

AN ABSTRACT OF THE DISSERTATION OF

Diana L. White for the degree of Doctor of Philosophy in Human Development and Family Studies presented on April 23, 2002.

Title: Intergenerational Responses to the Death of a Child

Abstract approved

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The death of a child is a traumatic family event. This qualitative study examined the experiences of parents and grandparents in 10 families who had lost a baby to SIDS, stillbirth, or birth defects. Key questions focused on support given and received, meanings attributed to the loss, continuing bonds, and adaptation. Significant *family support* was present in all families, but unskilled support was common. As expected, most support flowed from grandparents to parents. Relationships with maternal grandparents were particularly strong, especially those of mothers and adult daughters. Ambivalence was present in several intergenerational dyads. *Meaning making* was an important process, particularly for parents, and included making sense of what had happened and finding benefit from tragedy. Fewer grandparents than parents found benefit. Parents and many grandparents maintained *continuing bonds* with their babies through rituals or

symbolic representations. These methods of connecting facilitated communication within some families.

Participants were classified as adaptors, partial adaptors, in transition, or distressed. Parent *adaptors* were further in time since death than those in the transition and distressed groups, appeared more aware of support received, were tolerant of unskilled support, did not focus on the *why* of loss, experienced personal growth, and had integrated their deceased children into their sense of self. No clear patterns emerged for grandparents, although they seemed to feel their adult children were coping well. *Partial adaptor* parents were similar to adaptors in time since loss, but experienced lingering distress. They were more likely to be asking *why* and to express feelings of vulnerability. Partial adaptor grandparents were concerned about their adult children's continuing suffering. Parents and grandparents *in transition* were close in time to loss and felt distress. At the same time, they were optimistic and were experiencing positive emotions as well as feelings of sadness. They were reappraising their experiences and finding benefit. *Distressed* group members had very high levels of distress and were isolated from those in their social network, either through their own actions or through unskilled support. They connected to their babies mostly through feelings of sadness, they ruminated on *why*, and they did not identify benefit.

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Intergenerational Responses to the Death of a Child

by  
Diana L. White

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*Dedicated to my intergenerational family,*

*especially*

*Jennifer, Erin, Carrie, Ethan, Ben  
Jim, Pam, Tim,  
Mom, Dad, Dick, and Lucille*

# INTERGENERATIONAL RESPONSES TO THE DEATH OF A CHILD

## CHAPTER 1 INTRODUCTION

Although death at an early age has become rare in the United States, it still occurs: More than 100,000 individuals under the age of 30 died in 1995. Approximately one-third of these deaths happened in the first year of life, whereas another quarter took place between the ages of 25 and 29 (Bern-Klug & Chapin, 1999). Most of those individuals left behind grieving grandparents as well as parents and other family members. A substantial literature has developed focusing on parental bereavement, but little attention has been given to the bereavement of grandparents or other extended family members. Even less attention has been given to how intergenerational relationships shape bereavement experiences in families. Because it appears less often in early life and less visibly in later life, modern society is less equipped to cope with death than early in the 20th century. This seems particularly true when death occurs in childhood and young adulthood. As a society we have few rituals to help families and others in their social network to cope with these off-time catastrophic events. This study will explore the ways family members across generations respond to traumatic loss of an infant.

We do know that family members generally provide aid and comfort to one another during difficult times. We also know that social support from those who are important to us is a critical factor in adjustment to traumatic life events (Janoff-Bulman, 1992). Young bereaved parents probably receive much of this support from their own parents because until very old age, parents are more likely to give care than receive it (Bengtson & Harootyan, 1994). Although we can generally expect support to come from family members, we really know very little about the ways that family members help each other and what the experience means individually and to the family as a whole. The following case illustrates this point. It was developed from participants of two focus groups exploring support between mothers and grandmothers following infant loss (White, 1998).

Nancy and Grant were celebrating their daughter and first child Victoria's two-week birthday by going out to breakfast. Nancy was holding her sleeping daughter when Victoria suddenly went limp; she was not breathing. Grant grabbed her and ran with her to the hospital just four blocks away. Nancy said that was the beginning of their nightmare. Nothing could be done to help Victoria; she had died of sudden infant death syndrome (SIDS). Nancy described the year that followed as hell. She talked about the constant replay of her daughter's death, her shattered life, difficulties making it through each day, staying in pajamas for days at a time, and lying on the floor crying. She felt a great emptiness that seemed to isolate her from the rest of the world. She talked about being misunderstood and the lack of rules or guidelines to help her cope. She had to do a lot of soul searching to find her way through it. This, she said "was not pleasant." According to Nancy, her life-line that first year came from her husband, a support group, and an acquaintance (now a close friend) who had lost a baby to SIDS a few years before.

When asked to share a memory about Victoria, Nancy talked about Victoria's birth and the joy on her mother's and grandmother's faces. In the first weeks following Victoria's death, Nancy said she talked to her mother a lot and her mother had listened. She described her mother, Ruby, as a private person, however, and Nancy gradually talked less with her about her feelings. Instead, they each tended to talk to their peers about these matters. For the most part, this seemed appropriate to Nancy, although she did say she wished her mother would talk with her about it more. She knew that Ruby thought about Victoria and she described how Ruby demonstrated her caring in other ways. For example, Ruby gave them a tree that blossomed in the winter at the time of Victoria's birth date and then again in the spring. Nancy knew her mother grieved. She identified seeing her daughter's pain and not having a clue about how to help as the most difficult thing for Ruby. Nancy said that her own experience of being a mother helped her understand for the first time just how much her mother loved her. At the same time, she felt that Ruby could not understand fully the pain of losing a child without that experience herself.

Although Nancy had some things to say in appreciation for others who provided support, she talked extensively about experiences where support was not forthcoming. Her in-laws, never close before, had become estranged in the aftermath of Victoria's death. The in-laws felt that Victoria's death was a punishment from God. Furthermore, they did not approve of the funeral ceremony that Nancy and Grant created, so they subsequently held their own. Although they lived in the same community, Nancy and Grant had seen them only three times in the past five years. Nancy also talked about the loss of a formerly close friend who unexpectedly had not been supportive. For Nancy, this meant that she could not discuss with nor talk to her friend about her painful feelings related to Victoria's death.

The picture of family support that emerges for Nancy is familiar. The experience was devastating, she exhibited many depressive symptoms, and she had difficulty functioning that first year. Having people close to her with whom she could share her feelings was important. Those who had had similar grief experiences she could relate to personally were most significant. This included her husband, a friend dying of cancer, and other SIDS parents. She also had support from her mother, which she appreciated, but she did not seem to perceive this support as central. In contrast, the lack of support from in-laws and a friend seemed especially difficult.

Hearing the story from Nancy's mother enlarges the picture of family support. Ruby describes her joy at Victoria's birth and the pain following her death. Consistent with Nancy's description, Ruby said that the most difficult thing for her was seeing her daughter hurting so badly and knowing that she could not help. She said that at first she focused so much on Nancy's grief that she forgot her own. Later, Ruby felt a great sense of loss because she had not spent much time with Victoria during her short life. Because Grant had taken two weeks off when Victoria was born, Ruby had not wanted to interfere with their time together. Although she lived close by, she was waiting until he went back to work to spend a

lot of time with her granddaughter. She felt cheated and angry at the lost opportunity. Ruby did not wait to spend time with her subsequent granddaughter, visiting her early in life and frequently.

Ruby described many supportive activities she and her husband provided that Nancy did not mention. They immediately went to the hospital upon hearing the news. Ruby observed that the chaplain was not being helpful, so, with Nancy's permission, she contacted the minister who had married Grant and Nancy. She also contacted a friend who worked in the hospital. Both came right away. Ruby felt a sense of relief that supportive people helped them immediately to deal with this enormous tragedy. She also talked about how her husband's humor had helped the family cope.

In addition to concern about Nancy, Ruby had been worried about her older daughter, Anne, a nurse midwife working in another part of the country. Anne had tried to plan her vacation to be present at Victoria's birth, but had had to return to work just days before Victoria was born. Ruby said that Anne was devastated when she heard of Victoria's death. And, although the losses for her daughters certainly were not the same, Ruby recognized that the experience and grief was horrible for Anne as well. Anne returned home and helped make funeral arrangements, taking her stepfather to task when he suggested a casket that "looked like a Mary Kaye suitcase." Nancy and Grant asked Anne to take part in the funeral by dressing Victoria. Anne took this request very seriously, reading up on customs and rituals surrounding dressing the body. Ruby continues to worry about the impact of Victoria's death on Anne as well as on Nancy and Grant. At the same time, she is enormously proud of the depth of compassion she sees in them all.

Nancy described her in-laws' distaste for the funeral that she and Grant held for Victoria. It appears that some of Nancy's extended family also had some reservations. According to Ruby, some of her "outside" family were shocked and upset when the funeral was not held for over a week. Ruby intervened. She said that Nancy and Grant needed time to reflect on the meaning of their lives and

Victoria's life, and that Victoria's funeral needed to reflect their thoughts and feelings. Ruby herself found the process of planning the funeral to be very healing, especially for Nancy and Grant.

The holidays followed Victoria's death by only a few weeks. As a way to cope with this difficult time, Nancy and Grant asked if they could go with Ruby and her husband to their beach house. They went for three weeks where they read about SIDS, ignored the holidays, and spent quiet time. Ruby said that Nancy and Grant thanked them often for all they were doing during this time.

Nancy described her mother as a private person who did not talk to her a lot about Victoria's death. Ruby's story, however, shows a different dimension. According to Ruby, this tragedy became an opportunity for her family to change the way they handled things. She said that she never knew much about her own relatives because nothing was ever talked about. With Victoria's death, Ruby felt it important to "let others in and take some of our grief and gain some of their strength." She began to deal in a more open and straightforward way with the experience than was typical for her family. She said that the approach was quite a revelation for her 88-year-old mother. Ruby felt a positive outcome of Victoria's death was how much they "learned and gained as family people." She went on to talk about the outpouring of support from friends and acquaintances. It became apparent to her that "behind every door is a broken heart at sometime in someone's life and that it is important to be able to talk about those things."

This case illustrates the importance of the proposed study to bereavement and family research. From this example, we learn that two perspectives provide more information and insight than one into how a family copes with loss. Hearing both stories, provided a more complete picture of the ways that family members contributed to adjustment to this traumatic event. The experiences of these women were very different, although both shared the death of Victoria. Their different role relationships, differences in family stage, and different life experiences likely contributed to the way they grieved, interacted with one another, and made their

adjustments to this loss. Missing from this case, however, are the voices of the fathers and grandfathers who were very much a part of this process. Nancy identified her husband as a key support person during those months of intense grief. Ruby talked about the importance of getting men to talk about these issues; she felt that they have a lot to say and they should be encouraged to say it.

Although the meaning of this bereavement experience was not a focus of the pilot research in which Ruby and Nancy participated, it did emerge as a theme. Ruby talked about some of the positive things that happened in the aftermath of Victoria's death. These included new insights, new ways of dealing with family problems, and personal growth among family members. In contrast, Nancy's in-laws saw the death as punishment. This difference in meanings may help to explain the different relationships Nancy had with her mother and with her in-laws. Explicit discussion of meaning among family members is likely to shed more light on how family members relate to one another after loss.

Similarly, Nancy and Grant created their own funeral service to honor Victoria and they did not hold it until they were ready. This new ritual did not fit Grant's family rules. His parents could not accept the ceremony because it was not compatible with their religious values. As described earlier, their response was to hold a service more in keeping with their tradition. The result was a serious breach between the two households that continued five years later.

The purpose of the proposed study was to learn more about how families function during bereavement and to suggest implications for adjustment and healing. Specifically, this study examined how parents and grandparents responded to the death of a child. Research focused on (a) the meaning of this death to parents and grandparents and the extent to which those meanings are shared, (b) patterns of support among family members, especially between generations, and (c) family rules and rituals surrounding loss and bereavement. A life course perspective provided the foundation to examine the overall social context in which family bereavement occurs. Two other sociological theories, symbolic interactionism and

systems theory, also guided this research. These theoretical approaches focus on roles, the interactive and emergent process of meaning and rule making, reflectivity, and the social context in which family members interact.

## CHAPTER 2 LITERATURE REVIEW

According to Marshall, Matthews, and Rosenthal (1993), "the heart and soul existence of living in a family is not captured in the research literature" (p. 39). Included in this list of understudied topics is research on the meaning of family life to its members. Marshall and his colleagues suggested that family members construct and share meanings that have implications for social behavior within families. Another neglected topic area involves key transitions within families. These authors provided the example of transitions resulting from deaths of members of multigenerational families as an area that deserves more attention. They also discussed the importance of qualitative approaches to family studies as a means to better explain the complexities of family life. Qualitative research can broaden understanding of how families function and respond to their environment. In addition, Marshall and his colleagues argued that too often, we gather information about a family from a single informant. Without the perspectives of multiple family members, it is difficult to understand the intricacy of family relationships and the diversity that exists within and between families.

Luescher and Pillemer (1998) also criticized much of the prior research on families for many of these same reasons including the failure to develop measures of family life that reflect contradictory feelings. Their thesis was that intergenerational roles generate ambivalence and that many family members have both positive and negative feelings that exist concurrently simply because of the nature of roles held. For example, ambivalence is present in the conflicting norms of nurturance and independence. Family members are expected to take care of one another, but at the same time independence is highly valued. Luescher and Pillemer suggested that ambivalence will be heightened during transitional periods within families, such as death of a family member.

Kahana, Kahana, Johnson, Hammond, and Kercher (1994) offered their model examining the personal and social context of caregiving as an approach to capture the complexity of family life. Their discussion is relevant here because one might argue that support to bereaved family members is a form of caregiving. In their model, Kahana and her colleagues stressed the importance of focusing on the process of family interaction and exchange. They argued that traditional elder care research has given too little consideration to issues such as family cohesion, family conflict, symbolic meaning of caregiving to family members, and how negative aspects of a family network can result in negative well-being.

An important way to address the complexity of family life is to acknowledge that family relationships involve multiple players. Returning again to the caregiving literature, Lieberman and Fisher (1995) found that the severity of a chronic illness of one family member had negative impacts on multiple family members. Much of the research on caregiving has adopted a primary caregiving model, and the resulting focus on the primary caregiver has underestimated the numbers of people involved as well as ignored their contributions (Keith, 1995; Matthews & Rosner, 1988). Piercy (1998) emphasized the need to collect data from several family members, including care receivers and those in different generations, to increase understanding of the role of families in caregiving situations.

This research contributes to understanding about how multigenerational families respond to loss of their youngest members. It focuses on issues of family meaning making, family rules and rituals, and support related to bereavement. A qualitative approach is used to capture the perspectives of mothers, fathers, grandmothers, and grandfathers coping with infant loss. Below is a discussion of how symbolic interactionism, systems theory, and the life course perspective can be used to address key issues in multigenerational family bereavement research. This is followed by a review of research findings on intergenerational relationships, intergenerational caring and support, and grief and family bereavement. Within

these topics, issues of gender and generation, meaning making, and family rules are considered.

## THEORETICAL APPROACHES

Role expectations for bereaved parents and bereaved grandparents are not clearly defined in our society. Individuals and families, therefore, often have to develop their own definitions of these roles as well as determine what constitutes appropriate responses to and rituals following loss. *Symbolic interactionism* provides a framework for understanding how roles of bereaved person and support person are developed and changed over time. With this perspective, attention is directed toward the way that social interaction contributes to the development of shared meanings, and the interpretation of events among family members (Burr, Leigh, Day, & Constantine, 1979; LaRossa & Reitzes, 1993). Symbolic interactionism suggests that individuals who find themselves in these bereavement roles will need to define the meaning of their loss and their situations through interaction and negotiation with others.

According to Snow (2001), four principles of social interaction include interactive determinism, symbolization, emergence, and human agency. Interactive determinism stresses the importance of understanding the social context in which grieving occurs. This includes family members who are also bereaved but also support persons outside of the family system, the general community in which they live and function, and the culture in which they are embedded. Symbolization refers to the processes in which objects (including individuals) take on particular generalized meanings that often become taken for granted. Most families in our culture expect children to live beyond childhood. Emergence focuses on responses to new or novel cognitive or emotional states resulting when the taken-for-granted, routinized aspects of life are challenged, as occurs with bereavement, especially traumatic loss. Finally, in symbolic interaction, human agency is central. Individuals are intentional in their responses to life events. Although they may be

influenced by biological, structural, or cultural conditions, these factors do not determine individual responses.

*Systems theory* is a useful analytic tool because it emphasizes further the connections among family members (Broderick & Smith, 1979). Bereavement research has focused mostly on individuals with less attention to dyads or larger family units. In this research, family systems are defined as extended families. When children die, all family members are affected by their relationships with their children and others close to them. These relationships will shape the interactions among family members and the ways that they find meaning in what has happened. People generally do not grieve in isolation. The dynamic process of grieving and the role of mutual social support among those who share the loss, however, are little understood. Family systems also have histories of family rules and traditions that influence how families will process, or cope, with this off-time transition. When rules are not adequate to address the unique situation of off-time bereavement, a system may break down or develop new rules (Hanson, 1995). Systems theory helps focus on the self-regulating aspects of a family system to identify mechanisms and characteristics that contribute to successful adaptation to traumatic change.

*The life course perspective* also involves a dynamic approach to the study of change in families. This includes the construction of social meaning surrounding life events and the social context in which transitions occur (Bengtson & Allen, 1993). The social context includes dimensions of time. Relevant to this study are the concepts of historical and generational time. With respect to historical time, most of us live in a world where death is largely an experience of very old age. Changing demographic patterns in the United States mean that more than half of all deaths occur after the age of 75, and less than 4% of deaths occur before the age of 30 (Bern-Klug & Chapin, 1999). Indeed, 75% of those born in 2000 can expect to have at least one grandparent still living when they reach age 30 (Uhlenberg &

Kirby, 1998). When death does arrive in old age, it usually occurs within an institutional setting removed from the everyday life of a family.

Generational time refers to events or family transitions that alter interactions within families or change the ways that we view ourselves (Bengston & Allen, 1993). Many of these transitions are predictable including adult children moving away from home and forming new partnerships and households. Births, deaths, and participation in paid and unpaid work are other examples of normative life transitions experienced by families. Changes in family structure through divorce have become an increasingly common transition as well. In considering family time, these transitions may be characterized as normative or non-normative, and on time or off-time events. All transitions will influence the nature of the connections across generations. Non-normative and off-time transitions, however, are likely to add additional stresses to the family system. Although death is a normative family experience, the death of an infant or young child is not.

## INTERGENERATIONAL RELATIONSHIPS

### The importance of intergenerational relationships

One may ask why families, especially intergenerational relationships, are important to those experiencing loss. The theories guiding this research suggest some answers. With respect to symbolic interaction, families generally are the major source for socialization, especially in early life. Within the larger cultural and societal context, family members negotiate the meaning of such roles as mother, child, and grandparent, as well as how those roles will be carried out within their own family system. Although specific aspects of family roles are negotiated, mothers, for example, generally are expected to care for and nurture their children. Furthermore, it is expected that parents will provide food, clothing, and shelter for their children, and care for them when they are sick or hurt. Parental bereavement

can be particularly difficult because parents often feel that they have failed in their primary role of protector (Weiss, 2001).

Specific aspects of meaning and behavior will vary by family, but we see from the literature that family members tend to develop a sense of obligation toward one another (e.g., Antonucci & Akiyama, 1995; Rossi & Rossi, 1990). As with the definition of roles, the meaning of obligation will vary across families based on how meaning is negotiated through a history of interaction. In grieving families, obligation might involve exchange of instrumental support, such as financial assistance for the funeral or offering a temporary place to stay so that parents can be away from reminders of the baby. In other families, support may include listening to expressions of grief, helping with funeral arrangements, being a sounding board for ideas, or accepting values and behaviors that might be discounted by the rest of society.

Symbolic interactionism, therefore, suggests that families will be considered important to some individuals during times of crisis because those individuals were cared for and nurtured by their older family members since the socialization of early childhood. In addition, most individuals continue to function as part of broadly-defined family networks embedded in a larger culture (Snow, 2001). It is within this context that bereaved family members interact, share experiences, and develop understanding about the meaning of the experience. The meaning of family to these individuals may include a sense that family members are available to each other during times of bereavement. This may be especially true in families where there is emotional closeness and an existing pattern of exchange of help and support. A general or idealized sense of what families should provide may also exist for individuals where there is less actual experience of support among family members. According to symbolic interactionism, this meaning of family develops in part through interaction with individuals from other families and by incorporating societal norms into one's personal meaning of family or the generalized self as family member. Symbolic interaction is also helpful in

considering how family members respond to transform their notions of what it means to be family, or to change routines or perspectives when unexpected, traumatic events occur.

According to systems theory, when an individual family member experiences a loss, all others in the family will be affected to some degree. If this loss is death of another family member, then all parts of the system are directly affected. Based upon role and affective relationships, each part or unit of the family will be affected somewhat differently by the loss of a particular individual. Differences in response are also based upon the type of connections or attachments that exist between family members. The parent-child bond is the strongest intergenerational tie because of the direct link between them (Rossi & Rossi, 1990). The connection between grandparent and grandchild, although generally very important, tends not to be as strong as that between parent and child because their relationship is connected through the middle generation. Although they may all experience the loss of a particular child, therefore, the loss will have different meanings and consequences for parents, siblings, grandparents, and others.

### Grandparenthood

The life course perspective is especially useful for understanding intergenerational family relationships and complements key concepts of symbolic interactionism such as negotiation or symbolism. Relevant to this study are grandparent-grandchild and grandparent-parent relationships. Similar to bereavement roles, the grandparent role is not clearly defined and is negotiated among family members. Grandparenthood is a role prominent in both middle and old age; about half of grandparents have their first grandchild while in their 40s. By the time they are 70, 85% of men and 77% of women have grandchildren, and most have five or six (Szinovacz, 1998). According to Roberto (1990), 94% of all older adults with children are grandparents. Grandparenthood holds significant meaning and satisfaction for most grandparents (Cunningham-Burley, 1987; Kivnick, 1983;

Neugarten & Weinstein, 1964; Peterson, 1999). Response to the death of a grandchild is likely to be influenced by the meaning a grandparent attaches to the role. Perhaps some grandparents feel the loss of immortality through future generations or perhaps it is the more personal loss of being an indulgent companion, a teacher, or a resource person to a growing child that is especially difficult.

Bengtson (1985) identified four symbolic dimensions of grandparenthood. The first, *being there* represents a potential deterrent to familial disruptions and can be a calming influence during times of family transitions. The second is being the *family national guard*, and is described in more detail below. Third, grandparents often serve as *arbitrators* between their adult children and grandchildren. The last symbolic dimension discussed by Bengtson (1985) involves the *social construction of biography* in which grandparents help families build connections among the past, present, and future. Death of a grandchild means a loss of the connection to the future. It is also likely to mean being available to surviving parents and grandchildren.

Grandparenting styles are diverse (Cherlin & Furstenberg, 1985; Neugarten & Weinstein, 1964). On one end of a continuum of involvement in grandchildren's lives are grandparents who are engaged and involved in helping their children raise their grandchildren on a day-to-day basis with full disciplinary and decision-making authority. On the other end of the continuum, are those who have been labeled remote or distant. Remote grandparents tend to feel discomfort with the role and often have little contact or involvement with their children or grandchildren. The majority of grandparents fall in between these two extremes, identifying the role of grandparent as meaningful and satisfying. Contact with children and grandchildren is frequent, particularly when grandparents live near their children. Cherlin and Furstenberg have called those in this middle group *companionate grandparents*.

When all is well with their adult children, companionate grandparents adhere to a norm of noninterference. That is, they enjoy grandchildren and are engaged in family activities, but they do not play an authoritative role with their grandchildren. They leave raising grandchildren and other family decision making to their adult children. Companionate grandparents are likely to hold several other meaningful roles that may be more central to their lives and self-concepts than the role of grandparent (Troll, 1985).

#### Parent-grandparent relationships

The relationship between grandchildren and grandparents is often mediated by the parent generation. Ties between grandchild and grandparent appear to be stronger when the ties between parent and grandparent are strong (Hagestad, 1986; Hodgson, 1995; Matthews & Sprey, 1985). Aldous (1985) suggested that the adult child's needs for instrumental and emotional support are central and are what activate the grandparent support system in times of family stress. To help understand the meaning grandparents attribute to the loss of a grandchild, therefore, it is important to consider the relationship between adult children and their parents.

Generally, contact between generations is frequent and satisfying, and exchanges of support and resources common (e.g., Bengtson & Harootyan, 1994; Leigh, 1982; Logan & Spitze, 1996; Rossi & Rossi, 1990). Furthermore, interaction between adult children and their parents remains fairly consistent throughout the life course (Leigh, 1982). Leigh found the best predictors of interaction for all types of kin were affectional closeness, which included keeping in touch because one enjoys it, geographical proximity, and receiving or giving aid. Suitor, Pillemer, Keeton, and Robison (1995) identified age as one of three factors that influence relationship quality: Relationships with parents tend to improve as children age and grow into maturity. It appears that this bond continues to strengthen as adult children move from young adulthood to middle age (Suitor et al., 1995). The ages

of grandchildren and adult children, therefore, may be factors that influence the impact and meaning of the death of a grandchild.

Gender is critical to understanding adult child-parent relationships. Kinkeeping is often viewed as a woman's role with family traditions and rituals most frequently following maternal lines. Rossi and Rossi (1990) reported that both mothers and daughters identified affective closeness in their relationship as greater than the bonds between fathers and daughters, mothers and sons, and fathers and sons. Suitor and her colleagues (1995) also reported that mother-daughter relationships were particularly close when compared to other adult child-parent ties. They found that mothers were more likely to rely on daughters than sons as confidants and comforters and were less likely to become angry or disappointed with daughters. Similarly, daughters were more likely to report greater feelings of closeness and were more likely to rely on mothers as confidants.

Although relationships between adult generations are generally positive and close, parents and their adult children may not always view their relationship in the same way. Giarrusso, Stallings, and Bengtson (1995) found that, over a 20-year period, parents consistently reported more positive relationships with their children than their children reported with them. Gender did not appear to be a factor in the parents' reports, but adult children consistently reported higher levels of solidarity with mothers than with fathers. Rossi and Rossi (1990) found positive correlations between parents and adult children on four solidarity measures: associational, functional, affectional, and consensual. Correlations indicated the least agreement about affective solidarity. This finding suggested that, although there was general agreement about closeness, parents and adult children still had different perceptions about the relationship. Again, the closest relationships were between mothers and daughters.

In addition to differences in perceptions of relationships, it appears that boundaries between generations are not readily crossed while all is well with the adult child. The norm of noninterference described earlier illustrates one type of

boundary. This norm may continue even when grandparents have been enlisted to support their adult children. Thomas (1990) discussed the double bind that grandparents found themselves in as they tried to be supportive without giving unwelcome advice to their divorced single-parent children.

### INTERGENERATIONAL CARING AND SUPPORT

Family gerontology researchers consistently report finding considerable exchanges of care and support between generations. The obligation to offer support may be greatest from parent to child rather than child to parent because investment in family relationships tends to move down the generational ladder. Parents, for example, provide support to bereaved adult children while these children mourn the loss of their own children (White, 1998, 1999). In addition, as suggested by the generational stake hypothesis, perceptions about support or the quality of intergenerational relationships during bereavement may be different for parents and adult children. Gender and age are other factors likely to influence relationships as families grieve. The strong bonds between mothers and daughters may shape their grief experience in ways that are different than those of sons and their parents or fathers and their daughters. Finally, the meaning of relationships with grandchildren of different ages and at different times in parents' and grandparents' own lives and development may be among the important factors in understanding family bereavement.

Grandparents have been described as the family watchdogs (Troll, 1983) and the national guard (Bengtson, 1985; Hagestad, 1985). These terms imply that, although grandparents may not be integrally involved in the day-to-day family lives of their children and grandchildren, they are available for consultation, and often are considered as back up support in case something goes wrong. When things do not go right for their adult children, they come to the rescue making their parent and grandparent roles more central to their lives. They provide financial aid, housing, and emotional support to their single or never-married children, to

children who divorce, and to their widowed children (Aldous, 1985; Bankoff, 1983; Cherlin & Furstenberg, 1986; Clingempeel, Colyar, Brand, & Hetherington, 1992). The response of grandparents to a grandchild's disability affects the ability of parents to adjust (Seligman, 1991). Grandmothers especially are a major source of help to parents of children with disabilities (Green & Berger, 1997; Molsa & Ikonen-Molsa, 1985; Scherman, Gardner, Brown, & Schutter, 1995). When adult children are unable to take care of their own children, it is often the grandmothers who step in and fulfill this role (Apfel & Seitz, 1991; Minkler & Roe, 1993; Robertson, 1995).

Patterns of family interaction are developed over time and, as indicated by Hanson (1995), these patterns may be more predictive of process and outcome than the stimulus introduced to the system, in this case the death of a child. In a related area of study, Mirfin-Veitch, Bray, and Watson (1997) examined support from grandmothers following the birth of a child with a disability. Some of the grandmothers were perceived by mothers as supportive whereas others were viewed as less supportive even though all grandmothers provided substantial support on the basis of objective criteria. Levels of perceived support were related not to severity of disability but instead to historical relationships and the perception by family members that they were "that kind of family," one in which members helped one another in times of need. Supportive grandmothers also tended to come from families in which multiple members, not just grandmothers, provided support.

Although intergenerational support from family members in times of crisis is common, it clearly is not a universal experience. The remote or distant grandparents described by Cherlin and Furstenberg (1986) and Neugarten and Weinstein (1964) or the detached relationships between adult children and their parents described by Silverstein and Bengtson (1997) may not be helpful and indeed may cause additional pain to bereaved parents. Ingersoll-Dayton, Morgan, and Antonucci (1997) stressed the importance of considering both positive and negative exchanges finding that positive exchanges or aspects of a social network

are associated with positive well-being whereas negative aspects are associated with negative well-being. Negative aspects of a social network were particularly powerful when an individual was experiencing major stressful life events. Recall the case in Chapter 1, where Nancy seemed more affected by the lack of support from in-laws and a friend than by the positive support she received from her mother.

Life course, systems, and symbolic interaction theories again provide insight into why lack of support by family members is so difficult for people who experience loss, particularly if they have expectations that support will be forthcoming. Beginning with symbolic interaction, individuals may have an idealized understanding of family support and obligation. These views, as others, are socially constructed both with family members and within the societal context. The individual perhaps has interpreted the meaning of supportive persons through previous social interactions with both family members and other members of the social networks and through adoption of societal norms governing familial obligations. These interpretations, however, may not have been developed through explicit interaction with significant family members nor established within the context of crisis. The idealized view, therefore, may not be challenged until there is a crisis. At that time, meanings attributed to certain roles and expectations of appropriate responses may not fit expectations. As a result, new roles, expectations, and meanings must be established, a process negotiated under strained and difficult circumstances.

A slightly different scenario may also emerge. An individual may not have positive expectations for support from family based on past experience and patterns of interaction. At the same time, the person may hold generalized views of what family support should include. Discrepancies between personal experiences and the generalized view of what should be may not pose a problem in everyday situations, but a crisis may make such discrepancies particularly painful resulting in even greater strain between family members.

## GRIEF AND BEREAVEMENT

Although grief and bereavement have been addressed throughout this review, it is useful to define terms and to review the literature regarding current understanding of the grief process. Bereavement is defined as the objective experience of losing someone significant whereas grief is defined as the emotions associated with that loss. Mourning involves the outward expression of grief and is greatly influenced by cultural expectations or practices. Early conceptualizations of the grieving process used stage models. These views of grief suggested that normal or healthy grieving involved moving through grief in a predictable pattern. Typically, these models included an initial period of intense anguish characterized by depression and high levels of distress. These intense feelings gradually declined over time until the individual achieved some resolution or recovery, usually in a year or two. This end point was achieved by “letting go” of the relationship with the deceased and developing new relationships or interests. Those who did not follow this pattern often were considered to be pathological grievers who were at risk for adverse outcomes.

Recent studies of bereaved individuals, however, have shown that grief responses are more complex and variable than those represented by these models. Lund (1996) has compared the experience of bereavement to a roller coaster with many kinds of emotions coming in unpredictable ways. Bereavement outcomes often seem paradoxical. Across many studies, most people are found to be resilient and able to adjust to traumatic loss. At the same time, the experience of bereavement has long-term consequences. Many people, including those who cope well, will not recover from the loss (Stroebe, Hansson, & Stroebe, 1993).

In their classic review of the literature and confirmed in their recent review, Wortman and Silver (1989, 2001) identified four myths associated with coping with loss that are not supported by research. The first was that experiencing distress or depression is inevitable. In fact, although bereavement is often a difficult

experience, a sizable proportion of subjects across multiple studies do not exhibit depressive symptoms or high levels of distress. The second myth suggested that an absence of distress early in bereavement is indicative of pathological grief and puts a person at risk for a delayed grief responses. To the contrary, low levels of distress early in bereavement are associated with successful adaptation to loss whereas those who do experience high levels of distress early are most likely to display the same pattern of distress months and years later. Across studies, approximately 20% of bereaved respondents appeared to exhibit this long-term, intense grief (Lund & Caserta, 1997-98; Prigerson et al., 1995; Prigerson & Jacobs, 2001; Wortman, Silver, & Kessler, 1993). Delayed grief appears to be a rare event accounting for less than 2% of study samples (Wortman & Silver, 1989). The third myth had to do with the importance of working through the loss. Although many people benefit greatly from sharing feelings and talking about their losses, not all people want or need this form of expression (Pennebaker, 1990). Furthermore, rumination, which may be considered a form of working through grief, is actually detrimental to successful coping (Nolen-Hoeksema, McBride, & Larson, 1997; Nolen-Hoeksema, 2001). The final myth was the expectation that people recover from grief. Findings are inconsistent due in part to differences in conceptualizing and measuring recovery. In some studies, most widows and widowers seemed to experience declines in depression and return to a preloss level of functioning within a year or two of bereavement (Lund, 1989). At the same time, however, other studies have shown that bereavement has long-term consequences and that recovery is never complete (Wortman et al., 1993; Klass, Silverman, & Nickman, 1996). Those who indicate they never get over their loss include the 20% who continue to experience high levels of distress described earlier, but also included are those who have adapted well but still experience intense feelings of grief intermittently. These feelings may emerge with new losses, other important life transitions, or in association with anniversaries or special events.

Evidence such as that described by Wortman and Silver (1989, 2001) has contributed to what Fleming and Robinson (2001) describe as a major paradigm shift that is occurring within research and practice related to bereavement. Instead of the emphasis on individuals and phased emotional responses to loss, more attention is being given to the cognitive process of reconstructing meaning or rebuilding previously held assumptions. According to Neimeyer (2001), meaning reconstruction is *the* central process of grieving and a key to understanding adaptation to loss. This new paradigm helps address many of the limitations associated with the earlier framework, which emphasized a predictable progression toward recovery through relinquishment of emotional ties. Consideration of meaning in the aftermath of loss leads to an increased awareness of the ways that major loss affects a sense of identity, it allows recognition of a wider and more complex range of responses to loss, the possibility of positive consequences of loss are considered, and the processes of negotiating meaning within families and the larger social context are recognized (Neimeyer, 2001).

Davis, Nolen-Hoeksema, and Larson (1998) noted that the importance of finding meaning in major loss has been in the literature for many years, but they argued that poor conceptualization and inconsistent definitions limited the usefulness of the concept. They provided evidence for two distinct and unrelated components of meaning making. One is *making sense* and the other is *finding benefit*. Making sense has to do with coming to terms with how the event fits into a previously held view of the world. With significant loss, previously held assumptions may be severely challenged, such as life is fair, and events are mostly controllable or predictable. The greater the challenge to previously held beliefs, the greater the distress. Finding benefit means identifying positive outcomes as consequences of the loss. Finding benefit was further categorized as a growth in character, a gain in perspective, and strengthening of relationships (Davis et al., 1998). Other researchers have focused on positive outcomes from loss and have identified similar categories. For example, Calhoun and Tedeschi (2001) studied

posttraumatic growth, labeling three domains changed sense of self, changed relationships, and existential or spiritual growth.

This paradigm shift in bereavement and practice can also be seen in the way that adjustment or adaptation to grief is conceptualized. The notion that recovery from, or successful adaptation to, grief requires relinquishment of emotional ties to the person who has died has been challenged (Klass, Silverman, & Nickman, 1996; Neimeyer, 2001; Wortman & Silver, 2001). Not only do many bereaved individuals maintain attachments to those who have died, such attachments are increasingly viewed as healthy responses to loss. Klass and Walter (2001) identified four ways in which the dead continue to be part of our lives: sensing the presence of the dead, talking with the dead, the dead as moral guides, and talking about the dead. Klass and his colleagues (1996) proposed that these ways of connecting lead to a life-long process of constructing an inner representation of the person who has died. This in turn enables successful accommodation to loss. The process emphasizes both continuity and change. Relationships are maintained, but those relationships are necessarily renegotiated and transformed. Although Klass focused on parental bereavement, connections with those who have died occur throughout the life span. Troll (2001) described the intimate ties of the very old with those who had died. She found evidence of enduring attachments through continuing commitment, caring, cognitive intimacy, physical encounters, and interdependence.

According to Silverman and Klass (1996), more appropriate than conceptualizing recovery as an end point to bereavement is the concept of accommodation to loss. They argued that people are changed by the experience of bereavement and they do not get over it. Instead, bereaved people maintain bonds or attachments with those who have died by remembering the person and allowing the person to influence their present lives. This is accomplished through an ongoing process of negotiating and renegotiating the meaning of the loss over time. Thus, although relationships are not severed with death, the nature of the attachments will change over time. Family stories often include family members who have died and

family rituals are often created as a way to memorialize loved ones. Symbolic interaction theory is useful for considering how families create meaning and establish activities that symbolize their attachments to the deceased.

Responses to bereavement, then, are quite varied. None of the patterns identified by Wortman and Silver (1989) constituted a majority of respondents in any study and general patterns of responses were not predicted by type of or severity of loss. At the same time, however, certain characteristics of grief and bereavement do appear to be related to the intensity of grief and subsequent adjustment. These are (a) length of time since bereavement, (b) age of the person who died, (c) relationship to the person who died, (d) suddenness of the loss, and (e) gender.

Rubin (1993) compared two groups of SIDS mothers by length of time since bereavement. Mothers bereaved for less than 10 months experienced high levels of anxiety and lowered levels of general function. Those who were two to six years past the death of their child continued to grieve and their losses remained central to their lives. At the same time, however, the loss was no longer overbearing, the mothers did not experience impaired function, and they participated fully in family and community life. In fact, to Rubin, these women demonstrated considerable resilience. The literature on widowhood also indicates most widows adjust to loss, although this process may take longer than many people realize. Ross (1995) found that those who had been widowed less than five years had high levels of distress that could not be explained by lack of social attachment, social support, and economic support. Those widowed more than five years were similar to those who were single, married, or divorced in the significance of these variables in predicting well-being.

Death of a younger person is more difficult to cope with than death of an older person, as would be predicted by the off-time nature of death in childhood or even in middle age (Hansson Vanzetti, Fairchild, & Berry, 1999). Nadeau's (1998) research focused on families where an adult member died. Distress was highest in

families where the deceased was middle aged compared to families in which an older adult died. Parental bereavement is especially distressing at any time during the life course (deVries, Lana, & Falck, 1994). Again, this is consistent with the strength of the parent-child bond and the expectation that children will outlive their parents. Sanders (1988) reported higher levels of somatic reactions, more depression, and more guilt and anger with child death compared to other relationship losses. Rubin (1993) found that older bereaved parents were less resilient than younger bereaved parents.

Although findings are inconsistent, it appears that sudden and unexpected deaths may be more difficult for survivors than those that are anticipated. Compared to expected deaths, sudden death is associated with higher levels of depression, especially among women. Women and men tend to express their grief in different ways (Caroll & Shaeffer, 1994; Staudacher, 1991). Compared to men, for example, women express feelings more often and are more likely to seek support from others outside of their family. Men do not grieve less than women, although they are more likely to cope by being strong and keeping emotions to themselves or within their partnerships. Similarly, women use support groups more and are more likely to seek information. These gender differences may explain why women are over-represented in bereavement research (Lund, 1996). The role of gender will be discussed later in this review when examining grandparent bereavement.

As described above, a sizable minority of bereaved persons do not adjust to loss, and the intense feelings typical of early bereavement continue for many years. This type of grief seriously impairs mental and physical health and ability to function. To learn more about different patterns of grief, Prigerson and her colleagues explored variation in grief response and identified specific characteristics of those who experience what they first described as *complicated grief* (Prigerson et al., 1997; Prigerson, Frank, Kasl, et al., 1995; Prigerson, Maciejewski, Reynolds, et al., 1995) and more recently as *traumatic grief*

(Prigerson & Jacobs, 2001). Through their work, Prigerson and her colleagues noted distinctions among common experiences with bereavement, bereavement-related depression, and traumatic grief. Those with common experiences are those who adapt to their losses over time without requiring professional intervention. They fit the stage model patterns of grief or adjust without experiencing high levels of distress. Those with bereavement-related depression are clinically depressed but can be treated effectively with antidepressants. Complicated grief, in contrast, is not helped by antidepressant medications and continues at high levels of distress for years. Prigerson and her colleagues compared complicated grief or traumatic grief to posttraumatic stress syndrome. They identified seven symptoms that, at high levels, are unique to complicated grief: searching, yearning, preoccupation with thoughts of the deceased, crying, disbelief regarding the death, feeling stunned by the death, and lack of acceptance of the death. Although complicated grief and bereavement-related depression appear to be distinct, they may occur within the same person.

Regardless of the patterns of grief someone experiences, social support consistently has been found to be a critical factor in an individual's adaptation to traumatic life events (Cobb, 1976; Janoff-Bulman, 1992). Social support has been classified in different ways (Chesler & Barbarin, 1984; Cobb, 1976; Schuster & Butler, 1989; Vachon & Stylianos, 1988) but most classifications include some broad form of affective or emotional support. This type of support conveys love and caring, and the availability of someone to confide in and express feelings to without judgment. Vachon and Stylianos (1988) found high levels of instrumental support at the time of death and stable levels of emotional support over time to be most beneficial in widowhood. They also indicated that family support was most critical early in bereavement with friends or peers becoming increasingly important over time.

Although important to adjustment, one's social network may also add considerable stress to the bereaved. This occurs when support is not forthcoming or

when support offered does not meet perceptions of need. Nonsupportive behaviors included minimizing the situation, giving advice, and encouraging recovery (Lehman & Hemphil, 1990). Nonsupportive behaviors result in a lack of opportunity to express feelings and additional isolation because of one's failure to meet others' expectations regarding recovery.

#### Family bereavement

Bereavement research has focused mostly on individuals. With this focus, it is easy to lose sight of the complexities of loss including the interdependencies among family members and friends. Yet, bereavement is a social network crisis (Vachon & Stylianos, 1988). Although clinicians and researchers are increasingly focusing on ways in which death affects the nuclear family (Detmer & Lamberti, 1991; Gelcer, 1986; Gilbert, 1996; Hansson et al., 1999; Nadeau, 1998), grandparents and other extended family members typically have not been the focus of studies on parental bereavement. The impact of the loss on those outside the nuclear family and how that, in turn, might influence mutually supportive or nonsupportive behaviors has not been studied.

When extended family is considered, it is often in the context of support for bereaved parents. In studies, it is common for bereaved parents to indicate a lack of support from relatives presumably including grandparents. Over half of the nine couples in Brabant, Forsyth, and McFarlain's (1995) study indicated a lack of support from extended family. Examples given included family members who acted as if nothing happened, those who intruded on or smothered the bereaved parents, or those who could not talk about it. Callahan, Brasted, and Granados (1983) pointed out that family and friends often did not know how to respond and so they inadvertently said or did hurtful things. Comments that made parents feel others were minimizing their loss were common and included "you can have another child," or "at least you have another child at home." Several of the 10 mothers described by Farnsworth and Allen (1996) also indicated a lack of support

from family members and others. They generally felt discounted and silenced in their grief by many in their support systems. One theme was the lack of understanding of the mother's need to continue including the child who died as part of the family. Similarly, in a study by Lepore, Silver, Wortman, and Wayment (1996), a sizable proportion of bereaved mothers reported being unable to talk about their loss with people in their social networks. A variety of reasons were given including lack of access to people willing to listen (perhaps because others also were deeply affected), negative reactions from others, and inappropriate or insensitive responses. The majority of mothers wished to talk about their dead child. Compared with mothers who were able to talk as much as they wished, those who were socially constrained from talking were more likely to maintain the higher levels of depression associated with early bereavement and were slightly more troubled by intrusive thoughts over time (Lepore et al., 1996).

Although these studies highlight the lack of support from extended family for bereaved parents, it is important to note the variety of factors involved in parents' perceptions. First, not all lack of support was related to lack of interest or caring. The cause of nonsupportive behavior was sometimes attributed to common grief over the death of the loved one (Brabant et al., 1995; Lepore et al., 1996). Extended family may be considered nonsupportive because they grieve in ways that are different from or not recognized as appropriate by parents. As a result, parents may feel that grandparents do not care or appreciate the extent of their loss. Perhaps differences in the expression of grief are influenced by cohort experiences. Parents today are more likely to have access to support groups and to professionals who have had some training in grief and bereavement. Those in older generations may have had experiences with loss where bereaved persons were encouraged to "get on with their lives" and discouraged from talking about personal experiences with death.

According to Detmer and Lamberti (1991; Lamberti & Detmer, 1993), how family members respond to changes in the family system following death, coupled

with available support systems, will determine the course of the grieving process. They emphasized the importance of family members maintaining both cognitive and emotional functioning. Without both, family members may begin to make assumptions that others in their family experience and respond to the death in similar ways. Awareness that grief experiences are different may lead to resentment and conflict if these differences are not accepted as legitimate.

Hansson and his colleagues (1999) suggested that bereavement in families is as complex as bereavement in individuals. Using a family systems perspective, they conducted research to explore the impact of bereavement on families. They were interested in identifying families at risk for negative outcomes. They suggested that individual recovery from loss can be helped by strengthening or reconstructing available family support systems. They developed the Family Bereavement Inventory, a measure of the impact of bereavement. They demonstrated that family members can and do give voice to shared experiences. They also found that families scoring high on cohesiveness and shared values and activities experienced less negative impact from bereavement than conflicted families.

Gilbert (1996) also emphasized the importance of shared meanings among family members. Such meanings are socially constructed. If family members have generally positive views of each other and of their relationships, they are likely to develop mutually validated views of the loss and its meaning to other family members and to the family as a whole. In addition, communication is likely to remain open resulting in recognition and acceptance of the similarities and differences in their grief.

Nadeau (1998) focused her research on the process of developing meaning and the content of those meanings among families who had experienced the death of an adult member. She interviewed family members, in some cases from three different generations, together, individually, and in subgroups. Nadeau argued that family meaning is something more than a summary of individual meanings. She

presented evidence illustrating exchanges among family members that resulted in shared meanings that were not evident in individual interviews. In conversation, family members would make clarifications, add illustrative points, take exception, or extend meanings expressed by others. She emphasized the importance of interviewing many family members from different generations to understand how a death has affected the family unit. In her research, Nadeau found variability in the extent to which family members shared meanings surrounding the death. She found no consensus among all the members in one family, but family members did tend to agree on the basic meaning of the death. Individuals and subgroups within a family often had specific versions of the more general meaning. Like Gilbert (1996), Nadeau suggested that the ability of family members to interact and to share meanings positively affected their ability to cope with the death.

#### Grandparent bereavement

Very little attention has been given to grandparent bereavement. Yet, grandparents have unique needs and experiences related to grief. A group of SIDS grandparents formed a national organization, Alliance of Grandparents Against SIDS Tragedy (AGAST) to help address those needs. It also is an advocacy group for SIDS research and for programs to support SIDS families.

A recent review of the literature revealed only three empirical studies focusing on grandparent bereavement, but findings were consistent across studies (White, 1999). Although parents and grandparents had different role relationships with the child and although the centrality of that role was different for each, grandparents shared many of the same responses as the parents to the death of the child. Descriptions of grief responses in these three studies were similar to those of parents who experienced the loss of a child (DeFrain, Ernst, Jakub, & Taylor, 1991; deVries, et al., 1994; Farnsworth & Allen, 1996; Klass, 1997; Lang, Gottlieb, & Amsel, 1996; Lepore et al., 1996). At the same time, Ponzetti (1992) reported that parents expressed these feelings more often than grandparents.

A major, and perhaps the most important, finding in all three studies was the trauma grandparents experienced in witnessing the pain and sorrow of their adult children and their own helplessness in alleviating that pain. This appeared to compound their own grief at the loss of their grandchild. The anguish associated with being unable to help their children was a theme that crossed many of the response categories in all studies and was evident in the case study presented in Chapter 1.

Fry (1997) found that, over a six-month period, grandparents often put aside their own grief to attend to the needs of their children and their surviving grandchildren. The grandparents in the DeFrain study told of supporting children by calling and visiting, being available, paying for funeral expenses, and providing other instrumental support. Some grandparents also identified the importance of “butting out” when they were not needed and letting parents make the decisions required following the death of the child. Thirty percent of the grandparents had contacted a support group for information and about the same percentage had attended a support group with their adult children. Bereaved parents identified their own parents, in addition to their friends, as sources of support (DeFrain et al., 1992).

Grandparents identified being included by their adult children and being able to express their own feelings and emotions with their adult children as important sources of personal support they received from their bereaved children. Ponzetti and Johnson (1991) reported that about half of the respondents (51%) reported feeling closer to their children and 16% reported being closer to other grandchildren after the grandchild’s death.

A number of gender differences were noted. Consistent with the bereavement literature, grandmothers were more likely than grandfathers to express a desire to talk about the child who died (Ponzetti & Johnson, 1991). This is probably a factor in the higher response rate for grandmothers compared to grandfathers across all three studies. Grandmothers also reported emotional and

physical distress more often than grandfathers. The opportunity to talk about the child represented an important source of support for grandmothers (Ponzetti & Johnson, 1991). According to the DeFrain and his colleagues (1991-92), respondents, who were mostly grandmothers, were three times as likely to turn to daughters as to sons for support. Daughters were second only to spouses as support persons. The authors offer this as evidence that fathers are neglected in their grief. Fry (1997) reported that grandmothers were more likely than grandfathers to seek an outlet for emotional expression. In addition, they provided social support to others within and outside of their families as a way to foster their own healing. Religious beliefs were described more often by women as a source of comfort and recovery compared to men (Fry, 1997). Grandfathers, more than grandmothers, offered instrumental support to their children through performing tasks and offering financial assistance. They were more likely to talk about engaging in work as a means to help with their recovery. Ponzetti and Johnson (1991) found no gender differences with respect to feelings about adult children, anger, helplessness, and a need to make sense of the death. No significant differences between maternal and paternal grandparents emerged in their study.

In the DeFrain study, 52% of the grandparents indicated that they and their spouse had different coping styles. This is less than the 93% of the SIDS parents who identified that they had different coping styles from their spouses. Most respondents in both parent and grandparent studies, however, did not indicate that these differences in coping style added further distress to their grief. In fact, Gilbert (1996) suggested that marriages can be strengthened following bereavement when there is recognition of differences in grieving styles and when these differences are accepted as strengths. Research is needed to determine whether intergenerational relationships are strengthened when differences in coping styles across generations are recognized by family members and are interpreted as strengths.

which family rules and rituals are associated with or are a part of support within families.

Finally, we know that both gender and generation shape family relationships. Women are kinkeepers, caregivers, and providers of emotional support. The strongest ties in families are among women. Yet we also know that there are many similarities between men and women; both grieve deeply the loss of a child or grandchild even if they express this grief in different ways. We know there are generational differences as well. Parents feel stronger attachments toward their children than their children feel towards them. As issues related to grief are considered, we can expect that there will be differences among women and men and parents and grandparents in the ways that they give and receive support, contribute to the construction of meaning related to loss, and develop rules and rituals about how to respond to loss. These differences have implications for the ways in which families adjust to their bereavement.

## CHAPTER 3 METHOD

### RESEARCH QUESTIONS

The following research questions served to guide this research:

1. How are family members supportive of one another across generations in response to infant loss? How might support be influenced by type of loss, family structure, gender, and lineage?
2. What meanings do parents and grandparents find following the death of a child? How might this be influenced by factors associated with the death, time since death, gender, generations, and lineage?
3. To what extent do mutually developed family rules or rituals acknowledging continuing bonds with the baby contribute to mutually supportive behaviors among family members across generations?
4. How are family support, meaning making, and rules and rituals for maintaining bonds related to adjustment following infant loss?

### SAMPLE SELECTION CRITERIA

The intergenerational family composed of bereaved parents and grandparents was the unit of analysis for this study. Families were selected to be similar in terms of parents' marital status, age of the child who died, type of death, and length of time since bereavement. The goal was to include 5 to 10 families where the biological parents were still together following their child's death between one and five years before. The minimum of one year was chosen to allow families some time to adjust to their losses. In addition, all families would have experienced at least one year of anniversaries (e.g., birthday, death date, holidays). These are difficult transition points for most family members. It is likely that families do critical work during that first year to negotiate the meaning of loss, to determine or confirm family rules for grieving and coping with the loss, and to

maintain or establish new patterns of support (or nonsupport). The upper limit of five years was somewhat arbitrary, although recruitment of participants for research studies appears to be more difficult with length of bereavement (Neal, Carder, & Morgan, 1996). In addition, the character of bereavement changes over time for most people (Ross, 1995; Rubin, 1993). After five years, many adjustments have been made and detailed memories about feelings and family dynamics in the early weeks and years following the child's death are likely to diminish. Although the child who died is never forgotten, other life and family demands take up time and energy. The four-year time frame, therefore, was proposed to focus on the early bereavement experiences of families rather than on long-term adjustment.

As described in Chapter 2, women are over-represented in most bereavement research. In a study of families, it is important to hear the voices of fathers and grandfathers as well as mothers and grandmothers. A minimum of four people, the parents and at least two grandparents, were to participate in the research. Mothers and fathers were to be the biological parents of the child who died. Only those who were still married or cohabiting were to be included. In addition, attempts were made to include both grandmothers and grandfathers on each side of the family so that a range of grandparent/parent relationships would be represented across the sample

The cause of death in most families was expected to be sudden infant death syndrome (SIDS). Families where death had occurred from other causes were included as long as the child was under 16 months and the death was sudden and unexpected. Selecting families that had experienced similar kinds of losses at similar points in family development helped to reduce variability in the sample. deVries and his colleagues (1994) and Rubin (1993) suggest that parental bereavement experiences are influenced by stage in the life course. The parents and the grandparents in this study were expected to be relatively young.

## RECRUITMENT

Recruitment is often one of the most difficult aspects of bereavement research (Lund & Caserta, 1997-98). Multiple sources, therefore, were used to reach families including four organizations focused on support for bereaved parents: SIDS Resources of Oregon (SRO), Washington State SIDS Foundation, Association of Grandparents Against SIDS Tragedy (AGAST), and Brief Encounters. The first three groups provide support for SIDS parents or grandparents and are involved in a variety of activities to promote research and advocacy. Brief Encounters is a support group for those who experience pregnancy loss or neonatal death from multiple causes. Articles about the study were placed in the newsletters of each of these organizations. In addition, at the suggestion of the support group facilitator, a visit was made to the SRO support group meeting to explain the study in person and ask for participants. The advisor for Brief Encounters offered to make inquiries among the Board of Directors of that organization. Copies of the IRB application were distributed for that purpose. Included in all materials and presentations was information disclosing my status as a bereaved parent. Several participants indicated this shared experience was a factor in their consideration to participate.

The public health and medical examiner system was to be another source for families, particularly those who had not participated in support groups, because they maintain records of almost all SIDS deaths in Oregon. A protocol was developed for contacting families by mail using state lists. Approval from the medical examiner system was obtained, but the list of names was not available until after data collection was completed.

## THE SAMPLE

Members of 11 families responded to newsletter articles. After discussion with them about the study and the requirement for multiple family members to participate, eight of those families were recruited for the study. Those initiating

contact and who ultimately participated were seven mothers and one grandmother: two from SRO, four from Brief Encounters, and two from AGAST. No one responded from the Washington State SIDS Foundation. Support group facilitators and advisors also generated names of potential participants. Of that group, one father and one mother responded to direct requests to participate. All 10 contact persons secured agreement from their other family members to participate.

Only 4 of the 10 families met all of the original study criteria. Two families were less than one year from their loss, one four months, and the other seven. The mother in the most recently bereaved family did not want to wait until later to tell her stories, although all family members agreed to be interviewed a second time four months later. Although they were less than one year from loss, both families experienced the holiday season without their babies and could describe ways their families had responded. In two families only one grandparent was available to participate. In one, the only other grandparent lived distant and had serious health problems that precluded participation. In the other, a maternal aunt substituted for her father (the maternal grandmother was deceased); his children made the judgment that he would not want to participate because he never talked much about anything, especially the death of his grandson. One family did not include a father. The mother had adopted her child as a single mother. She was accepted into the study because her single status did not represent a change resulting from her baby's death. Finally, the death of one child followed illnesses related to multiple problems present at birth, so in many ways was predictable. His parents, however, did not expect him to die and so experienced his death as sudden and unexpected. All of those initiating contact about the study wanted very much to participate. In the interest of completing this project in a timely manner and because most criteria were met, all who volunteered were accepted into the study.

The sample consisted of five families who had experienced a SIDS loss and five families whose babies had died from other causes. Key characteristics of the sample are presented in Table 1. Deaths had occurred between four months and five

Table 1: Study Participants

Cause of death	Age at death	Time since death	Parents	Grandmothers	Grandfathers
SIDS	2 ½ months	4 months	Mother Father	Maternal Paternal	
SIDS	3 ½ months	1½ years prior	Mother Father	Maternal	Maternal
SIDS	3 months	3 ½ years	Mother	Maternal Step-maternal	Maternal
SIDS	7 months	4 ½ years	Mother Father	Maternal Paternal	Maternal
SIDS	4 ½ months	3 years	Mother Father	Maternal aunt Paternal	
Not determined	Stillborn at 32 weeks	3 years	Mother Father	Maternal Paternal	Maternal
Cord accident	Stillborn at 33 weeks	7 months	Mother Father	Maternal Paternal	Maternal
Complex medical conditions	Stillborn at 19 weeks	5 ½ years	Mother Father	Maternal	Paternal
Complex medical conditions	2 days	3 ½ years	Mother Father	Maternal Paternal	
Complex medical conditions	4 months	2 years	Mother Father	Maternal	

and a half years before. The SIDS babies ranged in age from 2 ½ months to seven months. Those who died of other causes included three stillborn babies (one a terminated pregnancy due to multiple and severe birth defects, one because of a cord accident, and one whose cause of death was never determined). Two babies died in the hospital following unsuccessful treatment for complex medical problems. One baby was two days old and the other was four months old.

Participants included 10 mothers, 9 fathers, 9 maternal grandmothers, 5 maternal grandfathers, 6 paternal grandmothers, 1 paternal grandfather, 1 maternal aunt, and 1 step maternal grandmother. Two of the fathers had been married before and each had a child from the previous marriage. Mothers were all in their first marriages with the exception of one mother who was a never-married single mother who had adopted her child. Ages of parents ranged from 25 to 45 at the time of the baby's death; the median age was 35. Although all families lost infants, they occurred at different stages of family development as suggested by this age range. The babies who died were first children in six families and second children in four. Surviving children ranged in age from 18 months to six years.

At least one set of grandparents were divorced in seven of the 10 families, some multiple times. Both maternal and paternal grandparents were divorced in two of these families. Two grandmothers and one grandfathers were widowed at the time of their grandchild's death. One other grandfather was widowed soon after. Grandparents in these families ranged from 47 to 83 at the time of their grandchild's death, with the median age about 60. Most, but not all of these grandparents had other grandchildren as well. The baby was the first grandchild for one side in only three families.

Family members lived all over the country. The families of the two people who responded to the AGAST newsletter lived the eastern United States. Most other parents lived in the Portland metropolitan area, except one couple who lived in southern Oregon. In only one family did parents and grandparents on both sides of the family live in the same community, and that family lived in the east. Five couples lived near at least one grandparent. In four families, grandparents on both sides lived at least six hours away. More older parents than younger parents tended to live distant from grandparents.

Many participants had family stories that shaped their responses to this current loss. For some, these events had occurred in the distant past. For others, ongoing circumstances formed responses to the death of their grandchild. Two

grandmothers recently had been treated for breast cancer. One of these grandmothers was also raising her infant grandson, born to a drug-addicted daughter. Another grandmother was caring for her terminally-ill husband (a step grandfather). Three families had experienced other child deaths. The oldest of these had committed suicide at age 19 not many years before. Two grandmothers had children who had died in infancy, and one of these had lost a second child as a teenager.

## PROCEDURES AND MEASURES

As originally proposed, qualitative and quantitative data were to be gathered in three phases. First, once multiple family members agreed to participate, all were sent a letter describing the research, two informed consent forms (one to return and one to keep), and a questionnaire to collect quantitative data about how individuals and families were coping and how they felt that the family as a whole was coping with the death of the child. As described below, this activity was completed as proposed. The second phase was to be a group interview to be held with each extended family. This was to allow family members to discuss together the impact of the loss and how the family responded. The group setting would also offer an opportunity to observe family dynamics and to identify emerging insights and meaning making among family members. Finally, individual interviews were to be conducted to build upon information presented in the larger family group, explore further areas of similarities and differences, and allow participants to explore issues they were not comfortable discussing in the larger group.

### Quantitative data

Quantitative methods are often used in tandem with qualitative methods. This allows researchers to combine the strengths of both approaches (Strauss & Corbin, 1990). In this study, quantitative data was used principally to describe the sample. Quantitative data collected included background information regarding

number of children and grandchildren in the family and previous experiences with loss. The questionnaire also contained three standardized instruments: the Family Bereavement Inventory (FBI), the Bradburn Affect Balance Scale, and the Inventory of Complicated Grief (ICG). Copies of all three measures are included in Appendix A.

#### Family Bereavement Inventory.

The Family Bereavement Inventory (FBI) was developed to assess the impact of bereavement on families and identify the characteristics of families that make them vulnerable to negative outcomes (Hansson et al., 1999). The instrument focuses on shared experiences of the family unit and is composed of 30 items derived from the literature covering such issues as emotional support and communication, family structure, family traditions, family cohesion, family conflict, and economic stability. The FBI has four subscales: Family disintegration/disruption, family self-esteem, family depression, and family stress. The items composing the family stress subscale, addressing issues such as the deceased's family responsibilities and lost income, were not used in this study because they were not directly relevant to infant loss.

Hansson and his colleagues reported high reliability across their studies ( $\alpha < .90$ ). They also presented evidence for criterion validity and discriminant validity. The scale correlated strongly with a criterion index measuring negative family outcomes, a severity of family disruption measure, severity of depression measured by the Center for Epidemiological Studies Depression scale (CES-D), the Texas Revised Inventory of Grief, and more. The FBI also appeared consistently to distinguish between families on the basis of the age of the person who died and type of relationship: Negative scores were associated with the death of a younger family member, especially if the family member was a sibling or child. Positive scores were associated with death of an older person who was a parent or other family member. Although most of the studies to develop the FBI collected data

from only one family member, it has been used with family pairs who experienced the death of a third family member. According to Hansson and his colleagues, agreement within pairs was higher than is typically found in family instruments ( $r = .47, p < .05$ ).

In addition to deleting one of the subscales, a modification was made in the response options for completing the FBI. In pilot testing, it appeared difficult for some parents to answer questions that included both sides of their extended family. In more than one case, experiences with the mother's side of the family were quite different from experiences with the father's side. On the questionnaire for parents, therefore, three response columns were provided, one for the nuclear family, one for the maternal side, and one for the paternal side. The data from the FBI was not analyzed for this dissertation.

#### Bradburn Affect Balance Scale.

This 10-item scale has met standards for reliability and validity and is commonly used in gerontological and bereavement research to assess overall mood (e.g., Charles, Reynolds, & Gatz, 2001; Rossi & Rossi, 1990). Five questions assess positive affect and five negative affect (Bradburn, 1969). The instrument is easy to administer and has been found to be useful and reliable. As described in the literature review, bereaved people experience a wide range of both positive and negative emotions during bereavement. We anticipated that after a year, many participants would score positively on the positive affect portion of the scale. The negative affect scale is related to scales measuring depression. Depressive symptoms are common in bereavement, although they generally subside over time. Given the extreme stress of loss of a child and the relatively short time frame of bereavement in this study, however, greater negative affect was expected, particularly with parents, than in the general population.

### The Inventory of Complicated Grief.

This 19-item instrument is proposed for this study because it has been found to distinguish traumatic grief from bereavement-related depression and more common responses to grief that include adaptation over time. Because sudden death of an infant or young child is associated with difficulties adapting to loss, it seemed useful to include this measure. At the same time, the authors suggested that those who experience complicated grief may belong to a unique population including those with a history of traumatic loss or poor attachments. Those who are experiencing complicated grief, therefore, are likely to have different family experiences from those who are not. Scores on this scale will provide useful descriptive information about the study participants.

Prigerson and her colleagues (1995) reported the internal consistency of the ICG measured by Cronbach's alpha was  $\alpha > .94$ . Factor analysis indicated that the scale measures a single dimension of complicated grief. Concurrent validity indicated high association with the Beck Depression Inventory, the Texas Revised Inventory of Grief, and the Grief Measurement scale. Those scoring high on the ICG also had significantly worse scores on several quality of life measures including general health, mental health, physical health, and social functioning. As expected with complicated grief, differences in scores between complicated grievers and others were not related to time since loss.

### Qualitative data

This study was unique in its focus on how families, as opposed to individuals, cope with bereavement. Qualitative research methods developed for focus groups were to be used (Morgan & Krueger, 1998). Focus groups are group interviews for purposes of exploration and discovery. Group discussions create a process of sharing and comparing among participants (Morgan, 1998a; Nadeau, 1998). They allow the researcher to observe interactions and they provide greater

detail than interviews on such issues as attitudes, opinions, and experiences. Focus groups also provide an emphasis on socially rather than individually created meanings (Berg, 1998), which is consistent with the purpose of this research. In this study, observation of group process was to be an important tool to help discover how family members develop shared meanings and negotiate their paths, either together or separately, through traumatic loss. Although focus groups generally are composed of strangers, they have been used successfully with families (Morgan, 1998b) and in exploring sensitive issues (Morgan, 1998a).

Because so many family members lived distant from one another, however, it was not possible to interview parents and grandparents together except in one family. In that family, only one grandparent was interviewed with parents. The interaction and sharing that took place in this family suggests that this is a good approach to understanding families and the ways that they negotiate meaning and family rules and rituals. Two other couples lived near a grandparent and their interviews could have taken place together. One parent requested that they not be interviewed with the available grandparent because of lingering tensions about strong disagreements between the generations regarding the treatment and care of the baby before he died. Their experiences surrounding the child's death were not something they felt they could discuss together even though both parents and grandparent indicated they currently had positive relationships with each other. The mother of the second couple said she had forgotten to make arrangements for the grandmother to participate, although she did make arrangements for her mother to be interviewed immediately following the interview with her and her husband.

Although intergenerational group interviews were not feasible, 12 parents in six families were interviewed in person as a couple, followed by individual interviews with eight of the 12. Those who did not participate in follow-up interviews were one couple, one mother, and one father. During the course of the interviews, it appeared that subsequent interviews with these four individuals would be difficult to schedule for a variety of reasons: multiple other demands on

time and energy, discomfort talking about loss, little more to say, and thorough and complete discussion of all issues of interest. As a result, all questions designed for both the group and individual interviews were asked of the three couples. Only one grandparent couple was interviewed together with separate follow-up interviews. These grandparent interviews were conducted by phone, as were interviews with 18 other grandparents and six parents. No other joint interviews were conducted over the phone. Interviews took place between October 2000 and April 2002. The semi structured interview guide is presented in Appendix B. All interviews were tape recorded and transcribed verbatim.

#### DATA ANALYSIS

Data analysis followed a grounded theory approach (Krueger, 1998c; Lofland & Lofland, 1995; Strauss & Corbin, 1990). Key themes or broad categories were identified and noted in the margins of the interviews. Of particular interest were categories related to shared meaning about loss, shared meaning about appropriate responses to loss, family rules about continuing connections with the child who died, and social support given and received. Second and third readings of the transcripts revealed other categories and subcategories. An analytic framework based on Strauss and Corbin (1990) axial coding model was then developed. This coding scheme is contained in Appendix C. The interviews were all coded based upon this framework.

After coding was completed, detailed descriptions of each family were developed as a way to manage the large amount of data (Knafl & Ayres, 1996). Both qualitative and quantitative data were used in constructing these summaries. The 10 - 20 page summaries were read by three colleagues familiar with family studies, end-of-life care, and bereavement. One had experienced pregnancy loss and another the death of her baby from SIDS. The process of creating these summaries and discussing them with others helped to identify themes and patterns within and between families and contributed to the synthesis of the data.

## CHAPTER 4

## RESULTS: PATTERNS OF FAMILY SUPPORT, MEANING MAKING, AND CONTINUING BONDS

## FAMILY SUPPORT

The research questions addressed here were: How are family members supportive of one another across generations in response to infant loss? How might support be influenced by type of loss, family structure, gender, and lineage?

Infant death, particularly sudden and unexpected, is a traumatic occurrence and was clearly experienced as such by these families. In this study, most described it as the most difficult situation ever experienced by their families, even in families familiar with hard times. All of the parents felt profound sorrow, describing their heartache and altered lives. Many, but not all, of the grandparents shared these feelings of personal loss as well. All grandparents expressed concern for their children and most described their pain at watching their children grieve while not being able to make things better.

Social support is considered a critical factor in helping individuals come to terms with great loss (Cobb, 1976; Janoff-Bulman, 1992; Nolen-Hoeksema & Larson, 1999). According to a paternal grandmother in this study, the loss of a baby is "something that's real hard to go through, but if you have the support of the people around, it doesn't fix it, but it makes it easier to cope." A father from another family also talked about the importance of support:

We were in a black cloud and just the family support and the friend support was the best thing that I could ever ask for to go through something like that. It's not something you try to deal with amongst yourselves, being like Marie [mother] and I, there's no way, we needed help to cope with it and we got it.

As reflected by these comments, receiving and providing support were part of the stories told by these families. Parents generally felt their families, or at least key family members, were supportive in the aftermath of their losses. This is expected

given the nature of a study that required participation from multiple family members and given what we know about support by family members in other realms. At the same time, however, individuals in every family except one, identified one or more family members who were not supportive or with whom there were ongoing tensions or conflicts. In this section, the range of supportive behaviors that occurred in families between parents and grandparents is described.

Social support has been classified in many different ways (Chesler & Barbarin, 1984; Cobb, 1976; Schuster & Butler, 1989; Vachon & Stylianos, 1988). Most include some broad form of affective or emotional support conveying love and caring, the availability of someone to confide in and express feelings to without judgment. In this study, two broad types of emotional support were apparent and were labeled *being present*, and *acknowledging the loss*. A second general type of support involves instrumental or practical support. This type of support was present in these families as well and involved *performing immediate tasks*, and *providing information*. Vachon and Stylianos (1988) found that high levels of instrumental support at the time of death and stable levels of emotional support over time were most beneficial in widowhood. Having family members present and/or offering support is not always perceived as support. Indeed, negative aspects of one's social network can be harmful to well-being especially when one is experiencing stressful life events (Ingersoll-Dayton, Morgan, & Antonucci, 1997). In this study, negative experiences were categorized as either *unskilled support* or *no support*.

How support was provided and received in these families is described below. As expected, parents were those in most need of support and grandparents responded by providing it, or attempting to provide it. Only a minority of parents and grandparents described support extending from parent to grandparent. Most of the discussion, therefore, describes the ways in which grandparents provided support. Attention also is given to issues of gender and family lineage.

## Emotional support

### Being present.

Support categorized as *being present* was one of the most helpful and frequently described types support. It also represented the most powerful and concentrated involvement between the generations, especially early in bereavement. Being present at the time of great sorrow included both emotional and physical presence. A sense of taking time and putting routine activities on hold was characteristic of those who provided this type of support. For example, a father expressed his appreciation for his mother-in-law, who he felt was supportive in contrast with his own family.

Her mother came down from [another state] and stayed with us for like a week . . . She was good and I liked that she took her time, a week off, and she was there for us, that was the difference. She stopped her life, maybe not for a long period of time, but she took time out. My family didn't; they went on as if . . . nothing had happened, and that was the difference.

Those who experienced this supportive presence felt both understood and cared for. Those who were present seemed to know when to talk, when to just listen, and when to be silent. A father whose mother stayed with them for nearly a month after his son's death, described her help this way, "my mom, she's going to be there for you, and just to listen or hear and not tell you their point of view." A maternal grandmother described her efforts this way: "I tried real hard not to kind of intrude. By that I mean I didn't ask a lot of questions, I just made it [easy] for them to offer any thoughts or feelings." In this and in other families where grandparents were emotionally present, parents often talked freely and at length about their babies, their feelings of loss, and all the associated emotions. Both mothers and fathers found this to be important, although mothers were more likely than fathers to speak extensively with other family members, most frequently with grandmothers. Fathers tended to talk more with wives than they did with their

mothers or mothers-in-law. An exception was a father whose wife did not talk about her grief. He talked mostly with his mother.

Being present also meant listening to expressions of grief, or observing responses to grief, without judgment. In most families, acceptance for the different ways that parents and grandparents grieved was considerable. A mother recalled gratefully the support from her parents during the initial months of bereavement:

They didn't preach, that was really helpful because there were times I could have been preached to, staying up till 4:00 in the morning. I would stay up until I was exhausted and then go to bed. My mom would say, "Well, I hope you can rest tonight," but she would never say, "Now don't stay up and drink that fifth of alcohol trying to numb yourself, don't starve yourself today, or don't eat a bunch of crud." She would just fix a meal and nurture unconditionally. And watch me struggle.

Physical presence took on special significance when the baby's grandparents lived far away. In this study, most families had at least one set of grandparents who lived distant. Typically, those who lived furthest were among the older grandparents in the study. Many of the adult children in these families had established independent lives many years before. Some were at first uncertain what their families would do. Although he felt many family members would have responded to requests for help, one father said appreciatively that it was his mother-in-law who actually "delivered. She got on the plane and got out here and no questions." A mother knew that her own mother was afraid of flying and disliked travel, yet she came and did what she could; "the fact that she came out, I think was very brave for her and the fact that she went to the funeral home, even though she was so terrified that I'd make her hold the baby." Another father talked about the effort his mother and sister made.

It was comforting to me to know that in a time like this with my family, that they'd take the time to come out. . . . that I'm part of the family and even though I'm 3000 miles away, they still consider me part of the family. So they came out and gave me emotional support . . . the event of them coming helped me.

Not all grandparents had to be geographically close to be present for their adult children or in-laws. For example, a paternal grandmother described how she stayed in close touch with her daughter-in-law by telephone and e-mail in the months following her grandson's death.

She gradually opened up a lot more about her feelings . . . she expressed constantly her ugly feelings as well as more higher, refined sentimental thoughts or whatever they were, they all poured out. And that was really good and I'm glad. That was probably the only thing I did, because I'm six hours away.

A maternal grandfather described his efforts to provide support after his granddaughter's stillbirth this way, "I didn't hop on an airplane and go out there, but I kept in pretty close touch via telephone and just tried to help her talk through it, and that wasn't very easy." Although clumsy at times, his daughter found his concern helpful.

I felt support from my father even though he was just so totally clueless, and my brother. They just didn't know what to do, but they were good in the aspect that they called and they called. . . . They would both just call me once a week just to see how I was doing. I think it made my father uncomfortable when I would start crying on the phone, but yet it wasn't like he rushed me.

A grandmother called her daughter long distance daily to monitor her well-being, and found the support going both ways.

I just like to hear her voice. I always know when she's up or down. She knows when I'm up or down. "Ma, you better go back on those pills," she'll tell me. . . . I just say, "what did you eat tonight?" and she'll tell me. . . just stuff, just to see that's she's okay.

Although a few of the grandfathers, especially maternal grandfathers, seemed to meet the criteria of *being present*, those described this way most often were grandmothers. During interviews mothers talked more frequently about conversations with their own mothers, seemed to spend more time with them, and called on them more for emotional support than they did their fathers. The strength of the mother-daughter bond as the most powerful of the parent-child relationship

was apparent (Rossi & Rossi, 1990; Suiter, Pillemer, Keeton, & Robison, 1995). Those identified as *being present* were more often maternal grandmothers than paternal grandmothers. Three of these mother-grandmother pairs appeared to be especially close prior to the child's death. These were among the younger mothers and grandmothers. Grandmothers had been emotionally attached to the babies and lived in the same community or recently had lived in the same community as their adult daughters. It was only in these three families that mothers and grandmothers identified ways that mothers provided support to grandparents.

Not all close mother-daughter relationships resulted in support that could be categorized as *being present*. Relationships in some families were ambivalent and were associated with unskilled support in three families as will be described below. In two of these families, paternal grandmothers seemed to substitute for the maternal grandmothers in providing the level of support of *being present*. It is interesting to note that both paternal grandmothers commented that they had been present for their daughters-in-law more than their sons. According to one,

I think if I had any regrets it would be that I haven't had a lot of time to connect with my son on that deep level like I have with Gail. But I've thought about it and the fact of it is that women often do this kind of sharing much more than men do. And the other thing I've noticed, I have three sons, two of whom are now married, and all of that exchange primarily happens between husband and wife.

This grandmother's observations about her own family seemed to match experiences of most families in this study.

#### Acknowledgement

Awareness of the impact of the loss on the individual and couple was an important source of support. Sometimes, especially when the baby was stillborn or just days old at the time of death, some family members did not fully comprehend the devastation experienced by parents. In contrast, grandparents sometimes commented that their children did not seem aware of the extent of their grief as

grandparents, whether the grief was for their grandchildren, their children, or both. Awareness, therefore, was often an important first step in acknowledging loss.

Although by itself, acknowledging the loss represented a somewhat less intense involvement by family than being present, it was no less valued as a means of support. Those who were perceived as being present usually acknowledged the loss as well. Included in this category were expressions of sorrow and sympathy. One of the oldest couples in the study made the painful decision to terminate their pregnancy when they learned their baby had multiple disabilities. They called their parents who lived distant "in the midst of that broken heart to at least reach out with the best expectations to those who should be closest to us." The father described their parents' responses as supportive. His wife responded,

You know, it's funny when you say our families were supportive. It's not as if they sought us out, brought up the topic, continued to sort of nurse us along. From our point of view, supportive was just saying, "we understand and we're really sorry." And with both of our families that pretty much meant that's the end of the story and we don't talk about it again. But there was that acknowledgement. That was by no means a guarantee when we chose to tell them, I think on either side. So it felt like a gift from both sides.

This couple received the support of *being present* from friends, health professionals, and support group members rather than their families. Because they received needed support from others and because they did not have expectations for more involved participation from their families, acknowledgement was enough to sustain positive family relationships.

Another important way of acknowledging loss was to continue recognizing birth and death dates. This was particularly important for those parents, usually expressed by mothers, who feared that their children would be forgotten, such as this mother: "She [paternal grandmother] always sends us a card. My mother usually sends us flowers. And those are helpful for me that people haven't forgotten her." As discussed under research question 3, family members often acknowledged the baby's death through participation in a variety of rituals or

adoption of symbolic representations of the baby. Such activities seemed to facilitate acknowledgement for those who found it difficult to talk or to be emotionally present in other ways.

Acknowledgement also meant talking about the baby or at least being able to listen when a parent wanted to talk about the baby. For example, this paternal grandmother said,

Usually if I'm going to say something about him, I say "I want to talk about the baby, is that going to bother you?" And she'll say, "oh, no, no, no, I like to talk about it." . . . She loves to talk about him, this baby. To this day she just wants to talk about him.

More frequently, however, others waited for parents to initiate discussion about their babies. Sometimes parents found grandparents receptive, but other times they were not. For example, this mother, whose daughter had been stillborn three years before, described both grandmothers as supportive, but was most comfortable talking about the baby with her own mother.

I was always the one to bring it up. But I brought it up with her [maternal grandmother] because the environment was such that it felt safe and okay to do that and even to this day I feel that way, whereas even with Paul's mom sometimes, I'm on edge to bring that up. I do occasionally, but I bring it up with reservation.

A mother of a stillborn infant contrasted support from her mother-in-law and mother:

I told her [paternal grandmother] I was so appreciative that "you'll talk about him." Because Mom called me all the time, but it seemed like she wouldn't talk about him. But I wanted to. This was my baby, I don't have him any longer. All I can do is talk about him.

For the most part it appeared that grandparents were receptive to their children's needs to talk about their babies and willingly engaged in conversation once initiated. Some of the mothers expressed appreciation for those who did not wait for them to lead the way, especially when they talked about the babies as individuals.

I realize the most wonderful thing people could do would be to remember Kyna and talk about how wonderful she was and the funny things she did. Even in 12 weeks she had this personality and she did these things and how funny they were. And that was really the most helpful thing . . . to talk about her as a person instead of getting caught up in the idea of death talk.

### Instrumental support

#### Performing immediate tasks

Funerals or memorial services were held in seven families. Grandparents provided substantial assistance in making the arrangements in three of these families, including contacting the funeral home, locating cemetery plots, and assisting their adult children in making a variety of decisions. These parents were among the youngest in the study, with most in their mid or late 20s. According to one of these fathers, "He [maternal grandfather] took control. If it weren't for him, a lot wouldn't have been done. We would have had no one to turn to." Another maternal grandfather described his role:

She [mother] asked me if I would handle contacting the funeral home and at least getting him moved from the hospital to the funeral home. So I did that. I called the funeral home . . . and explained to [funeral director] that they were young and didn't have a lot of money and to help them and if there was a financial issue to not get hung up on it and move forward and come to me and I'd help. Without stepping in front of them.

The reluctance to "step in front" of their children seemed common for these grandfathers who emphasized their helping role rather than their leadership role.

In the other families, grandparents provided a more supportive role under the direction of their adult children who took a greater responsibility for making arrangements. As examples, at parents' requests grandparents sent notices to the newspaper, made a display of photographs, and watched over surviving children. A

paternal grandmother supported her daughter-in-law's need for things to be just right:

She [mother] had a little layette thing with lace . . . she needed a pillow, wanted a pillow, so I ran around town to fabric stores until I found some matching eyelet and made a little pillow with some lace . . . to lay his head on.

A maternal grandfather, who was an accountant, helped his children set up a scholarship fund in memory of the baby from the memorial contributions that they received. Grandparents also helped pay for funeral expenses

In addition to funeral arrangements, many of the grandparents took on a variety of household tasks in the days following the loss, similar to those described by this paternal grandmother:

We looked after [surviving sibling] and we were just kind of in the background. We just kept answering the door, and people just brought food and flowers until it was just overwhelming. . . . we just did whatever we could. Cleaned up a little, cooked meals.

Tasks associated with childcare extended past the initial days following loss for at least one set of grandparents. Worried about what the loss might do to her daughter's marriage, a maternal grandmother described inviting her surviving granddaughter to their home frequently to give her parents time to themselves.

One of the most important tasks involved mobilizing support. Grandparents often received the initial calls and in turn called other family members. Once notified, these other family members responded with their presence or acknowledgement of the loss. One grandmother, who was not always skilled in providing support herself, went further in contacting others. This was much appreciated by her daughter whose son had been stillborn.

My mom encouraged a lot of people to write to me, who had lost babies that I didn't even know that they did, and these are people that I knew. . . . One lady wrote me a letter and she said, "I was hesitant to write, but your mom said to please do." Because it gave me hope, that they're happy people and they've endured this, so I will, too.

### Information

Surviving the loss of a child is often uncharted territory for family members. In this study, information was shared across generations to help each other navigate through it. For example, a paternal grandmother, who was perceived as very supportive, talked about how she was more attuned to information on loss and bereavement. When she heard something she thought would be of interest or help, she would pass it on to her daughter-in-law: "The kinds of suggestions I gave her were simply sharing . . . so anything I said to her I reminded her it was simply nothing out of my experience, certainly." Sometimes information was not received well by parents, especially if it was perceived as minimizing the grief experience or as pressure to get back to normal as described below in the discussion on unskilled support.

Providing information was the major way that three mothers provided support to grandparents. For example, a mother realized that her in-laws had misinformation about SIDS and she felt it was negatively affecting multiple family interactions: "I sent them information. Then things got a little [better] . . . They made some comments about the articles that were positive." The paternal grandmother in this family also expressed appreciation for the materials sent to her by her daughter-in-law. Another SIDS mother described how she helped her own parents:

I'm on the list server for the SIDS Alliance. If there's an e-mail or poem, I e-mail it to her, my dad. And then I told her about AGAST [Association of Grandparents Against SIDS Tragedy] and stuff like that . . . I called [SIDS Alliance] to find a support group in [their state] for them, which they've been going to now. It's not really open to grandparents, but they have some special meetings, and they had a walk-a-thon, and a Christmas memorial service, so they've been going to that now.

For the maternal grandmother in this family, her daughter was clearly providing more than information: "she tries to help me . . . who'd ever thought . . . my

younger daughter, mothering the mother, but that's what she seems to do sometimes." Information sharing, therefore, was part of the mutual support that extended across generations. Generally, it was the mothers who provided information and they most often gave it to their own parents with whom they shared close relationships. Grandparents in these families had had relationships with their grandchildren and grieved their loss. This grief was recognized by the mothers and most of the fathers. Fathers rarely talked about sharing information with grandparents.

#### Lack of support

##### Unskilled support

Most families described at least one family member, often a grandparent, who was not as helpful as they had hoped or anticipated. Parents compared these nonsupportive responses to those of other family members who listened without judgment, were accepting of the pace of grief, or met expectations about being helpful. Frequently nonsupport was attributed to clumsiness in offering support and a lack of knowledge or understanding about what was needed. According to one father, "I would say that both grandfathers were just totally lost as far as what to say, what to do . . . [this is] just something that life doesn't prepare you for, you don't get classes on it in school." His wife made a similar comment about her father-in-law, saying he "wasn't as supportive as I would have liked, but I don't know what I would have wanted. But I think he just didn't know what to do."

The combination of concern for distraught adult children, lack of knowledge about grief, and a lack of an emotional attachment to the baby who died, led to unskilled support in some families. This took the form of unwanted advice or messages to "move on" or "get over it." Such responses are common in bereavement and often lead to conflict or friction in social relationships (Lehman & Hemphil, 1990; Nolen-Hoeksema & Larson, 1999). A mother talked about the hard

times she and her mother had following her son's death, "Mom wanted to fix it and tell me . . . how it could have been worse." The maternal grandmother agreed that their relationship had been strained. Although they were on good terms at the time of the interviews (three years after her grandson's death), she still seemed bewildered by their arguments. She recalled this conversation:

She said to me one time after we had a big argument . . . she didn't want me to judge her or anything like that, or fix anything. . . . she just wanted me to be there to listen to her. But that's real hard for a parent to do because you have a tendency to want to fix things, you want to see things better for your child, you don't want them hurting. So that puts me in a whole different perspective, which she didn't understand. . . . and you can see sometimes things that are going on that they can't and you're very concerned. And so that's why you have to make your suggestions.

In this study, unskilled support in the way of unwanted advice came mostly from maternal grandmothers and seemed to cause more distress than the lack of skill demonstrated by grandfathers or paternal grandmothers. Mothers seemed to have greater expectations of support from their own mothers and were upset when it was not forthcoming. It seemed easier for them to overlook clumsiness from grandfathers or to be dismissive of ineffective efforts from paternal grandmothers. Most of the fathers seemed somewhat more tolerant of failed efforts at support, as was this father who said of his unskilled mother-in-law, "that's the best that she can do, and that's absolutely wonderful in my mind."

#### No support

Some of the parents and grandparents indicated that they did not receive support, whether attempted or not, from some family members. Not surprisingly, parents, mostly mothers, often acknowledged that they had not provided support to their spouses or to their parents, "I didn't do anything." Similarly, most grandparents said they had not received support from their bereaved children, but most added that they had not expected any. This grandmother expressed a common

sentiment when she said, "I think I was more concerned about them than I was for myself."

Occasionally, respondents, usually women, indicated they received no support from other family members. Two mothers who made these statements were among those who were most distraught and had the most difficulty functioning immediately after their loss. Their own stories and those of other family members contradicted the view of no support. It seems likely that the efforts of others to help either did not match their needs or perhaps did not penetrate their grief. The grandmothers who made similar statements were experiencing or had recently experienced multiple demands and stresses, such as a paternal grandmother who was raising her grandchild who had been born drug addicted. It also appeared that these women had ambivalent relationships with their adult children or children-in-laws.

Reports about no support were related to family history. In other words, ambivalence was not a new experience. Many of the parents, especially fathers, had strained relationships with their own parents that predated this loss. One father had stopped speaking to his mother for a year and a half after his son's death because

My mother disrespected Cory at his wake. My mother was worried about who was there. . . . In my eyes she wasn't feeling like I wanted her to feel. . . . I still have grudges.

More frequently, however, lack of support was associated with grandfathers. As described earlier, paternal grandfathers were underrepresented in this study. Only one participated. Six of the paternal grandparents were divorced, and none of the grandfathers from those families were interviewed. One had been missing for many years, two had been uninvolved fathers as well as grandfathers, and one was not mentioned at all. Only two divorced paternal grandfathers maintained relationships with their sons and their families, and these were strained. One father observed

It would not have been helpful if he had called more because . . . I just wouldn't believe, that he's just reading a script, basically, it is not heartfelt. . . . and so it wouldn't have been helpful.

Although these grandfathers did not provide support, the lack did not appear to cause distress, because none had been expected. Indeed, two of the uninvolved grandfathers attended their grandchildren's funeral. Although their presence was noted, it was not perceived as supportive and they were not talked about again for the rest of the interview. As suggested by Rossi and Rossi (1990), the divorced middle aged and older men in this study were socially isolated from their families, especially from their sons.

### Summary

Grief has been described as a social network crisis (Vachon & Stylianos, 1988). In this most difficult experience, families usually had at least one grandparent who was skilled and who provided a comforting and nurturing presence. Although intensity of the relationship with the baby who died affected the quality of the grief experienced by grandparents, it did not seem to affect their ability to provide a high level of support. For example, one of the most supportive grandmothers said this about her stillborn grandson, "while I am saddened, I somehow do not feel loss for a little one never known to me." This grandmother was effective in her support because she was aware of, acknowledged, and accepted her daughter-in-law's intense relationship with her son and her immense grief over his death.

Grandmothers and grandfathers who had developed close attachments to their grandchildren experienced more intense grief themselves and were very much involved in providing many different types of emotional and instrumental support to their adult children. In these families, mothers and fathers seemed more aware of grandparent's grief and exchanges of support appeared to be mutual. Lineage appeared to matter. Furthermore, these closest of intergenerational relationships were most often between mothers and maternal grandparents. Although maternal grandfathers in these families were viewed as very supportive, mothers and

grandmothers seemed particularly close, sharing more stories and spending more time together.

Grandparents were at times a source of strain. Relationships between parents and some grandparents were ambivalent in several families. Mothers seemed most distressed when their own mothers failed to provide adequate support even though they could attribute failure to lack of skill or knowledge rather than lack of caring. Mothers reported feeling misunderstood, isolated, and judged unfairly. As will be discussed in the section on Research Question 4 (Chapter 5), some of these mothers also had difficulty coping with their babies' deaths, especially early in bereavement. Skilled support from other family members, including mothers-in-law, was helpful, but did not seem to fully compensate for the lack of support from maternal grandmothers.

Some parents and grandparents reported receiving no support. Not surprisingly, and as acknowledged by parents as well as grandparents, many adult children often were unable to provide support to others. Most grandparents, however, did receive support from spouses, friends, and other extended family members; they had not expected support from the baby's parents. The few grandparents who received no support from anyone, seemed to be isolated or experiencing other family troubles. Grandparents who provided no support in contrast to providing unskilled support had a history of troubled or distant family relationships. These most often included divorced paternal grandfathers.

Finally, in spite of troubled, ambivalent relationships in some families, in the vast majority of families, emotional and instrumental support from at least one grandparent was offered, received, and perceived as helpful. Indeed, grandparents were key sources of support and were identified as such by most of the parents in this study. In this time of family crisis, intergenerational relationships were a comforting presence and a vitally important component of both parents' and grandparents' efforts to cope with this traumatic and unexpected family event.

## MEANING MAKING

The second set of research questions analyzed and presented here were: What meanings do parents and grandparents find following the death of a child? How might meaning making be influenced by factors associated with the death, time since death, gender, generation, and lineage?

As described in Chapter 2, Davis, Nolen-Hoeksema, and Larson (1998) provided evidence for two distinct and unrelated components of meaning making. One is *making sense* and the other is *finding benefit*. Davis and his colleagues' conceptualization of meaning fits the data presented in this study well. In terms of making sense of what happened, family members talked about their efforts to understand why these babies died, drawing on both rational (i.e., medical, physiological) and spiritual or philosophical reasons. Benefits emerging from tragedy were frequently described, specifically greater closeness in family relationships, changed perspectives or worldviews, and personal growth. These different ways of meaning making and the family context in which much of this was occurring are described more fully below. The process was dynamic and often contradictory for parents and grandparents alike.

### Making sense

Making sense involves coming to terms with how the event fits into a previously held world view. With significant loss, previously held assumptions, such as life is fair and events are mostly controllable or predictable, may be severely challenged. The greater the challenge to previously held beliefs, the greater the distress (Janoff-Bullman, 1992). Davis (2001), Wortman and Silver (2001), and others have reported evidence that individuals who are able to make sense of their loss are most likely to do so early in their bereavement. If meaning cannot be found soon after loss, those who appear to make the best adjustment stop searching for reasons that will explain why it happened. As will be described

below, those further in time from the death of their child or grandchild were less likely to talk about seeking answers to the *why* of the infant's death.

#### Physical/medical explanations

In this study, half of the babies died of SIDS between 2 ½ and 7 months of age. Three were stillborn, one was two days old, and another died at 4 months as a result of severe and complex disabilities present at birth. The two groups of families, those with a SIDS loss and those where deaths were due to other causes, were distinguished by their search to understand the *why* of the death, particularly in physiological or medical terms. By definition, the cause of a SIDS death cannot be determined after a thorough examination (autopsy, medical record, and death scene) and, therefore, remains unexplained. Multiple theories based on new research have been developed, but for many of the SIDS parents and grandparents, the lack of a concrete explanation for SIDS made it difficult to cope, particularly because the babies had seemed to be thriving. Many used the phrase that the death of a healthy, happy baby "doesn't make sense." One father's comments capture some of this feeling.

You just think of a hundred different things, like why didn't I get up in the middle of the night or why didn't I check on her, why weren't there any symptoms. . . . But every week you're hearing something new that they can maybe prevent or it could be caused by this or it's caused by that. That's what confuses me. That leaves me with the question of why. . . . I don't think they'll ever come up with anything to prevent it, to be honest with you. It's been going on forever.

Similarly, a grandfather also expressed frustration at the lack of an answer saying that his approach to solving problems is to

go to a textbook and try to find an answer. It doesn't matter whether it's an alarm clock that doesn't work or a kid dying of SIDS. I go try to figure it out. . . . But with this, I just don't understand it and it doesn't seem like there's enough being done.

Some of the parents, however, seemed to find the explanation of a physiological failure due to a previous unknown vulnerability to be adequate. According to one mother,

I guess some readings that I've done on it, make sense is, a brainstem disorder . . . something happens in the growing of the baby, growing so fast that it's just a neurological problem, that's why they can't trace it postmortem. That makes sense to me.

The concern for some of these parents was whether they had been responsible in some way, or whether they had cared for their babies as they needed to be cared for. A turning point appeared to come for one mother when, after seeking expert opinion, she concluded that she and her husband were not responsible, their baby had been well cared for, and they could not have prevented the death.

The *why* of the death in medical or physiological terms was not as central in the stories of the non-SIDS families. The physiological explanations seemed to make sense or were accepted more readily. Even in a family where no explanation for the death of a baby who was stillborn could be determined, the baby's parents did not respond by seeking answers on their own. As her father said,

They [doctors and health care system] spent a lot of time and resources on trying to figure this out. . . . I was thinking, well, I'm a good researcher, but what am I going to be able to figure out without the tests that they've already done. So, I didn't do that, I don't think Sara did either, that we did any research on our own trying to find out the answer because there really isn't. . . . I didn't really focus on that.

A grandfather in this family was one of the few persons not experiencing a SIDS loss who was troubled by *why* at first. As an engineer, he liked to have logical answers to problems. Eventually, he came to view Adrian's death as an act of God, which made him feel better and more hopeful that the next baby would be all right.

Philosophical/religious explanations

Although distinctions were observed between SIDS families and families of babies who died of other causes in seeking to understand *why* in medical or physical terms, no such differences were apparent in the ways that the two types of families considered philosophical or religious explanations. As with the grandfather above, many parents and grandparents went back and forth between trying to find a physiological explanation and a philosophical or spiritual one that made sense to them. "Because God wanted it that way" was a comment representative of a number of parents and grandparents, many of whom described their babies as angels. For some people, the view of the baby as God's special angel was comforting. Initially, Marie wrote an angry letter to God demanding to know who was taking care of her daughter who had died of SIDS. Soon, and still early in her bereavement, she felt comforted thinking this all was part of God's plan.

It makes me feel good because God brought her to me for a reason. Like reasons that nobody will ever know, but she was here for a reason, she was special. She was special to me and everybody else. . . . He brought me an angel, just for her to come here maybe for me to see how she is and how I love her and everything and He wanted to take her back. And that gives me comfort. She's up there with God and he's taking care of her.

She tried to share this vision with her husband, ". . . that's always how I try to cheer him up," although he did not seem to find this explanation as reassuring. A recently bereaved mother of a stillborn infant also felt her baby died as part of God's plan, but in contrast to the mother who found comfort, she agonized over what she had done to warrant God's punishment. She could not understand any other explanation for "why God gave me that baby for seven months to carry only to take him away." Punishment was the only thing that seemed to make sense to her on the basis of her past beliefs, yet she could not accept that explanation, either. She said, "I just don't understand it and I think I'll probably struggle with that the rest of my life." Her assumptive worldview of a just and benevolent God was shaken. At the time of the interviews, she had not altered her worldview to find a more comforting

explanation. According to Janoff-Bulman (1992), the inability to adjust one's world view in the aftermath of traumatic loss is related to continuing distress.

For this mother and some of the others, trying to make sense of this act of God was as difficult as it was for some of the families to make sense of SIDS. Some of the grandmothers (but none of the parents or grandfathers) who held beliefs that God was in control suggested he had made a mistake. A SIDS grandmother expressed her feelings this way:

And I say maybe God shouldn't have taken her. I mean, there are children in this world who are very sick and who have survived many things and it was a perfect healthy little girl. Nothing wrong with her and God took her. It's beyond anyone's recognition why, but it happened and we have to cope with it.

Another grandmother was firm in her belief that her stillborn grandson was happy and well, looking out for all of them. She tried to believe his death was God's will, but she kept going back to medical explanations, thinking the doctors and hospital were at fault for not noticing the problem earlier and averting the death.

I'm supposed to [believe this was God's will]. But I just, I can't. But I know everything happens. He knows everything, but I still keep thinking, geez, there could have been something done. . . . I just feel like the hospital really fell down on what they could have done . . . I just can't accept that because I can see no reason why it was better for this to happen.

In contrast to the view of God in control, others with religious beliefs were angered at the idea that this tragedy was part of God's plan or will. When people made such statements to one grandmother, she retorted, "he should be with my daughter, not up in Heaven." A grandfather made a similar statement, concluding, "he's in the wrong place, no little kid belongs in a cemetery." Others suggested that although God was not responsible, God was present to provide comfort.

Not everyone found meaning in contemplating religious or spiritual explanations. In responding to the question about why their baby died, some parents and grandparents said simply that these kinds of things just happen

sometimes. These individuals tended not to look for medical or physiological explanations. Some were not religious or spiritually inclined. One SIDS father commented that if he had a spiritual side at all, it was well hidden. Another father of a stillborn infant put it this way:

One thing I know for sure, is that he is not with us. . . . I've never been a religious person, or contemplated any thoughts that deep, so one thing I know is that our child is not with us and I can't put into it any more than that.

The issue of justice was frequently part of the philosophical discussion about *why*. Some parents and grandparents were angry or resentful that their babies died, whereas others lived and had unworthy parents because of life style or values. One SIDS father put it this way:

There are a ton of people who are pathetic role models—they don't have work ethic, and they don't have morals or ethics and they don't spend enough time with their kids and they do bad things to themselves or their people. They don't contribute to society, and they don't respect people, and they don't honor their spouse, and all of these things. So, why did I lose my kid, you know? It doesn't make any sense.

Finally, comments were made about the death of a baby being against the natural order of life where the old die before the young. A grandmother questioned God's decision to take the baby while she was old and continued to live.

### Finding Benefit

Finding benefit means identifying positive outcomes as consequences of the loss. Davis and his colleagues (1998) categorize finding benefit as a growth in character, a gain in perspective, and a strengthening of relationships. Similarly, Calhoun and Tedeschi (2001) labeled three domains of posttraumatic growth as changed sense of self, changed relationships, and existential or spiritual growth. Finding benefit, in contrast to making sense, appears to increase over time (Davis, 2001). As described below, this was reflected in the responses of these families.

Those further in their bereavement tended to talk more about benefit and positive consequences to their pain and suffering than did those who were more recently bereaved. Some of those reporting significant benefit talked about their resistance to finding positive consequences immediately following their babies' deaths. At the earlier points in their grief, finding benefit would have meant that the death was in some way acceptable.

Almost all respondents identified benefits or at least reported lessons learned as a family. Several talked about their own personal growth and maturity. The ability to reach out to others in pain, especially those who were grieving, was a positive outcome noted by many. Several had developed new philosophies and acted upon them by changing jobs or redirecting priorities so that they were involved in more meaningful work or spent more time in family-focused activities. Some reported no longer fearing their own deaths. Because this study is a focus on family responses to loss, however, only results specific to family relationships will be reported.

#### Improved family relationships

Continuity in family relationships in the aftermath of tragic loss was evident. Those who had at least a somewhat positive relationship with their parents or adult children prior to the loss typically talked about increased closeness in those relationships. Some resulted from the intense, grief-stricken conversations that occurred immediately after the death. One mother of a stillborn baby said that after grieving with her mother and brother, they all continued to share other facets of their lives in greater depth and frequency than they ever had before.

In response to the question about meaning, half of the parents indicated that they had achieved greater closeness as a couple, although most also talked about the great strain they experienced as they learned to relate to each other in a new way. At the time of their interviews, only one mother with a relatively recent loss indicated that she and her husband were experiencing difficulties in their

relationship in the aftermath of their baby's death. Both parents and grandparents commented that they did not know if growing closeness was a result of the experience of grief or a result of growing maturity that would have occurred naturally (Suiter et al., 1995). According to one SIDS grandmother, for example,

I do think she [mother] communicates with me more often than she used to. . . . As with most oldest daughters we've had our differences, but at the moment we seem to get along well. . . . So in some way, I think our interactions are better than they used to be when she was growing up; I think we're closer.

Increased closeness to an in-law was noted. At least two grandmothers felt that their sons-in-law probably saw them differently. One said, "we [had] a good relationship and everything, but maybe he looks at me more as somebody that cares even more." Similarly, the maternal aunt felt closer to her brother-in-law after being present with him in his grief during the week following his son's death. Kathy, a SIDS grandmother, talked at length about her son's wonderful in-laws, including two great-grandmothers, and how all of the grandmothers and great-grandmothers had cried together, developing a special closeness that she felt continued four years later. She also described a close, sharing relationship with her daughter-in-law. Although increased closeness was generally viewed favorably, it sometimes caused additional pain. Kathy's daughter in-law described her relationship with her in-laws this way:

They [parents-in-law] did come to all of the services and were there and have since been closer with us. It was like we had to pay our dues to be real people, at least for me. That was the first time—I had been married to my husband for several years—that his dad had hugged me at all. Even spoke to me, really. I think he was proud of me, but never really looked me in the eye or said anything up until that point. That was kind of hard to take because it was under such odd circumstances. I felt some resentment.

In contrast, several parents indicated that they already had been close to their families of origin and insisted this experience had not changed that. According to a SIDS mother,

Me and my family, we're very close. I mean we're the closest of I think any family could get. So, I wouldn't say it drifted us apart or anything. I wouldn't even say that it brought us closer, because . . . we're close to begin with.

Similarly, a maternal SIDS grandmother described some of the things she shared with and did for her daughters: keeping in frequent contact and responding to a variety of needs. She went on to say that she probably would have done those same things even if her grandson had not died.

Parents and grandparents rarely described improved relationships with family members as a result of their babies' deaths where previously there had been tension. One father, however, indicated he had become more even-tempered and this had implications for how he responded to stressful family situations: "I've matured a lot in my career as far as how I approach problems, picking my battles and when I want to argue something. And that has also applied with family members." He speculated that his maturity would have emerged as he grew older without this loss. An older father in the study talked about a family strength that emerges when one can accept bad behavior from a family member (related to their loss) and still maintain a relationship.

In only one family did the tragedy clearly result in improved family relationships where there had been bitter conflict. Margaret, a paternal grandmother, had not talked with her daughter in several years and had never met her daughter's three children. In addition, Margaret's ex-husband would not come to any family event where she would be present. When Margaret offered to stay home from the baby's funeral, Anne, her daughter-in-law, was furious that this bad family behavior would continue at this time. Margaret's son called family members and asked that they all participate. Not only did all attend the funeral, they reconciled that day. Anne did not welcome this development because she felt it took away from the focus on her son and could be viewed as a positive consequence of his death. She said, "I felt like it was almost because Sean died they were able to come together and I didn't want anything positive to come out of

that.” It should be noted, that although Margaret’s relationship with her own daughter improved dramatically, her close relationships with her son and daughter-in-law remained the same. All three reported that their relationships continued to be as close as they had been before. If anything, Anne became less tolerant of her father-in-law.

Parents and some grandparents talked in positive terms about how the experience shaped the ways they related to other children in their family. Two of the SIDS families who had surviving children talked about the special closeness they had with those children as they all tried to find meaning in their losses. Sharing the experience of her son’s death with her young daughter made their bond stronger, according to one mother: “We have something that will never tear us apart.” Similarly, a father talked about the strengthening of family relationships

especially towards our son, which he was an only child to begin with. I mean he was always spoiled and had a lot of attention, but it’s definitely more quality attention now, I mean like doing things together.

In addition to surviving children, the loss also influenced relationships with subsequent children. One mother’s first child, Asher, had been stillborn five years before. His death was followed by two miscarriages before she gave birth to Kenny. His mother described how Asher’s death continued to shape her life with Kenny, now two years old.

I really almost daily feel grateful because I think the intensity and the sweetness of our time with Kenny, my time with Kenny, is different because of that. So, Asher’s coming and going feels to me like just an important part of growing up as a family. . . . in many ways life is richer and the experience of Kenny is sweeter for having that loss, and having to work to get me out of the loss.

Several of the grandparents made comments that time with their grandchildren—both surviving and subsequent—was now more important to them. For example, one grandmother said, “It makes me appreciate the grandchildren, because they’re healthy, [those] that we do have. I think about that a lot.”

### No benefit or negative consequences

A few, mostly newly bereaved, found little or no benefit resulting from the babies' deaths. These individuals talked about meaning in terms of "grief and heartache," "a big hole, just awful," "nothing positive," or "terribly sad." A recently bereaved paternal grandmother said

[what the baby's] death did for the family was traumatize us, destroy us—it was so hard. I don't think there was anything good, positive, because we've always been close and tight, a very caring family. The only thing it did was devastate us.

As described earlier, not all grandparents were interviewed for this study. In many cases, these nonparticipating grandparents were not asked by family members to be involved, in part because of ongoing tensions and conflicts. It is interesting to note, however, that although respondents often linked closer family relationships to the aftermath of the baby's death, respondents generally did not connect the after effects of death to poor or deteriorating family relationships.

Negative consequences of the losses were apparent. For many, meaning was associated with an increased sense of vulnerability and a greater fear for surviving or subsequent children or grandchildren. Most respondents who described this consequence indicated it affected the ways that they related to their children and grandchildren. One father said he worried about his boys "all the time." His mother-in-law agreed, saying he worried so much because "he just thinks everybody is dying." A SIDS mother described it this way:

It has given me and my sister, my brother a sense of fear. I know I have a lot more phobias than I used to—planes and driving on bridges, and all sorts of stuff I didn't used to be afraid of.

### Variation in Meaning Within Families

Storytelling, or account making, has been viewed as a critical process in creating or finding new meaning in the aftermath of loss (Harvey, Carlson, Huff, & Green, 2001). Talking about what happened is a way to help people clarify their

thinking and their feelings. Each respondent in this study was asked to talk about what the baby was like, describe what happened, discuss how the family responded, and what the death meant to the family. In most of the families, basic stories were consistent among family members interviewed, suggesting considerable interaction between family members in the aftermath of the loss. Similarly, most individuals had a fundamental understanding about the significance of the loss for and its impact on other family members, although there were compelling exceptions as reported earlier. At the same time, however, little evidence emerged that shared stories or understanding, or even the mutual support described earlier, resulted in common meaning within families. Furthermore, looking across families, none of the meanings described in this section could be said to characterize most individuals, with the possible exception of the benefit of strengthened family relationships. Once again, the data emphasize the unique experience of grief even within the context of intimate social relationships.

Davis (2001) suggested that the two cognitive processes of making sense and finding meaning are distinct and are not significantly related to one another. This study adds support to this view. Some of those who found benefit also made sense of the loss, but others did not. At the same time, it is important to re-emphasize variability. Within the category of making sense, some focused on multiple aspects of meaning making whereas others talked about only one aspect. Similarly, some reported positive outcomes across many domains (i.e., relationships, worldview, personal growth), and others talked about one thing only. A small minority did not make any sense of the loss nor did they find benefit. This variation, too, underscores the unique experiences of grief and the very different journeys individuals make with it.

In addition to variation in meaning making, it is important to emphasize its dynamic nature. Although the data could be categorized as suggested by Davis and his colleagues (1998), it was evident that individuals did not always settle on a particular meaning or set of meanings. This was especially apparent in efforts to

make sense of the loss. On some days one thing made sense and on other days it did not, as described by this SIDS grandfather:

I have mixed emotions. There's days I just don't understand why and there's other days that I just know he had to be here for a reason. He had to serve his purpose and for whatever reason that is, we're not going to know.

Some parents, who seemingly had come to terms with the loss philosophically, still were seeking medical explanations. The opposite was true as well. Some of those further in time since loss, reflected back on their experiences. In doing so, they provided compelling evidence of the ongoing, often contradictory and ambivalent, process of meaning making that continued through the time of the interviews.

Although variability among individual family members is a central finding, some patterns based on generation or family role did emerge. Generally, mothers and fathers had more varied responses about the meaning of their child's death than did grandparents. Parents' comments covered more domains of meaning and it appeared that many had expended considerable energy reflecting on these questions. The grandparents who also had complex answers with respect to meaning also had strong attachments to the babies and saw them frequently. Their daily lives were more disrupted by the death than were the lives of some of the other grandparents.

Gender differences did not emerge as important in meaning making among parents. The close relationship with the child appeared more important than gender in shaping individual efforts to come to terms with such a momentous loss. Parents who indicated that they talked together about their child and their loss appeared to have similarly complex responses about meaning, even if their conclusions about meaning differed at the time of the interviews. Talking together was part of their meaning making process. The role of gender was more apparent in the grandparent generation. Recall that more grandmothers than grandfathers participated in this study. Cross generation discussion about the baby was most frequent between maternal grandparents and their adult daughters. Although several mothers reported

talking extensively with their fathers about the babies, they talked more often and in greater depth with their mothers. The paternal grandmothers who were identified as most supportive and involved in talking about the babies tended to talk more with their daughters-in-law than with their sons. These discussions appeared to be part of the meaning making process in both generations even though they did not all arrive at the same end point.

Calhoun and Tedeschi (2001) suggested that when people become more empathic with others who have suffered loss, as in the case of many of these parents, they seek more opportunities for intimacy with others through sharing and self-disclosure. This, in turn, leads to feelings of greater interpersonal closeness within and beyond family boundaries. Closer relationships were examples of benefits given in this study. Parents appeared more likely than grandparents to find this and other benefits. Similarly, Nolen-Hoeksema and Larson (1999) found that bereaved parents, compared to bereaved spouses, siblings, and adult children, were the most likely to identify positive consequences of their adult child's death. They suggested this group may have more need than others to construct some positive meaning because of the need to overcome the sense of injustice associated with child death. Attig (2001) described two responses to grief. One is to relearn the world, and the other is to come to terms with pain. Both the active search for meaning and the more passive experience of finding meaning are part of these processes. It may be that parents process grief in more complex ways than grandparents because of their strong attachment to their children and to their central role in their lives.

Recall that the strongest intergenerational tie is between parents and their children (Rossi & Rossi, 1990). It may be that parental loss requires more effort to relearn the world and overcome emotional pain. For grandparents, perhaps the process of coping with the loss did not require them to focus so much on their own identities as it did with their children who had lost a partner in a more central relationship. Calhoun and Tedeschi (2001) suggested that growth following

traumatic loss involves an acknowledgement and an integration of both positive and negative consequences of loss. It may be that grandparents were more apt to focus on the negative consequences of the death for their adult children, seeing first and foremost their pain and suffering. They seemed less likely to find comfort in their children's achievement of closer family relationships or greater appreciation of life. The lack of focus on benefit may also be a result of the role that grandparents played as their adult children and in-laws struggled to come to terms with the loss of a child. Pennebaker (1990) found that although emotional disclosure may be very beneficial to those who are doing the talking, those who listen often are affected in negative ways. That is, those who talk about feelings feel better afterwards, whereas those who listen frequently feel worse. As described earlier, parents, especially mothers, were most likely to talk and grandparents, mostly grandmothers, were most likely to listen.

In summary, most of the individuals interviewed were involved in meaning making. They were seeking to come to terms with the traumatic, non-normative family transition that had forced changes in their families, including many of the ways they enacted their roles. Meanings were socially constructed through emotional expression, story telling, and other day-to-day interactions within and across generations. Mothers and fathers talked about similar things in their search for meaning. Gender differences were more apparent in the grandparent generation. Although these data represent only a slice in the process, it is clear that the process was ever changing. Those closer in time to loss talked more about *making sense* of the loss than those who were further in time. The latter recalled their struggles with making sense and more frequently talked about finding benefit from the experience. Individuals struggled with conflicting meanings and were ambivalent about them, particularly early in bereavement. Throughout this process, however, the meanings attributed to the loss, were in the end, very much determined by the individual.

## CONTINUING BONDS

The final question addressed in this chapter is to what extent do mutually developed family rules or rituals acknowledging continuing bonds with the baby contribute to mutually supportive behaviors among family members across generations?

As discussed earlier, bereavement research is undergoing a paradigm shift. This includes a challenge to the notion that recovery from, or successful adaptation to, grief requires relinquishment of emotional ties to the person who has died (Klass, Silverman, & Nickman, 1996; Neimeyer, 2001; Wortman & Silver, 2001). Not only do many bereaved individuals maintain attachments, such attachments are increasingly viewed as healthy responses to loss. Connections or continuing bonds with babies who had died were apparent in this study, particularly for parents and the grandparents who had formed strong attachments to the babies. Connections were maintained in socially constructed ways through rituals and symbolic representations of the babies. In some families, members shared similar connections, whereas in other families, individuals had very different kinds of relationships or ways of maintaining them. Support among family members for the ways others observed relationships varied as well. In this section, the manner in which connections are maintained is described, beginning first with the first weeks and months following their infant's deaths. The transformation to a more integrated internal bond with the child is then explored. Throughout, the role of grandparents in supporting and shaping these bonds is considered.

### Connections in transition

#### Parting rituals

The period following death that culminates in a funeral or memorial service is often seen as the time for coming to closure or saying good-bye. It may be more appropriate, however, to view this as a starting point in the transformation of

relationships. Parents and others begin to move from a relationship with a living person to a relationship with a person who has died (Klass & Walter, 2000).

Parents generally spent time with their babies after death. Although traumatic, this time was precious. According to a SIDS mother whose baby had not been transported to the hospital,

I seen her just how I laid her down the night before. She looked peaceful, she had on her clothes, she had on her diaper. They didn't have to take none of that stuff off her.

A father had been on a business trip when he learned of his son's death. It took several hours for him to reach home and by then, his son had been moved to a funeral home. Four years later, his absence at the time of his son's death was painful to him. When grandparents lived in the same communities, they also spent time with the babies after death. Some grandparents traveled a great distance. One mother insisted that her child not be moved from the hospital until her parents could arrive five hours later. Although difficult for hospital staff, the mother was grateful she had insisted. Her parents were able to spend time with him while he still looked like himself.

The opportunity to spend time together was especially helpful for parents of stillborn babies. They forged a link to those children that they carried forward in their memories. Grandparents and extended family were present for the birth of only one of the stillborn babies. One father, whose family members were not present, described his experience:

We bathed [him], we weighed him, we did the footprints, the handprints, took pictures. I remember holding him wrapped up, holding him in my arms just looking at him and I remember the sense of wonder, just being surprised at what he looked like. You know, you have no idea what a baby will look like. And just looking at him even dead there was a certain sense of what his personality might have been and that was all pretty wonderful.

A mother spent some last moments with her daughter before she was cremated. She recalled

Over the course of that week, I had had a chance to think about all the things that I hadn't said to her that I had wanted to say and I got to say those things to her before they took her away.

Family roles need to be modified over time to accommodate the loss, a process involving both continuity and change (Hanson, 1995; Rosenblatt, 1993). Initially, many continued in their parenting roles, including advocacy. Weiss (2001) suggests that parents need to continue to act protectively toward their child because of the emotional bond. One mother was distraught because her baby had not been baptized and she did everything that she could to prevent her daughter's soul from "floating around where it has nowhere to go." Even though the minister told her it was unnecessary, at her insistence he baptized the baby prior to the funeral. *Taking care* is another parenting role. A mother described her funeral preparations with her daughter: "I put a little book of nursery rhymes in [with] her—you know she was cremated—but I put that in and one of her animals and I dressed her up in her prettiest dress." She asked her mother to recite the nursery rhymes as she had when she entertained her granddaughter the last time they had been together. Several parents worked to have just the right funeral for their child. One said it was important for him, as the father, to "take care of business." He stressed his responsibility "to take care of him."

Funerals were described as traumatic or devastating for families. At the same time, they also were recognized as opportunities for family and friends to show support. Those who had funerals or memorial services talked gratefully about the large number of people who attended. Sometimes it was the only time that distant relatives or those outside of the family had seen the child. One father described his pride in showing off his beautiful son. His wife found it important for others to see that he had not looked like a sickly baby. The funeral helped others make connections with the individual the baby had been and emphasized to them the baby's central role in the family and the resulting significance of the loss.

Not all families had a funeral or a formal memorial service for their children. Whereas the dominant culture provides some expectations for such rituals for those who have lived, there is little consensus about appropriate rituals for those who are born dead. The three families whose babies had been stillborn all made different choices about a formal gathering of relatives or friends. In one, the baby's mother described the annual memorial service held by the support group as a very "human" experience. Neither she nor her husband felt the need for any other public ritual. The mother in the other family that chose not to have a service seemed ambivalent about their decision. She did not feel she could have arranged a service at the time of her daughter's death, yet now she wished there had been a ceremony. It did not feel quite appropriate to have one three years after the loss. One other family with a stillborn son also had chosen not to have a service initially. Great numbers of extended family and friends had been present at his birth and continued to be present in the days immediately following. This outpouring of support and the time spent together was meaningful and beneficial to all generations. His paternal grandmother described the experience as being very complete. Later, however, the baby's mother began to think that the blessing her son had received in the hospital was not sufficient: "If I were to have a live child, I would have given him a funeral. This is not fair to Sam." Her decision to have a service after her extended family had returned to their communities was helpful to her. These three different choices were associated with very different responses of support from family members. Parents in the first family felt acknowledgement from grandparents at a distance had been enough. Grandparents generally were perceived as supportive in the second family, although family members tended not share feelings and concerns with one another. The maternal grandmother in the third family questioned the wisdom of her daughter for having the service because she was concerned about her daughter's failure to come to closure.

None of the parents in the five families who had cremated their babies had scattered ashes, although one of the baby's ashes had been buried in her maternal

grandmother's cemetery plot. Three of the mothers volunteered they felt more able to contemplate where and how to scatter ashes than they had earlier in their bereavement. Still, neither they nor the fathers seemed to feel any urgency about doing so and all were content to keep the cremains with them in their homes. One couple had no intentions of scattering ashes. The cremains were now contained within a backyard fountain symbolizing the child given to the parents by the maternal grandparents. The fountain was portable so it was something they could take with them wherever they lived. The mother in this family said that she wanted her own ashes to be mingled with his after she died. Grandparents generally were not involved in making decisions about cremation or burial, but supported and often helped implement those decisions.

#### Connections in early bereavement

Early in their bereavement, many of the parents wanted others to recognize the continuing presence of their children. According to one mother, "just because she's gone doesn't mean she's not still my daughter or a part of our lives." Indeed, conflict within some families occurred when parents perceived that grandparents did not hold this view or respond in ways that supported it. The mother quoted above resented her mother-in-law for failing to contribute as promised to the gravestone, although she was spending money on a living grandchild. Similarly, a father criticized his mother for not feeling or responding to his son's death the way he had wanted her to. He summed up his comments by saying, "I know she loved him, but that's the key word, she *loved* him. She should still love him." This feeling that others should "treat her like she's here" appeared to diminish over time. Parents furthest in time since loss did not make these kinds of statements. Nor did grandparents talk like this regardless of the time since loss.

A few parents connected with their babies through feelings of sadness early in bereavement. For example, one mother said "to be close to Craig I had to be sad, that was my link" and, "if a smile came across my face in the months afterwards, I

would be angry with myself for smiling or not thinking about Craig constantly.” Similarly, a father stated that although he hopes to be happy again some day, “right now I don’t want to because I can’t take him with me.” Not all parents felt this way, even soon after their loss. One mother said early on she and her husband did not cling to sadness because they felt “no child of ours would want somebody to feel so miserable.” Grandparents did not seem to find sadness to be a link to their grandchild, although they clearly expressed sadness for their loss and their adult children’s pain.

Some parents extended their parenting role to care of the cemetery plot. According to this mother whose son had died two years before,

I have gone to the cemetery every day and I continue to do that. And because it’s my way of parenting my son, so to speak, the best way I can. It’s all I have left, it’s what I can do to honor him.

Frequency of visits varied widely, from daily to sporadic visits once or twice a year. Women tended to visit the cemetery more often than men. In these families, fathers typically visited on anniversaries and holidays. One couple and their son, still early in their bereavement, went about every month. Taking a picnic or flying a kite made it easier and “more joyful” than going alone.

If they lived near or were visiting, grandparents went to the cemetery as well, although less frequently than the mothers. They rarely went with their adult children unless invited for an anniversary observance. Some parents and grandparents did not go often because they did not feel a connection to the child there, or the visit resulted in overwhelming feelings of grief. One father said that he and his wife purposefully did not go to the cemetery at designated times such as the baby’s birthdays or on holidays.

We go as a family two or three times a year, and it’s usually kind of random. . . We just do it when we feel like it, because we don’t want to view it as a burden. We want it to be by choice and then you actually might enjoy going there and having something to say or whatever to yourself. But we don’t want to make it a ritual because then it’s a burden.

At times, differences in visitation patterns caused conflict. For example, one mother felt most strongly connected to her son when she was at the cemetery, whereas her husband and mother felt the baby was not there. Perceptions of the appropriate amount of time spent at the cemetery varied. A mother in another family criticized her mother-in-law for her infrequent visits, although the paternal grandmother talked about how often she was there.

Associations have been found between maintaining attachments through memories and healthy adaptation to loss among widows (Field, Hichols, Holen, & Horowitz, 1999). Not surprisingly then, in this study, the most frequently mentioned way of maintaining connections was through shared memories. According to one grandmother, "we remember her for the days that she don't have right now, that she'll always be remembered." Part of the connection with the child through sadness may have been related to concerns that the baby would be forgotten. One mother, several years past the loss, recalled directing anger at her husband when she first caught herself thinking about something other than her son: "I thought it meant that I was forgetting him and that both of us were just going on with our lives in the most inappropriate way and then he wouldn't have meant anything." A few who still were relatively early in their grief described how they concentrated on their memories so as not to lose them. For example, this father talked about his efforts to keep his memories sharp:

Everyday, at least once a day, I have hard thoughts about him. I try to remember his gooing and his little laugh, his hearty laugh. I try to keep him in my memory. In my heart he'll always be, I don't ever want to forget him.

Several people kept journals, wrote poetry, or even wrote letters to God to express their feelings or to preserve memories. A grandmother said:

I sat down one time and wrote down everything I could remember about him. All the different times that we were together and the things that we did, and different times that I held him, and things

that went on, so that I could put that away. . . . those memories will be fresh for somebody.

Fears of forgetting had not come to fruition for parents further in time from this loss and these parents rarely expressed this concern. One father acknowledged that his memories would “soften over time, but I’m not going to forget. . . . certain details I might, it doesn’t make it less important.”

### Family celebrations

Holidays, birthdays, and other anniversaries involve celebrations crossing generational households. Rosenblatt and Elde (1990) suggested that family gatherings are important in part because of the opportunities provided to reminisce and share memories. These kinds of festivities, however, are often difficult in bereaved families as they learn and negotiate how to incorporate the one who has died into family traditions. This difficulty is illustrated by one family’s decision not to observe the first Christmas following the baby’s death. Members of both generations felt it to be a respectful and appropriate response to the loss. At the same time, the loss of family holiday time had its own pain. According to the maternal grandmother,

Every Christmas everybody gets together at my father’s house. We have a big thing Christmas Eve and . . . we used to always to go over to my father’s the next day, everybody again, or my house—we used to take turns. But this last year was awful. I think everybody just stayed in their own home.

At the time of the interview, the family had not decided the extent to which they would observe Christmas the second year. It appeared that some of the family traditions would return for the maternal grandparents, but would remain at levels far below previous years. It may be that these parents, by avoiding celebration, also isolated themselves from others who might have been sources of support, similar to patterns reported by Rosenblatt and Elde (1990). Another recently bereaved family did observe the first Christmas in their usual ways of gathering and celebration.

The mother and maternal grandmother both described how the grandmother cried at a family gathering on Christmas Eve and the difficulties they both encountered in maintaining Christmas for their son and grandson. The father also described the first Christmas as "rough." It may be that the presence of a surviving child in the family who did not observe Christmas would also have resulted in decisions to maintain traditions. It would be useful to talk with those in both families over time to gain their insights about how decisions to maintain or eliminate traditional holiday activities affected family functioning, cohesion, and continuing bonds with their child over time.

#### Emergence of an integrated bond

Klass (2001) described how parents' inner representation of the child who has died changes over time. According to Klass, when grief is as resolved as it can be, the child has become integrated into the parent's life in a way different from when the child lived. Grief does not end, but parents have learned to live with sadness and to associate their better selves with bonds with their child (Klass, 2001). In this study, some of the parents, most frequently those who were further in time from their child's death, appeared to have integrated that child into their own sense of self. They did not seem to require feelings of sadness to connect to their child, nor did they emphasize the importance of treating the babies as if they were present. Fewer made comments about fears of forgetting the baby, though some still worried about others forgetting. Some, typically parents, made comments that their child was with them at all times without conscious thought. A mother of a stillborn infant reflected, "When I look back on the last five years, I see less and less of the memories being negative or painful and more and more of them being incorporating and accepting." A father whose son had died two years before, described it this way: "I firmly believe that he's here in my heart and in my head and around us." Another mother had difficulty thinking about specific ways that she was connected to her son who had died of SIDS four years before. She said she

always had a “connection spiritually with him” without doing anything specific to bring him to mind. She went on to say that her connection to her son “wasn’t just something I talk about, it’s something that I experienced and it’s very, very dear to me.” As discussed in the previous section, many parents talked about becoming a better person because of their children who had died.

### Spiritual connections

As suggested by the previous comment, inner representations of the child often had a spiritual component. These connections evidently were established early in bereavement and were maintained over time. The majority of parents and grandparents felt their children continued to exist in some way beyond their own memories. Some of the parents described dreams they had about their babies that provided reassurance that they were happy and well. For many, continued existence was defined as being one of God’s angels. One father said “she’ll always be here with us, she’s also our little angel watching us.” Being with friends and relatives who had died previously was a comforting image for some. A father felt this way.

the little guy is up there in Heaven and he’s with my friends and family that have passed away. . . . I feel there’s this little spirit waiting for us, in a blink of an eye for him, we’ll be there. I hope he’s the first person I see. . . . Go up there and the first little guy I see is little Craig just waiting for me, “Hey, Dad.”

Not everyone held conventional Christian beliefs, although almost all had been raised in this tradition. One mother found comfort in the belief that her daughter had been her angel for many reincarnations and continued to watch over her. One grandmother described her belief:

The spirit is eternal and so that fragment of spirit that inhabits the soul is out there and that the potential for the quality of that soul to continue to be part of all of our lives is very possible. . .

A few, who said they were not religious, chose to believe in an afterlife simply because it was a comforting vision. For example, this father said,

I'd like to think that there's a greater being and that he's [son] reaping the benefits of being an innocent child, but I don't really know. But, obviously that's comforting to think and so I choose to think it.

### Family celebrations

According to Rosenblatt and Elde (1990), families develop rituals that are distinct from societal rituals and that help give meaning to the death. Such rituals were apparent in this study. Over time, some family celebrations appeared to be permanently changed so as to include the child who died. For example, one family felt the baby had waited for Halloween to die because he was their little "punkin." As a result, the holiday was a significant link to the child. Extended family members gathered in the evening at the cemetery:

We lit candles and [father] carved a pumpkin and my brother carved one and we had flowers and balloons and my mom said something. And then my brother and sister-in-law and mom left and [father] and I stayed up there and we talked a little bit.

The cemetery ritual was followed by a big family dinner. This mother and other family members expected a similar ritual to continue on Halloweens into the future, although the father indicated they would need to modify it to accommodate the needs of any subsequent children so they could participate in other more traditional celebrations.

Rituals specific to holidays and the baby's birthday were limited to the parents and their other children in several families. A factor for some may have been the geographical distance between households. Still, many rituals did not include grandparents even if they lived near, as noted by this maternal grandmother who was interviewed with the baby's parents: "I don't do a lot of ritualistic things like they do, [it's] something you guys do mostly on your own." In this family, parents and children visited a park where a memorial tree had been donated and then ate cake and ice cream. Another couple marked the day more simply as described by the mother:

We both take off from work early that day and we make sure we're together and we go walk down by the river . . . then we go out for Italian food for some reason and sort of have a meal. And I think we'll continue to have a meal. . . . It's a private thing. We have a candle that they gave us when we had her baptized that we light that night and then that's pretty much it. We talk about her and we miss her and we wonder what she'd be doing.

In at least one family, the grandparents who lived distant had a parallel ritual in their community to the ritual the baby's parents had developed for their son's birthday. According to the grandmother, "They lit candles and I have a candle right in front of his picture and I do that. . . . I look at pictures here . . . and think about him."

Family anniversaries falling on a birthday or death date of the baby were significant in several families. A baby was born on his grandfather's birthday and buried on the anniversary of his death, coincidences meaningful to both the father and the paternal grandmother. On those days, the baby's parents and siblings go to the cemetery and release balloons with notes to the baby. The father includes a note to his own father in recognition of their shared bond. His mother, who lives distant, places flowers on the church altar in memory of her husband and grandson.

One of the fathers who shared a birthday with his son found it very challenging. After three years, he decided to change his own birthday. He had come to dread the day, saying "How am I supposed to open gifts and go out to dinner and be treated like a king on the day that is not so good?" Although the day was noted, this family had no ritual by choice.

### Symbolic representations

Although the bereaved cannot maintain a physical intimacy with someone who has died, a multitude of physical objects often represent a kind of physical presence (Klass, 2001, Troll, 2001; Vickio, 1999). This was certainly true in these families. All had photographs. Except for the stillborn babies, these photographs were displayed in public places in homes and at work for both parents and

grandparents. Some were made into collages. Two families had paintings of their children; one of them had been painted as she might have looked at one year of age. All pictures served to stimulate conversations and memories. Photographs of other family members would sometimes generate discussion as well. For example, a paternal grandmother three years postloss reported:

Every time I see a picture with the other two [siblings], I say to Anne, "you know, I can't help imagining what he would look like now, pictured right with the two of them," and she laughs and says "I do that all the time."

Even when not discussed, parents and grandparents found it comforting to see the photographs displayed in each other's homes. It was a key indicator that the babies would not be forgotten.

Other symbolic representations abounded. One baby had been fascinated by a ladybug balloon. Now, every time the family saw a ladybug, they talked about how their son was present. The mother and grandmother collected and exchanged ladybug trinkets and toys. According to the grandmother, "the ladybug is something that's real, real, real positive. It represents the presence of Craig in her life, but all of us look for ladybugs. It's a good thing, it's healing." The baby's father said, "everywhere we go, there'd be one [ladybug] popped right out in a weird place. . . we're in a hotel or whatever and here's a little ladybug. . . . So it's was like, hey, he's not there [in the cemetery], he's everywhere." This family had experienced major conflict because of their very different ways of experiencing grief, the meanings associated with the baby's death, and their own ways of maintaining bonds. The shared symbol of the ladybug, however, helped them connect in a positive way with each other as well as with their baby.

Other symbols described included animals, collections of angels, Christmas tree ornaments bought or received in remembrance, and jewelry worn in memory of their babies. Several created memorial objects. In one family, members on both sides, including the maternal grandfather, made a quilt square. Sometimes symbols emphasized loss. A maternal grandmother looked forward to beginning a collection

of porcelain dolls for her granddaughter. According to her daughter, "if we go somewhere and she'll see a porcelain doll, she walks away from it because she knows she wanted to buy one for Brittany and she never got to."

Rosenblatt and Elde (1990) observed that shared representations such as these symbols facilitate communication in families and otherwise help family members cope with loss. The ladybugs, the symbols in other families not described here, and even the shared family anniversary dates were examples where shared symbolic representations gave family members common ground. As in the instance of the ladybug, they helped alleviate feelings of conflict or ambivalence. In another family where emotional expression did not come easily, creating a project together facilitated sharing the loss without speech. One mother and her parents had no common representations of the baby and in the months following his death had developed quite distinct meanings associated with his death. Not surprisingly, relationships were strained. The mother felt unsupported and judged unfairly and her parents could not understand why she continued to be so distressed.

#### Subsequent siblings

Six of the families had had subsequent babies and two other women were pregnant at the end of data collection. All acknowledged that these subsequent children had been very positive for all family members and had contributed to their healing. The other two families were hoping and waiting for another pregnancy. All of the parents and most of the grandparents who talked about subsequent children emphasized they were not replacement children and that the babies who had died would not be forgotten. Many parents and grandparents commented with regret, however, that they had fewer conversations about the babies who died because of the focus on the new baby. Indeed, some of the grandparents, especially those of stillborn babies, indicated the earlier pain of loss had subsided in large part because of the new grandchild as described by this maternal grandmother:

I felt badly, I just wanted to have a grandchild so bad. But of course now I have a grandchild now and he is over two-years old and it's been such a pleasure that I think that it just erased a lot of the other feelings that I had in the past.

In four families subsequent children were old enough to recognize pictures of, talk about, and draw their absent siblings. One mother felt that her subsequent son was an easy child to care for because "I think that she's kind of watching over him and looking out for him." Another found that money contributed to the adoption agency in her daughter's name was held by the agency for her next child. She described the connection between her two children this way:

When I got ready to adopt they said, "Well, you have all this money sitting here." I thought that was really amazing. So I feel in some sense Jackson is Kyna's legacy.

Several family members commented on how much the subsequent baby looked like the one who had died in two families. Both mothers felt the likeness to be painful and bittersweet at first.

### Summary

This study supports the presence of continuing bonds between the babies who died and their parents and grandparents. Some continued parenting roles of advocacy or caretaking as they prepared for funerals or cared for a cemetery plot. Funerals or memorial services were held for all babies who lived. The rituals associated with them were both painful and sources of support for participating family members. Rituals associated with stillborn babies were more varied and rules regarding participation by extended family members less clear. Still, these rituals helped to form attachments that continued at the time of the interviews. Parents early in bereavement talked about the importance of treating their children as though they were still present, and some emphasized connections through feelings of sadness. The need for these types of connections seemed to fade with time, however, as did continuation of parenting roles.

Other rituals or ways of connecting began early and continued over time. These included shared memories of the child; rituals associated with holidays, birth, and death dates; spiritual connections; and symbolic representations. The latter included photographs and a wide variety of objects representing the child. By the time of the interview, all of these ways of connecting had become embedded in individual and family life, although not all associated activities included both generations.

As discussed previously, the meaning of the loss constructed by parents and grandparents was unique to each individual within a family with little evidence of a shared family meaning. Continuing bonds with the babies likewise were unique. At the same time, however, the influence of family was more apparent in developing continuing bonds than in shared meaning, especially with respect to symbolic representations. Shared understandings about connections appeared to be especially important. When grandparents were supportive of or shared continuing bonds, relationships between generations appeared to be strong. Because they provided common ground, shared symbols helped to smooth relationships when communication among family members was difficult. This occurred in the presence of family conflict such as in the family that looked for ladybugs. It was also helpful when family members found it to difficult to talk about their grief or about the baby as in the family that created a memorial quilt. The lack of support for symbolic connections or rituals was associated with tensions between parents and extended family members. This occurred in some families where understanding about the significance of the loss was lacking or where grandparents were unskilled in their attempts to provide support.

Rituals mostly involved parents and their surviving children. They did not appear to cross households in the majority of families even when there was knowledge about and support for such activities. These included rituals related to cemetery visits and birthday or other anniversary observances. Separateness in ritual seemed to occur more frequently when grandparents lived distant, did not feel

grief for their grandchild, and were older. The absence of shared ritual across households was isolating when parents felt judged negatively by grandparents or perceived that grandparents did not understand their loss. More frequently, however, the lack of shared ritual across households was not viewed negatively. Nuclear family-centered activities appeared to be the normal pattern of interaction in other arenas as well. Parents did not expect grandparents to participate fully and were not distressed when they did not. It is likely that acceptance by grandparents of parents' rituals was sufficiently helpful. Time since loss also seemed to matter. Some ways of connecting faded and other ways gradually became a part of family life over time.

## CHAPTER 5 RESULTS: FAMILIES ADAPTING TO LOSS

This chapter addresses the question: How are family support, meaning making, and rules and rituals for maintaining bonds related to adjustment following infant loss? The multitude of ways that bereaved family members provided support, found meaning, and maintained continuing bonds in the aftermath of the death of an infant were described in the previous chapter. Particular attention was given to the ways that gender, generation, and family lineage influenced these activities. The focus in this chapter is on individual adjustment to this traumatic loss.

The process of adaptation to grief is complex, varied, and dynamic as reflected by the multiple and diverse models of coping that have been used to describe responses to bereavement (Stroebe & Shut, 2001a), as well as the multiple factors that have been associated with adjustment (e.g., relationship to the deceased, age of the deceased, social support, type of loss, circumstances surrounding loss, worldview). Adaptation is said to have occurred when the negative emotional and physical consequences of bereavement are reduced. Examples include people being less distressed (Nolen-Hoeksema, 2001), or positive emotion becoming predominant and individuals reintegrating into daily activities (Folkman, 2001). Over time, most people do experience reductions in suffering and manage to adapt successfully to traumatic losses, as reported in Chapter 2. Also as described earlier, however, studies consistently have found a sizeable minority of bereaved persons has difficulty adjusting to loss (Lund & Caserta, 1997-98; Prigerson et al., 1995; Prigerson & Jacobs, 2001; Wortman, Silver, & Kessler, 1993). These individuals tend to experience high emotional distress early in their bereavement, which continues at elevated levels for months and years. The intense suffering experienced is not explained by type of relationship loss, cause of death, or by other contextual factors.

As described in Chapter 3, parents and grandparents were asked how they felt they had coped with or adjusted to their babies' death. They also completed the Inventory of Complicated Grief (ICG; Prigerson et al., 1995) and the Bradburn Affect Balance (BAB) Scale. No statistical analysis was conducted on quantitative scores. Instead, individual scores on the scales were used in combination with qualitative data in categorizing respondents. Four groups representing different levels of adjustment or adaptation to loss emerged: *adaptors*, *partial adaptors*, *in transition*, and *distressed*. These groups were distinguished by the amount of distress they were experiencing as reflected by the ICG scores, and by levels of optimism and depression suggested by scores on the BAB scales. Groups, characterized by high, medium, and low scores on these scales, are presented in Table 2. More detailed information is presented in Appendix D. In the discussion below, the findings of the preceding chapter are examined to consider how family support, meaning making, and continuing bonds promoted or hindered optimal adaptation to infant loss. Patterns were different for parents and grandparents in the adaptor and partial adaptor groups and are described separately.

Table 2: Adjustment to Death of an Infant: Comparison of Groups

Adjustment Category	ICG	BAB+	BAB-	Mothers (N=10)	Fathers (N=9)	Grandmothers <sup>a</sup> (N=17)	Grandfathers (N=6)
Adaptors	Low	High	Low	3	5	12	3
Partial Adaptors	Medium	Low	Medium	3	2	2	2
In Transition	High	High	Low	2	1	2	1
Distressed	High	Low	High	2	1	1	

Note: ICG=Inventory of Complicated Grief; BAB+=Bradburn Affect Balance Positive Scale; BAB-=Bradburn Affect Balance Negative Scale; <sup>a</sup>includes step grandmother and maternal aunt.

## ADAPTORS

Members of six families were categorized as adaptors. This group consisted of 12 grandmothers (including the step grandmother), 5 fathers, 3 grandfathers, and 3 mothers. Although the group included some who were recently bereaved, most family members in this category were three years or more from their loss. Relationship to the child was a feature of group membership, with more grandparents than parents represented, and more fathers than mothers. This group as a whole was an optimistic one, with 4 as the average score on the BAB Positive Scale, and 1.5 as the average score on the BAB Negative Scale. Positive scores are higher and negative scores lower than the general population sample of the Rossi and Rossi study (1990). The mean score for the ICG was 12.6, well below the cut-off score of 25 indicating presence of traumatic grief set by Prigerson and her colleagues (1995).

### Parent adaptors

The eight parents in this group (including two couples) tended to be older (average age 36 compared to 34) and further from loss (an average of 3.5 years compared to the sample mean of 2.8 years). As a group they had more life experiences, including experiences with loss. According to one father,

I don't think it hurt any that we were older when this happened to us. I think it's easier if you've successfully handled more of life than if you were young. . . . When you're young and so much of life has been taken care of [for] you, you're just sort of following along and you haven't had the experience of seeing how much of it depends on the choices that you make. . . . I think that's really important to getting through grief. You have to have the feeling that you are responsible to a very large extent for how you live your life, how you feel in this life. Yes, bad things happen to you, but how you respond to them is very much a choice that you make and I think that's probably easier for someone who has very successfully gotten to an older age than I think someone who is younger.

His wife agreed, saying:

We're life-long learners and we like solving problems. We don't usually consider ourselves entitled to anything, including the status quo. I think those traits make it easier for us to accept, but not in a passive way. I guess to engage and struggle with what we're handed.

Another mother who was a social worker found that her prior knowledge was somewhat helpful to her, connecting her husband's lack of knowledge about loss and grief to his greater struggle over time.

Because I worked on a Hospice unit, I had some knowledge. . . . I think there were times that he [father] doubted that he should make it. . . . I always knew I could survive. I didn't like that I was going to survive, but I always knew it. I really loathed that I had to survive. I was more pissed off than I was sad. I felt like somebody came and robbed me. I think that was different. My perception of Bruce [father] was that he felt guilty he was still alive.

All but one of the eight parents were able to reach out to others in the midst of their pain early in bereavement. All of the fathers and one of the mothers talked about efforts to support their grieving spouses while maintaining their family roles. One of the mothers talked about supporting her grieving parents and another mother about her major role in helping her aging mother find alternative housing within weeks of her son's death. Most fathers in this group talked about their abilities to meet family obligations even in the early days of grief. For example, this father reflected:

I think I coped fairly well, as best as you can. Each day you get up and you've got to go [to work]. I was able to function and get to work and still do things even though I was very sad . . . so I would say overall, I feel like I coped with it fairly well.

### Family support

These parents received and were aware of a wide range of consistent family support beginning immediately after the loss. All experienced the support of those who were *present*, although this intense type of support was not always provided

by grandparents. Other health providers, friends, or bereaved parents sometimes filled this role. *Acknowledgement* of the loss from family members was prominent in all of their stories. In addition to recognizing support, with one exception, expectations for support were met. Similarly, it appeared that the needs for support were matched by the support received. According to one mother,

My expectations tend to be high and I would say that . . . I got what I bargained for in life. I would love to thank everybody and I know I have, but I don't know that it would ever be enough. I'll keep trying, it won't stop me, but there were a lot of times, a lot of support.

Although almost all provided examples of family members who had lacked skill in offering support, these were not central to the stories for six of the eight parents. Although some had experienced considerable strain in their families, most of these parents seemed quite forgiving and able to focus on intent to be helpful. For example, this father acknowledged his frustration with his mother-in-law when she seemed to make things worse for his wife by telling her to "snap out of it" and to move on, "but I can't fault her either, because she was just doing what she thought was best for her daughter." Because he understood his father's upbringing and traumatic life experiences, this same father was also forgiving of his own father's lack of obvious support. He went on to say, "I can see everyone's point of view."

On balance, positive support from key family members was reported often and seemed to outweigh the unskilled support or lack of support of others. Two of the parents in this group, however, clearly gained perspective with time and through professional intervention. A father and his wife learned how to be supportive of their different ways of grieving after counseling. A mother, after struggling for two years, sought professional help. She was treated for depression, a condition that appeared to predate her child's death but had been unrecognized. Both of these two parents, the father through counseling and the mother through treatment, reported gaining a whole new perspective and understanding of others. By the time of the interviews, the comments of these two parents were similar to

others in this group in terms of being accepting and tolerant of clumsy efforts at support.

### Meaning making

At the time of the interviews, *why* was not a central issue for these parents, in terms of either physical or philosophical explanations. A SIDS mother was one who had struggled with understanding SIDS earlier in bereavement. She remained interested in research, but at this point said, "I don't think I'll get the perfect answer and I know that's not possible, to get a perfect answer." Looking back, none of the other parents seemed to have struggled for an extensive period of time trying to find medical solutions to the puzzle of their child's death.

Adaptors represented a range of spiritual beliefs, although few described themselves as particularly religious. None offered religious explanations for the loss nor talked about death occurring as part of God's will. The general attitude seemed to be that tragic events happen in life and can happen to anyone. Those with religious beliefs felt their babies to be safe and well cared for.

Most parent adaptors described benefit emerging from their loss, including closer relationships, changed priorities, and considerable personal growth. As an example, this father said,

One other thing I've learned from the whole experience, and I've told a number of people on different occasions, is understanding grief better. . . . I learned something about making connections with people, I think—being open to, how to be more open . . . even if terrible painful things [are happening] in people's lives.

A mother said that she had learned to live differently: "You get what you get and you can't throw a fit because it's not going to help. I think you learn to surrender, to be powerless to a certain degree." This does not mean that this woman was passive in her response to loss; she clearly was not. She did not assume the role of victim nor did she continue to rail against what could not be changed. The mother

who had received treatment for depression also emphasized how her son's life had changed her and how she had been active in that change:

There are a lot of changes in me that I've made personally and things that I was willing to look at and made decisions to go about seeking resolutions for and ways of making myself a better person and a better mom and a better wife and a better person to be around. I don't know if I hadn't hit that low, I don't know if that that would have ever happened.

### Continuing bonds

Most of these parents had integrated their dead child into their lives; their children and their grief experiences had become a fundamental part of who they were and who they would be in the future. Memories were precious and cherished; none expressed fears that their babies would be forgotten. Three of the six families described specific rituals they had established surrounding birth and death dates. Two of these families also had identified symbolic representations of their children that were acknowledged and supported by grandparents. Field and colleagues (1999) found that widows who maintained connections through memories appeared to adapt better to loss than those who maintained connections through things. The parents in the two families using symbols reported that they or their spouses had considerable difficulty coping in the aftermath of loss. The presence of unskilled support was also more prominent in their stories than in the stories of the other parents.

### Grandparent Adaptors

Over 70% of the grandparents were in this group of adaptors and represented 8 of the 10 families. With one exception, they were further in time from the loss than the two families not represented. Just over half of these grandparents had not felt a strong emotional attachment to the child, including the grandmother in the recently bereaved family. Only one of those reporting lack of connection was the grandparent of a SIDS baby. The rest of those without attachment were

grandparents of babies who had died of other causes. A paternal grandmother of a stillborn baby reflected the sentiments of most of these grandparents when she wrote that the loss of this child had less impact than

a child that was known—a child alive with a personality, a little body, someone to bond and connect with—to remember, to miss and mourn. . . . While I am saddened, I somehow do not feel loss for a little one never known to me. I don't know if it is the wisdom of age and experience, the fact that I have six glorious grandchildren or just a philosophical aspect of my own personality.

Those who reported strong emotional ties to the babies included grandmothers of a stillborn baby, a baby who died of birth defects, and grandparents in three SIDS families.

Many of the grandparents in this group had experienced other traumatic losses. They included three grandmothers who, between them, had four children who had died. Two had died in infancy (acute infection and failed surgery), one in adolescence as a result of multiple and severe birth defects, and one as a young adult from suicide. Two grandmothers and a grandfather were widowed. One grandmother was widowed two years prior to her grandson's death and one grandfather lost his wife after a long illness in the year following his grandson's death. Others had experienced the deaths of parents, close friends, or other relatives. A certain stoicism characterized many of these grandparents, which may be a cohort affect. Several, especially those who were older, stressed the importance of keeping busy and not dwelling on the loss as a way of coping, both for themselves and for their children. This older grandmother of a stillborn baby described her philosophy this way:

I'm the kind of person, if I run into something that's obstructive or difficult, I just always learned that I have to learn to cope. . . . it was just something I had to accept and I did feel bad for a long time about it, whenever I thought about it. But, I was very active and I was busy all the time, so I had a lot of interests and a lot of friends that I saw frequently. And I didn't discuss it with them after I mentioned it, told them the first time.

### Family support

Unlike the parent adaptors, no clear pattern of family support, either given or received, emerged in the grandparent adaptor group. All provided or attempted to provide support to their adult children. Nearly half were described as *being present* and were among those who were especially skilled and sensitive in responding to their adult children. At the same time, some of the grandparent adaptors provided unskilled support. This group appeared to lack understanding about their adult child's needs or could not meet needs and expectations. None of the adult children of those grandparents who were described as unskilled were in the parent adaptor group. It is not known whether adaptors are more likely to overlook unskilled care or whether unskilled family care contributes to poor adaptation, or some combination of both.

Only one grandmother in this group reported receiving support from her daughter. As described in the last chapter, however, very few bereaved adult children responded by providing support to their parents. Many grandparents did not expect nor did they seek support for their own grief when it was present. As did the grandmother quoted above, most kept their pain to themselves and kept busy. Other grandparents reported receiving help and encouragement from other family members, spouses or partners, and friends and coworkers. Like the parent adaptors, the grandparents in this group rarely expressed dissatisfaction with the support they did receive.

### Meaning making

Again, no clear pattern emerged with these grandparents, even considering separately those with attachments and those without close attachments to the babies. Although answering the question *why* was not and had not been central to most, it remained an issue for two of the SIDS grandparents and for some of the grandparents who could not make sense of the baby's death in terms of their religious beliefs or in terms of justice. Many of the grandparents did report benefit

in terms of closer relationships within their families. Quite often comments were specific to closer ties with in-laws. Only one grandmother talked about the importance of meaningful work and the new projects she would pursue as a direct result of her grandson's life and death.

### Continuing bonds

As described above, more than half of these grandparents indicated that they were not emotionally attached to the babies who died. Many of these individuals, therefore, had connections to the babies only through their adult children. They were not directly involved in their adult children's ways of maintaining continuing bonds, although some acknowledged those connections in some way. For example, two grandmothers who happened to be described as unskilled gave their daughters gifts that were symbolic of the baby. Both those who reported emotional attachment and those who did not were among the skilled providers of support who were present and who acknowledged the significance of the babies' lives. They shared memories of the babies with their adult children, displayed photographs, and supported their adult children's rituals even if they did not participate. Those describing emotional connections to the babies tended to engage in more discussion about the babies and to participate more in a variety of rituals on their own. Reported support for an adult child's ritual was not always confirmed. For example, the maternal grandparents and step grandmother in one family all indicated they provided support to their daughter who lived across the country by placing flowers at the baby's grave. Their daughter (who was in the partial adaptor group) described it differently: "I called my dad this year and asked him to put flowers on Kyna's grave [on her birthday] and he said 'oh, are you still not over that?'"

## Summary

Although parents and grandparents who appeared to be coping successfully with the death of an infant shared some similarities, they were characterized more by their differences. As a group, both parents and grandparents seemed to have a positive outlook on life. In addition, prior life experiences seemed to shape their responses to this new occurrence. They seemed more aware of and accepting that life involves tragedy and, for the most part, they were active in shaping their responses. Parents faced their loss and made decisions about how they would live in a world without their child. Many of the grandparents focused on keeping busy and moving on as they had done many times before.

With respect to the key variables of the study, however, parents and grandparents were different. These parents generally felt supported; they felt their needs and expectations for support were met. Parents were able to see attempts at support and thus were tolerant of family members who were unskilled in their support. These parents were able to reach out in support to their spouses and to their own parents. In comparison, grandparents who have adapted to loss of a grandchild are harder to characterize. They reported a wider range of support both given and received from none to extraordinary.

In terms of meaning making, adaptive parents did not focus on questions of *why*. Finding benefit seemed especially important in terms of enhanced relationships but perhaps more importantly in terms of personal growth and changed priorities in life. Some of the grandparents who were emotionally attached to their grandchildren did continue to talk about *why* in physical or philosophical terms, although others did not. Many of these grandparents did find benefit, usually described as closer family relationships.

Parents in this group appeared to have integrated the child into their lives. They maintained connections through shared memories and felt secure in their attachment. Compared to some of the other parents, those in this group had fewer rituals. Those who had established rituals, tended to keep them within their own

households. Grandparents, in contrast, ranged from no connections to strong connections. Those who had established emotional attachments to the babies were more likely to engage in rituals related to birth and death dates, and to symbolic representations of the baby. Both those with and those without emotional attachment were successful in supporting the connections and associated rituals established by their adult children.

### PARTIAL ADAPTORS

Five parents and four grandparents, representing five families, were placed in an intermediate category of adaptation to loss. In many ways they were similar to those who were adaptors. They were fully functioning within work and family roles and most reported that they had coped or were coping well with their losses. As a group, however, they appeared more distressed than the adaptors. This was reflected by their statements as well as by their scores on the ICG and the BAB scales (see Table 2).

#### Parent partial adaptors

Partial adaptors included three mothers and two fathers; one couple was from the same family. As with the adaptors, parents in this group averaged three and a half years since the death of their child and most were in their mid 30s to 40s. As a group, however, they were less optimistic and appeared to be more depressed. The mean score on the BAB Positive scale was 2.2, nearly two points below the adaptors. It was also well below the score of 3.6 score found in age groups between 19 and 40 reported in the Rossi and Rossi (1990) study, and the average score of 3.83 reported by Charles and her colleagues (2001). The mean score for the Negative scale was 2.6, almost a point higher than the adaptor group. Again, using other studies as reference points, negative affect in this sample was much higher than in comparable age groups (Rossi & Rossi, 1990; Charles et al., 2001). The mean score on the ICG was 26.4, just above the cutoff point the scale developers

suggested indicated presence of traumatic grief. This interpretation should be viewed with some caution, however, because the scale was not developed using bereaved parents or grandparents (Prigerson et al., 1995). In addition, these parents were functioning at very high levels in work and family life. As suggested by the work of Moriarty (1990), the elevated ICG score is probably indicative of the high stress associated with parental bereavement rather than the presence of pathology.

### Family support

All of the parents in this group reported receiving considerable support from their families, particularly from the babies' grandparents. All had family members who came from out-of-town to be present and all continued to receive acknowledgement of their children's lives from key family members. In fact, only two mothers in this group described some family members who had been unskilled in their support. For the most part, however, what was offered seemed to compensate for what was missing for these two mothers. The only significant mismatch in support needed and received appeared to take place within the married couple in this group. For example, the father wanted to talk about his son's death with his wife, but the mother could not. Both, however, indicated that they supported one another in other ways. This mother cried through most of the interview and declined to participate in a second. She seemed surprised by her tearful response saying with a laugh, "I thought I was coping pretty good" when asked how she had coped with or adjusted to her son's death.

### Meaning making

The parents in this group seemed to have more issues surrounding questions of *why* than the parent adaptors. All except one mother was a SIDS parent, and the cause of her daughter's stillborn death had similarly never been determined. Although most of these parents did not seem to dwell on finding a cause, the lack of knowledge remained troublesome. For one of the SIDS mothers, the *why*

stress were identified to explain this profile. A maternal aunt (who functioned much like a maternal grandmother) and a grandfather expressed deep sadness at the death of the babies well known to and loved by them (both SIDS babies). Their scores on the ICG were 30 and 24 respectively. The other two family members, maternal grandparents from one family, were most troubled by the difficulty their daughter was experiencing in the midst of her grief seven months after her son was stillborn. Their ICG scores were low, 18 and 15, supporting their statements that they had accepted the death of the baby, but they were clearly at a loss to help their daughter.

#### Family support

The aunt and SIDS grandfather provided considerable instrumental and affective support to the parents; they were *present*, and acknowledged the loss in multiple ways. Both spent a lot of time with the parents either on the phone or in person. In addition, they felt they received support from the bereaved mothers. The aunt had been included and even received some of the baby's clothes from the mother whom she described as "always considerate of my feelings." The father received information from his daughter and was impressed by her maturity and ability to cope with the loss, especially compared to his son-in-law. Both, most notably the grandfather, had also received support from other family members and their community of friends. The aunt remarked, "I think a lot of times people don't understand how much it hurts the other family members, too. . . . we're so close, those kids are like my kids."

The grandparents of the stillborn baby had a large extended family. Both described being well supported by family as well as by their community. The trouble seemed to be how to help their daughter get back to her old self. As the grandfather described it,

I think we're still coping with Gayle's [mother's] condition, but we've coped well with Sam's death. As you get older you learn to accept it better, I guess. You never accept it, but you accept life, I guess is the way it is.

This was a caring family, but one unfamiliar with non-normative, off-time loss. They were unfamiliar with parental grief and, therefore, were unskilled in their support of their daughter. They were quite distressed at the tension in the family. According to the grandmother,

Nobody wants to say anything to her, but on the other hand, she's disrupting everybody else, too. She's making everybody else feel uncomfortable because a they're so afraid to say anything to her because for fear they do, that she'll cry, that she gets hurt again. So, it's tough on the whole family, it truly, truly is.

### Meaning making

Both the aunt and the SIDS grandfather were troubled by the question *why*. Although the aunt said she was not asking "why, why, why as often as I did in the beginning," she said, "you still think, why did that happen to us? . . . I think we try to do the best we can to understand, [but] you never understand *why* because it doesn't make sense." She also acknowledged, through tears, that "the saying is true, time heals. It's still hard, [but] I don't cry as often." The grandparents who were distressed at the depth of their daughter's grief knew why their grandson died. Although the grandmother questioned the competence of the doctors for their failure to know anything was wrong, they did not appear to focus their energy in this area.

### Continuing bonds

The aunt and maternal grandfather maintained bonds through shared memories and photographs. The aunt participated in specific rituals on birth and death dates through her presence or by sending cards and flowers both to the baby and to the parents. When in town, she and the mother visited the cemetery. The grandfather found it difficult to participate in rituals; few had been established in the family. He went with his wife to the cemetery on specific dates, but did so

reluctantly, "I go more out of loyalty and responsibility than any satisfaction I get from it, . . . It's just not a good experience for me."

The maternal grandparents of the stillborn baby indicated that they would always remember the baby, but participated in no ritual. They also appeared to be uncomfortable with their daughter's collection of memorabilia or discussion about the baby. According to the grandfather,

She's got little charms and little trinkets, and little things around the house with the name on. I don't ever tell her that's enough or anything like that. I try to, I basically try to change the subject after a short time.

### Summary

The parents and the grandparents of those categorized as *partial adaptors* were meeting their work and family responsibilities. They experienced positive emotion and, on the whole, appeared to be functioning well. They all had received considerable support from extended family members. This support appeared to have met most needs and expectations for support, even if some of that support was unskilled. Although numbers are small, it appears that the grandparents with emotional attachment to the babies were similar to the parents in this group. Partial adaptors were less optimistic than adaptors and appeared to be experiencing distress beyond lingering sadness related to their losses. They also had a more negative affect than the adaptors. As in the group of adaptors, meaning making seems to be key. The partial adaptors, however, were more likely than the adaptors to be asking *why*. In addition, the partial adaptors seemed more vulnerable to the uncertainties of life; they seemed more fearful. They also were more likely to talk about the injustice of the loss than those in the adaptor group.

A key to adaptation for grandparents without emotional attachment to the babies may be their perceptions of how their adult children are coping. The two in the partial adaptor group were concerned for their daughter and what they considered to be unhealthy levels of distress. Grandparents with similar levels of

attachment in the positive adaptor group felt their adult children were coping well. Sometimes this meant that they were dramatically better than they had been or were coping appropriately in the circumstances.

#### IN TRANSITION

The last two groups were composed of individuals who were experiencing considerable distress and sadness. They included parents and grandparents who were among the most recently bereaved in the study. Although small in number, two groups were identified and categorized as distressed or in transition. The transitional group was composed of three parents and three grandparents. All of those interviewed in the most recently bereaved family were part of this group (parents and two grandmothers). Others included a bereaved mother two years after her loss and a grandfather bereaved for one and a half years. Individuals in the transitional group differed from the adaptor and partial adaptor group because they were experiencing high levels of distress as indicated by the ICG. At the same time, they also seemed to be using adaptive coping skills as described below. Adaptors had reported using these same skills earlier in their bereavement. Parents were further distinguished from the high distress group by a generally optimistic outlook on life. Parent scores on the BAB Positive scale were about the same as for parents in the adaptor group, although grandparent scores on this scale were comparatively low. Both grandparents and parents had the same negative affect balance scores. These scores were somewhat high for the grandparents compared to those in the same age groups in other studies, but the parents' scores were similar to others their age (Charles et al., 2001; Rossi & Rossi, 1990). Negative Bradburn Affect Balance scores fell between the negative scores of the adaptor and the partial adaptor groups. The transitional group, therefore, was highly distressed, but parents held a generally optimistic outlook on life and neither parents nor grandparents seemed overly depressed. An exception was one paternal grandmother who was raising the son of her drug-addicted, incarcerated daughter.

The grandparents in this group were all emotionally attached to their grandchildren and truly were grieving a double loss—the loss of a beloved child and the grief of their adult children. Adult children recognized the grief of grandparents and felt it the same as their own, as suggested by this father speaking about his in-laws:

I think it hurt the grandparents as badly . . . they still have the same blood, so I would say, what's the difference between losing your son or your grandson? I felt [mother's] mom hurt as much as we did.

His wife felt the same way, saying, "I don't see a real difference between my parents and me and [father]. . . . My parents, I know that they grieve a lot like me and [father] do." Because of the similarities between the experiences of the grandparents and parents in the transitional group, they will be discussed together.

#### Family Support

The recently bereaved couple and the grandparents indicated they had received considerable and, for the most part, consistent support from family members, particularly on the maternal side of families. They shared many stories of caring and supportive relatives who were *present* with them in their grief. Exchanges of support between generations were noted and considerable instrumental support was described. One mother was especially grateful to her parents who she felt grieved as hard as she did and would do anything they could for her. Those reporting unskilled support or lack of support, however, were more critical of family members who failed to meet expectations than those in the adaptor or partial adaptor groups. For example, one mother talked extensively of her mother-in-law's failure to provide sufficient and appropriate support. Although criticism of her mother-in-law was not a new development in their relationship, it appeared to have intensified in bereavement. In spite of ambivalent relationships, however, the parents in this family had not withdrawn from family functions and activities on either side of the family. Overall, needs and expectations for support

appeared to be met for the couple and the grandparents, at least within the context of loss. An exception was the paternal grandmother raising her grandchild who described needs for support that she felt were not being met. She also talked about isolating herself to some extent by hiding her own feelings of loss to spare her son, saying

Sometimes I feel like my son thinks that I don't understand how bad he feels, but I think that's part of me trying to protect him from how I feel. And I talk to him and I tell him that it's terrible and I love him, but I can't take that pain away from them.

Irene, the mother two years postloss, had a different story. Irene seemed to have fewer coping skills and less experience at the time of her son's death than some of the other parents in the study. In addition, in the early months of bereavement, Irene and her family had responded very differently from one another. Unlike the others in this transitional group who were more recently bereaved and seemed to have better coping skills, Irene had withdrawn from everyone immediately after her son's death and again after the funeral. She felt her needs were not met in spite of the efforts of her husband and others. She described spending hours everyday at the cemetery crying on her son's grave and then becoming the self-appointed caretaker of the children's area. Her husband's way of coping was different and there was little understanding between them. Conflict with her mother that began with disagreements over medical treatment of her son continued to be a problem, further isolating her. Irene said, "I probably lost about a year of my life with my mom in the relationship." She eventually attempted suicide, an event that she describes as "hitting rock bottom." At the time of the interview she remarked,

I'm not really ashamed of what I did. I thought at the time it was the only choice I had. And maybe it's what brought Joe and I back together; maybe if I didn't do it that night our relationship would have ended . . . so it may have happened for a reason.

Irene and her husband subsequently received counseling, which both said was critical to their reconciliation and recovery. Two years after her son's death she and her husband had renewed wedding vows and she felt her relationship with her mother was back where it should be. She was no longer withdrawn from others and was able to laugh and enjoy herself without guilt. Although grief remained close by, it no longer overwhelmed her. She observed:

I think if people don't get out of that grief . . . they either don't make it somehow—either commit suicide or starve themselves to death or something—or they're that way for the rest of their life and very, very bitter. I can't remember consciously making the decision that I wasn't going to be one of those people . . . I don't know what the turning point was. I don't remember, you know, one day being in raw grief and in the next it was over. I can't remember the transition time.

### Meaning Making

*Why* was an issue for those in the transitional group, more so than the adaptor group, although the couple in this group said already it was growing less so with time. Religion generally appeared helpful to this couple, especially for the mother who felt her daughter had been born for a reason and that God was taking care of her. Some positive reappraisal also was occurring within the couple, generated by the mother's comments, about the nature of her death. Employing social comparison, the mother found her daughter's death and the events surrounding it were more peaceful and less traumatic than they could have been.

Irene said she had been on a spiritual quest since her son's death. She described herself as someone without religious beliefs who was searching, not quite successfully, for faith that would help her find meaning. She said,

I hated that Craig's life was sacrificed, for that if it was to teach us a lesson, it would teach me to be more caring. I mean, [if] I was a more caring person, maybe it would teach me the road to faith. Because if I hadn't lost Craig, I probably would never think about God, ever think about Heaven, ever think about any of that. There was no part in my life. And losing Craig, it brought me closer to God, or on the road to trying to find him.

All of the parents in this group were able to identify benefits resulting from loss, mostly closer family relationships. Irene also talked about becoming a more caring person and provided several examples of how she was reaching out to others in need. The grandparents did not report benefit. The grandfather said, "It's hard to believe that this has happened and I think it will take a little while to get over that." Still, grandparents talked about needing to keep busy and move forward. For example a maternal grandmother admitted she was having difficulty accepting her daughter-in-law's pregnancy. She acknowledged that, "I'm going to have to let something go" so that she could welcome this new grandchild when she arrived.

#### Continuing Bonds

All in the transitional group had strong connections to the babies who died; the babies seemed to be in the forefront of their thoughts most of the time. Indeed, parents talked about the importance of treating the babies as if they were still present in their lives and grandparents talked of their pain because, as the grandfather said, of their inability to "spoil the hell out of him." In contrast, the adaptor and partial adaptor group did not feel overwhelming pain when they thought about their babies. The transition group engaged more frequently in ritual focused on their children. For example, those in the transition group, especially parents, visited the cemetery often. This couple, however, already had reduced the number of visits. They also had made them nuclear family activities associated with enjoyable times as opposed to isolated visits in sorrow. Two years later, Irene continued to visit the cemetery almost daily, but she stayed for a shorter time and rarely cried. She also was no longer caring for all the gravesites in the area, although she still policed the cemetery against those who came to walk their dogs or skate board, activities she felt were disrespectful and inappropriate. These connecting activities did not seem so necessary for the adaptor group, because they had incorporated their children more into their everyday sense of who they were.

Symbolic representations of the baby were present in all three families. Irene saw signs of her son through many aspects of nature and found it helpful to look for those signs. The most recently bereaved family found the cemetery to be a central gathering place and they had taken great care selecting the gravestone full of symbolic meaning. Although at different points in time since bereavement, those in this group were similar in their activities focused on maintaining attachments. Although highly distressed, parents seemed to be moving from attachment through emotions of sadness to thinking about the babies as ongoing parts of themselves. For example, the mother had recently begun to put some of her daughter's things away, saying that it was time to do so.

I walked into the room one day and I said to myself, "maybe it's time," because the room, it does give me a sense of peace, but I was looking around and I looked up at the sky. I said, "Brittany, you have so much stuff in this room." And as much as I dust it, some things were starting to turn colors, . . . I didn't want it to be ruined, so I put everything in boxes.

### Summary

Those in this group were highly distressed about their babies' deaths. Disbelief that such a thing had happened was present, as were feelings of shock, being dazed, and profound sadness. At the same time, however, these individuals were not or were no longer withdrawn from others important to them. They were sharing the experience with others, especially within their families. They also were functioning well in their work and family roles. Perhaps more importantly, they appeared to experience positive emotion as well as feelings of sadness. They were able to do so without feeling they were neglecting the children who had died. Thus, they did not seem to be connected to their babies principally through sadness, but through shared memories, ritual, and symbols. Making sense of the loss remained difficult, but parents were beginning to reappraise the experience and were finding benefit. Finding benefit seemed to be more elusive for the grandparents. The

grandparents in this group experienced high levels of distress, perhaps in part as a response to their own children's high level of distress.

### DISTRESSED

The group that appeared to be experiencing the most difficulty adjusting to loss of their babies included three parents and a maternal grandmother. As with the transition group, they had very high ICG scores. This group was different from the transition group, however, in several ways. Parents especially were more pessimistic as reflected by the BAB Scale. This group had the lowest score on the positive scale and by far the highest score on the negative scale. This pattern of high negative affect and low positive affect made this group the most different from the general population (e.g., Charles et al., 2001; Rossi & Rossi, 1990). As did most of the other respondents, the parents in this group indicated they were coping well or at least coping better than they had. They gave mixed responses, however, in other statements and their reference point for success was quite different from those in other groups. For example, this father had contemplated suicide but had not acted on it. He felt his choice not to follow through was an indication he was coping all right:

I'm still alive. So that's a pretty good thing right there. Because I contemplated, . . . I wanted to die. Part of me did die and I know I'll never get it back, but I wanted to die. . . . when he first passed on I could have did it, I could have. But, here I am.

That he still was having major difficulties coping with the loss was clear in a later statement.

I still miss him every day, so I really don't think that I've changed in a year and a half. I still miss him. I may be even more miserable than I was before, meaning attitude-wise. . . . Cory is still an open wound. . . I don't forgive God, I don't forgive the daycare that he was at, I don't forgive the paramedics, I don't forgive the doctors. When I do forgive them, then I'll be on my way to being healed, but I don't see me forgiving them no time soon.

The maternal grandmother in the same family as the father quoted above talked about her own difficulties a year and a half after her grandson's death. She said, "I cry at the drop of the hat. . . . I keep thinking about him, . . . I don't know why." She went on to say, "It was supposed to be getting better, but sometimes I wonder. I was going back down to my blackness." The recently bereaved mother of a stillborn son expressed many feelings in her response to the question about coping. Although she thought she and her husband were doing well, her mixed feelings come through in this single statement:

We're able to laugh and have fun again. And I can talk about him [the baby] without breaking down. I think I've accepted it now, maybe, because I have no choice. Sometimes I just go, "no, I cannot accept this," and maybe it's because nothing bad has every happened to me. It's like, "this can't either." But I don't have any choice, except to go on. But time does, time is helping."

### Family Support

Similar to the other groups, those who were highly distressed described very supportive behaviors from family members. Unlike the other groups, however, there also seemed to be more serious mismatches between what was needed and what was received. Unskilled or no support was a bigger part of these stories, at least for the three parents. For example, Gayle had received considerable support from her extended, close-knit family at the time of her son's death although it dissipated soon after. She received caring and skilled support from her mother-in-law and she described her husband as her source of strength. At the same time, Gayle was quite isolated. No one in her family, even her husband, felt the strong bond that she felt to this baby. Her husband and her mother-in-law were in the adaptor group and although they were both supportive, they did not share her feelings. Her parents lacked knowledge about grief and were distressed over Gayle's apparent difficulty coping. They described her as ruminating over her son's loss and unable or unwilling to get back to her own fun-loving self. Their disapproval of her coping style and their avoidance in talking about her son was

further isolating. As described by Lepore and colleagues (1996), being constrained from expressing emotion in one's social network results in intrusive thoughts and elevated distress as is evident here.

Vicki and Bill were parents of Cory who died of SIDS. Both were in this distressed group as was Vicki's mother. All reported considerable support from Vicki's parents and other relatives on the maternal side. They described long-term conflicted relationships with Bill's extended family, but they neither expected nor sought support from the paternal side. In spite of the support, Vicki and Bill withdrew from old friends and many family activities, thereby isolating themselves. Vicki also left her job, and although began a new one did not feel her subsequent position provided meaningful work. Her closest friends became other bereaved parents. Strains in support occurred between the two parents. Bill was reported by all interviewed as the most emotionally distraught person in the family. He experienced major difficulties functioning, although he did keep his job. Still, he was unable to provide support to anyone else including Vicki. Although some of the fathers and one of the mothers in this study were able to support their more distraught spouses, Vicki found the role difficult.

It got to the point where I was supporting Bill. And that was kind of hard. And I still feel like, sometimes I just want to yell at him about it, that I had to support him. . . . he slept on the couch for, I'd say about a year, . . . And he wore black for a year. I mean stuff like that made it harder for me.

Vicki also described him as so focused on his loss, that he monopolized discussion at support group meetings and was insensitive to anyone else's experiences. Although she became active in the group, she discouraged him from attending, which may have isolated both of them further.

### Meaning Making

Those in this distressed group had difficulty making sense of their loss. The SIDS parents continued to seek answers to *why* without resolution a year and a half

later. The mother of the stillborn baby anguished over what she had done to warrant punishment from God:

I really want to believe he's in Heaven, . . . but it really tests your faith because you think, "Why would God let me suffer so much? Why would he do that to me? . . . I've had a lot of trouble with my beliefs and my faith since he died. Because I can't believe he would do something like this to me, when there's crack addicts and prostitutes that spit out baby after baby and never once hold them. They give them away or dump them in the trash and I think that's where I start to question how can there be a God when it's like that?"

Those in this distressed group did not describe any benefit from the loss except for an increased awareness of SIDS and loss. This awareness was associated more with an elevated sense of vulnerability and fearfulness than to a greater appreciation of life or developing new priorities.

#### Continuing Bonds

Distressed individuals maintained connections with their babies much like others in the study—they visited the cemetery, developed symbolic representations of the babies, and established personal rituals. The distinctive attribute of this group, however, was that feelings of loss and sadness were the dominant links to their children. Those in the distressed group tended to ruminate about their loss. That is, they engaged passively in repetitive thinking about how badly they felt and about the circumstances of their loss (Nolen-Hoeksema, 2001). As a result, developing insight or engaging in more healthy problem-solving activities was especially difficult for these individuals.

#### Summary

The distressed group experienced family support, but in some cases this support did not meet specific and important needs of the griever, nor did it compensate for lack of support from others. As a group, these individuals were isolated, often because they withdrew from their usual support system. Other times

it occurred because friends and family found it difficult to be with them. Those who were distressed could not make sense of their loss and were continuing to seek answers without apparent satisfaction. They also reported very little benefit resulting from the experience. Feelings of grief and sadness as ways of connecting to their children were predominant even though other ways of connecting were present.

### IMPLICATIONS

Although questions remain, this research provides some direction for parents and grandparents alike in responding to traumatic loss in supportive and adaptive ways. Each person comes to significant events with a range of life experiences, a set of beliefs and assumptions about the world, and a network of social relationships that will influence responses to loss. Most individuals appear to adapt to traumatic loss over time, but the connection with time is not direct. In this study, some of those relatively early in bereavement had adapted successfully to their loss, whereas others the same distance in time remained highly distressed or in transition. Other factors, therefore, are critical in understanding adaptation.

For parents, social support, meaning making, and continuing bonds influence adaptation. Deployment of the family support system, including grandparents, is initiated upon the death of a baby. Ideally, support will be provided by skilled individuals and will be characterized by those who love and nurture unconditionally, understand and acknowledge the significance of the loss, respond without judgment to needs of the individual, help with tasks that need to be done, and generally are present and available. The match between need and expectations on the one hand and the support offered on the other hand is likely to be especially important. In this study, even minimal levels of support from grandparents were appreciated if they met or exceeded parents' expectations. Expectations were based largely on history of the parent-adult-child relationships and family development stage.

Parents who were able to adjust to great loss were active participants in their own social support system. This means that even in the midst of profound grief they were aware of others' pain and efforts on their behalf. They recognized and were appreciative of the support offered even if they were unable to reciprocate at the time. Being tolerant of unskilled support and able to see the intent behind the effort was also beneficial. Although family support is important, it does not appear to lead directly to adjustment. In this study, those who were highly distressed had similar levels of skilled and caring family support available to them as those in the group that was adapting successfully to loss. The relationship between social support and adjustment, therefore, appeared to be indirect.

Other areas of interest in this study were meaning making and continuing bonds. Many individuals processed their experiences with others in efforts to find meaning. Although grandparents and other family members were part of the process of constructing the meaning of infant loss, usually through conversation, no evidence was found to support a family, as opposed to an individual, meaning. Those who were adjusting most successfully were active in making meaning. At the same time, they did not dwell for very long on making sense of the loss in either physiologic or philosophical terms. They had either accepted explanations early or had decided not to pursue them further. More energy seemed directed at finding benefit. Adaptors could identify positive consequences of their child's life or death, with personal growth and insight being especially important.

All of the parents in this study maintained connections to the babies who died. Those who had adapted well reported that these children were an integral part of themselves and would continue to be so into the future. Family support seemed directly related to the kinds of rituals families developed to maintain bonds with their children and grandchildren. Use of ritual and symbols often helped surviving family members maintain relationships with each other and minimize conflict or difficulties in communication. Rituals or activities that emphasized connections to children through negative emotion or that emphasized continuation of parental

roles without change were not adaptive. Making meaning and developing continuing connections with the babies was an interactive process. For example, those with spiritual explanations for the loss developed connections and associated rituals that were consistent with those views.

The relationship between the grandparent and grandchild appears central to understanding grandparent adaptation to loss of a grandchild. Because this study focused on infant loss, many of the grandparents in this study did not have an emotional bond with the baby who died. This influenced the significance of the loss for the grandparents, which, in turn, shaped their own meaning making processes. Those with strong emotional attachment to the child were similar in many ways to parents who struggled with issues of making sense and finding benefit. The issue of making meaning was less central to the adjustment of those who were not emotionally connected to their grandchildren.

Because grandparents were more givers than the receivers of support, the nature of the relationship with their adult child or child-in-law appeared to be more important in explaining adjustment of grandparents than did support they received from other family members. Grandparents seemed to be adapting better when they felt their adult children were doing well or were coping appropriately with their loss. Family history appeared influential. Perceptions of adult child well-being were shaped by the relationships they had prior to the grandchild's death as well as by their life experiences with grief and loss. Prior relationships influenced the extent to which they participated in rituals of connection to the babies.

## CHAPTER 6 CONCLUSIONS

Bereavement is both an individual and a family experience. When a family member dies, that family is irrevocably changed. The extent to which an individual feels that change and mourns that loss will be influenced by the nature of the relationship to the person who died as well as the relationship with those closest to the deceased. In this study, the focus has been on the death of the youngest family members and the ways that parents and grandparents coped with that loss, both together and individually.

Ten families were recruited for the study and between three and five family members were interviewed in each, some more than once. The 42 participants were asked to share their stories—the brief lives of the babies, how they supported one another following the death, the ways they talked about and remembered babies, the meanings they found in the experience, and their assessment of how well they had coped with the loss. The result was a set of rich narratives of deeply personal events, described almost uniformly as the most difficult individual and family situations ever encountered.

Results from this study confirmed many aspects of family life that have been described in the intergenerational literature and are consistent with a life course perspective (Bengtson & Allen, 1993). Most grandparents responded to the crisis in their adult child's life by providing a wide range of affective and instrumental support (Aldous, 1985; White, 1999). Many traveled great distances to be with their children and most increased contact with them during the most difficult early months of bereavement. This support was consistent with family history as suggested by systems theory (Hanson, 1995). As has been found in other studies, some grandparents in several families were involved neither before nor after the loss. For the most part, these detached or remote grandparents were not a part of this study, so this study contributed little to understanding their role in

family life. At the same time, because these grandparents had not been involved, parents seemed to have had very low expectations that they would be helpful and did not seem disappointed when they were not. Still to be determined is whether the lack of involvement or support by these individuals limits the social resources available to draw upon in hard times. For example, one of the fathers had been abandoned by his father in early childhood and had been estranged from his mother since adolescence. As a result, no other family member of that generation was available to offset the unskilled support provided by his mother-in-law in the aftermath of his son's death. This study does not allow us to determine whether this situation is a significant social resource deficit or whether other compensatory resources are typically in place.

As found in other family research, the parent-child relationship was the strongest intergenerational bond in this study (Rossi & Rossi, 1990). This is supported by the higher levels of distress experienced by parents compared to grandparents, even in families where grandparents were close to their grandchildren. In addition, grandparents focused their efforts on helping their adult children more than they focused on other family members or even on their own grief. An observation in this study that needs to be tested is whether adjustment to loss of a grandchild is determined more by the well-being of the adult child than by coming to terms with one's own grief.

This study also confirmed the importance of gender and family lineage (Rossi & Rossi, 1990; Silverstein & Bengtson, 1997; Suito, Pillemer, Keeton, & Robison, 1995). The mother-adult daughter relationship seemed the most central intergenerational relationship. All living maternal grandmothers participated in the study and interaction between mothers and daughters was a principal part of their stories. This was true even when relationships between mothers and adult daughters were characterized by strain or when relationships between fathers and adult daughters also were described as central. Grandmothers, more than grandfathers, were described as providing the most valued support. They also appeared most

responsible for causing pain through inappropriate or unskilled responses to the loss. Adult children had fewer expectations for support, or at least lower thresholds of acceptable support, from grandfathers than from grandmothers. Conflicted relationships involving grandfathers, especially paternal grandfathers, often meant that they were on the periphery of family life if they were present at all.

The need to understand ambiguity in family relationships is gaining prominence in family studies (Connidis & McMullin, in press; Luescher & Pillemer, 1998; Marshall, Matthews, & Rosenthal, 1993). This research, with its multiple informants confirms the importance of learning more about ambiguity. As suggested above, it certainly was present in these families. For example, a grandparent could do something that was perceived as incredibly helpful only to follow that by doing something that caused considerable hurt. Similarly, expectations for support were often conflicting. For example, one mother described one instance how she got irritated with her mother for trying to "fix it" when all she wanted to do was talk. Later, she followed her mother's unwanted advice to seek treatment for depression and faulted her husband for not providing this guidance. The cultural context also appeared to contribute to ambiguity with expectations, sometimes unmet, for support on the basis of gender as well as generation. More was expected from the grandmothers than the grandfathers. Similarly, several respondents talked about socialization patterns for women and men with respect to what are considered appropriate expressions of grief. Lack of clear societal norms and defined ritual for responding to infant loss, particularly for stillborn babies, resulted in uncertainty in many families about how to respond.

The findings of this study are also consistent with much of the recent research on bereavement. Meaning making, particularly for parents, emerged as a central process of grieving (Neimeyer, 2001). Two dimensions of meaning making, *making sense* and *finding benefit*, were apparent in this study and were related in different ways to adaptation to loss (Davis, Nolen-Hoeksema, & Larson, 1998). Those who had difficulty with and still struggled to answer *why* experienced more

distress than those who did not. Those who could identify positive consequences resulting from their experiences, particularly in terms of their own personal growth and development, seemed to be adapting better than those who could not. In contrast to research by Nadeau (1998), the attempt to focus on the family as a unit of analysis did not reveal the presence of family meaning. Part of the differences in results may be the conceptualization of meaning. Regardless, of conceptualization, however, in this study, many more differences were seen within families than between them and no pattern emerged to explain how family members might contribute to the development of another person's meaning beyond the very important role of serving as a sounding board or participating in conversations about the loss. It may be that meaning making is a very individual aspect of grief that is only indirectly influenced by family and others. This small cross-sectional study makes it difficult to draw conclusions about the process of making sense or finding benefit over time.

Consistent with bereavement research on continuing relationships in bereavement (Klass, Silverman, & Nickman, 1996; Klass & Walter, 2001; Troll, 2001), evidence was presented that parents in particular maintained bonds with the babies who had died. Ways of maintaining connections took many forms including shared memories, creation of symbolic representations, and construction of a variety of rituals. These connections were socially constructed by parents as well as by grandparents, other family members, and those in the parents' support network, providing an example of the principle of emergence (Snow, 2001). In many families, intergenerational participation in or support for the different ways of maintaining connections seemed to be adaptive. Rituals and open discussion about the babies provided a bridging function, especially in families with ambiguous relationships (Rosenblatt & Elde, 1990). At the same time, it was noted that those parents who seemed to be most successful in coping with their loss were less likely to talk about rituals and symbolic representations of the babies, although this may be related to time since loss.

This study also provided support for the idea that connections with children who have died change over time, becoming more integrated into the survivor's identity and more associated with the survivor's better self (Klass & Walter, 2001). It may be that with time, rituals and symbols become less important to ensuring the continuing presence of children or it may be that rituals and symbols are only partially adaptive.

Less clear in this research was the role of family support in adjustment to loss. Both parents and grandparents talked about its importance, and many could contrast positive and negative experiences. The presence of those who were understanding, caring, nurturing, and nonjudgmental was clearly viewed as beneficial. Parents and grandparents alike were grateful for this support and indicated it was helpful. Yet, this type of support did not seem to be directly associated with adjustment to the loss nor was unskilled support necessarily related to more difficulty coming to terms with loss. Several explanations are possible. First, in some situations unconditional nurturing may not always be what the mourner needs. An example may be someone who engages constantly in ruminative thought or withdraws into substance abuse or other self-destructive behaviors. Second, the lack of a clear relationship may be a confirmation that cognitive processes, including meaning making, may be more important than support in the process of adapting to loss. Third, the considerable support received in these families may have resulted in a restricted range of support observed. Although most families appeared to experience some level of unskilled support or a lack of support from some family members, all reported receiving considerable and appropriate levels of support from key family or from others in their support system. This may be unique to this sample because the study required participation from both parents and multiple grandparents. Those with a wider range of support and nonsupport experiences may have been excluded from participating. Fourth, time since loss may have been a factor that masked the significance of support. Many of the most supportive families were among those most recently bereaved. It

is not surprising that these families reported high levels of distress. Fifth, the role or the actions of the recipient of support may be more important than previously recognized. It was observed that those parents who appeared to be adapting well were not so overwhelmed by their grief that they were unaware of the extent of the support they were receiving. In addition, these adaptors appeared able to reach out to others in their family than those who had more difficulty coming to terms with the loss. Adaptors also seemed tolerant of those who tried but were not quite successful in attempts to be helpful. This all suggests that receiving support is an interactive process. Perhaps those who are mostly focused inward as they grieve are more passive recipients of support. They may, therefore, receive less support than is actually available to them. Finally, a question emerged from this research regarding the ability of those who are experiencing significant grief themselves to provide support. Many of the grandparents viewed as most supportive were themselves profoundly affected by loss of their intimate relationship with the baby. In many ways their experience of grief established a common bond with their adult child. Other grandparents were viewed as equally supportive, but did not experience the depth of personal loss. A question for future research is how shared grief and mourning experiences are related to parents' and grandparents' adaptation to loss.

The intent of this research was to examine families as the unit of analysis with a primary focus on parent-adult-child relationships. The attempt was partially successful. It was clear that these events were traumatic family experiences that extended well beyond the parents' households as suggested by family systems theory. A much more complete family story was available by hearing the perspective of several family members. Use of multiple informants also made clear the complexity of coping with traumatic loss. It appears that many individuals participated in this study as a way of supporting a family member and that they would not have participated otherwise. New voices were heard as a result,

principally fathers and those grandparents with little emotional attachment to the babies.

The study is not without limitations. The sample is too small to identify typologies of family relationships as suggested by Marshall and his colleagues (1993). Are there patterns of family responses to loss? As indicated above, no evidence was presented for family meaning. Yet there was mixed evidence with respect to patterns of response to loss within families. For example, in some families all interviewed were highly distressed and in others all were in the adaptor group. From this study, it is not clear whether these consistent patterns were perhaps simply an association with time since loss, shared significance of the relationships with the child, or familial patterns of coping. Several of the parents and grandparents provided examples of how maternal and paternal sides of the families were different in the ways they expressed emotion or the ways they dealt with difficult life events. A larger, more focused study might help understand whether these general patterns of responses in families influence the family as a whole as family members respond to loss, in turn leading to important insight into possible interventions with families to enhance support and skill in coping with loss.

One of the benefits of this research, which embraced the complexities and ambiguities that exist in families, is that it may help push the focus of research on bereaved families beyond a dichotomy of *good* family support and *bad* family support. As in other realms of family research and practice, it is likely more useful to identify skills needed to cope with loss and then to provide assistance to family members to help strengthen those skills. Many family members, who were distraught over what was happening, were not very effective in providing support although they tried. Sometimes this was tolerated and sometimes it was not. In this study, grandparents most often were the offenders. Yet those who were unskilled cared deeply about what was happening to their adult children and were usually attempting to help make things better. In the future, intervention studies might be

conducted that target grandparents. More effort can be made to help grandparents understand normal grief responses, particularly to losses that often go unrecognized, such as pregnancy or neonatal loss. Helping grandparents become more knowledgeable about the nature of parental grief and its lifelong impact is key to building skills. Grandparents who do not expect their children to be themselves within weeks, are not as likely to make hurtful comments about "moving on," or "pulling yourself together." Similarly, grandparents can be helped to become more skilled in listening. Being able to provide information as an alternative to providing advice when their adult children do not seem to be coping well would be beneficial in many families. Grandparents can also be encouraged to help their adult children integrate their babies into their lives in new ways through listening, sharing memories, and supporting ritual and symbolic representations.

Other intervention studies might target bereaved parents. Those who mourn appear to help themselves when they are aware of and are accepting of the support being offered, even if it is not a high level of support or is offered unskillfully. Reaching out, even in the midst of one's own deep grief, to other family members who are also grieving may facilitate the support of others and keep individuals from becoming socially isolated.

As suggested by previous research, this study supports the idea that it is not adaptive to continue focusing on the question *why* when no satisfactory answer is forthcoming soon after bereavement. Finding benefit also characterizes those who are successful in adaptation. For these individuals, the grief process has included painful inward reflection, which has resulted in personal growth. Although none would have chosen their loss to obtain greater wisdom, they value the life lessons they have learned and feel that they have stronger relationships with others because of them.

Parents who appear to be successfully adapting to loss are connected to their children in ways other than through feelings of sadness and loss. Establishing rituals or identifying symbols of the continuing presence of babies can be helpful.

Such activities can facilitate communication within and across households and provide common experiences related to the child. This seems especially important when talking about the baby is difficult for some family members or the support provided has been unskilled.

Family members traditionally have been major sources of support for those who are experiencing in difficult times. This was true for the families in this study. This research provides direction for parents, grandparents, and the helping professions to respond to traumatic loss in supportive ways and adaptive ways. This includes recognizing and accepting the individual nature of grief, fostering personal growth, and supporting the continuing presence of a beloved family member as a vital and continuing part of family life.

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APPENDICES

## Appendix A

ID# \_\_\_\_\_

**Family Bereavement Study Questionnaire (parent)**

Please complete the following questionnaire and bring the completed form to the family interview. We will not be discussing your answers to these questions directly, although they might help you think about the kinds of things you would like to talk about. I will use this information as a way to learn more about you and your experiences.

Name of your child who died: \_\_\_\_\_

Date of birth \_\_\_\_\_ Date of death \_\_\_\_\_

Does the baby have siblings born before or after his or her death?

Name \_\_\_\_\_ Date of birth \_\_\_\_\_

Name \_\_\_\_\_ Date of birth \_\_\_\_\_

Name \_\_\_\_\_ Date of birth \_\_\_\_\_

Name \_\_\_\_\_ Date of birth \_\_\_\_\_

Over the course of your life, have you or other family members experienced any other death of an infant or child? Please describe briefly including age and date (or approximate dates) of the event. (For example, your sister died in 1978 at age four of pneumonia; a 10-year-old cousin died in 1986 in an automobile accident.)

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What other experiences with death of close friends or family members have you had?

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6. I can't help feeling angry about his/her death.
- never    rarely    sometimes    often    always
7. I feel disbelief over what happened.
- never    rarely    sometimes    often    always
8. I feel stunned or dazed over what happened.
- never    rarely    sometimes    often    always
9. Every since she/he died, it is hard for me to trust people.
- never    rarely    sometimes    often    always
10. Every since she/he died, I feel as if I have lost the ability to care about other people or I feel distant from people I care about.
- never    rarely    sometimes    often    always
11. I feel lonely a great deal of the time ever since he/she died.
- never    rarely    sometimes    often    always
12. I have pain in the same area of my body or have some of the same symptoms as the baby who died.
- never    rarely    sometimes    often    always
13. I go out of my way to avoid reminders of the baby who died.
- never    rarely    sometimes    often    always
14. I feel that life is empty without the baby who died.
- never    rarely    sometimes    often    always
15. I hear the baby who died
- never    rarely    sometimes    often    always

II. Please think about events that may have happened to you during the last few weeks. In the past few weeks did you ever feel (*please circle yes or no*):

- |     |   |     |    |
|-----|---|-----|----|
| 1.  | So restless that you couldn't sit still.                          | yes | no |
| 2.  | Pleased about having accomplished something.                      | yes | no |
| 3.  | Bored.  | yes | no |
| 4.  | That things were going your way.                                  | yes | no |
| 5.  | Depressed or unhappy.   | yes | no |
| 6.  | Proud because someone complimented you on something you had done. | yes | no |
| 7.  | Very lonely or remote from other people.                          | yes | no |
| 8.  | Particularly excited or interested in something.                  | yes | no |
| 9.  | Upset because someone criticized you.                             | yes | no |
| 10. | On top of the world.  | yes | no |

III. Now, please think about how you feel today. Please check the box next to the answer that best describes how you feel right now.

1. I think about this baby so much that it's hard for me to do the things I normally do.

never    rarely    sometimes    often    always

2. Memories of the baby who died upset me.

never    rarely    sometimes    often    always

3. I feel I cannot accept the death of the baby who died.

never    rarely    sometimes    often    always

4. I feel myself longing for the baby who died.

never    rarely    sometimes    often    always

5. I feel drawn to places and things associated with the baby who died.

never    rarely    sometimes    often    always

16. I see the baby who died before me.

never    rarely    sometimes    often    always

17. I feel that it is unfair that I should live when the baby died.

never    rarely    sometimes    often    always

18. I feel bitter over the baby's death.

never    rarely    sometimes    often    always

19. I feel envious of others who have not lost someone close.

never    rarely    sometimes    often    always

Today's date: \_\_\_\_\_

1. Thinking about your family since the time the baby died, please indicate your agreement with each of the following statements by circling the appropriate number. Answer the first column based on your experiences with your spouse and your children, the second column based on your experience with the mother's side of the family, and the third column based on experiences with the father's side of the family.

	<i>Your Spouse &amp; Children</i>					<i>Mother's Parents &amp; side of the family</i>					<i>Father's parents &amp; side of the family</i>									
	Strongly disagree					Strongly agree		Strongly disagree					Strongly disagree		Strongly agree					
	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5					
1.	It seemed like we were angry with each other more after the death.					1	2	3	4	5	1	2	3	4	5	1	2	3	4	5
2.	The loss hurt our ability to communicate among family members.					1	2	3	4	5	1	2	3	4	5	1	2	3	4	5
3.	We drifted apart after the loss.					1	2	3	4	5	1	2	3	4	5	1	2	3	4	5
4.	There were a lot more family misunderstandings after the death.					1	2	3	4	5	1	2	3	4	5	1	2	3	4	5
5.	There was a lot of conflict in the in the family after the death.					1	2	3	4	5	1	2	3	4	5	1	2	3	4	5
6.	It seemed like we were less able to understand each other after the loss.					1	2	3	4	5	1	2	3	4	5	1	2	3	4	5
7.	We fought more after the death.					1	2	3	4	5	1	2	3	4	5	1	2	3	4	5
8.	Some of us did not get the support we needed from the family.					1	2	3	4	5	1	2	3	4	5	1	2	3	4	5
9.	It became difficult to know the family rules after the loss.					1	2	3	4	5	1	2	3	4	5	1	2	3	4	5
10.	There was tension in the family that had not been there before.					1	2	3	4	5	1	2	3	4	5	1	2	3	4	5
11.	The family did not help each other deal with their grief.					1	2	3	4	5	1	2	3	4	5	1	2	3	4	5
12.	The family still pulled together as a team.					1	2	3	4	5	1	2	3	4	5	1	2	3	4	5

		<i>Your spouse &amp; Children</i>					<i>Mother's parents &amp; side of the family</i>					<i>Father's parents &amp; side of the family</i>				
		Strongly disagree		Strongly agree			Strongly disagree		Strongly agree			Strongly disagree		Strongly agree		
		1	2	3	4	5	1	2	3	4	5	1	2	3	4	5
13.	Family members generally continued to feel good about being a part of this family.	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5
14.	The family sort of lost what it stood for.	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5
15.	Our family was more unstable after the loss.	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5
16.	We did not seem to be able to concentrate or get work done after the loss.	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5
17.	We were not as organized as we had been before the loss.	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5
18.	It became difficult to make decisions after the loss.	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5
19.	Life seemed to lose its meaning after the death.	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5
20.	I doubted if my family could survive another crisis.	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5
21.	We remain a proud family.	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5
22.	We retained our family self-respect.	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5
23.	We always knew we would survive the loss.	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5
24.	There was still much to feel good about in our family.	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5

ID# \_\_\_\_\_

**Family Bereavement Study Questionnaire (grandparent)**

Please complete the following questionnaire and bring the completed form to the family interview. We will not be discussing your answers to these questions directly, although they might help you think about the kinds of things you would like to talk about. I will use this information as a way to learn more about you and your experiences.

Name of your grandchild who died: \_\_\_\_\_

Date of birth \_\_\_\_\_ Date of death \_\_\_\_\_

Does the baby have siblings born before or after the baby died?

Name \_\_\_\_\_ Date of birth \_\_\_\_\_

Name \_\_\_\_\_ Date of birth \_\_\_\_\_

Name \_\_\_\_\_ Date of birth \_\_\_\_\_

Name \_\_\_\_\_ Date of birth \_\_\_\_\_

Do you have other grandchildren? Yes \_\_\_\_\_ No \_\_\_\_\_

What are their names and ages?

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Over the course of your life, have you or other family members experienced any other death of an infant or child? Please describe briefly including age and date (or approximate dates) of the event. (For example, your sister died in 1947 at age four of pneumonia; a 10-year-old cousin died in 1974 in an automobile accident.)

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What other experiences with death of close friends or family members have you had?

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II. Please think about events that may have happened to you during the last few weeks. In the past few weeks did you ever feel (*please circle yes or no*):

- |  |     |    |
|--|-----|----|
| 1. So restless that you couldn't sit still.                          | yes | no |
| 2. Pleased about having accomplished something.                      | yes | no |
| 3. Bored.  | yes | no |
| 4. That things were going your way.                                  | yes | no |
| 5. Depressed or unhappy.   | yes | no |
| 6. Proud because someone complimented you on something you had done. | yes | no |
| 7. Very lonely or remote from other people.                          | yes | no |
| 8. Particularly excited or interested in something.                  | yes | no |
| 9. Upset because someone criticized you.                             | yes | no |
| 10. On top of the world.   | yes | no |

III. Now, please think about how you feel today. Please check the box next to the answer that best describes how you feel right now.

1. I think about this baby so much that it's hard for me to do the things I normally do.

never    rarely    sometimes    often    always

2. Memories of the baby who died upset me.

never    rarely    sometimes    often    always

3. I feel I cannot accept the death of the baby who died.

never    rarely    sometimes    often    always

4. I feel myself longing for the baby who died.

never    rarely    sometimes    often    always

5. I feel drawn to places and things associated with the baby who died.

never    rarely    sometimes    often    always

6. I can't help feeling angry about his/her death.

never  rarely  sometimes  often  always

7. I feel disbelief over what happened.

never  rarely  sometimes  often  always

8. I feel stunned or dazed over what happened.

never  rarely  sometimes  often  always

9. Every since she/he died, it is hard for me to trust people.

never  rarely  sometimes  often  always

10. Every since she/he died, I feel as if I have lost the ability to care about other people or I feel distant from people I care about.

never  rarely  sometimes  often  always

11. I feel lonely a great deal of the time ever since he/she died.

never  rarely  sometimes  often  always

12. I have pain in the same area of my body or have some of the same symptoms as the baby who died.

never  rarely  sometimes  often  always

13. I go out of my way to avoid reminders of the baby who died.

never  rarely  sometimes  often  always

14. I feel that life is empty without the baby who died.

never  rarely  sometimes  often  always

15. I hear the baby who died

never  rarely  sometimes  often  always

16. I see the baby who died before me.

never  rarely  sometimes  often  always

17. I feel that it is unfair that I should live when the baby died.

never  rarely  sometimes  often  always

18. I feel bitter over the baby's death.

never  rarely  sometimes  often  always

19. I feel envious of others who have not lost someone close.

never  rarely  sometimes  often  always

Today's date: \_\_\_\_\_

IV. Thinking about your family since the time the baby died, please indicate your agreement with each of the following statements by circling the appropriate number. Answer the first column based on your experiences with your spouse and your children and the second column based on your extended family (*for example, your siblings, parents, nieces, nephews, cousins*)

	<i>Spouse and Children</i>					<i>Extended Family</i>				
	1 strongly disagree	2	3	4	5 strongly agree	1 strongly disagree	2	3	4	5 strongly agree
1. It seemed like we were angry with each other more after the death.	1	2	3	4	5	1	2	3	4	5
2. The loss hurt our ability to communicate among family members.	1	2	3	4	5	1	2	3	4	5
3. We drifted apart after the loss.	1	2	3	4	5	1	2	3	4	5
4. There were a lot more family misunderstandings after the death.	1	2	3	4	5	1	2	3	4	5
5. There was a lot of conflict in the in the family after the death.	1	2	3	4	5	1	2	3	4	5
6. It seemed like we were less able to understand each other after the loss.	1	2	3	4	5	1	2	3	4	5
7. We fought more after the death.	1	2	3	4	5	1	2	3	4	5
8. Some of us did not get the support we needed from the family.	1	2	3	4	5	1	2	3	4	5
9. It became difficult to know the family rules after the loss.	1	2	3	4	5	1	2	3	4	5
10. There was tension in the family that had not been there before.	1	2	3	4	5	1	2	3	4	5
11. The family did not help each other deal with their grief.	1	2	3	4	5	1	2	3	4	5
12. The family still pulled together as a team.	1	2	3	4	5	1	2	3	4	5
13. Family members generally continued to feel good about being a part of this family.	1	2	3	4	5	1	2	3	4	5

	<i>Spouse and Children</i>					<i>Extended Family</i>									
	1 strongly disagree	2	3	4	5 strongly agree	1 strongly disagree	2	3	4	5 strongly agree					
14.	The family sort of lost what it stood for.					1	2	3	4	5	1	2	3	4	5
15.	Our family was more unstable after the loss.					1	2	3	4	5	1	2	3	4	5
16.	We did not seem to be able to concentrate or get work done after the loss.					1	2	3	4	5	1	2	3	4	5
17.	We were not as organized as we had been before the loss.					1	2	3	4	5	1	2	3	4	5
18.	It became difficult to make decisions after the loss.					1	2	3	4	5	1	2	3	4	5
19.	Life seemed to lose its meaning after the death.					1	2	3	4	5	1	2	3	4	5
20.	I doubted if my family could survive another crisis.					1	2	3	4	5	1	2	3	4	5
21.	We remain a proud family.					1	2	3	4	5	1	2	3	4	5
22.	We retained our family self-respect.					1	2	3	4	5	1	2	3	4	5
23.	We always knew we would survive the loss.					1	2	3	4	5	1	2	3	4	5
24.	There was still much to feel good about in our family.					1	2	3	4	5	1	2	3	4	5

## Family Group Interview Questions

<i>Introductory</i>	Please tell me your name and how you are related to the people in this room.
<i>Opening</i>	As you know, we are here to talk about how families cope with the death of a child. Before we begin this discussion, I would like to know a little bit about [child]. Would you each share one of your favorite memories?
<i>Transition</i>	Please tell me how you learned that [child] had died and what you did right after you knew.
<i>Transition</i>	Was there a funeral or other kind of memorial? If yes: How do you think the funeral affected the family?  If no: How was that decision made? In what ways do you think not having a service affected the family?
<i>Key Question 1</i>	Think about immediately after [child] died and about the time since then. How have you helped each other cope with this tragedy?  Probes: <ul style="list-style-type: none"> <li>• What were some things that other family members did to help you?</li> <li>• What were some things that you did to help other family members?</li> </ul> Check for: <ul style="list-style-type: none"> <li>• Funeral arrangements</li> <li>• Place to stay</li> <li>• Being there; sharing feelings, talking</li> <li>• Cross generation support</li> <li>• Same generation support</li> <li>• Providing information</li> </ul>
<i>Key Question 2</i>	What kinds of things about [child] and [his/her] death do you talk about with each other?  Probes: <ul style="list-style-type: none"> <li>• who talks the most?</li> <li>• Are family members more similar or more different in the ways you think or feel about [child's] death?  <ul style="list-style-type: none"> <li>--How &amp; why child died</li> <li>--the way different family members express grief</li> <li>--reminiscing about the child</li> </ul> </li> <li>• Do you think that the way that you talk about the child and feel about the child's death has changed over time?</li> </ul> If grandparent missing, ask: How do you think that [grandparent] would

answer this question?

*Key Question 3*

What have been some of the biggest challenges for your family since [child] died?

Probe:

- What are some things that have been really difficult?

Check for:

- Trying to provide support while grieving
- Not understanding each others' needs
- Disagreements about what is appropriate
- Inability to talk when desired
- Expectations to talk when not desired
- Family members not filling roles as expected
- Disagreements, conflict
- Overwhelmed
- Family members being changed

*Key Question 4*

What are some things that you do to remember [child]?

Probe:

- Do you visit the cemetery?
- What do you do on [child's] birthday? holidays?
- death date?
- Other rituals?
- Do you do these activities as individuals, couples, family?
- Do you talk about these activities?
- When and how did these activities start?
- What happened to his/her room? Belongings? Who was involved?

*Transition*

All things considered, what do you think that the death of [child] has meant for your family?

Probe:

- Strengthened? If so, how?
- No change
- Increased strains? If so, how?

*Ending*

What are some of "life's lessons" that your family has learned as a result of [child's] death?

Probe: What advice would you give to other families facing this loss?

*Ending*

Do you have any other comments that would help us understand how families cope with traumatic events and what we can do to support them?

*Ending*

As an expression of my appreciation, I would like to make a small donation to a charity or organization of your choice in memory of [child]. Where would you like me to send it?

## Follow-Up Individual Interview

## Part I.

Review summary of family group interview. Ask questions emerging from that interview for clarification and/or expansion of earlier comments.

Ask:

- Do you have any additional comments that have occurred to you since the interview, or comments you would like to make that you did not feel comfortable making in the group interview?

## Part II.

As you know, I am interested in how families, particularly adult children and their parents, cope with the death of a child. I would like you to thinking back to the group interview as well as to the experiences with your [parents/adult children] that you have had since [child] died.

- How similar or different were your responses to the death of [child] from the responses of your [adult children/parents]?
- Some people say that women have one kind of experience when a child dies and men have another kind of experience. What kinds of similarities or differences did you observe in your family about the ways that the women (mothers and grandmothers) and men (fathers and grandfathers) responded?
- In a similar way, some people say that parents have one kind of experience when a child dies and grandparents have another kind of experience. What were some of the similarities or differences between the ways that parents responded and grandparents responded?
- People have very different ways of grieving and sometimes they have strong opinions about what is the appropriate way to grieve. How much agreement or disagreement did you observe in your family about how someone ought to behave when a child dies? [Probe re gender, generational differences]
- What about your religious or spiritual beliefs about where [child] is now? How much agreement do you think exists across generations about this? [Probe re gender differences]
- [If differences are mentioned] Do you think any of the differences you mentioned get in the way of giving or receiving support? If yes, in what ways? [Probe re gender differences]
- What are the biggest changes you have seen in the ways that you interact with other family members, especially with your [adult child/parents]? [Probe re gender differences]

- All things considered, as [parents/grandparents], how well do you feel you were supported by other family members after [child] died? What was the most important thing that your adult child/parents do to help you?
- What was something that your [adult child/parents] did that made it more difficult for you to cope?
- How has this level of support from your [adult child/parent], or lack of support, contributed to your own adjustment to your loss?
- All things considered, how well do you feel you have adjusted to or coped with the death of your child?
- How do you think your grief experiences have been shaped by your family (support given & received, meaning, coping)?

Appendix C

Analytic Framework [based on Strauss & Corbin (1990) Axial Coding Model]

Causal Condition	Phenomenon	Context	Intervening Conditions	Action/interaction Strategy	Consequences
<p>Death of Child</p> <ul style="list-style-type: none"> <li>• Cause</li> <li>• Age of child</li> <li>• Story</li> </ul>	<p>Family Grief Response</p> <ul style="list-style-type: none"> <li>• Intensity of feeling</li> <li>• Impact on individual, family function</li> </ul>	<p>Time since loss</p> <p>Family structure, developmental stage</p> <p>Geographical proximity</p> <p>Family history, previous significant life events</p> <p>Gender</p> <p>Generation, role relationship</p>	<p>Shared meaning about the death</p> <ul style="list-style-type: none"> <li>• What it is, significance</li> <li>• Why (medical, philosophical)</li> <li>• Injustice</li> </ul> <p>Shared connections to child</p> <ul style="list-style-type: none"> <li>• Emotional attachment</li> <li>• Memories</li> <li>• Symbols, anniversaries</li> <li>• Spiritual beliefs</li> </ul> <p>Shared grief experience</p> <ul style="list-style-type: none"> <li>• Similarities/differences in grief feelings, responses</li> <li>• Understanding, awareness of others' grief, observations of others' grief</li> <li>• Communication among family members about grief, loss</li> <li>• Time with family</li> </ul> <p>Life Experiences, skills</p> <ul style="list-style-type: none"> <li>• Level of maturity, ability to face loss, make choices, outlook on life</li> <li>• Knowledge about death, grief, Experience with loss</li> </ul> <p>Ongoing family challenges</p>	<p>Support given/received</p> <ul style="list-style-type: none"> <li>• Awareness, acknowledging loss</li> <li>• Being present, taking time</li> <li>• Not talking about it</li> <li>• Tasks, financial assistance</li> <li>• Mobilizing support</li> <li>• Advice, suggestions, information</li> <li>• Unskilled, unwelcome</li> <li>• Exchange, helping others, sharing</li> <li>• From outside the family</li> <li>• None</li> </ul> <p>Coping strategies</p> <ul style="list-style-type: none"> <li>• Support*/information seeking</li> <li>• Emotional expression*</li> <li>• Avoidance*, numbness</li> <li>• Withdrawal, focus inwardly</li> <li>• Distraction*</li> <li>• Rumination*</li> <li>• Reappraisal*</li> <li>• Moving on</li> <li>• Helping another family member</li> <li>• Activities related to child (see below)</li> <li>• Subsequent child</li> </ul> <p>Rituals, activities related to child</p> <ul style="list-style-type: none"> <li>• Funeral, parting</li> <li>• Cemetery, place</li> <li>• Memorial activities</li> <li>• Projects</li> </ul> <p><i>*Coping strategies described in Nolen-Hoeksema &amp; Larson (1999)</i></p>	<p>Adjustment/coping</p> <p>Individual insight, growth</p> <ul style="list-style-type: none"> <li>• Meaningful work</li> <li>• View of the world</li> <li>• Reaching out to others</li> <li>• Fears</li> </ul> <p>Family relationships</p> <ul style="list-style-type: none"> <li>• Relationship quality</li> <li>• Parenting/grandparenting experiences</li> </ul>

APPENDIX D  
Participants' Adaptation Category and Quantitative Scores

Adjustment category	Cause of death	Time since death	Relationship	ICG <sup>a</sup>	BAB <sup>b</sup> positive	BAB negative
Adaptor	Complex medical problems	3.5 years	Mother	20	4	4
Adaptor	Stillbirth	5.5 years	Mother	12	3	2
Adaptor	SIDS	4.5 years	Mother	18	4	0
Adaptor	Complex medical problems	2 years	Father	23	3	2
Adaptor	Complex medical problems	3.5 years	Father	13	4	2
Adaptor	Stillbirth	3 years	Father	9	4	1
Adaptor	Stillbirth	5.5 years	Father	8	5	3
Adaptor	Stillbirth	7 months	Father	12	4	1
Adaptor	Complex medical problems	2 years	Maternal grandmother	19	4	3
Adaptor	Complex medical problems	3.5 years	Maternal grandmother	25	3	1
Adaptor	Stillbirth	3 years	Maternal grandmother	10	5	0
Adaptor	Stillbirth	5.5 years	Maternal grandmother	3	5	1
Adaptor	SIDS	3.5 years	Maternal grandmother	3	5	0
Adaptor	SIDS	4.5 years	Maternal grandmother	6	4	0
Adaptor	Complex medical problems	3.5 years	Paternal Grandmother	13	1	3
Adaptor	Stillbirth	3 years	Paternal grandmother	12	5	0

## Appendix continues

Adjustment category	Cause of death	Time since death	Relationship	ICG <sup>a</sup>	BAB <sup>b</sup> positive	BAB negative
Adaptor	SIDS	4.5 years	Paternal grandmother	15	5	1
Adaptor	SIDS	3 years	Paternal grandmother	19	2	0
Adaptor	Stillbirth	7 months	Paternal grandmother	3	5	2
Adaptor	SIDS	3.5 years	Surrogate maternal grandmother	11	5	1
Adaptor	Stillbirth	3 years	Maternal grandfather	17	4	5
Adaptor	SIDS	3.5 years	Maternal grandfather	10	5	1
Adaptor	Stillbirth	5.5 years	Paternal grandfather	6	3	1
Partial Adaptor	SIDS	3.5 years	Mother	23	0	3
Partial Adaptor	SIDS	3 years	Mother	29	3	2
Partial Adaptor	Stillbirth	3 years	Mother	30	3	3
Partial Adaptor	SIDS	4.5 years	Father	24	5	1
Partial Adaptor	SIDS	3 years	Father	26	0	4
Partial Adaptor	SIDS	3 years	Surrogate maternal grandmother	30	5	1
Partial Adaptor	Stillbirth	7 months	Maternal grandmother	18	3	3

## Appendix continues

Adjustment category	Cause of death	Time since death	Relationship	ICG <sup>a</sup>	BAB <sup>b</sup> positive	BAB negative
Partial Adaptor	Stillbirth	7 months	Maternal grandfather	15	1	3
Partial Adaptor	SIDS	4.5 years	Maternal grandfather	24	4	3
In Transition	SIDS	4 months	Mother	56	4	2
In Transition	Complex medical problems	2 years	Mother	52	4	3
In Transition	SIDS	4 months	Father	38	4	2
In Transition	SIDS	4 months	Maternal grandmother	42	1	2
In Transition	SIDS	4 months	Paternal grandmother	29	2	4
In Transition	SIDS	1.5 years	Maternal grandfather	26	2	3
Distressed	SIDS	1.5 years	Mother	58	1	4
Distressed	Stillbirth	7 months	Mother	49	2	4
Distressed	SIDS	1.5 years	Father	48	3	5
Distressed	SIDS	1.5 years	Maternal Grandmothers	26	3	1

Note: ICG=Inventory of Complicated Grief; BAB=Bradburn Affect Balance Scale. "Surrogate maternal grandmother" includes step grandmother and aunt.