Family Bereavement Experiences after Sudden Cardiac Death

By

Dorothy “Dale” M. Mayer

A Dissertation

Presented to

Oregon Health & Science University

School of Nursing

In partial fulfillment

of the requirements for the degree of

Doctor of Philosophy

December 1, 2009

Approved

_____
Anne G. Rosenfeld, Ph.D., R.N., F.A.H.A., C.N.S. Professor
Dissertation chair

_____
Kathleen R. Gilbert, Ph.D., Associate Professor
Committee Member

_____
Judith Kendall, RN, Ph.D., Professor
Committee Member

_____
Michael R. Bleich, Ph.D., R.N., M.P.H., F.A.A.N.,
Dean, School of Nursing

Acknowledgements

I am deeply grateful for the dissertation support provided by Montana State University College of Nursing Helen Jacobsen Lee Endowment, Saint Patrick Hospital and Health Foundation, and the Dean's Award for Doctoral Dissertation. I appreciate the support of my committee, Anne Rosenfeld, Judith Kendall, and Kathleen Gilbert for their ongoing support and encouragement throughout the dissertation process.

A special thank you goes to Anne Rosenfeld, who has become my friend and mentor over the years. This dissertation would not have been possible without her ongoing patience and guidance. I appreciate her friendship and I am very thankful for her confidence in me.

This dissertation is dedicated to my husband, Douglas W. Mayer, who always supported and encouraged me personally and professionally, and whose sudden cardiac death inspired this study. I wish to thank my family, especially my children, Abigail, Andrew, and Christopher, who give meaning to my life and whose presence helped me maintain perspective as I completed my doctoral program. I also wish to thank Ralph A. Mackey, who encouraged me to persevere and helped me laugh and love after my life course was profoundly changed.

Thank you to my colleagues at Montana State University College of Nursing who supported my journey through the doctoral program and dissertation. Thank you also to my friends who were always available for support and encouragement over time.

I wish to acknowledge the seven families who allowed me to be a part of their lives. Thank you for sharing stories of your bereavement experiences with me. I am a different person for knowing you, and your family member who died a sudden cardiac death. I greatly appreciate that you opened your home and heart to me, and shared your grief with me through your stories.

ABSTRACT

TITLE: Family Bereavement Experiences after Sudden Cardiac Death

AUTHOR: Dorothy "Dale" M. Mayer

APPROVED: _____
Anne Rosenfeld, Ph.D., R.N., F.A.H.A., C.N.S.

Purpose:

The purpose of this study was to understand family bereavement experiences after the sudden cardiac death (SCD) of a family member. Aims included description of bereavement experiences and identification of meanings of loss across families.

Background:

Cardiac disease is the leading cause of death and SCD is on the rise, especially in younger adults. The SCD of middle aged adults, who are often in the prime of their lives, is devastating for surviving family members and greatly disrupts their sense of self and shatters their feelings of security. Bereavement research has focused on the response of individuals to grief and loss and little is known about the impact of SCD on multiple surviving family members. Family roles and tasks are radically changed after death of a family member and when the death is unexpected surviving family members are challenged to make sense of their loss.

Methods:

A qualitative approach, narrative analysis, was used to analyze family and individual stories of bereavement. Seven families who experienced the SCD of a family member within the last 5 years participated. Eligibility criteria limited the decedent's age to 20 and 55 years old at the time of death. Family interviews, which averaged 96 minutes, were conducted with a minimum of two family members, followed by individual interviews with 17 family members. Open ended

questions were used to encourage the sharing of stories. Participants talked about the decedent, the days preceding the death, the death itself, and their bereavement experiences.

Results: Five themes were identified across families: 1) Sudden cardiac death … boom; 2) Saying goodbye; 3) Grief unleashes volatile emotional reactions; 4) Life goes on … but never back to normal; and 5) Meanings in loss. At the heart of family bereavement experiences is the challenge of moving on with life, a life forever changed by the SCD of an important family member, while still remaining a connection to this important person. During bereavement, surviving family members took steps forward to build their new life, but these steps were frequently interrupted by hurdles and sudden "booms" of grief. Through this process family members generally found meanings in their loss.

Implications:

Sudden cardiac death has long lasting impacts on surviving family members. Sharing stories of loss may allow family members an opportunity to make sense of their experiences and help them identify meanings of loss. This in turn may facilitate their ability to continue living after a devastating loss. Professionals working with bereaved families may benefit from knowledge of the positive aspects of sharing stories of loss. Further research is needed before developing nursing interventions to support families after SCD of a family member.

Key words

Family
Bereavement
Narrative
Sudden cardiac death

Table of Contents

List of Tables and Figures

Introduction

Bereavement, as a universal human experience that all individuals will someday face, is an objective situation that occurs after the death of a significant person. Bereavement is an experience of such magnitude and intensity that rarely is one ever prepared to fully comprehend the meaning and cope with the emotional reactions that accompany the death of family member. Grief is defined as the subjective response to a loss (Stroebe, Hansson, Stroebe & Schut, 2001a). A grieving person, by nature of having experienced the death of a family member, enters a period of bereavement (Stroebe et al., 2001a). It is important to note that the death of a family member leaves a lasting impact not only on individuals, but on family members and family systems as well.

To date almost all bereavement research has focused on the individual responses to grief and loss. However in recent years researchers and clinicians have developed an awareness of the need to understand the family's experience of grief and loss (Gilbert, 1996; Nadeau, 1998; Neimeyer, 2001). This need arises from an appreciation that grief impacts not only individuals but family systems as well. Family roles and tasks are radically changed after death of a family member (Shapiro, 1994). The family structure is critical to both its individual members and the larger social order as individuals' efforts to organize into various family forms across cultures and over time as one of the most enduring practices of humankind (Gilliss & Knafl, 1999). The family has great importance as a fundamental social structure; therefore, this study will focus on family bereavement experiences. The purpose of this study is to describe the family's experiences after the sudden cardiac death of a family member in order to identify meanings of loss.

The causes and circumstances surrounding a death influence a family's reaction during bereavement with certain types of deaths being more challenging for survivors (Worden, 2002). These types of deaths include suicides, sudden death, sudden infant death, miscarriage and stillbirths, abortion, and deaths due to acquired immunodeficiency syndrome (AIDS). If the death is unexpected or occurs suddenly, for example from an automobile accident or a myocardial infarction, the surviving family members of the deceased are challenged to live in a world "…without purpose or meaning" (Parkes, 1975, p. 130). This loss of meaning can interfere dramatically with established family routines and habits that have previously provided a sense of safety and purpose for the family unit. Death, especially sudden death, results in a major threat to a person's sense of security and disrupts the "…taken for granted realities of everyday life" (Berger & Luckman, 1966, p. 101). The challenge that individuals and family's face during bereavement is a return to "…the order and security of everyday life" (Nadeau, 1998, p. 7-8).

Bereavement after sudden death has been noted by researchers and clinicians to be more challenging for survivors (Worden, 2002). For example, an unexpected or sudden death, as compared to an anticipated death, has been documented in both the clinical and research literature to cause "greater vulnerability to grief that is prolonged and difficult to integrate and resolve" (Parkes & Weiss, 1983; Stroebe & Stroebe, 1987). The challenge for surviving family members after a sudden death is to "make sense of their experience…" and to "…create order out of the chaos…" (Nadeau, 1998, p. 2). Research supports the idea that surviving family members who are able to find meanings in loss (Nadeau, 1998; Neimeyer, 2001) may experience more positive adaptation during bereavement than those who are unable to find meanings and purpose for the loss.

Deaths that occur in young adulthood, defined as between age 20 to 45 years, are experienced as out of sequence (Gilbert, 2001) and leave surviving family members facing unique challenges. This is the developmental age when adults develop personal relationships and focus on affection and love (Erickson, 1963). Surviving family members, who frequently are at the same developmental age, will often face overwhelming challenges related to dealing with their own grief and possibly their children's grief. At this developmental stage the bereaved frequently feel isolated and "different" from their peer group, which may add a sense of disenfranchisement (Gilbert; Worden, 2002). An out-of-sequence sudden cardiac death may stress surviving family members to a great extent.

Significance of the Study

Sudden cardiac deaths affect a large number of families on an annual basis. The American Heart Association (AHA, 2004) reports that approximately 335,000 people a year die of coronary heart disease before reaching a hospital. Most of these deaths would be classified as sudden cardiac death. About 80% of all sudden cardiac arrests happen at home (AHA) where family members may witness the arrest. Many sudden cardiac deaths occur during individuals' most productive years (AHA), and this fact alone will likely negatively impact surviving family members. Approximately 50% of men and 64% of woman who died suddenly had no previous symptoms of cardiac disease (AHA). Of particular concern is the fact that the sudden death rate has increased by 30% in young women and is rising in younger age groups (AHA; Center for Disease Control (CDC), 2001). These numbers provide a sense of the magnitude of the impact sudden cardiac death has on families.

Specific Aims

The specific aims of this research proposal are to

1. Describe the bereavement experiences of families who have survived the out of sequence sudden cardiac death of a family member.
2. Identify the meanings of loss across and within the family's experiences.

Nursing Implications

It is important to examine family experiences after sudden cardiac death because of the life altering impact of death on surviving family members. Nurses are often present at the time of death and are therefore in a position to assist families. The interaction between health care providers and survivors at the time of death may impact a family's grief response (Parrish, Hodren, Skiendzielewski, & Lumpkin, 1987). However, many nurses report a lack of education and a lack of skills to provide family support at the time of death (Mian, 1990; Scorro, Tolson & Flemming, 2001; Tye, 1993). Therefore, nurses and health care providers need knowledge about family bereavement to structure these interactions as supportive.

It is vital that we gain understanding of family experiences after sudden death of a family member before we develop nursing interventions to support these families. Although no one can take away the pain of grief, nurses are often present and may be in a position to help family members at this difficult time. Knowledge of family experiences after sudden cardiac death is especially important for nurses who work in cardiac units, emergency departments, and those working with families.

Researcher's Personal Experience

This research study was influenced by both professional and personal experiences. Professionally I have worked clinically as a nurse for 25 years, the last 20 years as a cardiovascular clinical nurse specialist. In this capacity I have worked with cardiac patients and their families in both inpatient and outpatient settings.

On a personal note, in June of 2000, my husband died suddenly after suffering a fatal myocardial infarction and cardiac arrest. As a nurse I was familiar with the clinical care provided initially by paramedics and later by nurses and physicians in the emergency department (ED). Despite of years of education and clinical experience, I was unprepared for my life once I left the hospital. Although supported by ED nurses at the time of my husband's death, nursing support ended abruptly once I left the hospital setting. Some families may not receive any nursing support at the time of a family member's death, especially if the individual is not transported to a hospital. A literature search revealed limited information of the impact of family bereavement, especially after sudden cardiac death. This personal experience, coupled with an awareness of the need for family support after sudden death, motivated me to enroll in a doctoral program so I could systematically investigate this topic. The goal of my dissertation research is to investigate the family's experiences after sudden cardiac death of a family member. Future plans include the development and testing of nursing interventions to support families after sudden death. I also plan to work with nurses to increase their knowledge and skill level to improve care of families after sudden death.

Review of Literature

The purpose of this chapter is to review the bereavement literature, including related grief and loss literature, which influences our knowledge and understanding of bereavement. This literature review will support the current study, which seeks to describe family experiences after the sudden cardiac death of a family member in order to identify the meanings of loss. The specific aims of this study are to

1. Describe the bereavement experiences of families who have survived the out of sequence sudden cardiac death of a family member and

2. Identify meanings of loss across and within families' experiences.

Both clinicians and researchers from many different disciplines have been interested in the topic of bereavement (Stroebe et al., 2001a). This interest has been aimed at both gaining an understanding of the bereavement experience as well as helping bereaved individuals. As Bowlby (1980) so eloquently writes,

> loss of a loved person is one of the most intensely painful experiences any human being can suffer. And not only is it painful to experience but it is also painful to witness, if only because we are so impotent to help. (p. 7)

Research on bereavement has had a multidisciplinary focus and includes studies conducted in the fields of psychology, sociology, nursing, gerontology, medicine, and epidemiology among others (Stroebe et al, 2001a). This multidisciplinary approach to bereavement has provided a wide range of information from experts in many fields. Stroebe et al. (2001a) in their *Handbook of Bereavement Research*, acknowledge that the bereavement experience has been empirically studied and can be considered, "…an established scientific

discipline" (p. 21). The purpose of this chapter is to provide a review of the current knowledge of bereavement and address the limits of our knowledge of bereavement.

Definitions of Terms

It is important to define the terms bereavement and grief. Because of common usage these terms may seem self-explanatory. However, there are important differences. Based on the work of bereavement researchers Stroebe et al., (2001a) the terms can be differentiated as follows: bereavement is an objective situation that develops after the death of someone significant while grief is the emotional or affective reaction to a death. Over the course of a lifetime all individuals will experience bereavement after the death of significant persons in their lives. These significant persons often include grandparents, parents, siblings, spouses, partners, children, and friends. Grief may occur in response to conditions other than death of a significant person, for example divorce, death of a pet, loss of one's job or a body part such as a limb. For purposes of this literature review this chapter will only address grief resulting from death of a person.

Models of Coping with Bereavement

According to Stroebe and Schut (2001) bereavement, especially coping with bereavement, has been conceptualized in three broad groupings: (a) stress theories, (b) grief theories, including phase and task models, and (c) bereavement models of coping. Initially reviewed will be the theories applied to bereavement with particular emphasis on the empirical evidence supporting these theories.

Stress Theories.

Stress theory conceptualizes stress in one of three orientations: (a) response based, (b) stimulus based, and (c) transaction based. Most germane to this discussion are the stimulus based and transaction based response to stress.

Stimulus based stress theory.

In a stimulus based model the term stress is synonymous with life events. Holmes and Rahe (1967) proposed that life changes, or "life events" were stimuli that served as stressor(s), which forced a person to respond. They theorized that, "too many life changes increases one's vulnerability to illness" (as cited in Lyon, 2000, p. 7). In this conceptualization the stressful 'life event' would be death of a loved one. This stimulus based model has several assumptions including that (a) life changes are normative and each change results in a similar response for all who experience this life change; (b) change is stressful regardless of the desirability of the change; and (c) when the stress level exceeds a common threshold of readjustment, illness occurs (Lyon). Later work by Rahe (as cited in Lyon) incorporated the idea that the person's interpretation of the life event as positive or negative might influence the impact of the stress.

When applying the assumption that 'life changes are normative' to the topic of sudden cardiac death one realizes that sudden cardiac death is often not anticipated. Although death is normative, it is the suddenness of a cardiac death due to acute myocardial infarction or ventricular arrhythmias that leave surviving family members unprepared. Another important consideration is related to the age at which the death occurs. The sudden death of a young person is certainly not considered normative and will contribute additional stress to an already stressful event. The surviving family members' acceptance of the death as a positive or negative event may influence the amount of stress associated with the death. This acceptance of death as positive or negative will be discussed in more detail in the section on family bereavement.

Sudden deaths and death at a young age will also be discussed further in the section on factors influencing bereavement.

Transactional based stress theory.

In the transaction based model Lazarus and Folkman (1984) proposed that stress is a result of the transaction between the person and their environment. This conceptualization suggests that stress is experienced when the demands of the situation outweigh available resources. This model would consider bereavement a stressor that may exert demands on individuals which surpass their resources. This model is well suited to the study of bereavement because it includes coping, which is defined as the efforts to decrease or manage the stress. These coping efforts may either be emotion-focused coping or problem-focused coping (Lyon 2000). One limitation of this model is that it only addresses one stressor, bereavement, when in reality the bereaved actually report numerous stressors such as changes in their financial status or living arrangements that occur concurrently with bereavement (Stroebe & Schut, 1999).

Empirical evidence related to the use of the transaction model of stress theory in relation to bereavement is evident in research conducted by Folkmann and colleagues (Folkmann, 1997; Folkman, 2001; Folkman, Chesney, Collette, Boccellari & Cooke, 1996; Folkmann & Moskowitz, 2000; Moskowitz, Folkman, Collette, & Vittinghoff, 1996; Park & Folkmann, 1997). These investigators conducted a longitudinal study, which included 253 men who were caregivers for partners with acquired immune deficiency syndrome (AIDS). This study utilized a repeated measures comparison group design to evaluate the effects of care-giving and bereavement on health, both mental and physical health, of partners of men with AIDS. The study included two groups of caregivers, one group of caregivers were human immunodeficiency virus (HIV) positive partners (n = 86); and one group of caregivers were HIV negative partners

(n = 167). These two groups were compared to a third group of HIV positive non-caregivers (n = 61) which served as a non-care giving comparison group. Participants were interviewed twice a month for two years and twice a year over the ensuing three years. One feature associated with this study is that all the deaths were anticipated out-of-sequence deaths of young men. All participants were young males with an average age of 39 when they enrolled in the study (Folkman, 2001).

Similar to studies conducted with conjugally bereaved individuals (Bornstein, Clayton, Halikas, Maurice, & Robins1973; Zisook & Shuchter, 1986) this study by Folkman and colleagues found increased distress and depressive symptoms throughout the period of care giving and through 7 months of bereavement (Folkmann et al., 1996; Folkman, 2001). Findings documented that participants frequently reported a positive state of mind and positive affect throughout the care giving and bereavement time period (Folkmanm 1997). This positive outlook was present at all interview times except for the time immediate surrounding the death of their partner. Folkman and colleagues (2001) theorized that coping, either active problem focused or positive reappraisal, were responsible for maintaining the positive affect during care giving and bereavement. The use of positive reappraisal coping was most evident at five years into bereavement when qualitative methods were used to ask participants to describe what they had learned and how they had changed as a result of their care giving and bereavement experience. The majority of participants reported only positive meanings, such as improved self worth and increased strength and wisdom, associated with their experience (Moskowitz, Acree, & Folkman, 1998).

Of interest to the current study is that Folkman (2001) acknowledged that the participants shared information in their stories related to the death of their partner. These stories revealed

coping strategies not captured via quantitative measures such as details on coping and adaptive tasks. These details will be addressed in the section on interpersonal coping models, specifically the dual process model of bereavement developed by Stroebe and Schut (1999). It is important to note that all participants in this study experienced a period of care giving prior to bereavement. This study of sudden cardiac death likely will not include the same level of care giving associated with an anticipated death. Research is needed to determine the impact of sudden cardiac death on coping strategies during bereavement.

Grief Theories.

Two of the most influential grief theories conceptualize grief and bereavement in relation to psychoanalytic and attachment perspectives. Sigmund Freud, who is considered the father of psychoanalysis, wrote a landmark paper in 1917 titled *"Mourning and Melancholia"* (1957) which was based on a limited number of clinical observations. John Bowlby (1980) took the first step away from looking at grief and loss as a pathological condition and moved the discussion forward to the loss of attachment. Grief and bereavement will be discussed in relation to the psychoanalytic and attachment perspective.

Initially grief, and the subsequent period of bereavement, was described using a psychoanalytical approach. Freud (1957) used the word "trauern," which translates from German as "mourning," to mean both the affect of grief and its outward manifestations. He compared mourning, which he defined as the "reaction to loss of a loved person…" (p. 243) to melancholia, which he defined as "related to an object-loss which is withdrawn from consciousness" (p. 245). Melancholia is what we would now call depression. Freud differentiated the loss associated with mourning as a conscious loss, while melancholia was an unconscious loss. Freud did not consider mourning a pathological condition but he considered

melancholia pathological and therefore required medical or psychological treatment. Freud identified similarities in that both mourning and melancholia involved dejection, lack of interest in the outside world, loss of capacity to love, and reluctance to participate in activities. He differentiated the two conditions when he identified the lowering of self-esteem only occurring with melancholia. Today, however, we acknowledge that self-esteem is lowered during bereavement (Stroebe & Stroebe, 1987) but that in most bereavement situations this eventually resolves without intervention.

Freud's (1957) paper, *Mourning and Melancholia,* greatly influenced subsequent clinicians and researchers including Eric Lindemann (1944), John Bowlby (1980) and Colin Murray Parkes (1970, 1971, 1972). Freud's description of the unconscious nature of mourning helped explain the cognitive manifestations of grief including an extreme preoccupation with the deceased as well as hallucinations and dreams of the decedent. Freud's work has been critiqued (Bradbury 2001) and his descriptions of normal and abnormal grief have been challenged (Stroebe & Stroebe, 1987).

The psychoanalytical approach to bereavement has focused on the need for "grief work" initially proposed by Freud (1957). This "grief work" was thought to be required in order for the bereaved to separate from the deceased. Freud wrote that "grief work" is "...carried out bit by bit, at great expense of time and cathectic energy…" (p. 245). During "grief work" the libido must examine each memory of the lost object and withdraw its attachment, also known as decathexis, from that attachment figure. No time frame is suggested for how long it takes this "work of mourning" to occur but Freud acknowledged that the work of grief is "extraordinarily painful" (p. 245). It is important to note that Freud's theory was not congruent with his personal bereavement experience at the time of his daughter's death. This will be discussed further in the

subsequent section on factors influencing bereavement. The concept of "grief work" will be discussed in more depth in a subsequent section as well.

Attachment theory, which was developed by the British psychiatrist John Bowlby, has been applied to the experience of grief and bereavement. Bowlby (1980) published a three-volume work titled *Attachment and Loss*. Volume III focuses on loss, including sadness and depression, and is applicable to the current study. John Bowlby is considered the father of attachment theory (Karen, 1990). Attachment theory addresses the fact that all infants become attached to their primary caregiver and this attachment is developed during the ages of 6 – 12 months. This attachment in the parent-child relationship is crucial for the child to develop a sense of self. These attachments are important and significant, especially during childhood, but are lifelong activities as later in life adult to adult attachment occurs. Bowlby (1980) defined developmental stages based on the bond between mother and child and that separations from the primary caregiver, often the mother, are disastrous. He states that, "a lasting or untimely disruption brings on anxiety, grief, and depression" (Karen, 1990, p. 41). Bowlby (1980) states, "the goal of attachment behavior is to maintain an attachment bond" (p. 42). Death, especially sudden death, abruptly ends the attachment bond of both children and adults. Even though Bowlby's (1980) attachment theory centered predominantly on the attachment that occurs between a child and a parent, his theory on loss addresses the idea that death of a spouse breaks the adult-to-adult attachment.

Attachment theory conceptualizes bereavement as a response to separation. Bowlby's (1980) research on attachment theory was conducted as observational studies with young children who were separated from their primary caregiver or attachment figure, generally their mother. During separation from their mothers children were described as initially being angry at

this separation. This period of anger, or protest, was then followed by a period of yearning for the return of their mother. When the attachment figure did not return this yearning turned into despair. This pattern of periods of anger followed by periods of yearning eventually leading to despair when the separation continued has been documented in studies of bereavement.

Empirical support for aspects of bereavement and grief, as conceptualized by attachment theory, is recognized in the research studies conducted by Colin Murray Parkes who viewed bereavement as a time of psychosocial transition (Parkes, 1971). Parkes, a British psychiatrist, was one of the first researchers to examine the impact of bereavement over time. Parkes' prolific program of bereavement research was conducted over many years both in England and the United States. For this review three studies will be discussed: (a) the London Study which was designed to develop a picture of normal grief (1970); (b) the Harvard study which examined the health status after conjugal bereavement in a young age group (Glick, Weiss & Parkes 1974; Parkes & Brown, 1972); and (c) a sub-study which involved a subset of bereaved individuals enrolled in the Harvard study that was analyzed for the impact of untimely and unexpected bereavement (Parkes, 1975). The study, which focuses on unexpected and untimely bereavement, will be addressed in the section on factors influencing bereavement, specifically type of death.

The London study conducted by Parkes (1970) was designed to establish a picture of normal grief in widows age 65 or younger. This study was designed to determine how 22 London widows coped during bereavement (Parkes). The study examined the first year of bereavement and included five interviews (1, 3, 6, 9, and 13months). The final interview was purposely conducted at 13 months in order to avoid "anniversary reactions" (p. 25). Participants were recruited via physicians in the London area. Both qualitative and quantitative data was

collected. The first part of the interview consisted of the widow's account of her experience. The second part of the interview was based on direct observation of the interviewer combined with the widow's account. For example, if the widow reported restlessness, the interviewer observed for hyperactivity and graded it as absent, mild, moderate, marked, or very marked. Information collected at the first interview consisted of the identification of the husband's terminal illness, circumstances of the death, and information related to the participants' life situation and family history. Subsequent interviews included the widow's report of events and reactions since the previous interview. At the final interview ratings of psychological, social and physical adjustment were collected.

Parkes (1970) documented the frequent initial occurrence of a state of numbness upon learning of the death of a spouse. This state of numbness was often followed by a strong sense of yearning and pining for the deceased loved one. Many widows developed a "perceptual set" (p. 451) or perception of their deceased husband and reported being very restless, which Parkes theorizes is a result of 'searching' for their husband. Parkes identified that widows developed a preoccupation with thoughts of the deceased, and this, along with pining for the deceased, was the "…central and pathonomonic feature of grief" (p. 451). Close to 50% of the participants were drawn to places and objects that reminded them of their spouse. Also evident over the course of the first year of bereavement were the emotions of anger, guilt, and social withdrawal. Many of the participants developed ways to alleviate the distress of bereavement, which included denial, partial disbelief, avoidance of painful thoughts, and remembering pleasant or neutral thoughts. Parkes described common manifestations of bereavement including a lack of appetite, sleep disturbances, and loss of interest in the outside world. Over the first year of bereavement these common expressions of grief decreased in frequency as more normal patterns returned. After

this study Parkes relocated to Boston and collaborated with bereavement researchers at Harvard in an attempt to "study a larger sample to discover why some people coped well with bereavement and emerged stronger and wiser and others suffered lasting psychiatric and other problems" (Parkes, 2001, p. 30).

In the Harvard Bereavement Study, researchers Glick, Weiss, and Parkes (1974), attempted to discover how bereavement affected both the emotional and social lives of younger people after the death of a spouse. This longitudinal study examined the course of recovery over the first year of bereavement and attempted to identify factors which either facilitated or hindered this recovery. Three interviews were conducted (3 weeks, 6 weeks, &13 months) and the final sample consisted of 49 widows and 19 widowers from the Boston area. Additional funding subsequently allowed for a late follow-up interview conducted between two and four years after the death with almost 90% of the original participants. Open-ended interviews were conducted and interviewers had a list of questions which focused on the participants' bereavement experience. This study is notable for its collection of both qualitative and quantitative data.

Early reactions to bereavement included shock and disbelief, crying, sadness, despair, sleeplessness, lack of appetite, disorganization, and occasional loss of self control (Glick et al., 1974). Reports of shock and disbelief were especially evident if there was little forewarning of the death. These reactions occurred, and frequently reappeared, throughout the first year of bereavement, diminishing in intensity and frequency over time. In respect to grieving, according to Glick et al. by the second interview at six weeks many respondents "seemed already to have passed through the worst" (p. 120) of their grieving. By about two months after the death of a spouse most participants, exact figures not provided, considered themselves 'recovered' enough

to deal with their responsibilities. Glick et al. concluded that for many participants the early phase of bereavement had ended between six to eight weeks after the death although some episodes of grief still occurred. Most participants reported experiences when they sensed the presence of their spouse and this presence was often found to be comforting. Glick et al. reported that 64% of the widows reported thinking of their spouse "often" or "a lot" (p. 143) after one year had passed since the death of their husband. In the Harvard Study Parkes and his colleagues (Glick et al.,) clearly documented patterns of anger, yearning and despair in bereaved adults grieving the death of their spouse. These findings were incorporated into phase models of grief resolution.

Phase models.

Bowlby (1980), and his colleague Parkes (1970, 1972) proposed similar models of grief resolution that involved included four phases: (a) phase of numbing; (b) phase of yearning and searching; (c) phase of disorganization and despair; and (d) phase of reorganization and recovery. Bowlby described the phase of numbing as being short lived and said it "usually lasts from a few hours to a week" (p. 85). The phase of yearning and searching is marked by restlessness, insomnia, and preoccupation with thoughts of the loved one. Phase three, disorganization and despair, and phase four, reorganization and recovery, are phases of variable emotions. During these phases it is necessary for the bereaved person to experience various emotions, and is marked by pining, searching, and questioning how and why the loss occurred. Bowlby proposed that it is only by recognizing the reality of the loss that the bereaved is able to redefine themselves.

The phase models of grief have been criticized since they imply a passive and somewhat step-wise progression through grief. Although they were developed after observation and

interview with grieving individuals, and it appear that these models address the progression of grief over time, there is little empirical evidence to support them (Gilbert &Smart, 1992). Even when researchers acknowledged that movement from one phase to the next was not distinct and that the phases often overlap (Parkes, 1971), assumptions were made related to progression through the stages. It was assumed that the resolution of grief would be achieved, and that these phases could be applied to individuals as well as families (Gilbert & Smart, 1992). These criticisms of the phase models of grief led to new conceptualizations including task models, and interpersonal coping models of bereavement including the dual process model of bereavement and continuing bonds.

Task models.

In a book written from a counseling perspective Worden (2002), a practicing clinician and researcher, identified a need for a more proactive approach to bereavement. Worden, who used the word mourning to indicate the process which occurs after a loss, identified tasks of mourning. Worden explicitly used the word task in the belief that it was more consistent with the idea of "grief work." These tasks allowed the bereaved to take action to overcome what they frequently describe as the helplessness of grief. Worden's tasks of mourning include the following four tasks: (a) accept the reality of the loss; (b) work through the pain of grief; (c) adjust to an environment in which the deceased is missing; and (d) emotionally relocate the deceased and move on with life. Task one includes both a cognitive as well as an emotional acceptance of the loss and occurs over time. The amount of time it takes the bereaved to accept the reality of the loss varies and cannot be predicted. Most individuals experience pain when someone they were attached to dies. Therefore task two involves confronting this pain, which may include feelings such as sadness, hopelessness, anxiety, anger, guilt, and loneliness among

others. The third task of mourning involves the behavioral adjustments the bereaved face after death of a loved one. Worden identifies three types of adjustment including: external adjustments in day-to-day living; internal adjustments to sense of self; and spiritual adjustment which includes the beliefs, values, and assumptions the bereaved is now experiencing. The fourth task of mourning involves emotional relocation of the deceased so the bereaved can move on with life. Worden acknowledges that this task requires the bereaved to "find a place for the deceased that will enable the mourner to be connected with the deceased but in a way that will not preclude him or her from going on with life" (p. 35).

Freud (1957), Bowlby (1980), and Worden (2002) all incorporated the idea of "grief work" into their theories. Freud proposed that the work of grief required the bereaved to face the reality of their loss in order to separate their libido from the loved–object. He believed that this work occurred "bit by bit, at great expense of time and cathectic energy" (p. 245). Once this work was done he believed that the ego would be "free and uninhibited again" (p. 245). Bowlby's attachment theory proposed that the bereaved must work through their grief and that it is only by recognizing the reality of the loss that allows the bereaved to redefine themselves. Worden's task model included a more proactive approach to grief and involved the tasks that should be done by the bereaved.

The idea of "grief work" led to the commonly held belief that individuals should "get over" the death of a significant person (Cook & Bosley, 1995). It has often been accepted that bereaved individuals must engage in "grief work" in order to "get over" their loss (Stroebe & Schut, 2001). Recently this idea of "grief work" has been challenged (Rosenblatt, 1993; Stroebe, 1992-1993; Wortman & Silver, 1989) as has the assumption that the bereaved will "get over" their grief (Stroebe & Stroebe, 1987). The concept of grief work, which Stroebe (1992-

1993) identified as the "grief work hypothesis," has only been tested in a small number of correlational studies (Wortman & Silver, 1989; Pennebaker & O'Heeron, 1984) and experimental studies (Mawson, Marks, Ramm, & Stern, 1981; Pennebaker & Beall, 1986; Pennebaker, Colder, & Sharp, 1990; Pennebaker, Kiecolt-Glaser, & Glaser, 1988) Findings of these studies have led to conflicting results and it is generally acknowledged that grief work is not a universal phenomenon (Stroebe, 1992-1993). However, both "grief work" and "getting over grief," still influence current thinking about bereavement.

Interpersonal coping models.

More recently researchers have conceptualized that that relocation of the deceased is not possible and have introduced the conceptualization of a continued, but different relationship, with the deceased. These conceptualizations include the dual process model (DPM) of coping with bereavement (Stroebe &Schut, 1999) and continuing bonds (Klass, Silverman, & Nickman, 1996).

Dual process model of bereavement.

Stroebe and Schut (1999) developed the dual process model (DPM) of bereavement initially to understand coping after the death of a partner but may be applicable to other bereavement situations. The DPM identified two types of stressors associated with bereavement: stressors associated with loss and stressors associated with restoration. Loss oriented stressors involved the bereaved processing the loss itself while restoration orientation stressors refer to secondary stressors that occur as a result of bereavement. The bereaved oscillate between loss-oriented experiences (for example, thoughts about the deceased or circumstances of the death) and restoration-oriented experiences (such as dealing with life changes since the death). The central component of this model involves the process of moving between stressors associated

with loss and stressors associated with restoration. Stroebe and Schut call this process of moving back and forth oscillation. The researchers theorize that this oscillation is important because it allows the bereaved to maintain their mental and physical health by allowing for adjustment over time.

Empirical work using the DPM of coping with bereavement includes a study of 200 widowed men during the second year of bereavement (Richardson & Balaswamy, 2001). The sample was divided into two groups depending on the length of bereavement. One group, labeled the early bereavement group, had been widowed less than 500 days; while the late bereavement group had been widowed greater than 500 days. Demographic factors (age, race, educational background, income level, and living arrangements) were similar between the two groups. Interviews consisted of questions that asked about experiences at the time of death, subsequent personal relationships and socialization patterns, along with the bereaved sense of well-being. Consistent with the DPM of bereavement responses were categorized into measures which focused on loss versus measures which focused on restoration.

Results supported the dual process model of bereavement and suggested that early bereavement has a greater focus on loss-oriented stressors while later bereavement focuses more on restoration stressors (Richardson & Balaswamy, 2001). For example loss-oriented stressors such as the circumstances related to the death itself have more impact during early bereavement, while other situations, for example dating, impact later bereavement. These findings have added empirical support to the proposed model of bereavement which describes bereavement as a process of movement between a loss oriented focus to a restoration orientated focus occurring over time (Stroebe & Schut, 1999).

Continuing bonds.

Klass, Silverman and Nickman (1996), in their book entitled *"Continuing bonds: New understandings of grief"* offered a concept of bereavement that was based on the suggestion that the bereaved do not detach from, but instead, maintain continuing bonds with the deceased. The thesis underlying this conceptualization of bereavement acknowledges that the bereaved have reported a continued, although different, relationship with the deceased. This phenomenon of continued presence has been documented in several studies (Glick, Weiss, & Parkes, 1974; Parkes, 1972; Rees, 1971; Stroebe & Stroebe, 1987). However researchers working from the psychoanalytic perspective frequently considered reports of the continued presence of the deceased as a type of hallucination or an indicator of chronic grief (Parkes & Weiss, 1983; Raphael, 1983; Rees, 1971). In spite of evidence that widows often reported a continuing bond with their deceased husbands, bereavement researchers did not change their conceptualization of grief to reflect the continued presence of the deceased. For example, Parkes and colleagues (Glick et al.,) noticed that widows were maintaining a connection with their deceased husbands and they documented that at one year 69% of the widowed participants in the Harvard study agreed that their actions and thoughts were still were influenced by their husbands. Glick et al., stated, "Almost all widows reported repeated experiences of feeling their husband was just about to arrive home, or was with them" (p. 146). These researchers acknowledged this phenomenon but never incorporated it into their theory of bereavement stating, "We are unable to give reliable figures regarding the incidence of the sense of the husbands presence…direct questions were not… asked…since we had not anticipated the phenomenon" (p. 146).

Klass and colleagues (1996) proposed the suggestion of continuing bonds as an alternative theory to the prevailing dominant paradigm of grief, which emphasized the need to detach from the deceased. It is important to note that empirically the evidence for continued

bonds with the deceased is somewhat limited but includes qualitative studies conducted by several researchers including Klass (1996), Rosennblatt; (1983), Shuchter and Zisook (1993), and Silverman and Nickman (1996).

Rosenblatt (1983) reviewed unpublished diaries from the 19th century and reported evidence of continuing bonds recorded in the diaries. Examples of a continued relationship included naming a child after deceased family member, reports of the continued sense of the deceased as well as continued spiritual connections with the deceased. Rosenblatt then compared the evidence in the diaries with the prevailing grief theories of the 20th century, which required detaching from the deceased and concluded that there was less emphasis on detachment in the 19th century.

Shuchter and Zisook's (1993) research utilized a multidimensional approach to examine conjugal grief experiences. They conducted a longitudinal study that included 350 recently bereaved widows and widowers. Participants answered a series of questionnaires and completed a structured interview 2 months after the death of their spouse. Follow-up questionnaires were also completed at 7 and 13 months after the death. Their results included identification of six dimensions of grief: (a) emotional and cognitive responses; (b) coping with emotional pain; (c) continued relationship with the deceased spouse; (d) changes in functioning; (e) changes in relationships; and (f) changes in identity. Of interest to this discussion is the dimension which addresses the continuing relationship between widows and their deceased husbands. Shuchter and Zisook reported that at 13 months after the death of a spouse 63% of respondents felt the presence of their deceased spouse, 47% felt their deceased spouse was looking over them and 34% reported conversation with their deceased spouse on a regular basis. This study confirmed that at 13 months bereaved spouses often maintain some type of relationship with their deceased

spouse. Further assessment revealed that elements of this continued relationship was evident in the bereaved reports of their memories and dreams, as well as their description of various rituals.

Klass's (1996) research, conducted in Japan, was specifically related to ancestor worship within the Buddhist culture. His report focused on the use of home altars, memorial tablets, graves and other rituals, as evidence of a continued relationship between the deceased, in the Japanese culture. He concluded, "…ancestor worship is an expression of the human community that cannot be separated by death" (p. 70). Although these results are instinctively believable and compelling toward the idea of continuing bonds, strong empirical evidence is not provided (Stroebe & Schut, 2005).

Silverman and Nickman (1996), as part of the Child Bereavement Study conducted in Boston, examined continuing bonds between bereaved children and a deceased parent (Silverman, Nickman, & Worden, 1992; Silverman & Worden, 1992). The Child Bereavement Study involved 70 families and 125 children. The children were, on average, 12 years old and were evenly male and female. Most of the parental deaths were fathers (74%) and the surviving parents were young adults with an average age of 41 years. These researchers utilized a subset of 24 families from the Child Bereavement Study to describe how children create connections to their deceased parents (Silverman & Nickman, 1996) and examine if the children's perceptions of their deceased parent change over time (Normand, Silverman & Nickman, 1996).

Silverman and Nickman (1996) described activities used by children to create connections to their deceased parent. They found that children often were able to describe where they thought their parent was (i.e., heaven) and that 81% they felt that their parent was still looking over them. Over half the children worked to maintain a connection with their deceased parent. Activities included visiting the cemetery and talking with their parent. Children also

stay connected by retaining personal possessions of the deceased parent. Almost all children reported thinking about their deceased parent several times a week. Silverman and Nickman (1996) concluded that bereavement may be a process that involves both cognition and emotion and that this process occurs in a social context in which a connection with the deceased is maintained over time.

The concept of continuing bonds has been challenged (Stroebe & Schut, 2005). Although the evidence provided by Klass et al.'s (1996) is inherently convincing, there is a lack of empirical evidence supporting the idea that continuing bonds between the bereaved and the deceased are associated with a better outcome for the bereaved. Additional research is needed to describe the types of continuing bonds the bereaved maintain with the deceased. These types of bonds then need to be examined in order to determine if certain types of continuing bonds "provide comfort and promote adjustment" (Stroebe & Schut, p. 48) in order to compare them to bonds that may "…reflect severe grief reactions" (p. 49).

Factors Influencing Bereavement

Type of death.

Research has supported the idea that an anticipated death, (for example death due to advanced age or a terminal diagnosis) allows for a gradual realization that change is imminent. However when a death is unexpected (for example, death due to an accident or a sudden illness) surviving family members experience a sudden and severe disruption in their world**.** This raises the question: What are the theoretical implications of sudden death?

Sudden death is defined as those deaths "that occur without warning" (Worden, 2002, p.125). Research that has been conducted after sudden death has established that sudden deaths are more difficult to grieve than anticipated deaths (Parkes, 1975; Rando, 1991; Worden, 2002).

It has often been theorized that younger people would have more difficulties during bereavement (Lindemann, 1944; Lehrman, 1956; Parkes, 1970; Pollock, 1961; Siggins, 1966; Volkan, 1970; Levinson, 1972); therefore researchers purposively recruited participants less than age 45 (Parkes, 1970; Glick et al., 1974).

As mentioned previously, Parkes and colleagues (1972; 1975) examined unexpected and untimely bereavement when they interviewed 68 Boston area widows and widowers under the age of 45 who lost a spouse to death. The study was specifically designed to obtain information about health status during bereavement. Each participant was interviewed three times (at 3 weeks, 6 weeks, & 13 months) over the first year of bereavement and most were re-interviewed once again in the subsequent three years. The bereaved group was compared to a non-bereaved control group (n = 68) matched for age, sex, family size, nationality, and occupational class.

Parkes et al. (1972; 1975) were interested in learning what influenced a 'good' versus 'bad' adjustment to bereavement. In order to do this they identified outcome measures which allowed identification of subgroups with 'good' and 'bad' outcomes. This then allowed for statistical analysis to successfully distinguish the groups by outcome. Of 18 key measures used in the study, seven variables were found to be most predictive of bereavement outcome. These variables included (a) the coders' prediction of outcome, (b) the presence of yearning, (c) the participants' attitude about their own death, (d) the duration of terminal illness, (e) socioeconomic status, and (f) the presence of either anger or (g) self reproach in the early weeks of bereavement.

Of importance to the current study is the duration of illness preceding the death. A 'bad outcome' during bereavement was more often associated with a brief illness or accidental death. In an attempt to examine the impact of both the "duration of illness and duration of termination"

(Parkes, 1975, p. 124) identified a subgroup of 24 participants who had less than two weeks forewarning that their spouses' condition was likely fatal and less than three days warning that death was imminent. They labeled this subgroup the Short Preparation Group and compared it to the remaining 46 participants, labeled the Long Preparation Group, who had more forewarning. Findings indicated that a sudden and untimely death seemed to cause a more difficult bereavement. Over all interviews the Short Preparation Group consistently demonstrated more disturbances in their physical health (sleeping, appetite, & concentration), along with restlessness, depression, and loneliness.

The initial interview, conducted in the first month of bereavement, indicated the short preparation group had an overall presentation of shock followed by anxiety and variable feelings including anger and guilt (Parkes, 1975). In contrast the Long Preparation Group was more accepting of the death, with less anxiety and emotional disturbance reported. This pattern continued in the later interviews as well. Parkes concluded that an unexpected death causes an abrupt change and it is the lack of preparation for that change that immediately throws the survivors into a world "…without purpose or meaning" (p. 130).

Parkes and Brown (1972) reported evidence of impaired health in the recently bereaved group compared to the control group at approximately fourteen months into bereavement. Impaired health included disturbances in sleep, appetite, weight, and increased use of alcohol tobacco, and tranquilizers in the bereaved group. The bereaved group also had more reports of depression, restlessness, worries, and difficulty making decisions. Caution is needed when examining the results of Parke and colleagues (1972; 1975) studies. It is important to note that the sample was self selected, 50% of the potential participants recruited declined to participate, and one sixth of the sample dropped out over the first year.

Bowlby (1980) addressed the impact of an untimely or sudden death. He stated "sudden death can be a great shock to a survivor and contribute to certain kinds of psychological difficulty" (p. 181) since the final view of the body will impact memories either favorably or unfavorably. It is assumed that Bowlby is referring to the fact that lack of disfiguration or mutilation of the body leaves the bereaved with better memories than a disfigured or mutilated body (for example due to automobile accident). In the case of sudden death the bereaved may receive notification in various ways. Bowlby stated "disbelief is made much easier when death has occurred at a distance and also when information is conveyed by strangers" (p. 182). He also stated that there "seems little doubt that the more direct the knowledge the less tendency is there for disbelief that death has occurred to persist" (p. 182). Activities that promote the direct knowledge include allowing the bereaved to see the body and using direct language to avoid conveying false or untrue information. Bowlby commented that keeping the death "secret," as sometimes occurs with children, "promotes vivid and persistent beliefs that the dead person is still living and will return" (p. 182).

In conclusion, it is reasonable to expect that the type of death may impact bereavement. Sudden death has often been thought to be more difficult for survivors than an anticipated death (Parkes, 1975; Rando, 1991; Worden, 2002) and when the decedent is young, the difficulties for survivors' may be greater still. For example, contrast the impact of death on families when a 90-year-old dies suddenly versus a 45-year-old mother of three young children who dies suddenly. However, these assumptions have been obtained primarily from the clinical literature with only limited empirical evidence supporting them. Well-designed research needs to be conducted in order to determine the impact of sudden death on the bereavement experience.

Out of Sequence/Untimely Death.

A death that occurs in a relatively young person is considered an untimely death (Lehrman, 1956). The normal sequence of life includes the assumption that older people will die before younger people, children will outlive their parents and grandparents will die before their grandchildren. Therefore, the death of a young person, even if anticipated, is considered as a death that occurs out of sequence.

It has often been theorized by bereavement researchers that younger people would have more difficulties during bereavement. Consequently studies have been conducted specifically with younger bereaved participants. The Harvard Bereavement Study, conducted by Glick, Weiss, & Parkes (1974), discussed earlier, purposely recruited participants under age 45. In this study the researchers reported a positive correlation between knowledge of the impending death of their spouse and their recovery over the first year of bereavement. This was in contrast to the participants' who did not have much forewarning of the death, many of whom displayed symptoms of "unresolved grief" at the end of the first year of bereavement. It is important to acknowledge that the researchers used the term "unresolved grief" to refer to the presence of anxiety in an unspecified number of widows and widowers at follow-up interviews two to four years after the death of a spouse. The presence of anxiety in a sample of bereaved spouses would no longer be considered an indicator of unresolved grief.

Other Factors.

A constant question asked by researchers and clinicians' working in the field of grief and loss is related to the duration of grief and bereavement. Initially clinicians and researchers both theorized that grief would resolve rather quickly. Freud (1957) described the end of grief as occurring "when the work of mourning is completed the ego becomes free and uninhibited again" (p. 245). He implied that the resolution of grief was straightforward although he

suggested that grief might be time-consuming and painful. However, when Freud experienced the death of his daughter he wrote to friends that he was experiencing a "grief without end" (Freud & Gay 1989, p. 392 - 393). Lindemann (1944) reported that with the help of a psychiatrist the work of an uncomplicated grief reaction could be settled over a four to six week period. Marris (1958) stated that "It may take two years or more to become reconciled with bereavement…" (p. 125). Bowlby (1980) stated that a minority of people never achieve a resolution of grief, but that a majority of people do so in 2 to 3 years. Parkes (1965) initially placed an arbitrary limit of 6 months on the duration of grief but stated a need for "further investigation" (p. 3). His later research related to grief after the death of a spouse indicated that grief was still present at 13 months (Parkes, 1972).

Research suggests that when death is sudden or traumatic it may take considerably longer for grief resolution (Parkes & Weiss, 1983) with some researches proposing that grief never resolves it just gets less intense. Parkes (1970) wrote about the duration of grief: "In some senses it [grief] never ends…" (p. 464) but as time passes features of grief become less common and intense.

In recent years there has been recognition that bereavement occurs within a social context, generally involving family and friends, and often includes a process of meaning reconstruction (Stroebe & Schut, 2001; Neimeyer, 2001). Research, based on symbolic interactionism and family systems theory, has been conducted in relation to if, and how, bereaved individuals participate in meaning reconstruction (Neimeyer) after the death of a family member. Of interest to this researcher is the suggestion that bereaved individuals often develop stories or narratives about the life and death of the person who has died (Stroebe & Schut, 2001). These stories or narratives can be accessed and examined for meaning in loss. Some researchers

have examined the process of meaning making with groups such as families (Nadeau, 1998, 2001) or examined grief in the context of family (Sharpiro, 1994).

Family Bereavement

Despite all we have learned about bereavement, the bulk of our knowledge comes from the perspective of bereaved individuals not families (Nadeau, 1998). Only a small number of research studies have been conducted on the family bereavement experience.

Davies (1987) investigated family grief after the death of a child. She utilized qualitative methods, specifically grounded theory and a systems perspective, with particular attention focused on how families dealt with memories of the deceased child. Davies purposely asked about what the families did with the children's belongings, specifically their clothes, bedroom, and special mementos. Davis also asked if the family had developed anything special to honor the deceased child. Findings documented a variety of family behaviors related to the child's possessions. Theoretically, Davis proposed that the child's possessions often serve as "memories with meanings" (p. 9). The family meanings attached to the memories may be congruent or discrepant; Davis hypothesized that that discrepant family meaning may negatively influence bereavement. More research is needed in order to determine if these findings are applicable when the deceased family member is an adult instead of a child. Further research is also needed to determine the impact of family meanings after the death of an adult family member.

Nadeau (1998) used qualitative methods, specifically a version of grounded theory, to identify how families found meanings after death of a member. A total of 48 individual family members from 10 families participated in this study. Nadeau reported that all families she interviewed were "eager to tell their stories" (p. 111), and the stories were both about the death itself and their experiences since the death. Nadeau documented that meanings were found

"embedded in the stories that families told…" (p. 71) and the meanings connected to the death impacted the course of bereavement. Patterns of meaning making occurred at several levels including the individual level, couple level, dyadic level, and family level. Nadeau identified factors which either encouraged or inhibited family meaning making. Meaning making was encouraged when families demonstrated acceptance of differences and interacted regularly as families and collectively shared together in rituals. Meaning making was inhibited or deterred when family dynamics included rules, which limited discussion of sensitive topics, or when family members worked to protect other family members from hurtful thoughts or comments.

Of particular interest is that two of the families in Nadeau's (1998) study experienced the sudden death of a family member. Both were out-of-sequence deaths occurring at young age: one a 49-year-old male who had a sudden cardiac death due to a myocardial infarction; and one a 39-year-old male killed in a plane crash. Meanings for these families included the idea that sudden deaths, especially if the decedent was young, were considered meaningless. Also noted was the idea that the unexpected death of a young family member may lead to negative meaning making or the inability of the family to find any meaning. These two families expressed meanings related to the death occurring too soon or prematurely. Often the death of the young family member was compared to the death of an older person. For example one family compared the death of a young father with children to the death of the elderly grandmother with cancer. It appears that families who experienced an unexpected death or the death of a young member had more difficulty making sense of the death (Nadeau, 2001). These findings need to be explored with a larger sample of families who have experienced the sudden death of a young family member.

Kissane and colleagues (Kissane et al., 1996a; Kissane et al., 1996b; Kissane, Bloch, & McKenzie, 1997) studied 115 families as part of the Melbourne Family Grief Study. Families completed measures of functioning, including grief intensity, psychological status, social adjustment, and family coping, at three intervals after the death of a parent. Five family types were identified: supportive; conflict resolving; sullen; hostile; and intermediate types. Well-functioning family types, supportive and conflict resolving, demonstrated improved grief resolution and adaptation compared to poorly functioning family types.

In spite of these research studies it is important to note that the literature on family bereavement is primarily of a clinical nature (Shapiro, 2001). Therefore, it is imperative that research examining family bereavement experiences be conducted. Due to the confounding factors that impact the bereavement experience it is important to obtain sample characteristics that minimize these confounding factors. Shapiro makes a case for clarity related to sample characteristics, such as the circumstances of the death, and a need to explicitly describe family demographics such as the family structure and stage of the family life cycle.

Impact of Bereavement

Meanings in Loss.

In recent years a movement has been underway to get away from the idea that bereavement involves "letting go or detaching" from the deceased in order to "move on" and "recover or get over" grief. Neimeyer (2001) suggests a conceptualization for grief that acknowledges "meaning reconstruction in response to a loss is the central process in grieving" (p. 4). Neimeyer (2005) has proposed a paradigm of grief which acknowledges that humans who have suffered a loss to death participate in meaning reconstruction as they cope with their loss. This paradigm utilizes a "constructivist" view which recognizes that human beings are constantly involved in a

search for meaning. Research conducted by Neimeyer and Anderson (2002) supports the idea that an ability to find meaning in experiences of loss predicts positive outcomes, in contrast to the inability to find meaning in loss which has been associated with more intense, chronic, and complicated forms of grief (Uren & Wastell, 2002; Davis, Nolen-Hoksema, & Larson, 1998). Neimeyer and Anderson (2002) studied people bereaved by violent death, such as suicide, homicide, and accidents. Neimeyer (2005) articulated that a meaning reconstruction model of grief may "enhance counseling and psychotherapy with bereaved individuals" (p. 29) as well as "deepen our scientific understanding of narratives of loss…" (p. 29).

Many bereaved individuals develop self-narratives, conveyed as stories, which provide significance to their life. The death of a significance person disrupts the taken for granted assumptions on which their life story was previously based. It is clear that reactions to loss due to death vary depending on the meaning applied to the death. Stroebe and Shut (2001) stated, "How a person feels and reacts on becoming bereaved is dependent on the meaning that is assigned to the loss" (p. 56). One of the inherent challenges in relation to bereavement research related to meaning is the difficulty in operationally defining the term "meaning." Researchers operating from the perspective of attachment theory (Bowlby, 1980) examined the attachment relationship in order to discover meaning of loss whereas researchers working from the perspective of psychoanalytic theory (Freud, 1957) examined the breaking of bonds between the survivors and the deceased. Parkes (1993) focused on the psychosocial transition of bereavement in order to delineate the mental and social aspects of loss. The dual process model of bereavement (Stroebe & Schut, 1999) conceptualizes meaning as a process that occurs during the moving between loss oriented and restoration oriented experiences. Nadeau (1998) studied how families make meaning from a family system perspective.

Clinically many therapists have assumed that the search for meaning is important after loss (Davis, Wortman, Lehman, & Silver, 2000). Empirically, this search for meaning has found that many individuals search for meaning in loss, and this search for meaning may be especially important when the loss is sudden and unexpected. (Cornwell, Nurcombe, & Stevens, 1977; Helmrath & Steinitz, 1978; Parkes & Weiss, 1983; Moos & Schaefer, 1986; Gilbert, 1997; Neimeyer, 2004;).

There is empirical evidence that demonstrates personal growth after struggle with a loss due to death. Calhoun and Tedeschi (2001) report that some, but not all, people report some aspect of personal growth after a struggle with loss. They term this posttraumatic growth. This growth can be manifested in many ways although it is important to note that this growth does not eliminate the pain and distress of loss. People who report posttraumatic growth can often identify both positive and negative growth. This growth is reported by a significant number of individuals who have experienced the death of a child, spouse, parent, or diagnosis of an illness (Calhoun & Tedeschi). Researchers have documented posttraumatic growth occurring in three categories: changed sense of self; change of relationships; and change in one's philosophy of life. A changed sense of self occurs when individuals express an increased feeling of vulnerability and acknowledgement that life is fragile and precious. Individuals report changes in their relationships when they describe being more empathetic and emotionally connecting with others. Some individuals report a different or new purpose in life, reflecting a change in their personal philosophy of life.

There is a great need to further investigate the phenomenon of posttraumatic growth. Questions include (a) does more loss, or sudden loss, mean more growth? (b) what is the impact

of certain deaths, say a sudden death, on posttraumatic growth? and (c) what is the impact of individual factors, such as personality, gender, and coping, on posttraumatic growth?

Stories of Death

Every death produces a story and this story will be somewhat different for each person telling the story. Generally the story includes the details of the actual death itself -- information about the circumstances of the death and specifics related to the sequence of events leading to and following the death. Also included are details about the circumstances surrounding each family member when they were notified about the death (Sedney, Baker & Gross, 1994).

Stories about a death enable the storyteller to articulate and organize the myriad of emotional laden events into a sequence containing some sense of order. According to Sedney, Baker, and Gross (1994) telling stories of a death can help make experience meaningful. One of the first activities suddenly bereaved individuals engage in is attempting to understand what has happened. Telling the story of their experience, which requires sequencing and structure to compose the story, can help achieve understanding.

Summary

In summary, this review of literature documents that historically there have been three major schools of thought that have been used to study the experience of bereavement. These schools of thought examined bereavement from the perspective of (a) stress theories, (b) grief theories, and (c) models of coping. Stress theory considered bereavement a life stressor that will eventually impact all individuals. Grief theories examined bereavement from the perspective of psychoanalytic theory (Freud, 1957), attachment theory (Bowlby, 1980), and psychosocial transition (Parkes and colleagues, 1971; 1972, 1983). These two perspectives have influenced researchers and clinicians alike and are centered on the idea that the goal of bereavement is

detachment, or, to use Freud's term, "decathexis." For this detachment to occur, the bereaved are expected to participate in "grief work." More recently, the third school of thought, specifically models of coping, have taken a step away from the idea of detachment in an attempt to incorporate the idea of a continued, albeit different, relationship which develops over time between the bereaved and the deceased. These conceptualizations include the dual process model of bereavement and the concept of continuing bonds.

Research conducted on the experience of bereavement includes both quantitative and qualitative studies with tremendous growth in the number of studies over the last 20 years (Genevro, Marshall, & Miller, 2004). Findings across bereavement studies indicate that although the experience of bereavement may be universal, the responses to loss after death are variable. It is now appreciated that the goal of bereavement may not necessarily be detachment and that a continued relationship between the bereaved and the deceased may not be indicative of abnormal coping. Loss due to death, although almost always distressing, may lead to growth; however, not all individuals experience distress during bereavement. Grieving individuals and families, in most instances, will progress thorough bereavement without a need for psychiatric intervention. However some individuals and families may experience a complicated bereavement with negative health consequences.

Recently there have been concentrated efforts to study the response to bereavement with a focus on determining how humans make sense of their experience. These efforts include meaning making as well as meaning reconstruction (Neimeyer, 2001; Neimeyer, Prigerson, & Davies, 2002). In these studies the experience of bereavement is often expressed via a story or narrative experience.

Most of what we know about grief and loss comes from the perspective of grieving adults. Essentially most empirical research on bereavement has focused on the death of a spouse (Stroebe & Stroebe, 1987). And the majority of participants in studies involving bereavement have been female widows living in Western countries (Stroebe et al., 2001a). Family bereavement is less well understood and the literature on family bereavement is primarily of a clinical nature (Shapiro, 2001). It is important to study the family bereavement experience since death not only impact individuals but families as well.

Although we know a great deal about the bereavement experience our knowledge remains somewhat limited. It is important to acknowledge that, as Neimeyer and Hogan (2001) noted, "[a]lthough the human experience of bereavement has often been studied; it has not often been studied well" (p.110). Gaps in the bereavement literature include the lack of an understanding of the factors and circumstances of death, which may place bereaved persons at risk of complications or lead to a deterioration in health status. Reactions to bereavement may also be influenced by pre-loss experiences such as care giving and the quality of the pre-loss relationship before the death. It is of particular importance to note that we do not understand how circumstance of the death may influence the experience of bereavement. It is also important to discover if and how individuals find meaning by asking if they are able to make sense of the death of a family member. This may be especially important with certain types of death. We also have a need to identify protective factors, for example resilience or personality factors, which may influence the bereavement experience. Also missing from the bereavement literature are the voices of the bereaved themselves, especially the voices of bereaved children.

Conclusions

Given our current knowledge of the bereavement experience it is important to recognize how this knowledge of bereavement literature reviewed here, along with my personal experience, influences the current study.

Bereavement is a universal experience and is likely one of the most challenging life experiences any individual will face. And although the individual experience of bereavement is important to study, it is essential that we recognize that bereavement generally occurs in a social context. Bereaved individuals grieve together with family and friends and we have a great need to understand the bereavement experiences of families. The bereavement literature contains an incomplete picture of the bereavement experience of families and rarely does this literature emphasize the voices of the bereaved.

The current study is designed to examine the family experience after the out-of-sequence sudden cardiac death of a family member. The experience of family bereavement may be different when the death is sudden and unexpected and the family member dies at a young age. One of the strengths of the current study is that it will examine the family experience from the perspective of the families themselves. The current study seeks to provide an avenue for these families to share their voices, as well as their stories of bereavement, with health care professionals. Stories, especially stories associated with the death of a family member, are usually quite compelling and often contain important information. The current study will collect stories after the sudden cardiac death of a family member in order to describe the family bereavement experience and attempt to identify the family meaning of loss. I believe these stories will contain significant information for nurses and other health care professionals caring for families.

Research Design and Methods

A qualitative research approach, specifically narrative analysis, was used to analyze stories collected from families and individual family members after sudden cardiac death of a family member. People live in stories and have a natural tendency to tell stories (Gilbert 2002), however, bereaved individuals are rarely asked to tell stories about death and grief (Caverhill, 2002). Reasons for not asking for these stories are related to the fact that talking about death is not comfortable. In fact, for many people death is a "taboo topic" (Bookbinder, Kiss, & Matzo, 2006, p. 91). "Narrative analysis takes as its object of investigation the story itself" (Riessman, 1993, p. 1). This qualitative method was chosen because the bereaved are socially isolated (Clements, DeRanieri, Viril & Benasutti, 2004) and frequently describe their grief and bereavement experience as a lonely trek (Clements et al.). It is documented that the bereaved are often socially discouraged from sharing stories about death and loss (Carverhill). Therefore I collected and analyzed family stories related to death, and experiences since the death, in order to identify meanings of loss.

This chapter outlines the conceptual guidelines that assured the methodological rigor of narrative analysis and concludes with a description of the study design. This includes strategies for finding participants, sample selection, data collection and analysis, and protection of human subjects.

Narrative Analysis

Narrative seeks to find the meaning people hold about their experience through stories. People often tell stories as a way to understand their world (Polkinghorne, 1988; Riessman, 1993); their stories can be a means of accessing the emotional aspects of an experience. Personal stories provide an avenue for individuals to arrange their experiences into an organized

format (Bruner, 1990). These personal stories may then provide the structure needed to allow individuals to "make meaning by creating and exploring our stories" (Gilbert, 2002, p. 224) with interested listeners.

Narrative analysis is a method of collecting and interpreting stories. Stories provide researchers with data in order to gain understanding and to clarify persons' experiences. Stories can also be used to discover new knowledge. Of particular interest to this researcher is that stories can identify implicit or hidden meanings embedded in an experience (Nadeau, 1998; Neimeyer, 2001). Endeavoring to understand the human experience narrative is a very appropriate method to utilize because humans have a natural inclination to tell stories (Gilbert, 2002). As a method, narrative is a suitable approach when investigating and attempting to understand experience.

Clandenin and Connelly (2000) state that, "narrative is both the phenomenon and the method of the social sciences" (p 18). The social sciences, including anthropology, philosophy, psychology, sociology, history, and others, are considered the "human sciences." Nursing has been described as a "practical human science" (Polifroni & Welch, 1999) whose purpose is to integrate theory and practice in order to improve patient care. Unlike the natural sciences, which have an aim of explanation and description, the human sciences have an aim of understanding or what Dilthey, a 19th century German philosopher, called "Verstehen" (as cited in Rickman, 1979). Dilthey distinguished the natural sciences and the human sciences when he delineated the difference between nature, which requires explanation, and mind, which requires understanding. Dilthey identified several characteristics unique to the human sciences; these characteristics include (a) the purposefulness inherent with human life, (b) the idea that humans make value judgments, (c) the importance that rules, norms, and principals have on humans, and

(d) the idea that human life is historical (as cited in Rickman). The central tenet of the human sciences is "Verstehen;" this understanding is a universal daily event for humans that serves as a source of all knowledge, is unique to humans, and is the essential element of the methods of the human studies (as cited in Rickman). "Verstehen" is both a complex process by which we understand human action as well as a method (Schwandt, 2000). To understand human action one must grasp the meanings that contribute to the action. Interpretative methods propose that human action is meaningful, but in order to find this meaning in action one has to understand the action. The act of understanding requires interpretation of the action (Schwandt, 2000).

Narrative analysis is an interdisciplinary method. Several disciplines using narratives to explore the human experience include sociology (Riessman, 1993), psychology (Polkinghorn, 1988), education (Clandenin & Connelly, 2000) anthropology (Geertz, 1995), and medical anthropology (Kleinman, 1988).

Various qualitative methods have been used to explore the bereavement experience. While each qualitative method has its own strengths and weaknesses, it is important for researchers to choose the method most appropriate for the research questions. Ethnography examines the impact of culture that influence an experience. Certainly social customs and cultural rituals may significantly influence the death and bereavement experience. However, the influence of culture was not the focus of this study. Phenomenology, with its focus on the lived experience, could be used to study the experience of family bereavement. Phenomenology seeks knowledge in order to gain description and find meaning (Welch, 1999). Phenomenology takes a philosophical approach when seeking knowledge leading to description and is influenced by the work of Husserl and Heidegger (Welch). Husserl's approach is focused on epistemology while Heidegger is more focused on ontology or the nature of reality. It is not the researchers'

intention to totally focus on epistemology or ontology in order to seek knowledge and description of the family experience after sudden cardiac death, therefore phenomenology is not the method utilized in this study. Grounded theory is a qualitative method designed to examine phenomena with a new perspective in order to develop theory. Grounded theory has been used to study the family bereavement experience (Nadeau 1998), however it is not the intent of this study to develop new theory.

This researcher has chosen narrative analysis due to the fact that the bereaved are often socially discouraged from sharing stories about death and loss (Caverhill, 2002; Steeves & Kahn, 2005). Narrative analysis seeks to discover what meanings people hold about their experience that can be discovered through stories. The out of sequence sudden death of a family member upsets the natural order and disrupts the surviving family member's lives in numerous ways. Narrative analysis fits well with the topic of sudden death and family bereavement since stories provide "structure to that which we experience, creating order in disorder and establishing meaning in what can seem a meaningless situation" (Gilbert, 2002, p 224). An essential element of the grieving process involves the quest to find meaning (Neimeyer, 2001). Therefore I collected and analyzed family stories related to the sudden cardiac death and experiences since the death of a family member, in order to identify the meaning of loss.

Philosophical Assumptions

Narrative analysis is a research methodology associated with the philosophical beliefs of social constructionism and post modernism. Social constructionism holds as truth the fact that humans do not discover knowledge; they construct knowledge. This construction of knowledge (epistemology) occurs as individuals make sense of their experiences and these constructions of knowledge may change over time or with new experiences (Schwandt, 2000). Individuals do not

construct knowledge in isolation, but in conjunction with others in the context of historical, social, and cultural experiences (Schwandt, 2000). The nature of knowledge is transactional involving two or more people and subjective with the participant being the knower (Lincoln & Guba, 1985; 2000). In a research setting the knower, or participant, will create knowledge with the researcher. Social constructivism provides a foundation for narrative, by providing a connection between stories and knowledge. With narrative the researcher asks the participant's to tell a story, specifically the story of their experience. Knowledge is created as the participant shares the story of their experience with the researcher. Meaning and truth are understood through the experience of the storyteller. Reality (ontology) is locally and specifically constructed based on context (Lincoln & Guba). An ontological assumption is that there is no discoverable truth (Lincoln & Guba, 2000) and in fact the truth may change over time.

Postmodernism, by character of its eclectic nature, is difficult to define. However postmodernism includes common attributes including the claim that ideas will change; research data is always located within a context; and that the nature of reality is transcendent (Welch & Polifroni, 1999). Postmodernism rejects grand narratives, which explain overarching or global concepts, in favor of 'mini-narratives,' which are local and personal and always under construction. These 'mini-narratives' are considered situated in context, temporary, and contingent, and they do not make any claims to universality or truth (Lincoln & Guba, 2000). Postmodern thought supports reflexivity and self-consciousness. Postmodernism also proposes that narrative structures are often fragmented and not continuous (Lincoln & Guba).

For purposes of this study it is important to define concepts important to social constructivism and postmodernism, especially as these concepts relate to the construction of knowledge and the meaning of stories. These concepts include hermeneutics, context, and

reflexivity including voice.

Hermeneutics.

Hermeneutics is defined as interpretation, specifically interpretation of another person's words. With narrative the researcher interprets another person's words and then explains this interpretation to others. Language is the vehicle by which communication occurs and it is through language that we discover meaning. In this study it is important to note that the participants were asked to share the story of their experiences after the sudden cardiac death of a family member. The researcher and participant collectively constructed knowledge and the researcher attempted to find the meanings people created in relation to their experiences.

Context.

When collecting stories it is very important to acknowledge the context, or circumstances of the environment, surrounding the story. Both the context of the story and the interactions between the storyteller and the listener are important. Narrative analysis assumes that context and interaction are essential in the construction of meanings (Bailey, 2001; Gee, 1985; Mishler, 1986). The storyteller and the listener interact together during the story and collectively develop meaning.

Reflexivity.

Reflexivity involves self-awareness on the part of the researcher. The researcher must be attentive to their role in the research process since stories are mutually constructed and the interviewer is part of story construction. Researchers using narrative must acknowledge their contribution to the construction of the story and the subsequent meaning in the stories. Attention must also be directed to both voice and perspective (Patton, 2002). The researcher must be attentive to their own voice, including their perspective, as well as the participants voice and

perspective.

A central difference between traditional qualitative research and narrative research is the subjectivity of cognition and the attempt to get away from the grand narrative to more local personal and subjective knowledge (Welch & Polifroni, 1999). This difference is part of what has been called the "narrative turn." The "narrative turn" has been connected with a shift from realism toward constructivism, which affirms that knowledge does not consist of one grand narrative. The "narrative turn" also includes the shift from modernism to postmodernism, which began in the 1980's and is still occurring. Postmodernism replaces the search for truth with the search for meaning (Rorty, 1980).

Historically qualitative research has undergone several paradigm shifts over time, these shifts are labeled "historical moments" by Denzin and Lincoln (2000). Interpretive methods, specifically narrative, have been influenced by the post-modern moment. Of importance to this study is the moment known as the "crisis of representation," which occurred in conjunction with/or during the postmodern period. In the mid 1980s researchers sought new models of truth, method, and representation (Denzin & Lincoln). This search for a new model of representation allowed researchers to appreciate they only have access to another's experience through imprecise means, specifically "talk, text, interaction and interpretation" (Riessman, 1993, p. 8). This "crisis of representation" forced researchers to ask the following question: How can an individual represent the experience of another?

Representational Issues

Representational issues are unavoidable with qualitative research, therefore it is important for researchers to acknowledge these issues. All narratives are representations (Riessman, 1993) and therefore interpretation is to be expected. Riessman identifies five levels

of representation in research process: attending, telling, transcribing, analyzing and reading. These levels of representation have permeable boundaries and decisions about representation enter the research process at frequent intervals. It is important for researchers using narrative analysis to understand these different levels, which are discussed below.

The first level of representation is that of "attending" to the experience, or being fully present during the experience. Attending to the experience includes reflection, remembering and recollecting the experience. For example, the researcher must be fully present during the interview but will undoubtedly focus on certain events. When thinking back on the interview the researcher will reflect, remember, and recollect aspects of the interview. What the researcher remembers today may be different that what they remember tomorrow.

The second level of representation is the "telling" of the experience. This requires both a storyteller and a listener. The storyteller shares the story, presenting the events in some sort of order. The teller also describes the characters and plot and connects the story together, which then allows the listener to interpret the events. It is through the talking and listening that a narrative is developed. It is important to note that any narrative is a self-representation (Riessman, 1993) due to the fact that the storyteller may change the story depending on the listener. In a research setting the story may be different than in a social setting. Also, the meaning of the story may shift because the story is constructed at the second level of representation during interaction between the storyteller and the listener.

The third level of representation described by Riessman (1993) is that of "transcribing." No matter what type of transcription, for example audio or video, is used, transcription will always be somewhat limiting. There is more to a story then the words alone. Words on paper do not capture the intonation, or silences, nor the gestures, or physical surroundings that are part of the story. The transcription of the story involves interpretation by the transcriber. Riessman tells us "meaning is constituted in very different ways with alternative transcriptions of the same stretch of talk" (p. 13).

The fourth level of representation involves the analysis of the transcript(s). The investigator begins to explicitly analyze the transcripts, which are already interpretations. The challenge is to identify similarities and differences across the experiences into some sort of summary. This is required in order to make sense of the experiences. The finished product will be a narrative or the researcher's interpretation of "what the interview narratives signify, editing and reshaping what was told, and turning it into a hybrid story" (Riessman, 1993, p. 13).

The fifth level of representation involves the written report. This report allows the reader to bring their own interpretation to the findings. All text can be considered "contested ground" (Poirier & Ayres, 1997) since the reader brings their own interpretation and background, including history and construction, to the text. Riessman (1993) reminds us, "there is no master narrative" (p. 15).

With narrative analysis it is important for the researcher to keep these levels of

representation at the forefront and to explicitly acknowledge that the final report does not contain "the one truth." Meaning is uncertain and contextual because it takes place during the process of interaction. There is no fixed or universal meaning. Interpreting experience involves representing reality and that reality is only incompletely and imperfectly presented (Riessman, 1993).

This leads one to ask the following questions: what is story? what is narrative? and how does one conduct narrative analysis? A "story" is the first person account of one person's experience. A story requires the presence of a teller as well as a listener. When conducting research with narrative you need at least two people; the participant is the storyteller and the researcher is the listener. The participant tells the story and the researcher listens to the story. There are several common attributes of stories; specifically plot, characters, sequence and a beginning and end (Polkinghorne, 1988; Riessman, 1993). Stories are often organized in a manner that reveals both the importance of the action as well as the role of the characters. This organization is considered the plot of the story (Polkinghorne). The purpose of the plot is to connect a series of events in order, which conveys the importance of these events to the listener. The plot also details the role of the characters in the story. Stories generally follow a sequence of answering the implied question of "what happened next?" Another attribute of stories is the presence of a clear start and finish. For example, frequently a story uses entrance and exit language, which conveys to the listener the beginning and ending of the story. The term narrative is often used to describe any oral or written text. Some scholars define narrative as: "the organizational scheme expressed in story form" (Polkinghorne, p.13). Most researchers agree that a "narratives" are discrete units of text, with clear beginnings and endings, which can be removed from the surrounding dialogue (Riessman, 1993). To be clear, the "story" is the

whole, and within the "story" there will be several "narratives."

For purposes of this study the "stories" collected were first person accounts which focused on experiences surrounding the sudden cardiac death of a family member and experiences since the death. More than one family member in each family was interviewed in order to explore the family experience after the death of a family member.

Narrative approaches

There are several approaches to narrative analysis including those proposed by Ayres, (2000a; 2000b), Labov (1972), Gee (1985), Polkinghorn (1988), Riessman (1993) and Mishler (1986). These approaches will be reviewed in order to identify the approach best suited to answer this study's research questions.

Ayres (2000a, 2000b) combined two qualitative methods: within case narrative and across case thematic analysis; in a study of family caregiving. Specifically Ayres used the narrative tool of overreading to examine or what was implicit, as opposed to explicit, in stories of family caregivers. Ayres (2000a) purpose was to explore the multiplicity of meanings family caregivers both brought to and from their experiences. Ayres (2000b) also described the process by which these family caregivers engaged in finding meaning in these caregiving experiences.

Labov (1972) proposes that narratives are related to a specific past event. His approach to narrative analysis includes identification of the organizing structure of each narrative. With fully developed narratives he identified six common elements: abstract or summary; orientation including time, place, setting, and individuals; actions such as the sequence of events; evaluation including significance and meaning of events; resolution or what happened; and coda or the end of the narrative. (Labov, 1972; Labov, 1982; Labov & Waletzky, 1967). Although this approach provides an organized framework to use when analyzing stories, it was anticipated that this

approach, by nature of such a structured framework, would not adequately capture the subjective experience of loss and subsequent meaning of the participants' experience. Labov's organizational framework does not attend to the relationship between the storyteller and the listener, and due to the participants' and researcher's shared experiences of loss, this approach was considered too limiting for this study.

Gee (1985) uses a linguistic approach by focusing his attention on the structure of a story. Specifically he uses a detailed linguistic-stylistic approach for the examination of narratives. His work focuses on oral storytelling traditions. Gee emphasizes that the structure of the story is what enables one to gain understanding or meaning of the story. His approach to narratives is to examine the grouping of words or clauses, the organization of the story including breaking the story into stanzas and listening to the pitch of the voice, the placement of pauses between words, and how lines of speech are grouped together. Gee (1985) acknowledges that human being make sense of their experiences via narrative and that all people, including children, "are masters of making sense of experience and the world through narrative" (p. 27). This approach appears to be most appropriate for use with oral narratives that are not centered on a single topic. Although this study collected stories after death of a family member, the focus was directed at the meaning of loss. Therefore, a linguistic approach directed at oral storytelling traditions is not well suited to answer the research questions/aims.

Polkinghorne (1988) identifies two distinct focuses when conducting narrative research with the purpose of the research directing the focus. One focus is termed descriptive narrative research, which seeks to identify how individuals find meaning in relation to past events. The second focus is known as explanatory narrative research and attempts to identify why human action occurred. Since this study focused on how individuals and families find meanings after

sudden cardiac death only descriptive narrative research will be discussed in this section. The goal of descriptive narrative research is to accurately describe how individuals, or groups such as families, make events meaningful (Polkinghorne). The researcher listens to the story of the participant and asks open-ended questions for clarification. The goal is to identify common themes or story plots. The researcher interprets the data in order to describe how participants ordered and organized their experience.

Riessman (1993) explicitly acknowledges that there is no standard way to conduct narrative studies. She offers guidelines that involve three major steps: (a) telling; (b) transcribing; and (c) analyzing. In the first step: telling, the researcher must encourage participants to share or "tell" stories "about important moments in their lives" (p. 54). This encouragement consists of setting the stage for the interview, asking participants a limited number of broad open-ended questions, and includes the participation of the listener in the conversation. Riessman suggests using less structure when developing the interview guide, so as to allow the participants to be in charge of how the interview proceeds. The goal is for the participant and the listener to develop meaning together, with the listener asking for clarification as needed. This clarification occurs as the listener asks questions or probes for more details and depth.

In the second step: transcribing, Riessman (1993) stresses the critical importance of both audio-taping and transcription with narrative analysis. It is important to note that each story shared with the researcher will be different from other stories, making each transcription different. Riessman proposes starting with a rough transcription that captures the words and other features of the conversations, such as pauses, laughter and crying. Then a more detailed study of selected portions of the transcription can be reviewed and re-transcribed for detailed

analysis.

The third step: analyzing, involves reviewing the transcriptions, often from several interviews. These transcriptions are examined closely with attention to what the participants have said. It is during this process of analytic induction that a focus for analysis often becomes evident. Riessman (1993) stresses that it is the careful and meticulous work done at this level by which "interpretative categories emerge, ambiguities in language are heard… and the oral record… provides clues about meaning" (p. 58).

Mishler (1986), in his book *Research Interviewing: Context and Narrative*, describes an interview as a "discourse between speakers" (p. 33). He emphasizes that it is this discourse where the intention or meanings are "contextually grounded" (p. 34). These meanings are developed together by talker and listener. Mishler proposes that telling stories is the main way humans make sense of experience. He encourages the use of unstructured interviews when attempting to elicit stories.

After consideration of the myriad approaches to narrative I chose to utilize Riessman's (1993) approach. I believe that only individuals who have had a family member die a sudden cardiac death can speak to their experiences. Individuals, who compose families, may have differing bereavement experiences. Gilbert (1996) suggests that families do not grieve, but family members grieve in the context of family. Therefore this study, which seeks to examine family bereavement experiences, must utilize an approach that allows for the examination of individual experiences as well as collective family experiences. Riessman's technique of narrative utilizes an approach that allows for examination of experiences while also incorporating some elements of the other approaches. Ayres (2000a; 2000b) makes a case for combining narrative techniques, via within case analysis, with across case thematic analysis, in

order to allow for examination of experiences. All families who experience the sudden death of a family member have a story. However, the telling of this story is often discouraged (Carverhill, 2002) and often this story is generally not shared with individuals outside the immediate family. I believe stories, specifically the story of the death and the story of one's experiences since the death, contain important information for health care providers and others in the community.

Narrative Analysis and Bereavement, Grief, and Loss

Narratives and narrative analysis are inherently multidisciplinary. Fur purposes of this discussion this section will be limited to narratives that have been used to describe the experience of loss. Harvey, Stein and Scott (1995) interviewed veterans of World War II for accounts of their loss and grief experience associated with the Normandy invasion in 1944. Most remarkable was that even though 50 years had passed since the invasion on the beaches of Normandy, all participants were able to describe their experiences in detail. Most veterans reported "lifelong grieving" (p. 315) associated with the trauma they witnessed. The study results indicated that veterans who were able to share the stories of their experiences with "friends, family, and especially other veterans" (p. 327) found this to be an effective coping strategy. The results of this study also indicated a time frame associated with sharing stories of loss. Most veterans reported benefit when the sharing of stories associated with the invasion occurred soon after their experience. This was in opposition to veterans who did not talk about their experiences for many years, since these individuals indicated, "they probably suffered over time because of their silence" (p. 329).

Gilbert and Smart (1992), using qualitative methods, interviewed twenty-seven married couples after fetal or infant death. A semi-structured format was used with attention directed to

collect both behavioral and subjective aspects of their experience. The participants were initially asked about their loss experience after the death of their child. Secondly they were asked about their grief, specifically what they found helpful from their spouse and others. Then they were asked about any changes, either individual or as a couple, made since the death. At the end of the interview participants were asked for suggestions that the researcher could share with others including heath care professionals, family and friends, and other bereaved couples. Marital partners were interviewed both separately and together in order to gain a subjective impression of their bereavement experience.

Results documented that parental grief occurs on both an individual level and a dyad level. Each partner must deal with their individual grief as well as their partners' grief and their collective grief. Marital partners may find that they have dissimilar, or even divergent, grief responses. Gilbert and Smart (1992) reported that most couples struggled through a difficult period after the death of a child and that initially the loss was overwhelming. However, many couples were committed to maintaining their relationship and even reported the couple relationship to be strengthened. If the marriage was to remain intact the couple must find ways to successfully cope successfully with these differences. Participants who found their relationship stronger report the following patterns helpful: a willingness to openly communicate both verbally and nonverbally, share emotions, truly listening to each other, and an appreciation of their shared experience.

Although not purely a narrative study, the research by Gilbert and Smart (1992) provided an opportunity for the reader to learn about the experience of parental loss from the grieving parents themselves. The researchers interspersed direct quotes from the participants along with their own interpretation of the study. This allowed the voice of the parents to be heard by the

readers of the text. This study provided a subjective view of bereavement from the individuals who themselves experienced the death of a child.

Narrative Analysis and Nursing

Narrative analysis is gaining acceptance among qualitative nurse researchers. Historically, nurses have frequently collected stories from clients, yet rarely have these stories been used for research purposes. More and more nurse researchers have come to appreciate the need to gain understanding and clarify the patients' experience. Narrative is considered a means to focus nursing inquiry on the human experience, discover new knowledge, and to uncover the knowledge rooted in practice (Sandelowski, 1994). In nursing narratives have been used to study care-giving (Ayres, 2000a; Ayres, 2000b), chronic illness, (Bailey, 2001; Bailey & Tilly, 2002, Knafl & Gilliss, 2002), and grief (Steeves, Kahn, Ropka, & Wise, 2001). Bailey (2001) collected what she termed "death stories" from patients who experienced an acute exacerbation of COPD. These death stories were labeled as either a "near-death story" or a "shadow-of-death" story. These stories offer compelling examples of the fear and anxiety COPD patients experience during acute exacerbations of their chronic illness. Steeves and Kahn (2005) conducted a study of bereaved elders in an attempt to understand their bereavement experience over time. Rosenfeld, Lindauer and Darney (2005) used mixed methods, including narrative, to gain understanding of women's response to systems of acute myocardial infarction. Nurses have used narratives to investigate caring (McCance, McKenna & Boore, 2001) and to help patients deal with suffering (Fredriksson, 1999).

This study of family bereavement experiences will provide nurses with the opportunity to learn firsthand from families about their experiences after the sudden cardiac death of a family member. It is imperative that nurses understand the family experience after sudden death in

order to develop nursing interventions that will be supportive to surviving family members.

Strengths and Limitations of Narrative Analysis

One of the strengths of narrative analysis is that it allows participants to share stories of their experience. Of course their voice is filtered to some extent by the researcher who makes decisions as the study proceeds. Stories of loss can be powerful and captivating and personal experience with a qualitative research class revealed that one interview containing a story of sudden death was captivating to all class members.

Consistent with qualitative research methods, no attempt will be made to generalize the study's findings to other bereaved families. However, the researcher intends to provide enough information about the study's participants so that health care providers, community members, researchers and research consumers may determine for themselves the relevance of the findings to their own settings. It is my belief that narrative inquiry offers an exceptional opportunity to explore the family bereavement experience.

In conclusion, although theoretical underpinnings for narrative are found in several disciplines, it is important that research methodologies are embedded in a defined philosophical stance, in order to develop a foundation for one's research. How are we to understand the experiences of bereaved families? I believe the best way to gain this understanding is to ask family members to share stories of their bereavement experiences after the sudden cardiac death of a family member. These stories will allow me to analyze the stories in an attempt to determine meanings of loss. These beliefs, along with sound research methods, made narrative analysis the research method of choice for this study.

Research Design

This study was designed to answer the following research questions: What are the

bereavement experiences of families after an out-of-sequence sudden cardiac death of a family member? and What do family bereavement experience stories tell us about the meanings of loss after the out-of-sequence sudden cardiac death of a family member?

Narrative analysis was the qualitative approach used in this study. Families who had experienced the sudden cardiac death of a family member were asked to tell stories of their bereavement experiences. Nadeau (1998) says that families have stories to tell after death and that these stories are often filled with meaning. For this study the stories collected included more than just the story of a family member's death, but also addressed the families' bereavement experiences. This qualitative method was chosen because individuals are inclined to tell stories and these stories can be a means of accessing meaning. The sudden death of a family member disrupts the taken-for-granted nature of day-to-day family life and forces the family to find meaning (Nadeau, 1998; Neimeyer, 2001). Narrative is an excellent method to collect stories and it is expected that these stories will provide rich data needed to capture the meaning of experience.

Stories can also serve as a vehicle for finding meanings, specifically meanings of loss. An essential element of the grieving process involves the human quest to find meaning in loss (Nadeau, 1998; Neimeyer, 2001), making narrative an appropriate method to use in this study.

Sample

The target population was families who have experienced the out of sequence sudden cardiac death of a family member to sudden cardiac death within the previous 3 months to 5 years. For logistical reasons a definition of family was needed that would neither be so broad as to include multitudes of family members, nor so narrow as to exclude potential family members. The chosen definition of family (which was modified from Fisher et al., 1998) was a group of

individuals living together, or in close proximity to each other, who identify each other as family. For the purposes of this study family included at least two members, one being an adult. In an attempt to understand family bereavement experiences, a family interview occurred first with all available family members. This family interview was followed by individual interviews of family members who were present at the family interview. Phone interviews were used for family members living out of the area, for example, a family member who lived out or state or two step-children who lived in another country. I was prepared to include children, between the ages of 12 to 17, however none of the families in this study included children in this age range.

As the mechanisms of sudden cardiac death have become better understood the definition of sudden cardiac death has evolved to include required components of natural, rapid, and unexpected (Myerburg & Castellanos, 2005). For purposes of this study sudden cardiac death was defined as "a natural death from cardiac causes heralded by abrupt loss of consciousness within one hour of the onset of acute symptoms" (Myerburg & Castellanos, p. 865). Out-of-sequence was defined as deaths that occurred in young adulthood, defined as between age 20 to 45 years (K. Gilbert, personal communication, 2005). However since it is well documented that women die of cardiovascular disease 10 years later than men (American Heart Association, 2006) the inclusion criteria for enrollment in this study was expanded up to age 55 for women.

From the target population listed above, a convenience sample of individual family members meeting the following inclusion criteria was recruited: (a) ability to speak and understand English; (b) had a family member die an out-of-sequence sudden cardiac death within the last 5 years; (c) the age of the decedent was between 20 – 55 years old; (d) the age of the participant was at least 12 years old and (e) the death was a sudden cardiac death, as verified

by a cardiologist or health care provider, an autopsy report, or be documented to have occurred within one hour after the onset of symptoms with no other obvious explanation or cause of death evident (Myerburg & Castellanos, 2005). The exclusion criterion included situations where only one family member of the decedent was available or agreed to participate in the study.

It was estimated that a purposive sample of approximately 8 to 10 families would be required for this study and both family and individual interviews were conducted. This sample size was determined after consideration of several factors including: the quality of the data to be collected; the scope and nature of the research topic; the amount and type of data expected to be obtained from each participant; and the method and study design (Morse, 2000). These factors are interrelated and will be addressed below. Since both family and individual interviews were planned it was expected that these interviews would produce rich and thick data for analysis since bereaved individuals are rarely asked to tell the story of a death. The bereaved have a particular need to tell, and retell, the story of their experience (Carverhill, 2002). This need to tell the story frequently leads to stories that are quite long and detailed (Nadeau, 1998). The study design specified that both family and individual interviews would occur and each family consisted of at least two members or more. Additional family members were recruited if they were willing and able to participate in the study.

The researcher utilized maximum variation sampling in order to investigate the full range of families' bereavement experiences with attention directed at the following three dimensions: time since the death; gender of the participants; and relationship to the decedent. Families with different bereavement experiences were sought to fully investigate the bereavement experience. For example, attempts were made to recruit families at different bereavement time periods with some families recently bereaved (between 3 months to 2 years since the death) and other families

longer into bereavement (2 to 5 years since the death). Also targeted were both bereaved male and female participants as well as different family relationships between the bereaved and the decedent (including brothers, sisters, spouses, children, parents and grandparents).

The final sample consisted of seven families from across Montana. Each of the seven families had a family member die a SCD within the last five years with a range of 1-5 years since the death (mean 2.07 years since the death). All decedents were males aged between 44 and 54 years old at the time of death (mean age of decedent 51.3 years old). Participating family members were between age 22 and 60 years old at the time of the family interview (mean age of 41.8 years old). Family relationship to the decedent included spouse, ex-spouse or unmarried partner (n = 5); best friend (n = 1); sister (n = 3); son (n = 1), adopted son (n = 1), step-son (n = 2); daughter (n = 2) or step-daughter (n =1); and niece (n = 1).

Recruitment

Recruitment efforts were directed towards families who had experienced the sudden cardiac death of a family member within the last five years, with a minimum time frame of at least 3 months past the death (Schoenberg, Carr, Peretz & Kutscher, 1970; Nadeau, 1998; Tolle, Tilden, Rosenfeld, & Hickman, 2000). It was expected that it might be difficult to recruit bereaved families willing to participate therefore three approaches to recruitment were employed.

The primary focus for recruitment was aimed at cardiologists and health care providers in Western Montana and Missoula County. Specifically cardiologists and other health care providers were asked to provide surviving family members with information about the study (See Appendix A). This information instructed potential participants to contact the researcher for information about the study. If response to the cardiologist's letter was not adequate to obtain a

sample of family members, the researcher asked registered nurses working in the cardiologist practices to directly contact potential participants. These office nurses briefly described the study using a script developed by the researcher (Appendix B) and asked if the researcher could contact the family. The telephone script for the researcher is located in Appendix C. A detailed step-by-step procedure list/algorithm to be followed once the researcher and potential participant made contact is included in Appendix D.

The second approach for recruitment involved advertising for participants. Flyers (Appendix E) were posted in physician offices, at grief support groups, and funeral homes. Grief support groups are conducted by several agencies in the area. Families First is a nonprofit organization committed to strengthening families which has a well established bereavement program. The Seasons Bereavement program provides bereavement support to families who have experienced the death of a family member. This group offers annual summer camp sessions, various outdoor wilderness activities for teenagers and an after school program for children and their families. Other bereavement support groups available in the area included programs offered by local mental health counselors and Hospice. Of particular note is that one counselor specializes in bereavement support after sudden death.

The third recruitment approach utilized snowball sampling (Lofland, Snow, Anderson, & Lofland, 2006). At the end of each interview adult family members were asked if they knew other families who met the study inclusion criteria. Since individuals and families live within social networks, these networks may serve as an opportunity for finding other families who qualify for participation in this study. An important feature to emphasize, especially when talking with family members and the public, was that the death is sudden and unexpected, although there may or may not have been knowledge or awareness of preexisting heart disease.

Recruitment took place in Western Montana, which is an area served by two community hospitals and each hospital has a large outlying referral area. Both hospitals offer cardiovascular services including busy cardiovascular catheterization laboratories. Also St. Patrick Hospital and Health Sciences Center performs over 250 cardiac surgical procedures a year. The International Heart Institute (IHI) of Montana Foundation is located in Missoula and its mission is to foster the provision of high quality cardiac care by conducting cardiac research, developing technology, and providing training and education. Both hospitals have social workers and hospital chaplains that provide bereavement support. The researcher, a cardiovascular clinical nurse specialist, has a well-developed professional working relationship with all of the cardiologists and other health care providers at both hospitals.

Similar to national trends, heart disease is the leading cause of death in Montana (Montana Department of Public Health and Human Services, 2003) with 404 deaths due to acute myocardial infarction in 2004 (Montana Department of Public Health and Human Services, 2006). It is expected that some of these myocardial infarction deaths would meet the criteria for sudden cardiac death. These 404 deaths include males and females of all ages, with 25 of these deaths occurring between the ages of 25 to 49 and 14 deaths occurring between the ages of 50 – 54 (Montana Department of Public Health and Human Services, 2006). It is important to note that these 39 young adulthood deaths are for one year and this study included deaths within the last 5 years. The researcher also considers the Vital Statistics Report an underestimate of the number of natural, rapid, and unexpected deaths due to cardiac causes. Therefore, the primary focus for recruitment was aimed at health care providers, specifically cardiologists who have extensive clinical experience with sudden cardiac death.

Once Investigational Review Board approval was obtained the researcher scheduled a

presentation at the weekly Cardiology Conference at St Patrick Hospital and International Heart Institute. This presentation notified cardiologists and other health care providers with cardiac patients about the study. This presentation was repeated for cardiologists and physicians at the Montana Heart Center.

Recruitment challenges.

Even with a three pronged recruitment approach identifying families who met the criteria for this study was very challenging. Initially the age criteria, which limited male decedents to be less than 45 years of age at the time of death, was too restrictive. IRB approval was obtained to expand the age of both male and female decedents to be between 20 and 55 years of age at the time of death. This expansion of the age criteria for the age of decedents change was helpful, although it was still challenging to identify families who met the criteria for this study.

The first recruitment approach targeted cardiologists and cardiac nurses. This approach, which was not successful, was particularly challenging due to an inability for cardiologists to easily identify families who had experienced the SCD of a family member in the last five years. At this point the researcher approached other health care providers including emergency room physicians and emergency medical technicians (EMTs) to identify families who qualified for the study. Emergency room physicians did have access to a list of decedents which could be more easily accessed for the identification of potential families. However, the workloads of hospital staff members, especially in busy emergency departments, greatly limited this recruitment approach. One EMT staff member, whose father had died a SCD many years before, willingly compiled a list of all cardiac transports to two local hospitals, and this list was forwarded to each hospital. In the majority of cases these clients transported to the hospital via ambulance survived the cardiac event and were discharged alive from the hospital. A small number of cardiac deaths

were identified via this mechanism; however, these charts had to be reviewed by a hospital staff member to determine eligibility. Again the workload of hospital staff members limited the amount of time they could devote to this project. One hospital did send out letters to families who appeared eligible for the study; however limited staffing at the hospital did not allow for a follow-up phone call from a hospital staff member.

Personal contact from a nurse knowledgeable about the study was more successful than letters sent without a follow-up phone call. In three cases potential participants had personal phone contact with a nurse knowledgeable about the study, specifically two cardiac nurses working in a cardiologist's office, and one nurse practitioner, and resulted in one family enrolling in the study. In other cases, one family did not respond to a letter and several phone calls from a nurse in a cardiologist office, and three other families' declined to participate after speaking with the researcher on several different occasions, some after repeated contact over several weeks.

The second recruitment approach involved placing advertisements in locations where bereaved families might learn about the study. The locations for advertisements included physician offices, grief support groups, counselor's offices, church newsletters, a university web site, a local public library, and email communication to professional groups such as college of nursing faculty members and parish nurses. This approach was successful in recruiting four families to participate in the study. Two families were recruited via word of mouth via the researcher's personal network of friends and professional colleagues.

The third recruitment approach, snowball sampling, used the participants themselves to identify other families who might qualify for the study. Although families often knew other families who also experienced the sudden cardiac death of a family member, these deaths were

often at ages younger or greater than the study inclusion criteria.

Procedures

When interested individuals contacted me (hereafter referred to as initial family contact person) they were told about the nature of the study: To collect stories of families who experienced the sudden cardiac death of a family member in order to identify the meanings of loss. The step-by-step procedures (Appendix D) included:

(a) I introduced myself and explained that the study was about family bereavement experiences after the sudden cardiac death of a family member.

(b) I read a list of statements about the study. After reading these statements I asked if these statements were true for the families' situation.

(c) If the statements were true it was expected that the family would meet the study criteria. At this point I asked the initial family contact person if at least two or more members of the family were willing to meet and discuss the study in more detail. The initial family contact person was asked to contact additional family members and these family members were encouraged to contact me directly to discuss the study. The initial family contact person and I determined a date and location for an initial family meeting. This initial meeting included several family members.

At the initial meeting with the potential family the study was explained again. If family members agreed to participate in the study I obtained written informed consent from each family member. The study consent form (Appendix F) is attached. Protection of human subjects is addressed in a following section.

Once informed consent was obtained, the participating family and I decided on a convenient time and location for the family interview. The family interview was scheduled

before the individual interviews of family members. It was expected that occasionally the research interview would occur on the same day and time that informed consent was obtained.

Interviews took place in the family home or another private location deemed suitable by me and the family. At the beginning of the family interview demographic family data was collected from the initial family contact person. Demographic data (see Appendix G) included information about the decedent (date of death, age, race, gender, and status of preexisting knowledge of cardiac disease). At the beginning of the family interview I collected information about the participants (age, race, gender, and relationship to decedent). This was done as a means of developing rapport before getting to the more personal stories of loss.

Confirmation that the death was accurately a sudden cardiac death was done via the participant's stories. It is important to note that 80% of all cardiac arrests happen at home (AHA, 2004) therefore family members may have witnessed some of these deaths. In these situations self-report from surviving family members was used for verification purposes. Also it was expected that stories of the death would include enough details to confirm the cardiac nature of the death and all stories were reviewed by both me and a nurse with expertise in cardiovascular nursing (A.Rosenfeld, Ph.D., RN).

Family interviews began by asking the family to tell the story of the death. Then families' were asked how the death had affected the family. Probing questions were developed to seek clarification and expansion. Families' were asked if and how they found meaning, or had they been able to make sense of the death of their family member. Also during the family interview I noted the behaviors and interactions that occurred between family members. After the family interview I documented these observations of family interactions in the field notes.

Individual interviews began with asking the individual to tell what it had been like for them individually since the death of their family member. Initial questions were broad and open ended in order to allow the story to come from the participant. Additionally participants were asked if their individual experiences associated with the death were similar or different from the family experience. Probing questions were developed to seek clarification and expansion. Specifically participants were asked about if and how they found meaning, or had they been able to make sense of the death of their family member. The interview guide (Appendix H) included questions for both the family interview and the individual interviews of family members. All interviews were tape-recorded and transcribed verbatim.

At the end of the interview all adult participants were asked if they knew any other families who might be interested in learning about the study. Flyers were left with participating families who were asked to share them with other potential families. These potential families were asked to contact the researcher for information about the study.

All participants were asked if they were participating in any bereavement support groups or seeing a counselor about the death of their family member. This question was asked in an attempt to determine if participation in such groups assisted participants and families to find meanings in loss.

To provide closure at the end of the interview all participants were thanked for sharing the story of their experience with the researcher. Participants were reminded that their story might be helpful to nurses, physicians and other families in the future. All participants were given a list of local bereavement support available in the event that that sharing the story of their experiences lead to distress.

All participants were given my business card with contact information. As a token of an appreciation one adult member of each family was given a gift certificate to a local grocery store. One family, who lived in a small town without a local grocery store, received a sealed envelope with an equivalent amount of cash.

Data Collection

With qualitative interviews there are three types of questions used (Rubin & Rubin, 1995). Initial or main questions are used to start and guide the conversation. The second type of question is a probing question, which is used to clarify responses or have participants elaborate on responses. Finally there are follow-up questions that pursue the implication of answers to the main questions. During the interview I remained open and flexible to different meanings that might emerge from the conversation. I was attentive for changing meanings and aware that situations might invalidate previously developed interview questions (Warren, 2002).

Data collection occurred via unstructured intensive interviews with the use of open-ended questions, which were designed to elicit stories (Lofland, Snow, Anderson, & Lofland, 2006; Mishler, 1986; Reissman, 1993). Intensive interviewing involves the use of an unstructured, yet guided, conversation designed to obtain rich and thick data for analysis. Questions were designed to elicit the participant's story and an unstructured interview format allows participants the freedom to share stories. Probes were used to obtain more details as needed. The interview guide (Appendix H) consisted of open-ended questions and was developed with an explicit aim of eliciting stories. This interview guide was evaluated by clinicians with bereavement expertise and by experienced family researchers.

It was expected that sharing stories of loss might be emotional for the participants (Horowitz, Ladden, & Moriarty, 2002). Consequently it was very important to provide closure at

the end of every interview. The interview guide (Appendix H) details the closure language that was used at the end of each interview.

Relationship between researcher and participant.

In order to get rich data it was imperative that the researcher and the participant develop a trusting relationship. The conversation was developed as a partnership, with the participant doing most of the talking. I was an interested and observant listener who probed for clarification and meaning. Mishler (1986) identified a need to empower participants so they were equal partners in the interview. The interview was an interactive process between the respondent and the interviewer. His emphasis was on the "discourse between speakers" (Mishler, p. 35–36).

Another suggestion to develop a partnership between researcher and participant was put forth by Johnson (2002) who suggested that the researcher share some of their own personal narrative with participants. This self-disclosure was suggested in hope of receiving equal self-disclosure on the part of the participant. It was expected that many participants would ask me about my own personal grief and loss experiences. In order to develop a trusting partnership I acknowledged my background as a nurse and my personal experience with sudden cardiac death, while remaining aware of the need to keep the focus on the participants' story and not my own story. This was done in order to establish a bond between myself and the participants. Our shared common experience of loss, plus a documented willingness of bereaved individuals to share their experience with interested persons (Gilbert, 2002), allowed for development of a trusting relationship between myself and the participants (Cook & Bosley, 1995).

During the interview I paid attention to my presence, and was aware that my presence influenced the story. Lofland and colleagues (2006) recommended a non-threatening demeanor in attitude as well body language. I was interested, cordial and attentive to the participant's

story, while at the same time functioning as one who wanted to learn from the participant. Simply stated the goal for myself was to "listen well and respectfully" (Heyl, 2001, p.370).

Field notes/reflective journal.

During the data collection phase I kept field or observational notes as well as a reflexive journal (Richardson, 2000). Field notes consisted of a description of setting, events, and people, as well as things heard and observed during the interview (Lofland, et al., 2006). It was important that I record these observations and thoughts soon after being in the field. My field notes contained more than just observations. As more interviews were conducted I recalled things not previously recorded. These recalled thoughts and observations were then added to the field notes. Since both data collection and analysis took place concurrently, thoughts related to analytic ideas and inferences (Lofland, et al.,) were added to my field notes. Specific to this study of family bereavement experience after sudden cardiac death, field notes included my observations of individual's experience with the interview process. I wrote these field notes soon after the interview took place.

I also kept a reflexive journal during the data collection process. The reflexive journal was a tool for self-awareness and reflexivity that allowed me to examine how personal experience and subjectivity influenced the data being collected and analyzed. This personal journal was used to collect/document my reactions in a location separate from the data and field notes. These writing practices were part of the analytic plan for this study and therefore will be discussed in the subsequent data analysis section.

Interviewing Children.

I did not expect that a large number of children between the ages of 12 and 17 would participate in this study, but was prepared to include adolescent children. However no families had children in this age range, therefore no adolescent children were included in this study.

Family interviews.

Feetham (1991) lists one purpose of family research "to examine responses of families and family members to expected and unexpected life transitions" (p. 56). In this study, family interviews, as well as individual interviews of family members, were included in order to obtain information about family bereavement experiences after sudden cardiac death.

Family research is unique in that it challenges the researcher to consider both the collective experiences of individuals, who collectively compose a family, in addition to experiences of the family. Consequently, researchers must consider additional conceptual and methodological issues related to the family as the unit of analysis. This study sought to learn about family bereavement experiences therefore family interviews, as well as individual interviews, were utilized. I expected that family interviews would be an important avenue for data collection related to family bereavement experiences after sudden cardiac death.

As a qualitative data gathering technique group interviews involved talking with several individuals at one time (Fontana & Frey, 2000). Traditionally group interviews have been associated with marketing research and have been broadly labeled focus group interviews. Researchers in several disciplines have used group interviews successfully when seeking information from more than one individual at a time. Types and dimensions of group interviews vary depending on the purpose of the research, as well as the setting, role of interviewer, and format of the questions (Fontana & Frey). The setting can be informal or formal; the role of the interviewer can be very directive, directive, or non directive; and the question format can be very

structured, structured, or semi-structured. All of these dimensions vary depending on the purpose of the interview (Fontana & Frey).

One major difference between individual and family interviews is related to the interactions that occur between participants during group interviews. These interactions were important and were often related to the preexisting relationship that existed between the participants. Advantages of family interviewing included obtaining rich data, accurate recall since participants may remind each other of different topics to add, and an opportunity to observe family interactions. Disadvantages included the possibility of domination of the conversation by one or more people, inherent family dynamics, and the public speaking aspect of talking in front of family members that may limit contributions of some participants.

I needed astute skills to conduct family interviews in order to maximize advantages and minimize disadvantages of group interviews. I attempted to keep one or more family members from dominating the conversation, while encouraging reluctant respondents to participate. I also actively sought to obtain responses from the family to ensure discussion of all participants.

Morris (2001) reported several characteristics inherent in group interviews in her research with cancer patients and their primary caregiver (often a married spouse). Morris documented the pair being interviewed as both speaking collectively to the researcher as "we" in addition to occasionally speaking between themselves. Morris proposed that the joint interview allowed "glimpses of "sharedness" under construction" (p. 559). Morris also suggested that the group interview allowed the researcher to obtain a fuller account since interjections, prompting, or interaction between the participants often provided missing information. The nature of the participants telling a public story was evident in Morris's study and she reported the participants were "telling a tale, a story they had already rehearsed in other situations" (p. 561). Morris's

participants were also willing to talk about death and other emotions associated with a diagnosis of cancer.

Researchers have used family interviews in to gain information on the family. Chesla and Chun (2005) utilized the family as a unit of analysis in their study of type 2 diabetes in Chinese American families and conducted family group interviews with 3-6 participants per group. In this interpretative study Chesla and Chun collected narratives from family interviews of persons with diabetes and their spouses. They reported several different dimensions of accommodation, including disclosure of diagnosis, maintenance of quality of life, and preserving family relationships, as described by Chinese American families.

Nadeau (1998) reported that successful interviews occurred when she interviewed family members collectively about death of a family member, before interviewing them separately. Nadeau utilized family interviews to increase the likelihood of obtaining information about family interactions than would not be present in individual interviews. She reported the most productive family interviews consisted of 4 family members, as this size allowed all family members to participate and interact in a reasonable time frame.

When utilizing family interviews there are several issues the researcher must consider. These include the matter of family gatekeepers who may limit the researcher's access to other family members. During family interviews the researcher must actively engage all family members to contribute data during the group interview. Limiting the size of the family group to 4 participants is one strategy that was used successfully in Nadeau's (1998) study as this allowed all family members a chance to participate in the interview. Too large a family group, defined as greater than 4 individuals, has been reported as unwieldy for the researcher and frustrating for the participants (Nadeau). In this study if a family member appeared reluctant to speak in the

family interview the researcher followed up with that family member during the individual interview.

Data Analysis

The stories collected were analyzed using Riesman's (1993) approach to narrative analysis, which required the steps of transcribing and analyzing to occur concurrently. Both individual family members' stories, as well as family stories, were broken down into narratives and these narratives were analyzed in an iterative fashion. The study also utilized across family thematic analysis.

Role of the researcher.

Qualitative interviewing is acknowledged to include the social interactions between the participant and the researcher (Warren, 2002). Qualitative interviews have several unique characteristics including the fact that although research interviews are conversations they are not social conversations. The interview is a research tool that involves a conversation between the researcher and the participant. Guided by the researcher, this conversation is designed as a means of gaining understanding of experience (Rubin & Rubin, 1995).

The researcher role during qualitative interviewing is crucial. It is well documented that individuals like to talk about themselves especially to someone who is interested in them (Rubin & Rubin, 1995). The researcher needs to develop a partnership with the participants in order to obtain what is known as "thick description" (Geertz, 1973). Steps taken by me in an effort to develop this partnership (Rubin & Rubin, 1995) included encouraging participation, remaining open to the participants, and developing a trusting relationship with the participants. To develop this partnership I listened to the story with respect and listened intently to what was said, as well as what was not said, by the participant. Non-verbal communication often conveys the

emotional context of dialogue and this context may need clarification or exploration. I listened closely in order to understand the meaning of what the participant was communicating (Rubin & Rubin) and I paid attention to the story line and asked for clarification or elaboration via probes or follow-up questions.

In narrative analysis the researcher must pay attention to more than the words used by participants. It is important to look for implicit, or hidden meanings, as well as explicit meanings. This is termed overreading (Poirier & Ayres, 1997) and requires the researcher to pay attention to silences, evasions, omissions, repetitions, and contradictions. This will be discussed further in the data analysis procedures section.

The conversation should stay focused on the research topic; however the researcher needs to remain open and flexible in the event that additional information important to the participant is shared. Although these side stories may initially seem off topic, however, these side stories may add depth and richness that was not expected.

In summary, the researcher is a very important part of the research process and must be cognizant of the importance of their role. Their presence influences the story and the goal is to develop a partnership with the participant. Researchers using narrative analysis should, "listen, report, interpret, and to recognize their own participation in the process" (Gilbert, 2002, p 229).

Data analysis procedures.

The goals for the family and individual interviews was to elicit rich thick stories in order to describe experiences of bereaved individuals who collectively comprise a family, and to examine across family stories for themes related to meanings of loss after the sudden cardiac death of a family member. Stories were analyzed in successive steps in an iterative fashion. The analysis involved a complex approach in order to balance individual stories, with family stories,

of bereavement experiences. The specific steps I followed during the data transcribing and analysis process are detailed below and listed in Table 1.

Table 1

Data Analysis Approach.

	Data Analysis Approach
Step 1	Family and individual interviews
Step 2	Rough transcription
Step 3	Listening/reading
Step 4	Overreading
Step 5	Coding
Step 6	Theoretical Memos
Step 7	Field notes and reflexive journal
Step 8	Development of narrative summaries for each family
Step 9	Within case and across case analytic strategies
Step 10	Themes across families
Step 11	Meta-story

Step 1 Interviews. Family interviews were done prior to individual interviews. All interviews were audio-taped and transcribed by the researcher. When the researcher was unable to keep up with the transcriptions a transcriptionist was hired to assist with this task. Riessman

(1993) stressed that transcription cannot be a separate activity from analysis since the two are intertwined. What is heard on the tape and transcribed to the paper shapes the researcher's interpretation.

Step 2 Rough transcription. The purpose of the rough transcription was to capture words and prominent features; for example pauses, crying, and or laughter; which occurred during the interview. The researcher was responsible for development of this rough transcription.

Step 3 Listening and reading. The researcher concurrently listened to all audio-tapes while reading the rough transcription in order to ensure that all nuances of dialogue, including false starts, pauses, and interruptions, were captured on the transcript. It was at this step where the researcher took special efforts to ensure that the appropriate nuances, such as pauses and signs of distress, such as tears or a cracking voice, were added to the transcripts. This was especially important for those transcripts typed up by a transcriptionist.

Step 4 Overreading. Poirier and Ayres (1997) emphasize the need to pay attention to what was not said, or implicit, within each story. This is termed overreading and this step included examining silences, evasions, omissions, repetitions and contradictions in the story. More specifically, overreading was a technique used by the researcher in order to identify what was implicit, or unspoken, in the story. The researcher was alert for episodes which included silences, endings, inconsistencies and repetitions. Overreading is used to identify inconsistencies, repetitions, and omissions, all of which may indicate distress during parts of the story. It was important that inconsistencies, repetitions, and omissions were identified, without an attempt to explain the reason they are part of the story. Poirier and Ayres (1997) stress that "silence, repetition and endings…" (p. 557) are tools used by the storyteller, which in turn, can help the researcher understand "the complexity of the teller's life" (p. 557). In sum, it was

important that I examined what was said, as well as what was not said, by the participants.

Step 5 Coding. Codes were identified by use of an inductive coding procedure. Initially each transcript was coded, and a segment of text was identified with a code. These codes were developed from the stories themselves. Codes were classified as either descriptive or categorical. Categorical codes were used to examine the context of the stories and descriptive codes were used to examine for meaning. I used the code list to ask how and why questions of the data, in order to examine the data on a deeper level. As additional interviews were completed, and as these transcripts were coded, previous transcripts were read, and reread, to ensure consistency and accuracy of the codes across transcripts.

Step 6 Theoretical memos. Theoretical notes included my thoughts while coding (Ryan & Bernard, 2000). These notes served as a place to record ideas about the data and provided a structure for working with the data in a systematic manner. These notes were used to link the data with my thoughts and assumptions. The purpose of the theoretical memos was to develop and document a written record connecting the data to the interpretation of the data.

Step 7 Field notes and reflexive journal. Field notes included my thoughts and observations after being in the field collecting data. Kavanaugh and Ayres (1998) suggest recording participant behaviors, including contacts and canceled or rescheduled appointments, in order to assess distress when researching sensitive topics. Due to the sensitive nature of the study topic it was important that I paid attention to all behaviors, which may have indicated distress. During data analysis the field or observational notes were examined for differences and similarities between observations compared to the family stories. Qualitative methods utilize an emergent approach to data analysis and therefore the field notes provided an avenue for discovery not anticipated or expected prior to the data collection. Field notes captured

observations across interviews that were subtle or not explicit in the participants' stories. In such situations field notes were used to explore implicit impressions or my observations across stories.

The reflexive journal was especially important due to my personal experience with sudden cardiac death. This journal was used to increase my awareness of how my own experience influenced the stories I was hearing from the participants. I used this journal to record my individual thoughts and reactions after hearing moving stories of loss from the participants. This journal helped me self identify when I needed to take a break from the data, which tended to occur when the participant's "death story" was close to my own "death story." This increased self awareness allowed me to build in breaks for self care activities. With qualitative methods the researcher is inherently part of the study and this journal provided a location for recording my individual perspective on the data. The reflexive journal was also the location where I documented an awareness of how my own knowledge influenced my analysis. This journal was used to describe and explain my role in the research process.

Step 8 Development of narrative summaries. The family interviews were quite detailed, and when combined with the individual participant interviews, resulted in lengthy transcripts. Data reduction techniques (Riessman, 1993) were used to summarize family bereavement experiences and at this step I developed a detailed narrative summary for each family. These summaries were written with the study aims in mind, as a means of capturing the essence of family bereavement experiences. In order to develop these summaries I immersed myself in the family transcripts, with a goal of producing a document which identified bereavement experiences and meanings of loss for each family.

Step 9 Within case and across case analytic strategies. Narrative summaries were compared within families and across families (Ayres, Kavanaugh, & Knafl, 2003) as shown in

Table 2. A within case analysis was done for each family in order to describe family bereavement experiences and identify family meanings of loss. Across case analysis was conducted with a goal of identifying patterns, such as similarities and differences, across families. The across case analysis initiated the development of themes (Table 2).

Table 2

Within- and Across-Case Analytic Strategies.

Comparison	Purpose	Product
Within Case – One Family.	Describe family bereavement experiences & identify family meanings of loss.	Detailed narrative summaries for seven families.
Across Case - Seven families.	Identify themes related to family bereavement experiences across families	Themes of: Sudden death … boom; Saying goodbye; Grief unleashes volatile emotions; Life goes on … but never back to normal; Meanings in loss.

Step 10 Themes. Even as the specifics associated with each families experience unfolded differently the analysis across family stories identified themes across family bereavement experiences (Table 2). These themes were modified and refined as the analysis proceeded. The researcher used powerful stories shared by the participants to exemplify the themes identified as part of the analysis. These themes captured family bereavement experiences and identified meanings of loss after the sudden cardiac death of a family member.

Step 11. Meta-story. In order to best convey the depth and breadth of the results I developed one story, a meta-story of family bereavement experiences. This step in the analysis approach was done to more fully convey the depth and breadth of bereavement experiences and best illustrate the five themes across families.

Methodological Rigor

Researchers must ensure the validity or trustworthiness of their findings, however traditional approaches of ensuring trustworthiness do not apply to narrative studies. When working with stories the researcher must account for postmodernism and the "narrative turn." As Riesmann (1993) states, "traditional notions of reliability simply do not apply to narrative studies" (p. 65). Therefore the methodological rigor of this study was ensured by utilization of criteria specific to narrative analysis established by Riessman. The four criteria include persuasiveness, correspondence, coherence, and pragmatic use.

Persuasiveness.

When evaluating the methodological rigor of a study the questions asked should be, are the results convincing, persuasive or believable, and credible? Riessman (1993) believes persuasiveness is strongest when theoretical claims are supported by the participants' stories and that alternative interpretations of the data have been considered. The results are persuasive and moving accounts of family experiences after SCD of a family member. Collectively, the researcher, dissertation committee members, and a qualitative student seminar group validated the believability, or persuasiveness, of the data and data analysis.

Correspondence.

The criterion of correspondence involves allowing the participants themselves to review the analysis. This procedure is considered a type of member checking. This criterion was

challenging with this study since stories and experiences are dynamic and evolving. Member checking was difficult since the original "story" may have changed, simply as a result of the telling of the story. It is also important to acknowledge that participants may not agree with my interpretation of the "story." As the researcher I accept full responsibility for the interpretation and the study results.

Coherence.

Coherence (Agar & Hobbs, 1982; Riessman, 1993) consists of three types: global; local; and thermal. Global coherence refers to the speaker's goal in telling the story, local coherence refers to what the narrator is trying to achieve, while thermal coherence refers to the specific content. The analysis is strengthened when all three kinds of coherence are present. In this study coherence was assured by my attention to the steps detailed in the analysis approach. Dissertation committee members and a qualitative research seminar were part of the methodological rigor.

Pragmatic use.

Pragmatic use, which is similar to transferability (Lincoln & Guba, 1985), examines whether others use the results in the future. This criterion speaks to whether the research provides enough thick description to allow others to determine if the findings can be transferred to their setting. The researcher found that the stories collected in this study provided a thick description of the family experience after sudden cardiac death. Transferability will be determined by those reading the findings to determine if the results can be applied or transferred to their setting.

Research with Sensitive Topics

Sensitive research topics include investigation of situations that may create a threat to

those who participate (Alty & Rodham, 1998; Lee & Renzetti, 1990). The death of a family member is a profoundly personal, and often distressing, experience. Consequently research on the bereavement experience may be threatening or stressful to participants, making it a sensitive topic.

Undoubtedly, conducting research on grief and bereavement with families can be challenging. However, by using well-designed and theoretically conceptualized research study techniques, such challenges can be overcome. Conducting this study included strategies to minimize distress and ensure participant safety. The interview guide was designed to be flexible so as to allow for breaks or ending early in the event participants experienced distress during the interview. A period of closure concluded each interview. Also, all adult participants were given the researcher's contact information for follow-up, as well as written information on local bereavement support available in the community.

Nurses are well skilled to research sensitive topics due to their astute clinical skills. These skills were used to assess for subtle changes that may have indicated increasing participant distress or emotional reactions. Although participants frequently cried while sharing stories of their bereavement experiences with me, they were never overly distressed to the point where I was concerned about their wellbeing.

Protection of Human Subjects

This study was submitted to Oregon Health & Science University (OHSU) Investigational Review Board (IRB). Since participants were recruited in Montana the study was also submitted to Montana State University IRB. Approval was obtained by both these boards. Information about this study was also submitted in a letter to the local IRB, the Joint Community Medical Center and Saint Patrick Hospital IRB in Missoula Montana, which did not see the need

for a third level of approval. The researcher obtained informed consent during the initial visit with the participant. Every family member over the age of 18 was asked to sign an informed consent form (Appendx E) after a review of the risks, benefits, and alternatives.

Risks, Benefits, Confidentiality

Risks.

Individuals may find it upsetting or painful to talk about the death of a family member. All participants were reminded that they could decline to answer any questions they found too difficult to answer. It is documented in the literature that it is not necessarily distressing for people to talk about loss (Nadeau, 1998; Tolle, Tilden, Rosenfeld, & Hickman, 2000). Cook and Bosley (1995) reported that individuals who had participated in bereavement research later reported their experience as positive.

It was expected that some participants might become upset during the interview and cry as they talked about the decedent. When this occurred I stopped the interview in order to allow time for participants to regain their composure. Before proceeding I asked if they wanted to continue or schedule another time to finish the interview. I remained alert for nonverbal indicators of distress, which may include delay tactics, missed appointments, flat affect, and even a lack of tears (Kavanaugh & Ayres, 1998).

A protocol was developed, with clinical experts with experience working with grieving individuals, to follow in the event any participants exhibited signs of increasing distress (crying, sobbing, or agitation). However, this protocol was not needed as none of the participants became overly distressed during the interviews. This was similar to another study with bereaved individuals; specifically, Nadeau (1998) who documented that, although such a protocol was included with her family grief study, it was not needed. Additionally, all participants received

information on local bereavement and grief support services at the end of each interview. This was done to provide participants with a listing of local bereavement resources in the event of a delayed grief reaction or a self-identified need for further follow-up.

The researcher had access to committee members with expertise on conducting research on sensitive topics and with vulnerable families. Dr. J. Kendall is psychiatric nurse who has conducted research with families and children with attention deficit hyperactivity disorder (ADHD). Dr K. Gilbert has conducted research with couples after the death of child; and Dr. A. Rosenfeld is a cardiovascular clinical nurse specialist with experience conducting research interviews with individuals after the death of a family member.

If the researcher noticed unusual depressive symptoms, suicidal thoughts or a potential for self-injury during the interviews, the researcher would have stopped the interview and assisted the participant in contacting his or her primary health care provider. Nurses are well skilled to research sensitive topics, due to their astute clinical skills. These skills can identify subtle changes that may indicate increasing participant distress or emotional reactions. The interviewer, by nature of over 20 years of nursing experience working with families at the time of death and personal experience with bereavement, was qualified to do this research and had the skills needed to adapt the interview schedule if required to allow for unusual situations.

Benefits.

Participants may or may not directly benefit from participation in this study. However, what is learned from participants may be helpful to nurses and physicians and other health care providers in the future. Some participants may find talking about their experience with an interested person helpful.

Confidentiality.

All participants were reminded that confidentiality would be maintained at all times. This confidentiality included statements made by members of the same family. The researcher remained committed to maintaining confidentiality at all times with the following exceptions: situations of suspected child or elder abuse or if a medical emergency arises. In the event of an emergency with any of the participants the researcher would have done whatever was necessary to preserve life and ensure safety.

The researcher was clear with all participants that confidentiality would be maintained at all times except in the above stated situations. This confidentiality included keeping what one family member said confidential from other family members. Audio recording tapes and transcripts were kept in a secure location without identifying information on them. Consent forms were kept locked in a separate location. All documents, which linked the participants identifying information with the data, were also kept in a secure and locked location. Audiotapes were kept until the transcription was verified as accurate by the researcher (and if needed by dissertation committee members) and then were destroyed.

Research records could be reviewed and or copied by the OHSU Institutional Review Board. All transcripts shared with dissertation committee members, including one member outside of OHSU, did not contain identifying client information. All participants received a copy of the study consent form for their records.

Conclusion

There is no question that this study of family experiences after sudden cardiac death was challenging. It was challenging both due to the sensitive nature of the topic along with the complexity involved with recruiting participants. Conducting research with bereaved families is considered a sensitive topic (Horowitz, Ladden, & Moriarty, 2002; Kavanaugh & Ayres, 1998;

Lee & Renzetti, 1990). However, bereaved families were often socially discouraged from sharing stories of a death. Yet stories are known to have meanings embedded within them (Mishler, 1986). These meanings are both important to the one telling the story-- the participant as well as the listener -- who is the researcher (Ayres & Poirier, 1996). It was expected that family stories of sudden cardiac death of a family member would contain information helpful to nurses, physicians, and others who work with grieving families. It was also anticipated that bereaved families would be willing to share stories with an interested researcher. It was imperative that the researcher remained attentive and considerate to the uniqueness of each story. This study was well designed, had a strong theoretical foundation, included built-in safeguards to protect participants, and will make an important contribution to family nursing.

Chapter 4: Results

Seven families in Montana shared compelling and captivating stories of their bereavement experiences after the sudden cardiac death of a family member. These stories were analyzed using qualitative techniques, specifically narrative analysis, in order to address the study aims which included describing family bereavement experiences and identifying meanings of loss.

Setting the Stage

Riessman (1993) highlights that there is "no *one* method" (p. 5) of narrative analysis, and emphasizes that personal narratives are especially valued because such stories are anchored in time and place. Stories, especially stories of difficult life transitions, provide an avenue for individuals to make sense of their experiences. When using narrative analysis the researcher must "set the stage" and acknowledge the context in which these results originate. Setting the stage involves positioning the setting, the researcher, the seven families, including their deceased family member, and the stories within context.

The Setting

The interviews were conducted in the Summer and Fall of 2007 in Montana. Montana is a large state, which ranks 4th in land mass size while also ranking 44th in population, thus resulting in a relatively low population density. Montana is a land of mountains and wide open spaces, and this is best illustrated by the state nickname "Big Sky Country." Approximately 54% of Montana is considered urban while 46% of the state is considered rural (Montana Department of Commerce, 2009). This study included families from both rural and urban parts of Montana although I should point out that the whole state of Montana has less than one million residents. Due to the large rural nature of Montana, data collection occurred over a wide area

across the state. Five families lived in the western part of Montana and two families lived in the central part of Montana.

The Researcher

The participants were willing to share very private and detailed aspects of their bereavement experiences with me. As the researcher I felt compelled to share some of "my story" with the participants as well. My interview guide (Appendix H) explained that my interest in sudden cardiac death came from both my background as a nurse and my personal experience. I deliberately mentioned my personal experience with sudden cardiac death of a family member. Most family members asked about my experience at some point, usually as the interview was coming to a conclusion. The questions were generally focused on whom in my family died and when the death occurred.

I intentionally used my personal experience as a means to develop a shared bond between myself and the participants so that they would be comfortable sharing the story of their bereavement experiences with me. This approach worked very well because all participants shared rich and compelling stories of their bereavement experiences. Since all the participants knew I was a nurse they frequently shared things they might not have told a non-nurse. For example, they frequently asked me questions about their family member's specific cardiac condition or explained the medical history of their family member. They told me about the physicians who cared for their family member and about the funeral home staff whom they worked with after the death. They asked me if I worked at the hospital or if I knew the surgeon or nursing staff that cared for their family member.

When one reads about grief, loss, and bereavement it appears so orderly; as one reads about a series of steps, or stages and phases that bereaved individuals' progress through over

time after a death. Even when this listing of stages and phases of grief stresses that grieving individuals may circle back or not progress through the stages or phases in the order listed it looks so methodical and neat and tidy. However bereavement is exactly the opposite; it is messy, ugly, volatile, and unpredictable, and impacts every fiber of one's being and every aspect of one's soul. Since all participants knew I had a family member die a sudden cardiac death, they frequently were very open with me about this unflattering side of bereavement. They told me how they threw things, walked around like a *"zombie,"* and screamed and raged about the unfairness of life. They told me that eating dinner alone was the hardest part of the day and how appreciative they were when someone brought food and ate dinner with them. They told me that it was months before they could sit thorough a church service without sobbing. They told me that even when their friends said to 'call anytime, day or night' they knew they would not call EVERY night at 3 A.M. when there were awake and crying. They told me about things that were helpful and things that were unhelpful during bereavement.

Participants trusted me enough to share with me very personal and private information about their lives and together we both laughed and cried. I was extremely honored to have not only met, but gotten to know on a personal level, the family members who participated in my study. They opened their homes to me and welcomed me briefly into their lives during 2007. A bond was formed between the participants and myself and I find that they frequently come to my mind as I recall their stories. For example, each December I recall a family telling me how their husband and father would sleep on the floor under the Christmas tree every year, and how this was an activity that he continued from when he was a little boy. I am certain that I will always think of this family when putting up my own Christmas tree each year.

I have great respect and admiration for the participants' ability to move forward with their life after the devastating loss of their family member. I appreciate their willingness to participate in my research study so that others may potentially benefit from their experiences. When participants asked about my story I shared enough information to answer their questions, while also being attentive to not allow the focus of the conversation to remain on my story This approach worked well and only one participant pressed to hear more details of my story and my experiences. In this situation I was able to refocus the conversation back to her story. Now I will present my story.

Researcher's story.

My husband, Douglas, had a cardiac arrest at home on the evening of June 23, 2000. I was in the kitchen downstairs and he was upstairs in the bedroom. I heard Doug cry out just before he fell to the floor. I immediately began CPR and called for my daughter Abby, then age 13, to call 911. I sent Andrew, then age 10, to open the front door of the house to direct the emergency medical service personnel to our location. My third son, Christopher, then age 6, was asleep in an adjacent bedroom.

A sheriff was the first to respond and he assisted me with CPR until the EMS responders arrived moments later. At that point I stepped aside and the paramedics took over and obtained IV access, connected a cardiac monitor, and began to administer medications and start defibrillation. These resuscitation attempts were unsuccessful and eventually Doug was transported to the Emergency Department (ED). I called neighbors to come over to stay with the children so I could go to the hospital. At the ED resuscitation efforts continued without success; eventually all efforts to resuscitate Doug ended. I was present in the code room and well supported by the majority of ED staff members. This is likely a result of my employment at that

hospital as many of the hospital staff knew me personally. When it came time to leave the hospital I clearly remember saying to a friend, who came to the hospital after a call from the ED staff, *"I know what to do here at the hospital, I do NOT know what to do when I leave the hospital."* Thus began my bereavement experiences. I was well supported by friends and family members in the months and years after Doug's death, although bereavement was certainly a time of major emotional upheaval as I struggled to take care of myself while also attempting to take care of my children. Bereavement was not pretty; in fact, it was horrible. It is hard to explain how horrible it is; in an attempt to convey the awful nature of bereavement I have often said that I would not wish a sudden death on my worst enemy. The ongoing support of family and friends, along with family bereavement programs, allowed my family to move forward, slowly and painfully at first. For many months we were in shock and disbelief, and I often wondered how life could be continuing when our world had ended. As a family we participated in an after-school grief program and the children enrolled in a summer bereavement camp. These programs were very beneficial as we began to live our lives without Doug's presence, a life forever changed.

At some point in time I began to wonder about what other families experienced after sudden cardiac death of a family member. As a cardiac nurse I knew that nurses support families after a successful cardiac resuscitation. For example, nurses have developed support groups for clients with implantable defibrillators, nurses have taught family members cardiopulmonary resuscitation (CPR), and nurses are involved with cardiac patients and families via their work in cardiac rehabilitation programs, etc. I had many questions about nurses' support of families when resuscitation attempts are not successful. These questions included (a) How do cardiac nurses support families when the patient is not successfully resuscitated? (b) What happened to

families who do not interact with heath care professionals at the time of the sudden cardiac death, are their experiences different from families who do interact with heath care professionals? (c) What happens when the surviving family members do not have family or friends to support them after the sudden cardiac death? (d) Are there things that cardiac nurses and other health care professionals could do to better support families after the sudden cardiac death of a family member?

Ultimately these questions propelled me to enroll in the nursing doctoral program at Oregon Health & Science University so that I could gain the skills needed to study family bereavement experiences after sudden cardiac death. My hope is that my program of research will lead to the development of nursing interventions to support families at the time of a sudden death. I recognized that before I could begin to develop nursing interventions I first had to gain an understanding of family bereavement experiences. I realized that the best way to obtain this information was to talk directly with bereaved family members themselves. This Family Bereavement Experiences Study is the first study in a program of research designed to investigate family bereavement experiences.

The Seven Families

The seven families will be introduced, along with their deceased family member. Family relationships, including the relationships between the participants, and to the deceased family member, are listed (See Table 3). Quotation marks and an italic font are used to present direct quotes from the participants themselves. All names are pseudonyms and also listed are the participants' ages, both at the time of the death and the time of the interview. The final column in Table 1 lists the time between the death and the interview.

Table 3

Family Characteristics

Family	**Name of decedent*/Age of decedent at time of death n = 7**	**Cause of death**	**Name of family members*/relationship to decedent n = 17**	**Participant current age/age at time of death**	**Time since death**
1	Mike 44 y/o male	Ventricular fibrillation	Ginny- unmarried partner	53/48	5 years
			Dave- best friend/business partner	50/45	
2	Ben 54 y/o male	Aortic dissection	Betty-wife	60/57	3 years
			Bill- adopted son	42/39	
3	Dick 54 y/o male	Cardiac rupture	Janet- sister	57/56	1 year
			Karen- niece	37/36	
4	Brad 54 y/o male	Myocardial infarction	Debbie- twin sister	54/56	2 years
			Connie- sister	57/60	
5	Jim 52 y/o male	Myocardial infarction	Alice-wife	53/52	1 year
			Irene- step daughter	23/22	
			Oliver- step son	25/24	
			Alex- step son	29/28	
6	Ron 54 y/o male	Ventricular fibrillation	Marie- wife	55/54	1.5 years
			Karen- daughter	22/21	
			Jack- son	25/24	
7	Bob 49 y/o male	Myocardial infarction	Diane- ex-wife	45/44	1 year
			Ann- daughter	25/24	

***All names are pseudonyms**

Family 1.

Mike was a 44-year-old man who lived with his unmarried partner Ginny, age 48, in a small town. Mike's family, although not exactly a "traditional family," included Ginny, his

partner of 11 years, and his best friend and business partner, Dave, age 45. Ginny identified Dave as "family" when she stated that she and Dave had *"the closest personal relationship with* [Mike] *outside of maybe his family - but even his family – he hadn't lived near his family for a long long time"* and Ginny portrayed the three of them as *"family enough."* Mike, Ginny, and Dave operated an outdoor touring business together and Mike was portrayed by Ginny as a *"very healthy"* guy who recently *"returned from about a 4 week backpacking trip."* Ginny came home from work one afternoon and found Mike on the floor. Ginny called 911 and an ambulance responded to the house. Ginny told me that, "*they worked on him for just a couple of minutes and they said it's too late you know he's gone."* After an autopsy Ginny learned that Mike died of ventricular fibrillation. The family interview with Ginny and Dave took place 5 years after Mike's death.

Family 2.

Ben was a 54-year-old male who was married to his wife Betty, age 57, for 19 years. Together they lived with their adopted son Bill, age 39, who is developmentally delayed. Betty is disabled with chronic pain, while Ben was disabled with migraines. This family lived in a house owned by Bill's birth family, and Betty and Ben both received disability benefits from the federal government. Betty talked about her life with Ben, specifically their living with disabilities saying, *"it was hard to be disabled* [but] *it was kind of fun because we were disabled together."* She reported that Ben often said, "*we're not worth a damn but maybe together we make one person."* Betty added that Ben used to say, *"we must have done something right – we got each other"* and then she added *"we had a good marriage."* Ben died of an aortic dissection in the hospital one week after a surgical repair of his aorta. Betty and Ben were older when they married and Betty explained their life together saying, *"we had a grand life … but* [we] *should*

have had longer to enjoy it." The family interview took place with Betty and Bill 3 years after Ben's death.

Family 3.

Dick was a 54-year-old man who lived in the same community as his older sister Janet, age 57. Janet's daughter, Kim age 36, lives nearby and she and her mother have a close relationship. Although Kim and her uncle enjoyed a close relationship when Kim was younger; in recent years Kim has grown apart from her uncle. Janet and Dick were employed at the same location and worked together on a daily basis. They also socialized together, mostly on various outdoor activities which Janet told me about saying, *"Dick was my downhill ski buddy …* [and going to the] *horse races was his activity that we did together."* One day at work Dick looked *"very pale and … was coughing"* and his co-workers told him *"we think you need to go home – we think you may be catching a cold."* Dick saw his physician and learned his blood pressure was low and he was instructed to stop his medication for hypertension. Dick was instructed to *"drink and drink lots of liquid and eat food that is high in sodium."* Dick stayed home from work for several days and when he did not call or show up after the weekend Janet had the apartment manager let her in to Dick's apartment where they discovered Dick dead in his recliner. After an autopsy Janet and Kim learned that Dick died from a *"cardiac rupture."* The family interview with Janet and Kim occurred 14 months after Dicks' death.

Family 4.

Brad was a 54-year-old man who lived in a small community near his twin sister Debbie. Brad also had an older sister, Connie age 57, who lived on the East Coast. Brad had been living in the same area as his twin Debbie for about six years although prior to this Debbie told me that, "*Most of the time in his adult life we didn't know where he was."* In spite of the fact that Brad

"disappeared for a while" both sisters talked about having a close relationship with Brad. Connie said, *"I felt like as if we were close* [pause] *in one way – I think he knew me very well – I think I knew him very well."* Debbie said, *"Brad and I were close … he was my twin"* and Debbie shared that she always felt a special connection to Brad since they were twins. Connie added that Debbie "*was more involved in his life in his – in his end years."* Brad had a myocardial infarction while driving and Debbie told me that that his car drifted off the road into a field. The emergency medical response team arrived to the scene and transported Brad to a local hospital. Debbie's son received a call from the coroner who informed him of Brad's death. Debbie received notification of the death from her supervisor at work and she went to the hospital where she saw Brad's body and told the hospital staff, *"I think he was a donor – and even if he wasn't, I donated him."* The family interview with Debbie and Connie took place 2 years after Brad's death.

Family 5.

Jim was a 52-year-old male who lived with his wife Alice, age 52, in a rural community. Jim and Alice worked together professionally and also worked making improvements on their small ranch. Alice has three children from a previous marriage and Jim had a very close relationship with Alice's children: Alex age 28; Oliver age 24; and Irene age 22. Jim and Alice were married for three years. Alice talked about meeting Jim three years earlier saying, *"I just had this … kind of stunning-like awareness that Jim was just such an unusual person and he had so much in common with* [my children, especially my sons]*"* and she talked about Jim's impact on her family saying that Jim *"was a Godsend of a person."* One fall day Alice and Jim spent time getting the ranch ready for winter and that night Jim woke up feeling sick. Alice asked Jim what was wrong and he said, *"I feel really nauseated and I'm throwing up and I have diarrhea."*

Alice offered him a cold cloth and suggested, *"well you probably just have the flu."* After about 15 minutes Jim laid *"down on the floor and roll[s] over to his side and … he was dead."* Alice called 911 and an ambulance responded to their ranch house and transported Jim to a local hospital. Alice blamed herself for not knowing Jim was having a heart attack saying, "*I should have known what was wrong with him, and saved him …"* The family interview with Alice and Irene occurred exactly one year after Jim's death. Alice was insistent that the family interview take place on the one year anniversary of his death. In spite of several offers to reschedule the interview for another day it became clear to me that it was meaningful for Alice to tell me her story and Jim's story on this day as a way to honor Jim's memory. Because Alex and Oliver live outside of the United States they participated in the study by telephone on a different day.

Family 6.

Ron was a 54-year-old male who lived with his wife Marie on a large farm in a rural area. Ron and Marie's children: Karen, age 25, and Jack, age 22, were attending graduate school and college respectively at the time of Ron's death. Ron was a *"very good farmer"* and the family had plans for Jack to assume responsibility for the running of the farm once he finished college. Marie showed me photographs from a trip she and Ron took to Alaska saying, *"we were married 26 years and that's the only time we ever took off* [in the summer]*."* Marie portrayed Ron saying he *"was the fun one - he had all the toys"* and she explained that every summer Ron would set up an area at the lake for the whole neighborhood to enjoy since Ron was the person who *"would bring … everything down* [to the lake] … *and then* [friends and neighbors] *would know to … run down for dinner tonight."* Marie continued saying that Ron *"was a camp director for the whole area down at the lake."* One morning Marie left for work early and returned home that afternoon to find *"nothing had changed, the coffee hadn't been made,*

everything was just how I left it." Marie found Ron on the floor of the bedroom and she called 911 and told them *"you have to send somebody… **I just need somebody here**."* It took 30 minutes before a neighbor arrived at the house and 45 minutes before the ambulance arrived. Ron's death, due to ventricular fibrillation, *"change*[d] *everything"* for this family and the biggest change was related to the operation of the farm. The family interview took place at the family home on the farm with Marie, Karen and Jack one and one-half years after Ron's death.

Family 7.

Bob, a 49-year-old male, was a construction worker and the father of Ann, age 25. Ann talked about her relationship with her father saying, *"my dad and I were **very, very** close … my dad pretty much – my dad and my grandma raised me - and I always lived with my dad, and we **talked** every day - **saw each other** every day - **had dinner** every day."* Ann said that one afternoon Bob called her saying, *"he was taking a break at work and he wanted to say 'hi' and see how my day was going – and he sounded great."* About an hour later Bob was found on the ground at his job site and an ambulance was called. Bob's mother received notification that Bob was being transported to the hospital and she called Ann. They wondered if "*maybe* [Bob] *had fallen off the scaffold or a tool incident or something;"* Ann drove to the hospital and arrived at the same time as the ambulance. Additional family members and friends came to the hospital and waited for news with Ann. Bob was initially treated in the Emergency Room and then was transferred to the cardiovascular laboratory. After some time the family received *"a page and they* [hospital staff members] *took us into a room and said he didn't make it."* The physicians were unclear about the cause of death and an autopsy was planned. The family wondered *"why* [Bob] *died"* and it is only when the death certificate arrived in the mail several weeks later at the family home that the family learned that Bob died of a myocardial infarction. Bob *"would never*

go to a doctor" and had a history of high blood pressure. The family interview included Bob's daughter, Ann, and Ann's mother, Diane, age 45. Diane and Bob were divorced but remained *"friends."* The family interview took place one year after Bob's death.

The Stories

Before presenting family stories of bereavement experiences I must acknowledge the representational decisions made during analysis. These decisions were guided by the aims of my study, while also remaining true to the stories shared with me by the participating families. Undoubtedly my own bereavement experiences influenced these decisions, as did my theoretical memos, reflective journal, field notes, and conversations with experienced qualitative researchers on my dissertation committee.

Story telling is a natural human activity and many of the participants were articulate and skillful storytellers. Family interviews often continued for several hours, averaging 96 minutes, with a range of 90 – 150 minutes. The family interviews included two or more members of each family and at the conclusion of each family interview an individual interview was scheduled with each member of the family. The participants' individual interviews were not as lengthy as the family interviews and lasted on average 45 - 90 minutes. Not unexpectedly, at the conclusion of seven family interviews and 17 individual interviews, I found myself with a large quantity of stories. These stories were transcribed from audiotape to a transcript, and this representational step is described by Riessman (1993) as "incomplete, partial, and selective" (p. 11). A conscious effort was made to keep the participants nuances of speech intact in all transcriptions, including all the "ums," "ahs," and other idioms of speech. As the listener of the stories I inserted additional information on the transcript, within brackets, to indicate non narrative elements

including pauses, sighs, laughter, and tears. Only minor grammatical changes were made to improve readability and clarify meaning.

The voices of the participants will be presented using an italic font and quotation marks. A bolded text is used for words that the participants particularly emphasized in their stories. The long transcripts were summarized through the use of a narrative reduction process and a detailed narrative summary (Appendix I) was developed for each of the seven families. These summaries included both family and individual bereavement experiences and were written with the study aims in mind in order to capture the essence of the family bereavement experiences.

Understanding why the stories were told the way they were told is central to the method of narrative analysis. My interview guide was structured so that I initially asked all the family members at the beginning of the interview for the story of the death. All families willing shared their "death story" with me and this story was often told with intermittent periods of visible distress including tears, cracked voices, and long pauses. This distress conveyed the depth of their loss and I was honored to be present with their grief while listening to their story. I remember getting tears in my eyes when Betty told me that Ben said, *"Kiss me honey, I'm dying,"* just before he experienced a cardiac arrest. I can still vividly remember listening to Alice's story of Jim's death at their home with bated breath and goose bumps on my skin. On occasion it was difficult for me to listen to these death stories; this was most often the case when their death story was similar to my own death story.

All stories were told in such a way as to convey to me, the listener, a description of their family member who died. Stories told by each participant consistently included details about the decedent that allowed me to achieve an understanding of this family member as a person, while also gaining a sense of how this family member was an important person in their lives. All

participants, without fail, described the personal characteristics of their family member, while also emphasizing the human connections they shared with this family member. For example, Marie in family 6 talked about her husband Ron saying, *"Ron was a very good farmer."* This sentence, combined with other comments describing Ron as the *"father figure of the family," "kind of the main bread winner,"* and *"the boss,"* conveyed to me Ron's role in the family. However Marie also said that Ron, *"was the fun one - he had all the toys … we had the* [motorcycle] *and then three boats …"* This description of Ron as the *"fun one,"* combined with other stories about Ron, expressed to me as the listener of the stories, a picture of Ron as the family member who organized vacations and holidays and other *"fun"* family activities. At the end of this family interview with Marie and her children, I had a clear sense of Ron's distinctive personal qualities, as well as his role in the family.

Some participants went beyond telling me stories about the decedent; they also showed me photographs of their family member who died. For example, Marie and her children shared with me many photographs of Ron working on the farm. They also showed me a picture of Ron on a motorcycle from a recent trip he and Marie took to Alaska. In another family Alice shared photographs with me, first showing me a wedding photograph of her and Jim together. Then she showed me a photograph of Jim as a coach. Later on, when reading Alice's transcript, I connect this photograph of Jim as a coach with Alice's comment that Jim, "*did not look like a cardiac patient."* Alice was using this athletic looking photograph of Jim as confirmation of her statement that Jim did not look like a *"cardiac patient."* Alice's comments related to Jim's appearance were consistent with Alice's bereavement experience, which included shock and self-blame after his sudden cardiac death. This information will be presented in a subsequent section.

The overall result of the way the stories were told by the participants was that I was able to gain a sense of *"knowing"* the family member that I did not meet. All participants told their stories in such a way as to convey the unique characteristics of their missing family members; this was important and meaningful to all families. The participants wanted me to *know* their deceased family members as persons and also wished for me to *know* their family members as they *knew* them. I concluded all interviews with a sense of the decedents as persons through the stories shared by surviving family members.

My interview guide situated the stories to begin at the time of the death, as family bereavement experiences started at this point in time. However all participants began their stories at an earlier point in time. Participants initially described their activities, along with the decedent's activities, in the days preceding the death. Participants then moved on to tell me the death story which provided the context for their bereavement experiences. It was only after the death stories were told that the participants were able to move on and share with me their bereavement experiences since the deaths.

Themes across Family Bereavement Experiences

Analysis of stories identified five themes across families, even as the specifics associated with each family's experiences unfolded differently. These themes are

Sudden cardiac death … boom;

Saying goodbye;

Grief unleashes volatile emotional reactions;

Life goes on … but never back to normal; and

Meanings in loss.

The results are presented using some of the participants' most powerful and compelling stories highlighted underneath the corresponding themes. I will also link the stories to one participant's profound description of bereavement. One day, when I was deeply immersed in the stories of bereavement experiences, suddenly a sentence that I had read numerous times before jumped out at me. On this particular day I realized that Marie's words captured common bereavement experiences that all families included as part of their stories. So what were Marie's words that captured my attention that afternoon? *"Taking one step forward, one step forward, try to get over these hurdles, then boom – there it goes."* This quotation from Marie portrays the bereavement experiences of family participants as a series of *"forward steps,"* encounters with *"hurdles"* or challenges, and periods involving *"boom*[s]" which intrudes suddenly, and unpredictably, at random intervals. Marie did not have to explain *"booms"* because I understood that she was referring to the random emotional responses associated with grief that intrude suddenly and unpredictably after the sudden cardiac death of a family member. One moment a bereaved individual might be functioning somewhat normally, and the next moment they may be upset or in tears. *"Booms"* might be something obvious, like someone mentioning the name of the person who died; or something subtle, like hearing a song on the radio. *"Booms"* are events or things that remind the grieving individual of their loss.

All families told powerful stories which conveyed the meanings embedded in their bereavement experiences. To some degree it seemed somewhat artificial to separate experiences and meaning, while still staying true to the stories told by the participants. One challenge associated with research on meaning making involves how meaning is defined. What does it mean to identify meanings in loss? I defined meanings in loss as the 'lessons learned' during

bereavement, or the part of the bereavement experience that survivors 'took to heart' and moved forward with into their changed life after the death of someone significant.

Before I collected data I naively thought that the meanings of loss would be clear in all stories. To some degree, in some stories, meanings were clear; especially when the storytellers spoke about one aspect of their experience over and over again; or where the speaker placed emphasis on certain words; or where the speaker included nonverbal communication including tears, sighs, or long pauses. Some families in my study made statements to the effect that the sudden death of a close family member was the *"hardest"* life event they have ever experienced. Members of one family expressed that they did not understand why life was continuing around them. Some families were able to make sense of the death and express appreciation for this person's presence in their life. For some families the sudden death of a family member may have prompted them to *"live differently"* or learn what is truly *"important."* This may, in turn, "facilitate positive adaptation" (Neimeyer, 2005, p. 28).

The stories shared by families in this study indicated that many aspects of their bereavement experience were meaningful. The analysis revealed meaning at two levels, the first level is the meaning that was embedded in their bereavement experiences. For example, all families told me that the funeral or memorial service was meaningful, the support of friends and family members was meaningful, and the sharing of stories about the decedent was meaningful. Information about meaningful bereavement experiences will be presented under the first four themes: Sudden death… boom; Saying goodbye; Grief unleashes a surge of variable emotional reactions; and Life goes on … but never back to normal.

However, the analysis also revealed another level of meaning and this second level of meaning was associated with an ability to identify meanings in their loss. This second level of

meaning will be presented under theme 5: Meanings in loss. An analysis of family and individual interviews revealed that if family members were able to identify some meanings in their loss then they were able to take *"steps forward"* after the sudden cardiac death of a family member. Certainly surviving family members faced *"hurdles"* and challenges along the way, but finding meaning allowed them to take *"steps forward"* into their new life, a life that was forever changed. The analysis also revealed that if family members were not able to identify meanings in their loss they were not able to take *"steps forward,"* in essence, becoming stuck, or not able to incorporate the loss into their life.

Theme 1: Sudden cardiac death … boom

Most participants began their stories with a description of a normal day, for example, *"it was a Wednesday, or a work day at least…"* However this normal day went greatly awry when a family member was found dead on the floor; or a phone call was received in the middle of the night; or when a family member suddenly became gravely ill. A sudden cardiac death occurred and boom, life was instantly and forever changed. Not surprisingly, all participants were shocked when they discovered, or were notified of, the sudden cardiac death of a family member. This was especially noticeable in the stories where the decedent and other family members had no awareness of preexisting cardiac disease, or when the decedent was asymptomatic. This shock was accompanied by a multitude of questions; questions which centered on why: Why did our family member die? It was very common for families to have questions related to the cause of death; as illustrated by an exemplar case of one family's experience.

A story of questions: why did the death occur?

Janet and Kim, in family 3, had many questions after Dick's sudden death. Janet was aware of Dick's recent visits to the doctor; she knew that his blood pressure was low and that his

medications were recently changed. Even with this knowledge, Janet was shocked when she arrived at Dick's apartment and found him dead. The police responded to the apartment, shortly followed by the arrival of the coroner, whom took control of the scene. Janet spoke with the coroner, describing that he "*introduced himself and … I found the coroner was very good … he* [coroner] *was very good about, you know: 'this is what we are going to do;' 'what funeral home do you want me to call;' … and he proceeded to take care of* [everything]*."*

Janet and Kim's initial questions were related to the cause of Dick's death: What happened to his heart? When did he die? Why didn't Dick's doctor *"do something different?"* Due to the nature of Dick's unexplained death an autopsy was required. Once the autopsy was completed Janet and her daughter Kim talked with the coroner, who explained the cause of death. Janet told me that Dick, *"actually had a hole in his heart probably the size of the tip of your thumb. He had a weak spot and evidently because it was working so hard with the lowered blood pressure it just wore that spot out… it was a heart rupture."*

Over time, Janet and Kim had additional questions such as: Was Dick in pain when he died? Was there anything we could have done differently? Janet and Kim talked with the coroner several times and Janet explained how helpful these conversations were saying, *"the doctor who did the autopsy, to be able to explain it, umm, so that I understood why the heart failed, umm, like Kim said to understand that it was painless, it was quick …* [because] *there is that feeling of: Oh I should have done something. But no, there was nothing* [anyone could have done]. *I mean this was 30 seconds and over with …"* Kim talked about the coroner as well saying, "*The medical examiner took a long time with us and talked to both of us. He was very helpful, he was very empathetic, and took all the time we needed. We even had to call him back a couple of times because we didn't understand and he was, he was very helpful, very helpful in*

determining the date of death … I was very impressed with him, the time that he took and the care that he took in explaining…[what happened to Dick].*"*

Sudden death can be challenging for surviving family members; Janet expressed this when she said, "*And you have to accept the fact that yea we are all going to die, that's not unusual.* [You] *kind of wish it would happen in a different way and you'd get this two week's notice* [laughter]. *It's the suddenness of it that's hard."* Kim pointed out that *"the suddenness is hard for us, the people that are left behind. The suddenness is not hard for* [Dick] *… and left behind is us and our suffering, and our* [thoughts of]*: Oh I wish I could have…"*

The ability to ask questions over time provided Janet with the knowledge needed to allow her to accept that *"there was nothing anyone could have done"* to prevent Dick's death. Janet also talked with Dick's doctor several months later and came to understand that physicians also wonder what they missed, and what they might have done differently. The ability to talk with both the coroner and Dick's physician were very helpful for Janet and Kim and allowed them to understand the complex nature of ventricular rupture.

What can we learn from this story of questions? For this family, the ability to have their questions answered, especially since these questions were answered by the coroner on several different occasions, was very helpful in gaining an understanding of what caused Dick's death. This information allowed Dick's family to accept, and make sense of "*the physical side …* [that] *the heart just gave out."*

Steps forward, hurdles, and booms: Certainly Janet and Kim are taking *"steps forward"* after Dick's unexpected death. Understanding what happened, and why it happened, allowed these surviving family members to take steps forward into their changed life. If surviving family members do not get answers to their questions they may get stuck, unable to take *"steps*

forward." A contrasting case, of unanswered questions, will be presented subsequently under the theme of meanings in loss.

Questions are common after a sudden death and since all participants knew I was a nurse they often directed their questions to me. Some questions were more physiological based such as: What happened to his heart? Why did it stop beating? Did he have a heart attack? Other questions were more symbolic or rhetorical in nature, such as why would God do this? Why did God let this happen? Surviving family members frequently speculated about preexisting symptoms of cardiac disease; wondering if a bout of heartburn or a pain when pressing on one's chest had anything to do with the death. One participant told me that her dad had recently quit smoking and she wondered if that was somehow related to his death. Another participant asked other members of a hiking trip if her partner had exhibited any symptoms such as pain, shortness of breath, or if he was slower than usual on a backpacking trip in the week before his death. Several families wondered why the decedent's physician didn't identify a problem, and intervene, before the death occurred.

Frequently some of these questions could be answered once the autopsy results were available. However, family members needed the autopsy results explained in a manner so they could understand what had happened. Do to the complex nature of cardiac physiology, and cardiac pathophysiology, this understanding did not necessarily come about after one conversation. Family members often needed to have the autopsy results explained several times before they truly understood what the physiology of what transpired. Many families reported that the ability to ask questions, especially over time, was beneficial as the struggled to understand what caused their family members death. Unanswered questions can leave families without the answers they need to incorporate the loss into their life. More rhetorical questions

often had no answers and some participants found resolution within religious or spiritual communities of faith. Some questions simply had no satisfactory answers.

Theme 2: Saying Goodbye

Participants expressed that they were ill prepared to say goodbye to their family member who died. Saying goodbye to someone important is heart breaking. On one hand, it was hard to believe what was happening and on the other hand, it was impossible to know how to say goodbye. It is hard to imagine how life will continue without the presence of this person; an important person needed to be alive and part of your life. It is shocking that this loved person has died and it is surreal to accept the reality of the death. Survivors walk around like 'zombies' struggling to understand why millions of people are alive, while the person they loved has died.

So how did families say goodbye to their family member? They consistently mentioned some sort of ceremony such as a funeral or memorial service. The funeral or memorial service is an important and meaningful way to say goodbye, an *"event"* even. The stories about the service or funeral included aspects of the experience that were important to surviving family members. The features of the service that were most meaningful to the families were: the number of people who attended the service; the people who spoke at the service; and the sharing of stories that occurred at the service. Due to the sudden unexpected nature of the deaths associated with this study, it was not surprising that several families spoke about how the service was a time and place where they said goodbye to their family member.

Saying goodbye is never easy. Two stories will be presented, one story exemplifies learning something new about a family member who has died, and one story illustrates a unique and special goodbye ceremony shared among friends.

A story of an "impressive" memorial service and wake.

Connie and Debbie shared a story about the wake they held for their brother Brad after his sudden cardiac death. Brad had a somewhat distant relationship with his sisters and for several years after his divorce neither Connie nor Debbie knew where Brad was living and they did not know how to contact him when their mother was dying. Debbie and Brad, who were twins, had a shared history of abuse as children and tension existed in their adult relationship. Several years prior to his death Brad moved to the same Montana town as Debbie.

When Brad suddenly died of a myocardial infarction Connie traveled to Montana and she and Debbie begin planning a memorial service. They were not expecting many people to attend the service and both sisters initially thought the room provided by the funeral home was too large. Debbie explained that they were expecting maybe five people to show up and they were shocked when they arrived for the service and saw the room full of people. They told me the room was *"packed"* and described an eclectic group of people including, *"people from work, college students, umm musicians …* [and] *bar people."* Some of Brad's friends asked if they could speak about Brad and Debbie and Connie said anyone who wanted to speak would be welcome to do so.

Much to Connie and Debbie's surprise person after person got up and spoke about Brad. They spoke about how much Brad meant to them, how he mentored them; how he helped them when they were struggling with failing grades or needed money to purchase books for college classes. Stories of Brad's ongoing help continued as people described Brad as a: *"really, really nice guy* [who] *helped me turn my life around; or he helped me get through school; or he helped me understand* [things]*."* All of these speakers provided new information for Connie and Debbie, who had no inkling about this side of their brother: a Brad who had many friends; and a Brad that was helping other people.

Connie made a point to include a story about a young man who made a very strong impression on her at the service. This young man asked if he could play a stringed instrument and Connie and Debbie decided to skip the music they had chosen in order for this young man to play his viola. Connie described an ***"incredible"*** version of Amazing Grace played in tribute to Brad, to mourn his passing. This young man then played a song to celebrated Brad's life; an Irish jig. Connie said *"Oh it was **awesome"*** and Debbie agreed as she commented to me that she had goose bumps just remembering this special tribute to Brad.

Eventually this diverse group of people, which Debbie called, *"Brad's extended family,"* moved to a bar that Brad frequented. The memorial service now changed into a wake, which is a ceremony, with origins in Irish culture. At the bar Brad's friends and family members celebrated his life, in the party atmosphere of a traditional Irish wake. Connie was especially impressed that someone associated with the bar, either the bar keeper or beer distributors, donated all the beer. This donation was meaningful for Connie in that she realized that Brad was respected and liked enough for someone to make such a generous donation. This wake also included another ceremony to honor Brad; a Native American passing over ceremony.

So what can we learn from this story of Brad's wake? This story demonstrates that family members may learn something new about their family member after the death. In turn this new information may be meaningful for surviving family members and positively influence their bereavement experiences. Connie and Debbie learned new information about Brad and the effect of this new information was that they changed their impression of their brother; a brother who they knew as *"arrogant"* and a *"bragger,"* to a brother who helped other people. Connie summed up the impact of this new information when she said, *"The whole wake – the **whole experience** impressed me … the whole thing was just the biggest surprise of my life … and I was*

*so **proud** of my brother by the time we were done."* For Connie and Debbie, the new information they learned about their brother at his memorial service and wake, completely changed how they thought of their brother.

Steps forward, hurdles, and booms: This family was very matter of fact about Brad's death. This pragmatic approach to death was the result of their upbringing and the somewhat distant relationship Debbie and Connie shared with Brad over his lifetime. Debbie described the family perspective on life and death when she said, *"… in our family we take death as a part of life … and so it's tragic when it happens and we miss him terribly, umm, – but you know, [pause] … umm, – you know, it's like, for lack of better words, is no big deal, you know, it's just part of life."* Connie added, "*And there is no sense picking apart what happened and how it happened, it happened … but you talk about the person."* Debbie continued, *"Now we deal with the loss and going on with the rest of our lives without that person."* Debbie and Connie are taking *"steps forward"* after Brad's death. Unlike other families, they do not face many *"hurdles"* as they take steps forward; this is likely due to their more pragmatic approach to death. They do not describe many *"booms,"* or intrusions of grief; again, this is likely related to their more no-nonsense approach to life and death.

A "cool" goodbye story.

Ginny shared a *"cool"* goodbye story involving Mike's male friends; a story that she found meaningful and important. Ginny explained that Mike's body needed to be moved from the location where the autopsy was performed, to the location where the cremation would be done. The distance between the two locations involved only a few miles but the fee for moving Mike's body from one place to another would be *"600 – 600 bucks."* Ginny told me that one of Mike's friends asked her, *"Could we, could we, just put him in my truck?*" Ginny replied,

"You'd be all right with that?" This friend replied affirmatively and at this point in the story Ginny paused and we laughed together.

Mike's friends took a side trip while transporting his body, and in between the two locations they stopped at the river *"and drank beer and had a big sendoff and said goodbye."* Ginny explained, now providing more details, *"so they all took him Mike … five or six* [guys]. *They went down to the* [name] *River, drank a bunch of …* [beer], *Schmidt beer, which is what those guys would drink when they were a low-lifeing it when they didn't have a lot of money … and they told stories about Mike. I bet they had him down there two or three hours."* Ginny mentioned that these male friends invited her to join them at the river but she declined because: *"It was all guys and I think they needed their guy time; and then I had already said my goodbyes; and I was like 'no, I think this is your chance'."*

Ginny emphasized that Mike's friends were glad for this time with Mike and she was pleased that they had a chance to be together one last time. Ginny also explained the significance of this goodbye ceremony taking place at the river, since in years past these friends often gathered together alongside various Montana rivers. Ginny was also appreciative of the fact that since Mike's friends transported his body from one location to another saved her money, although this was not the primary reason why she included this story. Ginny shared this story with me because it was unique and special, and she said in conclusion, *"It was pretty cool. And there's nothing illegal about that."*

So what can we learn from this *"cool"* goodbye story? Mike's male friends found a way to say goodbye in a meaningful and unique way, in a manner reminiscent of times they had spent with him in earlier years. They gathered together and shared stories and memories, while saying goodbye to a special friend. Ginny had an awareness that that the time at the river was *"guy*

time" and that Mike's male friends needed this time together to say goodbye to Mike. This story was important to Ginny because it illustrated that Mike's friends had an occasion to say goodbye and tell stories together, and it was *"cool"* and different. This story illustrates that saying goodbye; especially when saying goodbye includes sharing stories and memories with friends and family members together, is an important and meaningful activity.

Saying goodbye to important people in our lives is never easy and there is not a right or wrong way to say goodbye. This story of saying goodbye at the river is one example of saying farewell to an important friend. Families found many ways to say goodbye, including both traditional and non-traditional or creative ways, to say goodbye after the death of a family member. Families discussed other goodbye ceremonies, including the spreading of ashes, which often occurred at locations the family determined to be special to the decedent. Families told me about different locations where ashes were spread; including mountain lakes, a hunting camp, a buffalo jump, and a favorite high point of land located on the family farm overlooking a nearby lake.

For people close to the decedent the days and weeks that follow the death will include many more goodbyes to this significant person. Surviving family members are frequently confronted on a day to day, sometimes minute to minute, or hour to hour basis, of the person missing from their lives. Surviving family members face a myriad of minute details that remind them on a regular basis of the person who is missing. In many ways the surviving family members are not faced with saying goodbye one time, but saying goodbye over and over again. For example, Marie told me that it was *"hard"* for her to stand at the kitchen sink after Ron's death because the view from the kitchen window reminded her of Ron. Diane described leaving messages on rocks where she and Bob had been together.

Generally the funeral or memorial service allows family members say goodbye in a supportive setting surrounded by family and friends. Even though every family discussed a large number of attendees at the service, it is not the number of people alone that is meaningful for the families. Certainly a large number of people at the service provided an unforgettable visual impact to the families. The service also provided an avenue for friends and family members to come together to pause and remember the decedents' lives and acknowledge their sudden unexpected death. The number of people at the service provided family members with acknowledgement that the decedents' lives mattered.

Every family story included information about the people who spoke at the service or funeral. The majority of families described that the speakers at the service were family members or close friends of the decedent. One family hinted that the speaker at the funeral may not have personally known the decedent and this family described a minister meeting with family members to learn about the decedent's life. This information was then incorporated into the minister's tribute to the decedent at the funeral. Families frequently emphasized that it was important that speakers provide those in attendance with an accurate reflection of the persons who died.

Families find the sharing of stories about the decedent very important and meaningful and all participants stated that this story telling tends to occur in close proximity to the memorial service or funeral. These stories provide meaning for families as they allow those in attendance at the service to remember the decedents and reflect on the decedents' lives. Stories at the service provide a way for friends and family members to acknowledge the lives, and say goodbyes. All families conveyed that it is important that the stories that are shared at the service

need to be accurate reflections of the decedents. Meaning comes from the stories portraying an accurate reflection of the persons who died.

When the sharing of stories about the decedents end, and they often end somewhat abruptly, there is also meaning for families. Once the service is over most people get back to their day-to-day routine but for the bereaved family members whose lives are forever changed, a continued desire to share stories of the decedents continues over time, and for a longer time period than most people realize. Several families described a general reluctance among friends to talk with them about their decedents. Once the service is over, and especially as days and week go by, friends and acquaintances are often unsure if they should mention or talk about the persons who died. This uncertainty leads to a general avoidance of the whole issue; resulting in no mention of the decedents to their families.

Sharing stories communicates to the surviving family that their family members have not been forgotten. And while mentioning the decedents' names or sharing stories or memories of decedents may cause some distress for the bereaved, for example tears, they are already distressed. One family expressed the meaning associated with the sharing of stories when they pointed out that *"we can come back and tell each other: Hey, did you, you know, so and so … talked to me … yeah, so those are nice things that you can share."* Family members reported that sharing of stories about persons who died was important and meaningful; even when on one hand these stories reminded them of the persons' absences from their lives; yet, at the same time, it was nice to know that other people remembered their family members.

Theme 3: Grief unleashes volatile emotional reactions

The death of an important person, and family member, was a devastating loss for the seven families in this study. In all cases the death was sudden, and occurred in a person aged 55

years old or younger. Only two of the seven families had any idea their family member was even ill before the death occurred. Not surprisingly the initial reaction of all surviving family members was that of shock. This shock was followed by various other emotional reactions at different time periods after the death. One participant aptly described that she was unable to predict or "*map out how her emotions* [were] *going to go."* This inability to predict one's emotional reactions after a sudden death of a family member makes them *booms*. Participants talked about a wide assortment of emotional responses ranging from anger, guilt, depression, rage, apathy, and loneliness. Some participants wanted to blame someone else, like the decedent's physician, or even blame themselves for the death.

Two stories are presented as exemplar cases of the volatile emotional reactions that bereaved individuals experienced after the sudden cardiac death of a family member. It is important to note that these individual experiences impacted the other family members; therefore, the response of other family members to these individual reactions will be included in the stories. The first story is a story of self blame and the second story is a story of erratic emotions including apathy, desperation and loneliness.

A story of self blame.

Alice's story included an overwhelming aspect of self blame in that she felt totally responsible for not saving Jim when he died suddenly at age 52 of a myocardial infarction at home. Jim got suddenly ill one night and he suggested to Alice that maybe he should go to the Emergency Room or that Alice should call his doctor. Alice asked what was wrong and Jim told her he was having gastrointestinal symptoms, to which Alice responded that he probably had some sort of flu. Jim complained of his chest burning and Alice thought his asthma was acting up. She was shocked when she touched him and found his skin cold and clammy. Jim, who was

sitting on the couch with his eyes closed, moved to the floor, and Alice described that, *"he rolled over to his side and he turned gray and he was dead."*

The major focal point of Alice's bereavement experiences involved Alice blaming herself for Jim's death. She explained, *"I, of course, blamed myself like* ***completely*** *because I thought he told me to take him to the Emergency Room* [ER] *and when I took him to the Emergency Room and they pronounced him dead they said: ' You know had you gotten him here, he still would have* [died]*, he would have died … he would have died on the way'…"* The ER staff tried to tell Alice that they would not have known what was wrong with him any more than she did and that even if she had driven him to the ER he still would have died. Alice described her feelings saying, *"But I just felt, I felt* ***horrible****. Like: Oh my God … he was trying to tell me, but he didn't, he didn't tell me, he didn't have any … I don't know that he had any classic, you know, he had no arm pain that he said anything about, no neck pain, no chest pain… He talked about the burning in his chest … but, but I thought, like I said he always had this asthma thing."*

Alice returned to this again later in the interview when she said, *"cause I kept saying to everybody: 'If I'd just been a nurse I could have saved him'."* Alice explained this comment when she said, *"I did everything really natural with my food. And there wasn't anybody there who came to me, like a friend or somebody, or a kid that needed something, that I couldn't figure out how to help them."* Alice's self blame came up again in the interview when she said, *"the hardest part for me was believing that I should have gotten it somehow. I should have known what was wrong with him, and saved him, cause that's what I do, is save people."*

Alice blamed other people, specifically Jim's doctor, who was aware of Jim's symptoms but, "*didn't … didn't contribute it … to a possible heart condition."* Alice also blamed God saying, *"I was absolutely* ***horrified*** *that I didn't get protected by God. And I really believed, in*

some unconscious way I think, that God really would protect you if you did good work." Alice blamed herself instead of blaming Jim himself, as she explained saying, *"and I blamed myself in lieu of blaming him and then realized, you're not a medical doctor, and you didn't have any experience with anyone in your life that had ever been ill of this kind of thing…"*

Over time, bereaved individuals attempt to make some sense of their experiences. Over the days and months that follow the death surviving family members must sort out, or process, many events associated with the death itself. Part of this sorting out process includes dealing with the emotional reactions associated with these events. For example, Alice's blaming herself for Jim's death has changed over time. Alice told me at the time of the family interview that, *"just a week ago I was telling my best friend and then I realized that* [pause] *that it was bad enough to have lost my husband, it was enough punishment, if I had to be punished for something, and I thought* [that] *the worst possible thing I could do on top of that was blame myself."* Alice continued saying, *"Because it was obviously out of my hands. If had known anything different I would have done something."* She summarized saying, *"So now* [one year since Jim's death] *it all makes sense, now I can put it all together, but not then."* Alice's blaming herself for Jim's death, which was her focus for many months, changed over time. At the time of the interview, which occurred one year after Jim's death, Alice was beginning to accept that Jim's death was not her fault.

Certainly Alice's feeling of blaming herself for not saving Jim impacted Alice and caused her great mental anguish. However this self blame also had profound effects on Alice's family as well. Alice kept repeating over and over to her sons that she had not done enough to save Jim. Oliver stayed with Alice for one month after Jim's death, saying he was there to *"help my mom … to stay with her 24 hours a day 7 days a week, to make sure she would have somebody with*

her…" This time with his mom was very trying for him, which Oliver explained saying, *"it was taxing because it was like, digesting, it was like swallowing death every day."* Oliver saw his role as protecting her and serving as *"a shield for her … to help her with all the craziness even I didn't' foresee* [dealing with funeral home, lawyers, insurance companies, etc …]*."* Irene described getting ***"really angry"*** at Alice and screaming at her mother, who at one point *"went crazy like for 10 minutes, you know, in her room with the door closed and I could hear things being throw."* This behavior scared Irene as she had never seen her mother act like this. Irene admitted that at times she herself *"couldn't deal with* [Alice's grief] *anymore, it was like* ***way too much.****"* Irene screamed at her mom and told her, *"Get out of this.* ***Don't be so down*** *… Don't be so jaded about life.* ***You're still alive."***

Alice herself acknowledged that it was hard for her children to watch what she was putting herself through saying, *"I think that my kids have watched me be, probably really hard on myself and* ***really,*** *umm, kind of caustic, you know, as I move through this* [grief]*."* Alice explained that her children, *"didn't like what* [grief] *was doing to me, and you know, what I was putting myself through … or what they thought I was putting myself through, cause I don't know that it was really, it didn't feel like it was anything I could control."*

This story of self blame is one example of the volatile emotional reactions that bereaved individuals experience after the sudden death of an important person. So what can we learn from Alice's story of self blame? This story teaches us to appreciate that bereaved individuals face intense emotional reactions after a death and illustrates that these emotional reactions can be quite volatile. Alice described that Jim's death *"absolutely* ***slammed*** [me]*… cause I feel like I lost my* ***life*** *… it was* ***horrific,*** *you know, to lose him."* One year later Alice was just beginning to

accept that Jim's death was not her fault. I sensed that this year was very taxing, not only on Alice herself, but also challenging on her family as well.

Steps forward, hurdles, and booms: How did this family overcome the volatile emotional reactions of grief to take *"steps forward?"* It was impressive to hear how this self described *"very close knit"* family supported Alice through her grief, while also dealing with their own grief. This family was shocked when Jim died suddenly at age 54. Part of their *"ongoing"* bereavement experiences included many *"hurdles;"* such as emotional outbursts that included screaming in frustration at each other. Alice and her children are taking *"steps forward"* and continuing with their lives after Jim's death. I fully expect that this family will encounter *"booms"* of grief and loss in the future; but as individuals, and as a family, they are proceeding on with their life. Certainly their life has been forever changed, but they proceed with appreciation and thankfulness for each other, and Jim's brief presence in their lives.

A story of unpredictable emotions.

Betty and Ben met and married later in life and they lived in a small town in western Montana. Both Betty and Ben were disabled and they certainly did not live an easy life. Due to very limited financial resources they never had much money, but what they did have was each other. Betty described their life together saying, "*… we had good times … we had a grand life."* These good times together ended when Ben died suddenly at age 54.

Betty described Ben's death as *"the worst thing that could happen to me."* Her emotional reactions after Ben's death ranged from apathy: *"I just didn't care;"* to feeling like she was going crazy: *"For a long time I couldn't think about anything else* [but Ben's death]. *I would replay it over and over and over in my mind until I thought I was going to go cuckoo."* Betty talked about another reaction, this one involving thoughts of following Ben. Betty said, *"It*

wasn't very long after Ben died, it appeared one night. I was thinking I should follow him … thank goodness it scared me." Betty called her doctor, who reassured her that he did not think she was suicidal, and gave her permission to call him anytime day or night. Betty explained that this feeling of following Ben never returned and she said that just knowing she had someone she could call was helpful. Betty said, *"So that was helpful to have someone to call, I never had to call …"* but just having someone to call *"was huge."* Betty's apathy lasted for a long time, and at times she felt like she was going crazy.

Betty experienced feelings of anger and loneliness after Ben's death. She described her initial feelings of anger, explaining that she was upset and angry that Ben was no longer alive. This anger soon changed to feelings of loneliness; however this was a loneliness that could not be fixed. Betty described her loneliness saying, *"For me it's just lonely and it's not a hole that anyone else can fill, cause it's Ben's space."* Although Betty's emotions of anger, apathy, and desperation eventually resolved, her loneliness for Ben continued, and was obvious to me to still be present three years after Ben's death. I noticed the presence of a heavy sadness the minute I entered her house, a sadness that I later connected with her ongoing loneliness.

At approximately one year after Ben's death Betty halfheartedly agreed to attend a community grief group. Betty described that she normally did not *"do groups,"* however she consented to attend because of a personal connection she had with the hospice bereavement coordinator. Betty told me she did not think this group would be helpful, adding that she *"kind of went out of desperation."* Her participation in this support group helped Betty deal with her various emotional reactions. Over time Betty's apathy changed as she explained to me saying, *"It took me a long time to make up my mind to decide to live; not that I had decided to die; I just didn't care; and now I do care."*

Betty's emotional reactions impacted her family as well as herself. She explained that for a long time after Ben's death she did not take care of Bill because she did not know what he needed. I took this to mean that she was dealing with her own grief; therefore she was unable to help Bill with his grief. A weekly get together with a group of friends was very helpful, which Betty talked about saying, *"I don't know what I would have done without them* [pause]. *They were there for everything, and it was important for each of us to realize that everyone was carrying grief for different reasons* [pause] *and we all kind of grieved together* [pause]. *At first it was hard having them here* [at her house] *again, at least it was for me, but after the first week I knew it was right. I can't do without them."* Betty hoped that this group was helpful for Bill as well, since this group shared their grief with each other and talked about Ben on an ongoing basis.

So what can we learn from Betty's story of unpredictable emotional reactions? Betty's story illustrates some of the various emotional reactions, including apathy, desperation, and loneliness, and the long lasting nature of these reactions, that bereaved people may experience after a death. Betty grieved alone for a long time, until she reached a state of *"desperation."* Luckily Betty was scared when she considered following Ben and she sought help from professionals. One year after Ben's death Betty finally agreed to participate in a local bereavement support group and it turned out that her participation in this group was very beneficial. Since Betty was not a person with a multitude of social outlets, the fact that Betty finally agreed to attend this bereavement group illustrated her desperation after Ben's death.

Steps forward, hurdles, and booms: Betty faced many hurdles after Ben's death including major changes in her finances, and the emotional reactions of anger, apathy, and desperation. Betty's participation in a bereavement group was a huge *"step forward,"* a step that enabled her

to continue living. Betty encountered many *"hurdles"* during bereavement, including financial challenges and various emotional reactions. At three years after Ben's death Betty still feels a deep loneliness for Ben, and this loneliness remains as an ever present *"boom"* of grief that I suspect will be her constant companion.

Other participants also talked about the multitude of emotional reactions they faced during bereavement with some people wondering if they were going crazy. Participants described reactions including depression, (Ginny, Dave, Irene) anger, (Janet, Kim, Debbie), feeling guilty (Janet) blaming others (Alice, Janet), apathy (Betty, Alice) and loneliness, (Betty, Ginny, Janet). Ginny, described herself as having tough mental fortitude, yet at one point she wondered if she was *"going to make it."*

The stories shared by bereaved individuals conveyed that these emotional reactions can be overwhelming at times. Marie provided an insightful description of the all encompassing nature of emotions and grief after the death of an important person when she said, *'I don't know if anything compares to getting up in the morning and saying: Okay, now you're gonna go on with your life without* [Ron] *… I don't think people know how much it hurts, the physical pain in your stomach, …and how that loss is so huge, it just envelopes everything."* Alice talked about having experiences where she got *"so angry over something really stupid that … I realized how much rage I had in me – like right under my skin, you know. I was even like: Wow … where did that come from? Cause I didn't even know that I was walking around feeling like that, you know."*

Over time, the surge of these emotional responses generally lessens, but there is no set pattern to emotional reactions. The participants described that for the most part these emotional reactions changed over time, and generally at the time of the interview most family members had

stable emotions. Sharing their story with me often brought about tears but most participants thanked me for the opportunity to revisit their experiences and talk about their special family member who died. Several people mentioned that certain days, such as anniversaries, holidays, or birthdays, can bring about the return of some of their emotions, since they serve as reminders of their loss.

Theme 4: Life goes on… but never back to normal

After a sudden death many participants commented that they felt as if their life abruptly changed the moment they learned of the death of an important person. Even years later, with the passage of time, their lives were forever changed in the instant when their family member died. Participants frequently made statements similar to *"life goes on, but life never goes back to normal."* Several participants wondered why life was continuing around them (Ann, Diane) when they were feeling as if their life had ended. However life does go on and eventually bereaved individuals must go back to work (Alice, Ginny, Marie, Ann), back to school (Karen, Jack), and back to day-to-day activities (everyone). Yet this day-to-day life is forever changed. All families described aspects of their bereavement experiences as *"hard."* Most families identified changes and decision making as especially challenging.

Another *"hard"* aspect of bereavement, especially for women whose spouse or partner died, was the transition of self that occurred during bereavement. Two women, one of whom was married, and one of whom was part of a long term partnership without marriage, made comments about changes in their social life after the death of their spouse or partner. These social transitions were not easy to accept and involved psychological adjustments in their self image. Participants mentioned the transition from being part of a couple to being single as

particularly *"hard."* Ginny summed up this *"hard"* transition best when she said, *"lack of an intimate partner is a pretty major adjustment for anybody."*

Three stories of *"hard"* bereavement experiences associated with life continuing after a sudden death are presented. Family 6 told a powerful story which illustrated how life goes on, even after the loss of an important family member. The second and third stories will address *"hard"* social transitions that some participants, specifically women whose spouse or partner died a sudden death, faced during bereavement. One story deals with a wedding ring and the one story speaks to feeling socially out-of-place with friends after the death of a spouse or long term partner.

A family farm story.

Marie and Ron lived on a farm in North Central Montana; their family included two children Karen and Jack, both college students. Ron worked farming their land and Marie worked as a school teacher in a rural school. Ron's sudden cardiac death greatly disrupted all aspects of their lives. Their bereavement experiences centered on farm life, which greatly changed once Ron, the farmer, died. Marie and Karen characterized Ron's death as precipitating feelings of, "*everything stopped* [pause] *and everything changed,* ***a lot****,* [and] *nothing's been the same since."* Their life goes on and this life without Ron's presence is certainly not "normal," but as Marie said, *"We're trying, it's just not there yet."*

This family described having to make many decisions, "*hard"* decisions, after Ron's death, especially given that Ron had planted the crop before he died. Immediately the family had to make these decisions: Do we keep the farm? Do we sell the farm? Do we lease the farm? With the help of family members and friends, including neighboring farmers, and coupled with the age-old advice of *"don't make any major changes for at least a year,"* they decided to keep

the farm. Jack and Karen returned to college; but Jack struggled after his dad's death, stopped going to classes, and eventually dropped out of school and came home to *"begin farming."* Karen remained in school, but returned to the farm more frequently to be supportive of the family. Marie continued teaching, but changed to a school in town the following school year *"because there* [were] *more adults there."*

As a family they continued to operate the farm *"with lots and lots of help."* Marie's brother arrived to help them harvest the crop that first summer after Ron's death. Other friends and nearby farmers helped reorganize the shop and all the farm implements. Jack learned how to operate equipment he had never used before, including the sprayer and the air seeder. The first year after Ron's death yielded a very special crop; the crop which was planted by Ron and harvested by Jack. Marie, Jack, and Karen showed me picture frames made by a family friend. Some wheat from Ron's last crop was woven into these frames, which surrounded photographs of Ron working on the farm. Both the frames and the photographs were stunning and beautiful keepsakes which held special significance for this family.

Running the farm without Ron was a huge undertaking and the family encountered many stressful situations. They faced a multitude of additional decisions related to the day-to-day operation of the farm and they found that they were constantly asking themselves: What would Ron do? Would he do it this way? Would he do it that way? What should I do? Examples of these day-to-day decisions included: Where should the new fence go? How much hail insurance should we purchase this year? What variety should we seed and how much fertilizer should we use? What type of oil goes in this piece of equipment? Many of these decisions related to the operation of the farm were *"hard"* decisions to make, as Marie and Jack emphasized in their stories about operating the farm. For example Marie said that, "*Things like* [fixing farm

equipment] *are hard for us to do."* Jack added, *"every time I'm looking for something that I know we have but I don't know where it is,* [I'll] *think: Oh I'll just run in ask Dad real quick. And then you can't really do that so … that's been* [hard]*."* As a family they had discussions about these "*hard"* decisions related to the daily operation of the farm and over time they learned how to operate the farm without Ron.

This family made an important point when they talked about wondering when life was going to go back to normal. Jack started this conversation saying, *"it's weird. I was thinking: when is everything going to go back to normal?"* Marie responded with, "**There's no normal** … yeah – there's no normal – **it never goes back to normal**." When I commented that some grief experts often describe a 'new normal' Marie said, **"***We're not normal yet"* [laughter]. Karen added, *"Yea, we're not there yet, we're trying."* Jack explained that he sometimes wondered, "*How much longer do I have to do this* [farming] *by myself until I get some help? And it's like when I'm working it's like* [everything is okay], *then something goes wrong and it's like…* [When will things go back to normal?]

So what can we learn from this farm story? When Ron died suddenly this family was faced with many decisions, some of which had to be decided immediately and some of which had to be made on an ongoing basis. The majority of these decisions, which were characterized as "*hard"* decisions, were in relation to the family farm. These decisions were made collectively as a family, with lots and lots of help from friends and neighbors. One thought as to why it works for this family is the level of support they have in the rural farming community in which they live. Their life goes on, although at one and half years after Ron's death, this life still does not feel *"normal."* Overall this family is very proud of their ability to operate the farm successfully since Ron's sudden death. They recognize this as a major accomplishment with

Marie saying, *"I think Ron would probably, shake his head hilariously at, umm, at how well we've done. I think he'd be proud of us, but at the same time I could just see him going: Oh my God, they're using this, they're using that, oh my God, they're driving this. Oh, they're going to wreck everything. But we haven't."*

Steps forward, hurdles, and booms: Certainly this family is taking *"steps forward,"* especially as it relates to the operation of the farm. The farm story indicates that this family is moving on, with ***"lots and lots of help*** *from everybody"* and the farm is stable and secure. They face many *"hurdles"* as they take *"steps forward,"* for example purchasing additional farm equipment and keeping all the equipment running. They also face many *"booms,"* or intrusions of grief, but they keep moving forward. They are proud of their success and feel that Ron would be proud of them as well. Certainly this family did not expect Ron to die, they did not want him to die, and they would likely give anything to have him back as a part of their daily lives. Ultimately they are moving forward with life.

A story of a wedding ring.

Marie in family 6, talked about her wedding ring. Ron and Marie had been married for 26 years before Ron died a sudden cardiac death. About 18 months after Ron's death Marie was scheduled to have surgery and as part of her preoperative preparation Marie was instructed to remove all jewelry. Marie talked about how "*hard"* it was to take off her wedding ring saying, *"*[another] *big thing was finally taking off my wedding ring … I just couldn't put it back on* [after surgery]. *It was just too hard … Sometimes I look at it,* [voice cracking]*, but its like,* [pause] *I would just be pretending* [voice cracking]*."*

At the time Marie made this comment I understood her meaning, which was related to all that a wedding ring symbolizes. A wedding ring is a symbol: a symbol of love; commitment;

and fidelity. The symbolism associated with a wedding ring is influenced by culture as well as family traditions and the thoughts and feelings of the couple themselves. A wedding ring represents a commitment; a commitment that lasts 'till death do us part.' A wedding ring should be worn until the marriage has ended, which would be at the time of death or divorce. Marie found it *"hard"* to take off her wedding ring because it represented the end of her marriage, an ending she was not prepared for, nor had yet accepted. Marie still wanted to be married to Ron and she shared many comments that conveyed this sentiment. In her individual interview Marie said that before Ron's death her life in general was *"a whole lot easier because you had somebody to share it with. You could get through a tougher time because you knew when you got home that Ron was going to make it okay."*

This transition from a married woman to a single woman also impacted Marie's family, especially her daughter. While talking with me individually Marie mentioned a recent conversation with a girlfriend. This friend told Marie that when she felt 'ready' she would introduce her to her divorced brother; whom she described as *"a really nice guy."* Since Marie lived in a small town she felt it was important for her children to hear about this comment from her and not someone else. First Marie told Karen, who responded with tears saying, *"Mom, I'm not ready for this."* Marie tried to reassure Karen that she was not ready for this either. Ultimately Marie was appreciative that people were thinking of her in this regard but that at that moment in time Marie felt, "*my God, I don't want to do this. I don't want to go there* [laughter]. *It's like, geez. And then I thought, oh God, here we go … So that whole saga* [dating] *someday may open up but I just said: oh dear God, not right now."* In contrast, Jack's response was totally different than his sister's response. When Marie told Jack about a friend wanting to introduce her to her divorced brother, Jack replied, *"Oh yeah, that's nice …"* Marie and I

laughed together and Marie stated that Jack *"didn't miss a beat."* Marie commented on the differences in Karen and Jack's reactions saying, *"That's the difference between male psyche and the female psyche"* and we again laughed together.

What can we learn from this story of a wedding ring? Bereavement is a time of transition, and Marie's story of her wedding ring illustrates one of the more profound transitions that occur after sudden death. Surviving spouses must transition from being married, to being unmarried and this transition happens on several levels. Married individuals, like Marie, face a dilemma when their spouse dies; a dilemma with no satisfactory alternatives. On one hand Marie's marriage had ended with Ron's death, and Marie understood this on a rational level. Her wedding ring was now to some degree inappropriate, and she recognized that she was no longer a married woman. However on the other hand Marie did not want her marriage to end and she did not want to take off her wedding ring, and she recognized that wearing her ring would just *"be pretending."* This transition is neither simple, nor one that happens quickly or easily, for people whose spouse or life partner dies suddenly. The removal of a wedding ring is just a physical act, yet the removal of a wedding ring does not mean you feel unmarried. Taking off one's wedding ring actually includes a very complex psychological step. The psychological component involves mentally changing one's self-image from that of a married person to an unmarried person. This is not an easy transition, because for a long time, the bereaved person, who is suddenly now single, still wants to be married to the person who died.

A story of "not fitting in."

Both Marie and Ginny mentioned another social transition that occurred after the sudden death of a spouse or significant other. They talked about the transition from being part of a couple to being single. This is a transition that happens on both a social level as well as a

personal level. For example couples often socialize with other couples and the death of a spouse or partner upsets this balance. Both Marie and Ginny mentioned *"not fitting in"* with friends after the sudden death of a spouse or partner. Ginny talked about the challenges of being single after Mike's sudden death. Ginny said, *"I think one thing that was a little hard for me: It was certainly hard not being a couple anymore. My couple friends are couple friends, and they made some effort to include me anyway, which was good, and still do … but it changes the dynamics … literally, it changes the whole dynamic around the dinner table, and everybody knows that, but that was definitely a change* [pause]*."* Marie also mentioned that she did not fit in with her friends after Ron's death saying, *"It's hard, it's hard to be the third wheel. That's what I feel like a lot, in the couples, everybody's couples. They're good, they invite me places,* [and] *they take me places. I go places, but it's hard to, umm, hard to be an adult. I'm the first one to be the single … you don't fit in with the divorced people because that's a whole … different mindset* [laughter]*."* Marie explained that she and Ron always did *"family things"* with other couples and she acknowledged this as a *"hard"* transition with a large group of long term couple friends. These comments revealed that for some period of time both Marie and Ginny felt out of place in their previous social circles. Marie expressed this when she said, *"I'm the first one* [in my social circle] *to be single and you don't fit in."*

So what can we learn from this story of *"not fitting in?"* We learn that during bereavement women who experience the death of a spouse or partner must redefine themselves. This is a challenging and *"hard"* transition for women, especially women in their 40's and 50's, who reported that they often felt uncomfortable with their prior group of friends. While appreciating that their couple friends still included them in activities, at the same time they felt like they no longer fit it with these *"couples."* During bereavement these women needed to

redefine themselves, now as single women after many years of being in a partnership. These women must find their way in the world, now unexpectedly single. This change, or *"hard"* transition, involves not only a change in their self-image, but also a change in their relationship with friends. By necessity this change impacts their families as well.

Steps, hurdles and booms: Both Ginny and Marie are taking *"steps forward,"* into a new life as a single person. Challenges inherent in this transition include appreciation of being included in social activities with old friends, while also feeling out of place within social settings. Bereaved women are often reminded of their missing partner or spouse, especially around other couples. Ginny was the only woman in the study who mentioned being in a new relationship. She explained that when this relationship began she initially thought it *"would just be a crutch relationship where we just sort of helped each other through and then moved on."* She went on to explain that with the passage of years she recognized that *"we've established our relationship on its own two feet, it's not a part of the grieving process or because we are needy, because we genuinely enjoy each other."*

Theme 5: Meanings in loss

Many families expressed sentiments that illustrated that their bereavement experiences included learning what was really *"important"* or *"lived differently"* after the sudden cardiac death of a family member. It is in this "*living differently"* or new found knowledge of what is really *"important"* that they found meaning after the devastating loss of a family member. When family members were able to identify meanings in their loss such as recognizing what was important or changing how they live their life, they were able to take *"steps forward"* and continue their life, a life forever changed.

During the interviews all participants were asked if they were able to find meaning or make sense of their experiences since the death of their family member. Not surprisingly, some participants were able to clearly articulate how they identified meanings in their loss, while other participants struggled to express meanings in loss. Some participants spoke explicitly of *"living differently"* as a result of their bereavement experiences. Other participants spoke more implicitly about what they learned during their bereavement and took forward into their new life. One participant reminded me that his bereavement experiences were not over, but *"ongoing,"* and this is an important point. The meanings presented here are the meanings the families shared with me at the moment in time when the family and individual interviews took place. Meaning is dynamic and changing and the process of telling the story of their bereavement experiences itself may have changed the meanings associated with their bereavement experiences.

Two exemplar cases will be shared: the first story of *"living differently"* exemplifies how the participants identified meanings in their loss. In turn, the ability to identify meanings in loss facilitated survivors' ability to take *"steps forward"* after the sudden cardiac death of a family member. This story of *"living differently"* includes my interpretation of how six families identified meanings after the sudden cardiac death of a family member.

However, participants were not always able to make sense or identify meanings in their loss after the death of a family member. The second story, a story of unanswered questions, will be shared as a contrasting case describing one family's experience of persistent questions which remained unanswered over time. These unresolved questions prevented this family at the time of the interview from being able to identify any meanings in their loss after the death of a family member.

A story of "living differently."

The identification of meanings in loss was very unique for each family and participant; however some commonalities were present across experiences. Several participants described *"living differently"* or understanding what was truly *"important"* as a result of their bereavement experiences. Other participants spoke about their appreciation of being loved and some family members talked about a renewed appreciation for living, now that death had touched their life. Two young adult participants mentioned that they matured as a result of their bereavement experiences. Many participants mentioned the fact that death was inevitable and identified meaning in a newfound recognition of this reality. The analysis indicated that an ability to identify some meaning, or make sense, of their loss facilitated the taking of *"steps forward"* after the unexpected death of their family member. When participants were able to identify some meanings in loss, they were better able to incorporate the loss into their life. Meanings in loss were identified over time with no clear cut timetable for when or how any meanings would be identified. Family members needed time to process or sort out their experiences before they could begin to identify meanings in their loss.

Two participants spoke directly about the fact that as a result of their bereavement experiences they now lived *"differently"* or learned what is really *"important"* in life. These comments are presented as examples of meaning in loss, since their bereavement experiences prompted this change in how they lived their lives after the death of an important person. When asked how Dick's death affected the family, Janet (family 3) replied, *"I think for me,* [Dick's death] *has made me much more,* [pause] *aware of the reality of death, umm, the reality of needing to take care of our bodies, umm, of getting out there and living and enjoying and letting people know how important they are …"* Janet continued, *"Oh yea we have all heard it: Smell the roses, enjoy life while you can, da da da, but until you actually, you know, have something*

that hits you that hard, that unexpectedly, and if you don't run away from it. I mean if you really embrace the fact that somebody did die, you live life differently, you relate differently. Umm, you know, you don't worry about: Did I get my 40 hours in [this week]. *You worry about: Did I do something* ***good*** *…"* [Pause]. Alice (family 5) also talked about *"living differently"* when she explained that Jim's death changed her work with clients. Alice mentioned that she learned in school to keep her private life separate from her professional life as a therapist. She said that before Jim's death she was *"very, very, very private about* [her personal] *life* [with clients]*."* Alice continued, "*And* [Jim's death] *has transformed my work because I'm no longer that way. I share* ***a lot*** *with people… So that is something that my husband, through his death, taught me.* [And this knowledge] *was actually very healing for people, because he always told me that it was, that it was really okay to share something … he was* ***real,*** *so it's completely changed how I do my work."*

It is clear that Janet and Alice changed as a result of their bereavement experiences. They have taken to heart lessons learned during bereavement and now choose to *"live differently"* as a result of their experiences. Janet has a strong desire to *"do something good"* for others, while Alice has changed her approach when working with clients. The ability to identify meanings in their loss has prompted Alice and Janet to *"live differently"* and take *"steps forward"* into life, a life forever changed by their bereavement experiences.

Both Irene and Alice (family 5) talked about learning what is really important after Jim's death and this knowledge prompted them to *"live differently."* Irene said, *"I know I'm thankful – I'm definitely thankful for the time I had* [with Jim] *and I've, I mean I've just grown up so much from it, the experience and I just have* ***so much more*** *… this whole feeling on what's really important in life."* Irene continued saying, *"and those things that just seem so important just*

aren't important anymore … like I feel like I have more of a look into [pause] *the importance of really loving people … and showing that you love people, and that you really, really care* [Pause]. *I thing that's number one, I really do now."* Alice talked about how she changed saying, *"The result has been that I feel like now, I'm,* [pause] *really not the same person. The things that I used to think were important I realize are not important and the things I used to worry about or complain about … you know, like actual trivial things that seemed to matter and none of that matters anymore."* Alice tried to explain this to people at Jim's funeral when she told those present that, *"I feel like the world conspires to make you believe that all this mundane and material stuff is really important, or life and death, or critical or something. But it isn't, that is absolutely the conspiracy."* As a result of their bereavement experiences both Alice and Irene learned what is really *"important"* in life and as a result of this newfound knowledge they are *"living differently."*

Some participants stressed that through their bereavement experiences they learned the importance of love and this information was meaningful for them. Betty (family 2) talked about the importance of love when she talked about Ben saying, *"We only had 19 years* [together] *and that's not enough … we must have done something right, we got each other* [pause]. *We had a good marriage* [and] *I was* ***loved****."* Marie described that her *"life was better because of* [Ron's presence in her life]. *I don't have any doubt of that."* Alice summarized her experiences saying, *"I'm really okay because I had that experience of being really loved and really appreciated, appropriately."* Alice's children also recognized the special relationship Jim and Alice shared and they spoke of looking for the same love and respect in their own relationships. Participants identified meaning in the experience of being loved and they move forward with their life keeping this love close to their heart. Alice explained this when she said, *"I think something else*

… because like every time I get … into some dark place, I just try to remember that [Jim] *had so much confidence in me, it was just amazing and I really feel like I got something from that that I can't lose."*

Betty (family 2) expressed that she found meaning in Ben's life and the life they shared together for 19 years. When I asked if she was able to find any meaning in her experiences she stated, *"There is no sense to* [Ben's death] *… it just happened, umm … I've come to terms with it maybe, he is dead … it doesn't make sense to me that my lovely kind person died. Maybe I'm not understanding* [the question] *exactly … I don't think it's because I'm angry or bitter but just* [his life] *wasn't complete yet. You know, when his mom died two years ago, she was 87* [years old] *so that's like a full circle … So I don't think I will ever find any meaning* [in Ben's death]. *I find meaning and sense in his life* [tears]*."* Betty's comments illustrate that the age at which a person dies is often meaningful. Surviving family members often find it easier to accept the death of an elderly family member, who dies after living a long full life. Since all surviving family members in this study had someone die at age 55 or less, participants often struggled with trying to make sense of the death of a younger person. Comments often expressed included that there is no sense in someone who still had so much to give dying at a young age.

Sudden death precipitated major changes and expanded responsibilities, especially for young adults. Two participants conveyed that as a result of their bereavement experiences they matured, especially in relation to their peers. Irene, (family 5) who was age 22 when Jim died, described, *"I remember just feeling completely, like I grew up or something … because I had to* [take care of Alice]. Irene talked about staying with her mom immediately after Jim's death when she described, *"And I felt like,* [tears and voice cracking] *I felt really protective of my mother … and it was a total role reversal … I had to make sure she was eating, and she wasn't*

eating … she just had no appetite and she was really sad, obviously, and it was just horrible to watch and ***I was alone*** *…"* because her brothers had not yet arrived in Montana. Jack, (family 6) who was age 21 when his dad died, also talked about *"growing up"* after his dad's death, especially in relation to his friends when he said, *"Um, I feel like I've grown up a lot … compared to my friends and stuff. My friends just being kids and I had to grow up pretty quickly. So running the farm, that was pretty tough."* The major changes associated with the sudden death of a family member resulted in these young adults assuming more grown-up roles and adult responsibilities. In essence their lives were changed and these young adults now felt they *"grew up"* as a result of their bereavement experiences, especially when comparing themselves to friends their same age.

The majority of participants recognized the inevitability of both life and death. Every person who is born will someday die, and although everyone knows this on some level, several participants mentioned a renewed realization of the inevitability of death. Some family members identified meaning in this inevitability of life and death, especially since their own bereavement experiences brought this lesson close to home. Marie (family 6) mentioned that on the day Ron died a grandchild was born to one of his closest friends. She described this saying, *"There is a new baby born every day … you know, one life ends and another one starts and, umm,* [pause]. *I bet I never experienced that first hand or so close."* Marie identified meaning in the start of a child's life on the same day as Ron's death. Marie also shared her perspective on life and death during the family interview. Marie told me with her voice in a whisper, *"I think one thing we talked about, and I've tried to tell the kids, you know, it's not fair, it's s not right. But at the same time, we've very, very lucky, extremely lucky, to, you know, it's better to have a good dad, you know for a shorter time then all of these people that are stuck with bad dads for a long time.*

I mean the best thing would be to have a good dad for a long time but if we can't have a good dad for a long time… I mean we were lucky, and you just got to tell yourself every day [pause]. *Ron did a good job for us* [tears]. *I don't know why it happened* [Ron's death]*"* [tears]. Marie and her children were not ready for Ron to die at age 54, but everyday they reminded themselves how blessed or *"lucky"* they were for his presence in their lives. They identified meaning in his life and the positive impact he made on their lives. Ginny (family 1), talked about her newfound appreciation that everyone is going to die and identified meaning in this fact, especially now that death had touched her life so closely. Ginny said, *"I mean I actually have become more logical about death, if that makes any sense. Which by that I mean it's become very clear to me, everybody's not going to live to be* [age] *75 … Of course I knew that anyway, but when it personally happens to you, it hits home a lot faster … so you know making sense of it, I mean everybody dies, the only question is when and how."*

The ability to identify meanings in loss seems to be a prerequisite for moving forward after the sudden death of a family member. The way in which surviving family members identify or discover this meaning varies considerably and occurs over time. The majority of families talked about the meanings they identified in relation to their loss, and these families are taking *"steps forward"* after the death of their family member.

A story of unanswered questions.

Ann and her mother Diane (family 7) share with me the story of Bob's death at age 49. Bob collapsed at a job site and was transported to a local hospital Emergency Room (ER). Bob's mother received a phone call from one of Bob's coworkers and she immediately called Bob's daughter, Ann, who arrived at the hospital at almost the same time as the ambulance. Ann waited in the ER waiting room and other family members joined her as the news of Bob's

collapse spread among family and friends. ER staff members kept the family updated on the progress of the code situation and at one point Bob was transported to the Cardiovascular Laboratory. The family received a pager and was told to go to a waiting room which was closer to the Cardiovascular Laboratory. Time passed slowly and the family wondered if the pager was even working since they had not received any updates from hospital staff members. After 45 minutes of waiting the pager finally went off and the family was told that Bob *"didn't make it."*

The family recalled that the physicians reported conflicting information about Bob's heart. One physician thought there may have been a blockage in one of Bob's coronary arteries, but a second physician did not see any blockages. This family had questions about the cause of death and consented to an autopsy because they *"wanted to know what happened."* Someone at the hospital told the family they would call once they knew the cause of death. This family left the hospital without talking to the coroner.

For several days the family wondered if a confrontation with a co-worker a few weeks earlier might have contributed to his death. They told me, *"we thought maybe he had a concussion or something and - but until we got the autopsy report back … we didn't know that it was cardiac."* No one ever called the family to report what had caused Bob's death. Waiting to learn the cause of Bob's death was described as *"hard"* which Ann and Diane explained saying, "*it seemed like it took several days before … we found out* [the cause of death] … *and that was a hard part."* In fact it was only when the death certificate arrived in the mail, which listed *"cardiac arrest"* as the cause of death, that they even knew Bob had died a sudden cardiac death. For days this family wondered about his untreated high blood pressure and they felt guilty that Bob never went to the doctor. They wondered if his death could have been prevented if he had a physical exam by a physician.

At the time of the family interview, which was one year after Bob's death, the family asked me several questions: *"So this cardiac thing – it all happens within an hour? Once it, once it starts or something … is that* [it]*…?;"* and *"So for someone to drop like that, it means the - the heart isn't beating?;"* and *"Is there any time frame, was this going on a week before he died…?"* I attempted to answer their questions in general terms while explaining that I did not know anything specific about Bob's cardiac disease. It is my interpretation that these unanswered questions, which persisted for one year, limited this family's ability to move forward with their lives after Bob's death.

Ann and Diane did not have an opportunity to get any answers to their questions, nor did they have anyone who could help them seek out the answers to their questions. There was no physician to call and they never had an opportunity to ask anyone to explain what caused Bob's death. Bob's family never had an occasion to speak with the coroner and they did not know to call the coroner on their own. Ann told me the funeral home staff was *"helpful"* in a vague manner and I suspect the family questions about the cause of death were not addressed by anyone associated with the funeral home. My overall sense was that this family was not proactive, or assertive, in seeking out the answers to their questions. They were not able to make sense of what had happened to Bob's heart at the time of his death.

These unanswered questions were present even one year after his death, thus limiting their ability to understand why Bob died. This lack of understanding severely limited their ability to move forward. When asked if their thinking about Bob's death had changed over the last year Ann says, *"I still feel shocked every day … so many people say, or they try to tell you that it will get easier with time, and I don't think it does at all."* Diane added, *"It hasn't yet anyway."* At the time of interview the overall status of this family was that they were unable to

understand what happened in relation to Bob's death, and these unanswered questions left them stuck [stuck is my word, not their word] or caught in a sort of limbo. Without answers to their questions they were not able to move forward with their lives and were unable to identify any meanings in their loss.

So what can we learn from the stories of *"living differently"* and the story of unanswered questions? Death is inevitable; on some level everyone knows that the people they love and care about are going to die. Rarely are we ready for someone we love to die, especially when a family member dies at a young age and the death is unexpected. The first question all families asked was: Why did the death occur? Other questions included why did the heart fail? Why did their family member die? It was only when they understood what happened that they could then begin to incorporate the loss into their life. Living their life often included trying to make some sense of their experiences. Bereavement experiences were often meaningful for family members and for some participants these experiences prompted them to *"live differently."* If surviving family members had unanswered questions about the cause of death they were not able to get past the questions. The sudden death of a close family member often prompted surviving family members to *"live differently"* and it is in this *"living differently"* that family members were able to identify meanings in their loss. Moving forward with one's life after a devastating loss is certainly not easy for surviving family members. However, an ability to identify meanings in loss helps surviving family members begin to move forward with their life after the death of an important person.

Steps forward, hurdles, and booms: One of the first *"hurdle*[s]*"* all families encountered after the sudden cardiac death of a family member was the question: Why? Surviving family members had a need to understand why the death occurred. If the families' questions remain

unanswered, their ability to incorporate the loss into their life was severely limited. Family 7 was not able to take *"steps forward"* because they cannot get past the *"hurdle"* of their unanswered questions about Bob's death. Unanswered questions about Bob's death prevented this family from taking *"steps forward"* and they are stuck with the *"boom"* of why, which limited their ability to move forward, at least at the time of the interview.

Sudden death is shocking and presents an assault on the taken for granted nature of daily life. The challenge for surviving family members is to make sense out of the chaos they find themselves enmeshed in after the death. The ability to understand or make sense of their bereavement experiences, both on a physical and psychological level is important. Not everyone will be able to find meanings in their loss, but the ability to identify meaning appears to be an important step in moving on. All families had a need to understand the cause of death. Once some understanding of the cause of death was obtained, then surviving family members were likely to identify meanings in their bereavement experiences. Some participants then took another step and identified meanings in their loss that prompted them to live differently. In this study participants identified meaning in their loss which included the importance of love, the inevitability of death, and *"living differently"* or learning what is really *"important."* Not everyone who experiences a sudden death will necessarily be able to identify meanings in their loss. The ability to identify meanings in loss facilitates the ability of surviving family members to move forward in their life. In this sample unanswered questions about the cause of death limited one family's ability to take *"steps forward"* after the death of a family member.

Summary: A meta-story of family bereavement experiences

Stories of family bereavement experiences after the sudden cardiac death of a family member revealed both the joy of love and the agony of grief. In summary I will now present one

story: a story of family bereavement experiences. This meta-story will integrate participant's bereavement experiences, as well as my own personal bereavement experiences, as a way to convey the depth and breadth of this study's results. Although bereavement experiences undoubtedly began at the time of death all stories began at an earlier point in time, generally starting with an overview of the days preceding the death. At the heart of family bereavement experiences is the challenge faced by surviving family members; the challenge of moving on with life, a life forever changed by the sudden cardiac death of a family member. During bereavement, surviving family members must take steps forward into a new life and these steps forward are interrupted by hurdles and sudden unexpected booms of grief. Narrative analysis of stories identified five themes across families and these themes will be presented, using a bold and italic font, throughout this meta-story. The five themes are ***Sudden cardiac death … boom; Saying goodbye; Grief unleashes volatile emotional reactions; Life goes on … but never back to normal; and Meanings in loss.***

Death is inevitable and everyone knows this on some level. However, knowing this and living through this are two entirely different things. This story of family bereavement experiences began with a description of a normal day. Family members were engaged in their usual activities, including routine day-to-day activities, such as going to work, running errands, or doing chores to get the yard ready for winter. Even if a family member was ill there was an expectation that they would recover. However this normal day suddenly went horribly wrong when a family member died. ***A sudden cardiac death occurred and boom***, life was instantly and forever changed.

Sudden cardiac death is considered a natural death of cardiac causes that occurs rapidly and unexpectedly. Warning symptoms may or may not have been present and if symptoms were

present they may have been ignored, misunderstood, or even denied. Two families mentioned that their family member was totally asymptomatic before death, while five families had some awareness of pre-existing health conditions including hypertension, asthma, and migraines. Even with knowledge of ongoing health issues every participant described their family member as healthy and active. One family described their family member as disabled and living with a non-cardiac chronic health condition. The possibility of death was not on anyone's mind, no one had any expectation that their family member might die soon.

Due to the general lack of preexisting knowledge of the presence of heart disease, surviving family members initially reacted with shock and disbelief when they discovered, or were notified of, the sudden cardiac death of a family member. This shock was accompanied by a multitude of questions; questions which centered on why: why did our family member die? Surviving family members had a need to understand what happened and the universal question of why did the death occur was followed by other questions: What could I have done to prevent the death? What could someone else have done to prevent the death? Were there any warning symptoms? Why didn't I save him? Was he in pain? What went wrong? Questions tended to be either physiological based or more rhetorical in nature.

Understanding the cause of sudden cardiac death was occasionally difficult for family members, but if they were able to ask questions they were usually able to understand the physiological cause of death. Questions about the cause of death were usually directed by surviving family members to either the coroner or to the decedent's personal physician. Generally physiological based questions could be answered after an autopsy was completed. However, family members often needed several explanations in order to understand the complex nature of cardiac conditions. Some family members were able to describe the cardiac

pathophysiology that led to the death. Family members explained the cause of death saying: we would have needed the paddles to save him; his heart went out of sync; or he had a hole in his heart. Other family members were less clear about the cause of death and they voiced these questions: Did he have a heart attack? Why did his heart stop beating? Was his heart not working correctly in the days before his death? Understanding the cause of death did not happen immediately but tended to occur over time. One family called the coroner several times in order to get all their questions answered to their satisfaction.

Understanding the cause of death was an important aspect that facilitated surviving family members' ability to incorporate the loss into their life after the death of a family member. When surviving family members did not have anyone to direct their questions to, or did not receive satisfactory answers, they were often frustrated or stuck with unanswered questions. If family members did not know whom to direct their questions to, they were left in a sort of limbo. In one family unanswered questions about the death limited the surviving family members ability to move forward with their lives.

Saying goodbye to an important person in one's life, especially when this person dies suddenly and unexpectedly at a young age, is never easy. In fact saying goodbye to a loved one is heart breaking and surreal. There is no right or wrong way to say goodbye to important people in our lives. Families said goodbye in many way and generally mentioned some sort of ceremony which occurred after the death. Families often called the ceremony by different names, a funeral, a memorial service, or a celebration of life service. For purposes of this meta-story I am going to use the term service to represent any remembrance ceremonies that occurred after the death. There is much planning that goes in to the organization of a service; surviving family members were required to make all sorts of arrangements and decisions -- writing an

obituary notice, deciding on the location and format for some sort of service, arranging for speakers and music, and often organizing some sort of get-together or reception for out-of-town relatives and friends. These tasks can be overwhelming for surviving family members who are already shell-shocked and unable to make even simple decisions. The presence of many people, who surround the bereaved family members in the initial days after the death, enabled surviving family members to make decisions, organize, and plan some sort of service. In essence the service was an important event which held great significance for surviving family members and families had a strong desire that a goodbye ceremony provide an accurate reflection of their family members' lives.

Specific aspects of the service that were especially meaningful to surviving family members included the number of people who attended the service, the people who spoke at the service, and the sharing of stories. The presence of many people at the service communicated that the decedent's life mattered. However, it was not just the number of people present at the service that was meaningful, but also the support of friends and family members before, during, and after the service was meaningful. Family members conveyed that it was important that the service provide those in attendance with an accurate reflection of the person who died. These reflections, often spoken at the service, included the sharing of stories about the decedent. Sharing stories together was very important and meaningful to surviving family members as this demonstrated that the decedent was not forgotten and these stories often evoked both laughter and tears.

For surviving family members the days before and after the service often presented a sort of dichotomy. Family members spoke about all the friends and family members, who when they were notified of the death, interrupted their daily activities to attend, and even participate in the

service. Frequently these friends and family members traveled great distances to attend the service. This resulted in the bereaved family members being surrounded by caring and empathetic friends, many of whom arrived bearing platters of food and numerous dinners to the house. There was no shortage of people available to help with the myriad of details that needed attention. This support was helpful and healing for all involved.

However, at some point in time, generally once the service was over, these supportive friends and extended family members eventually returned to their own lives and activities. The house was no longer overflowing with people. While meals were still delivered to the house, the arrival of food was now on a more sporadic schedule. Bereaved family members found that eating, especially eating alone, was the hardest part of the day. Even when bereaved individuals recognized that their friends and extended family members would not hang around forever, their abrupt departure was somewhat unsettling and confusing. These were challenging days because, on one hand, bereaved family members want everyone to leave; but on the other hand, when everyone left they wondered how they were going to function. Not only had they lost an important person in their lives, they found themselves on their own. This is not to say that all friends and family members disappeared. Thankfully some people still called and checked in on bereaved family members, but as days and weeks go by bereaved family members found themselves somewhat more isolated with their grief and unpredictable emotions.

Bereaved family members discovered that life now included a rollercoaster of emotions and an unreal sense of disbelief. ***Grief unleashed volatile emotional reactions.*** These emotional reactions occurred with varying intensities and were more pronounced in the early days, weeks, and months after the death. Volatile reactions spanned the full spectrum of emotions and ranged from shock, anger, guilt, depression, rage, apathy, and loneliness. However this list does

not begin to begin to convey the qualities of the all encompassing and volatile nature of the reactions experienced after the death of an important family member. For example, shock and denial were common reactions, but the reactions of shock and denial led to feelings of suicidal thoughts, desperation, and apathy. Surviving family members talked about the anger they felt after the death of their family member, but continued to explain how much rage they felt, especially in that this rage was surprisingly close to the surface. It did not take much before they were yelling at their children, throwing things, or ranting and raving about the unfairness of death. Depression was common, though not everyone sought medical treatment for this depression. For some bereaved family members the loneliness was palpable and their heart was obviously broken; they were living with a hollow space in their heart that no one could fix. Occasionally, bereaved family members wondered if they were going crazy or if they were going to make it through this difficult time. For bereaved family members there was no pattern or predictable course to their volatile emotional reactions. At times surviving family members wanted to blame someone, or even themselves, for the death. Blaming oneself for not saving the life of a family member was especially cruel; it was not only for the person who blamed themselves, but also for other members of the family who had to witness this self-blaming over the ensuing months.

Frequently, bereaved family members began to wonder if they were going crazy, and questioned if they would ever feel good again. They walked around in a daze and went through the motions of daily living. They wondered if they would ever stop crying and if they would ever laugh again. Grief was all consuming and impacted every aspect of the participant's lives, with one family member explaining that many people did not realize that grief enveloped every aspect of her day and every fiber of her being. Family members talked about the intense pain of

grief and shared that it was hard to watch other family members grieving, mostly because they felt so helpless to help.

So what was helpful for bereaved family members? In simplest terms the greatest gift was that of presence. Bereaved individuals had no expectation that another person could erase their pain, and the presence of a friend who just listened was the most helpful. Checking in, talking together, and listening, described as lending an ear, was very helpful. Several participants emphasized the need for trust, an absolute necessity, before they would truly share their grief with another person. Families particularly appreciated when the support of friends continued over time. Another very helpful activity was talking about the decedent. Asking about the person who died, or sharing a story about the decedent was often healing and greatly appreciated by grieving family members. Shared stories could in turn be shared again with other family members. The sharing of stories about the decedent reminded surviving family member that the person who died was not forgotten by others. One woman expressed gratitude that not a day passed without someone stopping by or calling to check on her family. This ongoing support was a major aspect of this family's bereavement experiences and allowed the family to continue their lives in spite of a significant loss.

Family members often mentioned the unhelpful comments they heard during bereavement: 'I know exactly how you feel.' 'You should be over it by now.' 'You need to move on with your life.' These comments were not only unhelpful, they were quite hurtful. These comments only served to make the bereaved person feel more isolated with their grief. Family members explained that when expressing condolences it was better to acknowledge the loss with something as simple as 'I'm sorry for your loss.'

Bereaved family members expressed that after the sudden cardiac death of a family member ***life goes on… but never back to normal.*** Participants wanted life to go back to normal but they quickly realized there was no normal; every aspect of their life had been impacted by the death of an important person. Several participants remarked that they had not yet achieved sense of normalcy, even years after the death. Each day presented new challenges, both big and small. For example, financial changes after sudden death were often very challenging, especially if the decedent was the primary wage earner or kept the family business running. Major challenges included bureaucratic and legal issues; for example, for bereaved family members it seemed like everyone needed a copy of the death certificate. Legal issues must be dealt with immediately; even though legalities were the last thing bereaved family members want to think about. Another challenge involved roles within the family. After a death many family roles needed to be renegotiated; for surviving family members the death of one important family member frequently felt like many losses. Even within the same family, individual family members responded differently to the death.

Participants who lost partners found the absence of shared conversation challenging and the lack of companionship was difficult. One widowed woman talked about how much she missed talking with her husband. She often caught herself thinking 'I need to tell him this story or I should talk with him about this decision.' Even drying the dishes at the sink was hard, as this had been a shared activity; one of them washing the dishes and one of them drying the dishes. Just standing at the kitchen sink looking at the view out the window served as a reminder of her loss.

Bereaved family members faced many personal transitions as they attempted to figure out who they were now that an important person in their lives had died. Social transitions were

especially challenging for married participants or those in couple relationships. The transition of being part of a couple to being single was challenging. Several women shared that while they appreciated friends who included them in social activities, they felt out of place (like a third wheel) and they no longer felt at ease in previously comfortable social circles. New relationships were also challenging, as was deciding what to do with one's wedding ring.

Family members shared that, after the death of an important family member, in fact everything changed; vacations changed; social activities changed; friends changed. For some family members even their work setting changed. Even something as simple as the change of seasons often served as another reminder of the person missing from their lives. Birthdays and holidays were especially challenging for surviving family members who expressed the predicaments they faced. On one hand they had a desire to celebrate a holiday or birthday as they had in the past. However, past activities no longer seemed appropriate. One young woman explained feeling guilty due to the fact that her dad was no longer present at the traditional holiday celebrations.

Family stories of bereavement experiences were analyzed to identify ***meanings in loss***. The analysis of these stories revealed that meanings in loss occurred at two levels, with the first level the meaning embedded in their experiences, and the second level an ability to identify meanings in their loss. On the first level, all families included description of meaningful aspects of their bereavement experiences in their stories; for example, the service was meaningful as was the sharing of stories about the decedent. The support of friends was meaningful as were expressions of empathy and compassion for their loss. All families reported that aspects of their bereavement experiences were meaningful to them. All families shared stories which demonstrated that they had achieved this level of meaning.

The second level of meaning was associated with the ability of surviving family members to make sense, or understand, what had happened to their family member. Being able to make sense of their loss often allowed family members to identify meanings in their loss. There is no map or timeline for when and how families might make sense or identify meanings in loss. An inability to identify meanings in loss at the time of the family interview would not preclude a families' ability to make sense of their experiences at a later date. It might be that some families needed more time to make sense of their experiences than other families.

As discussed previously all families had questions after the sudden cardiac death of a family member. Being able to ask these questions, and receive satisfactory answers, seemed to be a prerequisite for meaning identification. Surviving family members often had rhetorical questions: Why would God do this? Why would someone who had so much to give die at such a young age? Why didn't we have more time together? Answers to these types of rhetorical questions were sometimes found in spiritual settings, and at other times these questions had no satisfactory answers. The ability to ask questions, either factual or rhetorical questions, seemed to facilitate surviving family members to process. In turn, this processing prompted some family members to identify meanings in loss.

For one family the inability to identify meanings in their loss were related to lingering questions about the cause of death. Their unanswered questions limited their ability to make sense of what had happened, or even understand the cause of death. These unanswered questions, present at one year after the death, limited this family's ability to make sense or identify meanings in loss. They appeared stuck with unanswered questions. As mentioned previously, if family members were not able to find meaning in their experiences they appeared

to be stuck or unable to incorporate the loss into their life. This seemed to be the case when the family members had unanswered questions about the death.

On the other hand several families were able to identify meanings in loss and these families talked about talked about learning what was really important after the death of a family member. In turn this new knowledge encouraged some participants to live differently after the sudden cardiac death of a family member. Frequently, family members described that the sudden cardiac death of a family member and their subsequent bereavement experiences was the hardest life event they had ever encountered. They often expressed their belief that nothing else would ever be as hard as the death of an important person. These sentiments often prompted bereaved family members to live differently or talk about what they learned. For some families it was in this living differently or leaning what was really important that they found meanings in their bereavement experiences. After the death of an important person surviving family members frequently realized what was truly important in life. Family members discussed sharing time with friends and family members as important, as was telling people of their love for them. Several family members expressed their appreciation for the decedents' presence in their lives. Love was an important theme, and many family members expressed gratitude for the experience of love; not only being loved but also appreciative of the experience they had which allowed them to express love to another person.

Living differently often involved a desire to do good deeds or help others. One family member shared that her bereavement experiences profoundly changed her work, in that she became more open with clients and realized the importance of honest communication. One woman expressed no longer worrying about whether or not she got her 40 hours of work in, but now worrying if she did something good and helpful for other people. Young adults commented

on growing up and maturing as a result of their experiences. A daughter took care of her grieving mom, providing food and assistance in the days and weeks after the death of her stepfather. This young woman described this experience as a complete role reversal, which ultimately changed, and strengthened, her relationship with her mom. A young man whose dad died compared himself to his peer group describing how more grown up and responsible he was as compared to his friends.

Family members expressed that as a result of their experiences they appreciate that the things they used to worry about are now only trivial matters. For example a flat tire was now recognized as nothing more than an inconvenience. Several family members commented on the inane nature of all societies' rules. For example a teacher commented on how upset people tended to get when a high school student wore a baseball hat in school. While other teachers felt this situation was worth getting worked up over, she now viewed this situation as a little thing, only requiring a reminder to the teenager to take off his hat.

Bereavement never ends, but is ongoing, an experience that continues over time. Certainly bereavement is a tumultuous time, but for some families this tumultuousness brought about positive changes. Moving on with one's life after the death of an important person is neither easy, nor smooth. Family members frequently encountered challenges as they returned to their day- to-day activities. They also confronted sudden intrusions of grief and reminders of their loss. The ability to make sense or identify meanings in their loss allowed surviving family members to take steps forward. Certainly family members faced many challenges or hurdles during bereavement, interspersed with sudden booms of grief, but each day allowed an opportunity for living their life, a life forever changed by the sudden cardiac death of a family member.

Chapter 5: Conclusions and Implications

The results of this research study provide a view of family bereavement after sudden cardiac death. At the heart of family bereavement experiences was the challenge of incorporating the loss into a life forever changed by the sudden cardiac death of a family member, while still maintaining a connection to this important person. During bereavement, surviving family members took steps forward to build their new life, but these steps were frequently interrupted by hurdles and sudden "booms" of grief. Through this process family members generally identified meanings in their loss. This ability to identify meanings in their loss helped surviving family members continue living their life after the sudden cardiac death of an important family member.

Sudden Cardiac Death

The heart is a symbol of both life and love. The heart begins beating before birth and pumps blood continuously throughout a person's life. When the heart ceases to function death occurs. The sudden cardiac death of a family member is heart breaking for surviving family members. As novelist and essayist Didion (2005) so succinctly wrote after the sudden cardiac death of her husband of almost 40 years, "Life changes fast. Life changes in the instant. You sit down to dinner and life as you know it ends" (p.3).

Sudden cardiac death is a broad term that encompasses unexpected natural deaths, with or without warning symptoms, resulting from a cardiac cause in persons without known non-cardiac fatal conditions. Sudden cardiac death is shocking, especially when the death occurs in a young person with no known history of cardiac disease. Even if the surviving family members have an awareness of preexisting cardiac disease, such as hypertension, or knowledge of a positive family history of cardiac disease, surviving family members have no expectation of

death. Everyone knows on some level that death is inevitable; every person born will eventually die. Sudden death is shocking and it greatly disrupts the taken for granted nature of life and the predictability by which we live our lives (Janoff-Bulman, 1989). As humans we expect the sun to rise and set each day; we go to work and expect family members to be alive when we come home. When a family member gets ill in the middle of the night we think he has the flu, not that he will die in the next few minutes. When we talk on the telephone to a family member we have no expectation that in a few hours time this family member will be dead.

When there is no forewarning or indication of an impending death surviving family members do not have a chance to convey important sentiments including: "Please forgive me, I forgive you, I love you, thank you, and goodbye" (Byock, 2004, p. 3). The inability to say goodbye to a family member who has died suddenly is tied to the term "unfinished business" which Worden (2002) identifies as a special concern for survivors of sudden death. The suddenness of the death may leave the survivors with regrets for what they did not say or do with their family member before their death. While the specifics of each family's situation will be different, the overall pattern of unfinished business is fairly consistent across studies of sudden death. Although not all family members will have regrets or sorrow for things not said before death, some family members will have unfinished business to deal with during bereavement. Similar to other studies of sudden death, this study of family bereavement experiences supports that some family members will be impacted by unfinished business during bereavement (Davies, 1991; Rodger, Sherwood, O'Connor, & Leslie, 2006-2007).

The findings of this family bereavement study support that bereavement is a very challenging and tumultuous time for surviving family members. Participants described bereavement as a time of taking steps forward after their loss, encountering hurdles and

challenges, and intrusions of "booms" or sudden bouts of grief. After sudden cardiac death of a family member, everything changes and for surviving family members the days, months, and years ahead become a time of great change; change that is both unwanted and unplanned. This study of family bereavement experiences after sudden cardiac death provides insight into the shocking life changing aspects which sudden cardiac death causes for surviving family members. Rodger et al. (2006-2007) reported similar findings in their study of bereaved partners who described their life after the sudden death of a life partner as a "slow and often tortuous experience" (p. 117).

Surviving family members interact with many different professionals at the time of sudden death including, but not limited to, police, coroners, sheriffs, emergency medical technicians and paramedics, nurses, physicians, social workers, and funeral home personnel. This study of family bereavement experiences demonstrated the powerful and long lasting impact interactions with such professionals has on surviving family members at the time of death. Families had vivid recollections of their interactions with professionals, even years after the death had occurred. They remembered who was compassionate and helpful and they remembered who was unsympathetic. Negative interactions had long lasting repercussions on bereaved families in that they vividly remembered who was uncompassionate, rude, or unsympathetic to their loss. All professionals who may find themselves in contact with suddenly bereaved family members at the time of death need knowledge of how their words and actions may be perceived by surviving family members. This knowledge can be used to structure interactions with bereaved family members to be of a positive nature, as opposed to a negative nature.

Families bereaved after sudden cardiac death need ongoing support in the weeks and months following the death. The suddenness of the death often does not allow for resources to be mobilized ahead of time. Generally support comes from friends and family members who help with day-to-day activities and the myriad tasks of living. Life continues even as surviving family members struggle with shock and find themselves unable to make even simple decisions. Legal and bureaucratic issues are overwhelming and seem never ending.

Meanings of Loss

Historically, grief, loss, and bereavement have been studied from the perspective of grief theories which focused on attachment (Bowlby, 1980). Since death irrevocably breaks the attachment between humans these grief theories suggested that the goal of grieving was to detach or disconnect from the deceased (Freud, 1957; Bowlby, 1980). Parkes (1971), who is a pioneer in the empirical study of grief and loss, viewed bereavement as a time of psychosocial transition and his research influenced the development of the subsequent phase and task models of grief. These phase and task models of grief also suggested that detachment was necessary before the bereaved person could continue living after the death of an important person. The concept of detaching or separating from the decedent is still moderately prevalent in society today (Cook & Bosley, 1995).

Recent advances in bereavement research have recognized that 'getting over' the death and detaching from the deceased person is not the goal, and these advances recognize a need for a continued, although different, relationship with the deceased. Klass and colleagues (1996) proposed the concept of continuing bonds which no longer stresses detachment as the goal of bereavement and recognize that the bereaved have a need to develop a new and different relationship with the deceased that will continue over time. The family bereavement study

supports that bereaved family members do not 'get over' a death, but during bereavement work to develop ways to maintain a connection to the person who died, thus supporting the concept of continuing bonds (Klass et al, 1996). Interviews with bereaved family members revealed the ongoing connections that surviving family members maintain with an important family member who has died. These ongoing connections included both tangible aspects, such as keeping the decedent's clothes and work tools, as well as intangible aspects, such as visiting a special waterfall or high point of land on the family farm.

Our knowledge of bereavement includes a model proposed by Stroebe and Shut (1999), the dual process model of bereavement. During bereavement bereaved individuals alternate between activities that focus on their loss, such as confronting grief, with activities that focus on restoration or their life after the loss. This model allows the bereaved individuals themselves to allow time for a respite from grief. The findings of this family bereavement experiences study support this model in that participants' describe their life as a series of steps forward, which are interrupted by unexpected hurdles and booms of grief which remind them of their loss. This model reflects the bereavement experiences of the participants who described the realities of bereavement such as the need to return to work so as to pay the bills, even after a devastating loss of a family member. Other researchers have also reported that this dual processing model of bereavement is reflective of experiences during bereavement (Rodger et al., 2006-2007).

The sudden death of a family member greatly disrupts the inherent security in the world in which most people live their lives (Janoff-Bulman, 1989). Using a constructivist approach Neimeyer (2001) has proposed a paradigm of grief that recognizes that bereaved individuals have to reconstruct their life story after a loss. Neimeyer suggests that for bereaved individuals the focus of grieving revolves around "meaning reconstruction" (p. 4) which proposes that

grieving individuals have a need to reconstruct their life story after the death of an important person. When the death is sudden and occurs out of sequence from the expected cycle of family life, the survivors are often faced with a painful quest to identify meanings in their loss (Neimeyer).

Narrative techniques, which allow bereaved individuals to talk about their experiences, are beneficial in assisting bereaved individuals with meaning reconstruction (Neimeyer, 2001). It is through the telling of stories that bereaved family members begin to make sense of their loss. The ability to make sense of their loss in turn facilitates continuing to live their life after the devastating loss of an important family member. Neimeyer, Prigerson, and Davies (2002) write about meaning from the multidisciplinary perspectives of sociology, psychology, and psychiatry. They propose that people seek meaning after a loss "by struggling to construct a coherent account of their bereavement that preserves a sense of continuity with who they have been while also integrating the reality of a changed world into their conception of who they must be now" (p. 235-236). They describe attempts at adaptation during bereavement occurring on two levels. On a societal level adaptation takes place thorough rituals, cultural influences, and heartfelt conversation with other people, which allow the bereaved to integrate the loss and cope with the volatile emotions of bereavement. On a more individual and interpersonal level bereaved survivors make attempts to integrate the loss into their already existing self narratives.

The results of this family bereavement study add to our current knowledge of meaning making as an important process during bereavement. The ability to identify meanings in loss helped bereaved family members continue living after the sudden cardiac death of a family member. Sharing stories of loss with supportive listeners was one way that bereaved family members were able to identify meanings in loss, thus making narrative an appropriate method for

uncovering or discovering meanings. Meaning making is recognized as an important process for those bereaved due to death (Neimeyer, 2001). Neimeyer and Anderson (2002) found that an ability to identify meaning in experiences of loss predicted more positive outcomes. In this family bereavement study families who were able to make sense of their experiences, or find meanings in their loss, were better able to incorporate the loss experience into their new life after the SCD of a family member. It is through the sharing of stories that bereaved individuals may begin to understand their loss. It is through this telling and retelling of experiences that the bereaved begin to make sense of their experiences (Nadeau, 1998; Neimeyer, 2001) and reorganize their loss experiences into their new life narrative (Neimeyer, 2001; Neimeyer, Prigerson, & Davies, 2002).

Narrative analysis and use of self

Narrative research has been described as containing elements of both art and science (Holloway, & Freshwater, 2007). Artistic elements of narrative research allow for creative communication of results, such as the telling of a compelling story, while also contributing new knowledge to the social or human sciences. As a scientific method of inquiry narrative research incorporates reflexivity, meaning, and specificity to the topic under investigation. While there is no standard way to conduct narrative studies (Ollerenshaw & Creswell, 2002; Riessman, 1993) narrative is an appropriate method for studying the experiences of people in the context of their lives. Narrative allows researchers to examine how individuals construct their world (Holloway & Freshwater, 2007). Polkinghorn (1988) identifies three levels of narrative: experience, telling, and interpreting; Holloway and Freshwater (2007) suggest another level, listening, since the story cannot be retold without careful and attentive listening.

Narrative studies involve an active role for both the participants and the researcher, who collectively identify meanings. Unlike other methods of research where the researcher is in control of the data, with narrative the participants themselves control the story. In this study the participants structured the stories of their bereavement experiences in a manner best suited to the message they wished to convey. It is important to acknowledge that the participants' stories, which are the raw data, change in both the telling of the story and in the listening of the story. It was up to me as the researcher to interpret the participants' stories and tell a different story. The story told by me will once again be interpreted by those who read or listen to my story of family bereavement experiences.

Due to the nature of the shared experience of loss the participants and I had in common it was relatively easy for a close connection to develop between us. "Narrative research is about relationships" (Holloway & Freshwater, 2007, p. 157) and as a narrative researcher I needed an advanced sense of self awareness and emotional skills to engage in the challenging nature of this type of research. In this study of family bereavement experiences I learned to remain keenly aware of my own capacity to listen the participant's powerful stories of loss. I built in breaks during data collection as a means of self care and also used a reflective journal to process my own thoughts and feelings during all steps of data collection and analysis. The participant's bereavement experiences resonated with my own bereavement experiences, as well as the stories I was hearing from other families who had also experienced the sudden cardiac death of a family member. Regular dialogue with colleagues enrolled in a qualitative dissertations seminar, as well as frequent interactions with members of my dissertation committee, were important in helping me maintain my emotional health.

Narrative analysis is an appropriate method to study grief, loss, and bereavement because the bereaved have a strong need to talk about their experiences. Yet sharing stories of loss is often socially discouraged because talking about death is often uncomfortable, at least for the listener. Neimeyer (2001) emphasizes the important benefits of sharing stories of loss. It is only in settings that are considered safe and trustworthy that bereaved individuals will share painful and personal stories of loss. The bereaved have a desire for others to hear what they have to say, while not minimizing their pain or offering superficial condolences. In listening to stories of loss we acknowledge the pain and suffering that are such an integral aspect of their bereavement experiences. In this study the participants and the researcher had a unique connection in their shared experience of loss associated with sudden cardiac death of a family member. Thus the participants were open and honest about their bereavement experiences, including unflattering and embarrassing aspects of bereavement. As the listener, I remained open and non-judgmental about what was being said and this in turn allowed the participants to feel secure enough to open up and share personal stories of loss. For example one participant made a comment about her wedding ring; and she described that it was "hard" to take off her wedding ring after her husband's death. On one hand I realized she was comfortable talking with me when she shared this personal information with me. On the other hand I understood exactly what she meant when she described taking her wedding ring off as "hard." I too wondered what to do with my own wedding ring after Doug's sudden cardiac death. It was only in retrospect that I realized I should have probed for more specifics about the "hard" aspects of removing her wedding ring.

Certainly my own bereavement experiences may have been a threat to my inductive thinking. Ultimately I think the shared experience of loss between myself and the participants provided a safe and trustworthy environment in which the participants spoke openly and honestly

with me, in a large part due to their awareness of my own bereavement experience. As the researcher I had both an insider, or emic, and an outsider, or etic, view of bereavement. While both emic and etic views are valuable it is important to be clear about how I managed the tension between these two views. I intentionally mentioned my own experience with the SCD of a family member, while remaining very aware of my role as the researcher. I consciously kept the interviews focused on the participants' bereavement stories, not my own bereavement stories, and this strategy worked well with most families. When pressed to share my own bereavement experiences I explained that at that moment in time I had my "researcher hat" on and was not at comfortable sharing my own personal experiences. This explanation worked well and satisfied the few participants who requested more details about my experiences. Through the use of a reflective journal I was able to differentiate between my role as the researcher and my own experiences as a bereaved family member.

As the researcher I also needed to remain aware of my own situatedness and positionality to the data. I was similar to my participants in that I had a family member, my husband Doug, die a SCD at age 46. One difference was that I was seven years out from his death, while my participants were on average only two years past the death. I was also different from my participants in that at the time of Doug's death I had much younger children who were enrolled in elementary and middle school. My family was also different from the families in my study in that my children and I participated in several family bereavement programs including an after school family bereavement program and several weekend bereavement programs. My children also attended an annual summer bereavement camp for many years and participated in activities for bereaved teenagers. Undoubtedly my own bereavement experiences inform this study, as does the bereavement experiences of the study participants.

Strengths and Weaknesses

In qualitative research it is important to include individuals in the sample who represent the experience under study. The findings in this study are limited to description of family bereavement experiences of Montana families who had a male family member die a sudden cardiac death within the last five years. This convenience sample, which consisted of seven families and 17 individual family members, has weaknesses in relation to an ability to represent a broad perspective of bereavement experiences. Not all family relationships are represented; for example, there are no parental or grandparental relationships to the decedent in this sample. The perspectives of school-aged and adolescent children who have experienced the sudden cardiac death of a family member are also not represented. In spite of a known increase in the number of young women dying of cardiac disease (AHA, 2004) and thus related case-finding attempts, all families in this sample experienced the death of male family member.

When family members lived great distances from each other it was necessary to connect them to the family interview via a speaker phone. The lack of face-to-face contact between the researcher and these family members living far away may have been a limitation. Also individual family members may have been reluctant to share their experiences openly and honestly in the presence of other family members. As a means to minimize this potential limitation the researcher intentionally scheduled the individual interview after the family interview. The collection of data at two different interviews, initially in a family interview, followed by an individual interview, enhanced the understanding of family bereavement experiences.

This study was designed with acknowledgement of the philosophical assumption that knowledge is created (epistemology) between the storyteller, who is the participant, and the

researcher. Meaning and truth are understood through the experience of the storyteller. Since experiences and meanings are known to change over time, the lack of a longitudinal design may not have been adequate to capture all the nuances of family bereavement experiences and meanings in loss. Criteria proposed by Riesmann (1993) were used to ensure the study was conducted in a methodologically rigorous manner. Traditional methods of reliability are not applicable to narrative studies, and validation becomes the key element. It is important to remember that stories told by participants are shared in a social context and may change depending on the audience, the meaning the storyteller is trying to convey, or even as a result of the telling of their story itself. Riessman (1993) suggests we ask if the interpretation is "reasonable and convincing" (p. 65). The results of this study are credible and believable as verified by the researcher's own personal bereavement experiences, who also considered alternative interpretations of the data during the analysis. Other graduate students enrolled in a qualitative dissertation seminar, and dissertation committee members, were also involved with the data during the analysis.

Ideally, the results of this study would have been reviewed by the participants themselves; however, this was not done for pragmatic reasons associated with time and resources. While this type of member checking would have strengthened the validity of the results it is important to also acknowledge the dynamic nature of stories. The meaning of the story told one day may be different on another day. There is no guarantee that the participants would agree with my interpretations and as the researcher I assume all responsibility for the results of this study.

Consistent with qualitative techniques sampling procedures intended for generalization were not used. However, by adhering to methods that support rigor in qualitative studies, the findings from this study may be transferable. As the researcher I recognize that it is up to the reader to

determine transferability of the results to other settings and I purposefully included thick descriptions of family bereavement experiences so that others may determine the transferability of the results.

Strengths of this study include the narrative approach which allows the voices of bereaved family members themselves to be heard. The focus on family bereavement experiences strengthens our limited knowledge of grief and loss in the social context of family. Bereaved individuals are often socially discouraged from sharing stories of loss and grief, and this study gave them a much welcomed opportunity to share these personal and painful stories with an interested listener. While sharing stories of bereavement experiences with other family members and the researcher may have been somewhat upsetting, all participants expressed heartfelt appreciation for the opportunity to share their stories. Family members expressed an appreciation of having participated in the family interview, and they were thankful for the chance to hear about other family members' bereavement experiences. Ultimately all participants were thankful for the opportunity to revisit their loss and often added their hope that their stories might be beneficial to other people including health care providers.

Recommendations for future research and practice

This study is the first in a program of research designed to increase our knowledge of family bereavement experiences. Following sudden cardiac death surviving family members face an enormous upheaval in their day-to-day functioning as a family unit and as individual family members. We need ongoing studies to further investigate the ways in which families manage this disruption in family structure and examine how they renegotiate family roles and responsibilities. Future studies should include a longitudinal design to better understand the effects of time on family bereavement experiences in relation to changes over time. Further

research is needed to examine how bereaved family member maintain connections to the decedent over ensuing years, especially as new relationships enter the family unit. Given that meaning making appears to facilitate surviving families' ability to continue living their life after the sudden cardiac death of a family member, further understanding of the process of family meaning making is needed. This knowledge is needed in order to develop nursing interventions to support the process of meaning making during bereavement. Since not all families engage in meaning making it is important to examine how meaning making may, or may not, support post-loss adjustment during bereavement.

Research is needed to understand the perspectives and voices of family members not represented in this sample such as school aged children, adolescents, and parents. It is also important to gain the perspective of families who have a female member die a sudden cardiac death. Future research using narrative techniques should be designed to include elements of member checking by taking the researcher's interpretations taken back to the participants for verification. It appears from this study that young adults may be socially isolated from their peer group during bereavement; research is needed to validate or refute this possibility.

Most of our knowledge about bereavement after sudden death comes from studies which focused on certain types of sudden death, specifically deaths due to homicide and suicide. Since suicide and homicide are considered traumatic deaths it is important that we study natural deaths separately from traumatic deaths. Natural deaths include accidental deaths, such as deaths due to motor vehicular or industrial accidents, and other accidental deaths.

This narrative research study has implications for clinical practice. The sudden cardiac death of a family member greatly disrupts the day-to-day functioning of the family. Families without an adequate social support system may find themselves facing physical health problems

and ongoing psychological distress. Ongoing communication with health care professionals over time may help minimize the detrimental effects of bereavement on families after sudden cardiac death. It is important to understand the role of health care professionals in supporting families both at the time of sudden death and over the ensuing months and years. Health care professionals need knowledge of what actions they can take at the time of death and following the death, which can support families during the tumultuous time of bereavement.

Surviving family members frequently struggle with multiple questions about the cause of death and may blame themselves, or others, for not preventing the death. These questions and feelings of blame can be detrimental to surviving family members who are often unable to take steps forward as they struggle with volatile emotions and unanswered questions. The findings of this family bereavement study demonstrate that bereaved families would benefit from follow-up contact with professionals in the weeks and months after the death. During this follow-up professionals could offer condolences from the staff that cared for the decedent, answer questions about the death, and provide support and referral to grief resources in the community. These actions on the part of professionals convey caring to bereaved family members and this caring in turn is appreciated by surviving family members. In two studies with bereaved persons, researchers reported on the importance of honest communication at the time of death and the long lasting positive impressions such communication had on families (Meert, Briller, Schim, Thurston, & Kabel, 2009; Rodger et al., 2006-2007).

Conclusions

The findings of this study are supportive of our current knowledge of grief, loss and bereavement. Participants in this study did not detach from the family member who died, but worked to maintain on ongoing connection with this important person, thus supporting the

concept of continuing bonds (Klass et al., 1996). Not surprisingly, unfinished business (Worden, 2002) was frequently an issue for family members after the sudden cardiac death of a family member. During bereavement surviving family members do move back and forth between activities that focus on the loss and activities that focus on restoration, thus providing support of Stroebe and Shut's (1999) dual processing model of bereavement.

This study of family bereavement experiences adds to our current understanding of bereavement by advancing our knowledge of the meaning making process of families'. Families attempt to identify meanings in their loss after SCD of a family member and the identification of meanings in loss assist bereaved families to incorporate the loss into their new life, a life forever changed after the death of an important family member. Being unable to identify meanings in loss, for example, having unanswered questions after the SCD of a family member, appears to prevent, or delay, a families' ability to identify meanings in their loss. This is consistent with Neimeyer's work (2001) on meaning making and meaning identification.

Narrative is a very suitable method to study family meaning making after the death of a family member since it is through the telling of stories that we are able to make sense of our experiences. Since the SCD of a family member greatly disrupts our taken-for-granted security in the world, the bereaved particularly have a need to tell and retell the stories of their bereavement experiences. Health care professionals should ask clients about their bereavement experiences in order to facilitate the process of meaning making after the death of a family member. This study also gives voice to bereaved families, who spoke in a brutally honest fashion about their bereavement experiences. Since bereavement is a universal experience the voices of those suddenly bereaved make us pause and reflect on our own lives and families.

Summary

For seven families in Montana whose family member died of SCD, family bereavement experiences initially include turbulent days filled with shock and disbelief. This shock and disbelief gradually gave way to loneliness and volatile emotional reactions. Over time family members made attempts to take steps forward into a new life, but these steps were frequently interrupted by hurdles and sudden "booms" of grief. Bereavement never ends, although the acute shock, disbelief and volatile emotional reactions which occurred early after the death of a family member does thankfully lessen over time. Surviving family members did not detach from the family member who died, but instead maintained a connection to their deceased family member. Some family members, if they were able to make sense of their bereavement experiences were able to articulate meanings in their loss. Some surviving family members learned what is really important, and this information in turn prompted them to live differently. An ability to identify meanings in loss often enabled surviving family members to take steps forward into their new life, a life forever changed after the sudden cardiac death of a family member.

References

Agar, M., & Hobbs, J. (1982). Interpreting discourse: Coherence and the analysis of ethnographic interviews. *Discourse Processes*, *5*(1), 1.

Alty, A., & Rodham, K. (1998). Pearls, pith, and provocation. The ouch! factor: Problems in conducting sensitive research. *Qualitative Health Research, 8*(2), 275-282.

American Heart Association. (2004). *Sudden deaths from cardiac arrest – statistics.* (Statistical Fact Sheet – Miscellaneous). Dallas, TX: Author

American Heart Association. (2006). Heart disease and stroke statistics - 2006 update. *Circulation, 113*:e85-e151.

Ayres, L. (2000a). Narratives of family caregiving: Four story types. *Research in Nursing & Health, 23*(5), 359-371.

Ayres, L. (2000b). Narratives of family caregiving: the process of making meaning. *Research in Nursing & Health, 23*(6), 424-434.

Ayres, L., Kavanaugh, K., & Knafl, K. A. (2003). Within-case and across-case approaches to qualitative data analysis. *Qualitative Health Research, 13*(6), 871-883.

Ayres, L., & Poirier, S. (1996). Virtual text and the growth of meaning in qualitative analysis. *Research in Nursing and Health, 19*, 163-169.

Bailey, P. H. (2001). Death stories: Acute exacerbations of chronic obstructive pulmonary disease. *Qualitative Health Research, 11*(3), 322-338.

Bailey, P. H., & Tilley, S. (2002). Storytelling and the interpretation of meaning in qualitative research. *Journal of Advanced Nursing, 38*(6), 574-583.

Berger, P., & Luckman, T. (1966). *The social construction of reality.* New York: Doubleday.

Bookbinder, M., Kiss, M., & Matzo, M. L. (2006). Death and society. In M. L. Matzo & D. W. Sherman (Eds.), *Palliative Care Nursing: Quality Care to the End of*

Life (2rd ed.). (pp. 89-115). New York: Springer.

Bornstein, P.E., Clayton, P.J., Halikas, J.A., Maurice, W. L., & Robins, E. (1973). The depression of widowhood after thirteen months. *British Journal of Psychiatry, 122*, 561 – 566.

Boss, P. (2002). Ambiguous loss: Working with families of the missing. *Family Process, 4,* 14-17.

Boss, P. (2004). Ambiguous loss research, theory, and practice: Reflections after 9/11. *Journal of Marriage and Family, 66,* 551-566.

Bruner, J. (1990). *Acts of Meaning*. Cambridge, Mass: Harvard University Press.

Bowlby, J. (1980). *Attachment and loss. Vol 3. Loss: Sadness and depression.* London: Hogarth.

Bradbury, M. (2001). Classics revisited: Freud's Mourning and Melancholia. *Mortality, 6*(2), 212-219.

Byock, I. (2004). *The four things that matter most: A book about living.* New York: Free Press.

Calhoun, L.G., & Tedeschi, R.G. (2001). Posttraumatic growth: The positive lessons of loss. In R. A. Neimeyer (Ed.), *Meaning reconstruction & the experience of loss* (pp. 157-172). Washington, DC: American Psychological Association.

Carverhill, P.A. (2002). Qualitative research in thanatology. *Death Studies 26*, 195-207.

Center for Disease Control and Prevention (CDC). (2001). Press release: *Sudden cardiac deaths are increasing in young people, especially among young women.* Retrieved May 5, 2007, from http://www/cdc/gov/od/oc/media/pressrel/r010301.htm

Chesla, C.A., & Chun, K. M. (2005). Accommodating type 2 diabetes in the Chinese

American family, *Qualitative Health Research,15*(2), 240-255.

Clandinin, D. J., & Connelly, F. M. (2000). *Narrative Inquiry: Experience and Story in Qualitative Research.* San Francisco: Jossey- Bass.

Clements, P. T., DeRanieri, J. T., Vigil, G. J., & Benasutti, K. M. (2004). Life after death: Grief therapy after the sudden traumatic death of a family member. *Perspectives in Psychiatric Care, 40*(4), 149-154.

Cook, A. S., & Bosley, G. (1995). The experience of participating in bereavement research: Stressful or therapeutic? *Death Studies, 19*(2), 157-170.

Cornwell, J., Nurcombe, B., & Stevens, L. (1977). Family response to loss of a child by sudden infant death syndrome. *Medical Journal of Australia, 1*(18), 656-658.

Davies, B. (1987). Family responses to the death of a child: The meaning of memories. *Journal of Palliative Care, 3*(1), 9-15.

Davies, J. (1991). A sudden bereavement. *Nursing Times, 87*(33), 34-36.

Davis, C. G., Nolen-Hoeksema, S., Larson, J. (1998). Making sense of loss and benefiting from the experience: Two construals of meaning. *Journal of Personality & Social Psychology, 75* (2), 561-74.

Davis, C. G., Wortman, C. B., Lehman, D. R., & Silver, R. C. (2000). Searching for meaning in loss: Are clinical assumptions correct? *Death Studies, 24*(6), 497-540.

Denzin, N. K., & Lincoln, Y.S. (Eds.). (2000). *Handbook of qualitative research* (2nd ed.). Thousand Oaks, CA: Sage.

Didion, J. (2005). *The year of magical thinking.* New York: Alfred Knopf.

Erickson, E. (1963). *Childhood and society.* New York: W.W. Norton.

Feetham, S.L. (1991). Conceptual and methodological issues in research of families. In A.L.

Whall. & J. Fawcett (Eds.), *Family theory development in nursing: State of the science and art* (pp. 55-68). Philadelphia: F.A. Davis.

Fisher, L., Chesla, C. A., Bartz, R. J., Gilliss, C., Skaff, M. A., Sabogal, F., et al. (1998). The family and type 2 diabetes: A framework for intervention. *Diabetes Educator, 24*(5), 599-607.

Folkman, S. (1997). Introduction to the special section: Use of bereavement narratives to predict well-being in gay men whose partner died of AIDS--Four theoretical perspectives. *Journal of Personality and Social Psychology, 72*(4), 851-854.

Folkman, S. (2001). Revised coping theory and the process of bereavement. In M. S. Stroebe, R. O. Hansson, W. Stroebe & H. Schut (Eds.), *Handbook of bereavement research: Consequences, coping, and care*. Washington, DC: American Psychological Association.

Folkman, S., Chesney, M., Collette, L., Boccellari, A., & Cooke, M. (1996). Postbereavement depressive mood and its prebereavement predictors in HIV+ and HIV- gay men. *Journal of Personality and Social Psychology, 70*(2), 336-348.

Folkman, S., & Moskowitz, J. T. (2000). Positive affect and the other side of coping. *American Psychologist, 55*(6), 647-654.

Fontana, A. & Frey, J. H. (2000). The interview: From structured questions to negotiated text. In N.K. Denzin & Y. S. Lincoln (Eds.), *Handbook of Qualitative Research* (pp. 645 - 672). (2nd ed.). Thousand Oaks, CA: Sage.

Fredriksson, L. (1999). Modes of relating in a caring conversation: A research synthesis on presence, touch and listening. *Journal of Advanced Nursing, 30*(5), 1167-1176.

Freud, S. (1957). Mourning and melancholia. In J. Strachey (Ed. & Trans,), The standard edition of the complete psychological works of Sigmund Freud (Vol. 14, pp. 243-258). London: Hogarth Press. (Original work published 1917)

Freud, S., & Gay, P. (1989). *The Freud reader*. New York: W W Norton.

Gee, J.P. (1985). The narrativization of experience in the oral style. *Journal of Education, 167*(1), 9-35.

Geertz, C. (1995). *After the fact: Two Countries, Four Decades, One Anthropologist.* Cambridge, MA: Harvard University Press.

Genevro, J. L., Marshall, T., & Miller, T. (2004). Report on bereavement and grief research. *Death Studies, 28*(6), 491-491.

Gilbert, K. (December, 2001). Traumatic loss and the family. *Family Focus on … Death Dying and Bereavement:* Published by the National Council on Family Relations, pp. F18-F19.

Gilbert, K. R. (1996). "We've had the same loss, why don't we have the same grief?" Loss and differential grief in families. *Death Studies, 20*, 269-284.

Gilbert, K. R. (1997). Couple coping with the death of a child. In C. R. Figley, B. E. Bride & N. Mazza (Eds.), *Death and trauma: The traumatology of grieving.* (pp. 101-121). Boca Raton: FL: Taylor & Francis.

Gilbert, K. R. (2002). Taking a narrative approach to grief research: Finding meaning in stories. *Death Studies, 26*, 223-239.

Gilbert, K. R., & Smart, L. S. (1992). *Coping with infant or fetal loss: The couple's healing process*. New York: Brunner/Mazel.

Gilliss. C.L., & Knafl, K.A. (1999). Nursing care of families in non-normative transitions: The state of science and practice. In A.S. Hinshaw, S.L. Feetham, & J. L. F. Shaver (Eds). *Handbook of Clinical Nursing Research.* Thousand Oaks CA: Sage.

Glick, I.O., Weiss, R.S., & Parkes, C.M. (1974). *The first year of bereavement*. New York: John Wiley.

Harvey, J. H., Stein, S. K., & Scott, P. K. (1995). Fifty years of grief: Accounts and reported psychological reactions of Normandy invasion veterans. *Journal of Narrative & Life History, 5*(4), 315-332.

Helmrath, T. A., & Steinitz, E. M. (1978). Death of an infant: Parental grieving and the failure of social support. *Journal of Family Practice, 6*(4), 785-790.

Heyl, B. (2001). Ethnographic interviewing. In P. Atkinson, A. Coffey, S. Delamont, J. Lofland, & L. Lofland (Eds.). *The handbook of ethnography* (pp. 369-383). Thousand Oaks, CA: Sage.

Holmes, T. H., & Rahe, R. H. (1967). The Social Readjustment Rating Scale. *Journal of Psychosomatic Research, 11*(2), 213-218.

Holloway, I. & Freshwater, D. (2007). *Narrative research in nursing.* Oxford, England: Blackwell.

Horowitz, J. A., Ladden, M. D., & Moriarty, H. J. (2002). Methodological challenges in research with vulnerable families. *Journal of Family Nursing, 8*(4), 315-333.

Janoff-Bulman, R. (1989). Assumptive worlds and the stress of traumatic events. *Social Cognition, 7*, 113-116.

Johnson, J.M. (2002). In-depth interviewing. In J.F. Gubrium, & J.A. Holstein (Eds.),

Handbook of Interview Research: Context and Method (pp. 103-119). Thousand Oaks, CA: Sage.

Karen, R. (1990). *Becoming attached*. The Atlantic, 35-70.

Kavanaugh, K., & Ayres, L. (1998). Focus on qualitative methods. "Not as bad as it could have been": Assessing and mitigating harm during research interviews on sensitive topics. *Research in Nursing & Health, 21*(1), 91-97.

Kissane, D. W., Bloch, S., Dowe, D. L., Snyder, R. D., Onghena, P., McKenzie, D., & Wallace, C. (1996a). The Melbourne Family Grief Study, I: Perceptions of family functioning in bereavement. *American Journal of Psychiatry, 153*(5), 650-658.

Kissane, D. W., Bloch, S., Onghena, P., McKenzie, D., Snyder, R. D., & Dowe, D.L. (1996b). The Melbourne Family Grief Study, II: Psychosocial morbidity and grief in bereaved families. *American Journal of Psychiatry, 153*(5), 659-666.

Kissane, D. W., Bloch, S., & McKenzie, D. P. (1997). Family coping and bereavement outcome. *Palliative Medicine 11*(3), 191-201.

Klass, D. (1996). Grief as an Eastern culture: Japanese ancestor worship. In D. Klass, P. R. Silverman & S. L. Nickman (Eds.), *Continuing bonds: New understandings of grief* (pp. 59-70). Philadelphia: Taylor & Francis.

Klass, D., Silverman, P. R., & Nickman, S. L. (1996). *Continuing bonds: New understandings of grief*. Philadelphia: Taylor & Francis.

Kleinman, A. (1988). *The Illness narratives: suffering, healing and the human condition.* New York: Basic Books.

Knafl, K. A., & Gilliss, C. L. (2002). Families and chronic illness: A synthesis of current research. *Journal of Family Nursing, 8*(3), 178-198.

Labov, W. (1972). The transformation of experience in narrative syntax. In W. Labov (Ed.), *Language in the inner city: Studies in the Black English vernacular* (pp. 354-396). Philadelphia: University of Pennsylvania Press.

Labov, W. (1982). Speech actions and reactions in personal narrative. In D. Tannen (Ed.), *Analyzing discourse: Text and talk* (pp. 219-247). Washington DC: Georgetown University Press.

Labov, W., & Waletzky, J. (1967). Narrative analysis: oral versions of personal experience. In J. Helm (Ed.), *Essays on the verbal and visual arts* (pp. 12-44). Seattle: University of Washington Press.

Lazarus, R., & Folkman, S. (1984). *Psychological stress and the coping process*. New York: Springer.

Lee, R., & Renzetti, C. (1990). The problems of researching sensitive topics. *American Behavioral Scientist, 33*(5), 510-528.

Lehrman, S. R. (1956). Reactions to untimely death. *Psychiatric Quarterly, 30*(4), 564-578.

Levinson, P. (1972). On sudden death. *Psychiatry: Journal for the Study of Interpersonal Processes, 35*(2), 160-173.

Lincoln, Y. S., & Guba, E. G. (1985). Establishing trustworthiness. In Y. S. Lincoln & E. Guba (Eds.), *Naturalistic Inquiry* (pp. 289-331). Thousand Oaks, CA: Sage.

Lincoln, Y.S. & Guba, E.G. (2000). Paradigmatic controversies, contraindications, and emerging confluences. In N. K. Denzin & Y. S. Lincoln (Eds.), *Handbook of Qualitative Research* (pp. 163-188). (2nd ed.). Thousand Oaks, CA: Sage.

Lindemann, E. (1944). Symptomatology and management of acute grief. *American Journal of Psychiatry, 101*, 141-148.

Lofland, J., Snow, D., Anderson, L., & Lofland, L.H. (2006). *Analyzing social settings: A guide to qualitative observation and analysis.* Belmont, CA: Wadsworth/Thomas.

Lyon, B. L. (2000). Stress, coping and health: A conceptual overview. In V. H. Rice (Ed.), *Handbook of stress, coping, and health: Implications for nursing research, theory and practice* (pp. 3-23). Thousand Oaks, CA: Sage.

Marris, P. (1958). *Widows and their families*. London: Routledge.

Mawson, D., Marks, I. M., Ramm, L., & Stern, R. S. (1981). Guided mourning for morbid grief: a controlled study. *British Journal of Psychiatry, 138*, 185-193.

McCance, T. V., McKenna, H. P., & Boore, J. R. (2001). Exploring caring using narrative methodology: an analysis of the approach. *Journal of Advanced Nursing, 33*(3), 350-356.

Meert, K.L., Briller, S.H., Schim, S.M., Thurston, C., & Kabel, A. (2009). Examining the needs of bereaved parents in the pediatric intensive care unit: A qualitative study. *Death Studies, 33,* 712-740.

Mian, P. (1990). Sudden bereavement: Nursing interventions in the ED. *Critical Care Nurse 10*(1), 30-40.

Mishler, E. G. (1986). *Research interviewing: Context and narrative.* Cambridge, MA: Harvard University Press.

Montana Department of Commerce. (2009). Census and Economic Information Center (CEIC): *Montana by the numbers.* Retrieved March 31, 2009 from http://www.ceic.mt.gov/pub_mtbynumb.asp

Montana Department of Public Health and Human Services. (2003). *The Burden of*

Cardiovascular Disease in the State of Montana. Helena, MT: State of Montana.

Montana Department of Public Health and Human Services, (2006). *2004 Montana Vital Statistics.* Retrieved July 5, 2006, from http://www.dphhs.mt.gov/statisticalinformation/vitalstats/2004report/2004table1 .pdf

Moos, R. H., & Schaefer, J. A. (1986). Life transitions and crises: A conceptual overview. In R. H. Moos (Ed.), *Coping with life crises: An integrated approach* (pp. 3-28). New York: Plenum.

Morse, J. M. (2000). Determining sample size. *Qualitative Health Research, 10*(1), 3-5.

Morris, S.M. (2001). Joint and individual interviewing in the context of cancer. *Qualitative Health Research 11*, 553-567.

Moskowitz, J. T., Acree, M., & Folkman, S. (1998, August)). *Depression and AIDS-related bereavement: A 3-year follow-up. New perspectives on depression in AIDS-related caregiving and bereavement.* Paper presented at the Annual Meeting of the American Psychological Association, San Francisco.

Moskowitz, J. T., Folkman, S., Collette, L., & Vittinghoff, E. (1996). Coping and mood during AIDS-related caregiving and bereavement. *Annals of Behavioral Medicine, 18*(1), 49-57.

Myerburg, R., & Castellanos, A. (2005). Cardiac arrest and sudden cardiac death. In D. P. Zipes, P. Libby, R. Bonow & E. Braunwald (Eds.), *Heart Disease A text book of cardiovascular medicine* (7th ed.). Philadelphia: Elsevier Saunders.

Nadeau, J. W. (1998). *Families making sense of death*. Thousand Oaks, CA: Sage.

Nadeau, J. W. (2001). Meaning making in family bereavement: A family systems approach. In M. S. Stroebe, R. O. Hansson, W. Stroebe & H. Schut (Eds.), *Handbook of bereavement*

research: Consequences, coping and care (pp. 329-347). Washington, DC: American Psychological Association.

Neimeyer, R. A. (2000). Searching for the meaning of meaning: Grief therapy and the process of reconstruction. *Death Studies, 24*(6), 541-558.

Neimeyer, R. A. (Ed.). (2001). Meaning reconstruction & the experience of loss. Washington, DC: American Psychological Association.

Neimeyer, R. A. (2004). Research on grief and bereavement: Evolution and revolution. *Death Studies 28*(6,) 489-490.

Neimeyer, R. A. (2005). Grief, loss, and the quest for meaning: Narrative contributions to bereavement care. *Bereavement Care, 24,* 27-30.

Neimeyer, R.A., & Anderson, A, (2002). Meaning reconstruction theory. In N. Thompson (Ed.), *Loss and grief: A guide for human service practitioners* (pp. 45-64). Basingstoke (UK) & New York: Palgrave.

Neimeyer, R. A., & Hogan, N. S. (2001). Quantitative or qualitative? Measurement issues in the study of grief. In M. S. Stroebe, R. O. Hansson, W. Stroebe & H. Schut (Eds.), *Handbook of bereavement research: Consequences, coping and care* (pp. 89-118). Washington DC: American Psychological Association.

Neimeyer, R.A., Prigerson, H.G., & Davies, B. (2002). Mourning and meaning. *American Behavioral Scientist, 46*(2), 235-251.

Normand, C. L., Silverman, P. R., & Nickman, S. L. (1996). Bereaved children's changing relationships with the deceased. In D. Klass, P. R. Silverman & S. L. Nickman (Eds.), *Continuing bonds: New understandings of grief.* (pp. 87-11). Philadelphia: Taylor & Francis.

Ollerenshaw, J.A., & Creswell, J.W. (2002). Narrative research: A comparison of two restorying data analysis approaches. *Qualitative Inquiry 8*(3), 329-347.

Park, C. L., & Folkman, S. (1997). Meaning in the context of stress and coping. *Review of General Psychology, 1*(2), 115-144.

Parkes, C. (1971). Psycho-social transitions: A field for study. *Social Science & Medicine, 5*(2), 101-115.

Parkes, C., & Brown, R. (1972). Health after bereavement: A controlled study of young Boston widows and widowers. *Psychosomatic Medicine, 34*(5), 449-461.

Parkes, C. M. (1965). Bereavement and Mental Illness. 1. A Clinical Study of the Grief of Bereaved Psychiatric Patients. *British Journal of Medical Psychology, 38*, 1-12.

Parkes, C. M. (1970). The first year of bereavement: A longitudinal study of the reaction of London widows to the death of their husbands. *Psychiatry: Journal for the Study of Interpersonal Processes, 33*(4), 444-467.

Parkes, C. M. (1972). *Bereavement: Studies of grief in adult life*. New York: International Universities Press.

Parkes, C. M. (1975). Unexpected and untimely bereavement: A statistical study of young Boston widows and widowers. In B. Schoenberg, I Gerber, A. Wiener, A. H. Kutscher, D. Peretz, and A. C. Carr (Eds.), *Bereavement: Its psychosocial aspects* (pp. 119-138). New York: Columbia University Press.

Parkes, C. M. (1993). Psychiatric problems following bereavement by murder or manslaughter. *British Journal of Psychiatry, 162*, 49-54.

Parkes, C. M. (2001). A historical overview of the scientific study of bereavement. In M. S.

Stroebe, R. O. Hansson, W. Stroebe & H. Schut (Eds.), *Handbook of bereavement research: Consequences, coping and care* (pp. 25-45). Washington DC: American Psychological Association.

Parkes, C.M., & Weiss, R. (1983). *Recovery from bereavement.* Northvale, NJ: Aronson.

Parrish, G. A., Holdren, K.S., Skiendzielewski, J.J., & Lumpkin, O.A. (1987). Emergency department experience with sudden death: A survey of survivors. *Annals of Emergency Medicine 16* (7), 792-796.

Patton, M. Q. (2002). 792-796. *Qualitative research & evaluation methods*. (3rd ed.). Thousand Oaks, CA: Sage.

Pennebaker, J. W., & Beall, S. K. (1986). Confronting a traumatic event: Toward an understanding of inhibition and disease. *Journal of Abnormal Psychology, 95*(3), 274-281.

Pennebaker, J. W., Colder, M., & Sharp, L. K. (1990). Accelerating the coping process. *Journal of Personal Social Psychology, 58*(3), 528-537.

Pennebaker, J. W., Kiecolt-Glaser, J. K., & Glaser, R. (1988). Disclosure of traumas and immune function: Health implications for psychotherapy. *Journal of Consulting and Clinical Psychology, 56*(2), 239-245.

Pennebaker, J. W., & O'Heeron, R. C. (1984). Confiding in others and illness rate among spouses of suicide and accidental-death victims. *Journal of Abnormal Psychology, 93*(4), 473-476.

Poirier, S., & Ayres, L. (1997). Endings, secrets, and silences: Overreading in narrative inquiry. *Research in Nursing & Health, 20*, 551-557.

Polifroni, E., & Welch, M. (1999). Nursing and philosophy of science: Connections and disconnections. In E. C. Polifroni & M. Welch (Eds.), *Perspectives on philosophy of science in nursing: An historical and contemporary anthology* (pp. 1-11). Philadelphia: Lippincott.

Polkinghorne, D. E. (1988). *Narrative knowing and the human sciences.* Albany, NY: State University of New York Press.

Pollock, G. H. (1961). Mourning and adaptation. *International Journal of Psycho-Analysis, 42*, 341-361.

Rando, T. A. (1991). Parental adjustment to the loss of a child. In D. Papadatou & C. Papadatos (Eds.), *Children and death* (pp. 233-253). Washington: DC: Hemisphere Publishing.

Raphael, B. (1983). *The anatomy of bereavement.* New York: Basic Books.

Rees, W.D. (1971). The hallucinations of widowhood. *British Medical Journal, 4*, 37-41.

Richardson, L. (2000). Writing: A method of inquiry. In N.K. Denzin & Y. S. Lincoln (Eds.), *Handbook of Qualitative Research* (pp. 923-948). (2nd ed.). Thousand Oaks, CA: Sage.

Richardson, V. E., & Balaswamy, S. (2001). Coping with bereavement among elderly widowers. *Omega: Journal of Death and Dying, 43*(2), 129-144.

Rickman, H. (1979). *Wilhelm Dilthey: Pioneer of the Human Studies*. London: University of California Press.

Reissman, C. K. (1993). *Narrative analysis.* Newbury Park, CA: Sage.

Rodger, M.L., Sherwood, P., O'Connor, M., & Leslie, G. (2006-2007). Living beyond the unanticipated sudden death of a partner: A phenomenological study. *OMEGA*, 54(2), 107-133.

Rorty, R. (1990). *Philosophy and the mirror of nature.* Oxford: Blackwell.

Rosenblatt, P.C. (1983). Bitter, bitter tear: Nineteenth century diarists and twentieth century grief theories. Minneapolis: University of Minnesota Press.

Rosenblatt, P. C. (1993). Grief: The social context of private feelings. In M. S. Stroebe, W. Stroebe & R. O. Hansson (Eds.), *Handbook of bereavement: Theory, research and intervention* (pp. 102-111). New York: Cambridge University Press.

Rosenfeld, A. G., Lindauer, A., & Darney, B. G. (2005). Understanding treatment-seeking delay in women with acute myocardial infarction: descriptions of decision-making patterns. *American Journal of Critical Care, 14*(4), 285-293.

Rubin, H.J., & Rubin, I.S. (1995). *Qualitative interviewing:The art of hearing data.* Thousand Oaks, CA: Sage.

Ryan, G. W., & Bernard, H. R. (2000). Data Management and analysis methods. In N.K. Denzin & Y. S. Lincoln (Eds.), *Handbook of Qualitative Research* (pp.769-802). (2nd ed.). Thousand Oaks, CA: Sage.

Sandelowski, M. (1994). We are the stories we tell: Narrative knowing in nursing practice. *Journal of Holistic Nursing, 12*(1), 23-33.

Schwandt, T.A. (2000). Three epistemological stances for qualitative inquiry: Interpretivism, hermeneutics, and social constructionism. In N.K. Denzin & Y. S. Lincoln (Eds.), *Handbook of Qualitative Research* (2nd ed., pp. 189-213). Thousand Oaks, CA: Sage.

Schoenberg, B., Carr, A., Peretz, D., & Kutscher, A. (Eds.). (1970). *Loss and grief: Psychological management in medical practice.* New York: Columbia University Press.

Scorro, L.L, Tolson, D. & Fleming, V. (2001). Exploring Spanish emergency nurses' lived experience of the care provided for suddenly bereaved families. *Journal of Advanced Nursing, 35*(4), 562-570.

Sedney, M. A., Baker, J. E., & Gross, E. (1994). "The Story" of a death: Therapeutic considerations with bereaved families. *Journal of Marital & Family Therapy, 20*(3), 287-296.

Shapiro, E. R. (1994). *Grief as a family process: A developmental approach to clinical practice.* New York: Guilford Press.

Shapiro, E. R. (2001). Grief in interpersonal perspective: Theories and their implications. In M. S. Stroebe, R. O. Hansson, W. Stroebe & H. Schut (Eds.), *Handbook of bereavement research: Consequences, coping, and care* (pp. 301-327). Washington, DC: American Psychological Association.

Shuchter, S. R., & Zisook, S. (1993). The course of normal grief. In M. Stroebe, W. Stroebe, & R. O. Hansson (Eds.), *Handbook of bereavement: Theory, research, and intervention* (pp. 23-43). New York: Cambridge University Press.

Siggins, L. D. (1966). Mourning: A critical survey of the literature. *International Journal of Psycho-Analysis, 47*(1), 14-25.

Silverman, P. R., & Nickman, S. L. (1996). Children's construction of their dead parents. In D. Klass, P. R. Silverman, & S. L. Nickman (Eds.), *Continuing bonds: New understandings of grief* (pp. 73-86). Philadelphia: Taylor & Francis.

Silverman, P. R., Nickman, S., & Worden, J. (1992). Detachment revisited: The child's reconstruction of a dead parent. *American Journal of Orthopsychiatry, 62*(4), 494-503.

Silverman, P. R., & Worden, J. (1992). Children's reactions in the early months after the death of a parent. *American Journal of Orthopsychiatry, 62*(1), 93-104.

Steeves, R., Kahn, D., Ropka, M. E., & Wise, C. (2001). Ethical considerations in research with bereaved families. *Family and Community Health, 23*(4), 75-83.

Steeves, R. H., & Kahn, D. L. (2005). Experiences of bereavement in rural elders. *Journal of Hospice and Palliative Nursing, 7*(4), 197-205.

Stroebe, M.S., Hansson, R. O., Stroebe, W., & Schut, H. E. (2001a). *Handbook of bereavement research: Consequences, coping, and care*. Washington, D.C.: American Psychological Association.

Stroebe, M.S., Hansson, R. O., Stroebe, W., & Schut, H. E. (2001b). Future directions for bereavement research. In *Handbook of bereavement research:Consequences, coping, and care* (pp. 741-76). Washington, D.C.: American Psychological Association.

Stroebe, W., & Stroebe, M. S. (1987). *Bereavement and health: The psychological and physical consequences of partner loss*. New York: Cambridge University Press.

Stroebe, M., & Schut, H. (1999). The dual process model of coping with bereavement: Rationale and description. *Death Studies, 23*(3), 197-224.

Stroebe, M. S., & Schut, H. (2001). Meaning making in the dual process model of coping with bereavement. In R. E. Neimeyer (Ed.), *Meaning reconstruction & the experience of loss* (pp. 55-73). Washington DC: American Psychological Association.

Stroebe, M., & Schut, H. (2005). To continue or relinquish bonds: A review of consequences for the bereaved. *Death Studies, 29*(6), 477-494.

Stroebe, M. S. (1992-1993). Coping with bereavement: A review of the grief work hypothesis. *Omega: Journal of Death and Dying, 26*(1), 19-42.

Tolle, S.W., Tilden, V.P., Rosenfeld, A.G., & Hickman, S.E. (2000). Family reports of barriers to optimal care of the dying. *Nursing Research, 49*(6), 310-317.

Tye, C. (1993). Qualified nurses' perceptions of the needs of suddenly bereaved family members in the accident and emergency department. *Journal of Advanced Nursing, 18*(6), 948-956.

Uren, T.H., & Wastell, C. A. (2002). Attachment and meaning-making in perinatal bereavement. *Death Studies, 26*(4), 279-308.

Volkan, V. (1970). Typical findings in pathological grief. *Psychiatric Quarterly, 44*(2), 231-250.

Warren, C.A.B. (2002). Qualitative interviewing. In J.F. Gubrium & J.A. Holstein (Eds.), *Handbook of Interview Research: Context and Method* (pp. 83-101). Thousand Oaks, CA: Sage.

Welch, M. (1999). Phenomenology and hermeneutics. In E. C. Polifroni & M. Welch (Eds.), *Perspectives on philosophy of science in nursing: An historical and contemporary anthology* (pp. 235-246). Philadelphia: Lippincott.

Welch, M., & Polifroni, E. C. (1999). Postmodernism and nursing science. In E. C. Polifroni & M. Welch (Eds.), *Perspectives on philosophy of science in nursing: An historical and contemporary anthology* (pp. 467-470). Philadelphia: Lippincott.

Worden, J. W. (2002). *Grief counseling and grief therapy* (3rd ed.). New York: Springer.

Wortman, C. B., & Silver, R. C. (1989). The myths of coping with loss. *Journal of Consulting and Clinical Psychology, 57*(3), 349-357.

Zisook, S. & Shuchter, S.R. (1986). The last four years of widowhood. *Psychiatric Annuals, 15*, 288-294.

Appendix A

August 1, 2006

Name
Address
Missoula, MT 5980_

Dear _____:

We are writing to inform you of a research study that you may interest you. Ms. Dale Mayer, a registered nurse and graduate student, is interested in talking with families who have had a family member die from sudden cardiac death in the last 5 years. Since _____ died suddenly of cardiac causes we thought it important that we tell you about this study. However it is up to you to decide if you want to be part of this study.

Ms. Mayer has been a nurse for over 20 years and is interested in learning more about family experiences after sudden cardiac death. By doing this study she hopes to identify information that would be helpful for families in the future.

We are going to have one of the nurses in our office call you in one week to ask if they can give your name and phone number to Ms. Mayer. Or you may call Ms. Mayer directly at 406 243 5609. Ms. Mayer will answer questions and provide more specific details about the study.

We want to remind you that your participation in this research study is totally voluntary and up to you. Calling Ms. Mayer does not mean you have to participate in this study; it only indicates that you want to know more about the study.

We hope you are doing well since _____ death and please accept our condolences on your loss. Best wishes to you and your family,

Brad Berry, MD Mark L. Sanz, MD. Cliff Sheehan, MD

Appendix B

Telephone Script for Nurses in Cardiologist Office:

Ms. Dale Mayer is a nurse and graduate student who is doing a study about family experiences after sudden cardiac death of a family member. Dr. _____ requested I call you and tell you about this study since _____ died a sudden cardiac death.

Ms Mayer is looking for families who:

> Have had a close family member between the ages of 20-55 die suddenly from cardiac causes within the last 5 years.
>
> Have more than one person in the family willing to talk with her about the death and their experiences since the death.

With your permission can we give Ms Mayer your name and phone number so she can call you?

Or

If you prefer you may call Ms Mayer at 406 243 5609

Appendix C

Researchers Initial Telephone Recruitment Contact

"Thank you for calling. My name is Dale Mayer and I am a nurse and a graduate student from Oregon Health & Science University who lives in Missoula Montana. I am doing a study about family experiences after the sudden cardiac death of a family member. I was given your name and phone number by Dr. _____ or nurse _____ who works with Dr ____. This study is about **family bereavement experiences after sudden cardiac death** and involves **two interviews** that can be done at a time and place convenient for you.

I understand that you:

A) have expressed an interest in learning more about this study.

OR

B) may be interested in participating in this study.

Is this a convenient time to talk? (If not arrange a time to call back).

I will read a list of 4 statements that need to be true for **families** to take part in the study If any of these are not true – then you would not be who I am looking for.

1. I am looking for families who have had a family member die a sudden cardiac death within the last 5 years – But not as recently as within the last three months.
   (If less than 3-4 months – explain that they do not meet the requirements to participate in this study,
   thank them and ask if you can call them in X months if you are still collecting data.)

2. The age of the person who died is between 20-55 years old at the time of death.
   Age 20 – 45 for males
   Age 20 – 55 for females

3. There are at least 2 or more family members I could talk with about their experiences since the death and

4. I would be able to verify that the death was from cardiac causes and not due to something else like a stroke.

ARE THESE STATEMENTS TRUE FOR YOU?

If those statements are TRUE for you – you are who I am looking for. **Note:** Record name and date on study contact sheet.

If those statements are NOT TRUE for you – you are not who I am looking for. **Note:** Record name and date on study contact sheet

If TRUE:
Would you be willing to meet and discuss this study in more detail? After I explain the study and you agree to participate then you would have to sign a permission slip. Then we would do the interview or schedule the interview for another day. The interview, which would be tape recorded, is expected to take 60-90 minutes. Initially some information about you and your family will be collected, and then you will be asked to tell your story of the death. You will also be asked about your experiences since the death of your family member.
Note to researcher: Record name and date on study contact sheet.

Are you willing to call other family members to talk about this study? Or do you want me to call them? It is fine if you want to talk with them first. May I call you in 1 week to see if I can call them? Please give them my name and phone number if they want to talk with me about the study.

Can we set up an appointment to meet, and talk more about this study? What day/time/location would be most convenient for you?
Options for the location of the interview include your home, or one of two offices located at the University of Montana.

Thank you for your interest in this study. I look forward to meeting you. I plan to call and remind you of our interview appointment one or two days before we are scheduled to meet. If you need to contact me at my phone number is 406 243 5609.

If NOT TRUE:
Thank you for your interest in this study - if you think of something later that may make these statements true please contact me at 406 243 5609.
Note to researcher: Record name and date on study contact sheet.
If decline participation: Record name and date on study contact sheet, include reason for declining participation if offered.

Appendix D

Step by Step Algorithm:

D. Mayer (DMM) makes presentation about study at both local hospitals including weekly Cardiology Conference and staff meeting at Montana Heart Center

Recruitment strategy #1 - Cardiologists and health care providers in Western Montana and Missoula County

DMM meets individually w/cardiologists/office RN's to review inclusion/exclusion criteria. Cardiologists identify potential participants and sends letter (Appendix A) to surviving families

Office RN office makes follow-up phone call (Appendix B) to potential participants and gets permission to give DMM name and phone number. DMM and office RN's talk via phone or in person on a weekly basis

DMM makes calls to potential participants (Appendix C) who have talked with office RN's

DMM calls potential participants who may respond directly to her after receiving to cardiologist letter (Appendix C)

DMM keeps a list of who/how many individuals she has spoken with and documents if they agree or decline - along with reason for declining participation if offered

Recruitment strategy #2 - advertising for participants

DMM will answer/return calls to potential participants who contact her in response to flyers posted at physician offices, grief and bereavement support groups, at offices of counselors and social workers, and with local funeral homes.

DMM will read statements that must be true to participate (Appendix C)

Recruitment strategy #3 - snowball sampling

At the end of each interview adult family members will be asked if they know other families who might meet the study inclusion criteria. If needed, DMM will review the statements that need to be true in order for someone to be in the study (Appendix C).

If the adult family member knows someone who may qualify DMM will ask the participant to give the potential participant a flyer about the study (Appendix E).

If the family does not know anyone who may qualify they will be encouraged to contact the researcher if they think of someone later.

Appendix E

Have you experienced the sudden cardiac death of a family member?

Dale Mayer, RN is recruiting families to participate in a research study about family experiences after the sudden cardiac death of a family member.

If you at least 18 years old and have:

~ had a family member die suddenly within the last five years **AND**

~ the family member who died was between 20-55 years old

Age 20 – 45 for males

Age 20 – 55 for females

~ the death occurred within one hour from start of symptoms

~ the death was determined to be due to a heart problem

Your family may qualify for participation in this study.

Qualified participants will:

♥Complete two interviews lasting about 60 - 90 minutes

♥You may or may not directly benefit but it may be helpful to nurses and doctors.

♥You may find it upsetting or painful to talk about the death of your family member. You may refuse to answer some questions.

♥Each family that completes the study will receive a $ 25.00 gift certificate for a local grocery store

If Interested: please call:

Dale Mayer, RN at 406 243 5609 IRB# 00003373

Appendix F

Oregon Health & Science University
Consent Form

IRB#: 00003373
Protocol Approval Date: 3/7/2007

TITLE: Family Bereavement Experiences after Sudden Cardiac Death

PRINCIPAL INVESTIGATOR:
Anne Rosenfeld, PhD., RN (503) 494-0133

CO-INVESTIGATORS:
Dorothy "Dale" Mayer, APRN, BC (406) 243 5609
Judy Kendall, PhD., RN, (503) 494-3890
Kathy Gilbert, PhD (812) 855-5209

PURPOSE:

1. You (meaning you and your minor children) are being asked to take part in a study because you have had a family member die of sudden cardiac death within the last 5 years. Your experiences since this death may be helpful to nurses and other health care providers. The purpose of this study is to understand what your family experience has been since the death of your family member. This study will use interviews to talk about your experiences.

2. This study involves one family interview and one individual interview with you and the co-investigator (Dale Mayer). The purpose of these interviews is to allow your family and you to share the story of your experiences. At least one other member of your family (maybe more) will be interviewed separately. It is expected that these interviews may take 60 – 90 minutes and if needed, can be done in two sessions.

3. It is expected that 8 - 10 families will be enrolled in the study in Montana. If needed, additional families may be found in other areas or phone interviews may be done.

PROCEDURES:

All members of the family over the age of 12 will be asked to be part of the study. At the first meeting a family interview with Dale Mayer, a nurse, will occur. Individual interviews will also be scheduled. You will be asked to tell the story of the death of your family member. You will also be asked to talk about your life since this death. At least one additional member of your family will have their own separate interview. It is expected that the interviews will take about 60-90 minutes and they will be tape-recorded and typed up.

All information collected will be kept in a locked file drawer or on a locked computer requiring a password. If you have any questions regarding this study, now or in the future, contact Dale Mayer at 406-243-5609 or Anne Rosenfeld at 1-503-494-0133.

RISKS AND DISCOMFORTS:

You might find it upsetting or painful to talk about the death of your family member. Some of these questions may seem personal or embarrassing. They may upset you. You may refuse to answer any of the questions that you do not wish to answer. If talking about the death makes you sad or very upset, we will give you information about help that is available in your community.

BENEFITS:

You may or may not directly benefit from being in this study, but what we learn may help nurses and doctors help families who have a family member die suddenly in the future. Being in this study and talking about your experiences may be helpful.

ALTERNATIVES:

You may choose not to be in this study. You may stop taking part in the study at any time. Talking to a nurse about your experiences will not affect your health care. You may find it helpful to talk with family, friends, or a counselor about your experience since the death of your family member.

CONFIDENTIALITY AND PRIVACY OF YOUR PROTECTED HEALTH INFORMATION:

All information you provide will be kept confidential. All information obtained from minors will be ensured the same rights to confidentiality as adults, with two exceptions: (1) according to Oregon Law, suspected child or elder abuse must be reported to appropriate authorities, or (2) when a child might be physically or psychologically harmed if information were kept secret, such as suicidal thoughts, significant physical or psychological illness or risk of injury.

In the unlikely event that information is discovered regarding abuse or neglect of a child, the study staff is legally required to report that information to the Department of Human Services-Child Welfare Division. If that situation should arise the information will be given to the parents or guardians before the report is made. Study staff will be available to provide support and referrals if requested. We will not use your name or your identity for publication or publicity purposes.

Information may be shared with members of the Oregon Health & Science University (OHSU) research team including Dr. Kathleen Gilbert at Indiana University, but your name will never be shared. All information you provide will be identified only with a code number and never linked to your name. Audiotapes will be destroyed at the completion of the study.

If you sign this form, you are agreeing that OHSU may use protected health information collected and created in this research study. The specific health information and purpose of each use and disclosure are described in the section below:

Interview results will be collected during the course of the study, which will be used to learn more about the families' experience after sudden cardiac death of a family member. This information will be used for teaching purposes and kept by the investigator for further analysis.

The persons who are authorized to use and disclose this information are:

- All investigators listed on page one of the Research Consent and Authorization Form
- OHSU Institutional Review Board

- The Office of Human Research Protections (OHRP)

We may continue to use and disclose protected health information that we collect from you in this study until the study is completed. While this study is still in progress, you may not be given access to medical information about you that is related to the study. After the study is completed and the results have been analyzed, you will be permitted access to any medical information collected about you in the study.

You have the right to revoke this authorization and can withdraw your permission for us to use your information for this research by sending a written request to the Principal Investigator listed on page one of the Consent and Authorization Form. If you do send a letter to the Principal Investigator, the use and disclosure of your protected health information will stop as of the date he/she receives your request. However, the Principal Investigator is allowed to use and disclose information collected before the date of the letter or collected in good faith before your letter arrives. If you withdraw, any information that was collected from you either will be destroyed or stored without any information that identifies you. Revoking this authorization will not affect your health care or relationship with OHSU.

COSTS:

You do not have to pay to be part of this study. Each family will receive a $25.00 grocery store certificate. The grocery store voucher is thanking you for your time spent in this research project.

LIABILITY:

If you believe you have been injured or harmed while participating in this research and require immediate treatment, contact Dale Mayer at 406-243-5609.

You have not waived your legal rights by signing this form. For clarification on this subject, or if you have further questions, please call the OHSU Research Integrity Office at 503-494-7887.

It is not the policy of the U.S. Department of Health and Human Services, or any federal agency funding the research project in which you are participating, to compensate or provide medical treatment for human subjects in the event the research results in physical injury.

The Oregon Health & Science University is subject to the Oregon Tort Claims Act (ORS 30.260 through 30.300). If you are hurt from taking part in this study and it is the fault of the University, its officers or employees, you can take legal action against the University, as agreed upon in the rules of the Oregon Tort Claims Act. You do not have to give away your legal rights when you sign this form. If you want more information, or if you have questions, please call the OHSU Research Integrity Office at 503-494-7887.

PARTICIPATION:

You do not have to join this or any research study. If you do join, and later change your mind, you may quit at any time. If you refuse to join or withdraw early from the study, there will be no penalty or loss of any benefits to which you are otherwise entitled. If you decide to stop being in the study, you may keep the grocery store voucher.

Dale Mayer (406-243-5609) and Anne Rosenfeld (1-503-494-0133) have offered to answer any other questions you may have about this study. If you have any questions about your rights as a member of this study, you can call the OHSU Research Integrity Office at (1-503-494-7887).

Your consent to take part in this study and your permission to let us use your protected health information are voluntary. You may refuse to sign this consent and authorization form. If you refuse to sign this consent and authorization form, your health care and relationship with OHSU will not be affected, however, you will not be able to enter this research study.

After you sign this consent form you will receive a copy of the form for you to keep.

SIGNATURES:

Your signature below indicates that you have read this entire form and that you agree to be in this study.

_____	_____
Subjects Signature	Date
_____	_____
Parent/Guardian Signature	Date
_____	_____
Dale Mayer, APRN, BC Signature Witness Co-investigator	Date

Appendix G
Demographic Data

Code: _____ Date: _____

Thank you for agreeing to share your story with me. Let me give you an idea of what we are going to do here today:

First I am going to ask a few questions about you and your family member who died.
Second I will ask you to tell me the story of _____ death.
Then I will ask you to tell me about you and your families experiences since ___death.

Now I want to get some information from you
First about the family member who died
Then about you:
Some of this information I may know from our phone call but I want to ask this again to be sure that I am clear and have this information correct:

Demographic Info:

Decedent:

1. Who in your family died? What was their name? May I use their name?	DEC name
2. When did _____die?	DEC date
3. Were they male or female?	Male Female
4. What was _____ age at the time of death?	DEC age
5. Did _____ have known heart disease?	DEC card dx
6. What was their race?	American Indian or Alaskan Native Asian Black or African American Native Hawaiian/Pacific Islander White
7. Were they Hispanic?	YES Hispanic NO Hispanic
8. Were they Latino?	YES Latino No Latino

Participant:

1. What is your name?	PART name
2. What was your relationship with _____?	PART relation
3. What is your age?	PART age
4. What is your gender?	Male Female
5. What is your race?	American Indian or Alaskan Native Asian

Black or African American
Native Hawaiian/Pacific Islander
Hispanic or Latino
White

7. Are you Hispanic? YES Hispanic NO Hispanic
8. Are you Latino? YES Latino No Latino

Appendix H
Proposed Interview guide

Thank you for participating in this study. First I need to collect some information about the person in your family who died – (this will be done with initial family contact person). His/her name was ____? May I call them by their name? Now I need everyone to sign a consent form and I need to get some information from each of you (See Appendix H). Once this is done we can get started.

Thank you for agreeing to take part in this study; I want you to know that I am a registered nurse. My interest in sudden cardiac death (SCD) comes from both my background as a nurse and personal experience; I had a family member die a SCD.

This experience made me think about other families who went through similar situations. Eventually I went back to school so I could study this. My goal is to help nurses and physicians learn how to be supportive of families after sudden cardiac death. I think that information from you, and other families who have had a family member die, will be helpful to others.

Before we get started will everyone here please say their name and we can make sure the microphone is working. Thank you for sharing background information with me. Now I want to have you do the talking. I have some questions to get started:

FAMILY INTERVIEW:

1. Please tell me the story of _____'s death.
   What occurred or what events happened before _____ died?
   Where was _____ when he/she died? Who was present at the death?
   How were family members not present notified of the death?

2. How has this death affected your family?
   What family activities have changed since _____'s death?
   What family activities have remained the same?

3. Please tell me about ceremonies, if any, which took place after _____'s death?
   What activities, if any, do you do as a family to remember _____ now?
   Please tell me about any family activities you do to remember _____?

4. Please tell me how as a family you talked about _____'s death?
   What stands out in your memory about that talk or those talks?
   Were there things that kept you from talking about the death?
   How did you, talk with other people, who are not part of the family, about _____ death?

5. As a family what meaning are you able to make of _____death?

Can you discuss how as a family you make sense of _____'s death.
Can you discuss how as a family you may see _____'s death the same way or differently?

6. In what ways do you think about _____death?
   Has this thinking changed over time? Say from early after the death (weeks to months) to later after the death (months to years)?

7. As a family what was helpful to you after _____'s death?
   As a family what was not helpful to you after _____'s death?
   Example - early bereavement (weeks and months) to late bereavement (years after the death).

8. Is there anything else you wish to share with me about _____death?
   Is there any information you wish to share with me or other nurses/physicians since _____death?

9. I've asked you a lot of questions, is there anything you would like to ask me?
   Or tell me that I haven't asked you about?

MY final question is if you know of any other families who might be eligible to take part in this study? If needed review statements that need to be true in order for someone to be in the study (Appendix D). If you do know someone, or think of someone later, will you please give them this flyer (Appendix E) and ask them to call me.

End of interview/closure:

Thank you for talking with me about _____'s death and your experiences since this death. It may be helpful to nurses, doctors, and other families in the future.

Sometimes after telling a story like this troubling feeling and thoughts may develop – in case this occurs I would like to give you this list of local people and agencies that provide support to those who have had a family member die. This list may be helpful to you.

Here is my business card – it has my name and phone number on it (as does the permission slip you signed earlier). Thank you again for sharing your story with me.

Here is a gift certificate to a grocery store – it is given in appreciation of the time your family spent with me today. Thank you again – it was a pleasure meeting and talking with all of you today.

INDIVIDUAL INTERVIEW:

Hi _____. Thank you for talking individually with me today. As you know I am talking with families about the SCD of a family member – and this study involves both a family interview and individual interviews. Today we are doing your individual

interview – in which I want to talk about your individual experiences since _____'s death. Before we begin do you have any questions for me?

1. At the family interview I asked for the story of _____'s death.
   Is there any thing you want to add or clarify from the family interview related to the story of _____ death?
   Was your individual experience associated with ___'s death the same or different from the family experience?

2. Please tell me what it has been like for you individually since _____death?
   What has changed (activities, routines, schedules, etc) for you since ____'s death?
   What has remained the same (activities, routines, schedules, etc) for you since _____'s death?

3. As an individual can you talk about if/ how you find meaning, or make sense of, __'s death?
   How does your experience related to _____'s death fit with your family's (parents, siblings, etc) experience?

4. Please tell me if the way you think about _____'s death changed over time?
   What did you think in the early months after ____death?
   What do you think about now _____ months or years since _____ death?

5. Please talk about what you found helpful immediately after ____ death?
   What did you find not helpful after immediately ____ death?
   What about later, say in the first months to year, what was helpful?
   What was not helpful later after the death?

6. Is there anything else you wish to share with me about _____'s death? Is there any other information you wish to share with me or other nurses/physicians since _____'s death?

6. I've asked you a lot of questions, is there anything you would like to ask me?
   Or tell me that I have not asked about?

7. One question I am asking everyone in the study is if you are (or have) participating/ed in any support groups or seeing a counselor about the death of your family member.

End of interview/closure:
Thank you for sharing the story of _____'s death and your experiences since this death with me. It may be helpful to nurses, doctors, and other families in the future.

Sometimes after telling a story like this troubling feeling and thoughts may develop – in case this occurs I would like to give you this list of local people and agencies that provide support to those who have had a family member die. This list may be helpful to you.

Here is my business card – it has my name and phone number on it (as does the permission slip you signed earlier). Thank you again for sharing your story with me.

ADOLESCENT INTERVIEW:

Hi _____. Thanks for talking with me today. Before we get to talking about _____ 's death can you tell me about yourself? (How old are you? Where do you go to school? What grade are you in? What is your favorite subject? What is your least favorite subject? What activities/sports do you enjoy?)

1. I am sorry that ____died. What it has been like for you since _____death?
   What has changed (activities, routines, schedules, etc) for you since _____'s death? What has remained the same (activities, routines, schedules, etc) for you since _____'s death? Please talk with me about your friends or family – how they treated you after _____ died?

2. What can you tell me about _____'s death?
   How did you learn of _____'s death? What ceremonies, if any, occurred after _____'s death? Were you involved in any of these ceremonies?

3. Please tell me a little about how you think about or remember _____? What about participation in any sort of activities to remember _____?

4. How about your friends? How did they talk with you about _____ death?
   How did you talk with them about how you are (or were) feeling?

   How about school? – how did people at school talk with you about ____'s death or how you are (or were) feeling about _____ death?

6. I am asking everyone for stories – I would like to hear a story about you and _____.

7. I've asked you a lot of questions, is there anything you would like to ask me?
   Or tell me that I have not asked about?

End of interview/closure:

Thank you for talking with me about _____'s death. This information may be helpful to nurses, doctors, and other families in the future.

Sometimes after talking about a death or telling a story about people who died - troubling feeling and thoughts may develop – in case this happens to you I gave (parent/guardian) a list of people that might be helpful for you. Thank you again for talking with me. Good luck with _____(school, work, friends, sports…).

Appendix I

Detailed Narrative Summary F001

Background:

This interview is with Ginny and a close friend and former business partner Dave. Ginny was the unmarried partner of Mike and they have been together for 11 years. Ginny, Mike and Dave ran a seasonal business together. Mike dies suddenly at age 44 of a ventricular arrhythmia. Although not a traditional family Ginny and Dave describe themselves as 'family enough" [419]. This interview takes place 5 years after Mike's death.

Routine day until:

Ginny describes," I was at work - that was a Wednesday… well a workday at least" [122-23]. She continues, "I was thinking I'd come home that day at noon, but ended up we had a staff meeting, so I needed to stay later… So I got home around five and I found M, and he was dead downstairs" [126-130]. She continues, "Well he had fallen - the chair had tipped over. He was on the ground and umm and I of course dialed 911. I was calling his name, but he clearly wasn't responsive and he actually - I could tell that he was dead. I still called 911 and I still did CPR on him and cardio all the stuff umm because I think I was just not believing at that moment, but I still actually knew he was dead even right then instantly"[130-37]. She describes the arrival of the Emergency Medical System saying, "And umm so then the folks from the ambulance came really quickly…they worked on him for just a couple of minutes and they said it's too late you know – he's gone" [137-43]. She adds, "I'd already had about half an hour down there with [Mike] when the sheriff or the coroner showed up - so I was talking to him and saying goodbye. [pause – voice breaking]. Then after the sheriff left he asked if I [tears] wanted more time and I said no [tears and voice cracking] (pause) so then (pause) then they took him [tears and voice

cracking] and I can't remember exactly, but it seems like there must've been somebody besides him. I'm sure there was (pause and crying) they took him and he was gone [tears]" [163-172].

Dave describes the shock he feels when he learns of Mike's death from Ginny. He says, "it was complete shock and dismay that something like that could have happened to him" [253-255]. Dave discusses the time he and Mike had just spent together saying, we'd had a really fun weekend just two days before and so that was part of the shock - that Mike had seemed so healthy and umm – strong and you know he was – he was just a big strong guy, you know, with an invisible disease" [247-51].

Ginny includes in her story the actions of the sheriff or coroner when she says, "somebody official came in…And they treated it temporarily as a crime scene umm which was a little unnerving definitely, you know –'What did you do?' and 'How did you move him?' I was like - I only rolled him over to do CPR. [The sheriff or coroner then asked her] "Exactly where was he laying? How long were you gone? When was the last time I had saw him?" [147-154]. She continues, "You know I could tell they were investigating the possibility of a crime scene - not that anybody accused me of anything but they were clearly considering it a possible crime scene until they until they – until they cleared that…and again, not that anybody said anything to me, but it was a little unnerving anyway" [154 - 161].

"People started showing up":

Ginny describes a neighbor who knocks on the door after seeing the ambulance and she says, [this neighbor] "immediately obviously called some people because – because then people started showing up pretty quickly and I hadn't made any calls" [179-181]. Ginny does make some phone calls to family members but says, "but I didn't call anybody local, not immediately…but a ton of people showed up here" [186-188]. She continues saying, "I bet there

were 30 people at least - some of whom I knew really well and some that I didn't know very well… there was **way** too many people …and I didn't know how to move anybody out" [195-206]. She describes asking people to leave saying, "I'm fine I can stay alone I don't need you to be here and I appreciate the concern and the offer [to stay overnight with her] but I don't need you to be here, in fact, I don't want you to be here. And so reluctantly, they all left - it was around midnight by then. And I went to bed, umm I actually slept - I bet I slept five hours. I was exhausted" [212-18].

Ginny describes the arrival of her mother saying, "within a few days my mom came… and actually [pause] it didn't work very well because she was so needy" [222-25]. Ginny continues, "I think …she [her mother] was just reliving my dad's death – and no he didn't die young and he didn't die of cardiac but – I still think that what she was doing" [233-36]. Ginny continues, "so it wasn't that helpful to have her around – umm – because she always wanted to do stuff that I didn't want to do [laughter] [237-39].

Service:

Ginny describes planning the service saying, "and we didn't call it a funeral - we called it a memorial service" [371]. She talks about the timing of the service saying, "because my brothers didn't either one come cause they couldn't make it happen that fast and they wanted it [the service] to be later, but his family - who is very religious, wanted it sooner. And I felt it was much more important to honor his family then my siblings" [266-70]. Ginny says Mike's siblings arrive from three states, saying, "and they all came" [355].

Ginny describes Mike's family as "pretty religious" [361] and compares this to Mike whom she describes as "an atheist – or as he said - a fully recovered catholic" [360]. She handles this difference in religious tradition up front with his family saying "But I told them that

because [Mike] was an atheist that I could not be comfortable having a religious service. And so they knew ahead of time, and I said, you know if you guys need to do something along that line that's fine, you know, there are all kind of churches around here and stuff but I don't know what they did and didn't do. But I didn't want them to be shocked that it wasn't a religious service" [362-69] and "we didn't hold it [the service] in a church. I think his family was okay with that – they all seemed okay. I was glad I told them ahead of time – and I said – this isn't about me but your brother was a devout atheist. I just don't think it would be a comfortable thing to do the God thing" [376-81].

All of Mike's siblings "took part in the ceremony" [355-6] and Ginny describes that one brother "did a really cool slideshow" [356] and "his oldest brother read something from the family, another brother wrote a letter" [357-59]. Ginny describes the service saying, "and we had a big feast… all kinds of wine, tons of food, tons of people, 300 or 400 people at least" [381-83]. Ginny continues saying, "a lot of people spoke including some of his siblings and many of his friends and Dave spoke and [Ginny] spoke … eight or nine people [spoke]" [372-74]. Dave adds "it was a very fitting service to [Mike] I think those closest to him were able to tell stories… and celebrate Mike's life" [384-387]. Ginny later says, "I remember looking forward to the memorial service, because I knew I was going to hear all these great stories – amazing stories about Mike and all these memories – and dreading the day after and going - Oh my God [659-62]. She clarifies dreading the next day when she says, "because I knew that the – then the ceremony would be over and the telling of tales [stories] and people would start to leave" [684-85].

When asked what it was like to speak at Mike's service Ginny says, "well I felt compelled to say something, because I didn't have a chance to say goodbye to him" [391-

92] and "I **liked** speaking in front of all [Mike's] friends, you know, and family and everyone was real supportive, obviously" [404-06]. Dave adds, "I just thought it was really significant and meaningful time to say goodbye, you know…" [413-14].

"Everything changed":

Ginny describes Mike's death as "a marker in my life that will remain forever" [127]. She continues, 'I'm saying that some things are such earth shaking ground moving soul searing events that everything else is marked by them" [128-130]. Ginny also talks about how "everything changed" [151] after Mike's death. She continues, "my daily routine changed, running the business changed, vacations changed, work… changed pretty quickly ..." [152-155]. She describes, "some of our friends have remained the same - but not all… and some new friends came in" [157-59]. She adds "I had a great community of people around me" [179-80]. She describes that this community of people "stuck around for a while – I knew they wouldn't stay forever and that they would fall away – especially those that were there sort of on behalf of Mike" [180-82].

Dave describes that Mike's death "very much changed everything – pretty much everything - it just changed everything" [440-42]. He continues, "it was the business [that changed], it was the friendship, and so life for me is significantly changed" [443-44]. He adds, "you know – your pick up – you move on – you keep keeping on – but umm – it was umm – painful and dramatic in my life… to not only lose someone that was not only such an inspiration and a – and a –[pause] – support - to really searching for that kind of relationship [again] and I haven't found it" [449-53].

Dave and Ginny talk about how their relationship changes after Mike's death. Ginny says, "it's a different dynamic – a totally different dynamic" [555-56]. Dave adds, "I have felt

closer to you since Mike's passing largely out of having – umm – shared umm – some of the conversations that we did" and "to me there's a stronger bond there then there had been before Mike's passing" [576-77]. Ginny confirms this change in their relationship when she says, "you like forge a whole new relationship… and its either you're going to have a relationship or you're not …but we needed to find our own relationship, which we did, that was stronger than before" [581-89].

Ginny talks about Mike being away for up to six weeks at a time saying, " I was used to extended periods of time without him[Mike] in my daily life… but having him not in my daily life forever is a different kind of adjustment and a different kind of loneliness" [198-202]. She adds, "now [he has] been gone for five years so… and you know 10 years from now it will be 10 years …" [204-06].

Grief:

Ginny says, "you know when you experience a loss like that I think everything's more vulnerable you know… I remember feeling like my soul had been seared – but in a way that made it stronger and brighter and clearer" [596-601]. She continues, "it was a very interesting feeling that I can't even capture anymore but I felt like that for a long time – a year or more and umm -I was more open to a lot of things – umm – different people – different sorts of relationships" [601-05]. She adds, "and people I had never been very close to started coming around and hanging out with me – they had been friends of Mike's - male friends - and they – they needed that too - and so we all needed that - they needed this space" [605-614]. Ginny adds that needing this space continues "that first year, especially those first months" [609-10].

Ginny talks about her perspective saying, "I mean I actually have become more logical about death – if that makes any sense – which by that I mean it's become very clear to me –

everybody is not going to live to be 75… of course I knew that anyway, but when it personally happens to you – it hits home a lot faster" [812-818].

Ginny talks about her grief in the early months after Mike's death saying, "I have a pretty good attitude and a pretty good mental fortitude to toughness and … I tell you during those first six months it was like –I'm not sure I'm going to make it" [207-10]. Other people tell her "of course you are and we'll help you… so that all changed" [210-211] and Ginny sums up these changes saying, "lack of an intimate partner is a pretty major adjustment for anybody" [211-212].

Ginny talks about attending a grief class saying, "I did go to a grief class but it was about six months later…I tried to go to one right away and the professionals were like – No you don't want to do that [attend a grief class right after Mike's death] you want to go later – you want to wait and process some on your own and do it [grief class] later" [929-933]. She continues, "I got a lot out of that [grief class] … part of what I got out of that is that same old – it's like that reflection back at you from other[s]" [940-942]. She continued, "I was like WOW – I mean really people do experience this [grief] in dramatically different ways" [961-63]. She adds, "it was kind of a way to measure yourself and also to hear other people's stories and what they did and … how they handled it [grief]" [970-74]. Ginny describes the group saying, "and men were invited but no men came – so it was all women… some had experienced sudden death – umm some not – actually most of them were [sudden deaths] - actually most of them were – but not cardiac" [947-50]. She described this "grief class as helpful" [1048] although she later adds, "it was not helpful to not know where to turn for help… I finally found it [a hospice] and finally called and made a few calls on my own behalf … [I] wanted to get into a group [grief class] and

having them go – well there is no course [in the summer] and your can't do it till [time has passed since the death]"[1130-36] was not helpful.

Dave recalls thinking, "why bother – life is so hard and you lose something [someone] so important to you – there's a piece of "give up" there – which to me rationalizes some of my depression" [989-992]. Dave describes societies reaction to death and grief when he says, "and in society in general that if you don't know what to say you don't say anything at all - and that becomes debilitating in - for me anyway in the sense in that I do want to talk about it [Mike's life and death] - I do want to – umm- deal with the affair [grief] - rather than trying to get busy and do things to avoid it or distract" [1124-1128]. Ginny also talks about being depressed saying, "I would definitely say I was depressed… I was definitely depressed. I didn't seek medical treatment for it – but I was definitely depressed. You just sort of have that dead tone in your voice and everybody notices " [1002-1006].

This family shares some perspectives specific to male grief. Ginny talks about Mike's male friends coming to visit her over the first year after Mike's death saying, "those guys were over here – not all of them – but two or three of them - all the time. Doing stuff with me – we were cooking dinner – they were gardening in my yard – they needed this space" [610-614]. She describes how, with her permission, two of Mike's male friends put together a sale of his sporting gear saying, "and so they did a Saturday sale and showed back up at my house with $2000 bucks… and I was glad because I didn't have to go through that stuff" [620-623]. Several of Mike's male friend s also "had a big sendoff and said goodbye" [642] when they transported Mike's body from the autopsy site to the cremation location. Ginny describes, "so they all went and got him and they took him down to the river and drank beer" [641-42]. Although Ginny was invited she did not go saying, "it was all guys and I think they needed their guy time" [653-54].

Ginny describes another male friend of Mike's who, "is a very quiet guy anyway – he walked into the house, gave me a big hug, sat on the couch and cried for two hours, and then he left - I bet we didn't say 10 words" [675-78]. She adds that another male friend "kind of did the same thing" [680]. Ginny describes that Mike's brother would "come up [to Montana] and just hang out – go boating for a few days – and you know – we didn't so much talk about Mike – he's not a big talker and he's not a big emotional guy at all – but still there was some connections happening and need for him and me both – you know – to have [time together]" [705-710]. Ginny also mentions a male friend of Mike's who "still can't talk about him [Mike] – or at least not to me – it brings him to tears every time he mentions his name" [1029-31].

Meaning:

Ginny's life has been forever changed. She describes Mike's death as "a marker in my life that will remain forever" [127]. She continues, 'I'm saying that some things are such earth shaking ground moving soul searing events that everything else is marked by them" [128-130].

Ginny talks about what she learned from Mike when she says, "and the thing about Mike - he lived every day to the fullest - got the most out of everything he ever did - he put his heart wholeheartedly into everything"[821-23]. She continues saying, "and he was the one that taught me about that - to be present - live in the present - this moment you're in right now is **all** you have - you don't necessarily have tomorrow - you definitely don't have the one you just lived through [chuckle]- so I learned that from him long before he died" [836-41].

Ginny experiences personal growth after Mike's death. In relation to the outdoor business they ran together she says, "I would I have to admit I got to be a much better guide because I read all the books that I had never really done before. So I was much more knowledgeable about all the places we went… because I used to just listen to Mike…and I knew

I could just re-spin those stories, but it was like - it's time for you to learn this stuff if you're gonna do it- really know it - so I did that"[513-19]. She continues, "Doing all the physical work [associated with the outdoor business] was a killer. Umm that was hard - probably good for me, I think it toughened me up a little" [542-44]. She also learns how to do remodeling work because the house was in the midst of a major remodel when Mike dies. She says, "and I did a lot of work on the house here and Dave [and others] helped but… that I probably would've never done if Mike was alive" [546-47].

Ginny speaks at Mike's memorial service and shares the story of how they met. Meaning comes from the fact that although they were unmarried, they have been together for 11 years, and before his sudden death they discuss having some sort of commitment ceremony. Dave describes this commitment ceremony as "a get together with their families to umm speak to their partnership" [39-40]. This implies that Ginny uses the memorial service as a time to publically speak to their commitment to each other since his sudden death prevents any future commitment ceremony.

Ginny also expresses that she looks forward to the service because she knew this would be the time and place where stories about Mike would be shared together. She acknowledges that once the service ends the sharing of stories would continue for a while, but that eventually "people would start to leave" [685] and get back to their own lives. The meaning comes from the bereaved wanting to hear these stories about the decedent. And this desire to hear the stories continues over time, probably long after most people realize. For example Ginny shares that a friend asks, "well we don't know if we should bring him [Mike] up or not "[1041-42]. Ginny replies, "I'm telling you all I'm giving you permission to bring him up whenever you want to – I – you know he contributed a lot to this community and to our set of friends so don't feel shy

about - you know - talking about him" [1042-46]. Ginny then adds, "but most people don't [mention or bring up Mike] [1046]. Ginny enjoys talking about Mike which she explains when she says, "talking about M was helpful – umm talking to Dave was helpful for sure - and talking to other folks who wanted and could talk about M - you know some people couldn't talk about it… which is not helpful to me is if no one talks about him" [1026-1032].

Appendix I

Detailed Narrative Summary F002

Background: This interview is with Betty and Bill and it is occurring 3 years after the death of Betty's husband Ben. Betty and Ben are both disabled and have been married for 19 years and Bill is their developmentally delayed 'adopted' son who has lived with them for most of their marriage. Ben dies in the hospital one week after having an emergency surgical repair of an aortic aneurysm dissection. Here is their story:

Normal day until:

Betty begins by saying, "I suppose I ought to start at the beginning – umm I was getting ready to leave one morning to go to a doctor's appointment and I heard Ben moaning and I went in and he said he had really bad (pause) heartburn" [30-33]. She continues, "But this was different – this was – something was really wrong … [his] moaning scared me… I said I 'm going to call the ambulance but of course he said don't be silly … but I was silly and I called the ambulance and by the time they got here - his flesh was mottled on his bottom and his legs" [35-41]. Betty calls EMS and ambulance personnel respond and she says, "They seemed at the house to be very slow and I knew that something was wrong with his heart – but I guess it was a matter of getting him stabilized before they moved him – but the ambulance ride was very slow too – what happened was his aorta was dissecting and perhaps that was why I just wanted them to get there [to the hospital] NOW kind of thing" [49-53]. At the hospital Betty says that a cardiac surgeon, "came and told us what was happening – they got him in right away – the ER doctor was on top of it – they got him in to - whatever you call that …" [58-60]. Bill answers, "MRI" [61] and Betty continues, "yea - MRI or CT scan – they had him in immediately – so they knew right what it was – Dr [cardiac surgeon] said if I get you into surgery there is a 90% chance you

will live and a 10% chance you will die – and there was no question it had to be done and they got him through surgery – it [surgery] was 8 1/2 hours [long]" [62-66]. Betty continues the story and says, "[Ben] lived for another week and seemed to be doing well but he came out of ICU and moved to the step down unit" [66-68]. Betty says the hospital staff "called me at 1 in the morning – it was Thursday night/Friday morning and said he [Ben] won't settle down and …I got there and he was really uncomfortable and I noticed that his legs were mottled again and I said [voice cracking and teary] - Get Dr [cardiac surgeon] now!" [69-73]. Betty describes that the cardiac surgeon arrives quickly and she says that Ben says to her, "Kiss me honey I'm dying" [77-78]. Betty continues saying, "I did [kiss him] and then Ben coded and I just telling Ben I loved him and they kept working and went back in there to repair the patch but the next day (pause) the neurosurgeon came and said Ben had left the building [brain death] and we had it [life support equipment] unplugged at 12:12 [76-81]. Betty later adds, "I had to turn off the machines - that sucks…but we had talk[ed] about stuff like this years ago [pause] and if there's a chance [of recovery] we should try but…" [140-43].

Funeral:

Betty describes, "We had a wonderful [pause] we had a wonderful funeral – we have a dear friend – who did his eulogy – he grew up with the family and he might have known Ben all his life – the eulogy was perfect it was just perfect – there were a lot of people at the funeral – a lot of people" [233-37]. She describes, "And um they had a… a reception - in the parish hall rights afterwards and they had brought – Ben used to take pictures – all the time and the other thing he did was make scrapbooks… – anyway there were 19 scrapbooks – one for every year we were married – or 18 ½ or 18 – they brought the scrapbooks and people mulled around and leafed through those - they could find themselves in there " [243-53]. Betty also says, "at the

church they have something we call a columbarium – a wall outside the sanctuary – where you can inter the ashes…Ben is interred there" [239-243].

Betty and Bill and friends have other ceremonies to remember Ben after his death including placing a memorial inside the wall during a remodel of their kitchen. Betty describes, "years ago Ben discovered that fruit stickers were beautiful and some of them are little tiny works of art – or they used to be…Every time he had a piece of fruit he took a sticker and put it on [a piece of] woodwork…so we tore down the piece of woodwork that had RM's fruit stickers on it…[and] we stuck it in the wall [during the remodeling] and put a copy of the eulogy and one of Ben's friends… had one of those pictures of Ben wearing one of those bouncy Halloween balls [on his head] so we stuck that in the back of the wall – and we had a board we could write a love note to Ben on so all our friends and Bill and I wrote notes to Ben and it's all in the wall there" [292-310]. Betty also describes that on Ben's birthday, "that first year and we all met at [a friends] house and they had a big feed and a birthday cake – they had transferred that [Halloween] picture onto the cake…and they had a little tombstone and they played – da da da da [death march] - [laughter] and it was Ben minus one – you have to know Ben [and his friends] sense of humor" [34-47].

Hardships:

Betty lives with chronic pain and her life, even before Ben's death, appears to be full of hardship. Both Betty and Ben were disabled and Betty shares that, "it was hard to be disabled – it was kind of fun because we were disabled together– Ben always said, We're not worth a damn but maybe together we make one person" [laughter] that was – we had good times [together]" [254-58].

Betty talks about her financial status after Ben's death saying, Betty describes that "my income is half – which is very difficult" [208]. She later explains, " I don't know how any of it works – we were both on social security disability – because we both worked - and because I made more than Ben my disability [payment] was slightly more – I can't remember how much more now but it wasn't much…my income is my social security" [126-30]. She continues, "and we were getting food stamps – and we were getting - I think $160 or $170 - and after Ben died it was $10 – I have no clue to what changed the regulations - but I had half the money and $10 [pause] [132-34]. She continues, "and I have to say – because Ben died on the 23rd – and didn't live an entire month – I had to send back all his – sent back his check… And that was cheap [voice cracked] [long pause] and so I couldn't pay for him to be cremated or buried –Ben's sister paid for the cremation and his brother paid for the columbarium [place of internment] [pause] and they [Social Security] give you like something like $200 or something towards…[burial]"[135-45]. She says, "it and it isn't easy – it never was easy for us – we never had any bills other than medical bills" [156-57] and "so financially it is hard [pause] [177].

Betty says, "I think the hardest thing I had to do was tell Bill that Ben had died" [362]. Betty later adds, "and I must say since Ben died Bill has grown up a lot…and it makes me sad that Ben hasn't seen this" [27-29]. Betty says, "I know I did not take care of Bill the way he needed when Ben died [pause]" [11-12] and "I could not really [pause] give him [Bill] what he needed and I don't know what he needed" [30-31]. My interpretation of this statement is that this Betty was not able to help Bill with his grief because she was dealing with her own grief and what sounded like depression.

Betty describes other things that were hard after Ben's death including the impact of Ben's death on their extended family when she says, "It [Ben's death] has been very very hard

on all of us" (See section on extended family). Betty describes, "making decisions was hard – not that I'm not used to making decisions… but I didn't care" [353-355]. Betty says, "it's a funny thing too – because it's almost – I'm not really afraid of much anymore …because it's like the worst thing that could have happened to me has already happened" [296-98].

Loneliness:

When asked how Ben's death has affected the family Betty speaks first about how Ben's death affected her saying, "Well it's lonesome" [150] and she later adds, "For me it's just lonely and it's not a hole that anyone else can fill – cause its Ben's space" [174-75]. She continues saying, "For a short while afterwards I was mad – I was angry – you're [Ben] supposed to be here …,But Ben and I were – when we got married I was 38 and he was 35 – we had never been married and so I felt alone [174176-78}. In Betty's individual interview she elaborates when she says while crying, "all we had was each other" [88] and "we had a grand life" [410] "but he should have had longer to enjoy it" [412].

When discussing her relationship with Ben and his death at such a young age (54 years old) Betty says, "For me I would have felt the same if he was 84 [years old] but – we only had 19 years and that's not enough. We used to say, "We must have done something right – we got each other." [pause] We had a good marriage … I was **loved** [emphasis on loved] – which is remarkable if you look around nowadays…Who would have thunk it bud? [directed to Bill]? Not me" [656-68].

Grief:

When asked how she thinks of Ben's death Betty says, "for a long time I couldn't think about anything else. I would replay it over and over and over in my mind until I thought I was going to go cookoo and I don't know why I did that – it was the worst possible thing that could

happen to me [tears] [451-54]. Later, when discussing how neighbors helped with the day to day chores at the house, she says, "I just wasn't there, I wasn't there" [615-16]. She later says, "I was pretty desperate" [703].

Betty describes that Bill has "a lot of trouble expressing any kind of emotion" [37-38] but she hopes that Bill's exposure to the weekly group of friends has been helpful to him and his grief. Betty says, "But he [Bill] has heard me – me – our group of friends especially – Ben has been talked about and we have all shared grief and our anger and whatever" [364-66]. She continues, "And I hope that at least being around me and our friends and hearing us talk – and sometimes contributing - that that has helped [Bill deal with Ben's death]" [33-34]. Betty speaks about how Ben's death has impacted Bill when she says, "I don't think you [Bill] feel as protected since Ben is gone – you have gotten a little more anxious about security – and making sure doors are locked" [163-65].

Betty adds, "everyone grieves differently – that's what I told Bill – cause you once said you [Bill] were worried that you don't cry – everyone is all different - I blub [cry] at commercials – you know that"[721-23]. Bill describes remembering Ben when he went to a local coffee shop that he and Ben used to frequent saying, "One time I went up there [coffee shop] with my friend and I don't know what it was but someone came to the door… I heard something that sounded just like what Ben would say but it was … it was a guy…[I] almost called him Ben…It was a student – it was the right hairstyle - I felt very uncomfortable that the was when we left- I kind of teared – just one tear – and I must have been thinking about Ben a lot at that time" [195-203].

Betty describes an experience she has after Ben's death saying , "it wasn't very long after Ben died –it appeared one night – I was thinking I should follow him…thank goodness it scared

me – and I called Dr [name] right away - cause it was so matter – it – it was so matter of fact – there was no hysteria about it – it was so matter of fact…and Dr C said, "I don't think for a minute that you are suicidal" – but you need to talk with somebody and you need to get somebody besides me – and you can call any time of day … and that was huge" [429-38]. Betty continues, "and [Doctor name] said who else do you have and I said I have friends but I can't tell them – and he said, "how about you priest?" and I said that's a good idea and I called [name] and he said you can call me anytime… and he said you know my home number – and anytime any day just call – and that never happened again" [439-44]. Betty finishes saying, "It took me a long time to make up my mind to decide to live –not that I had decided to die - I just didn't care – and now I do care" [444-46].

Family relationships/"Extended Family"

Betty says, "I was just thinking today how blessed Bill and I are to have each other – and I think we get along pretty well" [166-67]. Betty adds, "sometimes Bill has a little bit of trouble sharing his feelings – he has heard me talk – no that's not what I want to say – Bill expresses his feelings differently than I do and that's okay" [357-59]. Bill clarifies saying, "I ramble - Not as bad as I used to – but I ramble a lot" [360].

Betty describes the "extended family" she and Bill have when she says, "we have an extended family … a couple of friends who are also alone – everyone is wounded in our group [laughter] [166-69]. She continues, "It [Ben's death] has been very very hard on all of us – he was like a brother to [name] – every Friday we try to have dinner and a movie" [169-71]. Betty emphasizes the importance of this extended family and their weekly get togethers when she says, "It's very important - I don't know what I would have done without them – pause – they were there for everything – and it was important for each of us to realize that everyone was

carrying grief for different reasons [pause] and we all kind of grieved together [pause] At first it was hard having them here again – at least it was for me – but after the first week I knew it was right – I can't do without them" [389-84]. She adds later, "Yes everyone is grieving in different ways – none of us is perfect but…[pause] - yea Ben's death was a blow – I think more than – I honestly think Ben's death was the biggest blow to [this group of friends]" [648-50].

Grief Group:

Betty describes how helpful her attendance at a weekly grief group about one year after Ben's death was and says, "when this was first mentioned to me – it was I don't do groups – I just don't - but I thought I'll go and oh my God… it was like wonderful – it was wonderful" [518-21]. She elaborates, "we were so different from each other – and different experiences with what happened - mothers – friends - children – some were angry – **angry** – we were all angry some were … I don't know how… somehow we banded together – men and women and it was a huge start for me on the road [recovery]" [673-82]. She explains, "It was something I didn't think [would be helpful]… I kind of went out of desperation" [690-93]. She explains her attendance because it was recommended by the hospice bereavement coordinator saying, "I know her from church" [694]. When asked if she would have attended had she received a phone call or heard about it from someone else she says, "well if it was someone from hospice who had been helping me look after my person for months – than probably…I don't know – probably not knowing me I probably would not have gone…but again I was pretty desperate" [669-703].

Meaning:

When asked if she had made sense of Ben's death Betty says, "well there is no sense to that – not to me anyway and I don't think it's because I'm angry or bitter – but [his life] wasn't complete yet…so I don't think I will ever find any meaning…I find meaning and sense in his life

[but not his death]" [185- 193] Later Betty says, "there is no sense to it – it just happened" [417] and I've come to terms with it maybe – he is dead" [435] … "but no – there is no sense in it" [449].

Betty shares Ben's history of mental illness, saying," when Ben fought his way out of this [mental illness] he decided to be for something – not against something – and what he was for was kindness – and he was kind [tears and voice cracking][404-06]. She continues, "so we had a grand life [tears] and he fought so hard… but he should have had longer to enjoy it [tears]" [410-12].

Family Interactions with EMS, medical and nursing staff:

Betty and Bill talk about the paramedics coming to the house when Betty says to Bill, "You helped with Ben… I remember you [Bill] standing over there by the bathroom" [758-59]. Bill says "Yea I was watching them and the dogs…" [760]. Betty describes, "the paramedics and the guys from the fire department - the dog was trying to protect Ben and [the dog] didn't want those guys over there…And he [dog] is very friendly but he would stand between them and I said we have to get Rory [dog] out of there and the one fireman – [name] said "No you leave him alone - he is fine – my mother raises Cairn Terriers – he won't hurt us … and he [dog] just stood in the middle and just watched everything - bless his little heart [761-769].

Betty talks about the ICU nurses saying, "I was fortunate to be surrounded by strong nurses in the cardiac unit" [94] and "I was surrounded by strong women and that was a blessing I will never forget – cause [Doctor]loved my husband – so that was wonderful and Dr [cardiac surgeon] – I love that little guy – if anything goes wrong with me I want him to take care of it – he is a human being and that meant more to me than anything" [114-18]. [I thought about

adding more about MD's and family presence at code – decided not to do this since this was the only family who was actually present at the code].

Appendix I

Detailed Narrative Summary F003

Background: this interview is with Janet and her daughter Kim. Janet's brother Dick, who is Kim's uncle, dies suddenly at age 54. Janet and Dick are siblings and coworkers who also participate in many outdoor activities together. Here is their story:

Not a Routine day …

Janet describes that Dick, "had been receiving treatment for high blood pressure – and he was on a medication for that…he went to his doctor for a checkup and during that checkup his doctor said - Hum I am hearing a heart mummer that I haven't heard before and your BP seems to be staying elevated even though we have you on this blood pressure medication – so why don't we change your blood pressure medication and put you on something that's a bit more aggressive" [14-22]. She continues, " So they made that change - Dick started taking the new medication for his blood pressure and – it wasn't agreeing with him – it was making him kind of tired and thirsty…Dick did have some concerns about the heart murmur and the doctor didn't give him a whole of information on that other than …- Come back in and we are going to do a [echo]… and he did have the echo done – and he hadn't had the total results on that – umm – about a week before his death he was at work and busy painting walls and working on the ceiling – and he came off the ladder just looking very pale and he was coughing" [21-33]. Dick's coworkers say, "we think you need to go home – we think you may be catching a cold - – you know – you don't need to stay down here and make yourself more ill – and so we sent him home – and he came to work again a couple of days later and [Dick says] Yea you know my throat is still bothering me and I'm tired and maybe it will go away umm – it didn't go away and it got worse" [35-40]. Janet takes Dick to the doctor again who tells him the "echo didn't really show

him anything unusual – and he explained to him with a diagram where the heart murmur is…this BP medication is too much for you – and it's really dropping your blood pressure down- so lets take you completely off that – we will give you 5 days and see how things go and then we will do something else and in the meantime – golly – drink and drink lots of liquid and eat food that is high in sodium so - to raise your blood pressure back up" [42-49]. Janet takes Dick home and says "Okay - I'll check on you and I don't expect you to come to work for a couple of days "[52 -53]. Janet calls to check on Dick and she says, "he said I'm not much better – I'm still coughing a lot and my throat is still bothering me umm– but hopefully it's going to get better – Yea I'm trying to eat some of my chicken noodle soup - da da da da da … the last time we talked to him was Friday afternoon" [55-58] when Janet asks Dick "do you think you want to go to the doctor - now it is Friday afternoon – the weekend is ahead of us… " [65-66]. Janet says that Dick replies " I think I just need to do what the doctor said you know get my rest – eat my food – it will pass and that was the last time I talked to him" [67-69]. Janet continues, " I came to work on Tuesday - he didn't come to work – he hadn't left a message - and he wasn't responding to phone calls – so that's when I went to his apartment – he didn't answer the door – so I called the apartment manager and he came over and let me in and that's when we found Dick [voice cracks] [69-74].

Janet talks about the cause of death saying, "he actually had a hole in his heart probably the size of the tip of your thumb – he had a weak spot and evidently because it was working so hard with the lowered blood pressure it just wore that spot out… that's why we knew it was very quick, - it was totally painless" [697-705]. Janet adds how helpful it was that" the doctor who did the autopsy [explained] that it [Dick's death] was painless, it was quick – that was helpful… Yea - yea because there is that feeling of - Oh I should have done something – but no – there was

nothing [anyone could have done] I mean this was 30 seconds and over with so" and Kim adds, "there was nothing that could have been done even if we had been sitting right there" [491-92].

Crime scene:

Janet says, "the landlord had notified the police… actually the policeman when he came – because once the landlord and I went into the apartment and saw Dick - on the couch – then we went back outside and pretty much almost immediately it seemed like immediately the policeman was there and he kept us outside and he didn't want us inside at all – and so basically the landlord and I were just standing out on the landing [95-103]. Janet continues, " I made [some] phone calls umm – and then he – the policeman had called the coroner – and then the coroner came and introduced himself and got the details of the relationship – and he was way more comforting and easier to deal with than the police officer – the police officer – I don't know maybe he hadn't dealt with a lot of death – he [policeman] was very like – okay you need to be out of here – and then he was very – the landlord already explained who I was – but then he [policeman] was asking all the same questions "Well who are you and what is your relationship? And why are you here? and I found that very offensive umm – and it was just the tone and the manner that he used – umm he was doing his job but I felt he could have done it in a softer way I guess– (see TM on crime scene) and I found the coroner was very good – and he said - Now I am going to go in now and - can I get you anything? – and you know by this time the apartment manager had left and so I basically was just sitting in my car until other people like [Name] and [Name] could get there" [104-120].

Notifying people:

Janet describes notifying family members when she says, "Well I think I probably called Kim first… and so of course I called her and I said **Dick's dead** – which was like – how do I

even bother - begin to explain that - and of course she was in [name of town] at the time [laughter]– and I think she told me what to do – [chuckle] – but I called [minister at church] next – unfortunately he wasn't available – so I called [assistant minister at church] and she was available and she said … I'm on my way" [77-88]. Kim says, "I called [Name of friend]" [91]. Janet continues, "And then when they were removing the body - [Name] was here by then and so we just waited downstairs – Dick had a second floor apartment – and we were downstairs in the parking lot [pause]" [134-36].

Shock:

Janet says, "And just kind of - I – I would classify my state as being in shock – not – not being able to totally understand what was going on and in my mind it was – it was just like all the details just kept going – like what about this and what about that – and then it was like wait a minute– what am I going to do without Dick?" [137-41]. Janet explains a very big and important meeting was about to begin the next week at their work place when she says, "so in between trying to figure out what to do with the immediate death and taking care of all that – the shock of losing him – there was also this layer of – **He can't be dead** he's supposed to be doing all this stuff for me [laughter]" [145-49].

Service:

Janet and Kim talk about the service as Janet says, "Yea – yea - I was very pleased with that … I know [Name of the ministers] gave some good input as to the flow of the service - I think just my experience of having been at the church – I knew of a couple of things that I definitely wanted for Dick [voice cracking] and fortunately they all fit together and made a pretty nice service – you know with the bell choir – a couple of hymns that I knew were important [270-81]. Kim adds, "Lots of people wanted to be involved with it [the service] so it

made it very easy – there were lots of people got pictures and flowers and cleaned up the fountain – it just all came together – they just pitched in and did – so it wasn't even with much direction on our part… they wanted to be involved - the bell choir asked to play – the food was just taken care of afterwards…and you didn't have to worry about anything. People just stepped up and did it" [282-292]. Janet confirms saying, "that made it really nice" [293] and Kim adds "very easy" [294]. Janet emphasizes again how helpful people were in relation to the service when she says, "you know we talked about earlier the way people stepped up – with pictures and flowers - and to take care of this – and the reception [after the service] the whole service was taken care of … " [511-14].

Changes:

Dick's death leads to changes, as Janet explains, "cause Dick was the one [person I did] all of those sorts of outdoorsey things…Dick was the one I did those with - so I miss that [voice cracking & tears]" [200-03]. She continues, "I did not go skiing last winter [chuckle] – Dick was my downhill ski buddy … well I didn't go to the horse races – because that was his activity that we did together – we did not take our trip that we planned to [name of city] – I didn't float the river last year [voice cracking]" [193 -200]. Kim adds, "You have started doing more of those things again …Last year was hard – with it just being so new the - He died at the beginning of summer and those were things you would have done [together] [208-11]. Janet continues, "Kim has been pretty good about taking me on hikes [since] Dick wasn't much of a hiker" [203-04].

One death/multiple losses:

Janet describes the impact of Dick's death when she says, "so yea the business of working with Dick and losing him – made a very big impact in the sense that – it was - you know - you are losing a sibling – you lost a social person that you did social activities with – and then

you are losing a **very** important co-worker…So that was leaving a big void – so all those things added up together made it really hard for me umm – to know - How do I handle this? – What do I do? - What am I feeling? – so I won't describe it as a roller coaster – although it did have its up and downs – but it's also like a – an orb that kept changing – and sometimes it seemed like everything was fine – but at other times it felt like it was all out of whack again…So yea – in some ways having him as a coworker and somebody that I really depended on umm – that – at times that felt like it was the **biggest loss**"[249-65]. She discusses wondering if she could continue to work at the same place now that Dick was not there saying, "I did struggle probably in the first three months trying to determine if I could even continue to work in the [name of workplace] – cause it was hard to know if that's a natural grieving process to feel like I don't want to be around where the person has been and is not anymore" [242-46]. She clarifies saying, "that's why I said being at [work] at one point was like [big sigh] this [grief] is just too much because I can't get away from it"328-30].

Grief:

This family discusses talking to each other about Dick's death. Janet says, "Kim and I had our trip up to [name of town] [after Dick's death] - which was a good trip and so – and that was nice to do that" and Kim adds "that was right after [Dick's death] – that was a couple of weeks after [Dick's death" [214]. Janet also shares that Kim experiences a "double whammy" [358] of grief when she explains, "within 6 weeks [time] Kim is watching her best friend grieve the loss of their teenage son"[357-58] in addition to watching Janet grieve Dick's death. Janet and Kim talk together during their "Saturday mornings coffee walks and many of those times were spent talking about that [grief] - So how is [Name of Kim 's friend] doing with the loss of her son – and this is how I'm feeling about what I've experienced – I think we did a lot of those

talks when we were up in [name of town they visited four weeks after Dick's death] – we did a lot of that - so I think it's - its been good to have somebody who has been close to both deaths – and then could – could share some conversations about umm How does that feel? and How do you handle - deal with that?" [359-68]. Janet elaborates about her conversations with Kim saying, "Oh I think Kim did a lot of listening as I rattle about [pause] it wasn't fair – as I raged about the medical profession – as I felt pretty alone with trying to figure out – what now? So yea I did a lot of talking …" [345-53]. Kim says, "I just wanted to help – I was there for my mom [pause] at this – you know – stage in my life with my uncle – we weren't terribly close … so my concern was more for my Mom and her loss and how she was doing and just being available for her" [377-83].

Janet explains that talking with others was also helpful when she says, "oh yes – talking with other people has been extremely helpful …[Name] – almost immediately after the service came to me and said – Whatever we can do – however we can help – let us know - and because I know them and I trust them and I know that things are kept in confidence umm – I did take them up on their offer - umm – actually [Name] and I had three or four sessions – just - in her office just to talk about a lot of things that were going on and then I talked with [Name] a couple of times – more about the spirituality of things – What do you do with all those questions that you carry around? – When you're angry at God or wondering why God lets something like this happen – and so he gave me some – some insights as to how to deal with that – there aren't any answers – there are never any answers [to those questions] And [Name] definitely helped me to - claim my feelings umm – cause with her I could totally just talk about the raw feelings …where with other people – even though it was good to share with other people – but you kind of still had

to be the one to keep it together. So umm I thought that was really helpful – to know that I had somebody that - I could confide in and just be totally honest [pause] [393-414].

Janet shares that talking with some people was not helpful when she says, "the people that I didn't feel that closeness to that - were more or less just wanted to get the gory details and - you were - trying to function and they want to pull you back in [to grief] – it was like: Okay I'm fine – no I don't need to talk about it now – and you didn't feel like there was an honest empathy there – it was more or less to see how bad off the other individual is – you know - I don't know how to describe that – for some reason there are folks that feel like they need to get you into your worst moment and then they will go and tell everybody what a terrible time you are having"]553-62].

When asked how they remember Dick now [14 months after his death] Janet mentions "all the people that knew him… we can have lots of conversations" [312-13]. She adds "it's the people, just being able to tell some of the stories – to share those – to share that loss [voice cracking and crying]" [320-22]. Janet also says, "it's been helpful to have people to talk with … to be able to tell the story … to share those feelings" [540-42]. Janet explains her ability to talk about Dick now as compare to one year ago when she says, "I think it's now more of – we can tell more of the stories and not get so emotional … actually I wouldn't have been able to carry on the conversation – I mean really it would have been like – a year ago if people asked me something - you know – I would try to tell them how I'm feeling or describe how I was feeling – and I would dissolve into tears and then the conversation would be over …" [438-445]. She continues, "I think now it's easier to – to tell the story – to tell Dick's story – to celebrate his the good parts of his life but also to understand that – yea Dick was a complicated individual and he was not always the best person that he could be and you – you learn to accept that …you can

share that more fully with the people who knew that side of him - and you can also be more honest with the people who didn't know that side – to be able to say – you know he wasn't always perfect" [448-57]. Janet says, "now it's easier to talk about that – be more honest about that – but its also easier to talk about Dick and laugh about things – get angry about things – Yea I think its just more of an accepting – it's an accepting of – like Kim said – he didn't always take care of himself – he was attempting to – it takes a long time to repair what has been done over many years so umm" [461-66].

Janet talks about death, specifically sudden death, when she says "and you have to accept the fact that yea we are all going to die – that's not unusual - kind of wish it would happen in a different way and you'd get this two week's notice [laughter] – it's the suddenness of it that's hard" [466-69]. Kim adds, "the suddenness is hard for us the people that are left behind - the suddenness is not hard for him" [470-71] and "left behind is us and- our suffering – oh I wish I could have…" [477-78].

These comments illustrate that bereaved individuals want to talk and share their grief with others – but there is a need for this sharing to occur with people who are empathetic, trustworthy, and able to maintain confidentiality.

Reality of death /living differently:

When asked how Dick's death has affected the family Janet says, "well Kim and I have always been close – we have been through a lot over the years –I think for me - it [Dick's death] has made me much more – [pause] aware of the reality of death umm – the reality of needing to take care of our bodies umm – of – of getting out there and living and enjoying and letting people know how important they are" [155-60]. Kim adds in a quiet voice, "You were always good about that – that's not new" [162-63] and Janet says, "Maybe I say it more – maybe I show

more appreciation – don't take it for granted [pause]. I know I definitely feel that in my work with all the people at the [work place] [pause]" [164-66]. When I mention that most people know this on some level Janet says, "but it takes a death to bring it home [voice cracking] Yea - I mean we all say it … Oh yea - we have all heard it – smell the roses, enjoy life while you can - da da da – but until you actually – you know - have something that hits you that hard – that unexpectedly – and if you don't run away from it but I mean if you really embrace the fact that somebody did die – you live life differently – you relate differently. Umm you know - you don't worry about - Did I get my 40 hours in – you worry about - Did I do something **good?** [pause]" [172-79].

Decision making:

This family discusses decision making as Janet says, "Yea - you know – Kim definitely helped with making decisions… so that has been good to have a family member that is close – that can kind of step in there when you are doing the – huh – you want me to take care of something – I can't make a decision right now" [369-74].

Interactions with Health Care Professionals:

Kim talks about Dick's doctor calling Janet saying, "I think Dick's doctor was – I mean the minute he found out he called – and Mom was a little angry at first with him but he took time - he didn't have to call that day – I think he was very concerned about Mother and the family and he took the time to call – which I thought was nice" [515-19]. Kim says to Janet, "You didn't like that that at the time but I think since then it's passed" [519-20]. Janet responds, "It was annoying at the time – because it was like you saw Dick on Wednesday and within 5 days he's dead – how come you didn't [pause] do something different…" [521-523]. Janet continues saying, "but there wasn't anything for him to do – I had that conversation with him last October

so - and he felt the same way - it was very interesting to hear it from his side also and know he was shocked and he thought what should I have done? … it was an honest - What did I miss? – you know I'm trained maybe I should have caught something – and sometimes your just not gonna - none of us you know – we have all played that game" [523-34]. Janet agrees with Kim when she says, "as Kim said - you just have to say: There wasn't anything – it was going to happen and you just accept it and you just move on – and it doesn't mean you don't feel some anger and sadness but – you can't go back and change that [voice cracks]" [534-38].

Kim says, "The medical examiner took a long time with us and talked to both of us - he was very helpful he was very empathetic and took all the time we needed - we even had to call him back a couple of times because we didn't understand and he was – he was very helpful - very helpful in determining the date of death umm – I was impressed … the time that he took and the care that he took in explaining [496-503].

Janet speaks about a need for professionals to check in with bereaved families in order to answer questions or provide follow-up when she says, "I think the other part of it is – for the professionals - be they clergy, spiritual, medical, in some ways they need to do a little bit of maybe follow-up to…to - after the shock and the trying to go back to the reality and develop a routine – if there was some time when those folks can be back in touch to say: Okay what are you struggling with now? What questions haven't been answered? What more can we help you with? – I think there was a gap – if you're not aggressive about it – going out and getting some of that – you're always left with no closure – those would be things that I think would be – people who have to deal with those of us who have lost individuals – who have experienced a death – if there was some way to maybe do some follow-up – that would be helpful - and not everybody might want it but I think it would be helpful for those that did" [606-19].

Making Sense/Finding Meaning:

When asked if they were able to make sense of Dick's death Janet says, "Make sense of it – make sense of it in the way of understanding the physical side of what was happening or…? I mean I can understand physically what was going on…the coroners report you know – indicated that he did have clogged arteries - three of the four [coronary arteries] - umm – you look back at lifestyle, dietary habits, our heritage – and you know Yea - all of that can make sense umm - in the sense of – yea - the heart just gave out umm" [416-423]. She continues, "[Can I] make sense of someone dying when they are 50 years old and still had a lot to give? – No – that part doesn't make sense [pause]" [423-25]. Kim adds, "That's probably easier for me – I just think we won't know this side of the grave but there is something that is bigger and meaningful and … so that part of it is easier for me – the physical side is like [pause] – makes me more angry because its - we can prevent or do things – and he didn't do – or take care of himself for many years so… the spiritual side is actually easier for me – to have faith and understand" [426-32].

One point Janet stresses is the importance of providing an accurate picture of the decedent when she says, "I think that happens with a lot of people - when someone dies and umm - they get caught up in making them out to be this bigger than life - better than life – and I never got really caught up in that because I knew he [Dick] had the evil side also"[457-60]. She continues, "I think now it's easier to – to tell the story – to tell Dick's story – to celebrate his the good parts of his life but also to understand that – yea Dick was a complicated individual and he was not always the best person that he could be and you – you learn to accept that …you can share that more fully with the people who knew that side of him - and you can also be more honest with the people who didn't know that side – to be able to say – you know he wasn't always perfect" [448-57]. Janet says, "now it's easier to talk about that – be more honest about

that – but its also easier to talk about Dick and laugh about things – get angry about things – Yea I think its just more of an accepting – it's an accepting of – like Kim said – he didn't always take care of himself – he was attempting to – it takes a long time to repair what has been done over many years so umm" [461-66].

Appendix I

Detailed Narrative Summary F004

Background: This interview is with two sisters, Debbie (age 56) and Connie (age 60). Their brother Brad dies suddenly of a heart attack at age 54. Brad and Debbie are twins and live in the same town while Connie lives out of state. Here is their story.

Routine day until:

Debbie describes getting a phone call from her son at work saying, "I was at lunch cause I take late lunches – and umm – I just happened to be sleeping in my car that lunch time – and umm my supervisor came down and checked my car – saw me and told me – about it [the phone call] [43-45]. Debbie describes her actions saying, "and so I took off and went to the hospital and um – recognized him- you know" [43-46]. When she arrives at the hospital she says, "no he had already passed - yea he was declared – when was he declared? –Umm - I think technically they declared him there [at the scene] but because they were paramedics or EMT's- and they couldn't so they just declared him at the hospital" [84-87]. She tells the hospital staff, "oh I think he was a donor – and even if he wasn't I donated him – you know I'm a – I believe in donors – and umm - so I said whatever you can use – go for it you know" [47-49]. Brad has a heart attack while driving and Debbie describes, "okay what I can imagine is umm he had a heart attack and he was either slowing down already – but he had a major heart attack, died and his car went off into – drifted – went over the sidewalk and into the… grass area before the parking lot" [73-78]. She elaborates, "so did they do CPR and stuff?– I don't think so" [89] and "I couldn't quite understand this – [pause] but it took the paramedics - the ambulance or whoever - like 18 minutes to get there" [92-93]. Connie reminds Debbie, "They [EMS responders] could have been miles away and gotten there in record time for all we know" [100-01]. Debbie comments

that she did not think much about this saying, "No – I never - after the first initial – geeze how come it took so long – I never put a second thought into it – truthfully" [106-7].

Notifying family:

Debbie explains "Actually [pause] the coroner called the house here and my son [name] was there…because he was a senior in high school and he was home for whatever reason and - umm – …[name of son] called work and told work [about the call from the coroner]" [115-120]. Debbie phones her sister saying, "I left a message to call me immediately" [55]. Connie remembers "you left a message and I knew something was wrong – I could tell by your voice" [56-57]. Debbie describes that Connie "called the house first and umm – and [name of son] answered the phone and you said – Your mom called - What's up? – Because [name of son] told me this distinctively – [Aunt Connie] called and said - What's up? And umm he said - Well I'll let Mom tell you. And you told him – "[Name] you either tell me now or I'm going to come through this phone and rip your throat out" [laughter] [125-30]. Debbie continues, "and um and so [son's name] told you" [131]. Connie says, "I don't remember [her nephew] telling me – I really don't" [132]. Connie goes on to share that "but isn't it funny – I don't remember the actual - anybody actually telling me [that her brother died]– I remember you [Debbie] explaining to me [pause] the scenario – but I don't remember getting the actual news" [159-61]. Connie and her husband make travel arrangements and arrive in Montana within 24 hours of Brad's death.

Service:

Initially Debbie and Connie plan a service saying "we are expecting maybe 5 people to show up" [268-9]. Debbie describes, "yea we had a wake at [name] funeral – and umm – [Connie] and I put it on – we set it up and put it on ourselves – the pastor, my pastor couldn't do it cause he was going to be out of town, and umm I didn't feel it was right for someone who

didn't know him and stuff – so I asked my pastor – I said you know - Do you had to be an ordained minister? And he said No – I said okay – so [Connie] and I set up the service" [407-12]. Connie describes that when she arrives in Montana "a couple of [Brad's] friends had asked to meet me – and we got together at one of the little restaurants there – and umm" [414-15] and "one of them asked do you mind if we say something [about Brad at the service]?" [428-29]. Connie says, "after speaking to these kids and hearing what they were saying about [Brad] – Debbie and I decided that…so we decided that - you know – [Brad] had this humongous [pause] extended family that really liked and respected him – and we passed the word on – that anybody that wanted to get up and say something at his wake was more than welcome to" [421-39].

Much to their surprise Debbie says, "there were a lot of people at his funeral" [242] and Connie adds, "a lot of people that he helped and guided and supported" [243]. They describe, "we thought the room that they gave us – we thought it was way too big – we were like don't you have anything smaller – we are expecting…you know - the few people that we saw the first day – the place was **packed**" [267-270]. They describe an eclectic group of people at the service saying, "I mean people from work, college students, umm musicians, umm I mean…bar people…[from name of bar]" [272-4] and "most of these [people at the service] were college students in their I would say past their teens - but in their early twenties" [252-53].

At the service Debbie and Connie learn that their brother has been a mentor to many people saying, "yea he mentored them [college students] – umm lousy marks or failing – and he helped them umm - kids that didn't want to go home again that he talked into going home – umm money that he didn't have that he put out to help buy books – I mean the list of stuff that these people – these young people were just telling us in conversation and the **respect** that they had for him – …the fact that – wow he was a really, really nice guy and he helped me turn my

life around or he helped me get through school or he helped me understand why" [258-266]. Connie goes on to say, "afterwards [Debbie] and I were surprised by how many people he helped – I don't know about you [Debbie] but he never said anything about this to me" [283-284] and Debbie says, "No me neither" [285]. Connie continues, "so that's why we were so totally – **Holy Mackerel** – cause he – he just turned his life completely, completely around" [286-87].

Connie elaborates saying, "I mean kid after kid – adult after adult – got up and said something[at the service] – his boss from work and talked about how kind he was to the people there – to the elderly – umm one of the things that really impressed me at the ceremony – there was a young man there – who played the – the viola – … and this gentleman asked if he could play his viola" [444-449]. She continues, "This was – this was **incredible** – this young man got up…– I would say this was his ceremony – his tribute to [Brad] – he got up and he said this is to mourn [Brad] and he played this **beautiful beautiful** – oh he played Amazing Grace … I mean broke the whole place up … it was gorgeous - when he was done with that he said and this is to celebrate [Brad's] life – and he played this Irish jig" [451-459]. Debbie adds, "Oh it was awesome… I [have] goose bumps just thinking about it" [460-62].

Debbie and Connie share stories of other ceremonies that took place including a wake which occurs at a local bar, and a Native American "passing on ceremony" [470-71] which included the burning of sage. Connie says, "Because when they had the wake there [name of bar] – the distributors of this place **donated** the beer" [309-310] and Debbie adds, "lots of beer" [311]. Connie continues, "I mean they brought stuff in [beer] and when they started getting low – **they brought more in**" [312-13]. Connie concludes by saying, "and that says a lot about a person - because I'm in construction and your vendors don't give stuff away [laughter] they **don't** give stuff away" [315-16] and someone "told us the distributors were – were giving it

[beer] – but somebody liked him [Brad] and respected him enough to do that and that's unusual" [321-22].

The large number of people at the service provides new information about their brother to Connie and Debbie. Connie says, "and we found out he did **a lot** for **a lot of people**" [240-41]. Connie describes learning that her brother has changed from a "materialistic [person] to a very very simple simple living man – that reached out to **a lot** of people – that I think surprised us – I know it surprised the hell out of us" [229-31]. Connie later says, "it was such an incredible change in [Brad]" [539].

Impact of death:

In spite of not always knowing where there brother was at different times in his life, both sisters describe missing their brother. Connie says, " I feel as if we were close [pause] in one way – I think he knew me very well – I think I knew him very well – it was the type of thing where you could pick up the phone anytime and continue the conversation" [199-201]. She adds, "I miss his calls on my birthday, Christmas, I miss his teasing – I feel really bad for my sister because she lost her twin – she was more involved in his life in his – in his end years – Umm – I miss him – I do even though he and I weren't in touch as much as [Debbie] and I were - I really miss him – I miss knowing he is out there" [203-08].

Grief:

This family was very matter of fact about Brad's death. When asked if they talk about Brad's death as a family Connie says, "at first we did – but we never really dwelled or talked about the - the end" [646]. Debbie adds, "I don't think there is really a need – you know – and I think…in our family – we take death as a part of life … and so its tragic when it happens and we miss him terribly umm – but you know – [pause] … umm – you know it's like – for lack of

better words – is no big deal you know - its just part of life" [651-656]. Connie adds, "and there is no sense picking apart what happened and how it happened – it happened" [658-59]. Connie adds "but you talk about the person" [661] and Debbie includes, "now we deal with the loss and going on with the rest of our lives without that person" [671-72]. Debbie theorizes, "it was his turn [to die]" [109] and "I look back at this [Brad's death] and its not … as far as I'm concerned when its your turn – when God says - Okay – your out of here boy or girl – that's it no matter what you do or who you have around you"[698-702] and Connie says, 'exactly' [703]. Debbie emphasizes this again when she says, "you know – when it's your turn – it's your turn – it doesn't matter" [722]. Connie adds, "I think that – umm – [pause] he did what the Lord wanted him to do – umm – when he had done all that he could do for those people that he helped – he was done" [730-32].

Regrets:

Debbie expresses regret when she talks about dealing with her anger related to Brad "not taking care of himself after – umm the initial wake up call [hospital visit when his cardiac disease was diagnosed] I guess is a good way to put it" [674-75]. Connie says, "as for not taking care of things after his wake up call – most men don't – if they don't have a woman behind them pushing them – go to the doctor – take your pills you know" [689-91]. Connie continues, "most men on their own – umm … because most men think they are pretty well invincible" [691-92]. Debbie says, "I went with him – I went to the hospital and brought him back home and brought him back for his check up and stuff… cause I asked him – well how are you doing? – how are you feeling? have you seen the doctor?" [709-14]. Debbie continues saying that Brad told her, "No they cleared me" [714]. Debbie goes on saying, "so once in awhile I get this – you know I

never even did that [ask again about his heart disease] but it's not this heavy you know… its just a flash in the pan periodically but its not just something that bothers me per say" [715-20]

Debbie, [Brad's twin] expresses regret and sadness about her brother and their incest experience as children saying, "and I feel bad that **he was never** released from it [incest experience]" [749] and "I always felt saddened for him – and I still do – that umm – he never broke that chain – he never broke that cycle [of incest]" [753-54]. She continues, "I'm saddened – the legacy – … I think about with [Brad] he never – he never got healthy – he never got over it – so that's a sadness I carry for [Brad]" [768-774].

Meaning:

Connie says, "I was – I was – the whole wake – the **whole wake** experience impressed me" [516-17]. She continues, "the whole – the whole think is – was just the biggest surprise of my life I think – and – and I was so **proud** of my brother by the time we were done – you know I started out angry with him – you know he disappeared - …so to see [pause] what became of his life and the kind of person he became and the respect and the - the people that were willing to get up and talk and go out of their way – at his wake really – really made me very proud of my brother" [519-528]. In her personal interview Debbie shares her "dual feelings" [85] in relation to her twin brother saying, "it bothered me that I did not feel his death because of us being twins" [46-47] and "brother [Brad] and I were close and everything but because of the – the background crap [incest] I had a hard time letting him hug me still" [87-89]. Learning that her brother mentored others changed her thinking in that, "his whole life wasn't – you know – wasted… [knowing] that he did touch peoples lives for good' [112-114].

Meaning for this family comes from the fact that their brother, unbeknownst to them had "help[ed] a lot of people" [735] and "he just turned his life completely, completely around" [286-7].

Appendix I

Detailed Narrative Summary F005

Background: this interview is with Alice (age 53) and her daughter Irene (age 23) - decedent Jim was husband to Alice and step-father to Irene. Alice and Jim work together in a counseling practice and live on a small farm in rural Montana. Irene has recently graduated from college and is living and working out of state on the East Coast. Alice also has two sons, older brothers of Irene, who live in another country. Alice and Jim have been married for three years. Jim dies suddenly at age 54. It is important to note that the interview took place on the one year anniversary of Jim's death – I asked several times if the interview should be scheduled on another day – however both Alice and Irene felt like doing the interview on the anniversary of the death was an important way to honor Jim. Here is their story:

Routine day until:

Alice says, "Well we were just outside working all day on a Sunday and - we always worked together you know - we worked in our practice together and then we came here and worked together on our farm together because we had all these visions of what we wanted to do we here and were renovating and taking down old buildings and…" [25-30]. Alice goes on to say that Jim "he did **so many** things that day - it was just remarkable and he was really happy and vibrant and it was real sunny out - and it was chilly – and I was busy, busy, busy" [41-43]. Alice explains, "we were kind of like ships passing in the night all day long and I would go check him out and he would come and say "Hey look at this" and he was goofy and laughing and being just really silly you know all day and being really happy" [48-52]. They worked outside all day and "it was getting kinda late and we were hungry and so [Alice] made chicken soup" [53-4]. While Alice was working in the kitchen Jim received a call from his daughter who "was really upset

because her favorite uncle had died - that day - of cancer and she was really distraught and her mother [Jim's ex-wife] was having chest pain – and he [Jim] was telling [his daughter] – you need to tell you mother to go back to the hospital and have the tests done cause she could – she could have a heart attack" [65-70]. Alice describes that Jim "was **so upset** about the uncle that died - because he had know him – and he said I'm going to take a bath" [71-2]. Alice describes that she was "finishing up the soup and he came out and he ate soup with me and we talked a little bit about it - and then I was sitting up reading - we didn't really talk a lot about it – which was really unusual" [78-81].

Alice and Jim did some reading and then "talked a little bit and we went to sleep and then it was probably 9:30 or 10:00 o'clock or something" [89-91]. Alice awoke when she "heard [Jim] moaning in the middle of the night" [91-92]. Alice asked Jim, "are you okay" [97] and then says "he got up and he said he felt really sick and he started literally like running through the house – like just sort of all over the place in the house and - he went from room to room" [97-100]. Jim "said he felt really sick to his stomach and had diarrhea - and then he ran out – he went outside and walked around a little bit" [102-4]. Alice gets up to find Jim in the living room. She asks what is going on and recalls that "somewhere along the line he said -maybe I need to go to the Emergency Room" and maybe you should call [his doctor]" [111-13]. Alice asks what's wrong and Jim says he felt "really nauseated and I'm throwing up and I have diarrhea" [115-6] to which Alice responds "Well you probably just have the flu" [116-17]. Alice says that Jim "was having a hard time breathing" [122] and because Jim has a history of "bad allergies" [120] Alice asks, "do you need your inhaler?" [122-3]. Jim uses his inhaler and then tells Alice that "his chest burned – he said that - and that's what made me think he needed the inhaler and that his asthma was acting up" [126-28].

Jim then "sat down on the couch" [130] and "he had his eyes closed and he was just sitting there talking with me and I asked if he needed a rag - you know - a cold rag – did he need anything? – did he need to be covered up?" [130-133]. Alice goes on to say "I don't think he ever opened his eyes and I touched him and I was so shocked because he was so cold" [133-35]. His cold skin, "just absolutely - shocked [Alice] - and he was really sweaty" [137]. Jim says he needs to lay down on the floor and Alice asks, "**Why**?" [139]. Alice goes on to say, "and he laid down on the floor and he rolled over to his side and he turned gray and he was dead" [139-40]. After a long pause Alice goes on to say, "and it all happened - you know - probably in 15 minutes from the time I heard him groaning – moaning in his sleep" [141-2]. She adds, "I just couldn't believe it – I couldn't believe that somebody could die that fast" [152-53]. She adds, "it seemed like he died from the time he was sitting on the couch and he sat on the – he went on the floor and he was dead" [155-7]…"and it was a second" [159]…"from being alive to being dead" [161]. She adds, "but then I have read later – you know - since that - that he was probably dying through the whole 15 minutes and I just didn't know it" [161-63].

Alice says that she "started doing CPR" [142-43] and "got on the phone with 911 and they were trying to help me –cause I knew how to do CPR – I had taken a class but I had never done it on a real person – you know" [143-45]. Alice stays on the phone with 911 and "kept holding him trying to talk to him and do CPR" [148-49]. Alice says, "it must have taken like 15 minutes for the ambulance to get here – it just seemed like it was forever" [150-1].

Blaming:

A large part of Alice's story involves blaming herself for Jim's death. She

says, “I of course blamed myself like **completely** because I thought he told me to take him to the Emergency Room and when I took him to the Emergency Room and they pronounced him dead they said – “You know had you gotten him here – he still would have – he would have died …he would have died on the way…” [163-69]. The ER staff says, “And we would have to work him up – we wouldn’t have know what was wrong any more than you did – you know - it was logical to think he had the flu” [171-73]. Alice says, “ but I just felt – I felt **horrible** – like “Oh my God…he was trying to tell me – but he didn’t – he didn’t tell me – he didn’t have any - I don’t know that he had any classic – you know - he had no arm pain that he said anything about – no neck pain -no – no chest pain - he talked about the burning in his chest…but – but I thought - like I said he always had this asthma thing” [175-83].

Alice comes back to this later in the interview when she says, “cause I kept saying to everybody - if I’d just been a nurse I could have saved him” [1885-86]. She goes on to add that, “when I met Jim it was like this—I could see that he was sick - there was something wrong with him [1894-5]” and Irene adds, “And then she was trying to heal him all the time” [1899]. Alice explains this further when she says, “I did everything really natural with my food – and - there wasn’t anybody there who came to me - like a friend or somebody or a kid that needed something – that I couldn’t figure out how to help them” [1889-92]. The self blaming comes out again when she says, “the hardest part for me was believing that I should have gotten it some how – I should have known what was wrong with him - and saved him – cause that’s what I do - is save people” [1063-66]. Alice continues blaming herself when she says, “and I blamed myself in lieu of blaming him and then realized - you're not a medical doctor – and you didn’t have any experience with anyone in your life that had ever been ill of this kind of thing…” [1708-11].

Some people suggest to Alice that Jim was to blame and they say to her, "how stupid could he have been? …he was a smart man – what was his problem that he couldn't go to an appropriate doctor" [1679-82]. Alice responds "and I thought **how dare you** – he did go to the doctor" [1683] "he didn't understand that his chest pain was different than his asthma pain cause he probably had pain - all of his life - I think that he might have - and then he couldn't delineate" [1692-4]. She adds, "[Jim] was not a medical doctor" [1708]

Alice also blames others when she says, ""he was going to the doctor - you know and telling him that he was having these weird symptoms but they didn't—they didn't contribute it" [1674-76] "to a possible heart condition" [1678]. Alice goes on to say, "I just found myself being outraged – absolutely outraged – with the medical profession and with the lack of care that my husband got because he was going to doctors and he was telling them - I'm having this pain and then I was absolutely **horrified** that I didn't get protected by God and I really believed - in some unconscious way I think - that God really would protect you - if you did good work" [393-9].

Alice's blaming herself for Jim's death has changed over the year. She says, "just a week ago - I was telling my best friend and then I realized that [pause] that it was bad enough to have lost my husband - it was enough punishment - if I had to be punished for something - and I thought—and the worst possible thing I could do on top of that was blame myself" [1928-34]. She adds, "because it was obviously out of my hands - if had known anything different – I would have done something" [1936-7]. She also says, "so - now it all makes sense – now [one year since Jim's death] I can put it all together - but not then" [1708-1714].

Notifying family:

Irene describes receiving the phone call from her mother saying, "and Mom called me at – I think it was 4:30 in the morning [name of city] time – Eastern time and told me and I got on the plane at 8am…and I was here by like 1 or 3 [the next afternoon]" [198-202]. Alice places a phone call to her sons in the Middle East, saying "I called them when I came home from the hospital and talked to my sons – and they were both like totally in shock – you know" [221-2]. Alice says, "I remember talking with [Name] my oldest son and he said: **"What?"** – I just remember him saying "**What"** – he said 'I thought maybe the – the cat died or something' - you know - cause he couldn't understand why I would call in the middle of the night" [225-28]. Alice also says, "then I called Jim's daughter who he had talked to earlier that day" [237-8]. Alice elaborates, "I talked to her [Jim's daughter] and of course she was devastated and just in shock and she called her brother and - you know - they came out within a few days and then I must have called his sister…" [268-71]. Irene explains that family members start arriving saying, "I think they [Jim's children] got here two days after [272] and "My brothers got here – like the day after that or the night of the same day" [274-5]. She adds, "But we all had to wait - for everybody to get here" [277]. Alice calls Jim's sister, and his uncle and aunt "because they were really close" [286].

Service

Family members arrived for the funeral, which took place 4 days after Jim's death. Irene describes, "like all the family members that were gonna be here were here already" [755-6] and she goes on to say, "it was really awkward with his [Jim's] children because we're not close with them but they loved their father dearly…[758-9] and "they were both grief stricken and shocked and they wouldn't give – were just awkward with us – they didn't treat us like family" [767-9].

She continues, “so it just felt really weird because all the sudden it was like - it was their father and we were these weird outsiders or something” [773-775].

Irene goes on to talk about the funeral saying, “We got to the funeral home and there were people piling out – you couldn’t even fit in there” [784-]. She talks about the speakers saying, “people got up and spoke about him and they read poetry and here was music and singing and there was lots of crying and here’s also laughing and – my brothers both spoke and my mom spoke” [790-3]. Later in the interview she adds, “People said that they were—they’ve never been more touched and more like - I don’t know - it was so weird - it’s like they came to the funeral and they didn’t expect it to be the way it was - it was highly – it was almost motivating - cause I think—my brother spoke and my mom spoke - and [Jim’s] daughter spoke - and they all spoke about how much they loved [Jim] and - how their lives had been changed and - how it’s so important to live – and to love the people that you’re with - and to tell them all the time and show them how much you love them - because we spend so much time worrying about stupid things” [859-68].

Irene describes, “we brought the dogs in [to the service] … we brought the horses to the graveyard” [793-95] and “we sang a Hebrew hymn at the gravesite” [798-99]. Alice elaborates on the horses explaining, “The horses were there at the cemetery—[we] put [Jim’s] saddle on his favorite mare - and we put his boots on backward like they did in the Civil War days I think – and it was like really umm [pause] really beautiful too” [802-806]. She then talks about Jim’s gravesite, which she had just discovered two weeks prior to his death. She explains, “I went to try to find a gravesite for my mom who is very old and has dementia really badly and has for five years or so…I’ve been putting off doing her funeral plans and so I went out to the graveyard one day – and I told [Jim] I’m going to go up there and try to get this done because I’ve been putting

it off – do you want to come with me? And he said - I think I'm going to stay home - which again was highly unusual for him" [807-17]. She continues, "I found these two gravesites…that were just remarkably in this beautiful little spot and they were the only two left and they over looked the Bitterroot River" [818-821]. She continues, "I called [Jim] from the gravesite…and I said…**you've got** to see these gravesites - they are so beautiful - I said - I could die today with you and I would be just perfectly happy – and [Jim] started laughing at me and he goes - there you again with your morbid obsession with death – and he goes - buy 'em - I don't care if you go ahead a buy 'em – and I said - well, you ought to see them first don't you think? - and I said I really want you to come up here – and [Jim] said well – okay - he said - but you ought to just go ahead and get them if you think they're that great - I was like – no – no - I think you should see them …and [Jim] was cracking up and we were all making jokes about this stuff - and then I went home and again told him about it [826-41]. Alice says next, "And then two weeks later I was up there burying him" [843]. Alice goes on to explain other peoples reactions when she says, "Everybody was saying: "**How did you find these gravesites? It is so beautiful up here**." There are no places - you know - when you look at most of the cemetery it's dry - ugly and bare - and there's like one headstone after the other and this place was like a little alcove you know" [848-52].

Impact of Jim's death on the family:

When asked how Jim's death has impacted the family Irene says, "that's a very big question" [317]. My analysis of this family's story reveals that Jim's death greatly impacted this family and their story delineates the impact in three ways: first the impact on Alice's children, then the impact on Alice herself; and finally the impact on the community where Alice and Jim live and work.

Impact of Jim's death on her children:

Alice answers my question about the impact of Jim's death on the family by first talking about the impact of his death on her children. After a pause she says, "he was like a really good person [crying and voice cracking] …[pause]…he had a lot of **really good** impact on my family [tears and voice cracking]" [324-327]. After another long pause Alice goes on to share the story of how she and Jim met saying, "From the first time I met him I thought my sons would love him and that he would love them – and they were - are grown up men – you know – my oldest was probably 25 when I met Jim and my middle son was like 21 and Irene would have been 19 - and I just had this like – you know - just kind of stunning like awareness that he was just such an - unusual person and he had so much in common with them" [330-6]. Irene immediately adds that Jim and her mom also had a lot in common when she says, "and with **you too** – [Jim had] so much in common with you as well" [337]. Alice goes on to further explain that when she first met Jim, "I just remember stunningly remembering – you know thinking after listening to him talk about various things – they were very unusual things - that my sons would be like –you know- I just thought they would love him - and I knew that you [Irene] would get along with him and really like him too [350-54]. Alice adds, ""I just felt like it was umm – he was just a Godsend of a person" [383-4].

This comes up again in the interview when Alice says, "I look at my kids and I'm worried about them – I think I am worried about my oldest son – because I think that my sons really needed a man – like that they could depend upon – and then he was somebody they really looked up to and somebody who was consistent – and always loving – like he was just **loving -** like **really** supportive" [560-565]. Alice adds, "and I worry about –

them not having had that long - enough or something" [567-8]. After a pause she adds, "it just concerns me for him [her youngest son]" [570] "cause I know he really misses him" [572]. Alice adds, "but then - it's astounding how much somebody can change your [tears and voice cracking] so much about your life just in a really brief…[time period]" [574-6]. Here Alice is referring to the short time period that Jim and Alice knew each other, as they were married for just three years, after an 8 month courtship.

Impact of Jim's death on Alice herself:

Next Alice addresses the impact of Jim's death in relation to what her children witnessed in her reaction. She says, "– I think that my kids have watched me be – probably really hard on myself and **really** umm - kind of caustic you know - as I move through this [last year since Jim's death]" [383-87]. She adds, "and it's been so – overwhelming [391]. Alice adds, "I think that it's been – I have been really confrontive with - perhaps with my family and Irene adds with emphasis, **"Perhaps?"** [497]. Alice continues, "Well - it - perhaps with my family" [498]. Alice describes, "I was just caustic - you know - and so I know my kids saw that" [413] and "I think that – it's been hard on everybody because they really loved Jim and they really loved - being - around him and having him in our lives - and they didn't like what it was doing to me - and you know what I was putting myself through" [415-19] "or what they thought I was putting myself through - cause I don't know that it was really – it didn't feel like it was anything I could control" [421-3].

One month after Jim's death one of Alice's sons gets married and the family is all together for this wedding. Irene describes, "and it was like the most horrible experience ever" [589]. Irene goes on to explain, "I was there watching mom and she was like a zombie – we were like – it was like walking through [name of city] - like – the

walking dead – it was **awful**" [592-4]. Alice adds, "I remember crying walking through the streets…and I was just stunned by how many millions of people it looked like were walking around - but my husband wasn't there – he was dead" [595-602].

Alice talks about Jim's death being "horrific" when she says, "I was absolutely **horrified** that I didn't get protected by God and I really believed - in some unconscious way I think - that God really would protect you – if you did good work" [393-9]. Alice describes that she and Jim, "did really hard work" [401] and "I know we helped a lot of people" [403] and "and I realized it didn't mean anything – it was – it didn't mean anything about protection – it didn't mean that God was going to somehow intervene and protect my husband or me - and I was absolutely pissed off" [409-12]. Alice continues, "I **honestly** must have unconsciously believed that if I did this really - if I had some work to do in my life that really **mattered** - that I would somehow be - [pause] safe – it would be like a reason that I would be here" [428-33]. Alice goes on and says, "and then when I found out that that didn't matter – that's what – that's what was so devastating to me – you know – because I realized you could be so very good - obviously – and be absolutely **slammed –** you know **--** cause I feel like I lost my **life** [442-48]. She then adds, "and- it was just – it was **horrific** - you know - to lose him …[462]. Alice continues, "And you don't think that you are going to just **die** – it doesn't really come to your mind [545-46] and for him to die was **just not** in the picture – it just **absolutely blew me** …just completely knocked me down" [554-57].

Impact of Jim's death on the community:

Alice also describes that Jim's death has make an impact on the community in which they live. She says, "it was **horrific…**" [462] "and for the community I think to lose him" [462-63]. Alice talks more about this when she describes how busy they were

at their joint counseling practice in a small Montana town when she says, “”because everyone knew [Jim died]” [1605] and “we were seeing half the town [as clients] - and I’m not kidding” [1607]. Alice describes the challenges of living and working with her husband in their private practice in a small town when she says, “I was such an open book for the first few months after my husband died - even in [name of town] - and it was so bizarre because everybody knew - and because it was such a public funeral – you know - and I let everybody—I mean I didn’t keep it closed because of his therapy clients and because of mine and – and I thought - how can I do this? Like should I keep it closed like they teach you in school to keep your life completely private - or do I somehow become totally honest - and be this genuine person trying to provide—you know - I’ve never done this before [1212-21]. She finally comes to realize, “ how can I be a therapist if I’m going to be a fake? – like how do I fake my way through this one? - and I decided that I can’t do that” [1223-5] and adds “I never could before and I can’t do it about something this important” [1227-28].

Grief:

Alice compares her professional knowledge as a counselor with her personal experience when she says, “I thought I knew a lot about grief and loss cause I’m a therapist for God’s sakes and I’ve been helping people with this stuff forever…but I just didn’t have a clue…and I was **absolutely -** clueless - and I feel almost - I feel really **humbled** by the realization of how little I actually knew [about grief]” [617-24].

Irene adds that “people would say the weirdest things” [606] to her mother about death and grieving. Alice explains that the religious leaders in the Middle Eastern country where her sons live would tell her, “that anybody who died is really thrilled to die and that no one who dies

ever wants to come back and that Jim has to be very, very happy" [609-11]. Her response to these comments was, "**I doubt that**" [611. Alice tells the religious leaders, "I have a **really hard time believing that** – you know - that he would just instantly – as soon as he died be **so thrilled** to die – and I've read all that stuff you know…but it **doesn't suffice**" [613-17]. Alice tells the religious leaders "You don't **know anything** if you haven't been through this you have **no idea** – and if your wife died tomorrow- you know - maybe your religion would help you but **I truly doubt it** – and if – if you're hit and you have a family and your husband or your wife just dies in front of you – you're going to feel differently- I guarantee it" [626-31]. Alice adds, "But I just thought – **How dare you? - How patronizing**. How like - you know – that I am supposed instantaneously just be over this and it hadn't even been a month?" [632-4].

Alice describes. "I felt for a very long time **really** isolated with it [grief] – you know – and I think that at this point[one year since Jim's death] that I'm just getting more - where I just - have worked my way through enough of it and read enough - and I have enjoyed my own company enough to where—and thank God I have a few really close friends who I can tell this all to - so I don't feel like I lose my mind" [1321-26].

Alice expresses that "it's so hard to put [her experiences] into words – I feel like this whole experience [grief] has been **so hard** to put into – to have language suffice for it" [498-500]. Alice acknowledges that she realizes a few months after Jim's death that "I was going to be very careful about who I talk to deeply about this experience - because some people **just didn't understand at all** – like - that you would still be grieving after four months" [1229-31] and "I don't share with the people anymore unless I **really know** them very well and trust them because - I don't believe that very many people have their depth of understanding to get it…to

understand that you can really love somebody and that it can absolutely be—the loss is un—is un—there are no words to describe - what the loss has been like for me" [1260-66].

Now that one year that has passed since Jim's death Alice says, "And I feel like I am finally coming out of it [grief] - but – I think it's – in the long run - [pause] you know the only thing that I am really sure of is that I know that Jim left us all better than when he found us and that –and that – you know that what his death has shown me is what is really important" [511-17].

Living life differently:

Alice explains that she is now a different/changed person. She says, "the result has been that I feel like now - I'm [pause] really not the same person – the things that I used to think were important I realize are not important – and the things I used to worry about or complain about - I wish I could take back every complaint that I ever had…And every worry - you know – I mean silly worries like…you know like actual trivial things that seemed to matter and none of that matters anymore" [469-79]. Later Alice adds, "I think something else like - that for sure that I do now - because like every time I get really—into some dark place—I just try to remember that - he had so much confidence in me - it was just amazing - and I really feel like I got something from that that I can't lose" [1027-31]. She elaborates, " We [Jim and Alice] used to talk about – about you know – if you have just the faith and the mustard seed - you can move mountains - that was also very - one of those things that always made me wonder what he really meant and now of course I know exactly what he meant – and he did it all the time" [1047-51].

Alice discusses what she tried to convey about what's important when at Jim's funeral, "I feel like the world conspires - to make you believe that all this mundane and material stuff is

really important - or life and death - or critical or something - but it isn't - that is absolutely the conspiracy" [1356-59]. She adds, "I really got some incredible - fulfillment from my relationship with my husband – and that – that it hasn't gone away - and that it's still there - I don't feel like I have to like - replace him or I have to do something - to be okay …thinking I'm really okay because I had that experience of being really loved and really appreciated – appropriately" [1380–86].

Irene also addresses living differently in her individual interview when she says, "I know I'm thankful – I'm definitely thankful for the time I had [with Jim] and I've – I mean I've just grown up so much from it – the experience and I just have **so much more** … this whole feeling on what's really important in life" [22--25]. She continues saying, "and those things that just seem so important just aren't important anymore…like I feel like I have more of a look into [pause] the importance of really loving people… and showing that you love people – and that you really, really care [pause] I thing that's number one – I really do now" [231-240].

Changes:

Alice says that Jim's death has changed her work, "its really changed my work with people – and I don't think I – I think I was always fairly – I mean I know I was always very up front with people in therapy but I – but now I just - there are certain things I just can't tolerate in terms of my work – and I just only take certain people [chuckle] because I can't – I can't like - I even told the kids "I can't filter" – like if somebody – if you – like if somebody is super obnoxious – not clients – but people – I'm just like - I just can't be around it - you know [481-89]

Regrets:

Alice says, "And I regret [pause] so much work – you know – so much

consumption with work [530-538]. She then adds, “And with us working here [on the farm] and with trying to accomplish certain things cause - but then I think that’s ridiculous to regret it – because - what else do you do when you’re having a life? – you do everything that you think you want to do” [540-43]. She clarifies, “And you don’t think that you are going to just **die** – it doesn’t really come to your mind” [545-46] and for him to die was **just not** in the picture” [554].

Appendix I

Detailed Narrative Summary F006

Background: This interview is with Marie (age 55) and her two children Karen (age 25) and Jack (age 22) – decedent Ron was the husband of Marie and father to Karen and Jack and he died one year and 8 months ago. Marie and Ron live on a 5000 acre dry-land wheat farm 20 miles south of town and both Karen and Jack are college students. Ron dies suddenly at age 54. Here is their story:

Routine day until…

Marie says "well it was Wednesday night" [22-23] and I went to a meeting and by the time I returned home Ron had cooked a pizza and was watching TV. Ron has spent the day picking rock on the farm and ice fishing. After getting home, Marie, a school teacher, works on the computer getting a test together. Ron was in the extra bedroom watching a movie. They have a new puppy - Max - and Ron was up several times during the night checking on Max. Marie hears Ron get up in the morning for some antacids and she does not wake him before leaving for work.

Marie calls the house but Ron does not answer the phone and she "thought it was kind of strange that he hadn't called all day" [49]. She arrives home and sees Ron's truck in the driveway, "I came in the yard and his pick-up was there and I thought - Oh good, he is here" [50-51]. When she enters the house she notices, "that everything was just how I left it" [53]. Then she notices the door to the bedroom still closed and she "thought something is really wrong" [61]. Ron was on the floor and she tries to wake him "and then I knew" [66-67]. Marie says that the autopsy showed that Ron "didn't really have a heart attack; his heart defibrillized - it just

went out of sync – so they said that he probably just felt like he was fainting and you know - probably didn't have any pain. It was just – boom"[255-58].

"I just need somebody here"

Marie calls 911 immediately and asks them to send someone to her house – saying "You have to send somebody. You have to send somebody…you know, **I just need somebody here**" [69-79]. 911 calls several of the surrounding ranches to find a neighbor to go to Marie's house. It takes 30 minutes before a neighbor arrives and 45 minutes before the ambulance arrives.

Marie is alone in the house with her deceased husband for a long time and her only human contact is via phone first with 911 - then 911 connects her to a physician located at the hospital in town. This physician stays on the phone with Marie until the ambulance arrives at the house. The sheriff/coroner arrives at the same time as the ambulance. Being a rural area Marie personally knows all the emergency responders – all the ambulance personnel and the sheriff/coroner.

Marie says that the physician tells her what to do, "she told me to sit down – I can remember this – I sat in that chair – cause I was looking out the window and I could feel myself going like: "Someone has to come – someone has to come - some one has to help me – please Dear Lord" – and then the physician said, "Sit down – sit down – are you sitting down? - and now I want you to breathe deeply – I want three deep breaths now" [1919-24]. Marie also says that the physician then said, "Now go back in" and … "these are the things I want you to do" – and you know she wanted me to check for a pulse and do this and – and then Marie said "Okay" [1928-30]. The physician also talks with the neighbor and wants the neighbor "to go back in - and check on Ron" [1934-35]. Marie says that the physician was "on the phone – she had to be

on the phone for half an hour or 45 minutes - cause she talked to me and then she talked to the neighbor and she didn't hang up till the ambulance came – umm [1936-38].

I wonder if rural Emergency Medical Responders routinely connect a health care professional like a physician to the scene when the 911 response would be prolonged due to the volunteer nature of the EMS system in a rural area.

It is important to note that this story does not convey any sense of the house being considered a crime scene by the sheriff/coroner as other families have described. Is this due to the rural nature of this community? i.e. - everyone knows everyone – or the personal nature of knowing the sheriff/coroner who responded to the house along with the ambulance personnel?

Decisions:

This family has to make many decisions, some immediately and others later on. Marie describes that once EMS arrived one of the ambulance personnel took her and sat her down and said, "you know Ron] is gone and [pause] we're going to have to start making some decisions" [151-53].

One of Marie's first decisions was related to who should call Karen (then age 24) and Jack (then age 21), who were away at different colleges. Marie wants someone else to call the children but ambulance personnel said, "**You have to tell them** [about their dad's death] on the phone" [116-7] and Marie "thought – you know - like somebody else should say it – and the ambulance personnel said, "**No, you need to say it**" [pause] **and that was hard** [voice cracking] [119-20]. Marie explains the impact of having to tell someone a family member has died, "When you have to tell somebody—I think maybe that's the reason the ambulance personnel were making me say it—that's when the reality hits you - so like when you had to tell someone - even

if in your mind you think you're processing it until you have to tell somebody and share it - **Whoa! - that's a hard, hard thing**" [1468-72].

Another decision Marie has to make quickly is if she wants an autopsy done. Marie describes, "And then they umm – then they asked if we wanted to have an autopsy - and I said yes [voice in a whisper] - that you know – we wanted to know what happened umm – and the [name] - he [coroner] was happy because nobody knew what – you know what had happened" [172-5].

As a married couple Marie and Ron have always made decisions together and his death changes this. Marie says, "the hard part, though, is you always made every decision together" [430-431].

Also related to decisions Marie says that, "lots of people said, "Don't do anything for a year - hang in there for a year and don't make any big decisions," which was **excellent** advice" [327-29].

Changes:

Ron's death causes this family to experience many changes. Marie says, "Everything stopped and [pause] and everything changed – **a lot**" [267]. Karen says "nothing's been the same since" [269] [her dad's death].

The biggest change is just how the farm runs:

"Marie says, that Ron "was a good farmer" [500]. Before his death Ron had planted the wheat therefore the family had to make decisions immediately about keeping the farm, selling the farm, harvesting the crop, etc… As Jack said, "we all kind of had to change what our plan were and kinda – all of us kind of had to get back here – we had a lot to think about because we had the crop seeded and we had to figure out plans for the summer and working" [273-76].

The family plan always was that after Jack's graduation from college he would convert land that was in conservation to active farming and that eventually the whole farm would be slowly turned over to Jack. Marie describes, "the plan was that as soon as Jack finished school he was coming home…" [340-41] "…when that [land that was in grassland conservation] came out in five years we were going to break that up and Jack was going to start farming that over there"[343-45]… "we had this five year plan- and then slowly turn the farm over to Jack "[349-50]. Marie says, "so that's the biggest change is just how the farm runs…" [335].

The family reports a sense of accomplishment that they are running the farm – although they still second guess some of the decisions/changes they make. Marie says, "I think Ron would probably - shake his head – hilariously – at umm - at how well we've done – I'd think he would be proud of us- but at the same time I could just see him going - oh my God, …oh they are going to wreck everything. But we haven't" [352-57].

Changes in roles:

Many role changes take place as Ron's sudden death leaves a large void in the family. Marie describes, "not only do you lose your father and husband - you lose the income source - so we had to make a lot of decisions right then" [323-25]. And as a result of Ron's sudden death, there is no one in the family with the knowledge of the day to day running of the farm. This role is taken on by Jack, who drops out of college and returns home to farm. One of the first things Jack has to learn is how to run the farm equipment. Marie says, "I mean he'd run the combine a little but he never sprayed - he never seeded – umm - never run the air seeder… " [338-40]. Ron knew the location of every piece of equipment and Jack describes the challenges in assuming this role, "because every time I'm looking for something that I know we have but I don't know where it is - you'll think, oh I'll just run in ask dad real quick - and then you can't really do that" [410-

12]. Marie explains, “Yeah, you can’t ask him how to start something - you can’t ask him what – what was serviced last - you can’t ask him what kind of oil goes in this” [414-16].

Marie talks about Ron’s “big personality” [1026] being “not easy to - umm – to replace” [1026-27]. The loss of this “big personality” not only changes the day to day activities of each family member but also changes holidays and vacations. Jack says, “Holidays have been a lot different too” [597] and Karen elaborates, “We’ve all been kinda trying to make ourselves – you know - take family vacations and do things but it’s – it’s hard because part of you, Jack especially, you want to stay here because this is where you have all your memories and stuff - but then on the other hand it’s really hard to be here because it’s not the same” [611-16].

Ron is described as “the fun one – he had all the toys” [514] and his death leaves the family with out an organizer of family activities, as well as an organizer for the whole rural community. Marie says, “he was a camp director for the whole area down at the lake” [523]. Jack describes all his dad would do, “He made a camp ground that was like private – kinda - where locals would go to stay away from the busy stuff - he put the dock there - he’s always made sure the dock was at the right water level and then mow everything - make sure there was firewood – and he made the fire pits [532-36] . Marie adds, “and picnic tables…he’d empty all the garbage” [532]. Ron’s death has changed this summer routine, “and now that he wasn’t there – nobody—the kids kinda take care of it a little bit - but it’s not the same - that’s totally changed” [551-52].

Ron’s is also described as “the boss” [456-67]. Karen says, “he was the main stability in everybody’s life – like no matter what happened you could always call him and he would tell you what to do - or you knew - if you had a question or anything like that - you always knew that everything was always going to be fine because he always knew what he was doing” [457-62].

Karen relates how even her phone calls to the farm indicate changes in roles when she says, "the big things are when you call here [the farm] and they're stressed out and having trouble because they don't know what to do" [476-78]. With this field or they don't know what to do with that field – and that never used to happen because dad would just take care of it – so that's – you know – there's a lot of new stress that was never there before…" [476-481].

Changes in daily routines:

Marie returns to her teaching job at the school on the Hutterrite Colony in two weeks saying, "it was easier to go back" [387] [to work] by saying if she had stayed at home, "I think I would have gone crazy" [392]. Six months later Marie changes her job – still teaching but now in town, "in a small town - life - or social life revolves around the school" [377-78] and "there's more adults there" [381]. This change relates to changing the pattern set by Ron visiting her at the Hutterrite Colony School, since it was physically located near their farm. This change also reflects a change in Marie's social structure after the sudden death of her husband, in that she recognizes a need to be around more adults.

Both Karen and Jack return to college. Karen returns to graduate school where she focuses on school and returns home to the farm more frequently than usual, "I came back [to the farm] **a lot** - when ever I had a break or anything I always came back here" [306-07]. She did not return to her job – she tried but that was where she got the phone call about her dad's death and she said, "every time the phone rang I was just freaking out kinda- because that's how I got the call so…" [302-04]. Upon graduation Karen returns to Montana, finding a job within 200 miles of the farm. Jack also returns to college – but does not go to class and drops out about 4 weeks later and returns home. He says, "I dropped out and came home when it was time to spray it [the crop] – then I started farming" [288-90].

Karen describes another change, "One of the other big things we had to do is - we redid our living room" [1376-77]. They moved Ron's chair because it was disturbing to see someone else sitting in that chair. Marie describes the following when her brother Paul visits, "I would just come around that corner and he would be sitting there - it's not—there's nothing wrong with sitting there but he **shouldn't** have sat there" [1385-87]. This moving of furniture was described as being helpful, but that, "it was hard at first" [1391] because, "whenever you saw somebody sitting there - you'd just double take - you'd stop" [1393-95].

"We've had lots and lots of help"

Once the community hears that Ron has died, neighbors and family arrive at the farmhouse, "the whole house just filled up" [122] and "our real close friends – they never left- there was somebody here all the time taking care of stuff" [1591-1593]. This help consisted of having food and drinks in the house, Marie says, " you know keeping track of the food - keeping track of the phone calls - people would just—[name] went to umm – town that first day - you know [name] sent paper plates, cups, napkins, food - the food just came and came - they bought—[name] brought juice - he brought Crown Royal - they brought cases of beer umm – pop – I mean it – it never ended" [1593-98].

The family has been able to run the farm due to the generous help of family, neighbors and the community. Marie said, "we've been real lucky and **we've had lots and lots of help** – from everybody" [331-32]. Marie says, "My brother…he came and stayed with us on the farm [393-96] [that first summer after Ron's death] and her brother and another person came every day and "they went through stuff and they straightened out the shop and they reorganized the shop so that – you know - we knew where things were" [397-99]. Jack had run some of the farm equipment but there was a lot of farm equipment he had never used. Marie says, "Jack had to

learn how to run every piece of equipment…" [338]. Jack learns how to run the equipment from friends and farming families living nearby.

Marie, Karen and Jack all comment that help from friends and family and the rural ranching community continues over time. Marie says, "I swear that there isn't a day that goes by that somebody doesn't call or stop in to check" [1083-84].

Reminders:

The farm equipment serves as a reminder of his dad. Jacks describes, "driving the equipment is tough – if you're really busy and you're working you don't think about it but when you're sitting on the sprayer – you have a lot of down time and then you think about being in the same place – doing the same thing" [1296-99] There are frequently little reminders of Ron – Marie says, "some days I'll hear a song—my sister has said that too - that she'll hear a song that will remind her of" Ron [1286-1288]. Both Jack and Karen describe, "then there's a bag of candy sitting there" [1312] or "and I found a bunch of candy wrappers on the floor and I just lost it - because he used to sit in there and eat candy when he watched TV" [1314-16].

People share stories of Ron with the family. Karen says she and her brother both experience people sharing stories about their dad with them, "when ever [Jack] and I go anywhere it seems like somebody pulls us aside and wants to tell us stories about dad" [1045-46]. Karen goes on to explain that this is both good and bad, "part of it is really hard" [1056] and at the same time "It's always nice" [1060].

When talking about the annual 4th of July family celebration with friends Marie says, "but we sure have good memories" [592-3].

Funeral/celebrations/ etc:

Ron was clearly loved and well respected by many people. There were at least four celebrations or ceremonies after his death. There was a funeral and, "there were over 500 at his funeral - it was a big funeral - which is pretty big deal for" [706-07] a small rural town. The attendees at the funeral were a diverse group of people from the community, including, "old people, young people, Hutterites [like Amish], bikers" [772-730].

Ron and Marie had discussed cremation for themselves after Marie's parents died several years earlier. However Ron's mother was against cremation and knowing this, Marie, Karen and Jack together decide to honor Ron's wishes in relation to cremation, but plan the cremation for after the funeral. The initial plan was to spread Ron's ashes over the July 4th holiday at a nearby lake. When the family learns that several of Ron's friends won't be able to attend the celebration at the lake, they revise plans and, "so we went up to the highest point up here at the farm and we just read these poems and we had a barbeque here - it was **really nice** - that was really nice" [1180-82]. They hand out packets of ashes to attendees and repeat this again at the lake over the July 4th holiday.

Some ashes were spread at the hunting camp and many of Ron's friends keep his ashes with them – for example one of Ron's friends has some ashes in his Harley motorcycle.

Ron's mother plans a burial of some of Ron's ashes at a cemetery but Marie says, "grandma wanted to have this burial thing out at the cemetery and I just said, "No, I'm done" [1215-16]. Marie told her mother in law, "I did the funeral - I did the ashes at the farm, I did the ashes at the [lake], I'm done - it's over - I can't do another" [1216-18]. This seems like an important quote – indicating the family can only have so many funerals/celebrations – it also seems that Marie saying no to her mother in law's wishes for a burial was a big step. Saying no to attending a burial of Ron's ashes "was a big thing to say -no, I wasn't going to do it anymore"

[1226]. Marie says, "I don't know if she [Ron's mother] was upset because I wouldn't go or what - I just couldn't - I didn't want to do that - I didn't want to be there - that wasn't the way we planned it - If she wanted to do it – fine" [1220-23].

Change in family relationships: [move to changes above?]

Marie, Karen and Jack and continue to have a close relationship with Ron's parents although Marie did share that initially Ron's mother cried every time she looked at Marie. Marie says, "And that's hard – cause every time I go to grandma and grandpas, Grandma would just cry and cry - I would walk into the door and she'd start crying" [1691-93]. Marie finally had to talk with Ron's mother and say, ""I can't come here any more – you know - because every time I come here - I just can't do this - I can't cry" – [because] then I'll drive by and I won't stop because I'll just think: "God, I can't do this - I can't" [1695-98]. Marie says after this conversation, "it got better - but I did - I had to sit down and talk to her about it because - it was just too hard and then I wouldn't go there [stop and visit with Ron's parents]" [1698-1700].

Grief never goes away –"it's with you everyday"

Marie, Karen, and Jack indicate that they live differently since the death of Ron. Karen says, "your perspective changes a lot" [1279] and Marie said "it seem like we've been through the hardest thing in our life" [1259]. Marie says "I cannot get stressed out anymore … I can get stressed out. I mean I can't [get stressed out]…" [1269-70]. Jack finishes for her, "over little things…" [1271]. Marie says, "it seems like **all the rules are so ridiculous**" [1275].

This family's story indicates that grief never goes away "it's with you everyday" [1492]. Jack indicates thinking "when is everything going to go back to normal" [1855-56] and Marie adds "there is not normal" [1857]. Karen adds that, "I play little games with myself…but you think: Okay - I've done this for this long and now it should go back to

normal…" [1861-1863]. Both Marie and Karen indicate they are trying to get back to normal but Marie says "we're trying- its just not there yet" [1875].

On the same day that Ron dies the family receives a message that close friends experience the birth of a grandson. Marie says, "you know one life ends and another one starts" [853].

Reframing: (? correct term)

This family has a positive outlook on life. Marie says, "it seem like we've been through the hardest thing in our life" [1259]. They express increased knowledge and confidence in managing the farm although they continue to "second guess" some of the decisions concerning the farm. Jack describes his mother as, "you have a tough time making decisions and sticking with them - you're always second-guessing yourself" [433-4]. And Marie agrees saying that she thinks, "What would Ron do? - Would he do it this way? - Would he do it this way? - What should I do? And it's never the same situation." [435-7]. As Marie says, "but we're learning" [452]. And the family indicates that they think Ron would be proud of their ability to run the farm successfully.

Marie indicates that she "has a peace with it [Ron's death]" [1131] and that her "life was better because of it [Ron's life] [1128]. Then in a whisper Marie says, "I've tried to tell the kids you know - it's not fair – it's s not right – but at the same time –we've very, very lucky - extremely lucky – to - you know it's better to have a good dad –you know for a shorter time - then all of these people that are stuck with bad dads for a long time – you know – I mean the best thing would be to have a good dad for a long time but if we can't have a good dad for a long time… - I mean we were lucky – and you just got to tell yourself every day - [pause] - He did a good job for us [tears] I don't know why it happened [tears]" [1031-1041].

I think this is reframing – but this may be based on my personal experience and not what Marie meant.

Young adult reactions to death:

As young adults Karen and Jack have distinctive [don't know if this is the correct word] reactions to the death of their father. Jack, age 20 when his dad dies, says, "I think that's what I tried to do for a while was pretend like nothing happened" [1478-9]. Marie says that Jack took the death hard, "you were kind of rowdy and wild there for a while - right after it happened - a little out of control" [1659-61]. Even as Jack downplays this by saying, "I'm always rowdy" [1662] Marie goes on to say, "I do think that you have had some tough times missing your dad - especially right at the beginning" [1672-73].

Karen agrees, "Yeah, right at the beginning – well - it was tough for anybody" [1674]. She goes on to talk about her friends, saying "you try to go out with your friends and if you have one too many beers you're crying - and your friends are crying and you're all just a big mess" [1675-77]. Jack agrees, saying "I don't like when people do that - when they get drunk and then they start crying on your shoulder and you're like – I can't do this with you all the time – you know" [1679-81].

Jack and Karen's friends also miss Ron. When talking about Jack's best friend Marie says, "He misses dad" [1021]. Karen goes on to say that recently, "Yeah - even now - it's weird - even now I'll get a phone call and one of my friends—like the other day I just got one from my friend crying because he was like: "Oh, I was thinking about your dad" [1022- 24].

Jack and Karen assemble picture boards for the funeral and drive two hours to a large town to get supplies. Karen describes, "and that was nice too just to, Jack and I went by

ourselves just to get away - so we could talk the whole way down and talk the whole way back – and I think making those picture boards [for the funeral] is kind of healing…" [1740-43].

Appendix I

Detailed Narrative Summary F007

Background: This interview is with Diane (age 45) and her daughter Ann (age 25) – decedent Bob was the ex-husband of Diane and father to Ann. It is important to note that Diane and Bob, although divorced, remain friends and maintain frequent contact with each other. Bob dies suddenly at age 49. Here is their story:

Normal day until:

Ann says, "It was a Wednesday" [26] and she talks with Bob that afternoon saying, "he was taking a break at work and he wanted to say hi and see how my day was going – and he sounded great" [990-91]. She describes how later that afternoon her grandmother calls her and tells her that her dad is on his way to the hospital. They think there may have been an accident at the construction site. Ann says, "we thought maybe he had fallen off the scaffold or a tool incident or something" [43-4]. What happened was an un-witnessed arrest as Ann describes, "he just – no one actually saw it but - they found him on the ground maybe just a few minutes after he just fell over and collapsed" [28-30].

Ann arrives at the hospital at about the same time as the ambulance and she says, "they were kinda shocked – you know cause I was there so soon" [48-49] and she is directed to a little room. Additional family members arrive at the hospital and "we all just sat in a room – and prayed" [51]. When Bob is transferred from the Emergency room to the Cardiovascular Laboratory the family receives a pager and is sent to another waiting room on a different floor where they "waited for about 45 minutes and got a page" [54-55]. The family was taken into a room and told, "that he didn't make it" [55-56]. Ann describes, "we were all just kind of in shock" [58].

Saying goodbye:

Ann says that "they took him into another room – just for us to see him" [62] and that the family went in the room to say "our goodbyes" [64]. Ann describes wanting to say goodbye to her dad but being afraid, she says, "Umm, well I wanted to be alone I remember and then as soon as everybody left I got really scared [nervous giggle]" [575-6]. She goes on, "So my sister came back in with me and we stood there for- it was just a few minutes – I didn't really know what to say - Umm, we kind of - you know - touched his head lightly and gave him a kiss and just cried - I just couldn't believe what I was doing" [crying] [578-81].

Decisions:

One of the first decisions the family has to make is about an autopsy. Ann describes that the family members at the hospital "discussed whether or not we wanted to have an autopsy" [64-5]. Ann reports, "mixed feelings" [65] about this decision, but goes on to say, "but we also were very curious because it was so sudden and you know – wanted to know what happened so we decided to do it" [65-67].

All sudden unexplained deaths occurring within 24 hours of admission to a hospital are considered coroner cases. However this family does not remember talking to the coroner. Ann says, "I don't think we ever saw him" [622]. Diana says, "and then it seemed like it took several days before…" [632-33] and Ann continues, "We found out what it was [cause of death] – and that was a hard part" [634]. Ann describes, "I think someone [from the hospital] did tell us that they would call us when they found out [the cause of death] – and I don't think they ever did - we just got his death certificate and it has the cause of death on there" [637-39]. Ann goes on to say, "we were disappointed in that because we kinda lost all communication – with umm the hospital once we left and got home" [641-43]. Ann remembers the hospital staff "did send us a

card - but I don't remember anyone calling" [645]. The family learns the cause of death when they see the death certificate listing "cardiac arrest" [647].

Life goes on around you… but your whole life had stopped:

The first days after the death are described as, "it was all just kind of like a blur" [73] with family and friends gathering at Bob's mother's house. Ann describes that at the house, "we all just kind of sat there and cried" [70-71]. Ann goes on to say, "I really don't remember what we did or anything – I just kinda remember sitting there with everyone around and – it just seemed like life was going on around you but your whole life had just kinda stopped" [530-33]. Diane adds, "Yeah - you wonder why the radio is still playing - and the CD is still going – you know it's like…the world does go on and you don't understand why - and you don't want to be a part of it - at least I didn't" 535-38]. Diane adds that "It was very hard for me to deal with it - I developed a lot of anxiety and panic attacks – and [pause] I still do" [535-40].

Service

A service is planned and Diane describes, "There were so many people at the service that we didn't have room for all the people" [104-5]. Anne describes, "It was a beautiful service - a lady stood up - actually the pastor of the church - and umm - just kind of told the life of my dad umm - she had come to our house and we all sat around the table and talked and told stories and she kinda wrote a story from what she got from us and - so that was nice to hear" [150-4]. There were "tons of family - tons of people" [156] and Anne says, "well – we knew my dad had a lot of friends – it was just great to see them" [205-6] and "it was great to see how many people he touched" [208].

Changes

Changes in the family structure occur after Bob's death. Before Bob died

both Anne and her sister and Bob were living at their grandmothers house. Ann describes, "so we all were just a like a huge family – you know - we would sit down and have dinner every night and eat together - and see each other in the mornings - my dad passed away and my sister moved and I moved out – so we don't see each other as much" [114-118]. With further questioning these changes in the family structure may not be related to Bob's death since Ann's sister moves across the state when her husband "got a job offer that was better…" [122-3]. Ann moves out of her grandmothers house and says, "I moved in with my boyfriend so…" [123-24].

The family describes how hard the change of seasons can be. Diane says, "I don't want the snow to come because it's going to make me think about them" [family members who have died]. When asked if it is the winter season only or every season Diane says, "I think its every season" [682] while Ann adds, "It's fall for me" [683]. As Diane explains, "In the winter there comes the holidays – Thanksgiving – and the birthdays, and Christmas and New Years" [684-5]. The change of seasons is like a marker, a mark of a changing calendar as well as a mark of another season without the presence of a family member. The seasons of fall and winter lead into the holidays, which are often reported to be a difficult time of the year for grieving individuals.

Changes in holidays and birthdays:

Ann describes, "it's a lot different it seems but we don't—or at least myself don't always feel like celebrating or don't look forward to the holidays as much" [128-130]. Diane describes, "his birthday just passed a few months ago - we had a get together for his birthday – his mom got a bunch of balloons and everybody signed the balloons… everybody let them go" [166-71]. She goes on to say, "we tried to keep Bob alive a little

bit in our hearts" [173-4]. Both Diane and Ann describe how hard the Christmas holidays are. Diane says, "I didn't even want Christmas to come"- I just didn't even want anything to do with it" 179-80]. Ann adds, "Yea, I felt the same way - you almost feel guilty for having a good time- or at least I do"[181-2].

Grief never goes away:

When asked if their thinking about Bob's death had changed over the last year Ann says, "I still feel shocked every day" [413]. She goes on to add, So many people say – or they try to tell you that it will get easier with time – and I don't think it does at all" [415-16] and Diane adds, "it hasn't yet anyway" [417].

Diane describes that, "Its hard sometimes, [pause] and it never goes away" [193]. Ann describes that her father's death is, "the first thing I think of when I wake up every day" [419]. She goes on to say, "I guess it's gotten easier in a sense where if you're thinking about it all the time – every day - you know - I don't break down and cry – whereas a year ago - that's all I did - just sit there and cry – so it's kind of gotten easier but at the same time not that much [426-30]. Diane describes that, "you never quit thinking about it" [362]. Ann describes, "Some times I think I should have taken a little more time off of work because sometime I feel like I haven't really taken time to grieve as much as I should of" [565-67]

Young adult grief:

When asked if she is able to share her grief with her peer group Ann says, "I don't think any of my friends - have lost a – a parent - so – its hard" [920-21]. She goes on to say, "Sometimes I don't talk a lot about it – I feel like I bottle it up too much and – sometimes I feel like I didn't take the time to grieve when it first happened – so mainly I just talk about it to - with my family" [923-6].

She also explains that she has all of her dad's possessions including his clothes, work tools and truck, and that they are "they are special – they are kind of almost sacred – and very hard to get rid of" [770-71]. She shares that her boyfriend 'doesn't really understand' when she says, "my boyfriend used one of the tools and he didn't put it right back and that really upset me– and he didn't really understand why - cause I don't want any of it to - be not together and lose any of it" [812-815]. It is my impression that young adults – in their 20's – frequently do not share their grief with their peers.

Feeling cheated:

When asked if they had been able to make sense of or find meaning in relation to Bob's death Ann describes anger and explains that this anger is sometimes directed towards God. She says, "why would you [God] let this happen?...You could have prevented this" [311-13]. She goes on to explain that, "its never anger towards any of us or any family or friends or anyone" [315-6]. Diane says, "it's just – what happened" [317]. Both Diane and Ann describe that, "you feel cheated" [320]. Diane feels that "my kids got cheated – my grandchildren" [322-23]. She emphasizes, "I just feel like my kids – my grandkids were cheated - and so was Bob" [345-46]. She goes on to ask, "how can I be a mom and a dad too? "[336]. Ann says on some days she feels like she can make sense of her dad's death, "but I think deep down I never really will" [358-59].

Guilt:

Bob rarely went to the doctor and Ann says, "he had been to a doctor maybe twice in my life" [213]. Diane says "to get him to go to the doctor was like getting blood out of a turnip" [245-46]. She elaborates, "he had high blood pressure - and he never took medicine for it" [214-15] and they both agree that "We think if he would have went

to a doctor they could of - saved him" [243-4]. This leads Diane to later say, "why couldn't we get Bob to go to the doctor - you kinda feel guilty yourself" [481-82]. This leads Diane to wonder, "maybe if we could have gotten him to go to the doctor" [981-2].

Possibly adding to this guilt is the knowledge that Bob "had a confrontation with a co-worker" [215-6] a few weeks before his death "over this guy's tools" [222]. Ann says, "the guy pushed my dad down - and my dad hit his head on umm - the back of a truck - and hurt his elbow and something else" [223-5]. Bob did see a physician for pain medication and Diane says, "but if we could have just got him in there longer - or got the doctor to do something [like a physical exam] - but we didn't know – so we had no idea" [260-61].

The family wonders if this confrontation had anything to do with his death. Diane says, "Well - he was pushed in the chest so we thought maybe - that push had something to do with his death" [226-7] and Ann adds, "Or maybe the bump on his head " [228]. Diana adds. "maybe something got jarred loose or – or something happened to him with – what do you call it a – [concussion]" [229-32].