

WHO AM I NOW? EXPERIENCES WITH FORMAL GRIEF CARE AMONG
MICHIGAN BABY BOOMERS AFTER SPOUSAL LOSS

By

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ABSTRACT

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This qualitative study used a symbolic interactionist approach to identify, define and explore the experiences of formal bereavement care among 38 Baby Boomers (ages 46-64 at the time of interview) who have suffered spousal loss. This research investigated conceptions of shared culture, language, and meaning among survivors who have taken part in formalized grief care. An emphasis on the experienced reality of bereavement care coupled with the self as an agent of reflective action, are the focus for discussion. As well, there is an exploration of negotiation strategies to address a disrupted narrative and the subsequent reconstruction of individual and social selves following the death of a spouse. Interviews with these individuals investigated meanings surrounding terminal illness; death, bereavement, and support, along with how these meanings are constructed, institutionalized, legitimated and actualized. The research explored why some mourners attrition out of formal grief care earlier than others and explained how these support services aid us in the understanding of bereavement. Findings revealed one overarching key theme among these participant experiences after losing a spouse, namely, *compromised individual and social selves* as evident in an on-going effort to re-construct the past, present and future self. Four other themes emerged and include: 1) the importance of a support group as a *safe haven* to do 'grief work' and re-construct one's wounded self and life narrative; 2) the value of a *shared experience of spousal loss* with other widowed group

members; 3) the *significance of a community* where one's loss is explored; and lastly, 4) *unmet needs* surrounding both pre-loss and post-loss concerns. There was also a noticeable gap with regard to appropriate and effective grief care. This gap was evident between what the current literature recommends and what these five agencies offered in the groups. It was also noted through the participant stories which revealed an ineffective structure of support group care for the widowed, namely, inattention to readjustment stress related to tasks associated with practical needs. This finding, along with other emergent themes, offer insight into vital areas in need of attention by practitioners, the medical community, and the death and grief care industry who provide end of life and bereavement care. This research exposed particular needs for this group of Boomer spouses, such as a desire for improved pre-loss needs (e.g., coordination of care when there is an illness), and post-loss needs (e.g., advice for practical matters, such as financial concerns for themselves). A new model of grief work is put forth (Figure 5.1, Hilliker) that observes the temporal aspects of a disrupted narrative as the bereaved spouses look at who they are now, while re-constructing the past and contemplating the future. They examine the present struggles as well as a future without their spouse as they recreate the now fragmented and compromised self to adopt a new role as a widowed person. Recommendations are given for implementing a more holistic and hope based structure for support groups and include addressing both emotional and readjustment stress by moving away from an emphasis on a 'grief process' in the groups and through extending support group sessions which include topics of interest to the members as opposed to a pre-set agenda. Further research is warranted to determine the most critical concerns of mid-life widowed people in order to provide recommendations for those who offer programs for this type of care, in particular in the support group format.

DEDICATION

This dissertation is dedicated to the participants in this study, the bereaved spouses, who bravely shared their painful stories of loss and formal care with me.

An Irish Blessing in Time of Sorrow...

May you see God's light on the path ahead
When the road you walk is dark.
May you always hear,
Even in your hour of sorrow,
The gentle singing of the lark.
When times are hard- may hardness
Never turn your heart to stone,
May you always remember
when the shadows fall—
You do not walk alone.

-Island Ireland Quotes

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CHAPTER ONE - INTRODUCTION

A person born in the United States in 2010 has an average life expectancy of 77.9 years, which is increasing rapidly as modern medicine and knowledge about health improve and technology advances (Center for Disease Control and Prevention, 2010). For many of us, this longer life expectancy coupled with medical advances contributes to a belief that we can postpone death. This scenario adds to a lack of understanding the life experiences of grief and bereavement since we may have fewer deaths to face over the course of our lifetime. We also now live in a society unlike any other in American history, where the elderly have fewer children (who are often living in different states) to look after them than in previous generations, and one where life expectancy after age 65 is being calculated in decades rather than years (Min DeParle, 1998). As a result, when current age cohorts mature and prematurely experience the loss of parents, spouses and partners, and sometimes even face their own deaths (in particular the U.S. Baby Boomers), there is shock and disbelief. Since Boomers typically have smaller families than generations past and develop distinctive forms of particularly close attachments, their deaths may also create problems for survivors that were not faced in these previous generations (Doka, 2007). Unfortunately, as the Boomers in this study have learned through the untimely deaths of their spouses, not all of us will live into old age, and we could either face our own early deaths or we may become bereaved of those close to us.

Hockey, (In Curren, 2001) indicates that survivors of the death of close others, known as the *bereaved*, face an uncertain world when dealing with loss, one where they are anxious about the management and expression of emotion, along with choosing appropriate memorial services and the right professional for advice. Support systems for bereavement often include informal help from family, friends, and work colleagues and increasingly involve formal support

originating from outside this circle of close confidants. The latter may be associated with professionals and/or volunteers through agencies and organizations in the medical and health fields or other institutions (i.e., religious organizations, hospices, and/or businesses such as funeral homes, etc.). This study set out to explore the experiences of formal bereavement care for a select group of 38 Baby Boomers living in Michigan, who are mourning¹ the loss of their spouse and are all in their second and third year of bereavement. They were recruited through five agencies, namely, a funeral home, two grief support centers, a hospital/hospice, and a church-affiliated organization. In this chapter, I explain the statement of the problem, give the purpose and goals of the study, state the research questions and include the relevant theoretical framework, along with limitations. Lastly, a synopsis of chapters is given.

Statement of the Problem

Spousal loss is a significant and unsettling experience in the life course which has the potential to create a great deal of stress for the surviving spouse and significant others. In part, a conflicting emotional culture along with diverse belief systems and modified family patterns create a void in this area, one where grieving people seek answers to complicated questions. Formalized care for those suffering a significant loss, also known as *bereavement care services*, is one social network available for this population. Unfortunately, there is little attention in the scholarly research to determine whether this type of care is effective, appropriate and sufficient for the needs of those served. So that terms used throughout are well understood, I will first attempt to define common references in formal care services for bereavement.

¹ *Bereavement*, *grief* and *mourning* are used interchangeably in the literature but have completely different meanings. For this study, I prefer Walter's (1999: xv) definition of *bereavement* as "the objective state of having lost someone or something," while *grief* refers to the emotions that accompany bereavement," and *mourning* as "the behavior that social groups expect following bereavement."

Formal bereavement care services and community networks are general terms that include bereavement support which may come from professional networks consisting of healthcare providers and various other professionals (e.g., legal, religious, mortuary, etc.). Those who work directly with the bereaved individuals are people who may be in paid positions or hired and paid through contractual work as consultants, or they may be filling volunteer assignments. Grief care may include personal conversations with bereaved individuals, written information, and offerings of workshops and/or retreats. In addition, formal bereavement *community networks*, broadly defined as “those who may offer anchors of a different nature” (e.g., spiritual, church and community groups/agencies) including support groups and individual counseling services, generally offer emotional support (Lindsey & Yates, 2003:167).

These services are offered in communities through *bereavement care providers*. This reference is used in the field to describe those who organize and facilitate formal support (both for profit and not for profit) to survivors during their bereavement and come face-to-face with the grieving individual. There is a view in the grief care industry that care providers are to offer more expert advice and provide the necessary help to get through tough times (most often through written informational support, such as well-written grief books, etc.). They give various levels of care through one-on-one contact or in support group formats. Providers are those working for any business, organization, or agency (e.g., funeral homes, hospitals, hospice, private counseling centers, churches, etc.) offering direct help for bereavement. The term incorporates those who identify themselves using various titles, both professional and non-professional, such as bereavement or grief counselors, bereavement specialists, grief facilitators, etc., but excludes those who coordinate volunteers for support programs and have no direct

contact with the bereaved. The support programs include open and closed groups where facilitators provide educational information along with direction and support for the group.

In these support groups, there is a good deal of talk about a *grief process* and the importance of doing one's *grief work*. According to Klass, et. al., (1996:200), the *grief process* involves "the processes by which the bereaved move from the equilibria in their inner and social worlds before a death to new equilibria after death." Therefore, in order to move to new state of being, it is viewed that the emotional, psychological, somatic, and spiritual responses that identify grief are part of the very nature of this process. However, earlier studies (e.g., Wambach, 1985/86:201) note from the study of three widow support groups, that the grieving process is a social construct:

The grief process is a social construct which helps to link the grief and the mourning of survivors. While grief focuses within the bereaved on reactions to loss, mourning focuses outside the person on the public expressions of loss. As Kastenbaum pointed out, one can grieve without choosing any public display and one can publicly mourn without feeling any discomfort associated with grief. Yet, we do presume a relation between grief and its public expression. This relation is easier to discern when mourning customs are clearly evident and are routinely followed by social members. In the United States today, such mourning customs are ambiguous. Criticism of funeral practices, for example, has contributed to the "deritualization of grief.

Wambach (1985/86:201) continues to explain that because the grief process is a social invention (created by the bereaved, professionals and popular writers), it 'sets both a public and private course for the bereaved.' She goes on to suggest that this grief process occurs in two types of aid, as a timetable and as a guide, and that the grief process was accepted as an uncontestable fact.

The term 'grief work,' also known as the grief work model or the grief work hypothesis, advocates that one work through the pain associated with grieving. It is understood as "the painful effort required to make real the fact of loss" (Walter 1999:103). Many who use the term

are referring to the emotional pain associated with loss. To do the work, it is assumed that one must express the emotions as they are felt and work through them, as opposed to ignoring them and busying oneself as to distract away from them. As discussed, recent studies in death, dying, and bereavement continue to focus more on *grief work* and the *grief process* and are numerous in the scholarly literature (e.g., Arnold & Gemma, 2008; Brosi, 2006; Oates, 2003).

There is a general lack of research, however, on the topic of *bereavement care services*, with the exception of recent studies specific to symptomology (e.g., Bergman, et.al., 2010), who look at psychological distress and the use of bereavement services); or those explicit to a particular kind of loss (e.g., Wilkinson, et.al., 2007), who examine child bereavement support services; Rich, 2000, who explores post-pregnancy loss services); in precise settings (Roberts & McGilloway, 2008; Fauri, et.al., 2000), or to detailed needs in bereavement (Walsh,-Burke, 2000; Harrison & Harrington, 2001). Studies rarely focus on the experiences of bereaved spouses who use formal care programs and services. One exception is that of Levy & Derby (1992) who compare widowed spouses who join support groups to those who do not, and conclude that those who do join are more ‘psychologically distressed’ than those who do not.² Some of the older studies examine what services are effective for this population (Potocky, 1993) while others evaluate the bereavement program itself that is available for spousal loss (Sabatini, 1988).

In my view, on a substantive level, this is an important time to study the Baby Boomer cohort. A sociological exploration of mid-life spousal loss within the larger context of bereavement care is a timely topic due to the sheer number of aging Boomers alone. This

² Authors point out however, that he spouses in this 1992 study had various reasons for attending the groups. Some were seeking out their own form of grief support while others were not looking for a support group to join, rather, friends, family and professionals recommended the services.

extremely large generation, is often referred to as one that demands more services and knowledge than previous generations. Perhaps, as well, little tolerance of emotional upset from close others coupled with extremely busy lives may even contribute to increasing recommendations of formalized support for those who are bereaved. While the focus is on Boomers, the insights developed here have the potential to help in understanding how formal bereavement care is, and can be, beneficial for other groups of bereaved spouses regardless of age.

I chose to study Boomers in Western culture, in part because they are viewed as people who take a more active role in seeking out their own knowledge of medical and health concerns, including pre-arranging of their own funerals and those of family members (Cromer, 2006). This trend, in part, creates an increase in the demand for support services, including care for grieving individuals. Additionally, due to the medicalization of death and the use of hospice services, there is a response from the professional community to offer formal care and services for survivors. This care may include providing personal and/or group conversations, grief counseling, memorial services, retreats, workshops, and support groups. Bereavement care is offered for all types of death-loss and is administered by professionals, quasi-professionals, and volunteers in an array of programs accessible through institutions and businesses, such as funeral homes, private counselors, hospitals and other agencies (e.g., hospice). This study seeks to understand how this type of care is experienced by those who suffer from a significant loss as the result of the death of a spouse. The study of bereavement care is underrepresented in the scholarly literature and is a timely research endeavor as we anticipate the needs of this enormous aging population, the Baby Boomers. There were nearly 80 million people born in this age

group, between 1946 and 1964 [after World War II] when the birth rates peaked in the United States (Longino, 2005). In this research, the term *Boomers* is also used to identify this group.

Purpose and Goals of the Study

The purpose of this qualitative study is to illuminate the experiences of bereavement care for a select population of survivors who suffer spousal loss. Since the most utilized type of bereavement care of those interviewed is the support group, this task is accomplished by examining the interactions within the membership of the groups offered by these agencies. There is also an exploration of why mourners seek out formal support care, what their experiences of this care means to them, why some attrition out, and includes explaining how these support services aid in the understanding of bereavement. Goals of the study initially included looking at the role of the facilitators and providers of said care, including materials used that may impact the receivers of said care. The interview participants' stories, however, illuminate the importance of support group membership which was the most utilized type of formal care these participants sought out. Regardless, the overall purpose and goal of this study is to help to bridge gaps between those who seek these services with the practitioners who offer them. Through the method of personal interviews, this study aids those who have suffered the death of a spouse by providing an opportunity to tell their story and gain a new perspective regarding their loss and the support they have, both informally and through formalized grief care.

Another goal of this study is to explore the how's and why's related to formal bereavement care and the resultant participation by bereaved people. Questions at the forefront include, how do the survivors make sense of this formalized care? Why do some people attrition out after a certain level of care while others do not? For example, one bereaved spouse may accept informational materials to help with the loss, and be content with that level of support,

never to return for additional help. Another may choose to accept the informational materials along with an invitation to regularly attend support groups and/or individual counseling to explore strategies for coping. Still others may continue on with the organization by volunteering to assist with other groups of bereaved people. Some may opt to join several groups and seek out a grief counselor for individual sessions. By exploring these concerns, insight into bereavement in general terms is another possibility. As a result, a series of research questions are used and administered in personal interviews.

Research Questions

The following research questions are the focal point of interest in this study: 1) What is the experience of formal grief care for bereaved spouses?; 2) Why do some people attrition out after a certain level of formal care and others do not?; and 3) How do various types of formal support services aid our understanding of bereavement?

Rationale, Relevance, and Significance of the Study

The interests in the above research questions stem from the knowledge that while death is a universal occurrence, patterns of grief and mourning are not. They are shaped by belief and value systems which are not homogenous across societies. In the West, grief is recognized as a personal state and grows from a culture that views human life as revered above all other types of life, and honors and nurtures individual experience. Reactions to the loss of life vary between individuals and among cultures, ethnic groups, and by the emotional culture of the times. Most of us will, at some point in our lives, experience the death of a significant other. Whether this loss involves a spouse, domestic partner, parent, child or another close relationship, the fact is that with the passing of this person, our lives change. How we deal with loss has taken many

forms, and how we are helped through our time of grief ranges widely from being left completely alone to being surrounded by informal support and formal care systems and services.

Interdisciplinary studies on the topics of grief and loss are on the rise and sociologists provide noteworthy contributions, as Walter (1999) and others have shown. In particular, researchers recognize the complexity of the experience of losing a spouse. As Schuchter and Zisook (1986:295) note, “spousal bereavement is often the most profoundly disturbing and disruptive event in an individual’s life.” In more recent studies of the widowed, participants are often older widowed people (e.g., Zonnebelt-Smeenge & DeVries, 2003) when widowhood is more expected (age 65+). A larger percentage of women are widowed, and therefore women are more often the subjects in research studies. For these reasons, I attempt here to address gaps surrounding the concerns and issues of formal grief support for a younger set of the widowed, namely, Baby Boomer spouses (ages 46-64 at the time of data collection) and do not limit the population by gender or type of loss.

In addition, a great deal of our behavior and emotional expression in the West occurs as a reaction to social structure and culture. Modernity, as a particular arrangement of social relations and as a social structure, throws people into what Walter (2007) refers to as high relief when faced with misfortune. He suggests that there is a more fragmented social and geographical life of most modern individuals where there is a heightened sense of a need for help. The cultural response to this disorganized network of social contacts involves turning towards a new faith in science, progress and the experts to escape the isolation now felt. Our access to instant communication, such as in online venues, or through news sources, provides new ways for people to network and relate to one another, perhaps creating a new sphere of expertise or knowledge. Walter (2007) argues that the separation of home and work along with urbanization,

mobility, and longevity affect the social context where mourning occurs. This changing landscape, he posits, also produces a desire to find unity with those who have similar experiences, yet also creates ambivalence (as the self is viewed as the authority) about whether the individual is going about doing things in the right way.

The bereaved individuals in this study appear to want to have permission to grieve in their own fashion (self as authority), but also desire the knowledge as to whether they are doing things properly. All of these participants explore recommendations for formal support and seek advice outside of the informal support systems. There are numerous scholarly articles spanning decades on how people attempt to make sense and find meaning when facing a significant death and/or loss (e.g., Riley, 1983; Davis & Nolen-Hoeksema, 2001; Neimeyer, et al., 2008). Various avenues are available to people to undertake this task, however few researchers look at how formal bereavement care is experienced and understood by the bereaved population themselves, and how they make sense of this help.

This lack of research is recognized most recently in a systematic review of the current bereavement intervention literature by Forte, et. al. (2004). The authors advocate concentrating on types of interventions and care for bereaved persons that improve key outcomes and are of value for the bereaved individuals themselves. In my view, in order to accomplish this, the experiences, expectations and needs of the bereaved recipients of said care need to be known and evaluated. This dissertation addresses the formal care for bereaved spouses in an ever changing social landscape where the role of experts is blurry and rapidly shifting.

There is also a recognized gap between the information and programs that the service providers use and the information available and cited in the literature (Bridging Work Group 2005; Center for the Advancement of Health, 2004; Jordan, 2000; and Neimeyer, 2000). As a

result of this disconnect, it is noted that the consequence is a ‘general lack of understanding of grief in the service professions’ (Center for the Advancement of Health, 2004, In Breen and O’Connor, 2007:204). A report by the Bridging Work Group in 2005, for example, discusses how those who provide formal bereavement services prefer to obtain information on grief from popular books, their colleagues and from workshops instead of from publications in scientific journals. It is my hope therefore to disseminate these findings widely as a benefit to both those who provide bereavement care services and to the clients who seek help.

This dissertation approaches these concerns by interviewing those served through bereavement agencies in Michigan. In addition, it presents the types of information, advice, and support that are available both before and after a spousal death. In particular, problematic issues in spousal loss among the Baby Boomers are brought to the forefront in this study as an age cohort, according to Carr (2006) that will produce tens of millions of spousal/partner loss in the coming decades. More so than other generations, members of this cohort are also accustomed to seeking outside help for personal problems and believe “that everything should be fixed and everything can be fixed” (Pine, In Hall & Richter, 1990:S1:1).

This study provides the potential to gain a new understanding of formal bereavement care by interviewing the recipients of these services from five Michigan agencies and reporting results. Prior to this study, no researcher appears to have produced a qualitative report on whether or not we are meeting the expectations for care in bereavement of a younger widowed population (<65 years of age) who are recipients of formal care. Lastly, I believe that I accomplish the goals as set out above, and as the following chapters will attest, there are contributions to sociology (self and identity), thanatology (experiences of bereaved spouses), the sub-discipline of medical sociology (medicalization of grief, sociology of the body) and for

various other professionals (e.g., nurses, social workers, gerontologists, counselors, clergy, etc.) who provide care for the dying and the bereaved.

The significance for sociologists in general lies in the emergent theme of a compromised self for individuals experiencing a sudden life change, one where they need to learn an ascribed role and may find their informal support inadequate. Thanatologists stand to gain a new perspective on the continued importance of exploring the specific needs as brought forth in bereavement care narratives for Baby Boomers who lose a spouse. Discussions within medical sociology on the concept of medicalization, in particular of a normal life experience such as bereavement, will be aided as this study can shed light on the interests related to how grief continues to be constructed within communities of support groups. Additionally, those who study the sociology of the body may find value as it provides a glimpse of the pre-loss needs of caregivers [bodies caring for bodies] in end of life situations when there is a terminal illness. Psychologists, clergy and other professionals who work with clients in end-of-life or bereavement may benefit by hearing about the experiences, needs and preferences of this select group of Boomers. Lastly, identities such as patienthood and personhood are evident in these stories of loss and how they are played out appears to be an important contributing element in adjustment to bereavement. These findings may aid medical sociologists and gerontologists who examine identities, patienthood and personhood; family sociologists who study how people learn and embrace new social roles throughout the life course; and assist professionals, practitioners, and agencies who offer support in palliative and end-of-life care.

Relevant Theoretical Framework: Symbolic Interaction

The above discussion shows the need for a better understanding of meaning constructed within bereavement care for those who have experienced the loss of a significant other. One such

approach is to frame meaning construction through the use of symbolic interaction theory, based on Mead's (1934) core principles of meaning, language and thought. A humanistic orientation is adopted given its creative meaning, free will, rules, and liberation. Interaction gives humans meaning, yet these meanings can change at any moment (free will). There are rules for interpretation of the meaning, language and thought, yet people are free to find their own meaning (liberation). Mead (1934) along with Blumer (1937) argues that meaning is socially constructed by the way we interact with others as well as how we react from a range of agents and factors that influence us. Blumer (1937) first coined the term symbolic interactionism in an article where he explains how active participation in the life of a group influences the social development of an individual (Farganis, 2004). This approach looks at how people experience society and how they shape the reality that they experience.

Symbolic Interactionism (SI) teaches us that the reality people experience is variable and changing. It has its origins in the views of Max Weber, a German sociologist who emphasized understanding a particular setting from the point of view of the people in it. Its' key concepts include symbols, nonverbal communication (such as gestures, facial expressions, postures) and face-to-face interaction. Erving Goffman (1959) popularized a type of interactionist method known as the dramaturgical approach, where people are viewed as theatrical performers. The dramaturgist compares everyday life to the setting of a theater and stage. Just as actors depict a certain image, all of us seek to present particular features of our personalities while we conceal other features. So, in a support group for a bereaved spouse, for example, we may feel the need to project a serious and solemn image, whereas at a family wedding, we may want to look happy and friendly.

Other sociologists, including Homans (1958) and Blau (1964) have developed social-exchange theory which is the idea that interaction is guided by what each person stands to gain and lose from others. And Cooley (1902) whose work increased our understanding of groups of relatively small size, saw face-to-face groups such as families, gangs and friendship networks as the seedbeds of society. He felt that they form people's ideals, beliefs, values and social nature. In his famous concept of the looking-glass self he emphasizes that the self is the product of our social interactions. This self, according to Cooley, results from a person's imagination of how others view him or her. In a support group setting then, it is possible to adopt our self-identity based on incorrect perceptions of how others might see us (or how we might view ourselves) from comments or reactions to stories and expression or non-expression of emotion, for example. This interpretation could lead to either presenting or concealing features of our personality (dramaturgy) to depict a certain image. To explore the interactionist framework for this study, I use an interpretive reflexive analysis as I believe (following Mauthner & Doucet, 2003) that the researcher, their method and the data are not detached entities, rather, they are reflexively interdependent and interconnected.

This use of a symbolic interaction framework builds on the methodological and analytical approaches adopted during the construction of the interview instruments and contextual analyses. It is, in part, based on a critical approach to understanding the bereavement care experiences through interactions as discussed by these subjects. It attempts to get at questions regarding how these bereaved individuals receive, perceive and interpret information and support for their grief that is on offer to them by these agencies before, during and after a significant loss. These issues are important to generate knowledge in bereavement care. While exploring these experiences of care, questions at the forefront of my thoughts include: What social interactions are taking place

with this group of spouses? How do these interactions in a support group setting impact the experience of bereavement? Additionally, what type of knowledge should be created here? And how will it be beneficial in understanding spousal loss and bereavement in general?

Answers to these questions help with examining human communicative behavior from the participants' perspectives. This examination begins with the role of the self and progresses to an exploration of the self in society while facing a life-changing situation, namely the loss of a spouse. Symbolic interaction recognizes an individual's freedom of choice along with external constraints, acknowledging the validity of constraint but also emphasizing the importance of shared meanings. Using this approach enables an examination of the thoughts, feelings and actions of the bereaved so as to gain insight into the delicate relationships these actors have with each other, which includes the relationship with the deceased person. This approach draws from symbolic interaction theory but critics suggest that it typically ignores emotions. A study by Forte, et al. (1996), however, used this angle to examine the topic of grief in assessing and intervening in a bereavement group, and they found it useful. These authors claim that since emotions have their origin in group relations, then vulnerability to poorly adaptive grief is just as much a result of social environment as it is personality. Their pilot study uses Lofland's symbolic interaction theory to assess social workers and how they facilitate grief work with bereaved individuals. By interviewing 20 group members, the data show that shared grief work in a group setting helped the bereaved to compose social networks which then enables them to regain the number and types of connections that they had prior to the loss.

Interpretive Reflexive Analysis

An interpretive reflexive analysis is utilized that entails the shared understanding of what it means to be a widow or widower in a community of bereavement care support at a particular

time in history. The use of this type of analysis is aimed at gaining a deeper understanding of the nature of the bereavement care experience. How do survivors make sense of this type of care? Individually? As a shared meaning? How did the participants find out about the care, distinguish it, describe it, assess it, remember it, make sense of it, and talk about it?

Through the use of this style of analysis as a researcher, I critically reflect on what my biases and blind spots are and why I think the questions I am asking in this study are relevant. Through this reflection there is an openness and ability to hear questions and see challenges to these inquiries that I had not even considered prior to engaging in this study and with the text (e.g., ‘tell me about yourself’ was a much harder challenge than I had expected). It is during the interview that reflexivity required an analytic approach to account for and respect ‘the different meanings brought to the research by researcher and volunteer’ (Parker, 2000:14). The reflexive approach helped me to recognize that constructing is a social development, which is embedded in language and not positioned within one’s head (Steier, 1991). Through the words of these participants and their concerns, the original research questions are challenged and brought into focus.

The data are analyzed through recognition of themes and then by attempting to categorize conceptual issues relating to the substantive content of the research. I focus on answers to my research questions and how these spouses experience, describe and account for bereavement care to provide the thematic analysis. Next, based on reflexive reading of the transcripts and an attempt to understand the meaning of bereavement care in the social context of widowhood, I develop a conceptual framework.

Limitations

Limitations of this research include the study sample of people who are already receiving formal care. Research on the value of support groups for bereavement notes that it is difficult to ascertain accurate views because of the populations sampled, namely those who are self selecting and attending groups (Thuen, 1995; Thuen & Sandvick, 1998; Zonnebelt-Smeenge & DeVries, 2003). Demographic variables also prove limiting as participants are recruited in distinct areas within a large Midwestern state, and values of the Midwest may have influenced the results. Also, racial factors involving bereavement care participants is absent because almost all of those who contacted me to be interviewed self-identified as Caucasian (35/38). There are no special ethnic, racial or socioeconomic groups. The participants were financially secure, in relatively good health (37/38) and perhaps more educated than their peers. As a result, no generalizations of these findings are intended.

Additionally, results must be viewed within the context of other limitations, including sample size, participant recruitment, interview protocol, participant diversity and participant disclosure. The sample size allows for an exploration of relevant themes and aspects of a bereaved spouse's experience of care but because of the number of participants, any generalizations about the larger population of Baby Boomers should be done with caution. The final sample is also biased as it was self-selected (37/38) in that participants who were already attending support groups asked to be in the study. Because of the use of a symbolic interactionist framework, I am concerned more with the interactive and dynamic processes by which the widowed self is formed, and so there are little comparisons within the sample (unless there was an obvious disparity that was brought up by the participants, e.g., such as dating concerns by men with little mention by women).

The interview protocol could be viewed as insufficient as there are factors not included that may have an impact on the experiences of formal care (such as length of marriage, quality of relationship, etc.) which were not addressed. Participant diversity was limited due to the criteria and because of the type of individuals who are receiving support from these agencies. Initially, variation by age, ethnic background, gender, and type of loss (sudden vs. illness) was sought, but again, the limitation existed and was beyond my control. Lastly, participant disclosure may have been censored by a few of these participants due to the nature of the deaths (two suicides) or the nature of the relationship (same two are divorced). Even though I assured them all at the beginning of the interview that all information is confidential, obvious hesitation on some questions and probes due to the sensitive nature of the topic is evident, which shows a concern for complete trust in my ability to obscure their identities. Despite these limitations, the results raise important concerns for those who study spousal bereavement and for those who provide professional care to this population.

Synopsis of Chapters

Following this introductory chapter, which addresses the statement of the problem; purpose and goals of the study; research questions; rationale, relevance and significance of the study; and limitations, Chapter Two provides an overview of selective literature in the fields of selves, identities, negotiations and transformations of selves, small groups, support groups (including bereavement support group formats) and specific support groups for the widowed population. The review was constructed based on the main finding in this study which points to compromised individual and social selves as evident in an on-going struggle to re-construct the self after spousal loss. The selections within the categories echo concepts related to the findings from the data.

Next, after the introduction to Chapter Three, the research design section clarifies why a qualitative methodology was chosen by providing a methodological rationale, and describes the research design and experience where I give the reader specifics ranging from my assumptions to ontology, epistemology and methodology that dictates the paradigm selection, along with my interactions with participants in this study. I then move into the methods for subject recruitment, the sample, including the criteria for sample selection. Following are sections on the interview setting and human subjects protection. I then give more detail on the instruments used for this study. Next, I explain the pilot, the interviews and the confidentiality of collected data. A thorough discussion of the systematic coding system used from ongoing analytic memos during and after data collection, to field notes, tables, and transcription notes is provided. The chapter then moves into the steps used for pre-coding, and first cycle coding, which includes hand coding, development of a codebook, emotion coding and themeing the data. Second cycle coding is discussed and involves pattern and focused coding methods and entry of the data into NVIVO qualitative data software to organize data for analysis. Post-coding is then highlighted, which incorporates the analytic process between coding cycles and write-up.

Chapter Four- A Selective Historical Overview of Literature, Models and Theories in the Discourse of Death, Dying, Grief and Bereavement examines selective articles that were significant in the development of a discourse on grief and bereavement (including in the sub-discipline of the sociology of death). It also highlights grief models and theories over the years. Subsequently, it investigates the sequestering and medicalization of dying, death and grief, as well as specific medicalization of grief through the distinguishing of normal and abnormal categories. Then, an appraisal of contemporary emotional culture is presented along with a look at how meaning construction and narratives are a part of the landscape of bereavement services.

Next, the age cohort under study for this dissertation, the Baby Boomers, is introduced and discussed along with their demands for knowledge and services. Chapter Four then moves into an exploration of the extant literature on spousal loss. To accompany these concerns, there is an exploration of the nature of bereavement care and the most often used types of support provided. This includes personal conversations with professionals and examining support groups.

Chapter Five – Results-2, Suddenly Widowed, begins to report the findings of this dissertation on how Baby Boomer spouses currently define themselves and how they have dealt with some of the struggles related to their new social role. This entails listing the demographics of the population studied along with examining sociological concepts of the definition of self, narrative re-construction and reporting of experience. Insights are shared on how these spouses came to make sense of their new identity and their loss of a spouse. Lastly, a summary is given along with a key theme that begins to come into view, that of a fragmented self after the loss of a spouse, one that is conflicted, compromised and searching for meaning at both the individual and the social level.

Chapter Six –Results-2, Formal Bereavement Care, explores formal support, the heart of this dissertation, and looks at the experience of this care through personal conversations with participants which highlights the support groups, in particular. Discussions on how these surviving spouses desire a familiar person/place in the initial chaos and take on a search for normal through a shared experience is explored. Next, is a look at the four other themes that emerge namely, 1) the importance of a support group as a *safe haven* to do ‘grief work’ and re-construct one’s wounded self and life narrative; 2) the value of a *shared experience of spousal loss* with other widowed group members; 3) the *significance of a community* where significant loss is explored; and lastly, 4) *unmet needs* surrounding both pre-loss and post-loss concerns.

The concept of grief work in support groups is also examined along with the stress related to spousal loss, namely emotional and readjustment stress which are viewed through two postmodern models for bereavement, the Dual process Model of Grief and the Theoretical Model of Spousal Bereavement. Next, I discuss the overall helpfulness of the support groups as put forth by these bereaved spouses. A look into whether (and how) these spouses learn to be widowed is presented. Lastly, I include two final sections on areas of interest, which are on the difficulties of the ‘remnants’ from the deceased spouse and discussion on some unusual occurrences, or ‘extraordinary experiences’ for 8/38 of these participants.

Finally, Chapter Seven summarizes the ways in which these spouses construct an image of themselves through their stories of loss and subsequent experiences of formal bereavement care. It revisits the three initial research questions and shows how they are addressed and answered through this study. Recommendations for future research are also discussed based on the findings of this study, such as extending group support meetings, training facilitators to address concerns and topics as they arise including readjustment stress and identifying both pre and post loss stressors are critical. Strengths of the study are highlighted and discuss how this sample drew from a good representation of agencies who provide grief care. This includes discussion on the use of a wide geographic area of Michigan residents and the use of the same instrument for 35 of the 38 participants. In addition, the justification for use of NVIVO-9 data software program are given, which in part enabled an efficient organization of the data into parent and child nodes and decreases the error and provides additional clarity. The design of the interview guide is also presented as a strength as it provides ample space for open discussion. Lastly, strengths include peer debriefing by a thanatologist and a social worker/psychotherapist who are both currently work as practitioners with bereaved people. Next, implications for

practice, education and research are given and highlights how this study informs those working in the field of bereavement care. Further, it is outlined how information from these spouses helps us to recognize the need for more training and education for end of life care workers from an array of professionals. Implications in research include the a realization that there needs to be a wider dissemination of research in the communities who offer bereavement care especially in terms of recognizing the ongoing needs related to readjustment stress as these spouses point out. Chapter Seven comes to a close with final words about the storyline of this dissertation which has investigated the experience of formal bereavement care for these participants. It is a story where the bereaved spouse suffers greatly as they look at who they are now, while re-constructing the past. They examine the present struggles as well as a future without their spouse as they re-construct the now fragmented and compromised self to adopt a new and undesirable role as a widowed person.

CHAPTER TWO - LITERATURE REVIEW

Introduction

The 21st century ‘self,’ is constantly under construction. It is typical to hear the phrase ‘it’s all about the stories’ in reference to our selves, our experiences, and our lives, as the self is ‘storied’ or narratively constructed (Bruner, 1986; Rosenwald & Ochberg; 1992; Gubrium & Holstein, 2000). Some researchers, such as Gubrium and Holstein (2000) have noted that the self arises out of social situations. For example, in a world where social networking is connecting an individual to more strangers than real ‘friends’ on a global scale, we form our virtual identities. We find out who we are by how these others (who are only digitally connected to us) respond to our online postings and actions. This idea of learning about the self through the responses and actions of others has its roots in Mead (1934:138-40):

The individual experiences himself as [an object], not directly, but only indirectly, from the particular standpoints of other members of the same social group...[The individual] becomes an object to himself just as other individuals are objects to him...it is impossible to conceive of a self arising outside of social experience...

The idea of the social self began with Mead who argued that the self is a creation of both a mind (which must have a distinctively evolved brain) and a society in the sense of interactions with others. By the 1950’s, approaches to studying the self had split into two camps -- the Chicago School which argued that the self was impressionable under most conditions, and the Iowa School which asserted that the self was basically fixed and could be quantified.

Social scientists continue to debate the stability of the self, though what was once known in two camps has become many. Structural interactionists, for example, believe that the self is centered on specific roles and is therefore predictable. Dramaturgists, following Goffman, argue that the self plays to the audience, switching scripts depending on perceived notions of what the audience expects (or what the actor can get away with). The postmodernists have yet another

take, suggesting that the self is constantly being constructed based on social circumstances, and that each self is as genuine as the last.

If the self is a social construct, then new situations, such as becoming a widow(er), force the self to be reinvented. Experiencing the loss of a significant other, the focus of this research, places the self in a social space where various negotiations and transformations of both individual and social selves take place outside of informal support systems. Given contemporary society's shallow and often desolate response to death (Walter, 1999), it is often quite difficult for bereaved individuals to be authentic about their grief in public due to social sanctions for acting 'abnormal'. Intense expressions of grief have a tendency to frightfully remind people of their own mortality, which makes for an uncomfortable situation (Kinderknecht & Hodges, 1990). As a result, the bereaved person often seeks assistance from others who are outside the informal support system, or are given referrals for professional counseling. They are instructed on where to find formal support by well-meaning friends, family members and co-workers. These types of responses from informal systems can also contribute to making people "feel that their behavior is abnormal: society decides when one has grieved long enough, then lets the bereaved know that it is time to bury the dead and get on with the living" (Kinderknecht & Hodges, 1990:47). A new identity is then constructed in a new environment –where one learns how to manage communications with informal support networks, often presenting one identity with those in the informal network and another within grief and bereavement groups. A new social role is tried out in places such as support group settings where similar others and group facilitators act as friendly editors in the reconstruction of self in bereavement.

This chapter presents Walter's 1999 typology of the social context of bereavement in traditional, modern, late modern and postmodern societies and then moves into an overview of

selves and identities and negotiations and transformations of selves. This background is supplemented with a review of small groups, support groups, and includes a discussion on the types of support groups for the bereaved person and some of the distinct roles and orientation in these groups. Lastly, support groups specifically for the widowed are presented.

Selves, Identities, Social Roles & Self-Construction

At this point it is important to understand a distinction between self and identity. Identity is a term that is used throughout the social sciences to explain a person's formation and expression of their uniqueness or their group associations. It is anything for which a story can be told, whereas a self is the embodiment of a range of identities. A married family man with a job and career can be said to have the identities of a father, a worker, a husband, a son, a baseball fan, etc., and all of these, including how they are performed, become the self. In each case, the identity arises because it is in conflict with other identities, leading one to argue that identities are social -- created in interactions -- and therefore, the self is also social. When an individual experiences a loss of someone who is key in creating identities and self -- a spouse, close friend, etc. -- that identity is challenged, leading to a compromised self.

It would be pointless to maintain this distinction between the self and identities throughout this work, except to say that widowhood -- the focus of this study -- is a component of both an identity -- spouse -- and the self. For heuristic purposes, I will maintain the language of the self, as this entails the whole person, unless I am specifically talking about a precise identity that is grounded in the self. To understand the bereaved self in postmodern society, Walter's (1999:185,186) typology of grief contrasts death in traditional, modern, late modern and postmodern times (see Table 2.1 below). Walter (1999) explains that there has been a shift in this area, and that today we tend to see an interchange between public provisions and the

private experiences when dealing with many difficult situations. One example is that more people (mostly women) are writing³ about their private experiences of grief and many are being published in the popular media. Some perhaps do this as a therapeutic outlet alone, while others hope to help people who are struggling with the same experience and some authors note that they write for both of these reasons. It has been suggested that in postmodern times, narrative is replacing ritual. Since a great deal of re-construction goes on with life narratives, Walter [1999:187] points out that there is more training for professionals on the topic of bereavement in order to provide help with the disrupted narrative, in understanding the loss and in constructing the past, present and future story. He suggests that the experience for the individual:

...now becomes authoritative in a de-spiritualized, de-ritualized, de-socialized understanding of bereavement. At the same time, scientific medicine no longer ignores grief but categorizes and theorizes it, so that the bereaved individual describes his or her own experience with semi-psychiatric terms such as ... 'the grief process'...Grief is now regulated through these categories and through the possibility of expert counseling and mutual help groups...

Walter's typology (outlined in Table 2.1 below) presents the self in postmodern times as the authority and as free to define its own grief compared to traditional, modern and late modern times. In late modern times, he asserts that bereavement was dominated by professionals, whereas in modern times it was defined by the medical community, and in traditional times, religion was the authority in shaping death, dying, grief and bereavement.

³ In the last five years, for example, we have seen an array of memoirs on the topic of widowhood alone, including Mary Francis' (2011) *The Sisterhood of Widows: Sixteen True Stories of Grief, Anger and Healing*; Carol Brody's (2009) *Widows Wear Stilettos: A Practical and Emotional Guide for the Young Widow*; and Joan Didion's (2007) bestseller *The Year of Magical Thinking*, and many more.

Table 2.1 Walter's (1999:186) Typology: The social context of bereavement

	Traditional	Modern	Late modern	Postmodern
Social Context	Community	Public vs. Private	Professional expertise defines private experience	Private experience becomes public
Authority	Religion	Medicine	Therapist	Self
Bereavement Experience	Social Mourning	Private grief Anomic grief	The grief process Counselling	MHG (mutual help group)
Required Language	Ritual	Stoical Reserve	Expressive talk	Expressive /narrative talk
The dead	Group Ancestors	Privately experienced Publicly forgotten	Let go	Live on in conversation

If postmodernism is characterized by the ability to construct stories on one's own accord, the task then by professionals is to companion those who are grieving. This involves assisting with their attempts to construct the story of the death and loss and to aid in (re)constructing an image of who the deceased person was in the shared relationship, which is challenging given that the facilitators and the group members did not know the deceased person.

While postmodernists argue that all stories are legitimate and new stories are constantly emerging within the social landscape, the structural tradition of symbolic interactionism contends that individuals and groups maintain comparatively steady sets of social meanings and social relations (Callero, 2003). These meanings and relations include social roles (Collier, 2001) and identities (Stets & Burke, 2003) which serve as resources for self-construction. From this point of view, people come to see themselves as others see them; and there is much less leeway for new stories of the self (Kinch, 1963). Stryker (1980) notes that identities are "distinct parts of

the self defined by the meanings and expectations associated with network positions and role expectations” which are components of a social structure and have behavioral expectations as the result of social interactions (Callero, 2003:125). Callero (2003) also points out how Stryker and Burke’s (2000) research emphasizes the influence of the social structure on self structure, which in turn affects behavior. It is important to recognize that the social context or the conditions under which this self-view is most likely to occur needs consideration.

For this study, the support group format provides the social context for negotiating the self, along with the length of time that a person has been experiencing bereavement. The widowed self, for example, is ascribed and preserved in society as a social role, yet it is subject to alteration in a continuing interpersonal context within a group of other bereaved individuals. Each person, then, carries a stock knowledge of grief, acquired from personal experiences of loss and the resources within their social location. New circumstances pave the way to learn a new identity, one that is being constructed on a personal and social level.

Cerulo (1997:397) suggests that new communication technologies have opened the door to a wide range of ‘generalized others’ which alters ‘the backdrop against which identity is constructed.’ Further research by Altheide (2000) points out that the pervasiveness of technological devices can be seen in the founding of ‘media communities’ that add a new element to the physical and symbolic surroundings of our everyday lives. This in turn works to aid in the construction of a self that is less place bound, and as a result, the self is much less dependent on ‘the [real world] definition of the situation’ (Meyrowitz, 1997, in Callero, 2003). This becomes evident when, through advertising, the mass media construct and sell identity images that portray the self in a manner that benefits the production side of a consumer economy (Ewen & Ewen,

1992). Separateness and individuality are created and encouraged in various new ways, providing more impetus for the individual to continue consuming in search of a better self.

Along those same lines, Knorr Cetina (2001:525) refers to contemporary society as a ‘postsocial environment’ where the emphasis on individualism discards traditional forms of sociality. She notes that ‘the modern untying of identities has been accompanied by an expansion of object-centered environments which situate and stabilize selves, define individual identity just as much as communities and families used to do.’ In this sense, non-human objects, such as a cell phone or laptop computer, become resources for which one can base an identity.

Some scholars have suggested a post mortem identity (PMI) (Weigert, Teitge & Teitge, 1986) and more recently, a life-self and a death-self (Shoshana & Teman, 2006). The former identity, PMI, refers to the self’s identity after one dies and the body is disposed. According to Weigert, et.al, (1986:110), “identities are distinctively human, and they affect social relationships regardless of physical presence at, or conscious involvement in, interaction.” The authors continue their argument by noting that symbolic interactionists suggest that human beings are viewed as social objects and society as the organization of identities (i.e., Znaniecki, 1965).⁴ They also remind us that Simmel (1950:410) stated ‘Man does not end with the limits of his body or the area comprising his immediate activity.’ For these authors, this includes identities after one has stopped breathing.

The notion of identities both in life and death (Shoshana & Teman 2006:557) involves a concept of ‘transitory movements’ to suggest that there is a ‘waltzing’ movement between life

⁴ Along these lines, Tony Walter (1999:191) also contends that ‘the dead are the central actors’ in mutual help support groups for the bereaved, as members are free to talk about the dead without any judgment which then gives the dead a communal and social existence.

and death which bestows the self with meaning and situates itself at the center of the ‘self-work of agents.’ From this standpoint, the binary structure of life and death is no longer plausible.

Stets and Burke (2003) suggest that behavioral patterns within and between individuals have diverse levels of analysis, which is key to our understanding of the relation between self and society. Their research points out that people are at all times rooted in the very social structure that is, at the same time, being shaped by themselves. They assert:

At one level, we can look at the patterns of behavior of one individual over time and come to know that individual. By pooling several such patterns across similar individuals, we can look at the patterns of behavior across individuals to see how these patterns fit with the patterns of others to create larger patterns of behavior. It is these larger, inter-individual patterns that constitute social structure. (2)

Holding the assumption that there is a mutual association between the self and society (Stryker, 1980), it is understood that the self influences society and vice versa. In the former, this is accomplished through the behavior and actions of individuals which then results in networks, institutions, groups, organizations and so forth. When society influences the self, it is evident through shared language and meanings that enable someone to take the role of the other, engage in social interactions, and view oneself as an object (Stets & Burke, 2003). Gubrium and Holstein (2000:96-97) argue that these are “trying times for the self” because the social landscape has disappeared from the personal self:

The personal self remains our primary subjectivity—a self we live by—but it is now produced in a proliferating and variegated panorama of sites of self-knowledge. These are domains whose participants regularly turn their attention to questions of who and what they are, or could be. From counseling centers, therapy agencies of every stripe, and *support groups* [italics mine] to spiritual fellowships. Internet chat rooms, and television talk shows, personal selves have become big business, the stock-in-trade of a world of self-constituting institutions, which increasingly compete with each other for discerning and designating identities. (emphasis mine)

These observations are also made by others, such as in Gergen (1992) in *The Saturated Self*. Foucault (1988:11) showed great interest in both the interpretive process and substance—the continuing *how's* and the expansive *what's* of self-construction (in Gubrium and Holstein, 2000:101) and contends:

...the way in which the subject constitutes himself in an active fashion, by the practices of self...[These practices] are patterns that he finds in his culture and which are proposed, suggested, and imposed upon him by his culture, his society and his social group.

These views of Foucault (1988), Gergen (1992) and Gubrium and Holstein (2000) all point to the reflexivity of social action and social structure (see Garfinkel, 1967). This process of reflexivity, according to Mead (1934) and others (McCall & Simmons, 1978) establishes the nucleus of selfhood. The self, at its core, is defined by a reflexive process, the collective human experience of self-objectification, and is an important conceptual tool at the level of self-meanings, self-image and self-concept where the historical, cultural, and political specifics of identity are uncovered (Callero, 2003). Since the self materializes in social interactions within the context of a multifaceted and distinct society, Stryker (1980) [following James' (1890) work], contends that the self must be just as multifaceted and distinct (self reflects society argument). Stets and Burke (2003:8) argue that this view holds that “there are many different selves as there are different positions that one holds in society and thus different groups who respond to the self.” The majority of our interaction is with people who occupy positions (statuses) in groups in our society and “any identity is always related to a corresponding counter-identity” (Burke, 1980:8 in Stets & Burke, 2003).⁵ When these interactions are explored, one finds the existence of both agency and social structure (Stets and Burke, 2003). For example, in a college classroom, one

⁵ For example, a wife's identity is enacted as it relates to the husband's identity, child to parent, worker to employer, group member to facilitator, etc.

will find instructors playing the role of teacher and students playing the roles of students. On the surface it seems that everyone has their position in terms of an agreed upon social structure. The students, however, as agents, can produce a role through their behavioral selections and decisions and engage in negotiation, give and take, which includes conflict with the instructor and other students. It is important to identify that both social structure and agency are at work when examining interaction between identities.

Negotiations & Transformations of Individual and Social Selves

The individual or personal self is thought to be at odds with the social world (Gubrium & Holstein, 2001). This is exacerbated when the private and intimate space of the personal self is invaded by organizations and communications media where the self and its constituent identities can no longer originate from within (Gubrium & Holstein, 2001). This invasion has been accelerated in recent years by a proliferation of self-help books, television and internet programs, support groups, and other venues. Hughes (1984) referred to these institutions as ‘going concerns’ in the business of assembling and redefining personal identities. Riesman (1950), in his classic work on the American self, reminds us that one’s social self is a conforming victim of its times. Within this context, symbols and systems within society play a large role in shaping the self, though there is little reason to believe these symbols and systems give rise to a homogeneous population.⁶

Daniel (1984, In Gelech & Desjardins, 2010:63) suggests that ‘the self is a symbol that enters into dialogical relationships with the other symbols and systems of significance operating in society.’ Gelech and Desjardins (2010:63) extend this in two key ways:

⁶ It is important to note however, that although the social self is highly influenced by the times in which we live, it is also communicatively shaped as it is crafted in light of the social conditions and biographical particulars of our lives (Gubrium & Holstein, 2001).

First, others act as “coauthors” in the construction of the self by providing information about our personal qualities. The self is therefore largely public in origin, and under continuous reconstruction in light of new connections and interactions with others...Second, the self not only interacts with other selves, but also with the many symbols, signs, and meaning systems operating within local and global worlds, and is therefore grounded in particular historical contexts...

With the expansion of the human service industry, Gubrium and Holstein, (2000:110) highlight how the increase of professional self-constructive settings are leading to more negotiations for ‘troubled and untroubled selves’:

In the world of human services...the self is usually located at the heart of social and personal problems and their solutions. In practice, these institutions construct the troubled selves that they need to do their work...As Emile Durkheim (1964) taught us long ago, we need the visible presence of the “pathological” to assure us of what is ‘normal,’ suggesting that just as we have more troubled selves than ever before, we now have more untroubled ones as well.

Given the proliferation of signs and symbols in contemporary society, along with self-constructive settings, available others, and concern in the human services to assist with the reconstruction of identities and the self, there are numerous opportunities for negotiations and transformation of selves in the 21st century.

One strategy when negotiating conflicting versions of self or a new identity is to evaluate the situation in relation to others. Negotiation strategies, such as relational appraisals, enable one to form various versions of the self, both positive and negative, in relation to (perceived) similarly situated others (e.g., Abrams & Curran, 2010). Abrams and Curran (2010:381) studied maternal identity negotiations among low-income women with symptoms of postpartum depression, and found these individuals:

...negotiated a conflicting version of their maternal selves by viewing their depression and its symptoms as an entity outside of a core maternal self...mothers framed their troubled and depressed maternal identities as alien to their core, internal, or authentic selves.

By using a relational dialectics approach, the self is viewed as fragmented and multifaceted where contradictory and competing discourses battle for acknowledgement and identification in relationships (Baxter, 2004a,b). In this space, selves are constructed and performed (Baxter, 2004b; Baxter and Montgomery 1996).

The dialectic process is complemented by transformational activity such as writing about trauma in the life course. Writing has the potential to be an outlet experiences too painful to be discussed in speech which involves others to be immediately present. Various therapies in support groups and professional counseling arenas involve journaling thoughts and feelings on a daily basis and, in some instances, people are encouraged to write an entire storyline for therapeutic benefit. These activities are meant to help the person in negotiating and transforming the self. This transformational activity of self is often promoted in small groups.

Small Groups

Classic studies of small groups include Bales' (1950:33) who used an interaction process analysis as a method and defines his interpretation of the small group in the following way:

A small group is defined as any number of persons engaged in interaction with each other in a single face-to-face meeting or series of meetings, in which each member receives some impression or perception of each other member distinct enough so that he can, either at the time or in later questioning, give some reaction to each of the others as an individual person.⁷

This definition stresses that there is action involved on the part of the member/s as a mechanism of the small group. While there are numerous other definitions of what takes place in small

⁷ Although this definition is applicable to most small groups, Harrington and Fine (2000:314) point out that with the explosion of virtual communication we should question whether face-to-face contact is necessary for the existence of a small group.

groups, Bales' approach sets the foundation for my own approach to small group activity, which is discussed later in this chapter.⁸

Very recent work, such as Harrington and Fine (2000:314), helps to extend Bales' thoughts into the present. These researchers examine five mechanisms of small groups, namely, 1) the socialization of individuals to communal principles; 2) the space where these communal standards and expectations can be challenged; 3) the establishment of network 'clumps' or nodes where weak ties give way to a strong set of intimate ties; 4) 'spaces for the collective development, appropriation and interpretation of meanings and cultural objects'; and lastly, 5) small groups are realms in which status processes and social identity are made solid and individuals are assigned to social positions. As to the first mechanism of small groups, it is noted that because of the intimate setting of a small group and the importance of the group to the identity of its members, socializing those who attend is easily accomplished. At the same time, the small group is capable of challenging larger communal standards and expectations, which often can result in social change, i.e., social movements. This is possible because of the "diffusion of cultural forms: traditions that spread from group to group in social networks through weak ties, and then diffuse rapidly within each group" (Harrington and Fine (2000:314) . Second, space is also provided to develop a collective identity, one where meanings and cultural objects can be interpreted within and for the group. In these types of groups it is reported that status processes and social identity assignments, dependent upon the characteristics (ascribed vs. achieved), are made definite and these are used to allot social positions. Harrington and Fine (2000:314) point to how small groups function, referring to "controlling, contesting, organizing, representing and allocating features of groups." They recommend a resurrection of the study of

⁸ See section on 'Support Groups for the Bereaved Person.'

small groups in the social sciences. and suggest that groups are the micro foundations of social structure, one where the self transforms from an individual identity to a relational one and eventually to a collective self.

These various selves are not necessarily continuous. Smith, Coats & Murphy (2001:120, In Sedikides & Brewer) argue that in order to survive and thrive we need to successfully self-regulate at all three of these levels:

At the individual level, they [humans] need to profitably manage interactions with the environment (finding food and other valuable resources, and avoiding danger). At the relationship level, they need successful dyadic bonds (mediating care for infants, as well as sex and reproduction). And at the collective level, they need ties to larger groups (for transmission of culture).

When bonds are severed at the relationship level, the small group may provide the missing structure for dyadic bonds. However, the effects of the pressures to adhere to the standards of behavior in the group (or norms) may be problematic. Early sociological studies on small groups note that conforming to the norms of the group is expected to move people towards a particular goal, which provide a sense of order (King, 1962). According to this research, these norms then provide a structure so that social communication with other members in the group can be carried on. In essence, through these norms, group members are socialized in the small group. King (1962:37) posits that:

Sanctions often provide a more compelling reason for conformity, and all norms are provided with pressures to motivate conformity and discourage the tendency to nonconformity. Group pressures result from the group sanctions. These sanctions give support to the norms in the form of punishments for those who do not conform and in the form of rewards for those who do conform. These may be in varying degrees-negatively, from a mere frown to show disapproval to a death sentence for extreme punishment; positively, from a compliment to an award of honor.'

Because most individuals want to be recognized and accepted, they may conform to the norms even though they are not in total agreement with them. Wanting approval, individuals may limit their authentic self to gain a sense of belonging. Both authoritative figures and other group members (peers) are instrumental in persuading individuals to conform. Milgram's (1974) famous study of obedience highlights:

‘the immediate presence of an authority is powerful in enforcing the claims of the social system...Authorities have substantial power...yet peers...potentially have this degree of social control, as individuals look for cues to learn what behavior is right in a particular situation.’ (Corsaro and Rizzo, 1988, In Fine, 2000:315).

Social control is evident at the intimate level of the small group in what Fine (2000) refers to as a ‘particular hierarchy’ where people are positioned within the group. Equally important, Swidler (1986) suggests that people in groups use a cultural tool-kit ‘to create symbolic and ideological structures that constitute collective representations’ (In Fine, 2000:317). I turn now to a look at the support group format – a space where emotional experiences and self-regulatory mechanisms oscillate at the individual, relational and collective levels.

Support Groups

A particular feature of support groups that distinguishes them from other small groups is the effort to draw together people who have a specific common problem or need (Steinburg and Miles, 1979). Topics may be introduced related to the specific problem in an attempt to educate and engage participants. Some support groups offer social events or special annual group gatherings (reunions if they are no longer meeting as a group) to promote continued engagement.

There are various kinds of support groups, though two are most often referred to in the literature -- self-help and mutual-help groups. Mutual help, self-help, and mutual-aid are used with the above terms interchangeably throughout the general literature on support groups.

Among the major differences of these types of groups (including psychotherapy groups)⁹ are: 1) the role that professionals play (i.e., mutual help has a professional facilitator while self-help generally does not); 2) the extent and type of the group's change orientation, (i.e., mutual help aims at giving emotional support and information while self-help groups focus on change for members); 3) the size of the organization's membership; 4) the degree of local group autonomy (i.e., resource dependence and authority to make decisions); and 5) the complexity of the organization's program and philosophy (Kurtz, 1997:3-8). The groups, according to Kurtz (1997:9) may also be understood in terms of looking at an important similarity, that they are "made up of fellow sufferers."

Schopler and Galinsky (1995) use an analogy to make distinctions, placing self-help groups on one end and psychotherapy groups on the other with mutual help groups (also often called support groups) in the middle, as these have the capacity to overlap with models on either end of the continuum. Also, mutual help groups advertise that their main purpose is that of giving emotional support and information to persons with a common problem (e.g., bereavement support groups), while self-help propose effecting change in the members (e.g., Alcoholics Anonymous). Participants of various types of support groups show evidence of an insider identity as members understand each other because of a similar experience that is not shared by others outside of the group.

⁹ Psychotherapy groups (which often charge a fee) look to produce individual growth and change, are assisted by a professional therapist, and accomplish this task through relationships established among the limited number of members. Heterogeneity is valued, similarity of problem is not a qualification (Kurtz,1997:7)

Support Groups for the Bereaved Person: Mutual-Help Groups (MHG) and Self-Help Groups (SHG)

The loss of a significant other person is something that one must experience to know the emotional suffering of others who have had a similar loss. Numerous support groups have been formed around this experience – the loss of a significant other – and are referred to as bereavement support groups. Sociological studies of these groups are rare (Seale, 1998).¹⁰ One exception, is the participant observation study by Wambach, as briefly mentioned earlier, which shows that counseling can be interpreted as a ‘performative ritual’ (in Seale, 1998:197). In the three widow support groups studied by Wambach, findings show that widows and professionals (i.e., social workers, clergy and funeral directors) followed Lindemann’s (1944) ideas of the grief process¹¹ being set by specified times. Wambach (1985/6:209) argued that the grief process is “a structure for publicly expressing grief that is as important as, maybe more important than, mourning rituals.” Over two decades later, support groups for bereaved people are flourishing, and continue to use this grief process framework and grief work allegory. In general, support groups, as stated above, have goals of giving emotional support and disseminating information to people with a common problem (Kurtz, 1997). For bereaved persons, these are especially critical factors early in bereavement, even if the participants in the group are foreign to each other and dissimilar in terms of age, social class, and even type of loss in the initial stages of the

¹⁰ Carolyn Walter (1997:81) for example, reported on support groups for the widowed from a social work perspective, which provided a short summary of the literature but relied heavily on her own experiences in relation to the ‘purposes, practice principles, common themes, and evaluation approaches in designing and leading support groups for widows and widowers.’

¹¹ The ‘grief process’ has been explained by Tony Walter (1999:107) as ‘a process that changes you irrevocably...a process of transition...You shift from being an attached person to an unattached autonomous individual...’ He claims it was developed by ‘clinical lore’ which ‘posits, basically, one ‘grief process’, from attachment via emotional pain to autonomy.’

process. Fusion is key in bereavement support groups, though fragmentation can occur if losses are dissimilar and subdivides groups according to the type of loss (into widowed groups, bereaved parents, sibling loss, etc.) (Walter, 2007).

To facilitate fusion in a support group, solidarity is based on similar experiences rather than on pre-existing relationships found in traditional informal support systems. Participants often will bond and find relief for their pain when in the presence of others who have faced similar experiences. The more detached the participants are from informal networks, the more they claim to be understood only by the members of the support group. Modern conditions, such as social and family fragmentation including the geographical mobility of the family members, provide fewer opportunities for the person mourning to talk about the deceased person in everyday life. The group setting provides a space where the survivor can speak of the deceased, thereby gaining a 'shared reality that they are denied in conversation with those who actually knew them in life' (Walter, 1999:79).

It is also important to have the self-help group defined 'ideally' as 'a supportive, educational, usually change-oriented mutual-aid group that addresses a single life problem or condition shared by all members' (Kurtz, 1997:3). For bereaved persons, the self-help group is a place for reconstruction work. When psychological models are used in these settings, the goal has been to reconstruct the relationship to the deceased in order to accept the loss, and then rejoin the world of the living. Seale, (1998:4) suggests that the self-help group is "an imagined wider community of like minded individuals among whom the bereaved person can feel at home, symbolically aligning his or her biography with that of other members of the imagined community of the bereaved." This new community is made up of people whose bonds are not based on biology, geography or economics, rather it is in the "voluntary association and the

perception that others are like the self.” This self is an intimate one with a self-chosen identification that Walter (1999) explains as the setting for grief in a culture based on individual autonomy.

It is expected that the self will move from grieving to coping and moving on in support groups. To do this, some self-help groups for bereaved parents,¹² for example, help members find meaning in the child’s death. A longitudinal study of bereaved parents by Murphy, et.al., (2003, In Goss & Klass, 2005:262) found that many never accomplished this work. Rather, the death of their child remained a senseless event and they could not make sense of it. There were some parents who did find meaning from the loss, and the most significant predictor was that they had attended a support group. While there may be a number of reasons for this finding, it does point to a need for more work in the area of exploring the effectiveness of bereavement support groups, including their attention to emotion work.

In support groups for bereaved individuals, emotion work is the focus of many group meetings. Members share concerns over whether they are appropriately behaving as they should be. When we look to Hochschild (1983; 2003:56) who introduced the concept of ‘feeling rules’ as a personal emotion system that requires this ‘emotion work’ or ‘deep acting,’ we understand the struggles of the individuals. These feeling rules then, she goes on, ‘are what guide emotion work by establishing the sense of entitlement or obligation that governs emotional exchanges.’ Hochschild (1983; 2003) suggests that others give us ‘rule reminders’ which hold us accountable to explain our feelings which may signal that perhaps our emotional conventions are not appropriate and that they should be recognized as in need of repair. She highlights important

¹² Such as The Compassionate Friends (TCF), a national nonprofit, self-help organization with local chapters in the US and worldwide. This organization is devoted to providing support to parents, grandparents and siblings after the death of a child in the family.

problems of timing (one's grief is not expressed 'on time') and placing (having the right audience to receive your expressions) with respect to mourning and grieving. Next, her work explores the ambiguity and struggles related to grieving a significant loss as she points to 'misfitting feelings' surrounding the feeling rules related to death and mourning. She suggests that 'we can offend against a feeling rule when we grieve *too much* or *too little*, when we overmanage or undermanage grief' (64). Facilitators within the support groups for the bereaved often assist with these concerns surrounding feeling rules and emotion work.

The Role of Professionals

Mutual help groups are often led by a professional and linked to a social agency (or some larger, formal organization such as a hospital) (Kurtz, 1997:4). In bereavement after care services, professionals come to the table with various credentials and experience, most having had some formal thanatology training. The role in this setting involves facilitating the group (usually from 8-10 people) along with the aid of trained volunteers¹³ in helping group members to recognize the various emotions and experiences that make the grief journey complex.

Professional facilitators adopt a role in which they normalize the feelings and behaviors of all participants, even if at first the behavior may seem 'odd' and bordering on the pathological.¹⁴ They plan the actual meetings, decide on the format, length and frequency of meetings, communication patterns, goals, facilitation techniques, and stages of group development (such as empowering peer leadership within the group) (Kurtz, 1997:98). They

¹³ These volunteers may be students in Master's or Doctoral programs (i.e., such as nursing, social work, psychology, anthropology, or sociology, etc.), who are studying various aspects of death, dying, grief and bereavement.

¹⁴ One woman in the group I co-facilitated mentioned that she woke every morning to kiss the photo of her deceased husband, talk with him, and then walk two miles to his grave to cry, and had been doing so for nine months since his death. Participants looked to the facilitator with shock and fully expected a 'negative reaction' (of which of course she did not give).

accomplish the latter, in part, by explaining (with the help of videos, written information, guest speakers, and other venues), aspects of the grief experience. Most importantly, if affiliated with an organization which provides funding (such as the federal government's subsidy for a number of hospice organizations), they are to assess the progress of the participants and keep accurate records on group members, recording comments made by the bereaved, demeanor at meetings, and whether or not the members would benefit from additional referrals (such as grief counseling).

On the other hand, professionals rarely play an active role in self-help groups (which is why these groups are referred to as *self-help*), unless they are members themselves (Kurtz, 1997:4). One example is *The Compassionate Friends* (TCF) (see Footnote 12 above). The mission statement notes that the "leadership, both national and local, comes from parents...there are no professional facilitators" (Kurtz, 1997:177). The mission also emphasizes that TCF is a "mutual assistance self-help organization offering friendship and understanding to bereaved parents and siblings" (Kurtz, 1997:178). At times the group invites a professional speaker as a guest, but otherwise TCF meetings are run by bereaved parents who are trained only by their own unfortunate life experience of having lost a child.

The Extent and Type of the Group's Change Orientation

One difference between self-help groups and mutual help is that the latter does not aim at effecting change (Kurtz, 1997). Although change can occur, it is not the main focus of mutual help groups. This is not to say they share no similarities. It is important to note that in these support groups offered by various types of organizations, businesses and community agencies, there is no standard model of grief that is utilized and offered, rather it is idiosyncratic to the person facilitating the group. Five helping factors (or processes) are noted from research on

group processes and change mechanisms that appear in both types of groups. These include “giving support, imparting information, conveying a sense of belonging, communicating experiential knowledge, and teaching coping methods” (Kurtz, 1997:21).

These similarities help in different ways. For the mutual help group, disseminating information is the focus of activities, while change is central to the orientation of the self-help group. Kurtz (1997:24) notes several “life-altering goals” of the self-help group, namely, identity transformation, empowerment, insight, reframing, and formation of a new way of life. Understandably, in the case of an alcoholic who seeks out help from Alcoholics Anonymous, for example, there is a need to be transformed, empowered, have insight into one’s behavior, and to reframe one’s social network by changing associates and forming a new way of life to control the addiction. In bereavement, prolonged involvement in support groups could provide aid with interpersonal changes, such as in a belief about what is important in life, or changes in the belief of the self as resilient and strong (Videka-Sherman, 1982, in Kurtz, 1997:181).

These comparisons should not be overstated, as there are definite overlaps from one group setting to another. Aspects of helping others in a group, connecting with others who have similar experiences, and the extent and type of changes can be applied to all types of support groups. The major difference, as stated, is in the facilitation of the group by professionals.

In general, support groups for those who are bereaved play an important role for individual constructions of the self. For the widowed in particular, the formalized support group identity enables the widowed self to emerge through the collective, which consists of other individuals with similar experiences. Tony Walter (1999:70) explains the significance of telling

the story of the one who died and how the dead live on¹⁵ through conversation by highlighting four theoretical grounds. First, he suggests that in western society there is a decline of rituals but the dead can live on in communal memory as long as the group continues to talk about them, something that is difficult to do with people who have not experienced the loss of a significant other: “....reminiscence creates a place for the dead in the life of groups as well as of individuals. It is not just that the group may help the grieving individual; the individual can help the grieving group.”

The second component emphasized by Walter (1999:70) is on the importance of talk which he notes is featured by Seale’s (1998) work and based on Berger’s (1969) argument “that society is ultimately a defence against the chaos and anomie of death, with the insight of the ethnomethodologists (e.g., work by Sudnow, 1967).” Walter (1999:70) implies that it is the lack of religious ritual in a more secular society that creates a burden on “apparently banal everyday talk” for accomplishing the task of talking about the deceased to help the survivor cope with the death.

Thirdly, Walter (1999:70) posits that bereavement (regardless of whether this is a result of death, or other matters, e.g., unemployment, etc.) “is the state of being caught between the present, a past and a lost future.” This is a reference to a need to rewrite the past which Walter notes is critical if one is to make sense of the present which, in turn, impacts making sense of and moving into the future. This reflexive activity is defined by Frank (1995:65) as “the perpetual readjustment of past and present to create and sustain a good story.”

¹⁵ It can also be said that the connecting bond to the deceased is kept alive in the support group as they (the deceased) are center stage in conversation and the reason for the gathering of these survivors.

Support groups for the bereaved can be of great value for storytelling when those in informal support systems have tired of hearing repeated stories of the death and loss. Walter (1999) notes the importance of creating the story that has a beginning, a middle and an end which provides some detachment from crippling emotions. He also mentions how some bereaved individuals will write this story, providing another alternative to reconstruction processes. The fourth point made by Walter (1999) is that by telling the narrative of the deceased, the identity of who the deceased person was is made clearer to the storyteller, and also enlightens the storymaker on who they themselves are (Walter, 1996). When someone we love dies, it becomes important to know more about them, as that person is no longer able to help in the construction except through memories (Walter, 1999). A reconstruction of who the person was aids us in understanding the relationship we had with them. This may seem odd to someone who has never had a significant loss -- to think that one would not really know someone until after death -- but it is a common experience of bereaved individuals as part of an ongoing interaction (or connecting bond) with the deceased person. During this reconstruction, as one would imagine, there is a good deal of emotion work involved.

As stated earlier, Hochschild's work (1983;2003) is an important contribution which provides great insight here on the struggles of the bereaved population. Wilkinson (2005:109) moves Hochschild's (1983;2003) concerns forward for battling 'the deleterious effects of suffering upon human life.' He argues that the sociology of emotions has provided us with great insight but falls short as researchers are more concerned with the 'negative experiences and consequences of emotion than in the positive involvement of this within the concerns of humanity.' Wilkinson (2005) demonstrates the prospective for a 'sociology of suffering' that would motivate new imaginative connections with classical sociological theory. He emphasizes

the importance of examining *what suffering does to people* and how a sociological reaction to suffering must tackle the most disturbing questions of meaning. I find his argument timely and commanding on how suffering provides us with the potential to transform social relations if we are attentive to the needs of those in greatest despair.

Numerous accounts brought to our attention by the media¹⁶ can be examined to show us how suffering and loss can create a vulnerable self which may lead to ugly coping and sometimes an unconscious void that is replaced with inappropriate (and sometimes criminal) behavior. In the recent case of Linda Lusk, former mayor of Prosser, Washington, for example, there is speculation on the part of her family, that child sexual molestation charges against her were related to a lack of professional help for her grief after the loss of her own 14 year-old son, Taylor (Gerdau and Gomstyn, 2011). Other accounts of crime continue to provide headline stories about how loss and grief (i.e., job loss, divorce, etc.) are often part of the perpetrator's recent background (see McMillin & Perrusquia , 2010 on Jerry and Joe Kane,¹⁷ Sovereign Citizen Movement) and perhaps contribute to their need to displace their unresolved feelings of aggression. Although these are extreme cases, it fits well with the work of Wilkinson (2005) who reminds us that the obvious 'senselessness' of suffering has the power to significantly alter the ways we relate to society and ourselves. By attending to the lived experience of suffering, Wilkinson's new work considers the kinds of ethical structures required to foster greater empathy for 'the other.' There is great need for those suffering from loss to have an awareness of

¹⁶ Oftentimes these are reports about health problems related to distress, such as Broken Heart Syndrome where sudden or prolonged stress causes overwhelming heart failure or heart attack symptoms.

¹⁷ It is reported that the Kanes, who shot and killed two West Memphis police officers, traveled with the cremains of Jerry's late wife (his son Joe's mother). She always accompanied them on their road trips.

the tools and support they need and for others to recognize those who need help and support as well. Next, continuing to look at the support groups for distressed individuals, I examine this concept of suffering as it relates in particular to the widowed.

Support Groups for the Widowed

It has long been recognized in the literature that the loss of a spouse is one of the most stressful life events people can experience (Holmes & Rahe, 1967). Some scholars suggest that “preventive intervention early in the bereavement process may lessen the morbidity and mortality associated with the death of a spouse” (Yalom & Vinogradov, 1988:420). Carolyn Walter (1997) suggests that one way to provide this assistance is through support groups who offer help to this at risk population. She notes that the format of the small group is able to help diminish what is referred to as “intense social isolation experienced by most bereaved spouses”(Yalom & Vinogradov, 1988:420).

Within these groups, ‘social linkages’ that are made are viewed as important factors for positive reflection (Lieberman, 1989; Lieberman & Videka-Sherman, 1986). This reflection is on one’s own life and the relationships that have been severed. This includes ‘high social exchange’ through an expression of a wide array of feelings, both positive and negative and also provides an incentive for group members to gather outside of the meetings (in Walter, 1997). Lieberman & Videka-Sherman, (1986) found that these linkages formed and/or maintained outside the group setting provided more help compared to those members who attended the meetings only. Regardless of attendance, the positive reflections on one’s life and the linkages made within the group are important goals of the support group.

According to Carolyn Walter (1997:70) there are three important goals of bereavement support groups for the widowed:

...One is to assist the members to cope with the pain of grief and mourning (including the “holding on” and “letting go” processes) “by creating a temporary community in which they [are] deeply understood by peers” (Yalom & Vinogradov, 1998:443); a second is to help combat the social isolation that is so pervasive for this population and to provide “consensual validation” for spouses regarding their bereavement experiences (Yalom & Vinogradov, 1988); and a third is to support members as they begin to understand the changes facing them as they begin to fashion a new future for themselves.

In order to accomplish these goals, norms are “carefully cultivated and secured in the group process” (Kauffman, 1994:165). This is easier if the group is close-ended (time-limited), inducing a steady and unchanging membership (Walter, 1997). However, some research (Kauffman, 1994) indicates that there are certain other advantages of an on-going group. For example, new members may join an active group and learn from those who may be further along in their grief, in addition to providing the elders in the group with an opportunity to assess themselves by observing new members. Another “advantage of an ongoing group is that it can be available to diverse needs over time and see a person through the process, as needed” (Kauffman, 1994:171). Because a widowed person has to work through an identity change, from Us (the married couple) to Me (the surviving spouse), this ongoing group support could prove to be very beneficial in a successful transition. After a spousal death, for example, relationships often change with one’s family (in-laws, extended family) with friends (once coupled, now single and widowed) and other social networks, making it difficult for the bereaved person to relate to anyone other than those who suffer similar pain and share the same language.

Proper language usage in the group is also promoted by the culture of bereavement support groups through facilitators and other group members. Terms such as *grief triggers*, *grief process* and *grief work* are often heard from support group members with an understanding of their meaning without the need of in-depth definitions. Grief triggers, for example, are important signals that one is about to fall into a depressed mode and should not be ignored.. They may

come out of the blue in the form of favorite music once shared with the deceased person that will trigger an emotional reaction. In addition, learning how to effectively cope with anniversaries, holidays, birthdays and other family events without the significant deceased family member present is critical. While these triggers lead to difficult emotional experiences, they are considered part of the ‘grief process,’ which is commonly referred to by bereaved individuals in this study as a process everyone goes through after the loss where the grief will eventually lessen over time.

Support groups for bereaved people can challenge a society which expects one to get over it and move on, and assist bereaved spouses to grieve in their own time, and in their own way (Walter, 1997). They are beneficial in constructing the new identities of the widowed population whose self has been compromised at both the individual and social levels. The group provides an environment where the survivors can talk about the deceased without being judged or tagged as ‘pathological’, which helps to bring about a sense of relief to the afflicted and stigmatized person.

In Arthur Frank’s (1995) discussion on the body’s problems with illness, he points to Goffman’s (1959) classic work on stigma which displays how society demands a considerable level of body control from its members. When one loses bodily control, Frank argues that this is stigmatizing and special work is required to manage the lack of control. We can also apply this to the bereaved population who manage their emotions in various spaces and places to avoid losing control and embarrassing not only themselves, but others as well. But in the support group format, they are told that ‘tears are welcome here’ which relieves their fears and comforts many who are overly burdened and stressed from holding their expression of emotions at bay as they protect themselves and others. As they assemble the death and loss story within this group, they

do so feeling safe to say and express conflicting emotions and are assisted by others in reconstructing their new self.

Frank (1995:53) suggests that when a person is seriously ill, one's self is 'perpetually recreated in stories.' He further explains that these stories serve as 'the self's medium of being' that repair the harm that the illness has done to the person's sense of where they are in life and where they might be headed. This is also evident in the bereaved person when they have a significant loss as they struggle to find their way on a road that may have never been traveled. Frank (1995:54) goes on to quote Dworkin (1993) who noted that the illness stories are often reconstructed 'in conditions of fatigue, uncertainty, sometimes pain, and always fear' that result in a 'narrative wreck' which creates a need to find one's own voice in the situation.

There are types of illness narratives that our culture makes available, according to Frank (1995) namely, a restitution narrative, a chaos narrative and a quest narrative. I see parallels with this rationale that proposes a general type of narrative to bereavement stories as well. Restitution narratives for illness involve a storyline that says 'Yesterday I was healthy, today I'm sick, but tomorrow I'll be healthy again' (Frank, 1995:77). To some extent, the bereaved follow this logic by continuously examining the past, the present, and the future when reconstructing the narrative (see Figure 5.1, Hilliker). The chaos narrative of illness, however, assumes the stance that one's life will never be the same and never be better. They are told by what Frank (1995:98) labels the 'wounded storyteller.' This description reminds me of many bereaved individuals at the beginning of either a terminal illness diagnosis for someone they love, or upon the news of a sudden death. Lastly, are the quest stories, where in illness Frank (1995:115) suggests that it is only in these types of narratives that one can 'meet suffering head on...Illness is the occasion of a journey that becomes a quest...only in quest stories does the teller have a story to tell.' So,

too, in bereavement, it is only after the initial chaos and awareness of the reality of the death and loss, that one can now begin the quest to reconstruct the life narrative.

It is here in the quest story that we again recognize the opportunity for transformation. What differs, however, in illness stories and loss stories, is that when one recovers from illness it may be the end of the journey with complete recover/remission, whereas with a significant loss, there may not be an end to one's grief, but rather a new beginning of a very different life. What these two types of life experiences (illness and bereavement) do have in common in the quest narrative is that 'the teller has been given something by the experience, usually some insight that must be passed on to others' (Frank, 1995:118). By this, he states, that the teller moves from the quest story to a testimony. This is evident with a number of bereaved individuals, who either volunteer to help out others who suffer a loss or go on to write books and/or make other efforts to help, such as developing scholarship funds in memory of the person who died. Regardless of the kind of suffering, those who are transformed by it often want to help others with strategies that worked for them.

In the work of Hochschild (1983), Frank (1995) and Wilkinson (2005), it is evident that similar elements of Hochschild's concept of *emotional labor* are present for both illness, as Frank (1995) argues, and for the current topic of loss as brought forth here. People who suffer from illness as well as those in bereavement, are faced with comparable emotional tasks to make sense of their predicament since they have experienced a disruption to the life narrative. To find meaning and adapt to their new role, the bereaved self may need some assistance with the chaos storyline to bring it along and move to the 'present' with its' everyday struggles, and eventually look into the 'future' with less and less uncertainty and more hope. Temporal aspects of identity re-construction after loss are crucial with respect to personhood and suffering and aid us in

understanding how we can help the widowed person. For example, the ‘past’ life with their spouse is gone and can only be re-constructed through memories and stories with others from the informal support system who knew the deceased. One’s ‘present’ struggles, such as financial concerns or lack of intimacy, are also relevant in understanding the turmoil and chaos that accompanies spousal loss. And, lastly the emotional labor related to thinking about the future without the marital partner can also be overwhelming on the quest to repair one’s life narrative. These tasks are performed through various types of narratives as Frank (1995) points out, and may or may not be progressive, but can include one or all types of narrative, namely, the restitution, chaos and/or quest. Lastly, Wilkinson (2005) attends to an important aspect of human experience, that of suffering, and points out that if sociologists ignore what suffering can do to people, then we are left with a harshly reduced account of human experience which fails to tackle the most unsettling questions of meaning and morality.

In summary, contemporary selves are narratively constructed. For ‘troubled selves’ who join small groups in a formal support group setting (in general and for bereaved people) the compromised self that has been thrust into a new identity is nurtured and assisted. Participants are aided in adapting to a new identity, and the subsequent re-constructing of the self by friendly editors, or people who occupy positions (statuses) in groups, such as facilitators or long-time group members who have shared the same experience. This occurs through negotiations in self-constructive settings where troubled selves are of central concern as they enter and exit the group. Negotiation strategies include evaluations through comparisons (relational appraisal), where new identities are constructed, tried out and performed by participants where they learn how to construct the widowed self. Transformational activity, such as storytelling and writing about the new identity is another strategy. Norms cultivated include creating a group climate to

insure cohesion and the development of a particular language that has shared meaning. Indeed, today's troubled and untroubled selves are works in progress bombarded with social meanings and relations from many directions that greatly impact who we are and who we become.

Next, Chapter Three highlights and describes the methodological rationale, the design of the research including the setting and experience, methods for subject recruitment, the sample, along with methods used for human subjects' protection. It also presents the pilot, describes the procedures and instruments for data collection, data analysis including analytic memos along with field and transcription notes, coding approaches and analysis used in this study.

CHAPTER THREE - METHODS

Introduction

In qualitative research, the goal is to discover meaning. One goal of this particular project was to examine the formal grief support and not to generate a theory or new model for bereavement care. Rather, it was to examine this support in the lives of bereaved individuals and to see what would emerge from the data and how this information can be beneficial in challenging and extending dominant models and theories currently being promoted in work on grief and bereavement. This is accomplished by analyzing stories of contact with formal bereavement care providers through the recipients and their stories. It entails examining whether the encounter and support have had an impact on how bereavement care is interpreted. The task is to balance a symbolic interaction description with a discerning interpretation and reflexive analysis, which in turn holds these interpretations in the participants' experiences, interactions and stories. First, I will clarify why I chose a qualitative methodology.

Methodological rationale

The term 'qualitative' refers to specific methods of collecting and treating data but does not define the set of assumptions utilized to guide the researcher in his or her inquiry. Qualitative methods are often associated with alternative paradigms, yet they can also be employed within a framework of positivism. Guba and Lincoln (1994:105) note that 'questions of method are secondary to questions of paradigm.' To develop a methodological rationale, I first locate this inquiry within a paradigm, which guides me in my choice of method and in ontologically and epistemologically fundamental ways (Guba and Lincoln, 1994). Since it is critical that I outline my belief system in conducting this dissertation, I will define my assumptions concerning ontology, epistemology and methodology that dictate the selection of a paradigm.

First, beliefs about ontology depict one's perceptions of reality and question whether there is an objective world outside of us that can be captured and defined. Or, is reality more of an individualistic occurrence, something that is identified for and by people and their communities? I believe the latter, that people construct their own views of the world in ways that are meaningful to them. Given this assumption, my ontological location is one of relativism.

Next, epistemology defines our position on knowledge. How do we know what we know? What is knowledge and how is it gained? We may believe that a knower and the known are connected which makes the knower's position more subjective. Others may hold the position that the knower and the information to be known are completely separate. I identify with the former, holding a more subjectivist position as I contend that all acquired knowledge is filtered through individuals, and its' development is transactional, a creation for and by the knower (Guba & Lincoln, 1994).

Assumptions about methodology originate from a person's position on epistemology. Does the researcher have an impact on the subject or do they impact one another through the inquiry? What is their relationship? I hold the belief that researchers and their subjects mutually impact each other and therefore my position on methodology is one of hermeneutical/dialectical (Guba & Lincoln, 1994).

At this point, I can locate the paradigm that is consistent with these assumptions regarding ontology (relativism), epistemology(transactional), and methodology (hermeneutical/dialectical). A symbolic interactionist paradigm, the idea of society as the creation of meaning through interaction, captures these specific assumptions and is therefore my method of choice in collecting data and interpreting the experiences of bereavement care among Baby Boomers who have suffered spousal loss.

Methodology

In order to highlight the expressions of self-reflecting participants and capture the meaning this type of care has for them, including the overlapping features of their experiences of bereavement care, this chapter highlights how 38 Michigan residents were recruited and interviewed. The approach involves a more comprehensive focus and engaged position on the part of the researcher, rather than through the use of traditional methods where one remains separated from the field of study (Valentine, 2008). This chapter covers all aspects of the methodology, including comments on the research experience itself. I begin with a description of the research design, purpose of the interview and the questions, data collection methods (including details of the pilot study), mechanics of coding and some details of the sample.¹⁸ Lastly, the chapter lays out the interpretive and reflexive analysis process.

Research Design

The use of qualitative research provided an appropriate methodology to explore the experiences of bereavement care for Baby Boomers who have lost a spouse. Qualitative methods are preferred for obtaining complex details related to feelings, emotions, and thought processes (Strauss & Corbin, 1998). The use of a symbolic interactionist framework was employed to identify, define and explore the construction of meanings which arose during the experiences of care which includes capturing the interactive and dynamic process by which the self is formed. This approach requires a collection of interview data, written field notes and observations, memos that describe the researcher's impressions of the interviews, along with a transformation of the data through interpretation, resulting in creative insights into the collected data to identify units of significance (Groenewald, 2004).

¹⁸ Complete demographics are reported in Chapter 4 Results-1 Suddenly Widowed

According to Lofland and colleagues (1971) the essence of the research interview is the ‘guided conversation’ with all its simplicity of design and correspondence to the conversational procedures that are routine in social life. With this approach in mind, the project employs a qualitative exploratory descriptive design. Open-ended, conversational style, in-depth interviews with a focused interview guide [see Appendix D] are used to allow the freedom needed to probe for further information and are conducted with 38 respondents. Forced-choice questions are avoided so as to allow the participants to express themselves in their own terms within all dimensions of the interviews. However, all 15 questions on the interview guide are the goal and most are asked of each participant¹⁹ to seek patterns within this group.²⁰ In some instances, the participants gave lengthy answers and at times, the researcher skipped a particular probe which may have already been captured or was felt to be unnecessary given the thorough response to another question. The purpose of the interview instrument was to insure that key elements of the research questions are covered, which are: 1) What is the experience of formal grief care for bereaved spouses?; 2) Why do some people attrition out after a certain level of formal care and others do not?; and 3) How do various types of formal support services aid in the understanding of bereavement?

It is suggested by van Manen (1990:30-31) that human science research should be pursued ‘as a dynamic interplay among six research activities.’ It makes attempts to ‘ward off

¹⁹ An exception here is that the three pilots are approached with a list of bereavement care services [see Appendix E] with questions that follow along with the list that eventually led to the development of the Interview Guide [Appendix D].

²⁰ The interview guide contains 17 questions but after the pilot interviews, the last two questions are dropped due to the same responses from interviewees and the impression of useless data by the researcher. [see Appendix D]. Questions 16 and 17 are not used in the analysis.

any tendency toward constructing a predetermined set of fixed procedures, techniques and concepts that would rule-govern the research project.’ These research activities include:

- 1) turning to a phenomenon which seriously interests us and commits us to the world;
- 2) investigating experience as we live it rather than as we conceptualize it;
- 3) reflecting on the essential themes which characterize the phenomenon;
- 4) describing the phenomenon through the art of writing and rewriting;
- 5) maintaining a strong and oriented pedagogical relation to the phenomenon;
- 6) balancing the research context by considering parts and whole.

Addressing van Manen’s first point, I turn to this research endeavor as the result of previous work with bereaved individuals in a law office setting, as well as my own bereavement years earlier where there was a lack of formal bereavement care available. Although I did not encounter spousal loss, I have worked closely with those who have, including friends and a family member. While conducting this research, I discover meaning in the connections between my own bereavement and those in my clinical experiences as a grief facilitator of a support group. My search for meaning in loss within the bereavement care realm has taken form in my research questions for this study. I want to know about the experiences of those who receive formal grief support. Because I have been bereaved myself, I do not enter the research ungrounded. After a significant loss in my own life, I was directed by a professional in the local community to assist another bereaved person with her loss in order to bring meaning to my own. A stranger to me, I was put in touch with her as ‘one who knows the pain.’ At the time, there were no formal support groups that I was aware of in the particular small town I lived in, near Toledo, Ohio. It is from this space and from my professional paralegal work with bereaved clients that I came to be curious about what it is like for others and whether their support is sufficient. My own curiosity seeks meaning about the well-being of bereaved individuals and

desires to assist a growing population of suffering people which informs me as a researcher and as a sociologist.

As to van Manen's second point, 'investigating experience as we live it rather than as we conceptualize it', my experience of personal bereavement care along with my previous work with bereaved individuals are the starting points to investigate the experience for others. So, I ask, what is it like to experience formal grief support? I engage in conversations with other professionals who work in bereavement care. I then interview 38 bereaved spouses recruited from five distinct agencies, and it is through this process where they lay open their pain, grief and both informal and formal care experiences, that I came to know and understand their experiences and social interactions within the world of formal care settings.

The use of interviews involves an intensely personal and disciplined involvement on my part as it requires me to have an open attitude and a suspension of my preconceptions and biases. This is necessary to ensure that during the interview the participants are able to express the meaning of their care experience as fully as possible. It also means that I have to understand it and not prejudge what they say according to my personal or theoretical bias. The dialogue that we engage in consists of using standardized probes to assure that there were no leading questions throughout the interviews, but is often continued to help understand the meaning of what is being said. Kvale (1983:181) aptly describes this process:

The interviewer during the interview condenses and interprets the meaning of what the interviewee describes, and may "send" the interpreted message back. The interviewee then has a possibility of replying "I did not mean that" or "That was precisely what I was trying to say", or "No, that was not quite what I felt."...This form of interviewing implies a continuous interpretation-"on-line-interpretation,"...where the result is ideally a "self-corrective interview" with an "on the spot" verification or falsification of the interviewer's interpretations.

Direct contact with the participants helps to capture quotations surrounding personal perspectives and insight into experiences of this type of care. All interviews are audio taped so that I can be more fully attentive to each person's experiences. Each interview explores the interpretation of the formal bereavement care experience by use of specific questions, though additional questions were asked if topics were discussed that I felt needed more exploration. Finally, I jot notes and record my own personal observations of participants that could not be captured by a recorder, such as facial expressions, mannerisms, and environmental objects related to the deceased person (the latter when interviews are in homes, (see Appendix I). These notes are later transcribed into field notes and analytic memos.

As an initial test of the Interview Guide [Appendix D], a pilot with three individuals was conducted with participants who met the criteria as outlined for the project (discussed below). One goal of these interviews was to obtain information about the clarity and appropriateness of the interview questions. Another goal of the three pilot interviews was to minimize the potential for the participants feeling burdened during the interview. The elimination of redundancy and the adding of words for explanation results in questions that are easier to understand. These corrections to the language of the Interview Guide minimize the possibility for item non-response that will likely otherwise occur. As a result of the input from these individuals, more confidence in the layout and organization of the Interview Guide resulted. A more complete summary of the initial test of the Interview Guide is listed below. Data from these three interviews are included in the final analyses.

The Research Experience

In an attempt to understand the meanings that bereaved individuals give to their experience of formal care, in addition to the three main research questions that guided the inquiry, there are

other thoughts and concerns that are kept at the forefront of the interviews. For example, particular attention was given to the ‘language’ of participants and how they talk about, characterize and understand what is going on with support for them during bereavement. Are there accounts of conflicts between prior loss experiences and the information coming from the formal bereavement community to support them in their current loss? Along with listening for, and making sense of, the assumptions participants make about those who provide the care, I discovered what the recipients value and what they still desire from formal support providers, and these insights are equally important. Through this approach, I in effect, used “self as instrument” in the service of this research project (Rowling, 1999:168). As a result, I learned a great deal about what it means to be widowed from this group and the issues at both the individual and social levels for them. And although the findings emerge as a result of a two-way process, I have the additional tasks of collecting data, recording, exploring and explaining the constructions between myself and the participants in the form of a self-reflexive engagement with the project, which sets me apart from the interviewees and is detailed later in this chapter.

As I move towards the collection of interview data for this project, which began in the fall of 2009 and ended in late July 2010, I followed a collaborative model, viewing the participants as sharing in the research endeavor. I would also like to note that by taking a reflexive approach to research, I was more aware of how gaining access to the private lives of others can be one of conflicting and unpredictable emotions (as in Valentine, 2008). In addition, Guillemin and Gillam (2004) recognize this concern as a fundamental ethical tension. However, a review of the literature suggests that many bereaved individuals find it therapeutic to tell their loss story (Walter, 1996, 2001; Riches & Dawson, 1996; Rowling, 1999). This latter notion was confirmed by the participants, who seem eager to tell me about their experiences, and was also

validated through initial conversations with representatives of the five agencies who were involved in recruitment of subjects for this project

These five agencies -- a funeral home (Hensen Funeral Home), two grief support centers (Healing Place and Horizon of Hope Center for Grief Support) , a hospital/hospice (Good Fellow Health/Hospice), and a church-affiliated organization (Widowed But Not Alone)--recruit subjects who are using, or have used, the services provided through them. These services include grief support groups, social events, remembrance services and weekend retreats. More specifically, the funeral home provided support groups and remembrance services; the hospital/hospice offered support groups only; both grief centers held support groups and other events throughout the year, such as memorial services; and lastly the church-affiliated organization held religious services, grief support groups, and social events such as pot-luck dinners, picnics and dances. As a researcher, I had read the literature specific to interviewing vulnerable populations and involving sensitive topics which could provoke painful memories and emotions in both the interviewer and the interviewee [Riches & Dawson, 1996; Dyregrov, et al., 2000; Dyregrov, 2004]. I was certain that I was prepared for hearing the stories of the bereaved Baby Boomers who agreed to be interviewed. Surprisingly, I found myself easily drawn into the world of the widowed. Perhaps, I thought, this was in part due to the fact that I was interviewing within my own age cohort and at times imagining how I could easily be on the other side of the table. Self-care became an important part of my routine both before and after each encounter with the participants and included long walks and private talks with a close confidant without jeopardizing the privacy of those in the study.

Overall, the research experience was positive and without incident. Participants interviews in homes were cordial and welcoming²¹ and indicated a sincere desire to be a part of a research project that might provide help to other widowed people. Perhaps, though, they may have also been looking to a stranger with some expertise to get an appraisal of whether or not they are 'faring well' at this stage in their bereavement. Four participants in particular express a desire to help in additional ways (with this research study) if the need arises.²² Lastly, the research experience was instructive as it provided a deeper appreciation for the suffering and struggles of the Baby Boomer widowed population among a select group of Michigan residents.

Methods for Subject Recruitment through Michigan Agencies

The main research was conducted with 35 clientele recruited from five specific agencies located in Michigan. The pilot provided three interviews taking the total number to 38 participants. As mentioned, these agencies include a funeral home, two centers for grief support, a hospital/hospice and a religious affiliated organization.²³ One (1/35) participant in this study was recruited from Hensen Family Funeral Homes, who provide continuing care for the families they serve, including support group care. Four (4/35) interviewees were recruited from a center for grief support, namely Healing Place, who offer grief support to families and their children in the community. Nine (9/35) of the participants were getting grief support from a hospital hospice, Good Fellow Health Hospice. Twelve (12/35) were recruited from another grief center,

²¹ Those who met me in libraries and in agency offices are also pleasant and express a genuine interest to further the knowledge on formal grief care by participating in this research.

²² They are thanked and told that a note will be placed on their files for any future contact.

²³ Additionally, three remaining participants were the first to be interviewed and were made known through contacts within the bereavement community. These three fit the criteria for the study and either were participating or had participated in some type of formal bereavement care in Michigan.

Horizon of Hope Center who identify as a Christian based outreach center for grief support. Lastly, nine (9/35) bereaved spouses were recruited from a religiously oriented organization, Widowed But Not Alone which is a Catholic organization for the widowed who advertise ‘caring companionship and the opportunity for healing, spiritual development, education and new growth.’²⁴

I met in person with a representative for all five agencies after email and phone contact where the project was thoroughly explained. In the face-to-face meeting, the preferred recruitment protocol is determined and agreed upon by both parties. Participants are to be recruited using either a personal invitation letter signed by the participating agency [Appendix G] or through a newsletter announcement [Appendix H]. Time and other constraints made it difficult to expand the sample pool. In addition, a number of agencies originally expected to produce participants could not be involved in the research due to a lack of personnel to assist me.

Three of the agencies (the funeral home, the hospital/hospice, and one center for grief) chose to mail a personal letter of invitation to their clients [Appendix I], while the remaining two agencies (the other center for grief and the group for the widowed population exclusively) chose to include an announcement in their newsletter [Appendix J]. One representative also made calls to some of the people she knew in her organization who fit the criteria as she felt they would be willing to be involved in this study.

Sample

Sampling for this project involves a non-representative subset of the bereaved population. I used purposive sampling for the specific intention of gaining insight into the formal bereavement care experiences of bereaved spouses within the Baby Boomer population in

²⁴ Detailed descriptions of the five agencies can be found in Appendix L.

Michigan. This was accomplished by the use of the following types of purposive sampling, specifically, stratified, criterion and snowball.

First, a stratified sample of the larger sub-population was divided up by the characteristics of the particular subgroups of interest for the project, namely those who have lost spouses. Next, the use of criterion sampling was applied by choosing participants who have lost a spouse and/or partner between 1-3 years ago, were born in the Baby Boomer cohort (1946-1964), have been or are involved with formal bereavement support of some kind (i.e., on an individual basis or through support groups from the specified agencies for this research study); and have English as their primary language. Snowball sampling was also used through those initially interviewed who were asked if they knew of anyone in their support group who fit the criteria and might also be interested in participating in this project.

A total of 38 interviewees from 18 cities²⁵ within the state of Michigan agree to be interviewed. They reside in and around Lansing, Jackson, and southeast Detroit. The primary concern of the analytic approach adopted (discussed later in this chapter), is one that concerns a thorough account of individual experience, so the issue here for sampling is not quantity but rather quality (Saldana, 2009).

Description of Interview Setting

There were five interview settings -- the homes of participants, local libraries, a church building, one agency's office space, and a public gathering room where a support group met. Participants were asked if they prefer to meet in their homes or if they would rather meet in a public but private space. Fourteen of the 38 participants chose their homes for the interviews.

²⁵ Canton, Dearborn Heights, Fraser, Holt, Imlay City, Jackson, Lansing, Mason, Milford, Okemos, Parma, Plymouth, Romeo, St. Clair Shores, Stockbridge, West Dearborn, Westland, and Williamston

When visiting the homes, observations were made [see Appendix I] of the photos displayed and if there was attention drawn to the deceased person through way of shrines or other memorabilia, which were then recorded in field notes. The pilot interviews also helped to construct the observation list [Appendix I] which is addressed later in Chapter Five-Results 1-Suddenly Widowed.

Six of the participants met me in one of the agency offices. Private rooms in local libraries are also an option in some towns so that the participants could have a location that might be convenient for them (i.e., one woman met me on her lunch break which was close to her office). I met with fourteen participants in these library locations. Two participants opted to meet in a church in private space provided by the pastor of one town. One participant asked to come to my office located on campus after hours because she worked in close proximity to the university. And one participant requested her interview to be held at the support group meeting place two hours prior to the group gathering. All spaces were in a quiet and private place where interruptions are non-existent to minimal, where the bereaved individual seems comfortable to express emotions, and where privacy is respected.

Human subjects' protection

To insure no harm come upon the participants, I followed an ethical protocol as stipulated by Michigan State University's Institutional Review Board. Each interviewee, prior to the interview, signed an Informed Consent [Appendix A]. At the end of each interview, the participants were given the opportunity to further discuss and clarify any aspect of the research for which they may have questions [see Interview Guide, Appendix D]. Each participant is also presented with a list of bereavement support help available in the areas where they lived [see Appendix F as an example].

Instruments

Two instruments were used for collecting data from the participants. First, demographics were obtained on both the bereaved individual and on their deceased spouse [Appendix C]. For the bereaved spouse, they were asked to provide their name, address, gender, age, race, primary language, religious or spiritual preference, how many people are living with them after the death of the spouse, and their educational attainment. For their deceased spouse, the researcher obtains the name, relationship (i.e., spouse or partner),²⁶gender, age at the time of death, month and year of death, type of death (sudden or terminal illness), race, and their religious or spiritual preference. An interview guide [Appendix D] with 15 questions was then used for the purpose of giving some structure to the participants in discussing the loss of their spouse and the subsequent formal grief care.

Pilot

The research methodology included a pilot study with three participants who met the criteria and were recruited from formal agencies with personal contacts known to the researcher. This approach allowed for refinement of the interview protocol and testing of the recording equipment. These three participants offered comments regarding the interview process and the order in which the questions were asked, including the use of a list of bereavement care services as developed by the researcher [see Appendix E]. As stated earlier, data from these interviews were included in the analyses, and both demographic information on the bereaved and on the decedent were also collected.

Since the three pilot interviewees had difficulty with understanding the ‘list of services,’ it is deemed too awkward to keep in the study. A revision of the order of the interview questions

²⁶ Originally, spouses and partners were both sought in this research project; however the actual participants are either bereaved spouses (36) or bereaved ex-spouses (2).

resulted and the showing a list of services to the interviewee is discarded. There was also some minor refinement of the interview questions and probes. Reliability, defined as reproducibility and repeatability by Fos and Fine (2005), was validated as interviewees involved in this portion of the project express similar levels of understanding of the questions.

Interviews

After the three pilot interviews are conducted, the format for collecting data was changed by refining the Interview Guide for the remaining 35 interviews. Instead of the use of the awkward list with formal bereavement care services outlined, the researcher resorts to the use of an Interview Guide [Appendix D]. A brief standard introduction of the project was provided to all 38 participants before each interview begins and consent is obtained from all respondents. The research instruments for the project include Appendix C which was used to obtain demographics on both the bereaved person and the deceased, and an Interview Guide [see Appendix D]. Through the use of the latter guide, a sense of agency was provided to the actor and appeared to be valuable in their own lives. The guide allows probing where appropriate, and although there were a common set of questions to be addressed in each interview, there were allowances at the end of the interviews to cover topics and subjects that were not specified on the interview guide [see final two questions in Appendix D].

At the end of each interview, time was afforded to discuss the experience of participating in the research study with each participant (with no audio taping)²⁷ and in compliance with my university's Institutional Review Board, information was provided for local grief resources [see Appendix F]. The participants were also in possession of my contact information so that I can be

²⁷ However, notes were taken and transcribed for all conversations both before and after the tape was in use.

reached if difficulties arise following the interview. Lastly, all participants were sent a hand written thank you letter to acknowledge their contributions for this research [see Appendix H].

All audio files are on my personal computer located in my home. After transcription, the Word files were transferred to a flash drive and a hard copy of each transcript is kept in the locked file cabinet in my home. The audio files were also saved to a flash drive and the recorder is kept in a locked file in my home.

Confidentiality of Collected Data

The confidentiality of participants was achieved by assigning a unique number to each subject. Audio recordings indicate the first names of participants and I used these only to capture data and build rapport. The recordings are not utilized in any public forum and remain in my possession, and will be kept secure for 3 years. When this research is presented publicly, pseudonyms are used for bereaved participants as well as for the deceased spouses[see Appendix K] as well as for the five agencies involved in data collection [see Appendix L].

Data Analysis

Once I have the textual sources, the next step, according to van Manen's (1990) third point, was to begin the process of interpretation and identifying meaning units or themes. Data were analyzed to identify any themes that may add insight and knowledge towards issues facing this population after losing a spouse. Once the data were collected and the interviews transcribed, I worked closely with the text, coding for insights into the participants' experiences of care and how meaning about grief and bereavement was constructed before, during, and after interactions with formal care providers. The analysis of the interview data is intended to gain an intimate understanding of this experience through the stories of these spouses, and the interactions that may not be otherwise well understood, or perhaps may be taken for granted. A symbolic

interactionist approach was adopted to look for emerging patterns and meanings. An attempt to discover the meanings surrounding the experiences of care of the bereaved person was made by searching for words, phrases, semantic units, and themes which were then sorted into meaning units (such as previous loss experience; connections to informal support system, etc.) to make sense of meaning construction within this group (Bernard, 2006; Strauss, 1987).

This research study was not primarily concerned with creating a conceptual model, however some themes that emerged, such as viewing the support groups as safe havens and valuing the shared loss with similar others, follow experience patterns that can be compared to pre-existing grief models, and this was included in the analysis. The symbolic interaction approach offered an opportunity to understand how meanings are constructed surrounding these attempts to assist in bereavement from the perspective of bereaved spouses. For example, listening to accounts of how different groups of bereavement specialists – funeral directors, hospice nurses, counselors – discuss grief with the participants begs the question, how do the bereaved individuals perceive this support? Survivor stories were explored to uncover potential themes on the topic of how bereavement care providers contribute to understanding bereavement. The interpretive inquiry provided a description of the bereaved individuals' everyday support in their life-world in their own words (as noted by Smith, 1987).

The audio files of the interviews were transcribed into a Microsoft Word-processing program and converted for analysis using software for qualitative data analysis, NVIVO-9, where the text-based data were organized, managed and analyzed. A detailed coding and classification system was adopted and used as a guide [Appendix Q] for both hand coding and coding within the NVIVO-9 system [see Appendix Q]. The system was developed from the Interview Guide questions and probes, and contained four distinct categories, namely, 1)

definition of self;²⁸ 2) death-loss story;²⁹ 3) formal bereavement care services;³⁰ and 4) additional comments.³¹

Question one was initially constructed to allow for the participant to be relaxed and talk about themselves before having to stir up the death and loss story of their spouse. This question revealed the beginning of the central theme of the dissertation, that of a compromised individual and social self after the loss of a spouse. The answers to question one were coded as 'Definition of Self.' Next, the death-loss story was told in response to questions two and three on the interview guide. Given that I had preliminary information on both the spouse and the deceased prior to the start of the interview, I was able to insert the name of the deceased spouse and I had the cause of death (sudden death or one from illness). The answers to questions two and three were coded as "Death-Loss Story." The next 11 questions (4-14) involve the heart of the dissertation on formal bereavement care services and were coded as such. Lastly, question 15 was coded as 'Additional Comments' from responses to the inquiry about whether they have anything they want to comment on. The initial interview had two additional questions, 16-17, after the tape recorded interview that provided for an exploration of feelings about the interview and whether any questions were too difficult to discuss. They proved to be of little interest to the participants and produce little data, so they were discarded after interview three.

Pre-Coding: Field and Transcription Notes, Summaries & Analytic Memos

Pre-coding (Layder, 1998) of the data by highlighting significant participant quotes and passages that struck me as important or insightful (codable moments) was performed throughout

²⁸ Question 1 on Interview Guide [Appendix D]

²⁹ Questions 2 and 3 on Interview Guide [Appendix D]

³⁰ Questions 4-14 on Interview Guide [Appendix D]

³¹ Question 15 on Interview Guide [Appendix D]

the data collection stage (Boyatzis, 1998). As a result, these quotes become key pieces in serving as evidence regarding propositions, recommendations, assertions, and theory (Erickson, 1986; Lofland, et.al., 2006). They also serve as descriptive examples throughout the results sections. This process includes writing down words and phrases for codes on field and transcription notes for future reference when analyzing the data (preliminary codes). This was accomplished with my questions for the study in front of me, goals of the study, and a general list of questions to consider while coding the field and transcription notes as recommended by Auerbach and Silverstein (2003). These questions, addressed in part above, include:

- 1) How do these participants talk about, distinguish, and understand what is going on with support for them during bereavement?
- 2) How do these participants talk about conflicts between prior loss experiences and new information coming from the formal bereavement community to support them in their current loss?
- 3) What assumptions do participants make about the facilitators of support groups?
- 4) What are the central concerns of this sample with regard to support in bereavement?
- 5) What did I learn from my transcription and field notes as they relate to the overall research questions? And why am I including them?
- 6) What do the recipients of this care value about it and what do they still need?

Transitioning from pre-coding to more formal writing of the study included drawing up summaries for each transcript which give a snapshot of important quotes, along with a set of analytic memos after reflections on emerging patterns. These memos and summaries both make a contribution to the value of the analysis by careful reflection of the data.

First Cycle Coding

The coding scheme was modeled after Saldana's (2009) recommendations for qualitative research where the coding methods were divided into two main sections, first and second cycle coding. Those processes occur during the initial coding of data and were referred to as first cycle methods, divided into subcategories, such as exploratory, descriptive, procedural and theming the data. In addition, word and phrase coding of particular language of interest, such as those that became obvious throughout the collection of the data and were used by formal care providers, was also employed. This was accomplished by hand coding all 38 hard copy transcripts, using the developed codebook [Appendix N] which emerged from the interview questions, when collecting the data, and pre-coding. Themes were then transferred into this codebook [Appendix N] to define categories which were taken from a division of the Interview Guide questions by subject.

Second Cycle Coding

In the second cycle of coding, I engage in reorganizing and reanalyzing data coded using first cycle methods (Saldana, 2009). The task at this point was to “develop a sense of categorical, thematic, conceptual, and/or theoretical organization from your array of First Cycle codes” (Saldana, 2009:149). In this study, this was accomplished first by taking the codes from the written hand notes and then developing parent and child nodes through the use of NVIVO-9 software. First, parent nodes were created by sub-dividing the Interview Protocol. These consist of Widowed Identity; Death-Loss, Formal Bereavement Care and Additional Comments. In addition, parent nodes were created for Quotes of Interest, Extraordinary Experiences, Previous Loss Experience, Dating and Book Suggestions, which emerge from first cycle hand coding. Next, divisions within these categories were then listed and coded under the parent nodes as

child nodes in the NVIVO project file. An excel file was created listing the demographic information for the participants and linked to their interview files. And although NVIVO data software has sophisticated features to run summary coding reports and queries, I felt that it began to take me in a direction that was not consistent with my purpose and goals for the study. Therefore, I used it for organizing the data, creating practice models and helping to develop parent and child nodes, and textual analysis (e.g., frequent words used) which included finding coding errors. I do not use it further for the analysis as there was a temptation to quantify results and make comparisons, which is not consistent with a qualitative inquiry.

Post-Coding, Pre-Writing, Writing and Re-writing

Saldana (2009:185) describes the post-coding, pre-writing stage of the coding as one where, if all has gone well, the researcher will now “have several major categories, themes or concepts, or at the least, one theory (or through-line or key assertion or primary narrative, etc.).” Strategies were used in the post-coding stage to focus and begin to write. For example, I chose numerous quotes from the wide array of documents (transcripts, field notes, transcription notes, analytic memos) that struck me as the most representative of shedding light on my research questions. I arranged them in several ways, from the ordinary to the insightful and from the descriptive to the crucial which helped me to begin to write-up the results. This recurring collection of coding with transcription notes, field notes, analytic memos in connection with the hand coding and NVIVO coding of data, were a process termed ‘theoretical sampling’ and were not distinct linear processes but rather as Glaser & Strauss, (1967:43) recommend, “should blur and intertwine continually, from the beginning of an investigation to its end.”

“Writing separates us from what we know and yet it unites us more closely with what I know” (van Manen, 1990:127) The fourth interplay of the six research activities as van Manen

(1990) suggests, is to describe the phenomenon through the art of writing and rewriting. The writing stage separated me from the experiences of care, which in turn allowed for me to examine its essence. Writing moved me from internal to external as I relinquish, in some sense, the construction of a text and learn what I can say about it. The participant stories became abstract as I began to write about them.

The fifth point in van Manen's (1990:31) research activity involves "manipulating strong and oriented pedagogical relation to the phenomenon." By this he is referring to how the focus of the research should be guided continually and how it should demonstrate a pedagogical stance, one that can inform educational practice. He suggests that the writing, research and evaluative criteria needs to be oriented, rich, strong and deep. For example, for a text to be rich, he explains "the meanings of the lived sense of the phenomenon are not exhausted in their immediate experience. A rich and thick description is concrete, exploring a phenomenon in all its experiential ramifications" (152). This should include deep thought, radicalized thinking and action (in a pedagogic context). I chose to study the experiences of formalized care for bereaved individuals as the result of a deep personal questioning from within about their ongoing struggles from experiences of working one-on-one with this population. Additionally, I hope that it aids those who are bereaved of a spouse. This research informed my pedagogic practices, as symbolic interactionism is meant to show social life as 'process' rather than structure. It observes society as 'a complex web of collaborative actions in which participants are constantly reflecting, negotiating, and fitting their actions to others in order to achieve common objectives.' (Farganis, 2004:349). My pedagogic consideration lies with bringing to light some of the practical matters with suffering bereaved spouses and was sharpened and improved as a result of using a symbolic interaction framework.

Lastly, I exercise van Manen's sixth research activity: 'balancing of the research context by considering parts and whole' by having a concrete research plan as outlined in this chapter. I was (and am) fully aware of the effects this research may have on the people with whom the research was concerned; possible effect of the methods on the institution where the research is conducted; lingering effects on the actual Baby Boomer aged participants in the study; and the transformative effect on me as a researcher and as a spouse. To counteract the potential consequences, all participants were given a copy of other support services for grief in their respective living areas; I followed the consent approval as outlined by my institution for my own and their protection; and lastly, I practiced more self-care through exercise during the process of this research study and utilized ongoing talks with my spouse about this research topic.

Next, Chapter Four provides a selection of the literature, models and theories related to the discourse relevant to this dissertation, and includes the areas of grief, bereavement, death and dying. Concepts of sequestration and medicalization along with an appraisal of contemporary emotional culture are put forth. The age cohort, the Baby Boomers are introduced and an exploration of the extant literature on spousal loss. Bereavement care and a critical analysis of relevant literature are presented.

CHAPTER FOUR - A SELECTIVE HISTORICAL OVERVIEW OF LITERATURE, MODELS & THEORIES: DEATH, DYING, GRIEF & BEREAVEMENT

Introduction

For most people, the death of someone significant and the resultant grief is inevitable. Although the grieving experience may seem personal, all death and grief occur within social and cultural contexts that influence how life events are processed and understood. This influence typically begins within the family and comes in the form of support or challenges. It often continues through close others, such as friends, coworkers and others over the life course. Other sources of information and support include the media, self-help materials, and medical care providers associated with administering formal services for those dying and for those left behind after a death. Today, processing what was once private grief has become a public and social concern. One's experience of grief is addressed at many levels through various institutional caregivers, a process that often begins as soon as there is a diagnosis of a terminal illness. After a significant loss, bereavement care is part of the medical and social landscape. With the continuing push to medicalize all deaths and with the advent of hospice care, assistance with grief for survivors has become the accepted and compassionate response.

Given the complexity of bereavement in a multi-cultural society, however, practical issues (e.g., What types of support are available? Who defines bereavement care? Who administers it? Is this support helpful?) must be considered. For example, determining whether the formal support in place is considered 'bereavement care' may depend on the qualifications of the person or agency providing the services. This study presents the how's and why's related to formal bereavement care through the participation of bereaved spouses in these types of services. This chapter provides a conceptual framework to help understand the functions of this type of care through an examination of selective literature on: 1) death, dying, grief and bereavement; 2)

a shifting emotional culture; 3) meaning construction and narratives; 3) the Baby Boomer cohort; 4) spousal loss; 5) bereavement care; 6) symbolic interaction and interpretive reflexive analysis; and lastly, 7) a critical analysis of relevant literature.

To begin an exploration into the experiences of bereavement care, I provide a selective review of death and grief studies ranging from Freud (1917) through the first decade of the Twenty-first century. This review leans heavily on contributions from sociologists who study end of life topics which eventually led to the development of a sub-field in the discipline, referred to as the sociology of death, dying, grief and bereavement. It discusses changes in death and grief theories and models along with a look at the professionalization of medicine, sequestering of dying and death, and the eventual medicalization of both death and grief.

Development of a Discourse in Death, Dying, Grief & Bereavement: A Selective Review of Literature, Models & Theories

Early scholars in academic disciplines such as psychiatry and psychology (e.g., Freud, 1917) are well known for their development of an approach to help the dying and their bereaved family members cope with an impending death. In part, their studies evolve as the result of mass deaths which were the outcome of the First World War (Hockey, et.al., 2001). Systematic research on this topic later appears as a result of the Second World War (Small, 2001 In Hockey, et.al.,2001). Much of the scholarly work on death and dying continues on in these two respective disciplines for much of the early 20th century. In this early period, death was in the hands of the community and family. Kellehear (2007:251) notes that dying and death ‘began as a whole community affair with the dying being signalled to everyone by the biological death of one of its members.’ Bells rang throughout the town, curtains were drawn, and clocks were stopped. Death was public. Gradually, Kellehear continues, the deathbed scene (with the arrival of settlements and then urban developments) included more professionals and less community

members. Fast forward to the present where dying, death and grief are more public as they have moved from the family to more institutional settings. There is a professionalization of medicine and a medicalization of death and grief now engulfing us.

As a result, the general public as well as the scholarly community want to know more about how to deal with death and subsequent grief. We are less and less exposed to death experiences which brings a fascination of sorts with the unspoken topic. The 1940's brings ground-breaking studies, including one by Anthony (1940) on children's awareness and understanding of death. Lindemann's (1944) influential research into the Coconut Grove fire in Boston on acute grief processes among survivors of a devastating nightclub fire is also influential research. Using a psychoanalytic theoretical background, the study concludes that individuals need to *work through* grief to *break the bonds* to the deceased. This time period reflects an obsession with mental health concerns as deemed so by the medical professionals.

By the 1950's, as noted by Benoliel (1994), there is a surge of research interest in death and dying because of the rapid growth of organized sciences, as well as: a) funds for research in the area; b) the manifestation of the mental health movement (focusing on suicide prevention); c) an estrangement of many aspects of human existence connected with new technologies; and d) a prevailing death anxiety associated with the use of atomic weapons at Hiroshima and Nagasaki. There is an explosion of studies on the topics of death in this time period from various disciplines, including sociology. Again, since death is now medicalized and in the hands of professionals (medical, funerary, etc.), we are distanced from both death and grief in a sense, but fascinated with how people process these experiences.

Seminal studies include work by Gorer (1955) on the avoidance of death and empirical studies from Marris (1958) on widows in London. Feifel's (1959) contribution strengthens

recognition for the importance of the use of the sociological perspective. His influential research shows how legitimizing work on death by means of its power develops a multidisciplinary significance and a need for empirical confirmation,. Significant studies in other disciplines also made their entrance. Bowlby's work (1958, 1959, 1960) on attachment theory, for example, was brought forth from research on children who were separated from their parents.³² Basically, attachment theory is concerned with affectional bonds between people and their origins in childhood and adolescent relationships and the suffering that is caused by involuntary separation of these bonds or by their defective development. So, the focus now shifts from breaking the bonds to carefully examining their development, in life and after death.

The 1960's shows a new concern about the care surrounding those who are dying, evident in more sociological work. Parsons (1963), for example, suggests a central ideal type of American orientation toward the problem of the meaning of death. He describes a widely held, but criticized view at this time, that American society illustrates a kind of denial of the reality of death. Again, since families are no longer in the front lines of caregiving at the end of life (i.e., hospital deaths), we rely more on the medical professionals, which distance us from the realities of death. Now, expectations of the dying and survivors are that they face death in realistic ways (e.g., do grief work quickly and efficiently), in what he calls an active orientation to death. Parsons and Lidz (1967) further posit that American society assumes active, forward-looking members whose chief task is to carry out their social roles (In Charmaz, 1980). In failing to actively take on a new role, such as that of widow, one is considered to have a deviant orientation in response to a death.

³² Later, this theory was applied to bereavement by Parkes (1972), colleague of John Bowlby.

The search for meaning continues. Next, Fulton (1965) designs and teaches the first formal course in death and dying at an American university and subsequently writes one of the pioneering books using sociological theories, *Death and Identity*. Blauner (1966) explains how mortality and social structure interact to account for the meaning of death. In bereavement, for example, he argues that when mortality rates are high in a society, there is a large threat that death poses to the social system. In contrast, when mortality rates are low and people live out full lives, loss is less socially devastating. Consequently, there is a reduced amount of consideration given to the survivors resulting in normlessness when one is facing bereavement (Riley, 1983).

Glaser and Strauss' (1965) groundbreaking work addresses the issue of whether people die socially before they die biologically and what meaning this has for relationships. They present four types of awareness based on the behavior of dying people and their care providers: *closed*- where the person dying does not recognize the impending death even though those around them do; *suspected*-where the person dying suspects the others know and attempts to confirm or invalidate the suspicion; *mutual pretense*-where each person understands the significance but pretends that the other does not; and *open*-where both are aware and they act on this awareness relatively openly. The authors conclude that the essential distinction between social and biological death is apparent in the awareness of an approaching separation of self from others (Riley, 1983). Later work by Glaser & Strauss (1968) develops dying trajectories where the certainty and timing of impending death involved various factors including certain death at a known time, definite death at an unknown time, uncertain death but a known time when certainty will be established, and unconvinced death and an unknown time when these questions will be resolved.

Interest in the processes surrounding death continues to intrigue us through the 1960s. Sudnow (1967) provides accounts of the clichés, truths, and half-truths found useful for a dying person in a detailed study of the organization of death and dying in a modern public hospital. Sudnow describes what hospital staff refer to as ‘the dirty work’ of wrapping, ticketing, binding, cataloging and attending to the deceased body (Riley, 1983). It was during this time that psychiatrist Elizabeth Kübler-Ross’ (1969) seminal study on the processes of dying is introduced. Well known as the ‘stage theory’ of grieving for those dying, these steps include moving through five stages of denial, anger, bargaining, depression and finally acceptance. Eventually, this process was then applied to the bereaved survivors, but continues to be controversial as her observations were not intended for them. She also wrote and published a classic book in the field, *On Death and Dying*, in 1969 that was well received.³³

Moving into the 1970s, Pine and Phillips (1970) apply a sociological insight to functionaries of death, specifically the funeral industry. Parkes (1972), a psychiatrist, made significant contributions early in the 1970’s using the ‘grief work’ theory (and continues to do so),³⁴ identifying numbness, pining, depression and recovery as the relevant stages that follow significant loss. Research studies at this time focus mainly on the development of stages, phases and tasks of the grief work theory, which all imply that there is a goal to be reached.

³³ Some argue that Kubler-Ross’ work on the famous stages of grief as outlined in her book are not a work of scholarly research, rather, “it is a popular book of description, observation and reflection based on a series of dialogues with dying people.” (Kellehear, 2007, In Konigsberg, 2011)

³⁴ Four theories, identified by Parkes (1998), include *stress and crisis theory* which identifies reactions to grief by responses to stress we have developed; *Freudian* and *psychoanalytic theories* where repressed material is brought to consciousness in order to lessen psychiatric symptoms; the *attachment* premise and the *psycho-social transition theory*. Using a psychoanalytic theoretical background, grief was defined as a reaction to the loss of someone loved which elapsed without leaving traces of any unpleasant change.

Becker (1973) contributes to the development of thanatology with his view of society as a symbolic action system where one struggles to rise above death by being heroic. And Marris (1974)³⁵ explains behavior during bereavement through the psycho-social transition theory noting a need to adopt new roles, identities and skills along with reviewing one's philosophy of life. This latter theory proposes that life-change events, or 'psychosocial transitions,' require people to embark on a major amendment of their assumptions about the world. Kubler-Ross' (1975) work was now in use for those who were facing their own death and grieving their own loss of life. Later, the five progressive stages are used with the survivors of the death, in their bereavement process.³⁶ Others, such as Lofland (1976), along with Fulton and Bendiksen (1976), give us insight into behavioral processes of the bereaved, social structures, and disparate views of death in a way that helps to grasp the issues and problems that death creates in modern society.

In the 1980s, Charmaz (1980) argues that the cultural impact on grief was limited to the expectation that certain persons should feel grief and that this grief should be expressed and worked through. She suggests that our culture implies that the subjective interpretation of cultural meaning, in conjunction with the accumulation of personal experiences of the bereaved, gives rise to the very feelings that are defined as grief. Stephenson (1985) spoke of how there is great danger in looking at a solely psychological view of grieving as the entire responsibility

³⁵ Expanded later by Parkes (1993)

³⁶ In bereavement studies, models and theories have been used as frameworks for clinicians and practitioners for a number of years. Parkes (1998) made an important distinction between the two by separating them and identifying three influential models used to examine collective behavior, namely, the phase model which attempts to classify the processes of grieving; the medical model that notes how grief has many parallels with illness; and the grief work model that documents the agonizing effort required to realize the loss (Walter, 2001).

then falls on the individual which further implies an immature approach to the impact of the social environment.

Bowlby (1980) follows by expanding his attachment theory to adults in a psychoanalytic-cognitive theoretical background where four phases of grief, namely numbing, yearning and searching for the lost person, disorganization and despair, and reorganization are seen as necessary, and grief is viewed as a form of separation anxiety. Worden (1982) made recommendations to the mental health field that the focus should shift from stages and phases to tasks of mourning including accepting the reality of the loss, working through the pain associated with grief, adjusting to an environment where the deceased is missing, and emotionally relocating the deceased and moving on with life. Rando (1984) further develops this idea, discussing three tasks of grief that, in her view, are necessary to understand the experience and include emancipation from bondage, readjustment, and formation of new relationships.

British sociologists also make significant contributions in this timeframe with regard to hospital and hospice settings (e.g., Field 1989; Seale 1989; and May 1992). These studies produce an expansion in the areas of ethical and legal concerns. Around this same time period, in the U.S., standards are now set and a certification for death education and counseling are established. This occurs through the *American Death Education and Counseling* (ADEC), a thanatology association and interdisciplinary organization in the field of death, dying, and bereavement. Scholarly journals for publications are also making their debut (e.g., *Death Studies*; *Omega*). Specific to bereavement experiences, significant contributions are made by Hockey (1990) an anthropologist, in the examination of people living in residential care. In this study, participants continuously make references to their own age and talk about how they want the nursing staff to end their lives.

In the early part of the 1990's, the practitioners and professionals who work directly with the bereaved population expressed concern and were not content with the 'restrictive nature of stage theories' and as a result, 'fresh approaches were called for' (Dillenburg & Keenan, 2005:93). Littlewood (1992) responds with a look at new rites of passage after bereavement (e.g., marriage or childbirth) and whether they persist as a way of managing death in contemporary society. She considers attitudes towards death and dying in the West and discusses ways in which these attitudes affect one's bereavement. Next, Rando (1994) expands her earlier work to emphasize process measures related to grief that are oriented to the treatment of problematic mourning along with understanding healthy mourning through six processes. These are viewed as required for healthy mourning but not in a sequential way, and are known as the six 'R's', namely 1) *Recognizing* the loss, 2) *Reacting* to the separation, 3) *Recollecting* and re-experiencing the deceased and the relationship, 4) *Relinquishing* the old attachments to the deceased and the old assumptive world, 5) *Readjusting* and moving adaptively into the new world without forgetting the old, and lastly 6) *Reinvesting* in life (Small, in Hockey, et, al 2001).

In the mid-1990's, the work of Silverman and associates (1996) on continuing bonds with the deceased is viewed as falling within the psycho-social transition theory, representing evolution within a paradigm. This continuing bonds model is developed simultaneously by Walter (1996) and has received a good deal of attention. It came about as the result of a gradual realization by researchers (and the bereaved themselves) that people are not letting go of the deceased, but rather, they are continuing a bond with them in various ways that do not lead to being stuck in grief (Walter, 2007).³⁷ In previous times, as mentioned earlier, it was thought that

³⁷ Criticism, includes a study of 39 bereaved spouses by Field, et.al, (2003) who found that the greater the bonds with the deceased spouse, the greater the severity of the grief. Field's (2003) study suggests that continuing a bond with the deceased could be detrimental to a person.

one need to relinquish the bond with the deceased in order to accomplish a healthy outcome in bereavement.

Walter (1999) continues the work of Silverman and colleagues, and along with Riches and Dawson (2000), authors books based on empirical research and personal experiences of grief, on how it was managed and experienced at an individual and societal level (Exley, 2004). Walter has made major contributions in this area, especially with his writings in Clark's (2001) *Facing Death* series, as well as his own books, especially, *On Bereavement: The Culture of Grief* (1999). Here he discusses the social position of the bereaved and how they find themselves caught between the living and the dead, searching for some guidelines in a de-ritualized society where he writes at length about how he sees grief as policed and pathologized.

A fairly recent and well-received model of grief among bereavement researchers and care providers is the 'Dual Process Model' (Stroebe and Schut, 1999) which argues that mourners should work through the painful feelings and along with it, they need to learn new skills and get on with their lives. The emphasis is not on letting go of the deceased, rather, it stresses the backward and forward movements in grief. The authors suggest that this fluctuation cannot be done at the same time, therefore the survivors oscillate between being emotion focused and task focused. Walter (2007:132) notes that the most significant feature of this model is "that, being oscillatory in contrast to linear stage theories, it is impossible for it to become normative. No expert or well-meaning family member can tell the mourner what is 'normal' after, say, six months." Other recent attempts that remain somewhat popular in various settings include the Grief Wheel (Goodall, Drage, & Bell, 1994) which suggests there are no clear-cut dividing lines between each stage or phase of the grieving process but that each one merges into the next with some movement back and forth. Although it was viewed as advancing our approach because it

does suggest more permeable boundaries between stages, the grief wheel still holds on to the conventional idea of defining the experience of grief through stages. And yet, researchers had been noting that these stage theories were of little value for some time (e.g., Boohan, McGuiness & Trew, 1993) before the Grief Wheel came onto the scene and was intended to be used as part of training for medical personnel in the palliative care profession. The authors intended it to be used to ‘enable some people to move away from what is sometimes described rather rigidly as the ‘process of grief’ and permit a view of a more complex dynamic at work’ (Machin, 1995).

Borrowing from Small’s summary (in Hockey, et al., 2001), pioneering studies in the 1940’s through the 1960’s opened the field of death, dying, grief and bereavement. As society began to manage a person’s dying with few people present, eventually death became privatized. Kellehear (2007:251) suggests that ‘dying as a shared social, that is, interpersonal affair is becoming endangered as a publicly recognized form of conduct.’ Not only is there a privatization but there is a gradual sequestering of death and dying as both Kellehear (2007) and Walter (2008) posit.

Next on scene are service development, disciplinary progress and informal networks in the 1960’s and 1970’s. In the next decade we see a formalized version of networks and a building on the past. The 1980’s and 1990’s show an expansion of ethical and legal concerns as well as an unpleasant recognition that the scholarship is not advancing within the professions and through public opinion on the topics. The 1990’s show a revival of continuing bonds with the deceased, which carries over into scholarly studies in 2000 and beyond. This latter work includes the *Facing Death Series*, with books by Walter (2001), Hockey, et al., (2001), and includes textbooks by Howarth (2006) on the sociology of death for teaching undergraduates, and Kellehear’s (2007) summary of the current state of the sociology of death.

Walter's (2008) argument deserves special recognition as it shows the significance of the impact in this discipline from sociologists. He contends that it was Durkheim (1915) and his examinations of aboriginal rites (which were really funeral rites), that provides the foundation for a sociology of death. Durkheim (1915) believes that we need shared and performed practices in society to create 'categories of the understanding' without which collaboration and communication would not be possible, which he notes as the primary purpose of religion (Pickering, 2001:423). Walter (2008:317) also notes that Weber's (1930) work on the Puritan belief in predestination "privileged the human response to death." Responses to death and grief have changed immensely due in part to the privatization of medicine and the sequestering and medicalization of both dying and death. Parsons (Parsons and Lidz, 1967; Parsons, et al., 1972) also showed some curiosity in American deathways in his research studies.

Around this same time, Berger (1969:52) notes that 'Every human society is, in the last resort, men banded together in the face of death', suggesting that social order is created to keep chaos and anomie at a distance which come with death. Giddens (1991:161) reminds us in his discussion on the sequestration of experience that 'death is routinely hidden from view. In addition, death has become a technical matter, its assessment removed into the hands of the medical profession...'

A number of research studies in various disciplines outline the numerous theories and methods used to study these topics including Anthropology,³⁸ History,³⁹ Psychology,⁴⁰ and

³⁸ Van Gennep, 1960; Turner (1977) Danforth, 1982; Hockey 1990; Williams, 1990; Scheper-Hughes, 1993; Lawton, 2000; Davies, 2002.

³⁹ Aries, 1962, 1974, 1983; Stannard, 1977; and Vovelle, 1983.

⁴⁰ Freud, 1917; Bowlby 1969; Parkes 1996, Klass et al 1996, Stroebe and Schut, 1999

Sociology,⁴¹ as noted by Walter (2008). Regardless of which discipline was first or most important in laying this foundation, the topics of dying, grief and bereavement get a good deal of notice within scholarly discourse throughout the academic disciplines. A full understanding of where death and grief are situated both within sociology and society deserves a discussion to highlight the changes and challenges as reflected in the research, namely, the sequestering and medicalization of death and grief in society.

Sequestering and Medicalization of Dying, Death and Grief

Today's modern technological and medicalized landscape surrounding death has socialized the general public to talk about the dying and the their death as a 'series of medical events and interventions' (Walter, 2008:324). And, 'if no medical cause of death can be ascertained,' Walter (2008:324) continues, they are very upset. In other research (1994), Walter notes that the medicalization is part of a current process of secularization which has eroded the religious structure within which death was earlier seen. The soul was of great importance, for example, in deathbed scenes surrounded by family, close others and clergy. Today, the focus at the deathbed is generally on medications, machines and hope for recovery. We live in a time where we all, regardless of social class and wealth, have the worry of a 'medically induced long life' (Walter, 2008:324). Some research, namely Kellehear (2007) lays greater claim to the process of professionalization where both members of the clergy and medical personnel have stolen the knowledge of death away from the urban middle classes for at least two millennia (In Walter, 2008).

Giddens (1991) suggests that death, like mental illness, is sequestered to protect society. For example, Martin (2005, In Hilliker, 2006) a hospital employee, notes that when a patient dies

⁴¹ Glaser and Strauss, 1965, 1968; Blauner, 1966; Sudnow, 1967; Marris, 1958, 1974; Gorer, 1965; Seale, 1999; Walter, 1999; Riches and Dawson, 2000

in a hospital, the body is covered completely with a white sheet, placed on a special gurney (cadaver cart) which is designed to conceal the corpse by dropping the body down so it appears the cart is empty. The deceased body is transported to the morgue but the general public who may see the residents with the gurney have no idea that there is a body, as it is hidden. The body is then taken from the morgue using special back elevators and doors to unmarked vehicles owned by funeral homes. This sequestering continues as families of the deceased are then taken to a private room to display their grief so as not to upset other patients or visitors. Stephenson (1985:41) writes on 'avoided death':

...the lack of open observance of mourning and the individualization of grief have aided in banishing references to death in everyday living. No longer are those who are grieving easily identified. Any public display of strong feelings is considered inappropriate today. The relegating of death to institutions has removed death from the home, and hidden it behind institutional walls.

Mellor and Shilling (1993) also note that death is sequestered as they examine relationships between the sequestration of death, self-identity and late modernity. They argue that that the experience and organization of death have both become privatized by focusing on three central characteristics of high modernity: the growing role played by the reflexive re-ordering of biographical narratives in the construction of self-identity (Giddens 1991); the increased identification of the self with the body; and the shrinkage of the scope of the sacred.

These changes and subsequent research studies have impacted the models and theories surrounding the topics of death and grief. As we remove ourselves from the intimate details surrounding dying, by turning these concerns over to medical and funerary professionals, we become distanced from death. As a result, we find ourselves overwhelmed by bereavement as the shock and denial are often colliding and perhaps in need of constructing a story (or biographical narrative). Death and grief scholars have adapted their theories and models to

accommodate the changing nature of society. Each discipline brings a new debate and a new challenge, according to Walter (2008) from a denial of death to a sequestration and to an exposure.

Medicalization of Grief: Normal and Abnormal Labels

Reactions to losing someone close to us can be complex for various reasons. How we process the loss can be connected to the manner of death or the circumstances that surround it, a person's history of loss experiences, multiple losses over a short period of time, one's personality, the relationship to the deceased, and a lack of social support for the survivors (adapted from Worden 1991). The medicalization of death coupled with a more public response to loss, contributes to the medicalizing of grief with a need to distinguish what is a 'normal' response to what is 'abnormal'. This labeling surfaces in the medical community as grief and bereavement now need attention.

Reactions to grief are also categorized through the use of labels by grief scholars. For example, Worden (1991) suggests 'chronic' (where normal grief continues for an extended period of time with no satisfactory conclusion), 'delayed' (where reactions occur after a lapse in time post-death), 'exaggerated' (where a person is so overwhelmed by the symptoms that they develop major psychiatric disorders) and 'masked' (where one's reactions causes physical symptoms). This labeling provides a starting point for which to treat clients in the counseling arena and has been adopted in the bereavement care industry by some agencies.

According to Walter (1999), early in the 1990's, medical teachings (or what he refers to as clinical lore) put a great deal of emphasis on the three elements of expressivism, resolution and a notion of normal and abnormal grief. The first, expressivism, suggests that one who grieves should not only deal with their personal feelings but should also verbalize them. Next,

resolution implies that one should move along in their grief, letting go of the deceased person and return to emotional steadiness. These two expectations lead into the third, the 'normal' versus 'abnormal' labels, where not letting out feelings and holding on to the deceased will place one in the 'abnormal' range. In the past decade, however, there is a move away from this approach as we gravitate towards an acceptance of highly individualized grieving styles where diversity is recognized and an assortment of grieving behaviors are normalized.

Other labels are associated with grieving, such as complicated, chronic and traumatic grief. References to 'complicated' grief include irregular reactions following a loss of a loved one, for example, having signs of significant distress long after the death and the inability to function in one's everyday life. Some researchers (Prigerson, et.al, 1999:67) who previously used terms such as 'complicated grief' switched to 'traumatic grief' referencing both disorder and syndrome in their work and note:

Although we formerly referred to the disorder as 'complicated grief', we prefer 'traumatic grief' for several reasons. Similar to Horowitz, et. al (1997) we acknowledge the reaction to be a stress response syndrome and note that, as such, many of its symptoms resemble those of post-traumatic stress disorder (P.T.S.D.; e.g. disbelief, anger, shock, avoidance, numbness, a sense of futility about the future, a fragmented sense of security, trust, control). The trauma to which we refer represents a specific type of trauma - what appears to be a 'separation trauma'. . .

Others, such as O'Connor, et.al. (2008) indicate that daydreams about the deceased may present for some individuals a type of longing for the reward response that may make adapting to the reality of the loss more difficult. This view suggests that grief can be likened to an addiction and is labeled as chronic grief. Complicated grief, also referred to as 'prolonged grief disorder' is diagnosed using an assessment tool with various factors developed by Prigerson and colleagues (2009). These include separation distress, five or more cognitive, emotional and behavioral symptoms with a duration of at least six months from the onset of separation distress.

Supposedly, these cause clinically significant distress or impairment in social, occupational, or other important areas of functioning (e.g., domestic responsibilities). They must also not have a relation to other mental disorders such as Major Depressive Disorder, Generalized Anxiety Disorder or Post Traumatic Stress Disorder.

Re-emphasizing Walter's (1999) argument that the medical field defines normal grief by regulating and normalizing the emotions surrounding it, we can understand why there is so much research and terminology attempting to identify and define behaviors outside of what is considered normal and expected responses to loss. On the one hand, grieving is viewed as an individual experience and the person's emotions and behaviors are normalized, but on the other, there is a prescription from practitioners to keep within the realm of normal by utilizing these various models and theories to assist them. This paradox may contribute to a dependence on the formal care practitioners, where emotional expression is encouraged (although time-limited) but frowned upon in the presence of close others, such as in the informal support system.

Conflicting Emotional Culture

Societies have different norms for expressing emotions and vary in expectations for expressing these emotions and in regulating them. These differences are all part of what is known as an emotional culture. Cultural prescriptions for emotional expression and emotional control are passed on through various institutions in society. The family socializes us from early on and the media bombards us daily with messages on appropriate behavior and emotional reactions, for example. To explore the relationships between emotional culture and emotional experience, I study the bereavement care experiences of these 38 participants within a group setting. I attempt to gain an understanding of how their emotions have been created, maintained, and challenged while grieving the loss of a spouse. One element of 21st century emotional culture

– personal control over expression of emotion – plays an important role in these participants’ experiences of care. At this point, I provide background on how others approach the ways in which emotions are managed and expressed within the social environment. To understand emotional expression in contemporary society, I look to Hochschild’s (1979,1983) influential work that remains relevant today, that every society includes a set of norms to direct individuals on how they should behave and what they should expect concerning emotions. This is accomplished through ‘feeling rules’ which encompass the extent, direction, and duration of felt emotions for social situations. These feeling rules are recognized as significant because they serve as cultural teachings that form suitable emotional responses to one’s life events and experiences (Carr, 2006).

Individuals’ feelings surrounding life altering events are now vitally important. Feeling rules for grief are similar to other rules for feeling emotion, although they tend to last longer than other emotional states (Stroebe, et al. 2001). As these private feelings are firmly placed onto the public agenda (e.g., in medical training, hospital routines, through a new wave of specialists for care, and as an interest to the media, etc.), they are center stage (Walter, 1999). Although informal support for life changing events has existed throughout time from family, church, friends, neighbors and work colleagues, along with some types of formal support from physicians, and religious figures, a weakening of traditional support systems has altered the landscape for coping with life events within the family and with close others.

With an increasingly fragmented society due in part to the geographic mobility of the family, transient neighborhoods and career and job changes, people may seek more formal guidance on how to express feelings and others may refer those struggling with grief to professional communities. Although the individual may choose his/her own approach, there is a

curiosity in what the experts are advising. These experts come from a wide range of institutions with varying credentials and assist people with the expression of emotions, or provide guidance and empowerment for life changing events.

There is now a new wave of expert care providers. Life coaches, for example, became the rave in the early 21st century, as the media note in reference to the new trend, “Personal growth is hot. Diagnosis is not” (Peterson, 2008). Life coaching emphasizes empowerment and partnership with guides who provide their clients with confidence to get unstuck whether this involves relationships, careers, or just simply pulling their life together. The goal is to define a better future for the client. If you feel ‘stuck’ or particularly ‘worried,’ a life coach is your new option. According to Patrick Williams at the Institute for Life Coach Training in Ft. Collins, Colorado, life coaching will, “change the face of psychotherapy, helping people live a better life without the stigma of needing a diagnosis or a visit to a psychotherapist they don’t want or need” (Peterson 2008:4). However, experts in the field of mental health are concerned because this new field is virtually unregulated and even though those who provide the assistance take extensive coursework, others are working without any credentials. David Fresco, a psychology professor at Kent State notes that “there are no qualifications, no unified approach to coaching, no oversight board. Basically they fly under the radar screen of any sort of oversight” (Peterson, 2008, USA Today Online).

Bereavement care, as well, is on offer by those using an array of titles from various disciplines and industries (psychology, social work, religion, nursing, funeral homes, hospitals, hospice organizations, etc.) that suggest an expertise in the field of grief and bereavement (e.g., grief management specialist, bereavement care specialist, certified thanatologist, etc.). These titles are misleading as they imply that this area is well-established and specialized. A variety of

people ranging from qualified professionals to trained volunteers administer care. A report in 2005:382, from the *International Work Group on Death, Dying and Bereavement*⁴² notes that there is a failure to develop distinct criteria for the provision of social support for bereaved persons, including grief counseling and grief therapy, which contributes to a plethora of “inadequately trained persons working with the bereaved.”

There are some standards set by the *Association of Death Education and Counseling* (ADEC), who offer a Certification in Thanatology (CT) to those who hold a bachelor’s degree and two years of related experience in the area of death and grief work. However, agencies who offer bereavement care do not all require a person to be certified, nor do they require that those who work with the bereaved individuals have a college degree in some instances. Konigsberg (2011:111), whose work has caused controversy in the death and grief care industry suggests that the ADEC requirements⁴³ are inadequate because they do not require a graduate level degree or clinical supervision, yet they enable CT’s to use titles (e.g., bereavement educator) and to operate and facilitate support groups for various institutions and agencies “which essentially

⁴² “The International Work Group on Death, Dying and Bereavement (IWG) is an invitational international organization that seeks to advance and nurture the development of the field. Further, IWG provides leadership and support to those involved in death education, in the care and support of the terminally ill, in the care of the bereaved, and in promoting research, evaluation, application, and policy development in these areas.” (<http://www.iwgddb.org/>, accessed January 22, 2011)

⁴³ According to the ADEC website, the requirements for Certification in Thanatology (CT) include the following: ‘applicants must have: a) A bachelor’s degree (include transcript) and two years of verified related experience*; b) Or a master’s or doctorate (include transcript) and one year of verified related experience; c) 60 documented contact hours** in thanatology and related topics; and d) 2 letters of support from supervisors or colleagues.

* Related experience is self-defined.

** The 60 documented contact hours are defined as education in thanatology or specific topics identified in the CT® Content Outline in the Candidate Information Bulletin. You must provide documentation for these hours.’

puts them on the front lines for encountering the bereaved.” The main goal of these formal grief care providers is to help identify and draw out the pain of grief, also known as emotional labor, which some argue needs professional assistance.

There are significant shifts in the discussion of emotional labor and cultural scripts in general (e.g., Turner & Stets, 2006) as well as in relation to grief, noted by numerous scholars over the years (e.g., Gorer, 1965; Lupton, 1998; Walter, 2001, etc.). Anderson and Mullen (1998), for example, argue that there is a popular culture of sentimentality, which in turn values a person’s emotions to be something of great value in today’s society (including those from grief, [Walter 2001]). After a death-loss, for example, there are a number of circumstances brought to light by Walter (2001) involving money, inheritance and the shifting of social status that are affected. However, in modern times, many of these concerns have been regularized. Walter (2001) continues to highlight that with preventive health measures and other medical advances, most people now live until old age. As a result, survivors are rarely left destitute and status is no longer provided by parents and spouses (but rather, in part, by educational achievement). Because of these changes and advances, people have lengthy relationships and stronger personal attachments. The new distress in bereavement has turned to the emotional state of the person, regardless of gender, that now demands attention (as opposed to a loss of status or income as in previous times) and bereavement agencies attend to the expression of emotions as the top concern (Walter, 2001).

Another influence regarding feeling rules for bereaved people comes from the self-help industry. Kubler-Ross’ (1969) book, *On Death and Dying*, is a huge contribution to the cultural expectations on how one grieves when dying, and although outdated and controversial, is still in use in some circles of support today and has been transferred to the grieving survivor.

Assistance with feeling rules continues with hundreds of thousands of available popular references ranging from Canfield & Hansen's (2003) *Chicken Soup for the Grieving Soul* to Harvey's (2007), *Grieving for Dummies*. Personal memoirs that top the *New York Times* Bestseller list (e.g., Randy Pausch's (2008), *The Last Lecture* and Joan Didion's (2007), *The Year of Magical Thinking*) accompanied by many others (e.g., Joyce Oates' *A Widow's Story*, (2011) and David Plante's (2009) *The Pure Lover: A Memoir of Grief*,) are making frequent headlines. Perhaps, these narratives are coming out as the result of the 'self as authority' argument by postmodern scholars (see Walter's Typology, 1999:186 in Figure 2.1).⁴⁴ There are also display rules for grief which indicate how expressions of grief should occur, when it should be displayed, how long one should express grief and who is expected to show grief for whom (Kearl, 2002; Hochschild, 1983).

Grief is also policed, as noted in early work by Durkheim (1915) and most recently by Walter (1999). In the West, for example, the bereaved are expected to express feelings of anger, guilt, regret and sadness, but less acceptable are feelings of relief, happiness or surprise. The display rules on how to express grief also put parameters around how, when and how long, as well as who is expected to show grief for whom (Doka, 1989). In terms of our emotions and consciousness, Turner & Stets (2006:47) point out that although most sociological theories focus on feelings, emotions are not always conscious, rather, "emotions expressed by individuals are not always the same as those they actually feel," which contributes to the idea that grief is policed and scripted by the general public as in the medical community.

⁴⁴ In traditional times, for example, Walter notes that religion was the authority in bereavement and provided a script for the survivors. In modern times, the shift from religion to medicine as the authority and in late modern times, therapists became the expert of choice.

This conflicting emotional landscape brought forth an apparent need for experts in numerous helping professions to assist people with life changing events. In bereavement care, the provision of formal services through providers who range from highly educated and specialized individuals to volunteers, and who recognize the needs of all bereaved individuals, transcending culture, gender, race, religion, and class, are abundant. The emphasis on emotional expression contributes to an emergence of formal care providers who assist people through the roller coaster of feelings and emotions at the forefront of a traumatic life experience. Unfortunately, today's culture does not provide people with a clear sense of how to interpret the meaning of personal life changes, given the emphasis on individualization, and this gap contributes to an ongoing quest for meaning.

Meaning Construction and Narratives

With a decline in religious beliefs, changes in family patterns, various belief systems, weak informal supports, along with other factors, an individual experiencing a traumatic life event finds that they are situated in the midst of competing and contradictory meaning structures (Riches & Dawson, 2000). Some life experiences, such as spousal loss, may alienate people from any possible meaning structures held, which leaves them drawing on other social networks for support in making sense out of the situation and of the new roles in which they find themselves.

To help people understand their changed circumstances, support from informal and formal sources assist in the search for some meaning in the loss. Death in traditional society was assisted with a cultural framework through constructed rituals, ceremonies, and belief systems. These give a set of meanings to help in processing the loss and locate the death within a common set of assumptions already in place (Anderson & Mullen, 1998). A collective agreement is held

in this scenario with explanations for the event and recommendations for dealing with it.

Today's lack of assistance for meaning making among our informal support systems, coupled with weakened belief systems, fewer communal rituals, and a move away from religious ceremonies and towards a sole celebration of the deceased's life (without the body present, for example), impact adaptation to changing roles that come with the loss of a significant other.

An exploration of meaning-construction within these experiences is crucial since the self may be damaged by the trauma of death and loss. Riches & Dawson (2000) suggest examining questions, such as 'Are the bereaved guided or abandoned in today's society in their attempt to find meaning in their loss?' and, 'Are social networks and the experience of bereavement care adequate for the bereaved person to construct meaning and make sense of their loss?' Individuals may feel cut off from meaning structures they once had due to the unpredictability in which each family member may grieve the loss and be unavailable to one another for support (Riches & Dawson, 2000). Gubrium (1988) reminds us that the family has long been at the heart of an individual's treasured view of the world, so loose kin relationships leaves people wondering how to make sense of the death and the many strong emotions that occur. They may find themselves propelling into new social networks (mutual help groups) where bereavement care providers hold assorted training and experience from many disciplines of study and walks of life and where the emphasis lies solely for concern in the emotional realm.

Through interviews with 38 bereaved spouses, this study explores the meaning-making process during the experiences of bereavement care, specifically through an investigation of how spouses construct the care. Meaning-making is a vital element of the recovery process from any trauma (Harvey, 1996). Frankl (1992) discusses the significance of meaning by commenting on how the primary motivation in a traumatic life event involves a search for meaning and

purpose. Although the search is necessary, the construction of meaning is an ongoing process which takes place as new information is brought into focus (Pearlman & Saakvite, 1995). To facilitate the construction of meaning, for example, bereavement care programs often incorporate special memorial services, educational materials and other activities to help the bereaved with an ongoing opportunity to make sense of the loss and their current circumstances.

Support groups for the bereaved, as well as individual grief counselors, attempt to assist survivors with a reconstruction process. Parkes (1996) labels this a psychosocial transition; Walter (1996) names it biography; Stroebe (1997) calls it a process of restoration; Riches and Dawson (1996b) describe it as rethinking lives, roles and relationships; Balk (1997) refers to it as reminiscence; and Arnasson (2000) along with Neimeyer (2001) call it narrative (in Parkes, 2003). This process of reconstruction enables the bereaved person to create a story where they can make sense of their loss. As Walter (1999) suggests, the dominant ‘restitution’ story told in mainline culture, where survivors need to rapidly reinstate themselves to normality, is rejected in formal care, a place where they can mutually disclose their pain and share the life of the person who died. As noted earlier, some writers are producing books⁴⁵ that speak about their own private and painful experiences of grief (popular authors such as Pausch, Didion, Torres, and Jameson). Many are highlighted in the media, and the idea of the importance of a storyline is carried into the bereavement community. Books from past decades provided guides for the widowed (e.g., Foehner & Cozart, 1988) which used a step-by-step approach providing important practical tips (i.e., the table of contents often include the ins and outs of enlisting legal help or filing claims for life insurance, etc.). In a postmodern landscape however, the emphasis

⁴⁵ These popular writers also contribute to the invention of the ‘grief process’ as pointed out early on by Wambach (1985/86:208) who notes that ‘The social invention of the grief process points up the interactions among widow, popular writer, professional, and research investigator.’

on narrative construction has now warranted training for doctors, clergy and other professionals who can assist with this task of constructing a story with bereaved persons (Walter, 1999).

Those who work in bereavement care are also examining new ways to use the communicative arts as a tool for an outward expression of the inner conversations held by the bereaved person (Whiting & James, 2006). According to Neimeyer (2000), these formats include methodologies such as sacred art, guided journaling, photography projects, shrine making, life reviews, and videography. It is expected that these activities can assist in successful narrative reconstruction on offer through bereavement care. This assortment of activities may be of interest to those who are known for wanting new options in terms of products and services, those born in the Baby Boomer generation, and who are the focus in this sample.

Baby Boomers

The Baby Boomer generation are on record as the largest age cohort in the U.S. and in the world, and a cohort that historically has expected society to create new services to meet their needs (Dychtwald, 2000; Hall 1990). Baby Boomers are recognized as post World War II (b. 1946 to 1964), creating a diverse population with a spread of almost two decades. Mellor and Rehr (2005) suggest that because of this span, the Boomers display wide differences in their experiences. Yet, in terms of aging, the Boomers as a cohort look forward to more from life than their parents and grandparents did, as Johnson & Forman, (2009:32-33) point out:

There is one overriding reason why boomers simply can't accept the traditional paradigm of aging—they expect more from life than any previous generation. The result of historic changes in American life is that baby boomers entered adulthood with unprecedented access and options. They developed a bias toward having multiple choices for just about everything. The educational system, the social environment, and relative prosperity created a predilection for the availability of options in all areas of life. Building on these generational attitudes, boomers have defined the approach to every life stage they have moved through.

They expect to be in control. They want to make a difference. They insist on happiness and self-actualization, and they presume that they will manage even the physical changes that accompany aging.

By the year 2030, the last of the Baby Boomers will have turned 65, which will account for 18 percent of the population (Barry 2011). This scenario gives us almost two decades of catering to the needs of a very large (and to some, demanding) age cohort. Further, these expectations and needs will continue on into the Boomers' old age requiring a deal of attention from the grief care industry.

According to Gillon (2004), Boomers, in general, hold a sense of entitlement like no other age group. He claims, for example, that the way in which Boomers were nurtured and raised under the child-as-individual teachings of Dr. Benjamin Spock, along with the media's child-directed advertising, both contribute to this sense of entitlement. A Boomer himself, Gillon notes, "[i]t created a sense of entitlement that had not existed before...we became more concerned with our own emotional well-being, whereas to older generations that was considered soft and fluffy" (in Barry, 2011:A3).

This more demanding personality type is now at the heart of products and services in the death care industry. Boomers are recognized by funeral home directors, for example, as those who want a more personalized funeral for themselves and for their families, a sort of custom-designed service. Bill McQueen of St. Petersburg, Florida, inherited a funeral home after his father died unexpectedly and has changed the name from a funeral home to *Family Tribute Center* which operates under the motto of Love, Life, and Legacy (Albright, 2009). McQueen states that they gear their services more toward that of a hospitality business due to the overwhelming requests from Boomers for more individualized services. Although Boomers are viewed as a demanding age group with higher expectations, on a more positive plane, it has been

noted that they are seen as psychologically more resilient than their parents' generation (Mellor & Rehr, 2005). Boomers demonstrate that they are more willing than their parents to seek help when life's losses endanger their well-being (Washington Post, 2010). One such loss in this group, is that of a spouse.

Spousal Loss

Spousal death is one of the most stressful life events with scores of recent studies noting that the deceased spouse is deeply grieved (Zisook and Schacter 1991, Kaunonen, et al, 2000, and Bonanno, et al 2002). The Social Readjustment Rating Scale (SRRS) deems spousal death as an experience that requires the most intense adjustment (Carr, 2006). Fairly recent research specific to spousal bereavement has focused on particular concerns, including: 1) gender differences among survivors (e.g., Powers, et.al.,1994; Martikainen & Valkonen, 1996:1998; Bauer and Bonanno, 2001; Stroebe, et.al., 2001); 2) symptoms of stress (e.g., Avis, et.al., 1991; Liberman & Yalom, 1992; Hyrkas, et.al., 1997); and, 3) social support (e.g., Liberman & Yalom, 1992; Caserta & Lund, 1996; Thuen, 1997b; Duke, 1998; Kaunonen, et.al., 1999; Danforth & Glass, 2001; Stroebe, et.al., 2001).

An important theoretical model for spousal loss was developed by Utz (2006) and was adapted from an earlier bereavement model put forth by Stroebe & Schut (1999). In the extended model by Utz (in Carr et al., 2006:186) there is emphasis on "how the experience varies across individuals and social contexts." Extending the understanding of how people cope with the restoration-oriented tasks as outlined in the DPM by Stroebe & Schut (1999), the new model shows how these tasks play into a bereaved spouse's distinctive experience of bereavement.

In addition, an analysis on spousal bereavement (Bonnano, et al., 2002) for those aged 65 and older, known as the Changing Lives of Older Couples (CLOC) study, reports that older widows and widowers are resilient and show little or no depressive symptoms at six and then again at 18 months after the loss of their spouse. However, it was also noted that at this stage in life, many view the death of their spouse as a natural part of life and adapt somewhat easier than their younger counterparts. In the current study, it is brought forth that the adjustment tasks related to losing a spouse in what now is considered mid-life (46-64) is seemingly more difficult than losing a spouse in late life (>65+) when death is more expected.

Research on bereavement care experiences of surviving spouses has not received much attention, with the exception of some studies that are specific to a particular type of professional (Main, 2000; Wiles, 2002; Payne, et al, 2002). However, these do not focus on the care itself for the participants of the services, some of whom were bereaved of a spouse. Main (2000) looks at the views of bereaved patients (regardless of their type of loss) in a general medical practice to find out what the expectations are in the way of bereavement care from their doctors. Results show that the majority of the sample feel as if bereavement support is a very important aspect of the role of the general practitioner (GP). In particular, the survivors note that practical measures should be taken by the staff of the GPs' offices to readily identify them within the system so that office staff are more aware that they are recently bereaved which might provide more sensitivity (in Wimpenny, 2006:131). Along similar lines, Wiles, et al., (2002) looks at factors that influence general practitioner referrals of a bereaved person out to a bereavement counseling service. The study found that GP's see factors such as the nature of the death, the level of social support, and the reaction to the death as determining factors in what may contribute to abnormal bereavement. Counselors are interviewed by Payne, et al., (2002) to learn the approaches in use

for counseling bereaved individuals. The majority adopt strategies that involve telling the story of the loss, active listening, establishing a supportive connection, and allowing the person to deal with any unfinished business.

Recent studies that examine widowhood exclusively (Zisook and Schucter 1991; Powers et. al., 1994; and Bauer and Bonanno, 2001), and one in particular on younger widows and widowers, show that the younger surviving spouses are more vulnerable and exhibit increased psychopathy. It should be noted that the samples in these studies had age-diverse participants which do not explicitly reflect on the distinctive case of a particular group, such as Boomers. Carr, et al. (2006) look at the bereavement experience itself in numerous contexts (social, psychological and historical), and present research on widowhood from social scientists who study bereavement but nothing evidenced on the assessment of bereavement *care* experiences of surviving spouses, the focus of concern in this study.

An extensive review of the literature on spousal bereavement, produced under the direction of Wimpenny (2006) by the faculty of Health and Social Care at the Robert Gordon University in Aberdeen, Scotland, brings attention to five key messages for spousal bereavement. They note that the whole family should be considered in the process of spousal bereavement by agencies who offer support such as how to facilitate support mechanisms for the bereaved through family and friends. Next, they suggest how support services should recognize that families often report that symptoms of grief decrease over time even though these are severe in the initial period following the death. It is also recommended that practitioners know the importance of reminiscing for the widowed population and that the less secure an individual is, the less they reminisce. In addition, it is advised that through a systematic assessment to identify high risk factors, “services should provide a primary preventative focus of care for high-risk and

high-distress individuals” (p.74). Lastly, the authors stress the importance of education for both the bereaved individuals and the support providers in bereavement care to integrate the varied ways that grief may present itself.

Bereavement Care

As noted in Chapter One, bereavement care is a general term that incorporates bereavement support which may come from professional networks consisting of healthcare providers and various other agencies (e.g., legal, religious, mortuary, etc.) or from those working for non-profits. This support is variable and ranges from professional grief counseling to volunteer-based administering of grief services. Coordinators of this care may be those who are working voluntarily, those in paid positions, or those who are hired and paid through contractual work as consultants. This grief care includes a wide array of services, which can involve personal conversations with professionals, written information, and offerings of workshops, support groups, and/or retreats. These services can occur within formal bereavement *community networks*, which are broadly defined as “those who may offer anchors of a different nature” (e.g., spiritual, church and community groups/agencies) perhaps through support groups or individual counseling services, which generally offer emotional support (Lindsey & Yates, 2003:167).

Appropriate support is often evaluated first through understanding the bereaved person’s situation. For example, it would seem suitable for funeral home personnel to hold a conversation with the chief mourners immediately upon the taking and receiving of the body of the deceased to determine whether the survivors need help with practical matters. However, it may not be appropriate at the initial meeting to give the newly bereaved a great deal of informational support. This type of support may be beneficial once the shock has been absorbed and they have an informal support person with them to help process this new information. There may also be

cultural constraints and protections put in place by family members who may be restricted in voicing their preferences in the midst of the initial shock and their early grief circumstances. It is often a challenge for formal care providers today to know how to provide help for grieving people, one where cultural, social, and individual factors need consideration.

As noted by Walter (1999), the two most common types of bereavement care are individual counseling and mutual help support groups. He suggests four varieties of groups generally on offer, which include those who accommodate people whose relatives die in common events, groups for those who survive a death in separate incidents but the bereavements were of the same nature (i.e., spousal loss, child loss, sibling loss, etc.), groups who provide support for those who survive death as a result of violence, and, lastly, general support groups who utilize a professional to provide assistance through a bereavement agency. Walter also brings to the surface some important questions about the social dynamics within the mutual help groups, and explores whether or not they help the passage through grief. He refers to the groups as communities of feeling which create a subculture where the deceased is the central actor. Shapiro (1994:1996) suggests that people will continue to attend the group if the group's storyline is a good fit with their personal experience (in Walter, 1999). In other words, the narrative needs to allow for the dead to continue to live on, and the recognition that grief has no end and no cure but is transformative. This scenario can be encouraging to those who want to create and continue a story, and for most is more logical than having the focus on resolving or recovering from a senseless loss (Riches & Dawson 1996b in Walter 1999).

Articles of interest surrounding these interventions include those that explore timing and value, as well as the benefits of counseling. For example, Allumbaugh and Hoyt (1999) examine the effectiveness of grief interventions with self-selected clients at a particular time in

bereavement and suggest that early intervention (within a few months of loss) can be just as effective, perhaps even more effective, than that of psychotherapy in general. The literature also explores benefits of counseling, (e.g., Parkes, 2000) where those who suffer from traumatic and unexpected loss (and who were also vulnerable in other ways) could benefit from professional counseling. In the United Kingdom, a survey of ex-clients from Cruse Bereavement Support⁴⁶ by Gallagher and colleagues (2005), found that counseling is helpful to the majority with a few negative comments on the time it took to get from the initial referral to being seen as a client. Arnarson (2007) recently argues that grief counseling's role is to renew the self-governing individual that is at the core of contemporary society and politics, thus renewing not just individuals but also the social order (In Walter, 2008). Others, criticize professional grief counseling, such as Konigsberg (2011) who states one of the five common myths about grief is that 'Counseling Helps.' She cites research studies by the Association of Death Education and Counseling's Past President, Robert Neimeyer, PhD, and Joseph Currier, PhD. In response to Konigsberg's claims, Dr.'s Neimeyer and Currier responded in a TIME magazine article:

grief therapy is hardly necessary for the resilient majority of grieving people. ...which is that new approaches to therapy are demonstrably effective for mourners whose losses are sudden and traumatic, or whose grief is disabling and seemingly without end. With one in seven survivors struggling to make sense of their loss and move forward with their lives, professionals who specialize in helping them do so can be a godsend.

⁴⁶ This bereavement care program serves the needs of all bereaved people. "Cruse" is taken from the Old Testament in the Bible which refers to a widow's jar of oil (cruse) that never ran out, symbolic of the grief support. Although they do not identify with any religious organization and their services are open to all people.

Konigsberg's new book has created quite a stir in the grief industry, with mixed responses from both professionals and non-professionals.

Studies specific to an acute care settings such as a hospital where initial bereavement care for death is offered within the organization, suggest that issues of respect, dignity and communication by hospital staff were of great concern (Billings & Kolton, 1999). Research on the value of support groups for bereavement note that it is difficult to ascertain accurate views because of the populations sampled, namely those who are self selecting and attending groups (Thuen 1995; Thuen & Sandvick, 1998; Zonnebelt-Smeenge & DeVries, 2003). With respect to the experiences specific to support groups, Thuen (1995) highlights the value of social and emotional support on offer by the group itself (which is considered the most valuable part), along with the style of the facilitator being an important factor for those attending. Age and gender differences in support groups studied by Zonnebelt-Smeenge & DeVries (2003) report that the older widowed in the group experience greater difficulty in adjusting to the loss and being able to enter a positive phase in their lives.

There is also an assumption that proper and timely responses could have an impact on a person's bereavement journey. Silvey (1990:17) notes in a study conducted in a hospital that, "[a]ll remarked positively about any member of staff who responded to them in a *caring* or *empathetic* way" (my emphasis). Again, there were no general studies of bereaved spouses' experiences specifically addressing the programs provided to them through initial contacts upon the death, such as from hospitals or other agencies like hospice care, specific to a type of loss.

Some changes have been evident over the years through specific groups who organize around the type of loss, whether that is a relationship loss, such as spousal, child, parent, sibling, or friend, to a type of death, such as suicide or homicide. Providers of bereavement care

recognize that the more similar the group is in terms of type of loss and death, the more cohesiveness exists which provides advantages in adaptation for the members. Riches and Dawson (1996a) call these groupings ‘particular communities of feelings’ where certain types of mourners celebrate what they recognize as an experience shared only by the group members. In such a situation, the use of models and theories surrounding grief, for example, can be catered to the special needs of the group and the meanings that are important to them.

Critical analysis of relevant literature

As this review indicates, while the literature on bereavement care is limited, the current knowledge base that addresses the experiences of formal support for bereaved spouses is further lacking. In addition, as Baby Boomers age and face spousal death and bereavement, it is timely to address and analyze the care available to this cohort, and the meanings in which these individuals are constructing regarding this care. Data gathered here may provide an insight into the degree to which Boomers depend on their spouse for many tasks and how this affects their acceptance of bereavement care assistance and their adjustment to the loss.

As noted previously, multiple authors in bereavement care research focus on the effectiveness and timing of grief interventions and the benefits of individual counseling, with a few examining the social and emotional value of support groups, the style of the facilitator, and comparisons by age and gender of the widowed. It is clear from the current literature that there is a gap in addressing the concerns of the recipients of this care to determine helpfulness overall (both before and after death if there is an illness), and what improvements or suggestions they have to offer. In particular, little research is available that specifically explores experiences and expressed opinions and concerns of the Baby Boomer cohort with respect to formal care.

The research in the area of bereavement care takes divergent routes in terms of contributions. One group is more focused on adjustment to loss, while others concern themselves with grief interventions, (i.e., at what particular stage in bereavement support is sought). At this point, research provides important information to shed light on the helpfulness of formal support in bereavement, but fails to take into consideration the experiences of care in general from the bereaved person's perspective. The implications of this research may offer valuable information for the creation of training programs for practitioners, or at the very least, more holistic support services with potential to improve care for the Baby Boomer cohort.

Models and theories on grief changed over time as death became more medicalized. Eventually, as both dying and death were sequestered, and handled by professionals, we now feel less equipped to handle bereavement as we have a distanced relationship to death. In addition, as we moved from a traditional, community-oriented society where people lived, worked and died in towns and villages where the dying person was known to them, to one where in a globalized society, we pay our respects but are generally unable to support most people when they have a significant loss because we did not know the deceased. And as Walter (1999) points out, the authority has moved away from religion, medicine and therapist in bereavement to one's self as being the expert. This is reflected in the number of memoirs and advice for grieving by both famous authors and the average bereaved person who wants to offer help or advice to others. Lastly, a strong emphasis on individualism results in a huge adjustment when we lose close others as we have fewer relationships, which weakens our support system.

Although this review acknowledges that the studies noted herein contribute to the discovery of knowledge, countless questions remain. For instance, no research prior to this present study takes an interpretive qualitative approach using a sociological lens that asks how

Boomer spouses experience formal care during bereavement. There is clearly much more to be learned. Next, Chapter Five presents partial findings of this research, to hopefully begin to add to this much needed knowledge on grief care.

CHAPTER FIVE - RESULTS 1-SUDDENLY WIDOWED

Introduction

Spousal loss affects all aspects of a person's existence. Changes take place at both individual and social levels, and include the emotional, physical, mental, spiritual, and social impediments for re-entering personal and social interactions and relationships, which are thoroughly documented in the literature (Worden, 2002; Stroebe, et al., 1987). Even for those whose spouse is diagnosed with a terminal illness and who may provide years of care for an ailing partner, their lives are filled with other responsibilities, leaving little, if any, time to prepare for their changed status from married to widowed. So, even when the death is anticipated, it is challenging to prepare for it, and when it occurs, even caregivers feel suddenly widowed.

The analytical concepts and framework in this dissertation range from the intermediary strain on social role, role adjustment and support systems to the microlevel of personal experiences, that of bereavement and care. Using a symbolic interactionist approach, I am interested in the construction of reality, or the meanings of life, for people who are going through an experience. This chapter, and the next, provide insight into the experiences of grief and bereavement and the subsequent formal care provided for these participants, who have all suffered spousal loss. It incorporates what it means to be widowed and the emotional and expressive work that follow in rewriting the self after the loss of a significant other. Chapter Five examines the thoughts and opinions of formal bereavement care experiences of the 38

bereaved spouses recruited in this study. Both chapters highlight how active involvement in the life of a support group affects the social development of these widowed individuals as they attempt to answer questions about themselves, their deceased spouse and their support while grieving. Along with the death of a spouse, whether sudden or expected, comes the reality that one's lifeworld is forever changed. For those left behind, the consequence is bereavement, which involves an abrupt shift for the surviving spouse from the role of husband or wife to a widowed status. For those who do have children, whether they are young or adult aged, the bereaved spouse, upon the death, becomes a single parent. Regardless of whether the death is sudden or from an illness, these spouses describe the loss of one's spouse as a life- and self-altering experience.

This chapter first describes the demographics of the bereaved population under study, including age, gender, race, type of spousal death, months since loss, educational level, religious or spiritual preference, and the number of people living with the bereaved at the time of death. A limited amount of information (i.e., name, relationship to bereaved person [spouse or estranged spouse], gender, age, date of death, type of death [sudden or illness], race, and religious/spiritual preference) was also collected on the deceased person. I obtained this information so that I am able to personalize the interview as well as know how to probe on certain questions (i.e., sudden death or terminal illness). The chapter then examines the sociological concept of the definition of self where tireless efforts were made to redefine the individual self after the loss of a significant other, as well as attempts to define the new social self. Next, construction and reconstruction of narratives are addressed which provided a chance for these participants to reflect on the experience in a new way, and helped some to realize just how much support they have now, or had during the illness or sudden death, and in particular, during the initial part of their

bereavement. Lastly, a look at the expectations surrounding the grief experience which supply insight into the ways in which the meanings connected to being widowed form and the reflexive narration that follows. First, I will present the collected demographics for this cohort.

Demographic Overview

Face-to-face interviews are held with 37 individuals born between 1946 and 1964 (See Appendix P [1], Age Characteristics of Population) and one interview is conducted with a male participant who misrepresents his age.⁴⁷ His interview is included for analysis because of his experiences with formal grief support and because of the low rate of male subject participation. Women represent the majority of these interviewees [30/38] bereaved of either a husband [28] or an estranged husband [2], and the remaining eight men had their current wives die. After receipt of signatures on consent forms, I collected the demographic information, at which time I discovered that one woman had divorced and another had filed for a divorce before their husband's untimely death. Coincidentally, they both experience the loss of their estranged husbands by violent suicide [shotgun] and in both instances the estranged spouses leave notes implicating the role of the failed relationships in their decisions to commit suicide.

Race is self-identified (See Appendix K, Participant Characteristics) and almost all individuals [35] are Caucasian/White [2 are Asian and 1 is Multi-Racial]. The ages of these Boomers included one participant who was male and age 71; fourteen participants whose ages

⁴⁷ David misrepresented his age on the phone when I asked him if he was a Baby Boomer, born between 1946 and 1964. However, when he came to the interview, I was suspect about his age. Eventually, at an appropriate time in the interview, I question his age and he tells me that his wife was a Boomer and that he felt he was 'close enough' to the age cohort under study. He is actually 5 years older than the Boomer cohort. I continued on and kept his responses as data.

ranged from 60-64; seventeen in their 50's; and the remaining six were aged 46-49⁴⁸. English is the primary spoken language. Spouses are also asked if they had others living with them at the time of the death, along with the type of relationship [i.e., young children, teenagers, young adult children or grandchildren]. Occupants include children of the marriage, with two exceptions. In one instance a grandson moves in with his grandmother and in another, the spouse had one biological child and one foster child.

The remaining characteristics include Religious/Spiritual Preferences, Educational Attainment, and Number of People Residing with Bereaved Spouse at Time of Death By Participant Number, Age and Gender (Appendix P). Participants respond to my inquiry about religious or spiritual preference by stating that they either believe in God (3/38), have no inclination (8/38), or note a specific association to a particular sect with answers such as Christian (4/38), Protestant (3/38), Catholic (14/38), Lutheran (1/38), Presbyterian (2/38), Nazarene (1/38) and Non-denominational Pentecostal (1/38). One man simply stared at me and did not answer, even though I knew he heard my question because of the close proximity in the interview. He also gave no response when I asked him about whether his deceased wife had any religious or spiritual preference. The largest self-identified religious category is Catholic, and is due to the fact that one of the five agencies I worked with operated under the Catholic Archdiocese of Detroit and seven of the nine interviewees from this agency acknowledged Catholicism as their religious preference.

This sample's educational attainment (also reflected in Appendix P) includes those who finished grade school (1/38), high school (6/38), some college (7/38), Associate's degree (9/38), Bachelor's degree (7/38), and Master's degree (6/38), and one participant who holds three

⁴⁸ Average life expectancy in 2007 was 75.4 for men and 80.4 for females.[U.S. Census Bureau, Statistical Abstract of the United States, 2011]

Master's degrees and another who took coursework beyond his Master's. The demographics that represent these 38 bereaved spouses show us a fairly highly educated, White and female dominated religiously oriented group of Boomers. Next, we move into exploring the concept of the definition of self.

Definition of Self

Benjamin Franklin once said 'There are three things extremely hard: steel, a diamond, and to know one's self' (Myers, 2010). It was evident that ties to significant and generalized others proved crucial in the responses of these participants (Rosenberg 1991). Many of the constructions of the living self included references to the deceased spouse and/or members of their support systems, such as family members and good friends, along with occupational status and in some instances, faith is mentioned. An expression of how a part of themselves is now gone along with the shared role of being spouses, is stressed, and typically framed as problematic. Participants elude to a loss of personal identity in various degrees, depending on the quality of their relationship to the spouse as they construct the stories of loss.

These spouses all died before old age (according to today's standards and average life expectancy). Meanings assigned to their own lives after the death of their spouse include constructions of stories in some cases with little hope. These stories involve descriptions of loneliness and non-existent lives. Courtney, whose husband Hal dies very suddenly, defines her life and identity as nearly hopeless:

Okay. Well, I am 46 years old. It's hard for me to believe... I'm a registered nurse, I've been a nurse now for 20 years and I think of my life as 'before [Hal] died' and 'after [Hal] died' and this after part, ugh, it's hard, it's just a lonely, lonely existence going from being so happy, SO HAPPY, we were married for 14 years and 7 months to the day and just you know having somebody there every day that I just loved (crying) thought the world of you, took nothing,

so, crying already Laurel... I have a wonderful son... And of course, especially now, I just worry about him terribly (cries and laughs), terribly. But he's a good kid... I see him quite a bit. And he calls now just to make sure I ...haven't jumped off the cliff yet, he calls me a lot. And I have good friends at the hospital. And, it's just...I don't know I'm just kind of existing. [Courtney, whose 44 year-old husband Hal died from cardiac arrest]

Courtney's description exemplifies how the relationship to her spouse as her most significant other appears to be more important for defining the self than twenty years of work as a medical professional. It even appears to overshadow the importance of other family members that are still alive. A rebuilding of a sense of self, such as in the rewriting of a life narrative after such a significant death, is recognized as a continuing process (McAdams, 1996). Although she attempts to identify with her work as a nurse, Courtney quickly assigns a division to her old status in life -- when a married woman-- to her new role and status in life --now a widowed woman. She notes that she had a very different life before her husband died, one where she enjoys a happy marriage with a man who loves her deeply. After he dies, she describes her life as a 'lonely, lonely existence' where she is 'just kind of existing.' In a sense, there is no longer an anchored self, but one that is looking for a meaningful narrative. At the time of the interview, only 15 months from the death, Courtney's self narrative reflects nothing but loneliness.

Christina, 18 months past the death, also suggests, as Courtney did, a non-existent life:

Hm. I work part time for ... School District... I am what they call an office para-pro and a lunch para-pro. So I work in the cafeteria for one hour, I work in the office for three hours a day. I have two kids, two granddaughters and pretty much, a non-existent life (laughs). I don't know, I don't know, I don't have a lot going on. [Christina, now 55, whose husband Harvey, age 52, died suddenly from cardiac arrest]

Although she tries to maintain her self through work and family, she admits to 'pretty much, a non-existent life,' which could again be interpreted as a non-existent true self. Christina later tells me that she is overwhelmed with the role of maintaining her home, and seems almost

consumed by it. This may be another attempt to find meaning for the self after the loss of a significant other. She does not divulge her financial situation but it is clear (from meeting in her home) that she lives simply. She does not elaborate on friends or activities and at 55 years old and in good health, appeared to have no interest in anything other than her part-time work, her immediate family relationships, and maintaining her modest home. Christina, through my questions and reflecting on her own answers, wonders (out loud) if perhaps she is not moving along and engaging in an adult life as she should be.

As these spouses approach year three of their bereavement, a more engaged life with others emerges and they are less focused on their worries and on the past life with the deceased spouse. There are a few exceptions, notably Earl in the next example, whose grief as he approached year three of his bereavement, seemed to still consume him. In such a situation it is clear that, “[t]he fundamental crisis of bereavement arises, not from the loss of others, but the loss of self” (Marris, 1974:297 in Charmaz, 1980). One may no longer see their role of ‘husband’, for example, without the wife, which contributes to a loss of structure and meaning (Charmaz, 1980), and may also be the impetus for maintaining a connection to the deceased. Earl exemplifies this point as he is unable to construct a self when he is asked to tell me about himself:

Well, it was us, you know it wasn’t just me...it was 33 years of us together, so she would say that I am the wind beneath her wings and I would say she is the wind in my sails. And that was our marriage. So, while really there isn’t too much to say anyhow about me personally because it was...more ‘us’ [crying]. [Earl, 33 months post loss, and now 64 years old, whose wife Jenny, age 57, died three weeks after being diagnosed with a brain tumor]

Earl’s life seems meaningless. Marris (1974) posits that to accomplish the reconstruction of meaning, the bereaved need to re-establish continuity with the past without the deceased person through a detachment of symbolic meanings from the former mutual relationship. Since Marris’

thesis on loss and change dealt with resistance to change, perhaps the removing of the wedding ring, for example, a symbol of the former mutual relationship, might help to promote and maintain continuity of life. Three spouses mention their struggles in relinquishing the wedding ring, or seem to want to explain to me why they are still wearing the ring (I did not ask, although I add it to Appendix I after an interview where it seems to be of great importance to one bereaved spouse). One woman told me that she gave the wedding ring to one of the children, and another notes that she had it melted down and made into two rings, one to give to her daughter later in life and one to keep for her own memory (which she wears on her thumb during the interview on the left hand). Coincidentally, I observe that Earl in the above example wears his wedding ring the day of the interview, approaching the three year mark after his wife's death. Earl cannot see himself as an individual as he remains very attached to the deceased spouse and to the marital identity.

Earl later reveals that he has attended six support groups and also sought one-on-one counseling with a member of his church.⁴⁹ Such efforts fit with Walter's definition of a subculturalist within a support group subculture.⁵⁰ Walter (1999:193-95) develops a classification of the survivor's individual responses to bereavement through four categories,

⁴⁹ Almost all of this sample (36/38) attended at least one support group. One woman recruited from the funeral home did not attend their support group but felt that the pre-arrangements for her husband's death and a visit from their representative was considered formal support. Another woman attended the social functions only for Agency Five, Widowed But Not Alone group. Twenty participants attended the support group of the agency I was interviewing them from; 11 attended this group and another support group; 5 attended three support groups and one man attended seven support groups since the death of their spouse.

⁵⁰ Others, such as Hockey et al., (2001:114) note that the mutual help groups 'represent a kind of counter-culture.' They outline three ways in which these groups fit a label of counter-culture, namely, 1) places where models of grief that run counter to the culture associated with modernist process models that make closure their goal; 2) in specialized groups, such as MADD (Mothers Against Drunk Drivers) where death has occurred as a result of negligence, for example, and the

namely the *nomic* repairers, the isolators, the subculturalists and the innovators. This classification is based on Durkheim's (1952) twin dimensions of integration and regulation, where the *nomic repairers* are involved in work and other potential self identities; the *isolators* whose 'connection is so much with the dead that they are cut off from the living' – an effort to maintain the past self; the *subculturalists* who are also engulfed in the lost identity of spouse but seek out alternative social settings (such as a support groups) – self seekers; and the *innovators* who accept that the previous identity has been crushed and go on to recreate new selves. Walter (1999) notes that the bereaved person may be more or less socially integrated and more or less conventional. In the case of Earl, his interview narrative describes how he and his wife once spent their time together and how difficult it is after she dies to go to those places alone. They had a Sunday ritual, for example, where they would go out to a restaurant, the same one every week, and eat a meal together. He said it took him a long time before he could stir up the courage to go and eat alone, as such an event would conjure up feelings for the past self in the couple role. The routine and structure he once knew are gone, but the self constructed within those routines and structures remains. In time, he did venture out, and notes that each Sunday, it got a little easier. Although he could have chosen a new restaurant and a different day perhaps to eat out, he chose the same day and the same restaurant, and said that this was how a person *worked through grief*. He notes that you don't go around your grief, you go through it. This is a script commonly recommended by bereavement support group facilitators. Because of Earl's extensive record of formal grief care, he speaks the "true" language of the culture of bereavement support groups, an example of meaning being constructed in settings external to the individual.

Another woman, Debra, nearing 36 months post-loss, defines herself by describing her

group has activities of action; and 3) the validating of emotional expression which might be viewed as counter to the cultural social activity.

role of assisting her husband in his career. Her response to the question about herself is:

My husband was a [medical professional] and we—I ran his clinic for 29 years, put him through [medical] college, knew him 40 years and I was married 36 years when he passed away. [Debra, now a 60 year old female whose husband, Ben, age 58, died suddenly from cardiac arrest]

Throughout the interview, Debra notes several times how she feels she did not fit in with other widows because she has no children and has been a business owner all her life with her spouse. She thought that most of the concerns of other widows she spoke with in the support group involved things she was well aware of, like finances,⁵¹ since she did all the bookkeeping for the business and has a good sense of money. Although she attempts to continue to define herself through her role in the clinic and business, which no longer exists because she sold the business immediately upon the death of her husband, she mentions no other interests. It becomes obvious that her identity is anchored solely in the business and the marriage identity. Even now, three years after the death, she has little to say about any plans for a future. An isolator, according to Walter's classification, Debra seems cut off from the living, and is making little effort to develop a new sense of self. These were two distinct examples within the sample, Earl and Debra, while most others fit the description of nomic repairers, involved in their work and other self-identities, and that of innovators, who accept their lost identity of spouse and go on to create the new widowed self.

Participants' attempts to redefine the sense of self, even for those who maintain strong ties to the deceased, include descriptions of their occupational statuses. Most interviewed are still working (25/38), even though many of the women who are working (20/30) have only part-time work (10/20) and one woman specifically notes it is not a 'career,' just a job, something to

⁵¹ This was not a topic brought up by the facilitators in the group, rather this discussion took place after the group meeting.

occupy her time. Walter (1999:193-194) suggests that those whose view of the world is through involvement and identification with their work, are encouraged by society to distract themselves with work after loss. By doing so, people are integrated back into society and are provided some structure along with occupying the mind away from the trauma of loss.

Besides work, individuals are trying to make sense of the death by taking on some of the characteristics of the person who died. “Seeing self and aspects of the world through the eyes of the deceased may clarify thoughts and help the bereaved person deal with unfinished business” (Stroebe, et al, 1992 in Riches & Dawson, 2000:171). This is evident when participants speak at length about the history of the relationship with (or story of meeting) the deceased spouse. Their responses are often told in what I would describe as a reminiscing fashion. Some smile as they reflect on scenes of the past, and others weep. Littlewood (1992) refers to this type of behavior as ‘falling in love backwards’ where the bereaved individual is able to recall memories and enjoy them. For example, one participant’s story attests to Littlewoods’s idea as he comes full circle with the images of meeting his wife for the first time at a party during college:

...I said “Well, maybe this is not the right party for me to be at” so I headed towards the beer. They had the beer in the bathtub iced down, and grabbed a couple and was headed towards the door thinking maybe time is spent best elsewhere, when a sister of my friend saw me and she says “I’ve got to introduce you to somebody” and I said “Okay.” So I was standing by this refrigerator and there was a white door frame, something like this (points to an archway in his home) and there was a refrigerator here and then it was all white and around this corner comes this blue-eyed, red-headed woman with porcelain skin, most colorful thing in the room...

And then he ends with a description of how he watches his wife’s body being removed from their home by the undertakers:

And then, we had made arrangements with [name of crematory] to deal with the body and they showed up and they woke me up, I was by then of course exhausted and these two guys came in black polyester suits, they looked like so much stereo—they looked like Mutt and Jeff, one was tall and thin, one was fat

and morbidly obese, not fat, not stout, morbidly obese, black polyester suits, and again, they're like cartoon characters and they load her onto a gurney and they leave an artificial rose. Again, I understand the symbolism and what they're trying to say, we're taking your beloved but we're leaving this, okay. And then they take her out and the last time I see her is that her head goes in last into the little, not a hearse, but a little black van type thing and that was the last time I saw her. And I connected with the memory of seeing her for the first time which was also in my mind which I can still have access to. So, that's kind of what happened. [Adam, a 60 year old male whose 49 year old wife died from breast cancer]

Adam suggests that he 'married up' and that his wife loved him with all his warts. In essence, he relives the relationship, step by step, scene by scene, and by doing so, he learns about his new widowed identity through the re-construction of memories of the relationship. These conversations with the living (i.e., Adam and I through the interview, in support groups, etc.) contribute to constructing meaning for a new self for the bereaved individual (Walter, 1999). His stories and reflections on meeting his beautiful wife, and about the image of the role of husband, indicate attempts to deal with unfinished business as noted above by Stroebe, et.al (1992).

Other descriptions of self come through mention of one's family of procreation, the marriage, and details about their family of origin. Frequent definitions of a sense of self also came through educational attainment, home-residence, hobbies, fitness activities, religious affiliation, informal support systems, pets, their own health issues and their birth place. Almost all of the responses include talk of the relationship with the deceased spouse.

It is clear in this sample that the death of a spouse threatens one's sense of identity and may remove the 'core social connection' on which one relies for their sense of self (Berger, et.al., 1974; Giddens, 1991). Walter (1999) notes that when a marriage partner dies, re-discovery of who that person was appears to be a crucial element of the discovery and definition of one's self. The survivors I interviewed make references to their deceased spouses in their portrayal of

the new – and old – self with stories about how they met or about their marriage and life shared. These inclusions sketch a component of meaning that is constructed to fill a sudden void in one's life. Such meaning seems necessary to provide a strong and clear sense of self and purpose, as going from duo to solo is no easy task. Without maintaining connections to the deceased spouse, these individuals might have been unable to tell me who they were, and are, and make sense of their loss.

Construction of Loss Narrative

Interviewees appear to reflect a need to construct the last chapter of the spouse's life with precision. They included disappointment and regrets and emphasized who was with them at this critical time. Those whose spouse died as a result of a sudden death (14/38) tended to talk more about the amount and value of informal support from family, friends, church groups and neighbors, than do those whose spouse died after an illness. It is common for people to rally around others when there is a sudden and tragic death. Those in this sample who deal with prolonged terminal illness, however, have a different experience regarding support. Many caregivers were often left alone as members of their informal support systems carried on with their lives after the initial flurry of offers for help. There was little realization by others that caring for a terminally ill person is quite burdensome and overwhelming. For these caregivers, there was also a sense of being bereaved in spirit as they go about the caregiving, just knowing that the end of life is nearing for the spouse. The self appeared to be suspended between the past self and what would become the new self, soon to require an anchor in the identity of being widowed. Also of interest was that the interviewees whose spouses died after illness (24/38) did not appear to be 'better off' in bereavement because they had an awareness of the impending death. Although a few (3/24) noted they did most of their grieving while the spouse was ill, the

remaining made no mention of it. They informed me that grieving the about-to-be deceased spouse was and is an unbearable and lonely feeling which complicates their already vulnerable sense of self. Valentine (2008:65) suggests that this “tends to support the observation that such concepts [anticipatory grief] can become prescriptive in that some bereaved individuals end up feeling that they ought to have been more prepared and managed their grief better.”

Interviewees construct sudden death stories by going through the details of either the phone call notifying them of the death or of the description of the emergency scenario if the surviving spouse was present. References among those who died from both sudden death and illness trajectories include expressions of what they thought were early, but missed, symptoms related to the death, the collapses and 911 phone calls or emergency room experiences, the witnessing of attempts to revive the spouse, phone calls with the news of the death, or the delivery of the news (how it was given to them, who was with them, where it occurred, etc.). The illness and care giving stories included talk of treatments, procedures, tests, specialists, surgery, pre-loss needs, hospice experiences, delivery of terminal illness diagnosis, and prognosis. A theme that emerged in both types of death is that of unmet (pre and post-loss) needs, which are given mention here (Pre-Loss Care) but covered more thoroughly in Chapter Five along with the post-loss needs. There was some concern expressed in the stories about death’s intrusion, regardless of whether it was a sudden death or one from illness, and I felt it was worthy of inclusion. It is evident during these interviews that the intrusion of illness and death contributed to the wounded self and create a void so large that the survivor worries about his/her sanity as they process life without their spouse. Additionally, the unmet needs and other upsetting accounts before the death for those with terminal illnesses also weighs heavily on the surviving spouses.

Pre-Loss Care

Frustrating accounts related to a lack of sufficient care, depersonalizing treatment, misdiagnosis from the hospital and/or hospice personnel (and emergency rooms and walk-in clinics), along with a lack of coordination among medical professionals were told. One woman, Denise, whose 58 year old husband, Bob, died of cancer, still very upset, had this to say:

So we took him to the hospital and that just took forever and the coordination of care between hospice and the hospital and this was [St. John's] hospice and [St. John's] hospital, no coordination, none whatsoever...[Denise]

Next, Denise expressed her anger and disgust in a hospital's depersonalizing treatment, and the resultant helplessness to protect her dying spouse:

I was pretty much sleeping there and I went home one night to sleep and the nurse called me at 3:00 o'clock in the morning and says 'We can't find your husband.' And I'm like 'What do you mean you can't find my husband?' 'He's escaped.' And I get to the hospital and they—he went from the 11th floor down to about the 3rd or the 2nd floor basically going down stairways and elevators and he was like—when he explained it, it was kind of a—he was paranoid because he thought—he didn't know where he was and, um, the security people tackled him and brought him up and put him in restraints and this was before we were in hospice, why they didn't offer someone to sit so I could go home and get some goddamn sleep, excuse my French because when I get pissed sometimes I cuss, so and this was really, really, really hard.

Whether Denise felt guilt for going home and reconstructs this episode as a way to show she was in the right is difficult to say. She obviously does not want the responsibility for this episode because she desperately needed self-care at the time. The amount of detail in this account shows that the strain of continuous caregiving and the protection of the personhood of her spouse were important sources of meaning for her in re-constructing the story of the experience. After months of continuous caregiving, hospitalizations, treatments and specialists, the spouses had expectations of respite care, which appears lacking. Andy, for example, looked forward to a much needed break and notes:

...in the latter days, I was told that once hospice was called in, that I would get relief, there was no relief, there was absolutely no relief, hospice did nothing.
[Andy, now age 57, whose 67 year old wife, Fran, died of breast cancer]

Again, the caregiving aspect of the experience becomes a point of meaning for an individual who may be feeling guilty for not being able to do more for a spouse who is dying. Or, it is constructed as a way to project personal frustration onto an external entity, thereby freeing the self of guilt and allowing the care they provide for the spouse to be reconstructed as the good 'thing' in the experience.

Others are eye-witness to misdiagnosis, such as Christina, whose husband experienced pain and discomfort on their daughter's wedding day. The family convinced him to get medical attention. Christina had this to say:

We took him to the walk-in and the doctor said that he had bronchitis. And I said 'Bronchitis? He didn't cough all day long.' He was throwing up and I said to the doctor, 'He has a burning, like heartburn' I said, 'He's never had heartburn, he doesn't know heartburn,' 'Okay, well, he's got bronchitis.' And I said 'All right.' He gave a script... [we get home and] he says 'I'm going to go straight to bed' and I said 'That's fine' but I just wanted to sit up for a little bit. So I was sitting down here and I just heard this real quick "Christina" [spouse in distress calls out name of participant] and I wasn't for certain, so I went down to check on him and he was gone, I knew he was gone, but I went—I called 911, I went through all the steps, they worked on him, they took him and of course, we beat the ambulance to the hospital and the doctor came out and said there wasn't anything they could do and that's when everything—I said 'How do you go from bronchitis to this? How do you do that?' [Christina, now age 55, whose husband Harvey, age 52, died of a heart attack]

Christina, along with others, reflexively constructs, once again, the agonizing memories and accounts of failed attempts by institutions, agencies, and doctors to help their spouses. They discuss details about the frustration it causes, deflecting their own sense of helplessness onto others. Negotiations with the medical systems are fraught with miscommunication and a lack of coordination of care. A longing to protect the personhood of the dying person, through attempts to override the system, came into view through these stories. Examples include one woman who

kept sophisticated charts of her own on her spouse's blood sugar levels while other dying patients keep their own records of medications, and the like. Pride when the dying person goes home to die created some sense of autonomy at the end and brought peace to survivors.

Death's Intrusion

As one would expect, accounts of shock and disbelief surrounding the death itself throughout these stories of loss continued to be a point of frustration. One participant, Courtney, described her feelings of helplessness as she attempted to construct the day her 44 year old husband Hal, collapsed and died in front of her:

... he sat down on the couch and I looked over at him because I heard this noise and I said '[Hal], what are you doing?' I thought he was kidding around with me. But he was, his back was already arched a little bit and he was already agonal breathing at that point...And so I went over there immediately and I couldn't believe it, couldn't believe it, pulled him down to the floor, grabbed the phone real quick, called 911 and I knew he was already gone, he was already gone, but I did try CPR (crying), which obviously didn't work because we're doing this interview. And, the ambulance came. And of course the police officer in the other room was saying 'They're doing their best, just keep hopeful' but it's the down side of being a nurse. I knew everything, they kept pushing amps of Epinephrine...I actually came out [from the bedroom] and was watching, it was like a clinical part of me, it was feeling like it was—it wasn't [Hal] on the floor at that time, it was a patient on the floor and I was asking them, 'Had you got any type of a rhythm?' and they hadn't. Like I said he was clinically dead basically on the couch, totally unexpected, totally. We had just moved—we were in Boston six months earlier, complete physical for him, absolutely complete, healthy as a horse (laughs nervously). [Courtney, whose husband Hal dies of a heart attack]

A few participants (3/38) whose spouses lived a short while (less than six months) with a terminal diagnosis after an unexpected incident (such as a brain tumor discovered in stage four), were grateful for what they consider to be a short period of preparation for their grief. They go on to note they have time to adjust to the shock, and although it may have been short in duration,

the abrupt illness helped them to make some important realizations.⁵² In such a situation, the self does not need to be protected to the same extent as those who watch their spouses go through a long illness:

So, like I say, a lot of, you hear that stuff and then for some the suffering the spouses went through, where I didn't have that. [Hers] was less time, it gave me enough time to face reality I guess, that she was not going to make it, so I had no time to...I got used to home for a month to an empty house from the hospital. [Earl, a 64 year old whose 57 year old wife, Jenny, died after a short illness related to a brain tumor]

Discussions on symptoms, final diagnosis or cause of death, and the informal support systems in place were in both the deaths from illness stories and those that are sudden. All stories reflected the persons' relationship between cultural and individual perspectives in a reflexive reworking of events where memories were subject to an ongoing process of interpretative reconstruction (Giddens, 1991). The participants attempted to remember the details of this horrific event, while at the same time they assigned the value of their experience and re-examined it during the (re)telling (Valentine, 2008). In a context of medicalization and individualism, it is brought to light with these participants (as in Valentine, 2008) that the value placed on relatedness, intimacy and support, along with norms and sociality is crucial. Emily noted:

So, he was in the hospital, he was in Intensive Care and they were talking about moving him and my family came, my sister and brother and some nieces and nephews and we were talking because we had a family wedding that was coming up and we were all talking about that and everyone was in excellent moods and so was he. [Emily, aged 64 whose 66 year old husband Jake died of a heart attack]

Normative is the participation of family when a close other is in danger of dying (or is dying).

Descriptions of the way in which the death from illness stories had the flavor of a social event

⁵² Those who care for spouses with long illnesses appeared to prepare less for the death and subsequent grief. Perhaps they had hope that the spouse would not die after all when there is a slow progression of illness.

also brought comfort to the caregiver. Other informal support, such as that of strong friendships had value as Dana suggested:

...one of our friends who we were working with is a neuropsychologist, so we had her on board as part of our team, or we called them the posse... You know we joked that we had our own posse, you know we had friends who helped us. I had one friend who was working from home at the time and so I was able to go into work periodically... if [Brad] needed somebody to be with him, one of our friends would be with him and we were rotating through what friends would be with him on what days and things like that. [Dana, now 46, whose 41 year old husband, Brad, died of a brain tumor]

These scenarios provided a space to include not only family but close others in the dying spouses' experience, including those who have expertise in the medical field. The friends above offered the much needed help to the family so that the caregiver could continue to work.

The more social and relational aspects of one's experience of death can be described through concepts like that of romanticism, as imagination and symbolism come into play. Some value human sentimental relationships which are evident in the final moments of death:

She really—you could just see her fading away—it was not anything violent. People say it sounded really strange, but after she passed, and the Hospice people took the tubes out and cleaned her up, they didn't do any funny business, she had a smile on her face. Sounds rather odd, but one of my hobbies is photography and call me gross, but it's no worse than a public viewing at a funeral home, I took pictures. And people look at her 'you're gross' and I'd say 'you know, nobody would believe me otherwise'— My wife didn't look all that bad, I mean yes, pale and lame for anybody who knew her back when, but it wasn't gross. There was definitely a smile, they closed her mouth, and just there was this peaceful smile and eventually her jaw dropped as the muscles relaxed, but it's like, okay, okay, we don't want to make too much of this, but it's going to be one of those shaggy dog stories if I don't do it, so – but I felt better for having done it. [Brian, now 56, whose 58 year old wife, Gwen, died of a brain tumor]

This example has hints of romanticism, through his imagination and facial gestures while telling it (closed his eyes, smiled) and through his validation of emotion when 'feeling better for having done it.' He also used language (such as peaceful smile) to evoke an image he wants to capture

and share, yet is told ‘you’re gross’ by others who look at the postmortem photo. This scenario also provided a more social and relational aspect of the experience of dying, as she died ‘peacefully’ at home as opposed to in a more medicalized environments. (Valentine, 2008). Along similar lines, Adam, whose 49 year old wife, Farah, died of breast cancer, accompanied by friends and family, romanticized ritual in his description of ceremony he learned from his Tibetan Monk friend. He explained to me what occurs at the moment of his spouse’s death:

And so we all go outside, kids and all, the kids were there when she died and so everybody saw their momma stop breathin’ and stuff. And so we all went outside and had bare feet and grabbing things and just to be out of the heat, of course there’s been the fire going and everything, but just the fresh air, and so I said wow [30 degrees and snowing]. And I lift up my arms like this [participant lifts arms above his head] So we kept that part of the ritual short, came back in and then again maintaining her modesty, she was covered with sheets and stuff and all the tubes and things had been pulled out, we washed her body... we, everybody took, I had a bowl of rose petals that had been pulled off the roses and we just rubbed those into her body and we had finished. What happens is that the whole house is just filled with the smell and you see memory and smell are pretty, when you are drinking wine maybe you can taste five or six things, but smells, we have hundreds of smells we can find, really triggers the brain cells. And that’s real, that memory is cemented there and that’s probably the reason for that...So, then we did that and then we closed, everybody held hands, we sang Amazing Grace...[Adam, now 60, whose 49 year old wife Farah died of breast cancer]

Adam, a minister, borrows from various cultural sources for rituals at the death-bed scene, perhaps promoting a more diverse and individualistic belief system (McNamara, 2001) either for his, or for his children and guests’ need for inclusion in the memorable moment of the death of his beloved wife.

Lastly, there were two important omissions in these death and loss stories that deserve mention, death-bed conversations and talk of religious beliefs and values in an afterlife. Several participants (6/38) discussed what some researchers refer to as ‘extraordinary experiences’⁵³

⁵³ The mention of these experiences surprised me but may have not been encouraged by some groups due to institutional constraints. For example, some groups (i.e., Hospital/Hospice) may

(Parker, 2005) without being asked or prompted. Two of the six participants mentioned contact from their deceased spouse during the interview while the tape recorder was on, two others allude to such happenings, and two of the participants bring these stories up after the formal interview concludes. I feel they deserve to be explored in greater detail in future studies. They may be a common experience not being addressed in formal support arenas, though they are part of traditional thoughts and mythology about death, such as encounters with ghosts, the efficacy of séances, and stories such as Edgar Allan Poe's "Ligeia." One cannot be certain that others experience these types of encounters through dreams, visions, and feeling the presence of the deceased as described by these participants in this study. Nonetheless, the mention of these occurrences surprised me in the collection of the data.

Studies by Hallam, et al., (1999) and others (Bennett & Bennett, 2000) show how the deceased may sustain a social presence and significance in the lives of the living that may be experienced as real in both sensory and material ways (Valentine, 2008). With emphasis on the inner representation of the dead person and interactions of the bereaved individual, these experiences are often examined using a psychological lens where it is viewed as imaginary rather than real. Whereas the sociological perspective highlights the way people make sense of and connect with their world, and therefore "it is no longer a question of what is real, but rather how people act in relation to what they take to be real and meaningful for them" (Valentine, 2008:4). This ties into Thomas' (1923) observation that prior to self-determined acts there is always examination and deliberation going on, referred to as the definition of the situation. He notes that if we define things as real, then they are in their consequences. These extraordinary

have been hesitant to promote discussion of these experiences because they may be viewed as religious in nature.

experiences are described to me as dreams, visions and in some instances, hearing and seeing the deceased person by themselves or through a family member.

Adam, who admitted he was not the best husband in the marriage, had more than one experience of his young wife's presence after death:

But, the first dream I had was that she forgave me and then other dreams where, very still vivid, where I have them of different parts of growth and things like that. So, again, you can decide yourself, and you have to make your own calculus if these are messages from beyond or not, or just integration of ideas and thoughts, our memories.

Perhaps Adam's guilt for not being the 'best husband' inspired his dreams. Again, I did not ask the participants about any unusual experiences but several accounts were given to me both during the interview and after the recorder was off. In one instance, Colleen noted that she would like to talk with a professional, and suggested some kind of experience similar to others who made mention of extraordinary experiences:

There are some issues that I would like to talk to a professional about but I don't know who to go to. And it's more to the spiritual aspect about things that occurred and I can't explain but I know they were in faith, in spiritual and I would like a better handle on that. [Colleen, whose husband, Howard, died after a lengthy illness]

Next, Dawn was explicit in her descriptions and told me about how her young grandson is having experiences through dreams and in-person accounts of his deceased grandfather:

And my grandson has dreams, I don't know, I don't know if they're dreams or, but he says my husband comes to see him and he says, "I see him in the soccer field." And I don't think he's making these things up... And he's had so many...when my husband's sister passed away, well, we went there like the whole week she was having Hospice in the house and we would go down to [name of town] and be with her. And, he said to us on the way home, "Why did you walk through Papa?" "We didn't walk through Papa," "Yes, you did, Papa was sitting right next to her wheel chair and you walked right through him."... And one time he said to me (Laughs) we were at a soccer game, he was sitting in his car seat... he said, "Papa doesn't have his seatbelt on." I said, "Well, Papa's not here." "Yes, he is, he's sitting right next to you."... So, I reach over, I put the seatbelt on (Laughs).... But, he says he sees Papa all the time and I...I

talked to my priest about it and he said he would not make that up.[Dawn, whose husband Blake died of complications from a blood clot]

According to Parker (2005:275) the bereaved individual who is having these experiences is usually reluctant to discuss them with others out of fear that they may be ridiculed or that these experiences might be “explained away” (see also LaGrand, 2001; Peterson, 2001). Dawn, in the above account, noted that she did talk with her priest about the experiences her young grandson was having. Adam, referred to these happenings as ‘hauntings’ and actually thought it might be helpful to discuss them in a formal group setting.

Delores, in the following account, told me about a vision where God reassured her that her beloved is safe and this eased her own fears about death:

... I had the vision of an angel guarding me, and I knew ... if He cared that much about me to send an angel to watch over me, I could rest assured that He was taking care of [Brandon] on the other side too. After my vision, I knew without a doubt, that [name of deceased] had gone on a new journey (we loved to travel) and I was the one that was left behind. After the vision, my concern for him changed to selfishness and it was all about me.... I had to live without him and it wasn't fair. Do you know how many times an angel appears in the Bible and says, "Do not be afraid"-- A lotin fact that's usually what they say first. Well, after my vision I was not afraid of death. And that is what enabled me to go on.....MY FAITH and not being afraid. I think if we're searching hard enough, we can all validate our faith in the afterlife. I think maybe it's reaching that point ... that helps us go on.....sharing faith stories with friends can help in this. [Delores, whose husband Brandon died from a sudden heart attack]

These accounts of the extraordinary suggest a need to continue a bond with the deceased spouse. This Continuing Bonds Theory, developed by Klass, et al (1996) gives prominence to the inner representations of the deceased held by grieving individuals and the roles these may have in the grief process. Findings from 22 authors contributed to this research and suggest that bereaved people maintain real connections to the deceased. Their sharing them with me after the tape recorder is turned off, may indicate that the widowed are not sure if they can discuss these happenings even in the support group setting for fear they are outside of the normal range of

what to discuss. There may be uncertainty, yet a need to tell someone and perhaps get some feedback or some insight. Importantly, five of the six who reported these experiences identified with some religion or a believe in God, again indicating perhaps a desire to continue a bond beyond this earthly existence.

There was no mention about death-bed conversations, only regrets from spouses that they had no heart to heart talks with the dying. Second, no references were made about calling a priest for last rites, which was surprising given that 14 of the 29 who identify with some religion named 'Catholicism' as their religious preference. There is little talk of prayer with the dying person (one account is from Adam in the above quote). Rather, many seem most concerned with telling me about the medical details and whether there is a good death experience for their spouse,⁵⁴ one free of pain and discomfort.

These omissions were somewhat surprising to me since the majority of the spouses (29/38) identify with some religion (See Appendix P). Yet, it is consistent with a postmodern culture, one that identifies more with individualism, where death is medicalized and people associate less with organized religious institutions. In several of the interviews (6/38), faith sustained the survivors in their grief. They noted how the church community is there for them, but these are rare discussions. One man revealed how he seems to have lost his faith in God because he has yet to understand why his wife was taken. He expresses that there are many evil people in this world, and he can't understand why God would take his young wife, who was good and still needed by him and their adolescent children. Although I agree that his wife was young to die (49), and that it was tragic for his family, his description (where he later suggests that death is just unfair) reminds me of what the British say about Americans, "they talk as if

⁵⁴ I did not ask a specific question about the medical details, nor did I probe for information.

death is optional.” Along those lines, many of these spouses gave the impression that they think death should not occur in *their* family, and they have a wish to protect their family from it.

In these death and loss accounts, personhood, and the protection of it, for both the deceased and living appeared to be of some concern, which raises critical questions about what it means to be a person (Valentine 2008). Self-determination as argued by Filene (1998:173) “is a kind of fiction in the world of law, and even more so in the world of everyday experience.” For those who are dying, they often must rely on others and their interconnectedness with them to make important decisions. Although we strive for autonomy, some argue it is an illusion (Filene, 1998). Notes and stories shared about the deceased person from others reinforces that the bereaved person, their spouse, and the relationship all have meaning in the lives of others. Two participants mention that cards and letters that come in the mail are very meaningful and comforting. The stories that are told either personally or through other means, reinforce images of interconnections for the bereaved person. These stories constructed through conversations, cards and letters, along with the death and loss stories show the negotiation and development of meanings in both social and personal worlds of the surviving spouses. These meanings, as the interviews continue, were carefully tested and revised throughout our interactions.

Most Overwhelming Part

Delving into what was (or is) the most overwhelming part of the experience brings forth responses that include: stress related to caregiving; the entire experience as overwhelming (all of it); and the helplessness and burden of waiting for and watching the spouse die. Those who provide care for their dying spouse (24/38) often express how they are challenged to the limit with the demands upon them, and feel a strong need to be in control of their emotions. There is an obvious desire to protect the dying person from emotional upset in an already stressful

situation. I suspect this plays into the meaning of why almost all of those who provided care for the ill spouse felt it was *the most overwhelming part* of this experience. Additionally, those who answered that waiting for and watching the spouse die is the most overwhelming part perhaps may deny themselves from expressing painful emotions and deathbed conversations for a good reason. This again may be to possibly protect the dying person from feeling like a burden to them or from thinking about the inevitable. For those who note that ‘all of it’ was overwhelming (5 out of the 35 who were asked), three have younger children and again wanted to hold together to protect them from more stress through emotional displays of sadness. As a result, they remembered this time of caregiving as the most difficult. One other participant who responded that it was all overwhelming has serious health problems of her own, and yet was the sole caregiver for her dying spouse.

Caregiving Stress

Providing care is noted as the most overwhelming part in terms of not having adequate help during this time for several (6/24) whose spouses died of illness. Three of these participants once again suggested that hospice care was not adequate:

Taking care of [him], I was the only one that took care of him. I had hospice come in but I wasn’t satisfied with them at all and maybe because, you know what? You can read a book about how things are going to be with your spouse, of breathing and medication and just sedative, but when you’re in it...it’s totally different. So, I just ...the care of...because I was still trying to work while all this was going on. [Elaine, 56 year old female whose husband died from complications of liver transplant rejection]

This is a possible example of a deflection of feelings of guilt onto an external organization – having to go to work while a spouse is dying and leaving them in the care of strangers.

Literature on hospice shows that these organizations can make dying much less painful and less

stressful, though we still do not know enough about the emotional pain for those who are watching the dying take place. As Denise explains in the next account, she needed more help:

But dealing with the lack of coordination with people, the lack of help. One of the biggest things I can say is hospice should not be something that you have to wait until you are not taking treatment to be on that, it's absurd. Because that was one of the biggest things...but you should be able to—the caregiver needs to have help and that's one thing I felt was supremely lacking was help for me. [Denise, 51 year old female whose husband died of cancer]

Also, ties to significant others are important for the self, and when one is watching someone they love suffer, efforts are made to rectify feelings of inadequacy. Again, the pain and discomfort of the dying spouse that cannot be relieved (even by hospice caregivers) was oftentimes too difficult to bear:

Um, taking care of him at the end...Probably in the last two weeks. (Crying) The care itself, even though hospice came when I called (crying).[Participant needs my hand to regain composure, hangs on to me]. Even when they came (crying). It was very hard. [Elizabeth, now 62, whose husband, John, 63, died of esophageal cancer]

Each of these participants indicate the emotional toll that continuous caregiving created. Elaine suggested that there is no preparation for the extra demands that caregiving for a person at the end of life requires. She had to work to provide an income for the two of them, but also to continue their medical benefits which allowed for hospice assistance and paid for medications. Denise indicated the need to have help much sooner, and Elizabeth felt that even though she had called in hospice at a good time, she was still overwhelmed.

Eric explains the physical exhaustion as the sole caretaker of his wife throughout her illness. In the last month she was hospitalized and they used the in-hospital hospice assistance:

Yeah, her disease was very trying experience to try and meet her needs and still take care of [son's name] and myself... It was very exhausting, she had gone through like I say, originally when she had the liver cancer and became jaundiced, so they had to relieve the jaundice by having her have external tubes. So, she had to dress those external tubes on a daily basis, they became infected and then she

had to go in for to try to resolve those issues, running high fevers ...so and then in the final stages she was almost 15 days in the hospital for treatment wise and then another 15 days for just hospice wise, so it was about a month of continually going to the hospital and meeting her needs. [Eric, now 53, whose wife, Jana died of liver cancer at the age of 53]

Regardless of one's work status or gender, caregiving was described as a very overwhelming part of the experience of spousal loss, and by saying so, one constructs a caring, sacrificing self.

One spouse, David, who admitted that his marriage was troubled, felt conflicted in having to provide the care for the dying spouse:

The overwhelming part, I took care of her, I think it was, the reason was just because I was expected to, I was her husband. (Long Pause) Maybe, not so much love and emotion, but just, that's what I—I would probably expect her to do the same for me. And I just felt that that's the thing to do—the proper, the right thing to do. So that was probably the most overwhelming thing, part of that, just doing it, maybe not in having so much love and emotion in it, but just taking care of her. [David, whose 65 year old wife Irene died of breast cancer]

David's expectation that his wife would have provided the same care for him highlighted his commitment to the marriage relationship, which he later explained as a value engrained in him early by his family of origin – a strategy for maintaining a sense of self and for doing the 'right' thing (Hoschild, 1983). Denzin (1991) adds that to “do the right thing” requires us to disclose the selves we are, not just the selves we envision ourselves to be, and is not nostalgic for a centered self, but rather longs for a self that “will itself be a tangled web of all that has come before” (in Holstein & Gubrium, 2000:63).

These participants also attest to the additional stress and complexity that came with the demands of caregiving for someone with a prolonged illness. Medical advances have also changed the landscape of when and where people die, contributing to the challenges at the end of life for both the dying and their caregivers. Both caregiving and end of life emergency scenes

can make the experience of death so overwhelming that people have difficulty identifying one single part that was the most distressing as the next section illuminates.

All of it

Five participants (out of 35 asked) also noted that “all of it was overwhelming” in response to this question. Some are faced with dilemmas in the immediate situation, while others suggested lingering feelings. Brenda’s account was a typical response:

Well, (crying) it was all overwhelming, it’s hard to know what was the MOST overwhelming. I think just trying to make decisions about what to do, you know what do I do with my daughter, do I keep her in her room, do I let her see what is going on, I think the immediate, you know like in wisdom, what would be the best thing to do for her. There was nothing I could do for my husband, so I was trying to protect my child the best way that I could. [Brenda, now 47, discovered her 48 year old husband, Gerald, dead in his recliner one morning from a heart attack]

Although overwhelmed upon finding her husband, Brenda acted quickly and called 911 along with a family member to come over and be with her children. Her protective parental role was at the forefront of the self at the moment, or at least in the relaying of the story, she realized her husband was already gone and there was nothing she could do to help him. Others learned of horrific deaths by phone from relatives and explained the thoughts they had after the call, as Cindy recalled:

I don’t know if there was one most overwhelming (laughs nervously) part. A big feeling of guilt for having filed for divorce and kind of giving up on him and on our relationship and also guilt for not having taken some action when I first felt worried that he was contemplating. You know I just had that feeling in the pit of my stomach that this guy is not doing well and I’m worried about him... I don’t know, most overwhelming, I guess was just—you know right at the time was just all of that, how could this happen and it’s so senseless, it’s so—it didn’t have to be that way. If I could have prevented it, he could’ve been okay. [Cindy, now 49 whose 51 year old estranged husband, Harry, suicided]

Cindy, although there was a divorce from her spouse, made attempts to recreate her love for her deceased husband through this account as she stressed the tremendous guilt experienced for not

getting him help. While Connie, whose husband Herbert also suicided, focused in part on the symbolic meanings from the previously shared relationship:

I felt the tremendous amount of guilt, that I still carry, although I'm learning how to sort that out and...I mean a lot of overwhelming things stick out, I mean, hearing that he—hearing what he had in his backpack, he had a few items in his backpack, hearing that he had his wedding ring on when he shot himself, and hearing the comments his father made to me at the funeral home, hurt...And that in so many words. You know, picking out and ironing his clothes for that occasion (crying). You know just trying to help my kids sort through it all...[Connie, now 46 whose 47 year old estranged husband Herbert suicided]

Connie, in describing the most overwhelming part mentioned the wedding ring and other items in her spouse's backpack before he died. These symbols represent crucial dimensions of the prior shared relationship and surrendering them means relinquishing parts of one's self (Charmaz, 1980). Given that the couple had been divorced for a year at the time of the death, and that he had removed his ring while alive, and then placed it back on his left hand before he killed himself added to Connie's grief and guilt. She attempted to reconstruct the tragedy and her role in it. The death of her estranged spouse reshaped ideas about the relationship between them, the estranged spouse and herself.

The two respondents noted above experienced a sudden death of their (estranged) spouses. Two others in this study whose spouses die from illness, also find the entire experience overwhelming and simply state that they could not identify one thing in particular, but rather the totality of the experience over a period of time all seem to be very distressing.

Burden of watching and waiting.

A few of the spouses (3/38) explicitly note that watching and waiting for the spouse to die is the most distressing part of the death from illness experience:

Just watching him (crying)... [Beth, now 63 whose 61 year old husband George died after a long illness from emphysema]

Um, just knowing (crying) 34 years. [Cheryl, now 63 whose 67 year old husband Hank died from liver cancer]

Cheryl suggests that just knowing he is dying and she can't help him is a burden. Also, that they had been together 34 years was obviously significant. Next, Charlene immediately answers:

The waiting, yeah because when we—then we make an appointment with the oncologist. When he told us that you know, it is cancer, you just devastated. [Charlene, now 64 whose husband Henry died of lung cancer]

Given that Charlene and her husband shared a life together for decades, as most of these spouses did, they took for granted that they would grow old together. Watching her spouse linger and die was so overwhelming that it left no room for envisioning a life without him. Now that he is gone, Charlene discusses later in the interview the tremendous pain she still feels when she sees couples walking together. For years they shared a coupled lifestyle, one that she misses deeply. Again, evident in these examples are attempts to reconstruct meaning by detaching from the previously shared relationship as noted by Marris (1974).

These responses show the diversity in one's experience of losing a spouse. Of particular concern is the need for more pre-loss help for those who are providing care for a terminally ill spouse. Many express that it was a tremendous burden to carry the sole responsibility for working, caregiving, and in some instances child care. This point reveals the natural strain in a dialogue of individualism where one must act with both self-responsibility and genuineness (Beck & Beck-Gersheim, 1995; 2002). Again, it exemplifies complex identities as discussed earlier when conflicted with 'doing the right thing' in stressful situations where the self, a significant other, and the relationship are in flux.

Coping After the Loss

When asked what enabled them to go on, there is little, if any hesitation from the majority of the 34 respondents who were asked this question. They provide multiple answers and almost all of the replies are positive and indicate that they see no other way but *to go on* after the death. Responses vary and cover a wide territory that play into these spouses' resiliency including the recognition of informal support, responsibility for others (i.e., caring for children and animals), the feeling of having 'no choice,' and one's belief in a higher power (or as they note, it was simply their 'faith' in God that enabled them to carry on).

Value of Informal Support

The value of informal support systems, such as family, and friends was high on the list of enabling these spouses to carry on:

...I'm convinced that it is the support systems. And I have a much, much, better set of support systems than I would have to say the overwhelming majority of the people there [at the support group]. [Brian, a 56 year old whose 58 year old wife died from a brain tumor]

What enabled me to go on? That's a good question. Family, my kids [ages 20 and 24] in particular, because I talked to them—to my kids, before we even made the decision because we knew it was coming. And they were really supportive, they didn't want to make the decision. They just said 'Dad, you know whatever, we're there'. They were a really big support.[Dale, a 59 year old who had to take his 52 year old wife off life support after a sudden collapse]

Oh, support, support. My kids, my family, my sister, I had so much support. [Eleanor, a 59 year old whose 59 year old husband died of a sudden heart attack]

Social support for those who suffered spousal loss was an important resource for both emotional and practical help, especially in the immediate situation and initial aftermath. This support included a level of comfort where the bereaved have the space to express feelings about their loss. For those grieving, a sufficient network of support helps to relieve unpleasant feelings and concerns and can ease grief and stress reactions which in turn reduces psychosocial problems (Johnson, 1991; Sherkat & Reed, 1992; Thuen, 1997a, Thuen, 1997b). The informal support

present to these spouses at this critical juncture appeared to solidify their expectations of both perceived and actual support for crisis in their lives. In turn, this enabled them to reflect positively with a realization that this type of support is of great value to them in the initial stages of chaos and adds to a more confident self, one that can, and will, carry on.

Responsibility for Others

After hearing about the value of the support groups, the second most frequent response to the question about what enabled these spouses to go on included a reply of having a responsibility for others, to care for small children [in one case, animals] and being there for adult children.

I also had a son at home who had a horrible time dealing with his father's death. You know [my husband] was a 6'2" dynamic and totally fit person, and this is not the person who died, anyway. So, that, yeah, how did I go on? You just go on. You hurt like heck, but you have children and you go on. [Betty, now 55 whose 52 year old husband, Guy, died of pancreatic cancer]

Had to. I had animals. [Cheryl, now 63 whose 67 year old husband, Hank, died of liver cancer]

Again, the above answers came quickly, without pause. These spouses and others had to focus on the needs of others and their own grieving takes a backseat. First and foremost was attending to the well-being of others. Once the strong tie to a spouse was severed by death, it appeared that the protection once enacted for the dying spouse was then transferred to other relationships and became the point of focus in the emotional attachments for the self.

Simply no choice.

Several spouses noted that they had 'no choice' and some get agitated just thinking about it, often looking puzzled as to why I would ask such a question and sometimes asking back "What choice did I have?" Responses include one from Cindy:

I just felt I had no choice, I just had no choice, that the only other, you know either you go on, or you kill yourself and that is not an option (laughs nervously). [Cindy, now 49 whose 51 year old husband, Harry, suicided]

Cindy, knowing the destruction that suicide created from her spouse's death suggested that she did have a choice, but killing herself as he did was simply not an option for her. Next, Emily had a stark realization as she thinks about the question and constructs her answer:

I had no choice, I had no choice. I'm not old, I'm not ill and bedridden, I had to. There was no choice. You know a lot of things, a lot of things (Laughs) are different and I do differently now but I had no choice. And I had to get structure back in my life and I had to make decisions that we were making together to an extent, semi-future, now I had to make those decisions myself. I had no choice, what was my choice? What IS my choice? [Emily, now 64 whose 66 year old husband, Jake, died of a sudden heart attack]

Emily, at 64, defines herself as healthy and 'not old,' one who now is alone in making all the decisions in the household. She uses the term 'semi-future' as she talks about decisions now being made in her new role, one that is 'half' what it used to be. Next, Betty [somewhat angrily] snapped back:

I don't know if I had much of a choice! What was my other choice? My other choice was to die with him? Or, my other choice was to become depressed and somewhat catatonic and remain in my house? Then somebody would have had to give up their life and come home and take care of Mom. One of the sons. [Betty, now 55 whose 52 year old husband, Guy, died of pancreatic cancer]

These responses indicated frustration over having the burden of an untimely intrusion of the death of their spouses. Emily was keenly aware that she needed to return structure to her life amidst the crucial decisions she had to make alone on all fronts. Betty eluded to keeping herself together so that she did not become a burden to her children. After her caregiving experience, she knew the stress and demands of taking care of others, whether physically or being concerned with their mental well-being.

These responses also attest to a construction of a responsible, yet emotionally managed self. Just as Betty preserved her own self in the face of a demanding caregiving situation, she now feels a need to preserve a sense of self by circumventing the feeling rules. This, in turn, limits her emotional offerings to surface displays of the 'right' feeling, but she suffers anyway from a sense of being 'false' (Hochschild, 1983). Holstein & Gubrium (2000:47) note that in a world where false selves swarm the 'true' self, the real self is in danger of withdrawing inward. This leaves uncomfortable remnants and phony personas unsuitably aimed at others, and "valiant as it may be, the resisting self is still victim to the social." When an environment of commodified feelings and managed emotions are commercialized, Hochschild (1983) suggests that the 'true' self is, more often than not, infested by false selves that have been put into movement to help keep the demands of the social at bay. The question is whether U.S. society is moving in the direction where the death of a significant other is shaped by such false selves as others expect us to get over it quickly and get on with a productive life.

Faith in a higher power

Faith in God was another answer from this sample about what enabled them to go on after the death of their spouse:

I've learned so much, but you learn that God is there for you no matter what...[Donna, now 54 year old whose 49 year old husband died of pancreatic cancer]

Donna (who identified as a Catholic at the beginning of the interview) attested to feeling the presence of her God and had a strong belief that God will be there for her. And Delores (self-identified Christian), who needs to know that her deceased spouse is 'somewhere else' and did not just 'disappear,' talked with a strong conviction about trusting God's promises:

It was MY FAITH and trust in all the Lord's promises....I prayed to Him continually to hold my [Brandon] close to him and take care of him ... that was my only concern. It wasn't about me....it was about him. I prayed over and over,

to keep the doubt away and remind me that GOD had a plan in place...and [Brandon] just didn't disappear. That he was somewhere else.[Delores, now 59 whose 59 year old husband, Brandon, died of a sudden heart attack]

Elaine, a non-denominational Pentecostal, suspected that she was not at all capable of surviving this ordeal and attributed her strength to that of a higher power:

My God, that's who gave me the strength to go on...a higher power however people want to refer that to...Well, I know that He's there and He helps me because there is no way I could have made it through without...[Elaine, 56 year old whose husband, Jay died from complications of liver transplant rejection]

And although the three women above, Donna, Delores, and Elaine all identify with their faith community, in addition they are attending members of support groups. Durkheim's (1965) specific hypothesis on the protective influence of particular religions is supported here for the survivors who claim that their faith enabled them to go on.

Other responses include the importance of formal support, as in support groups, and a determination to go on with life. Some of the women talk about poor role models, namely their mothers, who became depressed after adversity, and these women were determined they would not go that route. A few spouses have unique answers (3/38), such as one man who said he was able to go on because he did not talk about the death and loss which he refers to as "it." possibly a form of denial, or a way of deflecting the painful memories associated with a real death. Another comes from a woman who tells me that the only way she can go on during the illness is because she held onto hope that he might not die after all. Again, as stated earlier, this question provoked a very quick response, in most cases without hesitation, indicating that there is no doubt about what enables them to go on after the death of their spouse.

All of these responses combined for carrying on after a significant loss, (realization of informal support, responsibility for others, having no choice, and faith in a higher power), demonstrate a recognition of the role of other (significant and generalized others). Whether this

was a family member or a higher being, sheer determination was evident, despite the tremendous difficulties involved, to accept what one cannot change.

The Experience of Grief

The ways in which these spouses experienced the grief over the death of their spouse was very diverse, but they all had a lot to tell me, especially about their expectations of what it would be like. One unique and descriptive account came from Brian:

Well, my expectation was that at first it was going to be—at first I was going to go through some kind of a shell shock thing, then I was going to hit some rock bottom, and then I was going to gradually going to pull my way out. [Brian, now 56 whose 48 year old wife, Gwen, died of a brain tumor]

Brian uses the term ‘shell shock’ to describe his expectation of the initial feelings in bereavement, a phrase that is associated with battle fatigue, meaning one has been worn down. After a lengthy caregiving experience for his wife, this terminology was consistent with the constant demands and pressure he was under. Next, he expected that he would hit rock bottom, which he did not, and then he noted that he would pull his way out. The interview continued and Brian actually said he was not surprised that he functioned and coped so well because that is the way he is wired and people have commented on it. He fares well under stress. Brian continued:

... by nature I’m an optimistic person, and I don’t know why but even when I get hammered with something I seem to have this ability to bounce back...

So even though Brian viewed himself as resilient, he originally described his expectations of the grief experience as rather gloomy. Perhaps, this is the hardest he has been hit in life, a time where he loses his confidence in his old self’s ability to ‘bounce back.’

Others have some idea of what to expect (but don’t elaborate). They mention how different this loss was from their previous loss experiences of parents and grandparents:

I had an idea, yeah, just from (crying) my father having passed away about eight years prior. I had an idea, but definitely nothing close to what I experienced.

[Brenda, now 47 whose 48 year old husband, Gerald died of a sudden heart attack]

I knew it was going to be hard and I grieved my Grandma, I grieved my step-dad but this is NOTHING like that, nothing like it. [He] and I were very close, we were really each other's world and to not have my partner and my teammate, my friend, my lover anymore is just—even though I was just writing in my journal last night and I said 'Even though I'm a whole person, I feel like there's a huge part of me missing'. [Denise, now 51 whose husband, Bob, at age 58 died of cancer]

Denise suggested that the loss of a close relationship can be compared to not being whole, but it is hard to situate the lost part, as she said, "I feel like there's a huge part of me missing."

Describing the loss as Denise does, in terms of a 'part' of her that is missing, we can see how connecting the physical body and/or emotional connection to the one who died, to her self, is a way for her to capture the deep pain she is experiencing.

Next, for Connie, who also had a previous loss comparison, and whose spousal loss was the result of a suicide, a description about her expectations for grief involves levels. She implied that a spousal loss is on a different plane than that of losing a sibling. She noted that her past experience with sibling loss and her current expectations are:

Not to that level. I mean I had experienced the death of a brother at a young age, but not to that level, I had no idea. [Connie, now 46 whose 47 year old husband, Herbert suicided]

Others continued to tell me that their expectation is that this loss might be similar to previous losses; however, this does not seem to be the case:

My expectation was to have it be similar to my mother's. I did of course miss her and adjusted with that but this was harder. [Edith, now 61 whose 68 year old husband, Jason died of blood cancer]

Edith and the others (Denise above) suggest that their previous losses reveal the extent to which those who died have formed an essential part of their sense of identity, less by one's role and more by the closeness of the relationship. With the death of the spouse, however, there is a

diminishment and interference of selfhood where both role and intimacy share involvement. Continuing on with the expectations of the grief experience, there were several (9/31) who simply had no idea of what to expect after the death.

For those who responded that they have no idea of what to expect in the grief experience, there are those who have not grieved any type of loss before this and have no comparisons or expectations:

I had no idea of what I would feel. I had been through so much in such a short amount of time. [Guy's] illness, [Guy's] hospitalizations, several of them, his pneumonia, his over...um, he was overmedicated. It was just non-stop, my life changed on a dime...[Betty, now 55 whose 52 year old husband, Guy, died of pancreatic cancer]

I didn't know...It was uncharted...It was a road I never went before...[Diane, now 53 whose 53 year old husband, Bernard, died of liver cancer]

I didn't know what to expect... I didn't know, so I went and bought books...[Elliott, a 54 year old whose 49 year old wife died of leukemia]

Elliott's search to know what is in store for him in the grief experience is partly accomplished through self-help books, as several (9/38) also note, yet he is unable to tell me the names of any in particular that were of help, just that they were. While Elliott's search came after the death, Diane tells me that she visited her local library and read everything she could about her upcoming role of being a widow. She is determined to prepare herself. She also read the Bible, cover to cover, three times in the three years during her spouse's illness. Books are recommended to some of the spouses by friends, family members and support groups and provided a few of these spouses with some idea of the road to be traveled.⁵⁵

Lastly, several (12/38) noted that they had no expectations [some even said 'none' as a response] whatsoever about the grief experience, and all of these particular replies came from

⁵⁵ A small list of books mentioned in the interviews that gave some help to these bereaved spouses is found in Appendix N.

those who lost their spouses from sudden death. Perhaps they had not experienced other losses in life to make comparisons, but it seems more likely that the sudden death of their spouse blindsided them. While in a state of shock, they simply had no expectations of the road ahead, and yet many are very anxious and express a desire to know what to expect, even now in years two and three of their bereavement.

Functioning

A wide range of responses about functioning were given including amazement by some spouses about how well they functioned in the aftermath and others by how quickly they ‘lose it’ during the grief process. Brian reflected:

Hmm. Well it surprised me was that I was able to function as well as I could. You know, I’ve heard of people being incapacitated, but I did okay. [Brian, now 56 whose 58 year old wife, Gwen, died of a brain tumor]

While others focus on losing it and on how out of control they felt and how unpredictable the waves of grief were and still are:

I think the fact that you could just lose it on a dime and not be able to regain it...oh, music, I still can’t listen to country music. Music blows me over the edge... I used to sing to him all the time and whenever the song came on “I’m amazed by you,” I would sing it in his ear, so whenever I hear that (crying) it just like whoosh I lose it and so...there was a pillow at the store and it said “All’s I want for Christmas is You,” well, my girlfriend, you know I’m just like sitting there on the floor just crying, my girlfriend’s just like ‘are you okay?’ ‘Yeah’ and it just took me a long time to be able to like when I totally lose it like that it took me a long time to regain it. [Barbara, now 47 whose 44 year old husband, Greg, died in a car accident]

Again, Cheryl testified to the sudden loss of control of emotions in a public but private space, that of her automobile, while out on the road driving:

I think what surprised me most when was all the crying would just all of a sudden

start. And I think the thing that worried me the most was when it would start in the car, that bothered me. Cause you'd get to going and you couldn't see to drive (Laughs).[Cheryl, now 63 whose 67 year old husband, Hank, died of liver cancer]

These bereaved participants expressed their concern about the loss of control and the uncertainty of where and when they might 'lose it.' Walter (1999:149) reminds us that the vast majority of the bereavement literature, books for the general public, and media documentaries encourage expressive individualism, as he notes that the aim is "to challenge private, personal and anomic grief." The message here is that there is only one way to grieve, by a natural expression of emotions, yet there are no guidelines about the appropriateness of where and how to do so. Sociologists have long argued that emotions are not natural but constructed and managed within situations (Goffman, 1959; Hoschild, 1983) along with philosophers who note that emotional expressions function as public manifestations of emotional experience (Wittgenstein, 1953). As a result, these bereaved seem caught between what is shown in public and what is felt in private realms (Goffman, 1959) and were anxious about expressing emotion as Barbara and Cheryl note in the above accounts.

How long it lasts and how difficult it is

Some comment that they were surprised by the intensity and length of grief. The following is a common response on this topic:

Well, people kept telling me they say 'It's going to get better and you are going to cry a lot at night' but it's not...I cry all the time. It doesn't matter what time of the day. You know the minute I thought about him, I cry. I walking, I

cry.[Charlene, now 61 and 15 months post-loss, whose 67 year old husband, Henry, died from lung cancer,]

The number of people who mention such an experience show that while emotions may be unpredictable (i.e., as Charlene notes by thinking about the deceased, or seeing other couples while walking alone, etc.), controlling them is much more difficult in a situation where the focal

point – the death of a spouse – is experienced at a much deeper level within the self. Again, these spouses go on to tell me about what surprised them:

Just how hard it was...And that it was never going to get better. [Earl, now 64 at 33 months post-loss, whose 57 year old wife died of a brain tumor]

Both Earl (above) and Dana (next), nearly three years from the death of their spouses, had similar concerns about the length of the grief:

(Pause) What surprised me the most? Boy...tough question. Probably the...hmmm. Maybe how long it lasts, really.[Dana, now 46 and 36 months post-loss, whose 41 year old husband, Brad, died of a brain tumor]

Many people in Western society generally are not comfortable with prolonged expressions of sadness and we tend to encourage others to return quickly to normalcy by telling them that their grief should let up or ‘get better’ as Charlene indicates. There is an assumption that one’s grief should only last a certain amount of time- a sense of management and control over one’s emotions- but this timeframe is not outlined in the groups for bereaved individuals. These participants state that they were surprised at how long the grief lasts and some add that it ‘was never going to get better.’ One social factor that may contribute to these assumptions includes the medicalizing of the experience of grief and labeling it into categories, such as normal or complicated. With the latter, it is assumed that the grief may not get better until they are treated by a mental health professional, especially those who appear to be suffering ‘prolonged’ symptoms of unhealthy behavior. There are continuous messages and assumptions that we need to restore normalcy and the sooner the better. One example is how most employers require workers to be back to work and fully functional after just a few days. Media reports also influence the general public through the use of photos (and stories) that depict the agony of the initial grief period but rarely follow-up to show how people’s lives are forever changed after a significant loss. Social factors abound, grieving the loss of a long-term relationship is a heavy

burden, one that leaves the bereaved person feeling unbearable loneliness, questioning their mental health, and searching for validation of feelings and reassurance that they either are okay or will be. Oftentimes, the people expected to provide this support – e.g., family members – are also grieving this deceased person, although a different relationship, and in their own way, which leaves the bereaved spouse searching for meaning and seeking to be understood.

Reactions from others

Several bereaved spouses in this sample were surprised at how other people react, oftentimes people in their own families. Clearly, the following quotes indicate an expectation that family members should be better equipped and more available to offer support and kind words. Family and other informal support was present and mentioned by most of the participants (31/38), but a few (4/38) made specific mention about how it was not quite how they had imagined it would be. As Denise notes below, not even the support from her immediate family was sufficient:

The certain people not even saying anything to me. People who I would have thought would have said something to me, didn't say anything to me. My sisters and I are extremely close, kind of like the three musketeers, but even they are not as supportive as I would have expected.[Denise, now 51 whose 58 year old husband, Bob, died from cancer]

Lifetime friends can also disappoint, as Eric suggests:

(Pause) Yeah, the way people react towards it, like my closest friend that I knew from high school became distant, the people that you thought would be supportive and be there for you were no longer that, what you expect them to be. I expected, you know, I got a, he's got (referring to young son) a Godfather and a Godmother and I expected them to be more there for him than what they were, but they weren't...[Eric, now 53 whose 53 year old wife, Jana, died from liver cancer]

And, unexpected blame from one's own family diminishes support for this woman:

...one thing that happened that was unsettling to me too was the fact that my relationship with his children soured and they blamed me for his death. And with his sister also, he had a twin sister. Anyway, I met the whole family before we married and not only did he and I get along, I got along with his whole family and he got along with my family. And so we met each others families before the marriage and we had a pre-nuptial agreement, everything was shared. And then to have that happen, that was unsettling too...[Edith, now 61 whose 68 year old husband, Jason, died from blood cancer]

A good deal of surprise and displeasure that one's own family members have difficulty knowing how to have conversations after the death was expressed by Edna:

I have a sister-in-law that, it's my husband's sister, it was like, the way she said it was like 'how do you like living alone?' She didn't mean it in that way but it just took me back that some people just don't know what to say or how to say it. [Edna, now 62 whose 67 year old husband, Jerry died of lung cancer]

In these narratives there was great dissatisfaction that those closest to them are not able to provide the much needed support and the space for them to grieve, as well as the narratives needed to feel good about the self during and after such a traumatic experience. Edna was fully aware that her relative had no intentions of hurting her as she recognized that people "just don't know what to say or how to say it." Some say foolish things or use clichés or platitudes they are familiar with just to indicate that they care at some level. Some people remain silent and distant for fear of upsetting further the already vulnerable grieving spouse. In general, bereaved individuals are often responsible for managing emotional displays when social structures (and the cultural script tied to them) produce discontinuity between what people actually feel and what they seem required to express to others (Turner & Stets, 2006). This, in turn, creates a frustrating clash between the emotion ideologies, feeling rules and display rules on one hand and the actual emotional experiences of the person on the other (Hochschild, 1983, 1990; Rosenberg, 1991; and Thoits 1990, 1991). In our social world, we are expected to keep our feelings in check, and as Hochschild (1983) reminds us, we are also expected to put the appropriate feelings

on display and to do it on demand, what she calls the ‘commercialization’ of feelings and emotion work, resulting in burnout and estrangement (In Holstein & Gubrium, 2000). When experiencing something as profound as spousal bereavement, this burdens the already compromised self.

Summary

In general, bereaved participants evidenced an overarching theme of compromised individual and social selves. Attempts to define the self, coupled with descriptions of the death and loss stories, reveal the complexity and diversity of the individual experience of spousal loss. They contribute to ongoing sociological debates on: (re)constructing self-identity within relationships, personification, and to society’s structures (Valentine, 2008). These spouses indicate the challenges that arise from becoming suddenly widowed. As they struggle to describe themselves to me in question one, many were unable to construct who they are now, without bringing mention of the deceased spouse. Next, as we move into the stories of death and loss, they continue to show efforts to re-construct the wounded self as they painfully recognize how they sometimes talk as if the spouse is still alive. They move back and forth in this reconstruction by recalling past and current stressors related to their emotions and from their attempts to adjust to this new role of widowhood.

Death and loss stories, in particular, revealed an attempt by the survivors to recount their experiences where they draw on the extensive discursive frameworks of medicalization, individualism, relationship and personhood. There is an obvious need to protect both the dying and other family members through reflections about the most overwhelming part of the experience of spousal loss. Although not expressed explicitly, the tone and nonverbal

communication indicate a need for stoicism in the face of adversity and a responsibility to create normalcy for others, including for the dying person by managing emotions.

Stories include descriptions of hospitals, medical teams, emergency and surgery rooms where spouses are dying in an unfamiliar and more often than not depersonalizing environment, and one where they have to negotiate and oftentimes coordinate the care themselves. There is a wide range of positions related to the professional help where the medical community is viewed as wonderful, to the other extreme where hospice, for example, was not at all a good experience. This span reveals how medicalization of death and grief can be both supportive of human value and dignity, yet dehumanizing (Seymour, 1999).

Death occurs typically at the end of a long illness for most of the spouses in this sample (24/38) with additional demands of caregiving. Participants noted that when you are involved in continuous caregiving of a terminally ill person, the focus lies with the concerns of the dying, and any other family members, in addition to maintaining some sense of normalcy throughout [i.e., working, shopping, cooking, cleaning, etc.]. This includes being able to financially support the family while attending to the dying person. The resultant alterations experienced in widowhood often include frustrating accounts of adjustment to a new role alone, which echoes those in caregiving, where they are the sole provider for the couple. These initial three questions and their probes, which covered a wide range of topics surrounding the experience of losing a spouse, indicate an on-going attempt to re-construct the self after such a significant loss.

It has been documented for decades that the transition from being a married person to suddenly widowed is a very distressing experience (Holmes & Rahe, 1967). Regardless of the type of loss, these 38 widowed spouses indicated that the pain associated with the abrupt loss of their spouse and revoked marital status, is unsettling and unbearable. Suddenly widowed,

participants confirmed the need to reinstate their competence to function as self-sufficient individuals. They attempt to do this by reconstructing their lives and their selves at both the individual and social levels. For the majority of these individuals, this reinstatement was not found in familiar support units such as family. Rather, it takes place through a component of post modernity, that of a shared experience with other grieving people in a grief support group setting, which is the topic of the next chapter.

CHAPTER SIX - RESULTS 2- FORMAL GRIEF CARE

Introduction

In the previous chapter, difficulties associated with trying to make sense of losing a significant other within the context of the self are evident. This chapter attests to other research that shows how the loss of a spouse in midlife disrupts the continuity of the life cycle, crushing hopes and dreams for the future (Wolff & Wortman, 2006) creating great uncertainty and a fragmented sense of self. As a result, these spouses sought out a safe haven, a shared experience and a significant community through formal care. This chapter also continues the theme of how a bereaved spouse works at reconstructing the self after spousal loss within a support group setting. In this environment, attempts are made by professionals to assist the bereaved (i.e., clergy, social workers, mental health professionals, etc) along with attempts by facilitators (some who are volunteers) and other participants in the support group settings. Since the preferred type of formal support by these spouses was the support group⁵⁶, in large part this chapter examines the experience within the group. It includes explanations for why some participants opted out of these groups earlier than others along with a general discussion about formal support services and their contributions during bereavement. This dissertation looks at whether the approach of

⁵⁶ All but one participant attended at least one support group meeting through the five agencies.

formal care changes the bereavement experience of losing a spouse, including the overall understanding of death within a (post)modern society; one where self is authority and experts sit on the sidelines, ready to assist, but hoping to see people help themselves.

Next, Chapter Six continues to show an evolving overarching theme from the data, namely, the *compromised individual and social selves* as evident in on-going attempts to re-construct the self. Four other themes materialize and include: 1) the importance of the group as a *safe haven* to do ‘grief work’ and re-construct one’s self and life narrative; 2) the value of a *shared experience of spousal loss* with other group members; 3) the *significance of a community* where significant loss is explored; and lastly, 4) *unmet needs* brought forth by way of suggestions for improvements of care by the recipients which include both pre and post-loss needs. A large gap in the structure of support group care, namely, inattention to readjustment stress related to tasks associated with practical needs, is also apparent when applying the postmodern theoretical model for spousal bereavement by Utz (2006).

First, as a researcher, I feel a responsibility to look for what is concealed within the experiences of care. I specifically look for clues on whether the care for these spouses could add to our understanding of bereavement in general. What is clear here is that bereavement is an undesirable state, one that can shatter the self when the loss is of a significant other. Bereaved individuals engage in attempts at reconstructing the self at both the individual and the social levels. During the period of interaction with these participants, I listen to the struggles that they encounter prior to attending the support groups, which gives me some insight into the complex and chaotic role of a surviving spouse. For those who are in caregiving situations, for example, they are forced to work hard at managing their emotions in order to protect the dying and other members of the family. After the death, the need to protect shifts from the dying person to

oneself and close others. Continued attempts to manage emotions around family, friends, and co-workers appear confounded by all of the practical tasks left solely on their shoulders. It is in formal care settings that these individuals seek answers and shared experiences that help to make sense of this new widowed self, and a lonely life for many.

The post-loss loneliness is emphasized by talk of coming home to all too quiet houses and feeling a need to get out and be around others, especially in the evenings. For younger Boomers, those with children still in need of parental care, not having another adult in the household is sorely missed. For the mature Boomers who are retired, the feelings of loneliness are intensified even more as they thought a great deal about futures that no longer included their spouses, but rather, a life alone. On all fronts, intimate conversations with the spouses are deeply missed. These participants help me to see the tremendous amount of adjustment required after spousal bereavement. Outside of the formal care realm, they worry that it may take a good deal more time to get it together -- (re)construct the new self -- as they pick and choose those individuals with whom they deem 'safe' with their thoughts and feelings. Such a situation ultimately limits the amount of reflexive conversations available to any given person. Oftentimes, even close others, including family members, cannot tolerate lengthy emotional outbursts, and attempt to help the bereaved person shake off the sadness quickly, for their own sake as well as that of the person who is widowed. Our culture focuses on the emotions surrounding death with concerns about whether the bereaved are in line with some constructed view of normal grieving (Bonanno, 2010). Carrying on in this unpredictable environment without formal support leads to worries that one will incur physical illness or become depressed from lingering too long over the loss or seeking out a new relationship too quickly to fill the void.

Although most of these individuals (32/37) found the organized groups helpful, it is important to point out that in addition to attending the support group through the agency they are or were involved with, other groups were also sought out with an interest in learning more about grieving. For the time-limited groups,⁵⁷ participants came to fear the end of the group sessions. This could be because they would no longer have a safe haven (as the support groups were described to me) where they could release emotions, talk about the deceased person (by name), and gauge themselves with other widowed people. There is an expressed need for more help (even from those several years into the bereavement) as they want to see what another group might have to offer.

In three out of five of agencies used in this research [a funeral home, a hospice/hospital and one center for grief], all bereaved people, regardless of the type of loss, are welcome and included in the groups. One center is designed to care for grieving children and their families, therefore, it meets the needs of parental, sibling and spousal loss. Lastly, two groups are specific to spousal loss and have programs exclusively designed for those who suffer from the loss of a spouse. In some of the agencies there were social functions that extended some of the time-limited, close-ended groups, which will be discussed later in this chapter.

According to the experiences of care for all participants, there was an emphasis within all five agencies on doing grief work in terms of expressing emotions and talking about what has happened. However, there is only one mention in this sample of help for managing all the practical matters and personal concerns that accompany spousal loss, such as attending to home maintenance and financial matters. These concerns are demonstrated in this chapter, which show

⁵⁷ Time-limited, or close-ended groups are usually conducted for 5, 6, or 8 weeks consecutively, and require that members commit to attending the group. When the program ends, the group is finished at the formal level. Some participants choose to keep meeting outside of the group (i.e., for dinner, coffee, etc.)

how these practical matters clearly cause continuous struggles for this group. I use two postmodern models for bereavement to discuss the emergent gap in care, the Dual Process Model of Grief (Stroebe & Schut, 1999) and Utz' (2006) Theoretical Model of Spousal Bereavement.

There is discussion next here in Chapter Six about the general lack of understanding among the participants about the grief work hypothesis, yet there tends to be an emphasis in support groups that one needs to do this kind of work. Grief work is explored and analyzed in a discussion that examines meaning in the context of support group attendance, in addition to suggestions for improvements in these group settings. Lastly, I discuss how several participants offer stories about extraordinary experiences of the deceased, which are not part of the original interview instrument. They are certainly a part of the lived experience of grief for those who tell the accounts to me. Additionally, they are worthy of inclusion with an eye on future research opportunities, as projecting a loss onto extraordinary events and circumstances may be part of the grief work in progress by those widowed. Yet, they are underrepresented in as a topic research due to measurement issues and cultural values related to the supernatural. Although only one participant mentions that he thought this topic could be addressed in a support group (experiences he refers to as 'hauntings'), perhaps further research might prove helpful about whether or not these extraordinary experiences are common and whether the topic should be explored in a formal care setting.

Formal Support for the Bereaved

Walter (1999) writes a thorough account on the culture of grief where he discusses the social position of the bereaved. He notes that bereaved people find themselves caught between the living and the dead, searching for some sort of guideline in a de-ritualized society where grief is policed and pathologized. He suggests that grief in late/postmodern society is regulated

through categories (the grief process and grief work) and through counseling and support groups. “The grief process replaces social mourning as the framework within which grief is regulated” (Walter, 1999:187). Just as therapy allows for clients to recreate themselves by leaving a space of ‘not knowing’ (Anderson & Goolishian, 1992), Walter suggests that bereavement support group facilitators might also embrace this path, helping the bereaved to rewrite their self and playing the role of a friendly editor (Hoffman, 1988; Cochran and Claspell, 1987; Reeler, 1993). I would add that other bereaved members in attendance at these groups also contribute to this restoration on many levels, as they discuss their own journeys of loss, providing tips and advice (indirectly) through their own stories.

As mentioned in earlier chapters, formalized grief care involves an array of services from informational support (i.e., brochures), conversations with professionals, and includes support groups and professional counseling. The main focus of this study turned to the culture of support groups for these widowed spouses, because in the interviews almost all spouses (37/38) identify with, and have some affiliation with, the groups for formal help with grieving. This is not surprising, as there appears to be many instances where these spouses describe their desire to be with other widows and widowers who are living through the same experience. Evident in these stories is that in order to learn how to be a widow or widower, these bereaved spouses and newly widowed want to spend time with others who are already operating in that role. These members live the new identity and are able to assist the newly bereaved with sorting out and sifting through what does and does not work, and attempt to support others on how to ‘work through’ the grief and suggest ‘how to *be* widowed.’

There is a general understanding [and oftentimes push] among care providers in these settings that those suffering from a significant loss need to talk their way through it (Parkes,

2003). One dominant model is the grief work model [also known as the grief work hypothesis] which advocates that one work through the pain associated with grieving which seems “required to make real the fact of loss” (Walter 1999:103). With this in mind, the facilitators or grief counselors help to create an environment that enables the bereaved to tell the story of the loss and discuss their struggles. Riches & Dawson (1996a) refer to the support groups as an “imagined community,” one that incorporates like-minded individuals who parallel their biographies and eventually rejoin the living (Seale, 1998, in Walter, 1999). In this community, the changing narrative is constructed and reconstructed to make meaning out of the death and loss. This phenomenon -- the reconstruction of one’s biography after a significant loss -- is an expression of the postmodern self (reflexive conversation with self and others) to help make sense of life experiences and of life itself (Walter, 1999). Because death is medicalized,⁵⁸ the compassionate response from the helping professionals is to *take care* of the survivors. But as a result of all this care and attention, grief too becomes medicalized and often confusing to the receivers of care. The task of reconstructing disrupted survivor narratives using discursive activity through support group settings may then be viewed in the bereavement community as one that requires the help of (professional and/or trained volunteer) formal care facilitators to be successful.

Crossley (2000) notes that discursive activity represents a valuable resource for adjusting to the social world and making sense of experience especially during vulnerable times.

However, if the focus is solely on the emotions in these groups, it may leave out some important aspects of grief care, such as teaching the person practical skills for their new role, in this

⁵⁸ Walter (1999:85) explains that in earlier centuries, the last chapter of people’s lives revolved around religious language and beliefs (i.e., ‘Did she die believing’) whereas by the 20th century people began to ask questions related to medical concerns, such as ‘Did she die in any pain?’, thereby medicalizing the experience of death.

instance, that of widowhood. Although Crossley (2000) suggests discursive activity is a valued resource, these spouses⁵⁹ (many who have attended several support groups and accessed grief counseling) are clearly irritated with their new responsibilities (such as maintenance of homes) and other aspects of grief (i.e., loss of control of emotion, being judged, etc.) in their social worlds. These groups provide help with emotional stress but it appears many attendees still struggle with the practical concerns.

While all of the bereavement care programs in these five agencies use a structured support group format over a period of weeks and months for this discursive activity, four also provide social functions, religious services, retreats and workshops or one-time memorial services. Two of these agencies, namely, Agency #4 – Horizon of Hope Center for Grief Support (HHCGS) and Agency #5 – Widowed But Not Alone (WBNA), offer regular social events (e.g., dances, potluck dinners) and these continue on indefinitely adding a social dimension for the widowed. The other agencies may have fundraisers to help support their activities, but I am not aware of other social events held specifically for the bereaved persons outside of the support group format.

The main discursive activity during group consists of releasing emotions and normalizing feelings as the participants tell their stories and struggles in the group setting. A script is provided in the group (whether through facilitators or other attendees, or both) that gives people a helping hand when their taken for granted reality, including their sense of self-identity, is

⁵⁹ All in their 2nd and 3rd year of bereavement, with the exception of one participant who is well beyond the 3 year criteria and this is made known in the collection of demographic information but her responses are kept as data.

threatened (Crossley, 2000). However, as will become clear, emotional stress⁶⁰ is the sole focus in these five groups which ignores other practical aspects when dealing with the loss of a spouse.

Given this look into the operation of support groups, it is important to consider the times in which we now live including the character of society that may impact our reality of death and loss. For example, fairly recent sociological and anthropological work (Hockey, 1990; Bradbury, 1999; Riches and Dawson, 2000; Francis et al., 2005) brings to light the increasingly varied and fragmented character of contemporary Western societies. It emphasizes a more interactional vision of society, one where people “make sense of their world through negotiation with each other” (Valentine, 2008:2). The social reality of death and loss within society consists of a diversity of meanings and worldviews, one where individuals use cultural scripts to not only construct meanings but to express emotions and act on the basis of those meanings (Hockey, 1996). In the world of these bereaved spouses, we witness the negotiations with informal and formal support systems to make sense of a new lifeworld while grieving this heart wrenching loss.

Participant Experiences of Formal Care

Since the most common type of bereavement service utilized by these spouses is the support group, the lived experience is analyzed through descriptions of the various conversations and activities in the group. Attempts from others (both participants and facilitators) to help the griever move towards new levels of personal growth is highlighted. I examine the caring interactions within a community of strangers who share a similar experience of loss, and point to

⁶⁰ Yet, current grief researchers, such as Silverman (2011: ADEC website) continue to stress that ‘We have learned over the years that when an individual loses a key member of his or her family, such as a spouse or a child, we cannot look at this as a purely emotional experience that focus on the mourner’s mental health. We have learned that grief is also a social experience, an economic experience and a spiritual experience as well.’

where other bereaved participants are seemingly more valued than the facilitators. The support group culture (of narrative discourse) and language (e.g., grief process, grief work, grief triggers, etc.) appear to offer a guideline (often through the direction of assigned facilitators) for navigating and reconstructing the individual and social landscape of bereavement, which give some direction for the widowed self.

Almost all participants in this sample (36/38) attended at least one support group. One woman recruited from the funeral home did not attend their support group but felt that the pre-arrangements for her husband's death and a visit from their representative was considered formal support. Another woman attended the social functions only for Agency Five, Widowed But Not Alone group. Twenty participants attended the support group of the agency I was interviewing them from; eleven attended this group and another support group; five attended three support groups and one man attended seven support groups since the death of the spouse.

Only a few participants (5/38) mention individual counseling. Several spouses (8/36) are still involved with the agency support groups, either through their ongoing attendance (5/36) at the group or in a volunteer position (3/36). Of special interest are discussions that highlight the real core of bereavement support group participation when the spouse recalls particular situations, conversations, and language used in the group that leave a lasting impression.

Throughout the stories of loss, subjects reconstruct personal conversations with professionals, both in and out of the support group. Some of these professionals and conversations are helpful, and some are not. First, I would like to show how prior to finding a group, the encounters and conversations with a range of professionals (i.e., counselors, social workers, support group facilitators and clergy) have both positive and negative aspects surrounding understanding the loss and incorporating it into one's life narrative.

Personal Conversations with Professionals

These widowed spouses provide accounts of conversations with professionals (which include volunteer facilitators of support groups) that take three basic forms: 1) some recollect both personal and public conversations with those they assume are professionals from the start of the terminal illness or scene of sudden death, which includes professionals and facilitators of support group meetings; 2) others spend a good deal of time struggling with this question and are not certain about the credentials of the people in hospital settings and those helping to facilitate the group; and 3) still others are forgetful about the conversations, which often are recollected later in the interview. A good deal of reflection for some time seems necessary before recalling accounts of personal conversations with various professionals throughout sometimes long illness trajectories. For several (9/38), hospice staff (which includes nurses and social workers) are the most often cited professionals, followed by facilitators of support groups, hospital social workers, clergy, mental health experts (i.e., grief counselors, psychiatrists, psychologists) and physicians (primary and in hospital). An unexpected reference is attributed to a specialized hospital team and in one instance, a Veterinarian is consulted at a routine appointment for a pet check-up where stories of loss are shared.

Conversations held with professionals and close others obviously seem to have less value to these spouses than conversations with other support group members who share a similar loss. This is consistent with aspects of postmodernity, in that “solidarity is based not on pre-existing relationships of kinship, neighbourhood, or work, but on a shared type of experience” (Walter, 2007:128). Stories of these spouses indicate that other types of formal support services (i.e., personal counseling, informational support, retreats, workshops, etc.) are less valued than that of the support group. In some instances, there is a good deal of negativity when talking about their

experiences with professionals, such as mental health practitioners and clergy. However, in defense of these professionals, this could be attributed to what some scholars call ‘ugly coping.’ This concept suggests that bereaved individuals may indulge in negative coping behaviors by directing anger at someone (such as a doctor, social worker, or other expert or institution) which can make them feel better about the loss (Bonanno, 2010). I explore this notion further, but first I recognize that in the immediacy of the death and loss, especially for those who experience loss as the result of a sudden death (14/38), there was a strong preference for familiar people for support rather than for a professional.

Desiring the Familiar

At the end of life there is a good deal of uncertainty and oftentimes chaos for those left behind. The spouses in this study often express a desire for the familiar faces and support from family and friends. Brenda, for example, appreciated the attempts made to help her, but felt a need of an informal support person (i.e., family member) in this chaotic situation:

I just had a ton of support both from family and friends immediately, you know, the police called a social worker who came and she gave me information about different services that were available. We already knew about [Healing Place] because of participating in some fundraisers ... and I had some friends who had used [Healing Place] and then that information was in the stuff that she gave, but she really wasn't a key person at that point because I needed people that I knew around me. So, my sister came immediately... the social worker that came tried to talk to me but I really did not want to talk to her. [Brenda, whose husband Gerald died at home of a sudden heart attack]

Although professionals made themselves available, Danielle expressed an adamant preference to grieve in her own way, which is alone. Still, the hospital social worker proved herself helpful and arranged for a final request:

...after he died, the social workers kind of like stepped in and the [specialized hospital] team was still there. They were so kind and I'm used to being me, myself and I. I didn't want any assistance. I didn't want any help, I don't—I can grieve all by myself. I didn't want anybody there when he had the operation, I

didn't want—I'll be by myself. And that social worker asked me, she must have asked me 15 times, if there is anything I want and I just looked at her and I said 'You know what? I just want to lay in the bed with him', and she made it happen. [crying] [Danielle, whose husband Bill died in a hospital of a brain bleed]

Danielle was atypical for this sample, preferring to keep her grief private and to figure things out as she always had, alone. Her story, however, was typical in the sense that grieving the death of a spouse includes access to professional help. In both examples, it is evident that there was a need to maintain a certain level of normality and familiarity, whether that is in a group setting or in isolation. As Brenda points out, she needed the presence of family around her, which obviously brings a sense of comfort and security. Danielle makes it clear that she preferred to deal with these situations alone. "I'm used to being me, myself and I. I didn't want any assistance," yet both informal and formal support highlight the presence, acceptance and eventual help of the professional other. As Glaser & Strauss (1965;1967; and 1971) and Sudnow (1967) suggest, "we may react to the threat posed by death by invoking and adhering to the norms of everyday reality" (In Valentine, 2008:61), and these norms are important enough to demand professional guidance.

Clergy are among the professionals that appear in several of these stories (10/38). They were viewed as sometimes helpful and at other times as just a part of the process. There was a sense that the importance of having a religious and/or spiritual guide was not a critical part in these dying and loss trajectories. I did not have specific questions related to help from clergy, but since most in this sample identified with some religion or acknowledge a belief in a higher power (29/38) I did probe to see if these professionals were a part of the process regardless of where the death occurs. When they were involved, in the accounts that are made known to me, clergy left little impression. Doris, reaches out to her priest indirectly by asking him to bless her home after her husband died there from a fall:

...I had a priest come to my house to bless my home after my husband died. And we had a brief conversation, but, you know, it left me, not empty, but not warm. So I figured, you know, I'm getting what I need through [Horizon of Hope Center for Grief Support] and that's where I focused.[Doris, whose husband Bruce died from an accident related to a fall]

No other details are given about Doris' reason for calling a priest to bless her home, but one can surmise that there was an expectation for a faith-based conversation with this professional about the recent death of her spouse. Expectations were that this person should know how to handle these crisis situations, as they are trained in ministry and counseling. For some, however, training was not enough:

...I honestly don't know that I had any [personal conversations with professionals] that I can think of. I truly don't. Our pastor is relatively worthless, I mean, he is about 38, 39 years old and has never had a significant loss in his life, what is he going to tell me? I'm not trying to be mean... [Brian, whose wife Gwen died of a brain tumor]

Brian assumed that a younger preacher did not have the necessary life experiences to help him make sense of losing a significant other, yet it is still the mention of a professional that should be kept in mind. We expect experts to help us (Giddens 1991), yet expertise (in bereavement) does not necessarily lie with formal credentials, but with real, shared experiences. Again, consistent with postmodernism as Walter (2007:130) points out, with its' deconstruction of meta-narratives of religion, in that "no longer can [a] priest or scientific expert tell us how to live, how to die, how to grieve. It all depends on personal choice, and on the community with which one identifies." In one case, clergy was on call at the hospital and the participant notes her experience throughout different stages of the death and loss. Others mention that they sought out a familiar religious figure to be present (3/38) such as Dale in the following example:

The pastor of our church was there when they took the life support equipment out and obviously prayed and we talked a little bit, but early on, I don't remember any long conversation. [Dale, whose wife Ingrid died in a hospital after a sudden collapse]

Dale was not too overly impressed by his pastor and could not recall anything that provided him comfort from this professional at this time. But one has to wonder about the level of his involvement with this congregation and whether this pastor knows the family well or not. Clergy, even those from one's own congregation, did not seem to be a first line of support during and after the death. This may indicate that the participants felt as if they (the clergy) have had little personal experience themselves with death and loss (other than at death-bed scenes) or because they are not viewed as professionals who are trained thoroughly in this experience. Rather, it appeared that the surviving spouses are eluding to doing the right thing -- call on the religiously ordained and pray at this moment. The experiences of clergy seemed almost forgotten, until I probe further about other conversations with professionals.

Surprisingly, since most of this sample espoused a belief in God or mentioned an organized religion (29/38), there is no talk of death-bed scenes where the soul and its transition is of concern (e.g., a priest being called in to administer the Sacrament of Last Rites). Rather, the focus appeared to be transferred to the medical aspects of the death. This again points to a postmodern landscape, with a more medicalized and institutionalized system of dying, where religious beliefs provide something of an 'optional extra' (Walter, 1997). Christina, shaking as she recalled her agonizing experience of an unfamiliar assigned professional clergy person called in by the hospital emergency room staff. She holds an exceptionally painful memory:

They had—I guess they're called Chaplains. I guess I just felt like—he kept, he kept pushing me, wanting me to go where he wanted me to be. "You need to come do this, you need to come do that." He just always had his hands on my shoulders just guiding me, guiding, not really what it felt like (laughs), being pushed. I guess maybe if they'd of been more—I don't know—he just didn't seem very—I mean he was compassionate—don't get me wrong... I just, I wasn't ready for—I know they had the legality that they had to go through (crying)... (crying) Everybody was there and we were out in that big room—I don't know, I just hated it. It was awful, it just was awful. I guess if they could have took you

someplace private and said “You know, this stuff needs to be done” but it wasn’t done that way... I mean I had to wait for him to get there but yet I had to hurry up and get papers signed. He was gone and I didn’t see what the hurry was then... it just went kind of weird. [Christina, whose husband Harvey was rushed to a hospital by ambulance and died after a misdiagnosis earlier in the evening at an urgent care center]

And although this story is not representative of others in the study, it was told with great emotion and deserves mention so that those in the field can be reminded of the tremendous sensitivity of the family members. The encounters that were recalled with religiously affiliated professionals were mostly viewed in a negative light where they were either referred to as inadequate or somewhat aggravating. Overall, the responses show a favor towards care from familiar others and perhaps a move away from a religious framework for initial support. The mounting legalities of paperwork, an essence of postmodern society, appear to take precedence over the spiritual and such requirements are strongly embedded in the memories of end of life scenes and are worthy of inclusion.

Professional one-on-one counseling from psychologists and grief counselors was also sought out, but was deemed too lengthy of a process. And, as with interactions with clergy, there was disappointment in the counselors. Cindy, whose estranged husband Harry suicided, for example, found herself extremely frustrated with the first attempt at private counseling, as she described a session with a psychotherapist:

His style was just to sit there and say “So, just talk,” and I’m really not a very good talker and especially when my brain and emotions were totally dysfunctional. You know I couldn’t—I was having a hard time completing any sort of a thought. “So, what’s on your mind?” Well, which minute are we talking about? The last minute? Five minutes ago? Yesterday? I just couldn’t—I didn’t know what to say, other than, “I’m really messed up, I’m really messed up.” I needed somebody to lead me through it more... I mean there were actually times we sat there in silence for minutes at a time and I stared at him and he stared at me, and I was like “I can’t do this.”

But Cindy, looking very disgusted as she recalled this experience, did not give up and was put in touch with a social worker who was able to provide some immediate relief through weekly sessions:

Cindy: I saw her fairly regularly for several months and I'm not sure—

LEH: What is it she did?

Cindy: She was very good at asking the right questions to get me to talk and not just a “How do you feel about that?” and “How does that make you feel?” and very good at telling me what's normal even though I knew a lot of what was normal and I knew—you know I've read books and stuff and people tell me “Yeah, that's normal.” But to actually—I don't know, just really seem to reinforce—and to suggest and to say “Now, you may find this and you may try this and...” In fact, one of the very first sessions she said “What do you really want?” and I said “Right now, I know I need to relax, I know I need to do these relaxation exercises and stuff, but I can't—my mother has sent me—emailed me relaxation type exercises, she has sent me books with chapters and I can't even just do it, I can't sit and read through them and do it myself, I can't.” So she had me lay on the floor and start to do it right now. Rather than just give me a handout and say “Go home and do this.” I told her “It's not working—you know I can't—just, something is way beyond me, you know I'm very limited here.” And so she did, she said “Okay, get on the floor and we're going to start here.” And I started crying and crying and crying all the way through the relaxation, I still didn't relax that much but to be just told to do it right now, I don't know it was just the first step—

LEH: To feel cared for.

Cindy: Mm. Mmm. So, she had a good insight at least for me, had a good insight as to what things are really important to address right now, what things aren't, what's okay to feel and when is it time to say “I'm not going to go down that road.” There are still times I feel like just sitting and breaking down and crying and you know they are very rare. But there were times there from last spring onto mid-summer where at least once a week I wanted to just let loose and do the pity party. And there were times when she discouraged it. She said, “You know, you are at the point where you need to get on—you know focus better and get on with it.” She just has an insight of when you need to be in that space and when you need to get out of that space too.

Although Cindy's bereavement differs on many levels because of the status of her relationship with the deceased (they were divorcing) and because of the nature of the death (suicide), her

account of the professional one-on-one counseling echoes others. There appeared to be little patience for the long and sometimes agonizing road involved in the process of one-on-one counseling. A speedy search for normality and bringing order to chaos was an important feature as clear in Cindy's expressions of "what's okay to feel" and "good at telling me what's normal." Perhaps some of these participants did indeed have a good therapist but did not want me to know about their encounters with professional counseling due to the stigma attached to mental health care.

Earl, in his experience of one-on-one counseling through a church community member, was told to remember that grief is individual. He seems agitated by the counselors words of reassurance and adamantly disagrees:

...I said "I'm doing all the right things, why is this so hard?" And he said "Well, there's no right way to grieve," he said, "everybody grieves different." I said, "No, everybody grieves different, but there's a right way," and to me the people sitting in the chair looking out the window, they may get to it, they may think this is the way I got to deal with it, but to me, if you get it out, then it gets a little easier..." [Earl whose wife, Jenny, died after a short illness related to a brain tumor]

Again, it is evident that Earl was (and still is) searching for normality as he notes there is a right way to do this. Other participants expressed counseling experiences similar to Cindy's first and therefore do not seek out another. The time-consuming task of re-writing the self through weekly sessions with a mental health professional (who may or may not have had a significant loss experience of their own) gave the impression of being unproductive for these spouses. Formal support preference for this sample lies in the support groups, where there are many voices providing personal experiences of loss. This move from a modern view of the professionals as expert to a community of other bereaved individuals being the experts is consistent with a postmodern shift.

Theme 1: Safe Haven

A major concern and expression of the lived experience in a support group format surfaces in the way that the participants stress the necessity of having a *safe haven*. This was (and still is for some) a place where they can release emotion, have their feelings normalized, occupy their time, and do ‘grief work’ while reconstructing a narrative. Donna, moving her fingers along the table to demonstrate working through her grief, attested to the grief work hypothesis, the important task of reconstructing the narrative, and having a ‘safe place’ to talk and re-tell the story:

They [the support group facilitators and attendees] would always say, “you don’t get over your grief, you have to go through it, you have to do the work.” And that’s exactly what it is, you can’t just get from here to here [participant moves finger on table from one end to the other] you gotta go through it and that was something that I had remembered. People think you just can go around it, but you gotta go through it, you gotta do the work. And in talking, that was the other thing that they teach you, the more you tell your story, the more you work through it and that was the whole purpose of the workshop and the meetings after so that you can continue to tell your story, no matter how many times, and if people are hearing it for a thousand times at your group, it’s okay, because everybody knew that that was a *safe place* that you could tell your story. And you might tell it differently each time, or you might cry less each time, or cry at different points each time, but if you told it, for me, I would walk away thinking I learned something this time from telling my story. So that was HUGE for me, just having a place to tell your story because other people that haven’t been through it, they don’t know, they don’t know what to say, and you know you might be boring them with some of your feelings or bringing them down, so many things. But when you are with people who have all been through it, when you are telling your story, there’s somebody across the room going “yep, yep, I know what you’re going through,” and they can all add their little two cents in. So that was really helpful. [Donna, whose husband died of pancreatic cancer]

A ‘safe place’ to tell your story implies there is no judgment and no time limits or need to edit the content of your story, (although as Donna notes it may be constructed differently each time, perhaps as one thinks more about the details as time moves on). Facilitators and group members help to edit the storytellers new self just by their witness to the story in their presence. That the

bereaved could only find this safety in a formal support group points to having a rejection from close others who were either too upset by the talk of the deceased person, or perhaps felt burdened watching the struggles and obvious pain associated with grieving a spouse. In the support group, the deceased person gains a social existence through the bereaved person's accounts. This in turn aids the bereaved individual in keeping hold of memories and a close image of the one who died, which is difficult when the relatives and friends dismiss the talk (Walter, 1999). By being with others who have experienced such a traumatic event, the social self begins to shift from the family or friends to the support group. One feels protected in this space (with other support group members) and exposed in others (with informal support members), including spaces that were at one time central for meaning and identity (perhaps the home), especially in the immediate death experience. Again, it appears that the more cut off from informal supports and the rest of society, the stronger the bond and reliance on the support group and its' members.

Several participants echo Donna's account that the group provides a lifeline, yet there are no specifics about how to accomplish the so-called 'grief work' other than references to talking and telling stories. Again, participants express their concerns about whether they were 'in line' with others who had a similar loss. Elliott, with a relieved expression, drops his arms from the table as he recalls:

So, I just went a few times and just listened and whew, realized just how many people had been going through the same thing. And then I started asking questions on what everybody did that would give me an idea if I was doing things right or if I was out of the ballpark in my thinking and all that type of stuff.... And it was really good to get some of the people that have been through it for five, six or more years on what they've been going through because then I know what to expect and where my path is headed and so forth. [Elliott whose wife, Justine died of leukemia]

Elliott's concern as to whether he is doing things *the right way* includes references to the task of going through his wife's possessions. According to Walter's (1999) typology, many of these spouses searching for normality were immersed in the lost identity (*subculturalists*) as they sought out an alternative society (the support group) which establishes, encourages and instructs them with the new identity (i.e., of a bereaved widow/er). Yet, Dana, for example, lifting her hands in the air, had a hard time identifying her reasons for continuing to attend a support group at first, other than feeling better from talking about the loss and listening to the stories of others:

I'll go to group on Tuesday night and on Wednesday morning, I feel better. You know just that whole process of talking about what had happened and telling my story over and over again, listening to other people's experiences, and appreciating the different perspectives and everything, and just that whole process, the next day, I feel better. [Dana whose husband, Brad died of a brain tumor]

As Dana continued, she was able to tap into other important factors related to attendance, such as having a 'landing place' to display emotions:

So, the group itself, like I say is just helpful between what the leaders will have to say and listening to other people's experiences and the opportunity to really process—and frankly working fulltime for most of this time, and not having a place to cry, and that was what I was looking for at the time, this landing place where I could—because otherwise I would just throw myself into work and stuff like that and not done—and to be honest, three years into it, I probably haven't cried as much as I should. I haven't done all the work that I probably should because I've got so many other responsibilities that I've kept my focus on during this time, but my goal and what [Horizon of Hope Center for Grief Support] did was that landing place, where I could sit down and know "okay, I've carved this time out, this is where you can be sad, and so on," so that was very helpful.

Dana allowed herself to feel sad once a week at the group meeting, an obvious effort at managing emotions. She works and has two small children so she may not want to express her sadness in front of her co-workers or her small children.

There were suggestions about help in processing grief from group participants which incorporates "what the leaders will have to say," but this was not the case in all of the support

groups. Dawn, with great confidence, noted how the facilitators of her group had to stay neutral:

Dawn: And the facilitators, you know, they helped too. They really couldn't say anything. They couldn't agree with you, you know what I mean, because they weren't professionals, they're volunteers.

LEH: So they stayed neutral?

Dawn: They had to stay neutral. And you understand that. Now the one we had, she had lost her husband, we had two ladies. The other one was a former nurse that worked with hospice people, very compassionate, she says "I've never lost anybody," but she was very, very compassionate, nice person. They get—I'm sure they put those people through interviews, but, yeah, to make sure they're a right fit. [Dawn whose husband died from a blood clot in his leg]

A neutral stance by facilitators in conversations, however, does not suggest that they shy away from prescribing ways of grieving. The participants recalled being told over and over that grief is an individual experience, yet many were still interested in some sort of grief etiquette standard (i.e., what is the right way to do this?). They also had a keen sense in recognizing the subtle messages and confirmations of those in the group when some members express emotions, including their disgust and anger about a particular part of the experience of loss. Nods of the head from facilitators and other bereaved in attendance along with encouragement to lean into the pain are all part of the support group scene that stress the grief work hypothesis (Stroebe & Schut, 1999). The group also reminds them that there is work to be done when one does face this reality. Some of these spouses have an expectation that there is a roadmap or guideline they might be given from the support group professionals, but learn early on that this is not the case. There is no formula or no manual handed out on how to grieve.⁶¹

⁶¹ In the self-help literature, there actually is a *Grieving For Dummies* reference book (Harvey, 2007), but to my knowledge this book is not being used in support group formats. It is filled with advice on coping with various types of loss and includes two fundamental facts about grieving, namely, it reminds the reader that they are not going crazy and that their grief will end in time. It also lists three basic tasks of grieving, to acknowledge the loss, experience the grief that the loss produces and incorporate the loss into the rest of life. In addition, it gives a popular

It is also evident that these spouses, once enmeshed in the group, realize that having the necessary space to talk openly about their beloved deceased spouse is helpful even if they are not given some magic formula on how to fix this grief state they find themselves in. It should be noted, however, that just telling the story proves problematic for a few (2/5 who attend only once), and could be why some group members eventually leave and do not go back to the group:

Plus, a lot of the same people came, so you looked forward to being with those people. After about a year, I started feeling I didn't want to hear all the new people there, because it was just rehashing, and I felt bad for them...[Dawn, who attended an ongoing grief support group for a year after her husband, Blake's death]

Five participants from the sample decide that the support group is not an environment in which they feel drawn to. One woman, who appeared sullen and sad, found it incredibly painful to keep re-hashing the story of the loss, so after two sessions she left:

...I don't know, it just was too hard to go each week. Because it was a weekly thing and it just was too hard to go each week and just tell the same story.
[Christina, whose husband Harvey died of a sudden heart attack]

Christina, who early on described her life as 'pretty much a non-existent' after the death of her spouse, was eighteen months post-loss and did not view 'talking' as a necessary part of her grieving. She seemed to have accepted that her married identity had been dissolved, but is now having difficulty anchoring herself in the widowed identity. Another participant, Andy, had an overall negative experience, and shows a good deal of anger, raising his voice at one point and standing up after his comment, pacing in his living room. He is greatly dissatisfied with the way in which the group facilitator put so much emphasis on expressing emotion:

...It was a slap in the face from them that they didn't get it. Males grieve different than females... It seemed to really focus on emotion and a year and a half later I'm still struggling to feel emotional in my body at all, would struggle

list of the mourner's Bill of Rights, reminding the reader that if they are grieving a significant loss that they have a number of rights during this mourning period.

with emotion so to think that I'm going to be emotional three months after my wife died was ludicrous in my opinion. [Andy whose wife Fran died of breast cancer]

Andy's experience of formal care within a support group is not representative of this group, but nonetheless, was one of frustration and disappointment. Bonnano's (2010) 'ugly coping' concept, however may apply here as Andy's story of the death and loss of his spouse was full of negativity. He was angry at the doctors, angry about his wife's care in the hospital and felt that hospice was useless. These negative comments continue into his bereavement experience about the insensitivity of the support group facilitators.

Theme 2: Valuing Shared Experience

Overall, there was a strong identification with these communities of strangers who share similar experiences in support groups. As the quotes testify, and as Walter (2007:130) notes, "...in the group there is relief, even on occasion ecstasy, at finding others who have experienced the same feelings. Previously isolated individuals bond with each other." Participants share with me how membership in the support group was (and is) very meaningful and gives them a chance to look forward to an outing and some relief from the loneliness. They have a place to go where their feelings and thoughts are normalized. Courtney, in a rather quiet and hushed tone, points out:

Just having some place to go every week, outside of work of course, just to have something to do, just different people to see helped tremendously and then hearing other people, not necessarily in the same situation but there are some commonalities with anybody that's in grief. And just having people say, "No, you're not going crazy, this is normal." I actually sat and told them how my mind, I used to be such a positive happy go-lucky person and now I'm not, I just think horrible things are going to happen. I sit at home and think okay here's chest pains I'm probably going to die right now and I was telling them how I've gotten obsessed with making sure I have brand new underwear because when I die alone in my chair and the EMS come, (laughing) I got to make sure my nightgown is always pulled down when I'm sitting there, it's just warped, my mind has gotten warped (laughing). But to hear people say, "Well, that's

normal,” I’m like, “Okay, good.” [Courtney, whose husband Hal died of a sudden heart attack]

Others suggest that it is through chosen topics (such as guilt) presented by facilitators and discussed in the support group among the members, that their fears eased up about whether they were still in the normal range. Donna, tilting her head to one side, is animated and somewhat hyper as she recalled a particular group meeting:

...[the facilitator], who is the head of it [the group] would get up and talk about, say if we talked about ‘guilt’ or ‘regret’, then she’d do just a little thing and it was amazing how, sitting there listening to her, you just—I can relate to everything and for me it was so helpful to know that what I was going through, what I was feeling was normal because you don’t know what normal is when you’ve never been through something like that, and you think you’re going crazy because, like I said I’ve always been a very kind of in control, a planner, got everything under control, I know what I’m doing and I, my mind was so scattered, sometimes I didn’t know myself. I thought “you know I used to be able to do this, to keep things in order” I knew what I was going to do, and I would have days when I just—I couldn’t think, my mind was just—there was just nothing there, and it’s scary, to go through that... [Donna, whose husband Brad died of pancreatic cancer]

Donna talked about her panic associated with having little control and not knowing what normal is. One term often used in these group settings and throughout the grief literature is that of a ‘new normal.’ There is the old normal, their life before the death, and now the ‘new normal’ after the death, which indicated and implied that there is a new way of life to be learned and lived. Donna also noted that “...my mind was so scattered, sometimes I didn’t know myself,” and in my opinion, this was obviously a very frightening experience as she described it, and one that may benefit from acknowledgements by others’ accounts of similar happenings and feelings.

Participants stress the importance of the mutual help aspects of the support group and also the significance of having role models to help them navigate through the storms. Brenda closed her eyes during her recollection of how she found reassurance that she would get through her grief when listening to others:

...there was somebody in the support group who had already gone through that and so it was wonderful to be able to just share and have somebody else share, you know “this is what we did” and you know assure me that they make it through and you know it’s going to be okay and (Laughs). Yeah...you know as time has progressed and I’ve become one of the older people in the group, and you know I can see other women come in who are—and KNOW exactly how they were feeling. And it was nice to be in a group where you could talk with people who know what you are going through. [Brenda, whose husband Gerald died of a heart attack]

As Brenda suggested, other widowed members who appear to be ‘okay,’ and are able to tell their stories in a way that included some kind of healthy grieving tips, are a critical gauge for the spouses so that they too can construct a ‘new normal.’ This provided an environment where “the more cut off from the rest of society, the more members feel the group to be the only place where they are understood” (Walter, 2007:131). In this space of shared experience, one can perhaps get in touch with an authentic self as they are able to fully express their pain and let go of it without upsetting others, which is counter to what occurs in many informal settings. Generally, with close others, bereaved individuals must manage their emotions so as not to cause additional worry and stress for those who love them and evaluate them. In the support groups they felt better understood, where others experiencing a similar loss provided recognition of their struggles. This mutual help was an important component of why some stayed in the groups. Diane, touches her heart and tears well up in her eyes, as she described some of the stories of loss among other group members:

We had 12 of us. Every single one of us lost a husband in the past 3 to 6 months. So from that point on, immediately I kind of feel, I cried—but I cried for others—I got myself up to the top [participant holds hand above her head] I kind of feel that I was on the ceiling of that room looking down at everybody and myself, so I don’t feel pity at all—I cannot feel—you know my heart went out to someone else—some young lady who lost her husband when her son was only 2 and then there was another lady who—she fell in love with this guy but their family really strongly against—after like maybe 20 years, finally the 2 found each other, so they kind of started live together, nine months together, they loved, they were talking about getting married, whoops, one day he died. So a lot of those made

me believe that I can help others, rather than feel pity for myself. So I think after my husband passed away and everything became pretty smooth when I say that, smooth in a way, challenging, but in a way because I prepared myself—[Diane, whose husband Bernard died of liver cancer]

Diane tells how she prepared herself before the death (meaning she grieved during her husband's illness). However, she also expressed to me that she still feels she needs help and how helping others turned out to be just the help *she* needed. Brown, et al., (In Carr, et al., 2006) presents the interpersonal and spiritual connections that are maintained and altered after the death of a spouse. Although the spouses in their study are older than this group, they found, in part, that by increasing one's level of social integration by giving support to others (rather than receiving support) one's loss is dealt with in a healthier fashion. This could explain why some of these spouses, although they note that they did not seem to 'fit' in the groups, continue on in some fashion, volunteering and attempting to help others who have lost a spouse. They may have witnessed some kind of healing within themselves after being beneficial to other participants, which gives meaning to their pain.

Theme 3: Significance of Community

Riches & Dawson (1996a) refer to support groups as communities of feeling which create a subculture where the deceased can be the central actor. Shapiro (1994:1996) suggests that people continue to attend the group if the group's storyline is a good fit with their personal experience. In most cases, the bereaved person's narrative needs to allow for the dead to live on (at least for some time), along with a recognition that grief has no end and no cure, but can be transformative. This scenario is encouraging for those who want to create and continue a story. It is more logical than having a focus on resolving or recovering from a senseless loss (Riches & Dawson, 1996b). Yet, at the same time, it is unsettling as they realize that although the grief will lessen, life will never be the same.

The support groups provide the space for those who need to talk about the deceased. Such a space can be prescriptive, as in suggesting that everyone needs to tell a story and work through their grief in order to be healthy. This is accomplished through constructing and telling the story of the loss and death along with the expression of emotions felt. Earl, in a hushed tone, told me how he felt that any mention of his deceased spouse, even in the family, was uncomfortable and yet he desperately wanted to talk about his wife:

I guess, well, for me to talk about [Jenny]. Oh, yeah, it was a big thing. I thought of, yeah, go stand on a street corner, let me tell you about [Jenny]. So, it gave me a chance to talk...[Earl, whose wife Jenny died after a short illness related to a brain tumor]

Expression of emotion is encouraged by facilitators and participants, so for those who were more private, this can be problematic. Overall, this group felt that they benefit from talking and expressing emotion and that the care from these agencies was very helpful as reflected by their attendance at weekly sessions, social events, and volunteering in the groups. Small (1998) points out that grief is now more public and openly expressed, and the boundaries blur between public and private realms. In the mid to late twentieth century, the norm ensures an individual's grief does not intrude too much on others, while these same others should not encroach on a person's private grief (Gorer, 1965; Walter, 1999). Today, we see an amplified emotionality, one that privileges the open and shared expression of grief (Walter, 1999). This approach suggests that emotional expression of feelings is linked with self-authenticity and claims a therapeutic value invested in emotional release (Lupton, 1998; Hockey, 2001).

While emotional release in a safe space was important to these participants, other benefits were alluded to, including: the significance of structure provided them within the support groups; being with others who have had a shared loss; how their feelings are validated and normalized; and just an overall sense of being in a safe place to talk about their deceased spouse or recall

memories. Barbara, whose husband Greg died suddenly in a car accident, lights up and smiles as she tells me how grateful she is for not only having had a space to share memories, but also for being in a group who actually had good marriages:

....the funny part about [support group] was the group that I was in with, it was AMAZING. A lot of us were married to our best friends. And it was like, you know, —the woman who led the group—she said this is really unusual to have so many people in one group that were married to their best friends. And we had all been together 15-25 years and so that was kind of awesome. That was a really good experience because we could talk about our memories and they were all happy memories, you know. It was like a really positive environment. . .
.[Barbara whose husband Greg died in an automobile accident]

This particular support group had the storyline and composition that she needed to fit both her spousal and widow identities. Others reflect on why they attended groups, and identified how the groups were helpful. For example, Delores speaks about how she attends the group to get help with ‘fixing it’:

You know when somebody dies like that, as you are aware, you —the first thing you want is for somebody to fix it. It’s like you want to go —when something’s broken, you get it fixed and you feel better. I wanted to get to [support group], when I heard that they had something, I wanted to get there so they could fix it. It was so funny because at the first meeting, I cried all the way there, it was an 8 week session, that 8 week session is the most important, it was the most, it was the best thing that I could have done for myself. I cried all the way there because I didn’t want to have to go there but I needed it—it was my lifeline. When I got there, the first thing [the speaker] said was “You can’t fix it, we can’t bring him back, we can’t bring her back, we can’t do that but we can help you get through it.” And that’s exactly why I think everybody goes initially. I mean it’s like, “fix it, fix it, help me, I need help.” So I’d cry all the way there and I’d cry all the way back and I did that for all 8 weeks. Probably but I needed it so bad, it was the best thing I ever did and met some very, very dear friends that to this day we see each other all the time, support each other and talk. And they are the ones, they are the ones, somebody that’s been through the same thing that helps you validate your feelings.[Delores, whose husband Brandon died from a heart attack]

The central restoration story suggests that in mainline culture a bereaved person needs to rapidly repair themselves and align with normality (Walter, 1999). Delores is reminded by the speaker that this is not the way things will work out. The story of loss that is acknowledged in this group

is either a ‘chaos’ story recognizing how bad things are and that there may be no end to the grief, or a ‘quest’ narrative where the long journey of grief is likened to a pilgrimage of personal growth and transformation (Frank, 1995).

The cultural theme of a shared experience was also an important aspect of the support group. Repeatedly, both men and women, regardless of the manner of death, agreed that the most vital characteristic of the group is feeling understood by others who have a *similar* loss. They formed a bond with members in the group who know the pain and struggle of losing a spouse. There are statements made throughout the interviews that reflect the need to have a place where they can feel free to express themselves. They explained how talking and telling along with the expression of emotion is encouraged in the groups and emphasized that the dead can be mentioned, which is usually not the case around friends, co-workers and even in some families as it is thought to have the potential to upset the survivors. People turn to strangers with common experiences for their sense of community in postmodern society and as mentioned earlier, will attend support groups if that group’s storyline fits their personal experience better than what was accessible to them elsewhere (Shapiro, 1996). When there is no fit, they may wander until they find a group (or counselor) that acknowledges their experiences. Several of the spouses in this study told me that they wanted to see what other groups had to offer. As stated earlier, they finished one group and then looked for another and a few (3/38) were even attending two support groups simultaneously. One man attended six groups and also obtained one-on-one counseling. He mentioned the importance of being able to tell people about his beloved wife in these groups. He was excited when I gave him even more resources available in his area at the end of the interview. And although he told me that he has a very large informal support system (nine sisters-in-law and adult children) who live in close proximity, he preferred

a group of strangers for his support system, perhaps a group where he would be free to construct an image of his deceased spouse.

The tremendous difficulties accompanying spousal loss result not only from the physical absence from everyday life but they are also absent from the reciprocal emotional aspect of the relationship. Feelings of grief are amplified when the relationship is one where the other, the now deceased, loved back. The surviving spouse can no longer be significant to the deceased person, they are not in their lives and thoughts as they had once been. Perhaps this is a symbolic representation of the death of part of one's own self since a dimension of it no longer exists when the other spouse dies. In essence, one's self is disorganized and fragmented when there is a significant loss. Not only is the physical presence of the spouse gone abruptly, but so too is the companionship, affection and intimacy that the other spouse often provided. After such a major loss, the self needs to be transformed with new meanings and the construction of a new structure for life.

As reported earlier, they had no choice but to go on after the death. The support group became a lifeline and anchor. It enabled them to face the reality of their situation. Denzin (1991) notes that the social self draws from diverse sources for identity, which results in a more socially, formulated self. There is a concern about what close others would say or think about decisions they were making related to sorting through the possessions of the deceased, or appearing well-adjusted too soon after the loss. There are worries that they have to look a certain way to others, and to some extent, even in the support group setting. For example, although there was an expectation that emotions need to be expressed in the group, after a certain time it is viewed as unhealthy. One widow told me that she listened attentively during the group meeting to a group member recall the struggles of widowhood, who also cried at times throughout the re-

telling. At the end of the meeting, she learned from others that this person's spouse died six years ago, and she is horrified to think that six years from now, she might be in that 'space.' Overall, the seasoned group members reflect healthy adjustment to bereavement which is one reason why the newly bereaved continue on in the group. Cooley's concept of the looking-glass self, as described in Chapter Four, can be of value here as it reinforces the importance of how others can shape our self-identity because the self is the product of our social interactions. This widow feared that this example of another widow could be her destiny.

Theme 4: Unmet Needs: Pre-Loss and Post-Loss

Unmet needs surface in these interviews and include both pre-loss and post-loss requests. Some spouses had broad concerns related to the overall experience of spousal loss while others had specific suggestions for meeting pre-loss needs, for example, better coordination of care. There was also an emphasis on a more sensitive notification of the news of terminal illness as well as of the news of a death. Pre-loss needs for those who care for a spouse in an illness, sometimes over a long period of time included a desire for respite care (when at home) and help with coordination of care in medical settings from doctors, specialists and hospitals. Dana, starts and then stops her story, as she struggled to recall the numerous hospitalizations and the lack of an organized care plan for her dying husband:

Coordination of services would be really helpful, that was really, that was really hard, again, in their defense I understand that you are dealing with people who are just not fully equipped to understand what they are hearing, but overall having somebody there would have been good. That was a big thing. And also, and I guess my expectation was that there would be somebody there in that role and so I was very frustrated and angry that that was not the case and that I had to do so much.

Dana, went on to tell me that in the realization that she had to sift through the best care plan for her dying husband, she thought about how hard this experience is and was for her, a college educated woman. She wondered how others in these situations (who may not be educated or

have the same resources and contacts as she had), would make their way through this maze. She emphasized how much more stress she experienced during the time when she had to make those decisions.

Next, a very unusual story of pre-loss help also surfaces. At the end of a long and tiring caregiving experience, while her husband was being cared for in a nursing home, Dorothy attempted to get some pre-loss help for her grief before her spouse died by walking into a grief support group. She shifts back and forth, crossing and un-crossing her legs, folding her arms, as she recalled the experience and her anger and disgust about not being able to get the support she needed WHEN she needed it the most, prior to her husband's death:

Dorothy: I went because I just needed to—I needed—I just—one of the reasons we probably didn't talk was because some lay people don't understand it but he was alive I walked into this group at [name] church and I said, "You know—"and they said, "No, you can't be here, you know you can be here but you won't get anything out of it." So for all intensive purposes my husband was dead, he was gone. I can't tell you how brilliant he was, he was so uniquely brilliant—

LEH: So you watched him decline and lose all of that and you were grieving—

Dorothy: Absolutely, I was—... So, that caused me a lot of stress...(Pause)
Expectations of the grief experience...after, I never—you know after he died, I once again went into this group—I went in, I mean you can sit here and I said, "He's alive but you know he's not alive and I need to be here," and they were just like, "well, you can go in but. . ."

LEH: They didn't think it was going to help.

Dorothy: Right.

LEH: So, then after his death, you went back—

Dorothy: Yeah, but can I tell you something?

LEH: Sure.

Dorothy: I did go back after and I went twice to that 8 week thing and I sat there and listened and then I said, "You know what, I needed this, I needed this when he was alive." I needed this at the end. I needed to come in here and just watch

all this because everything I was hearing was what I had been going through for a long, long, long time. [Dorothy, whose husband died after a long illness related to Diabetes]

Dorothy had contemplated her upcoming new role of widow, and in her mind she began to prepare for it before the death of her spouse. She needed help in doing so, but was not welcome at the group because she did not fit the expected script of this support group for bereavement. Dorothy explained to them how she lived in limbo at the end of the caregiving, in what might be viewed as bereaved in spirit but not in reality. She specified that is why she sought out and attempted to attend a grief support group before the death. Her pre-loss needs for her emotional well-being were greater before the death than after. However, she was rejected in her attempt, because in the group's eyes, there was no way to talk with a soon-to-be-bereaved spouse who is not yet actually widowed.

Another suggestion was that there could be a more sensitive notification of the news of terminal illness as well as of the news of the death. Several participants told me about the delivery of the news of an illness that was terminal by specialists in medical offices when the patient was alone, or over the phone, as in Elliott's case with his wife, Justine:

Well, it was kind of weird [laughs] because she had two canker sores that she couldn't get rid of and I had gone to the store to buy the medication, and that didn't work and finally, she says, "ah, I'm just going to go into the doctor's to see if they can have something." So, she went in, she had an appointment, she went in and they did blood work and that and I would say that evening, she got a phone call from the doctor stating that she had to go into the hospital right away, that her white count was like through the roof and that it looked like she had leukemia. So, they told her over the phone [laughs nervously].

Elliott, while laughing nervously, had tears welling up as he recalled how the news is given to his wife. He was not able to protect her or choreograph this story. Others, like Brian, are still bothered and agitated about the way in which doctors had no regard for their patients in these sensitive situations. Brian, imitates the way in which he feels the doctors acted, in a nonchalant

manner as he recalled how they told his wife, Gwen, about her brain tumor, prefacing the doctors words with ‘Gee...’ indicating how ridiculous it was:

We both coincidentally had conferences up in Traverse City and she just broke down crying saying, “I’m having trouble with my handwriting, I think I’ve got a pinched nerve or something.” So, very carefully, we got in our separate cars, drove back, took her over to the doctor, dropped her off, and of course I went to see a client, and they just routinely x-rayed her and so she was by herself when the Dr.’s came in and told her, ”Gee, you have a brain tumor the size of a walnut.” And, it’s like, if I had but known, I would have been there. But she said, ”no, go, go, go, go, this will be no big deal.”

This was a huge regret Brian has yet to resolve which may, as in Elliott’s case, be tied into failing to protect his wife from emotional suffering. Dawn, whose husband Blake was rushed to the emergency room after waking up in the night and not being able to breathe and subsequently dying in their home, (pronounced dead at the hospital), suggested:

...I really think the hospital...should do something and not just send you home. They had a social worker there, I didn’t even know what he was. They never...and the pastor, they never even said, ”This is the pastor, this is the social worker.” They took us, after my husband passed away, they took us into this room and here’s these people....

Continuing on when probed, Dawn offered a better way to approach and help the family:

LEH: So, what do you think they could have done? What would have been a better scenario for you and your family?

Dawn: I think, “We’re so sorry that this happened.” You know, just given the heartfelt thing, I think it was really cold.

LEH: Maybe sit down with you?

Dawn: YES. And, “I know your mind isn’t clear right now, but let me give you some phone numbers. We want to help you, help your family.” We got nothing.

The importance of a proper introduction and overall demeanor of those who have the delicate task of delivering this news was a critical concern and seemed to have a lasting impact on the bereaved spouse. A large part of one’s self in these instances was ripped apart with the

news of the death of their spouse, and yet the newly bereaved had little time to adjust. Rather, they are thrust into a cold new world of institutional processes, one where there seems to be little respect for their unfortunate situation.

Although there was a good deal of nervous laughter when re-telling the ways in which the news of the terminal illness or death is delivered, it was evident that there are emotions buried towards those whom they felt were insensitive. Protecting the personhood of their loved one has strong meanings assigned through these stories, yet while thrown into these situations, there is little control and a yielding to those in authority. For those who died in their homes, there was a much more relaxed reconstruction of the end of the life story from the bereaved spouse. For those who had a more unsettling experience and who could find others who had similar unfortunate endings in the support group, it appeared to me that the connection alone seems to ease the wound. This bonding shifts the power of expertise from the medical professionals (facilitators) to the bereaved persons as there was now a mutual experience of suffering among group members. Just an understanding from others that this occurs and that the frustration and helplessness shared seems to bring comfort for those still struggling with these unfortunate experiences.

Of the most concern after the death, or post-loss, were topics that relate specifically to the support groups and include: extending the number of group sessions or not being limited in attending the groups (i.e., about to be widowed vs. already widowed); concern about where emphasis should be in terms of social events or grief recovery sessions, or both; and a need for the facilitator to adjust to the topics that those in attendance wish to talk about.

Extending group sessions was brought up because some of the participants felt that the group ended too abruptly. This left them no safe space to express their emotions and feelings

without judgment and no close others to share their experience with. Dawn, age 61, whose husband Blake died suddenly, had this to say:

Dawn: Once you finish the class, it stops (slams hand down on table).

LEH: Too abrupt?

Dawn: Yeah, and I wish it could have gone on, if people wanted to go on, and I'm sure they would have.

LEH: But when you finish those weeks, it was kind of...

Dawn: Yeah, it's like, you're on your own now.

Dawn, at 22 months post-loss, who had grown accustomed to expressing her emotional stress in the group, now suddenly had no safe place in which to do it. Noticeably absent in her interview, were references to other support systems, such as family or friends, as she only identified with her part-time work. Later I learned that she had children and grandchildren. Others, like 56 year old Cathryn, whose husband Hugh died after a short illness, wanted to know that she could come back, and that there would be no time limits:

...I guess just having the grief support groups available. Knowing that you're not—it's not like they take attendance—that you can come and go...I mean 5, 8 years down the road, you know you can stop in—you don't have to be coming all the time, I mean you can just stop in...

Cathryn wanted to know that she could stop by and engage in discussions in a safe place if the need arose. We see that solidarity was formed within the group structure, one that provided stability when all other support systems appear inadequate once the bond with the group is formed. Perhaps Cathryn wanted the reassurance that at 5 or 8 years post loss, she is doing 'okay,' and the only place to do so would be in a support group of others who are widowed. This appeared to be the only space where she could determine her abilities in this role. Although mourners were told that everyone grieves individually, they were also emulating the role of

others who were further along in their grief and who offered them a gauge with which to measure their own grief trajectory.

Two of the groups (Agency 4, Horizon of Hope Center for Grief Support; and Agency 5, Widowed But Not Alone) proposed ongoing social events where the widowed continue meeting for years. People start out with the grief recovery sessions and then move to the social events. For people being supported by other agencies (who did not have the resources or personnel to continue to provide events) all that was available was the two month group. Delores, for example, would like to have seen that eight weeks turned into twelve weeks or more:

LEH: What could be more helpful, if anything?

Delores: Uh, hmm. Well, I would have liked to have seen that 8 weeks turned into 12 weeks (laughs) or more.

LEH: Because you had to make a decision at the end of the 8 weeks?

Delores: No, I missed the weekly, I missed the weekly.

LEH: Having that to look forward to.

Delores: Yes, and the small group intimate—we had connected so well with our little group that I would have liked to have continued that for a longer period but we are—they do provide other groups that you can join, which we did with the starting on with my friends but it was a bigger group setting. And I don't know if we were really quite ready because we didn't start with that right away. We waited a month or two.

Delores mentions the 'intimate' nature of the small group, perhaps a replacement for the intimate role her spouse once played in her life or a replacement for emotional and social activities they once had as a couple. It appears that there may be a dependence on the group support and perhaps a frustration for those professionals and volunteers overseeing the groups who may think that many bereaved individuals have not moved on or shown some kind of

progress. In a few instances, it is brought to my attention that facilitators and counselors attempted to remind the person that at some point, they should look to the future.

Agency Five (Widowed But Not Alone), with over 700 members, is situated just outside the Metro Detroit area. They hold monthly social events in various areas for the members. These events, I am told, are better attended than the support group sessions that address grief recovery, suggesting a need for more social events and agendas for these individuals. The social gatherings that are held include a religious service with a potluck afterwards providing a social space to be with bereaved others in an environment where the deceased is not the center of discussion. Eric, 27 months past the death of his wife, who attended this group, however, was agitated when I asked what improvements could be made, as he continues to feel a need for more grief education. He was disgusted to learn that this agency offers a grief recovery program, as he had only attended the social events and he never even learned about the other group, until our interview. Eric noted:

Eric: ...maybe more encouragement to participate in their support programs, versus just being a social aspect that people just get together and socialize with, so there was no pressing or no encouragement of doing those specific programs.

LEH: To attend like the educational—

Eric: Right. I mean they were promoting their dances and things like that but they weren't promoting the educational ones, although they were there if I really wanted them, I could have went to them.

LEH: So, you weren't even really aware that they have these types of, I think they have, it's called Grief Recovery and it's like an eight week program.

Eric: No, I wasn't even aware of that.

Eric, possibly because he was in his early 50s and had a young son at home, had more pressing concerns than attending social events. He had more of an interest in connecting with an educational grief recovery group that would continue to gather in an intimate space to learn

about the struggles of everyday life as a widower. This may indicate an ongoing need to have other widowed people ready to assist with re-writing the self, as suggested by Walter (1999). This includes a space where support group members (along with facilitators) can provide editing through affirmations, suggestions and advice about his ongoing daily struggles. Eric only saw advertising about the social events of this group and felt that they were heavily promoted.

The spouses who participated in the social events saw these gatherings as a welcome alternative to the grief recovery sessions, a breath of fresh air from the continuous re-hashing of death and grief. Since I have no statistics on the larger extended group who attend the social events (such as months post-loss) I am guessing that they may be farther away from the death, with new needs to rejoin the living and get on with life. One participant, Earl, who attends both the grief recovery programs and the monthly social gatherings for this same agency (#5), referred to these two seemingly separate realms as phases, where in Phase I you grieve and in Phase II you get together for social events:

Earl: Yeah. With [Widowed But Not Alone], you go to dances and a lot of things, you don't even talk about the grieving stuff, it's just Phase II.

LEH: So you called that Phase II?

Earl: Yeah.

LEH: The social.

Earl: Yeah.

LEH: So the attendance at support groups was Phase I?

Earl: Yeah, that would be the 'doom and gloom', I mean you would laugh at different things, but the [name of agency] is the next step.

LEH: A little lighter.

Earl: Yeah, it, because a lot of them women and men in our meeting, it's been years ago already, so it's not really, they've gotten on and learned to live with their loss more.

As part of these social events, one agency provided a religious service so spouses were able to identify with their faith tradition, which for the most part appeared to bring comfort. In one instance, however, Eleanor, became very animated with her voice and her hands, as she recalled how offended she was after attending a Mass where the celebrant of the service, in her view, overplayed the 'widowed' identity:

My cousin was with the [support group] and she encouraged me, one or two, they have every couple months, a Mass, a [support group name] Mass and I think I was a widow two, three months and she goes, "Why don't you come to Mass with us and meet people?" So, I went with her, I came home and I cried the rest of the day. I walked into this area, I seen, I was probably one of the youngest people there, I went into the church and the priest in his sermon told me probably 10 times throughout it that I am a widow. I went home and I thought, "This isn't what I want to do on a beautiful Sunday afternoon." And, actually since then, it's been a couple of years, I've only gone to one other Mass. I just, you know this whole thing, it's too overwhelming. And so then, I went to a few more things, I went to a dinner, and it was kind of okay. And I find I do better on a smaller group level with the [support group]. I have met a lot of people in our area, my age, little by little, I'm doing more. Actually, this past spring, I co-chaired the retreat for the weekend.[Eleanor, whose husband, Jared died of a heart attack]

Eleanor associated her new status of widowhood to being 'old' where even the mention of 'widow' was troubling for her to hear. The fact that the Mass was populated by people older than herself, and the constant reminder that she is widowed was problematic to her sense of self. Later she comments on her volunteer work with the group, "I'm doing good with that, I'm seeing them more as people and not as widows and widowers." This may be a projection of her own sense of self to others with similar experiences, helping her to reassure her own scripts. Since many of these spouses also indicated that they still feel married, perhaps Eleanor is not quite ready to accept this new status and role as she continued to have strong feelings for her deceased husband. Their decades long marriage coupled with the fact that he died suddenly, and at a

relatively young age in today's standards (age 59), there was no chance to say goodbye or express her gratitude and love to him. Although she does not attend another religious service affiliated with the agency, she does currently attend the support group regularly as she thinks it helps to do her grief work, a very necessary part of grieving that will lead to a healthy outcome according to the support group script.

Grief Work

The grief work hypothesis is based on psychoanalytic models of grief (Freud, 1917; Lindemann, 1944, etc.) and suggests that for the bereaved individual to have a healthy psychological adjustment to loss, they are required to deal with and assess their thoughts and feelings about the deceased. It is assumed that if a person distracts themselves or avoids this 'work of mourning' (as Freud called it), then this points to denial and may result in delayed, prolonged or chronic grief. Grief scholars, notably Stroebe (1992), and Bonanno and Kaltman, (1999), have challenged this long held psychoanalytic view. Others as well, Wortman and Silver (1989), challenged the assumption that grief work is necessary for a successful adaptation in bereavement. They found that people who did not show distress after a significant loss did not always experience subsequent difficulties.

However, the idea of doing one's grief work in support group settings is still encouraged, and the need for emotional expression is a large part of the landscape of such groups, including for those in this study. Grief work is also referred to as 'active grieving' where the bereaved sets aside time to think about and face the memories of the deceased (managed emotions). On the other hand, mourners are reminded in these groups of their personal choice on how to grieve. Diversity is emphasized and notable within the script given inside the group. All behaviors are normalized and validated and participants are told that grieving is an individual experience.

Phrases used to explain doing the necessary grief work include ‘leaning into it’ and allowing oneself to ‘feel the pain.’

Footnote and Frank (1999:168) discuss grief work in the bereaved role as comparable to Parson’s sick-role theory where being ill positions a person within a role defined by socially ordered expectations of being sick. These authors propose that the bereaved role captures “several dimensions of the prevailing discourse of the social ideal of bereavement” because the role is to be temporary, occupies an excluded class that had some benefits (i.e., time off from work), and one where professionals are entitled (and expected) to intervene and offer help.

Also in the late 1990’s, the Two-Track model of bereavement was introduced by Rubin (1999) who argues that the loss process is conceptualized along two distinctive but interactive axes that focus on overt and covert features of the response to loss. Track I explains biopsychosocial functioning after loss where Track II is concerned with the ‘bereaved’s ongoing emotional attachment and relationship to the deceased ‘(Rubin, 1999:681). This model highlights the importance of examining the continued relationship of the bereaved person to the deceased person to assess and intervene with the client. It is similar to the next model for discussion, the Dual Process Model of Grief, in that they both underline that there is no single predictable passageway through grief (Neimeyer, 1999).

Dual Process Model of Grief

More relevant, in my view, is Stroebe and Schut’s ‘dual process model’ (DPM) where it is recognized by Walter (2007) as a postmodern model of grief. Stroebe and Schut (1999) argue that mourners should indeed ‘work through’ the painful feelings, but that there is much more to it. The authors advocate that the emotional and readjustment stress cannot be done at the same time, and that survivors oscillate between being emotion focused and task focused. While

attending support groups, the individuals I interview inform me that they are able to concentrate on the emotion-focused side of grief. But, in my assessment from their stories, the struggles outside of the group seem to be all consuming and overwhelming, which involve a good deal of the task-focused elements not being addressed in groups. These relate to everyday living and concerns about practical matters (i.e., household maintenance, etc.) along with the emotional stress, which are reflected later in this chapter. These practical matters involve the demands and tasks of life for the bereaved person, now living a life without the help of the person who died. Unaddressed in the group, for the most part, are discussions about the struggles related to these concerns in order to restore normal functioning after spousal loss. Bales (1950) developed a model, one of equilibrium, which is similar and suggests that a group generally deals with instrumental (task-oriented) and expressive (socio-emotional) issues separately. Groups often deal with the instrumental issues first and then gradually move on to the expressive issues to keep the group going.

The DPM is recognized as helpful in moving away from viewing grief as a linear process of stages or phases and offering a more flexible approach that permits individual, social and cultural diversity (Valentine, 2008). However, it is also met with some criticism as this same author, Valentine (2008:125), points out that there is still too much weight given to individual psychology rather than social context. She argues that the DPM suggests that there certainly is a 'healthy adjustment' needed in bereavement. For example, she notes that this model implies there is a 'time-bound process of 'oscillation' between the demands of the living and the dead' and that it fails to recognize that for some, the deceased becomes a permanent part of their everyday lifeworld and of their sense of self. They may still oscillate, but they may identify more with the loss-oriented side of the model. For example, a number of the spouses I interview

tell me about having ‘extraordinary experiences’ of the deceased (i.e., dreams, sensations of presence, etc.) which may be considered loss-oriented, and according to the literature could be viewed as problematic if they remain focused on the deceased person and fail to adapt to the changed relationship. Valentine (2008) does not believe that the DPM fully captures how for some survivors the deceased may live on as a permanent part of their identity without the danger of being considered ‘chronic’ grief.

Theoretical Model of Spousal Bereavement

Adapting the bereavement model put forth by Stroebe & Schut (1999), Utz (in Carr et al., 2006:186) identifies another significant characteristic of bereavement specific to spousal loss, which is “how the experience varies across individuals and social contexts.” Utz (2006) suggests that coping abilities after a spouse dies are associated with risk factors such as how couples designated their social roles and everyday tasks in their married everyday life (task allocation), whether they expect and anticipate the death of the spouse (nature of death), and whether they have sufficient support (social support) for the tasks they face in their new role of widowhood. The practical everyday tasks, which may include for example, home maintenance and financial responsibilities, are considered ‘secondary stressors’ and part of the restoration-oriented coping.

Extending the understanding of how people cope with the restoration-oriented tasks as outlined in the DPM, the new model by Utz shows how these tasks play into a bereaved spouse’s distinctive experience of bereavement as there are obvious other kinds of stress, besides the emotional, associated with losing the spouse. Additionally, the nature of death, whether it was sudden or anticipated, may also play a role in the readjustment to the loss of the spouse. Lastly, the role of social support is addressed, both at the informal and formal levels, both actual and perceived, which again, can impact one’s adjustment to spousal loss. This model suggests that

one also needs to learn new skills to address “the stress associated with losing the instrumental arrangements that allowed the married couple to operate efficiently”(Utz, in Carr, 2006:171). Building upon Stroebe & Schut’s (1999) work, Utz’s model illustrates the two main types of stress that result from losing a spouse, specifically the stress of losing an emotional attachment (loss-oriented stress) and the ensuing stress due to the disturbance in the “economic and practical arrangements that the couple shared and maintained” (restoration-oriented stress) (Utz, In Carr, et al., 2006:185). Utz’ (2006) work examines how older bereaved spouses cope with the economic and practical challenges of spousal loss and how these everyday adjustments contribute to the overall experience of losing a spouse. My findings with younger aged bereaved spouses partially parallel Utz’s (2006) model.

Evident in this younger group of surviving spouses, and consistent with Utz’ (2006) model for late life spousal loss, both emotional and readjustment stress are strongly identified. Emotional stress, and the subsequent formal care in support groups plays a large role in assisting them with the expression of the emotions and feelings mainly through talking and telling about their experience. These spouses also articulate their frustrations for many other aspects of the transition from being a married couple to a single person that are obviously unattended to in support groups. These concerns include help with the added responsibilities related to the maintenance of homes and financial concerns (mostly by the females) and the dating concerns and need for a companion (mostly by male participants). Suggestions to improve care from these agencies include requests to extend the group sessions, perhaps in part, hoping to address some of these additional needs. As noted earlier, almost half of the spouses in this study (17/38) also sought out other support groups in addition to the one through the agency they are recruited from for this study which may indicate an attempt to find more help for these other concerns (e.g.,

financial, dating, etc.). To speak to the criticism of Valentine (2008), a more thorough follow-up study of this sample is in order which might focus solely on the two suggested notions outlined in the model provided by Utz (2006). Utz' (2006) model is useful in the present context when approaching and interpreting the experiences of these bereaved spouses. To recognize this gap in formal care in a support group format that emerges from this data, the following sections address both the emotional and readjustment stress experienced by these participants.

Emotional Stress

Expressions about feeling better after attending a support group meeting were frequently heard in these interviews, however, no one identified any acquired skills to provide help outside the group in everyday life. There is an acknowledgement that a loss of control of emotions is unpredictable and frightening. In fact, a number of these interviewees described a loss of control in the public realm as surprising and unsettling. As mentioned in Chapter Four, for example, one of the younger widows, Barbara, who is 17 months past the death of her husband from a car accident, noted she would "lose it on a dime and not be able to regain it." As she stared off into the next room, eyes filled with tears, she attempted to tell me about not being able to listen to country music because it stirs up memories of when she used to sing to her husband, and now when she hears these songs, it's like "...whoosh I lose it." Cheryl had a fearful look on her face as she also expressed concern over the unpredictability of emotions in public:

I think what surprised me most when was all the crying would just all of a sudden start. And I think the thing that worried me the most was when it would start in the car. That bothered me cause you'd get to going and you couldn't see to drive (Laughs). [Cheryl whose husband died of liver cancer]

The space in her car provided a private place to cry in without judgment by others, though it is still problematic for a number of reasons, including her own safety and that of those around her. Remaining strong is still highly valued in our society, so losing control outside of a safe place is

problematic. Showing emotion publicly, especially for long periods of time, makes others uncomfortable and is bothersome to the bereaved person. The support group space is also a place to show emotions, but in a more supportive and safe venue, a place where widow/er narratives can be shared, and, in a sense, tried out. Unfortunately for many of these participants, the support group narratives do not translate into being able to manage one's "expected" normal self in other spaces.

Stroebe and colleagues (2005:395) review research on the impact of expressing and sharing emotions across four social spheres related to grief, namely social support, emotional disclosure, experimentally induced emotional disclosure and grief intervention. They conclude that "in none of these areas is there evidence that emotional disclosure facilitates adjustment to loss in normal bereavements." Wolff and Wortman's work (2006) challenges the theoretical assumption that it is essential for bereaved people to 'work through' their feelings in order to make progress in bereavement. Although their review of research and findings are based on the Changing Lives of Older Couples (CLOC) study, they point out considerable variability in whether any specific grief work is beneficial.

For the spouses in this study, the shared experience appeared to be an equally critical aspect of group attendance. All but two of the fourteen *sudden* death survivors, for example, feel that the formal grief care was quite helpful because of the companionship factor:

Their retreat, it was for two days, I just went for one day and it was very, VERY helpful, just the camaraderie, the same boat, everyone's in the same boat.[Emily]

Emily only attended the social events after the retreat, and the symbolism of a shared identity and companionship within those settings was meeting her needs. She did not express emotion during the interview and did not mention the importance of the support group for this concern.

As well, one of the fourteen spouses who did not find the group all that helpful said she just did

not fit in with the others. She expressed that the support group taught her nothing new. She does not mention that it was a good outlet for her emotional expression and she spends a good deal of time explaining why the group was not a good fit. She noted that it was because she has no children and that there were many conversations about children and grandchildren, and even the facilitator would remind the participants that “they always have their children to think about.” Nevertheless, she volunteers (for this same organization) after her group sessions end and she is involved in fundraisers and social events at the time of our interview. As stated earlier, maintaining some level of social integration -- in this case by giving support to others who do not fit the normal script – in my view, may help her to cope with her grief in a healthy fashion. Or, this behavior implies that she has been given something by the experience of formal grief support, usually some insight that must be passed on to others. Since she never mentioned emotional stress, nor shows any when recalling her husband’s sudden death, perhaps her continued contact with the agency is to provide help for others with adjusting to single life and all the tasks that come with it.

Readjustment Stress

Utz’s (2006:186) model outlines another critical aspect of bereavement, one that she explains as “how the experience varies across individuals and social context.” These factors include the amount of help for the new workload (such as maintenance, financial, or cooking and cleaning tasks) waiting for the bereaved person after the death (Social Support); how, prior to the death, the spousal couple allocated social roles and everyday responsibilities (Task Allocation); and whether or not the spouse’s death is anticipated (Nature of Death).

Utz (2006) challenges assumptions about spousal bereavement by attending to readjustment stress in addition to the emotional stress. There is of course the emotional void

created after the spouse has died, but also, as evident with the spouses in this study, there is the void from a lack of active physical help from the spouse no longer present. There is a great deal of frustration about concerns with all the practical issues from becoming suddenly widowed (i.e., home maintenance, financial concerns and dating). Throughout, the interviews include stories of the aggravating demands of adjusting to life without the physical help of the deceased spouse. This grief is not static, but oscillates between emotional stress and readjustment stress. This is clear in Danielle's discussion about what else the support group could have done to help her adjust. She actually can't think of how they could possibly help, as she mentioned a list of new tasks (mow the lawn, put the gas in the car, etc.), along with her usual ones (cook, clean, etc.). She ends with telling me that yes, you need help, but she's not sure how they can offer it as she suggested that you just have to muddle your way through it:

LEH: [Q D.13] So, looking back Danielle, can you describe for me what you think might have been more helpful (if anything) from [Horizon of Hope Center for Grief Support]?

Danielle: ...no, I don't think anything would be more help because it's all new, it's just all new and you have to kind of like find what you're going to do. I mean you're a couple here...and now—not only do you mow the lawn, you cook, and you put the gas in the car and buy the gas to put in the lawn mower—I think the overwhelming...that now you have two jobs...I don't think that you could sort that out yet.

LEH: So you need a little guidance on how to get through everything and do two roles now, take care of everything.

Danielle: Yeah, but I don't even know how—I think that you just cry for the first month because you don't know what else to do.

Danielle's description supports both the DPM and Utz' model. She was experiencing grief in a wavelike manner. Seemingly, she was frozen initially and locked into the emotional stress associated with the loss and the realization that she was solely responsible for all tasks related to everyday living. The oscillation between loss-oriented and the restoration oriented stress is

evident. She recognized in that first month that she had to face taking on both roles which adds to the emotional stress. When Emily loses her 66 year old retired husband who has 'done everything' (As in Task Allocation, Utz, 2006) while she works outside the home, she has a rude awakening. Here she recalled (at the end of the interview but with great feeling) about all the changes she has been forced to adapt to:

My husband was retired, so the aftermath is now all of a sudden, every single thing that he did I have to do. Everything. I never pumped gas for my car; I never went to the bank (Laughs). I knew where the bank was, I knew to the penny how much was in our accounts but I never had to bother to cash a check. I didn't even know when the bank hours were, much less, I never had to bother because he was retired and he was at home. A multitude of things he did that now I have to do, I think that was the biggest change, the biggest change and some of it caused grief. You know, like making the decisions and right or wrong, it's my decision, that's pretty much the bulk of it.

I mean like I said, since his death was sudden, we were not prepared. I was not prepared, my children were not prepared...one man [at the support group] said, "I'm standing in the grocery store and I don't even know what kind of soap to buy to wash my clothes." And that's true. All of a sudden, I have to get the oil changed in my car, oh, even better, I have to buy the tabs for my license plates and I have to put them on...I thought this was a big process and I had to call my son and say "What do I do? Do I peel the old ones off, what do I do?" I didn't know what to do. So all of these things. So, again, you ask people, so, and again with [name of agency], when I heard that man say that, well I didn't have the soap issue because I know that, but I have funny little things that I didn't even expect to do or question...that's some of those things, you think about, and "Oh, my gosh, I have to do that too and do that too."

Emily also discussed her concerns about maintaining the home. She has grown children living in other states who provide her with some social support through phone calls, but are not there physically to help (As in Utz, 2006, Social Support). The tasks allocated for home maintenance and finances in the pre-loss days lie solely with the husband and when he died suddenly she was forced to deal with these issues (As shown in Utz, 2006, Task Allocation and Nature of Death). Although the lack of topics of this nature are major

concerns for the care of spousal loss, the overall helpfulness of the group as a sounding board and safe haven to express emotions was evident.

Overall Helpfulness of Support Group

When asked about how helpful the support group was, Eleanor, now 59, who lost her husband suddenly from a heart attack, tells how it was helpful to listen to and get advice from other widows and widowers she meets in the group and stressed how it is not only the emotional you need help with:

First of all, he was 59 and I was 58 and oh my goodness, how am I on my pay? My income has changed by two-thirds. Am I going to make it? Am I going to keep my house? And what am I going to do? My husband did everything, I couldn't pump gas. Thank goodness I could do, I did the finances so I knew all that but who's going to mow my lawn? It's not only the emotional, it is your whole life, has changed. How am I going to do this? And that has helped me in talking with people as to "Okay, I'll get a landscaper, he can mow my lawn." So you solve the problems and I think by being with the support groups, and they do help you, support groups, with your emotional and your grief, but it's more than just that, it's all these coping with life now and moving ahead.

Though none of the participants suggest a list of specific topics the group facilitators or guest speakers could have followed to address their needs and meet new demands, they find it helpful to be around others who are experiencing similar stress in readjusting to life without a partner. They have conversations outside of the group meeting and limited exchanges within the group about topics they are struggling with. Anxiety by a younger male Boomer, who told me that he is considering selling his home and moving his pre-teen son and himself because of all the maintenance explained:

So whether or not to stay here or to get a fresh start somewhere else in an apartment, which is not, probably not the ideal environment. Although there are children that are in apartment complexes but it's a lot less maintenance, the grounds, you know. [Eric, whose wife died from liver cancer]

There is a deeper meaning here that goes beyond moving because of maintenance concerns as he had re-painted the entire inside of the house, removed all the photographs and other wall decorations and boxed them up. It appeared to me that he was trying to remove some of the material possessions, or 'remnants' related to his memories of his late wife. But I felt that by the way he glanced around, sighed heavily, and realized that he may have to leave the home completely, he may be learning that you cannot simply erase the spouse and all the memories. Perhaps this act of renovation is not enough, and now he is thinking that moving to an entirely different location might provide some relief from the painful memories associated with his deceased wife.

Several of the participants expressed frustration about the home maintenance (mostly women). Although there are no formal instructions offered through support groups for issues surrounding these concerns, I believe the bereaved spouses share their knowledge with each other on the readjustment tasks on some level. Christina, age 55, became overwhelmed and started to cry as she thought about how much she now has to deal with and how it might have been helpful to have had some individual counseling. I attempted to help by asking her about the hardest part for her right now. She lives in a trailer with a small lot size, but the maintenance issues continue to compound her grief:

LEH: What's the hardest part now?

Christina: (laughs while crying) Well, the maintenance, the maintenance here.

LEH: Of your home?

Christina: Yeah. Wednesday, I ran out of water, no water! I said 'Oh my God.' Friday, finally I got water again. I didn't have to worry about that stuff, that was all his. So, it's figuring out why, what's wrong, why and do I...to me it was the pump. Well, it wasn't the pump, it was a leak elsewhere. I never had to worry about that. Never did, that wasn't my job, my job was inside, his was outside. You know, it's that kind of stuff that ...

LEH: Makes it challenging—

Christina: Yeah. It does. I don't know, just so many things.

LEH: You said that being alone is very difficult.

Christina: Yeah, it is. I hate nights, I just—but it's the maintenance, it's just how do you—I don't have the mentality for it—he was very smart and he knew whether—he just knew that stuff—I don't know maybe it was a guy thing, I have no idea, but it's not my cup of tea. (Laughs)

These accounts attest to the ongoing and stressful nature of readjustment after spousal loss. They could be addressed more directly by support groups if they were willing to rework the contemporary scripts that frame grief work as solely getting through the emotional turmoil. People prefer to have some idea of what to expect and how to adapt when they are thrust into new roles. Even though the spouses indicate that they just want a place to go where others have had a similar experience (the support group), they are actually getting tips as they listen to stories about how particular situations are handled by others who have lost a spouse. These are usually shared after group meetings, in one on one encounters.

The newly bereaved entering the group take on the role of others, echoing work by Parson's (1951) and as described by Morris (1967:xxviii-xxix) who drew on Mead's (1934) work, as a new type of universality, a *social universality*:

...The individual transcends what is given to him alone when through communication he finds that his experience is shared by others, that is, that his experience and the experiences of others fall under the same universal (in the first sense of that term). Where the particulars or instances of this universal fall within different experiential perspectives, universality has taken on the social dimension. The individual has, as it were, gotten outside of his limited world by taking the roles of others, being assured through communication empirically grounded and tested that in all these cases the world presents the same appearance...where this is attained, experience is social, common, shared; it is only against this common world that the individual distinguishes his own private experience.

These spouses demonstrate this social universality in that it is only through being with similar others that they can examine and construct the new role of widowhood and their own private experience of the loss of their spouse. The behaviors of others in the group are adopted if they view the other as appearing to be 'okay' and functioning well. Comments are made about the individualistic nature of grief, however as participants gain insight from those who are farther along in their grief experience, they take on some of these coping styles. This imitation helps many spouses to feel that they are aligning with others they think are adopting normal behavior, since in their eyes, these people, although strangers, appear to be coping and functioning better than they are. They also look to other widowed members for tips on future relationships.

Dating and Commitment

Some of the respondents (mostly the males) were more interested in dating while others (mostly women) were determined not to give up their symbolic ties to their marriage and chose to continue to wear their wedding rings. Perhaps others struggle with this same unease but do not bring it up. One man indicated that he kept his on to keep away the 'riff-raff' as he had no interest in dating, indicating that he would be vulnerable if he removed the ring. One woman showed me her deceased's husband wedding ring that had been melted down and made into two rings, one for her and one for her young daughter. As stated earlier, one of the participant's whose husband suicided included telling me about how upset it made her that, even though they were divorced, he had put his wedding ring back on before he shot himself.

Since the wedding ring is a recognizable symbol of love, a circle signifying eternity with no beginning and no end, it is no surprise that spouses who value the meanings attached to the wedding ring may have great difficulty removing it upon the death of their partner. These rings

can also be ‘treasured romantic gifts filled with memories’ and taking them off is one more loss (Feinberg, 1994:143).

I also thought that these spouses might show me informational materials given to them from the agencies to help them but only two men (both interviewed in their homes) showed me notebooks and do so half-heartedly. This could mean that these materials are helpful initially but they are not materials that the bereaved spouses refer to again and again.

Other issues that surfaced throughout the interviews include dating and meeting others. Those who talked about this topic were anxious about why the grief facilitators did not discuss or know that they would want more information about meeting others. They were often disgusted about how they were shut down when they brought sensitive topics up, as Barbara tells in this example:

Barbara: ...a lot of the guys in the group after we left the class would pull me aside and talk to me. And a lot of them wanted to move on quickly and they were like talking to me about somebody they met or that there was something they were feeling about somebody—and I talked to [the support group organizers] and said, “You know, [name], our group leader, never been married, never had any children, her first loss was her parents and that was a few years ago and she’s probably 60 something, in her 60’s.” So whenever we would get into—the guys would get into a touchy subject about maybe dating, I said that she would just turn it around and not—

LEH: She was a facilitator?

Barbara: Facilitator. And she would talk about, “let’s talk about, let’s talk about your spouse, and your death and your experience and your grieving,” and I told the facilitator, I said “You know, the guys, they think different.” I said, And they wanted to talk about a few other things about moving on and about you know meeting somebody and [she] would just shut that right down, right there, Johnny on the spot because we were there to grieve about our spouses. And I said, And some of them were trying to feel like they were moving on and consequently all of them left, they didn’t come back, which I thought that they still had a lot of work to do. [Barbara whose husband died in a car accident]

This provides an example of when a facilitator, with little experience of her own, decides to steer these spouses in the direction of their ‘grief work’ or Phase I as Earl described earlier, the gloom and doom phase of grieving. This facilitator moved the group back to the expected script and away from discussing these other topics of interest, and as a result lost the men in the group. A better outcome might be to bring in a guest speaker, someone who has either personal knowledge or expertise, and can address these topics. Studies show that although women are more often widowed, they are less likely to remarry after the death of their husbands (Cleveland & Gianturco, 1976). Lee, et al., (1998) notes that widowed men are more likely than women to get involved in romantic relationships and to remarry than widows are. In a study of middle-aged bereaved people, Hustins (2001) finds that at the end of the first year of bereavement, only 7% of women became involved in some type of sexual relationship compared to 54% of men. Clearly, these studies indicate a larger interest by men to be involved in another relationship after the death of a spouse.

To show how dominant this theme was with those I interviewed, six of the eight men talk about an interest in dating, or concerns about meeting someone and two of these six men have lady friends they are involved with. Out of the 30 women interviewed, three told me they are dating, and one was remarried (the latter participant, however, falls outside of the criteria of being bereaved 1-3 years for this project). Most of the women in this study, if they even mention dating, seem to have little interest in another partner at this point. Carr (2004) notes that men are quick to form new relationships after spousal loss, which re-establishes emotional closeness, especially if they were emotionally reliant on the wife. With evidence from the Changing Live of Older Couples (CLOC) study, Carr (2004) reports that the pattern was reversed for women. The more emotionally reliant women are on the husband, the less interested they are in pursuing

subsequent relationships after the death. Wolff and Wortman (2006) note that Carr's (2004) findings suggest that widowed men want and need social support and those who have strong informal support are less motivated to find a new wife and confidante. This may be indicative of women's stronger support systems in general, where they have networks to help with various aspects of the grieving process, where men are more likely to seek a new person to become a close companion. The younger the men are (in this study), the more they talk about their desire to find a companion and less about their informal support systems. The women, regardless of age, note the importance of friends and family as a means of support at this time and in the foreseeable future.

Again, the overall helpfulness of the group was expressed to me in the interviews and viewed most favorably in terms of having other widowed people to share the journey and learn from. However, as noted the group could also work against the bereaved, in their failure to address important issues, such as dating and financial concerns. It also became evident that through language and non-verbal gestures, one's own selfhood may be threatened in the group as emphasis is placed on constructed norms about how to be widowed. Given that symbolic interactionist theory argues people bestow meaning on their interactions with others—that selves are emergent and socially constructed, the examples presented here examine how these group members value their interactions within the group. So, how might this impact one's selfhood and ultimately, how does it shape widowhood?

Learning How to be Widowed

American essayist and poet, Ralph Waldo Emerson, once said that 'to be yourself in a world that is constantly trying to make you something else is the greatest accomplishment' (Myerson, 2005). This study has brought an awareness that although the bereaved spouses view

grief support groups as helpful; they also seem conflicted about constructed language and norms they learn from within. These spouses don't appear to connect their current sense of frustration and ongoing struggles to their sense of a fractured and wounded self, in their search for a widowed self. In one respect, the group members and facilitators suggest how to be widowed (not through direct advice, but rather by sharing what has worked well for them, or how they adjusted after the spouse died), yet at the same time individuality is constantly encouraged within the group, which may contribute to their ongoing stress and confusion.

A strong self concept involves having a distinct identity, unique from others, regardless of similar roles, as in widowhood. And although they heard that 'everyone grieves differently' and 'your grief is unique', there was still an innate desire to do things like others who seem well-adjusted. They appear to have little confidence that all will be well. As the quotes have displayed, one of the constant concerns involved knowing whether they are doing okay and whether they are in line with others who have lost a spouse. Questions that surface often include 'Should I get rid of the clothes? Should I take off the wedding ring?' Once feelings and behaviors were validated in the group for the bereaved spouse, their worries and anxieties settled down, but the curiosity remained, followed by worry, when listening to the stories of loss from others who are widowed. These stories often include attending to tasks once done by the deceased person. Widows and widowers in this study, however, found themselves empowered each time they were able to complete the role of their now deceased spouse.

For example, Charlene (C in the excerpt below), when asked whether anything surprised her during her grieving, sits up straighter in her chair across from me. Her stance is that of subdued as she begins to answer the question, but she gradually moves to excitement and eventually she expresses pride in herself as she describes this story:

C.: When he's there, he's taking care of our things and now that he gone you have to—I mean I have to do it, but ...

LEH: Things like?

C: Well, just like have to replace battery for the smoke detector.

LEH: The batteries.

C: The batteries, yeah. And, I never done it before. You know that's the thing, he did everything. And then, one night, I get ready to go to bed and then I open the door and I was walking through the kitchen and I saw something flew by and I thought 'Oh my God a bird in the house.' So, I then look up again and I hear it come by again and I realize it wasn't a bird, it was a bat.

LEH: A bat?

C: Yeah, a bat. Oh my God, I was terrified. I don't like the animal—I mean that bat. I was like Oh, God. So, and it flew by and I, you know, ducked down next to the butcher block, and while I was down there I realized you know I say to myself 'You are the only one at home right now, I need to take care of this thing.' So then I get up and somehow it gave me a little strength, you know, thinking about that, knowingly, that you are it. You know you gotta take care of this thing, even though I was still, you know, after I find out where it is and I just couldn't touch it. So I have to have my son-in-law over and he took care of that for me. [Charlene, now age 64, whose husband Henry died at of lung cancer]

Others told me similar stories where it seemed like a defining point in their grief experience as they realized that by doing things the deceased spouse used to do, they felt empowered and have greater confidence that all will be well. Next, Diane, recalled how her deceased husband used to make all the arrangements for vacations for the family and how she never organized any of it when he was alive. But her children are still fairly young and she wants to get some sense of normalcy back into their lives by doing some fun things 'as a family.' With fondness, she constructed the scene, which was a turning point for her:

Diane: I know that I don't want to overwhelm myself because all my life I was pretty speedy, I was running, like 100 miles, I don't really look at stop sign, that's how I conduct my life, you can see I got all my three Master's, I worked for United Nations, I got into this country for only this few years, I accomplished quite a bit, a job and I put a lot of people who are native born behind. So I was

running like that. And then with my husband's cancer, it was truly a stop. So that's when I found 'Ewe, I have a lot of garbage that I need to kind of deal with.'

So, I think that's—and so I learned that I need to slow down, so 2009 I kind of—I give myself only one major thing per month, so 'don't rush honey, don't rush' so I do only one thing a month, major thing, one a month, okay. Small things, one a week, if I don't get it, I don't get it. Okay, major thing I gotta accomplish. So I think I pretty good, you know compared with other widow, I have to say I am blessed, through all this I am now able, I am still able.

There's a lot of other things that kind of gave me this, like my husband passed away in September of 2008 and February of 2009 I took both kids to Disney. It was—when we got there, we found out it was ten years ago we went there, it was exactly ten years. And then we went there and you know—I ask kids where they wanted to go, that was our first family trip of three. You know family trip of three of us. I asked them where they want to go, and they want something light, really light, I said 'Hey, let's all be kids, let's go to Disney'. No one can be sad when they're in the Disney world right? Let's just go. So we went there and then there was one night and we go there usually when we travel with four of us, my husband will do all the—you know renting the car, hotel—that night we went to all the fireworks and so we left there pretty late and I was driving. While I was driving, just spurred out of my mouth, I thought 'I am able' you know, I said it out loud to myself and here my daughter said 'Mom, you are'. [Laughing] Yeah, and my son said 'Mom we are proud of you'. And I said 'I need to give myself on the back of my pat, so here my come my kids they pat me'. You know those were the moments where I found a turning, where I get out of something. I start saying 'hey, I can do this, I can do this, I rent a car'. And I had fun. [Diane, now 53, whose husband Bernard died after a three year illness from cancer of the liver]

Again, each task performed is described as an accomplishment and offers hope. It helps these widowed persons to learn to be confident about their new status of being on their own after often several decades of having a teammate. These scenarios beg more questions, 'Would these spouses be this confident if they never attended a grief support group?' 'Did they learn how to be in this role by listening to others who were farther along in their grief?' Or, do they learn by doing? Perhaps, little by little, task by task, all widowed persons learn how to be widowed by doing what needs to be done. An earlier response may provide some insight from one participant who snapped back angrily at me when I asked her how she coped when her young husband died,

as she answers her own question, ‘What choice did I have? I had no choice.’ Others, throughout the interviews, made comments about how you simply ‘go on about life.’

In order to ‘go on,’ almost all these spouses (37/38) chose to attend formal grief support groups. Yet several (12/38) mention specifically that it was their informal support, including family and friends, that helped them to cope. Regardless, they still attend support groups and a few (5/38) tell me that they sought out individual grief counseling. As mentioned earlier, twenty participants attended the support group of the agency I was interviewing them from; eleven attended this group and another support group; five attended three support groups and one man attended seven support groups since the death of the spouse. This scenario confirms that the spouses presume that the informal support persons are not equipped to provide the necessary support needed. Yet, as I propose in Figure 5.1 below, those who knew the deceased are the link to the past, which will help in the reconstruction of the new widowed identity through stories and memories related to the deceased person.

We very well may be ignoring an important association to help bereaved spouses with reconstructing their new widowed self. As Giddens (1991) reminds us, the past needs to be recovered and the future to be contemplated by way of the present. Much of our research in bereavement dwells on behavior and labeling through categories (e.g., normal, abnormal, complicated, delayed, etc.) when perhaps we should look at strengthening the informal support systems to assist in reconstructing the past, which seems to be a concern of many bereaved people in their initial grieving. With these spouses, I saw a continuous attempt to heal by talking about their deceased spouse (and who they were) their current frustrations and struggles, and their fear of the future alone (see Figure 5.1). Giddens (1991) reminds us that a person’s identity is not to be found in behavior but in the capacity to keep a particular narrative going. So, how

does one do this when they have had a major disruption to their autobiography presenting an uncertain future? The support groups do provide the space for this course of narrative reconstruction at the formal level, which I see as a quest for wholeness. However, there is a need that is recognized to assist the informal support persons to feel adequate to help strengthen the healing for these bereaved people. By providing a community-wide grief education program for informal support persons (i.e., family, friends, work colleagues, etc.) I believe that they can help with the construction of the new widowed self and the reconstruction of the disrupted narrative.

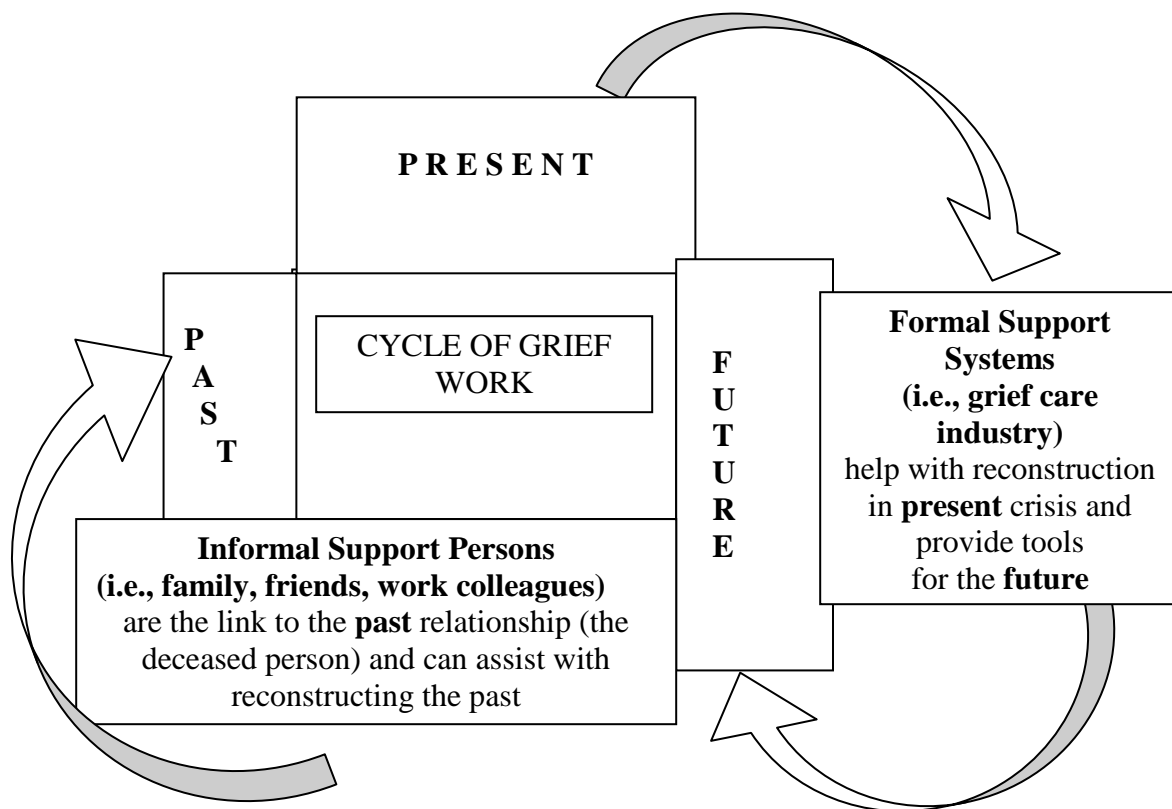


Figure 5.1 Cycle of Grief Work for Reconstructing the Disrupted Narrative after Loss through Informal and Formal Support (Hilliker, 2011)

I abandoned the oscillation models discussed above (Stroebe & Schut; Utz) and moved forward with the development of my own model from hearing the stories and struggles of these 38 bereaved spouses who are in mid-life. Although Stroebe and Schut (1999) make a valuable contribution which takes us away from the linear models used in the past, the problem with the Dual Process Model is that it focuses on behavior (adaptive coping). And although the theoretical model for spousal bereavement by Utz looks at the importance of recognizing the readjustment tasks and practical matters that are stressful in spousal bereavement and suggests that we consider social support as a factor in bereavement, it falls short in examining the tremendous impact that family, friends, co-workers and other informal supports can have. The proposed model presents needs at both the informal support level for a community-wide grief education program which has the ability to equip those closest to the chief mourner (e.g., family, friends, work colleagues) with the knowledge necessary to support them. Additionally, this research has pointed to a need in the formal support systems, specifically grief support groups, to provide more tools to assist the bereaved person in helping themselves with reconstruction of their new identity after a disrupted narrative, addressing both present and future concerns. The groups can do so by having a more client-centered and holistic program that has ongoing sessions and is not time-limited.

In summary, this chapter attests to other research that shows how the loss of a spouse in midlife disrupts the continuity of the life cycle, crushing hopes and dreams for the future (Wolff & Wortman, 2006) creating great uncertainty and a fragmented sense of self. As a result, these spouses seek out a safe haven, a shared experience and a significant community through formal care.

These accounts revealed that although participants refer to grief work and the importance of going through some kind of process, they do not specify what this means. They attempted to interpret statements made by facilitators and other grieverers to express emotion, allow themselves to feel the pain of grief, and lean into it instead of shy away from grief and its sting or keep emotions bottled up inside. These language references were adopted and in a sense limit the reconstruction of an authentic self. The self now exists in this experience to a degree that it can only be accountably communicated within an interpretive community, one where it is “now as much narratively constituted as actually lived” (Holstein & Gubrium, 2000:71). Building on Nikolas Rose’s (1990) claims about how the soul or self becomes more and more governed or discursively created by emerging institutional communications, Holstein and Gubrium, (2000:71) analyze the construction of the self in postmodern times:

Rose’s storyline jibes with postmodern claims of self construction, if not with hyperreality or evanescence. It shows how the business of self construction has now spread well beyond the psychological sciences. Selves are now paraded and bandied about in diverse institutional sites, from pastoral counseling, self-help groups, and mental commitment hearings, to romance novels, television talk shows, and advice books. Much like Bentham’s Panopticon, we have taken on board—within ourselves—the language games and associated subjectivities of Foucauldian ‘guardians’ of all kinds, inciting ourselves to display and communicate the selves expected of us and that we assume others, in turn, share with us.

Holstein & Gubrium (2000) continue to point out that now, as Lyotard (1984:15) suggests, we have a myriad of sites that inform and present the self with “a fabric of relations that is now more complex and mobile than ever before.”

At the same time, it is apparent from other struggles and concerns that the spouses in this study share together, that they are not working through their grief in its’ entirety, rather they limit themselves to focus on and experience only the emotional self, and whatever emotions come about (this emotional self is highlighted in support groups as mentioned earlier). This is similar

to Ironside's (1996: xvii) observation that "[y]ou do not work through bereavement. It works through you." As a result, the emotional charge and unsettling feelings and frustrations that come with the loss of a spouse, move them to continue to search for a guideline on how to grieve, or a roadmap of sorts on how to adapt and function in this role of widowhood. Once in a support group there was a great deal of observing, imitating and adapting to the ways of others who have gone through a similar experience of loss. This resulted in a re-construction of sorts of the remaining self. Continuous struggles outside of the group were evidence that the more task-focused elements of the grief experience are still problematic and unaddressed. Emotional work was at the forefront of the help agendas offered by these five support groups

Although a good deal of scholarly debate has been held on the necessity to 'work through' memories, thoughts and emotions that are associated with grief, Wolff and Wortman (2006) contend "little empirical evidence supports the necessity of 'working through' the loss." These authors go on to note that Nolen-Hoeksema, and colleagues (1997) for example, find that thinking about the relationship with the person who died is linked with worse long-term adjustment. However, their research also suggests that it is recognized that for those who have difficulty expressing their emotions, or in cases where the loss is particularly traumatic, working through the grief can be beneficial (Lumley, et al, 2002; Jordan & Neimeyer, 2003).

This chapter shows how these spouses see the formal care from support groups, along with their members (and in some instances the facilitators), as a welcome refuge from the oftentimes conflicting and contradictory messages available to them from informal support systems. Although well meaning, this includes close others where support is limited by an uncomfortable silence when emotions are expressed. These spouses preferred to evaluate for

themselves others who have had a similar loss, who are sane and functioning, and willing to provide insight into an unfortunate shared experience.

The support group format then provides a counterculture of sorts in terms of emotional expression and talk about the deceased person. As the group members painfully reconstruct both their individual and their social self, they were aided in this journey by strangers of ‘imagined communities’ (Riches & Dawson, 1996a). The new community allowed them to learn a new identity, widow or widower, and get closer to a self that is thought of as normal within the space of the support group. This is in opposition to the outside society (including informal support systems) where there was little tolerance for talk related to the death, or of the deceased, or for lengthy emotional outbursts.

In reality, the re-construction of a new self is influenced by friendly editors (Walter, 1999) such as facilitators and other group members, who supplied a language (i.e., grief work, grief triggers, grief process, lean into it, work through it, etc.) which does not leave these spouses content, but rather still searching. These findings echo Giddens’ (1991) work where he notes that a person’s identity is not to be found in behavior but in the capacity to keep a particular narrative going. These groups (through accounts of others who are seasoned and newly widowed) also assisted the bereaved spouses with their curiosity about ‘how to be’ widowed. And although to some extent this help appears beneficial, many were still struggling to grasp their new identity. The support group strangers, both bereaved members and facilitators, appeared to eventually become ‘close others.’ In this role, they did contribute to bringing a sense of order to chaos, and in so doing, contributed to assisting the newly bereaved spouses, in part, with their untimely new role of widowhood. Paradoxically, the message is that they need to work through grief, it should fit a certain script, but at the same time, they are told to do it in

their own way. As a result, these mourners continued their quest for meaning. Some find meaning through ugly coping (as discussed earlier, Bonanno, 2010) while some find it by helping others, and the remainder roam in the wilderness, hoping they will soon find their way. Regardless, formal grief care, in particular the support group, played a large role in the reconstruction of the self for these spouses. As they attempted to adapt to a new identity, the group offered some sense of peace and helped most find some meaning in their unfortunate circumstances during the second and third year of their bereavement. Next, Chapter Seven summarizes the dissertation which includes recommendations for future research.

CHAPTER SEVEN - SUMMARY

Introduction

This study identified, explored and articulated the thoughts, opinions, and expectations of 38 Baby Boomers in Michigan concerning their experiences of formal bereavement care after their spouses die. This involved describing the meanings constructed by these individuals about this type of care before, during and after the death of their spouse. Secondly, the dissertation examined the experiences within a support group setting which is the preferred choice of formal support of almost all participants (37/38 attended at least once). It is expected that the findings can challenge and extend dominant models and theories being promoted in the scholarly grief literature and being adopted by some professionals in the grief care industry. After a selective review of grief models and theories, one widely used model in particular, Stroebe & Schut's (1999) Dual Process Model of Grief along with Utz' (2006) Theoretical Model of Spousal Bereavement were identified in helping to partially understand these spouses' experiences. However, my contribution as outlined in Figure 5.1 above (Cycle of Grief Work for Reconstructing the Disrupted Narrative after Loss through Informal and Formal Support) brings into focus the temporal nature of identity reconstruction following spousal loss as evident in the interviews.

First, in their attempts to answer my inquiry about who they are (tell me about yourself), many of these participants struggled with a wounded self which resulted in an on-going attempt to re-construct their past, present and future identities. Through a recollection and re-telling of the death and loss stories, survivors recounted their past and present experiences. Concepts of suffering and human agency are evident as spouses uniquely work through their own grief where they are instructed in groups that the self is authority and individualism is emphasized. By

managing their emotions, this served as a protective cover of one's personhood, first for the dying spouse, next for themselves and lastly for those in their informal support systems as well.

Next, participants described their personal experiences of formal care and in particular, that of the support group care as Chapter Five reports. One aspect of these experiences that is not anticipated going into the interviews is the continued effort to reshape and redefine the self with the help of others in a support group setting (strangers initially). At times, the self remains in the past, attached to an individual (the deceased spouse) who has been a vital part of their lives, but who is no longer there physically, although, in most cases, still loved. A number of strategies are used to try to understand the loss and redefine the now widowed self in a formal care setting. Maintaining attachments to the deceased spouse is accomplished by including them when reconstructing one's narrative through discursive activity (telling and re-telling the story in the group). The reconstruction of the present identity, now widowed, and search for meaning occur for both widows and widowers, regardless of the nature of the death and is encouraged in the support group through the facilitators, other group members and through social activities (generally after the grief education support meetings). Meaning is sought through attending workshops, memorial services, and social events, and by visiting more than one support group or through seeking out individual counseling services. For several of these participants (6/38), additional meaning about the death is discovered through an 'extraordinary experience' such as visions or dreams of the deceased spouse. There is also uncertainty expressed about one's future throughout the interviews where participants attempt to repair the disrupted narrative.

Findings from interviews with 38 Michigan residents born between 1946 through 1964 reveal one overarching key theme, namely, the *compromised individual and social selves* as evident in a continuous struggle to re-construct the past, present and future identity. Four other

themes emerge and include: 1) the importance of the group as a *safe haven* to do ‘grief work’ and re-construct one’s wounded self and life narrative; 2) the value of a *shared experience of spousal loss* with other group members; 3) the *significance of a community* where significant loss is explored; and lastly, 4) *unmet needs* were brought forth by way of suggestions for improvements of care by the recipients and include both pre and post-loss needs. Pre-loss needs such as respite care in caregiving, better coordination of care in general in medical settings and attendance at some type of support group prior to the loss were concerns of this group. There was also an expressed need for a more sensitive notification of the news of terminal illness and/or death in many of these situations (as noted in Chapter Four). Improvements for post-loss include a desire to have an extension of group sessions in terms of weeks the group is offered.

A large gap is apparent in the support group care, namely, an inattention to readjustment stress related to tasks associated with practical needs when applying the theoretical model for spousal bereavement by Utz (2006). As reported in Chapter Five, the sole emphasis in these groups from these accounts was on the emotional stress experienced, where in essence, the stories of these surviving spouses show that a more holistic approach would be beneficial, one where they can gain valuable knowledge on issues of concern in their daily lives which will aid them in moving forward with their lives. They continue to exhibit tremendous readjustment stress from various issues related to spousal loss, including home maintenance concerns and dating issues. I now return to the initial research questions, and list the strengths, and implications of this study, along with recommendations for future research.

Research Questions

The following research questions were the focal points of interest: 1) What is the experience of formal bereavement care for bereaved spouses?; 2) Why do some people attrition

out after a certain level of formal care and others do not?; and 3) How do various types of formal support services aid in the understanding of bereavement? Exploring the experiences of formal care with these participants revealed that the support group is a [mostly] useful format in terms of assisting with emotional stress, but an inefficient means of addressing the overall widowhood experience. The support groups appeared to ease some stress for the bereaved, as the quotes highlighted how problematic it is for many to express an authentic self outside of this group community (at the informal support system level). The survivors are constantly managing emotions in their social world to protect themselves and others, which is exhausting. However, the cultural expectation in the formal care industry is that a participant needs to work through the emotions and feelings related to the relationship (i.e., past role of spouse) to the deceased in order to lessen their pain from loss. A good deal of time needs to be allotted for this grief work and the construction story. But, as this study brought forth, and others have recognized, bereavement involves much more than an emotional experience. Further, this leaves these newly widowed people without tools for the future. The improvement of care for individuals in support groups is to address the gap where the additional needs presented in terms of readjustment stress. Since experiences of these spouses reveal a continuous struggle and search for meaning, indicative of a need for a more holistic approach in formal care services, one that is sensitive to the concerns of the group of recipients of care.

There is also the possibility of a loss of one's unique selfhood as the bereaved person takes on the role of others in the group setting. Since theories of phenomenology and symbolic interaction have similar concerns, exploring the lived experience of bereavement care deserves mention as Chapter Three points out. van Manen (1990) suggests that a researcher needs to connect four vital existential themes that permeate the lifeworld, which are lived space

(spatiality), lived body (corporeality), lived time (temporality) and lived human relation (relationality or communality). First, the space of the support group in which these spouses find themselves, affects the way they feel and express emotions. Some groups meet in churches, while others have spacious private rooms in which to place group members. It is in this space that the bereavement care has meaning. Group members also sit in close proximity during the meeting hour which gives an intimate space and feeling of closeness to others. With respect to the corporeality or lived body, in the compassionate gaze these other widowed people (along with the facilitators) offered, the recipient may lose their authenticity as the body is now the object of someone else's gaze (Linschoten, 1953; Sartre, 1956; van Manen, 1990). In addition, lived time (temporality) slows down for the bereaved person in the group as they reflected on past memories of the deceased or on details of the loss. In the temporal dimensions of past, present and future, the bereaved recalled, reminisced, and reconstructed the disrupted life narrative and the self. Lastly, there is a relationality or lived other that is maintained within the group space, a lived relationship. To some degree the widowed looked to others in this collective social group for meaning as they developed a spoken relation which then assisted in going beyond self. These four existentials then, lived body, lived space, lived time, and lived relation to others form an elaborate harmony called the lifeworld and allow us to recognize a vast richness of meaning (van Manen, 1990). This aids in lessening the suffering and creating a feeling of security to move forward.

Next, the support group experience appeared to strengthen the bereaved spouse as they form a bond between strangers with a similar experience within that group. It is important to note that the experience of other group members grieving the loss of a spouse are valued by participants over the experts, volunteers, and facilitators. Problems that are recognized, however

included a shift in the focus from the bereaved individual to the group facilitators, and allowed for the latter to control most of the interactions with the members. This resulted in some attrition, while others met outside of the group to concentrate on their concerns that are not being addressed, and yet still others dropped out entirely. These ongoing struggles of the bereaved reflect wider social questions regarding what constitutes effective grief care for those who seek it. Attrition for others is in part due to the overall one-sided support coverage which focused on addressing only emotional stress. This stress should not be overlooked, but can be problematic when members of the support group do not identify with their emotions, or having to rehash the death story, which made it difficult for some people to move beyond that experience. Repetitive pain felt each week for others in the group from those who could not bear to tell the story again and again, or listen to other painful accounts of loss, resulted in their decision not to attend after initial visits.

In response to the last research question of interest dealing with an understanding of bereavement in general, the overall contribution of this dissertation is that it adds to the discourse on the importance of considering the temporal nature of identity reconstruction following a life-altering role change. It recognizes that the bereaved attempt to protect personhood, their own, the deceased and close others. It also provides a closer look at how bereavement appears to be viewed as an undesirable life experience because of the great suffering it brings, yet it is inevitable that someone we love will die within each of our family units. Existing formal care services imply that we must address the experience of grief at a level that makes a personal and oftentimes private struggle, public. Evident in the array of answers from these spouses about how they learned about the services (Appendix D., Q. 11, *Was the agency that provided bereavement care for you recommended by someone?*), points to the concern that this

bereavement is not only undesirable, but also that those closest feel inadequate to handle it and provide support. Through recommendations from informal support persons (i.e., family, neighbor, co-worker, church members) as well as from professionals (i.e., physicians, dentists, medical examiner, masseuse, social workers) and from the agency that may have provided care for the dying spouse (i.e., hospice, hospital), a message is sent that the survivor needs help. Several of these spouses saw advertisements in church bulletins and in one case, a televised ad, which encouraged them to seek help. The minority went online (3/38) and searched for some type of support themselves, but most (32/38) are told about where they could 'get help.' When there is a significant loss, people want to help the bereaved individual in some way. However, recommending a support group sends a strong message to people that they would benefit the most from some type of professional setting. As a result, bereavement becomes largely ignored by informal support persons and there is a general sense that it can be resolved or treated professionally, and until help is sought the person is viewed as in an unhealthy state where their grief is sometimes policed and regulated. Many of these spouses had hopes of being instructed, once in the group, on how to get from point A to point B and be done with grief.

In addition, those who led the groups had power to enforce the definitions of grief, bereavement and normal behavior, and encourage those grieving to work through the experience of loss by following a very specific script through language and non-verbal gestures. Through a specific use of terms and phrases, (i.e., '*grief process*,' implying there is an established way to grieve or a set of procedures to do so, which might include a beginning and an end; and '*grief work*,' where it is suggested that one must do the emotional work associated with a loss), an implication exists that there should be some outcome and that this is the only way to achieve a healthy adjustment. The language of the formal grief care agencies placed control in the hands

of the professionals and volunteers who offered it, which brought both benefits for some, but costs for others and needs to be carefully weighed. It was clear in the interviews that at times, many individuals in these support groups did not look upon facilitators as the real experts, but found those who had shared experiences to be much more enlightening and helpful. However, members of the group are also influenced by those who lead them. All in all, the notion that grief specialists and an array of other professional support services exist for the bereaved, confirms the idea that bereavement is an undesirable condition that needs attention, as opposed to a normal life experience.

Lastly, a more thorough follow-up study of Baby Boomers is in order which might focus solely on the two suggested notions outlined in the model provided by Utz (2006). As noted in the literature on grief and bereavement, attention to both emotional and readjustment stress is pertinent for a significant loss. However, the dominant focus (at least in these five agencies) was on the immediate emotional stress of the present and the importance of expression of emotion and doing one's grief work, leaving a wide gap that needs attention. With respect to widowhood, for example, it could be advantageous to bring in guest speakers, someone who has either personal knowledge or expertise in the areas of interest to the group, and could address topics related to the readjustment stress involved, such as financial concerns, cooking for one, dating issues, etc., which could greatly reduce their uncertainty about the future.

Strengths

While there are limitations as stated earlier, there are also a number of strengths. First, studying formal care for spousal bereavement from a sociological perspective had an important practical dimension. We cannot improve this care for those similar to this sample who attend support groups without understanding the structure of the groups and how the group members

and facilitators interact with each other. Chapter Two brought forth insight on small groups, support groups and bereavement groups in order to understand these concerns.

Next, the sample came from a good representation of agencies who offered bereavement care, including a funeral home, a hospital hospice, two grief centers and one large organization whose goals are specific to serving the widowed population. The data collected across these five sites in 18 cities, and in different geographical areas within the state of Michigan also increased the transferability of findings. As well, all data collected from these agencies used the same protocol increasing dependability of findings. The use of NVIVO qualitative data software enabled an efficient organization of the parent and child nodes which offered an additional clarity to understanding the phenomenon of formal bereavement care through the use of queries.

Although I used semi-structured interviews with a guide of 15 questions and probes, these are open-ended and gave a space for the spouses to tell me their version of events as I set aside my own agenda. This approach enabled me to enter their world and strengthens this inquiry by providing their experiences, thoughts and concerns surrounding the death of their spouses and the subsequent care for their grief. My findings come from the central concerns expressed by the responses these participants shared with me about their experiences of grief care. It also gave space to allow the past to be recovered and the future to be contemplated by way of the present (Giddens, 1991). The stories of loss and subsequent formal support are not only remembered events, they are actual lived experiences of formal bereavement care, which are not difficult to remember (all participants were in the second and third year of bereavement) as some of these spouses continue to be involved in support groups at some level.

Further, peer debriefing increased credibility of the study. This included discussions about the analytic process, findings and conclusions with other sociologists and researchers in

the fields of selves, identities, grief and bereavement. Specifically, I consulted with two experts, one in the area of thanatology, Dr. Richard Gilbert and one practicing psychotherapist, Ms. Claudia Combs-Wise. Both read and gave feedback for the study. Dr. Gilbert has extensive experience in thanatology and end-of-life issues and is a prolific writer, whose books include *HeartPeace: Healing Help for Grieving Folks* (Abbey Press), *Responding to Grief: A Complete Resource Guide*, and *Finding Your Way After Your Parent Dies: Help for Grieving Adults* (Ave Maria Press). Claudia Combs-Wise, LMSW, ACSW, PLLC, Psychotherapist and Field Instructor, who counsels bereaved individuals in her practice, was gracious with her opinions after reading a draft of this dissertation. Both professionals proved very beneficial with their suggestions and comments.

Implications

For Practice

These participants indicated how unprepared they were to deal with the loss of their spouses. Some had no previous loss and had no expectations of grief or how to deal with it. Others, with previous loss experience, note that this loss of their spouse was much harder than losing a parent or other significant person. This study has the potential to aid practitioners who work with the bereaved to be prepared to take an active role in helping people to understand the complexity of their grief and the unique issues that have an impact on it. With respect to the experiences specific to support groups, Thuen (1995) highlights the value of social and emotional support the group itself offers, which includes the style of the facilitator as being an important factor for those attending. Additionally, essential information was provided here to inform those in the bereavement care field of the needs of Boomers. This can assist agencies with furthering their understanding of how to effectively assist spouses both before (when

caregiving, if this is the case) and after the deaths. Effective, meaningful and holistic interventions that include the concerns of those seeking out support, as outlined throughout this dissertation can help to ease suffering. Participants shared their rich personal experiences of support needs and grief interventions, which in turn can inform procedures and protocols for those who will continue to provide services to future bereaved spouses, in particular in the Baby Boomer cohort.

In Education

Helping to educate those who provide end-of-life care support, such as physicians, social workers, hospice workers, bereavement care providers, nurses and clergy about the concerns brought forth from these spouses could ease stress for future survivors and their families. Ogle, et.al (2005) point out that because of the continued cure-focused emphasis in medicine, we fail to recognize the importance of motivating change within the medical profession. Formal training in medical school lacks sufficient end-of-life care modules and there is a reluctance on the part of many residency directors to teach upcoming physicians about how to bring about a ‘good death’ for their patients (Ogle, et al, 2005). A statewide survey of 275 Michigan residency programs by these same authors found that fewer than half (46%) provide formal training in end of life care, and some do not even offer a single optional lecture. Given this statistic, the concerns of these participants for better coordination of care at the end of life and more sensitivity related to news delivered to families, are no surprise. An implementation of death, dying and grief courses into curriculums for professionals, to include refresher courses as technologies advance and family units change, would be an asset. As new developments emerge in the medical community, with online medical records for example, one would think it might be easier to have a smooth coordination of care among doctors and specialists, but this did not seem to be the case among

the 24 participants whose spouses died of illness which often required many hospitalizations over the course of their illness.

In Research

A wider dissemination of research findings to a broader and interdisciplinary scholarly community on the need to address the concerns for an uncertain future, such as dealing with readjustment stress related to spousal bereavement would be beneficial. Producing concrete tools to attend to the practical matters is critical to the future well-being of the widowed. Equally important are the effects of an insensitive delivery of the news of terminal illness and/or death overlooked and underrepresented in research studies. Some of these spouses also expressed a desire to have additional resources for their grieving adult children. Future research on the topic of bereavement care for spousal loss might include a bibliographic resource that can be made available to the grief care industry.

In general, sociologists who study selves and identities may be enlightened on the abrupt role change (spouse to widow/er), along with the temporal aspects of identity reconstruction; namely past, present and future constructions. This reconstruction involves both the individual and social selves. Because a bereaved individual may not want to draw negative attention to themselves by displaying the chaos they feel in front of informal support persons, oftentimes they seek out an imagined community for help with this task of repairing the wounded self. It could be advantageous to explore other abrupt loss and role change (i.e., gainfully employed worker to unemployed; married to divorced status) along with the support systems in place for them, and how people adapt to various types of stress in these new life experiences.

With regard to medical sociology research, an entire volume of *Sociology of Health & Illness* was recently devoted to the concept of body work (Volume 33, 2011) and highlights the

body as one of the ‘longest standing areas of sociological interest’ (Shilling, 2011:336). This dissertation brought forth a concern with bodies caregiving for bodies through both dying and grief trajectories, and illuminated the professionals who work closely with them. It may be of interest in medical sociology with new insight given its symbolic interactionist emphasis. It has the potential to raise important questions at the individual (sociology of the body-at end of life), social (medicalization- of death and grief), and societal levels (social construction of the community- in particular the formal support group) among scholars studying in this sub-discipline.

Recommendations

Thanatologists continue to work towards improving the care of the dying person and their survivors in today’s complex, multi-cultural, and highly technological society. Several of these professionals, working together under *The International Work Group on Death, Dying and Bereavement* (IWG)⁶² note that “the need for appropriate bereavement care has not received sufficient attention” (Corless, 2005:382). It is my ardent hope that this dissertation is a catalyst for more research regarding care for those in these stressful situations, that their voices will be heard and their concerns addressed, specifically for the millions of Boomers and others who will lose a spouse and seek formal care.

⁶² “The International Work Group in Death, Dying and Bereavement (IWG) is an invitational international organization of 150 members from 17 countries who are leaders in the field in their own countries. IWG provides leadership and support to those involved in death education, in the care and support of the terminally ill, in the care of the bereaved, and in promoting research, evaluation, application, and policy development in these areas. IWG conducts regular meetings at which leaders in the field can, in an atmosphere of shared collegiality, work and study together. By doing so, IWG promotes both the acquisition of knowledge and the promulgation, evaluation, and testing of assumptions that can then be disseminated to others, thereby serving a catalytic role.” (Corless, 2005, retrieved from: <http://www.iwgddb.org/>, opening page)

Reflecting on these care experiences for spouses instructs us on what is important to them after such a significant loss. Toscani, et al. (2005) note that care at the end of life for a person indicates the performance of our health systems. I add that the care that continues to be offered to the survivors for adaptation to widowhood and healthy day-to-day functioning is just as important an indicator of our health systems as taking care of those in medical need. Knowledge from the chief mourners as reflected in this study has the potential to add to the quality and efficacy of that care. This sociological exploration of the most advantageous care for survivors of spousal loss is timely as Baby Boomers age, lose significant others, and are either referred to formal support systems or seek out care for their bereavement.

Based on the emergent themes derived from the experiences of these spouses, scholars and bereavement care providers may benefit from the articulated and anticipated needs of these Baby Boomers. Gaining insight into the issues brought forth from this study, as stated earlier, will be beneficial, such as extending group support meetings, and training facilitators to address the concerns and topics of the group as they arise. This should include helping to identify both pre and post loss needs for families of dying persons. This study illustrated that bereaved spouses ages 46-64 at the time of the interview, can begin to adjust to losing their spouses through kind companioning, listening, validating feelings, and normalizing behaviors offered by support group members. Additionally, it shows that by discussing a wider array of topics that cause readjustment stress in spousal loss, we might help alleviate some of their present and future concerns, aiding many in moving forward. Designing specific services for this population is a critical step in the right direction. The bereavement care industry can adapt to the needs of Baby Boomers after loss by listening to the concerns of this group and surveying their own clients to see if they have similar interests, rather than assuming that the main focus lies solely on

current emotional stress. Since these participants identify more with the other widows and widowers in the group, it is also expected that they could benefit from having exclusive age-specific groups to attend, but this should be determined.

Future research might address the current system of support for the bereaved spouse, in particular for those who will be most likely to seek support (e.g., those with limited informal support). Support groups could offer a more holistic program by holding seminars as part of their grief recovery sessions. In these seminars, they can address the psychosocial, spiritual and other needs to assist the bereaved in adapting to their new life alone but this will involve changing the basic structure of the program. This approach could include discussion groups on home maintenance, cooking for one, or how to meet other people with similar interests. Private surveys of the attendees might provide the facilitators with additional information, such as a desire to talk about extraordinary experiences they may be having. These groups generally meet for eight weeks. In the first two weeks, participants could be directed to tell their stories of loss and talk about their current struggles, which would address the emotional stress. In weeks three and four, the facilitator could introduce a more hope-based approach by helping the members to think about their strengths and the resiliency they have had in previous crisis, and draw on this along with skills used to effectively cope. Next, in weeks five and six, practical matters could be the focus, including examining the current concerns and struggles within the group. And, lastly, in the remaining two weeks, drawing from the community, speakers could be sought (i.e., self-care experts, financial planners, real estate brokers, etc.) and might be accessed to help with the readjustment tasks at hand. By doing so, a limited emotion-focused group is abandoned. Ideally, these groups could offer an additional series of sessions for those who want to continue.

I believe it could also be advantageous for future research to take an in-depth look at what formal grief care facilitators believe are the support requirements for bereaved spouses both before (when there is a terminal illness) and after the death. Since they have the authority in framing ideas about bereavement support, it would be helpful to recommend to them to do an inquiry of their participants.

Final Words...

In this dissertation, a narrative re-construction of the past, present and future identity was viewed through the grief work hypothesis as an important aspect of mid-life spousal bereavement. This work was accomplished by the bereaved spouse in part through the support groups. The sequestering of dying and death, the protection of personhood, and the great suffering related to the taboo topics of both death and grief were all contributing factors to the difficulty of repairing the disrupted life narratives of the survivors. With the professionalization of medicine and the sequestering of death and dying, these experiences are no longer private where one is surrounded by family members and other community close others for long periods of time. Rather, in the 21st century, the dying are hidden away, while most of the family ‘await the call.’ As Kellehear (2007:253) so adequately describes, ‘Institutionalisation that physically removes people, ...competing policy priorities ...often block our view.’ Others who have had a similar experience acknowledge the need for the members to talk about what has occurred in their experience, the death and loss story and the disruption it has created, which involves talking about the past and the deceased person. A conflicting emotional landscape has resulted in an apparent need for experts in numerous helping professions to assist people with these life changing events, and in this case, one that used to be attended to by family and close others. As in dying, many of the bereaved also continue to protect personhood, their own and that of others,

exhausting themselves, grabbing on to the first life raft thrown their way, which may come in the form of recommendations for formal grief support.

In bereavement care, the provision of formal services through providers who range from highly educated and specialized individuals to volunteers, and who recognize the needs of all bereaved individuals, transcending culture, gender, race, religion, and class, are abundant. The emphasis on emotional expression has seemingly contributed to an emergence of formal care providers who assist people through the roller coaster of feelings and emotions at the forefront of traumatic life experience. However, today's culture does not provide people with a clear sense of how to interpret the meaning of personal life changes, given the emphasis on individualization. In this specific case, where the talk of death and grief are limited to private settings of counseling or support groups, this gap contributes to an ongoing quest for meaning.

Most of this dissertation covers the micro-level issues which occur at the level of the participants and their support groups where meaning is assigned to bereavement. The tremendous emotional stress is eased as most are able to feel understood and have their thoughts, feelings and behaviors normalized. Equally important, and largely unaddressed, is the need to know how to readjust to present and future life without the deceased's help in everyday tasks. We need to thoroughly examine the necessary tools for bereaved people to work through this identity reconstruction process when support systems fail.

Utz' (2006) model for older bereaved spouses, adapted from the Dual Process Model by Stroebe & Shutz (1999) was somewhat useful as a conceptual framework to show its' relevance in the lives of these Baby Boomer aged spouses as well. However, although the stories reflect a strengthening of coping mechanisms from sharing in and attending the groups, I found that these spouses were engaged in a continuous process of narrative reconstruction through temporal

aspects of past role of spouse to their present and future role of a widowed person, rather than oscillate in their bereavement as Utz suggests. The support group provides space for the emotional stress and relieves suffering for many, but falls short on offering help with the practical matters associated with losing a spouse. Newly bereaved people wrestle with the overwhelming experience of widowhood and, in part, look to others, the more experienced bereaved spouses, for learning their new role of widowhood. They also understand and communicate how they have to 'learn by doing' and being fully in their new role. This includes recognizing the ongoing stress and frustration of having to learn how to uncouple from the married relationship, reconstruct their narrative, and fill the role once held by the deceased person, in terms of everyday tasks, now and for the rest of their lives.

This dissertation has shown that when a Boomer is faced with [or is dealing with] the death of a spouse, they experience a compromised sense of self and identity. They find that in the immediate crisis, they prefer the familiar, whether this is through space [home over hospital] or persons [family, close others over professionals] and this provides great comfort. The spouses become protective of the personhood of the dying spouse and of the emotional state of both themselves and close others. Attempts are made to minimize emotional outbursts and save from upset, which results in more stress. After the death, this protective role continues on and shifts from shielding the dying to protecting oneself and close others from worry about their well-being. While grieving, they manage emotions and appear as if all is well, and this is an exhausting effort. There is a quest for meaning that may begin in some instances when death is anticipated. There is also an ongoing need of the bereaved spouse for an understanding from others about their situation.

Some seek out formal care on their own to continue to protect close others from knowing the depth of their suffering. Others grab the first lifeline thrown their way, which comes through a recommendation often from others for professional help from the grief care industry. In their quest, and in a support group specifically, there is an ongoing re-construction of self as they grapple with making sense out of the past death event and attempt to determine how to be a widow or widower. Their unique selfhood is at stake; however, as many observe and then imitate the role of others in the groups, they adopt the values and language of the group. Through particular language (i.e., grief work, grief process, new normal, etc.) and non-verbal gestures (i.e., nods of the head) their feelings and behaviors are validated and normalized. They are intrigued with others who have lived through it and are seemingly well-adjusted.

For most of these spouses, the support group is an anchor. It provides them with a dialogue for the personification of a wounded self, and this helps to account for who and what people are as they experience bereavement. For a few (4/38), the quest leads them on a journey of their own and they opt out of the group early on. Others settle with 'ugly coping' to get by. But for those who regularly attend the groups, they adopt the storyline of the support group which becomes a safe haven to express emotion. They value the shared experience and may even to some degree integrate the ways of other widowed members from this significant community into the new self. Some also desire to continue on with the groups thereby having a gauge for themselves as they look to other widowed people for normalcy and for help into their future. In addition, because the group-based identity meets their emotional needs, there may be strong ties that make these others' views about the self important. Since many support groups are time-limited, they do this through ongoing interaction by extending their involvement in a volunteer role. From my inquiry about other support used, it is clear that the reconstruction of

one's individual and social selves were in constant development and flux and people may continue to search for help or stay involved in the group on some level, until they reach a satisfactory level of functioning and a stronger self-image.

Lastly, because the focus in these groups is on addressing emotional stress, a 'grief process,' and individualization associated with grief, these spouses continue to struggle with the readjustment stress and uncertainty about whether they are grieving properly which complicates their bereavement. A large gap in assisting the spouses with practical matters in bereavement care also exists as identified earlier. This gap could be narrowed and these concerns need to be addressed by the health care and grief care systems. Although formal care is helpful in dealing with loss, many people are left still searching and could benefit from a more holistic and hope based program, one less focused on a grief process which is hard to determine and varies greatly.

In closing, the results of this dissertation demonstrate that much is yet to be learned about pre-loss, post-loss and appropriate bereavement care needs for those whose spouse has died in midlife. The findings also illustrate the multiple parallels in the experiences of Baby Boomer aged spouses with elderly spouses when grieving a husband or a wife. Data for spousal bereavement did not support a recent model, Utz' (2006) theoretical model, where the bereaved spouse oscillates between the emotional and the readjustment stress. Rather, I theorize that the disruption of one's narrative due to spousal loss creates a continuous reconstruction of one's past, present and future identity. This temporal choreography is critical for sociologists and others who study identity reconstruction as unresolved suffering can alter our relations to society and to ourselves. In my view, as reflected in the main finding of this study, perhaps for this type of significant loss, it's not a grief process that a bereaved spouse has to work through, but rather, the process of re-constructing one's identity as considerable changes are in need of attention. An

equally important observation is that immersion in a support group and anonymity may initially bring a temporary loss of one's unique selfhood. As the newly widowed join the group, it is problematic to adjust to one's new role of widowhood as they attempt to determine whether or not they are in the 'normal' range by comparing themselves to other widowed persons. Validating all of their behaviors and feelings as 'normal' while they listen to a variety of solutions from other widowed persons (and read popular books in the media, some with outdated advice) created confusion and frustration, which needs clarity. In the professional world of bereavement care as outlined in these five agencies, the self has been viewed as the authority as all griever's experiences are normalized. Those I have interviewed, however, still have a great deal of anxiety about whether or not they are doing their grief work in a way that will result in a healthy outcome. A grief 'process' implies there is a beginning and an end, yet it is not clear in these groups *where one is* in the process, which concerned many participants. A clearer view with an emphasis on one's past, present and future identity (e.g., marital role, widowed role) may prove to be a better support. Providers of bereavement care can ease these worries by recognizing the temporal aspects related to an identity reconstruction process, rather than suggesting that the bereaved person has to go through a grief process (one that is not made clear to them). They can also adopt a structure of care that addresses topics that are of concern to the bereaved spouses throughout the course of the group. This approach may more effectively address the needs for a large cohort of Boomers who seek these services and attempt to heal a fractured and wounded self after spousal loss. Most of these spouses who regularly attended support groups (34/37) found a safe haven in the support group where they felt understood, had their feelings and behaviors validated and normalized and began to re-construct the wounded self. They valued the shared experience of spousal loss with members in the group and relied on

the support group community as a significant source for relief from managing emotions on a day-to-day basis in other formats. And although these spouses had a good deal of anxiety about their loss and continued grief, and seemed unaware of their attempts to reconstruct the past, present and future identity, I believe that on some level, the mutual help groups aided these bereaved spouses in reflecting on *who they are now*.

APPENDICES

APPENDIX A

Initial Consent Form For Bereaved Participants

Dr. Tobias Ten Eyck, Principal Investigator
Michigan State University
Department of Sociology
316 Berkey Hall, East Lansing, MI 48824
Phone: 517.353.8671
Email: teneyck@msu.edu

Laurel Hilliker, Co-Investigator
Michigan State University
Department of Sociology
316 Berkey Hall, E. Lansing, MI 48824
Phone: 517.862.9221
Email: hillike2@msu.edu

The Sociology Department at Michigan State supports the practice of protection for human subjects participating in research. The following information is provided so that you can decide whether you wish to participate in this study. Your participation is strictly voluntary and is greatly appreciated. You should be aware that even if you agree to participate now, you are free to withdraw at any time.

You are being asked to participate in a research study attempting to examine the bereavement care experiences of bereaved spouses and/or domestic partners. You have been selected as a possible participant in this study because you contacted the co-investigator, Laurel Hilliker, after being invited to participate by: (name of agency)

If you choose to be a potential participant by signing and returning this consent form, I will then contact you by phone to obtain some basic information on yourself and your deceased loved one, which will help me to choose a diverse group of participants for this research project. If selected as a participant, I will then proceed with arranging an interview with you. You will then meet with the co-investigator on only one occasion (at your convenience and your choice of location, time, and date). A two hour audio-taped interview (approximately) will be conducted with a limited number of participants to gain some understanding of the bereavement care you have experienced. The audio taping of this interview is required to be a participant in this study, so that you are given full attention by the interviewer. Even if you are not selected for an interview, you will receive a list of grief support services available in your area, if you would like them.

The goal of this study is to explore the experience of bereavement care for the recipients of such care. From these interviews, it is hoped that new knowledge will be gained, which can contribute to the scholarly literature in the field of death, dying, grief and bereavement, and would benefit all involved.

The data for this project will be kept confidential. This work is a dissertation research project. In collecting data and writing up the dissertation results, identities of the participants will be concealed to ensure confidentiality. If quotes from or details about individuals are used, names will be changed. The results of this study may be published or presented at professional

meetings, but the identities of all research participants and their deceased loved ones will remain anonymous. The data will be coded and an identifier key maintained separately and locked in a file cabinet in the home of the co-investigator, where I will be the only person with access.

All information collected will be protected, stored in a locked file cabinet, and kept for three years due to required regulations for research on human subjects. After the three year time frame, the tapes will be erased or destroyed and all other information related to the participants in this study will be destroyed.

Information about you or your deceased will be kept confidential to the maximum extent allowable by law, unless information shared in the interview is exposed (such as revealing an unreported suicide or homicide) which requires me to report this information to authorities.

The potential risks associated with this sensitive topic about the loss you have experienced may cause some distress or discomfort for which I am prepared to address. A resource list of referrals for counseling and/or support groups will be readily available to you. You are also entitled to stop the interview at any time. A possible benefit of this research is that providers of bereavement care may gain additional knowledge of how to best meet the needs of those grieving a significant loss. This will enable those who work in the field to hear directly from you, and learn what helped and what hindered your bereavement process.

Thank you for your willingness to consider participating in this study. If you have any questions about the study, please contact the investigators: Laurel Hilliker by phone at 517-862-9221 or by email: hillike2@msu.edu, OR Dr. Toby Ten Eyck by phone at 517-353-8671 or by email: teneyck@msu.edu.

If you have questions or concerns about your role and rights as a research participant, would like to obtain information or offer input, or would like to register a complaint about this study, you may contact, anonymously if you wish, the Michigan State University's Human Research Protection Program at 517-355-2180, Fax 517-432-4503, or e-mail irb@msu.edu or regular mail at 207 Olds Hall, MSU, East Lansing, MI 48824.

Your participation in this research project is completely voluntary. You have the right to say no. You may also change your mind at any time and withdraw.

X

Sign above and return form if you agree to participate

Date here

☐ **Please indicate with a check mark if you agree to be audio-taped for this interview**

Sign here if you **do not** agree to participate but would like the listing of bereavement resources

You will be given a copy of this form to keep.

This consent form was approved by the Social Science/Behavioral/Education Institutional Review Board (SIRB) at Michigan State University. Approved 11/21/09 – valid through 11/20/10. This version supersedes all previous versions. IRB # 09-1035.

APPENDIX B

Letter To Bereaved Interviewees

Dear (Name of Participant):

Date:

I am writing to confirm our phone conversation on _____. I appreciate your willingness to participate in my research. As you know, I am interested in studying your experiences of bereavement care. This research study has the potential to inform those who work in the area of bereavement care as to how they can be most helpful to those who are grieving.

The interview in which I am inviting you to participate in is on _____ at _____ and will take approximately one to two hours. I do realize that it may be difficult for you to re-experience your thoughts and feelings about your loss and I am very grateful for your willingness to take part in this study. There will be time after the interview to talk about this experience. I am prepared to discuss referral options for further support if that is something you are interested in pursuing.

Also, please note that I may be accompanied by a research assistant, who is also being required to sign this confidentiality promise and is instructed not to discuss any part of your story.

Your identity will be protected in this process. You may wish to use a different name in the interview, (which will be audio taped). When the results are summarized in my dissertation or in a research article, your name will not be used to ensure complete confidentiality.

I hope that you will feel free to contact me if you have any questions at this time or if you need to reschedule our appointment. I will call you one day in advance to confirm the interview time. I look forward to meeting you on _____ at _____ p.m.
at _____.

Thank you in advance for your agreement to assist with my dissertation research.

By signing below, you have my guarantee to protect your privacy:

Laurel Hilliker, Doctoral Student
Department of Sociology
Hillike2@msu.edu, 517.862.9221

By signing below, you have the research assistant's guarantee to protect your privacy:

_____ Date: _____

APPENDIX C

Preliminary Information Form

Introduction: Hello, my name is Laurel Hilliker and I am a doctoral candidate at Michigan State University in the Department of Sociology. As I explained by phone, I am mailing you this document to obtain preliminary information on yourself and (use name of deceased partner or spouse.)

Enclosed please find a stamped envelope to return this form to me. I will then make a determination and notify you either by mail or by phone as to further consideration for an interview. Thank you in advance for agreeing to be a part of an important research project.

C1. Name and contact information (address, phone and/or email address):

C2. Male or Female

C3. What is your age today?_____

C4. Which of the following best describes your race?

C4a. __American Indian or Alaskan Native

C4b. __Asian or Pacific Islander

C4c. __Black or African-American

C4d. __White

C4e. __Another race or multiracial:_____

C5. Is English your primary language? _____

C6. What is your religious or spiritual preference? If any_____

C7. How many people were you living with at the time of the death?_____

C8. How much schooling have you finished?

C8a. __grade school

C8b. __high school

C8c. __some college (but did not graduate)

C8d. __Associate's Degree

C8e. __Bachelor's Degree

C8f. __Master's Degree

C8g. __Higher (PhD/JD, etc.)

C8h. __Other (for example, certifications, ordinations, etc.)_____

And, now, I'd like to ask you the following information about your (if mentioned in first phone call, insert name of deceased person, otherwise use deceased spouse/partner) deceased spouse/partner:

C9. Please tell me the name of the deceased:_____

C10. What was the relationship of the deceased to you?

C9 a) Spouse or C9b) Domestic Partner

C11. Was the deceased male or female? _____

C12. What was the age of the deceased at the time of their death?_____

C13. What was the month and year of the death?_____

C14. Did (if mentioned in first phone call, insert name of deceased person, otherwise use deceased spouse/partner) die a sudden death or one from an illness?

C15. Which of the following best describes the race of the deceased?

C15a. __American Indian or Alaskan Native

C15b. __Asian or Pacific Islander

C15c. __Black or African-American

C15d. __White

C15e. __Another race or multiracial:_____

C16. What was the deceased's religious/spiritual preference?, if any?:_____

APPENDIX D

INTERVIEW GUIDE

Introduction:

This interview is being conducted to understand more about the ways that bereaved spouses and domestic partners are cared for during their bereavement by those who offer grief education and support services. I hope that you will be comfortable expressing your feelings and views, knowing that all personal information gathered about you and your family will be kept confidential. When I report these results for my dissertation project or share them with other professionals, I will do everything possible to make sure that you are not identified in any way. The interview will take approximately two hours or less. If you have any questions about any issues we are talking about, or you want to go on to another topic, please tell me. This interview is being audio-taped and I will be taking notes throughout. Since we may only meet today, I would like to talk with you briefly at the close of the interview to make you aware of available grief support services. Okay, are we ready?

1. *To begin, I'd like for you to tell me a little about yourself, perhaps you can talk about your work, your family, or whatever you'd like for me to know about you.*

2. *Because I now know that _____ (use name of deceased) died*

'suddenly', OR from 'an illness', can you tell me more about:

2a) the sudden death

(i.e., how the news was delivered, who was with you, the arrangements, the funeral, etc.)

OR

2b) when you learned the illness was terminal?

(i.e., who was with you, what happened, who the caretakers were, etc.)

2.1 Probe- What was the most overwhelming part of this whole experience for you?

2.2 Probe- What enabled you to go on?

3. *Next, can you tell me what your expectations were of the 'grief experience'?*

3.1 a. Probe- What surprised you the most in the grief process?

4. *Can you now tell me what types of personal conversations you had with professionals about the death of _____, and with whom?*

5. *Did you receive information about how to cope and what to expect?*

6. *Were you aware of any support groups that were available for you to attend and what professionals you might consult?*
7. *Did you receive any follow-up information from the agency, and if so, what was it?*
8. *Did a representative from this agency visit you at home?*
9. *Did you attend any support groups or special memorial services?*
10. *Did this agency offer or provide you with any individual grief counseling?*
11. *Was the agency that provided bereavement care for you recommended by someone?*
12. *Was any of this grief support helpful?*

12.1 Probe- If yes, how was it helpful? **12.2 Probe-** If no, why not?

13. *Looking back, please describe for me what you think might have been more helpful (if anything) from this particular agency who assisted you with your grief experience?*
14. *Did you get any other bereavement support from other agencies? Or any other sources?*

14.1 Probe: If so, was it helpful, or not?

15. *Is there anything that I have not asked you that you would like to comment on?*

Shut off the tape for the final questions:

16. *How have you felt about this interview?*
17. *Were there any questions too difficult to discuss?*

Lastly, present the participant with the list of Lansing Area Bereavement Services

APPENDIX E

FORMAL BEREAVEMENT CARE SERVICES

LEVEL ONE

- Personal conversation about the death/loss
- Written or verbal informational support (i.e., may include brochures, newsletters, etc. on how to cope, what to expect, and the times/places of support group meetings or local area professionals who specialize in grief counseling)

LEVEL TWO

- Follow-up telephone calls from bereavement care agency
- Letters, cards and/or gifts from bereavement care agency

LEVEL THREE

- In-person bereavement home visits from an agency's representative

LEVEL FOUR

- Peer support through support group attendance
- Special Activity attendance, (i.e., memorial services, holiday events)

LEVEL FIVE

- Individual grief counseling

APPENDIX F⁶³

List of Bereavement Care Providers

Funeral Home Community Bereavement Services

Gorsline-Runciman Funeral Home – *Navigating Through Life's Landscapes*
Contact: Gwen Kapcia at 517.333.3636

Palmer, Bush & Jensen Family Funeral Homes
Contact: 517.268.1000

Faith Organizations/Church-Sponsored Bereavement Support

South Lansing Church of the Nazarene
Contact: Larry Vert at 517.323.4355

Trinity United Methodist Church
Contact: Rae Franke at 517.322.0484

Hospice Community Bereavement Support Programs

Eaton Community Hospice Survivor's Support Group (Meets in Charlotte)
Call: 517.543.5310

The Hospice of Lansing and Ionia Area Hospice – *Passages Through Loss and Grief*
Understanding Your Grief: 10 Essential Touchstones
Contact: 517.882.4500

Ingham Visiting Nurse Services of Michigan – *New Tomorrows* - 8 week grief education series,
registration requested
Contact: 517.975.9909
Or Ron Hutson at 517.975.9913

Great Lake Hospice Grief Support
Contact: Charles Krueger at 517.351.4100

Sparrow Hospice Bereavement Services
Grief Support Groups; Seasons of the Heart (6 week grief education series; pre-registration
required); Coffee hour-informal social support for spouses; Memories in a Mirrors –daughters
without moms; Memorial Services twice a year-Spring and Fall; Holding Hope for the Holidays
Contact: 517.364.7208

⁶³ A resource was provided for each specific area within the state [i.e., Jackson, Macomb county, etc.]

APPENDIX G

RECRUITMENT LETTER

Date:

Dear: _____

You are being asked to participate in a research study being conducted by a sociology doctoral candidate from Michigan State University, Ms. Laurel Hilliker. She is going to be conducting this project to look at the experiences of bereavement care services provided to you by our agency. She hopes that the results of this study will contribute to a better understanding of the needs of the bereaved individual.

You have been selected to receive an invitation to participate in this study because we believe you may meet the criteria as outlined in her proposal for the project, which is the following:

- 1) Bereaved no less than 1 year and no more than 3 years;
- 2) Have received formal bereavement support of some kind (i.e., on an individual basis or through support groups from one of the agencies named in the research study);
- 3) Have experienced the loss of a spouse or domestic partner;
- 4) Belong to the Baby Boomer cohort (born between 1946-1964); and
- 5) Have English as the primary language

Please be assured that our agency representative has met with Laurel to ensure that your privacy is protected at all stages in this research process. There is no requirement that you have to participate, and even if you decide to initially, you can stop the process at any time. Laurel is looking for 15 participants to interview in the next few months. If you are interested, please either email her at: hillike2@msu.edu or call her at 517.862.9221(cell). She will inform you as to the next step after you contact her. If you have any questions, please feel free to contact us: **(Agencies addresses will be added at a future date).**

We wish you peace of mind and heart.

Sincerely,

(name and address of agency)

APPENDIX H

Newsletter Recruitment

A grief and bereavement sociology researcher at Michigan State University is looking for 15 participants to be involved in a study about their experiences of grief care services for her dissertation project. If you have lost a spouse or domestic partner at least one year ago and no more than three years ago, feel that you have received some type of bereavement services from our agency, were born between 1946 and 1964 and English is your primary language, and most importantly, if you would want to be considered for an interview as a research participant, please call or email the researcher directly. Her name and contact information are as follows: Ms. Laurel Hilliker, phone: 517.862.9221 or email: hillike2@msu.edu.

APPENDIX I

Interview Observation List⁶⁴

- K1. Wearing wedding ring
- K2. Photo of or personal belonging of deceased prominently displayed or shown to researcher
- K3. Any shrine visible in home in honor of deceased person
- K4. Funeral cards or other objects from funeral or memorial services shown to researcher
- K5. Program books, leaflets, brochures or other memorabilia from grief program shown to researcher

⁶⁴ These themes will be developed in an iterative process as the project develops as is standard practice in qualitative methods.

APPENDIX J

Final Thank You Letter To Participants

Dear (Name of Participant),

Date:

I want to express my gratitude to you for participating in the interview about your experiences of formal bereavement support. I appreciated your willingness to trust me with such an important part of your life. Please know that your input to the study was greatly valued. It is my hope that the results of my study may inform providers of bereavement services with more knowledge on how to respond sensitively to the needs of those who are grieving a significant loss.

Sincerely,

Laurel Hilliker
Doctoral Candidate
Michigan State University
Department of Sociology

APPENDIX K

Participant/Deceased Characteristics Using Pseudonyms

Agency#, Pseudonym, Age and Race Description of Participant [age of participant is at time of interview, age of decedent is at the time of death] Age and Diagnosis of Deceased

0-001-Andy- 57 year old white male, professional auto body worker whose 67 year old wife (**Fran**) died of breast cancer

0-002-Adam- 60 year old, multiracial [part Cherokee Indian-Scottish/Irish] male, a retired minister and academic, whose 49 year old wife (**Farah**) died of breast cancer

0-003-Ann- 57 year old female, part-time teaching assistant at a private elementary school, whose 69 year old husband (**Frank**) died as a result of several health problems and ongoing illness related to a bleeding ulcer

1-001-Beth- 63 year old white female, retired administrative university assistant, whose 61 year old husband (**George**) died as the result of a long illness related to emphysema

2-001-Brian- 56 year old white male, who works as a vocational rehabilitation counselor, whose 58 year old wife (**Gwen**) died of a brain tumor

2-002-Betty- 55 year old white female, working as a part time editor, whose 52 year old husband (**Guy**) died from pancreatic cancer

2-003-Brenda- 47 year old white female, retired teacher, now working part-time at her church, whose 48 year old husband (**Gerald**) died from a sudden heart attack

2-004-Barbara- 47 year old white female, part-time worker at an elementary school, whose 44 year old husband (**Greg**) died suddenly in a car accident

3-001 Charlene- 64 year old Asian female, unemployed, whose 67 year old husband (**Henry**) died of cancer of the lung

3-002-Cheryl- 63 year old white female, unemployed, whose 67 year old husband (**Hank**) died from cancer of the liver

3-003-Cathryn- 56 year old white female, assistant in a medical office, whose 54 year old husband (**Hugh**) suddenly after a short illness related to a brain aneurysm

3-004-Christina- 55 year old white female, works part-time as an administrative assistant in a school district, whose 52 year old husband (**Harvey**) died of a sudden heart attack

3-005-Cindy- 49 year old white female, who works in accounting position, and whose 51 year old estranged husband (**Harry**) died of a sudden death by suicide

3-006-Colleen- 58 year old white female, who works in the health care field, and whose 67 year old husband (**Howard**) died as the result of complications of alcoholism

3-007-Connie- 46 year old white female, who works at a medical center and does medical coding, whose 47 year old estranged husband (**Herbert**) died of a sudden death by suicide

3-008-Courtney- 46 year old white female, who works as an registered nurse, and lost her 44 year old husband (**Hal**) died of a sudden heart attack

3-009-Corrine- 52 year old white female, who is self-employed, and whose 70 year old husband (**Haden**) died from renal failure related to several combined illnesses including diabetes and congestive heart failure

4-001-Donna- 54 year old white female, who works part-time for a property management company, and whose 49 year old husband (**Brad**) died of pancreatic cancer

4-002-Debra- 60 year old white female, who lost her job as assistant to her husband's professional chiropractic business, and whose 58 year old husband (**Ben**) died from a sudden heart attack

4-003-Diane- 53 year old Asian female, who works as a sales manager, and whose 53 year old husband (**Bernard**) died from cancer of the liver

4-004-Danielle- 63 year old white female, who works in real estate, and whose 65 year old husband (**Bill**) died as a result of a brain bleed

4-005-David- 71 year old white male, who is retired from food sales, whose 65 year old wife (**Irene**) died of breast cancer

4-006-Doris- 62 year old female, who is retired, and whose 56 year old husband (**Bruce**) died from an accident related to a fall

4-007-Denise- 51 year old white female, works for a publisher, and whose 58 year old husband (**Bob**) to cancer [adenocarcinoma, related to epithelial tissues]

4-008-Dorothy- 64 year old white female, retired from nursing, and whose 71 year old husband (**Barry**) died from complications related to diabetes

4-009-Delores- 59 year old white female, who is a homemaker, whose 59 year old husband (**Brandon**) died from a sudden heart attack

4-010-Dana- 46 year old white female, who works as a counselor and mediator for a county court system, whose 41 year old husband (**Brad**) died of a brain tumor

4-011-Dale- 59 year old white male, who works as an engineer in the auto industry, and whose 52 year old wife (**Ingrid**) died from a sudden collapse related to cardiac arrest

4-012-Dawn- 61 year old white female, who works two part-time jobs, one as a teacher of enrichment courses and another in a bakery, and whose 58 year old husband (**Blake**) died suddenly from a blood clot in the leg

5-001-Elaine- 56 year old white female, who works two part-time jobs, and whose 55 year old husband (**Jay**) died from complications due to alcoholism

5-002-Eric- 53 year old white male, who is retired, and whose 53 year old wife (**Jana**) died from liver cancer

5-003-Edna- 62 year old white female, who works part-time as a secretary, and whose 67 year old husband (**Jerry**) died of cancer of the lung

5-004-Earl- 64 year old white male who is retired, and whose 57 year old wife (**Jenny**) died after a short illness related to a brain tumor

5-005--Edith- 61 year old white female, who is retired from teaching, and whose 68 year old husband (**Jason**) died from a short illness related to blood cancer

5-006-Elliott- 54 year old white male, who works in auto industry, and whose 49 year old wife (**Justine**) died of leukemia

5-007-Eleanor- 59 year old white female, who works as a billing assistant for a transport company, and whose 59 year old husband (**Jared**) died of a sudden heart attack

5-008-Emily- 64 year old white female, who works part-time, and whose 66 year old husband (**Jake**) died from a sudden heart attack

5-009-Elizabeth- 62 year old white female, who is retired, whose 63 year old husband (**John**) died from esophageal cancer

APPENDIX L

Brief Descriptions of Five Agencies

Pilots – 3 total who sought bereavement care from various agencies in the Lansing, Michigan area. They were recruited by the researcher contacts made with area support groups.

Agency #1 – Hensen Family Funeral Homes [1 participant]

This funeral home is a locally owned and family operated Michigan business [since 1926] with three locations in Mid-Michigan. They provide traditional funeral and cremation services. They also have a Continuing Care Coordinator who offers grief support for both the families they serve and the greater community, including coffee hours once monthly, closed-ended support groups [5 weeks] an annual Remembrance Service and presentations on specific topics.

Agency #2 – Healing Place [4 participants]

Healing Place is a nonprofit, community-based organization with a mission to create awareness of and support for grieving children and their families. Through peer support group programs, Healing Place helps children to cope with the death or life-threatening illness of a parent, sibling or other close family member or friend. They are committed to reaching out to all grieving children and their families throughout Mid-Michigan, and provide group support services at no charge.

Agency #3 – Good Fellow Health Hospice [9 participants]

Good Fellow Health is a community-owned and locally-governed health system. They are entering their 10th decade of serving the people of south central Michigan with local health care. All grief support events are free of charge for participants and open to the public. Support groups are designed to address the emotional, educational and social needs of those who are coping with a death.

Agency #4 – Horizon of Hope Center for Grief Support (HHCGRS) [12 participants]

Horizon of Hope Center for Grief Support is a Christian based bereavement outreach center that provides grief support services to adults, teens and children through groups, individual support, seminars and other resources. HHCGRS is a tax exempt, approved 501(c)(3) organization and is funded primarily through private donations and fundraising events. The Center receives no state or federal funding and does not charge a fee for any of its services to individuals. Their goal is to help each individual who seeks out grief support services to find HOPE and healing. People of all faiths are encouraged and invited to participate. They specialize in offering age and loss specific support to all who are grieving. Support groups are free of charge and typically people

are placed in a group with others who have had a similar loss. They have an eight week series which also offers specific groups for parent loss, sibling loss, suicide loss, etc.

The Center has developed an 8 week series called From Grief to Hope that is offered in churches and funeral homes all over southeastern Michigan at various times throughout the year. The series begins with a live presentation from a grief specialist which provides information and education about the grief process. Following the presentation the participants attend age and loss specific small groups facilitated by trained facilitators – many of which have experienced a similar loss. The From Grief to Hope workshop is also offered in a half day seminar format at certain times of the year. They also offer several ongoing groups for adults and children which meet throughout the year for those who are dealing with specific losses. As a resource center, they have an updated referral list of qualified counselors and lists of other groups available in southeastern Michigan.

Agency #5 – Widowed But Not Alone (WBNA) [9 participants]

Widowed But Not Alone was formed under the auspices of a Catholic Archdiocese, Office of Family Life. The need for a support group for the widowed was identified by widows themselves at a retreat held in 2002. Several months later this group was established, and since then membership has grown at a rapid pace [nearing 700]. The group offers an opportunity for social, spiritual, educational and grief support. Participating in the WBNA ministry, members are able to expand their circle of friends and ease the feeling of isolation that accompanies the loss of a spouse. The group offers widowed men and women of all ages, within the Archdiocese, caring companionship and the opportunity for healing, spiritual development, education and new growth. Enrichment activities meet a variety of needs to facilitate the journey from grief to a new sense of joy and purpose. Widowed men and women of all faiths are welcome. The group charges a small fee for dues which represents the primary income used to defray costs of printing, mailing and/or distributing newsletters, brochures, etc. Any residual dues income is used to cover some expenses of other social, educational and spiritual events.

Total Participants Interviewed: 38, which include 3 from pilot interviews to test Interview Guide

APPENDIX M

Bibliotherapy: Recommended by Participants

Feinberg, L. (1994). *I'm Grieving As Fast As I Can: How Young Widows and Widowers Can Cope and Heal*. New Horizon Press.

Gray, E., (2009). *Essence of Grieving*. Mosaic Publications. Using Poetry as a Guide for the Grieving Process.

Haugk, K.C. (2004) *A Time to Grieve*. Stephen Ministries.

O'Shaughnessey, J. (2007). *The Greatest Gift: A Return to Hope*. Nelson Publishing & Marketing.

Schwiebert, P. and DeKlyen, C. (2005). *Tear Soup*. Grief Watch Publications.

Westberg, G.E. (2010) *Good Grief: 50th Anniversary Issue*. Fortress Press.

Williams, D.R. (2001) *Grief and Mourning: When someone or something you love is no longer there*. Decapolis Books.

Wolfelt, A., (2004) *Understanding Your Grief: Ten Essential Touchstones for Finding Help and Healing Your Heart*. Companion Press.

Young, W. P. (2008) *The Shack*. Windblown Media.

APPENDIX N

TABLE A AGE CHARACTERISTICS OF POPULATION

Year of Birth	# of Participants [n=38]⁶⁵	Age
<i>1939 (1)</i>	<i>1</i>	<i>71</i>
<i>Mature Boomers (23) Ages 56-64</i>		
1946	4	64
1947	3	63
1948	3	62
1949	2	61
1950	2	60
1951	3	59
1952	1	58
1953	2	57
1954	3	56
<i>Youngest Boomers (14) Ages 46-55</i>		
1955	2	55
1956	2	54
1957	2	53
1958	1	52
1959	1	51
1961	1	49
1963	2	47
1964	3	46

⁶⁵ Thirty-seven were Boomers, however, one participant misrepresented his age, he was not a Boomer, rather he was 71 years old.

APPENDIX O

TABLE AD Additional Demographics

Int. #	Age	Gender	Religious or Spiritual Preference	Educational Attainment	#of Addl. Residents and Relationship if known/Extraordinary Experience Noted
0-001	57	M	Would not answer	A.A.	
0-002	60	M	Christian	M.A.+	2 [teenagers] Ex. Experience
0-003	57	F	Catholic	B.A.	1 [young adult]
1-001	63	F	None	Some College	1 [young adult]
2-001	56	M	Presbyterian	M.A.	1 [teenager]
2-002	55	F	Christian	B.A.	1 [teenager]
2-003	47	F	Protestant	M.A.	2 [young children]
2-004	47	F	None	Some College	1 [teenager]
3-001	64	F	Catholic	Grade School	
3-002	63	F	None	B.A.	
3-003	56	F	Presbyterian	A.A.	1 [young adult]
3-004	55	F	None	High School	
3-005	49	F	Protestant	B.A.	1 [young child]
3-006	58	F	Catholic	A.A. Cert. for Med-Tech	Extraordinary Experience
3-007	46	F	None	High School	2 [young children]
3-008	46	F	None	A.A.	
3-009	52	F	None	A.A.	

TABLE AD Additional Demographics, cont.

4-001	54	F	Catholic	Some College	2 [teenagers]
4-002	60	F	Catholic	A.A.	
4-003	53	F	Christian	MBA+2 M.A.'s	2 [1 teenager, 1 young adult]
4-004	63	F	Protestant	A.A.	
4-005	71	M	Believes in God	Some College	
4-006	62	F	Catholic	M.A.	Extraordinary Experience
4-007	51	F	Believes in God	A.A, B.A.	
4-008	64	F	Believes in God	A.A.+	
4-009	59	F	Christian	High School	Extraordinary Experience
4-010	46	F	None	M.A.	2 [young children] Ext. Experience
4-011	59	M	Nazarene	M.A.	1 [young adult]
4-012	61	F	Catholic	B.A.+	Extraordinary Experience
5-001	56	F	Non-Den. Pentecostal	Some College	
5-002	53	M	Lutheran	Some College	1 [young child]
5-003	62	F	Catholic	High School	
5-004	64	M	Catholic	High School	
5-005	61	F	Catholic	M.A.	
5-006	54	M	Catholic	A.A.	
5-007	59	F	Catholic	High School	
5-008	64	F	Catholic	B.A.	
5-009	62	F	Catholic	Some College	1 [young adult grandson]

BIBLIOGRAPHY

BIBLIOGRAPHY

- Abrams, L.S. & Curran, L. (2010). Maternal Identity Negotiations Among Low-Income Women With Symptoms of Postpartum Depression. *Qualitative Health Research*, 21, 373.
- ADEC, Association for Death Education and Counseling. *Certification in Thanatology*. Retrieved from: http://www.adec.org/Certified_in_Thanatology/2099.htm.
- Albright, M. (2009, December 1). Death Rituals Changing as more opt for Cremations. *Tampa Bay News*, November 29, 2009, Retrieved from: <http://www.tampabay.com/news/business/retail/death-rituals-changing-as-more-people-especially-boomers-opt-for-cremations/1054885>.
- Allumbaugh, D.L. & Hoyt, W.T. (1999). Effectiveness of Grief Therapy: A Meta-Analysis. *Journal of Counselling Psychology*, 46, 370.
- Altheide, D.L. (2000). Identity and the definition of the situation in a mass-mediated context. *Symbolic Interaction*, 23,1-27.
- Anderson, H. & Goolishian, H. (1992). The client is the expert: a not knowing approach to therapy, in K. Gergen & McNamee, S. (Eds) *The Social Construction of the Psychotherapeutic Process*. London: Sage.
- Anderson, D. & Mullen, P. (Eds). (1998). *Faking It: The Sentimentalisation of Modern Society*. London, Social Affairs Unit.
- Arnarson, A. (2007). Fall Apart and Put Yourself Together Again: The Anthropology of Death and Bereavement Counselling in Britain. *Mortality*, 12,48-65.
- Arnold, J. & Gemma, P.B. (2008). The Continuing Process of Parental Grief. *Death Studies*, 32(7), 658-673.
- Anthony, S. (1940). *The Child's discovery of Death*. New York: Harcourt.
- Aries, P. (1962). *Centuries of Childhood*. London, UK, Cape.
- _____. (1974). *Western Attitudes toward Death: From the Middle Ages to the Present*. Baltimore: Johns Hopkins University Press.
- _____. (1983). *The Hour of Our Death*. London, UK: Penguin.
- Arnarson, A. (2000). Biography, bereavement, story. *Mortality*, 5(2), 189-204.

- Auerbach, C.F. & Silverstein, L.B. (2003). *Qualitative data: An introduction to coding and analysis*. New York: New York University Press.
- Avis, N.E., Brambilla, D.J., Vas, K. & McKinlay, J.B. (1991). The effect of widowhood on health: A prospective analysis from the Massachusetts Women's Health Study. *Social Science & Medicine*, 33, 1063.
- Bales, R.F. (1950). *Interaction Process Analysis: A Method for the Study of Small Groups*. Cambridge, MA: Addison-Wesley.
- Balk, D. (1997). Death, bereavement and college students: a descriptive analysis. *Mortality*, 2, 207-220.
- Barry, D. (2010, December 31). Boomers Hit Another Milestone of Self-Absorption: Turning 65. *The New York Times*, Retrieved from: <http://www.nytimes.com/2011/01/01/us/01boomers.html?pagewanted=all>.
- Bauer, J. J., & Bonanno, G. A. (2001). Doing and being well (for the most part): adaptive patterns of narrative self-evaluation during bereavement. *Journal of Personality*, 69, 451.
- Baxter, L.A. (2004a). Relationships as dialogues. *Personal Relationships*, 11,1-22.
- Baxter, L.A. (2004b). Dialogues of relating. Anderson, R., Baxter, L.A. & Cissna, K.N., (Eds)., *Dialogue: Theorizing difference in communication studies*, Thousand Oaks, CA, Sage Publications.
- Baxter, L.A. & Montgomery, B.M. (1996). *Relating: Dialogues and dialectics*. New York: Guilford.
- Beck, U. & Beck-Gerhshheim, E. (1995). *The Normal Chaos of Love*. Cambridge: Polity Press.
- _____. (2002). *Individualization*. London, Thousand Oaks, New Delhi: Sage Publications.
- Becker, E. (1973). *The Denial of Death*. NY: The Free Press.
- Bennett, G. & Bennett, K. (2000). The presence of the dead: an empirical study. *Mortality*, 5(2), 139-157.
- Benoliel, J.Q. (1994). Death and dying as a field of inquiry. Corless, I.B., Germino, B.B., & Pittman, M., (Eds). *Dying, Death and Bereavement*. Boston, MA: Jones and Bartlett.
- Berger, P. (1969). *The Social Reality of Religion*. London: Faber.

- Berger, P., Berger, B. & Kellner, H. (1974). *The Homeless Mind: Modernization and Consciousness*. London: Penguin.
- Bergman, E. J., Haley, W. E., & Small, B. J. (2010). The role of grief, anxiety, and depressive symptoms in the use of bereavement services. *Death Studies*, 34(5), 441-458.
- Bernard, H.R. (2006). *Research Methods in Anthropology*. New York: Alta Mira Press.
- Billings, J. A. & Kolton, E. (1999). Family Satisfaction and Bereavement Care Following Death in the Hospital. *Journal of Palliative Medicine*, 2, 33-49.
- Blau, P. (1964). *Exchange and Power in Social Life*. New York: Wiley.
- Blauner, R. (1966). Death and social structure. *Psychiatry*, 29, 378-94.
- Blumer, H. (1937). Social Psychology. Schmidt, E.P. (Eds.) *Man and Society*. Englewood Cliffs, NJ: Prentice-Hall.
- Bonanno, G.A. (2010). *The Other Side of Sadness: What the New Science of Bereavement Tells Us About Life After Loss*. New York, NY: Basic Books.
- Bonanno, G.A. and Kaltman, S. (1999). Toward an Integrative perspective on bereavement. *Psychological Bulletin*, 125(6), 760-775.
- Bonnanno, G. A., Wortman, C. B., Lehman, D. R., Tweed, R. G., Haring, M., Sonnega, J., Carr, D. & Nesse, R. M. (2002). Resilience to loss and chronic grief: a prospective study from pre-loss to 18-months post-loss. *Journal of Personal Social Psychology*, 83, 64.
- Boohan, M., McGuinness, C., & Trew, K. (1993). Individual differences in adaption to widowhood. The Psychological Society of Ireland, 24th Annual Conference, Sligo, Ireland. *The Irish Psychologist*, 4, 37.
- Bowlby, J. (1958). The nature of the child's tie to his mother. *International Journal of Psycho-Analysis*, XXXIX, 1-23.
- _____.(1959). Separation anxiety. *International Journal of Psycho-Analysts*, XLI, 1-25.
- _____.(1960). Grief and mourning in infancy and early childhood. *The Psychoanalytic Study of the Child*, VX, 3-39.
- _____.(1969). *Attachment and Loss*, Volumes 1-3. New York, NY, Basic Books.
- _____.(1980). *Loss: Sadness and Depression*. New York, NY, Basic Books.

- Boyatzis, R.E. (1998). *Transforming qualitative information: Thematic analysis and code development*. Thousand Oaks, CA: Sage Publications.
- Bradbury, M. (1999). *Representations of Death*. London and New York: Routledge.
- Breen, L.J., & O'Connor, M. (2007). The Fundamental Paradox in the Grief Literature: A Critical Reflection. *Omega*, 55(3), 199-218.
- Bridging Work Group. (2005). Bridging the gap between research and practice in bereavement: Report from the Center for the Advancement of Health. *Death Studies*, 29, 93-122.
- Brody, C. (2009). *Widows Wear Stilettos: A Practical and Emotional Guide for the Young Widow*. Far Hills, NJ, New Horizon Press.
- Brosi, W. A. (2006). Understanding Grief as the Process of Loss Evolves. *Death Studies*, 30(2), 193-197.
- Bruner, J. (1986). *Actual Minds, Possible Worlds*. Cambridge, MA.: Harvard University Press.
- Burke, P.J. (1980). The self: Measurement implications from a symbolic interactionist perspective. *Social Psychology Quarterly*, 43, 18-29.
- Callero, P.L. (2003). The Sociology of the Self. *Annual Review of Sociology*, 29, 115-133.
- Canfield, J., & Hansen, M.V. (2003). *Chicken Soup for the Grieving Soul: Stories about Life, Death and Overcoming the Loss of a Loved One*. Deerfield Beach, Florida: Health Communications Incorporated.
- Carr, D. (2004). Black/White differences in psychological adjustment to spousal loss among older adults. *Research on Aging*, 26, 591-622.
- Carr, D. (2006). Good Grief: Bouncing back from a spouse's death in later life. *Contexts*, 5(4), 22-27.
- Carr, D., Neese, R., & Wortman, C.B. (Eds.) (2006). *Spousal Bereavement in Late Life*. New York, NY: Springer Publishing Company.
- Caserta, M.S. & Lund, D.A. (1996). Beyond bereavement support group meetings: exploring outside social contacts among the members. *Death Studies*, 20, 537.
- Center for Disease Control/National Center for Health Statistics. (2010). *FastStats. Deaths and Mortality*. Retrieved from: <http://www.cdc.gov/nchs/fastats/deaths.htm>

- Center for the Advancement of Health. (2004). Report on bereavement and grief research. *Death Studies*, 28, 491-575.
- Cerulo, K.A. (1997). Identity construction: new issues, new directions. *Annual Review of Sociology*, 23, 385-409.
- Charmaz, K. (1980). *The Social Reality of Death. Death in Contemporary America*. . Reading, MA: Addison-Wesley Publishing Company.
- Clark, D., (Ed.) (2001). *Facing Death Series*. Buckingham: Open University Press.
- Cleveland, W.P. & Gianturco, D.T. (1976). Remarriage probability after widowhood: A retrospective method. *Journal of Gerontology*, 31, 99-103.
- Cochran, L. & Claspell, M. (1987). *The Meaning of Grief: A Dramaturgical Approach to Understanding Emotion*. New York: Greenwood.
- Collier, P. J. (2001). The differentiated model of role identity acquisition. *Symbolic Interaction*, 24, 217-35.
- Cooley, C. H. (1902). *Human Nature and the Social Order*, New York: Charles Scribner's Sons.
- Corless, I.B. (2005). Future Trends in Dying, Death and Bereavement: A Call to Action. *Illness, Crisis & Loss*, 13(4), 377-385.
- Corsaro, W. A., & Rizzo, T.A. (1988). Discussions and Friendship: Socialization Processes in the Peer Culture of Italian Nursery School Children. *American Sociological Review*, 53, 879-94.
- Cromer, M. (2006). *Exit Strategy: Thinking Outside the Box*. New York, NY: Jeremy P. Tarcher/Penguin.
- Crossley, M.L. (2000). *Introducing Narrative Psychology*. Buckingham: Open University Press.
- Danforth, L. (1982). *The Death Rituals of Rural Greece*. Princeton, NJ, Princeton University Press.
- Danforth, M.M., & Conrad Glass, J., Jr. (2001). Listen to my words, give meaning to my sorrow: A study in cognitive constructs in middle-age bereaved widows. *Death Studies*, 25, 513.
- Daniel, V. (1984). *Fluid signs: Being a person the Tamil way*. Berkeley, CA: University of California Press.

- Davies, D. (2002). *Death, Ritual and Belief: The Rhetoric of Funerary Rites*. London, UK-Continuum.
- Davis, C. G. & Nolen-Hoeksema, S. (2001). Loss and Meaning. How Do People Make Sense of Loss? *American Behavioral Scientist*, 44, 726–741.
- Denzin, N.K. (1991). *Images of Postmodern Society: Social Theory and Contemporary Cinema*. Newbury Park, CA: Sage Publications.
- Didion, J. (2007). *The Year of Magical Thinking*. New York, NY: Vintage Books.
- Dillenburg, K., & Keenan, M. (2005). Bereavement: A D.I.S.C. Analysis. *Behavior and Social Issues*, 14, 92-112.
- Doka, K. (1989). (Ed) *Disenfranchised Grief: Recognizing Hidden Sorrow*. Boston, MA: Lexington Books.
- _____. (2007). *Living with grief: Loss in later life*. Washington, DC: Hospice Foundation of America.
- Duke, S. (1998). An exploration of anticipatory grief: the lived experience of people during their spouses' terminal illness and in bereavement. *Journal of Advanced Nursing*, 28, 829.
- Durkheim, E. (1915). *The Elementary Forms of the Religious Life*. London, UK, Unwin.
- _____. (1952). *Suicide: A Study in Sociology*. London: Routledge.
- _____. (1964). *The Rules of Sociological Method*. New York, Free Press.
- _____. (1965) [Originally published 1912]. *The Elementary Forms of Religious Life*. New York: Free Press.
- Dworkin, R., 1993. *Life's Dominion: An Argument About Abortion, Euthanasia, and Individual Freedom*. New York, NY, Knopf Press.
- Dyregrov, K., Dyregrov, A., & Raudalen, M. (2000). Refugee families' experience of research participation. *Journal of Traumatic Stress*, 13, 413-426.
- Dyregrov, K. (2004). Bereaved parents' experience of research participation. *Social Science & Medicine*, 58, 391-400.
- Dychtwald, K. (2000). *Age power: How the 21st century will be ruled by the new old*. New York: Jeremy P. Tarcher/Putnam.

- Erickson, F. (3rd ed.) (1986). Qualitative methods in research on teaching. M.C. Wittrock (Ed.). *Handbook of research on teaching*, 119-61. New York: Macmillan.
- Ewen, S. & Ewen, E. (1992). *Channels of Desire: Mass Images and the Shaping of American Consciousness*. Minneapolis: University of Minnesota Press.
- Exley, C. (2004). Review article: the sociology of dying, death and bereavement. *Sociology of Health & Illness*, 26(1), 110-122.
- Farganis, J. (2004). (4th ed) *Readings in Social Theory: The Classic Tradition to Post-Modernism*. New York, NY: McGraw-Hill.
- Fauri, D. P., Ettner, B., & Kovacs, P.J. (2000). Bereavement services in acute care settings. *Death Studies*, 24(1), 51-64.
- Feifel, H. (Ed.) (1959). *The Meaning of Death*. New York: McGraw-Hill.
- Feinberg, L. (1994). *I'm Grieving As Fast As I Can: How Young Widows and Widowers Can Cope and Heal*. Far Hills, NJ: New Horizon Press.
- Field, N. (1989). *Nursing the Dying*. London: Tavistock/Routledge.
- Field, N. P., Gal-oz, E. & Bonanno, G. A. (2003) Continuing bonds and adjustment at 5 years after the death of a spouse. *Journal of Consulting and Clinical Psychology*, 71, 110.
- Filene, P. (1998). *In the Arms of Others: A Cultural History of the Right-to-Die in America*. Chicago, IL: Ivan R. Dee Publisher.
- Foehner, C., & Cozart, C. (1988). *The Widow's Handbook: A Guide for Living*. Golden, CO: Fulcrum Publishing.
- Foote, C.E., & Frank, A.W., (1999). Foucault and Therapy: The Disciplining of Grief. Chapter 7 in Epstein, L.(1999). *Reading Foucault for Social Work*, West Sussex, England: Columbia University Press.
- Forte, J., Barrett, A., & Campbell, M. (1996). Patterns of Social Connected-ness and Shared Grief Work: A Symbolic Interactionist Evaluation. *Social Work with Groups*, 19(1), 29-51
- Forte, J., Hill, M., Pazder, R., & Feudtner, C. (2004). Bereavement Care interventions: a systematic review. *BMC Palliative Care*, 3, 3. Retrieved from <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC503393/>.

- Fos, P.J., & Fine, D.J. (2005). *Managerial epidemiology for health care organizations*. San Francisco: Jossey-Bass
- Foucault, M. (1988). *Technologies of the Self*. Amherst: University of Massachusetts Press.
- Francis, M. (2011). *The Sisterhood of Widows: Sixteen True Stories of Grief, Anger and Healing*. Garden City, NY: Morgan James Publishing.
- Francis, D., Kellaheer, L., & Neophytou, G. (2005). *The Secret Cemetery*. Oxford: Berg.
- Frank, A. (1995). *The Wounded Storyteller: Body, Illness and Ethics*. Chicago: Chicago University Press.
- Frankl, V.E. (Ed.) (1992). *Man's search for meaning: An introduction to logotherapy*. Boston: Beacon.
- Freud, S., (1917/1984). Mourning and melancholia. Freud, S., (1917). (Ed). *On Metapsychology*, 11, 251-67. London: Pelican Freud Library.
- Fulton, R. (1965). *Death and Identity*. New York, NY: John Wiley & Sons.
- Fulton, R., & Bendiksen, R., (Eds) (1965). *Death and Identity*. Bowie, MD: Charles Press.
- _____. (1976). *Death, Grief, and Bereavement: A Bibliography: 1845-1975*. New York, NY: Arno Press.
- Gallagher, M., Tracey, A. & Millar, R. (2005). Ex-clients' evaluation of bereavement counseling in a voluntary sector agency. *Psychology and Psychotherapy*, 78, 59.
- Garfinkel, H. (1967). *Studies in Ethnomethodology*. Englewood Cliffs, N.J., Prentice-Hall.
- Gelech, J.M. & Desjardins, M. (2010). I am Many: The Reconstruction of Self Following Acquired Brain Injury. *Qualitative Health Research*, 21(1),62-74.
- Gerdau, R., & Gomstyn, A., (2011). Did Grief Turn Loving Mom Into Sex Offender? *ABC 20/20*. Retrieved from: <http://abcnews.go.com/US/grief-turn-loving-mom-sex-offender/story?id=14924854>
- Gergen, K. J. (1992). *The saturated self: Dilemmas of identity in contemporary life*. New York: Basic Books.
- Giddens, A., (1991). *Modernity and self-identity: Self and Society in the late-modern age*. Palo Alta California: Stanford University Press.

- Gillon, S.M. (2004). *Boomer Nation: The Largest and Richest Generation Ever and How It Changed America*. Chicago, IL: Simon & Shuster.
- Gilmore, L. (2001). Limit-Cases: Trauma, Self-Representation, and the Jurisdictions of Identity. *Biography*, 24(1), 128-139.
- Glaser, B.G., & Strauss, A.L. (1965). *Awareness of Dying*. Chicago: Aldine.
- _____. (1967). *The discovery of grounded theory: Strategies for qualitative research*. New York, Aldine de Gruyter.
- _____. (1968). *Time for Dying*. Aldine: Chicago.
- _____. (1971). *Status Passage*. London: Routedledge and Kegan Paul.
- Goffman, E. (1959). *The Presentation of Self in Everyday Life*. Anchor Books, New York, NY.
- Goodall, A., Drage, T., & Bell, G. (1994). *The bereavement and loss training manual*. Winslow, Telford Road, Bicester, Oxon OX6 OT5, UK.
- Gorer, G. (1955). *Modern Types*. Cresset Press. London.
- _____. (1965). *Death, Grief, and Mourning in Contemporary Britain*. London: Cresset Press.
- Groenewald, T. (2004). A phenomenological research design illustrated. *International Journal of Qualitative Methods*, 3, 1, Article 4.
- Guba, E., & Lincoln, Y. (1994). Competing paradigms in qualitative research. Denzin, N. & Lincoln, Y., Eds., *Handbook of Qualitative Research*, 105-117. Thousand Oaks, CA: Sage.
- Gubrium, J. (1988). The family as project. *Sociological Review*, 36(2), 273-96.
- Gubrium, J.F., and Holstein, J.A. (2000). *The Self We Live By: Narrative Identity in a Postmodern World*. New York, NY: Oxford University Press.
- Gubrium, J.F., and Holstein, J.A., (Eds) (2001). *Institutional Selves: Troubled Identities in a Postmodern World*. New York, NY: Oxford University Press.
- Guillemin, M. & Gillam, L. (2004). Ethics, reflexivity and “ethically important moments” in research. *Qualitative Inquiry*, 10(2), 261-280.
- Hall, D.T. & Richter, J. (1990). Career gridlock: baby boomers hit the wall. *Academy of Management Executive*, 4(3), 7-22.

- Hallam, E., Hockey, J. & Howarth, G. (1999). *Beyond the Body: Death and Social Identity*. London and New York: Routledge.
- Harrington, B. and Fine, G. (2000). Opening the 'Black Box': Small Groups and Twenty-First Century Sociology. *Social Psychology Quarterly*. 63(4),312-323.
- Harrison, L. & Harrington, R. (2001). Adolescents bereavement experiences prevalence, association with depressive symptoms and use of services. *Journal of Adolescence*, 24(2),159-169.
- Harvey, G. (2007). *Grieving For Dummies*. Hoboken, NJ: Wiley Publishing, Inc.
- Harvey, M.R. (1996). An ecological view of psychological trauma and trauma recovery. *Journal of Traumatic Stress*, 9(1), 3-23.
- Hochschild, A.R. (1983). *The managed heart: Commercialization of human feeling*. Berkeley, CA: University of California Press.
- _____. (1990) Ideology and Emotion Management: A Perspective and Path for Future Research, 117-142. *Research Agendas in the Sociology of Emotion*, Kemper, T.D. (Ed) Albany, NY: State University of New York Press.
- Hockey, J. (1990). *Experiences of Death. An Anthropological Account*. Edinburgh: Edinburgh University Press.
- _____. (1996). Encountering the "reality of death" through professional discourses: the matter of materiality. *Mortality*, 1(1), 45-60.
- Hockey, J. (2001). *Responding to Grief: Dying, Bereavement and Social Care*. Basingstoke, Hampshire: Palgrave.
- Hockey, J., Katz, J., & Small, N. (Eds) (2001). *Grief, Mourning and Death Ritual*. Buckingham: Open University Press.
- Hochschild, A. R. (1979). Emotion Work, Feeling Rules, and Social Structure. *American Journal of Sociology*. 85, 551-575.
- _____. (1983, 2003). *The Managed Heart: Commercialization of Human Feeling*. Los Angeles, CA: University of California Press.
- Hoffman, L. (1988) Like a Friendly Editor: an interview with Lynn Hoffman, *Family Therapy Networker*, Sept/Oct. 44-46, 76-81.
- Holmes, J.H., & Rahe, R.H. (1967). The social readjustment scale. *Journal of Psychosomatic Research*, 11, 213-228.

- Holstein, J.A., and Gubrium, J.F. (2000). *The Self We Live By: Narrative Identity in a Postmodern World*. New York, NY: Oxford University Press.
- Homans, G.C. (1958). Social Behavior as Exchange. *American Journal of Sociology*, 63(6) 597-606.
- Horowitz, M.J., Siegel, B., Holen, A., et.al. (1997). Criteria for complicated grief disorder. *American Journal of Psychiatry*, 154, 905-910.
- Howarth, G. (2006). *Death and Dying: A Sociological Introduction*. Cambridge, UK: Polity Press.
- Hughes, E.C. (1984). *The Sociological Eye*. Transaction Books. New Brunswick, New Jersey.
- Hustins, K. (2001). Gender differences related to sexuality in widowhood: Is it a problem for the male bereaved? D.A. Lund (Ed.) *Men coping with grief: Death, value, and meaning series*, 207-213. Amityville, NY: Baywood Publications Company.
- Hyrkas, K., Kaunonen, M. & Paunonen, M. (1997). Recovering from the death of a spouse. *Journal of Advanced Nursing*, 25, 775-779.
- International Work Group on Death, Dying and Bereavement. Retrieved from: <http://www.iwgddb.org/>.
- Ironside, V. (1996). *You'll Get Over It: The Rage of Bereavement*. London: Hamish Hamilton.
- Island Ireland Quotes. *In Time of Sorrow...* Retrieved from: <http://islandireland.com/Pages/folk/sets/bless.html>
- James, W. (1890). *Principles of Psychology*. New York: Holt Rinehart and Winston.
- Jamison, K.R. (2009). *Nothing Was the Same: A Memoir*. New York, NY: Knopf.
- Johnson, J. & Forman, P. (2009). *The Hourglass Solution: A Boomer's Guide to the Rest of Your Life*. Cambridge, MA: Da Capo Press.
- Johnson, T.P. (1991). Mental health, social relations, and social selection: A longitudinal analysis. *Journal of Health and Social Behavior*, 32, 408-423.
- Jordan, J.R. (2000). Research that matters: Bridging the gap between research and practice. *Death Studies*, 24,457-67.
- Jordan, J.R., & Neimeyer, R.A.(2003). Does grief counseling work? *Death Studies*, 27, 765-786.

- Kaunonen, M., Tarkka, M.T., Paunonen, M. & Laippala, P. (1999). Grief and social support after the death of a spouse. *Journal of Advanced Nursing*, 30, 11.
- Kauffman, J., 1994. Group thanatropics. V. Schermer & M. Pines (Eds), *Ring of fire*. 149-173. London: Routledge
- Kaunonen, M., Paivi, A. K., Paumpmem, M. & Erjanti, H. (2000). Death in the Finnish family: experiences of spousal bereavement. *International Journal of Nursing Practice*, 6,127.
- Kearl, M. (2002). Guide to the Sociology of Death: Death Across Time and Space. Retrieved from: <http://www.trinity.edu/~mkearl/death-1.html#cu>.
- Kellehear, A. (2007). *A Social History of Dying*. Cambridge, UK: Cambridge University Press.
- Kinch, J. (1963). *Social Psychology*. New York: McGraw-Hill.
- Kinderknecht, C., & Hodges, L. (1990). Facilitating productive bereavement of widows: An overview of the efficacy of widows. *Journal of Women and Aging*, 2(4),39-54.
- King, C.E. (1962). *The Sociology of Small Groups*. New York, NY: Pageant Press.
- Klass, D., Silverman, P.R. & Nickman, S.I. (Eds) (1996). *Continuing Bonds: New Understandings of Grief*. Bristol, PA and London: Taylor & Francis.
- Knorr Cetina, K. (2001). Postsocial Relations: Theorizing Sociality in a Postsocial Environment, 520-37. Ritzer, G., & Smart, B. (Eds) *Handbook of Social Theory*. London: Sage.
- Konigsberg, R.D. (2011). *The Truth about Grief: The Myth Of Its Five Stages And The New Science Of Loss*. New York, NY: Simon & Schuster. .
- Kübler-Ross, E. (1969) *On Death and Dying*. New York, NY: Simon & Schuster.
- _____.(1975). (Ed). *Death: The Final Stage of Growth*. Englewood Cliffs, NJ: Prentice Hall.
- Kurtz, L.F.(1997). *Self-Help and Support Groups: A Handbook for Practitioners*. Sage Sourcebooks for the Human Services, 34.
- Kvale, S. (1996). *Interviews. An introduction to qualitative research interviewing*, Chapter 6, Ethical Considerations, p.109-123. London: Sage publications.
- LaGrande, L.E. (2001). *Gifts from the Unknown*. New York: Authors Choice Press.
- Lawton, J. (2000). *The Dying Process: Patients' Experiences of Palliative Care*. London, UK: Routledge.
- Layder, D. (1998). *Sociological practice: Linking theory and research*. London: Sage.

- Lee, G.R., Willetts, M.C., & Secombe, K. (1998). Widowhood and depression: Gender differences. *Research on Aging*, 20, 611-630.
- Levy, L., & Derby, J. F. (1992). Bereavement Support Groups: Who Joins; Who Does Not; and Why. *American Journal of Community Psychology*, 20(5), 649-662.
- Liberman, M.A., & Yalom, I. (1992). Brief group psychotherapy for the spousally bereaved: a controlled study. *International Journal of Group Psychotherapy*, 42, 117.
- Lieberman, M. (1989). Group properties and outcomes: A study of group norms in self-help groups for widows and widowers. *International Journal of Group Psychotherapy*, 39(2), 191-208.
- Liberman, M., & Videka-Sherman, L. (1986). The impact of self-help groups on the mental health of widows and widowers. *American Journal of Orthopsychiatry*, 56(3), 435-449.
- Lindemann, E. (1944). Symptomatology and management of acute grief. *American Journal of Psychiatry*, 101, 41-8.
- Lindsey, A.M., & Yates, B.C. (2003). Social support: Conceptualization and Measurement Instruments, In Frank-Stromborg, M & Olsen, S.J., *Instruments for Clinical Health Care Research*, Sudbury, MA: Jones & Bartlett Publishers.
- Linschoten, J. (1953). Nawoord. *Persoon en wereld*. van den Berg, J.H., & Linschoen, J. (Eds). Utrecht: Erven J. Bijleveld.
- Littlewood, J. (1992) *Aspects of grief: Bereavement in adult life*. London: Routledge.
- Lofland, L.H. (1976). *Toward a sociology of death and dying*. Beverly Hills, CA: Sage Publications,
- Lofland, J., & Lofland, L.H. (1971). *Analyzing social settings*. Belmont, CA: Wadsworth Publishing Company.
- Lofland, J., Snow, D. Anderson, L., & Lofland, L.H. (4th Ed) (2006). *Analyzing social settings: A guide to qualitative observation and analysis*. Belmont, CA: Thomson Wadsworth.
- Longino, C.F. (2005). The future of ageism: Baby boomers at the doorstep. *Generations*, 29(3), 79-83.

- Lumley, M.A., Tojeck, T.M., and Macklem, D.J. (2002) The effects of written and verbal disclosure among repressive and alexithymic people. Lepore, S.J., & Myth, J.M. (Eds), *The writing cure: How expressive writing promotes health and emotional well-being*, 75-95. Washington, DC: American Psychological Association.
- Lupton, D. (Ed) (1998). *The Emotional Self: A Socio-cultural Exploration*. London: Sage.
- Lyotard, J-F. (1984). *The Postmodern Condition: A Report on Knowledge*. Minneapolis: University of Minnesota Press.
- Machin, L. (1995). Teaching package reviews : The bereavement and loss training manual. *Palliative Medicine* ,9, 176-177.
- Main, J. (2000). Improving management of bereavement in general practice based on a survey of recently bereaved subjects in a single general practice. *British Journal of General Practice*, 50, 863.
- Marris, P. (1958). *Widows and Their Families*. London: Routledge.
- _____, (1974). *Loss and Change*. London and New York: Routledge.
- Martikainen, P.& Valkonen, T. (1996). Telling relatives that a family member has died suddenly. *Postgraduate Medical Journal*, 72, 413.
- _____, (1998). Do education and income buffer the effects of death of spouse on Mortality? *Epidemiology*, 9, 530.
- Martin, M. (2005). Personal Communication. Pt. Huron, Michigan Hospital. Hilliker, 2006. Letting Go While Holding On: Postmortem Photography as an Aid in the Grieving Process. *Illness, Crisis and Loss*, 14(3), 245-269.
- Mauthner, N.S., & Doucet, A., 2003. Reflexive Accounts and Accounts of Reflexivity in Qualitative Data Analysis. *Sociology*, 37(3),413-431.
- McAdams, D.P. (1996). Personality, modernity, and the storied self: A contemporary framework for studying persons. *Psychological Inquiries*, 7(4), 295-321.
- McCall, G.J., & Simmons, J.L. (1978). *Identities and interactions*. New York, Free Press.
- McMillin, Z., & Perrusquia, M. (2010). Police killers identified as activists on mission to spread anti-government message. *The Commercial Appeal*. Retrieved from: <http://www.commercialappeal.com/news/2010/may/21/relatives-id-west-memphis-suspects/>
- McNamara, B. (2001). *Fragile Lives*. Buckingham, Philadelphia: Open University Press.

- May, C. (1992) Individual care? Power and subjectivity in therapeutic relationships, *Sociology*, 26, 589–602.
- Mead, G.H. (1934). *Mind, Self and Society*. Chicago University of Chicago Press.
- Mellor, M.J. & Rehr, H. (Eds.) (2005). *Baby Boomers: Can My Eighties Be Like My Fifties?* New York, NY: Springer Publishing Company.
- Mellor, P. & Shilling, C. (1993). Modernity, Self-Identity and the Sequestration of Death. *Sociology*, 27, 411-32.
- Meyrowitz, J., 1997. Shifting worlds of strangers: medium theory and changes in ‘them’ versus ‘us’. *Sociological Inquiry*. 67, 59-71.
- Milgram, S. (1974). *Obedience to Authority*, Harper and Row.
- Min DeParle, N., (1998). *Testimony on Preparing for the Retirement of the Baby Boom Generation*. Before the Senate Special Committee on Aging. Department of Health and Human Services. Retrieved from: <http://www.hhs.gov/asl/testify/t980218b.html>
- Morris, C. (1967). *The Philosophy of the Act*. Chicago, IL: University of Chicago Press
- Murphy, S. A., Johnson, L. C., Wu, L., Fan, J. J., & Lohan, J. (2003). Bereaved parents' outcomes 4 to 60 months after their children's deaths by accident, suicide, or homicide: A comparative study demonstrating differences. *Death Studies*, 27(1), 29–61.
- Myers, D.G. (2010). The Self in a Social World. Chapter 2 in Social Psychology. 10th edition. New York, NY: McGraw-Hill, Companies, Inc.
- Myerson, J. (2005). *Supplement to Ralph Waldo Emerson: A Descriptive Bibliography* New Castle, DE: University of Pittsburgh Press.
- Neimeyer, R. A. (1999). Constructivist psychotherapy. *Encyclopedia of psychology*. Washington: American Psychological Association.
- _____. (2000). *Lessons of loss: A guide to coping*. Center for the Study of Loss and Transition, Memphis, TN.
- _____. (2000). Grief therapy and research as essential tensions: Prescriptions for a progressive partnership. *Death Studies*, 24, 603-610.
- _____. (2001). (Ed) *Meaning reconstruction and the experience of loss*. Washington, DC: American Psychological Association.

- Neimeyer, R. A., Holland, J. M., Currier, J. M. & Mehta, T. (2008). Meaning reconstruction in later life: Toward a cognitive-constructivist approach to grief therapy. D. Gallagher-Thompson, A. Steffan & L. Thompson (Eds.), *Handbook of behavioral and cognitive therapies with older adults*, 264-277. New York: Springer Verlag.
- Nolen-Hoeksema, McBride, A., & Larson, J. (1997). Rumination and Psychological distress among bereaved partners. *Journal of personality and social psychology*, 72, 855-862.
- O'Connor, Wellisch, D.K., Stanton, A.L., Eisenberger, N.I., Irwin, M.R., & Lieberman, M.D. (2008). Addicted To Grief? Chronic Grief Activates Pleasure Areas Of The Brain. *NeuroImage*. 42, 969-972.
- Oates, M. (2003). Understanding the grief process. A first step to helping bereaved Clients. *Journal of Professional Counseling, Practice, Theory & Research*, 31(1), 29.
- Ogle, K.S., Mavis, B., & Thomason, C. (2005). Learning to Provide End of Life Care: Postgraduate Medical Training Programs in Michigan. *Journal of Palliative Medicine*, 8(5), 987-997.
- Parker, I. (2000) Looking for Lacan: virtual psychology. K. Malone and S. Friedlander (Eds) *The Subject of Lacan: A Lacanian Reader for Psychologists*, pp. 331-344. New York: SUNY Press.
- Parker, J.S. (2005). Extraordinary Experiences of the Bereaved and Adaptive Outcomes of Grief. *Journal of Death and Dying*, 51(4), 257-283.
- Parkes, C.M. (1972). *Bereavement: Studies of Grief in Adult Life*. London: Tavistock.
- _____. (1993). Bereavement as a psychosocial transition, in Stroebe, M., Stroebe, W., & Hansson, R.O., (Eds) *Handbook of Bereavement: Theory, Research and Intervention*, Cambridge: Cambridge University Press.
- _____. (1996). (3rd Ed) *Bereavement: Studies of Grief in Adult Life*. Routledge: London.
- _____. (1998). Traditional models and theories of grief. *Bereavement Care*, 17(2), 21-3.
- _____. (2000). Counselling bereaved people-help or harm? *Bereavement Care*, 19, 19-21.
- _____. (2003). Bereavement. *Mortality: Virtual Themed Issue*. Retrieved from: <http://www.tandf.co.uk/journals/archive/bereave.pdf>.
- Parsons, T. (Ed). (1951). *Toward a general theory of action*. Cambridge, MA: Harvard University Press.
- _____. (1963). Death in American society: A brief working paper. *American Behavioral Science* (Special Issue), 6, 61-65.

- Parsons, T. & Lidz, V. (1967). Death in American society, in Edwin S. Shneidman (Ed), *Essays in Self-Destruction*. New York: Science House.
- Patton, M.Q. (2002). *Qualitative Research & Evaluation Methods*. Thousand Oaks, CA: Sage Publications.
- Pausch, R. (2008). *The Last Lecture*. New York, NY: Hyperion.
- Payne, S., Jarrett, N., Wiles, R. & Field, D. (2002). Counselling strategies for bereaved people offered in primary care. *Counselling Psychology Quarterly*, 15, 161.
- Pearlman, L.A. & Saakvitne, K.W. (1995). *Trauma and the therapist: Countertransference and vicarious traumatization in psychotherapy with incest survivors*. New York: W. Norton and Company.
- Peterson, K.S. (2008). Health and Behavior. *USA Today Online*. Retrieved from: http://www.usatoday.com/news/health/2002-08-04-lifecoach_x.htm
- Pickering, W.S.F. (2001). *Emile Durkheim: Critical Assessments of Leading Sociologists*. Florence, Kentucky: Taylor & Francis.
- Pine, V.R. (1990, May 20). Solace After Bereavement: Counseling Services Grow. Hall, T., *The New York Times Edition*.
- Pine, V.R., & Phillips, D.L. (1970). The Cost of Dying: A Sociological Analysis of Funeral Expenditures. *Social Problems*, 17(3), 405-417.
- Plante, D. (2009). *The Pure Lover: A Memoir of Grief*. Boston, MA: Beacon Press.
- Potocky, M.. (1993). Effective Services for Bereaved Spouses: A Content Analysis of the Empirical Literature. *Health & Social Work*, 18(4), 288-301.
- Powers, L. E. & Wampold, B. E. (1994). Cognitive-behavioral factors in adjustment to adult bereavement. *Death studies*, 18, 1.
- Prigerson, H.G., Shear, M.K., Jacobs, S.C., Reynolds, C.F., Maciejewski, P.K., Davidson, J.R., Rosenheck, P.A., Pilkonis, R., Wortman, C.B., Williams, J.B., Widiger, T.A., Frank, E., Kupfer, D.J., & Zisook, S. (1999). The Consensus criteria for traumatic grief. A preliminary empirical test. *British Journal of Psychiatry*, 174, 67-73.
- Prigerson H. G., Horowitz, M.J., Jacobs, S.C., Parkes, C.M., Aslan, M., et al. (2009). Prolonged Grief Disorder: Psychometric Validation of Criteria Proposed for *DSM-V* and *ICD-11*. *Public Library of Science Medicine* 6,8.

- Rando, T. A. (1984). *Grief, dying, and death: Clinical interventions for caregivers*. Illinois: Research Press.
- _____. (1994). Complications in mourning traumatic death. Corless, I.B., Germino, B.B., & Pittman, M. (Eds.). *Dying death and bereavement: Theoretical perspectives and other ways of knowing*, 253-271. Boston, MA: Jones and Bartlett.
- Reeler, T. (1993). Psychotherapy and story-telling: A Popperian conjecture. *Changes*, 11(3), 205-14.
- Rich, D. E.. (2000). The impact of post-pregnancy loss services on grief outcome: Integrating research and practice in the design of peri-natal bereavement programs. *Illness, Crisis, & Loss*, 8, 244-264.
- Riches, G. & Dawson, P. (1996a). Communities of feeling: the culture of bereaved parents. *Mortality*, 1, 143-161.
- _____. (1996b). Making stories and taking stories. *British Journal of Guidance and Counselling*. 24(3), 357-365
- _____. (2000). *An Intimate Loneliness: Supportive bereaved parents and siblings*. Buckingham, UK: Open University Press.
- Riesman, D. (1950). *The Lonely Crowd: A Study of the Changing American Character*. New Haven Connecticut: Yale University Press.
- Riley, J.W. (1983). Dying and the Meanings of Death: Sociological Inquiries. *Annual Review of Sociology*, 191-216.
- Roberts, A., & McGilloway, S. (2008). The nature and use of bereavement support services in a hospice setting. *Palliative Medicine*, 22(5), 612-625.
- Rosenberg, M. (1991). Self processes and emotional experiences. (Eds) Howard, J.A., & Callero, P. *The Self-Society Interface: Cognition, Emotion and Action*, 123-42. New York: Cambridge University Press.
- Rosenwald, G.C. & Ochberg, R.L. (1992). *Storied Lives*. New Haven, CT: Yale University Press.
- Rowling, L. (1999). Being in, being out, being with: affect and the role of the qualitative researcher in loss and grief. *Mortality*, 4(2), 167-181.
- Rubin, S.S. (1999). The Two-Track Model of Bereavement: Overview, Retrospect, and Prospect. *Death Studies*, 23(8), 81-714.

- Sabatini, L. (1988). Evaluating a treatment program for newly widowed people. *Omega: Journal of Death and Dying*, 19(3), 229-236.
- Saldana, J. (2009). *The Coding Manual for Qualitative Researchers*. Thousand Oaks, CA: Sage Publications,
- Sartre, J. P. (1956). *Being and nothingness*. New York: Philosophical Library.
- Seale, C. (1989). What happens in hospices: a review of research evidence. *Social Science and Medicine*, 26(6), 551-9.
- _____.(1998). *Constructing Death: The Sociology of Dying and Bereavement*. Cambridge, MA: Cambridge University Press.
- _____.(1999). Awareness of Method: Re-Reading Glaser and Strauss. *Mortality*. 4,195-202.
- Scheper-Hughes, N. (1993). *Death without Weeping: The Violence of Everyday Life in Brazil*. Berkeley, CA: University of California Press.
- Schopler, J. H. & Galinsky, M.J. (1995). Expanding our view of support groups as open systems. *Social Work with Groups*, 18(1),3-10.
- Seymour, J. (1999). Revisiting medicalization and natural death. *Social Science and Medicine*, 44, 691-704.
- Shapiro, E. (1994). *Grief as a Family Process: A Developmental Approach to Clinical Practice*. New York: Guilford Press.
- _____.(1996). Family bereavement and cultural diversity: a social developmental Model. *Family Process*, 35(4), 313-32.
- Sherkat, D.E., and Reed, M.D. (1992). The effects of religion and social support on self-esteem and depression among the suddenly bereaved. *Social Indicators Research*, 26, 259-275.
- Shilling, C. (2011). Afterword: Body Work and the Sociological Tradition. *Sociology of Health & Illness*, 33(2), 336-340.
- Shoshana, A., & Teman, E. (2006). Coming Out of the Coffin: Life-Self and Death-Self in Six Feet Under. *Symbolic Interaction*, 29(4),557-576.
- Silverman, P. (2011). ADEC Response to ‘The Truth About Grief.’ Retrieved from: <http://www.adec.org/source/blog/post.cfm/adec-response-to-the-truth-about-grief>
- Silverman, P., & Klass, D., (1996). Introduction: what’s the problem? Klass, D., Silverman, P., & Nickman, S., L., (Eds) *Continuing Bonds: New Understandings of Grief*. Bristol, PA and London: Taylor & Francis.

- Silvey, S. (1990). Bereavement care in hospitals. *Bereavement Care*, 9, 17.
- Simmel, G. (1950). *The Sociology of Georg Simmel*. Kurt H. Wolff (Ed). New York: Free Press.
- Small, N. (1998). Death of the authors. *Mortality* 3(3), 215-228.
- Small, N. (2001). Hockey, J., Katz, J., & Small, N. (Eds) (2001). *Grief, Mourning and Death Ritual*. Buckingham: Open University Press.
- Smith, D.E. (1987). *The everyday world as problematic: A feminist sociology*. Boston: Northwestern University Press.
- Smith, E.R., Coats, S., & Murphy, J. (2001). The Self and Attachment to Relationship Partners and Groups: Theoretical Parallels and New Insights. Sedikides, C., & Brewer, M.B., (Eds). *Individual Self, Relational Self, Collective Self*. Philadelphia, PA.: Psychology Press.
- Steier, F.(1991). *Research and Reflexivity*. Sage Publications, London.
- Steinberg, M. & Miles, C. (1979). Transformation of a Group for the Widowed. Chapter 6, pp.67-79. Liebermann, M.A., & Borman, L.D., and Associates, *Self-Help Groups For Coping With Crisis*. San Francisco, CA: Jossey-Bass Publishing.
- Stannard, D. (1977). *The Puritan Way of Death: A Study in Religion, Culture, and Social Change*. New York, NY: Oxford University Press.
- Stephenson, J.S. (1985). *Death, Grief, and Mourning*. New York: Free Press.
- Stets, J.E., and Burke, P.J. (2003). A sociological approach to self and identity. *Handbook of Self and Identity*, (Eds.) M. Leary, J. Tangney, 128-52. New York: Guilford Press.
- Strauss, A.L.(1987). *Qualitative analysis for social scientists*. Cambridge Cambridgeshire: Cambridge University Press.
- Strauss, A., & Corbin, J. (1998). *Basics of qualitative research: Techniques and procedures for developing grounded theory*. Thousand Oaks, CA: Sage Publications.
- Stroebe, M., & Stroebe, W. (1987). *Bereavement and Health*. Cambridge, MA: Cambridge University Press.
- Stroebe, M.L. (1992). Coping with bereavement: a review of the grief work hypothesis. *Omega*, 26(1),19-42.
- _____.(1997). From mourning and melancholia to bereavement and biography: an assessment of Walter's New Model of grief. *Mortality*, 2, 255-262.

- Stroebe, M.S., & Schut, H. (1999). The dual process model of coping with bereavement: rationale and description. *Death Studies*, 23, 197-224.
- Stroebe, M. S., Hansson, R.O., Stroebe, W., & Schut, H. (2001). Introduction: Concepts and Issues in Contemporary Research on Bereavement, 3- 22 in *The Handbook of Bereavement Research: Consequences, Coping, and Care*. (Eds) Stroebe, M.S., Hansson, R.O., Stroebe, W., & Schut, H. Washington, DC: American Psychological Association.
- Stroebe, W., Schut, H., & Stroebe, M.S. (2005). Grief work, disclosure and counseling: Do they help the bereaved? *Clinical Psychology Review*, 25(4), 395-414.
- Stroebe, M., Gergen, M., Gergen, G., and Stroebe, W.(1992) Broken hearts or broken bonds? *American Psychologist*, 47(10),1205-12.
- Stryker, S., 1980. *Symbolic Interactionism: A Social Structural Version*. Menlo Park, CA: Benjamin/Cummings.
- Stryker, S., & Burke, P.J. (2000). The past, present and future of an identity theory. *Social Psychology Quarterly*, 63, 284-97.
- Sudnow, D. (1967). *Passing On: The Social Organization of Dying*. Prentice Hall, Upper Saddle River, New Jersey.
- Swidler, A. (1986). Culture in Action: Symbols and Strategies. *American Sociological Review*. 51,273-86.
- Thoits, P.A., (1990). Emotional deviance: research agendas. Kemper, T.D. (Ed.) (1990). *Research Agendas in the Sociology of Emotions*, 180-203. Albany, NY: State Univ. NY Press.
- _____.(1991). Gender differences in coping with emotional distress. In *The Social Context of Coping*, J. Eckenrode, (Ed),107-38. New York: Plenum Press.
- Thuen, F. (1995) Satisfaction with bereavement support groups. Evaluation of the Norwegian Bereavement Care Project. *Journal of Mental Health*, 4, 499.
- _____.(1997a). Received social support from informal networks and professionals in bereavement. *Psychology, Health and Medicine*, 2(1),51-59.
- _____.(1997b). Social support after the loss of an infant child: A long-term perspective. *Scandinavian Journal of Psychology*, 38, 103-110.
- Thuen, F. & Sandvik, O. (1998). The Norwegian Bereavement Care Project: an evaluation of the first twelve years. *Bereavement Care*, 17, 24.

- Thomas, W.I. (1923). Definition of a Situation. In, *The Unadjusted Girl*. Boston, MA: Little, Brown and Company.
- Torres, A. (2008). *American Widow*. New York, NY: Villard.
- Toscani, F., DiGiulio, P., Brunelli, C., Miccinesi, G., & LaQuintana, D. (2005). How people die in hospital general wards: A descriptive study. *Journal of Pain and Symptom Management*, 30, 33-40.
- Turner, V. (1977). *The Ritual Process*. Ithaca, NY: Cornell University Press.
- Turner, J.H., & Stets, J.E. (2006). Sociological Theories of Human Emotion. *Annual Review of Sociology*, 32, 25-52.
- Utz, R. (2006). Economic and Practical Adjustments to Late Life Spousal Loss. Carr, D., Nesse, R.M., & Wortman, C.B.(Eds) (2006). *Spousal Bereavement in Late Life*. New York, NY: Springer Publishing Company.
- Valentine, C. (2008). Bereavement Narratives: Continuing bonds in the twenty-first century. New York, NY: Routledge.
- van Gennep, A.(1960). The Rites of Passage. Chicago, IL: University of Chicago Press.
- van Manen, M. (1990). Researching lived experience: Human science for an action sensitive pedagogy. Albany, NY, SUNY Press.
- _____. (2002). (Ed) *Writing in the Dark. Phenomenological Studies in Interpretive Inquiry*. London, Ontario: Althouse Press
- Videka-Sherman, L. (1982). Effects of participation in a self-help group for bereaved parents: Compassionate Friends. *Prevention in Human Services*, 1(3), 69-78.
- Kurtz, L.F. 1997. *Self-Help and Support Groups: A Handbook for Practitioners*. Thousand Oaks, CA: Sage Publications, Inc.
- Vovelle, M. (1983). *La Mort et l'Occident, de 1300 a` nos jours*. Paris, France: Gallimard.
- Walter, C. (1997). Support Groups for Widows and Widowers. Greif, G.L.& Ephross, P.H. (Eds). *Group Work with Populations at Risk*. New York, NY: Oxford University Press.
- Walter, T. (1994). *The Revival of Death*. London, UK: Routledge Press.
- _____.(1996). A new model of grief. *Mortality*, 1, 7-25.
- _____.(1999). *On Bereavement: The Culture of Grief*. Berkshire, England: Open University Press.

- _____. (2001). From Cathedral to Supermarket: mourning, silence and solidarity. *Sociological Review*, 49(4), 494-511.
- _____. (2007). Modern grief, postmodern grief. *International Review of Sociology*, 17(1), 123-134.
- _____. (2008). The Sociology of Death. *Sociology Compass*, 2/1, 317-336.
- Wambach, H., J.A., (1985/86). The Grief process as a Social Construct, *Omega*, 16(3), 201-11.
- Washington Post. (2010). New programs reach out to seniors touched by loss. *Daily Herald: Big Picture. Local Focus*. Retrieved from: <http://www.dailyherald.com/story/print/?id=4004440>
- Weber, M. (1930). *The Protestant Ethic and the Spirit of Capitalism*. New York, NY: Scribner.
- Weigert, A. J., Teitge, J. S. & Teitge, D. W. (1986). *Society and identity: Toward a sociological psychology*. Cambridge, MA: Cambridge University
- Whiting, J., & James, E. (2006). Bearing Witness to the Story: Narrative Reconstruction in Grief Counseling. American Counseling Association. *VISTAS Online*. Retrieved from: <http://counselingoutfitters.com/James.htm>
- Wiles, R., Jarrett, N., Payne, S. & Field, D. (2002). Referrals for bereavement counseling in primary care: a qualitative study. *Patient Education Counseling*, 48, 79.
- Wilkinson, I., 2005. *Suffering: A Sociological Introduction*. Polity Press, Malden, MA.
- Wilkinson, S., Croy, P., King, M. Barnes, J. (2007). Are we getting it right? Parents' perceptions of hospice child bereavement support services. *Palliative Medicine*. 21(5), 401-407.
- Williams, R., Jr. (1990). *A Protestant Legacy: Attitudes to Death and Illness among Older Aberdonians*. Oxford, UK: Oxford University Press.
- Wimpenny, P. (2006). *Literature Review on Bereavement and Bereavement Care*. The Joanna Briggs Collaborating Centre, Faculty of Health and Social Care, Garthdee, Aberdeen, UK The Robert Gordon University.
- Wittgenstein, L. (1953). *Philosophical Investigations*, Trans. G. E. M. Anscombe. New York: Macmillan.
- Wolff, K., and Wortman, C.B. (2006). Psychological Consequences of Spousal Loss Among Older Adults: Understanding the Diversity of Responses. Chapter 4 in Carr, D., Nesse, R.M., and Wortman, C.B.(Eds) (2006) *Spousal Bereavement in Late Life*. Springer Publishing Company, New York, NY.

- Worden, J. W. (1982). *Grief Counselling and Grief Therapy: A Handbook for the Mental Health Practitioner*. New York: Springer.
- _____. (1991). (2nd Ed) *Grief Counselling and grief therapy: A handbook for the mental health practitioner*. London: Springer.
- _____. (2002). (3rd Ed) *Grief Counseling and grief therapy*. New York, NY: Springer Publishing Company.
- Wortman, C.B., & Silver, R.C. (1989). The myths of coping with loss. *Journal of Consulting and Clinical Psychology*, 57(3), 349-57.
- Yalom, I., & Vinogradov, S. (1988). Bereavement groups: Techniques and themes. *International Journal of Group Psychotherapy*, 38(4), 419-446.
- Znanieck, F. (1965). *Social Relations and Social Roles*. San Francisco, CA: Chandler Press.
- Zisook, S. & Schuchter, S. R. (1991). Early psychological reaction to the stress of widowhood. *Psychiatry*, 54, 320.
- Zonnebelt-Smeenge, S.J. & DeVries, R.C. (2003). The Effects of Gender and Age on Grief Work Associated with Grief Support Groups. *Illness, Crisis and Loss*, 11(3), 226 – 241.