REFLEXIVE CONVERSATIONS WITH BEREAVED MOTHERS: 
A FEMINIST AND CONTEXTUAL PERSPECTIVE

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(ABSTRACT)

In this study, the experiences and perspectives of 10 bereaved mothers were investigated. The research was guided by a feminist and contextual perspective. A contextual theory of stress supports an examination of the perspectives of individuals in families regarding the impact of stressful circumstances. Individuals are assumed to be both active and responsive to the social system which includes individual, dyadic, familial, social, community, and cultural levels of analysis. A feminist perspective emphasizes reflexivity, collaboration, emotionality, and accessibility in the process of research and focuses attention to broader cultural ideologies which influence the lives of individuals. Women’s lives carry with them the assumption of motherhood and the protection of children. When a young child dies, mothers find themselves in a marginalized social category.

The following research questions guided this study:
(1) What are mothers’ stories who have had the experience of a young child’s death? (2) In what ways do mothers perceive
that the death of their child has changed and continues to change them? (3) What are the applied implications of mothers' perspectives? (4) How are respondents and researcher affected by their work together in the study?

Qualitative interviewing was the method of data collection, and each respondent was interviewed twice. Respondents were recruited from bereavement support groups (SHARE, Compassionate Friends, and a hospital support group) and from hospital and early intervention professionals. Criteria for inclusion in the study were as follows: The child's age at time of death must have been between birth and 2-1/2 years; the death must have occurred 2 to 14 years prior to the initiation of the study.

Much of the literature regarding bereaved mothers has compared them to fathers and found them to be more seriously affected by depression and somatic complaints which change little over time. This study broadened the focus to attend to the mothers' perspectives of their experiences on multiple levels. This shift in focus illuminated cognitive, emotional, behavioral, and spiritual changes in the women, their efforts to preserve the memory of their child and to teach others. While the interviews were emotional for the mothers, they provided a place within which to reflect on their experiences.
In memory of

Thomas David Farnsworth

October 13, 1984 - May 9, 1985

and all the young children

who were remembered

by their mothers in this study
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Pursuing and obtaining a doctoral degree is a long, sometime lonely process made memorable by the people who provide support and encouragement along the way. Many people provided these special touches to me during this journey.

To the mothers who participated in this study, I am grateful to you and changed by the time we spent together. I hope that this document honors and affirms the experiences you have shared with me. Your words have taught me, enriched me, and further transformed my own understanding of long-term maternal bereavement.

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# TABLE OF CONTENTS

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>ABSTRACT</td>
<td>ii</td>
</tr>
<tr>
<td>DEDICATION</td>
<td>iv</td>
</tr>
<tr>
<td>ACKNOWLEDGMENTS</td>
<td>v</td>
</tr>
<tr>
<td>I. INTRODUCTION</td>
<td>1</td>
</tr>
<tr>
<td>From Margin to Center:</td>
<td></td>
</tr>
<tr>
<td>The Use of the Self in Research</td>
<td>1</td>
</tr>
<tr>
<td>Statement of the Problem</td>
<td>12</td>
</tr>
<tr>
<td>Purpose of the Study</td>
<td>13</td>
</tr>
<tr>
<td>Research Questions</td>
<td>15</td>
</tr>
<tr>
<td>II. REVIEW OF LITERATURE</td>
<td>18</td>
</tr>
<tr>
<td>Conceptual Perspectives</td>
<td>19</td>
</tr>
<tr>
<td>The Contextual Model of Family Stress</td>
<td>19</td>
</tr>
<tr>
<td>Feminist Perspectives on Motherhood</td>
<td>22</td>
</tr>
<tr>
<td>Review of Bereavement Literature</td>
<td>25</td>
</tr>
<tr>
<td>Summary</td>
<td>32</td>
</tr>
<tr>
<td>III. METHODOLOGY</td>
<td>34</td>
</tr>
<tr>
<td>Overview</td>
<td>34</td>
</tr>
<tr>
<td>Pilot Study</td>
<td>38</td>
</tr>
<tr>
<td>Description of the Sample</td>
<td>38</td>
</tr>
<tr>
<td>Sample Selection</td>
<td>38</td>
</tr>
<tr>
<td>Sample Respondents</td>
<td>40</td>
</tr>
<tr>
<td>Procedures</td>
<td>49</td>
</tr>
<tr>
<td>Analysis of the Data</td>
<td>53</td>
</tr>
<tr>
<td>Summary</td>
<td>55</td>
</tr>
<tr>
<td>IV. RESULTS</td>
<td>56</td>
</tr>
<tr>
<td>Talking About Myself</td>
<td>59</td>
</tr>
<tr>
<td>Remembering the Child Who Died</td>
<td>60</td>
</tr>
<tr>
<td>Birth Recollections</td>
<td>60</td>
</tr>
<tr>
<td>Interactions with Medical Staff</td>
<td>64</td>
</tr>
<tr>
<td>Fathers’ Reactions/Interactions</td>
<td>67</td>
</tr>
<tr>
<td>Other Children’s Needs/Concerns</td>
<td>71</td>
</tr>
<tr>
<td>Mementos</td>
<td>73</td>
</tr>
<tr>
<td>Reliving the Death</td>
<td>75</td>
</tr>
<tr>
<td>Details of the Death</td>
<td>76</td>
</tr>
<tr>
<td>Mothers’ Thoughts, Feelings, Actions</td>
<td>78</td>
</tr>
<tr>
<td>Funerals/Memorial Services</td>
<td>80</td>
</tr>
</tbody>
</table>
Humor 82
Sources of Help 84
Living Since the Death 86
Changes in Mothers 87
Couple/Intimate Relationships 91
Experiences with Other Children 92
Extended Family Relationships 94
Paid and Unpaid Work 95
Support Groups/Therapy/Medical Care 99
Reaching Out to Others 102
Prior Death/Bereavement Experiences 103
Prior Experiences with Death/Bereavement 104
Methodological Codes 106
Mothers' Perceptions of the Research Process 106
Comments by the Researcher 108
Collaboration with Doctoral Advisor 111

V. DISCUSSION AND CONCLUSIONS 113

Overview 113
Discussion of Findings 114
Deepening Consciousness 115
Redefining Oneself 118
Teaching Others 120
Connecting as Researcher and Researched 123
Conclusions 124
Limitations of the Study 127
Suggestions for Further Research 128
Summary 129

REFERENCES 131

LIST OF TABLES

Table 3.1 Birth Order 42
Table 3.2 Child's Death 44
Table 3.3 Educational Background 46
Table 3.4 Narratives of the Respondents 47
Table 5.5 Questions/Codes/Findings 125

APPENDICES

A. Interview Guides 140
B. Informed Consent 147
C. Coding Categories 152
D. Vita 154

viii
REFLEXIVE CONVERSATIONS WITH BEREAVED MOTHERS:
A FEMINIST AND CONTEXTUAL PERSPECTIVE

CHAPTER ONE
INTRODUCTION

From Margin to Center:
The Use of the Self in Research

I entered my doctoral program in 1990 with a story to
tell, an experience which continues to influence my life
over time, and, perhaps, a search for comprehension of a
seemingly incomprehensible experience. Frequently, I have
"left out" the personal, because it seemed trivial and
inappropriate in academia; but as I have read and studied, I
have located epistemological, theoretical, and
methodological underpinnings which bring me back to what I
know well, the lived experience as a source of knowledge, a
foundation for the creation of social science (Baber &
Allen, 1992; Belenky, Clinchy, Goldberger, & Tarule, 1986;
Krieger, 1991; Thompson, 1992; Van Manen, 1990). The
perspective of bell hooks (1984) seemed appropriate in my
heading, From Margin to Center, as I begin with myself in
this dissertation.

With lived experience as a basis for my work, I begin
with a personal narrative attentive to the possibility that
my own experiences may possibly be our experiences (Van
Manen, 1990). Personal bereavement experiences informed me
as I conducted my inquiry—from gaining access to other
toformulatingconceptualizationsbasedon
the data. Emerging from the margin (hooks, 1984), I
acknowledge the use of the self at the very beginning,
affirm that personal knowledge influences my research, and
recognize that the personal both liberates and constrains my
understanding of the topic of inquiry (Baber & Allen, 1992).
As a bereaved mother, I am sensitized to the stress of a
child’s death, the ramifications on multiple levels of an
individual’s life, and the potential for change in a woman’s
life. Yet, these were my own perceptions of the bereavement
process as I began my work; they may not be shared by all
bereaved mothers. The very ideas that liberate my
understanding may make it difficult for me to understand
others. This is a dialectic tension within which I work, a
tension which drives me to question myself, to reflect upon
my own practice, and to critique the idea of "the truth" in
social science.

Prior to placing my sample of respondents in the center
of analysis, I now reveal a small portion of my story as
others have done in their own work (Allen & Walker, 1992;
Baber & Allen, 1992; Ferguson, 1991; Hochschild, 1989;
Krieger, 1991; Ruddick, 1989). As each author shared a
portion of her experience in her writing, her ideas and
abstractions about social life became visible to me. They
wrote specifically about who they were as people and how they came to their knowledge claims; in doing this, I felt they were speaking directly to me in a way that was connected, accessible, and articulate.

As I now share myself, I desire to conduct "social science that does not deny the self, but seeks to use its potential" (Krieger, 1991, p. 2). The potential of the use of self is to facilitate reflexive conversations and understanding between me and a diverse sample of respondents as we co-construct oral narratives in the context of a relationship between women who share at least one common event—the death of a young child. Then the language of the respondents will be visible in the study, and the generalizations that I build will be based on the specifics of their lived experiences and designed to be useful and accessible to people (Krieger, 1991; Westkott, 1979).

In 1985, my second child, Thomas, who had Down Syndrome, died at the age of 7 months. He had spent the last 6 weeks of his life in a university medical center undergoing and recovering from open heart surgery. The weeks were long and hard, as we watched him improve, only to slowly slip away. I cried rivers of tears at his bedside, as I gradually came to embrace the inevitable, my powerlessness as his mother to kiss the wounds and heal them.
I did more than cry. I became an activist, resisting those who said that bereaved mothers are passive and need to "get on" with their lives. Perhaps "getting on" with one's life after the death of a child involves change for mothers-in priorities, values, and behaviors. Perhaps "getting on" with one's life is best accomplished in a social milieu which is supportive of women's strengths and changing needs. While I felt supported by many people, there were some who voiced that I should "be over that by now" or "you can have another baby" or "you can't question God's will." Such words did not land softly on my ears, and they led me to theorize about other women's experiences. The admonitions of others obscured my experience and hinted that I had been evaluated and found to be lacking in my ability to cope. Is this a singular experience, or could this possibly be our experience as bereaved mothers?

As a white, middle-class, educated woman in late 20th-century America, I was not prepared on any level to bury a child. The sociohistorical context within which I live renders the death of a baby an unexpected and, thus, nonnormative experience (Walker, 1985). However, a value of the educational process for me has been learning that my own experience is not necessarily universal, coming to "decenter" from my personal biases, and recognizing that others have a great deal to teach me (Allen & Farnsworth,
1993). I entered the study ready to learn and hopeful that researcher and researched would engage in a process of learning from one another, "decentering" from personal biases toward understanding of our respective experiences, an understanding which is never finished.

In the center of my vision as I worked were the women who allowed me into their lives. I worked to provide a safe space where they would not feel judged, admonished, or evaluated—a space for conversation and reflexivity (Greene, 1988) for the purposes of constructing knowledge (Belenky et al., 1986; Thompson, 1992) which is useful (Westkott, 1979) and sensitive toward their lived experiences. Reflexivity involves talking, listening, and sharing, thus enabling people to become more aware of their own experiences and sensitive to the experiences of others (Allen & Farnsworth, 1993). Through our reflexive conversations, we collaborated, or participated together, to construct knowledge which is close to lived experience, thereby acknowledging the connection between the knower and what is known (Allen & Farnsworth, 1993; Belenky et al, 1986; Du Bois, 1983; Fonow & Cook, 1991; Thompson, 1992). During my own child's illness, I learned about heart monitors and medications and came to know the medical staff as friends and teammates. I listened to and talked with other parents who shared the hospital experience. I was never to see
again those who disappeared in the night when their own child died, those made weary by the surgery experience. I watched others happily pack to return home when their child was released from the hospital. And sadly, I saw children who had never left the hospital in their lives and never seemed to have a visitor from the outside. Observing and participating in a bitter side of life in this way, while I did not realize it at the time, led me to empathize with the multiple experiences of parents who have dying children or have experienced the death of a child. These reflections provided me with a basis for researching the experiences of others (Van Manen, 1990).

I breastfed Thomas when he was strong enough to nurse, frequently changed toys in his crib and played tapes to provide visual and auditory stimulation, and watched in disbelief as the medical staff suctioned him multiple times to revive him near the end of his life. I maintained connections with my husband and 4-1/2-year-old son 70 miles away, and we learned about being a family when times were very, very hard and unpredictable. My husband, Dave, maintained our household, mothered our older son, and tended his own career during this time. He and our son, Michael, came to the hospital as often as possible; but, by necessity, we were often separated physically.
Dave and I learned that it was very important for young siblings to be included and supported to the greatest extent possible when a child is dying in the family. We gave Michael choices: about going to the hospital, about going to the funeral home and funeral, about choosing how to say good-bye. We learned that even at his young age, he was quite capable of understanding that death was different from "going on a trip" or "sleeping." He decided to say good-bye to Thomas by drawing some pictures and placing them in the casket before the funeral. These are images and memories I carry with me that change me and impact the way I view lives and my responsibility as a researcher.

The night Thomas died, I kissed him and watched him peacefully die. Dave and I sat together holding him, somehow knowing our lives had been altered, but unable to comprehend the meanings the experience would present over time. Since his death, I have experienced bitter grief which humbles me again and again. I have read extensively about the issue of parental bereavement by authors who have been either parents, professionals, or both simultaneously. I have written about my experience as a bereaved parent (Farnsworth, 1988), and I have processed the ideas of others based on my personal understandings.

I have attended lectures, national and regional conferences, and self-help group meetings such as
Compassionate Friends and SHARE. In the self-help group meetings, I spent many hours listening to others' experiences and gradually learned how to cope with and use my own experience. I have listened to tapes and written poems to explore my own feelings and needs. I have given workshops, lectures, and guided discussions on this topic for groups of physicians, nurses, social workers, students, educators, and parents. And gradually I have learned to sit quietly by the bedsides of other children who were dying, understanding the inadequacy of words, to support their families in my position as therapist in an early intervention program for children with special needs. And I have asked myself: What authority, if any, do I have?

Acquiring a feminist consciousness, I have come to privilege women's experience as a source and justification of knowledge, and I am liberated in knowing that there are multiple realities based on personal locations of individuals (Baber & Allen, 1992; Thompson, 1992). Over time, my questions about authority have been evolving into an appreciation of constructed knowledge (Belenky et al., 1986) as my advisor and committee members have challenged me to expand the boundaries of my personal understandings. I have learned that intellectual critique is an important part of the process of generating new knowledge; for it is in critique that we come to recognize plurality of experience.
and to recognize that social life is far more contextual, far more complex than previously imagined. A constructivist approach to knowledge assumes that what is known is created by human knowers, rather than discovered (Baber & Allen, 1992; Hare-Mustin & Marecek, 1990). As human knowers with the capacity to reflect upon experience, we actively select, order, and organize our thoughts, as I have done in constructing my personal story as a bereaved mother. In this study, I set out to understand how other mothers construct their stories.

Constructed knowers weave together what they know from personal experience with what they learn from others. They move beyond academic disciplines and their methods as the sole source of authority, and reclaim themselves as sources of knowledge. The self is allowed back into the process of science. Constructed knowers consult and listen to the self (Thompson, 1992, p. 10).

My educational and personal experiences have become increasingly integrated, whole, and satisfying, as I have discovered ways to use and locate myself in my work. The complex, often contradictory, nature of bereavement that I have experienced within and as a result of connections with others seems to be linked theoretically and methodologically in contextual ways of knowing. That is, experience is
rooted in contexts, both micro and macro, short-term and long-term; and we approach holistic understanding by examining lived experience from the perspectives of individuals (Rosenblatt & Fischer, 1993; Walker, 1985). The dialectic, the tension, is that holistic understanding cannot be fully achieved.

There are many contradictions in my experience. I feel happy and productive, yet the pain of the death of my child still emerges and revisits in a powerful way from time to time unlike other deaths that I have experienced in my life. I have come to accept the pain as a teacher which pushes me to consider my purposes in life very seriously and to use my sources of knowledge in ways which create meaning and are useful and empowering to others (Du Bois, 1983; Fonow & Cook, 1991; Westkott, 1979).

For these reasons, I believe women's experiences are best viewed by using theoretical and methodological underpinnings which allow the many contexts in individual lives to be visible in the research process. Even with the best intentions as a scholar, I am aware of the ethical tensions involved when researcher's conceptualizations of people's lives do not fit their own interpretations (Stacey, 1988; 1990). Respondents have articulated the "impossibility of 'writing culture'" (Stacey, 1990, p. 274); that is, the impossibility of capturing the totality of an
individual in the process of research. For these reasons, I believe it is important to locate ourselves in our work, to acknowledge the limitations of our assertions, and to be careful with the lives of our subjects (Allen, 1989). As a feminist researcher who will question and reflect upon my work, I accept ownership for the document; yet I believe respondents have the right to read and respond to my work (Blaisure, 1992; Stacey, 1990; Thompson, 1992).

I want to make visible the lived experiences of other women who have experienced the death of a young child, to lift their experiences from obscurity and potential devaluation using the skills that my privilege has enabled me to pursue. What are other women's stories who have had the nonnormative experience of a child's death in 20th-century America? I privileged reflexivity and collaboration in the process of research and pursued an agenda to improve the lives of others who face the death of a child (Fonow & Cook, 1991). As a feminist researcher, I am also open to the possibility that other women's experiences will be different from my own and that they will undoubtedly educate me and others during the process of our collaboration (Fonow & Cook, 1991).

With my "self" acknowledged and attended to (Krieger, 1991), I began to approach other bereaved mothers, to pose questions and listen with care (Belenky et al., 1986), and
to be careful with the lives of those who allow me to gain access to their sources of knowledge (Allen, 1989).

Statement of the Problem

Moving from the personal voice to state my research problem, I am informed by an extensive parental bereavement literature approached from various theoretical and methodological perspectives. Individual perspectives, such as a psychodynamic approach, assume that unconscious processes and individual factors determine bereavement outcomes; while contextual perspectives view self in relation to multiple factors which are fluid and changeable over time. In this study, bereavement refers to mothers' experiences related to the death of a child; and bereaved refers to the person who experiences the loss (Cleiren, 1993), for purposes of this study, the mothers.

Frequently, bereaved mothers are absent in the knowledge about them. Their experiences are often described in terms of symptoms, such as depression or somatic complaints, which are believed to change little over time (Cleiren, 1993). Their grief experiences have been compared to that of fathers and other groups of individuals, such as spouses, adult children, and siblings (Zisook & Lyons, 1988). We know little about the contextual circumstances within which bereaved mothers are situated or their attempts to create meaning from their experiences.
A feminist and contextual perspective guided me to attend to bereaved mothers as individuals, to illuminate multiple contextual factors guided by theory, and to consider their experiences over time. What are mothers’ perspectives on their bereavement? How do bereaved mothers adapt and cope over time? How do culture and historical time influence their experiences? What are their thoughts, feelings, and actions? What are their stories of change?

While painful symptoms, such as guilt, shock, and loss of control appear to be part of the bereavement of mothers, how do other contextual circumstances influence them? An individual’s life is a complex tapestry, a web of interrelationships between and among many variables, such as age, race, class, gender, sexual orientation, and functional status (Baber & Allen, 1992). Focusing on measurement of symptoms and comparisons along gender lines serves to construct a certain reified picture of bereaved mothers in which mothers assume responsibility for emotionality in families (Glenn, 1987; Marshall, 1991). What do we learn when we shift the focus to mothers’ words?

Purpose of the Study

Noting the absence of mothers’ voices and contextual circumstances in traditional research, the purpose of this qualitative dissertation was to bring mothers into the discourse, into the construction of the knowledge about and
for them from a feminist perspective (Gorelick, 1991; Westkott, 1979). They were not compared to other groups. What are their constructions of experience on multiple levels?

Have mothers found the support they need to adapt to their bereavement? Are mothers sabotaged by traditional ideology which limits their access to a full range of work and family opportunities and holds them disproportionately responsible for child outcomes? Is emotionality in bereavement necessarily negative? These are some of the questions I had as I planned my study.

A feminist perspective led me to begin with the experiences of bereaved mothers in the study. A contextual examination places women’s experiences in multiple interdependent levels of the social system. Entering into reflexive conversations with bereaved mothers allowed their circumstances to become more visible and their lives more complex and more diverse.

I placed myself on the "same critical plane" with the mothers in the study (Harding, 1987), consulting and examining my own experiences, affirming the use of self, and working to forge connections with the participants (Belenky et al., 1986). The use of personal experience surrounding the death of a child informed me, as I framed questions and formulated abstractions from the data, yet worked to respect
the diversities of others (Baber & Allen, 1992; Krieger, 1991; Ruddick, 1989; Thompson, 1992).

In addition, the influence of gender ideology, such as ideology of motherhood, was of interest in this study (Baber & Allen, 1992; Chodorow & Contratto, 1982; Glenn, 1987, Thompson & Walker, 1989). The ideology of motherhood obscures the actual work of mothering which appears to give rise to distinctive ways of knowing (Ruddick, 1989). Do women themselves articulate a prescriptive ideology for their lives as "perfect mothers" (Chodorow & Contratto, 1982)?

In addition to making the experiences of the respondents visible, additional purposes of this study were to reveal what was helpful to the women after the death of a child, as well as experiences which were hurtful. Women’s experiences were valued as a source and justification of knowledge (Thompson, 1992).

Research Questions

Bereaved mothers’ lives have often been portrayed in social science literature with a focus on the event of a child’s death, resulting symptomatology, and comparisons with other bereaved individuals. The contextual nature of their bereavement experiences from their own perspectives has been a gap in the literature. Several research questions intended to broaden the focus and increase
holistic understanding of their lived experiences were central in this study. A contextual theory of family stress begins with the assumption that change or stress is constant and that coping, or adapting to stress, is always evident (Walker, 1985). The women were encouraged to reflect upon their experiences in the context of a relationship with another woman sharing a similar experience (Fonow & Cook, 1991).

The following research questions guided this study:

1. What are mothers’ stories who have had the experience of a young child’s death?

2. In what ways do mothers perceive that the death of their child has changed and continues to change them?

3. What are the applied implications of mothers’ perspectives? That is, what can the sample of women teach others (such as, health care professionals, educators, and other parents)?

4. How are respondents and researcher affected by their work together in the study?

If inquiry focuses primarily on symptomatology and comparisons with others, it is possible that bereaved mothers will come to view their own lives as problematic and hopeless. It was the specific intent of this study to increase understanding of the mothers’ lives contextually,
to explore change, and to free them to become collaborators in the construction of knowledge which can be useful to themselves and others (Westkott, 1979).

Specific attention was paid to the consumer of social science research in Research Question 3, as I gathered data from the respondents which could be given back to educators, health care professionals, and other parents in the form of oral and written reports. Thus, the study has an action orientation (Fonow & Cook, 1991). Feminist practitioners are also concerned with the empowerment of women. In sharing their stories and sources of knowledge, mothers may be empowered to teach others.
CHAPTER TWO

REVIEW OF LITERATURE

Three topics will be discussed in this chapter: the theoretical framework guiding the study, feminist perspectives on motherhood, and a review of selected bereavement literature. The contextual model of family stress (Walker, 1985) guided this project toward holistic understanding of the experience of maternal bereavement from the perspective of a sample of women, the mothers, who participated in the study. The contextual model is consistent with a constructivist paradigm of knowledge which recognizes a relationship between the knower and what is known. Feminist perspectives on motherhood are also compatible with a contextual theory of family stress. An analysis of cultural/historical contexts illuminates the ways that traditional perspectives of women in families influence women's experiences in stereotypical ways following the death of a child. In the review of bereavement literature, I will discuss a number of related studies from the wealth of literature on this topic which guided me to a feminist and contextual analysis of the experiences of bereaved mothers.
Conceptual Perspectives

The Contextual Model of Family Stress

The contextual model of family stress (Walker, 1985) supported an examination of the perspectives of individuals in families regarding the impact of stressful circumstances. Based on the literature, the death of a child is assumed to be stressful for parents (Bowlby, 1980; Cleiren, 1993; Gilbert, 1989; Lindemann, 1944; Schiff, 1977; Smart, 1992; Stinson, Lasker, Lohmann, & Toedter, 1992). But, it is not enough to assume that there is a "family" perspective that is representative of the viewpoints of all family members; the perspectives of individuals in families are important in moving toward contextual understanding (Walker, 1985). This study will attend specifically to the perspectives of mothers.

In addition, the contextual model of family stress supported an examination of the rippling effect of stress on multiple interdependent levels of the social system from the perspectives of the respondents (Walker, 1985). The individual level is concerned with the person, in this case, the mothers. What are their reflections on their bereavement experiences? The dyadic level assumes that there is a couple relationship, such as a partner or a spouse. If the mother identifies a dyadic context, how does this relationship influence her experience? Moving to a
family level leads to an understanding of the definition of family for the mother. Who is in the family? What is the nature of these relationships following the death of her child? Are they helpful or detrimental in her bereavement process?

The fourth level of the social system is the social network, comprised of friends, neighbors, co-workers, and others such as support group members with whom the mother comes in contact. Do these relationships exacerbate stress, or are they helpful? Moving to the community level requires that mothers reflect upon others more distant from everyday life--institutional representatives, such as doctors, nurses, social workers, ministers, and teachers. What has been the nature of these relationships for the respondents? Lastly, the broadest context, the cultural/historical requires the mothers to reflect upon the ideologies of the culture and the influence of history on her as an individual. What messages have they internalized about themselves as women in society? How do they think the experiences of bereaved mothers are influenced by the historical context? An analysis of the cultural/historical context guided me to consider feminist perspectives on motherhood.

A contextual theory supports an examination not only of the way mothers have been influenced by the social system,
but the ways the mothers have acted to influence the system. Thus, the theory assumes that stress is circular; mothers are both active and responsive to the social system (Walker, 1985). The individual is at the center of a complex system. At the broadest level, cultural and historical contexts place the individual mother’s experiences in the stream of history to gain understanding of the influence of the macro-level on her experiences (Walker, 1985). The holistic perspective of the contextual theory of family stress requires appropriate methodology, such as qualitative and ethnographic methods which allow the voices of respondents to be visible in the research (Rosenblatt & Fischer, 1993; Walker, 1985).

A feminist perspective, with an emphasis on reflexivity, collaboration, emotionality, and accessibility to others is appropriate for contextual study (Allen & Farnsworth, 1993; Fonow & Cook, 1991). Experiences in conducting earlier pilot interviews led me to believe that the respondents and I would enter into a connected relationship with each other in which emotionality was not avoided. In focusing upon the words of the respondents, I attempted to avoid mystifying language which may impede shared understandings. My similar lived experience as the researcher should increase the validity of the data (Acker, Barry, & Essevel, 1991), as I draw upon my own "story" as a
frame of reference. While I did not "have to go through the process of getting to know the special perspectives and nuances of meaning" of the respondents (Acker et al. 1991, p. 146), I worked to attend to diverse perspectives, seeking clarification and elaboration of the meanings of others. In addition, a feminist perspective is attentive to women's experiences in society and examines the construction of motherhood as a "social institution" (Rich, 1976).

Feminist Perspectives on Motherhood

A feminist and contextual perspective led me to examine standard sociological assumptions about gender in families and to recognize traditional families as one possibility among many (Baber & Allen, 1992). A traditional family form, also referred to as the benchmark family, consists of a heterosexual legal marriage, an instrumental male breadwinner, an expressive female homemaker, and the presence of biological children (Cheal, 1991; Parsons & Bales, 1955; Scanzoni, Polonko, Teachman, & Thompson, 1989). Motherhood is assumed to be a natural role for women in which they are idealized as "all-loving, kind, gentle, and selfless" (Andersen, 1993, p. 159). As an institution, motherhood "involves a complex set of social relations organized around specific functions. Once established, institutions also involve a system of power relations, a
division of labor, and the distribution of resources" (Andersen, 1993, p. 159).

Under traditional arrangements, men's highest achievement is found in being a "good provider" (Bernard, 1981), while women's lives carry with them the assumption of full-time homemaking and emotional caretaking of the "family" (Andersen, 1993; Glenn, 1987; Okin, 1989; Parsons & Bales, 1955). Feminist scholars have noted that rigid traditional arrangements and assumptions pattern individual lives in stereotypical ways leading women to hold disproportionate responsibility for emotionality and child outcomes (Baber & Allen, 1992; Chodorow & Contratto, 1982; Marshall, 1991; Okin, 1989; Ruddick, 1989).

In addition, a feminist analysis reveals social prescriptions which value a certain type of motherhood—"motherhood within the context of a male-female relationship" (Baber & Allen, 1992, p. 148). Mothers who do not share this social context, such as single mothers, teen mothers, disabled mothers, foster mothers, and lesbian mothers, are invisible and marginalized (Baber & Allen, 1992). Motherhood, under traditional cultural arrangements, becomes idealized and attainable only by those with middle-class privilege (Andersen, 1993; Glenn, 1987).

While stratifications based on gender became idealized in America in the 1800s with the separation of home and work
during early industrialization, a recent examination of media images and childcare manuals revealed continuing messages to women that ultimate satisfaction and fulfillment are located in marriage and motherhood (Marshall, 1991). As Baber and Allen (1992) demonstrated, the actual practice of motherhood takes place in multiple social contexts. Diverse family experiences are often invisible or marginalized in the literature.

Operating in tandem with traditional assumptions about motherhood is the current social milieu in which many parents have come to have confidence in the survival of their children (Dally, 1982). However, many families do not have access to financial and medical resources which facilitate the care of families. When a child dies, the idealization of motherhood can very rapidly turn to blame, feelings of failure, and self-reproach (Chodorow & Contratto, 1982; Dally, 1982; Ruddick, 1989). Families without access to needed resources are doubly marginalized when a child dies.

Ruddick (1989) argued that the actual practice of mothering gives rise to distinctive ways of knowing which tend to be sentimentalized and relegated to women. One need not be a biological mother or female to practice maternal thinking (Ruddick, 1989). Children place demands on mothers for preservation of their lives, nurturing in order to grow,
and guidance toward social acceptability (Ruddick, 1989). These demands give rise to distinctive ways of knowing based on loving attention and connection. Ruddick (1989) referred to this as "holding. To hold means to minimize risk and to reconcile differences rather than to sharply accentuate them" (pp. 78-79).

In summary, feminist perspectives of motherhood directed my attention to the social context within which mothers practice. The death of a child, thus situated, may be accompanied by blame and/or pathologizing on the part of the social system, as well as the belief in mothers that they have failed in their natural "roles" (Andersen, 1993). Feminist and contextual perspectives worked in tandem in this study leading to a "rethinking" of the disproportionate responsibility for children that many women assume in society and to ask broader questions—How does the social system influence the bereavement of mothers?

Review of Bereavement Literature

Related literature on bereavement is extensive and approached from a variety of theoretical frameworks which has "not led to the emergence of one 'most suitable' theory" (Cleiren, 1993, p. 30). While an exhaustive review is beyond the parameters of this study, a number of perspectives will be mentioned to illustrate that theoretical orientations differ in the "specific sources" to
which symptoms of bereavement are ascribed (Cleiren, 1993). For example, psychoanalytic theories focus on individual factors, such as unconscious processes in the course of bereavement (Lindemann, 1944); while a sociobiological approach emphasizes the role of genetic survival or propagation of genes into the next generation in bereavement reactions (Littlefield & Rushton, 1986). Phase and stage models attempt to chronologically describe reactions following a loss (Bowlby, 1969; 1980; Kubler-Ross, 1969); while cognitive theories focus on the information processing of bereaved individuals (Lazarus, 1966). Thus, theoretical orientations are diverse in their purposes and perspectives and lead to different conclusions. The contextual circumstances of bereaved mothers have been a gap in the literature.

The impact of the death of a child on parents is generally considered to be the most traumatic loss in human experience (Bernstein, Duncan, Gavin, Lindahl, & Ozonoff, 1989; Gilbert & Smart, 1992; Johansen, 1988; Schiff, 1977). Frequently, bereaved parents' experiences have been studied from individual perspectives. Often, the choice of instruments in bereavement research focuses on the measurement of psychological symptoms, such as the Beck Depression Inventory (Beck & Beck, 1988) and the Grief Experience Inventory (Sanders, Mauger, & Strong, 1976).
Mothers have been found to be more seriously affected than fathers or other comparison groups (Cleiren, 1993; Littlefield & Rushton, 1986; Miles & Demi, 1984; Sanders, 1979-1980; Zisook & Lyons, 1988). Cleiren (1993) found bereaved mothers (N=30) in the Netherlands to be the most depressed group in comparison studies of fathers, spouses, siblings, and children with little change "over time." Structured interviews were conducted in which the interviewer posed questions and asked respondents to select from pre-coded answering categories the answer that most closely reflected their experiences. Cleiren’s (1993) investigations occurred at 4 and 14 months after the death and concluded that "for the mothers in particular, grief is not likely to wear off. Depression and somatic complaints are common, and in many cases change little over time" (Cleiren, 1993, p. 267). This conclusion led me to wonder about the context of time in bereavement processes. What do we see at 4 years, 6 years, 10 years after the death of a child?

Leahy (1992) began with the assumption of depression in a comparison study of women bereaved of a spouse, child, or parent. Administering the Beck Depression Inventory Short Form, Leahy (1992) found that bereaved mothers were significantly more depressed than the other two groups with 60% of the mothers in the moderate to severe depression
range. While I do not disagree that the death of a child is
off-time and is accompanied by a sense of powerlessness and
sadness, again I wondered about the mothers’ experiences
over time, about the social system within which they were
situated, and about the nature of other people’s support or
lack of support. The average length of time since the death
in this study was 10.7 months, rendering long-term
bereavement invisible.

In a Scandinavian comparison study, Dyregrov and
Matthiesen (1987) compared mothers’ and fathers’ grief
experiences following the death of an infant, using an 18-
page questionnaire which asked questions about symptoms,
somatic complaints, and general well being. The sample was
diverse in terms of age, education, and type of infant death
(stillbirth, neonatal, and Sudden Infant Death Syndrome –
SIDS). Time since death was 1 to 4 years. Again, mothers
reported significantly more difficulty than fathers in terms
of anxiety, self-reproach, sadness, intrusive thoughts, and
sleep disturbance. The women perceived family and friends
as less supportive than did fathers. The authors concluded
that the differences between mothers and fathers could be
due to differential attachment of women to children,
different reactivity of men and women, underreporting by
men, or a different social situation (Dyregrov & Matthiesen,
1987). It is also unclear how the lengthy questionnaire might have influenced the results.

A sociobiological study frequently cited in the literature began with the assumption of a biological basis of all social behavior: "Its central tenet is that individual organisms behave so as to maximize their inclusive fitness by propagating as many of their genes as possible into the next generation" (Littlefield & Rushton, 1986, p. 797). The authors assumed that the most biologically costly event is the death of a child and investigated the grief intensity of 263 bereaved parents, using a bereavement questionnaire. Items were rated on a 7-point Likert Scale ranging from no grief (1) to total devastation (7). Several conclusions by the authors were that (a) mothers grieved more than fathers, (b) healthy children were grieved for more than unhealthy children, (c) male children were grieved for more than female children (Littlefield & Rushton, 1986, p. 801). How do we know that the Likert Scale is measuring actual differences? Again, the issue of underreporting of fathers could account for the differences. Culturally, fathers generally are expected to control their feelings and to return to work and perform as before (Stinson et al., 1992).

Bohannon (1990) studied 33 bereaved married couples using the Grief Experience Inventory (GEI) at 3 data
collection points over a one-year period. The length of time since the child's death of various causes was up to 5 years. The GEI has 135 true-false items measuring 12 scales. The scales include denial, despair, anger, guilt, social isolation, loss of control, rumination, depersonalization, somatization, death anxiety, vigor, and physical strength. Bohannon (1990) chose the GEI, because bereaved parents reported that lengthy questionnaires were intrusive during bereavement and that they did not have the energy or desire to complete them. However, the specifics of the parents she was referring to and the length of time since the death were not clear. Based on results of the GEI, Bohannon (1990) concluded that husbands grieved at lower levels of intensity than their wives and that husbands' intensity remains lower over time. She concluded that there were gender-related differences in grieving. She also found that negative feelings about the marriage seemed to diminish over time. While this study emphasized individual symptoms of grief and differences between men and women, the nature of individuals' personal and social circumstances was not visible.

Several qualitative studies have addressed the processes of couples following infant and fetal death. Gilbert (1989) focused on the dyadic context in the study of parents following infant or fetal death. Through interviews
with 27 married couples, she identified factors that led to conflict and stress in the relationship as well as factors which minimized stress as both parents adapt to "strong and frequently unfamiliar thoughts and emotions" (Gilbert, 1989, p. 605). Factors which reintroduced stability into the relationship were open and honest communication, "perception of a shared experience, sensitivity to each other's needs, flexibility...and a positive outlook" (Gilbert, 1989, p. 624). This study, guided by parents' own perspectives and words, led to an understanding of the dyadic context following the death of a child by the use of qualitative methodology.

Smart (1992) investigated the marital helping relationship following pregnancy loss and infant death using qualitative methods. The death was viewed as a stressful situation affecting both spouses, and the emotional support of spouses was explored. While a minority of the 27 couples did not provide help to each other, most couples described emotional support in their relationship as mutual. Some conflict and misunderstanding between spouses after the death are normal, as is mutual helping (Smart, 1992). Gilbert and Smart (1992) described the healing process of 27 couples using qualitative methods. As a couple plans for the birth of a child, "all plans [include] the coming of life, not the loss of life" (Gilbert & Smart, 1992, p. 179).
When those plans are not realized, women tend to feel betrayed by their bodies; while men tend to feel angry (Gilbert & Smart, 1992). These qualitative studies begin to make visible the complex experiences of bereaved couples by relying on the data of individuals to formulate conclusions.

Summary

In this chapter, the conceptual perspectives guiding this study and a review of bereavement literature have been discussed. Mothers have been found to be more seriously affected in traditional comparison studies which group the responses of mothers with others; thus, individual perspectives and contexts were not visible. Qualitative studies begin to address the importance of understanding the processes of couples following infant or fetal death, and they begin to tell a story of the experiences of bereaved couples.

The current study will add to the research record by focusing specifically upon the experiences of bereaved mothers. The feminist perspective within which I work leads me to begin with the experiences of mothers, to treat these experiences as a source and justification of knowledge, and to allow the mothers' words to be visible in the study (Thompson, 1992). I view the goal of research as the illumination of multiple perspectives, not the truth (Baber & Allen, 1992, Krieger, 1991). An additional feature of
this research is my explicit use of self as an orienting frame of reference to grasp the complexity of the experiences of others.
CHAPTER THREE

METHODOLOGY

Overview

The purpose of this study was to examine the experiences of mothers who have had a young child die between the ages of birth and 2-1/2 years. A feminist and contextual theoretical framework guided the investigation (Walker, 1985). Qualitative methodology was used to expand holistic understanding of the mothers’ lives, in contrast to studies which focus solely on the "event" of a child’s death and symptoms of grief. Qualitative research, with its emphasis on meanings and perspectives, is particularly appropriate for acquiring a "firsthand acquaintance with the sphere of life under study" (Blumer, 1969, p. 32). Based on many interactions with other bereaved mothers and my own bereavement process, these experiences are far more complex than a description of symptoms and problems. For these reasons, qualitative methodology was a useful tool in the present study.

Lived experience is not a concrete entity; rather, it is the meaning of experiences as constructed by people who reflect on them (Van Manen, 1990). This study is an attempt to place the mothers’ experiences in the center of analysis (hooks, 1984) and to examine their perspectives of multiple contexts toward approaching holistic understanding. During
in-depth interviews, I asked bereaved mothers to explore their experiences and perspectives with me in a confidential setting.

Together, we explored change on multiple levels. A feminist perspective honors women's experiences as a source and justification of knowledge with the potential for empowerment (Thompson, 1992). In addition, an explicit research strategy involved my willingness to be known to the mothers as a bereaved mother. In my initial contact with them, I stated that I was working on a graduate degree in family studies, that I have been interested in parental bereavement for many years, and that my desire to learn more stems from the fact that I, too, have experienced the death of a young child. Thus, I viewed my lived experience from a theorized position, a tool for gaining access and establishing safety, as well as a frame of reference to be consulted in the process of analytical work with the data (Acker et al., 1991). As a researcher, I recognize that my own experiences and perspectives influence all phases of the study.

A feminist perspective is concerned with the empowerment of women. I viewed the mothers as collaborators in the construction of knowledge about and for them, and their words illustrate key concepts in this document (Belenky et al., 1986; Fonow & Cook, 1991; Rosenblatt &
Fischer, 1993; Thompson, 1992; Westkott, 1979). Feminist practitioners are attentive to issues of methods, agenda, epistemology, and ethics as they conduct research (Thompson, 1992), but disagree "on whether some research methods are more feminist than others" (Thompson, 1992, p. 3). Most feminists argue that any method, qualitative or quantitative, can be feminist. Thompson (1992) pushes researchers beyond debate about "qualitative versus quantitative methods of data collection and analysis" (p. 4), encouraging us instead to be willing to reflect upon our work. I chose qualitative methodology for my work informed by issues of theoretical framework (Walker, 1985) and the complex nature of the phenomenon under study. Personal experience, as well as review of empirical literature, added to my theoretical sensitivity (Strauss & Corbin, 1990) to the phenomenon under study and provided further reflections and undergirding for the study.

While research on women documents and corrects for sexism, "research for women is consciously aimed at emancipating women and enhancing their lives" (Thompson, 1992, p. 4). As I approached the study, I consciously reflected upon "What can participation in this study do for the women, the bereaved mothers?" Thompson (1992) and Walker (1985) guided me to examine the broader social context within which women are located, to assist women in
becoming aware of themselves as active agents, and to affirm multiple ways of knowing (Baber & Allen, 1992; Belenky et al., 1986). In addition, I attempted to link their experiences to each other by providing each woman with a copy of the results. It was my hope that having access to the results will contribute to the visibility and acceptability of multiple reactions to the death of a child.

Epistemological questions are concerned with the nature of knowledge. In this study, I began with my own experiences as a bereaved mother and desired connections with respondents similarly situated, thus acknowledging personal concerns and commitments (Gergen, 1988) and knowledge based on personal constructions (Thompson, 1992). The experiences of the respondents were viewed as sources and justifications of knowledge toward illumination of multiple ways of knowing, not the truth (Baber & Allen, 1992; Thompson, 1992).

Thompson (1992) encourages feminist researchers to reflect upon whether our work is "empowering" or "exploitive." The second ethical issue Thompson (1992) addresses concerns "oppressive objectification" of the subjects of study. The actual words of respondents illustrate the study, and they were invited to contribute their feedback on the results. Their privacy was guarded by the use of pseudonyms. They were advised of the right to
pass on questions, to ask questions at any time, or to stop an interview.

Pilot Study

I interviewed 3 bereaved mothers (age 32, 34, and 75) in an earlier study using in-depth interviews. The purpose of that study was to examine the influence of the historical context on bereaved mothers' experiences. Based on those interviews, I learned that women who agree to participate in a study of this nature need time to reflect upon their experiences, to share photographs and other mementos, and to be in a comfortable location. Those interviews lasted between 2 and 3 hours and were rich with descriptive data. I left the project feeling that followup interviews would have been a valuable addition to the study. In the current study, I allowed sufficient time for interviews and incorporated the use of followup interviews to clarify details from the first interview, to gather information on prior bereavement experiences and the impact of the research process, and to provide support to the mothers who participated.

Description of the Sample

Sample Selection

Ten bereaved mothers participated in this study. The sample was delimited to mothers to avoid comparisons with others, such as fathers and siblings. The child's age at
time of death was between birth and 2-1/2 years of age. Since I was concerned with long-term bereavement experiences, the length of time since the child's death varied from 2 to 14 years prior to initiation of the study. Mothers have frequently been studied during the first year or two after the death of a child giving a picture of depression and grief that changes little over time. Other factors, such as race, class, and family structure varied to allow multiple voices and family experiences to be visible in the study.

To obtain the sample, I contacted bereavement organizations, such as SHARE and Compassionate Friends, in several Virginia locations. Hospital social workers, early intervention practitioners, ministers, funeral directors, and chaplains were additional target contacts for potential respondents, as well as the use of "snowballing" (Taylor & Bogdan, 1984). Snowballing refers to asking current respondents to recommend others for the study (Taylor & Bogdan, 1984). The question I asked the mothers to obtain additional names was: "Do you know of other mothers who might be interested in this study?"

Two women did provide a total of 3 names of those who would participate in the study. However, I had two concerns which led me to avoid using these names at this time. Upon listening to the mothers talk about the prospective
respondents, I became concerned that the sample might become homogenized, or too similar, if I pursued them. Secondly, I wanted to insure the privacy of individuals who participate in research. Wanting to be inclusive, yet striving to protect anonymity, I elected not to contact these mothers at this time. I later explained to the respondents that I had reached sample limitations for the current study and that I would keep the names and numbers they provided to call at a later date when I could add to my research.

Hospital personnel provided 4 additional names. These names were not used, because 2 of the mothers had experienced the child’s death less than one year ago, and 2 mothers lived too far away for me to pursue at the present time (4 hours driving time, each way per mother). The total number of names (17) I received and the willingness of mothers to share supported an initial conceptualization grounded in lived experience: Mothers appear open to a vehicle for remembering a child who died.

**Sample Respondents**

The Compassionate Friends organization provided 5 names; 3 of those 5 mothers had attended the support group. The SHARE Director provided 1 name. Two names were provided by an early intervention professional. Helping professionals within 2 hospitals provided the final 2 names. All 10 mothers agreed to participate when I initially called
them. The telephone conversations were relaxed; and in several cases, the women began to talk freely and at length at this time. Each conversation began with the mention of my personal experience with a child's death to establish my similar bereavement status with the mothers and discussion about the study. The calls lasted from 30-75 minutes and served to begin the rapport-building process.

All of the respondents resided in small cities or rural areas of Virginia. The 10 respondents ranged in age from 23 to 47 years. Eight women were white; 2 were black. Eight women were currently in heterosexual marriages; one had been a single parent at the time of her child's birth. One was a single parent at the time of the study, and 1 mother cohabited with the father of the child who died. Nine mothers had at least 1 living child at the time of the child's death. All of the mothers had at least 1 living child at the time of the study. Table 3.1 provides birth order information of the child who died. The age of the child at the time of death varied from 2 days to 14 months; time since death varied from 2 years to 14 years.
### TABLE 3.1 Birth Order of Deceased Child

<table>
<thead>
<tr>
<th>Mother's Name</th>
<th>Birth Order of Deceased Child</th>
</tr>
</thead>
<tbody>
<tr>
<td>Angie</td>
<td>1st of 3</td>
</tr>
<tr>
<td>Belinda</td>
<td>2nd of 3</td>
</tr>
<tr>
<td>Beth</td>
<td>5th of 6</td>
</tr>
<tr>
<td>Jan</td>
<td>2nd of 2</td>
</tr>
<tr>
<td>Jill</td>
<td>1st of 3*</td>
</tr>
<tr>
<td>Kathy</td>
<td>5th of 7**</td>
</tr>
<tr>
<td>Marie</td>
<td>4th of 5***</td>
</tr>
<tr>
<td>Terry</td>
<td>2nd of 3</td>
</tr>
<tr>
<td>Val</td>
<td>2nd of 2</td>
</tr>
<tr>
<td>Wendy</td>
<td>2nd of 3</td>
</tr>
</tbody>
</table>

*Deceased child has surviving twin.

**Kathy had 2 prior stillborn children; child in study is twin.

***Marie had 1 additional infant death in 1976.
In two cases, mothers had experienced other child losses beyond the parameters of this study, such as stillborn children or early infant deaths beyond the time parameters of the study. While they were encouraged to talk and reflect upon those losses, I told them that I would focus on the death of a child from birth to 2-1/2 years between 2 and 14 years ago for the current project. Table 3.2 summarizes information regarding the child's death.
<table>
<thead>
<tr>
<th>Mother's Name</th>
<th>Child's Name</th>
<th>Age of Child at Death</th>
<th>No. Yrs. Since Death</th>
<th>Cause of Death</th>
</tr>
</thead>
<tbody>
<tr>
<td>Angie</td>
<td>Billy</td>
<td>3 mos.</td>
<td>4.5</td>
<td>Prematurity/Respiratory</td>
</tr>
<tr>
<td>Belinda</td>
<td>Jacob</td>
<td>2 days</td>
<td>5</td>
<td>Placenta Abruption</td>
</tr>
<tr>
<td>Beth</td>
<td>Peter</td>
<td>3 mos.</td>
<td>14</td>
<td>Cardiac/Meningitis</td>
</tr>
<tr>
<td>Jan</td>
<td>Andrew</td>
<td>11 mos.</td>
<td>6.5</td>
<td>Cardiac Disease</td>
</tr>
<tr>
<td>Jill</td>
<td>Elizabeth</td>
<td>3 wks.</td>
<td>6</td>
<td>Cardiac Disease</td>
</tr>
<tr>
<td>Kathy</td>
<td>Kelley</td>
<td>3 wks.</td>
<td>7</td>
<td>Cardiac Disease</td>
</tr>
<tr>
<td>Marie</td>
<td>Tommy</td>
<td>3 mos.</td>
<td>12</td>
<td>Sudden Infant Death Syndrome</td>
</tr>
<tr>
<td>Terry</td>
<td>Jimmy</td>
<td>13 mos.</td>
<td>2</td>
<td>Birth Trauma/Respiratory</td>
</tr>
<tr>
<td>Val</td>
<td>Charlie</td>
<td>14 mos.</td>
<td>3</td>
<td>Hirschsprung's Disease</td>
</tr>
<tr>
<td>Wendy</td>
<td>Sam</td>
<td>2 yrs.</td>
<td>7</td>
<td>Sudden Accident</td>
</tr>
</tbody>
</table>
All of the women, when asked about religious identification as part of our background discussions, said they were Christians (5 Baptist, 3 Christian, 1 Lutheran, 1 Methodist). Four (4) women did not attend church on a regular basis.

Four women were currently employed outside of the home on a regular basis. One woman was unemployed due to the closing of her former business, and one mother home schools 4 of her children and manages a consignment business part-time. Two mothers had been employed, but elected to be homemakers while their children were young. Another mother was a homemaker and a student pursuing a bachelor's degree. One woman primarily identified herself as a homemaker, but also substitute teaches.

Educational backgrounds of the respondents are reflected in Table 3.3. Of the 6 mothers who had post high school education, 1 had an associate degree, 1 was pursuing a bachelor's degree, 3 had obtained bachelor's degrees, and 1 had some graduate coursework in linguistics.
<table>
<thead>
<tr>
<th>Mothers' Education</th>
<th>Completed 7 to 11 yrs.</th>
<th>High School Graduate</th>
<th>Post High School</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>1</td>
<td>3</td>
<td>6</td>
<td>10</td>
</tr>
</tbody>
</table>

Table 3.4 summarizes the narrative data for each respondent. The narratives illustrate the theme of diverse lives and multiple voices in contemporary American culture.
TABLE 3.4 Narratives of the Respondents

Angie: Angie was a 23-year-old woman whose 3-month-old son, Billy, had been born prematurely and died due to respiratory complications. She was a high school graduate and had been employed previously as a security guard. She was a Baptist, but not involved in church. She cohabited with the father of her children and 2 living children.

Belinda: Belinda was a 40-year-old woman whose 2-day-old son, Jacob, died following complications associated with placenta abruption. She was a high school graduate who was employed in an office until the business closed recently. She was active in the Baptist church. She was in a heterosexual marriage and had 2 living children.

Beth: Beth was a 42-year-old woman whose 3-month-old son, Peter, died surrounding complications associated with cardiac disease and meningitis. She held a bachelor’s degree in nursing and was pursuing a nurse midwifery certificate. She worked as a labor and delivery nurse. She was active in the Christian church and was in a heterosexual marriage with 5 living children.

Jan: Jan was a 47-year-old woman whose 11-month-old son, Andrew, who had Down Syndrome died following open heart surgery. Jan held a bachelor’s degree in sociology and was an elementary school teacher. She was an active Methodist and in a heterosexual marriage with 1 living child.

Jill: Jill was a 36-year-old woman whose 3-week-old daughter, Elizabeth, died following complications surrounding cardiac disease. She held a bachelor’s degree, worked previously in a bank, but identified herself primarily as a homemaker. She was a Lutheran with active church involvement and in a heterosexual marriage with 3 living children.
Kathy: Kathy was a 34-year-old woman whose 3-week-old daughter, Kelley, died due to cardiac disease. She had an associate degree in bookkeeping, manages a consignment business on the weekends, and home schools 4 of her children, but primarily considers herself a homemaker. She was very involved with the Christian church and was in a heterosexual marriage with 5 living children.

Marie: Marie was a 44-year-old woman whose 3-month-old son, Tommy, died due to Sudden Infant Death Syndrome (SIDS). Another infant, Sarah, had lived 3 minutes and died many years earlier. She held a bachelor's degree and had some graduate work in linguistics during missionary training. She was a substitute teacher but primarily identified herself as a homemaker. She was active in the Christian church. She was in a heterosexual marriage with 3 living children.

Terry: Terry was a 31-year-old woman whose 13-month-old son, Jimmy, died due to complications surrounding birth trauma. She was pursuing a bachelor's degree and had previously been a nurse's aide. She was a Baptist, but was not currently involved in church. She was in a heterosexual marriage with 2 living children, 1 born since Jimmy's death. She was a single parent when her first child was born.

Val: Val was a 32-year-old woman whose 14-month-old son, Charlie, died following complications associated with Hirschsprung's Disease. She was beginning to pursue her high-school equivalency diploma at the time of the study. She was employed as a nurse's aide, was Baptist, but not active in church. She was a single parent with 1 living child who was born prior to Charlie.

Wendy: Wendy was a 36-year-old woman whose 2-year-old son, Sam, died suddenly following an accident. She was a high school graduate who had recently returned to work as a cafeteria worker in an elementary school. She described herself as a Baptist with irregular church involvement and was in a heterosexual marriage with 2 living children.
Procedures

As I received the names of potential respondents, I called them and provided a brief overview of the purpose and methods of the study. I informed them that I was conducting a study of bereaved mothers' experiences based on their own words and perspectives, not surveys or tests, and that in-depth interviews would be the primary method of data collection. Qualitative interviewing involves "repeated face-to-face encounters between the researcher and [respondents] directed toward understanding [their] perspectives on their lives, experiences, or situations as expressed in their own words" (Taylor & Bogdan, 1984, p. 77). Strauss and Corbin (1990) and Walker (1985) recommend these methods to uncover individuals' experiences with complex phenomena, such as bereavement. While there is no universally accepted approach to qualitative research, "all approaches have in common a focus on meanings and other subjectivities in or about families" (Rosenblatt & Fischer, 1993, p. 168). Qualitative methodologies guided by a feminist perspective directed the search for holistic understanding of the particularly complex phenomenon of bereavement (Walker, 1985).

Respondents were informed that the study involved two interviews. The interview guides were linked to contextual theory and contained specific questions designed to focus
the women's attention to their experiences on multiple levels (See Appendix A). As part of the procedures, I informed each respondent that I am the mother of a young child who died, that I have been interested in this topic for many years, and that I will strive at all times to treat their views and perspectives with respect and confidentiality.

With mothers' agreement to participate, I asked a few general orienting questions, such as their child's name, date of birth, and date of death, to determine eligibility for participation. After ascertaining eligibility and receiving their agreement to participate, I scheduled the first interview at a mutually convenient time and place. These interviews lasted between 2 and 3 hours each. Prior to initiation of the initial interview, each respondent was given a consent form which described the study and addressed the protection of subjects (See Appendix B). They read the form, were encouraged to ask questions, and signed indicating informed consent prior to initiation of the interviews.

While an interview guide oriented the sessions, and I gave mothers a verbal overview, I did not adhere rigidly to the guides in an attempt to be respectful of individual storytelling styles. For example, some mothers gave cues that they preferred to be asked specific questions; others
seemed to enjoy following a chronological style without excessive interruption (Riessman, 1991). One mother pointed out that she recalled her experiences "like a movie camera, that's how I remember it" (Beth). Another mother stopped and waited for me to ask the next question (Angie).

Cannon, Higginbotham, and Leung (1991) have pointed to the exclusion of many people, such as minority and working class women, in much qualitative research. I was inclusive of diversity believing that multiple voices would contribute to the richness and complexity of the findings and support the feminist and contextual perspective guiding the study. I learned that bereaved mothers have much in common in terms of the desire to remember the child who died; however, other contextual circumstances, such as financial circumstances and the support of others vary and add to or minimize the stress associated with the death of a child.

The respondents were invited during the initial telephone contact to share written materials, such as journals, poems, or letters, for further illumination of their experiences (Gilgun, 1992; Rosenblatt, 1983), as well as photographs or other mementos which might facilitate discussion and be illustrative in the data collection process. While this was not required as a formal part of the interview, mothers shared and talked about numerous materials they valued. These mementos provided richly to my
understanding of their experiences and were coded during data analysis. In essence, mementos seemed to provide physical evidence of the child’s existence and were important to the construction of memories for the mothers.

The second interview was a followup approximately 1 month after the initial interview. The purpose of these interviews was to gather information on additional contexts influencing the mothers’ experiences; for example, since the first interview, they may have recalled other experiences they wished to share. It was also an opportunity for me to ask about other bereavement experiences they had had. Ideas from the first interview could be elaborated on at this time. This interview provided an opportunity for me to respond to their questions and to thank them for their participation. I also sought feedback about the research process. How did the process affect them? This question yielded data that was analyzed as a separate coding category.

Each mother was given a small gift during this interview to thank her for her contribution. Two of the mothers sent cards to me. One mother (Belinda) mentioned that she would like to meet the other mothers at some point. A lunch was scheduled for respondents who were interested in participating.
I invited the mothers to read and respond to the Results chapter. They reported being moved by reading the words of the other mothers. Jan was "brought to tears," and Wendy "could relate to every one of those other moms." Jill said, "I read the draft with tears flowing down my cheeks, not just for my dear Elizabeth, but for all the children." Jill asked me to include some information regarding the support of her extended family during her daughter's illness and death, as well as the sustenance that her spiritual beliefs have provided her since Elizabeth's death. These items were added to the document.

For potential longitudinal work, I asked for permission to contact respondents approximately one year after the current project is conducted. All of the mothers were willing to be contacted again.

Analysis of the Data

Interviews were audiotaped, transcribed verbatim, and analyzed using approaches articulated by Allen (1989) and Taylor and Bogdan (1984). Two copies of each transcript were made, and the originals were stored unmarked and uncut. Each transcript was identified by a code known only to the researcher. The transcripts were then read a minimum of two times prior to initial coding.

After a minimum of two readings, I began the process of open coding by writing key themes and categories in the
margins (Taylor & Bogdan, 1984). Initially, I identified 64 codes. My doctoral advisor and I met twice to discuss the coding categories, and she asked me questions that required me to justify my conceptualizations of the data. After six additional examinations of the data informed by her feedback, I reduced overlap in the codes ending up with 30 codes in 6 coding families (See Appendix C). The codes reflected the substance of the interview data in the following coding families: Talking About Myself, Remembering the Child Who Died, Reliving the Death, Living Since the Death, Prior Death/Bereavement Experiences, and Methodological Codes.

I began the process of reading the transcripts and marking passages with code numbers. Transcripts were then cut and sorted into piles by code number. The cutting and sorting process, while lengthy, enabled me to connect with the data in new ways, to recognize overlap, to locate significant themes across respondents, and to achieve a higher level of abstraction based on a thorough and systematic examination of the data. Codes which represented the most common themes in the data are illustrated by the respondents' words in Chapter Four.

By allowing the length of time since the child's death to vary from 2 to 14 years, respondents were able to reflect upon their perceptions of the ways the death had changed
them. These changes were of particular importance to the feminist and contextual perspective guiding the study since women’s lives tend to be viewed in terms of symptoms and problems after the death of a child. What changes over time may be occurring that are not visible in traditional measures of grief? Chapter Four provides a discussion of the results of the study.

Summary

In summary, qualitative methodology informed by a feminist perspective provided a valuable link to the contextual study of mothers’ bereavement experiences after the death of a young child. These methods were chosen to further the feminist goals of empowerment and inclusivity by allowing respondents’ verbal accounts to be prominent in the study.
CHAPTER FOUR

RESULTS

This study is based upon in-depth interviews with 10 bereaved mothers who share the common experience of the death of a young child between birth and 2-1/2 years of age. Believing that there is much more complexity in bereaved mothers' lives than the frequently articulated problems of depression and somatic complaints (Cleiren, 1993), I attempted to broaden the research focus in this study to attend to the multiple contexts within which mothers experience the death of a child, to view the women as creators of knowledge about themselves, and to produce social science which is nonoppressive to them (Thompson, 1992).

I located a sample of women for whom the death of a child had occurred from 2 to 14 years prior to the onset of the study desiring to learn about mothers' perspectives of their experiences over time, in contrast with a large body of research which has focused on the initial year or two following the death of a child. The mothers described cognitive, emotional, behavioral, and spiritual changes that are not captured in traditional research. They identified sources of help that were meaningful to them after the death of their children. I found it valuable to converse with them, to learn from them, and to share in the complexities
of an experience that is generally obscured in everyday life. Yet it is everpresent. I recognize that our work together is but one representation of a complex and everchanging phenomenon. The qualitative research design, with an emphasis on respondents' actual words and reflections, seemed an appropriate methodological basis to capture the complex meanings of bereavement for the mothers.

Recognizing the diversities of families in late 20th-century America, I wanted to include mothers of various backgrounds and family structures in the study (Baber & Allen, 1992; Cheal, 1991). Listening to women's diverse perspectives and experiences furthered my own respect and empathy for their strengths and concerns and guided me to further "decenter" from my own perspectives to respect the knowledge of others (Allen & Farnsworth, 1993).

The interviews took place in respondents' homes during the winter of 1993-1994, a winter besieged by ice and snow storms, school and business closings, and widespread power outages in Virginia, the state of residence of the respondents. These unexpected contextual circumstances demonstrated vividly that the lives of bereaved mothers are filled with the same frustrations that occupy other lives. These mothers continue to be mothers, partners, employees, students, volunteers, and citizens. These lives, like other lives, are whole and complex; yet they have been touched by
a statistically unlikely event. A tension within which I worked was an awareness of the similarities and differences of bereaved mothers’ lives to the lives of mothers not touched by the death of a child. My goal was to take seriously the impact of bereavement on the mothers, yet not marginalize the mothers for their diversity.

Listening to the tapes and examining the transcripts many times led me to articulate a number of themes that were common in the data. Mothers remember the children who die regardless of the circumstances of the death; furthermore, they do not want to forget their children. When speaking about their children in a safe setting, they speak with authority and rich detail. Their words were clear, powerful, and interesting to me. As a feminist researcher, I wanted to be careful with the lives of those who participated in the study, and I asked each mother to read and respond to a copy of the results as discussed in Chapter 3. Based on thorough examination of the transcript data and obtaining feedback from my doctoral advisor, I identified 6 coding families in the data: Talking About Myself, Remembering the Child Who Died, Reliving the Death, Living Since the Death, Prior Death/Bereavement Experiences, and Methodological Codes. All 6 coding families will now be described.
Talking About Myself

At the beginning of the initial interviews, I asked each mother to talk in general about her life: when and where she was born, where her parents are now, her relationships with siblings, her education, her work identification, religious/spiritual identification, who is in her family now, and any health concerns she has. These topics served to acclimate both of us to the interview situation and to give me an overview of each woman's past and current experiences. These discussions also established firmly that the women were authors of their own experiences and that I was a respectful listener and conversational guide. In Chapter 3, Table 3.4 Narratives of the Respondents provides a general overview of these background discussions. This information helped me to orient to each mother's contextual circumstances, such as couple relationships, living children, extended family support systems, social and community support, and perspectives on mothering. When respondents referred back to these contexts during the course of the interviews, I had an orienting framework within which to understand their perspectives and did not have to interrupt them to ask them to identify people, circumstances, work, and so on. In short, background discussions helped me "get to know" each respondent and to establish a respectful tone for the
interview. Based on these developing connections, I began to feel accountable to each woman and wanted to provide an account that is as close to lived experience as possible.

Remembering the Child Who Died

When I asked the mothers to tell me about the child who died, they spoke eloquently about their memories. Examining the data, I identified codes that reflected the content of these discussions. They recalled details of the child’s birth and interactions with others, such as medical staff, fathers, and the needs/concerns of other children in the family. Sharing mementos of the child with me, I began to see the importance of memories in the mothers’ ongoing lives and to understand the void left after the death, the loss of hopes and dreams for the child. Speaking candidly about their perspectives allowed contextual layers, such as individual reactions, reactions of fathers/partners, family, social, and community responses, to be visible to me.

Birth Recollections

Mothers recalled numerous details of their child’s birth, such as time, medical staff who were helpful or upsetting, and frequently a sense of or very real evidence that their babies were in trouble medically. Birth memories appear to be an important construction of the life of a child, memories that may be painful, yet important to mothers. The narratives below represent some of the initial
experiences and concerns of the mothers when their children were born.

Jill, as a first-time mother, recalled having a vague sense of trouble after the birth of her twin daughters:

I was awake for the C-Section, and I saw Elizabeth. They [medical staff] were in a hurry there, take the first one, grab the second one, and Dr. T. told me that everything was fine. No problems. They were fine, and I went to my room, and they brought them in around 4. Actually, this is something I've never told anybody, but I was holding one of the twins, at the time Twin A and Twin B. I knew we were going to name one of them Lisa, and uh, I do remember seeing a little blue, right here [pointing to corner of lip], on one of them's lips, and I thought, I wonder if that's normal? I didn't say anything, thought maybe I'm just seeing it. I was in a lot of pain, on a lot of drugs. And, uh, we played with them all evening. [The next morning], Dr. T. came in about 7:30...and told me that she [Elizabeth] had a murmur and that they would probably have to send her to [university medical center]. (Jill)

Beth recalled the birth of her fifth baby, the most difficult birth she had experienced:

I remember the planning, trying to find a doctor in the area that would allow my children to come and see me, not be present for the birth particularly, but come and see me in the hospital. Someone who would do a natural birth, not use a lot of drugs, and someone who would attempt to have no episiotomy, those sorts of things....I had terrible back labor....I was very uncomfortable....And I was concerned....At times, I was really tired and discouraged and wanted a C-Section. And that's not typical for me, but I remember the birth being extremely difficult. Afterwards I had great concern about the appearance of the baby; but...people...sort of passed that off....all through the week, I kept saying, 'There's something wrong with my baby, there's something wrong with my baby,' partly because the baby wouldn't nurse....I just felt that something was drastically wrong. (Beth)
Terry remembered the birth of Jimmy as "the most frightening experience in my life." At 39 weeks in the pregnancy, she went to the hospital, because she no longer felt fetal movement:

Dr. D. was on call, and when I got there, the baby's heartbeat was real strong, but they couldn't get him stimulated to move, and he [physician] said, 'Well, you're so close to the due date, let's just go ahead and get the baby out of there.' While he was on the phone with the anesthesiologist, the nurse yelled, 'I want her on the table now!' I had no anesthesia, and he cut me while I was awake. The nurses were holding my head and my arms, and I was screaming, 'Knock me out!...when I woke up, my husband was there, and he was trying to tell me that the baby had had a heart attack [voice breaking]....They transferred him to [university medical center] to put in a gastrostomy tube, because he had no suck at all. He was on oxygen, he was on the ventilator for a long time; then he had a collapsed lung and pneumonia. (Terry)

Jan remembered Andrew's birth following a difficult time conceiving:

I had had an epidural, so it was so easy as far as I was concerned. I knew everything to do, I had read all the books, I did all the breathing...and when Andrew was born, I had made the decision before he was born that I would have my tubes tied, and when he was born, immediately the doctor said to me, 'Jan, he looks fine.' [I learned later that she'd had the tubal ligation at this time.] I saw him. I held him....things are really fuzzy for me for a number of hours....he went into some real difficulty....I knew, you know, in my heart I knew it wasn't anything that, you know, I knew it was serious....they told me he needed to be in an Intensive Care Nursery....They had him ready, he was in an ICU Unit, I mean a portable unit, and in just no time at all, in a few minutes, he was going to be transported to [another hospital]....and so I checked out of the hospital with no baby, I'll never forget that, I'll never forget leaving there that day without a baby. (Jan)
Belinda was at home alone when she began having labor pains. After locating her husband and daughter, they drove her to the hospital:

I was really frightened. They checked me in quickly, and uh, they had to do a C-Section, and you know, I didn’t really feel anything, they put me out really quick, so I didn’t really feel or hear anything. When I came to, they told me my baby was in serious condition....I had a placenta abruption, so he went without oxygen for a while, so that caused him to have severe brain damage....when I went in to see him, I was just devastated. They had him hooked to all this machinery and everything. I didn’t understand all that stuff. (Belinda)

Birth recollections were vivid and powerful memories for the respondents; as they shared their stories, they seemed to remember deeply. I heard the anguish in their voices and saw their tear-stained faces. As they spoke, I also became involved, touched, as I recalled birth recollections of my child who died. My own journal recollection follows:

His entrance into the world seemed quick and uncomplicated....I noticed that Thomas was quiet and less active than Michael had been at birth. I was not concerned--individual differences only, I reasoned.... Having 2 wonderful boys was going to be great....Little did I know that this was the calm before the storm.... the obstetrician came in and somberly said, ‘We need to talk.’....Immediately, horror and panic rose in my chest....‘Your baby looks a little funny.’ Alone, I died a little inside....‘Your baby has some of the characteristics associated with Down Syndrome.’ (Liz) .

Instead of detracting from my awareness and understanding, these memories connected me to the points the mothers were making and augmented my understanding. I
remembered the fear, the terror, the loneliness—the gut-wrenching recognition—"something is wrong with my baby!"

One by one, hopes and dreams begin to collapse, and mothers were deeply connected to these realities.

**Interactions with Medical Staff**

Interactions with medical staff were very positive or very negative. Mothers recalled details of interactions with medical staff and other professionals that provide useful information to professionals who address the needs of families faced with the serious illness and death of a child. Mothers in this study reported a desire to have their needs for information and support addressed by professionals in a caring, responsive manner.

Jan recalled the moments when she was first informed of her child's disability by a physician. These brief moments made a lasting impression on her:

He sat down at the foot of my bed and told me....First, he told me that he had a heart defect...but he was trying to be real upbeat about it, and I just immediately broke down and just sobbed and sobbed and sobbed and sobbed, and he looked at me and said, 'If you don't be quiet, I cannot tell you what's going on.'...He became very uncomfortable and agitated, because I was so upset, and he did not know how to deal with it. He did not know how to handle it. Whereas if he had just let me get some of that emotion out for just a few minutes, then I would have been able to go on and talk to him more, but I have to say that had a lasting effect on me for a long time....I was very hurt over it....And then he said, 'I haven't told you the worst part yet.' He said, 'Your child has Down Syndrome.' And at that point, I really did think that I was just going to absolutely die. (Jan)
Val recalled not feeling heard or taken seriously by physicians when she felt something was wrong with Charlie:

I'd carry him back and forth to the doctor, back and forth, and they seemed to tell me it was normal, which in some cases, I guess it is. You know they'd try to get him on the right kind of milk and all that...and anyway this went on. Doctors here just basically told me that it was normal for him to go 4-5 days without using the bathroom...I'd sit up all night with him screaming. (Val)

It was only after Charlie's death that an autopsy revealed that Charlie had Hirschsprung's Disease—a disease of the colon—which could have been treated if diagnosed.

Beth, at the university medical center while her husband was at home 70 miles away with the other children, recalled a conversation with the surgeon when she was trying to make a decision about heart surgery for Peter:

I thought he was a cocky person, and I said, 'Well, are you the best person to do the job?' And I don't think I understood the importance, the magnitude like I do now of the problems. He said, 'Well, it's like flying Eastern Airlines or United.' I'll never forget that. I thought it was so stupid. And I said, 'Well, I don't care who you're flying for as long as you're the best person flying.' (Beth)

She also felt a lack of support from the pediatricians when she reluctantly made the decision for Peter to be on a respirator, because her husband, out of town, felt Peter should receive this support:

I felt I had to, because he [her husband] wasn't there; he wasn't seeing what I was seeing. The toughest thing for me at that point was the lack of support from the pediatricians...he was like, 'Well, you don't want to do that, so why are you doing it?' (Beth)
Nursing staff were not always in touch with the mothers' stress of dealing with a child's chronic illness who do not get respite from the intense care:

I have a problem with the nurses on the pediatric unit, because whenever Jimmy got sick and had to go to the hospital, the doctors would tell me, use this time to rest. At that time, we didn't have any help at home, they'd say, 'Go home, rest.' The nurses would make you feel you had to be there all the time. (Terry)

In contrast, other medical professionals had a gift for responding well to the emotional needs of the mothers:

I'll never forget Dr. T. examining him. He examined him exactly the way he would have examined a live baby. The SAME way, I remember noting that. (Marie)

This same pediatrician, himself a bereaved parent, gave Marie the gift of memory of her first infant's death many years earlier:

I said, 'Dr. T., do you remember the first child that I lost?' And he said, 'Yes, I do. It was a little girl, wasn't it?' And I said, 'Yes.' He said, 'You were teaching school then, weren't you?' And he said, 'Your principal and his wife brought you in. It was on a Tuesday, wasn't it?' And I said, 'Dr. T., how can you remember all these things?' I'll never forget this. He looked at me and said, 'Ms. J., they're the ones we remember, the ones we lose.' (Marie)

Jill commented on the humanity of one of the cardiologists when she took her other twin daughter for periodic checkups several years after her daughter's death:

Finally, finally, Dr. R. became human and said, 'I don't know what you've gone through, cause I've never gone through it; but I do know if something were to happen to one of my children, I don't know if I could live through it.' And I thought, 'She's human. She's
not a doctor, she’s human.’ And that was the first
time I’d seen a human side to her. (Jill)

Beth recalled a simple action of one of the nurses
which has been helpful to her:

I don’t remember her name; but she was really sweet.
She had the foresight to take a 3 X 5 card, and this is
weird what you remember, but I have it in my recipe
box, and as the doctor was talking, she wrote down
everything he said, and I have it in my recipe box [14
years later]. It tells me exactly what was wrong with
that baby. (Beth)

The above narratives reflect common desires among
mothers with critically ill and dying children when they
interact with medical professionals: Come down, come down,
just briefly, acknowledge the pain, the suffering. Accept
these powerful emotions as real and valid. Accept. Respect
the knowledge that mothers have. Then we can begin to work
as partners for the most appropriate treatment of the child.

Fathers’ Reactions/Interactions

Bereaved mothers in the study talked about dyadic, or
couple, relationships during our interviews. In 8
instances, the couple relationship involved marital
relationships with the biological father of the child who
died. One biological father cohabited with the mother. Val
spoke about the man to whom she was married at the time of
Charlie’s death and also about Charlie’s biological father,
who was in treatment in another state for drug and alcohol
addiction.
A common theme appeared in the data analysis, as I studied the data regarding the couple context. From the women's perspectives, the men tended to be primarily task-oriented in the forms of support they provided to them. While this form of support was appreciated by the mothers, they frequently spoke about not knowing how the men felt about the child's death, almost a longing to have access to men's emotional lives. Once the child died, men tended to portray a "get on with life" response. For the mothers, this was not so easy to accomplish. While mothers were also task-oriented, they wanted to talk about the child, to locate a place in the present for the memories, and to learn from the child's life.

Jill recalled her husband, Bill, gathering up things for her shortly after she gave birth to their twin daughters. When he learned that one of the babies was being transported to the regional university medical center, he ran home, gathered clothes, and raced to follow the ambulance to the hospital so he could be involved with the baby's treatment.

Similarly, Jan's husband, Ben, stayed calm, in control, and made calls to friends and relatives from the hospital when they were told that Andrew had Down Syndrome. Yet she said, "I know he was absolutely just completely torn up inside." Jan described the difficulty they had had in
getting pregnant, their happiness over becoming parents, and their persistence in having a second child. When Andrew came home from the hospital, Ben had been very involved with his care; they took turns inserting the feeding tube and caring for him.

Angie spoke of her partner, William:

He was there for me; but he has a hard time, he holds back his feelings. He really didn’t know what to say to me. (Angie)

Similar to the other fathers, Angie said he was task-oriented in his responses and took care of all the funeral arrangements.

Beth recalled that her husband, Richard, worked full-time and was in school full-time during Peter’s illness.

His energy was very focused, and she said:

I don’t think he was supportive; he didn’t show a lot of emotion... one night I needed to go back up [to the hospital 70 miles away], and he didn’t understand that. He said, ‘Alright, I’ll drive you up in the morning.’ And I said, ‘No.’ It was like 5 o’clock at night. I said, ‘I need to go NOW, SOON, TONIGHT.’ And he still didn’t understand. (Beth)

She called a woman friend who came to drive her to the hospital that night. With 4 young children at home, household labor was an added source of strain to her:

And I was exhausted and that kind of continued, and it caused trouble here at home, because Richard didn’t understand when I came back home [from the hospital], you know; I would try to put things together, try to be home, maybe clean a little bit, pack, and get the laundry ready, and go back up. (Beth)
Kathy referred to her husband, Randy, as a "quiet person, he doesn't really express his emotions." Yet she also recalled that he was supportive of her by attending Compassionate Friends support group meetings and going with her to doctor's appointments. As a minister, she said he compared himself to David in the Bible, "you know; it's done, it's over, my grieving is done, now move on." With the stillborn babies' deaths they had experienced previously, Kathy said, "his life went on." When the third baby, Kelley, a twin, died, he was very angry; because she was going to be "his" baby when they came home, while Kathy was going to provide the bulk of care for the other twin:

He would go up there [regional hospital] and do things, and there was always this thing that Kelley was his baby, and Kim was mine [weeping], like when we brought her home, he was going to be the one to rock her...but I've never really seen him cry over it. (Kathy)

At the time of Charlie's death, Val was married to Dave, not Charlie's biological father, but "the only Daddy Charlie ever knew." They have since divorced, and Val attributed the divorce to the stress of Charlie's death. She recalled:

A week after Charlie died, he was like 'Are you going back to work? Are you going back to work?' Well, I felt like he was pushing me in a corner, smothering me...he just couldn't understand anything like that [her emotions], so he just took it upon himself to start running, you know, instead of sitting there looking at me crying, or trying to go get help with me. I asked him to go get therapy with me. He wouldn't go, so he just started running and drinking with a bunch of
boys...staying out all night and it just ended our marriage. (Val)

The narratives above illustrate some of the complexity of dyadic relationships during a child’s illness and after the death. While task support was a strength of the men, the mothers seemed to want emotional comfort that often was not found in the couple relationship. Eight current marriages had experienced the child’s death, and 6 women voiced increased commitment to the couple relationship. Some women seemed to grow in compassion for their partners, as evidenced by Belinda’s words:

I came to realize that he was going through something, too. It was not just me. (Belinda)

But this growth of compassion seems to be a process, a process that is captured when talking to mothers long after the death when they can reflect upon growth and change in the couple relationship.

Other Children’s Needs/Concerns

During the illness and death of a child, mothers had concerns for the other children in the family, often feeling that these children had unintentionally been neglected during the stress and strain of managing an illness and dealing with a child’s death. Beth said that strangers took care of her 4 young children during Peter’s illness, often the children were separated from each other, and that:
Strangers did my laundry, I couldn't thank anybody, because I don't know who did it. (Beth)

Belinda was concerned for her 13 year-old daughter who was "waiting for that baby" and was devastated when he died. Jill was understandably frightened that Elizabeth's twin might also have a serious heart defect and insisted that she be followed, even though the doctors said she was fine. Terry felt that her older son was neglected, not intentionally, but:

None of his friends' parents would let them come over, because they thought it would be a burden having another child here with Jimmy being so sick. (Terry)

Marie, who lived on a farm with numerous relatives and friends close by for support, was able to include her 3 and 4 year old very well after Tommy's death from SIDS. These living children, with their matter-of-fact questions, were a comfort to her:

They were there as much as possible during his pregnancy and birth, why not his death? That is life. They need to know these things....over the next few months, they'd ask, 'Wonder who's feeding Tommy now? Changing his diapers?' You hear that and you cry, but it was helpful; because I realized that Tommy was very much a part of our lives, he was very much remembered by them, and very much a real person. That is what we wanted. (Marie)

Mothers had concern for their other children, but managing all children's care and needs all the time was impossible. Clearly, those with the support of partners, families, and friends benefitted from these additional
support systems. The mothers' voices vividly educate those who want to provide help to families. The message they seemed to offer was: Support our whole family. Help us care for our children. We need both emotional and task-oriented supports as we face these tragic experiences. Those who define "family" flexibly and recognize the permeable boundaries of family are those who lend a hand, cook, drive, invite children over, and take them to movies or a playground. Again, I consulted myself and remembered those friends and family members who provided care and support to us by doing these things when our child was in the hospital and Michael was 4 years old.

Mementos

When a young child dies, families have not had a long time to get to know the child, to watch the child grow, and to interact with the developing personality of the child. Yet, for the mothers who participated in this study, memories of the child live on. How do mothers construct memories of little ones whose lives were so short? In common for all the mothers in the study was the role of mementos in affirming the special place of the child in their lives. During our initial telephone contact, I had mentioned that they were free to show me things, such as photos and books, if they would like; but I did not make this a formal part of the interview. During the course of
the interviews, all of the mothers initiated some discussion of mementos, either by showing me the items or telling me about the importance of such items to them. They shared baby books, photographs, birth certificates, locks of hair, blankets, crocheted caps, cards, and, in Marie’s case, a poem written by her husband, a tribute to the very special place of the child who died in their family. Other mothers mentioned writing letters to the child who died or writing in journals wanting to keep details of the child’s life fresh. One mother, Terry, asked me if she could bring out a videotape of her child in the hospital and after his death in the funeral home. We watched portions of the tape together; it was a powerful memento of Jimmy’s life and death.

Belinda, whose baby died at 2 days of age, said:

This little blanket here, I slept, this is what they had him covered with, so I slept with this thing for I know about a year....This was as close as I could get to him. (Belinda)

Recognizing the importance photographs of her baby would hold for her over time, Belinda recalled:

So I asked her [the nurse], can you still take photographs? I want pictures as if, like they were born and living, kind of like they do....I got pictures. I can’t keep a face in my mind, you know....I think it makes the situation better to have something to look back on. (Belinda)

Jill told me about a chest that her husband had given her the year after their baby’s death that she cherishes:
I put all her stuff in it the year after she died, blankets, hair, I find myself pulling it out, matching it up with Lisa’s [surviving twin]. I could not tell that to anybody else, unless you’ve been through that and know how important that is. If this house caught on fire, besides getting my children out, I don’t care what, I’d throw the chest out the back window to make sure I got those things out, because it would kill me to lose them. I’ve got very few pictures of her. I’ve had copies made and have them scattered throughout. So if my house catches on fire, I still have those pictures. It’s almost a desperate feeling that you have, and you’ve got to make sure that nothing happens to those....I mean I’ll never forget her in my mind, but I still like to be able to look; and these are ones when she was first born and she looked so good, instead of all that apparatus [IVs, heart monitor, oxygen, etc.]. (Jill)

Val told me about the Glow Worm she had purchased for Charlie for Christmas the year he died:

That’s my little security...it stays on the back of my bed, and just about every night before I go to bed, I’ll reach up and push it, and you know, it glows up and it just makes me feel better. (Val)

Again and again, mothers referred to the mementos and the importance they held in their ongoing lives. I became aware that while the mementos serve a purpose in constructing memories, they are also mothers’ active strategies of providing help and comfort to themselves, learning about what they need to cope, and becoming more aware of the needs and coping styles of others.

Reliving the Death

Each mother, as the interviews unfolded, seemed to be almost "reliving" the child’s death as she wove the details of her perceptions and experiences during that time. The
mothers recalled time, places, events, noteworthy reactions of other people, and sometime clothing, blankets, or weather conditions. As they did this, their conversation flowed without hesitation, frequently accompanied by a release of tears. Feeling the intensity they had carefully crafted, feeling briefly "inside" their experiences, and deeply focused on their detailed descriptions, I often wept with them. Whether the woman had been bereaved 2 years or 14 years, the "reliving" seemed to occur leading me to conclude that it occurs a lifetime. Kalish (1985) has stated that people struggle to find an "adequate story of the dying and death" (p. 188), and the respondents seemed to share their stories fully and willingly, albeit painfully. Beth said, "It’s almost like a movie, and that’s the way I remember it."

Details of the Death

One mother, Wendy, recalled the sudden, accidental death of her 2-year old son, Sam, 7 years ago in this way:

Well, I know that day we had bought the house, signed on it, gone to the bank and did all the paperwork, and we had come back home and was packing everything and getting ready. We’d just discussed that day that we hadn’t had his picture made for a long time; we planned on having his picture made that week and all, so we were getting everything ready, we were all excited about it. Al, my husband, had loaded up 2 trucks getting them ready to go, and I was standing out on the edge of the road talking to a lady from down the road. Al thought he was with me, and I thought he was in the truck with Al. And I was standing there talking to her and all of a sudden I heard this lady, somebody’s voice
holler, and I turned around, and I stood there and I saw the whole thing. I saw him...he had evidently been trying to climb up on the tailgate of the truck and when Al went to back up, he fell off, and Al backed up over top of him; and I screamed for him to stop and he didn’t know...so he pulled up over him again a second time. I went into shock. I fell out on the ground, I don’t know how many times, and I was just screaming. (Wendy)

Another mother, Jan, whose son died following open-heart surgery at the age of 11 months recalled his death in this way:

He looked good, he looked...for some reason, he looked like he had grown up. He looked like he had changed from a little baby to a little boy. They had his hair all fixed and, of course, they had explained to us everything about how he would have to be completely quiet, that they would have to keep him totally sedated for those first few days. We would just go in and, I thought, again, it was more than I could stand just to see it, but we talked to him and did everything we could, you know...you feel so helpless, you feel like you’re not doing anything. We saw him that evening, we saw him that morning....We left the hospital at about 11 o’clock [a.m.], we stayed through the visiting time. We thought things were really looking up...[then] we left the hospital and went over to the corner. We were just going to get something to drink. I was looking through the shops; in fact, I bought him a little Virginia shirt....I came out of the store and looked up, and there was a nurse and another person, the chaplain, walking toward me, and I just couldn’t believe it. She said, ‘You’ve got to come back to the hospital right now.’...I knew, I mean, I knew for sure, and I looked right at her and I said, ‘He died.’...I just began to sob, because I knew for sure. (Jan)

Terry remembered the death of her 13-month old child, Jimmy, 2 years ago at home:

I was here by myself, [my other son] was at his Dad’s, [my husband] was at work. It was the day I was supposed to get him christened, the chaplain from
hospice was coming to christen him....And he died before she ever got here. (Terry)

The pediatrician had told Terry that Jimmy would keep getting pneumonia, that it could be treated, but the end result would be the same--death. She described her decisions to guide him lovingly toward death:

So I decided to withhold antibiotics the last time he got sick, because [with emotion] I couldn't stand to watch him suffer anymore. And I cut all the monitors off and tried to help him be as comfortable as possible. I discontinued the oxygen....He was on an apnea monitor, oximeter, oxygen; at the end, the reason I discontinued the oxygen was he was on the highest liters of oxygen a baby could be on, and it still wasn't bringing his oxygen saturations up; so why have him uncomfortable with that amount of oxygen blowing in when it wasn't doing him any good. He had seizures all the time, he was on seizure medication. (Terry)

Marie's husband woke up early one morning to get ready for work and went in to check on the baby:

Something told him that something was wrong, and he went over and touched him and his head was cool [long pause, weeping silently]. Anyway, he picked him up and realized that he was dead, and he called me. I remember that was the worst part, and I think that is my worst memory now, not of Tommy, but of Russ. The anguish in his face....He said later he remembered being so horrified, you know, of his death, but also horrified that he had to tell me. (Marie)

This passage revealed a compassion for the pain of the partners toward one another, a sense of care that was indicated in the words of 6 of the mothers.

Mothers' Thoughts, Feelings, Actions

After their child's death, mothers' thoughts, feelings, and actions were strong and sometime unexpected. The
experiences of 7 mothers reveal some of the intensity they experienced in the wake of their children’s deaths:

They told me that Sam didn’t make it, and I collapsed right there on the floor in the emergency room and went into some kind of, I was screaming and screaming. (Wendy)

I don’t think we’ve been taught that this is normal.... We want people to put it under, not think about it anymore, and I’m finding that that’s not so....This was a person who had a very short life; and it’s hard for me sometime, you know, it’s hard still when someone asks, ’How many children do you have? ’ (Beth)

[When she was so sick, I remember thinking] I don’t know if I can do this much longer, this up and down and up and down. [After she died] I remember at first, it was like all the time, you know [thinking about her]; I would just do crazy things, like leave my groceries at the grocery store or just do things like that. Then, in time, you learn to cope with the everyday lifestyle, you have to if you have other children, because they need you, too. (Jill)

He got sicker; they took us into some room, and I was kind of sick, too, from having the baby. I was not very strong, it took all the energy away from me....And the day that we went into that little room they just passed him around, and we sort of said our good-byes to him. (Belinda)

I had been a Christian, at that time for about 10 or 11 years. We had been through some things before. Well, the first child’s death. And because of the first child’s death, I knew what was coming. I knew the grief, the heartache, and I was very angry at God that first death....[I remember thinking] God, you have got to show me; the circumstances are screaming calamity at me, but you’ve got to show me if this is for my welfare, because I CANNOT do this again on my own. (Marie)

When we got in that night, I literally tore the trailer apart. I mean I screamed, I hollered....I got rid of the baby bed and everything before they even buried him, and I kind of regret that in a way, because I needed that after all of this was over with to be some
kind of security, to give me time to sit down and really appreciate and go through his things. (Val)

Shortly after her son's death, Jan and her family went to her sister's home near the university medical center. Her thoughts, feelings, and actions paint a picture which can be described in one word--inconsolable:

I couldn't even make myself get up. In fact, I stayed on my sister's living room couch, her living room couch. I mean it was, you know, the most formal room in her house. It wasn't like I was in a bed or anything, but I could not move. They would come and try to get me to eat. They would try to talk to me. I didn't even really want to talk to them. I was so hurt, and I knew they were so hurt....Now it doesn't even necessarily seem rational or anything, but I remember asking the nurse, 'Where is his life?' I said, 'This is his body, but I want to know where his life is.' And she, of course, said, 'We don't know.' (Jan)

While mothers' thoughts, feelings, and actions were most intense shortly after their child's death, all reported that "it gets better with time." Over time, you learn "where your tank is" (Beth); but there are still questions and circumstances that are difficult for individuals, questions like, "How many children do you have?"

Funerals/Memorial Services

Funerals and memorial services were both positive and negative for the mothers in this study. They offered an opportunity to publicly acknowledge and grieve the child's death; but they were also the source of financial stress for
some and anger for others who felt that some people came out of curiosity, not genuine concern for the family. Mothers spoke candidly about the harsh reality of selecting tiny caskets, a marker of a statistically unexpected death at this time in history.

Marie recalled making decisions about the funeral following her infant son’s death from Sudden Infant Death Syndrome (SIDS) at 3 months of age. Her words revealed a very proactive, family involvement with the burial:

My cousin...is the owner of [a funeral home], so naturally, that’s where we went....he was just as kind and good as he could be, and I remember going down there, and I remember that they only had one baby coffin--tiny baby coffin. And I did not like it. It was too ornate....I may have said I would like something plain, and he said, ‘Well, Marie, we’ve got, normally, we don’t use a vault for an infant like this. There’s a wooden crate that it came in.’....Anyway, we looked at that and it was just a plain pine box, but it wasn’t exactly like a crate like you would think of. It was a little nicer than that. And I said, ’Yes, I like that much better. Can we have that?’....And you know, we lined it with a blanket....I knew instinctively that the more we could do ourselves, the better off we would be....we had a private burial with just the immediate family and the grandparents....We buried him in the family graveyard, which is up here [on the hill near the house]. The service, we planned that ourselves. (Marie)

Other mothers talked about the expense involved in funerals, the difficulty of selecting tiny caskets, and the behavior of other people at funerals which was problematic for them:

Everybody knows when you die, you go to the funeral home, whatever, but it never really sinks in until
you’ve been through it. I mean, when we left the hospital, I guess the last thing I remember is, ‘Call [the funeral home] in 2 hours.’ That is the last thing on my mind, to have to go pick out a casket for your child. To me, that was about the hardest thing throughout the whole funeral process...to sit in that funeral home and have the funeral director tell us, well, ‘We have small ones, and we have big ones; but it’s hard at this age.’...Everybody you’ve ever known comes around and a lot just being nosey, like I said that goes back to my family just being nosey, people who had never seen my child showed up at the funeral home, aunts, uncles I never even knew I had saying, ‘Oh, ain’t he a pretty thing.’ Stuff like that. Oh, I used to be so mad....And another thing, it’s a shame what it costs....$630 to dig a hole....It was a year after that before we could even get Charlie’s stone, and that cost $940. (Val)

This may be cruel to say, but a lot of times, people tend to gather around you that you don’t know very well out of curiosity, instead of out of real concern....I remember thinking, ‘Who are all these people?’...I think if I had it to do over again, I’d probably have a private service, just people you know. (Jill)

Humor

In spite of the gravity of a child’s death, many of the mothers recalled events that made them laugh. Frequently, humor was located in things living children said or did. Humor served to break the intensity of the child’s death for brief moments.

Beth recalled her young son who had connected Peter’s death and going away as a family vacation:

Seth came skipping in the house and said, ‘Peter died, and we’re gonna go on vacation.’ (Beth)

As Marie was showing me Tommy’s baby book, she laughed as she shared some humorous observations:
He looked very much like the other children. We laughed and said we were just having clones of Russ [her husband]. They all looked like him. You can see I had begun writing down different things he was doing...the pediatrician said, 'From casual observation in the nursery, Tommy seems to be a very easy, calm baby compared to the others.' (We laughed together here.) (Marie)

When it came time to bury him, you could just walk up to the place, we put him in the box and, John put the lid on; and I remember this, there was a screw--this is interesting--a screw in either corner of the thing, and we started walking up with [the 2 older children aged 3 and 4], and Ben was so mechanical minded, he wanted to know how God was going to get those screws out to reach down and get Tommy out....And we had to explain that that was no problem for God, that he could reach right through that. But all through that time, their practical questions just really helped. (Marie)

Jill recalled an experience in the funeral home with her brother, sister-in-law, and husband, which she said "you can't just tell to anybody." Her words follow:

My brother leaned down to kiss her and, to most people, this would sound really strange; but her little casket was a little white wicker casket, and he hit it, it was almost like on a luggage stand. And he hit it, and she was rocking back and forth, and we all burst out laughing as we were trying to catch it. You know to say that to anybody, it's just awful, but it broke the tension. (Jill)

Humor in the data served to reconceptualize the experiences of bereaved mothers as far more complex than the depressive symptoms which have been a focus in the bereavement literature. Bereaved mothers' lives, while touched with tragedy, have seeds of humor and possibilities for growth and change.
Sources of Help

I gleaned information from the mothers about the support that they perceived as helpful near their child's death. What do they remember when asked to think about sources of help? Whom and what do they perceive as helpful? Particularly striking in the data was that the respondents tended to mention other women as significant sources of comfort and help, even though fathers were generally supportive in dealing with tasks.

Beth talked about a friend who was a fellow LaLeche League leader. LaLeche League is a support network for women choosing to breastfeed their babies. The friend, Diane, came to the hospital when Peter was born and brought Beth a lunch and some money. This was a tremendous support to Beth at a time when money was a concern for the large family. Another LaLeche League friend drove her to the hospital 70 miles away late at night one evening when she felt an urgency to go and check on the baby. Beth spoke of another LaLeche League leader she met who lived near the university medical center and the help she provided:

She had a beautiful house, and she made us a beautiful meal, and gave us a beautiful room, and woke us up in the morning. (Beth)

Another person she recalled as helpful was a nurse who quizzed her on water-soluble vitamins to keep her focused during Peter's stressful illness.

84
Jan recalled a nursery nurse who spent time with her, a woman who was skilled in infant stimulation and gave her support and information:

She was certainly the highlight of that whole experience as far as people who helped me. (Jan)

Kathy’s special source of support was a beloved Grandmother who had faced numerous tragedies including the death of her mother in her lap, the deaths of 2 children and 2 husbands:

I gained a lot of strength from her knowing what she went through in her life... She was such an important part of our family. You could turn to her when you had a problem. (Kathy)

Terry spoke of a physical therapist who had been important to her. She felt that all she had to do was "pick up the phone" if she needed anything. Terry also told me that her third child was going to be named after this woman if he had been a girl. She also spoke of the hospice volunteer, also a neighbor, who was a source of help and friendship when relatives did not provide the support she had hoped for:

She lives 4 houses down, and we are really good friends now from that. She and her husband claim to be Michael’s [later child’s] grandparents. They were there when he was born. They’re older than us. She and I are really good friends. (Terry)

Angie, without hesitation, said her mother was her primary source of help. She was also a bereaved mother:
She was always there, even though she has 4 other grandchildren. She kinda got attached to the baby. (Angie)

Marie recalled another mother who saw the obituary in the newspaper and called her to offer support, a woman she became friends with and who invited Marie, her husband, and 2 other couples who had experienced the death of a child over for dinner:

There was an immediate rapport between us. (Marie)

Wendy had an older woman on her street who loved her child with whom she could talk and remember Sam:

Sam meant a lot to her. I mean she loves my other 2 children, but to her and her sister, he was SPECIAL, and we talk about him a whole lot. We sit down, and something will come up...things he would say or do. (Wendy)

The narratives above suggest that the sources of help the mothers remember and appreciate involve practical assistance as well as emotional support.

Living Since the Death

Respondents told their stories, painstakingly attending to details and significant experiences both personally and with others. To me, it seemed as though they were weaving together details of their experiences, so that I might enter into and understand the complexities of their children’s deaths. Memories and emotion persisted whether the mother had been bereaved 2 years or 14 years providing evidence of the centrality of a child’s death in the ongoing narratives
of the mothers. Over time, they seemed to be engaged in a process of change, change which had cognitive, emotional, behavioral, and spiritual elements. While all felt that bereavement related to the death of a child lasts forever, all said that over time they grew to learn things about themselves, not to take things for granted, and to be more compassionate toward others.

Changes in Mothers

As the respondents talked and reflected upon their experiences since their children's deaths, I became aware that a learning and changing process was occurring, learning about one's self, values, and preferences, and articulating these ideas to others. Spiritual, cognitive, and behavioral change seemed to occur in the mothers' lives. Often, growth and change came after tremendous pain.

Val said her growth and change occurred after she hit "rock bottom." She recalled July 4th after her son's death in November 3 years ago:

I took pills and ended up in the hospital for 9 days, and then I had to go over to the psychiatric ward, and I think that was the best thing that ever happened to me. They told me if you sign yourself in, you do have somewhat of your freedom, so I, you know, signed myself in and I got a whole lot out in the open, I worked through a whole lot....I realized that other people had some really rough problems, too, even though it wasn't losing a child. (Val)

She also talked about having more compassion for her oldest child, that she now takes the time to listen to him when he
comes in with a problem. As a single parent, she realized her many strengths. She learned to set priorities for her family of 2 and is now working on her high-school equivalency diploma and has plans to enter a medical technology program at the community college.

Wendy shared that her spiritual beliefs provide her with a sense of comfort, yet she articulated a respect for the diverse beliefs of others:

I believe in God, too, knowing, the way I was brought up, believing in God, that he wasn’t old enough to get saved; but to know, he was at that age where knowing he died, knowing he’s OK, and that one day, if I live the life that I should live, if I bring my kids up right, one day I’ll see him again. That, too, has helped a lot. Different people have different religions and beliefs, but that’s the way I believe. I believe I’ll see him again, and that’s helped me a whole lot. (Wendy)

Jill also spoke of the importance of spiritual beliefs:

The moment she died, all those blue skies turned black, and it poured rain for only 5 minutes, and then there wasn’t a cloud in the sky. I honestly believe the heavens were crying with me. I looked at Pam [sister-in-law] and said, ‘Please say the Lord’s Prayer with me. And I kissed my little girl good-bye....Religion doesn’t mean going to church every Sunday. It’s a spiritual belief that has helped me cope with my loss. I know I’ll be with Elizabeth again. I know those skies darkened and rained, because God felt my pain and the loss of my daughter. (Jill)

One way that change is manifest in bereaved mothers’ lives is through the work that they come to do, work that, for some, is intimately and powerfully connected to their understanding of the death of a child. Beth’s reflections
on her work as a labor and delivery nurse illustrate this point:

The other strange thing, I might mention,...I have finished nursing school, and I do work in labor and delivery; and I've had a lot of dead babies to deal with. But what's always been real dear to me, has been life, in general, the birthing in general, and I always looked forward to having that first delivery that I would get to do. And my first delivery was a stillborn. And I didn't anticipate that. It was in the middle of the night, and the doctor was on his way, and I knew he wouldn't get there, and the midwives were tied up in deliveries of their own. I knew inside that I was gonna have to, and just for moments, I didn't want to do it [weeping together here]...then I had to just remind myself that, who better to deliver this baby than me? And the voice said, 'Don't you know what it's like to lose this baby?' And with all the courage I could muster, I did an excellent delivery. And after, I took care of the mom, and she said, 'He looks like he's gonna breathe.' And I said, 'He's beautiful.' And I had to step out of myself, and that was really hard, and yet, who better than me? I didn't think it was weird to touch and kiss that baby....I thought [my first delivery] would be a happy thing, and yet that was the happiest thing in a lot of ways.

(Beth)

Whether mothers reach out to others in paid work, volunteer work, or within their own families and circles of friends, there was a common element among the mothers—they have learned lessons about living and dying that they can now share with others. Beth, in her work as a labor and delivery nurse, also reflected on her growth as a patient advocate:

So I always go on those two things, introducing who I am and asking, 'What special plans did you have for this birth that I can assist you with?' Those things are important, because that birth experience is something that you live a lifetime. Birth and death,
both of them ought to be just as well orchestrated, so I do just as much when babies die, and it hurts we [weeping] to bathe a baby and dress a baby, even the little teeny weeny ones. (Beth)

Her words also reflect a cognitive appraisal of situations to maintain a healthy balance between stress and relaxation:

I am in charge of my mental health, and it’s not the external, and there’s a lot of things I will and will not do depending on where I am in that. If I’m really tired, really low, or have a professional burden, you won’t see me out at a heavy movie...I do a quick assessment; it’s almost through that experience you know where your tank is. Because at the time [during child’s illness and death], you have no power. Now it’s a part of me. (Beth)

Belinda shared that she kept trying to trace back to the day she got sick wondering if something she did caused her baby to die:

I realize now that it was nothing I did. (Belinda)

She was inspirational in the beginning of the SHARE Bereavement Program in her area:

The nurse said I kind of opened the doors....And they put Jacob’s picture up all over the hospital, and my picture, and that makes me feel good, too....I had something good to offer somebody else. (Belinda)

Terry is now pursuing a degree in special education:

I think its made me more compassionate....I never thought that I could deal with anybody who had disabilities like that, you know, retarded; and because of him, I got involved with [the early intervention program] as a special needs facilitator and found out it’s something I like and I am good at. (Terry)
When we shift the analysis to mothers' reflections on their experiences, a broader picture of bereavement becomes visible. It is a different picture of bereavement from symptoms which change little over time. The mothers collectively painted their pictures of pain and triumphs.

**Couple/Intimate Relationships**

Mothers reflected on couple/intimate relationships since the deaths of their children. While partner relationships had been strained by the death, most of the mothers felt they had adapted and learned new ways of dealing with conflict. Mothers said their partners reacted differently to the death; but, for half of the mothers, they voiced evidence of adjusting and "pulling together" over time. The mothers said that partners could not be expected to meet all of their needs. It was important for individuals to seek help outside of the relationship, as well. Kathy shared her perceptions of her relationship with Randy:

> We have learned, especially since Kelley died, we’ll stop each other and say, 'What are you upset about?' And we’ve learned to talk things out more; and we’ve found out that the majority of the time, you know, it’s nothing either one of us has done. It’s something else going on in our lives that has us upset. But we’ve grown in that way. (Kathy)

> It’s something, day by day, pulling together, you know, all of us pulling together, Al and I pulling together, that’s helped me make it through it....He’s real talented with plumbing, electrical, carpentry, heating/air conditioning. Everybody says that’s his
way of dealing with it....I think that going through this has drawn us closer together, made us realize how much we need each other to survive through things. (Wendy)

Normally when you have a crisis in your life, a husband and wife are supposed to help each other; but when a child dies, to me, it's a totally different thing, because you are both in bad shape....And sure, there are times when you help each other; but you cannot rely on each other. You just can't....and as I have talked to other women, I know it's typical of men not to show their emotion...they passionately pursue hunting or fishing or building, and that's their way of working it out....But I really advise people to find someone other than their husband to talk to. (Marie)

It brought us closer together, and we learned not to take things for granted. You know, you get pregnant, you know you're gonna have the baby. Like with Tammy, I never thought about anything going wrong. (Belinda)

I'm the type that likes to talk about things; but he doesn't....He's a carpenter. He had his hammer, and he could knock the hell out of things, that's what he told me months later, that's how he released his frustration....But emotionally, I think we bonded closer. (Terry)

Just because you're married doesn't mean you're intimate in all things, and this is definitely one of those things....so I think it's every man out for themselves. If you need help, you better get some. (Beth)

**Experiences With Other Children**

In addition to dealing with the loss of their children, the respondents addressed the issue of the other children in the family since the death. They were concerned about their other children, wondered if their needs had been adequately met, and felt distressed over what these children were
facing at such an early age. The following quotes were representative of the mothers’ concerns.

We tried to make it easy to talk about Andrew and death and that kind of thing and to give him [older son] opportunities...I hope that what he needs is happening, but I don’t really know for sure because he didn’t go through what I consider grief. I don’t know if he ever even cried. He was 6 years old...I have had questions about that...Should he have been with a counselor. (Jan)

My main concern was my other daughter. She had a really, really hard time with it; so I had to pick myself up so that she could get better....When Teresa went away to school, I felt like I was losing Jacob all over again, and it was rough on me. (Belinda)

You get tired, you get frustrated, you get angry at times. I mean, my son, he’s 10 years old. Like I said, he’s going to therapy now for a lot of stuff that he has dealt with in 10 years. I mean he has been through a tremendous lot to be a 10 year old child, and I took all of that for granted... but now he comes in and if he has a problem, I take time to sit and listen to that problem...I lost so much time while I was going through this grieving process. (Val)

It’s come up, it’s caused problems. Ann was 8 years old, and I used to say, ‘We can’t have anybody come over. We can’t have anybody come over, the baby’s so sick, so vulnerable to things. We can’t do that.’ So in anger, a year after the baby had died, she said, she was upset because she wasn’t getting a birthday party or something, a little kid being nasty said, ‘Well, I’m glad Peter died.’ That kind of thing. And yet, when we moved back here just a few years ago...as a teenager in high school...she was very angry with me, because I did not put a grave marker on the grave, and [weeping] she had gone to the cemetery and said she couldn’t find the baby. (Beth)

The year that he died, Cam was doing good in school, but after that, he started having problems. I don’t know whether it was due to what happened. I thought before that he was doing real well; he was just in kindergarten and ended up having to repeat kindergarten. I’ll always believe it was because of
what happened. He couldn’t concentrate and deal with everything....Having another one, you think it’s gonna help, but it’s not going to fill the place....Andy came along, and he’s just like Sam....It’s a hard thing to deal with. (Wendy)

Extended Family Relationships

Like other categories, extended family relationships were sometime positive and sometime negative for the mothers. Positive extended family relationships were characterized by "being there" for the mothers, communicating with respect, and keeping the memory of the child alive:

My father stayed en route to the hospital with my husband during that time. My mother spent the night in the hospital with me; she screened all the calls....My parents not only offered emotional support, but financial as well....And my sister-in-law and brother, who are both in the medical field, stayed with us constantly and loved Elizabeth as if she was their own child. My family was so important to me. (Jill)

Family’s very important to me....I just don’t know what people do who don’t have family to lean on for support. (Kathy)

My family was there in a heartbeat. My mom was at the hospital....She hurt really bad through it all. (Val)

Both of my parents were dead at the time, but Dennis’ parents were living. They were very helpful to us. They came over, spent a lot of time with us. (Belinda)

Marie appreciated the open and honest communication from her sister-in-law:

My sister-in-law had a baby about 6 weeks younger than Tommy. Our friendship was just honest enough that she just finally came over and said, ‘I feel awful, guilty that I have the live baby and you don’t. I don’t know what to do.’ I told her that it was somewhat painful,
but I didn’t want to cut myself off from my nephew, that yes, it’s going to be hard; but we just have to do it together. (Marie)

Terry spoke of her disappointment surrounding her mother’s reaction to Jimmy’s life and death:

The biggest problem that my mom and I have is that she’s so outspoken; she’s selfish. She’s never had to want for anything in her whole entire life! I feel like she doesn’t understand. When Jimmy was born, when Jimmy was alive, when Jimmy died, that was when I needed her most; and she wasn’t there for me, and I resent the hell out of her. (Terry)

Al’s mother, she’ll be counting the grandchildren, and she doesn’t act like Sam was ever here. We’ll count him; Al will include him, and she’s like, ‘Oh, yeah, I forgot about him.’ But his family overall was real supportive....My sister helps me to remember him, not just the bad things, but the good things. (Wendy)

I don’t think Richard’s mom ever saw the baby. She didn’t come for the funeral. She felt she would send money and that would suffice. (Beth)

Like other aspects of the mothers’ experiences, extended family relationships were more complex than can be captured in a few short examples. Relationships are complex and vary over time. What is noteworthy in the data, however, is what characterizes these relationships as helpful for bereaved mothers: "being there," respectful communication, and preserving the child’s memory.

Paid and Unpaid Work

The interviews revealed the very central place of work in the lives of mothers. All of the women in the study wanted to be mothers, and all of the mothers worked whether
their work was paid or unpaid. Feminist scholarship raises consciousness of the frequently invisible labor of mothering. During the followup interviews, I was attentive to their work as mothers fed, changed, and rocked sleepy babies. The followup interviews tended to be a time for meeting more members of the family, for relaxing the intensity of the initial interviews; and I saw how the threads of life had been picked up in the context of family. I watched Jill set up a play environment for her toddlers, so we could talk in the far corner of the family room. I heard Wendy respond to questions from her oldest child. I saw Angie provide a snack for her child and a visiting niece. Clearly, these mothers were engaged in a practice which involved the growth and development of children (Ruddick, 1989). Their work was based on connections, attention, and caring; and the women took their work seriously.

Some mothers had made difficult decisions related to paid employment to meet the needs of their children. Angie, who planned to return to her job as a security guard after her son, Billy, was born resigned when he was born prematurely at 27 weeks weighing 2 lbs. 3 ozs. requiring intensive care in a hospital 70 miles from her home. Likewise, when Jan's son, Andrew, was born with Down Syndrome and cardiac disease requiring surgery, she took an
extended leave of absence from her teaching position to manage his complex care involving the use of a feeding tube. Kathy, the mother of 3 children, 2 of whom were stillborn and a third child who died at the age of 3 weeks, Kelley, home schools her living children and acknowledged that the deaths of 3 children influenced her to want her work to be "home-based as much as possible." Kathy also manages a consignment store and Christian book business, but views paid work secondary to the responsibilities of mothering:

I like to make sure they [children] are fed good... That's a very important thing; I like family time sitting down to the table to eat. Just about every meal, we try to eat it together. (Kathy)

Jill, who has 3 living children, resigned from her banking position shortly after her daughter's death transferring her attention to the work of mothering:

It's a 24-hour a day job, and it's different, but it's fun. It's rewarding. I think it's real important at this age to be at home with your children. I know a lot of people can't. I'm just fortunate that I can. We give up other things for that, to be here. (Jill)

While she preferred this for herself, her interview was sensitive to mothers who had no choice or who needed the outlet of outside work.

Jan identified a double-bind that bereaved mothers may find themselves in:

I think that it is good that women are having more of a life of their own, they are more independent, they feel like that can make it own their own; but with that has come, maybe, women think they should be able to handle
everything, too. We are supposed to handle everything, the working mother--she's supposed to handle her job, her home, and I think there are a lot of women that think they should be able to handle whatever comes along, and I did not feel that I was handling it very well....I wanted to be a mother more than anything else, but I let society kind of, you know, pull me in this other direction, career, money, have a good life. I would hope that young women would follow their heart. (Jan)

Val, the mother of a 10-year old, discussed her position as a single parent:

There are a lot of women that are losing children that have no one. You have to [work], you have no choice, not unless you just want to wallow and lose everything....I feel like I am a better mother than I was before this happened....You have a tendency to take a lot for granted. (Val)

The mothers articulated the complexities of work and family for contemporary women and the additional tensions that the illness and death of children introduced into their lives. They recognized the urgent, compelling nature of the work of mothering and the lack of support in society for this work. Sadly, bereaved mothers are influenced by cultural proscriptions: Good mothers protect their children. The mothers seemed to feel the weight of culture as they struggled with defining themselves as "good mothers" in spite of a child's death. Collectively, they offered messages about the unexpected nature of family circumstances over time and the desire to have their work, paid and unpaid, acknowledged and respected.
Support Groups/Therapy/Medical Care

Living since the death of a child involves identifying and locating appropriate help. While people may locate help within families and friendship networks, often the mothers wanted or needed more assistance outside of their familiar circles. Typically, these additional sources had a time-limited value; but were, nevertheless, invaluable for acquiring new understandings, ways of coping, or developing friendships with others who empathized with their experiences. The mothers had differing opinions about these sources of assistance, support groups in particular, as the following narratives describe:

Oh, I got the letters [from Compassionate Friends]; I had to call and ask for them, some information about it. They had a number to call, a person to talk to, never could get in touch with them. So I felt like, this is not a very organized bunch. (Terry)

Val attended a Compassionate Friends memorial service in December following her child's death in November and felt out of place:

If I had to give a message to anybody, a bereaved parent, or whatever, my first message would be, and I would not...this is my personal opinion, I would not recommend Compassionate Friends. I would recommend just any kind of therapist, just go talk to them, just get it out of your system, cry and do what you want to do. You will feel better when you leave the office....You've got to get to the point where you feel good about yourself again. (Val)
Kathy talked about seeking medical attention and attending Compassionate Friends support groups to deal with depression after Kelley's death:

Being a minister's wife, I was trying to...it was saying that I was weak and that I wasn't a strong Christian if I had to seek medical attention, that maybe that was wrong or something. I had to get over that hump...One thing that kind of helped me see that it was OK was that we had a lady in the church that had a nervous breakdown. And, about that same time that I was having my problems so bad, and mine had gone on severely for about a year before I sought help, when I saw how the church responded to this lady, then, it made me feel like I could seek help and not be ridiculed because of it....Also, going to Compassionate Friends was a big help. Through Compassionate Friends, we had met other friends, you know, like Tammy; we've become pretty close, still keep in contact with each other every week. (Kathy)

Wendy felt that attending a support group was helpful for the couple relationship:

We [Al and I] got a call about Compassionate Friends; that's why we went, because I felt like...I didn't blame him for what happened [the accident], but I felt like maybe he thought I blamed him. I thought if we didn't get some help, we would split up over it...being able to talk about it helps a whole lot. (Wendy)

The doctors kept telling me that she was going to be OK, and she had surgery and got sicker. I desperately needed to go talk to somebody to get perspective back in my life. You find yourself going a little bit over the deep end now and then until you can find someone you can talk to....when I got help [counseling], I learned that they did all they could for her; I got my perspective back. But I think it's very important to talk to somebody....My husband doesn't understand why I read the Compassionate Friends newsletter. I said it helps me know I'm not by myself. (Jill)
Jan felt that having an active part in starting a support group in her area helped to create a broader sense of meaning from Andrew's life and death:

Sandy [social worker] came to see me in the hospital. My sister and I were anxious to get a support group started, and Sandy took that up. I know some good things came out of Andrew's life and death....The group was a wonderful place for me to go and tell my story and helped me see that other people were going through other things, and that they felt just the same way you did, that you weren't strange or overreacting. It was really good....I said I don't think the pain ever goes away, but I do think that with time, it does lessen. Everyone in the support group told me that. I didn't know if I'd ever be able to say that, but after 7 years, it definitely has lessened. (Jan)

We had a Sunday night very informal sharing group already established at our church, and so we went regularly. I just lived for that meeting; because you could share how you felt. I mean that went on for a year or more, as much as we needed to, and people never seemed to tire of it or, you know, they really gathered around us and really helped us. (Marie)

The SHARE group, they sent pamphlets and stuff to read. That helped a lot. And the woman, Ellie, she used to call quite often. (Angie)

I meet with Ellie [SHARE coordinator], we have become good friends....She seemed to know exactly when to call, and I could dump my whole self over on her; she just don't know what she done....it hurts not to remember, if you're just trying to go through it alone and not tell anybody. To me, it helps sharing with other people, especially somebody that's not related, just to know that they care. (Belinda)

These illustrations suggest diverse needs for support following the death of a child. An important message to newly bereaved parents from these quotes is that if one
source of help isn’t meeting your needs, do not hesitate to seek out other sources.

Reaching Out to Others

Mothers bereaved over time expressed knowledge which can be useful to others, such as other parents and professionals. To other families, Beth offered the following thoughts:

Plug into your resources, know well who they are and who you can trust with these kinds of things, because it comes about very quickly those people who are uncomfortable and those who are not gonna be your biggest allies. And then, to trust yourself with your feelings and know and pursue. If something doesn’t seem right, maybe it’s not, and to pursue and be persistent and keep knocking on the door; and if you don’t get satisfaction, go someplace else. Listen to yourself. (Beth)

Jill cautioned other parents to recognize that:

If you have a trauma somewhere in your life, it’s going to bring a flood of memories back. It’s not necessarily that you’ve fallen backwards...I remember at first thinking, Am I ever going to feel normal?...Know that with time you will be able to go on; but there’s still always going to be that empty feeling inside....I think it’s important to remember the child. I took little Christmas trees to [2 of her friends] to put on their children’s graves. I think things like that are special. (Jill)

Jan learned the importance of allowing others to help:

A lot of times we think that we have to go through it all by ourselves, and I did learn that there are a lot of good people that want to help....I came to believe that God sends people to me when I need them the most, that people have entered my life that have been absolutely invaluable, friendships I have now that I would not have had. (Jan)
Several of the mothers stressed the importance of medical professionals taking mothers seriously by listening carefully to their perspectives on a child's condition. Belinda also added a crucial point for all who work in medical offices: Be attentive to what has happened to the mother when she returns to the office for checkups. She recounted returning for her checkup and suffering alone in the waiting room with pregnant women. No one in the office acknowledged her baby's death:

And when I got in and the doctor, he was writing in a chart with his back to me, I was about to explode with pain, it hurt so much, and when he said to me, 'How's the baby?' I was destroyed. No one knew. (Belinda)

The data in this category were rich with examples of reaching out to others, informing others, and trying to improve the course of bereavement for those who follow. The women, with their powerful and articulate accounts, captured my attention and my emotion. I could almost "feel" myself in the waiting room as Belinda shared her experience there. Collectively, the mothers seemed to say: These things are important; they affect people's lives. The mothers were not passive and depressed; they were actors filled with knowledge and sensitivity.

Prior Death/Bereavement Experiences

How does the death of a child compare to other experiences with death? During the followup interviews, I
asked the respondents to reflect on other experiences with death that made an impact on them. The respondents had varying experiences with death prior to the death of their child. However, all 10 mothers agreed that prior experiences did not compare with their child’s death. The death of a child by all was viewed as unjust and off-time, unlike the deaths of older persons who had "led their lives." (Terry)

**Prior Experiences with Death/Bereavement**

The following data illustrate the mothers’ varying prior experiences with death and bereavement. All of the women reported that the death of a child was qualitatively different from their prior experiences.

My father’s death at 76 was traumatic, because he was my pride and joy. But there was no comparison, really, because after a couple of months you realize when a person is older, you wouldn’t want them back to lay and suffer. (Val)

When I became a teenager, my mother lost a baby. I think I was around 16 at the time. Hers, it was more like her just being sick or something. I don’t remember her grief being real bad. I had been away at camp, my little brother had been with me, and Mama had been sick all week....I remember coming back in and all these clothes from camp, cooking, cleaning of the house, everything was just turned over to me...she was 7, 8 months along....See I wonder myself what went through her head, a lot of my feelings, I didn’t hide from my kids. The deaths of the children were very much an open subject with us. Where with Mama, it happened, it’s done, it’s over, move on. (Kathy)

Although her mother’s death was difficult, Wendy said her child’s death was the most severe for her:
Sam's [her child] death was the hardest. When you lose a parent, it's difficult, depends on how close you were, like with me, it was like losing my best friend [her mother]. I crawled into a shell for a long time, didn't want to do anything. Would put off going to the doctor, she always went with me. It was like I was a child again. Al's daddy was close, but it wasn't like losing Mama; but then, when Sam died...I went into a deep depression. (Wendy)

Prior experiences did not prepare Beth for the intensity of a child's death:

[As a child] my dog got hit by the school bus, and I grew up in rural Maine; and really we were not allowed to have much emotion. I remember as a kid being really upset, and the way I handled it was--you stupid dog! [Grandma died when I was a teenager] I got real angry and did not go to the cemetery...I remember thinking I would rather remember her, as I knew her--well or near well. I wouldn't do that now. (Beth)

I remember losing my grandfather. It was hard, but nothing compared to her. And then, I'd never lost anybody. I mean an aunt died 10 days before Elizabeth, someone I had been close to, but never saw anymore; so I don't think anything compares to losing her. I've always heard people say it's so much harder to lose a child, even more so than a husband or a wife. (Jill)

Just older people had died, but I really hadn't had that much experience. Just no comparison to his [Billy's] death. (Angie)

My mother and my father died, that was really hard for me. They were the first people to die that were very close to me. And then, after I had Jacob, and he died, it was no comparison. (Belinda)

My grandmother died when I was in 6th grade...and I felt very close to her, but my mother kind of shoved us next door, because there were people coming...we were made to go to school....There was a boy in high school that died of cancer, and then a girl that was killed in a car accident--my way of dealing with death was--not to go. [When Jimmy died] it was different, the funeral, everything....more emotional; because when an older person passes away, they have led their lives.
Yes, it's sad, but we know life is gonna come to an end. (Terry)

As I look back on it now, I know that my perception of just about everything was that bad things weren't going to happen to me and that somehow I would be able to fix it or everything would work out OK. So you know, really, my Dad's death I guess was the closest that I had ever been to death. But still, it was just, you know, the kind of thing that, Dad was 81 years old, he was very sick; he is better off now, and I never let it stop my life. (Jan)

In '76, I had my first child. She lived a few minutes. I did everything wrong....only in years later did I really realize what I did. But laying on the delivery table, and there was a team of doctors working with her, but she just couldn't make it. I remember when Dr. B. turned back to me and nodded his head, I said, 'Well, I can have another baby.' And I treated the death as an unfortunate delay....we had no funeral, we did not name the child, I never held her, never looked at her....I continued on in that mode, and consequently had lots of problems. (Marie)

Methodological Codes

Mothers' Perceptions of the Research Process

Participation in the study appeared to be a bittersweet experience for the respondents. They mentioned that after the passage of time, most people expect the child's death to be a part of the past, to be forgotten; so there are fewer people with whom to share their memories and perspectives about the child's life and death. The interviews provided a time and place to do so. Other people tend not to mention the child who died, because they don't want to "upset you" (Jan). Discussing the death of a child is a taboo topic. Since I shared a similar experience, the respondents seemed
to feel that I would understand. However, talking to me was deeply emotional, and most were surprised at the depth of feeling evoked in the initial interviews. The data suggests that bereaved mothers are hesitant to share the range of their experiences with others who may not be sensitive to the topic:

It was easy for me to talk with you. I wouldn’t have told you half of what I told you if you came in here, like what I told you about the funeral home, somebody else might have been horrified at that; but I thought you would probably understand that. I wouldn’t have opened up half as much, there’s no way. I would have felt like it was none of your business, even though I volunteered to do this. (Jill)

Jan offered the following perspectives about participating in the interviews:

I feel like I spent a lot of time talking about his life, but you don’t have many people you can talk to about it, and I feel like it has been therapeutic for me. This is the first time that I have really told this whole story. You don’t go up to people that you meet now, you don’t even tell them, you know, you don’t have many people that you can talk to about it....You are thinking about it all the time anyway. It means a lot to me now if a teacher friend will say something to me about him or will just remember something that we haven’t talked about for a while. It means a lot to me, because I will never forget Andrew as long as I live, and I don’t want others to forget him either, because we do think his life was very meaningful. (Jan)

Another respondent, Terry, said:

It helped me to talk about it, because I always feel like, I like to talk about him....the day that you left here, I was down for a little while; but it wasn’t, I was anticipating that I was going to be depressed, but I wasn’t....it was real easy to talk with you. (Terry)
This has been good. As I said, it brings my baby alive a little bit every time I do something that’s concerning him....I told my husband that that was a really nice lady to come over here and take an interest, you know, makes me feel like it’s keeping Jacob’s memory alive....remembering all that stuff’s kind of painful, sad, sometime, you know; but I like knowing that somebody else cares. (Belinda)

I’ve never met you before, but I’m comfortable with you....[but] I was amazed. I knew there would be a risk in discussing that, an emotional risk, but I was willing to deal with it again. But when you sit down and you have permission to just totally do that, I am totally in shock about how powerful the experience is, and I want to say that’s good....It shook me a little bit, but it renewed where I am coming from, where I want to go, and my practices. (Beth)

It’s a little bond there, knowing you have been through this. You put me at ease, because you didn’t fault me for my feelings; whereas talking to my sister-in-law and my mother, it’s hard to talk about it because they look at me strangely. (Val)

It’s been a positive thing....It helped me to talk to you about it. I talk about it; but talking to you about it was different, because you and I know what it’s like. (Wendy)

It’s been helpful, cause I haven’t talked about it in...a long time. (Angie)

Comments by the Researcher

I was moved and challenged in many ways by the study. I was touched by the intricate and painful stories of the mothers and often wept with them as they reflected on their experiences. I attempted to listen attentively, to provide support, and to share snippets of my own experience which affirmed some of the points they were making. I recognized
the centrality of a child's death in their lives and in my own and felt deep grief at times.

In spite of the pain that I saw and experienced, the respondents taught me about women as actors in the social system who grow and change in response to their circumstances. They told me that the pain of bereavement had lessened with time and support. As individuals with diverse circumstances and perspectives, they illuminated the usefulness of a contextual theory of stress as an organizing framework to study these experiences.

As I analyzed the data, I took notice of my own words during the interviews and included my reflections about my comments as part of the data analysis. Undertaking the study from feminist and contextual perspectives guided me to take women's experiences seriously, to connect with them, and to attend to the social system within which they were situated. They, in turn, seemed to take the commitment to participate seriously and were generous with their time and reflections.

They welcomed me into their homes and often offered me a snack or a beverage. Sometime I played with or talked to children or chatted briefly with fathers. One older sibling gave me a ceramic angel, and I told him that I would place it near my computer for "good luck" while I was working on my paper. I sent each mother thank-you notes following each
interview, and 2 of the mothers sent me cards. Feminist practices are rooted in personal connections between people. I provided affirmation and reflections on their work during the interviews, such as:

Right, you're doing a great job. To me, it's so visual, thinking about you walking out of the hospital... 'cause to me, I remember that.

So a whole lot of love and a whole lot of knowing just how fragile life is, how easily it can all change.

I tried to make my own processes visible to the mothers by explaining why I asked certain questions, such as the demographic data, that the information fits with the theory and makes visible the many contexts in mothers' lives. To mothers who were returning to school or getting ready to apply for jobs, I provided support and encouragement.

On occasion, I thought it would be helpful to link mothers' experiences with each other, to make them aware that similar themes were in common among them:

That's a theme that seems to be running through the interviews....that physical activity seems to be a way they [men] deal with the child's death.

Every mother that I've asked that question to has said 'forever,' that it [bereavement] never goes away totally, but it gets easier with time.

When I started this project, I had no conscious awareness of what I would gain in the process. Connecting with other bereaved mothers, talking and listening, has been valuable to me. The data illustrate many of the
complexities and triumphs of long-term maternal bereavement. While there are diversities among bereaved mothers, there is simultaneously a common ground.

Collaboration with Doctoral Advisor

My doctoral advisor, Katherine, was a source of collaboration and insight during this process. As I conducted interviews, transcribed tapes, and developed a coding scheme, she provided steady, behind-the-scenes consultation to me. I benefitted from her feminist practices of reflexivity, emotionality, and connectedness.

Through her feedback, I came to recognize the importance of a good coding scheme as a blueprint for managing the large volume of qualitative data. With the coding scheme, I could then begin to analyze the data across respondents to see which categories were representative of the data. The words of the mothers provided the foundation for my conclusions.

She also provided a model of keeping reflexive journals in her teaching and research practices. Journaling helped me capture some of the ups and downs of qualitative research and made me keenly aware of myself during the process—times of fatigue and grief, times of increasing understanding of the qualitative process, and times of elation over the visibility of new themes and ideas.
As I collaborated with the mothers, Katherine collaborated with me, providing support, giving me feedback on my writing and understandings of the data.
CHAPTER FIVE

DISCUSSION AND CONCLUSIONS

Overview

In this study, I investigated the perspectives and experiences of 10 bereaved mothers related to the death of a young child. A feminist and contextual perspective focuses attention to the multiple contexts within which mothers are situated and their efforts to influence their circumstances. Contextual theory guided me to attend to individual factors, as well as the mothers' perspectives on multiple levels of their social systems: dyadic, family, social, community, and cultural contexts (Walker, 1985). Feminist perspectives directed my attention to the voices of the respondents, to respect their multiple experiences, and to strive to produce results which are nonoppressive (Baber & Allen, 1992; Thompson, 1992). Women were viewed as a source of knowledge, and their knowledge was rooted in their lived experiences.

With an emphasis on connections, emotionality, and reflexivity, feminist research "penetrates 'official' explanations" (Fonow & Cook, 1991, p. 1) which essentialize women's experiences. Researchers and researched alike become more conscious of the social construction of knowledge, and women are brought into the center of the construction of new knowledge (hooks, 1984). Rather than
essentialize bereaved mothers as depressed with little change over time, the use of reflexive practices provided opportunities for women to talk, listen, and share and to become more conscious of personal situatedness within multiple social contexts. Researchers who make use of the self in their feminist practices make connections with respondents by sharing some of their own struggles and vulnerabilities (Belenky et al., 1986). By sharing my own bereavement status, I desired to connect with respondents and to establish an affirmative atmosphere for reflexive conversations.

The research questions that guided the study were:

(1) What are mothers’ stories who have had the experience of a young child’s death?

(2) In what ways do the mothers perceive that the death of their child has changed and continues to change them?

(3) What are the applied implications of the mothers’ perspectives? That is, what can the sample of women teach others?

(4) How are respondents and researcher affected by their work together in the study?

Discussion of Findings

In-depth interviews with the mothers yielded stories which were rich in contextual information. In common to all the women in the study was the love of and desire to have
children, and they were connected to their children through the actual practices of mothering (Ruddick, 1989). They shared painful stories of their children’s lives and deaths, as well as their experiences with others in their social system. The feminist and contextual perspective guided me to connect with the respondents, to share emotionality, and to pose reflexive questions toward shared understandings of their experiences. Feminist researchers acknowledge that their own personal histories influence their work. Several overall findings which correspond to each research question will now be discussed: Deepening Consciousness, Redefining Oneself, Teaching Others, and Connecting as Researcher and Researched.

**Deepening Consciousness**

In common for all the mothers in the study was the desire to remember and talk about the child who died. Their interviews, conducted 2 to 14 years after the death, suggested a process of deepening consciousness as a response to the loss. Becoming aware of their altered status as mothers, they were simultaneously "inside" and "outside" (Westkott, 1979) of the actual practices of mothering. Having and valuing other children did not alter the centrality of the deceased child to the mothers. They were mothers without the physical presence of the deceased child to validate their status.
All of the respondents possessed mementos of the child, such as baby books, articles of clothing, blankets, photographs, locks of hair, and special toys of the child which were cherished in the mother's ongoing life even though the deaths had occurred from 2 to 14 years ago. In essence, these items were all the mothers had as physical confirmation of the child's life, and the mothers seemed conscious that open discussion of a deceased child as confirmation was awkward in their daily lives.

While the mothers varied in the frequency with which they looked at or handled the items, the mementos seemed to provide a sense of comfort and security to them, as evidenced by Beth's words, "At special times, like his birthday, I like to look. I like to indulge." The items helped to preserve the memory of the child in a cultural context in which open discussions of death are generally taboo (Stinson et al., 1992). Like others whose social status has been altered, the mementos seemed to provide bereaved mothers with a vehicle for commemorating the child's life (Richardson, 1989).

All of the mothers presented evidence in their interviews that they had to choose selectively when, where, and with whom they could discuss the child's death. It was socially unacceptable to share the range of their emotions in most aspects of their daily lives. Numerous examples
provided evidence of their "outsider" status. For example, Jan said that while her employer was supportive during Andrew's illness and death, there was still the expectation that when she was at work, everything was OK, and she was expected to go on as before. Beth mentioned that she had talked about her experiences with others in the workplace, and "it made people uncomfortable." Belinda discussed feeling "outside" of the discussions of pregnant women and new mothers in her workplace. Jill talked about friends who expected her to be ready to have a party shortly after her daughter's death. It was difficult for others to empathize with the rupture in the mothers' lives brought about by the child's death. Consequently, the mothers learned to be guarded—simultaneously inside and outside as mothers.

However, they were not only reactive, they were also actors in the social system who set out to locate safe people or to create situations which met their needs for sharing and remembering. The people with whom they shared their emotionality tended to be other women, such as friends, sisters, grandmothers, counselors, or other bereaved mothers who responded empathically to their concerns and experiences. As sources of help, the women integrated task-oriented help, such as transportation or childcare, with emotional support in the form of listening, talking, and sharing. The data indicate that both emotional
and practical support was valued by the mothers, thus freeing mothers from essentialist bias. While male partners were often supportive in practical ways, the women learned that partners were "going through something, too" (Belinda) and that it was acceptable to locate others for needed support. Gender stereotypes encourage men to be stoic and unemotional (Stinson et al., 1992), and the mothers learned that partners could not depend upon each other to meet all of the other's needs.

Redefining Oneself

All of the mothers' interview data suggested that they had grown and changed in response to their circumstances related to the death of a child. Frequently, growth and change involved reaching out to others in ways they could not imagine prior to the child's death. Mothers helped start bereavement support groups; they assisted other women through the labor and delivery of stillborn children; they became patient advocates in hospitals. Others became more conscious of the needs of living children and partners and discussed "pulling together" as a family and empathizing with the pain of all after a child's death. Another woman became more aware of the needs of people with disabilities and entered a special education degree program to use her knowledge in teaching. Still another mother who is currently involved in childrearing told me that as she plans
ahead, she would like to have some involvement with hospitalized babies.

While some women became more "home-based" in their work, they recognized that they would continue to change over time; and they respected the choices and circumstances of other women who wanted or needed to work outside of the home. All of these examples suggest a deepening consciousness, respect for the diversities of others, and a process of redefining oneself as an individual, a partner, a mother, a friend, and an employee. Most of the women also felt that living through a child's death gave them a heightened sense of confidence in their abilities to cope with other adversities in their lives. But the contradictions were everpresent as well. They spoke of their own personal vulnerability, especially with respect to their living children.

The mothers shared that the death of a child, while tragic in their lives, often was the catalyst for them to learn that they needed to rely on others and that they could not cope with the experience without the help of others. While they reported that the pain over the death of a child did lessen over time, all the mothers reported that this particular bereavement lasts "forever," in comparison to other deaths they had experienced. Holidays and birthdays
continued to present challenges, as did questions like, "How many children do you have?"

Mothers are blamed or idealized for their work (Ruddick, 1989). Many American mothers are influenced by cultural images of idealized mothers as "all-loving, kind, gentle, and selfless" (Andersen, 1993, p. 159). Bereaved mothers often blamed themselves in some way for the child's death. Wendy said she initially blamed herself for not taking Sam to her mother-in-law's home, while she and Al loaded the moving truck. Angie wondered if her baby would have lived if she had awaken earlier to check on him. Redefining the self involved recognizing that they were not to blame for the death, recognizing that mothering is actually a contradictory experience, and relinquishing themselves from guilt over the child's death. Interviewing the mothers years after the death enabled me to see that they had come to redefine themselves as good mothers in spite of the child's death. While the death of a child was profound for the women and was accompanied by feelings of failure and depression, their abilities to grow, to change, and to redefine their lives were also evident.

Teaching Others

With death frequently occurring within hospital environments, many Americans no longer have exposure to the actual experiences and tasks associated with death,
particularly the death of a young child (Dally, 1982; Johansen, 1988; Schiff, 1977). Many people in a mother’s social system do not know how to respond when a child dies and frequently end up avoiding the subject or making comments which were perceived negatively by the mothers. Respondents were filled with emotion and pain when their child died and wanted comfort, listening, and practical help with living children as they struggled to adapt. They were in a position to teach others about these things, as Kathy did when she was on a panel discussion at a university hospital. In her special education classes, Terry was empowered to teach others as she shared the realities of the life and death of a child with special needs. Beth, as a nurse and patient advocate, taught other professionals how to interact with newly bereaved parents.

Mothers were able to teach others about the value of supportive networks in dealing with stressful circumstances. A contextual perspective (Walker, 1985) directs attention to the buffering effect of supportive networks during stressful circumstances, as well as to the mothers as actors who create socially acceptable ways of dealing with the pain and remembering the child. The mothers learned that they could teach others to provide comfort to themselves in the form of writing journals, speaking about their experiences to empathic audiences, and engaging themselves in meaningful
work. They found that it helped them to talk, to share, and to teach others about their experiences.

And the mothers taught about families and their diversities and strengths. The family form and structure were inconsequential; the meaning of family was what was important to them. They taught that families, whether single-parent, cohabiting couples, created families, or legal marriage provided buffers to deal with the child’s death. Yet, a contradiction was that they learned that families could not meet all of their needs as individuals. As actors in the social system, they taught that each individual also has a responsibility to herself.

Mothers can also teach professionals who provide services to families. Most salient in the data was the message "Listen to mothers." Mothers provided the bulk of care for their children, even when assisted by others; and they want to be taken seriously when they voice their concerns and perspectives. They needed acknowledgment of the child’s death in medical offices when they returned for checkups. The medical office was a place that marked the developing pregnancy; returning without a baby was even more traumatic when no acknowledgement was made of the child’s death. Medical professionals who responded in a caring, responsive manner were perceived as helpful by the mothers.
Connecting as researcher and researched

Feminist practitioners acknowledge connections between researcher and researched and privilege the place of emotionality as a vehicle toward shared understandings (Belenky et al., 1986; Fonow & Cook, 1991). Knowledge, therefore, is not absolute; rather it is negotiated between actors. As a researcher who shares the personal experience of long-term maternal bereavement, I had a genuine interest in the experiences of the sample of mothers. The mothers reported that knowing of my experience helped them feel free to talk and share honestly. It gave them permission to share their perspectives without fear of criticism or upsetting me.

However, most were surprised at the depth of emotionality evoked by the interviews. Having permission to talk freely was very painful; and they became more aware of the risk of marginalization in their everyday lives. The process of research seemed to provide an unexpected benefit: It became an unexpected support network as a safe place for reflexivity surrounding the child's death. Becoming deeply connected with the mothers' words personally as well as intellectually (Belenky et al., 1986), I often wept with them as I recognized my own continuing learning, growing, and vulnerability.
Conclusions

The research questions guiding this study led me to attend to the mothers' perspectives on maternal bereavement and to mothers as knowers who could teach me about their experiences (Belenky et al., 1986). Feminist practices provide confirmation that women can be trusted to "know" and to teach others (Belenky et al., 1986). As a researcher who is also a bereaved mother, the study was attentive to the relationship between researcher and researched (Acker et al., 1991; Belenky et al., 1986; Fonow & Cook, 1991). I began the study with an interest in the women's experiences in their everyday lives related to the death of their children and located those experiences within multiple contextual levels of the social system (Acker et al., 1991; Walker, 1985).

Table 5.5 reflects the relationship between the research questions, the coding categories derived from the data, and the key findings. While the key findings are not discrete to a particular research question, they are located next to the question most relevant to the finding.
TABLE 5.5 Research Questions keyed to Codes and Findings

<table>
<thead>
<tr>
<th>Research Questions</th>
<th>Coding Categories*</th>
<th>Key Findings**</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 &quot;Stories&quot;</td>
<td>100s - 500s</td>
<td>1</td>
</tr>
<tr>
<td>2 &quot;Changing&quot;</td>
<td>400s</td>
<td>2</td>
</tr>
<tr>
<td>3 &quot;Implications&quot;</td>
<td>200s - 500s</td>
<td>3</td>
</tr>
<tr>
<td>4 &quot;Relationship between researcher/researched&quot;</td>
<td>600s</td>
<td>4</td>
</tr>
</tbody>
</table>

* 100s - Talking About Myself  
  200s - Remembering the Child who Died  
  300s - Reliving the Death  
  400s - Living Since the Death  
  500s - Prior Death/Bereavement Experiences  
  600s - Methods Codes  

** 1 - Deepening Consciousness  
  2 - Redefining Oneself  
  3 - Teaching Others  
  4 - Connecting as Researcher and Researched  

The key findings of the study pointed to the usefulness of a feminist and contextual perspective for approaching holistic understanding of maternal bereavement. Mothers practice within a social context in which they are idealized and blamed for child outcomes (Andersen, 1993; Ruddick, 1989). Internalizing the weight of culture, mothers often
blame themselves after a child dies. Their bereavement has been essentialized as problematic and symptomatic leaving invisible the ways they are actors in the social system.

Their words reflected that they became conscious that open discussion of a child's death is socially taboo (Stinson et al., 1992); they were both "insiders" and "outsiders" as mothers. They were still mothers of the child who died without the physical presence of the child as confirmation of their status. The contradiction of belonging and not belonging provided the women with a double vision of reality—knowing deeply about the dialectics of birth and death, power and powerlessness (Ruddick, 1989; Westkott, 1979). Their altered status provided the women with a basis for deepening consciousness and critical examination of their lives leading to change.

In redefining oneself, the mothers worked to locate or create opportunities to reflect on their child's life and death. Frequently, their work and family practices reflected increased empathy for the experiences of others and numerous activities to teach and help others. The mothers were teachers on multiple levels of the social system—to fellow students, to other parents, and to medical professionals. While mothers were expressive of their feelings, they were also instrumental or task-oriented in their reactions to a child's death by planning funerals,
caring for other children, and teaching and helping others. The feminist and contextual perspective guiding the research process enabled mothers' instrumental and expressive activities to become visible. Rather than view bereaved mothers as either instrumental or expressive, the in-depth interview process revealed them as both instrumental and expressive.

Researcher and researched were similarly situated as bereaved mothers, and the research process provided an opportunity for connections and mutual reflexivity. Permission to talk in an affirmative atmosphere led to shared emotionality and the generation of rich data which were connected to the mothers' lived experiences. Using my own status as a bereaved mother who is also a researcher enabled me to reflect upon the perspectives of the mothers, to reduce distance between researcher and researched, and to engage the personal as a vehicle for theoretical understanding (Krieger, 1991; Ruddick, 1989). Maternal bereavement appears to require ongoing adjusting and processing, and the data reveal the ways women are active and creative in the process.

Limitations of the Study

This study would have been strengthened by interviewing a larger sample of women. The illumination of the experiences and perspectives of bereaved mothers of other
circumstances and cultures would strengthen the results. Also, shortcomings of the interview method have been noted in the literature as there may be "discrepancies between what people do and what they say they do" (Blaisure, 1992, p. 99).

While my personal experiences as a bereaved mother added to my understanding of the nuances of the mothers' perspectives, it is possible that my vision may have been simultaneously restricted by my experiences (Baber & Allen, 1992). As Taylor and Bogdan (1984) articulated: "Data are never self-explanatory. All researchers draw on their own theoretical assumptions and cultural knowledge to make sense out of their data" (p. 142).

Suggestions for Further Research

Several ideas in this study warrant further study. A longitudinal study based on interviews with multiple family members would increase understanding of the family level of stress over time, the meanings of the death to various family members, and the attempts of these members to adjust to the death. All of the mothers in this study have agreed for me to contact them in one year providing a basis for longitudinal work.

As the study progressed, I felt it would be informative for the mothers to come together in a focus group format to share their perspectives on several issues. For the people
who did not find support groups helpful, a discussion on this issue would serve to provide more data on increasing mutual support group effectiveness. Focusing on bereaved mothers as teachers could be addressed in a group format and simultaneously add to women’s empowerment. In addition, the social construction of motherhood could be addressed in such a forum to raise women’s consciousness of the ways various forms of media serve to constrict their images of themselves (Marshall, 1991).

A study of fathers’ bereavement was suggested by this study. From their perspectives, the mothers stated that their male partners were generally unemotional and task-oriented relative to the child’s death. If men had a strongly emotional reaction, it generally occurred close to the time of death and not before or since. It is important to stress that these were the women’s perspectives. How do the men perceive their own reactions to the death of a child? What are their perspectives of the ways they provided support to mothers? Do they feel that they were adequately supported? If not, what would they like to teach others about their experiences?

Summary

This study investigated the bereavement experiences of mothers related to the death of a young child. The findings illuminated the mothers’ perceptions of some of the
complexities of their lives. The women discussed the influence of multiple contexts within which they were situated, but they also made visible activity and growth processes which are revealed when the focus is shifted to their perspectives long after the death. Bereaved mothers are located in a cultural context which simultaneously idealizes and blames women for child outcomes and in which discussions of death, particularly death off-time, are taboo. Such social contexts were a source of added stress and marginalization relative to the illness and death of a child.

Mothers want to preserve the memory of their children and become involved in a growing and changing process as they work to locate and/or create appropriate support systems for themselves and others. They have much to teach professionals about interacting with themselves and their families.

During the process of conducting the study, I became aware of how much time had passed in my own bereavement—a long process of adjustment, of negotiating a comfortable space in my life for the memory of my child to exist in the present, to exist, but not to consume all of my time, my energy, my love.
REFERENCES


Initial Interview Guide

Thank you for agreeing to talk with me. I'd like to learn about your experiences surrounding the death of your child. As I mentioned when we first spoke, my 7-month old baby died in 1985. You may have some questions you'd like to ask me before we begin [pause for response].

I realize that it is sometimes hard to talk about a child's death. I want you to know that I don't feel there is "one right way" to think, feel, or act and will respect what you tell me.

Are there things I can do to help make you more comfortable? Please take your time in responding and don't hesitate to ask if you have needs or concerns.

INDIVIDUAL LEVEL QUESTIONS:

1. Could we begin by having you tell me about yourself?
   Birthplace:
   Date of birth:
   Educational Background:
   Work Identification (paid or unpaid):  
   Tell me a little about your parents (where they live, relationships with them, etc.):
   Your Sisters/Brothers: Their Ages: Place of Residence:
   Your Religious Identification:
   Your Children's Names and Ages:
   Any Health Concerns:
2. Tell me about your child who died. Name:
   Date of Birth:
   What was it like when he/she was born?
3. When did she/he die?
4. Tell me about that time?
5. How have you been affected by this experience? [Use
   probes to elicit thoughts, feelings, actions, and so
   on.]
6. [If the death occurred many years ago, try to follow the
   woman's perception of the bereavement experience over
   time.] How have your experiences changed over time?
   stayed the same?
7. In your opinion, how long does bereavement last after
   the death of a child? [Define bereavement as thoughts,
   feelings, and actions after the death.]
8. Were there times your grief seemed less powerful? What
   was different about those times? [Probe to uncover how
   the mothers were supported by others.]

DYADIC LEVEL QUESTIONS:
1. Are you in a primary relationship with someone (partner,
   spouse)? Name: How long? [If relationship has
   changed, obtain information about each, if possible.
   Will be guided by cues of the woman.]
2. How did ____ support you after the death?
3. How has this relationship changed over time?
4. What would you like to be different?

FAMILIAL LEVEL QUESTIONS:
1. How would you define your family? i.e., Who is in you family? What relationship to you?
2. How did each of these people react to the death?
3. Were these family members helpful/not helpful to you? How?
4. What would you like to teach other families?

SOCIAL NETWORK
1. Next, consider your social network. Define this group; it could be friends, neighbors, co-workers, perhaps religious group. When ____ died, what did they say and/or do?
2. What was helpful? Not helpful?
3. If you could teach these people something about your experience, what would it be?

COMMUNITY
1. How have members of your community responded to ____ death?
2. Have these things been helpful/not helpful to you?
3. Now consider others you came in contact with surrounding
_____ death, such as doctors, nurses, counselors, social workers, teachers, other parents, and so on. Tell me how they responded to _____ death.

4. What was helpful/not helpful to you?

5. What would you like to say to each of them now?

6. If the systems we come in contact with could be changed to help us better, what would you change? what would you teach?

CULTURAL/HISTORICAL

1. With what cultural/ethnic group do you identify?

2. What messages do you feel young girls receive about how they should live? [probe for "good mother" if necessary].

3. Where do these messages come from?

4. How would you like to change these messages?

5. Do you think you are a good mother? How has _____ death affected you as a mother?
Second Interview Guide

NOTE: The primary purposes of the second interview will be (1) to gain an understanding of additional contextual influences surrounding death and dying that may affect respondents’ bereavement experiences, (2) to fill in gaps remaining from the first interview, (3) to respond to any questions the respondents may have for me, and (4) to thank them for participating in the study.

1. Thinking back over your life, what bereavement experiences stand out to you? Please begin with your earliest memories, moving forward to the present time.

   The following open-ended statements are a guide in reviewing each significant experience:

   The experience was __________________
   My feelings were __________________
   Parents/friends/others were _________
   I learned__________________________

2. How do these experiences compare with your experiences since ___ death?

3. Think back now over our time together. Are there questions you’d like to add to the study? If so, what? How would you respond?

4. Are there things that you would like to add from any of the other questions?
5. Do you have other questions for me?

6. How has this interview experience affected you? [Talk about how I have been affected by the interviews.]

7. Would you be interested in my contacting you in about a year to get back together for a followup interview?

8. Thank you for talking with me... [Closure, good-byes, affirmation, a small token from me to each respondent as a "thank you"].
Title of Project: Reflexive Conversations with Bereaved Mothers: A Feminist and Contextual Perspective

Principal Investigator: Elizabeth B. Farnsworth

I. THE PURPOSE OF THIS RESEARCH

You are invited to participate in a study of the bereavement of mothers who have experienced the death of a young child. The purpose of this project will be to increase understanding of the ways the death of a child affects mothers on multiple levels. This study involves 10 subjects.

II. PROCEDURES

The procedures to be used in this research are in-depth interviews. You will be asked to be available for two interviews with me. I expect that the initial interview will last 2 to 3 hours, and the followup interview will last 1 to 1-1/2 hours.

You may experience uncomfortable feelings as you reflect on your child’s death. However, parental bereavement literature also suggests that talking about a child who has died is a way of commemorating the child’s life and may be helpful to bereaved parents.

I will attempt at all times to be respectful and supportive of your experiences. If at any time, however, you wish to discontinue an interview or withdraw from the study, please indicate to me that you wish to do so.

I am a graduate student researcher at Virginia Tech, and this study will be conducted under the direction of my major professor, Dr. Katherine R. Allen.

III. BENEFITS OF THIS PROJECT

Your participation will provide information about the bereavement process of mothers that may be helpful to other parents and helping professionals; however, no guarantee of
benefits has been made to encourage you to participate in this study. As noted above, talking about a child who has died may help parents commemorate or honor their child, and this may be a possible benefit to you as a participant.

You may receive a synopsis or summary of this research when completed. Please indicate to me that you are interested in receiving a synopsis. I am interested in your feedback on a draft of the Results if you are interested; however, this is not required.

IV. **EXTENT OF ANONYMITY AND CONFIDENTIALITY**

The responses of individuals who participate in this study will be kept strictly confidential. At no time will the researcher release the results of the study to anyone other than individuals working on the project without your written consent. The information you provide will have your name removed and only an identification number or pseudonym will identify you during analyses and any written reports of the research.

The interviews will be audiotaped for transcription purposes. They will only be reviewed by Elizabeth B. Farnsworth and will be erased following transcription.

Ethical standards in the conduct of research do require, however, that the researcher assist individuals in locating therapeutic assistance, if needed, or to break confidentiality to obtain services should a respondent present a danger to self or others.

If as a result of this project, we determine that you should seek counseling or medical treatment, the following are available:

- The Compassionate Friends Support Group (804-385-6030),
- Resolve Through Sharing Support Group (804-947-4642),
- Crisis Hot Line (804-947-4357),
- The Assessment Center at Virginia Baptist Hospital (804-947-4444),
- Lynchburg Counseling Center (804-847-8000).

If assistance other than that listed above is needed, please talk to me, and I will help you locate appropriate services.
V. FREEDOM TO WITHDRAW

You are free to withdraw from this study at any time without penalty.

VI. APPROVAL OF RESEARCH

This research project has been approved, as required, by the Institutional Review Board for Research Involving Human Subjects at Virginia Polytechnic Institute and State University and the Department of Family and Child Development.

VII. SUBJECT'S RESPONSIBILITIES

I know of no reason I cannot participate in the study. We will set up interviews at a convenient time and place. I agree to call Elizabeth Farnsworth if unable to keep an appointment.

__________________________
Signature
VIII. SUBJECT’S PERMISSION

I have read and understand the informed consent and conditions of this project. I have had all my questions answered. I hereby acknowledge the above and give my voluntary consent for participation in this project.

If I participate, I may withdraw at any time without penalty. I agree to abide by the rules of the project.

Should I have any questions about this research or its conduct, I will contact:

___________________________  703-586-6102  Phone
Elizabeth B. Farnsworth
Investigator

___________________________  703-231-6526  Phone
Katherine R. Allen
Faculty Advisor

___________________________  703-231-6077  Phone
E. R. Stout
Chair, Institutional Review Board
Research Division
APPENDIX C
CODING CATEGORIES

100 TALKING ABOUT MYSELF
101 Current age and birthplace
102 Education
103 Work Identification
104 My parents (where they are, relationships with them)
105 My siblings (where they are, relationships with them)
106 Religious/spiritual identification
107 Names and ages of my children
108 Health concerns
109 Current residential arrangements

200 REMEMBERING THE CHILD WHO DIED
210 Birth recollections
211 Interactions with medical staff
212 Fathers’ reactions/interactions
213 Other children’s needs/concerns
214 Mementos (books, journals, photos, blankets, clothing)

300 RELIVING THE DEATH
315 Details of death (time, place, what happened, etc.)
316 Mothers’ thoughts, feelings, actions
317 Funerals/memorial services
318 Humor
319 Sources of help

400 LIVING SINCE THE DEATH
420 Changes in mothers (cognitive, emotional, behavioral, spiritual)
421 Couple/intimate relationships
422 Experiences with other children
423 Extended family relationships
424 Paid and unpaid work
425 Support groups/therapy/medical care
426 Reaching out to others

500 PRIOR DEATH/BEREAVEMENT EXPERIENCES
527 Prior experiences with death/bereavement

600 METHODS CODES
628 Mothers’ perceptions of the research process
629 Comments by the researcher
630 Collaboration with doctoral advisor
APPENDIX D
VITA

ELIZABETH B. FARNSWORTH

Rt. 1, Box 87AA3
Goode, VA 24556
(703) 586-6102

EDUCATION


Post-master’s coursework, 1990, Department of Counselor Education, University of Virginia.


B. A., 1980, Department of Psychology, Lynchburg College. cum laude.

Extensive reading and on-going seminars and workshops in grief and loss, parenting, and therapeutic issues.

PROFESSIONAL EXPERIENCE


Assistant Professor (Adjunct): Central Virginia Community College. August 1993 to present. HLT 226 AIDS Awareness.


Consultant: Technical Assistance Center at Lynchburg College. 1988 to present. Lecturer/workshop presenter.


HONORS AND AWARDS

Graduate Student Teaching Award, 1992. Department of Family and Child Development. Virginia Polytechnic Institute & State University.

Chi Sigma Iota (Counseling Academic & Professional Honor Society).

Psi Chi National Honor Society (Psychology).

REFEREED PRESENTATIONS

Farnsworth, E. B. (Submitted for consideration). Reflexive conversations with bereaved mothers: A feminist and contextual perspective. Round Table, Feminism and Family Studies Section, National Council on Family Relations, Minneapolis, Minnesota.


Farnsworth, E. B., & Dwyer, S. (Submitted for consideration). Ethical considerations in qualitative research: Feminist perspectives. Round Table, Feminism and Family Studies Section, National Council on Family Relations, Minneapolis, Minnesota.

PUBLICATIONS


PROFESSIONAL AFFILIATIONS

National Council on Family Relations.
   Feminism and Family Studies Section.
   Families and Health Section.
Qualitative Family Research Network.
Association for Death Education and Counseling.
National Certified Counselor (NBCC-NCC).
American Counseling Association.
Virginia Counseling Association.

PROFESSIONAL SERVICE

Association for Retarded Citizens - past board member.
Mental Health Association - past board member.
Compassionate Friends - past board member.
Rape Companion Program volunteer.
Volunteer - "Developing Understanding of Self and Others"
   DUSO Puppet Program for Elementary Schools.
Parents Anonymous Sponsor.

INVITED PRESENTATIONS AND WORKSHOPS

"Grief Counseling and Communication," Presenter to RTS
Bereavement Services Counselor Training Course, Virginia
Baptist Hospital, Lynchburg, Va., March 18, 1994.

"Families and grief," Guest lecture to Families and Children
Under Stress class, Virginia Tech, Blacksburg, Va., October
4, 1993.

"Families and grief," Guest lecture to Families and Children
Under Stress class, Virginia Tech, Blacksburg, Va.,

"Parental grief: Toward contextual understanding," Southwest
Virginia Regional Coordinating Councils, 2nd Annual New

"Families and grief," Presentation to Marriage and Family
Dynamics class, Virginia Tech, Blacksburg, Va., April 9,
1993.

"Families and grief," Presentation to Marriage and Family
Dynamics class, Virginia Tech, Blacksburg, Va., March 31,
1993.

"Gender: What is it, anyway?" Presentation for Women's History Month, Woman's Resource Center, Lynchburg, Va., March 15, 1993.

"Responding to the bereaved student," University of Virginia EDHS 589 course, Lynchburg, Va., June 30, 1992.

"Helping families adjust to the birth or death of a child with special needs," Technical Assistance Centers I and II Regional Conference, Fairfax, Va., April 3, 1992.


"Accessing early intervention services," Central Virginia Community College, CHD 216 course, Lynchburg, Va., June 1, 1990.

"Supporting the grieving parent," Danville Memorial Hospital, Danville, Va., April 5, 1990.

"Life after diagnosis: What now?," Kluge Children's Rehabilitation Center, Charlottesville, Va., March 8, 1990.


"How to start and maintain parent support groups," Kluge Children's Rehabilitation Center, Charlottesville, Va., February 9, 1989.

"Journey through grief: Help, hope, and insight," Georgia State University, Atlanta, Ga., October 24, 1988.

March, 1994

160