhlenberg, 1980). Historians suggest that the more frequent occurrence of child loss in preceding centuries made the experience less devastating than it is suggested to be today, since parents often expected such a trial and many times lost one or more children. Additionally, they point out that different economic conditions, larger family sizes, and less idealistic social attitudes all combined to lessen the likelihood of intense emotional parent-child attachments (Aries, 1974; Smart, 1993; Stone, 1977). Pollock (1983) reviewed almost five hundred diaries and autobiographies covering a span from the sixteenth to the nineteenth centuries, finding that there were many records which displayed solid evidence of parental grief upon a child's death. These findings and others suggest that the distinctive difference between parental reaction to a child's death in past centuries versus today is not whether parents feel strongly but the manner in which those feelings are expressed (Smart, 1993). While the degree of parental attachment to children in former times as compared to today may remain an open question (Stahl, 1991), it is
certainly possible that the relative infrequency of child loss in contemporary society (versus former centuries) increases the sense of its tragedy. In any case, tens of thousands of children die each year in the United States and set in motion a series of changes that will influence their parents for the remainder of their lives (Knapp, 1986).

The Context of Parental Bereavement

Although this study does not focus explicitly on parental bereavement, all other aspects of the parental experience when a child dies are embedded in the context of parental bereavement, and so the bereavement process must be clearly understood. The grief that parents endure following a child's death may be the most intense and long-lasting of all human encounters with grief (Edelstein, 1984; Sanders, 1989; Schwab, 1990). A variety of research studies have provided insight into the meaning of child loss and the process that parents undergo when a child dies (Bernstein, 1997; Knapp, 1986; Rando, 1988; Sanders, 1980).

The "psychology of loss," as some scholars have called it (Parkes, 1988), is a universal aspect of human experience. All individuals undergo changes and transitions that result in gains and losses of one kind or another. A loss is conceptualized as occurring when a person, object, ideal, or opportunity that carries emotional value to the individual becomes absent or inaccessible. Different types of loss may include loss of a loved or valued person, loss of health or social roles, loss of external objects, or loss of individual capacities due to maturation (Edelstein, 1984; Parkes, 1988; Weiss, 1988). Loss generally prompts the onset of mourning or bereavement, which is "an adaptive
process [that] includes reactions to loss as well as readjustment to an external environment that has changed" (Edelstein, 1984, p. 11). While some scholars use the terms "mourning" and "bereavement" interchangeably, others define them as different aspects of the loss experience (Sanders, 1989). For purposes of this study, the terms are considered to be equivalent and both refer to the set of reactions and adaptive processes that follow a loss. Death of a child is a particularly severe type of loss that may initiate extreme and long-lasting emotional distress or grief (Parkes, 1988). Grief is "an individual's subjective emotional response to loss" (Bernstein, 1997, p. 4), and involves a variety of emotions that tend to be intense and persistent when an individual experiences loss of a "primary" relationship or "relationship of attachment" (Weiss, 1988). Parkes (1988) has noted that the impact of a life change event such as a child's death on an individual brings about a psychosocial transition because it requires a major revision of held assumptions about the world, is permanent rather than transitory in its implications, and takes place over a relatively short period so there is not much chance to prepare for it. The processes involved in bereavement after a child's death reflect the ongoing struggle of this profound psychosocial transition.

A number of theorists have proposed models of bereavement that outline an individual's mourning process after a loved one's death (Bowby, 1980; Engel, 1972; Fenichel, 1945; Freud, 1917; Parkes, 1986; Pollock, 1961; Sanders, 1989; Sullivan, 1956). While these theories all have certain distinctive components, they generally overlap or complement one another in charting the different tasks of mourning that an individual experiences (Parkes, 1988; Sanders, 1989). Lindemann (1944) notes that such
"grief work" requires dealing with the pain of grief, releasing the lost individual, adapting to a new life without the loved one, and establishing a new identity. The bereaved person passes through different phases of the mourning process that may be marked by particular emotional tasks, but such phases are not invariant and every individual walks the path of bereavement by his or her own route (Bernstein, 1997; Sanders, 1989).

The initial reaction of a parent to a child's loss is characterized by utter disbelief and denial (Weiss, 1988). Theorists have generally termed this short-lived phase of mourning "shock" or "numbing," and point out that it serves a temporary but important function of buffering the psychological trauma of the loss and allowing time to manage the necessary details that follow a loved one's death (Bowlby, 1980; Knapp, 1986; Parkes, 1986; Sanders, 1989). In the case of a sudden or violent death, the shock tends to be much more pronounced than when the death is expected (Knapp, 1986). During this period the parent often experiences emotional numbness for hours or days that precedes the onset of very intense emotions. Other aspects of this mourning phase may include confusion, restlessness, feelings of unreality, or helplessness. This period is a critical time for parents to receive social support and assistance in daily affairs (Sanders, 1989).

The next phase in the bereavement process is referred to as disorganization or awareness of loss (Edelstein, 1984; Knapp, 1986; Sanders, 1989). The parent develops an awareness of the reality of the child's death and is exposed to a life that is now absent of this most meaningful relationship. This phase becomes the emotional opposite of the first phase as the mother or father undergoes a wide range of varying and intense emotions. Struggling through these emotional assaults is extremely demanding both
physically and psychologically, and so parents or others may become frustrated by the continuing fatigue and difficulty (Sanders, 1989). During this time of acute mourning a central component is often separation anxiety, leading to feelings of insecurity and lack of control (Parkes, 1986). The feeling of being "out of control" is compounded by the variety of unmanageable emotions that a parent encounters upon realizing the child is gone. Parents at this phase may exhibit a characteristic pattern of yearning for and searching for the lost child. They express a deep and overwhelming longing to see the child again, to be with them and touch them, and may often turn to share something with the child then find themselves alone (Bernstein, 1997; Sanders, 1989). Another common feature of the disorganization phase occurs as parents pass through intense feelings of anger and guilt. The anger may be felt toward unsympathetic friends or family members, God, oneself, the helplessness of the situation, or even the deceased child (Sanders, 1989). Knapp (1986) suggests that fathers and mothers tend to express this anger differently, with fathers often striking out at inanimate things and mothers often internalizing the anger. Guilt experienced by the parents takes the form of causal guilt, a feeling that oneself is to blame, and survivor guilt, which is the sense that it is not fair to continue living oneself when the child died (Lifton, 1968; Sanders, 1989). Parents may also express guilt later on when feeling pleasure or joy, and then realizing their child is not there to experience it (Knapp, 1986). An important consideration during the phase of disorganization is the effect of such prolonged stress upon the individual, since health problems are usually exacerbated during this time (Bernstein, 1997).
Another major phase of bereavement for parents is marked by depression, despair, loneliness, and a sense of separation from life (Bowlby, 1980; Knapp, 1986; Parkes, 1986; Pollock, 1961). Many parents have suggested that this becomes the "worst period of the entire grief process" (Sanders, 1898, p. 73), a time when they face the challenge of assimilating their child's loss alone and must process the paradox of continuing on in life in the face of death. It also tends to be the longest phase of mourning and may last for up to several years. While others may be ready to return to normal functioning and the patterns of daily living, a unique characteristic of parental bereavement is the determination by parents to never forget the child who died (Knapp, 1986). At this point the parent must "grapple with the difficult internal work of adjusting to a world in which the loved child no longer exists" (Edelstein, 1984, p. 57). No others can make this internal readjustment for the parent and it is enormously difficult. The sense of loneliness and private despair that mark this phase, as well as the tendency to withdraw socially, make sense when it is understood that this portion of grief work is largely internal. Parents in this phase of mourning often feel despair and helplessness, receive diminished social support, and experience fatigue, a need for more sleep, and a weakened immune system (Sanders, 1989). Thinking extensively about the deceased child and sifting through precious memories dominates much of a mother's or father's mental activity during this time (Bernstein, 1997; Knapp, 1986). Although this phase of mourning is the most difficult, it also provides the opportunity for parents to conserve emotional energy and make choices that enable them to begin restructuring their personal world and life perspective (Sanders, 1989).
A final phase of bereavement experienced by parents has been variously termed reorganization, recovery, or healing/renewal (Bowlby, 1980; Edelstein, 1984; Parkes, 1986; Sanders, 1989). As these terms suggest, the primary facets of mourning at this point involve gaining greater control over one's grief, reorganizing one's sense of self, and returning to a better level of functioning (Sanders, 1989). This transition toward acceptance of the loss and a renewed ability to participate in and enjoy life takes place gradually (Knapp, 1986). The emotions of grief still occur but are less prevalent, though occasionally bouts with "shadow grief" will bring back the original sense of loss (Peppers & Knapp, 1980). However, the parent's adaptation to the overwhelming loss of a child makes it possible to reach out to others, begin new activities, and experience life as meaningful again (Edelstein, 1984). Much of the paralyzing guilt that troubled earlier phases of the bereavement process begins to dissipate and allows the parent to re-establish sustaining connections to others and society (Bernstein, 1997). Although a bereaved parent never forgets the death of a loved child, the loss and pain associated with the child's death diminishes and no longer dominates the landscape of life as it once did.

**Important Factors in a Child's Death**

When parents experience the death of a child they enter into a reluctant fraternity with other bereaved parents who have undergone a similar ordeal. However, although a child's loss wreaks the same intense tragedy upon parents, each parent walks the road of grief individually and each child's death carries its own unique characteristics. There are a variety of factors that have been studied which seem to bear some importance in the
way a child's death is experienced by parents. These factors include the nature of the child's death, individual characteristics, and sources of support.

**Nature of the Child's Death**

It is generally agreed by most bereavement researchers that the circumstances of a child's death have an important influence on how parents experience the loss (Bernstein, 1997; Edmonds, 1993; Knapp, 1986; Lundin, 1984; Miles & Demi, 1992; Nelson & Frantz, 1996; Parkes, 1975; Rando, 1986; Sanders, 1989; Seguin, Lesage, & Kiely, 1995). This may be the most critical situational variable affecting the particular course of bereavement that a parent takes. The intensity of grief confronted by parents remains high in every circumstance, but the ability to cope and long-term bereavement outcomes may be quite different depending on the mode of death (Knapp, 1986; Miles & Demi, 1992; Parkes & Weiss, 1983). Edmonds (1993) reviews several studies that seem to show little difference in grief level for participants following a loved one's death when comparing type of death, but notes that these results may be confounded by failing to account for the participant's relationship to the deceased. Few studies have limited their investigation of bereavement differences due to type of death to parents who have lost a child, and those that have suggest little or no statistical difference on measures of bereavement symptomatology, family closeness, or other grief-related areas (Miles, 1985; Nelson & Frantz, 1996; Seguin et al., 1995). However, the research evidence does consistently suggest that the pattern of bereavement and key issues for the parent can vary depending on how the child died (Miles & Demi, 1992; Rando, 1986; Sanders, 1982-83).
Knapp (1986) suggests in his qualitative study of over 300 parents who have lost children that different critical issues in bereavement and differing tracks of mourning can be identified based on the manner of a child's death. A common theme in the bereavement literature identifies the disparity between sudden versus anticipated death and the consequences of particular modes of death in these categories (Bernstein, 1997; Bowlby, 1980; Edmonds, 1993; Miles & Demi, 1992; Parkes & Weiss, 1983).

Perhaps the most common form of sudden death among children occurs due to accidents of one type or another. More than 45% of the participants in Knapp's (1986) study lost a child in this way, and other studies also report a significant proportion of participants whose children died due to an accident (Miles, 1985; Miles & Demi, 1992; Nelson & Frantz, 1996; Seguin et al., 1995). Official statistics show that death by accidental injury accounts for the highest percentage of deaths among children between ages one and twenty-five years, between 36% to 43% of all recorded child deaths in that age group each year (Hoyert, Kochanek, & Murphy, 1999). A child's sudden and accidental death launches parents into a world of shock and intense confusion, which seems to diminish the parent's ability to cope and extend the grieving process (Edelstein, 1984; Glick, Weiss, & Parkes, 1974; Lundin, 1984; Parkes & Weiss, 1983). Miles & Demi (1992) compared 132 bereaved parents, thirty-two whose child died by accident, and accident-bereaved parents indicated the most distressing aspect of grief was loneliness. These parents also reported the highest levels of guilt related to death causation and childrearing. This means that they felt guilty about possible action or inaction that may have contributed to the child's death, and also about negative feelings,
perceived failures, or regrets about their parenting efforts. The sudden nature of accidental death may result in "unfinished business" or emotional conflicts that are not resolved, making the grief process more complicated (Bernstein, 1997). Edelstein's (1984) interview study of sixteen bereaved mothers whose child died an accidental death led to her conclusion that this type of death may prompt more searching behavior and hopefulness in the parent. She suggests they "had a strong desire to know more and to find answers" because the suddenness of the child's accidental death left them "no time to prepare and satisfy themselves with reasons" (p. 16). Social support may also be affected by type of death, since parents who lose a child suddenly both seek out and receive more social support than other bereaved parents (Schwab, 1995-1996; Thuen, 1997). A final feature of the bereavement experience associated with sudden loss was the tendency of parents to believe that the child still existed "somewhere else" and that they would eventually be reunited (Knapp, 1986). A child's sudden and accidental death burdens parents with unanswered questions, but other forms of sudden death also carry a severe impact.

Another form of sudden death that takes an enormous toll on parents and families is homicide. In addition to its unexpectedness, a child's death by homicide includes the difficult features of violence and intentionality. Death by homicide has been termed "unnatural dying" (Rynearson, 1987), and parents of a murdered child must struggle with both the violent ending to their child's life and the fact that their child died by someone else's deliberate intent. Rinear (1988) studied 331 parents who lost a child by homicide and noted that the grieving was particularly intense and drawn-out in such cases,
somewhat similar to post-traumatic stress disorder. Because homicide is a deliberate act of commission it tends to incite extreme feelings of anger, helplessness and revenge in parents (Beigel & Berren, 1985; Knapp, 1986), and Rynearson (1987) suggests that such a death is particularly traumatic due to its characteristics of violence, violation (exploitative), and volition (purposeful intent). Parents feel this type of death to be particularly wasteful and struggle to find any sense of meaning in the child's death, though some do maintain the ability to find meaning that helps them to cope (Edmonds, 1993). Children who die in this manner are more often young adults, yet parents still feel a protective responsibility for them and wonder if they might have done something different to prevent the murder (Knapp, 1986). Other particular difficulties that occur when a child dies by homicide include facing the insensitivities of the criminal justice system, dealing with the anger and desire for revenge that may be directed at the perpetrator, and worrying about whether the child suffered a great deal. The process of learning the details of the child's death can be complicated, and the nature of the criminal sentencing process can be especially painful when a plea bargain results in a sense of the warped view of a child's worth in society (Knapp, 1986). Many parents, feeling understandably alone, seek out support groups formed by other parents whose children were killed in this manner. Such groups include Parents of Murdered Children (POMC) and Save Our Sons and Daughters (SOSAD), two national organizations that reach out to parents and help them to cope (Knapp, 1986). As Bernstein (1997) notes, "Murder is a special circumstance of sudden death that brings with it all the impediments inherent in sudden deaths and many more" (p. 57).
A third form of sudden death that occurs among children, usually in adolescence or young adulthood, is suicide. Some scholars have suggested that the effect of suicide on parents or other family members is like putting a psychological skeleton in the survivor's closet and condemning them to a ceaseless search for answers (Ness & Pfeffer, 1990). Difficult aspects of dealing with a child's death by suicide include the suddenness of death, intense parental guilt, public aspects of the death, and the fact that the child voluntarily chose to die in this way (Bernstein, 1997; Knapp, 1986; Pretorius, 1992). While some researchers have suggested that a child's suicide triggers a more difficult bereavement process for parents (Osterweis, Solomon, & Green, 1984; Stroebe & Stroebe, 1987), others indicate that the lack of systematic research on this topic leaves us without substantive conclusions on that point (Sanders, 1989). However, the existing research does point out some critical factors in the bereavement process when a child dies by suicide. Miles & Demi (1992) studied 132 parents who had lost a child either by suicide, accident, or disease, and the suicide-bereaved parents indicated that guilt was the most dominant and distressing aspect of grief for them. In particular, over half of these parents noted that guilt feelings related to causation of death and childrearing were most prevalent. It seems important to note that these types of guilt are closely tied to the parental role, specifically feeling responsible for the child and parenting activities, and parents who experience a child's death by suicide may sometimes face problematic parenting concerns (McIntosh & Wrobleski, 1988). Parents may also become burdened by the social stigma associated with suicide, feeling that "the suicide exposes [them] to the world as an unfit parent" (Bernstein, 1997, p. 58; Pretorius, 1992). Wheeler (1994)
surveyed 203 bereaved parents and found that child loss by suicide was associated with a lower sense of purpose in life for these parents as compared to other bereaved parents. This may indicate the difficulty of coming to a meaningful resolution of the child's death when suicide occurs.

Anticipated death of a child refers to circumstances in which the death is preceded by some period of time in which an awareness of the eventual death is clear and parents can anticipate potential difficulties and face them. Rather than suffering an instantaneous loss, the parents must endure the "struggle to save the child sentenced to death by a dreaded disease" (Knapp, 1986, p. xii). Diseases or conditions that attack and kill children range from leukemia and cancer to cystic fibrosis and heart problems. Anticipated death occurs less often than sudden death among children, and it brings a different set of challenges for parents and the child. An obvious and critical difference is that when a child is diagnosed with a serious illness or disease, parents can still maintain some hope that the child will recover through medical treatment. During an anticipated death the shock and denial that accompany sudden death are shifted to the moment of diagnosis, and is generally followed by numbness and intense bouts of anger (Bernstein, 1997; Friedman et al., 1963; Knapp, 1986). The anger expressed by fathers and mothers during this initial period tends to differ, with fathers expressing it more outwardly through hostility and mothers often turning it inward through withdrawal, self-blame, or insistent personal demands (Knapp, 1986; Miles, 1985). As families move into an interim period of taking care of a terminally ill child, parents often experience "anticipatory grief" and actually begin the bereavement process prior to the child's
passing. This anticipatory grief work assists parents in managing the intensity of bereavement and usually results in a better adjustment process to the child's death (Rando, 1986b; Videka-Sherman, 1987). Bereaved parents whose child dies in this way express feelings of guilt about rearing the child and caring for the child during illness, worrying about their inability to reduce the pain or decisions that they now see as mistaken (too much treatment, etc.) (Miles & Demi, 1992). Those parents whose child dies after a short-term illness tend to adjust more quickly than parents who endured a long, drawn-out period of illness and final death (Rando, 1983; Sanders, 1982-83).

Because anticipated death involves going through the dying process with the child, some unique characteristics emerge for the family. While parents often tend to focus on the future with their children, during a terminal illness those priorities often shift and "moment-to-moment happenings become primary to parent and child" (Knapp, 1986, p. 44). Time and shared experience in the present become vital for parents, though somewhat tinged with pangs of sorrow. Another characteristic that families experience is the maturing of the dying child. Parents often note that even very young children exhibit a mature wisdom and understanding as they come to face their own death (Knapp, 1986). Parents undergo an interactive process in which they help the child to prepare for his or her death, and they are also assisted by the child to face that possibility (Cook, 1983b). The care needed by a sick and dying child can be intensive and is frequently exhausting to parents and other family members (Bernstein, 1997). Children and parents cope by focusing on the present, encouraging hopes for recovery, planning and enjoying activities together, and looking for sources of understanding and support (Artinian, 1982; Cook &
Several researchers have emphasized the support that parents and children may derive from religious explanations of the dying process and death itself, such as passage to heaven or eventual reunion (Cook & Wimberley, 1983; Knapp, 1986).

A special circumstance of anticipated death, due to the conditions of the disease and its stigmatic nature, occurs when a child or young adult dies of AIDS (Bernstein, 1997). The specter of this disease can be particularly frightening because there is no known cure, despite advances in medicine that allow much better treatment for it. Additionally, the number of individuals affected by AIDS is rising rapidly and those who face it are often stigmatized due to false perceptions about the disease (Sanders, 1989). Little research exists on the bereavement experience of parents whose children have died from AIDS, but some findings indicate difficulty in dealing with the social stigma associated with AIDS, diminished social support from others, and distress associated with the extended and painful process of death that often occurs in AIDS sufferers (Bernstein, 1997). As with other types of anticipated death, family members and the child tend to slow down and focus on the present, plan and enjoy desired activities together, and proceed through the difficult tasks of anticipatory grief (Brown, 1993). Dane (1991) highlights the importance of providing counseling services and other types of assistance to families or individuals who have a loved one dying of AIDS, since they often face increased challenges in the bereavement process. No type of death that parents experience when a child dies can be dismissed; each challenges the resources and abilities of parents to cope with the loss and move into the future. A particular type of death may
bring differing patterns of bereavement issues and processes into the parent's life, but most importantly, it is critical to acknowledge the immensity of a child's loss for parents and develop a better understanding of how parents can be helped in such a crisis (Sanders, 1989).

**Individual Characteristics and Child Loss**

Individual characteristics that influence the way a parent experiences the loss of a child need to be taken into consideration when studying this topic. Bereavement researchers have identified a number of factors that seem to affect a parent's bereavement experience. These include culture, parent's gender, age of the child, personality traits, and the nature of the parent-child relationship (Bernstein, 1997; Bohannon, 1990-91; Bowlby, 1980; Cook, 1983b; Edmonds, 1993; Knapp, 1986; Parkes, 1986; Rando, 1986b; Raphael, 1984; Sanders, 1980; Sanders, 1989; Stroebe, Gergen, Gergen, & Stroebe, 1992). In-depth research on the impact of most of these factors remains to be conducted.

The investigation of culture as a significant influence on parents as they deal with a child's death is limited, but a number of studies and reviews have addressed its potential importance (Balk, 1994; Grabowski & Frantz, 1993; Rosenblatt, Walsh, & Jackson, 1976; Stahl, 1991). Culture, of course, affects the individual due to cultural background but also embraces a broader sociocultural context. Cultural expectations regarding grief expression, the nature of the parent-child relationship, etc., can shape a parent's response to a child's death. A comparison of 100 Anglo and Latino individuals grieving death found that Latinos illustrated significantly greater grief intensity than Anglos (Grabowski
& Frantz, 1993), a finding consistent with other comparative studies (Reimer & Templer, 1995). Stahl's (1991) investigation of thirty Jewish-Oriental women illustrated that both their cultural background and historical differences in views of death led to distinctive attitudes toward the death of a child. Such research indicates that parental reaction to a child's death may vary significantly in intensity, expression, and cultural rituals surrounding death (Rosenblatt et al., 1976). Historical changes within a given culture or regional differentiation within a culture also need to be taken into account when considering how culture influences the experience of child loss. For example, a number of researchers have examined differences in parental bereavement and cultural mores within Anglo-American or specific European cultures historically, suggesting that there have been meaningful changes in cultural customs regarding grief expression through time (Aries, 1974; Rosenblatt, 1983; Smart, 1993; Stroebe et al., 1992). Differences in parental bereavement across cultures remains a largely unstudied but important factor in understanding the experience of a child's death.

The potential influence of gender on how a parent experiences the death of a child is so complex and closely linked to the parental role that it is legitimately a topic deserving of its own detailed study. Feminist scholars have noted the impact of gender on the social meanings we construct about developmental pathways and becoming a parent, particularly as it pertains to mothers (Gilligan, 1982; Ruddick, 1989), and some research has focused specifically on the bereavement experience of mothers or fathers individually (Edelstein, 1984; Farnsworth, 1994; Schatz, 1986). Bernstein (1997) summarizes the argument concerning how gender may impact bereavement in stating that
"this culture has traditionally taught men and women to express themselves differently and to grieve differently" (p. 106). Most bereavement research on this topic focuses on grief intensity and emotional expression of grief. It has been suggested that mothers tend to be susceptible to greater distress than fathers when a child dies (Parkes, 1988b). A number of studies have indicated that mothers express greater intensity of grief and more physical or psychiatric symptomatology than fathers (Bohannon, 1990; Fish, 1986; Rando, 1986b), particularly when an infant dies (Peppers & Knapp, 1980). Edmonds' study of 40 bereaved mothers and fathers who lost a child in the Pan Am Flight 103 disaster (1993) does reveal some differences in mothers' and fathers' sense of meaning, which she suggests may be attributable to gender. However, other studies have found no difference between parents in their reports of grief (Martinson, Davies, & McClowry, 1991), and additional research on a parent's sense of purpose in life after child loss has shown no demonstrable difference between mothers and fathers (Florian, 1989; Wheeler, 1994). Qualitative studies of parental bereavement seem to indicate differences between mothers and fathers most often (Bernstein, 1997; Cook, 1983; Edmonds, 1993). While it is certain that gender plays a role in how parents experience a child's death, the contradictory findings reported thus far highlight the need for a more in-depth, careful investigation of this subject.

A child's age at death has been suggested as an element to consider in evaluating how parents react during bereavement, but it seems clear that "for the parents, the death will always be untimely" (Sanders, 1989, p. 164). It simply seems to be an unfair aberration when a child dies before a parent in our society today (Smart, 1993). Although
a child's age does not seem to make a dramatic impact on a parent's grief reaction (Rando, 1985; Schatz, 1986), the mourning issues faced by the parent may vary because the parent-child relationship differs according to a child's developmental level (Bernstein, 1997). For example, with young children there is more direct involvement in a child's day-to-day activities and when the child dies that major portion of life disappears. By contrast, the relationship with children in later adolescence or young adulthood tends to focus on their individuation from the family and their future. Since developmental issues in the parent-child relationship are closely tied to a child's age, age can be helpful in considering what particular issues may be present for a parent. Bernstein (1997) succinctly points this out in stating, "Different ages, different stages, different issues, same pain" (p. 45). Whatever research may discover on the influence of a child's age at death on parental bereavement, for parents the question has little relevance: a loved child is gone and they feel great pain (Rando, 1985).

A parent's personality traits are also among the individual factors that impact parental response during bereavement. While the effect of personality as a variable in the bereavement process has been suggested by a number of scholars (Bernstein, 1997; Bowlby, 1980; Parkes, 1986; Raphael, 1984; Sanders, 1989), actual empirical studies of the relationship between personality and the mourning process are few (Sanders, 1979; Stroebe & Stroebe, 1987; Vachon, Sheldon, Lancee, Lyall, Rogers, & Freeman, 1982). The general suggestion is that particular personality traits interact with grief distress during bereavement such that a parent's response becomes more distressed, or certain traits may facilitate effective coping (Raphael, 1984). Particular personality traits that
have been put forward as potential influences on bereaved parents include neuroticism, anxiety, proneness to guilt and self-blame, excessive denial, inhibited emotional expression, locus of control, high dependency needs, and emotional stability (Bernstein, 1997; Sanders, 1989). Individuals with certain personality types may be more vulnerable to the difficulties of losing a child, largely due to inabilities to grieve in an adequate manner (Bowlby, 1980). Vachon et al. (1982) administered questionnaires on general health and personality factors to 72 bereaved women in a study that showed a significant correlation between emotional stability and low distress, while women indicating high bereavement distress tended to be anxious and emotionally unstable. Additionally, research by Stroebe and Stroebe (1987) on the relationship between personality characteristics (emotional stability and locus of control) and depression in bereavement has established that parents high on neuroticism and low on internal control were more depressed than those parents who were low on neuroticism and high on internal control. Four types of bereavement associated with particular personality types were suggested by Sanders (1979), including a disturbed pattern, a depressed pattern, a denial pattern, and a normal grief pattern. Research on this topic is difficult due to the inability of researchers to conduct personality inventories with parents prior to a child's death, but efforts to understand the linkage between personality and parental bereavement should continue.

A final factor of importance to consider in parental response during bereavement is the nature of the relationship with the child, which includes relationship type, personal feelings, and functional quality of the relationship (Bowlby, 1980; Sanders, 1989). It has been found in a number of studies that losing a child elicits greater distress and grief than
losing a parent or spouse (Osterweis et al., 1984; Sanders, 1980), and parental distress can be particularly high when the child who dies is an only child (Wheeler, 1994). The attachment bond between a parent and child forms early, especially for mothers, and it is recognized as the most powerful human bond. When this attachment bond is severed parents may feel like a part of them has been amputated and the pain is intense (Bowlby, 1980; Layne, 1992; Palmer & Noble, 1986; Sanders, 1989). When a child dies grief may become more complicated if there are unresolved negative feelings held by the parent toward the child. Particular feelings that have been associated with problems in bereavement of a child include ambivalence, guilt, and anger (Drenovsky, 1994; Miles & Demi, 1992; Raphael, 1984). Such feelings can exacerbate the confusion and emotional pain already present when a child dies. The functional quality of a parent's relationship with a child may be diminished when the child is involved in rebellious activities or the relationship has become conflictual. Drug or alcohol abuse, juvenile crime, emotional problems, or other difficulties that children may experience often challenge the quality of the parent-child relationship, and when a child dies in this circumstance parents may report regret, guilt, and even horror at a sense of relief (Bernstein, 1997). The nature of a parent's relationship with his or her deceased child plays a significant role in the way a parent manages the strenuous emotional tasks of mourning a child's death.

**Sources of Support in Child Loss**

Among the most critical factors that influence a parent's course of experience when a child dies is the type of support that the parent receives during the time of
bereavement. Social support is universally recognized by bereavement researchers as a major resource for parents and it is increasingly a subject of study and concern (Artinian, 1982; Ben-Sira, 1983; Brabant, Forsyth, & McFarlain, 1995; Cook & Wimberley, 1983; Klass, 1991, 1993; Rando, 1985; Schwab, 1995; Thuen, 1997; Videka-Sherman, 1987). As Rando (1985) notes, "Bereaved parents are often left without many of the social and emotional supports desirable for coping with the grief process" (p. 20). The types of social support received by bereaved parents can be broadly classified into informal support resources, formal support resources, and religious support resources.

While the need for positive and caring support for parents after a child dies may seem obvious, parents' actual experience demonstrates that often the support given is inadequate and less than helpful. Bereaved parents sometimes describe feeling like "social lepers" when others avoid them, chastise them for grieving "too long," or pay little attention to the child's death so as not to bring up a difficult subject (Rando, 1985). It has been suggested that other parents may simply not know how to give sensitive support or may be uncomfortable with a bereaved parent because of their own anxieties (Bernstein, 1997; Sanders, 1989). Additionally, many individuals expect the process of bereavement to take a much shorter time than it actually does, and bereaved parents go through an especially long period of mourning. This expectation or other expectations about how parents "ought to" grieve can make bereaved parents feel judged rather than loved (Bernstein, 1997). Formal sources of support such as doctors, clergy, and social workers may also unintentionally avoid the loss or act judgmental when dealing with parents. This becomes difficult for parents who are already in emotional pain and thus may be
especially sensitive to perceived criticism or judgment (Brabant et al., 1995; Videka-Sherman, 1987). The vulnerability of bereaved parents must be taken into account when reaching out to assist them.

Informal support resources upon which bereaved parents rely include spouse, family members, kin, and friends. Support received from such informal sources is the most important for parents during bereavement, and carries more weight in facilitating adjustment to a loss than any other factor (Ben-Sira, 1983; Klass, 1991). Bernstein (1997) succinctly states, "The presence of a backup team of caring family and friends is indispensable" (p. 50). The support given takes a variety of forms, but early on the most helpful is simply a constant, comforting presence, which is best provided by known and loving friends or family members. The numbness of initial grief also creates a need for practical, hands-on grief support such as cooking meals, cleaning, taking care of other children, running errands, etc., and this is also where support from informal sources is highly needed (Bernstein, 1997; Knapp, 1986).

Stroebe & Stroebe (1987) suggest that three basic support functions for the bereaved are instrumental support (doing tasks, etc.), emotional support (listening, etc.), and validational support (normalize grief, etc.). Such forms of support are each important at different stages of the mourning process, but emotional and validational support particularly in later stages of bereavement. For bereaved parents a vital consideration may be that a primary source of support, the spouse, has suffered the same traumatic loss and therefore cannot provide as much support as usual (Rando, 1985). The need to meet relational responsibilities as well as deal with their own grief adds increased pressures to
bereaved parents. Parents who feel that they receive adequate support from family and friends tend to rely to a much lesser degree on other formal support sources such as self-help groups (Schwab, 1995). Thuen's (1997) study of 165 bereaved parents showed that mothers tend to receive more support from informal sources than fathers do, especially when a child's death is unexpected, partly because women tend to express their grief more openly than men. Attention to bereaved parents' ongoing need for informal support should be a central component of efforts designed to educate about bereavement and provide meaningful and lasting sources of help to such parents.

The complex bereavement process that parents endure when a child dies can also be helped by assistance received from such formal support sources as organized support groups, medical personnel, therapists or social workers, and clergy (Ben-Sira, 1983; Brabant et al., 1995; Knapp, 1986; Sanders, 1989). Although support given by family and friends seems to be more important and helpful during the early stages of bereavement (Thuen, 1997), the long and difficult road of acute grief that parents face can be eased through aid from formal support sources (Knapp, 1986; Sanders, 1989; Schwab, 1995). The most frequently mentioned source of positive assistance to bereaved parents is support groups of other parents who have also lost a child, which includes organizations such as the Compassionate Friends and Kinder-Mourn, Inc. (Bernstein, 1997; Klass, 1991; Knapp, 1986). Knapp (1986) suggests, "No other resource in the community is as effective in dealing with the aftermath of such losses" (p. 19). Parents express almost an aching need to share their grief with someone who knows intuitively what they are going through because they have also gone through it (Schwab, 1995).
Support groups like Compassionate Friends provide a venue in which parents can express themselves without fear of judgment, receive acceptance, and see the example of other parents who have suffered and survived a child's loss (Bernstein, 1997; Klass, 1991; Schwab, 1995).

Therapists and social workers may be able to help parents accept the child's death, cope with guilt and anger, and resolve concerns caused by depression, loneliness, or fear (Hare-Mustin, 1979; Rappaport, 1981; Videka-Sherman, 1987). Sanders (1989) points out the need to identify a therapeutic intervention strategy that is consistent with the specific needs of a grieving parent. Some studies actually show little difference between parents who participate in therapy or support groups and those who do not in their bereavement experience (Forest, Standish, & Baum, 1982; Videka-Sherman & Lieberman, 1985), so understanding of this form of support in bereavement remains limited. The effect of support received from clergy seems largely dependent on the willingness of clergy to go beyond dogma and ritual and reach out in sensitivity and compassion (Bernstein, 1997; Brabant et al., 1995). These formal sources of support cannot fully compensate when informal support resources are lacking, but they can provide a meaningful and long-lasting complement to more immediate sources for bereaved parents.

Parents may also turn to religious support resources when dealing with the loss of a child, searching for meaning in the loss or relying upon the promise of particular religious beliefs that bring comfort to them (Cook & Wimberley, 1983; Edmonds, 1993; Klass, 1993; Wheeler, 1994). Although reliance on religious sources of support may be
facilitated through discussion with clergy, believing friends or family, the source of support lies in the religious beliefs or meanings that a person believes in or holds to be valuable (Cook & Wimberley, 1983). Some studies show that many parents' religious beliefs tend to become stronger after a child's death, although this occurs mostly with those parents who already felt some religious commitment prior to the loss (Binger, Ablin, Feurerstein, Kushner, Zoger, & Mikkelsen, 1969; Cook & Wimberley, 1983; Miles & Crandall, 1986). It is common for bereaved parents to question God's mercy and to feel intense anger at God when a child dies during the earlier stages of bereavement (Edmonds, 1993; Knapp, 1986). Over time as parents search for resolution of their grief they may rely upon particular religious concepts for some comfort and peace, including such theodicies as reunion with the child in an afterlife, the child's death serving a higher purpose, or even death as a punishment for parental wrong-doing (Cook & Wimberley, 1983). Edmonds' (1993) study of bereaved parents and college students showed that change in the participants' sense of cosmic meaning was tied to belief in God and religious practices, with 88% of mothers expressing some change as compared to only 42% of fathers. An ethnographic study by Klass (1993) indicated that parents often undergo a complex change in religious understanding and experience spiritual connections with the inner representation of the deceased child. Religious sources of support can diminish anxiety and enable bereaved parents to find some measure of meaning in the traumatic loss they have experienced.
Child Loss and Parental Identity

The meaning of one's life as a mother or father serves as one of the primary components of identity for those who are parents (Cowan & Cowan, 1992; Whitbourne, 1986). When a child dies this sense of identity is disrupted and parents face the monumental challenge of reconstructing a coherent sense of self as a parent. The bond between parents and children provides a rich source of self-meaning for a mother or father that becomes a foundation for one's sense of parental identity (Bowlby, 1980; LaRossa & Reitzes, 1993). Many bereavement scholars understand the connection between loss of a child and loss of a parent's sense of identity, though it has been seldom studied as specific topic. Rando (1985) makes this connection, pointing out that "the process of mourning for one's child involves not only dealing with loss of the loved child, but with the loss of part of one's self" (p. 19). Parkes (1986) has gone so far as to call death of a loved one, especially a child, "psychological mutilation" due to the manner in which a bereaved person feels their own sense of self has also been attacked and torn from them. A child's death impacts a parent's identity in multiple ways that include loss of a sense of self, alteration of the parent's future, feelings of parental inadequacy, and deprivation of parental activity. Parents cope with these challenges in both positive and negative ways and there may be some differences between mothers and fathers.

Parents who lose a child often feel bereft of their own identity as if they themselves had also died (Edelstein, 1984; Knapp, 1986), partly because the more meaningful a particular role is to someone the more difficult it is to deal with a transformation in that part of one's identity (Thoits, 1991). Attachment theory
emphasizes the deep emotional ties and self-fulfillment that characterizes the parent-child bond, thus contributing to the importance of one's work as a parent (Bowlby, 1980). Parents often identify their children with themselves as they see the similarity in features or mannerisms and the developmental experiences that they once passed through. This high degree of meaning and identification with a child makes the loss of that bond a severe loss for the parent's sense of self as well. The extent to which a parent's sense of identity is wrapped up in being a parent and not in other roles will probably increase the difficulty of the mourning process (Bernstein, 1997). Sanders (1989) points out, "When a child dies, the parent grieves not only for the deprivation of being without their child but also for the lost aspects of themselves as well" (p. 163). The process of parental grief may be so extended because the parent must not only adapt to the child's death but they must also re-construct their own identity in the process. This involves coming to see themselves and the world in a new way that fundamentally changes their sense of individual identity (Klass, 1993).

An important element of parental identity includes not only what is now but what will be, for parenting is both an experience in the present and an investment in the future (Hooker, Fiese, Jenkins, Morfei, & Schwagler, 1996; Wheeler, 1994). Parents carry expectations of participating in their child's future accomplishments such as graduation or marriage. A child's death frustrates such parental expectations and leaves parents to cope with the pain of what will never be (Knapp, 1986). In Edelstein's (1984) study of sixteen bereaved mothers she discovered that a major theme in their bereavement was the loss of future hopes related to the deceased child. She suggests that the grief felt for this loss is
at least twofold. First, the "mourning for [the child] is for all the things that the child will miss (p. 41)." Second, the parent mourns his or her inability to complete the joys and labors of parenthood with that child, and so must deal with the ongoing frustration of not finishing their future aspirations. In a sense, the parent's sense of future identity is arrested and must be changed. Edmonds (1993) has reported that some parents draw a sense of purpose from the ideal of continuing on with something that was meaningful in the life of the child, thereby attempting to continue the child's future insofar as possible. When that part of a parent's identity that was planned for the future has been taken forever it can never be reclaimed, but parents can mitigate the emptiness of that future by filling the hole in space with memories and new activities (Knapp, 1986).

One's sense of personal esteem as a parent is tied to a process of self-evaluation in which the parent assesses the adequacy of his or her own efforts with a child (Rando, 1985). Another blow to parental identity that seems to occur when a child dies is a devastation of this sense of personal adequacy. It has been noted that "the death of a child screams 'failure' to a woman (or man) who has devoted herself (or himself) to that task" (Edelstein, 1984, p. 33), meaning the task of successfully parenting a child. Bereaved parents may feel anger and often guilt because of a perceived failure to love, nurture, and protect the child that was in their care (Rando, 1985). Since such love and protection are seminal aspects of parental adequacy then a parent's sense of identity is diminished when a parent thinks of himself or herself as a failure. Miles & Demi (1992) studied guilt in 132 bereaved parents and found that "death causation" and "childrearing" guilt were the most prevalent guilt feelings among most parents, both of which include
concern about many actions related to parental adequacy. Most "guilt" concerns seem to be parental adequacy concerns, such as not adequately helping the child through the illness or not being more loving and involved with the child. A number of studies show that mothers tend to feel this aspect of identity loss more intensely than fathers do (although both experience it), perhaps because mothers tend to spend more time in parenting and invest more of their personal identity in the mothering role (Cook & Wimberley, 1983; Edelstein, 1984; Edmonds, 1993). Overcoming the feelings of parental failure associated with a child's death requires patience, effort, and time to reach a more balanced perspective.

A child's death impacts parents specifically in the conduct of their everyday activities because much of a parent's time is involved in caring for a child's needs. The loss of parental activity that occurs as a result of the child's passing may be one factor that leads to the bereaved parent's tendency to search for the child (Edelstein, 1984). The parent is left, in a sense, with a diminished sense of self because a significant portion of the activity that engaged their daily life has been removed. As Rando (1985) has written, "Much of parental identity centers around providing and doing for one's children, a basic function of the parent . . . the death of a child robs parents of their ability to carry out their functional roles" (p. 20). Thus, a parent who has spent much time advising, meeting needs, resolving concerns, and performing daily tasks for a specific child no longer can fulfill those functions for that child, although they may continue them for other children. The parent's identity again is detached from the activities that provide the substance of parental meaning. Some parents never seem to adapt to this void of activity, but many
parents in time fill the space by becoming involved in meaningful and altruistic activities (Bernstein, 1997; Knapp, 1986). They may volunteer with an organization that aids youth, donate time or money to worthy causes, take up new hobbies, or create memories of their deceased child (scrapbooks, etc.). Such activities tend to aid parents in re-establishing a connection to life in a meaningful way. Parents whose lives are already filled with other activities such as parenting other children or a career may not struggle with this aspect of identity loss so greatly, but research on this topic remains to be done.

**Child Loss and Family Relationships**

A family's resiliency in the aftermath of a child's death depends on a number of factors, including social support, world view, coping competencies, and resources (Klass, 1991; Knapp, 1986; Sanders, 1989). Not only the members of a family but the entire family system is changed when a child dies, and there may be significant shifts in the roles, structure, and processes that characterize the family (Arnold & Gemma, 1983). An effort to understand how child loss affects parents must also be accompanied by attention to the family relationships of the parents. A child's death has a potent influence on the marriage relationship of many parents (Rando, 1985). Additionally, how a parent responds to a child's loss will also have important implications for the manner in which they relate to other children that they might have (Bernstein, 1997). The impact of child loss on family relationships can thus be seen in influences on the marital relationship and also on parental behavior with remaining children.
Probably the most studied topic related to child loss and family relationships is how a child's death affects the quality of the marital relationship (Bohannon, 1990; Borg & Lasker, 1981; Lehman et al., 1989; Littlefield & Silverman, 1991; Rando, 1985). Some older studies have cited very high rates of marital breakup or failure following the death of a child (Schiff, 1977), but these tended to have extremely small and unrepresentative sample sizes that should not be counted on for generalizable results. Bernstein (1997) reviewed this literature and suggested, "The only reasonable conclusion is that the percentage of parents who divorce following the death of their child is simply not known at this point" (p. 102). However, it is known that parents do face significant challenges in relating to one another following the death of a child (Rando, 1985). The primary explanation for such marital difficulty has been that parents' grief experiences are so dissimilar that each spouse follows a differing "grief roller coaster" and thus they each tend to be "out of sync" with one another (Rando, 1986). A longitudinal study of 33 bereaved husbands and wives by Bohannon (1990) showed no evidence of such an asynchronous grieving pattern, but rather indicated consistently higher levels of grief intensity for wives as compared to husbands. Also, there were few significant relationships between parents' grief levels and their feelings about the marital relationship, with most of them feeling about the same or better concerning their marriage at a year after the child's death. The high levels of marital breakup suggested in early studies have not been replicated by the latest research (Bernstein, 1997; Bohannon, 1990; Sanders, 1989).
The particular difficulties faced by marital partners following a child's death sometimes makes it hard for them to understand one another, thus diminishing communication and mutual support (Bernstein, 1997; Rando, 1985). In the early months of bereavement spouses tend to cut off much communication with one another due to their own intense pain and a desire to avoid causing more pain for their partner (Schwab, 1992). During this time spouses may often feel anger, irritability with each other, the need for privacy, and a lack of understanding regarding one another's coping styles in dealing with grief. Differences in expectations may lead to misunderstanding and couples must struggle with fatigue and meeting the continuing demands of life (Rando, 1985). There is usually a cessation of sexual intimacy for some time following the child's death and individual partners vary widely in their readiness to resume this aspect of marital life (Schwab, 1992). While the first several months of mourning can be hard on marital partners, those who do separate tend to be those who had marital problems prior to the child's loss. Over time the patterns of marital interaction tend to resume, albeit somewhat modified, and many couples report they feel better about their marriage than ever before since they have come through the ultimate trial together (Bernstein, 1997).

Parents who have other children when a child dies, or who have subsequent children, confront a change in their own lives that will consequently also change their parent-child relationships. Although little research has addressed this topic, a number of studies have reported findings that are relevant to how bereaved parents interact with their other children. An immediate concern for bereaved parents is how they will manage their continuing parental responsibilities during the intense period of early mourning. The
state of numbness and fatigue characteristic of this time makes it difficult for parents to perform many basic functions, and so their parenting capacities may be diminished (Arnold & Gemma, 1983). Parents are placed in a difficult position psychologically because, as Rando (1985) points out, "Parents who have other children must continue to function in the very role that they are trying to grieve for and relinquish, that is, the parental role" (p. 22). The bereaved parent's feelings of failure in relation to the deceased child may be projected to their feelings in relation to surviving children. It should be noted that sometimes younger parents will attempt to soon have another child, and sometimes a child born after a sibling's death can be seen as a "replacement child." If parents displace continuing feelings of guilt or obsessive mourning toward the new child then emotional problems can result (Johnson, 1987). In any case, the early period of mourning may be the most difficult for parents and surviving children because all family members are struggling through grief. Children may feel guilty for having lived when a sibling has died, and parents may become so focused in their grief that surviving children receive less attention and support than is needed (Bernstein, 1997).

Although bereaved parents do face a struggle in continuing to parent their remaining children, they also report that they feel closer to their surviving children after a child's death (Lehman et al., 1989). This feeling may accompany a bereaved parent's desire to value family cohesiveness and strengthen personal relationships after a child has died (Bernstein, 1997). Thus, although parental capacity may be diminished for a time, a parent's desire to better his or her future parent-child interactions may actually intensify following the loss of a child. An expected and oft-mentioned consequence of losing a
child is increased parental protection and concern for surviving children. Parents may prohibit activities that could lead to injury and tend to be more watchful of a child's friends or where they are at any given time (Arnold & Gemma, 1983; Bernstein, 1997). Another aspect of continuing parent-child relationships is that parents describe how much more sensitive they have become to the precious nature of their children (Edelstein, 1984). Although a child's death does "knock parents out of the parental box to some degree and for some length of time" (Bernstein, 1997, p. 158), parents seem to make their relationships with surviving children a higher priority following such a loss. Further attention to how a child's death impacts bereaved parents' interactions with their surviving children should be given priority in future research on child loss and family relationships.

Summary

This chapter included an overview of the significance of child loss and the context of bereavement that parents experience upon a child's death. It also surveyed the literature on important factors that affect a parent's bereavement experience, including the circumstances of a child's death, individual characteristics, and sources of support during the mourning process. Potential impacts of a child's death on a parent's sense of identity were also reviewed, as well as the effect of child loss on family members in the context of marriage and parent-child relationships. These topics provide a context for understanding child loss and developing further efforts to study its influence on parental identity and parental behavior.
CHAPTER III

RESEARCH METHODS AND PROCEDURES

Scholarly inquiry into the subject of parental bereavement repeatedly affirms the weighty and long-lasting impact of a child's death on parents and other family members (Bernstein, 1997; Bohannon, 1990; Knapp, 1986; Miles & Demi, 1992; Rando, 1985; Sanders, 1980). Most research on child loss has focused on the parents' mourning process, social support for bereaved parents, or other dimensions of dealing with loss. However, this study grew out of the need for further research on other important but infrequently examined aspects of how parents respond to a child's death, specifically the influence of a child's loss on parental identity and subsequent parenting behavior. This chapter will present a theoretical context justifying the use of a qualitative approach in this study, outline the research design and procedures used in collecting parental accounts of child loss, and give details about how these collected stories were analyzed.

A Qualitative Approach to Studying Child Loss

The selection of a principal methodology for any research study should be guided by the expectation that the methodology chosen will be consistent with the aims of the research and appropriate to the research topic (Bailey, 1994). Additionally, the assumptions of the researcher also play a role in the choosing of a particular research methodology (Marshall & Rossman, 1989). For this study's purposes a qualitative research approach was selected, and the particular method of study utilized was
conducted in-depth personal interviews that focus on collecting personal narratives. The appropriateness of a qualitative approach for this study rests upon the goals of this study, assumptions about the research process, and the nature of the topic being studied.

The objectives for this research project on parental responses to a child's death are multi-dimensional, and cannot therefore be strictly confined to a narrow definition of the study's intended outcome. A qualitative methodology is especially valuable in this circumstance because it furnishes the flexibility that is needed to include differing but complementary research objectives (Tesch, 1990). The importance of child loss, combined with the still limited information available regarding its influence on parental identity and parenting behavior, leads to the following objectives for this study. First, to gather narrative accounts of parents' experience in losing a child and their perception of its impact on their parental identity and behavior. Second, to explore the meaning and content of child loss for parents as it is articulated by parents themselves. Third, to identify recurrent themes or patterns in parents' narrative accounts that provide fresh insight into how parents' identity and behavior are affected by a child's death. Fourth, to develop theoretical concepts that provide a better understanding of parental bereavement and adjustment following a child's death. Fifth, to consider implications of findings from the study in assisting bereaved parents through clinical intervention, support group participation, or family life education. Sixth, to provide an atmosphere in which the researcher and participating parents can discuss the experience of losing a child and share their individual understandings. A qualitative methodology for this study provides the most suitable approach, both philosophically and practically, for meeting these objectives.
and reaching levels of understanding not available through other avenues of study (Daly, 1994; Gilgun, 1992; Miles & Huberman, 1994).

The study objectives of gathering parental narratives, exploring the meaning of parents' narrative accounts, and creating a supportive research atmosphere all fit well with the advantages of qualitative research. These objectives all reflect the context of exploration in the research study. Since inquiry into the topic of study remains limited, a qualitative approach allows for a structured but open research method in which a great deal of information can be compiled and then explored systematically in a supportive atmosphere (Miles & Huberman, 1994). A qualitative methodology also fits well with the goals of identifying particular themes in parents' response to a child's death, developing theoretical concepts that enrich our understanding of child loss, and considering implications for giving practical assistance to bereaved parents. These objectives relate to desired outcomes from the study and a qualitative approach is most effective for pursuing them. The discernment of broad, repeating patterns or themes and the development of "grounded theory" concepts is a central feature of much qualitative research (Barritt, Beekman, Bleeker, & Mulderij, 1985; Gilgun, 1992; Glaser & Strauss, 1967; Rosenblatt & Fischer, 1993; Strauss & Corbin, 1990). The differing but complementary objectives outlined for this study thus fit comfortably with the philosophy and methods of a qualitative research strategy.

The researcher's assumptions concerning the research process needed in this particular study were also significant in the selection of a qualitative approach. With a focus more on interpretation and theory development, rather than testing of specific and
pre-determined hypotheses, an important assumption was that the research process would be more subjective and interpretive than objective and analytic. A qualitative approach explicitly recognizes the subjective nature of the research process and provides a means for allowing subjectivity while also pursuing scholarly rigor (Rosenblatt & Fischer, 1993). Another important assumption was that the development of understanding in this project could only occur through a participatory interaction with willing parents who would share their stories. The opportunity to associate personally and work toward a supportive relationship seems essential when doing research with bereaved parents. Both the intensity and the intimacy of the bereavement experience encourage the need for such a relationship between the researcher and participants, I would suggest, if information is to be meaningful and comprehensive. A qualitative approach makes possible the creation of a collaborative and more sensitive research process (Farnsworth & Allen, 1996).

The nature of a research topic is instrumental in considering how to select a methodology that is appropriate. Studying the experience of parents who have lost a child prompted attention to the need for acting with sensitivity, gathering substantive information, and listening to the individual voices of each parent. These considerations not only encouraged the selection of a qualitative research approach, they were supported by previous examples of research on parental bereavement that utilized qualitative methods (Bernstein, 1997; Edelstein, 1984; Farnsworth & Allen, 1996; Knapp, 1986; Layne, 1992; Lehman et al., 1989; Riches & Dawson, 1996). The decision to interview parents and gather narrative accounts was augmented by a desire for sensitivity to particular participant concerns or reactions and the more personal nature of an interview.
I was struck by the comment of one bereaved parent in a former study, who commented, "I don't know where it fits on graphs and tables and things, and you can't--I hope to God--you can't do that sort of research for this kind of question" (Edelstein, 1984, p. 6). The specific nature of the topic, which has not been studied extensively, also encouraged the use of an approach that would generate a large amount of substantive information. The interview process in qualitative research is particularly useful for that purpose (Rosenblatt & Fischer, 1993). It also seemed critical to hear the individual voices of the study participants and not let them be obscured by a more impersonal research method that would mask the expression of their feelings and experiences. Feminist theory has been especially powerful in initiating this kind of realization regarding social science research, and suggests that "[parents] express a strong need to have their voices and experiences heard with respect and tolerance" (Farnsworth & Allen, 1996, p. 366). Qualitative research allows for such expression of lived experience and enables hearing the voices of bereaved parents who are willing to speak of their pain and share what they have learned with others.

Narrative Accounts and Parental Bereavement

Qualitative research can provide an avenue of understanding about family life because of its openness to varieties of experience among individuals when trying to understand a specific topic. Hawkins and Dollahite (1994) suggest that it is a method which "would allow for analyzing [persons] in families within their own frame of reference and respecting their own lived experiences" (p. 775). In this study personal
narrative accounts of how parents experienced a child's death and its impact on their sense of identity and parental behavior were gathered through qualitative interviews. The definition of narrative accounts for this study is "the stories people tell about their own experiences, along with the meanings they attach to those stories" (Dollahite, Hawkins, & Brotherson, 1996, p. 350). The value of a narrative study for researching effects of child loss on parental identity and parenting behavior is supported by other examples of such research and narrative theory.

The centrality of personal stories in understanding any particular experience is increasingly recognized in the social sciences (Kotre, 1984; Mair, 1988; McAdams, 1993; Palus, 1993; Polkinghorne, 1988). Rosenblatt & Fischer (1993) point out that what people "communicate often comes in the form of organized accounts that could be called family stories. These stories are not incidental to the analysis. Their interpretation is a key analytic tool" (p. 170). Specific research on parental bereavement has tended to focus on the grief experience, and has been characterized by measurements of grief symptomatology, measures of grief distress or social support, or interviews with parents about their loss experience. Interview studies that explore the stories of bereaved parents have become increasingly utilized and mark a number of significant research efforts (Bernstein, 1997; Edelstein, 1984; Finkbeiner, 1996; Knapp, 1986; Sanders, 1980). In Knapp's (1986) massive study of over 300 bereaved parents he noted that listening to their personal stories allowed him to reach a small but valuable degree of vicarious understanding of the trauma of losing a child, and it also attuned him to both the similar and unique elements in each parent's story. In another study Bernstein (1997)
interviewed fifty-five bereaved parents and shared many of their stories about experiencing and moving through the aftermath of a child's death. Farnsworth focused on mothers' stories of bereavement in her doctoral research in order to discover how they interacted with the social system and changed as a result of the loss (Farnsworth & Allen, 1996). It has been noted that the narrative technique may be particularly appropriate for collecting the emotionally sensitive information that participants share during bereavement (Riches & Dawson, 1996). These and other studies demonstrate an increased focus on examining narrative accounts when studying bereavement and the potential contributions of this approach.

Studying parents' narrative accounts also seems logical when considering the connections between narrative theory and how individuals represent their personal identity and behaviors. The primacy of personal narratives in understanding the meaning of how individuals present themselves and their experiences has been asserted by a number of scholars (Bruner, 1990; Howard, 1989; Sarbin, 1986). McAdams (1993) has set forth a "new theory of human identity" that centers in "the idea that each of us comes to know who he or she is by creating a heroic story of the self" (p. 11). In other words, not only an experience itself but the telling of that experience in a narrative form becomes important to the formation of aspects of identity. Additionally, in narrative theory one's identity is not seen as fixed but rather is developmental in the context of being anchored to certain core self-understandings (Bruner, 1990; McAdams, 1993). Narratives serve a dual function in that they both capture the factual experience of an event (though the presentation of the facts is selective and dependent on the individual) and express the
meaning that any particular event holds for an individual (Dollahite, Hawkins, & Brotherson, 1996). It is the process of narrating one's life experience that is involved in the making and re-making of one's self. As Funkenstein (1993) notes, "The identity of an individual and the identity of a group consists of the construction of a narrative, internal and external: the narrative construed by and the narrative construed about the subject" (p. 23). Events that impact dramatically the course of one's life narrative, then, would hold serious implications for one's identity and future life experiences.

Recognizing that when parents lose a child it constitutes a life event of enormous impact, it becomes important to consider how personal narratives might provide insight into changes in parental identity and subsequent parenting experience during bereavement. Riches & Dawson (1996) suggest that one reason communication between marital partners is severely constrained during bereavement is because each parent is re-ordering their parental self-narrative. Verbal and nonverbal communication, part of the medium for communicating one's own narratives and understandings about life, may be hampered by the chaos within one's sense of identity due to the child's death. A child's death represents a "nuclear episode" in the narrative of one's life, a particular life episode that is one of the climaxes of a personal life story (McAdams, 1993). Such episodes become extremely important in the narratives that people share about their own lives, and so the bereavement experience tends to be linked with important personal narratives. The difficult emotional trials that a parent passes through during bereavement are both captured in such personal stories and shared in telling others of one's experience. As Gersie (1991) notes of narratives and bereavement, "Since time immemorial metaphor
and the story's sequential imagery have been used to activate people's emotional and
cognitive ways of coping" (p. 214). This would suggest that an understanding of parents'
bereavement experience when a child dies can be deeply enriched by paying attention to
the stories that parents tell of their experiences. Personal narratives can thus open a
window of insight into parents' experience of child loss in a way that provides meaning
and also values personal expression.

A final consideration in using parental narratives for the purposes of this study is
that it allows parents to reflect back on their experience and share how their lives have
been shaped because of a child’s death. A particular difficulty in studying the impact of a
child’s death on parents exists in the fact that generally it is not possible to evaluate what
the parent’s life was like prior to a child’s illness or death (except through retrospective
analysis). Even if a child has not died but suffers from an illness, the family’s
circumstances are changed and a parent’s attitudes and behavior are affected. Therefore,
comparison of parents’ identity and behavior both before and after a child’s death
becomes very challenging from a methodological standpoint. It might also be noted that
there would be ethical concerns in trying to study parents who have not lost a child, and
then somehow waiting for such a tragic event to occur and studying them again. Some
research has been conducted with parents who have lost children gradually due to illness
or chronic conditions, but again, the child is still dying and family conditions have
changed. The qualitative approach permits a retrospective view of personal experience
that parents can share and they are able to relate their own perceptions of how they have
been influenced and changed (or not) by a child’s death.
Research Design

This study involved gathering parental narratives concerning loss of a child and learning how such an experience impacts parents. Specifically, it examined how the experience of a child's death affects a parent's sense of identity and subsequent parenting behavior. In order to collect information that is supportive of and consistent with the research questions and objectives guiding this study, a qualitative research design was selected for the project.

Parental accounts of child loss were gathered through conducting in-depth, qualitative interviews with individual parents. Study participants in the study included both mothers and fathers who have experienced a child's death, and interviews were conducted with nineteen parents. Interviews were only conducted with one parent from a family. Pilot study interviews were done with three bereaved parents in order to pre-test the interview questions and make adjustments to fit with the study's defined objectives. These and all other interviews with participants were done by the researcher, who had previous training and experience in developing and conducting qualitative interviews in social science research. The research interviews were each conducted in the home of the study participants during the spring and summer of 1998, each lasting from one to two and-a-half hours in length. Each interview followed a semi-structured interview schedule of questions but allowed for open-ended response, and interviews were tape-recorded and later transcribed for analysis. The research design focused on fostering description and interpretation of meaning in the experience of bereaved parents through sharing of their personal accounts. This approach was employed in the hope of learning new insights and
providing the opportunity to respectfully "listen to people talk in their own terms about what [has] been significant in their lives" (Josselson, 1003, p. ix).

**Research Design Issues**

Specific issues related to the methodology being used in the study emerged during the research design process. This section discusses the most salient issues to the study and how they were approached in the design process.

**Researcher Competence**

Although the qualitative approach in research may yield an added amount of flexibility, this does not require a corresponding decrease in attention to meeting the requirements of good scholarship (Gilgun, 1992). Such requirements may differ to a degree in qualitative research, and one of the important elements is the ability and training of the individual who collects research information. Miles and Huberman (1994) note that due to the intimate involvement of the researcher in gathering and analyzing information, researcher competence must include familiarity with the qualitative research process and the topic being studied. The ability to trust oneself as researcher and for others to exercise such trust becomes important since the quality of the research depends largely on the researcher's ability (Walker, 1996).

As the primary investigator in this study, I felt compelled to strengthen my background in the qualitative research process and my understanding of parental bereavement. I completed extensive coursework in general research methods at both the master's and doctoral level, which provided familiarity with the research process and the
need for attention to issues such as reliability and systematic study. At the master's level I completed one seminar course that focused on the development and mechanics of a narrative study in qualitative research. I also conducted a research study on father-child relationships using that method and published the results as my master's thesis, providing extensive experience in study design, data collection, and qualitative analysis. At the doctoral level I completed two courses in qualitative research methods and also continued participation in qualitative research projects that involved data collection or analysis. In addition, during the last five years I have conducted and transcribed numerous qualitative, in-depth interviews conducted as part of my work as a family history researcher. My professional activities have included writing, presenting, and publishing professional papers that were based on qualitative research.

In order to further my knowledge of the topic of parental bereavement, I read widely in the literature available on this topic, prepared a review of the literature in preparation for this study, and conducted a small pilot study with bereaved parents as part of a qualitative research course. As the researcher, I also had personal experience with bereavement in the loss of a family member. An older sibling of mine (a brother) was killed suddenly in an auto accident several years ago, and thus I was quite familiar with the challenges of bereavement. One reason for my interest in the study topic was due to my own experience in witnessing the impact of my brother's loss on my own parents and their subsequent experience. I have participated in many discussions with other individuals who have lost a child or another family member. In asking study participants about their willingness to discuss their experiences, a number of them also indicated that
they felt more comfortable talking to someone who also had personal experience with and understanding of loss of a child within the family. Thus, specific work experience, university graduate work, qualitative research experience, and personal familiarity with the topic all contributed to my knowledge and preparation.

**Reflexivity and Reactivity**

Reflexivity involves an awareness of one's own subjective position in the research process and a critical examination of the ongoing research experience (Allen & Walker, 1992; Hammersley & Atkinson, 1983). The researcher's stance in a qualitative study, as defined in this project, necessarily encompasses both the effort to subjectively immerse oneself in hearing and responding to participants and the need to objectively step back and make sense of the information that is shared. Careful consideration of the need to be "reflexive," or to appraise one's own contributions to the research process, was furthered by keeping notes on personal reactions during the study and considering their implications. One significant personal factor that emerged during the interview process was my own background in losing a sibling. In sharing this fact with study participants, they often asked me to share some of the experience and how it had affected me and members of my family. This exchange of stories and personal thoughts seemed to enhance the communication and willingness to share during the interviews. I noted this tendency during the first interviews in the study and was careful to allow time for such exchange in the other interviews. Also, it was apparent that the intense nature of the topic made the interview process somewhat emotionally demanding, so that at times I found
myself fatigued after conducting interviews. If I felt such emotional fatigue, then I would let one or two days go by before conducting further interviews and allow a chance to regain energy for the research process. By taking note of personal reactions in this way, particular biases that may have influenced the research process and analysis were more easily accounted for and minimized.

Another issue in qualitative research relates to reactivity, or the understanding that study participants may tend to behave differently when taking part in research than they would in more normal conditions (Cozby, Worden, & Kee, 1989). For example, a parent may not disclose some things in telling a story or may embellish others. However, since a personal narrative expresses what a parent has chosen to share in a particular setting, then the concern regarding reactivity should be secondary to respect for the parent's choice. Efforts to minimize reactivity were taken by providing a comfortable interview atmosphere, using questions that were designed to foster honest disclosure, and encouraging participants to focus on what was most meaningful to them. Additionally, it is important to note that in a study that examines narrative accounts the focus centers more upon increased understanding of the topic and not control of participant responses.

**Reciprocity**

One issue in research design relates to what has been called reciprocity, or the consideration of what is done to make certain that participants receive proper compensation for their involvement in a study. Daly suggests that the "researcher and participant(s) establish a relationship that is based on a fair exchange" (1992, p. 7). It is
not uncommon for researchers to pay study participants a certain amount as reimbursement for their participation in a research project. Considering the personal nature of the topic being studied and also limited funds to conduct the research, payment of a monetary amount seemed less appropriate as a means of reciprocity in this study. Instead each interview participant was supplied with a personal copy of the transcript from their own interview, as well as a personal letter of appreciation. This attempt to meet the ethic of reciprocity will hopefully not only provide a form of appreciation for their involvement but a lasting contribution for their own interest and purposes.

Ethical Considerations

Qualitative research on family life demands attention to the major ethical issues that arise from such a process. Prominent ethical concerns involve the informed consent of study participants, understanding the risk-benefit potential of the research process, and handling emotional reactions during research (LaRossa, Bennett, & Gelles, 1994).

The ethics of informed consent suggest that study participants should receive sufficient information about the proposed research to make a decision about the potential risks or benefits of participation, as well as providing for voluntary participation and the option of withdrawing from the study as desired (Diener & Crandall, 1978). Prospective study participants were contacted individually by phone after giving their permission directly to the researcher or through another contact to the researcher (such as through a grief support group leader). The study was clearly described, and if the individual showed an interest then additional information was provided. This information included
a letter outlining the proposed research project and use of the results, and an informed consent document. Participants were encouraged to review this material and then were contacted a second time to determine their willingness to participate in the study, and to allow them to ask any particular questions they might have had concerning the research project. Each participant who agreed to be interviewed for the study was then asked to sign an informed consent document that specified an understanding of the purpose and potential uses of the research, their willingness to participate in the interview, permission to use the information gathered, a recognition of confidentiality to be provided, and an awareness of their right to not answer any question or withdraw at any time from the project (a copy of this document has been attached in Appendix 1).

Potential risks and benefits associated with participation in a research project need to be accounted for in any study. The positive or negative results that a participant may experience need to be addressed, particularly as it relates to participation itself or the use of information shared by participants. Participants in this study were given the chance to evaluate risks and benefits prior to participation through the initial contacts and opportunity for informed consent. Confidentiality for the participants was dealt with in two ways. First, all information gathered through the research process, such as audio tapes or transcripts, was assigned a neutral identification code and kept in a locked location by the researcher. Second, the participant's name and identifying details were changed during use or presentation of the information. These steps were intended to minimize risks associated with public exposure and ensure the privacy of the participants (LaRossa, Bennett, & Gelles, 1994). Additional risks in this project seem to be minimal,
as bereaved parents report that they think often of their experience and nearly always express a positive response to the opportunity to discuss their experience. Thus, perceived risks, such as bringing back a tragic memory or triggering negative emotions, tend to be less consistent with the actual experience of qualitative studies in bereavement (Bernstein, 1997; Kitson, Clark, Rushforth, Brinich, Sudak, & Zyzanski, 1996; Knapp, 1986). Participation in the interview process may even produce some benefits in that participants receive a chance to reflect on their experiences in an ordered setting, share their stories with someone who recognizes the importance of their loss, and may feel that they are making a contribution to a better understanding of parental bereavement (Kitson et al., 1996; Farnsworth & Allen, 1996).

One ethical concern that is consistently raised is the prospect of emotional difficulties that may arise from talking about a difficult and sensitive topic. The potential for an emotional reaction to discussion of a child's loss needs to be acknowledged and not minimized. During the interview process a respondent may become emotional and shed tears, express anger, or feel embarrassed at an expression of emotion. In such circumstances during this study, efforts were made to be empathetic and to assure the study participant that such emotion is both understandable and appropriate (Kitson et al., 1996). While a few participants expressed such emotion at times in the interview process, all willingly completed the interviews and expressed appreciation for the opportunity to participate.
Participant Selection and Description

The selection or sampling of participants for interviewing in the research process involved obtaining access to a very specific population: bereaved parents. Due to this reality and the exploratory nature of the study, purposive sampling was used in a number of ways to identify, contact, and encourage the participation of individuals in the proposed study. Purposive sampling enables a focus on a specific population and also is meant to capture a wide variety of information that will enable the development of substantive theoretical understandings (Lincoln & Guba, 1985). The sampling processes planned for use in this study included "key informant" sampling and "snowball" sampling. Key informant sampling was accomplished through identifying knowledgeable persons in the target communities who were able to provide information on the topic and also links to other persons with similar experience or knowledge. The identification of key persons for this study was accomplished through contacting local grief support groups, other institutions, and individuals in order to facilitate a request for study participants, and also through identifying bereaved parents who were already known to the researcher. Snowball sampling was then pursued through asking such key persons or volunteer participants to identify other individuals who might be willing to participate in the designed study (Lincoln & Guba, 1985; Miles & Huberman, 1994). Formal initiation of these contacts proceeded after obtaining Human Subject approval from the Institutional Review Board (IRB) of Oregon State University. Through these procedures nineteen study participants were eventually contacted and agreed to participate in the research project.
Participants in the study consisted of thirteen mothers and six fathers from two mid-sized communities in Oregon and Utah. Study participants were all Caucasian and ranged between the ages of 40 and 93 years of age, although most were in their forties or fifties. The average age of mothers in the study was 59 years and the average age of fathers in the study was 56 years. Nine women in the study were married (first marriage for all but one), two were divorced, and two were widowed. The married women averaged 37.2 years of marriage, while the divorced women averaged 10.5 years single and the widowed women 3 years. All six men in the study were married (first marriage for all but one) at an average of 26.8 years. Family size for mothers in the study ranged between 2 children and 10 children, with the average being 4.6 children per family. Family size for fathers in the study ranged between 2 children and 7 children, with the average being 5 children per family. Nearly all of the study participants described themselves as having a mid-level socioeconomic status, with four suggesting they were “low to middle,” thirteen stating they were “middle,” and two saying they were “middle to high.” All study participants had completed at least a high school education, with seventeen of the nineteen actually completing a college degree or some college education. Ten of the thirteen mothers in the study identified themselves as being currently active in a faith community, and five of the six fathers in the study also identified themselves as being active in a faith group. Table 1 summarizes the demographic characteristics of female study participants, and Table 2 summarizes the demographic characteristics of male study participants.
<table>
<thead>
<tr>
<th>Participant #</th>
<th>Mother's Age at Time of Interview</th>
<th>Number, Age and Gender of Children</th>
<th>Marital Status</th>
<th>Self-Described SES</th>
<th>Education Level</th>
<th>Occupation</th>
<th>Active in Faith Group</th>
</tr>
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<tbody>
<tr>
<td>#A1</td>
<td>54</td>
<td>10 Children - F (dec), F (30), F (27), F (26), M (22), M (21), F (19), F (17), M (15), M (14)</td>
<td>Widowed (for 2 years)</td>
<td>Middle</td>
<td>College-level Studies</td>
<td>Secretary</td>
<td>Yes</td>
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<td>#A2</td>
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<td>6 Children - M (dec), M (30), M (27), F (25), F (22), F (21)</td>
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<td>College Graduate Degree</td>
<td>College Instructor</td>
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<td>#A3</td>
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<td>Married (2nd marriage, 32 years)</td>
<td>Middle</td>
<td>College-level Studies</td>
<td>Retired</td>
<td>No</td>
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<tr>
<td>#A4</td>
<td>50</td>
<td>2 Children - M (dec), F (21)</td>
<td>Divorced (for 2 years)</td>
<td>Low to Middle</td>
<td>College-level Studies</td>
<td>Office Manager</td>
<td>Yes</td>
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<td>3 Children - M (40), M (37), F (dec)</td>
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<td>High School Degree</td>
<td>Homemaker</td>
<td>Yes</td>
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Table 1, Continued

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<tr>
<th>Participant #</th>
<th>Mother's Age at Time of Interview</th>
<th>Number, Age and Gender of Children</th>
<th>Marital Status</th>
<th>Self-Described SES</th>
<th>Education Level</th>
<th>Occupation</th>
<th>Active in Faith Group</th>
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<td>College Degree</td>
<td>Home Health Care Nurse</td>
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<td>#A7</td>
<td>55</td>
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<td>Middle</td>
<td>College Degree</td>
<td>Emergency Room Nurse</td>
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<td>80</td>
<td>4 Children - F (59), M (dec), M (50), F (48)</td>
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<td>Middle</td>
<td>High School Degree</td>
<td>Retired</td>
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<td>Middle</td>
<td>College Degree</td>
<td>College Instructor</td>
<td>Yes</td>
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<td>Participant #</td>
<td>Mother’s Age at Time of Interview</td>
<td>Number, Age and Gender of Children</td>
<td>Marital Status</td>
<td>Self-Described SES</td>
<td>Education Level</td>
<td>Occupation</td>
<td>Active in Faith Group</td>
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<td>47</td>
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<td>College Degree</td>
<td>Homemaker</td>
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<td>College Degree</td>
<td>Elementary School Teacher</td>
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<td>#A13</td>
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<td>3 Children - M (32), M (dec), F (29)</td>
<td>Married (for 37 years)</td>
<td>Middle</td>
<td>College Degree</td>
<td>Elementary School Teacher</td>
<td>No</td>
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Table 2. Demographic Characteristics of Male Study Participants

<table>
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<tr>
<th>Participant #</th>
<th>Father’s Age at Time of Interview</th>
<th>Number, Age and Gender of Children</th>
<th>Marital Status</th>
<th>Self-Described SES</th>
<th>Education Level</th>
<th>Occupation</th>
<th>Active in Faith Group</th>
</tr>
</thead>
<tbody>
<tr>
<td>#B1</td>
<td>61</td>
<td>7 Children - F (dec), M (dec), M (30), F (30), F (28), M (26), F (21)</td>
<td>Married (2nd marriage, 7 years)</td>
<td>Middle</td>
<td>College Degree</td>
<td>Business Owner</td>
<td>Yes</td>
</tr>
<tr>
<td>#B2</td>
<td>40</td>
<td>4 Children - M (dec), F (10), M (6), F (3)</td>
<td>Married (for 19 years)</td>
<td>Middle</td>
<td>College Degree</td>
<td>Apartment Landlord</td>
<td>Yes</td>
</tr>
<tr>
<td>#B3</td>
<td>47</td>
<td>5 Children - M (24), M (21), M (dec), M (15), F (11)</td>
<td>Married (for 27 years)</td>
<td>Middle</td>
<td>College Degree</td>
<td>Plumber</td>
<td>Yes</td>
</tr>
<tr>
<td>#B4</td>
<td>58</td>
<td>6 Children - M (29), M (28), M (dec), M (21), M (19), F (16)</td>
<td>Married (for 31 years)</td>
<td>High</td>
<td>College Degree</td>
<td>Corporate Executive</td>
<td>Yes</td>
</tr>
<tr>
<td>#B5</td>
<td>93</td>
<td>6 Children - F (62), M (60), F (dec), F (56), F (54), M (51)</td>
<td>Married (for 66 years)</td>
<td>Middle</td>
<td>College Graduate Degree</td>
<td>Research Scientist</td>
<td>Yes</td>
</tr>
<tr>
<td>#B6</td>
<td>41</td>
<td>2 Children - M (dec), M (5)</td>
<td>Married (for 11 years)</td>
<td>Low to Middle</td>
<td>College Degree</td>
<td>Computer Technician</td>
<td>No</td>
</tr>
</tbody>
</table>
Three of the study participants were recruited through contacts made with grief support groups, six were recruited through individual contacts made by the researcher, and ten were recruited through referrals from other study participants. The participants were often very willing to participate and volunteered to assist with referring others for the study. Limitations on potential participants were that the child's death had to have occurred at least two years prior to the interview taking place, and that the child be between the ages of 18 months and 25 years at death. These requirements allowed for the participant to have passed through much of the bereavement process and limited the study to exclude parents of adult children over age 25.

**Interview Development and Procedures**

This section profiles the content of the interview schedule that was utilized in the research interviews and the research process that was involved in the study.

**Interview Content**

The development of useful interview questions and a constructive interview process is fundamental to the success of a qualitative study that uses this method. Questions that are designed for use in a structured interview schedule should be developed early in the research project, then refined as feedback is obtained through outside reviewers and from actual interview participants (Miles & Huberman, 1994). In order to organize a structured but flexible set of questions for use as the interview protocol in this study, first the study was conceptualized and questions were created that it was hoped would elicit the desired information. These questions were reviewed by
graduate student peers in a qualitative research class and recommended changes were
given. Next, the literature on parental bereavement and its relation to parental identity
and subsequent parenting was explored, and this brought a more explicit focus to the
study and the interview questions to be developed. Since several pilot interviews were
planned in order to test and refine the study questions, the interview protocol was then
developed after consideration of number and variety of questions, standardization,
interview format, and specific content and purpose of each question. The interview
questions were intended to further the objective of gathering parents' narrative accounts
regarding their experience and feelings following the death of a child. This initial set of
questions was used in three interviews and feedback was taken from the participants,
resulting in a final revision of the interview protocol in which questions were dropped,
added, and refined. The pilot interviews were not included in the analysis for the study
but did contribute to the interview questions and focus.

A structured interview schedule was then used to guide the interview process.
Each interview was different and therefore the order of questions was adapted as needed
to allow for seeking additional information or adjusting to participant responses. The
interview questions were intended to provide the opportunity for participants to reflect on
and share specific feelings, experiences, and stories about their lives as parents following
a child's death. Fifteen questions were developed for the interview guide: 6 questions
about the parent's feelings and experiences regarding parental identity, 4 questions
regarding their relationship with the deceased child, and 5 questions regarding their
parenting attitudes and behavior with other children (a copy of this document has been
attached in Appendix 2). Each question was also followed up by asking about the personal meaning of a particular experiences that were shared. The interview ended with two follow-up questions to obtain feedback about the interview and the participant's willingness to be involved in the research project. Thus, the interview schedule was structured but also flexible enough so that both comparable and unique information could be gathered from each interview.

In order to ensure construct validity of the interview questions, or making sure that they were conceptually grounded, each question was linked to some aspect of the theoretical context of parental bereavement. Each question's clarity and usefulness was examined by obtaining feedback and making revisions during the development and pilot interview process. Two other aspects of validity that are important to evaluate in a qualitative study are contextual and interpretive validity, or whether information gathered is thorough and whether it is reflective of genuine reality. The interview process allowed for careful questioning and thus encouraged contextual validity. A focus on personal narrative accounts that reflect actual experience also invites interpretive validity.

**Interview Procedures**

Preparation for conducting the interviews for this study was facilitated by developing the research design, formulating an interview protocol, and conducting a small pilot study in which several interviews actually took place. Additionally, an in-depth exploration of the relevant literature, as well as obtaining feedback and instruction from graduate advisors, served to provide a foundation for understanding the topic and
guidelines for conducting the interviews. Ethical guidelines were formulated for the study and also informed the interview process.

Each interview was set up with participants who had agreed to be interviewed for the study at a time and location that was convenient for them. Each interview was conducted individually and the interviews lasted from one to two and-a-half hours. The interviews were tape-recorded with the permission of the participant on a small, portable standard tape recorder on hour-long, high quality audio cassettes. Small, clip-on microphones were used to facilitate ease and clarity of communication during the interview as it was recorded. This usage of light, less obtrusive recording equipment seemed to foster a more informal, positive interview atmosphere.

Each interview participant was informed that they could request that the recorder be turned off at any point if they felt uncomfortable or wanted to converse without being recorded. Several participants asked for the recorder to be turned off at some point during the interview. In each case it was to take a break either to gain composure during an emotional moment or usually to change locations and show mementoes related to the deceased child. Nearly all study participants openly welcomed the opportunity to share stories about their deceased child and even the details of their loss experience, although the interview participants were often somewhat emotional when recounting the actual child's death. At these times the interview itself sometimes slowed down as an exchange of thoughts and feelings between the participant and researcher took place. During the interviews some participants took time to show pictures of the child, break for a visit a deceased child's memorial garden or other important spots, or to simply discuss and share
thoughts in a more relaxed setting. All interviews were completed and participants expressed favorable comments about being able to assist in the study. All of the recorded interviews were transcribed by the researcher for purposes of study and analysis as part of the research project.

**Analysis of Materials**

The first step in the analysis process for this study consisted of transcription of the recorded interviews by the researcher. A transcript can be prepared in differing formats, ranging from a verbatim record that depicts each pause and mis-statement to an edited account that focuses on specific textual structures (Kvale, 1988). The focus of this study is on parents’ narrative accounts and consideration of these accounts as holistic or thematic units of meaning, so the transcription was prepared in an edited format with each narrative remaining in the context of discussion recorded during the interview. The interviews were transcribed by the researcher for familiarity with the interview content and due to past transcription experience.

The next step in the analysis process required organizing the interview material so that it could be systematically read and analyzed. This required an extensive reading and re-reading of each participant’s interview transcript. Organization of the material was facilitated through identifying broad categories or themes into which the material might be put. These categories included (1) parental identity issues; (2) parental behavior and the deceased child; (3) parental behavior and other children; and (4) other issues. Each individual transcript was then read and marked in general so that the information could
later be more carefully organized by focusing on specific content and meaning aspects of
the material. At this point an important consideration was how to manage the large
amount of qualitative data gathered from the study. Qualitative analysis can be
performed systematically through individual organization of the material or through
computer-assisted analysis efforts, using such programs as The Ethnograph,
HyperResearch, or NUDIST. There are advantages and disadvantages to each approach.
For this study I selected to perform the analysis by doing individual organization and
using a simple word-processing computer program to help organize the information
systematically. This allowed for making linkages between ideas and organizing the
material across multiple contexts in a manner that fit with the needs of the study.

At this point the material from the interviews was more formally organized by
coding it for specific content or expressed meaning related to the experience of losing a
child, feelings about parental identity, etc. This type of coding has been called
“descriptive coding,” in which segments of material are identified by a particular code tag
(Miles & Huberman, 1994). This initial coding step is important to the analysis because
it makes it possible to develop a working sense of those concepts that seem most
prominent in the interview material. It should be noted that such coding efforts are
subject to revision during the analysis process in qualitative research. The descriptive
codes formulated at this stage of the analysis allowed material to be grouped under
specific categories (some portions of material were put in several categories) within the
thematic codes mentioned earlier. For example, descriptive codes identified for the broad
category of “Parental Identity” included such items as “Expectations” and “Sense of
Adequacy.” All interviews were read and systematically coded in this manner according to the content shared by parents in their interviews. Research databases for each thematic category were developed with material from the interviews grouped under specific codes.

A more extensive process of second-level coding was pursued after the initial descriptive coding process had taken place. This aimed at discerning broad, repeating patterns or themes in the material which could supply key findings and serve as a basis for developing grounded theory concepts (Barritt, Beekman, Bleeker, & Mulderij, 1985). This step in the process might be called pattern coding. The first coding effort was a descriptive endeavor that resulted in an overview of the data, while the second coding process was more explanatory and ties the research material to the development of a broader conceptual map of the loss experience among bereaved parents. This provided an important linkage between the interview material and the development of grounded theory concepts. Particular thematic concepts can be developed which attempt to give a heuristic understanding of the research topic. As Miles & Huberman (1994) have noted, underlying the process of qualitative analysis there must be “a conceptual structure, whether prespecified or evolving,” and the process itself consists of “refining or recasting parts of the conceptual structure [the researcher] brought to the study” (pp. 62-63). It has been suggested that the goal of qualitative analysis is to find such common themes that give conceptual order and direction to the topic being studied (Barritt et al., 1985). This stage of the analysis provided insight into the key patterns that were reflected multiple times in the experiences shared by many parents participating in the study. In this way
the individual voices of the mothers and fathers could be joined in giving a collective voice to the primary features of the parental experience when a child dies.

A final step in the analysis process involved comparison of materials across all of the interviews in order to further the coherence of conceptual understanding. This has been referred to commonly as the "constant comparative method of analysis" (Strauss & Corbin, 1990, p. 62), and again is a fundamental aspect of much qualitative analysis that is tied to the grounded theory approach. Concepts can be evaluated and refined by comparing them in a systematic way, and then the development of a further theoretical basis for understanding the parental experience of child loss can be attempted. This part of the analysis process included both looking for consistencies and being attentive to contradictions in the material that need to be accounted for. This analysis process resulted in a body of findings from this study that are described in the following chapters.

**Summary**

This chapter presented a rationale for utilizing a qualitative approach in studying child loss, the usefulness of parental accounts in understanding the research topic, the research design and methods used for collecting the data, and the process of analysis that was followed for this study. It also points out the manner in which the research methods and procedures fit with the topic and needs of the study, providing a context that allowed for exploration of the subject and sensitivity to the study participants. This review is meant to provide an overview of the methods employed in this research project and facilitate presentation of the study findings.
CHAPTER IV

PRESENTATION OF FINDINGS

This study focused on examining parental accounts of a child’s death as related by mothers and fathers who had lost children themselves. The purpose was to identify patterns which provide insights into parents’ experience and how a child’s death impacts their sense of parental identity and their subsequent parental behavior. The presentation of the findings from this project is broken down into four specific chapters covering differing aspects of the research analysis. The rationale for this pattern and the manner of presentation are described in this short chapter.

As the scope of this research project and the voluminous nature of the materials obtained through the participant interviews became apparent, it became necessary to determine how to present the findings for the study. The death of a child and its impact on a family is a singular, powerful event that reverberates across all aspects of a family system. The challenge of presenting the results from this study has been to capture the totality of that experience while also allowing the results to be grouped around central themes of analysis. The manner in which multiple themes intersect in a parent’s experience makes a systematic exploration of the data more difficult but also more needful. One father who participated in the study, Tom, shared a striking metaphor of the experience of a child’s death that illustrates the complex interweaving of themes related to such an event:
I like to paint. I painted [in] watercolor years ago and I recently started again. In your life, you go through your life and you do things. Everybody eventually establishes some direction and goes through life doing different things. Someone becomes a truck driver and listens to country as he drives a truck. Someone becomes a big-shot lawyer and drives a nice car. Another person is happy working as a mechanic in a garage. These people are all very unique and very colorful people. Very interesting people who are all individuals.

What makes them an individual in my view is that they’ve been working on this painting of their entire life, adding a little bit of color here, making a little corner of the picture develop more, to the point that every person’s painting is unique and different. As you paint you have an idea of how you would like it to look. You think that you might put the paint in [a certain spot], or you want to make a picture with mountains, or you think that you’ll put some trees here and mountains there and a waterfall. So you keep working at it and developing it. You have this vision of where it’s going to go and what it’s going to be like. You keep working at it and when you’re done there it is, somewhat like you pictured depending upon your skills, but it’s a very unique thing. Each one is different. You’re never going to paint one the same as anyone else. It’s always kind of what you thought because you’re the artist. In it are all the things you value, your likes, your dislikes, your abilities, your [wants for the future], because you are planning as you go.

You think [to yourself], “I want to do this and I want to do that; therefore, my painting will be like this and that.” Then you have a child. If you’re close to the child, you become a role model and they do all the same things that are similar to yours. Andy liked tools; I liked tools. Andy liked to fish; I liked to fish. So he starts to become something like you and it is great. Then all of a sudden he dies. All of the things that you loved to do and that you shared with him are now too painful to even think about doing any more. The things that you’ve done and built up over a lifetime [regarding] who you want to be or develop into are gone. They’re there in the background but they’re too painful to think about doing any more. For me it felt as if someone had taken my painting, ripped it off the easel, put up a blank canvas and said, “You have to start over, you can’t make that same painting you were making any more.” It was gone. That painting you’ve worked on for years to develop is gone.

For me, well, I used to be homeless in Texas. I was young. I lived out of my pickup truck. . . . I came to Oregon and got job logging. I was a big macho man and all of that. I got tired of working in the snow, so I went to school, met my wife, somehow graduated and got a good job. We bought a house and then we had a family, and the boys . . . looking at them in the back yard I knew I’d reached the high point of my life. From the time I was homeless in Texas and woke up
one day and said that I didn’t want to be that way any more . . . that was my
reward. That was the end of my road right there--watching them play. I had
made it. I had climbed the mountain and there I was.

My whole entire painting could be mapped up to that moment . . . and then Andy
died. It was all gone. All my effort. All the work that I put into that moment of
my life was gone. The painting was gone. I had to start over.

I still have the components I painted with. I have my son Jimmy. I have my
skills. I have a job. I still have some vague idea of what kind of things interest
me and [what I might want to] accomplish in life. But the whole brush and focus
is all different and gone. It’s like I’ve had to re-start over my whole entire
painting and re-define the things that make me happy or bring joy. I can’t go
fishing any more. I find no joy in using tools. I find myself trying different
hobbies and activities, as if I’m trying different hats until I find what I like. I
played with taking pictures for a while. I played with playing games for a while.
I’d like to try doing some model planes some day, and maybe I’ll like it and
maybe I won’t. I keep trying these different things out for fit and feel as I try to
re-establish myself, and I re-establish what’s going into my new painting--my
new self as it were. Parts and pieces of it are still the old me. I found myself
taking some of those old parts and pieces and putting them on my new painting,
but other parts of the painting are totally new. So this new painting is my new life
that I have to rebuild and re-create for myself, this new image of what it is
supposed to be like down the road.

Down the road it was supposed to be one of the boys going to college if he wanted
to or one of the boys going into the service if he wanted to, and them getting
together with their families or both of their families coming for the holidays.
Now it’s just Jimmy. I don’t know what he’ll want to do. I’m not sure how he’s
going to fit into my painting down the line.

When I was a child we used to go canoeing up into Canada. My dad took this
picture of me and my brother in a canoe on the lake, framed by the trees, and out
in the middle of nowhere. It was really pretty. On my painting was that canoe
with my boys in it . . . now that part of the painting is gone. I have to find
something else to put there. So I guess the metaphor of the painting is a way of
illustrating how much it changes your life and how you have to restructure your
whole entire life, and how you view your life as progressing down the line from
where you are now.

This metaphor highlights the numerous and interrelated impacts that a parent must deal
with when a child dies. These include dealing with the emotional pain, reconstructing a
sense of parental identity, mourning the loss of unfulfilled future expectations, and relating to other family members in new and healing ways. Yet what unites all of these themes is the singular experience of a life-altering event that sets the parent on a new and difficult path in life's journey. The findings presented in the following chapters represent the variety of themes that have emerged from this study of parents who have shared the same unique experience: a child's death.

Through the analysis process, broad thematic categories were developed that guided the analysis and preparation of the findings. The details of the analysis process are outlined in Chapter 3. To a degree, these categories and the method used to present the findings follow a chronology that developed during the actual study interviews. In that context parents generally followed a pattern in which they focused first on their experience as parents with the actual loss, described the impact of the child's death on themselves, discussed the effects of the loss on how they related to the deceased child after the loss, and then addressed the impact of the loss on their relationships with other children. In order to follow this natural chronology, the findings were broken down into four primary chapters that fit the following themes: (1) parental experience during the actual loss; (2) impact of the child's death on parental identity; (3) parental behavior in relation to the deceased child; and (4) parental behavior in relation to other children. It is hoped that this pattern will allow readers to follow the progress of a child's death in its immediate context and what a parent experiences, its effect on parental identity, and then its influence on the behavior of parents.
The multiple chapters provide a connected and expanding perspective on the loss experience while also focusing on distinctive and central aspects of a child’s death for parents and the resulting implications. As with the metaphor of the painting, each chapter brings to the fore different themes that emerge from the central experience of losing a child. Many quotations and personal accounts from the study interviews have been included to illustrate the findings and to allow the genuine experiences and perceptions of the bereaved parents to be represented. There is also a sense of redundancy which seems built in to the loss experience and which may be discerned across chapters. For example, if a parent loses a child suddenly (loss context) they often carry a sense of guilt about not being available to help the child (parental identity), but a later response to this feeling might occur as parents become more protective of surviving children (parental relation to other children). Thus, while findings in a chapter may focus on specific themes they also link with patterns or findings that are described in other chapters. This reflects the challenge in qualitative research of separating out in a discrete manner those themes which in reality are woven together as a whole experience.

Another practical reason for dividing the findings into multiple chapters is so that they will be more easily digested by readers. Understanding such a weighty subject as child loss and its implications takes time and study, yet it may be less difficult for readers if the findings are presented in a thematic fashion that links them together. This consideration and the need to keep the findings focused has resulted in making choices about what to include in the study analysis.
In describing the findings the primary themes within a chapter are identified and then key patterns in the parental accounts related to these themes are presented and analyzed. The quotations and stories used to illustrate these themes have been kept as close as possible to the participant’s own words, although the words alone cannot capture the emotional expression or bodily gestures used to communicate these experiences. Some added explanation to provide context for the reader has been added as needed. The participants and their family members have been identified in the study by pseudonyms in order to preserve their confidentiality. Participants in the study were identified by a coded number. Tables with descriptive information are provided at the end of this chapter for easy reference while reading the chapters that follow. Each participant quote is identified by the person’s identification number in these tables in parentheses at the end of the quote. Tables 3 and 4 provide information about parent and child characteristics related to the child’s death (separated by gender into mothers and fathers), including a participant identification number, parent and child pseudonyms, gender and age of child, cause of death, and years since child’s death at the time of the interview.
| Participant 
# | Mother’s Pseudonym | Gender of Child, Age of Child, and Cause of Child’s Death | Child’s Pseudonym | Years Since Child’s Death |
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>#A1</td>
<td>Ellen</td>
<td>Lost daughter at age 17 due to spinal meningitis</td>
<td>Rebecca</td>
<td>14 years</td>
</tr>
<tr>
<td>#A2</td>
<td>Jean</td>
<td>Lost son at age 24 due to auto accident</td>
<td>David</td>
<td>8 years</td>
</tr>
<tr>
<td>#A3</td>
<td>Anne</td>
<td>Lost son at age 23 due to auto accident</td>
<td>Gary</td>
<td>15 years</td>
</tr>
<tr>
<td>#A4</td>
<td>Stacy</td>
<td>Lost son at age 22 due to motorcycle accident</td>
<td>Jeff</td>
<td>3 years</td>
</tr>
<tr>
<td>#A5</td>
<td>Pam</td>
<td>Lost daughter at age 24 due to brain cancer and related problems</td>
<td>Linda</td>
<td>8 years</td>
</tr>
<tr>
<td>#A6</td>
<td>Carol</td>
<td>Lost daughter at age 20 due to auto accident</td>
<td>Lisa</td>
<td>3 years</td>
</tr>
<tr>
<td>#A7</td>
<td>Peggy</td>
<td>Lost daughter at 18 months due to accidental fall in the yard</td>
<td>Tina</td>
<td>15 years</td>
</tr>
<tr>
<td>#A8</td>
<td>Laura</td>
<td>Lost son at age 6 due to polio</td>
<td>John</td>
<td>49 years</td>
</tr>
<tr>
<td>#A9</td>
<td>Martha</td>
<td>Lost daughter at age 20 due to train-pedestrian accident</td>
<td>Jessica</td>
<td>2 years</td>
</tr>
<tr>
<td>#A10</td>
<td>Amy</td>
<td>Lost daughter at 22 months due to cancer</td>
<td>Gina</td>
<td>12 years</td>
</tr>
<tr>
<td>#A11</td>
<td>Dora</td>
<td>Lost daughter at age 15 due to auto accident</td>
<td>Jennifer</td>
<td>40 years</td>
</tr>
<tr>
<td>#A12</td>
<td>Virginia</td>
<td>Lost son at age 17 due to brain cancer</td>
<td>Eric</td>
<td>6 years</td>
</tr>
<tr>
<td>#A13</td>
<td>Sandra</td>
<td>Lost son at age 19 due to auto accident</td>
<td>Matthew</td>
<td>11 years</td>
</tr>
</tbody>
</table>
Table 4. Father and Child Characteristics Related to Loss Context

<table>
<thead>
<tr>
<th>Participant #</th>
<th>Father’s Pseudonym</th>
<th>Gender of Child, Age of Child, and Cause of Child’s Death</th>
<th>Child’s Pseudonym</th>
<th>Years Since Child’s Death</th>
</tr>
</thead>
<tbody>
<tr>
<td>#B1</td>
<td>George</td>
<td>Lost son at age 2 due to cancer</td>
<td>Corey</td>
<td>30 years</td>
</tr>
<tr>
<td>#B2</td>
<td>John</td>
<td>Lost son at 18 months due to household accident (ladder fell on child)</td>
<td>Alex</td>
<td>17 years</td>
</tr>
<tr>
<td>#B3</td>
<td>Ken</td>
<td>Lost son at age 4 due to drowning</td>
<td>Ryan</td>
<td>14 years</td>
</tr>
<tr>
<td>#B4</td>
<td>Michael</td>
<td>Lost son at age 16 due to auto accident</td>
<td>Brent</td>
<td>8 years</td>
</tr>
<tr>
<td>#B5</td>
<td>Jim</td>
<td>Lost daughter at age 15 due to auto accident</td>
<td>Sarah</td>
<td>40 years</td>
</tr>
<tr>
<td>#B6</td>
<td>Tom</td>
<td>Lost son at age 5 due to auto-pedestrian accident</td>
<td>Andy</td>
<td>2 years</td>
</tr>
</tbody>
</table>
CHAPTER V

PARENTING IN THE CONTEXT OF A CHILD'S DEATH

This study focused on parents who undergo the death of a child and how that experience affects their sense of parental identity and subsequent parenting behavior. Each study participant has passed through that experience in a unique and tragic context, with no person's loss being quite like that of another, although there may have been similarities in the child's type of death or other factors. In order to furnish a more clear understanding of the context of child loss for these parents, a general description of the types of loss experienced and some specific examples follow in this chapter. Additionally, the primary parenting issues that tend to arise before, during and after the child's death will be highlighted. This sets forth the contextual background of loss that parents endure when a child dies and the specific issues they face in the parental role.

Context of the Child's Death

The context of a child's death sets the stage for the issues that a parent will engage and struggle with individually and within the family system for years afterward. How a child dies determines such critical issues as how and when a parent learns of a child's passing, whether the parent is present at the time of the child's death, or what decisions the parent must make for the child's welfare. The child's type of death influences the loss context and key issues for the parent who cares for the child (Miles & Demi, 1992).
For this study the participant sample was limited to those parents whose children had died as a result of accident or illness.

Thirteen of the participants in the study experienced the loss of a child quite suddenly through a variety of accidental deaths. This information is provided in Table 5. The most common type of accidental death in this category (and in the overall study) was due to automobile accidents, with eight of the participants losing a child in this manner. Five of the eight children who died as the result of an auto accident were male; three were female. All of the children were drivers or passengers in a vehicle when the cause of death was an auto accident, except in one case where the child involved was a pedestrian. Also, all but one of the children who died in this way were teenagers or young adults between the ages of 15 and 24. Two other study participants lost children suddenly in traffic-related accidents, one as a result of a motorcycle accident and another as the result of a train-pedestrian accident. These children were also in their older years. One study participant each lost a child as a result of the following: drowning, accidental fall, and household accident (falling ladder). Interestingly, in each case the child involved was less than 5 years old. Although the sample for this study is not representative and therefore not generalizeable, the pattern of older children dying as a result of traffic-related incidents and younger children as a result of other random accidents is interesting. Also, the distribution of child deaths occurring primarily due to sudden, accidental causes is consistent with other research (Knapp, 1986; Miles & Demi, 1992; Seguin et al., 1995).
Table 5. Child Deaths Due to Accident

<table>
<thead>
<tr>
<th>Participant #</th>
<th>Cause of Death</th>
<th>Gender of Child</th>
<th>Age of Child</th>
<th>Yrs. Since Death</th>
</tr>
</thead>
<tbody>
<tr>
<td>#A2</td>
<td>Auto Accident</td>
<td>Male</td>
<td>24</td>
<td>8 yrs.</td>
</tr>
<tr>
<td>#A3</td>
<td>Auto Accident</td>
<td>Male</td>
<td>23</td>
<td>15 yrs.</td>
</tr>
<tr>
<td>#A4</td>
<td>Motorcycle Acc.</td>
<td>Male</td>
<td>22</td>
<td>3 yrs.</td>
</tr>
<tr>
<td>#A6</td>
<td>Auto Accident</td>
<td>Female</td>
<td>20</td>
<td>3 yrs.</td>
</tr>
<tr>
<td>#A7</td>
<td>Accidental Fall</td>
<td>Female</td>
<td>18 mos.</td>
<td>15 yrs.</td>
</tr>
<tr>
<td>#A9</td>
<td>Train Accident</td>
<td>Female</td>
<td>20</td>
<td>2 yrs.</td>
</tr>
<tr>
<td>#A11</td>
<td>Auto Accident</td>
<td>Female</td>
<td>15</td>
<td>40 yrs.</td>
</tr>
<tr>
<td>#A13</td>
<td>Auto Accident</td>
<td>Male</td>
<td>19</td>
<td>11 yrs.</td>
</tr>
<tr>
<td>#B2</td>
<td>Household Acc.</td>
<td>Male</td>
<td>18 mos.</td>
<td>17 yrs.</td>
</tr>
<tr>
<td>#B3</td>
<td>Drowning</td>
<td>Male</td>
<td>4</td>
<td>14 yrs.</td>
</tr>
<tr>
<td>#B4</td>
<td>Auto Accident</td>
<td>Male</td>
<td>16</td>
<td>8 yrs.</td>
</tr>
<tr>
<td>#B5</td>
<td>Auto Accident</td>
<td>Female</td>
<td>15</td>
<td>40 yrs.</td>
</tr>
<tr>
<td>#B6</td>
<td>Auto Accident</td>
<td>Male</td>
<td>5</td>
<td>2 yrs.</td>
</tr>
</tbody>
</table>
## Table 6. Child Deaths Due to Illness

<table>
<thead>
<tr>
<th>Participant #</th>
<th>Cause of Death</th>
<th>Gender of Child</th>
<th>Age of Child</th>
<th>Yrs. Since Death</th>
</tr>
</thead>
<tbody>
<tr>
<td>#A1</td>
<td>Meningitis</td>
<td>Female</td>
<td>17</td>
<td>14 yrs.</td>
</tr>
<tr>
<td>#A5</td>
<td>Brain Cancer</td>
<td>Female</td>
<td>24</td>
<td>8 yrs.</td>
</tr>
<tr>
<td>#A8</td>
<td>Polio</td>
<td>Male</td>
<td>6</td>
<td>49 yrs.</td>
</tr>
<tr>
<td>#A10</td>
<td>Cancer</td>
<td>Female</td>
<td>22 mos.</td>
<td>12 yrs.</td>
</tr>
<tr>
<td>#A12</td>
<td>Brain Cancer</td>
<td>Male</td>
<td>17</td>
<td>6 yrs.</td>
</tr>
<tr>
<td>#B1</td>
<td>Cancer</td>
<td>Male</td>
<td>2</td>
<td>30 yrs.</td>
</tr>
</tbody>
</table>
Six of the nineteen study participants experienced a child's death as a result of disease or illness. This information is provided in Table 6. The most common cause of death in this category was cancer, with four of the parents losing a child due to varieties of this disease, and the children ranging in age from infancy to young adulthood. In these cases parents were usually able to anticipate the death of the child beforehand and spent anywhere from eight months to several years parenting the ill child prior to death. One study participant lost a child to polio and another had a child die from spinal meningitis (died three weeks after onset of the illness.) There were no discernible patterns related to gender or age among the child deaths due to illness. A child's life-threatening illness can last variable periods of time and invoke intense parenting challenges.

The nature of a child’s death has important implications for a parent’s adjustment during the grief process and the social support received and expressed by parents (Bernstein, 1997; Edmonds, 1993; Rando, 1986). While a variety of research studies have examined the relationship between the type of child death and factors such as guilt expression of parents, grieving patterns, or social support (Knapp, 1986; Miles & Demi, 1992; Rando, 1986), less has been done in examining the parenting experience in the specific context of various types of death. This study has limited its sample so that participants who have experienced a child’s loss only by accident or illness (exclusion of homicide and suicide as causes of death) were included. However, this does provide the opportunity to assess how the nature of a child’s death shapes the parental experience during the period before, during, and immediately following a child’s passing. It also
seems critical to provide a framework for understanding the context of experience that a parent lives through when a child dies.

**Parents and the Loss Experience**

Most parents fear a threat to the life or security of their child more than any other potential concern as a parent. When such a concern is actually realized and a parent’s child dies, the resulting influences may carry a significant and lasting impact for the remainder of one’s life. The nineteen participants in this study each shared their own account of losing a child and how it has influenced their parenting experience, furnishing a great deal of information that can contribute to a better understanding of how a child’s death shapes a parent’s life. But it is critical to always remember that behind each participant’s account there stands a bereaved mother or father who has treaded the thorny path of grief with courage and endurance. It has been wisely said that words cannot capture the dimensions of a loved one’s loss. One commentator who attempted to frame the experience of a parent in losing a child noted:

Parents who lose a child are multiply victimized. We are victimized by the realistic loss of the child we love, we are victimized by the loss of the dreams and hopes we had invested in that child, and we are victimized by the loss of our own self-esteem. Not unlike the survivors of the concentration camps, we cannot comprehend why we did not die instead (Kliman in Linzer, 1977, p. 191).

Whether bereft of a child because of an unexpected and virulent illness or an intoxicated driver’s loss of control, parents who must endure a child’s loss nearly all agree that its effects on individual and family life are dramatic. A series of narratives retelling the loss experiences of several study participants are included next in this chapter to highlight the
powerful nature of a child's death as a life-changing event. This not only illumines the varied contexts of a child's death but allows the participants to share in their own words what this event was like for them. When asked about her loss experience one study participant simply stated: "It was the holocaust of my life."

**Child Loss Due to Accidental Death**

A major source of accidental deaths among children is due to auto and other traffic-related incidents. Ten of the thirteen study participants who lost a child as a result of accidental causes did so because of a traffic-related incident. Five of the children who died were passengers in the vehicle, three were driving the vehicle, and two were victims of traffic-pedestrian accidents. Prominent factors related to the cause of the accidents were driver error or recklessness, poor weather conditions, and what might be classified as "random" factors (striking a deer, a blown tire, etc.). Children who were killed as a result of traffic-related incidents were either killed instantly or lived only a few days after the accident.

For those parents who are present at the time of a child's involvement in a traffic-related accident, there is a terrible suspense associated with learning the fate of one's child. This is particularly true if the child has some hope of survival and the parents must wait for the final outcome. One father, Tom¹, whose son was injured fatally in a car-pedestrian accident recounted the post-traumatic "flashbacks" he experienced repeatedly

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¹ All participants have been given pseudonyms to respect confidentiality.
as a result of seeing his son be struck by a vehicle. He also shared the painful memory of his son’s accident and subsequent death:

We were trying to pack and get the house ready to sell and so there was a lot going on. That tended to get the boys riled up pretty good and excited. I went to sell my old commuter car to a friend, and I’m not sure why but Andy wanted to go with me. I was tempted to have him stay home and normally I did, but for some reason I thought it would be fun for him to have one last ride in the car. So we both got in the car and drove to Joe’s house and we sold it to Joe. He drove us back in his truck and pulled over to the side of the street that was on the opposite side of the street from our house.

Normally the street was a very quiet street. We got out and I turned to talk to Joe for a bit, and Andy was playing with a stick in the grass behind me. But he was still pretty excited and wound up, and he said, “I’m going to race you to the house,” then he took off out into the street. I looked up like I normally do to see if there were any cars coming and there was one coming, and I said, “Andy, watch out there’s a car!” And he didn’t stop. He kept running out and I tried to grab him and stop him. I remember screaming his name really loud and I just missed him by a couple of feet. I just stood there horrified. You have these heroic images of people jumping in the way and pushing people out [of the way]. I was frozen and I couldn’t move. I was just so scared with fear that he was going to get hit. I thought he was going to make it but at the last second he caught the car out of the corner of his eye, and he kind of froze and turned towards it just as the car hit him. It threw him through the air for about thirty feet. The car never even had a chance to hit the brakes because he ran out from in front of Joe’s truck. The driver of the car never had a chance to see him.

He was laying in the street, very still, and had blood coming out of his ears, his nose, and his mouth. He wasn’t breathing. I remember running up to him, screaming his name. [My wife] was in the front living room and she heard the sound of him being hit, and she heard me screaming. She came running out and screaming with Jimmy in her arms . . .

I got him breathing again by giving him mouth-to-mouth. I remember he cried a little bit once in pain, and I was thinking, “My God, he’s still alive,” then he passed out again. I don’t really remember how long it took the ambulance, but to me it seemed like they were there within seconds. I looked at the accident report later and it was ten minutes from the time they were called to the time they got there. They happened to be on their way back to the station and were just several blocks away. I was so scared that I was never going to see him again when they put him in the ambulance.
The neighbors drove us to the hospital. The hospital wasn’t too far away, only about twelve blocks away, and we were just so scared. From the emergency room waiting area we could see them rushing in and out and yelling. After a while they kind of calmed down and were working calmly and I thought, “Thank goodness.” Then the paramedics came out and they walked right past us without looking at us or making any eye contact, and that was really scary.

The doctor came and talked to us and told us that he was still alive, that he was in a coma, and that he wanted him to be airlifted down to Loyola’s trauma center in downtown Chicago. It is evidently a very big, well-known university hospital. We said yes and so they airlifted him out within twenty minutes. Once again I felt like I wasn’t ever going to see him again as I watched that chopper lift up and head towards Chicago. The neighbor drove us all the way to Chicago and it was two hours before we had a chance to see him in the ICU. They had him on a breathing apparatus and he was still alive. They explained to us that what had happened was that he had a crushed pelvis, a broken collarbone, and a broken jaw, but the big thing was that his brain was bruised. Like any kind of injury the tissue tends to swell, and that’s what happened in his brain—it was swelling. They had a pressure monitor attached to his skull, and if the pressure rose too high it would cut off the blood flow to his brain and he would be brain dead. It was a matter of just trying to tough it out. If he could make it through four days, then he would probably recover. But it takes four days for the brain to swell and start to go down.

He didn’t quite make it. It took four days and on the fourth day they declared him brain dead. We were pretty devastated. Crushed. He was the center of our lives and he was gone. We still have difficulty coping and dealing with it. We’re able to put on sort of a “game face” every day and just go through the motions, but when we stop and start to reflect we still feel very aimless, lost, without purpose or direction. It’s very hard to pick up the pieces and move on. (#B6)

This father expresses the sense of suspended animation that occurs for a parent who must wait upon the outcome of his child’s fate, and then the searching aimlessness that occurs when a child goes suddenly and leaves dozens of questions unanswered. His sentiment of feeling “lost, without purpose or direction” characterizes the chaotic nature of a parent’s experience when a child dies suddenly.
While some parents are present when a child's accident occurs, in general they must learn the startling facts related to their own child from an outside or unfamiliar source. In this study six parents who lost children due to traffic-related causes learned of the child’s death from police or other official sources, but only two parents learned it from a family member. Coming to know of a child’s death in this sudden, stark manner heavily assaults a parent’s sense of control and personal stability. A mother in the study, Anne, whose son died as the result of an auto accident recounted her experience in this context:

We’d gone to bed at close to 1:00 a.m. in the morning. We had just gotten into bed and the doorbell rang. It went through my mind, “Gee, that’s strange.” We had a little opening in the door and I was going to get up because Darin was not feeling good... the first thing I thought was that I’d just heard from my daughter and had talked to her on the phone and knew where she was, but I didn’t know where my son was. I went to the door and called through the door, “Who is it?” and they said, “It’s the police.” I thought again, “I don’t know where Gary is,” and then I opened the door and looked and they were there. . . . this police officer came in, this young man, and I went and got Darin. This man asked for Darin, my husband, and so I went and got Darin. Bless his heart, I don’t know how he knew how to do it, but this guy went right down the line of how you break this news to somebody. He asked for ID . . . just giving you a chance. When he said “Do you have a son named Gary?” there was a clue, and then he told us that there had been an accident and that Gary had “expired.”

I think that one of my reactions was . . . my husband was standing up but I had sat down, and I wanted to tell Darin to sit down, but I was afraid that if I did this guy was going to say that Gary had been killed. I was watching Darin when the fellow broke the news and right away I said, “Sit down,” because I thought he was going to collapse. This fellow said, “Can I make any phone calls?” and I told him who to call and he stayed with us a little bit. But I sort of went into shock. I turned ice-cold and somebody recognized that and got a blanket for me or something. But my reaction to it was that I knew exactly what it was. I had no doubt. There was no delusion in my mind that this had not happened. I just had such a sense of the finality of it.
We learned that he had been riding with this guy who had lost control of the car and hit a bridge up at Jefferson, the only unprotected railing bridge I think there is in the state, and so we didn’t know much about the accident but that Gary had been killed instantly. Later on we learned that this guy had been drinking beer and smoking pot, and that he had quite an impressive driving record. He hit the bridge railing and it went right through the car and right through Gary. Another thing we learned because we got a lawyer and he had a private detective look into this for us (also our next door neighbor was a private detective and although we didn’t use him he checked into things for us on his own), and it wasn’t a big mystery, but one thing that we did learn was that the first car on the scene of the accident was of two EMT’s from that area who had just come from their graduating class. So we knew that there was somebody there not only with knowledge but with equipment, and if anyone could have saved Gary he would have had a chance.

My best friend and Darn went over and got my daughter. She was staying with a friend and they brought her home. Of course, some of the concerns that you feel as a mother... I was very concerned for her and it gives you a focus. I guess the overall effect... The first person who came to me was a friend of mine whose son had been killed in an accident, and I was so glad to see her. Other people came but she’s the one I focused on. Then the second person was the friend whose child had committed suicide. Those were the people, I didn’t really want to talk to any of the other people, those were the people that I wanted to talk to and, of course, my question was, “How do you survive? How on earth did you get through this?” He was killed October 10, 1982. (#A3)

The mother of this young man notes the powerful physical and emotional impact (shock) of such a swift transition from being the parent of a living, breathing child to the parent of an “expired” child. But it is important to note her heightened protective sensitivity toward her remaining child, a young adult daughter, which indicates both a continuing parental focus and concern. Perhaps the most glaring fact of a child’s sudden death is represented in her simple and final statement about his loss—its finality and the utter lack of any opportunity to hope for a miracle.

Parents may also lose children through a variety of other accidental circumstances. One of the challenges associated with a child’s sudden death for parents
seems to be a heightened sense of guilt about the circumstances of death (Bernstein, 1997). The speed of a child's death may frustrates a parent’s ability to gain a sense of control and leave a mother or father wondering what might have been done differently. Numerous and challenging decisions face a parent whose child is near death or has died suddenly. These might include providing direct medical assistance to the child, determining whether to resuscitate the child if he or she dies, or making the choice about whether to continue medical treatment. Not only are the parent’s faculties already challenged by the shock of the experience, but the parent must also face immediate and critical decisions of consequence. This combination of factors may certainly contribute to the tendency for parents in these circumstances to question their decisions and express guilt about their actions.

Confusion, shock, guilt—these and other emotions swirl around a parent when an accident claims the life of a child without warning. For a parent, the aftermath of such an experience is filled with new and often terrible traumas. Yet while aspects of their loss experience are unique, they share the common pain of loss with other parents who lose children in a different way.

**Child Loss Due to Illness**

A second source of accidental deaths among children occurs as a result of various types of disease or illness. All six study participants who lost a child because of disease or illness expressed a hope that medical science might eventually find a cure for cancer or what caused their child’s death. Interestingly, however, most of them also shared a
strong recognition of the limitations of medical intervention in the face of overwhelming disease conditions. Parents with an ill child generally feel an intense motivation to find some type of successful intervention, but also begin to realize the "trade-off" that comes in having to see one's child go through pain or suffering that cannot be prevented. Parents whose children contracted a disease or illness endured the challenge for anywhere from eight months to four years.

When a child dies because of illness the death is usually anticipated for some time as the victim struggles with the effects of the affliction. It should be noted that children may die from a host of physical causes ranging from heart disease to malnutrition, and that only a very few are represented in the sample for this study. However, a child may become sick and die quite quickly or unexpectedly during the course of an illness, so that there is still little anticipation of the death and therefore little time to prepare for the loss. Two of the parents in the study group lost children rather quickly or unexpectedly to illness. One mother's daughter died swiftly due to the effects of meningitis, while another's son passed away unexpectedly while recovering from polio in the hospital. The mother whose son died of polio, Laura, shared the following account:

In 1948 in the fall there was an epidemic [of polio], and there were several in [our town] that had polio. I was unaware of it and so when John developed symptoms (they were like flu), we took him to the doctor and he said, "Well, he has polio." So we took him to Portland by ambulance. I was with him a whole month. They put him in an iron lung the day after we got up there because he couldn't breathe on his own. He had bulbar polio and was completely paralyzed.

When I got home I realized life would never be the same and so I had a big sobbing session in the bathroom, but then I never cried after that.
I wanted to share with you the fact that we are a family of faith. John trusted that the Lord was going to make him well some day, and we did too, but then as time went on he was moved to Shrine[r's Hospital]. The custodian wrote to me and said that he had been reading to John every day from Paul Bunyan, but one day [he] said, “Let’s not read from there today, let’s read from the Bible.” The custodian asked him what he wanted him to read and he said from Revelations. He told me that he had asked God to make him well during the night. I said, “And then what happened?” and he said, “He laid His hand on my forehead.” So when we got word 8-1/2 months after he entered the hospital that he had finally passed away on a Saturday morning, it wasn’t a sorrowful time. The mourning was tempered with a knowledge that he was in a much better place.

In the paper they described it as a tragedy, and everyone was affected in that the whole town seemed to be in mourning, because he had been a point of interest in the paper [during] all this time. . . .

I might mention, just as a matter of coincidence, that the nurse had said we could take him home as soon as we could arrange treatments at Eugene in the hospital school. So I had applied, and [his dad] said to him, “When do you think you’ll be coming home?” He said, “Oh, I’ll probably be discharged Saturday.” Well, the following Friday I got the mail and in there the heading on a letter said, “Eugene Hospital School for Crippled Children and Spastics.” I made a choice. Even though before I was determined that he would be well, and it happens that in every family in every situation you want to believe that they’re going to recover, but I just rejected that notion and [thought] that if that’s what he was going to be then I didn’t want him to go through that. He had said that he would probably be discharged Saturday, and that’s what happened. (#A8)

Although this mother’s boy died despite the family’s hopes to the contrary, the sense of tragic chaos that exists in the accounts of sudden loss does not loom in this account.

Instead there is a sense of resignation and even peaceful acquiescence to the child’s passing. She notes that the local paper “described it as a tragedy,” but that for the family “it wasn’t a sorrowful time.” The buoying influence of her own and the boy’s faith, as well as the time allowed to adjust to the possibility of his death before he actually died, seems to have allowed for a more accepting response to the child’s loss. Additionally, it may well be that this mother’s perspective has softened considerably since the death as it
had been nearly fifty years since his passing. But the narrative does highlight the
difference between learning of a child’s death suddenly and being able to anticipate the
possibility of child loss for some months.

A concern that all parents who lose a child seem to share is whether their child
experienced pain, suffering or fear during the transition to death. If a child dies by
disease or illness this concern becomes a reality for the parent that can be difficult to bear.
Whereas the parent bereaved by a child’s sudden death is tortured by wondering whether
the child experienced pain, a parent bereaved by a child’s slow death is tortured by the
reality of watching the child experience pain. Ellen, whose teenage daughter struggled
with meningitis and eventually died, detailed her loss experience:

She took sick on March 3rd, 1984. The night before she took sick she’d gone to a
dance with her boyfriend and felt fine. The next morning she woke up and was
not feeling good. She had a headache and was achey, so we thought she had the
flu. She just laid on the sofa most of the day . . .

About 11:30 p.m. that night I was upstairs with my husband. She came upstairs
and she almost collapsed on the bed. She said, “Mom, my back is burning.” I
looked at it and there were little spots all over her back. Within just a few
minutes those little spots went from dots to about the size of a dime and I
immediately went and called the doctor. They had to call and get him, so while I
was waiting for them to call me back I said, “We can’t wait, we’re just taking her
in.” So we called the emergency room and told them we were coming. Just as I
hung up the doctor called and I told him we were on our way in and were bringing
her in to the emergency room. He asked if it was hives and I said, “No, it’s not
hives, it looks like blood vessels are breaking and there are bruises.” We had to
carry her down the stairs because she was so weak. We got her into the car and
took her to the hospital.

They did a spinal tap and it was clear, which was not what they were expecting
because if it’s meningitis it should show something, but they still were thinking
that it could have been meningitis. He gave her five times more penicillin than
normal. She was just one sick little gal. Her blood pressure was down to forty
and she was really going downhill fast. But I still did not know how grave the
situation was, because we thought they'd give her something and we'd go home in a day or so. They admitted her into the hospital and I spent that night alone with her.

I went home and packed, and when I came back she was in a coma. So it had been twelve hours from the time we put her in at midnight, and by noon she was in a coma. We followed the ambulance up to Portland in our car. It was fifty-five miles an hour and that guy did not waver, but it was the longest ride in my life. In fact, her doctor here jumped in the ambulance with her and said he was going too. The pediatrician had given her to an internal doctor who knew her and had a daughter who was the same age as Rebecca. So he rode all the way to Portland with her.

They got her up to Portland and did blood work on her, and by the end of that evening they confirmed it was meningitis. The meningitis was already taken care of because of that high dose of penicillin they'd given her, but what it had caused was a breakdown in her blood vessels. All of her blood vessels became like a sieve and blood was just gushing out. Her kidneys had failed and so they were doing dialysis. They were doing everything from that shunt they had put in her side early on that night. In fact, if they hadn't gotten that in her life would have been even shorter, because they couldn't get any vein to work after that. They tried to put a new shunt in and they couldn't get a good vein anywhere. So that kept her alive for three weeks. She stayed alive up in Portland but was in a coma the whole time. They told us that the medicine they had to fly in from Texas was very, very strong medicine, and that if the disease didn't kill her then the medicine would. Yet she almost bottomed out at this very low level for three weeks.

Her feet, toes, and fingers turned black, and it just kept going up and up. The only thing that stayed white was her chest, her face, and parts of her back. Then she just bled profusely on the bed sheets. They put her on a special bed to try and save her skin the best that they could, but they couldn't stop a lot of the blood. They were giving her so many kinds of antibiotics but nothing could stop this breakdown in her circulatory system. The blood specialists up there were working every minute they could on what they could do, and everything that they could do was done.

We never came back to Corvallis the whole three weeks that we were there. Friends in Philomath took a motor home up there for us to live in and stocked it with food. The hospital let us stay for three or four nights, but when it looked like it was going to be longer these friends just brought up their motor home and we lived there in the hospital parking lot for the rest of the three weeks.
She lived for another three or four days. On Friday I knew that she was going to die on Saturday. They all knew from all of the signs that it was getting close. They were giving her life support and almost 100% oxygen. They’d gotten down to maybe 80% at one point but had to go right back up, and by Friday night she was still 100% oxygen and having dialysis. There was nothing she was supporting on her own. We had no idea how many organs were involved in this disease, but it looked like everything that was measurable was affected. The only thing we didn’t know about was her brain and that’s because she was in a coma. So if she had lived there would be no quality of life at all.

We told them that we did not want to have this prolonged, but at the same time we could not just not do anything. So to make her comfortable they were giving her one of the antibiotics (instead of all of them) and they were still giving her oxygen. On Saturday morning the family all came up and saw her, and her friend came up too. I kind of lost it. They had taken the tube out of her mouth used for feeding her. All these flowers were in the room and it looked like a funeral. I guess I lost it. I went back to the motor home and just said, “Lord, take her. I can’t go on.” (#A1)

The length of this account parallels the extended nature of the experience a parent often undergoes when children die because of disease or illness. Perhaps the most distinguishing feature of this type of loss for parents is the challenge of seeing one’s child in pain. Another mother whose child died of cancer commented that seeing one’s child “strapped down for scans” or suffering chemotherapy burns makes a parent “feel like a traitor because you’re taking her there.” A parent feels as if he or she is betraying the child’s trust that they will be protected from harm by the parent. Another study participant suggested that seeing one’s child suffer was even more difficult than the child’s actual death. Indeed, the mother mentioned above noted her “relief” at her child’s death because it is “hard to see your child in such pain,” and the death brings peace to both the suffering child and the anguished parent. Ironically, a parent may also feel relief simply due to returning to a sense of “normalcy” rather than living constantly in
suspended animation, waiting for the child to expire. Parents express guilt about such feelings also. A final important feature of this type of loss as contrasted with sudden loss is that parents are usually allowed to be there when a child dies and feel a sense of closure about the child’s transition to death. Five out of six study participants who lost a child to disease or illness were present at the time of death.

These contrasts in experience highlight how the nature of a child’s death shapes a parent’s experience when a child dies. Whether a child dies suddenly or as the result of an extended physical struggle, parents must face a variety of issues before, during and after the child’s transition to death. These issues are influenced by the context of loss and require parents to enter new paths and make critical decisions which shape not only their future but the future of their families.

**Primary Parenting Issues During Child Loss**

Much of a parent’s experience centers around building a strong relationship with children, giving children guidance or protection, and providing children with needed care. These parental activities are often challenged or focused in specific areas as a result of a child’s death. One scholar has noted that a child’s loss “robs parents of their ability to carry out their functional roles, leaving them with an overwhelming sense of failure and attacking their sense of power and ability” (Rando, 1985, p. 20). However, while parents’ emotions and abilities are affected by a child’s illness or death, they also continue to function in a parental capacity in a number of ways during the loss experience. The primary themes related to parenting issues during child loss that
emerged through analysis of the participant narratives were: (1) parental *connection to* the child; (2) parental *care and responsibility for* the child; and, (3) parental *protection of* the child. These themes are reflected in a parent’s experience before and during the loss of a child, and may vary according to factors discussed earlier in this chapter such as the nature of a child’s death.

**Parental Connection to Children During Loss**

Becoming a parent launches both parent and child on a pathway toward the formation of a relationship that is typically deep, enduring, and affectionate. Bronfenbrenner and Morris (1997) suggest the parent-child relationship is normally characterized by a profound, almost “irrational attachment” that consists of strong socioemotional ties. Factors that disrupt this emotional attachment are perceived as threatening. One theorist posits that a parent’s emotions act as a “barometer” that highlights “the impact that environmental stresses and supports are having on the family” (Dix, 1991, p. 4). The intense and overwhelming variety of emotions that parents are struck by when a child dies profile the depth of loss for a parent when the connection to a child is sundered. Parents in this study experienced the challenge to their sense of connection with a child in a variety of ways. They expressed both the emotional difficulties of this trial and the strategies they used to maintain a sense of connection to the child before and during the loss experience.

Several study participants discussed feeling the connection to their children threatened by death some time prior to the child’s actual death. Each of them expressed
this as occurring through an emotional or spiritual sense or experience that warned them of a child's potential death and the need to prepare themselves and be attentive to the child. In each case the parent checked on or contacted the child and tried to confirm the child's well-being. One mother was motivated to study the concept of life after death and the whole experience of death itself for several years because of such a warning. Two parents felt this threat because of a dream about the child's potential loss. Martha, a mother whose young adult daughter was killed, recounted this story:

Well, I don’t know if you’re going to be able to understand this, but [my husband] is here because he can verify this. Two weeks before she was killed I had a dream that she was going to die. I remember waking up at about 2:00 a.m. and I was crying and screaming or something. He said, “What’s wrong?” I said, “One of the girls is going to die.” I saw it so vividly. I saw the casket. I couldn’t see which one it was exactly because I could only see the nose, and both of the girls have a similar nose, but I knew that something was going to happen. In fact, that night I couldn’t get back to sleep because in my mind I kept thinking of all the things I had to do to prepare. I had to call people, make funeral arrangements, etc. I was going through this mentally because I’d had this dream.

I thought that maybe one of the girls was ill, so I called Jessica first. Our daughter Cindy has always suffered from very severe allergies and asthma. I remember calling Jessica and asking her if she was okay and she said, “Yes, why?” I said that I’d had this weird dream and then I told her about it. She said, “Mom, it’s probably Cindy.” So she asked me to check and make sure that she was getting her shots, etc., and so I called Cindy. Cindy said, “I’m fine, mother. You’re having one of those dreams again.” So they dismissed it.

When I got the phone call and found out that Sunday that Jessica had died, I felt under control because I had done this already. I had experienced this two weeks ago and so I knew what I had to do. I knew that I had to call Cindy, I knew that I had to make the funeral arrangements, I knew I had to tell my boss, I knew that I had to call relatives—I knew what I had to do. So I was in control the whole time. I can’t explain it. (#A9)

This dream prompted a sense that she might be separated from one of her children, so she contacted each child to re-connect with them and confirm their well-being. However,
when she learned of her daughter's death the warning became reality. The sense of warning that she'd experienced earlier perhaps allowed a stronger sense of emotional control during the actual loss itself. While this sense of prior warning about potentially losing the connection to a child was expressed by only a few study participants, its occurrence suggests the often deep and sensitive nature of the parent-child bond.

A second pattern associated with parents being warned that their connection with the child might be cut off was displayed in contexts where the child was dying gradually or the parent had a few days with the child before his or her death. In these cases the parents were warned either openly or subtly by others that the child might or probably would die, and were encouraged to communicate with the child before death. In some instances the time of diagnosis of an illness was the moment when this warning occurred. This warning allowed parents to realize the seriousness of the situation and take steps to focus on their connection to the child while he or she still lived. One mother, Ellen, was warned by a medical worker about the critical nature of her child's condition:

Early in the morning, probably around 5:30 a.m., I could tell that this was really getting critical. I called and told my husband that I'd reached the end of being able to endure and needed some help and moral support. He called some other friends and they came, and then my husband came. When this little nurse went off duty, she came back up and said, "Mrs. Bunker, I think you need to make sure that you talk to your daughter and get anything said that you need to say." That just shocked me. This was really serious. It was about 7:00 a.m. in the morning, and then the doctors came in and there was a lot of things that they were trying to do to her. (#A1)

As she indicates, the warning signal that one's connection to a child might be permanently cut off by death is shocking and at times quite difficult to accept. As a result of this warning from a medical professional, this mother and her family took steps to visit
and express love to the dying child before her passing. One study participant whose infant daughter was diagnosed with cancer and told that there was a 5% chance of survival determined that her child would be among those children to survive. She later stated in her interview, “I think parents deserve to be given hope.” Individuals working with parents who are facing a child’s loss must therefore walk a delicate tightrope between providing a clear warning of the need to connect with the child while still alive and yet trying to furnish a reserve of hope for the parents.

Another primary theme associated with a parent’s connection to a child was reflected in the narrative accounts of all six study participants who lost a child gradually (to illness or disease). Each of these parents chronicled the specific challenges related to being slowly separated from the child over time as opposed to a sudden separation, as other parents in the study experienced. For parents who knew that the child’s death was coming gradually, the signs of separation from the child were marked one step at a time by small “losses” or “deaths” that began to occur. Such losses identified by the parents included loss of the ability to smile, loss of immune capacity in the body, inability to respond to parental communication, and loss of the capacity to breathe on one’s own. These small losses pre-figured the greater and final loss of connection with the child that parents were warned of or anticipated might be coming. One father, George, whose son died of cancer said of this experience, “They gave him no chance to live, so we knew he was going to die. So when he actually died it was anticlimactic because he’d died a hundred times already.” In a sense, parents in this context begin to lose connection gradually to the children they have known, children who laughed and sang and breathed
freely. Pam, the mother of a young woman who died of a recurrent cancer, profiled her experience of such gradual losses:

Linda had a second brain surgery on April 27, 1989. Because she’d had extensive radiology treatments previously, that was not an option for treating this new tumor. Originally when we discovered the tumor there weren’t any “symptoms,” so to speak, that were visible. At that point we decided to leave well enough alone. But within a few weeks after that she did develop paralysis on one side of her face. So she lost her smile, or she had a half-smile.

They then decided that they could attempt a surgery and it was . . . because of her previous surgery and the radiation treatments and the massive hydrocephalus, things were pretty displaced within her brain. So it was a very difficult surgery to perform and they didn’t remove very much. The doctor felt that there was a trapped nerve he could probably release to allow her to smile again, but he wasn’t able to [do it] . . . the only thing that came from the surgery was a positive diagnosis of the type of the tumor.

We were wondering what we could do and we did investigate the possibility of a little more radiation because she hadn’t quite received the maximum amount when she was two years old. But that was not possible.

We did take her down to San Francisco and there and at Harvard University [they] have the best doctors for recurrent childhood brain tumors. We put her through their clinics down there and about all they could offer was chemotherapy. You feel like you have to do something. One of the hardest days of my life was when I actually took her in for chemotherapy because I knew that it wouldn’t do any good. I have educated myself somewhat about these types of things, and chemotherapy on the brain at that time still was not making it through the brain barrier hardly at all. I think since that time they have come up with some things that are showing a little more promise. Her type of tumor was a blastoma, which is the most aggressive of all brain tumors.

She did take the chemotherapy and through it all she was a true “trooper.” She, of course, did not feel very well, but when she got over the initial treatment a little bit then she was ready to be on the go again. She said it was not going to keep her down. So she had, I think, four treatments which were several months apart. She was due for her next one and her blood counts were too low for her hemoglobin, and then the next time we went back her platelet count was too low, so she had a blood transfusion. She went back again and they were both too low, and then she had another blood transfusion. About three or four days later she had a seizure. With the location of her tumor she should not have had seizures, but she was
taken up to Salem Hospital because [her insurance] was under Kaiser. When we took her there she was in very critical condition because she had three more seizures after that, and it took about three days before they could really figure out what might be wrong with her. . . .

She had this on a Tuesday and on a Friday they had come up a diagnosis of what they called “TTP,” which is an extremely rare blood disease involving the platelets. The treatment for it is what they call “plasmaphoresis,” which is like a dialysis treatment, and the doctor said they would give her three treatments and see if she responded. Well, with each treatment she got worse. After the third treatment, the next day the doctor told me they could do dialysis. I asked if it would do any good and he said, “No.” So at that point we discontinued treatment . . . (#A5)

This mother’s account highlights the variety of continuing losses that build up as an ill child progresses toward death, and the struggle which parents undergo in trying to maintain hope in the face of such losses. She notes that one of the “hardest days” was taking her child in for treatment when she knew it would not be of any benefit. While parents face this daily struggle related to the child’s progress, at the same time they are given an opportunity to focus on connecting with their children that parents who lose a child suddenly do not receive. Most parents take advantage of this and try to connect meaningfully with their children in the time that remains to them.

An important factor associated with the pattern of loss detailed above is that the parents of a slowly dying child often begin the grieving process well before the child’s actual death. This “anticipatory grieving” is stimulated by the various losses a parent perceives in the relationship and a recognition of the child’s probable death (Videka-Sherman, 1987). Asked about this experience, one mother said, “I think it was when the tumor came back, when we knew that it had come back and the surgery did not accomplish much of anything . . . maybe that was the start of the grieving process.”
emotions associated with grieving, such as anger and sadness, are experienced intensely by some parents before the child ever dies and the parent must deal with the emotional upheaval while remaining hopeful for the child's life. A parent feels the loss of connection occurring slowly and begins grieving earlier for the potential separation that looms in the future.

For a parent whose child is dying slowly in this manner, opportunities to socially and emotionally connect with the child during the time before death become critical. This becomes even more significant very close to the time of death. Parents connect with the child primarily through visiting individually or with others, talking, and doing things that are meaningful for them and the child (playing music, etc.). Some modes of social and emotional connection at this time might be termed "informal," such as talking quietly at the bedside or discussing favorite experiences. Such informal, intimate connections are only possible in the loss context when a child is dying gradually and the parent can be present to interact. Laura, who lost her son to polio, described such a connection:

On Easter I went up to see him and that visit was like a diamond in a setting of velvet. It was altogether different. He asked what kind of crowns we were going to wear in heaven and he said, "Guess what, Mom, I learned a Bible verse in class." I said, "What was it?" and he said, "I am the resurrection and the life. He that believeth in me, though he were dead yet shall he live." I thought later that was his gift to me because it was only a couple of weeks after that he died. It was something for me to remember that was special and that had meaning. (#A8)

Her description of the experience as "like a diamond in a setting of velvet" reinforces the value that parents place on these emotional connections with children prior to death. At times the attempt to connect is more "formal" and may include a last meaningful visit by family members and friends to the child, interactions with religious leaders, or a
reassurance of the parent's love. Other children, grandparents, relatives, or close friends of the child are invited to visit and communicate with the child. These strategies for connecting with the child may provide a more formalized, meaningful context that takes on the atmosphere of a "good-bye" ritual. However, the style of these more formal attempts to connect with the child tends to be personalized according to the family's background and personalities.

A final important theme related to parental connection to children during loss centers around the time of a child's actual death. Death as a life event separates a parent from the child by eliminating the social, emotional and physical responses from the child that are the substance of parent-child interaction. It is deeply traumatic for a parent when the parent-child connection is threatened or cut off and most parents try to maintain the connection in some way. Because parents may lose a child in a number of different ways, the context of a child's death has a significant influence on the parenting issues involving connection at the time of death. The findings from this study showed that parents experience loss of connection with a child at the time of death in three contexts: gradual loss with the parent present, sudden loss with the parent present, and sudden loss with the parent not present.

Five of the participants in the study experienced a child's death gradually and were present at the time the child passed away. The nature of this event as described by these parents was dramatically different than it was for other parents. Rather than being a highly traumatic occasion, each parent acknowledged some emotional anxiety but also spoke of feelings of peace, connection and love being experienced as the child died.
Several features of the parents' experience in this context stood out. One was the peaceful, often spiritual sense that accompanied the child’s passing in this context. Four of the parents specifically mentioned these feelings and noted what they felt were very significant spiritual components of the event. One mother described the moments of the child’s death as “beautiful,” and said that “it was an experience I would just love to experience again.” Although emotionally grieved because of the child’s death, the actual moment of death was very peaceful and she felt a strong connection to the child. Another facet of the child’s passing in this context was that parents were able to gather family around and symbolically almost embrace the child within the family circle as he or she died. The presence and support of family in a positive, loving manner seemed to make the experience much more emotionally calm. Perhaps the most critical feature of the child’s passing in this context was that the parents were able to touch or hold the child tenderly and feel the physical connection to the child. Every parent mentioned this aspect of connection in this context. Amy, whose infant daughter died of cancer, described her experience in this way:

It was early in the morning at about 5:30 a.m. and she woke up. She had thrown up a little bit of bile the night before and that’s why Eric felt it might be near and our doctor felt the same. She woke up, and I think she had a hard time standing at this point, but she was sitting in her crib and said, “Aah, aah, aah!” She had a lot of expression and I remember thinking, “This is going to be a good day, Gina is really strong today.” So I lifted her out of the crib and took her over to the changing table that Eric had built and was just kind of holding her there. She just kind of gulped and reached up, and I felt . . . I don’t know, it was just one of those experiences where you get a little feeling she was reaching toward something. Medical people might say it was a reflex, but she seemed to be reaching toward something not me because I was in another direction. Basically she seemed to stop breathing. Eric then got up immediately and came over and I said, “Eric, do something.” He said, “Dear, I think she’s gone.” I think he might have turned her
over or done something, but basically she was gone . . . and we just held her. Probably for half an hour we just held her and then we woke up each of the children and had them come out into the living room and they held her. She was still warm. They had some disappointment that they hadn't been there, but I think it was a real beautiful experience that they all held her and kind of got to have their little special time.

This account includes each feature mentioned above and shows how a parent’s opportunity to make and feel connections to the child at the time of death is enhanced when the context of death is gradual and the parent can be present. There is also almost a feeling of permission to leave from parents who have seen the child suffer and realize they need to let the child move on. The parent is able to take action to connect with the dying child by being present at the time of death, having family members close by to share the experience, and holding or touching the child in love.

An additional five study participants had children die suddenly but were able to be present at the time of the child’s death. This involved a diverse set of factors that included both positive and negative aspects for parents. Each of these parents was personally involved at the time of a child’s accident in some way, either as a witness or in providing help and assistance quickly to the child. Three of the parents directly administered first aid to the injured child and another provided assistance and prayer (but was also involved in the accident that took the child’s life), while the last parent was involved in an intense search for the injured child. This loss context demanded the most of parents in terms of action-oriented personal response and decision making as a parent. The sudden and dramatic nature of the experience also resulted in a severe emotional shock to these parents and later feelings of guilt about whether they responded
appropriately in helping the child. Feelings of guilt associated with personal impact on
the child's death seemed most intense among these parents. The sense of these narratives
is of a raw, dramatic and intensely emotional experience at the child's time of death.
Jean, a mother whose son was killed in an auto accident that she was also involved in,
reviewed her experience:

I stayed with [my daughter] for a few more minutes, and there was a woman to be
there with her, so I walked over to where my son was. There were a bunch of
men working around his body, and instead of doing ... my instinct was to just
walk up and tell them all to get away from him and let me at him. Let me touch
him. Let me touch his face. Let me see him. I don't know why I didn't do that.
I have always regretted it. But I could see that they were working on him, on his
breathing, and so I just knelt down and held on to his legs. There was so much
blood beneath his body, and I could see that it was coming from his head, and I
thought that you just can't lose that volume of blood from your head and remain
alive without being a vegetable. I prayed that if his brain was gone that his body
would go also. I just knelt there and held on to his legs. I remember that I had
blood in my hair, and I had blood all over my clothes, not from my own blood—it
was his. Although nobody said he was dead, it was in the air and in my bones I
knew it. (#A2)

The poignancy and sadness of these narratives is almost overwhelming due to their
intimate and tragic nature. There is a sense of loneliness about the experience these
parents pass through that is quite different from those parents who have a child die
gradually. One father held his child alone for an hour after the death in a quiet hospital
room, and later said, "I don't know if that helped me or made it worse."

Two additional aspects of the experience when a child dies suddenly with a parent
present are the opportunity to touch or hold the child and a concern for the child's
potential quality of life. As with parents who lose a child gradually and can be present,
parents who lose a child quickly find it important to touch or hold the child. All five
parents who lost a child in this context, both mothers and fathers, spoke of touching or holding the child at the time of death. These parents also understood the severity of the child’s injuries in each case and felt concern about the child’s potential quality of life in the future, expressing worries about brain damage, inability to function, etc. In these circumstances some parents either expressed hope the child would be taken or actually made decisions to let treatment be discontinued so that death might ensue. Thus, parents in this context were faced with the child’s loss and took action to make a final connection with the child (through physically holding or touching them), while also feeling the need to let the child pass away so that the child’s future quality of life would not be destroyed.

Peggy expressed her experience in this context succinctly:

The next morning we decided to have the respirator shut off, so they shut the respirator off and she continued to breathe through the tube, and we asked the neurosurgeon to take the tube out. I held her while she died, and it was good... it was comforting to me. I didn’t watch them take the tube out. I remember people wanted me to put her on the bed and stop holding her, and myself thinking that was crazy. I remember the thought, “I have to get a whole lifetime of holding in and I can’t put her down.” (#A7)

In this account the mother expresses the urgency to connect with the child felt by parents who are suddenly faced with a child’s loss. They are confronted suddenly with the loss of “a whole lifetime of holding” and other parent-child connections, and must do what they can to adjust quickly in intense circumstances. These parents receive a last opportunity to be with the child but for them it is all too brief.

Nearly half of the parents in the study, nine of nineteen participants, were not present when their child died suddenly. All but one of them had children die in traffic-related incidents. One of the first items of focus for these parents when they learn of the
child’s death is an intense need for knowledge about the circumstances of the death. This is accompanied by a corresponding sense of fear and concern that the child was alone or suffered at the time of death, which these parents seem to find disconcerting or troubling. Other common facets of the loss experience in this context include a tremendous sense of shock. For some parents this leads to a sense of unreality about the child’s death that persists and leaves their memories about the time of death confused, while for other parents there is a cold certainty about the child’s loss. Every parent expressed an immediate tendency to seek out support from others when they learned of the child’s death. It may be that the sense of sudden loss of the strong bond with a child magnifies their need to feel connected with someone else at the time they feel this shock and loss of connection. Parents feel a variety of emotions, including guilt and anger, that stem from a recognition they were either not aware of the child at the time of death or that they now have been forever robbed of a further opportunity to connect with the living child. They were cut off from the child physically at the time of death and this fact is mirrored in their emotions, with many of them expressing grief at the sudden emotional cut-off that is experienced. Stacy expressed these feelings in her story:

He loved baseball and it was the night of the Seattle Mariners’ last game before they went to the World Series. He called me at work and said he and his friend were going to watch the game. We started talking about Thanksgiving and he said that he was going to ride the bike. I said, “No, you promised after you drove it home last time that you would not ride that bike again on the highway to come home. I’ll buy a plane ticket or anything, just please do not ride that bike like that.” The weather wasn’t bad here and I had no idea what the weather was like in Seattle.

They went to the game and were on their way back. It was a bridge he’d crossed a thousand times, and the minute he hit it he lost control. He was killed instantly.
That was at 9:40 p.m. Well, as a mother you always think that you have this instinct and that you’re going to know when something happens to your child. Well, I was watching the game at the same time and then I went to bed. I suppose I was reading a book when my child was in the street somewhere... I’ve never gotten over that. I’ve never gotten over that.

They did not call me. They said that they couldn’t find his wallet or anything, but apparently he had a telephone number and my parents’ name in his pocket. I found that very hard to believe, but anyway they called my parents....

When I answered the telephone I heard my mother crying, so I had already prepared myself and thought, “Well, if Mother’s crying, it must be Daddy.” So I was all ready for the news... I knew that if my mother was calling me at 4:30 in the morning crying and saying, “Oh, Stacy”... I can remember that. I just knew that it was my dad. Then she said, “Stacy, Jeff’s been killed.” I do remember saying, “No, Mom, that’s not so. No, that’s not so.” Then I don’t remember anything else about that or what else she said to me. My friends came in.

I do remember that I picked up the telephone and called my boss at 4:30 in the morning and said, “I can’t come to work today.” I said, “Jeff’s been in an accident and he was killed, so I can’t come to work.” So I knew that I was in and out of shock. I don’t remember... I remember that I had lots of people come to the house that day. I was told that I discussed funeral arrangements. We didn’t see Jeff. I said that I didn’t want an open casket because I knew Jeff would hate it, and I’ve always hated that part about funerals. But now I know that I did that because if I didn’t see him then I wouldn’t have to believe it.

A friend of mine told me later on that they had said we shouldn’t have an open casket... and when your child has been hurt that badly you do almost die. You just can’t believe that something has happened to your child. (#A4)

Her memory of various details related to the time of the child’s death and soon after are somewhat garbled and hazy, reflecting the emotional chaos that this sudden loss of connection provokes. Jim, who went out for a few hours with his wife and came home to find a note directing him to the hospital, commented:

It came to us... if it had some warning. We had no warning at all. It just came to us without any preliminaries, and you just can’t realize it happened to you... I went down to the coroner’s place that night after we got home and had found out that she was gone, and I told the man that I wanted to see her. The car had
crushed her face so badly that he didn’t feel it would be good for us to see her ... so we never did see her remains. (#B5)

Not only does he comment on the lack of warning when a child dies so suddenly and the parent is not present, but his account highlights the tragedy of such a separation—not ever being able to see his child alive again.

**Parental Responsibility and Care for Children During Loss**

Much of the parenting experience consists of providing guidance and giving care to children who are developing socially, emotionally, and intellectually. Parents tend to feel a strong responsibility for assisting children in their development and taking care of their needs (Cowan & Cowan, 1992). The assumption of such responsibility by parents pushes them toward becoming generative, caring adults who nurture the next generation (Snarey, 1993). One writer has commented regarding parental responsibility that being a parent “isn’t just another lifestyle choice,” but that rather it is an “ethical vocation . . . of the weightiest sort” (Elshtain, 1993, p. 3). One of the primary features of a parent’s experience during the time of a child’s illness and/or loss is the challenge to a parent’s ability to care for and be responsible for the child. Parents feel a primary responsibility to do for their children at a time of crisis, and yet conditions related to the loss context may make being responsible for the child difficult. Basic parental functions such as guiding the child’s behavior, meeting specific needs, or caring for the child directly may quickly disappear or be changed. However, parents do engage in various means of providing care or taking responsibility as is possible during a loss.
A parent’s responsibility for a child during a child’s death is cut off or challenged largely by three factors: nature of the child’s loss and the parent’s presence; severity of the child’s condition; and effects of the experience on the parent. The nature of a child’s death determines whether parents have the opportunity to be responsible for or care for the child at the time of loss. As was indicated earlier, approximately half of the study participants were not present when their children died as a result of sudden, accidental causes. In this setting parents simply lost the opportunity to be responsible for the child’s welfare. Parents who were present when or soon after the child died were able to continue making decisions and attempted to respond to child needs. The severity of a child’s physical condition often affects a parent’s capacity to be directly responsible for the child, as the intense medical needs of the child usually overwhelm a parent’s knowledge and skills and require the supervision of trained professionals. Direct responsibilities related to giving physical care to the dying child are usually assumed by others, although parents may be able to provide some physical care and also respond to other needs (talk to the child, etc.). Parents may feel displaced or inadequate in responding to the child’s needs when others take responsibility for the child or the needs are beyond their abilities to care for. A final challenge may occur if a parent is somehow affected during the loss, such as being a victim or being emotionally traumatized so that responding to the child is difficult. These various factors can challenge the parent’s ability to be responsible for a child directly, but this study showed that parents also make every effort to still be responsible and care for their children as much as possible.
Parents faced with a child’s death first seek information about the circumstances of the illness or accident, the child’s condition, and the potential avenues for a positive outcome. The parents who lost a child slowly (five study participants) all sought out information about the child’s condition so that they could be responsible in making informed decisions about the child’s treatment during illness. The severity of the child’s condition challenged their knowledge and parenting skills, but they sought to be proactive in their responsibility for the child. Pam, whose daughter had childhood cancer recur, was quoted earlier in this chapter regarding her efforts to find the best treatment for her daughter. Her awareness of her child’s past treatment history, potential avenues of treatment, the best treatment locales, and effects of the disease demonstrated a deep commitment to gaining the knowledge that would help her to be responsible in making decisions for her child’s welfare.

Those parents who lost a child suddenly but were present at the time of death (five study participants) had less opportunity to be responsible for the child, and generally exhibited strong “searching” or “rescue” behavior intended to learn about, find and assist the child in need. Jean, who was involved in an auto accident with her children, remembered:

I rounded that curve in a Blazer and a deer jumped out onto the highway right in front of the car. I swerved hard to miss the deer, hit it anyway, and the car rolled several times and came to rest upside down, and I was left in the car. I was conscious the whole time and was left in the car upside down hanging from the seat belt. My children had been thrown clear from the car. My son was twenty-four at the time and my daughter was seventeen. I immediately began to call their names.
A highway patrolman was indeed right by the accident and saw it, and began to run from his car as soon as my car hit the ground. He called to me as he ran past me, but he was really running to my children who were on the highway. I just hung there in the car waiting for him to come back with some news for me. Within just a few minutes my brother-in-law’s head appeared in my car and [he] asked me if I was all right. He had been shortly behind me and asked me how I was, and I asked him about my children. I said, “Go find out about my children, and when you come back tell me the absolute truth.” (#A2)

While lying upside down in a smashed vehicle, this mother focused on being responsible for her children as she called to them and sought others to find them and verify their conditions. This focus despite effects related to the experience limiting her capacities show again the high level of responsibility felt and pursued by parents in a loss context.

For all those parents who lost a child suddenly and were unable to be present at the child’s time of death (nine study participants), the sense of being cut off from any opportunity to be responsible for the child was dramatic. These parents did exhibit a strong tendency to seek information regarding the cause and circumstances related to the child’s death, and then to focus on taking responsibility for straightening out concerns or issues that arose related to the child’s passing. But the context of the child’s loss denied them the opportunity to be actively responsible at the time of the actual death.

Once parents have some knowledge regarding the circumstances of the child, many of them are active in assisting with or seeking out medical treatment for the child. Eight of the study participants spoke about their involvement in being responsible for ensuring the child’s treatment was as helpful as possible. Amy, whose husband was a physician, recounted their search for a successful treatment for an infant daughter afflicted with cancer:
We tried an inter-operative radiation [technique] in Denver, Colorado in November. That was something that Eric had done some research on and found that they’d done five neuroblastoma cases and three were still alive. That was pretty good statistics. At that time insurance allowed you to do those kinds of things, but I don’t think it would now. It was a $30,000 operation. So we flew to Denver.

Gina there had surgery that was experimental, in which they open you up in one room and do the surgery, remove the tumor that had grown again, and then wheel you down the hospital with her abdomen open and then radiate the remaining tumor that they couldn’t get because it was wrapped around vital organs right there on the spot. Again there was about 5% of her tumor remaining that they weren’t able to get, but they radiated and felt pretty good about it and closed her up. She came through that surgery great. She just fought back and was doing great. We took her to the pediatrician here in town and everything looked pretty good. We were all kind of hopeful and had a great Christmas.

About three days after Christmas I took her back to the doctor and when she pressed on her abdomen she could feel that the tumor had already begun to grow again.

By this time we knew that Gina’s cells, which had been sent to UCLA, were some of the fastest, rapid-dividing cells that they’d ever seen. So the tumor did grow again. At this point we didn’t know what else to do. We were trying to decide what else to do but the tumor was beating us and growing so quickly. (#A10)

This narrative illustrates the lengths to which parents often go in seeking out medical assistance for a dying child, which may involve high costs and also high risks, yet even these dedicated parents were frustrated by the severity of the child’s condition. Parents in this situation may exercise great care and responsibility for a child, but sometimes they struggle with the question of whether they might have done more because of feeling frustrated in their efforts by conditions beyond their ability to control.

The substance of parent-child relationships occurs in the interactions that take place as parents care for children directly in a variety of ways. Because some of these basic interactions and parental functions are negated by a child’s illness or death, parents
may be limited in how they are able to care for the child during the loss. Parents in the study who had the chance to provide some direct care to a child before his or her passing felt great comfort in being able to still exercise some parental responsibility. This may make the grieving process less difficult for them at a later time (Rando, 1983). Several parents in the study discussed their efforts to continue being actively responsible for the child in some manner through giving direct physical care to the child prior to the time of death. Amy’s infant daughter died of cancer, but she was able to breast feed her daughter and told of what that meant to her:

It was extremely comforting. As a mother, at the end the only thing she would eat was my breast milk. I felt like, as a mother or a father, you have to feel you’re doing everything you can. If you reflect back and think, “Why didn’t we do this?” or “We could have done this” . . . if someone told me to play music in the key of B minor, I had tapes in the key of B minor that Gina was listening to. If someone told me that green was healing, I tried a green light and green stuffed animals and a green blanket. My sister gave me a lot of green things. Vitamins. Grape juice. You name it. So the fact that I could breast feed her and she still would drink that, and the fact that I was there for her . . . you look back and all of a sudden those things loom larger afterwards than they do before. (#A10)

Carrying out such parental functions can be fundamental to a parent’s sense of identity during a loss experience. Whether playing music in the key of B minor or giving a foot massage, these expressions of care by parents help them to maintain a sense of responsibility in the face of a child’s death. The loss strips them of the opportunity to be responsible for the child in some aspects, but when death is gradual the experience is not so severe.

Parents may also find themselves doing things to directly or symbolically care and be responsible for the child soon after the death. While the opportunity to care for a
living child has been taken away, parents still feel the intense need to be responsible for
the child and may do so in various ways. Some activities are simply part of the parent’s
continuing responsibility, but others may be voluntarily pursued by the parent. Tom,
whose son died in an accident, spoke of this continuing sense of responsibility and what
he had done after his child’s death:

I think that physically and psychologically as a parent you really feel this urgent
need to be very involved with your child. [That means] to do things for them, to
do things with them, or to do things because of them. . . . I find flowers at the
greenhouse and will think, “Yeah, Andy might like those, so I’ll get some of
those.” So I plant those at the cemetery. The bird bath and the squirrel [in the
back yard]—we saw those and thought, “Andy liked squirrels, let’s get that for the
back yard because of Andy.” So we still find ourselves wanting to do things for
him . . . Andy liked squirrels and so I got the bird bath with a squirrel for him.
We still have a tendency to need to do that and to want to do those things. I think
it’s more for ourselves to feel like we’ve accomplished something in the way of
doing something for our child even though he’s gone. [It] tends to relieve the
feeling that you’ve ignored him. [It] tends to relieve the guilt that you’re not
taking care of him or that you’ve just totally abandoned him. You don’t want
that. You don’t want to be like that or to feel that way. So we don’t tend to go
overboard, but we do enough little things like that to make us feel like we haven’t
ignored him. (#B6)

This father’s insight that a parent often feels “physically” (direct care functions) and
“psychologically” (mental responsibility for) an “urgent need to be very involved with
your child” marks the vital role that a parent’s sense of responsibility plays in the
parenting process. In his own case, he notes trying to continue some “parental” activities
following the child’s death so that the sudden loss doesn’t leave him always feeling that
“you’re not taking care of him or that you’ve just totally abandoned him.” These
activities seem to soften the emotional impact of losing responsibility for one’s child.

Caring parents are emotionally confronted with the sense that their capacity or
opportunity to be responsible for the child is lost or diminished when a child is dying or had died. Yet such parents also continue to seek ways to mentally and physically be responsible as they learn of the child’s needs, facilitate or provide medical assistance, and provide direct care to the child prior to and during the loss.

**Parental Protectiveness of Children During Loss**

One of the most troubling aspects of the loss experience for parents who have children die is the sense of failure that many experience in feeling they did not or could not protect their children. Protection of one’s children seems to be a fundamental aspect of the parent’s role. Bahr (1992) suggests this is because most parents experience a sense of “obligation and duty to ensure that necessary nurturance and care of family members continues” (p. 289), usually for as long as children remain at home. Parents who lose a child often tend to feel that they have somehow forsaken this obligation or have not lived up to its requirements. A parent’s sense of control in relation to the child’s well-being is undermined and may leave a mother or father feeling angry, confused or worthy of blame. The emotions related to this aspect of parenting during a child’s loss may be the most intense of all, as parents are plunged into an emotional hurricane that threatens their sense of self and their ability to function.

Parenting a child prior to and during the loss experience draws a parent into a world of pain and confusion. Some of the effects of this world of emotion on parents after the child’s death are discussed in the following chapters. But during the time of loss a prominent feature of the experience for parents is a sense that they are losing or have
lost control in being able to protect their children. There was an interesting pattern related to gender in the study in this area. Only two of thirteen women in the study mentioned anger as a primary emotional response to this feeling of being unable to protect the child, and both of those accounts mention anger as being directed at others who attempted to limit the mother’s efforts to protect or help her child. Yet four of six men cited anger as being a strong emotional component in their sense of not being able to protect the child. The remaining two men were very subdued and focused in their response to the child’s death at the time of loss. The most common emotional response discussed by women in their accounts was a sense of vulnerability or feeling out of control at the time of the child’s death (several talked of anger as a later response). This pattern is consistent with a similar pattern noted in earlier studies of parental bereavement, which suggest men tend to express these emotions outwardly in anger and women more inwardly through withdrawal or self-blame (Knapp, 1986; Miles, 1985).

The experience of parents in feeling unable to protect a child during the time of loss also is influenced by the nature of the child’s death. For parents who have a child die slowly, they begin to experience a gradual loss of control over being able to assist the child’s welfare. They generally continue to be very involved in making critical decisions about medical treatment, but the progress of the child’s disease or illness tends to blunt the effectiveness of such parental efforts. In particular, these parents find themselves unable to control the child’s pain or suffering and this becomes the greatest challenge to their sense of inability to protect the child. The continuing siege of pain that a child
might endure due to cancer or other problems tends to frustrate and debilitate a parent’s perspective. George, whose son endured cancer, recounted:

We took him in every week to the university and they gave him radiation therapy, and then they would give him a shot of chemotherapy. But they gave him no chance to live, so we knew he was going to die. So when he actually died it was anticlimactic because he’d died a hundred times already. At first you have hope that maybe you’ll beat the odds. But eventually you accept the fact that he’s going to leave, so you prepare yourself for that. You just kind of hope that it will happen quickly, and get it over with so he doesn’t have to suffer . . . this really was not a surprise, and it was totally expected. It was a relief that he was gone, not that he was gone, but at least that he was out of his pain. (#B1)

Seeing a child go through treatments that are ineffective or may even exaggerate pain is difficult for parents, and as the father notes, a parent will sometimes try to prepare himself or herself and hope the child will soon be “out of his (or her) pain.” Parents of children who are dying gradually may go to great lengths in looking for sources of treatment that can provide hope, attempting to stave off the child’s decline and the feelings of slipping out of control that accompany it. But they also struggle with seeing the child’s pain and eventually often decide that to protect the child from further pain they must accept the fact that the child cannot recover. So, parents with an ill or dying child fear the child’s death, but the emotional distress resulting from being unable to protect the child from suffering may be even more difficult in this circumstance.

Mothers and fathers who lose a child suddenly face a different challenge to their sense of protecting a child. In these circumstances the transition to death is so rapid (no gradual loss of control) and the accompanying shock is so great that a parent may literally be thrown out of balance mentally and emotionally. This does not hold true for all parents, however, as some parents in the study described their reaction as being very
controlled and focused when the child died suddenly, and they seemed to find ways to re-
assert a sense of parental control in the situation. Ken, whose young son drowned,
remarked:

I was still out looking when they found him. I just happened to stop at a phone to
call and check in on what other information might be coming to us. Dad told me
that I needed to come back. I wasn’t aware of the situation at that point. [My
wife] was there and didn’t know, but she knew that something was going on,
because of the reactions of everybody else around. I finally got back and [my
father] met me as I got out of the car.

They brought him to us and we had a chance to be with him there for a little
while. Originally they had wanted to do an autopsy. I did not want that done. It
wasn’t as important to me how he’d died as the fact that he was gone, and I didn’t
want his body cut open just to do some exploring. Under the law they probably
should have had an autopsy, but it was an unintended death. (#B3)

Though unaware of exactly the situation until he returned from searching with others for
the child, this father’s assertiveness in attempting to protect his child is demonstrated as
he immediately establishes his parental authority by protecting the child from an autopsy.

Parents who are able to re-assert this sense of control in some manner when a child dies
suddenly have a somewhat less chaotic emotional experience at the time of loss. Another
father, John, whose young son was injured fatally in an accident, described his feelings in
the situation as “pure carnage.” He emotionally shared his account:

I panicked. I got in the car. [My wife] was in hysterics, almost like the kind
where you need to slap somebody. . . . I never slapped her but I yelled and said,
“If you don’t drive as fast as you can, run all the lights that you can, honk your
horn and go as fast as you can” . . . I didn’t say it real calm, I said it very loudly in
between breaths that I was giving him. I knew that his neck was crushed . . . and I
just felt so helpless that I couldn’t do anything, but I did everything that I knew to
do. I think that’s the moment that I knew that . . . unless something immortal . . .
there was no way. But I didn’t want to tell her that. I just said, “You’ve got to
go, just go, and I’ll do what I can.”
When we got to the hospital I remember that I just jumped out and ran inside with him. They met me at the door. They saw me coming in and after I gave Alex to them I knew that... I didn’t think they were going to be able to do anything for him. I felt that there was nothing we could do. He was turning color and I don’t know how long he’d had the ladder on there, but it was just pure panic. I’m a pretty big guy... and inside I wanted to tear the hospital apart, you know, but I couldn’t. I was just gentle and calm.

I had a feeling of rage, panic, and calm. It’s like somebody had their hands on my shoulders calming me down. But on the inside... I couldn’t have hit anything if I’d tried. I couldn’t have tipped a table over or knocked a glass over, I knew that it wouldn’t solve anything, but I had those feelings of rage and of just tearing the whole hospital down, the whole thing, not just the room but the whole building. I couldn’t do anything. (#B2)

This father communicates clearly the helplessness and rage that engulfed him due to the shock and his inability to do anything to save his child’s life. For most parents in this situation, whose sense of ability in protecting a child derives partly from being able to take action in the child’s behalf and seeing their own influence, the feeling that accompanies being forced to watch helplessly as a child dies is devastating. This challenge to a parent’s ability to protect his or her child and the difficult emotions that accompany it represents one of the most clear and pressing issues faced by a mother or father prior to or during a child’s death.

Summary

A child’s death begins an assault upon a parent’s functioning and sense of self that can last for years beyond the actual time of death itself. But the time leading up to and during the child’s loss also shapes the parent’s experience and sets the stage for the parent’s future. Parents may experience a child’s death in a variety of contexts, though for this study all participants lost a child either to accidental causes (most of them traffic-
related incidents) or illness. Parents who have children die due to accidental causes face such challenges as emotional confusion, mental shock, and significant feelings of guilt. Those mothers or fathers who have children die because of illness or disease can usually anticipate the child’s death and attempt to prepare themselves for it, but also must deal with the concern of a child’s suffering or pain over an extended period of time.

Before and during a child’s death parents also face a number of common issues that can impact their responses and emotional well-being. Analysis of the study participants’ narratives indicated that the primary issues highlighted by parents during this period of time in a child’s loss were the feelings of connection with a child, their sense of responsibility and care for a child, and their ability to protect a child from suffering or death. In connecting with a child prior to and at the time of death, parents may be warned of the child’s potential loss, observe the small losses associated with a gradual death, or focus on whether they were present when the child died. Parents who feel challenged in their responsibility for a child for various reasons still attempt to gain an awareness of the child’s condition, seek out or help to provide medical assistance, and give direct care to the child in meaningful ways. Protecting a child is complicated for parents by complex emotional responses such as helplessness, intense anger, or a concern for the child’s suffering. Despite the challenges faced when a child’s life hangs in the balance, parents try to do all that they can in fulfilling these fundamental dimensions of parenthood and caring for their children.
For most adults who become parents, over time the experience of being a mother or father becomes a primary focus of their life and activities (Cowan & Cowan, 1992). Parenthood becomes a significant factor in shaping their sense of self now and in the future (Erikson, 1964). This sense of personal identity consists largely of one’s self-meaning in particular roles (LaRossa & Reitzes, 1993), which for parents again is influenced highly by the activities associated with their parental ties and obligations as a mother or father. A child’s death radically alters a parent’s bond and association with a specific person who has defined their parental experience and thus their experience of self as a parent. White (1988) has indicated in his research with bereaved parents that they often “look as if they have lost their own ‘selves’ as well as the loved one” (p. 29). One of the fundamental goals of this research study was to investigate what common elements or themes might emerge in the accounts shared by parents about how a child’s death has influenced their sense of identity as a parent. The primary themes identified by the study participants that related to how parents viewed themselves and their parenting role after a child’s death focused on: (1) the sense of self as a parent; (2) the parental bond with the child; (3) the parental performance; (4) the parent’s future orientation; and (5) the parental orientation or philosophy.
Child Death and a Parent’s Sense of Self

The experience of becoming a parent and then attempting to be a successful parent has a profound capacity for influencing an individual’s sense of personal identity (Erikson, 1964; Galinsky, 1981). This is because parenting itself draws a person into a set of relationships that require an enormous investment of one’s time, commitment, personal presence, mental attention, and emotional responsiveness, yet can also provide deep and powerful feelings of connection and fulfillment to the parent. Parenthood changes a person’s most intimate relationships and individual commitments for a lifetime, thus changing a person’s understanding of who they are and who they will become (Cowan & Cowan, 1992). A child’s death strikes at the heart of this sense of meaning for parents by sundering the relationship to a child and transforming the nature of one’s present and future existence. In particular, the loss of a child seems to affect the way parents feel about themselves in the parenting role, as well as the sense they have about their status and parental relationship to the deceased child.

Feelings About Oneself as a Parent

Parents who identify very strongly with their role as a parent may experience a child’s death as a death of part of themselves. Thoits (1991) suggests that a person’s sense of identity in a particular area will be most strongly affected by a stressor when the person values that role highly. Five of the study participants, three women and two men, spoke of such feelings after losing a child and indicated a powerful sense that a portion of their identity had died or was now missing as a result of the child’s death. These parents
express a feeling that they will never be the same as a person and often indicate that this sense of identity loss has robbed them of focus in life and made it more difficult to function. Stacy, whose son died in a traffic-related incident, shared her perspective:

You do lose a sense of your identity. I see his friends and somehow I’m not a part of that any more. There is something very different... you lose your history. You’ve lost the future with that child. You’ve lost all the hopes and the dreams. You won’t get to see the weddings, you won’t get to see the grandchildren. The part of our lives and of us that belonged to them is not there any more. That part of us died. Part of us died. I do feel very empty that I don’t have Jeff there, and I feel as if part of my identity has been taken away from me. (#A4)

These parents share a sentiment that it is as if someone has brutally robbed them—of themselves. This kind of expression is the most dramatic response to a child’s death that parents discussed as it related to their feelings about themselves as parents. Another father, John, struggled to express the magnitude of what he felt had been lost after his son’s death seventeen years earlier:

I really feel I lost a part of me. Part of me and part of [my wife]. Part of us was never going to be the same again. It was like taking an arm off of my body or a leg, or half of my body, or the most valuable part of my body... I don’t think there’s anything I have physically that would equal what we lost, but it was like part of me died when he died and even worse. I don’t know how to say it in words. (#B2)

He equates the sense that he has lost part of his identity to the loss of “the most valuable part of my body,” but the loss is almost indefinable because it has removed a part of the self that involves deep feelings about who he is as a parent and a person. Parents who express this in their narratives seem to struggle for some time with the challenge of re-defining a sense of themselves and facing the future.
For some parents the death of a child may trigger a strong sense of self-condemnation as a parent because they assume some responsibility for the child’s death and therefore perceive themselves to be a failure as parents. This seems most likely if the parent was personally involved in some way at the time of the child’s death. Three parents in the study, two mothers and a father, indicated that this feeling was an important component of their emotional response to the loss. It is associated with an intense feeling of guilt and much questioning of oneself. As one mother noted, “It is kind of like someone says, ‘What are we having for dinner?’ and you think, ‘My God, I couldn’t keep my child alive, how can I decide what we’re having for dinner?’” The sense of self-blame and personal failure expressed by these parents can be very difficult to overcome. Jean summarized her feelings this way:

My driving was the instrument of my son’s death. That’s been a hard burden, a really hard burden to know, even though I believe that God took him and that it was in God’s plan to take him then. I was the instrument of his destruction, and I felt like the ultimate failure as a parent. I know that that affected the way I parented my other children for a while. That’s been a really heavy burden that I still feel eight years later. It doesn’t matter that it’s not rational. (#A2)

In these cases, it is as if a person’s feelings about themselves as a parent are twisted into a tortured and painful self-portrait of complete parental failure. One father, Tom, spoke of similar feelings:

I think the biggest thing I felt was personally feeling very guilty and responsible. You expect to hold and protect your child from all harm in the world, to shield them and nurture them and raise them to be strong. I felt that I failed in all of those areas. I felt very worthless as a parent. I felt that I could not prevent what had happened to him, although maybe I should have . . . that I should have been keeping my eye on him instead of turning to my friend Joe, that I should have taught him not to run out in the street, etc. Your mind just goes through this whole range of very heavy guilt—would have, could have, and should have—all of
that. I think that was by far the biggest feeling I had. I was really punishing myself very hard for what had happened.

Naturally, on top of that is piled the pain of losing someone you love very much. As far as being a parent and my relationship to him as a parent, I think by far the greatest thing is the feeling of failure to protect and save him from harm. I felt at the time that there were a whole bunch of things I could have or should have been doing. I would also think that I shouldn’t have taken him [with me] in the car, etc. Down the road I’ve had to make myself realize there were many things that were very circumstantial, and I’ve had to accept that it was just a damn accident. It wasn’t out of maliciousness or ignorance or any kind of inattentiveness on my part. It could have happened almost anywhere. It could have been something else. Sure, maybe if I’d been looking a certain way maybe I could have stopped it, but then again who’s to say that something else different might not have happened? That took a lot of work and realization for me to accept that I wasn’t a failure as a parent. (#B6)

This father’s experience profiles the struggle that these parents pass through in their feelings about themselves. The child’s death and their connection to that event becomes for a time the defining narrative of their experience as a parent. However, over time these parents all seemed to make progress in re-framing their loss experience and coming to understand that circumstances were beyond their control and their parental identity cannot be summed up by the label of “failure.”

Another aspect of many parents’ sense of self that seems to be affected by a child’s death is their feelings about their capacity as parents or to be parents. Snarey (1993) has noted that a threat to one’s generative capacities as a parent, such as a child’s loss, may have strong implications for one’s sense of self. He writes that a “threat to generativity will have a significant impact upon a [parent’s] selfhood” (1993, p. 24), often resulting in a “chilling” effect upon a parent’s sense of their own capacities. Six study participants mentioned this pattern and described feelings of doubt about their instincts or
abilities to parent well after the child’s loss, both then and in the future. Following the
loss, four mothers and two fathers indicated that they now felt doubts about their ability
in the past and future to make good decisions for their children, provide the care their
children needed, or even to be a parent again. One father indicated he and his wife had
waited many years before having children again because of such concerns. A mother,
Anne, recounted:

You lose trust in your own decision making. For most people, when their kids are
maybe not successful or maybe not doing well in their lives, then you lose
confidence in any decision you’ve ever made including having them. Things
seem like a mistake and you didn’t do it right. Guilt is still, sixteen years later,
the last remaining vestige for me besides just a sense of sadness and loneliness
connected to the loss of this boy. [The feeling] that I didn’t do it right. . . .

Actually I thought I’d done a pretty good job with parenting until [my son] was
killed, and then I didn’t think and I probably don’t think today to a degree that I
did. If I had it to do over again with what I know now about parenting . . . I didn’t
know much about parenting. I thought because we had such a good relationship,
my children and myself, that I was doing a good job. But I was much too focused
on myself and not on them. I was making myself my career instead of making my
children my career. (#A3)

Parents such as this mother feel distress at whether they performed well as parents before
the child’s death and often worry about their ability to parent in the future. It takes time
for them to gain perspective and for them to feel reassured by others that their child’s loss
does not mean they have no parenting skills.

One of the most challenging impacts of a child’s death upon a parent’s sense of
self can occur in the way a parent feels in the parental role. Parents may experience
feelings of confusion, uncertainty, or difficulty in carrying out their activities in the
parental role of mother or father. Nearly half of the study participants, including six
women and two men, discussed feelings that indicated discomfort or confusion in the parental role. The women who expressed this suggested that these feelings may be a particular challenge for women who often fill a primary role as parents in the family and identify themselves with that role. Since the role is dramatically changed following a child’s death, then continuing to carry on the functions of the role can be emotionally difficult or even ambiguous. Carol, a mother who expressed this ambiguity, said:

I have no focus now. That’s one of the big questions. . . . I raised my children to be young adults. I was here to consult with them when they needed another opinion. I tried not to make their decisions for them. I would try to tell them from my experience and the mistakes I had made . . . so, I have no focus. This is three years later. I still am saying, “Okay, God, what do you want me to do?” This is not a fulfilling job. What do you want me to do for other people? What is my focus now? I have no focus—none. So many things are just absolutely stripped and taken away, and I cannot get back. . . .

My parenting seems to have ended, because a lot of people can still add to their family if they choose to do so. You can’t replace that child, but you can put someone there who then gives you a lot of busy work. I have none. There’s nothing for me to do. I have a son in the military, which requires nothing but an occasional phone call or care package. I have an older son with his own family and wife. Even though they live with me we don’t see a lot of each other. . . . so, it’s like my parenting has stopped.

[Being a parent] is part of who I am. There’s a term out there called an “earth mother” and that is me. I’m a natural caregiver. That’s what I’m doing [in my job]. . . . When you can’t do that any more you wonder, “Who am I? What am I here for? What is the purpose? What is the point?” (#A6)

Parents may express feelings of personal frustration with not being able to focus on the role of being a mother or father because it has changed so dramatically. The primary challenge seems to be the separation from being a “mother to ___” (a specific child) and the loss of well-defined parenting functions that shaped the parental role.
Other parents described the emotional difficulty of performing certain role functions that do continue. Parents are sometimes conflicted in the parental roles they fill because they feel a need to perform certain role obligations, yet they find it emotionally difficult to do so because of grief-related distress. In particular, nearly every woman pointed out the challenge of maintaining the role of “kin keeper” during holiday times, usually a family role performed by mothers, because of conflicting feelings about that role function. Martha, who lost her daughter, explained her feelings this way:

It’s really hard for me to do holidays. I feel sometimes that I’m letting my other two children down. Jessica loved Christmas and her birthday, so it’s very hard, especially with the twins, to feel happy because one of them is here but the other child is missing. So that’s real hard. It has changed in that I used to look forward to holidays and now I do not. The other two children are here... I know that the first Christmas I willed myself to be ill so I wouldn’t have to do Christmas. The thought of not having her around for Christmas was unbearable. The second Christmas someone talked to me and encouraged me to do Christmas, and I put up a few decorations but I couldn’t do it extensively. Who knows about this year? It’s just too difficult. So that part has changed, and I feel that I’m letting the children down because I don’t do a lot for Christmas in the way that I used to. The focus is not so much on what we give them. I do try.... Holidays are just very difficult for me to deal with. (#A9)

The conflict here is obvious. While this mother’s conception of being responsible in the parental role at holiday season demands one set of attitudes and actions, the grief-related emotions due to her child’s loss evoke a different set of attitudes and actions—a recipe for emotional distress. Parents may not only feel conflicted emotionally in carrying out functions of the parental role, but may also feel distressed because they feel they aren’t meeting the needs of the family. Another mother, Anne, shared her feelings about this dilemma:
For women, we are generally the caretakers and the ones that kind of hold things together. When this happens you can hardly breathe. You can just hardly breathe, let alone do anything else or think about anything else or care. You may go through some of the motions but that’s all you’re doing. You’re just on automatic. Then you have the situation where you know that if you break down at a particular time, if things are going okay in the family and you break down, then you’re going to upset everybody else. If your husband is having a good day or a good time and you’re not, then if you say something you’re going to bring him down. That’s not your role. That’s not our role in the family. Our job is to put things together and not tear them apart. So you’re so conflicted and sometimes, of course, you can’t help it. (#A3)

Since a parent’s sense of self is tied to personal perceptions of how he or she functions in the parental role, these feelings of conflict and ambiguity related to fulfilling role functions can be very challenging for parents to face after a child’s death.

While a child’s death has many impacts that make parents feel lost or challenged in their parental role, parents also describe a pattern in which they are able to affirm their positive feelings about themselves as a parent when a child dies. A child’s death often prompts parents to evaluate their efforts in parenting the lost child or other children, and many parents feel a confirming sense of reassurance about how they have performed. Again, nearly half of the study participants (five women, three men) indicated this distinctive pattern in their narratives. These parents acknowledged their shortcomings but emphasized that upon reflection they had positive feelings about themselves as a parent and the time and effort given to the child who died or other children. When asked about how his son’s loss had affected his feelings about himself as a parent, Tom reminisced:

When I first became a parent, actually when Lori was still pregnant with Andy, a friend of mine at the lab had some really great kids... they really had their act together. They were very well-rounded boys. They respected their elders, they were very intelligent and did well in school, they knew how to work on cars and get them running from scratch—just everything I wanted my boys to be. I asked
him how he did it and he said, “Just spend as much time with them as you can when they’re young because later it’s too late.” So I did. Looking back at that I can feel very confident that I did everything I could as a parent to do what I could for him. I did all those things. I involved myself in whatever he was involved in. If he wanted to get down and follow the bugs through the grass we did that together. We flew kites together. We went fishing together. We did all those things, and I also tried to explain things to him about the world. I tried to make him understand right from wrong. I tried to be firm and discipline him, not out of hate or anger, but out of love. I promised myself never to put my hand on him to discipline him; instead, I would make him sit on the couch and make him understand why it was wrong to do what he did. So, looking back at it I feel pretty good that I did the best I could. That part felt good. . . . I can look back at that and say I was successful as a parent, insofar as he was becoming the person that we wanted to see him become. His own person with his own interests and his own likes, but at the same time a very straightforward, intelligent, honest person who was responsible. So I’ve had to learn to look past the immediate guilt and failure and look at my success, and that’s what I’ve had to work at for the last few years. I think that I can confidently feel that way, though I still feel a lot of the pain of losing him. (#B6)

This father’s narrative captures the positive perspective that he carries about his parenting efforts with the child who later died, but also shows that such feelings came amidst working through other feelings of “guilt and failure” after the loss. Perhaps the key aspect of the parental narratives reflecting this theme is that for those parents who highly valued the parental role and focused on being a good parent, they were able to find a positive sense of self despite their pain at the loss. In some contexts, parents expressed a sense of personal failure at the child’s specific loss but also a sense of personal satisfaction at their overall parenting effort. These parents illustrate the diverse features of a parent’s experience with their sense of self when a child dies. While parents may struggle with negative perceptions of themselves, there are many who find some comfort in knowing that they tried to parent their children as well as they knew how.
Sense of Status as a Parent

Another dimension of a parent’s sense of self relates to how parents conceive of themselves regarding their status as a parent. Each parent identifies himself or herself as the mother or father of a specific child with whom they have a relationship. Does this sense of status as the child’s parent change if a child dies? Parents in the study indicated that this sense of status continues for them in the way they feel the child is connected to the family after death and in the way they identify themselves as a mother or father to a certain number of children.

Most parents who have a child die undergo some feelings of difficulty related to their sense of themselves as a parent, but at the same time they continue to maintain their sense of identity as a parent to the child who has died. Although the parental relationship with the child has been altered, the parents’ sense of themselves as the parent to that specific child is not removed. In other words, their status of being a parent to that child does not disappear as a result of the child’s death. Fourteen of the study’s nineteen participants, including eleven (of thirteen) women and three men, indicated a strong feeling that they still were and would always be the parent of the child who had died, even though the context was now different. One mother commented:

I am a parent to him eternally. I know that. I know that. I know that only a change in perception and the condition of my body and his separates the communication of our spirits. (#A2)

Another mother said:

They say that you may lose the physical child but you never lose the relationship. He will always be my son, forever twenty-three. . . . (#A3)
A mother whose daughter was killed noted:

I am her parent, no matter what. Even though she’s not here, I am still her parent. . . . I can’t imagine ever not feeling like a parent to her. . . . I think perhaps being the mother of that child . . . I think that’s a bond that can never be taken away. (#A6)

And a father said:

We’re a family. He’s not here with us physically but he’s still part of our family. My children talk about him. He’s in their prayers almost every night. (#B2)

These and other comments from the narratives highlight the strong sense of parental status that most parents continue to feel even after a child has died. Some parents expressed this simply as a natural feeling while others indicated it was part of a religious conviction. In any case, it suggests that a person’s identity status as a mother or father can and usually does become a fundamental component of their sense of self that continues on despite the loss of a child.

The corollary to how parents feel concerning their status as a deceased child’s parent is how they identify themselves as a mother or father when asked about the number of children they have. Several study participants indicated that this was one of the most difficult questions to face within the weeks and months after a child’s death, and many parents came up with various strategies for responding to this question. Ten of the parents in the study discussed this issue (eight women and two men) and nine of the ten indicated that they identified themselves as the mother or father of a number of children that included the deceased child (i.e., three rather than two if one has died, etc.). One mother, Ellen, explained her response this way:
I talk about her as part of the family just like she is still part of the family. I had a hard time right at first. Do I say that I’ve gone nine kids or that I’ve got ten? Back and forth, back and forth, because then you always have to explain. I finally said, “Look, I’ve got ten kids.” If they’re uncomfortable if I say that she passed away, then they’ll have to deal with it. But I can’t say that I don’t have [ten kids], I mean, she was there almost eighteen years. You can’t just say that you have nine kids. So I always say that I’ve got ten kids, but the oldest one passed away and so I have nine living. In fact, my kids asked that question, “What do we say?” I said, “What do you feel like?” They said, “Well, we still would say that we’ve got ten kids.” I said, “That’s right, you’re from a family of ten, be proud of it.” (#A1)

While some parents wrestle with feeling uncomfortable about discussing a child’s death or fear others may be uncomfortable, most parents indicated they felt it would be a greater disservice to the lost child to discount their life by not including them in the “count” of the family circle. One child’s mother pointed out that she would always “count [my daughter] as my child” because “the pain of her birth is just as real as the pain of her death.” These parents seemed to feel that they not only wanted to recognize the child’s life, but also the fact that being a parent to the child was a part of their identity they wanted to be known and remembered.

**Sense of Relationship to the Deceased Child**

Most parents emphasize that their sense of parental status to a deceased child is permanent and continues. This also raises the related question of how parents perceive the nature of their relationship to a deceased child following the child’s death. While this is explored extensively in the next chapter, the specific question of how this ties to their sense of themselves as a parent is addressed here. In the study interviews, parents were asked how they perceived the nature of the relationship to their deceased children if they
indicated a sense of continuing parental status. Parents responded by describing their views of the child’s condition after death and their sense of how they now related to the child as a parent.

Ten of the study participants (six women and four men) indicated some type of belief that the child still existed in some manner following death and therefore the parental role was still part of who they were. This was expressed in different ways but usually included a sense that the child existed somewhere in a different realm (“heaven,” another dimension, etc.) and had changed somewhat. For example, Stacy suggested:

I know that he is around. If I honestly felt that Jeff ceased to exist, I wouldn’t know what to do. I’ve had to come to the conclusion that I’m not leaving [him] behind. . . . we’re not leaving Jeff behind at all. I feel Jeff has moved on and has just gone ahead of us. He just went ahead of us. (#A4)

Her references to his leaving them and going on to another frame of continued existence mirror the comments of many other study participants. A father in the study commented that he just “accept[s] the idea that Corey is gone and that he’s doing something someplace else.” A number of parents were more explicit about their child’s condition following death, believing that the child could still influence affairs in the family’s life or that the child had developed an increased level of maturity or growth since death. One mother said she felt her lost child had grown “so much wiser,” while a father who lost a young son noted that “my understanding of where he’s at and what he’s doing is that he’s a full, mature individual now.” This conception of the child’s condition after death connected closely with feelings that parents expressed about the nature of the relationship they now felt to the child as a parent.
The two themes parents identified in their feelings about the nature of the parent-child relationship after a child’s death were a sense of curiosity about the child and an absence of parental functions related to the child. Although only two parents mentioned their curiosity about the child, each noted that the separation made them wonder about the child’s current condition and activities. Jean, whose son was killed instantly, said:

I had the same feelings that I had when he had gone away on long trips. . . . I was just curious about him like I’m curious about all my kids . . . I was anxious, just like I was when I had sent him to Mexico or sent him to college. I was thinking about typical parent things like, ‘Boy, I hope he adjusts to this okay,’ or ‘I wonder if he’s already missing us a lot and I hope that won’t keep him from adjusting to this change,’ or ‘I hope that he can tell how much we love him and how much we remember him.’ (#A2)

A sense of the child’s continuing existence makes possible such curiosity, and therefore parents may feel there will be a future connection with children again. Another theme over half of the parents (ten participants) commented on was a feeling that though they still carried parental status to the lost child, they did not have a sense of needing to perform actual parenting functions for the child. They normally explained this as being a result of both their sense of the child’s growth (see paragraph above) and their lack of opportunity to “parent” the child. Amy, who lost an infant daughter, explained:

The part that’s tricky for me right now is that as a mother you always feel like you know a little bit more than your children. You have the experience and understanding, and you’re imparting that to them and sharing with them. . . . In my perspective . . . her body lies up in Oak Lawn Cemetery, but her spirit is very intelligent . . . this is where I got into a little identity crisis. I went from being her mother and being a very important figure in her life, [the person] that protected her, fed her, nourished her, and held her when other people poked and examined her, to a position where suddenly she knows more than I do and she’s pretty amazing. I see her spirit as being of full stature and so that causes me to not know quite how to relate to her any more. All of a sudden she has a few things that she can teach me, of course, beyond what a child teaches you. (#A10)
Parents may be challenged by the contrast between continuing to feel they are the child’s parent, but also thinking that the child has grown beyond the need for a parent’s guidance and assistance. Another study participant, Tom, shared a similar feeling:

I feel like I want to be a parent, but there’s a big void there. I can’t be his parent because he’s not there to be a parent to . . . he’s progressed beyond that point where I can have any kind of definitional influence on his life. I feel that his spirit is still there, but that his spirit is now independent and on its own. I can still feel his presence and his love, but as a parent . . . I don’t have that any more. He’s not there. (#B6)

He indicates that both the child’s absence and the child’s growth have given him a sense that for him there are no longer any parenting opportunities or functions related to the child that he can perform. Thus, although parents may continue to identify themselves as the child’s parent and believe the child exists in another sphere, any sense of an active or functional role for the parents in relation to lost children seems to diminish or disappear.

**Child Death and Separation of the Parent-Child Bond**

A child’s birth presents parents with an opportunity to begin a family association that requires ethical concern, generational commitment, and caring responsibility (Brotherson & Dollahite, 1997). It has been suggested that to bring a child into the world is “to take on a lifelong responsibility, a lifelong relationship” (Lee, 1976, p. 82). At the heart of this relationship lies the parent-child bond, an emotional and psychological attachment that shapes both the parent’s and child’s sense of who they are and also the functions that sustain the relationship (Bowlby, 1969). The death of a child transforms the bond between a parent and child and impacts the emotional tie that has been forged in the relationship. Since a parent’s sense of self is rooted in this bond and the connection a
parent feels in the relationship, a child’s death strikes a sharp blow at a parent’s identity (Parkes, 1986). The previous chapter detailed how a child’s death impacts a parent’s connection with the child prior to and during the loss experience. For parents, the primary impacts occurring after a child’s loss that affect this area include the pain of separation from the parent-child bond, the accompanying emotional reactions, and the loss of connection to a unique child.

**Parental Separation from Self**

Perhaps the most devastating and dramatic effect of a child’s death, particularly if it is a sudden death, occurs in the manner it separates a parent from the parent-child bond in a way that causes great emotional and physical trauma to the parent. As mentioned earlier in this chapter, parents may experience a child’s death as a death of part of themselves, and they often describe this feeling in terms of the pain that they experience. It seems critical to note that being a parent represents a role that is unique in its contribution to a parent’s sense of identity because the parent himself or herself (except in cases of adoption, etc.) has been involved in the creation of the child that is theirs. A mother and child, especially, are literally joined physically before the child becomes a separate individual, and thus the relational bond they share is mirrored by the actual physical bond that precedes and produces the child’s existence. Thus, the relational bond between parent and child is not only an association of two persons, but a deep connection that is part of who they are as human beings. The depth and profundity of this connection
may explain the equally strong reaction by a parent when this bond is changed by a child’s death.

Ten of the nineteen participants in the study (seven women, three men) described a very strong emotional response to the loss of their children, and all of these were mothers or fathers who lost a child suddenly. All but one indicated that the pain they experienced was intense both emotionally and physically. Six of the participants, all women, stated that the pain of the loss was so unbearable that they either wanted to die or seriously considered committing suicide to escape the despair. In describing the feelings that were experienced when they learned of a child’s death, seven of the parents gave graphic and similar accounts that expressed a feeling as if part of themselves had been removed or ripped out. One woman, Anne, commented:

The first thing that comes to mind is the physical pain, the pain in my heart, just the wrench like my heart had just been torn out. . . . You don’t think about anything else. There is nothing else that is of importance. You don’t care about anything else. And especially, that disappointment of waking up in the morning . . . you’re not going to kill yourself, but where’s that Mack Truck when you need it? (#A3)

Another mother, Carol, remembered:

When I got that phone call there was such a pain and constriction in my heart that I thought I was going to die. I could not imagine life without her. . . . That phone call wasn’t coming that afternoon and I wasn’t going to have any more kisses or hugs or beautiful cards from her. When she actually was flown home and was in the mortuary and could be touched . . . I can’t even put into words the reality of seeing your child laying there. Their life is just starting . . . I don’t know. I can’t hardly describe it. (#A6)

John, a father recalled:

The panic and having your heart ripped out . . . I don’t know how to describe it. I don’t know how to describe the pain that went on. (#B2)
And another father, Ken, said:

I don’t know how to explain it, aside from maybe feeling like your heart’s been torn out of your chest. (#B3)

In these descriptions each parent suggests that the feeling of loss is so intense that words cannot adequately depict the pain, but in attempting to describe the emotion each also uses the metaphor of one’s heart being physically torn from one’s body. Each account frames the situation as if the child were an extension or part of the parent’s self, so that the parent-child bond is incorporated deeply into the parent’s sense of identity, and when that bond is suddenly severed by the child’s death it is as if the parent’s life and identity has also ended. Perhaps no imagery is so appropriate in capturing the emotional assault these parents describe as that of having the source of their lives, the heart, being torn from them so that they are separated from the most important part of themselves. If some parents who experience a child’s death feel physically and emotionally as if they themselves have also been killed, it is not difficult to understand why they might also express the actual sentiment of wanting to die literally.

Five of the parents also used other descriptions of the pain that accompanied the sense of loss, ranging from a feeling of being shattered to having the center of one’s life vanish. These various accounts provide vivid images of what a parent experiences when a child passes away. One father articulated the sense of loss as being “an open wound that never healed” that was just “always there, like a cut on your arm,” and in searching for words he finally simply said, “I don’t know if there’s a way of saying it—it’s like we were sent to hell.” Another mother, Stacy, tried to explain:
Emotionally I felt as if... have you seen those machines on the road that roll out the pavement? That's what I felt like. I felt like I had been run over by one of those. (#A4)

One of the women, Carol, stated:

It's like feeling you're going to be shattered into millions of pieces and nobody will find the pieces to put you back together... [most people] have not lost a child that they have carried and nurtured and helped to develop into who they are. That's part of what is missing and what is cut off. (#A6)

Shattered into a million pieces. Run over by a steamroller. Sent to hell. These images capture what a parent may feel when the parent-child bond is sundered and why a child's death can become an existential crisis for some parents. The effect on a parent's sense of self may thus include a shattering of one's sense of identity or a feeling of being placed in a strange and unfamiliar world in which the parent has to search anew for who they are and must construct a new sense of self. In essence, the parent has been separated from a relationship that defined their sense of meaning in the parental role and supported the functions of that role.

**Emotional Reaction to Separation of the Parent-Child Bond**

Beyond the intense feeling some parents express that they have physically been severed from the parent-child bond, most parents also articulate a wide range of accompanying emotions that stem from the sense of being separated from the child. In much of the literature on the psychology of loss, these feelings are described as being part of the "separation anxiety" that a parent experiences when a child dies (Parkes, 1986; Weiss, 1988). The parent-child relationship is generally classified as a primary relationship of attachment, and if either member of the relationship is unable to achieve a
sense of reassuring contact with the other under threatening conditions then they are likely to express high levels of emotional distress due to this separation (Weiss, 1988). The intense and varied emotions that accompany such a separation highlight the connection to a parent’s sense of security in their world. In this study parents cited emotional reactions to this separation of the parent-child bond that included grief and missing the child, intense emotional pain, shock and denial, anger, and sadness.

The emotions experienced by a parent as a result of the child’s absence range widely and the mourning process has been well documented (Bowlby, 1980; Parkes, 1986; Sanders, 1989). Parents in the study expressed emotional reactions ranging from anger to depression to despair. The reactions that characterized the parents’ early response to a child’s loss, particularly a sudden loss, were shock and denial followed by intense pangs of mourning, sadness and depression as the parent searches for the bond that has been lost with the child. Five study participants related experiences of shock and five expressed feeling denial when they learned of the child’s death, and all of these parents lost children suddenly. This pattern of shock and denial is more common for parents who lose a child without warning (Knapp, 1986). Stacy, whose son died in a traffic accident, initially denied his death and then wandered confusedly through the funeral services, insisting on a closed casket funeral “because if I didn’t see him then I wouldn’t have to believe it.” The shock and denial experienced emotionally by these parents may be an important buffering mechanism because it blunts the initial pain of the separation from the child. The emotional shock may leave a parent feeling that they are experiencing a dream or an unreal nightmare, and so they continue to search for the child,
not fully accepting that the separation from the child is truly real. Other parents may know it is real from the beginning and the shock of the separation is simply intense, so that they must be protected from the negative physical effects of shock.

The emotions that follow the initial phase of grief may include anger, depression, sadness or loneliness. Dealing with the sense of separation from the child elicits all of these feelings and more. The parent has experienced a powerful emotional connection that provides meaning and direction to their sense of self, but the child’s death changes that and leaves a parent to deal with the emotional upheaval that follows. Amy tried to explain the emotions she experienced after her daughter’s death:

I think the feelings that came later are the ones . . . there is just an overwhelming sadness. A lot of times it’s just, “Give her back, give her full of cancer, just give her back. I’ll take her blind. I’ll take her with all her limbs amputated. Just give her back.” . . . I didn’t realize you could feel so strongly. The emotions I felt were so strong and so deep. I remember in the weeks that followed just crying in bed. I remember one time [my husband] and I just holding each other and both crying, and a crying coming out of me that was almost primal . . . a moaning. Not just like I’m crying now, but a wrenching of the soul. So I was just kind of amazed and still am amazed at the depth of emotion. (#A10)

This mother seems to indicate that these deep emotions stem partially from a longing to be with the child again, to have the bond re-joined in any way, so that the relationship is made whole again. Many parents indicated a loneliness that resulted due to the loss of the parent-child bond. One bereaved mother, Sandra, remembered:

When the reality hit in that [my son] was not coming home, that was . . . I was just depressed. . . . It’s just such a void. You just have so many hopes and dreams for your children, and then knowing that there’s none for him any more. It’s just such a void it’s overwhelming, that you’re not going to have him to be with you for the rest of your life. (#A13)
The void left by the child’s absence causes parents to wonder what might have been if the child had lived, and they experience a loneliness for both the child and the unfulfilled future relationship. Some parents may even feel resentment or anger toward others who continue to have a relationship that they have lost. In all, fifteen of the study participants described such varied emotional reactions to a child’s loss and observed that it made them struggle with their sense of the future.

**Separation from Relationship with a Unique Child**

One significant feature of the parent-child attachment is that the bond between a parent and child involves a relationship with a specific figure who cannot be replaced. The parent may re-direct their parental energies or focus on other relationships, but they cannot substitute another person for the child who has been lost (Weiss, 1988). Parenting takes place in the context of a relationship with a specific individual, and the uniqueness of each person and relationship makes each loss significant and overwhelming.

Seventeen of nineteen participants in the study emphasized the theme that separation of the parent-child bond meant a separation from all that made this particular relationship unique, including a child’s personality, activities and the relationship association.

The factors that make a parent-child relationship unique are interrelated and work together to make a distinctive and meaningful relationship. Thus, while it is possible to identify specific factors that the parents discussed in their accounts, it is difficult to separate them out for purposes of analysis since the parents describe them in relation to each other. The bond as it existed provided a structure for the parent’s sense of self
because of the unique role interactions with a specific child, and when the bond dissolved then this structure that provided the context of meaning for a parent’s identity in their role as mother or father also dissolved. Jean, who discussed what she felt had been lost to her when her son died, said:

I miss him singing. I miss listening to him sing. I miss sitting at the supper table and asking each other trivial historical questions. He was a historical buff, like I am, and we’d play kind of a game. He was an avid reader, like I am, and he just picked up all kinds of trashy trivial information, anecdotes and such, and he was more willing than my other children are to play this little “let’s-exercise-our-brains” game with me. It was fun, and I miss the fun of doing that. I miss watching him roughhouse. I just miss all his little eccentricities. (#A2)

Such aspects of the child’s personality as his singing, his intellectual ability, and other tendencies are missed by the mother, and also the activities that those tendencies made part of the relationship between mother and son. The interactions that took place because of those activities are lost to the parent.

The attachment bond shared by a parent and child is reinforced by the occurrence of regular interactions that provide a rhythm and familiarity to the relationship, providing a secure base in each person’s life. The parent’s sense of self in the relationship is patterned upon these regular interactions, and the pattern is upset dramatically when the parent and child are separated. A father, Tom, recalled:

As a parent I would say the biggest joy I had was having Andy old enough to the point that he and Jimmy could play together, then sitting back in a chair and watching them play in the backyard together. That was the high point, I felt, of being a father. . . . I remember watching both of them from across the yard [as they were] in the garden, and one of them had my hoe and the other one had my shovel. They were trying to dig this hole and would get a couple scoops at a time. Then they’d stop and both get down on their knees and poke around, and then both stand up and whack, whack, whack [with the tools]. They’d get down and poke a little bit more, then stand up and whack, whack, whack. I’m not sure if
some poor worm was really getting it . . . but to watch stuff like that. To take them both out and fly kites together. All three of us would get all the lines tangled up. To do what Andy called “fishing,” which means I would throw my line in the water, throw his line in the water, and then everybody would throw rocks in the water and scare all the fish away. To do all of that . . . that’s the part I feel like I’ve lost the most. (#B6)

The unique aspects of interaction that came together in the bond with his son who died have vanished. He is left with the question of answering who he will now become as a parent since the parent he was has been lost. For parents who feel the loss of this bond, it is not what they experience but rather what they no longer experience that signifies the relationship that shaped their parental identity has forever changed.

In essence, parents miss the opportunity to be a parent to a specific child they loved once a child dies. They have invested themselves in being a parent to a Samuel, Jonathan, or Angela, and the resulting bond has defined who they are and what they do for much of each day. It also shapes who they expect to be and what they plan to do tomorrow. The loss of the parent-child bond thus separates them not only from a vital relationship but from part of who they define themselves to be. Laura, who explained what was now gone due to her son’s death, said:

Well, I lost him. One time he came in from outside, he was such an enthusiastic child, and I was at the stove cooking. He was telling me about something and he had these mannerisms of how he’d get so excited. His hands would illustrate what he was saying. I can still remember that moment and I thought to myself, “I hope I never forget this moment.” Just the dearness of him, everything about him, the light, so enthusiastic about what he’d been doing, the movement of his hands.

Another one was remembering Carolyn and he playing on the front porch. He’d say, “Now you is the fireman and I is the policeman!” and he would play out the whole scenario. He had a loud voice like his Daddy’s side of the family. You could hear him, and he whistled all the time. That’s the only child I’ve ever heard who’d be doing something and whistling. We’d go downtown and he’d be
whistling away. He was just a happy child. What I missed was that presence, that sense of joy that he brought with him. (#A8)

The presence of a child, the joy shared by a child, the funny little quirks that a child might possess—these combine together and form the substance of a parent’s emotional tie to a child. They make each relationship unique and individual. One mother suggested that “there are certain unique things that I think every child, every person, has that maybe fill certain needs of ours,” and it is these unique aspects of a relationship that disappear for a parent when a child dies.

Child Death and Parental Adequacy

An important part of a parent’s sense of identity is linked to a parent’s self-assessment regarding their adequacy in fulfilling the basic functions of a parent (Rando, 1985; Weiss, 1988). A child’s death strikes at a parent’s sense of adequacy because of the guilt feelings associated with the loss and the parent’s inability to be responsible for or protective of the child any longer. A parent may feel guilty about something left undone or a perceived mistake in caring for the child, and may also be troubled at being left without any further opportunity to watch over the child. The previous chapter outlined how a parent’s care and responsibility for and also protection of a child were threatened prior to and during a child’s death. These key parental functions are transformed for a parent upon a child’s death and the parent must then deal with the related impacts upon their sense of parental adequacy.
Parental Responsibility and Care for the Child

One of the primary themes that parents in the study identified as a challenge in relation to their parental identity during the loss experience was the difficulty in being responsible for or caring for their child. The previous chapter explored factors that influence parents in fulfilling these functions during the loss and how parents continue efforts to be responsible in a variety of ways. This chapter deals with how a parent’s sense of adequacy is impacted by specific factors and the emotional impact this has on parental identity. Any factor that challenges a parent’s ability to be responsible for the child will be difficult because "much of parental identity centers around providing and doing for one’s children, a basic function of the parent" (Rando, 1985, p. 20). Eleven study participants, nine women and two men, commented on feelings about their adequacy as parents related to being responsible or caring for the child at the time of or following the child’s death. A parent’s sense of adequacy in fulfilling these parental functions may be affected if the parent cannot be present or the child is absent, others hinder the parent’s efforts, or the parent experiences guilt about various aspects of care and responsibility for the child.

Five of the parents indicated a frustration with not being able to care for or be responsible for the child because they could not be present with the child. All but one of these mothers lost a child suddenly. It should be noted that in each case the mother tried to do all that she could to be actively responsible for the child and that this instinct was very strong. But they were challenged at both the time of loss and later on after the child’s death because they weren’t with or available to the child. Three mothers who lost
children suddenly noted feelings of frustration at not being available when their children were killed. One mother, Anne, whose son died in an accident, expressed both mental concern for her child’s welfare and her sense of unease at not being aware of his location so that she could confirm his well-being. The parents who spoke of this feeling noted the regret that they felt in their parental roles because of being unable to assume more responsibility for the child’s welfare due to not being present. It is as if, for them, their absence in the moment of the child’s death marks an absence of parental adequacy.

For all bereaved parents, being separated from the child leaves them feeling unable to directly care for the child. The weeks and months following a child’s death may leave parents searching for the tangible experiences that allowed them to be more responsible for their children. A mother who lost an infant, Amy, said:

I think the hardest thing after Gina died was that my arms were empty. My arms had been full because she needed to be held, she needed to be lifted, she couldn’t walk after she’d had the surgery, etc. I was always holding her way beyond what a twenty-month old would have been held. Then I’d go into a store and see someone giving their baby a swat, and I’d just feel, “How can you do that?!” In my heart I’d just cry, “But you have a child!” (#A10)

Her separation from the child has stripped her of being able to perform the parental functions that had defined her role and identity as a mother to this child. As she indicates, to actively be responsible for a child you must actually have a child to care for. Death nullifies that physical association between a parent and child.

After a child’s death parents still have a strong sense of need to somehow be responsible for the child, but this can be further frustrated by hindrances that others introduce into the situation. Parents often assume such responsibilities as making
decisions about memorial arrangements and handling of the child’s physical remains, but others sometimes make it more difficult for parents to be actively responsible for such matters. For example, Carol had a daughter die in another state, and recalled attempting to gain information on her child’s death and trying to make memorial arrangements:

She had missed [her class] the day before because of icy, bad weather. She had chosen not to go. I had told her many times that I would rather she have to take the class over again and be safe than go when it wasn’t safe . . . She took her boyfriend’s 4-wheel drive pickup and went to class. She was coming back home and went up a real small hill that was icy, and coming around the other direction was a large truck going too fast and the truck hit her and killed her. It rolled her over into a feedlot ditch. The lady who saw the accident said she had to presume she was killed outright. I later found out that she had broken her neck and had a lot of cuts and contusions.

That state is quite interesting. I was not notified for many, many hours. They claimed that they could not find her driver’s license (and she was never without it), so they assumed she had no [family] out of state. She was a registered owner of the truck she was in with her boyfriend. The news was on the radio before family was notified, and in the pictures that were in the paper she had not even been removed from the accident scene yet. She was still in the truck. I personally took offense at that. I don’t care how many years I have been in medicine, when somebody passes away that is somebody’s loved one and you do not become so crass that you forget that. You take as much care as possible even if it’s a perfect stranger that is in your care for the moment.

It was very difficult to get answers. The police officer who called out here lied to me and I don’t take that very well. Everything seemed to focus around the fact that her father was back there, even though I was her legal guardian. We spent a long time just trying to get answers, which to this day we still do not have. It seems as if there’s some kind of unnecessary cover-up and we don’t know why. I can’t get the pathology report. What they tell me over the telephone does not correspond with what I saw. The father’s situation did not help. He was not going to allow us to bring her back here to be buried, even though this is where she was born and raised. . . . [My son] just told his father what would happen, that we would bring her home and the services would be here. (#A6)

Despite this mother’s desire and efforts to be responsible for her child by learning about the circumstances of her death and arranging for her memorial, she had to struggle with
the hurdles that were placed in front of her by others involved in the situation. Although not addressed in this study, such difficulties are commonplace for parents who have lost children through homicide and they often feel doubly victimized (Knapp, 1986). When parents face such challenges it strikes yet another blow at their sense of worth and ability as a parent.

Guilt associated with various dimensions of providing care or being responsible for the lost child troubled a number of the parents in the study. Nine of the study participants (seven women and two men) focused specifically on feelings of guilt connected to their performance of these basic functions as a parent to the child. Research has shown that mothers tend to struggle with this sense of inadequacy more often than fathers do, although both can obviously be affected (Cook & Wimberley, 1983). Parents indicated feeling guilty about a variety of parenting issues that included not giving adequate time or care to the child, not making good decisions for the child, not expressing love to the child and feeling anger or relief towards the child.

Those parents who expressed a sense of guilt following a child’s death about their own parental performance noted both broad child-rearing concerns and specific issues related to the loss experience itself. The two general areas of this theme coincide with research that indicates the most prevalent guilt feelings among parents following a child’s passing focus on “childrearing” and “death causation” (Miles & Demi, 1992). The most common theme related to guilt for these parents was not providing sufficient time or care to children as a parent prior to the death. One of the mothers, Jean, shared her feelings about not reaching her son as she wished:
I feel much regret about not being able to nurture him sufficiently through the [emotional] crisis that he went through in the semester before his death. I think of what he told me, that sometimes he would come from his apartment and he would come home in the middle of the night and let himself in the door, and he would just come and sit in the living room. He would just sit there in the dark and listen to the rest of the family sleep and it just comforted him. I think, “Oh, my heavens, why on any of those nights didn’t I wake up?!” Even though I spent week after week having lunch with him, I still feel a lot of grief and guilt that I wasn’t able to help him more in that. (#A2)

This mother’s account not only expresses the type of general care for a child that parents may feel they did not perform adequately, but also suggests that if a child is troubled in some way prior to the death these feelings of guilt might be complicated even more. In a difficult parenting circumstance the parent may already feel vulnerable, and the child’s death has the potential to limit opportunities for parent-child resolution while magnifying a parent’s sense of inadequacy. Other parents noted specific feelings of guilt in relation to their performance when the child was diagnosed with an illness or needed assistance.

Ellen, whose daughter contracted a fatal illness, recalled:

As far as being a parent, you wish, you wish that you had been more observant when she first got sick. I kept saying, “Why didn’t I take more time with her that day? Why didn’t I recognize how serious this was?” I had all of these kids that were in soccer games and was going from one to another to another . . . did I just not realize how sick she was? You feel remorse that you didn’t spend some more time. But at the same time, there were no indications as a parent that it was more serious until that night. That night when it was obvious that she was so ill, then we immediately took her in. (#A1)

If a parent feels that his or her performance in caring for the child might have made a difference if they had acted differently, perhaps even in saving the child’s life, then the sense of guilt and questioning about their actions as a parent might follow them for years. This sense of guilt associated with parental action during the child’s loss tends to vary
according to the type of loss, ranging from concerns about not getting a child appropriate treatment to failure to do CPR correctly in an emergency to ingesting substances that may have contributed to a child’s genetically related disease. These guilt feelings are closely associated with a parent’s sense of their performance in being responsible for a child.

A closely associated aspect of guilt to that discussed above which parents shared was feeling guilty about the decisions they made as a parent in relation to the child. Four parents described these feelings and all seemed to focus on what might have been if they had decided something differently. A father, John, whose son was in a freak household accident while in day care stated:

I felt that we fell short somehow. Felt guilty. Maybe if I would not have taken him up there, or maybe he was telling me not to go up there when the dog was out there . . . you know, the guilt about things that really didn’t make sense but you were trying to make sense out of life and what happened. Why did I even have to have him in the day care? Some people leave their kids there eight hours a day. I don’t leave mine there. . . . But there’s just a ton of guilt. You feel that you’re responsible for it. I feel like the reason it happened . . . you know, at the time felt like I did it myself. It’s not true. But maybe I should have done something different on the CPR. Maybe I should have performed a tracheotomy. I didn’t know how to do that but maybe that would have saved his life. (#B2)

Questions crowd a parent’s mind when a child dies. This father uses the word “maybe” five times in this short account, a reflection of how parents can be haunted by the decisions they made and re-play them again and again. A mother or father’s sense of adequacy in the parental role tends to be reinforced by evidence that the decisions they make result in positive outcomes for their children. Guilt about one’s past decisions frustrates that process, especially if questioned by others, and makes parents unsure of their parental capacities. A mother who had made the decision to disconnect a child from
life support systems recalled that others had questioned this decision and told her it was equivalent to killing the child. Such comments may further threaten a mother or father’s sense of adequacy in the parental role.

Parents may also experience guilt for not expressing love to a child or feeling anger or relief in relation to the child’s loss. Three parents in the study discussed such feelings and the associated sense of personal blame or defeat as a parent that can accompany such guilt. Feeling anger at the family difficulties connected to a child’s loss or relief at the closure of a child’s long illness is not uncommon, but parents tend to associate such feelings with parental inadequacy because they are not considered to be appropriate reactions as a parent. Such feelings act as guilt-making mechanisms that parents must overcome. One mother, Stacy, related:

I have these guilt feelings. . . . I can remember that day when he called and his friend was there. I always said, “Jeff, I love you,” and he always said, “I love you too.” We got ready to hang up and both paused, and I don’t know why I didn’t say it. I was waiting for him to say it first and we hung up. I started to call back to say, “I love you, son,” and in my mind I thought, “Why are you doing this? You’re always so afraid something is going to happen, you can tell him that the next time.” I’ll never do that again. So I feel horribly guilty that was not the last thing he heard me say. The last thing he heard me say was, “Be careful.” (#A4)

While this mother typically expressed her love to her son, the unfortunate timing of his loss coincided with an occasion when she did not do so and thus left her struggling with a sense of guilt as a mother. The guilt associated with these various expressions of emotion suggests to parents that they have somehow failed or that their role performance as mother or father does not meet the right standards. Overcoming these feelings of parental inadequacy requires time and the positive support of others.
Parental Protectiveness of the Child

Protection of a child is one of the most fundamental aspects of a parent’s role and also a measure by which parents evaluate themselves in the parental role. This is because typically “parental relationships aim at the protection of the other” (Weiss, 1988, p. 42). Parents who lose a child must often wrestle with feelings of inadequacy that arise from the belief that they have somehow failed in their protective role. One scholar has noted that a child’s death “assaults the sense of self” because a parent’s “omnipotence over the child [is] rendered useless and ineffective” (Rando, 1985, p. 20). The previous chapter discussed some of the issues that parents face in being protective of children prior to and during a child’s loss, including gender differences and how the type of death influences a parent’s feelings. This chapter discusses the themes that parents in the study expressed in relation to their feelings about the protective role after the child died. Parents focused on the sense of helplessness they experienced and concerns about parental failure.

Parents who experience a child’s death, either gradually or suddenly, all indicate a feeling that they have lost control. Parents who watch a child die slowly cannot prevent the child’s pain and suffering, while parents who lose a child quickly cannot intervene to protect the child from harm. Ten parents in the study shared feelings of helplessness that occurred primarily following the child’s death. Amy, whose child died of cancer, said:

I came out of that experience really a little angry at both orthodox and unorthodox medicine. That was because both those in orthodox medicine who tried to help us and those in unorthodox medicine—neither of them had the answer. As a parent it was like, “Get your act together, guys! Go find a cure!” Why can we send people to the moon and we can’t save a child’s life? So neither worked and I think I became pretty skeptical about either profession having the answers. (#A10)
One father in the study who experienced a similar loss subsequently developed the philosophy that “if all my children were to die tomorrow and it was in a quick, peaceful way . . . it would be a blessing,” reasoning that enduring the helplessness of a child’s suffering was much too difficult as a parent. A parent’s instinct is generally to protect and mitigate a child from harm, but a gradual death challenges that instinct. Other parents who lost children suddenly noted the stunning transition from invulnerability to vulnerability that a parent undergoes in their sense of themselves. Stacy commented:

You just are helpless . . . losing a child happens to somebody else. You find out just how vulnerable you are. It is the most devastating thing that will ever happen in your life. Losing a parent won’t be as bad. Losing a spouse won’t be as bad. Losing a child is the ultimate . . . it is the worst thing that can happen to you. (#A4)

When a child dies, parents transition rapidly from a world in which they have exercised control and protection of their children to a world in which such security has vanished. Parents must now struggle with a sense that the parental world is highly unstable and their abilities to protect a child may be inadequate. These feelings about their parental abilities and the vulnerability of their children have implications for their future parenting behavior and will be discussed later.

A second theme related to the parents’ protective function that was expressed by seven study participants was a sense of failure in the parental role because of not protecting the child. Some parents felt this in a “global” sense about their overall performance as a parent, while others felt it only specifically in response to the loss of this particular child. The feelings of failure can haunt a parent and contribute to the guilt
a parent faces after a child’s death. Peggy, who had tried to help her daughter who died in an accident, noted the questions and concerns she felt:

Was it my fault? If I’d gone out there the first time my son [asked me], would she still be alive? If I had not let them out in the backyard by themselves would she still be alive? Did I do the CPR right? I’ve had people say that we should never have shut the respirator off, that it was the same as killing her. . . . There’s still times when I get real down, primarily on her birthday, then I still blame myself and I still feel guilty . . . that feeling of powerlessness . . . [I feel that] I should have been to as a parent, as a nurse . . . I should have done something. It was my job to make sure that she grew up healthy . . . and I failed. (#A7)

These questions and the associated loss of one’s sense of success as a parent can trouble parents long after the child’s death. These questions are to a degree the unanswerable questions that undermine a parent’s positive sense of self. Parents often consider protection of a child’s life to be their greatest responsibility, and the feelings of guilt experienced by some parents when they lose a child provide the ultimate paradox. As one father noted, some of his most powerful guilt feelings were associated with his “feeling of failure to protect and save [his child] from harm.” The burden of guilt that parents endure when they carry a sense of failure in not having protected their child from harm may have the strongest impact of all on a parent’s sense of adequacy. A child’s death seems to shout failure to some parents, and they are left to face the emotional struggle of reconstructing a coherent parental identity in a new future.

**Child Death and Parental Expectations**

Much of a parent’s identity centers not only in the present existence with a child but also in the future possibilities as a parent and a child’s developmental potential. As one scholar has noted, “The child serves as a tie with the traditional past, but also, and
perhaps more importantly, with the future and with our sense of immortality” (Schwartz, 1977, p. 196). A parent hopes for a bright future of experience with a child and expects that the child will carry on the values and heritage of the family. Death circumvents these hopes and slams the door on a parent’s sense of the future. This becomes yet another obstacle for parents to overcome in fashioning a new understanding of themselves in the present and future after a child’s death. Sixteen of the study participants, eleven of thirteen women and five of six men, indicated that this dramatic reversal of their parental expectations and future with the child who died was a major source of grief following the loss. The parents’ narratives suggested that these mothers and fathers struggled with both their own lost opportunities in the future and the child’s lost opportunities and future.

The first dimension of loss in this area that parents describe is a sense of losing themselves in the future and all of the experiences that they might have enjoyed as a parent. They know that they will not see this child graduate from school, attend this child’s wedding, or bounce this child’s own sons and daughters on their knee. Five parents focused on this theme, two mothers and three fathers, and mourned the future possibilities for themselves as parents that were now gone to each of them. As one father noted, “I feel like I’ve missed out on sixteen years of being a father, [and] I feel jealous that I haven’t had that opportunity.” Parents must now reconsider and re-configure the “possible selves” that they have incorporated into their sense of parental identity (Hooker, et al., 1996). One mother, Carol, explained her feelings this way:

[I lost] part of my future. The grandchildren she would have provided. My dreams of success for her. Those are all gone . . . all of those things have changed as to what I was looking forward to, and I was looking forward to being a
I had moved into a phase where everything my kids did had become so exciting because they're such dynamic young people. To just have that plucked right out of your life is not only losing the hugs, the kisses, the cards, the phone calls, and the physical-ness of that person being taken away from you, it is all of these dreams and hopes that you've talked about together and were going forward. (#A6)

A child's death means not only the death of the child, but the death of a parent’s future as well. The part of a mother’s or father’s future identity that belonged to fishing trips with a child or attendance at a school performance vanishes. This requires a slow and painful re-construction of the parent’s sense of self in the future, as one father said, creating a “new life that I have to rebuild and re-create for myself, this new image of what it is supposed to be like down the road.”

The life experiences of a parent make up the framework of a parent’s life story, establishing a context in which parents can develop a sense of themselves that belongs within a coherent narrative (Bruner, 1990; McAdams, 1993). As with any story, the person involved thinks ahead as to what will be told and experienced in the future of the developing story. In Chapter 4, a quotation from Tom likened his parental experience to working on a painting over a lifetime that reflected his likes, dislikes, abilities, wants for the future, and desires for his children. Then, referring to his child’s death, he said that “it felt as if someone had taken my painting, ripped it off the easel, put up a blank canvas and said, ‘You have to start over.’” A mother or father’s investment of self in a child and their future, in the story that binds them together, must now be changed to fit the shape of a new story that leads to a different future. This same father, Tom, stated:

I had this whole expectation of watching them grow up together, and watching them have someone to talk to about mom and dad when they couldn’t talk directly
to [us] about mom and dad. To watch them share and do things together, to do all of those things. I had this whole idealistic family picture about how all of that was supposed to be, and how my role as a father was supposed to be, and I feel all of that’s gone and has been stripped away. I feel like I was working very hard, writing a whole book of my life, up to the point where I decided to clean up my act and go back to school. I met my wife, got a job, got a mortgage, had two kids. I was really into the family thing and the house and the wife and the whole nine yards... and to have someone take all that and throw it away. [It was like someone] giving me a blank book and saying, “Okay, now you have to start all over again.” That’s the sense of loss that I’ve had from all that. I feel that this whole vision and the whole way that my life was supposed to go is gone, and the very central and key character in that story was me as a father and how I related to the boys. Now I feel like all of that is gone. (#B6)

His account gives a dramatic picture of how part of a parent’s identity involves a sense of oneself in the future, and that when one is a “central and key character in that story” the death of a child can alter the scene so much it’s like starting over again. Of course, for a bereaved parent the tragedy is that it is not simply a story—it is reality.

A second primary influence of a child’s death on parental expectations is the loss of the child’s future opportunities and development. Sixteen of the parents in the study, nearly every participant, discussed aspects of this theme and their sorrow that expected opportunities in the child’s future would now go unfulfilled. This sense of loss is for the child and the parent’s hopes for the child, rather than focusing on the parent’s lost future (although they are obviously connected). Ten study participants, seven mothers and three fathers, specifically addressed the impact of knowing the child would not now be able to participate in such opportunities as graduation from high school or marriage. These parents seem to long for those important life events in behalf of the child and ache for what their children cannot experience. Jean indicated her feelings about this issue:
One of the things that I feel the most residual grief about . . . is that I so looked forward to seeing him marry, have children, and be a husband and father. . . . That is always just tugging at my heart that I can't see that with [him]. I miss it intensely. That's the thing that I miss most, seeing that, and seeing him function in that way. (#A2)

The longing these parents express for such lost opportunities for their deceased children shows how they have invested their parental role with a sense of the child's future experience. At times it may be difficult for them to participate in activities that remind them of these passages their children will miss, while at other times parents seem to take comfort in seeing others close to the child (siblings, friends, etc.) enjoy these occasions. A mother whose daughter passed away told of how difficult it was to help her son's fiancé pick out a bridal gown because she felt that "I should be there doing that with my daughter." A father, Ken, recounted:

You lose all the future, all of the experiences that the other kids go through—rites of passage, graduations from this and that, the ball games, the opportunity to play ball together, the opportunity to go through Scouts, the campouts, everything that you do with all the other kids—you lose all those opportunities for that time. So that whole future, all of your expectations of what you have as a parent for a child, is lost. The opportunities that they would enjoy—all of those are gone. (#B3)

These milestones mark the present and future of a parent's relationship with a child. Their disappearance robs parents of seeing their children experience and appreciate some of the seminal events of life.

Another dimension of the child's future that was grieved by parents included the suspension of their child's growth and potential. A child's death means that the child's development and future potential will be unrealized and also unobserved by the parents in their lifetime. Nine parents commented on this specifically, expressing the sentiment that
it was difficult to see that “the developing character that you influenced is stopped.”

Parents often see part of themselves carried on through a son or daughter’s growth and future, and when the child’s future self is denied then the parent’s future is affected also.

A mother in the study, Martha, explained:

[My husband] and I have often talked about what she would be doing now. Where would she be? She had ambition and she had goals. She had a mission in life. She was on track to graduate in four years with a double major and she was an honor student. She was focused and she knew where she was going. There was never any doubt with that child where she was going. We miss that. . . . You lose the sense of what they would have become if they had lived and also what their contributions to society would have been. (#A9)

A child’s death leaves parents wondering what might have been. Indeed, many parents suggested that the children they lost seemed to be particularly unique and this heightened the parents’ difficulty with a child’s unrealized potential. These parents are challenged by the knowledge that their children will never see the passage to full maturity in this life, and therefore the parents themselves will never see part of the future they had dreamed.

A few parents did mention that distress over the child’s unfulfilled potential was not a source of concern to them, primarily because they could not know the future or the child’s future seemed uncertain to them already. Three mothers in particular noted this and suggested that they simply did not know what choices their children would have made. One mother thought her son’s future was “up for grabs,” because he had been involved in a variety of problems that ranged from drug use to dropping out of school to minor criminal offenses. These parents took a more philosophical approach to their child’s unfulfilled future and seemed more willing to accept its loss. Thus, the context of
what is happening in a child's life and the parent's views about future possibilities may either lessen or intensify a parent's anxiety about the child's unrealized potential.

**Child Death and Orientation to Parenting**

A parent's feelings and beliefs about the meaning of parenthood, the value of relationships, and the importance of parenting comprise a significant aspect of a mother or father's sense of parental identity (Okagaki & Divecha, 1993). The feelings and beliefs that a parent holds contribute to the parent's image of what a parent ought to do and how they fit that image, and affect a parent's motivation and orientation to different aspects of the parent-child relationship. One of the potential impacts of a child's death upon a parent's sense of identity is how the parent's feelings and beliefs are influenced or changed by the loss experience. Some parents report dramatic shifts in their beliefs or feelings while others indicate very little change at all following a child's death. Parents reported being affected in their perspectives on parenthood and the value of relationships, their focus on what is most important as a parent, their motivation in parenting, and their own growth as a parent.

**Feelings About the Parental Role**

One theme identified by some parents following a child's death was the impact it had on their feelings about parenthood itself and the parental role. While only four parents discussed this theme in depth, they commented on how much they had deepened in their appreciation of the parental role and its importance after the loss experience. One mother described a new appreciation for the growth that being a parent had brought to
A father, George, indicated a marked change in his feelings about losing a child and that he’d become much more accepting of life and death as a parent. He stated:

I think the thing that has changed is that I have a different perspective in terms of losing a child, and it is a more acceptable experience than before. In other words, when my little [son] was diagnosed with cancer I knew he was going to die immediately. That was a very shocking experience. If [another child] were to go it would not be the same shocking experience. I’ve already been through it... in other words, I don’t think I could be hurt again the same as I was with the first experience. I guess there’s kind of a residue of feelings and insulation against letting yourself be hurt again like that. I just think that dying is as much a part of life as being born... I think that most parents, wherever they are at, love their children just as much as I do, and some things are just beyond our control. (#B1)

The various types of changes that parents experience in their perspectives on parenthood are certainly not uniform, but each indicates a shift in how parents have viewed the experience of being a parent to a child.

**Feelings About the Value of Family Relationships**

In general, parents believe that the relationship they share with a child is important and entails responsibility and caring. But the death of a child is likely to prompt an increase in a parent’s depth of feeling for the value of any relationship with a child and the significance of their own actions as a parent. Twelve of the nineteen participants in the study, nine women and three men, expressed a dramatically deepened appreciation of their family relationships with a spouse, other children, or relatives after losing a child. In describing this they almost universally identify this aspect of change as one of the few positive experiences coming out of the child’s loss. A child’s death serves
as a powerful catalyst for parents to realize the worth and value of their family relationships. Anne, a bereaved mother, mentioned this:

I think that it’s a wake-up call as to how precious the people that you love are in your life. I think that’s one of the senses that I had—I didn’t cherish my children enough. I took them for granted, in a sense. There’s something that I read at the time of Gary’s death that meant so much to me. A man had written and said, “I know something that you don’t know unless you’ve lost a child, and that is that those children mean ten times more to you than you ever dreamt they meant.” I think that is true. When I say that I didn’t cherish my children enough, [I mean] if I had it to do it over again I would have been more focused on them and their lives. I think that I find myself, when I am involved with others such as in a close relationship with my neighbors and their children, I think I am more nurturing and deal with them in a more constructive way than I would have, a more helpful way. With my daughter and granddaughter, I think that I have a different kind of awareness. My son’s death brought my brother and I together. We weren’t estranged or anything, we just kind of led different lives and weren’t terribly close, in a sense, so that was something positive that came out of Gary’s death. That has remained to this day. (#A3)

Parents express deepened feeling for family relationships that help them to realize the value of relationships with children and grandchildren. As another mother said, “You don’t know what you have . . . you know what you have but you just don’t know how valuable it is until you don’t have it any more.”

The parents who expressed this deepened appreciation note that they take more time and attention to care for the children who remain with them after losing a child. They become more thankful for these children and recognize that they have been privileged in becoming a parent. A mother stated that she now “looks at each of my children with a greater sense of how delicate existence is and how important they are to me and how much I love each one of them.” These deepened feelings of appreciation and insight into the worth of family relationships seem to continue with the parents long after
the child's death. In referring to his feelings and interactions with his family some
sixteen years after losing a son, John stated:

I cherish them. There's nothing on this planet, not one thing on this planet, that I
cherish more than my children and my relationships [with them] and the love that
I have [for them]. . . . I think it is because it makes me more aware of it and the
appreciation . . . I could live in a mansion or a tent or a van down by the river, but
with my family it would be a palace. As long as I'm with my family it doesn't
matter where I'm at. As long as we are able to survive then I'm happy. (#B2)

Such beliefs and feelings play an important role in the image that parents have of the
work they do as mothers and fathers and how they perform that work. Parents may also
gain a different perspective on what is most important in their relationships.

**Feelings About the Focus of Family Relationships**

A child's death can prompt parents to reconsider their perspective on what is
important and take steps toward a new way of thinking or acting in their lives and
relationships. Such changes in a parent's perspective tend to lead toward shifts in a
parent's behavior also. A parent may evolve in their sense of self toward new priorities
in their parenting as a mother or father. Seven of the study participants, five women and
two men, highlighted such changes during their interviews. These parents discussed
changes in their feelings about what they felt to be important, how to relate to others, and
what should be emphasized in daily living.

Six study participants, four mothers and two fathers, shared feelings about a
change in what they perceived to be important as a parent. One primary aspect of this
was that they each felt a greater desire not not take things for granted and to avoid being
hindered by matters they consider to be trivial. They expressed this by indicating a desire
to "not sweat the small stuff," to "see trivial irritations as trivial," and to cultivate "a better appreciation" for what was important in their individual and family lives. The parents identified this as another of the few positive dimensions that they might have gained through the loss experience. A mother, Stacy, remembered:

Another thing that has changed for the good is that you learn what's important and what's not important. . . . When I was at the office some people were getting so upset because they couldn't find this or that, and I said, "Hey, that's small stuff. In the larger scope of life it doesn't matter. It really doesn't matter. Worry about something you can do something about". . . .

I was raised in the South and you do things on a big scale socially. There's a certain way you do this or that, a certain way to wear this or that . . . I could care less. Your shoes need to be dyed to match your dress . . . that is the most absurd thing. A lot of my upbringing and a lot of the social things are just absurd to me now. I don't know where all of that stuff got started. It just doesn't matter. Watching a beautiful sunset with your child or seeing your child be happy—that's what matters. It doesn't matter if you're wearing white after Labor Day. I think you have a better appreciation. (#A4)

Having experienced the ultimate loss, parents seem to develop the capacity to measure the importance of an issue quickly and then act accordingly, often feeling some matters are now of little relevance and dismissing them quickly. Parents must balance this feeling of urgency to focus on that which is most important with a degree of patience for those who don't feel this same urgency. Another mother, Carol, shared an interaction with a child that was shaped by her sense of what was and was not important:

We bought this dining room set because my daughter wanted it for her house, and so she talked me into buying it. My son barbecues like you cannot believe. He barbecued the other night and set something down in a pan holding a wonderful chicken and onion dish. We put it on the table thinking something was thick enough to protect it and so he was safe. The kids cleared dinner and I heard a panicked voice say, "Mom, do you remember when you said that you could take stains out of wood?" I said, "Yes." He said, "Come see what I've done." I said, "Oh, yeah, well let's put some stuff on it." I talked about like I am talking now,
not excited at all, and he was just anxious. I said, "Well, it's no big deal, it's just a table." They were dying about it and I said, "No, no, the important thing is you kids, not the table. I can fix the table." That's the change in us. The table is just a thing and I can go buy it tomorrow. (#A6)

The tendency of some parents to avoid trivial matters after a child's death can thus influence how they relate to others by encouraging them to focus on a person's emotional well-being rather than potential irritations.

Parents who experienced a change of perspective regarding what was important after a child's death also emphasized a decreased focus on external things and money and the importance of time together. These feelings were strengthened as a result of the child's death. Concerning his feelings about money, Ken said:

I have been less inclined to be concerned about the dollar. By that I mean that there was a point in time when I intended to make money and build a larger business, but the size of the business became less important as the need to be with and around the family increased. (#B3)

His child's death led to changed beliefs and feelings as a father about what he really needed to focus on for his children and family, such that he decreased his business expansion and spent more time with family. This demonstrates how changes in parental beliefs or feelings can affect a parent's overall orientation to parenting in different ways. Another example might be how a parent chooses to now spend time in the family. Tom, who lost a young son, noted:

My whole life has taken off in a different direction because of him and his loss. Primarily, in a nutshell, you tend to realize what's important and what's not. . . . We tended to live our lives . . . there were things we were trying to teach him to notice and appreciate, but we were too busy ourselves to listen to what we were trying to say to him. Now, instead we find ourselves doing those things because of him and the reminder he gave us that life is so short. You really need to get out
there and do those things, or that day which you wasted is now gone. So, how you spend your time has become very important to us. . . .

You tend to grab these things and try not to let every day or every week slip by without accomplishing those joys in life, rather than sitting and staring at the wood and saying we ought to do this or go there. Now we do that stuff. We make the time for that. If there’s something that seems important, we really try to weigh the relative importance of it versus trying to wring that extra drop of life out of something. We tend to go for the extra drop of life. . . .

I think that’s probably [one of] the biggest changes he’s had in our lives. We’re starting to do things, hobbies and stuff, that we always wanted to do but never really made time for before. The old things we used to do with him are too painful to do, fishing or working on the house, etc. I started to pick up tools again, but I no longer find any joy in them. I always wanted to take a watercolor [painting] class, and so I did. I loved it. [My wife] is finally getting into a quilt she’s always wanted to do. So we’re starting to . . . he still has that much influence in our lives, in that he’s still directing what things we do and how we do them to the point that we make decisions based upon, “Well, we’ve lost Andy, and we don’t want to lose the opportunity again to do these things.” Who’s to say that I couldn’t be going to work tomorrow and get in an accident that leaves me a paraplegic? Do I want to say, “Hey, I made it to work every day that week,” or “That was really cool going to the beach that one last time.” I’ve started to think a lot along those lines. (#B6)

A child’s death can be a powerful influence in re-shaping a parent’s orientation regarding what is most important and how one enacts that in the family. Parents are forced to re-examine their lives and priorities when a child dies and may find themselves changing.

Another aspect of a parent’s focus in the family that may be affected by a child’s death is the rhythm of daily living. The father quoted above includes the thought that as parents they now try “to wring that extra drop of life out of something,” and this reflects yet another theme from the study—a focus on living in the present moment. Several of the parents mentioned a transition in their feelings and attitude toward living in and savoring each moment and experience rather than rushing along through life. This pattern
connects with the tendency to focus on what is perceived to be most important and to value time and relationships in the family to a higher degree. One mother simply said the effects of the experience now made her “stay in the moment and savor the moment.”

Another mother, Anne, recalled:

One thing that happened immediately was that I stopped living in the future. I only live my life essentially day by day, whereas it [had been] always that my thoughts were more toward what was going to be happening tomorrow. That was quite a radical change. . . . I still pretty much focus on the here and now, which is a good thing. That probably ties in with appreciating what you have, valuing what you have. (#A3)

These aspects of parental orientation toward life and family experience reflect some of the changes that a child’s death may initiate in a parent’s thoughts and feelings, and also represent one of the few areas that mothers and fathers identify as contributing positive aspects after such a loss.

**Feelings About Motivation to Be A Good Parent**

One portion of a parent’s orientation to the parenting experience is shaped by the feelings and beliefs they have about what it means to be a good parent. Having been challenged in their own efforts to successfully rear and care for a child, bereaved parents often feel even more strongly about the need to parent well after a child’s passing. Existing feelings and beliefs may be intensified or they may discover new patterns of thinking and acting in their parental role. The child’s death may impact their parental commitment, their desire to assist other children, or their willingness to take action on a child’s behalf.
When a child dies it may not change a parent’s feelings or beliefs about commitment to a child’s welfare, but such feelings or beliefs might be intensified and magnified as a result of the experience. Five of the study participants (three women, two men) talked about this theme in their interviews and how losing a child affected their parental feelings about being committed to a child. They indicated that their feelings had already been strong and that the particular priority they placed on caring for children as a parent was already firm. So, losing a child did not change their feelings so much as it reinforced strongly for them an already existing belief that a high commitment to children and family life is important. One of the fathers, George, explained:

I don’t know that it really changed me. I think, you know, my family was everything in my life, and my goal has always been to raise children with a good example, to provide them a home and food and the things that they need, so I can’t really say that it changed anything... My whole motivation in life was to have a family and enjoy their company. That’s it. So that hasn’t changed before or after I lost [my son]. It’s still the same. (#B1)

This subtle pattern is interesting because it suggests that parents who already carry a strong belief about parenting well may not be impacted so strenuously in their beliefs about parenting when a child dies. Instead they find their motivation to be a good parent strengthened by the assault coming from a child’s death.

Some parents who have lost children find themselves feeling a stronger desire to be aware of and assist their remaining or other children. Four of the study participants cited this as a factor that was affected by a child’s death. These parents expressed a strong desire to be aware of their or other children’s emotions and experiences to be able to assist them if needed as a parent. For example, one woman talked of feeling more
“anxious to share in the joys and sorrows of my children’s lives” so that she might give them better parental support. This increase in the intensity of a parent’s feelings about being aware of or ready to assist children may help to re-shape a mother or father’s orientation to parenting. One mother considered her parenting orientation after losing a son and said, “I’m a lot more serious about parenting and that responsibility than I used to be.” She had seen parenting as more of an exercise in providing for someone’s physical needs rather than supplying emotional support and caring, and now expressed a new focus in caring for and assisting her children and grandchildren after having a child die.

Loss of a child also affected some parents regarding their parental expectations and acceptance of children. Four mothers and a father mentioned their feelings about being accepting of children as they were had deepened, and that they believed much less strongly now in putting pressure on children for external achievement. This had an immediate impact on the way they interacted with their remaining children. One mother noted that she did not “put as much pressure” on her child in certain ways and her desire was just for the child to “be happy on the inside and make a contribution to society.” They indicated changing their reactions to children by imposing less of their own desires and being more responsive to the child’s feelings or activities. A father, Tom, talked of how his child’s death affected interactions with a young son in this way:

I find myself almost every day re-evaluating what’s important and what’s not. I had to go into town to make a payment to the insurance company for the cars and had some other errands to do. I was supposed to go to the grocery store, the post office, etc. On the way Jimmy wanted to go to Peavy Arboretum. It was such a nice day and he said, “I want to throw rocks in the water.” I started telling him that we had to do this and that, but I was thinking, “You know, that payment’s not due until next week, I can go to the post office later, we can eat what we’ve got in
the cupboard for tonight, etc. Let's go throw rocks, because he's not going to be that young any more.” So we did that. We went and threw rocks. I came home and at first [my wife] had a minor fit, and I said, “Hey, look,” and I explained it to her like I told it to you. She said, “You’re right.” So I find myself being more impulsive and doing things when he asks me to do them. I find myself more willing to follow his lead in what he wants to do. Sometimes I’m very tired and the energy isn’t there and I don’t want to play, but if it is there I find myself very willing and able to give over to [his desires]. (#B6)

His account exemplifies how some parents shift in their feelings and beliefs away from a focus on external activities or achievements toward an emphasis on family time together or family unity. The parents' views about being more accepting of children and time with them link with other new or deepened feelings and beliefs.

What a parent thinks and feels about being a good parent can also be shaped by a child’s loss when the parent makes choices related to their children. Four of the parents, three mothers and a father, discussed their tendency to now be much more conscious of their choices and how their decisions as a parent might affect their children. These parents tend to become more careful in the decisions they make and more deliberative about how those decisions will impact their remaining children. A father mentioned that “as a parent now, I find myself thinking more critically about what is the right thing to do for [my child] by helping to grow, develop and understand.” This critical appraisal of one’s decisions shapes the parent’s orientation by helping them to focus on the child’s best interests. A mother in the study, Stacy, shared her feelings about buying a home and how it affected her daughter:

I really try to make her feel now that . . . we bought this house after [my son]’s accident. She’s lost a lot. She lost her house, she lost her dad, she lost her brother. She’s lost a lot in less than twenty-one years. In a lot of ways that does concern me quite a bit. I try to make her feel that this isn’t just my place.
Sometimes she’ll say, “Mom, it’s your house” and I’ll say, “No, it’s our house.” Before I would just go ahead and do things the way that I wanted to do it, but now I don’t do that. I try to include her in all the decisions so that it’s reinforced that we are together. (#A4)

Notice that the mother in this account is very careful to make decisions so that her daughter will know that they are together in the family decision-making process. This indicates how her feelings about being sensitive to a child’s needs and making appropriate decisions has been magnified due to losing another child. Taking such care in making decisions may help parents to maintain or strengthen a positive sense of self in the aftermath of a child’s death.

A final area that parents suggested can be impacted due to a child’s death is what parents feel about taking conscious action on behalf of children’s welfare as a parent. Five parents, including two mothers and three fathers, described an increased tendency to focus on a child’s well-being and take conscious action to help any child. In other words, they felt that they now would and did take action in some situations as a parent whereas they would not have done so prior to losing a child. These situations tended to revolve around taking responsibility as a parent and protecting children from neglect or abuse.

This tendency may be linked to the struggle a parent undergoes when a child dies in not being able to fully protect or be responsible for the child, and therefore the tendency to focus on this in critical situations might be magnified after a child’s death. Carol recounted:

I’m probably going to get thrown in jail one of these times, or at least arrested, because I have no patience and no tolerance to see someone abusing a child verbally, physically, or any other way. I have been known, and fortunately I live in a very small town, to remove that child from a parent’s arms and say, “When
you get your act together, we’ll be in the banana section.” I go to the banana section or the grape section and we help ourselves to the fruit, and I pay for it later. I may have a child whose eyes are so big they’re going to fall out of their head, but I’m telling them they’re safe and the child calms down. . . . I would have not done that before. I might have offered the parent some help with the child in the store, but to actually physically remove the child and then lecture the parent . . . no, I wouldn’t have done that before. (#A6)

This mother’s feelings about taking action on a child’s behalf have obviously intensified following her child’s death, even leading her to act on behalf of another person’s children to try and help them. Part of the reason for this shift in parenting orientation may be that as a parent in this situation she can exercise some control and make a difference, whereas most parents feel stripped of that ability when a child is dying or has died.

This pattern seemed quite strong for fathers in the study. The change in their feelings about taking action on a child’s behalf was reflected in their behavior, ranging from resolving concerns with a child when conflict occurs to always attending a child’s school events. Tom, a father, described how the shift in his feelings was seen in his behavior:

I find, when I see someone with their kids and riding their bicycles on the edge of the road . . . I see people all the time and they are kind of getting irritated with their kids, [saying things like] ‘Keep pedalling’ or ‘Just keep on moving.’ Cars are passing less than three feet from them going about thirty-five miles per hour. More than once I’ve stopped and said, ‘Hey, if you’ve got a minute, let me tell you a sad story.’ I tell them about [my son] getting hit and killed, and I say that I’d appreciate it if they’d think hard about that because I don’t want to see them go through that and have it happen to their child. As often as not they’ll tear up and they have the kid get off and they’ll walk the bike for them and hold their hand and say that they appreciate it. A couple of times I had people tell me to mind my own business and stuff. . . . I guess it’s part of that protectionism coming out. You tend to want to be very protective, even if [the child] is not your own, though you tend to be very protective of your own too. (#B6)
Whether being protective or resolving a question, parents may become more active in consciously acting on behalf of a child’s welfare, and in this way the orientation of a mother or father to the parenting experience may be modified or changed.

Feelings About Parental Growth and Sensitivity to Others

The experience of losing a child generally lands like a bombshell in the life of a mother or father, leaving chaos and ruin behind for the parent. But while it is normally a devastating event for parents, a child’s death may also prompt significant change in a parent’s individual development and relationships with others. Parents in this study indicated some important themes related to how they had grown as individuals following a child’s death and how it had changed their interactions with others.

A parent is launched on a new and painful journey in life when he or she loses a child, and this journey may lead to unexpected and significant patterns of individual growth. Six parents in the study talked about learning a variety of important lessons through the experience of losing a child. They noted that these lessons had resulted in much personal growth that had changed who they were as individuals and also as mothers and fathers. The lessons learned and shared by these parents were often profound and tended to be unique to the growth experience of each person. One woman, Laura, who had lost a child to illness and was now dealing with health problems herself, stated:

I do want to say that along with [my son]’s faith he was always such a cheerful child at home. It was something I missed terribly, but it also helps me now when I’m not well myself as an inspiration to be cheerful and optimistic. If he went through what he did with the attitude that he had, he was an inspiration for a lot of other people, but especially for me. . . . You need the inspiration of someone else to fall back on as you tend to do when you’re my age. You tend to look back a
little more and you get strength from that. I have Parkinson's but I also just had a pacemaker put in, and I have a breathing problem, so all of that tends to or it could depress me if I let it. But I'm not going to do that. I'm going to be as cheerful with the Lord's help as I can. . . . After being strong it's not easy, but you can't sit and feel sorry for yourself. John never knew that his example was going to continue on for that many years. (#A8)

This mother describes how she has learned critical lessons in facing adversity and remaining positive due to her experience with child loss and her child's own example, and that her personal growth through life has been significant because of that experience. It often takes time for parents to sense this kind of change and growth following a child's death. A mother commented, "I feel, if anything, it's helped me as a parent . . . it took a long time to see the benefits, but they're there--they're tangible." Another father commented on how his life had changed dramatically as a result of losing his child, and spent much of his interview describing the growth he had experienced following the child's death and the lessons he had learned in that process. These journeys of parental growth arise from enormously difficult circumstances but contribute to the manner in which a parent reconstructs a sense of identity in the months and years after a child dies.

A related aspect of change that parents experience may be in their sensitivity to and interaction with others following a child's loss. Nearly every participant in the study (seventeen of nineteen parents) noted a heightened sensitivity to and compassion for others after losing a child. This was expressed in a variety of ways and some of these will be examined in the next chapter, but primarily this involved increased feeling for others in general and for those who had lost a child specifically. In some cases, the
parents not only felt a greater sensitivity but also took specific action to reach out to others who had undergone a child’s loss.

Six parents (two women and four men) expressed a higher level of sensitivity to others in general following the loss. It should be noted that due to the open-ended nature of the study interviews, parents who felt similarly but did not express it in the interview context may have also been part of the study group. These parents indicated a changed sense of awareness toward the troubles and concerns of others, and this was particularly noted by fathers in the study. One father summarized simply, “I think I care more about people, no matter who they are or what color they are or what religion they are.” These parents expressed a greater empathy for others who are hurting in a general way and often took action to be of comfort or help. Such actions included listening, taking care of material needs, or providing emotional comfort. Another father, Michael, shared how he felt he had been changed in this way:

My emotions are closer to the surface than they were before [my child] died. I would be willing to cry with my kids before, but my emotions are closer to the surface now. It’s like my emotional quotient got raised or unleashed or opened in some way as a result of this experience, and I sense it as a permanent change. So, I am more empathetic and willing to listen. (#B4)

Such increased empathy and awareness of the challenges of others tends to occur for parents at a time when they are also emotionally vulnerable because of the bereavement process. While some parents find attention to others’ needs helpful at such a time, for others it may be too difficult for them. However, those parents who describe this sense of increased compassion for others suggest that for them it is a permanent change in who they are as a person and a parent.
For those parents who lose a child, the sense of affinity with others who have passed through the same experience can be very strong. Most parents in the study shared stories of how they felt a strong emotional tie to others who had lost children and some of them reached out in various ways to help others in that situation. Ten women and four men in the study described feeling more sensitivity for others who had lost a family member or loved one after their own loss. One mother, Pam, recalled:

I think because [my child] was sick and had a brain tumor, that any time I’ve heard of another child with a brain tumor there’s a special feeling that I have. . . . I guess that for other children if I learn they have cancer, and especially brain cancer, that really perks my attention. (#A5)

This added sensitivity to others who have experienced a family member’s death is linked closely with the wide variety of organizations and support groups that minister to the needs of bereaved individuals who have lost those they care for, whether by homicide, suicide, accident or illness. Parents who have lost a child gain this added sensitivity to others because they know that seeing a child die means a parent will join the unwilling fraternity of mothers and fathers who have faced this most shattering loss. Any mother or father who loses a son or daughter goes through a transition in their parental identity that becomes permanent, moving from “mother” or “father” to “mother or father of a child who died.” It does not seem unique that these parents gain an increased measure of understanding for others who have passed this portal of pain.

**Summary**

Each man or woman who becomes a parent enters a process that invests them with a new identity that will change and develop as they rear and raise their children. This
parental identity as a mother or father is influenced by such components as a parent’s sense of himself or herself, the nature of the parent-child bond, the parent’s assessment of adequacy in filling the functions of parenthood, the parent’s investment of self in the future with a child, and the parent’s philosophy of and orientation to being a parent. All of these aspects of parental identity are affected by the death of a child in the family. Parents who lose a child experience a wide spectrum of emotional reactions and psychological responses, but some consistent patterns and themes can be found through a careful study of this process. These patterns indicate both the common ground and the uniqueness of each bereaved parent’s walk through the expanse of grief that follows upon the loss of a precious child.
CHAPTER VII

PARENTAL BEHAVIOR AND THE DECEASED CHILD

While a child’s death often strips parents of some of the direct functions of parenting (protection, etc.) and attacks their sense of parental identity, most bereaved parents still consider themselves to be the parent of the deceased child and carry a deep interest in the child’s existence after death. The more traditional approaches to helping persons struggling with grief tend to focus on an individual’s need to abandon their attachments to the lost person or experience and “move on.” Those who do not or cannot overcome these strong attachments may be diagnosed as suffering from “delayed grief” or “pathological mourning.” As one therapist has noted, the therapeutic interventions for a person experiencing grief due to a loved one’s loss tend to emphasize “efforts at encouraging the forfeiture of this relationship” (White, 1988, p. 29). White (1988) writes that such persons are told that the resolution of their grief “will be evidenced by a fully experienced ‘goodbye,’ acceptance of the permanence of the loss of the loved one, and a desire to get on with a new life that is disconnected from that person” (p. 29). However, for parents whose relationship with a loved child has come to permeate a great portion of their self-identity and life experience, such abandonment may seem to mean an even greater loss of self and of one’s past. A primary goal of this study was to investigate the parental behavior of mothers and fathers after losing a child in relation to the deceased child himself or herself. Do parents truly abandon and disconnect from the relationship? Or do they still consciously act as a parent but in a different way?
The results from the study indicated a varied pattern of behaviors in which parents express interest and concern related to the deceased child rather than just moving beyond the relationship. Key themes that study participants focused on and that were identified in the study analysis included: (1) the fear of forgetting the child; (2) the parental activity related to the child immediately following death; (3) the parent's sense of connection to the child; (4) the parent's effort to remember or memorialize the child; and (5) the parent's extension of care or nurturance related to the child.

Parental Fear of Forgetting a Deceased Child

Perhaps the most intense fear that parents experience after a child's death is the concern that the child will be forgotten by the parent or by other family members and society in general. Parents who have experienced a strong and caring connection to a child dread the thought that the memory and meaning of that relationship might dissipate or vanish from their minds. Approximately half of the study participants, nine women and one man, expressed a fear that the lost child would be forgotten by them or by others in the months and years following the loss. This shows a difference between mothers and fathers in the concern expressed by parents about the child being forgotten, which may be related to the primary role that mothers usually occupy in the family as the “kin-keeper” and the harbor of family memory (Thompson & Walker, 1991). This fear of forgetting the child may be part of the motivation for some of the behaviors that parents engage in related to a deceased child following a loss. These parents expressed concern that loss of
their grief might mean forgetting the child, that other family members might forget the child, and that they needed to take conscious steps to remember the lost child.

Some parents identify the grief that they feel for a child’s loss with the emotional connection to a child, and if the emotions of grief begin to subside then they fear that this means they are forgetting the child. Such concerns can stir guilt and remorse in the parent. Two mothers in the study indicated their concern at losing the child’s memory if they lost that sense of grief. One of these mothers, Anne, noted:

[There is] the business of staying connected, that is, as long as I remember. One of the greatest fears is that we’ll forget, especially when we’re starting to heal and the pain isn’t as great. You find yourself laughing sometimes and then you think, “Good grief, what am I laughing about? My son is dead.” You take it away from yourself and you feel guilty. (#A4)

She suggests that the “business of staying connected” requires remembrance, and the emotional pain serves as a measure of that remembrance by the parent. To forget the pain, to laugh, is to potentially disconnect from the reality of the child’s loss. These mothers suggest that they remember the child through the pain. It is interesting to note that this mother suggested that part of the aftermath of the child’s loss involves the “business of staying connected” to the child, as opposed to disconnecting oneself from the child. Yet if the child’s memory is embodied by the grief a parent feels, then this may make it more difficult to process the emotional challenges associated with the child’s loss. Another mother stated that she was “afraid to let go of the grief, because I feel that if I let go of the grief . . . then I have to let go of him, and I don’t want to let go.” This challenge of “not letting go” and thus not forgetting the child serves as a strong motivation for parents to act in ways that link them to the deceased child.
Not only do parents worry about themselves forgetting the lost child, but they may also feel concern that other family members or persons will forget the child. How parents act to help other children remember the deceased child is explored in the next chapter, but it should be noted here that the fear of forgetting the deceased child extends to the worry that others also may forget. This reflects the parent’s interest in continuing to include the deceased child in the family circle. As one parent in the study, Stacy, reflected:

I think of my daughter and hopefully she’ll get married one day and hopefully have children. I’m so afraid that they won’t have the privilege of knowing Jeff. Jeff would have been a wonderful uncle. He would have been a great dad. He would have just put everything into it. I’m just so sorry with all my heart that we will not have that, and I live in fear . . . sometimes when I’ll talk to Kim I will say, “Now, when you have children are you going to tell them about Jeff? Are you sure they’re going to know about Jeff?” (#A4)

This fear that other children or family members might not remember or include the deceased child in the family’s future illustrates how parents continue to identify the child within the family’s identity. It may also prompt parents to take steps to ensure the child will be remembered in appropriate ways.

The most prominent indicator of the role that fear of forgetting a deceased child plays as a motivation for parental behavior was highlighted in parents’ comments about consciously taking steps to remember or connect with their lost children. Eight parents in the study, seven mothers and a father, specifically mentioned this fear as a motivating factor in their efforts to maintain a connection or memory with a deceased child. While such parental activities ranged from talking about the child to putting up pictures of the child to creating memorials to the child, the primary factor these parents emphasized as a
reason for their behavior was the fear they carried about themselves or others forgetting the child. One mother suggested that “probably the hardest thing for a parent is when other people don’t recognize that they existed.” Another mother, Carol, remarked:

I think as a parent your biggest fear is that somehow your child is going to be forgotten, and you can’t bear that thought. I am not a picture person who has family photos up and stuff. I just don’t do that. And yet, after Lisa was killed I looked around and there’s photos everywhere. I don’t remember having them up or putting them up like that. I know they were there, but I just was not consciously aware of them. So, I think you do it because you don’t want that child forgotten. That’s your way of keeping connected with them, especially if you don’t have other children at home who are going to be asking you questions so that you can talk about that person. (#A6)

As she states in her comments, for parents it is almost unbearable to think that the child they loved and cared for so much may not be remembered by themselves or others. So, parents do different things to help them “keep connected with [the child],” many of which are outlined further in this chapter. Martha noted ways in which her daughter was remembered by others and said:

It really touched me as a parent to know that she meant so much to so many people . . . I feel that it’s a way of perpetuating her memory so that people will not forget her, and so it’s really important for me that this continue because I don’t want Jessica to ever be forgotten. That’s a big fear. (#A9)

For bereaved parents, the possibility of forgetting the child who died seems to be an additional burden of concern that can be assisted as they and others take steps to make sure the child’s memory is somehow continued.

**Parental Activity Following a Child’s Death**

A child’s death takes away the context of parent-child interaction and thus deprives parents of many parental functions such as listening to a child’s concerns or
helping a child with homework. But immediately following a child’s death the parent must still bear major responsibility for handling of affairs related to memorial arrangements, the child’s possessions, etc. Although this study did not pursue in-depth analysis of this specific aspect of a parent’s experience during a child’s loss, it is important to acknowledge this pattern for many parents. The analysis for this dimension of parental behavior following a child’s death was limited to determining primary themes that related to parental activity immediately after a child dies. There appears to be quite intense and ongoing responsibility for parents in the first days and weeks after a child’s loss, which then diminishes as a result of the child’s absence and the conclusion of necessary affairs related to the death. This parental activity related to the deceased child tends to focus on management of the child’s remains and management of the child’s memorial services and affairs.

Probably the first and most immediate decision that a parent must make in behalf of a deceased child is how to manage care of the child’s bodily remains. This includes both making sure the child’s body is appropriately taken care of and arranging for the child’s burial or other means of interment. Seven of the study participants, five mothers and two fathers, recounted events from their loss experience that related to this theme. Parents may sometimes be involved with preparation of the child’s body for viewing purposes, decisions about how the child’s remains will be handled, or choices related to where the child’s remains will be located. While it is not easy for parents to face these decisions that involve saying good-bye to a child’s physical reality, at the same time there
are parents who find involvement in this process comforting (particularly if they have lost a child suddenly). Carol, whose daughter died in a traffic incident, related such feelings:

I’ve been around dead people for a long time, and I kind of knew what I was walking into even though it was my own child. I have a place in my mind where I can do what has to be done without allowing emotions to take over . . . [I] went down there and discovered that it might have been my child, but it was not my child. It did not look like her and wasn’t her hairstyle or anything. So I shocked the mortuary by taking her makeup off and putting new makeup on and recombining her hair, and literally undressing her to look and see. . . . It was a way of being able to sit and talk with her and tell her good-by. . . . To be able to touch her and make her look like she should have looked. (#A6)

This mother indicates a powerful maternal sense that overrides the emotional difficulty she feels because of her child’s loss and allows her to continue as her daughter’s caring, attentive caregiver. For her, the “good-by” experience of physically caring for her daughter’s physical self provides an opportunity to continue “mothering” and engaging in parental functions, while also giving her a last chance to share an emotional tie with the deceased child. The decisions that a parent must make in this context can be made difficult by the parent’s emotions or the attitudes of others. One mother said what she remembered most about her child’s burial was “hearing them drop that thing over the vault— I always hear that.” The interment of the child’s bodily remains seems to symbolize a transitional cut-off point in the immediate period after a child’s death which can be difficult. Another mother, Peggy, mentioned what it was like when her daughter was cremated:

At some point somebody said the first decision was whether we would have her cremated or buried in a casket. [My husband] felt very strongly about having her cremated and so I just said okay. Cremation doesn’t bother me, but I didn’t have any strong feelings one way or the other. . . . [The funeral director] asked if we wanted to see her before she was cremated, and we didn’t. He told us the time
that she would be cremated and that any time up until then we could come in and see her. I wish we’d have done that. So, I would watch the clock and think, “Now she’s being cremated.” That bothered me. (#A7)

Her account reveals the sense a parent has that their opportunity to actively care for the child has truly been ended at this point. This can be a very sensitive time for parents, as are the weeks and months that follow as parents ride an emotional roller-coaster of grief. Although the decisions related to the child’s interment allow a parent to continue some parental activity immediately following the child’s death, the substance of the activity for parents is all too painful and often what a parent never expected—to say good-bye to a child.

A second broad theme identified by study participants regarding parental activity related to the deceased child immediately after death was the management of the child’s memorial services or other affairs. For example, parents must usually assist in planning a memorial service, take charge of a child’s possessions or personal affairs (financial issues, etc.), or plan other remembrances related to the child. Nine parents in the study, seven women and two men, discussed such parental activity following a child’s death. Their personal responses to this experience of being responsible as a mother or father for planning a child’s memorial service or writing a child’s obituary ranged from emotionally fulfilling to intensely draining. Generally, however, the parents in the study indicated that being able to have an involved role in such efforts was positive and meaningful. In their accounts they tended to focus on the meaning of creating a personalized atmosphere that really affirmed the deceased child’s personality and life. Jean recalled:
It was really important to me to have beautiful music, because this son was somewhat musical and loved music. It was really important, and I remember that I had called an old choir director of his and asked if some of the kids from the choir at the high school could come and sing a couple of his favorite songs. This man called friends, old friends that sang with this son, even though he was many years out of high school. He also called other kids who had sung with my other children in choirs, so that there was a large group of young people to sing. They were up in the choir loft and there were so many of them, and it was so wonderful to me. Instead of resenting that they were alive and my son was dead, they looked so beautiful to me, these young people. They looked so vibrant and so alive, and I enjoyed their singing so much. (#A2)

This mother’s experience was an uplifting memory of her child and what he had valued in life, and the personal nature of the music and those who sang it carried a deep meaning for her. It may be that parents who are able to feel this atmosphere and assist in its creation have a better experience emotionally at this time. While others may try to protect parents at such a time because of their emotional vulnerability, such parental activity can allow them to feel some sense of positive involvement at a difficult time.

It is a shock for parents any time when a child dies and others may wish to protect bereaved parents. The mothers and fathers in this study generally desired to be involved in such parental activity even though it was hard. As one mother said, “One of your senses is that this is your baby that you’re burying, and you have to try to do the best for them that you can.” Arranging services so that the child himself or herself would be approving was a motivation that some parents mentioned. Tom remembered his feelings right after his son died:

I remember being able to concentrate and focus on him still, making arrangements for his funeral, etc. So I guess in a very strange sense, and I’ve thought about this before, that immediately after he died the parenting part [of the relationship] is still there. You’re still focused and thinking about your child and what you need to do with them. Anything outside of that I could not think about or do. 

couldn’t even spell my name. But I could calmly discuss funeral arrangements, the type of casket, etc. . . . I remember looking back and thinking how strange it was that, as broken up and unable to deal with things as I was, I still was able to sit there and objectively sit back and focus on this and this and this. What do you want to eat? What about the flowers and stuff? What about the songs? . . . I guess to me it’s kind of a sign of just how important he was, that above all else he was so important to me that I could still take care of him, even in immediate death. He had such a huge impact on me that I could still do that. As for myself, or taking care of myself, that was of less importance than me taking care of him. He still had such power over me that I could still, even through all the haze of grief and anguish and loss, sit back and think about what I needed to do to take care of him. (#B6)

This father’s account captures the sentiment of nearly all the parents who commented on these specific aspects of parental activity following the child’s death. Parents tended to see taking care of these details as a last opportunity to give loving and sensitive care to their child, and to make sure that what took place would be pleasing to the child. These dimensions of parental activity that immediately follow a child’s death can thus be challenging, but they also allow parents to feel an emotional connection and to actively provide care in a final good-bye.

**Parental Behavior to Connect with a Deceased Child**

It has been suggested earlier in this study and by other research on the experience of a child’s death that losing the tangible connection and emotional bond with a child is one of the most difficult aspects of a parent’s trauma (Parkes, 1986; Weiss, 1988). Bereaved parents undergo intense emotional anxiety and grief when the parent-child bond is sundered. Although some therapeutic models of bereavement encourage parents to disconnect from this strong emotional attachment to a deceased child, it may be that parents who incorporate this attachment into their lives in a new and different way deal
with the grief process more effectively (White, 1988). One important theme that parents discussed extensively in their interviews was how they attempt to maintain an emotional connection to their deceased children following a child's death. Study participants shared a wide variety of behavioral strategies which they utilize in fostering a sense of emotional connection to a child who has passed on.

Connection Through Talking about the Child

As indicated earlier in this chapter, parents carry a fear that themselves or others might forget a child who has died. One way in which they attempt to allay this fear is to talk about the lost child with others. This allows parents to remember the child and to encourage others to remember also, while giving them an emotional tie to the child’s life and memory. Parents indicated that fostering a sense of connection to the deceased child by talking about him or her was occasionally difficult, but that they normally enjoyed sharing meaningful stories and talking about the child with others in the family.

Talking about a deceased child with others can be made more difficult by one’s own feelings or by the reaction of others. Occasionally, parents will avoid talking about a child who has died due to these feelings or responses. Several parents in the study shared experiences in which talking about the lost child was hampered because of these factors. Parents were much more reluctant to talk about the lost child with others when it involved discussion of how the child died rather than the child’s activities or life experiences. A mother in the study commented, “It seems like you don’t want them
forgotten, and so you just want to talk about her, and yet sometimes it's painful to talk about her at the same time.” Parents are caught between wishing to talk about the child they have cared for and not wanting to feel the emotional pain that memories of the child can provoke. Also, parents may feel it is difficult to talk about a deceased child because others avoid them and the topic due to not knowing what to say or how to express themselves. One mother, Dora, remembered this experience:

I wanted so much to talk to people and I found that people were afraid to talk to me about [my daughter]. They seemed to avoid it. I wanted to talk about her. I would have liked it if they could have said a few things to me about [her], and then just sat and listened to some of the things that I wanted to say. (#A11)

A parent’s desire to connect with a child’s memory encourages them to talk about the child with others, but experiences like this can be frustrating to bereaved parents. Parents may be caught between what they want to do and what others allow them to do.

One of the most rewarding aspects of talking about children who have passed on for bereaved parents is that they are able to share meaningful stories about the child’s life and memory with others. The actual interviews for this study often included extensive “before” and “after” listening sessions that were simply focused on hearing the parent tell story after story about the child they had lost. Seventeen of the nineteen parents in the study, all but one woman and one man, shared a variety of entertaining and touching stories about their deceased children and also discussed the value of such conversation. They indicated that this is one of the most positive and meaningful ways to foster a sense of connection with a deceased child. One mother, Jean, recalled such an experience:

One of the most gracious and thoughtful things that somebody can do is something that [my son’s friend] did. He just sat down by me one time and said,
“Let’s tell ‘David stories.’” It was so fun. We’d tell each other anecdotes and we’d kind of try to top each other. We’d tell stories about what a prodigious eater he was, or funny stories about how his mind could concentrate on fourteen things at once. I know my kids have the best intentions in the world, but they don’t talk about him very much. I would just give anything for somebody to just sit down and say, “Let’s talk about David.” I have had some wonderful friends who were willing to listen to me tell them “David stories,” and they gave me a lot of their time and their listening hearts. It helped me a lot. (#A2)

The telling of such stories about children allows parents to emotionally link with the child’s memory, and also capture and preserve the essence of the child in a vivid and tangible way. Such stories seem to serve a larger purpose of symbolizing the child’s meaning in the life of the parent and they can be used to illustrate that meaning to others.

The manner in which stories of a deceased child serve as powerful symbols is tied to the larger meaning they express to parents. As an example of this, one of many stories that the parents told is included here. Jean shared this story:

Once we’d gone on vacation and came back and instead of having toilet paper all over the big silver maple tree in front of our house, which is huge, there were colored ribbons all over it. It just charmed our family. We couldn’t imagine who’d done it. We [inquired] all over the neighborhood and the church congregation to find out who’d done it, and we couldn’t. We didn’t find out for about a year. It was a family who had kids the age of our kids. They’d been in our home a lot. It was [a young man in that family]. When this young man had gone on a mission [for his church], I don’t know why, he’d asked his mother and his sisters to put some ribbons in that tree, not on all of their family’s important occasions but on all of our family’s important occasions, of joy or sorrow. We only found this out about a year after the fact.

The morning of my son’s funeral I got up and I just thought, “Oh, Lord, how will I ever do this day?” And I opened the curtains and looked out at that huge silver maple tree, and it was covered with silver and white ribbons. I felt a surge of absolute joy and confidence, then I felt, “I can do this.” It was just an overwhelming visible symbol of somebody’s love, support, and concern in a celebration of David’s life. It was so beautiful and it made me feel so good—I just love to tell this story. (#A2)
Just as the experience she recounts serves as an “overwhelming visible symbol” to her, so do this and other stories act as symbols of a child’s life for parents. To recall the story is to recall the child. This allows parents to make an emotional connection that allows them to remember loving and positive interactions with the child instead of the child’s death.

Another important way that parents foster a sense of connection to a lost child is by talking about them with others who know or care about the child, such as other family members or close friends. Parents in particular often make a point of discussing the lost child with other children in the family. Eight parents in the study, five mothers and three fathers, indicated that talking about the lost child and sharing memories of that child with other children was an important form of personal connection. In this way, parents are able to alleviate the fear that other family members will not remember the child. They are also able to continue the child’s presence in the family identity through such discussion, such that the deceased child is woven into the fabric of the family portrait as if they were still alive. One mother, Ellen, mentioned doing this:

As far as just staying connected with Rebecca . . . I talk about her as part of the family just like she is still part of the family. . . . When they’d draw pictures, they would always draw a picture of her. In school when they’d have to draw their family and write the names, they’d draw her, even the younger ones that don’t remember. In fact, very few of them remember Rebecca. Just her sister that was so close to her and then the next one. . . . [Her sister] remembers events, and that’s what most of the kids remember. We have a ton of pictures and so as they look through those pictures we talk about what happened and what she was like. That brings up a lot of discussion. I don’t have this strong fear any more that she’s going to be forgotten, because she becomes a part of our discussion many times. . . But we just talk about her a lot. It doesn’t feel like you have to do anything extraordinary because she’s part of what we are now. (#A1)
As this mother notes, the objective of such discussion about the deceased child in the family is to help the deceased child to become “part of what we are” as a family. This emphasis on including the child in the family’s identity may help parents feel that they haven’t simply ignored the child’s memory following the death. A father, John, whose first child died shares with his children:

   We share with them about Alex. We let them know that they have a brother and that he died before they were born. We share pictures and we keep that memory in our house all the time. It’s our way of healing. Every day I talk about him . . . [They talk about] how he would be, that he would be graduating, etc. (#B2)

Although the other children in this family never even met their oldest sibling, yet they know of him and talk about him because of the parents’ effort to keep his memory in the family circle. Talking about the deceased child with other family members allows parents to reinforce their sense of connection to the child and provide a continuing place for the child within the family.

**Connection Through Talking to the Child**

In addition to talking about their lost children, some parents in the study indicated that they also talk to their deceased children mentally as if they were still present. Although only a few parents described this activity, for those who practiced it there seemed to be a strong sense of comfort and connection associated with it. This practice was always done by parents who had a sense of the child’s continuing existence in another sphere. The parents described talking to the child directly to invite the child’s attention to something and also talking to the child mentally to make a connection.
When asked how they talked to a deceased child and if they imagined the child’s responses, the parents who described this behavior said that it was a mental one-way conversation by them toward the child that included a feeling of emotional connection. Two parents mentioned talking to their deceased children mentally and inviting their attention to certain things. This seemed to focus on mentally drawing a lost child’s attention to a situation that would be of interest to them, such as an activity the child had enjoyed or a family event (a birth, etc.). Such an invitation presupposes the parent’s belief that the lost child can be aware of or is interested in such things. Another situation in which parents invited the deceased child’s attention through mentally talking to them was in times of crisis or concern. Anne, a mother who felt strongly about this, said:

One of the things that I do and that I encourage others in a [support] group to do is that if something is happening, ask your child to help you and tell them what you need. See if you can pull in some extra power there in any situation. When my daughter has had some physical problems, such as before she went in to have her baby, I said, “Tell Gary to do such-and-such” and I was telling him too. Now, that’s a head trip but it still is something that makes you feel a little more powerful in a powerless situation. It is comforting. I can’t sit here and say it isn’t true. (#A3)

By inviting a deceased child’s attention, a parent can hope that the child will be watching them or that the child might lend some type of other-worldly assistance in time of need. These possibilities also allow a parent to feel connected to the child through a personal mental communication.

Parents also talk to a deceased child mentally just to make an emotional connection and feel closer to the child. Five parents in the study, four mothers and a father, shared examples of doing this and talked about the context of this communication.
It was interesting to note that parents seemed particularly apt to engage in this behavior when they were in locations where they felt the child’s memory. For example, a number of the accounts shared by parents took place at the burial site of the child, and others included special places of shared memory that involved the deceased child. Martha noted that she talked to her deceased daughter in this context daily:

I talk to her every day. The day after she was killed we were driving up to Salem to make funeral arrangements, and I told [my husband] that I wanted to build a memorial pond for her. I did it. For me it is so comforting to just go and sit out there and hear the sound of water . . . to just sit out on the bench and talk to her. I guess the relationship does change because I don’t see myself as parenting her, as in her asking me advice and me telling her this and that. It’s more telling her I love her and what I’ve been doing, then saying, “But why am I telling you this, you already know this.” . . . I think it’s just crossed over into a different dimension. Now it’s not so much a two-way exchange now, as much as I’m talking and she’s listening. (#A9)

Special places may evoke the child’s memory and prompt parents to talk of their feelings and hope the child is listening. This effort to communicate thoughts and feelings to the deceased child allows parents to feel that they can still reach out and try to feel an emotional connection to the child. One mother who did this suggested that “it’s a way of soothing some of the pain for me, [meaning] to go and talk things over with her.” She would often go to the cemetery in the evening and have dinner and watch the sunset while talking to her daughter. Talking to lost children in such places may help parents to imagine the child’s physical presence more readily and the effort to communicate is an example of how many parents perceive that the parent-child emotional bond transcends even the experience of death.
A number of parents in the study expressed a feeling of connection to their deceased children that came through praying for the child. These parents included the child in their individual prayers and often also in prayers with the entire family, praying for the deceased child specifically as they prayed for their other children. This practice was commented on by four of the parents in the study, two mothers and two fathers, and each of them also indicated a commitment to their particular religious belief. It may be that more parents actually practice this strategy, since there was no specific question in the interview that asked about this practice. One mother indicated her desire to pray for her deceased child was motivated by the Jewish saying that states: “To a Jew, ‘I believe’ means ‘I remember.’” She indicated that her belief in her child’s continued existence and hope for his well-being was reinforced as she brought up his name in spiritual remembrance through her prayers. The prayers for the child seemed to focus on the child’s happiness and the parent’s future connection with the child. A father, John, shared his feelings:

Well, during our family prayer we include [my son]. Every night when I say my prayers . . . I probably say three or four a day even if I’m sick or away on vacation, but he’s always one of the people that I talk of and ask for him to be . . . I ask that I can take care of him and that one day we’ll be there. (#B2)

This father’s prayer includes a hope that there will a future bond with the child and that they might be re-united with each other. This mirrors a pattern shown in other research that bereaved parents have a “strong impulse to search for and recover the individual who has died” and this may include a belief in a future “reunion in heaven” (Cook &
Wimberley, 1983, p. 229). Parents also pray for the child’s welfare in their current state of existence. A mother noted her prayers were for her deceased child to “be happy doing whatever it is he’s doing” and to “know that we remember him and that we love him intensely.” Prayer thus seems to be an important behavioral strategy for some parents to foster a sense of current and future connection with a child who has died.

**Connection Through Spiritual Linkage with the Child**

One of the strongest themes shared by parents in the study when asked about connecting to a deceased child was feeling a linkage with the lost child through some type of spiritual connection. Although the study did not set out to explore the spiritual dimensions of a parent’s experience in losing a child, many parents included this aspect of the bereavement experience in their personal accounts. The analysis in the study was limited to examining those behavioral strategies or experiences that parents reported which served to give parents a sense of emotional connection with the lost child. Parents talked about a variety of things that included actually seeing or feeling the lost child personally, dreaming of the lost child, learning of the lost child through another person’s spiritual experience (dream or feeling, etc.), feeling a spiritual linkage with the child, and sensing the child’s influence through various signs.

Past research on the spiritual connection of parents to deceased children has described this phenomenon as the “parents’ continuing interaction with the inner representation of the dead child” (Klass, 1993, p. 255). Such interaction has been defined broadly, including thoughts or memories of the lost child, and places such interactions
within the realm of a parent’s unconscious or imagination. In other words, these experiences tend to be represented in much research as a “psychological representation” or a “hallucination” of the parent’s senses, rather than as an actual interaction with the continuing embodiment of the deceased child (Klass, 1993; Rees, 1975). However, in this study most parents who reported such spiritual connections to a child themselves felt that they represented a tangible and real association with the deceased child in some manner. The balance between a parent’s personal description and belief about an event and an academic interpretation of such an event can be delicate, and in this case I have chosen to let the mothers and fathers speak from their point of view as much as possible. The dimensions of this type of experience have been ordered from most intense and personal to least intense and personal.

The most dramatic and personal type of spiritual connection that parents in the study reported was the experience of personally feeling and seeing what they felt was the spirit of the lost child immediately following the child’s death. This experience was reported by only two parents in the study, both mothers, and each of them described it as a very comforting and transcendent event. The context of each experience was quite similar, occurring within twenty-four hours after the child’s passing and either at the home of the parent or at the hospital. One of the mothers, Dora, who reported such an experience gave this account:

[Ours] was a large house and our bedroom had a door on the east. We slept facing the door on the west side of the room. On this night I just got thinking of her... I was thinking of her and suddenly it was as though she came [through the door]. There was a man with her and he was taller. They came right towards us. She stood there at the side of the bed looking down at me and at [my husband]. As I
reached [toward her], it seemed like the man turned her away and they walked off down the hall. I think that experience really gave me a little comfort. (#A11)

The mother’s account is brief but her reaction to it emotionally was very strong in an appreciative and positive manner. Such encounters do ease a parent’s anxiety and serve to give them some peace of mind related to concerns for their lost child. Interestingly, this particular account was shared by a mother who had lost her child more than forty years before the interview took place, and yet her memory of this event is quite clear in its detail. It was also real enough in her experience that she actually reached out to the child during the experience. The other parent who shared this type of encounter described it simply as “beautiful.” This dimension of spiritual connection to a deceased child allows parents to feel an emotional tie and brings them a sense of comfort.

Another type of spiritual connection that many parents expressed was personally feeling the spiritual presence of the deceased child. Researchers have reported that it is not uncommon for family members to report feeling or sensing the presence of a family member who has died (Kalish & Reynolds, 1981), with as much as 40-50% of bereaved persons having such an experience at some point (Rees, 1975). Feeling or sensing the spiritual presence of a family member who has passed on is the most common among the various types of spiritual connection that have been documented (Rees, 1975). In this study, six parents shared over a dozen experiences in which they felt or sensed the spiritual presence of the lost child personally. It was quite common for the parents to indicate that their experiences had occurred during the first several months after the child’s passing. The location and context also seemed quite important to this type of
experience. In all but one of the accounts, the experience took place in the parent’s home or another location of special meaning to the family, such as a place of worship or a place of special family memories. Being in these locations may help parents to be more receptive to this type of experience as they associate the child’s memory with these places. The context also seemed quite important, with these spiritual connections usually occurring at a point of individual transition (in the grief process or in one’s life) or during association with family in a special way (a family gathering, family worship, etc.).

The emotions and feelings that were evoked by these experiences were strong and parents expressed appreciation for these types of experiences. While some clinicians and scholars have regarded the parent’s retention of such experiences of mental or emotional association with the lost child as a sign of “pathological grief” (Klass, 1993), others have suggested that these experiences are part of a parent’s healthy resolution of grief (Rubin, 1985). One mother, Jean, shared such an experience and its meaning for her:

I go to the Scottish festival and they play “Amazing Grace,” and when my little old adrenalin starts to pump when they play “Amazing Grace” it’s like [my son] is standing beside me and I can feel his blood sort of quicken. The one-year anniversary of his death happened to be the Scottish Festival . . . I went with [my other children], but I knew it would be hard. I knew what I was letting myself in for. I knew it was going to be hard but I wanted to do it . . . When those bands massed and played “Amazing Grace,” [my daughter] and I absolutely dissolved into tears, and I felt David’s presence very strongly. What I felt like doing was laying my whole body out on the ground and bawling my eyes out, but I just kind of felt like he said, “You can do this, Mom, you can do this. Remember me, but don’t fall apart” . . . [To me it means] that we’re connected. That he still loves the same things, he’s still enchanted by our Scottish ancestry, and that we’re still connected and can still talk to each other in a spiritual way. That we can still communicate. (#A2)
The powerful message that this mother felt through her experience was that her child still cared about her and the family and that they can still find connection to each other through such events. She comments that to feel the child's presence specifically meant for her that they were "still connected," and so this experience helps to bridge the emotional gap with the child that parents often experience at a child's death. Another mother shared an experience in which she felt her daughter's presence very strongly while shopping several weeks after the child had died. She remembered walking into the store at mid-afternoon and then feeling her deceased daughter's presence and smelling her perfume, and she said that "all of a sudden that perfume was really overpowering and I knew she was there." The detail shared by this mother in her story was quite extensive. Ken, a father who shared one such experience, recalled:

There was one specific experience where I knew he had been in the house. In fact, I knew right where he was and where he was standing. I don't know how to explain how I knew as much as it was . . . it was my senses. I smelled him. I smelled him, in fact, I think it was actually the smell that woke me up. I'm not sensitive with my nose and I would not, for the most part, say that you can identify an individual by his or her smell. Yet we do, we have our own smells that are unique to us, and he did and I knew that he was standing right by me. So there are those times, as well as the times when you feel the presence, the peacefulness, especially at family events and rites of passage, weddings and such things when you know they're there for it. (#B3)

This father highlights being able to sense the presence of his lost child in the home on one specific occasion, and also mentions other experiences more vaguely that relate to feeling the child's presence at family events, etc. His account represents some of the key characteristics that seemed to emerge from the accounts shared by parents in this study.
These spiritual encounters provide another means of connection for parents to deceased children and seem to affirm the power of a parent’s emotional bond with a child.

Dreams that parents experienced were another avenue by which they sometimes felt a spiritual connection to the deceased child. Three parents in the study, all mothers, shared dreams which they considered to be significant and which communicated a message from the deceased child. They distinguished these dreams from other dreams about the lost child that included various memories, etc., suggesting that these dreams were more vivid and significant. They were also unique because in each instance the parent had a chance to speak to or listen to a message from the child. One mother, Martha, remembered this experience:

When I was by myself one night I remember dreaming about her and stroking her hair. She was wearing her favorite pajamas. I remember talking to her and saying, “Why don’t you go and take a shower and we’ll go shopping.” She sat up and I remember saying to her, “Oh, by the way, what do you think of the memorial garden I made for you?” It seemed to trouble me that I was mentioning the memorial garden to her when I was going to take her shopping. Then she looked back, and it’s the only time she’s ever said anything to me, and she said, “Mom, I can’t stay. I’ve got to go.” That was it. So I know that she’s with me all the time. . . . You cannot explain this to a person that has not experienced it. Unless you’ve experienced something like that . . . people can label it and say that it’s imaginary, but until it happens to them they won’t understand it. (#A9)

In this dream the mother has a chance to interact with the deceased child in a way that is positive and meaningful, and the child clearly communicates a message to her that she finds important. Another mother had a dream in which she communicated with her deceased son and felt that “he looked happy and contented where he was,” helping her to feel reassured about the child’s situation. While parents often dream of a child who has died, these specific dreams seem to represent a class of experience in which the parent
has a more unique and realistic encounter that allows them to gain a positive knowledge of the child’s status. Such dreams also provide the opportunity for a form of emotional connection that mirrors the actual connection parents once experienced.

Sometimes parents will feel a sense of connection to their lost child through the experience of others who have had a spiritual encounter with the child’s presence through similar means to those already described, such as a dream or a strong feeling of the child’s presence. Five of the study participants, all women, shared nine experiences in their narratives that reflected this type of connection with their deceased child. In each case but one the person who had experienced a spiritual connection to the parent’s deceased child was a family member, such as a father, a daughter, a nephew, etc. The parents described feeling a connection to the lost child through learning of the child’s presence or status as it was communicated to them from others who had felt the lost child’s influence. The experiences that other family members shared generally belonged to one of three categories, either a spiritual warning from the lost child, a spiritual dream of the child, or a spiritual encounter with the child’s presence before their own death.

Stacy recounted a dream that her daughter had shared:

I know that a dream brought my daughter a lot of comfort. She dreamed about him a few weeks after the accident. As I said, they were extremely close. She said that she dreamed he was at home and she was coming home. She said she was walking down the stairs and I motioned her in and said, “Hurry, Jeff’s here.” She said that she walked in and was so mad at him for doing this, so she just jumped all over him and said, “Jeff, how could you possibly do this to us?” She said that he put his hands on her shoulders and looked at her and smiled, then said, “Kim, you would not believe how beautiful it is. They will only let me stay a little while.” (#A4)
In her interview this mother expressed a positive feeling of connection to her deceased child because of her daughter’s experience with him in this dream. Since only about half of parents indicate they have had such an experience themselves, feeling this connection through the experience of another family member can help them to identify with the deceased child. Peggy, a mother who had cared for her ill father, told of feeling such a connection because of her father:

Five years ago my father died of cancer, and I helped to care for him while he was dying. I took care of him at night and my mother took care of him during the day with the help of my sister. One day Mom woke me up and said, “Your dad wants to say good-bye to you.” He would have periods of being lucid. At night he became confused but during the day he was always very lucid and he said, “I want you to know that I saw Tina.” “While I was sleeping,” he put it, “I saw that tunnel and that light, and I went to the light and they told me,” and I don’t know who he meant for “they,” “but they said it wasn’t my time yet, but that they would be waiting for me.” There were his parents and Tina. So while I’ve never had a time where I felt her presence, that experience was very comforting. (#A7)

This awareness of the child that comes to a parent through another’s experience can provide comfort and a sense of connection, as this mother indicates, even if they themselves have not had a firsthand experience. Encouraging bereaved parents to be sensitive to the experiences of other family members around them may be a means of helping them to find this emotional connection after a child’s death.

For some parents, the bond they feel with their children seems to be so strong that a sense of the child’s presence in their lives continues in a very meaningful way after a child dies. Only two parents in the study, a mother and father, suggested that this was their experience but it was quite striking. These parents indicated a very powerful sense of the child’s presence in their lives, particularly at times or in locations that reminded
them of the child, whether at home or hiking a mountain. As the mother, Martha, explained it:

I think I’ve always felt connected to [her] . . . and still am. She’ll never leave me. I always have her in my heart. The connection is always there. The connection was there before she was born. The connection was there when she was alive. The connection is there in death too. (#A9)

This sense of connection seems to be embedded so deeply in the parent’s identity and psyche that, although the child’s loss is traumatic, the parent manages to maintain a sense of the child’s presence in his or her life. These two parents both lost children suddenly and also expressed high levels of grief in the aftermath of losing their children, so perhaps the fact that they feel such an intense connection with the child strikes deeply when the child dies but also lets them maintain a sense of connection. The father’s account of this feeling was shared by Tom, and reflects the comfort that a sense of spiritual connection to the deceased child can generate for a parent:

I miss his physical presence tremendously. I tend to have some very strong feelings since the accident about how things are spiritually. To me, spiritually, he is all around me. You see the wind in the trees, you look at the mist coming out of the mountains, and that is his spirit there—his spirit is part of that. I’ve lost his physical presence and I miss that. I miss holding him. I miss the feeling of how his hair smelled. I miss hearing his laugh, tickling him, watching him play with something in the backyard . . . I miss Andy. I miss Andy a lot. I miss being with him and doing things with him. However, I feel he’s still very much a part of us and still very much here all around us. I get a lot of comfort by thinking about it that way. I really do. Sometimes I think it’s a crutch to get through the day, and other times I become very convinced that it’s reality. The only way that I can really cope is to think that, but at times I swear that I can really feel his presence.

If you go to the top of Mary’s Peak on a very windy day with the rain slashing at you . . . that’s him. He’s right there. To watch the sunset or the seagulls flying along the surf . . . that’s Andy. He’s right there. I feel very strongly and passionately about that. I was never very much a church-oriented spiritual person, but I still felt something there and some sort of spirituality about a person and
their presence and their place in the universe. [I felt] that there was something about it all. I’ve read some of the things that American Indians believed and some of that kind of made more sense to me than the stuff I was reading in the Bible.

I remember at the hospital that I was the last one out of his room. I spent ten minutes just sitting there, just staring at him and holding his hand, and trying to convince myself that he just looked like he was asleep because that was the last image I wanted of him. I remember asking the earth to take his presence and bless him, and to put it into Oregon so that I could be with him. So when I go to all these wild places I feel like he’s right there and I feel like he’s got his arms around me. If I’m feeling very depressed and blue, or just stressed at work or around the house, then I know it’s time to go and talk to Andy. I go to some of these wild places and I come back feeling very much refreshed by that sense of being there with him. (#B6)

Because of the father’s belief that the child’s presence can be felt or accessed through going to places that carry his spirit, such as the mountains or the coast, he is able to seek those places out when he wishes to feel a connection to the child. The ability these parents seem to carry to feel a strong connection to their deceased children makes it possible for them to deal more positively with the child’s loss.

A final dimension of connecting with a child through a spiritual sense that parents described was to see a “sign” or symbol indicating the child’s presence or influence.

Four parents in the study, all mothers, talked about the tendency to look for the child’s influence and see it in signs or symbols that have special meaning related to the child.

One of the mothers, Stacy, linked her child’s memory with hearts and shared this experience of connection:

I always kiss [my son’s] picture every night and say, “You know, you’re my heart.” I’m always looking for things. I think that’s one thing you do as a parent when you lose a child. You look for things because you just want something to hang on to. . . . I went out on the porch one night and this friend of mine looked up and said, “Oh, my God.” I said, “What?” She said, “Look at that!” The moon was shining so brightly and I looked and there was a heart-shaped cloud in front
of the moon, and the moon was shining right through that heart-shaped cloud. She just said, “That’s a heart!” I said, “I know!” It knew that it was a sign. (#A4)

In this context parents look for the little coincidences or the small occurrences that give them a sense that the child is nearby and is still involved in the parent’s life. These familiar or meaningful evidences send the parent a message that the child still exists and allow the parent to feel a connection linked to a sign of the child’s continuing influence.

**Connection Through Touching the Child**

One of the aspects of a child’s absence that impacts bereaved parents the most is the loss of the child’s actual physical presence. Most parents enjoy the opportunity to hold their children, hug them, or run a hand through their child’s hair, and this physical touch allows them to make a tangible connection with the child that is real and reassuring. A father captured the emotional loss linked to his son’s absence, saying, “I miss his physical presence tremendously. . . . I miss holding him, I miss the feeling of how his hair smelled, I miss hearing his laugh and tickling him.” Touching a dying or deceased child was one of the primary themes that parents discussed in the study when asked about how they felt connected to a lost child. They tended to focus on touching or holding the lost child at the time of death and taking care of the child physically at the time of death.

It was noted in an earlier chapter that only about half of the parents in the study were able to be present with their child at the time of death. For these parents, this opportunity to be with the child and touch or hold them at the time of passing was an important experience emotionally and psychologically. Seven of these parents, three
mothers and four fathers, noted the desire they felt to touch or hold the child at the time of the child’s death. One father, John, talked about being with his deceased son after the child had died at the hospital:

[My wife] kept thinking that were going to bring him home from the hospital. In the back of her mind she told me that she felt he would come home, and after they pronounced him dead I held him for at least an hour in a room, just [my son] and I . . . and she never did. She just left. . . . There were tears but I didn’t want to be with anybody. I just wanted to be with my son, and then I wanted to be with my [my wife]. I didn’t care to be with anybody else. . . . It didn’t give me any comfort. I know that sounds crazy . . . the comfort I had was holding [my son]. (B2)

Being able to hold his son was nearly the only source of comfort for this father at the time of the child’s death, and it is interesting to note there seems to be a poignancy in his story in reflecting that his wife never had that opportunity at the time of the child’s death. Each parent who talked about the comfort and meaning that came to them from touching or holding the child at the time of death emphasized its importance. Peggy, who held her child when she died, commented, “I’m sure that I wanted her to know that we were there . . . I wanted her to know that we were still holding her and loving her.” Touching or holding a child at the time of death thus seems to give parents a feeling of parental care and personal meaning at the close of the child’s life.

A second dimension of touching children at the time of death was associated with the parents being able to physically take care of the child. Three parents described this and suggested that it gave them a meaningful opportunity to continue actively performing parental functions for the child, which is important to parents whose functions are
suddenly stripped away when a child dies. Pam, a mother in the study whose daughter
died of cancer, explained what this opportunity meant to her:

One of the things that I remember is that the last two mornings [my daughter] was
alive they would give the baths in ICU at about 6:00 a.m. in the morning. I had
been a CNA (certified nurse’s assistant) for a while and asked if I could help. So
the nurse said “Sure,” and I washed her legs from the knees down, I washed her
feet, and I’m so glad they let me do that. In the hospital sometimes there is really
nothing you can do that’s helpful, and that meant a lot to me to get to wash her
feet . . . that I got to help, I think, that I was able to do something. (#A5)

To be able to “do something,” to physically care for the child a last time, can provide a
final sense of closeness for parents. However seemingly mundane the task, for a parent
faced with no longer being able to perform such tasks for a child, this type of physical
care seemed to be a helpful and comforting means of connection.

**Connection Through Association with Activities Meaningful to the Child**

One of the behavioral strategies for connecting with a child following the loss that
parents focused on was associating with activities that had been meaningful to the child.
Activities that had been meaningful to the child while he or she lived became more
meaningful to parents as they connected with the child’s memory by observing or
participating in such activities. Parents in the study specifically mentioned the sense of
connection provided by music the child had enjoyed and also by involvement in other
activities of interest to the deceased child.

Four of the parents, two mothers and two fathers, described the strong feelings of
emotional connection and memory that listening to music a child had enjoyed brought to
them. This sense of connection could have both positive and negative overtones. One
mother did listen to her daughter’s music but found much of it to be “strange hard rock” that she could “hardly stand,” yet listening to it still consoled her. Another father mentioned that sometimes if he was in a somber mood he would turn off music that reminded him of his son because the connection it evoked was too painful. But parents often listened to music that had been meaningful to children because of the uplift the music provided them. Jean recalled such an experience:

David loved music. “Danny Boy.” [My husband] and I had gone to a concert of [a local] choir, and they sang a version without the words of “Danny Boy.” Well, you don’t need to sing the words, because I’ve got them written on the cockles of my heart. When they sang that version of the melody of “Danny Boy” . . . that music is the most straight-on connection I have with David, even more than prayer . . . music, it’s like it just cuts through everything. . . . Music just lifted his heart. He took almost a childish delight in it, and he took so much delight in the musical talents of his siblings—just cherished it. I can just feel it, not my pleasure but his pleasure, his utter delight in that. . . . Sometimes I sit down at the piano and play “Danny Boy.” I don’t care if it makes me feel sad. I don’t care—that feeling of connection that I feel when I play it. I like that feeling of connection, and it’s worth it to me to feel sad just to have a feeling of connection. (#A2)

The power of music to provide such a connection seemed to stand out in comparison to other kinds of activities that might be associated with a child’s memory. Music touches the senses in a dramatic way and thus acts as a catalyst in giving parents a meaningful sense of connection to a lost child.

Parents may also associate with other activities that were meaningful to the child in order to establish a sense of connection. The variety of activities that parents described in this context ranged from continuing a child’s hobby to eating foods a child liked to playing games that a child enjoyed. Four parents spoke of associating with such activities to feel an emotional link to the child, again two mothers and two fathers. One mother,
Sandra, recounted how she and her husband had continued a child’s interest in collecting baseball cards:

In thinking about both my husband and I in this way, Matthew had a baseball card collection and we’ve continued that. We’ve continued buying the set of baseball cards. Who knows what we’ll ever do with them, but that’s just something that kind of makes us feel that Matthew is still here. (#A13)

Note from her account that the intent of engaging in the activity is to “make us feel that [our son] is still here”—to feel a connection to him. A father who shared some examples told of how his son had raised crackerjack marigolds in the garden as a child, and so every year he now tried “to grow crackerjack marigolds because that was the flower he’d raised.” Presumably, if the child had raised petunias that would be the father’s flower of choice. These examples illustrate how parents may associate with various activities that relate to the deceased child in order to feel a sense of connection, and in doing so they may try to maintain continuity that preserves a sense of the child’s place in their lives.

**Connection Through Association with Persons Meaningful to the Child or Parent**

Fostering a sense of connection to the deceased child by associating with persons who were meaningful to the child or understand losing a child emerged as another strategy used by parents in the study. Just as there may be some activities that parents engage in to feel closer to a deceased child, there are also persons who were meaningful to the lost child that trigger a parent’s sense of connection to the child. Such persons often had a personal relationship with the child and can share memories with a parent. There may also be persons who help a parent feel closer to their deceased child because of their own past experience. Parents identified association with family members, with
friends or families close to the deceased child, and with others who had lost a child as being helpful for them to feel close to the lost child.

Other members of a parent’s family, particularly children, seem to stimulate memories of the deceased child for parents. Thirteen of the study’s participants discussed how involvement with other family members, especially the deceased child’s siblings, helped them to remember and feel close to the child. These are persons who often have known the child and can share memories with the parent. One mother recounted how a daughter had named her own son after her brother who had died, and to the mother this meant that her son’s “memory just goes on down because they know that he was special.” Parents who have loved a child feel comforted to know that not only themselves but others cared for and remember the child who died. Another mother in the study, Stacy, spoke of how her daughter tried to find ways to help her connect with and remember the son she had lost:

Jeff got his degree posthumously. [My daughter] said that she didn’t want flowers at graduation, but she does want one red rose with a purple and gold ribbon. She said, “Jeff didn’t get to walk at his graduation, so I would like for him to walk with me.” I’m very touched. She does a lot of things like that. She tries to include him when she knows that it’s very important to me. On Mother’s Day if I get flowers, I get two. Without saying that she knows I miss him, she does things to remind me that she knows I miss him. (#A4)

This mother’s close association with her daughter helps her to feel that someone else also remembers her grief and the son that she misses.

As with family members, there are often friends of the deceased child or other families who knew the child that died and express a continuing interest in and love for that child after death. Again, this provides parents with a reassuring message that the
child they loved and lost is not forgotten, as they sometimes fear will happen. Four parents in the study, two mothers and two fathers, specifically noted how association with such friends or other families who knew the child had helped them to feel connected to their lost child. Sandra mentioned their association with others and how it helped them:

We’ve stayed connected with some of the families, many of the families, that we saw when the kids were involved in high school. To a certain point when we get together with them we talk about [our son], in particular thinking about athletic endeavors. Men particularly seem to be able to recount a lot more of the sports events than women can. I can’t ever hardly remember one game from the other, but my husband really enjoys talking about different games or things where there was some neat situation that was involved. So, certainly staying connected with families that not only knew him as a baseball player but also growing up. We’ve stayed involved with those people. (#A13)

By sharing and hearing stories about their children with others, the value of a child’s life and its impact on others is validated for parents. After experiencing the influx of distressed friends that came to their home after his son had died, Michael remembered that he was “overwhelmed by how impactful [my son’s] death was on so many other people.” For him, understanding the influence of his son’s life through association with others who had known his son led to major changes in his own life. As parents associate with a deceased child’s friends or others that knew the child, they are able to appreciate the child’s life in a greater perspective and feel connected to the child in a deeper way.

Perhaps one of the most distinctive aspects of association with others that was important to parents following a child’s loss was the degree to which parents sought out other bereaved parents. Parents in the study both desired the companionship of others who had been through the experience of losing a child and reached out to other bereaved parents after their own loss. Thirteen of the study participants described this in various
degrees and it is explored more extensively later in this chapter. But it is important to note that for most parents there is an acknowledgment that their lives have changed after a child’s death. Many parents spoke of the feeling that they experienced as if they were joining an exclusive club—to which they desperately wished not to belong. But at the same time these parents are often drawn to each other. One mother in the study who worked in a hospital noted that when she tells newly bereaved parents that she also lost a child, then “very frequently (if not always) it changes their demeanor to me and our relationship completely.” Another mother reflected on this desire to associate with others who had lost a child also and remarked, “It’s like being in this club and as soon as you see somebody else going through the initiation you think, ‘Oh, I’ve got to contact them.’” The connections between parents who have experienced a child’s death allow a mother or father to know that while they have joined this exclusive club unwillingly, at least there are others who have passed through the experience and can share some understanding. The mutual support and understanding that can be received in this type of association helps parents to feel closer to their own child as they see others who have a similar feeling for a deceased child.

Connection Through Participating in an Event Related to the Child

After a child’s death there are often various events which take place that allow others to remember the child specifically or which include the child in a general way. Such events may range from school happenings to special remembrances of the child to birthdays or holidays. A parent’s participation in such events can furnish an opportunity
to remember the lost child and connect with them in a meaningful way. A number of patterns related to this kind of participation in various events by bereaved parents emerged through the study analysis. One important distinction that became clear was the necessity of distinguishing between “one-time” events that related to the child and “annual” events that parents participated in monthly or yearly. Parents in the study reported participation in a variety of one-time events, specific events to remember the deceased child, memorial occasions related to the child like a birthday or death date, and in annual holiday events.

Although it may be more common than indicated, parents reported only a few incidents of attending events that occurred only once and to which the child had a connection. These included such one-time occurrences as the deceased child’s school graduation or a music festival the child would have attended. Parents shared only five incidents like this but felt a positive connection to the child when they participated on such occasions. Ellen, whose daughter died in high school, shared such an event:

At their 10-year class reunion [her classmates] asked me, along with a couple of other parents who’d had children die since the class had graduated, to come to their afternoon gathering for the reunion. So I made up a picture book again with a few pictures of Rebecca and information on what the family is doing now, and I wrote a little letter to the students. We took it and they put it on display. We had a good visit. Some of them I could remember faces or names, though you forget a lot, but it was a nice experience and it was nice of them to invite us to come back and participate. They made a name tag for Rebecca with her picture, so we took that and put it in her scrapbook. So her classmates have been very nice to remember her. (#A1)

Although infrequent, parents who participate in such affairs seem to enjoy them and find a renewed connection to their child’s memory.
Another pattern that parents described was the tendency to create specific memorial events related to a deceased child that the parent could participate in. These also tended to be one-time occasions but they were designed to focus specifically on the deceased child. Examples that parents in the study shared included planting of a tree in memory of the child or letting balloons go that carried thoughts about the child. These types of experiences are discussed more extensively later in this chapter, but the point here is that by participating in these events parents were able to establish a sense of emotional connection to the lost child. One mother who lost a daughter told of how she did not know what to do on the first Christmas after her child’s death, and so she sent out a request to those who had known her daughter to write “memory notes” of the child that could be read together by the family at Christmas time. She recalled that “I had them in a little basket and on Christmas night we sat around and we read those memories.” This was only a one-time event but it was specific to the child’s memory and provided the mother with a chance to connect with her daughter’s memory in a meaningful way.

The most common theme that parents described regarding participation in an event related to the child’s memory was experiencing the anniversary of the child’s birthday or death date. These events occur annually and the parent must determine how to deal with the related emotions that exist at these times. Ten parents in the study remarked on the significance of these annual dates after a child’s death and how they dealt with the feelings that surrounded these occasions. It is important to note that the emotions experienced could be both very positive and very negative. A child’s birthday and a child’s death date both serve as powerful reminders of all that a parent has
experienced with a deceased child—the child’s birth and the child’s loss. These memorial
days related to the child occur each year and represent perhaps the most significant
experiences the parent had with the child during the child’s lifetime.

When a deceased child’s birthday occurs a typical question that arises for the
bereaved parent is whether they will still celebrate it or avoid it. Each parent handles this
concern differently. Of the parents in the study who discussed this topic (ten parents),
two of them indicated that they struggle emotionally and simply try to avoid the painful
feelings associated with this event. Although they obviously remember and feel a
connection to the child at this time, the feelings are difficult and the parents do not try to
participate in an active memorial for the child. The other parents (eight) who spoke about
facing the child’s birthday each year indicated that they all tried in various ways to
highlight or reach out to the child’s memory by holding some type of memorial event like
a birthday celebration. Some of these activities were initiated by the parents themselves
and some were begun or carried out by others and the parents were encouraged to
participate. One mother, Stacy, provided an example of such an event:

One thing that my mother-in-law has done for us that I really do appreciate is
around his birthday. My mother-in-law is Catholic and so on his birthday she has
a mass set in his honor that day, so it’s as if he’s with us to celebrate his birthday
in that particular service. (#A4)

This memorial event on the child’s birthday each year has become an annual occasion
that allows the parents to participate and feel close to the child at that time. Participation
in such events seems to give parents a positive, uplifting way to remember their deceased
child when the child’s birthday comes.
A second difficult day that bereaved parents experience on an annual basis is the child’s death date. Again, parents experience a variety of emotional reactions at such a time that may be positive or negative. Five parents spoke of this day and acknowledged that this day of memory may be the most difficult one to face. Some parents visit the child’s burial spot or design a memorial to help them feel close to the child on that day, but others simply try to struggle through the sadness they feel at recalling the child’s loss. But all of the parents clearly expressed a feeling of connection to the lost child on that day which tended to be characterized by sadness and reflection.

Another type of annual event in which parents participated was a holiday occasion such as Christmas. Families often have traditions that occur during holidays and that help to develop a family’s identity and memory (Doherty, 1997). Parents may add a special event to these traditions at a holiday time that helps to include the lost child and provide a means of connection to that child’s memory. Five of the study participants shared stories about participating in such events at holiday time and all suggested that a positive feeling of connection resulted from such activity. Tom mentioned what they did in his family and how it helped them:

At Christmastime, we find it very helpful to still hang [our son’s] stocking up. We might put a few toys in there because we just need to do that, and then we let [our other child] have them. We also put a bouquet of flowers in there. We need to still have [those things]. We need to still be able to celebrate Christmas with him . . . so, we tend to find these little ceremonies, these little rituals we’ve developed that are very personalized and are to perpetuate his presence and his memory. It’s [so that] we don’t just simply forget him and move on. (#B6)

Such family traditions can become annual events that help parents and family members to perpetuate a child’s memory. Because parents feel a continuing need to connect with the
deceased child emotionally in some manner, these annual holiday events can provide a supportive context for parents to experience such a connection.

**Connection Through Visiting a Location Related to the Child**

Just as particular events may evoke thoughts of a child’s life and personality, so too do certain locations serve a similar function for bereaved parents. Another prominent theme parents described was visiting a particular location related to the child. It was very common for parents to discuss their visits to particular locations and even to establish such locations (which is discussed later in this chapter). Visiting a favorite park or going to the cemetery provided an opportunity to think of the child. The two primary types of location that parents described visiting were sites that were meaningful to the child or family and the child’s burial site.

Five parents in the study described the sense of connection they experienced with a deceased child by visiting locations that were meaningful to the child or the family. Such locations included places that the family or child had enjoyed visiting, places of solitude that the parent enjoyed, or memorial locations that carried the child’s memory. The important element of this experience for parents was being able to visit some place that they associated with the child or where they could consciously think about and feel close to the child. A mother who had moved from the place her child died noted that “there’s no place out here that I associate with her, so there’s nothing physically that I go to around here.” This sense of need that she felt to visit places connected to her child’s memory was frustrated after the move, but each time she returned to her former home she
would visit the zoo or other places that brought her a memory of the child. Parents may find places that they visit that just allow them to remember the child. Peggy reported:

There are times when I know that I really need to go through it again. It's like I've lost touch with her. . . . We have a house at the coast, and sometimes I just say, "I'm going to the coast and I'm going alone." [My husband] knows. I come back and I feel good. It's like I've touched base with her again. . . . I think it is a way of staying connected with her. (#A7)

This visit to a place of reflection helps her to re-connect emotionally with her deceased child. For her and other parents, visiting such locations of meaning can have almost a therapeutic effect as they get in touch with feelings associated with the child.

The most common location that parents discussed visiting and feeling a connection to the deceased child was the child's burial site. In feeling a connection, the emotions that parents experienced could be positive and pleasant or sometimes negative and painful. Eleven parents spoke about this experience and shared various experiences in visiting the child's place of burial. While most did so on a regular basis and felt positive about doing so, a few parents expressed an aversion to visiting the child's burial location. Stacy commented:

Jeff is buried in my hometown in Louisiana. Going home is not the same any more. I can never drive down the road to my parents' house any more without passing that cemetery. I try not to think about that because I know that, for me, Jeff is not there. But that headstone is there and it's such a horrible reminder. So I try not to think about it. (#A4)

This type of strong emotional reaction can obviously limit a parent's desire to visit the place where a child is buried, and seems akin to the distress that some parents feel if they come within the vicinity of where the child died.
Other parents find themselves drawn to the location of the child’s final interment. Another mother said, “I literally, for a long time, lived at the cemetery, and was there every day for hours.” In going to the child’s burial spot a parent is often able to take flowers or otherwise care for the location and this may help them to feel close to the child. A father in the study suggested, “The closest thing I can do for him physically is to go out to the cemetery now and then and try to take care of his grave.” Because they are close to the child’s earthly remains, parents who visit the child’s burial spot often feel more able to connect with the child. One mother, Sandra, reported:

I do go up to the cemetery, not as frequently as I did in the first few years. I go up there and have private conversations with him once a month or so ... I like to go up there and sit and just visit him a little bit. It seems like it’s a quiet, peaceful place, so it’s a place that I can go and commune with him a little bit. (#A13)

Some of the parents indicated that such visits were part of a regular pattern for them. John, whose child was buried far away in his hometown, told of such a visit:

Every time we go back to Wyoming ... he’s buried there in Lovell, Wyoming right there by two pine trees. He faces the Big Horn Mountains straight ahead and then off to his left are the Pryor Mountains and the Rocky Mountains are behind him. He’s in this valley and it’s just a beautiful place. He’s there and we go and we put flowers there every year. At the end of this month we’ll be leaving to go back to Montana, and we’ll take a two-hour drive down there to take flowers and have a family prayer and talk about it. The kids talk about it all the way there and they talk about it on the way back. (#B2)

The sense of this father’s visit to his son’s place of burial almost carries the feeling of a pilgrimage, a personal journey to a revered and important location. For those parents who feel such a tie to a child’s burial spot, these visits seem to provide a means for renewing the emotional bond they feel toward a deceased child.
Connection Through Looking at Tangible Sources of a Child’s Memory

A final theme that emerged from the parent’s narratives related to connecting with a deceased child was looking at or possessing tangible sources of the child’s memory. Such “tangible sources” may include a child’s letters, clothing, pictures of the child, or even the child’s physical remains (cremation, etc.). Each parent tends to connect in a personalized way through this type of association, but there are some general patterns which the parents described. These included looking at or keeping pictures of the child, reading a child’s personal records, possessing and using a child’s clothing or other items, buying something associated with the child, and keeping the child’s remains.

The most common behavior that parents described in relation to using tangible sources of memory to connect with a child was keeping and looking at photographs of the child. Nine parents in the study discussed doing this (seven women and two men) and the comfort that accrued from keeping the child’s picture in a place where they could see it often. Some of the parents mentioned taking pictures of the child at the time of death and of the funeral or burial. They recommended doing this because seeing these pictures “helps with the finality of it and especially later on when the shock wears off,” though they acknowledged that looking at such pictures later could also be painful. In general, though, most of the parents simply shared the meaning of having a photographic image of the child close by. One mother commented, “My house is surrounded by his pictures, not that it wasn’t beforehand, but it’s surrounded by his pictures and I kiss it every night.” Some parents recorded the child’s room or possessions in photographs, and many of them compiled scrapbooks of the child’s many pictures. Sandra, another mother, said:
I’ve always loved having pictures out. I have a lot of pictures up on the cabinets and I have lots and lots of scrapbooks. Every once in a while I will pull out a scrapbook. Like on Mother’s Day, I will do that or at various times and look at the kids in their different stages of their life and remember. I do have a scrapbook of [my son’s] years in high school so I’ll pull those out. That certainly makes me feel closer to him when I do that. Those are wonderful to have. Pictures have always meant so much to me. We have a couple of videos of the kids and every once in a while I’ll put on a video. Now that’s one thing my husband hasn’t wanted to do, I don’t know why, but we have a lot of videos of [my son] playing football or baseball. Every once in a while when I’m alone, I often do that. (#A13)

While viewing a child’s pictures can help some parents, others may not feel comforted by such an activity, such as her spouse’s unwillingness to watch videos of the child. Of course, such modern technologies as video photography vastly enhance the potential for capturing a child’s image and voice and activities. This also raises the interesting question of what bereaved parents might have done prior to the advent of photography. In any case, it seems that keeping and looking at photos of a child acts as a common means of connection for some bereaved parents.

Another activity that some parents may engage in is reading or looking at the personal records left behind by a child. Such records might include drawings, letters, a journal, or other written records or works of art. Only a few parents in the study mentioned looking at this type of record to connect with a child. Some parents took a child’s drawings or letters and compiled them so that they could be easily seen or viewed. Jean spoke of how she used such records to feel closer to her son:

I read through his letters. Sometimes I read his journal, just to remind myself what went through his brain when he was doing the things that were either turning points or trivial [moments] in his life. (#A2)
The personal records that a child leaves behind can, as this mother notes, help a parent to understand and connect with the child’s thoughts and feelings while they were alive. While the parents in the study did not discuss this extensively, it raises interesting possibilities about how parents might consciously connect with a child’s memory following a loss.

When a child dies there is usually left behind a variety of possessions that had meaning to the child and that also potentially have meaning to the bereaved parent. Such items might include pieces of clothing, jewelry, or other possessions. Four parents in the study, all mothers, talked about such items and the emotional connection that exists with a deceased child because of such items. As with other tangible sources of memory, parents may experience either a positive or negative emotional response to the possession or use of such items. Stacy received her son’s shoes after he died and stated, “For some reason his shoes bother me a lot . . . somehow the idea that he’s not standing in those shoes is devastating to me.” So, the emotional association with such an item can be difficult. But parents may also feel an emotional attachment to such possessions and can find it difficult to give away a child’s clothes or clean a child’s room because of such emotions. Parents seemed to feel more comfortable wearing jewelry related to a child than wearing clothing or using other possessions (driving a child’s car, etc.). Carol spoke of the connection she felt by wearing a certain piece of jewelry:

Another connection I have is that I wear a ring that I gave her. That is hers and it’s just always there, and it will always be there now. The same with my necklace. This is very strange. It’s two Celtic hearts and then a rose. [She] sent me the same identical heart that I sent her for Valentine’s Day, and I had already given her the rose to put as a little dangly thing on her wristwatch. So now I have
the two hearts for my boys and the rose for my girl. [I wear them] all the time. I never take them off. (#A6)

For this mother, wearing a ring and a necklace associated with her daughter’s memory serves as a constant and permanent tie to her lost child. Deciding what to do with a child’s possessions if they die and how to use them can be a difficult question for bereaved parents to face. But some of them find comfort and a positive association with the child through keeping and using such possessions.

Two parents in the study talked about continuing to buy things they associated with the deceased child as a way of feeling connected after the loss. This pattern ties to the idea of finding and using tangible sources of memory to foster a linkage to the deceased child. One father would buy flowers or toys or items to display in his yard that he felt his son would have liked. Carol also bought and displayed things that reminded her of her lost daughter. She recalled:

One thing I did for her . . . my boys will think I’m totally nuts, but that’s okay because I’m an old woman who wears purple and red and I’ve been doing that for a lot of years. Lisa loved Princess Diana. I could never get her to write to her because she was so shy. She said, “Oh, she wouldn’t want to hear from me.” Of course, Diana was killed as well. They came out with a plate with this beautiful white rose on it, and the rose looks so fresh you could pick it, so for memory of Lisa I bought that plate and will hang it with a picture of Princess Diana someplace here in my house when I get them both framed. (#A6)

Although perhaps only she will fully know and understand the meaning that this item holds for her, for her it establishes a continuing memory of the lost child. It is likely that most of a parent’s efforts in this area are highly personalized and unique according to their memories and the child’s interests.
A final source of memory that was commented on by one of the parents in the study was possession of her child's actual remains. This practice is more common in non-Western countries where cremation is an accepted practice, but it has become more and more prevalent in the United States over the last three decades. The person's cremains (ashes, etc.) are normally kept in an urn or some other appropriate container and may be placed in the home of the family or in another accepted place. While only one mother in the study discussed this, she noted that the child's ashes were kept in the closet and that it was comforting to know that they were there close by. In a sense, this practice removes the need for a parent to visit a burial location and transfers that atmosphere directly to the parent's home or other place where the remains are.

**Parental Behavior to Remember or Memorialize a Deceased Child**

Since parents who lose a child generally possess a strong fear that themselves or others might forget the child, it seems logical to ask whether bereaved parents take steps to counter this fear and maintain the child's memory. Another of the over-arching themes that emerged from this study regarding parental behavior in relation to the deceased child was that parents do make intensive efforts to remember and memorialize the child. The broad function of all the parental behaviors related to this theme seems to be the preservation and perpetuation of the memory of the deceased child. Many of the activities described in the previous section link with this theme, as parents were often engaging in the act of “re-membering” or connecting with the existing or continuing memory of the lost child through association with some source of memory (a location,
The parental behaviors described in this section tend to highlight the act of "memorializing" the lost child's memory. This essentially consists of creating or collecting sources of memory related to the deceased child either through preserving an existing source of memory or creating a new source of memory. The previous section outlined behavioral strategies used by bereaved parents to feel an emotional connection to deceased children. This section highlights specific actions that parents take to preserve or create sources of memory that can make such a connection possible. Some of these activities have been previously described and will be mentioned only briefly.

**Preserving a Source of Memory of the Child**

Parents who make the effort to preserve existing sources of memory that relate to a deceased child are cognizant of the value these sources hold for themselves and others. For example, a mother knows that the baby blanket she made for a child who later died has a history and purpose that give it broader meaning. The blanket is not useful only for warmth but also for providing a mental catalyst of memories in the past related to the child. It is, in essence, a symbol with a deeper meaning about the relationship between a parent and child. Bereaved parents tend to value and preserve these sources of memory because of such symbolic meaning. In this study the parents seemed to focus on preserving items such as awards or mementoes that honored or linked to the child, gathering and keeping records or pictures of the child, and continuing events that were associated with the child.
Those parents who attempted to preserve awards the child received or mementoes of the child’s life, such as a child’s clothing or other possessions, found a sense of comfort in possessing certain things related to the child. Seven parents in the study, all women, talked about making the effort to preserve for their own enjoyment or use a variety of objects related to the deceased child. The general absence of any mention of this by men in the study may indicate a gender difference that indicates mothers focus more intensely on this kind of issue. The women described making efforts to keep clothes, awards or other mementoes with personal meaning related to the child. One mother kept some of her deceased son’s clothes and other possessions in an armoire just to occasionally remind her of him and have his things close by. Another mother described treasuring a bandanna that her son had worn and which his friend from Alaska had given to her after the son’s death. Any of these items can serve as a memory point or a special connecting link for a parent with the child’s memory.

A second source of memory that parents attempted to preserve existed in the form of various records or pictures related to the child. Six of the parents (five women and one man) discussed their efforts to gather pictures, letters or other personal records associated with the deceased child. Their efforts tended to focus on collecting these records and then putting them into a form that would present the child’s memory, such as a scrapbook of photographs or a collage of drawings. One woman who lost a daughter said, “We made up a scrapbook for her, with all of her newspaper clippings, pictures, etc. . . . you just don’t want them forgotten, so those kinds of things help.” Her comment echoes the motivation of many parents who go to the effort to gather and preserve such records of a
child's life. They desire a lasting source of memory that will make sure that the child won't be forgotten.

A final theme discussed among the parents in the study that related to preserving a source of memory connected to the deceased child was the continuation of particular events associated with the child. Only four parents discussed this pattern, a seemingly small number, but that may be because in the analysis a focus was on the continuation of events in a manner similar to what occurred prior to the child’s death. Many parents focused on memorial events but they took on a very different nature when compared to events prior to the child’s death (discussed later in this chapter). The events that these few parents did focus on continuing related either to birthday or holiday traditions, such as having a birthday cake or putting up the child’s stocking. In most cases this continuation of a memorial event related to the child seemed to diminish in importance after a few years. This may be because the parent’s emotional distress lessens and the need for such strong reminders of the deceased child decreases.

Creating a Source of Memory Related to the Child - Personal Records

Bereaved parents who wish to create a source of memory related to their deceased child often turn to the development of personal records that capture the child’s life or the parent’s feelings. Seven parents in the study, five mothers and two fathers, shared examples of trying to create various personal records related to their deceased children. These records were intended to become a new source of memory that they and others could rely on and appreciate. Examples of such records included writing personal
experiences and important memories of the child, writing poetry about the child, and putting together books that memorialized the child. During the interviews the parents often willingly and enthusiastically shared these records. Parents often sought out information or stories from others that they could use for such records. One mother noted, “I sort of search out anecdotes about him [and] plan the anecdotes I want to write down.” A mother who wrote some poetry in remembrance of her child, Laura, submitted it to the local paper and quoted it from memory in her interview:

At times when we would take a walk my son would run ahead,  
There was so much to interest him he couldn’t slowly tread. 
“Oh, Mommy, see this! or that!” whatever he would find,  
And then he would hurry on with me a ways behind.

“I’ll get home before you do,” he would say to me,  
“But I’ll wait there for you,” and on he would flee.  
This time he’s gone on ahead to where all things are new,  
He’s reached home before I have, and waiting for me too. (#A8)

This poem and other types of personal memories that parents record serve to capture their feelings and the meaning of their relationship with the child they cared for. Creating such a record gives parents a chance not only to use their own memories but to search the memories of others regarding their child’s life and experiences.

Creating a Source of Memory Related to the Child - Memorial Events

A pattern shared by parents related to creating new sources of memory of a deceased child was the origination by parents of what might be called “memorial events.” Such events consisted of the parents organizing and promoting a one-time or annual occasion for themselves or others that focused on remembering and honoring the
deceased child. These efforts to memorialize the lost child through some type of formal or informal occasion generally tended to occur at times that already brought a memory of the child such as a birthday or holiday. The two categories of event that emerged from the analysis were one-time events and annual or regularly held memorial events, mentioned earlier in the section entitled “Connection Through Participating in an Event Related to the Child.” That section focused on how parents feel a connection through such events, while this section addresses the types of such events that parents create.

One-time memorial events that were described by parents in the study all tended to take place shortly after the child’s memorial services and served specifically to remember the child. It should be noted that memorial services were not included in this category. The type of event ranged from a memorial concert to a reading of stories others had shared about the deceased child. Only three parents in the study, all mothers, described putting on such an event. One that took place soon after one child’s memorial service was shared by Carol:

A strange thing had come up one time. Lisa said if anything ever happened to her, she was an organ donor and she wanted to be cremated. I said, “Well, where do you want me to sprinkle you?” and she said, “Oh, just everywhere, mom, I love the ocean and I love the mountains.” So I had jokingly said, “Well, I’ll put you in balloons and let you just go everywhere.” She thought that was a great idea. [We did] have a standard service, but we [later had] the balloons out at the cemetery and the balloons had notes in them about who she was. So we let them go [out there]. (#A6)

This one-time event allowed the child’s parent to fulfill her child’s wish in a small way and gave other friends and family close to the child a chance to celebrate the child’s life.
Such events seem designed to provide a distinctive opportunity to remember and appreciate the child who has died.

The more common type of memorial event that parents in the study reported was an annual or regular event designed to foster the deceased child’s memory. In this pattern parents described taking action to create a memorial event of special meaning related to the lost child that occurred on a regular basis. In nearly all cases the event was tied in with an already existing memorial occasion such as a birthday, a child’s death anniversary, or a holiday. Seven parents in the study (five mothers and two fathers) shared approximately a dozen different accounts of creating such annual or regular memorial events. There was no discernible pattern reflected in the specific nature of each event. Instead there seemed to be a focus on personalizing the event so that it matched the wishes and personality of the parent or child. For example, in a family that enjoyed music, Jean described this annual event:

The first few years of the anniversary of his death my girls would go out with me and they’d stand and sing hymns at his grave. They’d sing “Amazing Grace” and then they’d just sing some hymns at his grave. That was lovely and it’s a lovely memory. (#A2)

Though the description of this annual memorial event is quite limited, it shows all the characteristics that have been mentioned. It occurred annually on a particular memorial occasion (child’s death anniversary), took place in a specific location (child’s burial spot), and involved particular individuals in a certain activity (singing of hymns by family members). Also, it accomplished the mother’s desire for this occasion—to become a “lovely memory” associated with the deceased child.
The combination of timing, location, and special meaning that characterizes these memorial events transforms them into sustaining sources of memory for the bereaved parent. As a source of memory associated with the child the event serves somewhat as a catalyst that evokes thoughts and memory of the lost child. Pam shared a memorial event that has gained meaning for her:

Linda died on the 27th of April and her birthday is on June 6, which was about five weeks later, and as her birthday approached... I found that we really didn’t know how to act. We didn’t know what we were supposed to do. I thought, “Well, a birthday cake?” Then I decided that I didn’t think so. She was buried in San Diego so we really couldn’t go there. So I got to thinking and it took several days to figure it out. I remembered that she liked chocolate, and she always had a chocolate birthday cake, chocolate ice cream with chocolate syrup, chocolate candies of some sort on the cake, and sometimes chocolate milk. So it was a “chocolate occasion.” I decided that what we needed to do was go out and eat chocolate. So we went over to Lebanon, picked up my son, and went to a restaurant and about all they could offer us that was chocolate was hot fudge sundaes. But that’s what we did. So it is tradition now that on her birthday we have chocolate in one form or another.

Several years ago right after my husband died I was wondering what I was going to do. It was on a Sunday and I think her birthday was the next day. I was in church and my mind was totally on what we were going to do about this. Then I remembered mud pies. We often went up to a place in Monmouth and had mud pies. I knew two people there, one was Linda’s friend and another friend of mine, so I asked them if they would go with me and have mud pie because it was her birthday. So we went out and had soup and mud pies. That was very helpful. So that is what we do on her birthday. (#A5)

Again, in this memorial event the parent finds it meaningful to participate annually in a way that brings sweet memories of the lost child. The creativity of this activity is important because those annual memorial events that parents seemed to most appreciate were those that illustrated this kind of creative spirit. A father in the study, Tom, shared a different type of creative event that his family holds on the birthday of his deceased child:
You tend to create a personalized . . . a personal ceremony that helps you to remember and feel that you haven’t forgotten or let go [of him]. He died two days before his fifth birthday. On his fifth birthday we went to his favorite playground and let loose five balloons. A year later we were at Harris Beach State Park and we let loose six balloons. The year after that we were out on the beach somewhere and we let loose seven balloons. I sure know that somewhere some seagull is choking on some old balloon, and someone is mad at me, but that’s what we did to help celebrate and to help remain connected with him a little bit. We still celebrate his birthday. (#B6)

This event also combines a memorial occasion with a specific activity that is meaningful to the family for remembering the child. The father’s comments are insightful in providing a context for why parents create such memorial events, noting that such a personalized occasion helps “to remember and feel that you haven’t forgotten or let go” of the child. These events, while diverse in nature, share some common characteristics and serve the common purpose of acting as opportunities for parents and others to remember lost children.

Creating a Source of Memory Related to the Child - Memorial Locations

Another pattern that parents in the study demonstrated in creating sources of memory was the establishment of “locations of memory” (i.e., memorial locations), essentially places that a person can visit and participate in remembrance of the lost child. It was noted earlier in this chapter that parents often visit particular locations in order to find a sense of connection to a deceased child. This section discusses the type of locations that parents consciously create in their efforts to preserve the child’s memory. These locations are intended to serve as lasting sites that carry a child’s memory and allow those who visit the site to feel a connection to the child. The three primary types of
memorial locations that parents described in the study were the child's burial place (location of the child's remains), specific memorials dedicated to the child, and locations of special meaning related to the child.

Among such locations the child's place of burial is a common destination. The burial place houses the bodily remains of the child and preserves a specific location that provides a tangible link to the child's life and memory. Five parents in the study, four women and one man, discussed their efforts to make the child's burial site a place of memory related to the child. This involved going beyond simply having the child's remains interred to carefully planning a site and the memorial design so that it reflected the child's memory. These parents described being careful and selective in their choice of a location for the child to be buried. They attempted to find a place that had meaning to the family and which would allow them to feel comfortable with the child's final resting place. They also made extra efforts in encouraging the inclusion of elements in the memorial (gravestone, etc.) that reflected the child's memory and place in the family.

One mother, Carol, described her child's resting place:

We went out to the cemetery and you saw her headstone. That was done in honor of her and who she was as a person. . . . I took her high school graduation picture and they laser imprinted it on the headstone. It's a great big heart-shaped stone of black marble, and on it is her graduation mortarboard, her ballet slippers, a little angel, and a saying that says, "Listen to the whisper of the dream within your heart." At the bottom are roses and a Celtic cross with the words "Love" on it and 1 Corinthians, which was her favorite Bible chapter, because she truly did believe that love could heal the whole world if we would just do it one person at a time and stop being so selfish. There's also a hummingbird down on the bottom because she loved hummingbirds.

On the back of it is a picture of her horse standing on a cliff. That was quite an achievement because her own little pony rolled on her in the yard when she was
four or five years old, and so the fact that she'd actually learned to ride a big horse was very impressive for her. Her boyfriend’s dad gave her a horse and a beautiful saddle and bridle, when her own dad would not do that for her, and she used to ride the feedlots back there in Nebraska with her boyfriend. So it was quite an accomplishment. Off the cliff it goes down to a beach scene, and she loved the beach and the ocean, and she would go agate hunting with me. One of the largest agates she ever found she ended up giving free of choice to a couple from Connecticut. Then on the beach is shown a beautiful unicorn and down below it are the words “I Believe.” The reason the unicorn is there and the reason that she believed in unicorns was because I sang the Irish rover’s song to her about the unicorn not getting on the Ark. So she always believed in that... [I felt] pleasure at being able to put all that together to have people look at that and have a sense of knowing who she was if they didn’t know her, and a sense of comfort if they did know who she was. (#A6)

This mother’s narrative provides an arresting example of how the child’s burial place was turned into a larger symbol of her life and interests and beliefs. The images on the gravestone, from the ballet slippers to the unicorn, reflect the child’s memory and allow people to have a sense of the child. Knowing that a child’s burial place can be a place that may last for generations, some parents make an extra effort to make it an enduring location of memory for themselves and others to visit and remember the deceased child.

It is not uncommon to find, in parks or at schools or in other places, a plaque or other sign indicating that a particular monument or tree or building is dedicated to the memory of a particular person. Often these memorials are dedicated to the memory of someone who has passed on and it is not infrequently a child. Five mothers in the study talked about establishing specific memorials that were dedicated to a child’s memory after they had lost a child. They often described such efforts being planned and carried out together with a spouse or with the support of a local school, the community, etc. The memorials that were created varied quite widely but included such places as a library
within a building, a bench at a local park, a tree with a plaque on the grounds of a local school, and even a baseball field. The parents commented that they were appreciative of these physical reminders of their child’s life and hoped that they would serve the purpose of preserving the child’s memory in a meaningful way. These special locations of memory were distinctive in that they were oriented to public use and were specifically identified as existing in memory of the deceased child.

A third type of memorial location that parents identified in their interviews was the establishment of locations of special meaning related to the child. These locations tended to be primarily for the private use of the parent or family and were not overtly identified as being in the child’s memory, although they were clearly intended to be locations of special meaning in memory of the child. Again five parents, all women, talked about creating such locations after a child’s death and the value of those places for them to remember the child. In every case the location consisted either of a memorial tree or a memorial garden that was planted or developed to honor the child’s memory. Jean, who had planted a pine tree in her son’s memory, spoke of its significance to her:

I like just a few little visible symbols. I love the pine tree. If we ever move from this house, it’s the tree that I will miss. I love the big ponderosa pine. It’s grown crooked at least two or three different times, especially after storms, and it always straightens out and goes for the sky. I love that. That’s [my son]. I love that sometimes on his birthday or the anniversary of his death we put white ribbons on that tree. (#A2)

As a source of memory this tree carries a special meaning for the mother. She compares the tree and its growth to her child’s memory in such a way that it seems to serve as a
visible symbol of a metaphysical relationship or person. Another mother, Martha, who
designed a memorial garden in her child’s memory, spoke of its meaning:

I wanted a beautiful place that not only [my husband] and I and [her siblings]
could enjoy, but her friends as well, and so that to me is very special because I can
go out there and talk to her and really feel her presence when I’m there. It’s
special also for a lot of reasons because so many of our friends contributed
flowers for the garden. . . . It’s a very special garden because of what it means to
me and also what it means to [my husband].

I saw how hard the architect worked to build this. Jessica always had a fondness
for hearts, and when the architect was done he stood atop and looked down and
said, “Look at the shape, it’s heart-shaped.” He didn’t design it that way. It is so
beautiful too because of all the work that [my husband] has done around the
garden. I feel like though I designed it and it was my idea to build the memorial
garden, it’s also something that she gets from her dad too because he has toiled
just as much as the architect in building steps, etc. It just looks so beautiful that I
feel she’s surrounded by both mom and dad and that’s really special to me. (#A9)

As a memorial location this garden brings together a place with a person and continues as
a symbol of the child’s memory. All of these locations, whether burial spots or public
memorials or private gardens, thus contribute to keeping a child’s memory alive.

Creating a Source of Memory Related to the Child - Memorial Symbols

In addition to events and specific locations, parents in the study also identified a
variety of other sources of memory that they created following a child’s death. In general
these might be called “memorial symbols,” essentially including a variety of things that
are intended to preserve and honor the deceased child’s memory. It should be noted that
this pattern of memory sources overlaps with and often includes other sources described
in this section (such as a tree or a park bench dedicated to the child’s memory). Three
general types of memorial symbols related to a deceased child emerged from the study, and these were physical symbols, natural symbols, and financial or educational symbols.

Physical symbols of a child's memory can be widely different, but this category would basically include all physical items or reminders of a child’s memory that are created or developed with the purpose of remembering the child. This means, for example, that the personal records and some public memorials (a park bench, etc.) mentioned earlier in this chapter as sources of memory would also be included in this category. It might also include various other physical items dedicated to the child’s memory. Several parents talked about the items that they use as physical symbols to help remember a child. One father in the study created a “medicine bag” with items that reminded him of the child and carried it with him everywhere. A mother commented:

The ornament tradition I have continued each year, and there is some significance to each ornament that I pick out. Some of them relate to her, like the second year I found a white kitten, and that reminded me of her kitten dying on the same day that she did. One of them of a little girl with long blond hair that was tied back was [similar to] the way that she wore her hair . . . so I was happy when I found that. (Pam; #A5)

The ornaments are precious to this mother and are a readily available physical symbol that reminds her of her daughter. These items seem to provide a tangible tie and memory of the deceased child for some parents.

Natural symbols connected to a child’s memory have already been described in the previous section and tend to include trees, gardens, etc. The distinction here is that these symbols are living things that the parent may often care for. Five parents in the study talked about creating such natural symbols to memorialize the child, and included
planting trees at their homes or particular flowers at the child’s school. One mother noted, “I have a private garden here at the house that has a bench, an angel, and rose bushes and plants that people gave.” These living things also remind parents of the lost child and help them to keep the child’s memory alive.

A third category of memorial symbols that emerged in the study analysis was financial or educational symbols, primarily in the form of memorial scholarships bearing the deceased child’s name or other financial endowments used for educational or other purposes. Creation of such scholarships or contributions in a child’s memory was quite common among the study participants. Nine parents, seven women and two men, talked about their experience in establishing a scholarship or other financial/educational assistance memorial in a child’s name. One participant, Carol, explained:

She has a scholarship set up and the criteria has to be an average girl student. . . . With her scholarship usually whoever gets it has in some way known her younger brother or her, and we often will get a card that wants more information about her. . . . I think you do it because you don’t want that child forgotten. That’s your way of keeping connected with them. (#A6)

Such memorials can be anonymous or public, but in either circumstance they serve the function of keeping the child’s memory before the parents and others.

**Parental Behavior to Extend Care Related to a Deceased Child**

After a child’s death parents find that the care and nurturing behavior they performed in behalf of the child must be channeled in new directions. Struggling with the loss of basic functions of parenthood like giving protection or extending care often leaves parents feeling somewhat lost as to what they will now do (Rando, 1985).
However, an important dimension of parental behavior following the child's loss seems linked to finding ways to continue providing such care and assistance. Although most individuals give care to others in a variety of ways in the normal course of their daily experience, the focus in this study was to explore whether parents indicated any behaviors that were linked specifically to their experience of losing a child. This emerged as a primary theme and consisted of parental behavior in extending care or assistance that was related to the deceased child. The behaviors were eventually classified according to how they were linked with the parent's experience in losing a child. Parents described some care and assistance they extended by the following criteria: (1) care given because of their experience in losing a child; (2) care given in place of what would have been given to a lost child; and (3) care given in behalf of (or as proxy for) the deceased child.

**Emotional Support and Outreach Given Because of Parent’s Loss Experience**

Perhaps the most common pattern identified by parents in extending care to others was providing emotional support and outreach because of their own experience with losing a child. The loss experience sensitized them to the challenges that others might face and they felt motivated to assist others who seemed to be in need. Parents in the study described giving such care through reaching out to others who also lost a family member, doing educational outreach to teach about losing a family member, and providing emotional support and physical intervention to help children when under stress in a family.
Having experienced the pain and trauma of losing a family member, bereaved parents in the study discussed numerous examples of extending care to others in order to assist them in their own adjustment to a family member’s death. Thirteen parents in the study, nine women and four men, shared their experiences in reaching out to others who had lost someone after having had their own loss experience. In describing their efforts they very specifically cited their own motivation as being rooted in their own experience with losing a child. Parents talked about reaching out in various ways, but primarily through individual contact or involvement in a grief support group. Four of the parents, three women and a man, emphasized their work with grief support groups and reaching out to others. It was very therapeutic and empowering for each of them and they felt also very helpful to others. Anne, who established her own grief support group after losing a son, described her experience:

I wanted to have people at my house the next day. Only bereaved parents. . . . I had quite a network and I had a lot of resources available, and obviously this was my therapy. . . . I had a counselor friend who agreed to come to the meetings the first little while, just to make sure that if anybody got in trouble there would be a professional there who could help. The thing that we offer at the G.R.E.G. group is a chance, and hopefully a confidential place, where you can say what you’re thinking and feeling and needing that you can’t say other places. This isn’t a therapy group . . . there’s nobody there who can work with you as a therapist. That’s not what we offer. We offer our group in addition to anything else that you’re doing. . . .

It’s in his memory. It’s to honor his life. One of the things I said when we first met, there were about fifteen of us and all of us except for the professionals were newly bereaved, was about naming the group. We had come up with this Grief Realization and Education, grief realization being for us and education being for the community and those around us so they’d know how to behave and help us. That stood for G.R.E.G. I figured if I started the group and was doing all the work that I got to name it. What the group members said was that they liked the idea of having it as a child’s name. It gives it a little more honest reality. (#A3)
Establishing and continuing this grief support group was a help both to her and to others, and it was clearly tied to her own child’s memory. It was important to her to reach out to others who knew her own pain, other bereaved parents. Another mother, Pam, who directed a grief support group spoke of her motivation in reaching out:

I learned so much from Linda’s death, and I can share with people who have lost their children some of what I’ve learned that may be helpful for them. When the former leader wanted to give it up after 10 or 11 years I really took it over with fear and trembling. . . . I call sometimes but they’re very open to call me at any time and I’m happy to talk with them. But at this point that’s as much as I’m doing. I’ve been given all this learning and information so that I can share it with others, and hopefully in some way help them. I can understand. I know where they’re coming from. We speak the same language, and only in your support groups do you find that. It’s a non-judgmental thing. . . . I’ve never been to a support group meeting that I didn’t learn something from somebody. So I think in this way I’m carrying on not specifically to remember her, but because of her and what I’ve learned from her and her death. I can share with others and I want to help others if I can. (#A5)

She also notes that her desire to help others and share their experience by giving emotional support is linked with her own child’s loss.

Nine of the parents, six women and three men, talked about reaching out to others individually (rather than through a support group). They often indicated that they were more comfortable with a low-key, personal encounter rather than a group discussion atmosphere, but that they were very motivated to reach out to others who lost a family member. One father spoke of how only a few days before his interview he’d attended the funeral of a friend’s child, and that he’d pulled the other father aside and asked to speak to him soon so that he could share some things from his own experience. These personal encounters are a way of communicating their understanding about what it means to lose a family member. Although some parents understood the concern that they might say
"something wrong," one mother suggested that "the worst thing is to say nothing at all or to do nothing." Stacy stated simply:

I reach out to other parents. Nobody reaches out to a parent who has been through this like a parent who has been through this. I think that is our mission. (#A4)

Having a child die gives parents a desire to reach out to others in similar circumstances which they may not have had before. One father, Ken, recalled:

We have had, over the years, friends and acquaintances who have lost children, and knowing how that affected us I think probably encouraged us to give support in ways that we probably would not have done before. (#B3)

This increased motivation is likely connected to the painful knowledge a parent has earned. Parents who have lost a child understand the dynamics of grief in a way that, they often feel, others cannot understand unless they themselves have also experienced it.

Peggy, a nurse, spoke of how her own loss changed her response to others:

Before there was always a sense of [reticence] about being the one to stay with the parents who had just lost a child, or who had a child that was very ill or had an accident. Now I always say, "I'll go be with the parents"... not because I think I can offer them anything. But because I understand. It doesn't scare me any more. I know what they're going through.

I'm sure that you've read about how health care providers don't look somebody in the eye when something bad has happened. I certainly do now. I encourage them to stay with the child as long as they want. I remember those feelings when people were saying to put her down. I don't do that. I know that they will naturally come to the point of being ready to stop holding. And I encourage parents to hold their child or at least touch them if they can't hold them, and it doesn't bother me when they stay in the room when I'm caring for them any more.

I talk about what they're going to be feeling in the next days and weeks. I try to tell them that whatever they do feel is okay, and that they shouldn't be ashamed of their feelings, whether it be anger, sadness, etc. (#A7)
Her ability to understand and communicate to other bereaved parents the desire to hold a child, the confusion of feelings, and other aspects of the loss experience makes her more able to care and comfort them. The care that bereaved parents extend because of their own loss may be the most powerful behavior that is related to losing a child.

Another type of support and outreach provided by parents because of their own child’s death is education outreach to others about losing a family member. Five parents in the study shared such efforts. One mother mentioned that “as a memorial to [our daughter], within that first year we sponsored a grief support seminar.” They often share with others how they can be most helpful when they know someone has experienced a child’s death. They may also try to teach about safety measures or ways to avoid the type of loss they experienced. Stacy taught courses on motorcycle safety and said:

In my son’s accident he was riding a motorcycle and lost control, which is very ironic because where I work we work with a group called the “Teen Oregon Motorcycle Program.” It’s for the education of young people who must at least have a driver’s license, for the novice on up to the experienced rider, and I work very closely with them. I work daily with them. . . . A parent will come up and say that they want to register their child for the program, and I will just look at them and feel like saying, “Have you lost your mind?”

I do work with them and they have a wonderful record with this program. I work with them daily. I bought a motorcycle for them so that they could train young people. If they’re determined to ride it, then they need to know what to do. . . . I was uncomfortable with it before, but I had no idea that it would become a mission [for me] now. That is really what it has become. . . . The one thing I do when I’m talking with young people who are going to register for the class, especially if they’re lackadaisical about it, is that this is not a toy. Then I will tell them that I lost my child in a motorcycle accident and it happened in a flash—this is not a toy. It is something to be taken very seriously and you need to be very responsible about it. So that’s what I do now.
I talk to young people and adults who are coming to this course. Hopefully, if I can save a parent the horror of losing a child, then maybe I can help in this way. I think I do it now with a different purpose. (#A4)

Being able to teach others about safety measures or how to approach someone who has lost a child gives bereaved parents an opportunity to reach out from their own experience in a positive way. These educational efforts have benefit both to the bereaved parent and those who learn.

Occasionally some parents who have lost a child will become motivated because of their loss to reach out to be protective or caring toward other children under stress. Three parents in the study described various situations in which they took action to be protective of a child in difficult circumstances. This tendency was described earlier in Chapter 4 as one of the aspects of a parent’s orientation to parenting that is affected when a child dies. Examples of this are included in that chapter also. In such cases, the parent intervenes in behalf of another child because of their own experience in not being able to help a son or daughter. As a father suggested, “I guess it’s part of that protectiveness coming out. You tend to want to be very protective, even if [the child] is not your own.”

**Time or Means Given Because of Parent’s Loss Experience**

Parents who have experienced a child’s death also extend care by giving time or means to causes and efforts they feel will benefit others, and sometimes these are linked to their own child’s death. Four parents in the study talked about giving of their time or means to prevention or relief efforts that would be of benefit to others who have also experienced a family crisis. One mother, Peggy, noted:
[Parents] find a way somehow so that the child won’t be forgotten, and some very good things have come out of that, like lights at railroad crossings and sometimes signal lights. If a doctor’s child has had a major illness then they might go in and do a lot of research on that, and of course it’s because of the child dying and it’s one of the things that they can do. (#A5)

As she suggests, bereaved parents may feel a deep motivation to make a difference because of their own child’s loss and many benefits have come from such efforts.

Examples of parental behavior cited by parents included educational efforts for prevention of accidents, fundraising for charitable agencies committed to children, and donations to families in need after a loss. Martha became very involved in giving time to a meaningful cause related to her child’s loss:

I found that Jessica was not the first one to have died at that street corner where she was killed. There have been numerous accidents there with pedestrians. Now what I’m doing as a cause or mission is trying to work with the railroad and the city of Salem to do something about these pedestrian railroad crossings. That’s what I’ve been doing for the last two years... I decided something had to be done. So the first few months I met with representatives from the railroad, who dismissed me right away. I was not about to let it go.

Over time I started talking to reporters. A neighbor of mine suggested that I call this railroad representative who was a friend of hers. She felt that if anybody would help me that he would, so I called him and let him know that something needed to be done. I told him I was not going to go to my grave until I saw something done, and if he didn’t want me out there at night painting those pedestrian railroad crossings white-yellow then they needed to do something now. At first he thought, “Oh, well, maybe she’ll lose interest or tire out.” I kept calling and calling and calling, until finally he said we’d get a meeting together and maybe assemble a task force. I said, “When?” He said, “Well, how about in six weeks?” I said, “No, how about next week?” He said, “Well, I don’t know if we can do it that quickly.” I said, “Try.” So he did...

I feel that this is my new mission in life. I have never been really comfortable speaking in front of groups, but all of a sudden I’m before TV reporters and cameras and giving speeches. I feel that if I don’t do it then we will have other people killed the same way. I don’t want another family to lose a child. If I could keep this pain from happening to another mother... I would do anything.
If it meant going out and doing what I'm doing now for the rest of my life to know that I kept somebody's child from being killed and I kept this pain from occurring for another parent, then I will have accomplished something. (#A9)

This mother's story is quite involved and not all of it is included here, but it provides an excellent example of how a parent's behavior in giving time to a particular cause or effort can be linked to their own loss experience. Perhaps she summarizes the feelings of many parents in saying, "If I could keep this pain from happening to another mother . . . I would do anything."

**Emotional Support and Outreach Given to Others in Place of Deceased Child**

A second distinctive theme identified in the parent's narratives was related to their efforts to give care to others in place of what they might have given to their child. Such efforts generally seemed to occur not so much out of a conscious effort to give to others in place of the child, but because of a parent's deep-seated need to nurture and care for others that must be re-directed when a child dies. A mother or father's need to love thus often combined with seeing an individual in need of love and the parents would then extend care or assistance. These efforts to care for others included outreach to many individuals across differing situations.

One of the challenges for a parent when a child dies is that they are surrounded by many others also grieving the child's death and in need of comfort. Among these may be the child's friends. Three parents talked about the time they took to reach out to the friends of their deceased child who were also grieving. In each case the child who had died was an older child of at least high school age. Ellen recalled:
I invited four of her girlfriends to our home and we talked about her. We talked about death. We talked about where she is now. We talked about the experience of death and how we can mourn for her here but know that she’s in a better place. That was something I did which was probably just as much a benefit for me as it was intended to be for them. Hopefully it did help them. They made several comments that it did help them, but I think it was also for me to be able to share that with them and share about her. (#A1)

She notes how her caring discussion with the child’s girlfriends was meant to benefit them but also benefitted her. Such friends may look instinctively to the child’s parent for recognition of their own grief at such a time. Parents who have cultivated a relationship with a child’s friends may thus find themselves “parenting” them after a child’s death.

Some families experience the circle of family life following a child’s death when a new child or a grandchild is born in the family. Parents may also encounter students or other children in need of a parent’s love. These situations may provide an opportunity for parents to exercise their need to care and nurture after a child’s death. Five parents in the study, all mothers, shared nearly twenty different experiences in which being able to care for new children in the family or other children fulfilled a need they felt to nurture.

The arrival of new children in the family circle can help parents to feel that life will continue and that they still have much love to share. One mother had a new baby approximately a year after the death of another young child, and she commented, “To have a baby in the home again, to have our arms filled, to be nursing–he filled a great need in me.” Another mother noted that her new baby “mended the hearts of the whole family.” Not only children but grandchildren can bring this healing opportunity for a parent. Jean, who became a grandmother a couple of years after her young adult son passed away, observed:
When my granddaughter, my first grandchild, was born, and when I would take care of her and just hold her body and put my hands on her body, it felt like I was giving her a blessing or a benediction as I would hold her in my arms. It kind of felt like she was doing the same back to me. Just by letting me hold her she was blessing me both body and spirit. It was so healing to me to take care of her, and it reminded me of why life went on. (#A2)

This mother’s story highlights the comfort that can come through such caring to a parent who has been deprived of the ability to care and nurture in the parenting role because of a child’s death. She notes that for her it was a healing experience emotionally to care for a child again and it reminded her of the continuation of life (often many bereaved parents feel that they want life to end).

Parents may also extend their need to care outside of the family circle to other children or young adults who they perceive to be in need of nurturing. They may be drawn to the needs of children who are students or to others who remind them of their own child. One of the mothers who lost a teenage son, Sandra, told of eventually inviting a young man from another country to live with their family several years after her son’s death. This young man reminded her of her own child because of his similar interests and he lived with them off and on for eight years. She noted:

I guess that [experience] more than anything else helped us, and particularly me, move back into a more normal life. I had a kid at home again to spoil, so to speak, and to take care of and to think about coming home and cooking meals for. That was really helpful for me. As a mother, I just kind of needed that again. . . . He was a familiar person in an unfamiliar place and so he needed some help, and that probably helped me move more back into life. (#A13)

This mother felt a familiarity to this young man and reached out to him because of his needs. As with the parents who felt caring for their own new child or grandchild helped them to heal, so did caring for this young man give this mother a renewed sense of self as
a parent. Another parent in the study, Jean, who was involved with students recalled her reaction after losing a child:

I am a teacher of college-age students and I went back to teaching very soon, and that intense need that I had to nurture and just pour out the nurturing that I felt, I just poured that out on these college students, whether they wanted it or not. I needed to do it so badly and it wasn't hard for me to love them besides my own kids. I just loved them and nurtured them like a mother hen. Instead of interfering with my teaching, I believe that this enhanced it, and it was a big blessing to me. (#A2)

Although deprived of the opportunity to care for the precious child they have raised and loved, some parents find that giving care to other children provides them with the next best thing.

**Material Assistance Given to Others in Place of Deceased Child**

Another pattern that emerged from the study was providing various types of material assistance to individuals or groups in place of the child. In other words, parents often decided to do something positive for someone else, usually in the child's memory, since they were no longer able to provide such things for the deceased child. The primary examples of this shared by parents in the study were giving scholarship or other financial assistance to others, donating financial or other assistance in the child's name to various organizations, or passing on the child's things.

Seven parents in the study talked about their efforts to establish scholarships or other forms of financial help to aid other children in pursuing educational goals. As mentioned earlier in this chapter, the establishment of such forms of help serves both as a memorial symbol of the child's life and a way to care for others in place of the child. In
every case the scholarship set up by the parents had specific criteria that reflected the interests or personality of the deceased child. For example, some were given to students in music if the child had been involved musically, while others required a screening process that helped the parents to identify a young person with their child’s interests and values. This pattern seems to confirm the idea that such assistance is given in place of what might have been given to the child who died. Often the parents are themselves involved in selecting the recipient of the scholarship. Carol stated:

My sense of parenting her now is through her scholarship, for example, to see that it goes to the same kind of young woman that she is. There’s a special criteria and so you look for that in other young people. . . . The criteria has to be an average girl student. It can’t be a straight “A” student or a straight “B” student.

The first scholarship recipient was very ironic. She was a ballerina just like Lisa was, and she was also headed into school to do criminal justice and work for children. So it was just really kind of strange to have this young lady following in the same footsteps. . . . I think as a parent your biggest fear is that somehow your child is going to be forgotten, and you can’t bear that thought. . . . So, I think you do it because you don’t want that child forgotten. (#A6)

This mother’s comments reflect her sense that she wants the assistance to be given “to the same kind of young woman” that her daughter had been, and in fact she describes a scholarship recipient who apparently had many of her daughter’s own interests. She also suggests that giving the scholarship provides a sense of parenting that is connected to her deceased child.

Parents may give material assistance related to the child by providing donations in the child’s name to various organizations they find appropriate. Six parents discussed their efforts to give such donations and how they were connected to their child’s memory. Generally these examples consisted of making a financial donation in the child’s name to
a place like the Ronald McDonald House or other organizations which support children
and families, but also included giving books to the library in the child’s name, etc. Carol
also recounted how her support of certain groups was linked to her child’s memory:

I support Project Patch, which is a ranch in Idaho for what are called “garbage
children,” and so money that I would normally spend on her is donated to
different things in her name. Westminster House in her name, St. Jude’s Ranch in
Colorado, or other things that will help other children who are not as fortunate. . .
. Mostly it is financially supporting these places that I have screened and picked
that do wonderful work for young people. (#A6)

Her financial support of these various organizations is linked to their efforts to do work
for young people. It also ties to giving in place of what might have gone to her child.
Such efforts allow parents to know that their child’s name is recognized somewhere and
that others, usually children, can benefit from the assistance that might have gone to their
own child.

One other type of material assistance that parents mentioned was passing on items
that had belonged to the child to others. Only a couple of examples were given that
reflected this pattern, but they consisted of parents giving the child’s clothing or other
items to friends or needy organizations. A mother suggested that her daughter would
have said to her, “Don’t forget me, but you have no use for those things, so give them to
people that need them.” That is what some parents did.

**Emotional Support and Outreach Given to Others in Behalf of Deceased Child**

A final theme that came from the study analysis on parental care related to the
deceased child focused on emotional outreach or support that parents extended in behalf
of the child. In these situations the parent essentially acted as a proxy for the child and
suggested that they did what the child would have done. Parents suggested that this occurred primarily in two ways, either caring for another person that the child would have cared for or participating in an activity in which the child would have participated.

Two of the parents mentioned their efforts to reach out and care for someone they felt the child had cared deeply about, and in each case they indicated that their efforts were carried out in behalf of the deceased child. One mother who extended friendship to her young adult son’s friend commented, “I love Don (son’s friend), and when I love him I can feel my son’s approval. I can feel his fondness for this friend and his pleasure that we have gotten to know each other.” Another mother, Martha, felt compelled to fulfill the promise that her daughter had made to a young friend living in a foreign country to take her to Disneyland. After her daughter died, this mother made a concerted effort to fulfill this promise:

I finally found the address and it took a year. We got Senator Wyden to help us and sent her a ticket last summer. She arrived with the Willamette group and so she was chaperoned on the way here. She didn’t speak a word of English and had never been away from home. She traveled thousands and thousands of miles and I took her to Disneyland, then [my husband] and I took her back and met all of these people on another continent that had met our daughter and knew our daughter. . . .

I never saw it as parenting. I saw it as a way of perpetuating her memory and also of fulfilling a promise she had made to a child . . . fulfilling a promise my daughter had made to a child and just showing them what she was all about. She really loved this little girl and cared about her. (#A9)

This mother’s care was extended in behalf of care that her own daughter would have given if she had lived. She saw it not as giving care that would have gone to her own daughter, but as a way of perpetuating her daughter’s memory and fulfilling her
daughter's promise. These examples did not represent a common pattern, but the parents who discussed this seemed to feel a deep kinship with their deceased children as they cared in this way.

Parents also shared examples of participating in activities that they felt their deceased child would have enjoyed or participated in themselves. Only two examples were shared by parents in the study, and these involved participation in a high school graduation and in a charitable endeavor. In these circumstances the parent may be officially asked to represent the child (as when a child graduates posthumously), or they may simply choose to participate in something they feel the child would have participated in also. The mother who was involved in charitable work simply stated, "I worked at A.C. Gilbert House building their outdoor Discovery Village, for her, because that's something she would have done." Participation in such activities may provide parents with a special opportunity to feel close to the child's memory and do something in the child's behalf.

Summary

Although parents must struggle with their new parental future when a child dies and the direct functions of parenting seem to be suspended, bereaved parents seem to find ways to connect with the child’s memory and continue their efforts to nurture. Parents who have lost a child carry a fear that they or others might forget the child. They must continue in the parental role immediately after a child dies as they plan memorial arrangements and carry out other functions. They also engage in a variety of parental
behaviors related to the deceased child that include finding ways to feel emotionally connected to the child, making efforts to remember or memorialize the child, and extending care and assistance related to the child. These themes in a parent’s behavior after losing a child show that despite the loss there are significant ways in which mothers and fathers continue to seek a meaningful and empowering connection to the child who has died.
CHAPTER VIII

PARENTAL BEHAVIOR AND OTHER CHILDREN

The intensity with which a child's death impacts a parent's emotional stability and sense of identity is akin to the effect of a tidal wave crashing upon the shore of a vulnerable coastline. A parent's emotions are thrown into confusion and it can become very challenging to restore a cohesive sense of self as a parent. Even though most parents do come to some kind of emotional resolution it can take years and the parent has become a different person than they were prior to the loss experience. Because many parents also have other children who they must continue to care for after losing a child, the manner in which they respond to a child's loss can have a critical influence on their parent-child relationships and their behavior they as a parent (Bernstein, 1997). One researcher has noted the challenge for bereaved parents who must "cope with the conflict of trying to disengage themselves from the parental role with regard to the deceased child, while at the same time to continue this role with regard to their surviving children" (Rando, 1985, p. 22). While evidence from the previous chapter suggests that parents may transform more than disengage from the parental role with the deceased child, it seems clear that parents who are struggling with grief at a child's death do face significant issues related to their continuing parental role. Examining these issues and the way a parent's behavior toward their other children is affected by a child's death was a key purpose of this study. The study analysis indicated the following primary themes associated with parental behavior related to other children: (1) the parent's effort to mediate the lost child's death
for other children; (2) the impact of the loss on the dynamics of the parent-child relationship; (3) the parent’s increased protectiveness of other children; (4) the parent’s desire to be more involved with the other children; (5) the parent’s increased acceptance of other children; and (6) the parent’s increased attention to parenting quality.

Parental Efforts to Mediate Lost Child’s Death for Other Children

A parent who loses a child is placed in the complex situation of dealing with the sudden absence of one child while also needing to continue parenting other children. The foremost concern that a parent may encounter with other children upon a child’s death is how these children will deal with the loss of a sibling. Loss of a family member can be devastating for any person and it is no less difficult for siblings of a deceased child. One mother in the study who had twins and lost one of them noted that at one point the remaining twin told her that she “did not understand what I am feeling, [because you] only lost a daughter but she had lost part of herself.” Parents in the study generally responded by trying to mediate the difficulty of the loss experience for their other children in various ways. The parents did this through directly managing the other children’s interaction with aspects of the loss experience at the time of death, assisting other children to adjust emotionally to the loss, and providing opportunities for other children to connect with the deceased child.

One of the first things that parents did regarding their other children was to take responsibility for how their other children interacted with various aspects of their sibling’s death. In other words, parents took a mediating role in trying to be emotionally
strong for other children, sharing feelings with other children, and making sure that child interaction with the deceased child was appropriate. Nine parents in the study described a variety of examples in which they tried to mediate the impact of the lost child’s death for the other children. Parents were concerned about being protective of the emotional experience of their other children and minimizing their exposure to negative aspects of the loss experience. Peggy, whose daughter died of a fall while in the yard with her sibling, remembered her concern for her son:

We found out her cause of death, which was a ruptured diaphragm and a ruptured stomach. Her stomach contents had all gone into her lungs and so she’d suffocated. So she had a fall, but why she had a fall we don’t know. She had to have fallen from the climbing structure, and because of all the prednisone she was on her tissue was very frail. She landed just right, but why she had that fall... Terry has said that he remembers seeing her like she was all of a sudden frozen, just staring out, and then she fell. He remembers trying to nudge her with the little whiffle bat, a little plastic bat... but that’s a three-year old’s memory, and a three-year old can’t discern between fact and fantasy. We never did ask him what happened. As much as we wanted to, we were both very aware that we did not want to make him feel guilty. (#A7)

In this case her concern as a mother for her living son’s emotional well-being takes precedence over her questions about why her daughter had a fall, and so she doesn’t ask questions of her son that she feels might give him a more negative emotional response to the loss. Again this fits a pattern of trying to minimize negative effects of the loss for other children. Parents tried to make sure that the interaction of other children with the aftermath of the child’s death was also protected. Jean was in the auto accident in which her son died and she recalled:

When I came home several of my neighbors were in my front yard... my clothes were still all bloody and my hair was all bloody, and as these women began putting their hands on me as I walked in the house and said, “What can we do for
you?,” I said, “Help me get these clothes off and help me get this blood out of my hair before my daughters come, because I don’t want them to see me this way.” My face had already started to purple up from black eyes and bruises and stuff, and I didn’t want this to scare them, and so I remember being so anxious to take care of that. (#A2)

The account shows her desire to make sure that her other children would not be overly traumatized by seeing her injuries after the loss. This pattern extended to how parents mediated the contact of other children with the deceased child as well. They tried to be present with their other children and explain the loss of the sibling in a calming way.

Another facet of the parents’ efforts to minimize negative aspects of the loss experience existed in their efforts to be emotionally comforting to the surviving children. Some parents talked of trying to remain emotionally stable for their other children, while others spoke about helping their other children to understand the loss. In one family with a number of older children who lost a baby sister to the effects of cancer, the mother remembered bringing the children to be with the lost child shortly after her death.

Parents, in the midst of their own grief, often still tried to be a guiding influence for their other children at this difficult time. Ken, a father who lost a young son in an accident and also had an infant son, spoke of trying to be sensitive to the young child’s needs:

[My youngest son] was just shy of a year old. He turned one on the 28th of June and Ryan died on the 23rd. With all of the confusion [related to] his passing, so many people in and out of the house, both [my wife] and I not being as aware of what the kids’ needs were as we could have been and probably should have been, and with him particularly because he was a baby and the assumption of course was that he had no idea what was going on . . . I remember he was generally a pretty good kid. He was not only inclined to minimal crying and fits but he usually went to bed pretty good. But for a few days immediately after and even prior to the services, he was just very hard to handle and was not sleeping. We weren’t sleeping much anyway, but it was nice to try and get a little rest and just have some quiet and peace, which he wasn’t allowing too much.
I remember one evening it just seemed to strike me that nobody had told him what was going on. So I went in and got him, took him out, and we were sitting on the porch in the middle of the night, and I just talked to him basically the way that I talked to the other kids. I tried to explain it to him . . . there was a real peace that came over both of us and he quieted right down. It seemed that he just understood, on a spiritual level I’m sure, because it certainly wasn’t on an intellectual level at that point. (#B3)

In these examples the parents reach out with tenderness to their other children and try to make certain they are not isolated emotionally following the loss of a sibling. Whether discussing the loss with children or reaffirming their beliefs and values, these efforts to include the other children and be protective of their emotional well-being highlights an important issue that bereaved parents and others must consider.

A second important pattern appeared in parents’ efforts to help other children adjust emotionally to losing a family member. Thirteen parents in the study, eleven women and two men, discussed numerous examples of the need for increased sensitivity to other children and their emotional challenges in dealing with the lost child’s death. Some children that parents described seemed to follow a normal pattern of grief and emotional adjustment, but quite often parents described needing to be supportive of children who had quite severe emotional difficulties following the death of a sibling. These children tended to struggle with depression, a sense of personal responsibility related to the loss, and involvement in various risk behaviors. Anne spoke of her daughter’s emotional challenges after her son’s loss:

In this process there were things with my daughter. I know how I felt but I think she was probably more profoundly impacted than any of us were. She and her brother were very close. I would say that within six years she was an alcoholic and this [had been] a girl who didn’t drink or smoke. Within a few years after her brother’s death she started drinking and she’s an alcoholic today, in and out of
treatment, and what I call a “periodic alcoholic.” She can go for a period of time and then she starts again. Who knows what would have happened if Gary hadn’t been killed? She describes herself as the poster child for denial, and she is just only now really believing that he will not come back and that he’s gone. . . . My daughter felt like her brother was partially her responsibility and that’s one of the things she’s had trouble with [since his death]. She felt she could have prevented that situation. (#A3)

A child’s death may thus trigger new parenting challenges with other children because of the emotional struggles they may face following a loss. Another mother, Carol, mentioned the challenges with a child’s sibling:

Having to deal with her younger brother . . . he’s going through what we call the “wo-sho-cos” at the Compassionate Friends. Would haves, should haves, and could haves. If he had not been in Nebraska, she wouldn’t have been there. She would have been here. Would she have been safe? Would she still have been killed? We don’t know. That’s where quantum physics and random acts of nature come in. (#A6)

Seeing one’s other children struggle with the grief process following a sibling’s loss can be difficult, and sometimes parents feel victimized not only by their own mourning but because they must worry about their other children’s emotional difficulties.

Parents in the study also shared different examples of steps they took to help other children work through the emotional challenges they experienced. As with parents, other children in the family will experience grief in very unique ways according to their own temperament, background and developmental stage of life. An infant will have different emotional needs than a fifteen-year old sibling after a child’s death. Being sensitive to these differing needs and reaching out to help other children is one of a parent’s main challenges. In one family with a number of other children, the mother Amy discussed her efforts to help them:
We had to deal with things such as talking about death with the kids and talking about their feelings afterwards. Alisa especially . . . her teacher noticed her handwriting went from real smooth to real chaotic. She was writing nice little lines and then after Gina died she started to write sideways and fill up the page. They say that her age group is one of the hardest ages because they can't always bridge reality and they're not sure where it all fits in. . . . With the other children we let them grieve and we let them talk about it. We let them go and write essays at school. Many of them wrote all kinds of essays through middle school and high school about how this affected them. So we always tried to be real open and talk about it, and not ever make them feel that they couldn't talk about it because it was too hard for us. (#A10)

She demonstrates how parents assist their other children by being open to their emotional needs and helping them to deal with their feelings, whether through writing about them or discussing them with each other. Other children may struggle with their sense of place in the family and the parents must reassure them and help them to adjust. One father noted his young son felt some loss of direction because his older brother had been his "guide and role model in learning ways to do things and how they're done." So, the father spent time trying to be the child's playmate and helping him find a new role. Ken recalled:

We've had a second son who I think as a direct result of losing [our other child] and his ability to deal with that . . . he had feelings of maybe that he should have been the one to have gone . . . so I think he became more of a risk taker, and as a result he did some pretty stupid things and was involved in some pretty stupid things, as a direct result of his perception of the death and how it affected him and where his standing was in the family. It was quite a challenge for a while, not only in dealing with him and his outbursts, but also in trying to help him understand that we didn't care for one more than another. (#B3)

Parents may be challenged by the emotional difficulties that their other children face after a sibling dies, but the parents who discussed these concerns showed evidence of actively trying to assist their other children to heal from the trauma of the loss experience.
A further pattern related to parents’ efforts to help these children feel a connection to the deceased child. Seven parents in the study shared a dozen experiences that reflected this theme. In these examples the parents tried to give their other children various opportunities to experience an emotional tie to the lost child. Such opportunities most commonly consisted of the parents and children discussing or remembering the deceased child or the parents encouraging children to participate in some type of memorial activity related to the deceased child. These parental efforts to help other children feel connected to the lost child correspond closely with such activities mentioned in the previous chapter. It seems important to parents to help their other children feel the continuing place of the deceased child in the family circle. Children also feel a natural curiosity and desire to know about the deceased sibling. One mother talked of how her children would pick up the child’s photo album and ask her to tell them about their sister who had died. As parents respond they help children to feel closer to the lost child. Parents also shared experiences in creating an opportunity for their other children to feel a connection by giving them mementoes of the child to wear or having them participate in memorial events linked to the child who died. One mother encouraged all of her children to wear something that had belonged to a deceased brother when they graduated from high school or college. These efforts to link their surviving children with the lost child’s memory allow both parents and children to share the experience of losing a family member in a way that strengthens their own ties to each other.
Parent-Child Relationship Dynamics Affected by a Child’s Death

When a child in a family dies it not only changes the relationship of that child and the parents forever, it also transforms the relationships of all other members of the family to each other. Each family member must face the struggle with grief and deal with the influence of that struggle on their own well-being and their interactions with other family members. A powerful theme articulated by parents in this study concerned the impact of a child’s death on the parent-child relationship dynamics in the family following the loss. The emotional messages and interactions exchanged by surviving family members, particularly between parents and children, can be dramatically affected. The influences of the loss can be seen in the continuing interaction between parents and children, the parent’s challenges in the parental role, and the changes in family roles and relationships.

Although a parent’s life may be thrown into crisis with the illness or death of a child, no parent is granted a reprieve from being the mother or father of other children at the same time. One of the important patterns in parental experience with other children during the loss experience is the need to balance care of other children with attention to and care of a dying or deceased child. Eleven of the study participants, nine women and two men, shared a variety of stories reflecting the challenges that exist in balancing between the needs of surviving children and dying or deceased children. Of course, this situation is exacerbated when one child is ill and dying and the parent must care for and be with them to make decisions. While parenting the ill or deceased child, the other children (especially if they are young children) have continuing needs and the parent
must somehow balance in meeting the needs of both. One mother, Pam, recalled feeling this conflict in caring for a daughter with cancer:

One of the things I used to be concerned about when she was little is that I did not want [the other children] to resent her because of the attention she required. So I had this big idea about somehow giving her what she needed and being able to give them what they needed, and them not resenting the fact that she had to go to the doctor so often and all of these other things. . . . I did not want them to resent her. I remember talking with them after she had died and maybe apologizing to them because of all the care that I’d had to give her . . . but the older one said, “Oh, no, Mom, you did a good job.” So I thought, “Okay, well I won’t argue and we won’t talk about that any more.” So if he didn’t resent her, and I was especially concerned more with the older son than with my younger son, then I’m very grateful and hopefully I achieved what I was trying to do. (#A5)

This example highlights the challenge parents face in wanting to meet the needs of other children while also needing to give physical care and attention to a dying or deceased child, as well as feeling emotionally drawn to care for the child whose life is threatened. As expressed here, parents often worry that their children (or even themselves) may feel resentment at having to give so much attention to the dying or deceased child.

In these circumstances assistance from others is extremely helpful and deeply appreciated by parents. A number of parents expressed gratitude for family, friends, or organizations like the Ronald McDonald House that aid parents in the intense situation surrounding a child’s illness or death. It is in such circumstances of intense parenting need that the idea of “the village” (i.e. the extended social support system) caring for children in need can be truly helpful. In a crisis situation the parenting decisions and demands can be so high that meeting the needs of other children in the family personally can be very difficult. At times parents must weigh the costs and benefits of how they will
handle meeting the needs of everyone in the family. One mother, Peggy, had to decide about whether to end a dying child’s life support and recalled the process:

[Deciding to end life support] was the easiest decision that we had, and it was because of our medical backgrounds. We knew that everything had been done. We had no guilt about the chances . . . I mean, yes, there’s always a chance, but at what price? I’ve watched families having a child kept alive on the respirator for months. I’ve watched what that does to a family . . . and you smell them dying. There’s a smell that comes with death. I have no doubts about that [decision]. And I felt that I had a responsibility to [my other two children]. I mean, it was hard! You want to hang on to that hope. I guess that in one sense I took over early from the day that we had the respirator off, feeling that I had to care for my other children too. It was not just Tina and me, it was the five of us. (#A7)

Balancing between the needs of a dying child versus other children in the family during the crisis of a loss experience is difficult. As parents seek this balance they are often just beginning a process that will continue for some time in the parent-child relationship.

Following the crisis period of a child’s illness or death, parents then face the personal difficulty of dealing with the emotional consequences of losing a child. At the same time the parenting demands of caring for other children tend to continue unabated. Eleven parents in the study, ten mothers and a father, remarked on the various and ongoing challenges associated with the continuing demands upon their time and energies as a parent. These demands may range from caring for an ill child to giving daily care to helping a child cope with grief. Some parents were relieved by the chance to focus on something besides their own grief, while others felt that their grieving was made more difficult because of such parenting demands. A mother who felt this latter emotion, Martha, talked about the demands to care for other children:

I really felt that I did not have time to grieve because I was so worried about Jessica’s sister. During the week after she died we had a lot of people, and Cindy
is not a people person. She lives in Seattle and was here with her boyfriend for two weeks, and I think she was just wanting some quiet time and time alone. She could not understand why I would want to be around so many people, because she is the opposite. Because of the closeness and the bond with twins I worried so much . . . I knew what I had to do. I knew that I had to take care of [her and her brother], and [my husband] and I had a lot of things that we had to do yet in life. (#A9)

In this instance the mother suggests that focusing on her daughter’s continuing needs made it more difficult for her to go through the grief process. Parents may also feel that giving attention to their own needs makes it difficult for the other children to receive enough parental attention. A father in the study, Tom, described this experience:

It’s hard to jump back in the water and totally give myself over to Jimmy as a father. . . . My whole enthusiasm for it isn’t quite like it was. I feel also that I’ve let him down a lot in some respects, in that as we tried to recover from the shock of losing Andy we could not deal with a three-year old. He went through about a year and a half or two years of not really having his parents. There were two people there who kept him clothed, bathed, fed, and read him stories, but they weren’t really there for him. They weren’t really a happy, functioning unit as a family. So he’s had two years of development that he’s missed, and as a parent I can see that too. (#B6)

Most parents seem to encounter the additional challenges that accompany a sense of being lost in the parental role or overwhelmed by the grief that makes continued parenting difficult. It has been noted that a child’s loss knocks parents out of the parental box for a period (Bernstein, 1997). These concerns with ongoing parenting demands highlight the process a parent experiences in that context.

The parenting of other children after a child’s death tends to be complicated even more by the emotional ups and downs of the grief process. Another of the important themes that parents shared was the impact of losing a child on their emotional and physical energy for the tasks of parenting. Eleven study participants, nine women and
two men, cited numerous examples of more difficult parenting of other children due to
the effects of depleted emotional and physical energy during the grief process. Some of
the specific effects on their parenting that they described included loss of energy for
caregiving, increased anger and impatience, and conflictual feelings about parenting-
related tasks (celebration of holidays, etc.). Losing a child takes a toll on parents
physically because they often sleep less and experience a great deal of fatigue. They are
also emotionally drained by the powerful emotions accompanying grief that can result in
guilt and depression. This combination of emotional and physical fatigue can make being
responsive to the needs of other children difficult. A mother, Peggy, recalled:

[I remember] feeling so, so depressed, and not being able to respond to the kids
the way I normally would have done and the way I felt that I should. I remember
feeling like I was in the bottom of a whirlpool and the rest of life was going on up
above, and I was swimming around between anger and guilt and sorrow and I
couldn’t climb back up. . . . Those days when it was a challenge to get out of bed . . .
for days and weeks I would go with two or three hours of sleep because I
couldn’t fall asleep. Then, obviously, with little kids you have to get up! You
can’t stay in bed. So, physically being so exhausted . . . I remember just figuring
I’d done a good job if I had them dressed, if I made sure they were safe and fed.
And I couldn’t do anything more than that. And then you’d feel guilty that you
weren’t doing more. (#A7)

Her account dramatizes the emotional maelstrom of a parent dealing with grief, as well as
the challenges of physically wearing out due to stress and lack of sleep. These factors can
make it more difficult to give sufficient care to children, which may also make parents
feel guilty about not caring enough for them. Another mother mentioned this and said
she “had felt that my other children were neglected, and I was feeling guilty that I
couldn’t give them that much attention.” This pattern of difficulty in caring for other
children due to emotional and physical fatigue was most common in the first months and
years after a child’s death. Overcoming this challenge and resuming a more balanced relationship with other children can thus take some time.

Additional aspects of parenting difficulty associated with parental fatigue included conflict within the parental role and increased feelings of anger or impatience as a parent. The struggles experienced by some parents in feeling comfortable in the parental role after a child’s death were discussed earlier in Chapter 5. Parents, for example, may be caught between not wanting to perform certain role functions but feeling obligated to do so because of their role as a mother or father. Parents in the study seemed to adjust to these feelings of parental role conflict over time after two or three years following the child’s death. Another factor some parents expressed concern about was the lack of patience they found in themselves at times due to emotional or physical energy loss. Tom discussed the impact on how he responded to his young son:

The grief is a very physically debilitating thing. Emotionally it wrings you out and, as a result, physically you feel very drained and tired a lot. So it was hard to have energy to deal with Jimmy emotionally, such as with temper tantrums and stuff . . . I think that, in fact, the thing that impacted us the most as far as physical maintenance was the amount of patience we’ve had. Not much patience at all because the energy wasn’t there to deal with it. If he started pitching a fit about not wanting to have a bath, or it’s too hot or cold, or he doesn’t want to come out now—I didn’t want to put up with that. I wouldn’t tell him that but he could tell I might be very upset. (#B6)

Losing a child can lower a parent’s energy levels and make them feel less patient when faced with stress in parenting other children. These patterns may be important for those working with parents after a child’s death to give attention to and help parents as they make emotional adjustments in the parental role.
Another challenge to some parents that emerged from the study was a sense of role reversal in relation to their surviving children. This theme was discussed only by five mothers in the study and in each case it related to their relationships with other children who were young adults. The women noted that their other children expressed much concern for them as parents in the aftermath of the loss and often took on added responsibility in assessing the parent’s well-being, thus giving them a sense that their children had reversed roles with them and taken on a protective “parental” demeanor. This sense of role reversal worried parents who felt that perhaps the added responsibility and worry their young adult children felt towards them would be too stifling or stressful. A mother noted her child was “like a mother hen with me now.” The concern of other children for their parents’ welfare tended to occur in the form of protectiveness and extra nurturing behavior. Carol shared the following example:

My older son and his new wife live with me upstairs. I do go to Compassionate Friends every month and it’s late at night sometimes. We don’t have a shut-off time and the kids know this. My life is on the calendar. They know that... In [my son’s] recovery business he did a recovery for a man in Salem. The man called and we started talking on the phone. It ended up with this man asking me for lunch, and I said, “Okay, fine.” We met in a public place in Salem and went to lunch. He then asked me out again, however, this time it was in the evening. I did not come home and the kids did not know where I was. I had left right from work, went to Salem and had dinner, and then came home. They were in bed. No big deal.

Well, I guess it was a big deal. It happened again and I was out very late. At midnight [my son] comes padding down the steps. He normally has to get up about 2:00 a.m. to go to work. He asks, “Where have you been?” “Out.” “You had my wife worried. She’s been waking me up every half hour. Where were you? You didn’t tell us you were going anywhere.” I said, “Look, I had a date, I went out, and I’m fine.”
The next time came around and I was going out, and I said to the kids as I was leaving, “By the way, I’m going out tonight and I’ll be late.” Dead silence. So I came back just to tease them and said, “Can I go out tonight if I’m a good girl and come home on time?” The thing is that it’s parental role reversal. I am to take my own car, I am to meet in a public place, and I’m to be home by 9:30. If they’re at my house, then they’re to leave by 9:30. It’s a fear of one more loss. We’ve had so many. (#A6)

This shows how other children sometimes take on a parental role toward their own parents after a child in the family has died. The pattern shows how the dynamics of a parent-child relationship may become altered by the loss of a child.

Parents who lose children may also find it challenging to make the adjustment to changes in family roles and dynamics that occur following the loss. A child’s death forces parents and other children into new roles and ways of relating to each other that require individual adaptation. Five parents, three mothers and two fathers, noted the impact of losing a child on the growth of other children and how they were required to adjust as parents. Generally, the parents saw the changes in family roles that related to a child’s loss as challenging but not incapacitating. However, parents and children both grieve for the family’s former situation and must work to create a new future together. As one parent noted, “It takes a while to overcome what the family was and then [face] what it becomes.” One of the fathers in the study, Tom, explained this experience:

The sense of loss for the whole family structure is a very big part of it. In the whole family Andy was . . . the thing we didn’t realize until immediately after he was gone was just how big a part of us he was. He was Jimmy’s guide and role model in learning ways to do things and how they’re done. He defined Lori’s daily patterns of what she engaged in and her whole role as a mother in taking the boys here and there, etc. Jimmy usually went along for the ride because he was so young, but she was always going to his play group, school, etc. My whole role as a father [was involved with] watching him grow and develop into a young man and be successful. So, he was a very central part of all of us. As a parent you
never really think about the ultimate. What would happen if you lost your oldest [child] or the child who is most centrally involved in everything? It's so awful to comprehend or even think about that your mind doesn't even go there, and then when it happened you never realized how much of an impact he had on all of our lives until he was gone. So, in a sense we all lost different parts and pieces of our roles and relationships to each other when he died. (#B6)

Dynamic shifts in parent-child relationships sometimes occur in a family after a child's death. This father later mentioned the challenge of trying to go from a “four-person family” to a “three-person family” and how it meant re-defining the relationships and roles within the family. As family roles change the other children also grow and develop in new ways. Ellen noticed one daughter’s growth in a new role as oldest child in the family after her sister passed away:

[My daughter] has become a much more assured person. She will never be as outgoing as others, but she is much more so than she had ever been and so that’s a blessing in disguise. She’d held back and let Rebecca take the limelight, because she did so many things. . . . No experience is wasted on us. Every experience is for our growth, even though it may be painful to go through at the time. (#A1)

Her attention to her daughter’s growth in new ways shows that this mother is aware of how a child’s death has transformed the roles and relationships within the family system, for her as well as her other children. Parents and surviving children both need to make adjustments in this process and re-define the way they may relate to each other.

Relationships with other children in the family may also be affected by the way a parent’s marital relationship is impacted following a child’s loss. The impact of a child’s death on marital relationships has been studied by a number of researchers and it seems clear that the resulting stresses tend to push couples toward conflict or bring them closer over time. Nine parents in the study, five women and four men, commented on how their
marital relationships were affected as result of the child’s death and how this impacted their remaining children. The other children tend to be affected indirectly as the parents struggle in their personal relationship to cope with different grieving styles. One woman, Peggy, spoke of feeling that as a result of the years of coping with grief she had also lost a relationship with her husband in some ways during that period. She noted:

You realize this person that you’re married to, who has always been a rock, isn’t . . . I don’t think our marriage has ever been him taking care of me or me taking care of him, but you rely on each other emotionally, and it was at that point that I really realized how I couldn’t . . . he wasn’t going to help fix everything. Because he couldn’t, not because he wouldn’t. It started to dawn on me how we were going to do down this path, but certainly not together. (#A7)

This mother’s experience shows how a husband or wife often feels loneliness after the loss and the difficulty of knowing that a spouse can’t just “fix everything.” As parents experience such stresses in the marriage the children may receive less attention or see more parental conflict. In contrast, children may also see the example of parents who work together to overcome the pain of losing another child. One father noted that although prior to the loss of his son he never came home for lunch, since that time he had come home to have lunch with his wife each day for fifteen years. This fundamental adjustment in the marital interaction indirectly affects the environment of the home for other children. Another father, John, commented:

There’s nothing that could take away the things that [my wife] and I have gone through together, it’s like going through a battle. We can relate to things that I don’t think . . . not taking away from someone else’s relationship with their wife or saying that it’s not as strong as mine . . . but there are things we’ve gone through in our life having that happen, good and bad, that it’s like walking on sacred ground. I have a certain trust with my wife. (#B2)
The powerful emotional tie reflected in this husband's feelings for his wife indicates a deep level of interpersonal support, which again has an indirect influence on how they support each other as parents in providing a positive home atmosphere for their children. Thus, the effects of losing a child on the marital relationship indirectly influence other children due to the impact on the family environment.

A final theme that parents described regarding how a child's death affects parent-child relationships was simply in the quality of the relationship with remaining children. Four parents, three mothers and a father, talked of how relationships with their other children had deepened significantly as a result of passing through the loss experience together. They felt a shared understanding and bond that was deeper than before. A mother, Anne, mentioned how she and her daughter had grown closer to each other:

I think we were close before [the loss], but it certainly brought us closer. It's wonderful to have somebody with whom you can say anything that you're thinking about that child. If I say something to my husband, he's likely to come up with some story that he remembers that maybe wasn't so positive, although I must say he does come up with some beauties once in a while. Those are just gems and gifts. But here's a classic example of what I'm talking about with my daughter. She and I were downtown in Corvallis during the next year after Gary was killed and some young man called out, "Hey, Mom, wait up." Just his tone of voice and everything...I didn't say what I was thinking and [my daughter] said it out loud, "That's something you'll never hear again." That was exactly what was going through my mind. To have somebody who can be so in tune with what you're thinking and feeling, and to verbalize it and say it out loud. (#A3)

Other parents in the study mentioned growing closer to their other children and cherishing those existing relationships more deeply. Many parents made efforts to more consciously spend time with their other children and build those relationships. These
strengthened emotional ties that some parents experience with other children reflect a
diversity of patterns in which parents focus more on caring for these children.

**Parental Protectiveness of Other Children**

Parents who have lost a child come to know through intimate experience how
truly vulnerable their relationships within the family can be. As a result, they tend to be
more concerned about the potential of similar losses with other children. One of the
strongest themes that emerged in the entire study was the tendency for parents to be much
more emotionally anxious and protective of their remaining children following the death
of a child. Approximately fifteen of nineteen parents, twelve women and three men,
indicated this pattern in their parenting of other children and shared over thirty examples
in varying situations. Parents expressed concern about a variety of child-related issues
and indicated heightened emotional anxiety, increased mental attention to children, and a
much stronger tendency to take protective action related to their other children.

The primary concern that parents expressed in feeling more protective of their
other children was the fear of potentially losing another child. Thus, parents who had
children they perceived to be “risk takers” felt especially vulnerable and anxious when
considering the actions of those children. Anne noted these feelings:

> Well, I think my daughter’s alcoholism is just about the worst. That is a terrible,
terrible thing to deal with, it’s just hideous. . . . Having lost one child and also
having a child who is sometimes in life-threatening situations, [such as] if she’s
drinking and driving or make decisions or blacked out . . . it’s just a nightmare.
All I can do is just hope that today she’s not drinking and that yesterday she
wasn’t drinking. Five days ago she might have been. You just hope that there are
the non-drinking days and that maybe some day there will be a miracle and she
will stop. (#A3)
This account illustrates two key issues, the first being that a parent’s fear of potentially losing other children can be very powerful, and the second being that having a child who takes risks that put them in danger adds immeasurable anxiety to the emotional equation. Another mother mentioned that a bereaved parent will do “anything that will keep [other children] safe” because “you know firsthand that children can die.” Parents also expressed concern about other issues such as a child’s safety, health, or particular life choices. Jean, whose children sometimes made choices that she was worried about, shared such feelings:

As my children have made lifestyle choices that I disagree with, I have maybe been disproportionately anxious, not angry, but anxious about those choices, because anything that takes them further from the family is a problem with me. . . I know [I give] pressure. I know it [is] overt. I know it [is] guilt-making. I know it [is] all of that stuff. But I can’t help it. (#A2)

This mother’s concern for choices made by her children makes her more likely to put pressure on them in ways that she knows can make the parent-child relationship more difficult, but she says clearly that she “can’t help it”—the anxiety for their welfare is so strong. Concern about these issues and others places parents in a situation with their other children that requires balance and understanding from both sides.

Although being protective of children is a fundamental part of a parent’s role, at the same time parents must moderate this tendency to protect and allow children to grow and explore the world around them. A bereaved parent’s ability to temper such tendencies is more difficult due to the extreme emotional anxiety that occurs when they fear for a child’s well-being. This emotional anxiety can become almost paralyzing and
parents may become panic-stricken if they feel unable to take some action to protect their children. Stacy, whose young adult daughter was growing, expressed such anxiety:

My daughter will be twenty-two in November and she’s getting to be near the age Jeff was when he died. I get very nervous about that. My greatest challenge is to not smother her to death. On one level I want her to grow up and be an adult and move on with her life, but on the other level I want to sit there with my hands around her and protect her. I don’t want her hurt.

So, I guess that’s it . . . just being more controlling and more fearful. I freaked out one time. She was coming home one weekend and there was a hailstorm here. I was hysterical because she was driving home and she had no experience in such weather. She wasn’t even in the hailstorm but she was late, and I just freaked out. We bought her a car . . . I wanted a HUMVEE! I just think that I need to just watch, because I want her to have all of the opportunities and I want her to be happy. I’m just so afraid. I’m just really afraid. (#A4)

This account captures the tension between intense feelings of concern for a child and the challenge of not smothering a child. Parents often struggle with achieving this balance due to the overwhelming nature of their feelings of anxiety. Another mother described times after her son died when her other children would leave the house and take the car on an errand, and she would “lie on the bed and just break out in a cold sweat” because of feeling “an intense need to protect.” At times parents may become overly protective and stifle the freedom of their other children to make choices or participate in certain activities. At other times parents will try to keep silent and yet suffer great internal stress because of the anxiety. A parent commented, “I think as a parent that we have this tendency anyway to control, and when you lose a child it borders on paranoia.” Being able to deal with such intense anxiety and keep a healthy relationship with their other children presents a key challenge to bereaved parents.
Another aspect of parental protectiveness that parents described was a heightened tendency to monitor the activities of their children. In other words, they talked about giving a great deal of mental attention to thinking about and watching the circumstances and safety of their other children. Anne, a mother with grandchildren, discussed how this affected her interactions with them:

I watch my granddaughter like a hawk. When I'm taking care of her and she's with us, she is essentially never out of my sight except when she's sleeping. That relates back to taking chances. I supply my daughter with all sorts of safety equipment. I just sent her a baby seat. She's getting bigger now and this is the right kind that you get with arm straps, etc. I'm just very aware of that. I think that is the biggest change all around—the awareness that I can't take chances with this. (#A3)

Monitoring of a child's welfare may become a consuming exercise in attentiveness to the child's activities and awareness of safety concerns. The first aspect shows that parents have a need to know mentally where their other children are and what activities those children are engaged in. The second aspect indicates that parents pay more attention to the details of their children's lives and what might keep them safe. Parents in the study suggested that they were much more likely to call children often, ask about a child's whereabouts and activities, encourage children to check in with them regularly, and question the appropriateness of certain activities they felt were unsafe. A father, Tom, spoke of his efforts to monitor his young son's activities:

He's old enough to want to go and play with a few kids here and there in the immediate neighborhood, and we know he needs that as part of his development and as part of being a child, but we can't help but be extremely nervous when he's out there. I'm out there all the time fiddling with the car, pulling weeds out of the grass, or [other things] when he's doing it just so that I can watch him out of the corner of my eye and make sure that he's okay. I don't trust him to be around the corner. If he's around the corner I find myself walking down there every three or
four minutes to make sure that he’s okay. He’ll just be sitting in the dirt and playing with his friends.

We went and interviewed his kindergarten. We like the teachers and the school and all of that. He likes it and is looking forward to it. But when we were talking about it [my wife] said something about the bus, and I said, “What about the bus?” He’s going to be taking the bus to school. Man, I just panicked! There’s no way you’re going to let my child out of my sight and trust him on a bus and to have some person that I don’t know . . . to trust them to put him on the bus and have him come back. The fact that I would let him out of my sight for a whole day didn’t occur to me. That’s the protection thing coming in [to play]. Protection is a very influential part of being a parent. (#B6)

This father’s account provides a good example of ways in which parents try to monitor their children’s activities and mentally consider the safety of various situations. He is very active in monitoring his son’s activities in the neighborhood by keeping his son within eyesight or checking on him regularly. He also expresses concern about letting his son out of his sight for a day and trusting others to take care of him. It seems that if a bereaved parent’s ability to actively monitor their child’s safety or activity involvement is threatened, then the emotional anxiety again becomes very high. It is thus important to be sensitive to a bereaved parent’s need to protect children by being aware of and monitoring a child’s circumstances.

Parents in the study suggested that another dimension of parental behavior related to their increased sense of protectiveness was the tendency to take protective action on behalf of a child. It is not uncommon for parents to be much more aggressive and proactive in taking action to be protective of their children. This may be positive in some situations as parents assist children through difficulties and head off potential concerns. But it may also have negative consequences, particularly with older children, if parents
undermine a child’s autonomy and conflict with children about choices or activities that the parent sees as threatening. Parents, however, often feel that they have no choice but to act since they cannot cope emotionally with feeling helpless in the face of a perceived threat (after losing a child). Martha shared a story related to her efforts to take such action and the effect on her relationship with her son:

My son announced about a month and a half ago that he was getting a motorcycle. At the time I had quite a bit of his money in my bank account. I freaked. I called my friend and told her what my son was intending to do and that I was going to stop him. I knew that he couldn’t get a motorcycle without that money, so what I did was that I took the money out of my account the very next morning when the bank opened. I put his money under my name in a certificate of deposit for a year. I don’t regret what I did, but it really angered him because he felt that I stole his money. I just kept saying, “Well, if that were the case, you would have zero dollars.”

He became very angry with me and didn’t talk with me for a week. I would have been a little upset and said, “A motorcycle? Let’s go look at a Harley-Davidson.” But because of the experience I’d been through and the fact that my friend’s son had died on a motorcycle, there was no way on earth that this child of mine was going to get a motorcycle. I didn’t care. He was twenty-one years old and I had both father and son against me. I said, “I don’t care.” If I had given him the money and he’d gone out, purchased the motorcycle, and something happened, I would have felt like I was responsible for his death. This way I feel like I’m keeping him from killing himself on a motorcycle, if that makes any sense. It has had negative effects on me in that way.

Almost every decision I make that involves the kids is influenced by Jessica’s death. The motorcycle. If I hadn’t lost her, I probably would have said, “Okay, let’s go and look for something.” (#A9)

This mother’s story provides a good example of how parents feel compelled to take action to protect other children from perceived threats, and yet such action can sometimes have negative consequences in the parent-child relationship. Most parents suggest they are much more willing to endure the ups and downs of a relationship than face the
prospect of losing another child. If they are able to take some action, then it seems that
they at least have done something to exercise some control. In losing a child most
parents felt powerless and without control over the situation. Parents attempt to minimize
risks for their other children as much as possible. One father, John, recalled his
behaviors:

You know how a person locks a door and then goes back to check the door and
make sure it’s locked? Even though they know it’s locked? I do that with my
children now. I’ll worry about them getting hit by a car and I overly worry about
it. Here we have a pretty safe environment and I’m not trying to instill fear in
them that a car will run them over, but for example, if they walk up to see Phase II
apartments then I make them walk in the grass. I don’t want them to walk in the
street. I kind of over-protect them that way..

Every night in the middle of the night I get up and check on all of my children.
Every night. 3:00 a.m. in the morning. For a long time I used to see if they were
breathing. I would stick my head down and listen. I still catch myself doing that.
I do check to see if I hear a noise, and the first thing I do is go to my kids’ rooms.
I sleep great but I have a little alarm clock that wakes me up. When [my son]
slept out in the tree house I came out every hour. I don’t want to be too protective
and I want them to be kids, but I don’t let them see me do this— but I do it. (#B2)

These efforts to actively protect children seem to help parents psychologically and
emotionally feel that they are doing all they can for the welfare of their children. Yet
parents must also allow their children some autonomy to make their own decisions and
grow through participating in a variety of experiences. Striking this balance between
protecting children and allowing their autonomy can be a challenging issue for a bereaved
parent following a child’s death.
Parental Involvement with Other Children

Parents who lose a child often struggle with a sense of identity after the child’s death, and in reframing their role as a parent they may express a desire to be a better or different kind of mother or father. This was true of a number of parents in this study. As suggested earlier in Chapter 5, parents may find themselves valuing family relationships more and giving more of themselves in those relationships. Several patterns in this study that linked to a parent’s involvement with other children after losing a child were focused on a parent’s desire to have more connection with their remaining children. Parents expressed a need to give more of themselves to other children, a commitment to more time with other children, and a desire to be involved enough to make a difference in their children’s lives.

Some parents in the study discussed their feelings about being more determined to give of themselves in a way that was meaningful to their other children. Seven parents, four women and three men, shared examples of such feelings and their related efforts. In general, these examples consisted of parents making the effort to be more nurturing and attentive in giving of themselves to their remaining children. The parents also expressed a strong sense of the satisfaction and enjoyment they gain from positive involvement with their other children. Tom spoke of being involved with his son in a meaningful way:

Just sitting in a chair and holding him while he falls asleep. Simple stuff like that. Something simple like that is so much more intense and meaningful than it used to be. I’ve always enjoyed holding the boys in my lap, but now when I hold [my son] either just sitting in my lap and watching TV or carrying him on my shoulders . . . I don’t ever want that to stop. It’s just become so incredibly special. That’s the single most important thing for me in my life—just to have him next to me and to play with him. (#B6)
The sense of meaning that this father carries from his involvement with his son reflects the feelings that bereaved parents expressed about trying to give more of themselves in the relationship with other children. For him, a simple activity such as holding a child has intensified and deepened. This focus on giving of themselves to feel a meaningful relationship with children seems to provide parents with a sense of positive feedback.

Parents in the study also talked of being more committed to spending time with their children after a child had died. Only four parents, two mothers and two fathers, discussed this pattern but it was a significant factor in the parenting of their other children. These parents shared a feeling that they needed to set aside or protect family time with their children that would provide a chance to connect with each other. One mother mentioned that losing a child had not changed her so much, but that her son’s death “made me more intense in certain ways that I already had a commitment.” One of these existing commitments that intensified was a focus on protecting time for family relationships. Another mother, Sandra, commented:

I try to spend as much time as possible with [my other children]. It’s a fleeting time and life is so fragile. You just never know. When I hear people talking about how important their job is or how important their golf game is, I think it’s so important to spend that time with their kids because you may not have it tomorrow. (#A13)

Her story captures the sense that some bereaved parents often express, in feeling that time with children is so valuable and should therefore not be displaced by other commitments. Parents may rearrange their priorities or patterns in order to accommodate more time for the family. A father, Ken, reported:
I probably have spent more time with them. It’s probably affected the way that I parent in that regard. I rarely miss something which the kids do, whether it be a ball game, a school play, or anything that they’re involved in. I will adjust my schedule to be able to accommodate that and go be a part of it. (#B3)

Parents who make such behavioral changes or commitments in relation to their other children seem to have been changed in ways because of the loss experience. Whether they find a deepened commitment to time with family or make it a new priority, in each situation the parent is attempting to emphasize the desire they have to be involved with their other children in a meaningful way.

One of the feelings that bereaved parents sometimes talk about is their discouragement at being unable to have done anything as a parent to prevent the child’s death. In contrast, after losing a child some parents then express a very strong desire to be involved enough with their other children to make a difference on matters of concern. Four parents in the study, three mothers and a father, indicated such a desire and shared examples of how it influenced their involvement with other children. These parents felt strongly that they wanted to avoid any regrets in parenting their children and this motivated them to be highly aware of and involved with their children’s daily lives. At times they even gave counsel that their children did not want to receive, but again they felt it was critical to try and make a difference in the child’s life. A mother who worked on her son to stop smoking said, “I’m not the type of parent that will allow a three-year old to cross the street alone and let the child learn by himself or herself . . . I would rather avoid the problem [instead of] being faced with the situation.” For these parents, the
desire to be involved in their children’s lives extended to making sure that they had done all they could to make a difference in the child’s quality of life.

**Parental Acceptance of Other Children**

A common theme articulated by parents in the study regarding their parental behavior was an increased acceptance of their other children. This concept was expressed as a sense of the value or worth of children as they were and the need for parents to recognize this fact. Parents who expressed this sentiment after losing a child tried to make it apparent in their parental behavior toward remaining children. They focused on acceptance of other children through valuing children as they were and not putting pressure on them for external achievement, and also through being more patient with issues related to their other children.

Five mothers in the study highlighted their efforts to value their other children and not push them toward needing to achieve or compete with other children. Instead, they focused on helping these children to realize their own interests at a pace that was suitable for them. One mother stated, “I think that just the acceptance of them, whatever their gifts and shortfalls are, is [positive] and not trying to change them.” These women indicated that losing a child had changed their perspective and that they were more willing to accept their other children and the interests pursued by the children. Martha talked of how this affected her interactions with her other children:

All the kids are bright but Jessica just had different goals than the other two kids, and so we sort of measured the other two kids by her. They felt a resentment because they felt that they could never compete with her. I pushed them because I felt that everybody is born with the same ability and you make of it what you
want. That is what I wanted to instill in all three kids. When we lost Jessica I began to look at the other two kids differently and I accepted their limitations. I think it took the heat off of them because they felt they were always competing with her and lagging behind. In their eyes we were measuring them according to her achievements, so now that she is gone they feel in a positive sense that we look at them for who they are and we don’t put this pressure to do something that maybe they don’t want to do or can’t do. (#A9)

This pattern may be important for the well-being of children because sometimes other children will feel the need to step in and try to replace the lost child. Parents seem to need to reassure children that they accept them as they are and they are each valued as an individual with individual talents and gifts.

A second aspect of parental behavior in which parents discussed being more accepting of their other children was in the patience that parents gave to children when concerns arose. As was noted in Chapter 5, after losing a child many parents feel a need to focus on things that are most important. This theme was reflected here in parents’ behavior as four parents in the study, three women and a man, shared examples of being more accepting of a child’s faults and not being concerned any more about trivial matters with children. A woman who had a young son said that she felt that now “if they break something it’s not that big a deal—they’re still alive.” One of the mothers, Jean, talked about how her perspective had changed:

I see trivial irritations as trivial. I’m kind of a volatile person. I’ve tried to learn patience as an acquired skill, and I think that if you’re a hard-working parent then you do learn some of that, but it’s not my long suit. So, to be irritated if somebody cut in front of me in a car, or irritated if my kids burned down all my bushes, or once I spanked one of my kids and my niece for writing on my walls with permanent magic marker—all of that, all of it just completely faded away. I think I’m more patient with my children, my grandchildren, and my husband. I just think I’m more patient because things that are trivial seem trivial. (#A2)
Although she did not find herself to be a particularly patient person, this mother noted that losing a child had helped her to be much more patient with her other children regarding the little irritations of family life. Some parents even worry that their willingness to accept the mistakes of other children may lead to spoiling those children. However, most parents seem to feel that they have become more mature as parents in relating to their children and that this challenge has made them more aware of what is truly important in family relationships.

**Parental Attention to Parenting Quality**

A final theme articulated by parents regarding their behavior in relation to surviving children was a tendency to give increased attention to the quality of their parenting efforts. This ranged from being more conscious of passing values on to children to being sensitive and responsive to a child’s particular needs. Eleven of the study participants, seven women and four men, addressed differing aspects of this theme in their interviews. The key aspects of this theme included being more reflective of passing on parental values, showing love and affection with children more readily, and being responsive to a child’s needs.

Five parents suggested that losing a child made them feel more conscious and reflective about their parenting efforts and the values that they wished to pass on to other children. They took more time to engage in thoughtful self-evaluation of their parental performance and tried to make adjustments accordingly. These parents tended to be more
self-critical and considered their decisions carefully to assess the impact the other children in the family. Amy explained how her parenting had changed after her loss:

I think it opened up communication between myself and [my husband] in terms of how we wanted to raise our kids. The kids would come up with these questions and they were big questions. They were hard questions. It wasn’t just something like, “Can I play with Billy today?” They’d ask, “What’s going to happen to me if I die?” They were asked at a younger age than might be usual, and so we had to think about what we wanted to say to these kids. We had to communicate about our philosophy of parenting. I think we’ve had to define that... I think it’s helped me go deeper with my kids to give them meaningful answers to their questions and not pat answers. (#A10)

The example provided by this mother illustrates how such aspects of parenting as communication about family values and consideration of parenting philosophy were addressed more carefully after a child’s loss. Not all parents will experience this type of change, but it seems clear that some parents are driven to become more conscious of the quality of their efforts. A father in the study said that as he and his wife discussed their parental interactions with their other children, they then “changed our parental relationship with our kids.” Making such parental adjustments in the interest of a child’s well-being is an example of giving greater attention to the quality of one’s parenting.

Parents also indicated a strengthened desire and commitment to make sure that interactions with their remaining children were loving and positive. Six parents in the study described their efforts to be more kind and loving after having experienced a child’s loss. This was especially true in situations that required a parent to correct or discipline a child. This attentiveness to the quality of parent-child interaction is reflected as parents speak of being more loving and caring with their children. John commented:
My kids get in trouble, they do things sometimes and get in trouble, and the first thing I do if they get sent to their room or if they have gotten into trouble enough, is that I will go in there before they come out and talk to them about what they did wrong. Then we resolve it and hug and kiss so that everything is fine now. That’s one thing that I’m not against, a child getting corrected, but I am against not working it out and then taking care of it and showing them, “I still love you and I know you love me. We’re going to work through this problem.”

One thing I know I am better at is that I listen to my children. I don’t just treat them as a little person that has no feelings or understanding, or as if they don’t know because they’re too young to know. I work on treating them as if their problems are just as important as my problems or the “big picture of the world.” Their little things that they’re dealing with . . . I hope that I give them all of my attention. I think their problems are as important as my problems, and I try to resolve those things. I don’t always have an answer but we try to find it together. I think it’s made me more aware of their needs. (#B2)

Parents in the study who talked about this pattern in their parenting said that they were careful to give more love and attention to their remaining children after having a child die. Some of them lamented having come to such a focus in their parenting so late in life, but they still felt it was critical to emphasize loving interactions with their remaining children. These efforts provide another picture of how parents who lose children may give more attention to their parenting quality with remaining children.

A final aspect of giving more attention to parenting quality was shared by parents who spoke of being attuned to and responsive to the particular needs of their other children. Five parents in the study reflected on their attempts to interact with their children in a way that was more attuned to their children’s needs. As in the story above, parents seemed more sensitive to the understanding that a child’s problems and needs are as important as the parent’s problems and needs. They often adjusted their parental
behavior to be more consistent with the needs of their children. Martha, who lost a
daughter she felt very close to, shared her thoughts:

Jessica was so much like me in personality and goals and so we had much more in
common than I had with the other two children. It’s difficult even now to relate to
Cindy’s music. I often find myself sitting and pretending to like it, whereas
before I couldn’t even stand to hear thirty seconds of her music. Jessica’s music
was classical and soothing and calming, but this music makes me really nervous.
Yet I find that when I’m with her and I’m in her apartment asking her questions
about particular rock groups that I could care less about, I think she likes that. It’s
like, “Gee, Mom, I didn’t know that you knew anything about Nine Inch Nails,”
or whatever the group is, and so I find myself looking for things that are important
to her and matter to her. (#A9)

Although not necessarily interested in her daughter’s music, she is interested in her
daughter and exhibits a strong desire to be responsive to her remaining daughter’s
interests and needs. Other parents in the study spoke of how they shifted their parenting
attitudes and actions in a similar way to be more consistent with a child’s needs. One of
the mothers talked about how she had adjusted her daily schedule to be more flexible and
responsive to the personalities of her other children. These efforts help parents to connect
more genuinely with their children and may also help them to feel better about
themselves as parents. As discussed in Chapter 5, parents who lose children are
somewhat prone to seeing themselves as parental failures, and giving such strong
attention to their parenting quality may help to ease this sense of failure.

Summary

The relationships between a mother or father and their children are complicated
and transformed when a child in the family dies. Parents fear any threat to their other
children and often struggle with their ability to parent due to the emotional trauma of the
grief process. However, parents generally continue to be attentive to their remaining children as they help these children cope with the loss experience. The parent-child relationship can undergo some transition as parents balance continuing demands, adjust to difficulties in the parental role, and experience impacts on the relationships in the family. Parents often find their behavior toward other children magnified as they seek to be protective of those children, give of themselves to the children, accept children as they are, and focus more attention on their parenting quality. The patterns indicative of how parental behavior towards other children is affected by a child’s death demonstrate that parents must balance their desire and efforts to be supportive of children while allowing for changes to take place as new roles and relationships in the family are defined.
CHAPTER IX

DISCUSSION OF FINDINGS AND CONCLUSION

This chapter includes a discussion of key findings from the study analysis and the implications for increased understanding of how a child's death impacts parental identity and subsequent parental behavior. Discussion on limitations of the study, future directions for research in this area, and application of the findings are presented in the latter part of the chapter. The chapter closes with a set of concluding observations.

Discussion of Findings

The findings from this study were presented in four chapters addressing specific thematic areas related to the impact of a child's death upon parents. These findings were developed through an intensive analysis of the qualitative interviews conducted as part of the research study with parents who had lost children. The first portion of this chapter reviews and summarizes the findings from the major areas that were examined in this study: (1) Parenting in the context of a child's death; (2) Parental identity as related to a child's death; (3) Parental behavior as related to the deceased child; and (4) Parental behavior as related to other children in the family after a child's death.

Parenting in the Context of a Child's Death

What do we have to learn from parents who have gone through the experience of having a child die? Perhaps the first message is that we should not underestimate the tremendous impact of a child's death on parents, and therefore we should take conscious
steps toward minimizing the likelihood of such an occurrence. When a child does die, the *manner* of the child's death seems to be an important factor in a parent's experience (Knapp, 1986; Miles & Demi, 1992). The context of experience that a mother or father passes through prior to and during the actual death of a child establishes a particular pattern of loss and influences the parent's grief and subsequent behavior. For example, a parent who is not present at a child's sudden death undergoes a very different loss experience than a parent who cares for a child who dies slowly from cancer over several months. This study showed that the context of a child's death has a direct impact on how parents experience the loss and sets the stage for some key parenting concerns.

Participants in the study had children die through illness or accidental causes. Approximately two-thirds of those in the study lost a child due to accidents, and a majority of these were older children who died as a result of traffic-related incidents. The prevalence of this manner of death highlights the concern of older youth being placed in risk situations. Traffic-related incidents are the leading cause of accidental death among children between ages one and twenty-five years in the United States (Hoyert, Kochanek, & Murphy, 1999), and this raises the question of what policies or programs might be encouraged to minimize the risk of such accidents. Bereaved parents themselves have been responsible for some educational efforts, such as M.A.D.D. (Mothers Against Drunk Driving), and some states have official panels that review child fatalities and whether they might have been preventable. Examples of such efforts were also provided by some parents in the study who were active in providing educational guidance on vehicle safety or in promoting safer traffic-related policies. The findings from the study suggest a need
for such educational efforts, particularly with adolescent populations. All other accidental deaths were of young children, suggesting a need for continuing emphasis and education on child safety guidelines. About one-third of the parents had children die as a result of illness or disease, the most common being cancer-related deaths. Although not a statistically representative sample by any means, the patterns in this study do reflect patterns consistent with data available from more extensive research on the context of child loss (Hoyert, Kochanek, & Murphy, 1999).

Although it was difficult, during the study it became clear that recounting and understanding the particular details of the child’s death was critical to making sense of the parent’s reaction and later behavior. The findings showed some similarities in the experience of parents whose child died from an illness versus an accident in these loss contexts, but also highlighted the distinctive nature of each loss.

In all cases the parents who lost a child due to accidental causes had the child die instantly or within a few days of the incident. Shock and confusion were common parental reactions stimulated by the speed of the child’s death and the fact that most parents learned of the death from an outside source. Weiss (1988) has noted that this is a typical reaction to sudden loss. Edelstein (1984) also interviewed parents who lost a child due to accidental causes, and the sense of being unprepared that study participants expressed was similar to the emotions shared by bereaved mothers in that study. The lack of control over the circumstances also contributed heavily to a parent’s sense of guilt related to the loss. Often parents who lose a child suddenly express a greater sense of guilt than other bereaved parents (Bernstein, 1997; Miles & Demi, 1992). Parents were
faced with making sudden decisions of critical import that strained their abilities and left them feeling numb. One therapist has suggested it is important to help parents “say hello” again to children who die suddenly because the opportunity to say good-bye was never available (White, 1988). The findings suggest that losing a child suddenly is likely to evoke feelings of guilt associated with the loss or the sense that a parent has lost control of life and its functions.

Parents who lost children due to illness watched their children live anywhere from eight months to four years before death. These parents struggled with the hope the child would live and deep grief at the child’s suffering because of illness. The actual time of death for these parents tended to be much less traumatic and more tranquil. This was consistent with other findings that have shown anticipated death gives parents a greater opportunity to manage their grief (Bernstein, 1997; Rando, 1986b). Study participants seemed to feel they had time to prepare themselves for the child’s departure and typically felt that they had done all they could to help the child. In a study of grief differences based on the nature of a child’s death, it was shown that parents who have a child die gradually tend to experience lower distress levels than other bereaved parents (Miles & Demi, 1992). The findings suggest that parents who have a dying child should be encouraged to make the most of available time and may need assistance with the difficulty of seeing a child’s pain. The differences in a parent’s experience due to the type of loss should be considered when providing education or assistance to the bereaved.

Some significant patterns related to the primary concerns that parents identify in losing a child emerged from this portion of the findings. Parents indicated that they were
most challenged in their parental role during this time in (a) their connection to the child, (b) their care and responsibility for the child, and (c) their protection of the child. These themes tended to recur throughout the study. One of the important insights that can be drawn from these findings is an understanding of the core aspects of parenting and their importance. Research on parenting has suggested that parental nurturance, control, and provision of structure are key aspects of parenting (Brock, Oertwein, & Coufal, 1993; Smith, Cudaback, Goddard, & Myers-Walls, 1994). In this study, parents identified through a crisis experience the most fundamental concerns that exist for a parent when a child’s welfare is at stake. These findings provide insight on key parental issues at times of crisis with a child that may also have broader application to parenting.

A prominent theme identified by parents in the study was the profound sense of loss associated with the separation of the parent-child bond upon a child’s death. Other scholars have also noted that the emotional separation that occurs for parents when a child dies is a central aspect of the loss experience (Weiss, 1988). Various aspects of how parents react to this circumstance are included in the discussion below. Parents who saw the threat of this separation or felt it occurring gradually (death by illness) took steps to remain connected emotionally to the dying child, talking with the child or reaching out in other ways. The actual time of loss marked the point of separation and consisted either of gradual loss with the parent present, sudden loss with the parent present, or sudden loss with the parent not present. Parents who were present at the time of loss felt more able to have a final connection to the child through giving care, touching the child, or other means. These results are similar to findings reported by Knapp (1986) and Bernstein
(1997) in large-scale examinations of how loss context seems to affect parents. The study findings help to show the magnitude of this dimension of loss for parents and also how parents may attempt to mitigate its negative effects. Understanding a parent’s anxiety at such separation can help others be sensitive to their emotional needs.

Another critical concern for parents prior to and during the loss experience was the challenge to their capacity to perform basic parental functions for their children. In particular, their ability to directly engage and care for the child may be limited. Rando (1985) has suggested that this is one of the more difficult issues for a parent to face when a child dies. The findings showed that factors associated with a parent’s ability to care for the child and be responsible during the time of loss were the nature of the loss and the parent’s presence, severity of the child’s condition, and effects of the experience on the parent. For parents who were “cut off” from the opportunity to provide immediate care because they were not present at the time of the child’s accident or death, there was a strong sense of remorse and loss. Parents do continue making a strong effort to give care to the child through gaining awareness of the child’s condition, assisting with medical treatment, and giving direct care by any means possible. Being able to give such care was comforting for parents and made them feel more positive in their efforts to contribute to the child’s well-being. These findings suggest the importance of finding ways to enhance parental opportunities to provide assistance and care if a child’s life is threatened or has been taken and practical examples that parents have provided.

Protection of children was another vital challenge for parents during the loss experience. As with giving care to the child, often a parent simply lost the opportunity to
be protective in a manner that they wished with the child. Men tended to respond emotionally to this by expressing anger and frustration, while women tended to feel guilt and self-blame in not protecting the child. Other studies have commented on a similar pattern of emotional expression by parents (Knapp, 1986). Parents who lost a child gradually were particularly affected in feeling unable to protect the child from suffering. It is not uncommon for bereaved parents to indicate frustration at being unable to halt a child’s pain (Knapp, 1986; Miles & Demi, 1992). Those who had children die from accidental causes struggled with feelings of shock and tried to re-assert some parental control. This pattern seemed to have particular significance as related to a parent’s sense of identity and subsequent behavior toward surviving children.

**Parental Identity as Related to a Child’s Death**

The meaning that parents experience in their role as a mother or father comprises the essence of their sense of parental identity. A child’s death challenges a parent’s sense of self and creates a number of concerns that parents must face and deal with in the aftermath of the loss. Themes emerging from the study analysis showed that the issues related to parental identity revolve around the parent’s sense of self in the parental role, the parent-child relational bond, the parent’s adequacy as a mother or father, the parent’s sense of future expectations, and the parent’s feelings and beliefs about being a parent.

Parents in the study described a variety of feelings related to how they felt about themselves as parents after losing a child. Bereavement scholars have noted the powerful impact a child’s death has on a parent’s sense of self (Parkes, 1986; Sanders, 1989). The
findings from the study confirmed this pattern and illustrated specifically how a parent's sense of self was affected. This is significant because no other study has systematically investigated the effect of a child's death on aspects of parental identity and the most common themes. Parents expressed many negative and difficult feelings, including a sense that they had lost part of themselves, a concern they had failed as parents, and a doubt regarding their capacity to be good parents. Some parents described confusion and frustration at performing some of the tasks associated with the parental role. These negative impacts on a parent's sense of self have been documented by others (Klass, 1993; Sanders, 1989). However, there was also a distinct pattern in which parents affirmed their feelings about having tried to be a good parent, which was mostly discussed by those who felt they had valued the role highly. This finding provides useful information about factors that might mitigate some negative effects of child loss.

Although many parents did experience negative feelings associated with their sense of self in the parental role, nearly all parents in the study continued to feel a strong sense of parental status (to the deceased child). This shows that the child's death does not remove their sense of being the child's parent, but rather it attacks their feelings about themselves as a parent. Approximately half of the participants also indicated a belief that the child still existed in some manner and thus a relationship between them also still existed. This is consistent with research by Cook and Wimberley (1983) and Knapp (1986) that showed belief in a child's continuing existence was an important factor in dealing with grief for some parents. The finding from this study also suggests that parents use this belief as a foundation for efforts to continue relating to the child after
death. Parents did not feel the relationship still required them to perform particular parenting tasks for the deceased child (i.e., no sense of parenting "demands"); instead such activities focused on feeling connected to or remembering the child, as discussed in Chapter 7.

The relationship between a parent and child is dramatically transformed when a child passes away. Parents experience this bond as a deep connection that is severed when a child dies, and one of the important insights from the study was the depth of pain that a parent experiences when this bond disappears. In describing the experience as "a holocaust" or like "being sent to hell," parents articulated the painful reality of a child's death that has been suggested by many scholars (Bernstein, 1997; Rando, 1985; Sanders, 1989). The wide variety of emotions that parents described in connection with the separation of this bond included denial, anger, depression, and sadness. These emotional reactions fit clearly into the bereavement patterns that are described in varying models of grief (Edelstein, 1984; Parkes, 1986; Weiss, 1988), and these are outlined in Chapter 2. Nearly every study participant also commented on the difficulty of being separated from the particular child who died, describing each child as unique and special in personality, and also as part of a unique and irreplaceable relationship. This finding captured in a concrete way the substance of why parents miss the child so intensely when a child dies. Understanding the depth of loss that parents experience when this relationship is sundered makes it possible to render better assistance to bereaved parents. This also has implications for models of therapeutic practice that encourage parents to emotionally disengage from the former relationship, particularly those that rest upon a psychoanalytic
framework of analysis (Freud, 1917; Lindemann, 1944; Sanders, 1989). Perhaps such models should be reconsidered and parents should be encouraged to deal with the loss in ways that do not foster complete abandonment of the child’s memory.

Most mothers and fathers engage in varying levels of self-assessment regarding their efforts and performance in the parental role. As noted earlier, a child’s death causes parents to feel great distress regarding their care for and protection of children. This may bring feelings of inadequacy related to their parental performance. Over half of the study participants commented that they felt concern about their adequacy as parents because of not being present when the child died or feeling hindered by others in their efforts. This concern was reflected by these parents in their feelings of guilt associated with not performing basic functions of parenting. The various types of guilt defined by parents in this context included feeling guilty about not giving adequate care to the child, not making good decisions, and failing to express love adequately to the child. These guilt patterns mirror those described by other bereavement researchers (Miles & Demi, 1992; Rando, 1985). Parents also described a sense of inadequacy or personal failure because they had not protected the child sufficiently. This is similar to a finding by Edelstein (1984) in her study of bereaved mothers that a child’s death seems to announce a parent’s failure. Again, these primary themes suggest how fundamental these components of parenting are for most mothers and fathers. These patterns of concern about parental adequacy suggest the importance of helping bereaved parents to address their feelings of guilt and inadequacy following a child’s death.
A strong sentiment discussed by many bereavement scholars and the parents in this study was that a parent's vision and hope for the future is blurred by the loss of a child (Edelstein, 1984; Knapp, 1986). This was one of the findings discussed most by the parents in the study regarding the impact of the child’s death on parental identity. Over three-quarters of the participants explained the grief they experienced in having to abandon hope both for their own and the child’s lost opportunities in the future.

Edelstein (1984) has also noted that bereaved parents’ grief for unfulfilled expectations is a twofold feeling of having lost both the child’s and one’s own future. Parents who saw themselves attending a child’s high school graduation or wedding ceremony now described a future barren of such possibilities with that particular child. These parents lose a sense of who they will become as a parent in the future. Most parents also commented extensively on the sense of loss they felt for the child in not being able to grow up and grow old. These children, parents know, will never be able to hold a child of their own, and their potential to become kind, caring contributors to society has vanished. Only parents who felt their children had a “risky” or uncertain future did not describe this as a major source of grief. It seems apparent from the strength of this particular finding that helping parents to reconstruct a coherent and promising vision of the future as a parent needs to be a key focus in the healing process.

A final aspect of a parent’s sense of identity affected by a child’s loss is the parent’s feelings and beliefs about being a parent and the importance of relationships. Some parents in the study indicated very little change in their feelings and beliefs on this topic, while others reported quite dramatic changes in this area. Some studies have
mentioned findings related to this, but again none have made a systematic study of this aspect of child loss. Approximately two-thirds of the parents interviewed in the study expressed a deepened sense of appreciation for the parental role and the immense value of family relationships. Bernstein’s (1997) interview study of bereaved parents also found that parental attention to family unity and family relationships was increased after a child’s death. Many parents indicated that this change in perspective translated into a change in how they prioritized their activities as a parent. This included attempting to avoid trivial distractions as a parent, focusing on time and quality experience with children rather than money or external achievement, and valuing the present moment. These findings suggest specifically how parents try to translate these changed feelings into their family experience. It has been suggested that parents may feel more sensitive to the precious nature of children after losing a child (Edelstein, 1984). The study findings also showed a similar pattern, as parents indicated a greater desire to assist children and accept them as they are. Related patterns emerged later in the analysis regarding parental behavior with surviving children. The shaping influence of a child’s death on a parent’s feelings and beliefs about parenting thus seems to have important implications for a parent’s behavior in the future.

**Parental Behavior Related to the Deceased Child**

This study broke new ground in research on bereavement by examining how parents function in relationship to their deceased child after a loss experience. It has been common, particularly in the literature on models of grief and coping after a loss, to
suggest that parents must somehow disengage themselves emotionally after a child’s loss to move on (White, 1988). While there is certainly the need for parents to deal with the reality of being separated from the child, the findings from this study clearly seem to indicate that parents make a concerted effort to maintain a linkage with the deceased child. Connections with other research findings in this area are very limited due to the lack of other studies on this topic. The findings associated with this topic were focused on parental fear of forgetting the child, parental activity shortly following a child’s passing, parental behavior to connect with the child, parental behavior to remember or memorialize the child, and parental efforts to extend care related to the child.

Many parents who lose children carry a fear that the child will somehow be forgotten by them or others as time passes following the loss. Half of the study participants commented on this fear and indicated that it was a motivating factor in their efforts to keep connected with the child and to preserve the child’s memory. A few parents felt that if they stopped feeling the intense grief experienced early on following a child’s death then they would be forgetting that child, as if the pain itself tangibly linked them to the child’s memory. Parents also expressed worry that other members of the family or friends might let the child fade from memory. This fear of forgetting the child was a strong motivating factor for parents to take action to keep the child’s memory alive in their lives and for others. This finding provides insight into the emotions that may motivate bereaved parents in some of their actions. It also provides sound knowledge regarding a key concern held by many parents who have lost a child.
Although a child’s death may deprive parents of many of the direct parenting functions that typically occur with a child (Rando, 1985), one pattern that emerged in the study was the continuation of parental activity in some areas shortly following the loss. Parents seem to be primarily responsible, with the cooperation of others, for planning the management of the child’s remains and the child’s memorial services and other affairs. While this seems logical, it is important to note the impact that these parental responsibilities have on a parent. In the midst of grief they must continue to bear the burden of parental decision making, but some of the parents derived a sense of comfort from being able to do such things in the child’s behalf at this difficult time. This finding ought to alert those providing support to bereaved parents that the parents should not necessarily be shielded from performing such efforts when a child dies. Rather they might be assisted so that they do not have to engage these responsibilities alone, but are also given the opportunity to make a substantive parental contribution to the child.

The difficulty of losing the connection to a loved child and a parent’s efforts to overcome this trauma were noted as key findings in previous areas of the study. This important theme is represented most prominently in the way a mother or father behaves in relation to the deceased child. Researchers have noted that a bereaved parent will engage in “searching” behavior for the dead child and try to find the missing relationship (Edelstein, 1984; Weiss, 1988). The study analysis showed ten key behavioral patterns described by parents that allow the parent to connect emotionally with the deceased child in some manner. Every study participant discussed several of these patterns in their personal narratives, highlighting the breadth and diversity of this theme in the parent’s
individual experiences. The findings suggest that discovering and implementing ways to connect with the deceased child represents one of the most pervasive and important aspects of a parent’s behavior following a child’s death.

The behavioral strategies that were described by the study participants were widely varied and personalized according to the parent’s relationship with the deceased child. However, the specific patterns that emerged as key findings were: (a) talking about the child; (b) talking to the child; (c) praying for the child; (d) feeling a spiritual connection to the child (various ways); (e) touching the child; (f) associating with activities meaningful to the child; (g) associating with persons meaningful to the child; (h) participating in events related to the child; (i) visiting locations related to the child; and (j) looking at tangible sources of the child’s memory. Some of these types of behavior have been documented in other studies of parental bereavement (Bernstein, 1997; Knapp, 1986). Klass (1993) and others have documented the experience of bereaved parents in feeling spiritual connections to a deceased child (Kalish & Reynolds, 1981). It is likely that attention to such practices is encouraged by some organizations that are organized by bereaved parents such as Compassionate Friends (Klass, 1993). The findings from this study on that topic confirm this behavior and provide an understanding of the diverse means that make this possible.

These patterns of behavior should be further explored to provide more insight into this important dimension of a parent’s behavior following a child’s death. The findings hold the potential for developing a more comprehensive theoretical understanding of how parents adjust in the parental role following a child’s death. They also contribute a set of
specific patterns to our knowledge that can be built upon in offering educational and therapeutic avenues of support for bereaved parents. Existing sources of research provide only a preliminary view of this area of parental bereavement, and further research on this topic may be one of the greatest potential contributions arising from this study.

Another category of parental behaviors was associated with parental efforts to not forget the deceased child and also to create ways to emotionally connect with the child’s memory. Parents concerned about losing the child’s memory described a variety of strategies to remember and memorialize the deceased child. This set of findings was also a very strong theme in the study. One pattern involved preserving existing sources of memory related to the lost child and several behavioral patterns focused on the parents’ efforts to create new sources of memory related to the child. These innovative efforts again provide a set of specific findings that give a broader picture of practices that parents engage in to preserve a child’s memory.

The behavioral patterns that parents described in creating new sources of memory included: (a) creation of personal records; (b) creation of memorial events; (c) creation of memorial locations; and (d) creation of memorial symbols. These findings and the analysis provide the foundation for new theoretical concepts and substantive examples of how parents memorialize their deceased children. About a third of the parents discussed creation of personal records such as scrapbooks, histories, poems, etc. remembering the child. Parents who created memorial events either held a one-time event or focused on annual events linked to existing times of memory such as a birthday, holiday, etc. The memorial locations emphasized by parents were the child’s burial place, special
memorials dedicated in the child's memory, and other locations of special meaning linked with the child. The memorial symbols that parents described were grouped into physical symbols, natural symbols (linked with memorial locations), and financial or educational symbols (memorial scholarship, etc.).

The behavioral patterns above that parents described point out the deep-seated nature of the parent-child attachment and the need to maintain family memories. On a much smaller scale, these patterns seem to mirror the massive efforts of Egyptian pharaohs and Chinese emperors to memorialize deceased royalty. Parents look upon their own children as being precious and wish to perpetuate that understanding for themselves and others. These findings demonstrate a wide array of parental behaviors focused on preserving and perpetuating the deceased child’s memory. This is a strong indication that the effort to remember and memorialize a deceased child also plays a prominent role in a parent’s adjustment to the loss experience.

Parents who lose children may often feel a desire or motivation to reach out to others as a result of their own loss experience. A major theme in the findings from the study was the behavior of parents in extending care or assistance to others that was related to the deceased child. Such efforts were distinguished from typical attempts to care for others by the manner in which parents identified a linkage between their behavior and the loss experience. The parents described care they extended because of their loss experience, care they gave to others in place of what they would have given to the deceased child, and care given in behalf of (as proxy for) the lost child. These patterns indicate what a powerful motivational experience the death of a child can become for a
parent in their efforts to care for others. Organizations like M.A.D.D. (Mothers Against Drunk Driving) or efforts like the Children's Miracle Network (fundraising effort for ill children) have had their genesis in the experience of parental bereavement and reflect in a larger sense the findings from this part of the study.

Two-thirds of the study participants indicated efforts to reach out to others who had lost a family member because of their own loss, either through formal support efforts in a grief support group or by contacting them individually. Informal support efforts (individual contacts, etc.) are considered to be most helpful for bereaved parents (Ben-Sira, 1983), and those who receive such assistance are less likely to seek out formal supports (Schwab, 1995). About a quarter of parents in the study also involved themselves in educational efforts designed to teach about safety or adjustment to loss through formal efforts like support groups. Such groups have been found to be very helpful for some bereaved parents and can aid in the long healing process (Knapp, 1986; Schwab, 1995). Those parents who participated in such groups described their own experiences enthusiastically, providing a personal view of the positive benefits that such efforts can furnish. Parents who described extending care to others in place of their deceased child spoke of reaching out to friends of the child, new children or grandchildren, and others outside the family circle. Some scholars have suggested that bereaved parents who involve themselves in such altruistic efforts seem to find greater meaning and cope better than those who do not (Bernstein, 1997; Knapp, 1986). Edmonds (1993) found that parents may find a sense of purpose in continuing on with something that was meaningful to the child. These efforts to reach out to others were
widespread among study participants and may be help parents to regain a sense of meaning in life.

Another means of extending assistance was providing educational or financial gifts in the child's name to others or to organizations. More than half of the parents in the study indicated they had extended assistance in such a manner. This finding suggests that parents may often wish to memorialize the child in a concrete, tangible way. Memorial scholarships at colleges and universities or financial gifts to charities seem to represent this desire of parents. In a few cases the parents also stated that they had reached out to others or performed service because they felt the child would have done so and they wished to act in the child's behalf. These patterns highlight some of the ways in which parents try to transform the difficulty of the loss experience into an opportunity to help others. The variety and abundance of parental efforts to extend care and assistance to others suggests that these behaviors help parents to express their need to nurture others after a child has died.

**Parental Behavior Related to Other Children**

A final area of investigation in this study involved seeking to understand how a child's death influences a parent's behavior toward other children in the family. It has been suggested that losing a child makes the parenting process more difficult as parents try to adjust emotionally and regain their sense of self (Bernstein, 1997; Rando, 1985). Some studies have examined the effect of a child's death on parental behavior toward other children in a cursory fashion, but little in-depth research on this specific topic has
taken place. Therefore, related research findings tend to be scattered and somewhat difficult to find. Findings from this study suggest that losing a child has a strong influence both on the parent-child relationship and the way a parent acts toward the remaining children in the family. Key areas of focus in the findings were the parent’s effort to mediate the lost child’s death for other children, the effects of the loss on the parent-child relationship, parental protectiveness of other children, parental desires to be involved with other children, parental acceptance of other children, and the parent’s attention to the quality of their parenting efforts.

In the process of losing a child, the parent must not only care for themselves and make decisions related to the deceased child’s affairs, but must also continue to care for the needs of their bereaved children. Some researchers have suggested that parental responsibilities are much more difficult to perform immediately following a child’s death (Arnold & Gemma, 1983; Rando, 1985). It has been found that a parent’s energies are diminished and this makes parenting more difficult (Bernstein, 1997). But parents do think about the welfare of their remaining children, and the study findings produced many examples of parental efforts to mediate the impact of the loss experience for their surviving children. They did so primarily through managing the interaction of their children with aspects of the loss, helping their children to cope emotionally, and giving their children opportunities to feel a connection to the lost child. About half of the parents in the study took steps to be protective of their other children’s emotional experience during the period of loss, trying to minimize negative impacts that might have taken place due to the trauma of seeing a sibling who had died. Two-thirds of the study
participants noted a need for increased sensitivity and attention to their bereaved children after the loss. These findings suggest that the parenting needs in a family may intensify quite significantly following a child’s death, in addition to the negative impacts on a parent’s emotional and mental well-being. They also show that many bereaved parents are very responsive to these needs and actively assist surviving children to deal with the grief process, while others may struggle because of the grief they themselves are experiencing. Families who have lost a child may need assistance in directing attention to these needs and focusing on how parents and other children in the family might be sensitive to each other in these circumstances.

A child’s loss impacts the parent-child relationship in a variety of ways that were shared by participants in the study. These are seen primarily in the interactions between parents and children, the parent’s challenges in the parental role, and shifts in family roles and relationships.

The normal interactions between parents and their other children are changed significantly when a child dies. Slightly more than half of the participants indicated the challenge of balancing between the needs of their other children and the needs of the child who was dying or had died. This concern may be particularly acute when a child dies gradually (Videka-Sherman, 1987). The dynamics of such a pattern can be highly stressful because parents fear other children may become resentful at not receiving sufficient attention or care, particularly in cases where a child dies gradually. More than half of the parents also commented on the struggle of facing the continuing demands of parenting after the child’s death. The conflict a parent feels between having lost the
parental role to one child while continuing it with others can add to the difficulty of the grief process and has been mentioned in other research (Rando, 1985).

The challenges a parent may face in the parental role arise first of all from dealing with the physical and emotional fatigue brought on by the grief process. Arnold and Gemma (1983) noted the significant challenge to a parent’s capacities that arises due to such a crisis. Over half of the study participants stated this was a significant factor that influenced their ability to parent after the loss. This seems to be a time when extended social support is more critical for bereaved parents (Ben-Sira, 1983). Parents may also find it difficult to fulfill certain role functions because of emotional pain or sadness (celebrating the holidays, etc.). Those parents who were able to find creative ways of working through these conflicts seemed to do much better in the aftermath of the loss than those who did not. Parents may also experience a sense of role reversal with their older young adult children during the loss experience, as children become concerned about the parent’s ability to cope with the loss. The findings from the study about role discomfort and role reversal provide new information about the effect of a child’s death on how parents function in their roles with other children.

Family roles and relationships affected by the loss experience include the whole configuration of the family, the marital relationship, and the quality of the parent-child relationship. A number of parents indicated that it required some time and patience to form new ways of interacting without the presence of the deceased child in the family. An indirect influence on the parents’ involvement with their other children also occurs as parents make adjustments in the marital relationship. Research on the effect of child loss
on marriage by Bohannon (1990) has shown that parents must adjust to differing levels of
grief expression and styles of grieving in the marital relationship. Parents generally
described either being drawn closer or finding themselves emotionally separated during
the loss experience, and of course this affects the emotional climate of the home and
family. The connection made in the findings between marital adjustment and its indirect
effects on parenting provides a new look at interactions in the family system after a child
dies. Another effect some research has suggested is that bereaved parents may feel closer
to surviving children (Lehman et al., 1989). Some parents in the study also shared that
their relationships with other children deepened quite markedly in the period after losing
a child. These patterns confirm existing findings and generate new insight into the
impact a child’s death has on the family system and how parents and children must re-
configure their relationships to each other. Further research may define more clearly the
patterns of adjustment that occur in family roles and relationships after a child dies.

A child’s death robs parents of any feelings of security and leaves them feeling
vulnerable to other potential trials or troubles. This seems particularly true in their
concern for the safety and welfare of their other children. Bereavement researchers have
often noted the increased concern of parents for remaining children, even though the topic
has not been a focus of academic study (Arnold & Gemma, 1983; Bernstein, 1997;
Rando, 1985). Three-fourths of the study participants described an increased tendency to
be protective of their other children following the loss experience. Many of them shared
their fear of losing another child. The findings showed that these efforts to be more
protective included heightened emotional anxiety for parents, an increased effort to
monitor the activities of their children, and a greater tendency to take protective action on behalf of children. Overall, this was one of the most pervasive and consistent findings that emerged from this aspect of the study. It not only highlights a dimension of parental behavior directed toward other children that has been reported in the research literature (Arnold & Gemma, 1983; Bernstein, 1997), but it furnishes insight into the motivation for this behavior and specific dimensions of it as well. It may be that more extensive analysis can provide understanding about exactly what parents tend to focus on in their protective behavior with other children.

Just as bereaved parents may seek to find a connection with their deceased child, many parents also indicate a desire to feel more connected with their surviving children. These feelings were discussed earlier and are reflected in their efforts to be more involved with their children in various ways. Existing research has shown a tendency for bereaved parents to make efforts to strengthen relationships with surviving children (Bernstein, 1997; Edelstein, 1984). Patterns that emerged in the study findings showed that parents try to facilitate this connection through giving more of themselves to children, making a greater commitment to time with other children, and being involved enough to feel that they can make a true difference in the child’s life and happiness. Parents described reordering their priorities and making a greater effort in these areas to be involved with their other children in a meaningful way. At times, such involvement may be in spite of the child’s wishes and can strain the parent-child relationship. Some research has shown that parents who focus too intensely on relationships with other children after losing a child may actually harm the relationship (Johnson, 1987). Parents must find a balance
between being attentive and being overly intrusive with their remaining children. The findings from the study which profile the struggle a parent feels in losing the connection to a child give insight into the motivation of parents to be more involved with other children. Parents are more likely to feel such motivation because they do not wish to lose or take for granted the strong emotional ties with children that remain. In the future it may be beneficial to study this pattern from the child's perspective to learn more about how children experience a bereaved parent's increased desire and effort to be involved with them.

Some parents in the study reported that losing a child caused them to become more accepting of their other children. This finding was exemplified in the efforts of parents to value children as they are without pressuring them to achieve, and also in expressing greater patience with children when challenges arose. The pattern some parents described in not putting pressure on their children to achieve contrasts with other findings described in the research, in that some parents or even children seem to push for being a "replacement" of the lost child (Johnson, 1987). This seems to reflect the larger conflict between needing to construct a new life without the deceased child and yet wanting to retain that child's memory and place in the family. It may be that the tendency of some parents to be more accepting of their children moderates this tension if it exists within a family. Also, as parents express greater patience with concerns about children they note that this results from a deepened understanding of what is most important in family relationships. Bernstein (1997) has also mentioned that this deepened sense of what is truly important is common among bereaved parents. Thus, for some
parents losing a child serves as a catalyst in moving them to focus on the quality of family relationships and to be kind toward one another.

A final theme in the findings related to parental behavior with other children was the effort by parents to give added attention to the quality of their parenting. Over half of the study participants focused on ways to improve the quality of their parenting after a child’s death. These behavioral strategies included being more conscious of passing on their values and beliefs, giving greater love and affection to children, and being responsive to the needs of their children. As some parents struggle with a sense of failure in the parental role when a child dies, these attempts to improve and strengthen their parenting quality may serve to moderate such negative feelings of self-doubt. Such efforts to change seem more likely among parents who feel a need to improve their efforts and parental focus. Some parents in the study suggested that the child’s loss only reinforced their existing emphasis on being a good parent, while for others it seemed to be a catalyst to prioritize their parenting efforts. The increased attention to parenting quality certainly benefits both parents and their remaining children.

**Implications for Understanding Influences of Child Death on Parents**

A particular challenge associated with qualitative research studies is delving through the mass of findings and identifying those with the greatest potential to offer useful information about the topic of study that is new and relevant. I would suggest this is especially true with a topic such as the impact of a child’s death on parents, which is not only a difficult topic but a “messy” topic that does not lend itself easily to discrete
understandings. But I do believe there are some key implications from the findings of this study that may be valuable in understanding how a child’s loss affects a parent’s sense of identity and subsequent behavior.

First, the findings related to parenting in the context of a child’s death demonstrate that how a child dies is a critical factor in how parents experience the loss. The findings provide several important insights. They suggest the importance of doing as much as possible to prevent the tragedy of a child’s death. But they also show that if a child does die, the manner of the child’s death will bring up different critical issues of parental concern. Practitioners may be able to use this knowledge to understand better how to assist parents during the time of a child’s illness or death. The findings also indicate that the fundamental concerns of parenting at the time a child dies will tend to focus on the parent’s sense of connection to the child, the parent’s ability to care for the child, and the parent’s sense of control or protectiveness toward the child.

Second, the findings related to the influence of a child’s death on parental identity show that when the parent-child bond is shattered a parent’s sense of identity is shattered also. The study results suggest key aspects of a parent’s sense of identity that are affected, thus providing potential guidance for scholars and practitioners who work with bereaved parents and their concerns. Parents wonder if they were successful as a parent, mourn for the lost relationship, and feel as if they have lost the future. The findings point to the reconstruction of one’s parental identity as a central task in the healing process.

Third, the findings about parental behavior in relation to the deceased child show that connecting with and remembering the child in diverse ways are fundamental aspects
of the parental reaction to child loss. These findings seem to recommend a new direction for thinking about the bereavement process that suggests parents transform rather than disconnect from the relationship with a deceased child. Parents employ multiple, creative behavioral strategies for making emotional connections to or memorializing a deceased child. The child's death also serves as a strong motivation for many parents who use the crisis experience as a source of insight and increased empathy in providing assistance and care to others.

Fourth, the findings about parental behavior in relation to surviving children show that a child's death has a definite shaping influence on these parent-child relationships. These effects can be both positive and negative. Parents often desire to be more involved with children or become more accepting of them, and they help children to deal with their own grief. But they must also adjust to new relationship patterns in the family and may be challenged in their parenting by the physical fatigue from grief or the emotional anxiety of being concerned about a child's safety. The findings suggest that significant attention should be given to the way a child's death can affect continuing relationships between parents and their remaining children.

This study has made progress in providing new information about how a child's death affects parents in multiple ways. However, the topic is large and a great deal of opportunity exists to conduct more research and generate new information about it. The remainder of this chapter addresses implications of the study for future research and application.
Limitations of the Study

Some limitations in this study related to the sample, methodology and analysis must be considered in the use of findings obtained through this research. These limitations serve as a reminder of the inherent barriers and trade-offs that exist in designing and conducting any purposeful research project.

The qualitative interviews used to gather narrative accounts for this study were conducted from a limited sample of persons living in two urban communities in the western United States (Oregon and Utah). The study participants included both mothers and fathers (thirteen women, six men) and generally consisted of Caucasian, mid-level economic class members (with some few exceptions). While the sample was fairly diverse across categories of age, gender, and personal background, there was little variation across racial or ethnic background and socioeconomic status. It is important to conduct further research with increasingly diverse populations to examine whether the findings from this study are consistent for parents of differing cultures, statuses, or religious (and non-religious) backgrounds.

Study participants recruited from this study also were quite likely to have participated in a grief support group or were known by and referred to the researcher by other bereaved parents. Since it is difficult (if not impossible) to recruit a truly representative and random sample of bereaved parents for a study, the sampling techniques used were focused on finding a sufficient number of willing study participants who would also be somewhat diverse in gender, age and experience. The study was advertised in local communities and individuals were also encouraged to respond in this
manner. A small number of study participants specifically asked to be allowed the opportunity to participate in the study. Thus, there may be some degree of sample “bias” due to limited selection procedures or self-selection of participants in the study.

However, the size of the sample (n=19) was appropriate for a small-scale study exploratory study using qualitative research methods. Future research efforts should include broadened techniques of participant recruitment for the study and increased numbers of participants to decrease the potential for bias and increase the potential for developing findings that are widely represented in the experience of bereaved parents.

The research methodology used in this study consisted of conducting in-depth qualitative interviews with bereaved parents and allowing them to share their narrative accounts and personal insights about the loss of a child. Qualitative research is somewhat less precise than other quantitative methods in obtaining results that are easily replicable and generalizeable. However, the use of a qualitative approach that focused on parental narratives seemed most appropriate to this particular research project. It should be noted that such narratives represent a parent’s interpretation of personal experience (Dollahite, Hawkins, & Brotherson, 1996), and also that such narratives are added to and re-interpreted over time (Bruner, 1990). Parents who were interviewed varied widely in the length of time it had been since the loss experience and thus may have focused on different aspects of the experience. Research projects in the future might include interviews with individual parents over a length of time (longitudinal approach) to see if or how their narratives change, or might attempt to discern differences in what parents focus on based on length of time since the loss. The limitations of a qualitative approach
must be taken into account regarding the consistency or broad applicability of findings due to limited sample size, but it must also be remembered that the purposes of such research may have a different focus.

The analytical focus of this study was interpretive and exploratory for the purposes of gaining a better understanding of how a child's death impacts parental identity and behavior. It also was designed to generate findings that might be used in building a better theoretical understanding of the processes associated with child loss. While it should be noted that multiple-case sampling methods were utilized to increase confidence in the strength and stability of the findings (Miles & Huberman, 1994), the findings are meant to be assessed more on the basis of depth and meaning rather than easily measurable and replicable criteria. Further work must be done to derive patterns of experience that can be studied and verified using diverse methods of research. The findings from this study, though I believe they are significant in their implications, must be accepted as emerging from an investigation that is exploratory in breaking new ground and also defined by the limitations of interpretive analysis. Every effort has been made to ensure that the analysis was careful and reliable so that personal bias from the researcher would not interfere with or arbitrarily influence the findings.

**Future Directions for Research**

This study of parents' experience in losing a child and its impact on their lives accomplished several purposes originally outlined for this research project. First, it allowed for study of the topic to take place in a positive, participant-oriented atmosphere
that ensured sensitivity to the emotional nature of the issues involved. Second, it supplies a body of detailed information gathered through in-depth qualitative interviews that can be used in further study of how parents experience a child’s death. This information furnishes substantial knowledge on the specific questions of how a child’s death impacts parental identity and subsequent parental behavior. Third, it provides an examination of the patterns apparent in how parents respond to child loss and the meaning associated with those patterns. These findings will be used to develop and refine theoretical understanding related to the impact of a child’s death upon parents. Finally, the collection of parental narratives and the findings developed from the study establish a basis for the development of materials and approaches that can be used in reaching out to parents who have lost children through counseling, education or other mechanisms. A number of avenues for further research also need to be considered and pursued.

This research project establishes a foundation for future research on how parents experience a child’s death and its impact on their sense of parental identity and future parenting behavior. These factors have still not been studied extensively and so much opportunity exists for new avenues of investigation in this area. Since this study is exploratory in nature it represents a beginning point in the study of some of these topics. For example, a future research project might utilize the findings obtained in this study and build upon them to explore topics such as parental identity after a child’s death or parenting of other children after a child’s death. Such projects could expand the knowledge derived from this study in a more in-depth and comprehensive manner. In this way a better understanding of specific content areas studied in this project could
continue to be developed. It might also be possible to refine the analysis of these topics to look at such patterns as possible gender differences or how the loss is experienced by both parents within one family (interview both mother and father, etc.). The research could also be expanded to look at the loss of children by homicide or suicide. Continued research on the topic areas focused on in this study needs to be a first priority.

The information gained from this research project ought to be useful for those professionals who are interested in the topic of loss in general and its impact on families. There may certainly be similarities in some of the patterns shown by parents in this study to other experiences of loss. Death of a child represents one major and extremely difficult type of loss for families, but other loss types that impact parents might include the kidnapping of a child, a child’s involvement in behaviors that remove them from the family (drug usage, prison term, etc.), or other ways in which parents feel a child becomes lost. Comparison of the parents’ experience in these contexts to the findings from this study may provide useful and compelling insights into the similarities or differences among these varieties of loss. In particular, such comparisons may help to give added insight into the way that parents adapt to loss related to a child and concerns that should be addressed.

Another avenue for continuation of research on the topics in this study exists in trying to verify and strengthen the findings from this study through research with differing sample groups, i.e. through interviewing parents who are more ethnically or culturally diverse, etc. The findings from such research efforts might be compared with this project to discern those patterns that seem most consistent across parents’ experience
versus those that seem particular to specific groups. For example, other patterns of significance might be obtained through interviewing parents who have lost children during war or through random violence, or by interviewing parents from other cultures such as Africa, Asia or the Middle East. In addition to studying these topics from a parent’s perspective, it might be useful to attempt to create a broader family perspective through research with spouse’s perceptions, perceptions of children in the family, perceptions of parents’ siblings, etc. Other children in the family may have a valuable perspective to contribute on how a parent’s behavior changes following a child’s loss. Comparison of a child’s view with the parent’s view would give greater depth of understanding to this process of how parents cope with loss. The research idea might also be broadened to look at how grandparents experience a grandchild’s death and its impact on their sense of identity and parenting behavior. All of these opportunities to study the topic with other individuals or groups present an exciting array of research possibilities.

One important research possibility that concerns a primary purpose of the study is the continued development of substantive theoretical concepts that relate to the experience of child loss. Extending this project into a larger and more comprehensive study should be pursued in order to enhance the findings from the study. These findings can then be used to further develop, broaden and refine the theoretical ideas and patterns emerging from this research. This seems to be important not only because of the lack of well-developed theoretical concepts regarding impacts of a child’s death on parental identity and parenting behavior, but because the findings in this study do seem to challenge some of the theoretical notions currently in existence related to coping with a
child's loss. It was noted elsewhere in the study that some scholars and counselors promote models of coping that encourage parents to disengage from the child's memory, while the findings in the study place a parent's efforts to connect with and remember a deceased child at the center of the loss experience. The research on this project could be continued to develop alternative or complementary models of theoretical understanding in the area of child loss as it affects parents.

An additional area of investigation related to this research might be pursued through using other research methods to look at the same topics. Qualitative methods can be useful for generating findings that can then be used in the development of survey instruments or other mechanisms for studying a topic. Further research might involve the development and testing of such methods to use in conducting further research on how parents experience a child's death. Other methods that could be used to study the topic might include focus groups, open-ended questionnaires, analysis of content materials such as personal records, etc. These and other methods present a variety of opportunities to further insight into the impact of a child's death on parents through using multiple methods of study.

**Application of Findings**

The application of the findings from this study may take place in a wide variety of contexts. If the findings can be used to further understanding of the complex issues associated with a child's death, perhaps progress may be made in providing needed education and assistance both for those who are bereaved and those who wish to help
them. Finding ways to apply these findings for the benefit of parents, families, and professionals is one of the designated purposes of this study.

Perhaps the first benefit that may come from this study is a reminder of the need to reach out and assist bereaved parents and families who have experienced the loss of a child. The findings from this study illuminate the powerful trauma and intense emotional difficulty that can occur for parents when a child dies. At times parents describe feeling like they have become outcasts from society because so many people do not know how to respond to them in their grief. Whether a parent's loss has been in the past or will occur in the future, the findings of this study can sensitize all who become aware of them to the difference that a caring and listening individual can provide for those who face the trauma of a child's death.

Another unexpected but seemingly positive outcome of this study for some participants was the opportunity to share their experience with a person who was willing to listen. Although this dimension of the research experience cannot be transferred to the research setting as an explicit objective, it does suggest some lessons for future application. A first lesson might be that researchers in this domain of family experience should be familiar with both the emotional intensity and the potential "side effects" (i.e., appreciation to share memories and feelings) that occur when interviews on the topic of child loss are conducted. The researcher should be prepared for the emotional nature of the topic that may provoke strong feelings both in themselves and the study participants, and be prepared to change the course of the interview or refer someone for further assistance. Researchers can also approach the interview in a positive manner as it seems
evident that many participants value the opportunity to share their experiences. A second lesson might be that this positive dimension of the experience may have application in a therapeutic or counseling setting, in that individuals who have experienced a child's loss may find some growth and progress in being able to re-frame or share their story in a positive atmosphere (White, 1988). This is an idea that is being explored in some fields of therapy through such approaches as narrative therapy (White & Epston, 1990).

One important application of the findings can occur through developing publications for both professional and lay audiences on the topic of the study. Such publications might be in the form of research articles, educational materials, or articles and books for a general audience. Many organizations exist that are concerned with providing support to parents or family members when a child dies, and such materials might be especially targeted at these types of institutions or even prepared for their specific use. The findings from this study seem to have a relevance to the experience of parents and others who deal with the death of a child that can be shared. Also, the findings may be promoted through traditional means such as research publications and presentations to professional or academic audiences in order to contribute to a scholarly understanding of parental experience related to a child's death.

The fields of counseling, social services, and therapy also seem to provide a valuable setting in which the findings from this study might be developed and utilized. A great deal of research has addressed such topics as coping styles or social support, but the findings from this study provide additional insight into important dimensions of the loss experience. Parents who struggle with their sense of personal identity or in relationships
with other children may at times be helped by formal sources of assistance such as counseling. The findings from this study can be developed to provide information and guidelines for those professionals working with bereaved parents and family members. They may also furnish insights into the coping processes of parents, particularly in relation to the deceased child, that professionals can draw upon as they try to assist parents with managing the trauma of a child’s loss. Other professionals who may benefit from familiarity with these findings in their work might include health or medical professionals (nurses, physicians, etc.), social workers, or clergy. Working with other professionals to find and develop opportunities to apply the knowledge provided by these findings in various clinical settings represents an important avenue of application.

A further opportunity to apply the findings from the study may exist in fostering collaborative activities focused on issues in bereavement between professionals and bereaved parents or organizations to support bereaved parents. Such activities might include conferences, workshops, seminars or other informal and formal mechanisms for exchanging information and insight on how parents experience a child’s death and its impact on their lives. This type of exchange would provide the chance for parents to tell their story and sensitize others to critical dimensions of the loss experience, while also allowing professionals to both learn and provide feedback in a learning atmosphere. For parents who sometimes feel misunderstood and professionals (or others) who may not always be fully aware of the varying responses to a child’s death, such an exchange or collaboration could facilitate important steps to growth and mutual understanding.
Conclusion

This study illustrates that a child’s death has an important and lasting influence on a parent’s sense of identity and subsequent parenting behavior. The themes and patterns of behavior identified through the study analysis furnish a framework for understanding how losing a child affects parental efforts to cope and parents’ family relationships over time. The findings give depth and meaning through these patterns and the personal narratives that support them. Research that has suggested the importance of such life cycle events as a child’s death to parents gave direction to the formulation and design of this study (Bernstein, 1997; Knapp, 1986; McAdams, 1993; Neugarten, 1979; Rando, 1985; Thoits, 1991). A qualitative approach was developed for the study to allow parents to share their personal experiences and insights in a manner that would generate a better understanding of how parents experience a child’s death. This study has built upon the foundation suggested by prior research and offers a set of findings that furnish increased understanding of parental responses to child loss and also raise additional questions for further study.

A final and important outcome of this study lies in its potential for helping individuals, families, and scholars to understand what truly occurs when a child dies from the perspective of a mother or father. The study was designed to explore parents’ experience with loss from within their own perspectives and to respect the powerful voices and lived experience which exist in their personal narratives. The use of personal narrative may be uniquely suited to this intent because of its capacity to reach people on an individual level and communicate the meaning of an experience (Dollahite, Hawkins,
& Brotherson, 1996). The individual voices of parents who have lost children to cancer, polio, or the tragedy of a traffic accident, carry the message of what it means to face the pain and heartbreak of knowing that the laughter of a child’s voice will never be heard again. Of all the thoughts, memories, and stories shared by parents in this study, one of the most poignant that constantly recurs in my mind is the statement of a mother who sat in a hospital room with her infant daughter and held her for the last time. In her grief she said that in that moment she remembered thinking, “I have to get a whole lifetime of holding in and I can’t put her down.” Such a sentiment can only be captured in the story of a mother. The stories shared by the parents in this study remind us as scholars and human beings of the need to always remember the privilege of life itself and the potential beauty of the relationships that we share.
REFERENCES


Thuen, F. (1997). Received social support from informal networks and professionals in bereavement. Psychology, Health, and Medicine, 2(1), 51-63.


APPENDICES
APPENDIX 1

Informed Consent Document

Title: The Influence of Child Death on Parental Identity and Behavior

Investigators: Karen Hooker and Anisa Zvonkovic, PhD, Co-Principal Investigators; Sean Brotherson, PhD Graduate Student

I acknowledge that I am being asked to participate in a research project to learn more about how the experience of a child's death impacts a parent's sense of identity and parenting behavior. This research project has the specific purposes of providing further information and insight on parental bereavement and adjustment following a child's death, important parenting issues for parents who have a child die, and how parents can be more successfully helped to cope with a child's death. Also, this project is meant to help produce materials designed to assist parents, educators, and clinicians in coping with this difficult experience.

I have received an oral and a written explanation of this study and I understand the following things will happen as a participant in the study:

- I will be asked to participate only if I am a parent whose child died at least 2 years prior to the interview and the child was between the ages of 18 months and 25 years.

- I will participate in an interview for 1-1/2 to 2 hours about the experience of having a child die and subsequent feelings and experiences as a parent. This interview will be tape recorded with my permission. I may ask to not have something recorded at any time or may ask for something that has been recorded to be deleted from the interview.

- I may experience feelings such as sadness or anger related to my child's death during the interview. If I am having such feelings I am free to pause or stop the interview at any time. If I feel a desire for assistance in managing such feelings, I may use the information provided concerning grief support groups and grief counselors to obtain a referral. I understand that the researcher and/or Oregon State University will not provide psychiatric, psychological, or counseling care, or payment for such care, should I seek assistance in managing such feelings.

- I will be given a written transcript of my interview in appreciation for my participation in this project, unless I request not to receive a transcript.
The information obtained from my participation in this study will be used to increase understanding of parental bereavement and improve efforts to assist bereaved parents.

My privacy will be protected by the researchers in the following ways: (1) any information I provide will be identified by a code number and kept confidential; (2) only the investigators will have access to this information and it will be kept in a secured place; (3) my name or the names of family members will never be used if the information I share is related in presentations or written materials/publications based on this research; (4) I can request that any information I provide will be deleted from the written transcript of the interview; (5) audio tapes of the recorded interview will be kept in a secured location for five years and then destroyed to protect confidentiality.

My participation in this study is entirely voluntary, and I am free not to answer any question that I do not wish to answer at any time during the interview. Also, I may end the interview at any time I wish or refuse further participation and withdraw from the study at any time, without any penalty or loss of benefits to which I am otherwise entitled.

If I have questions about this research study, I can contact Karen Hooker, Anisa Zvonkovic, or Sean Brotherson, Milam Hall 322, Department of Human Development and Family Sciences, Oregon State University, Corvallis, OR 97331, at (541) 737-4765. Any other questions I have should be directed to Mary Nunn, Sponsored Programs Officer, OSU Research Office, (541) 737-0670.

Understanding of Compliance: My signature below indicates that I have read and that I understand the procedures described above and give my informed and voluntary consent to participate in this study. I understand that I will receive a signed copy of this consent form.

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Signature of participant

Name of participant

Date signed

Address

Phone number

Signature of investigator

Date signed
APPENDIX 2
APPENDIX 2

Interview Schedule

Influences of Child Loss on Parental Identity and Behavior

I want to thank you for being willing to meet with me and share your feelings and experiences regarding a most difficult challenge—the loss of a child. Can we spend a few minutes getting to know each other before we begin the interview? (5 minutes)

Before we begin I want to confirm that you understand the purposes of this research project and the steps that will be taken to protect your privacy. (Review informed consent document and willingness to participate)

Although this interview is being recorded for a research project (confirm permission), I would like it to be as informal as possible, and I would like the focus to be on you sharing the stories and insights that you have gained from your own personal experience. I'd like to begin my finding out a little more about you and then about your experiences as a parent.

Child Loss and Parental Identity - Questions

(1) Can you tell me about your life currently and a little bit of history to put our discussion in context?

(2) Can you tell me the story of your experience in losing your child?

(3) Can you remember how you felt initially upon realizing your child's death? In particular, how did you feel about yourself as a parent? (What meaning do those feelings or perceptions have for you now?)

(4) In what ways has this experience changed you as a parent? How has the change occurred? Can you share any stories that illustrate these changes in you as a parent?

(5) How do you feel this has affected you in your feelings about yourself as a parent now? Can you share any examples?

(6) How do you feel this has affected you in your behavior as a parent? Can you share any stories that illustrate this?
Parental Behavior and the Deceased Child - Questions

(7) How would you describe your sense of being a parent in relation to your child who has died? (What meaning do those feelings or perceptions have for you now?)

(8) Can you share any stories of how you remain connected to ______ as a parent? (What meaning do such experiences have for you?)

(9) Can you share any stories of how you remember ______ as a parent? (What meaning do such experiences have for you?)

(10) Can you share any stories that reflect caring or giving you do that might be related to ______? (What meaning do such experiences have for you?)

Parental Behavior and Other Children - Questions

(11) Can you share any stories of how this experience has influenced your attitudes or behavior with your other children as a parent?

(12) Can you share any experiences that illustrate how your child's death may have had negative influences on parenting your other children?

(13) Can you share any experiences that illustrate how your child's death may have had positive influences on parenting your other children?

(14) Can you share any challenging experiences you've had as a parent with your other children that you feel were influenced by ______'s death?

(15) Can you share any particularly meaningful experiences you've had as a parent with your other children that you feel were influenced by ______'s death?
Conclusion of Interview

At the end of the interview ask these two questions:

(a) What was this experience like for you?

(b) Why were you interested in or willing to participate in this project?

After these questions have been answered, please complete the interview by sharing the following:

When I have had a chance to make a transcript of the interview (2-3 weeks) I will mail the transcript to your home.

As you've been told, at some point I may wish to use information that you have provided during our interview in the presentations, papers, and books that will be done as a result of this research project. Your privacy will be protected and in order to ensure confidentiality your name, the names of family members, and any other identifying details will be changed.

Thank you so much for being willing to share your experiences with me. I will do my best to use what you have shared in ways that will help other parents and families.