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How Life Marker Events Affect The Grieving Process of Elderly Caregivers Who Have

Lost Their Spouses:

An Exploratory Study

Augsburg College Lindell Library Minneapolis, MN 55454

Gayle E. Galarneau

Submitted in partial fulfillment of the requirements for the degree of Master of Social Work

AUGSBERG COLLEGE MINNEAPOLIS, MINNESOTA

2001

MASTER OF SOCIAL WORK AUGSBURG COLLEGE MINNEAPOLIS, MINNESOTA

CERTIFICATE OF APPROVAL

This is to certify that the Master's Thesis of:

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Acknowledgements

Thank you to all the people who helped me during the writing of this thesis:

Michael Schock, my thesis advisor

Lois Bosch and Adele Mehta, my thesis readers

Thank you to my parents who always encouraged me to pursue my goals.

Finally, thank you to my friends, especially Rosalie and Bob Gies for your support.

Abstract

An Exploratory Study of How Life Marker Events Affect The Grieving Process of Elderly Caregivers Who Have Lost Their Spouses.

Gayle E. Galarneau

June, 2001

This exploratory, descriptive, qualitative study examines how life marker events, holidays, birthdays, anniversaries, affect the grieving process of elderly caregivers who have lost their spouses. The study looked at what feelings the participants remembered having on life marker event days during the self-defined periods of their bereavement. The purposive sample was chosen from clients of Senior Community Services. Four women between the ages of 75 and 85 who had lost their spouses not less than eighteen months and not over two years prior to the study being conducted participated in structured interviews. The interviews consisted of open-ended questions that helped the participants to define chronological time periods in their bereavement and then encouraged the participants to remember their most significant feelings on days of life marker events during the second and third self-defined time periods of their bereavement. I found in my research that the participants did not experience or did not remember experiencing several of the emotions usually associated with grief theories. Feelings of shock, denial, anger and guilt were denied by the participants. Another common theme in the findings is that each of the participants reported feelings of relief that their husbands were no longer suffering. Each participant was careful to point out that the relief felt was not for themselves, but for their husbands. One unique finding that I did not see in the literature is that the participants felt more sad on life event marker days that had celebrated by the couple alone. Holidays and birthdays that had been celebrated

with other family members and friends were reported to be less difficult for the widows than wedding anniversaries and other private celebrations. Based on these findings, further research is necessary on the grieving process of elderly caregivers who have lost their spouses.

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Chapter One: Introduction

An Exploratory Study of How Life Marker Events Affect The Grieving Process of Elderly Caregivers Who Have Lost Their Spouses

Overview

Spousal bereavement is considered the most profoundly disturbing and disruptive event in a person's life. Its effects are experienced on every level and in every daily activity (Shuchter, 1986). Throughout history, literature suggests that the death of a spouse has profound effects on the surviving partner. However, it has only been in the twentieth century that systematic efforts have been made to understand the process of grieving the loss of a spouse or life partner (Shuchter, 1986).

There are numerous, current models that describe stages or phases of grief. The stages of grieving, like the stages of dying are no longer thought to follow a linear prescription. A grieving person may appear to accept the death, then suddenly be overwhelmed with contrary emotions.

In addition to losing their spouse to death, caregivers see their loved ones deteriorate physically, mentally or both physically and mentally over a period of time, yet the bond between the couple often becomes stronger during the time of illness (Caine, 1988). Life marker events such as anniversaries, holidays and birthdays can trigger intense feelings of grief for all who have lost a loved one. Social workers who work with the elderly and with elderly caregivers need to have a good understanding of what factors may affect the grieving process of their clients.

Research Purpose and Significance

The purpose of this study is to explore the impact of life markers on elderly women who have lost their spouses. The potential significance of the study is the increased knowledge of the grieving process of elderly women.

Overview of Chapters

In chapter one, I lay out the purpose of this research study. The potential significance of this study is to gain a better understanding of the grieving process experienced by elderly caregivers who have lost their spouses. Chapter two will review the literature on theoretical frameworks of grief and present information that other research studies have shown. Chapter three will discuss the methodology and the research design. The findings of the research are in chapter four. Chapter five will discuss the study's findings, conclusions and implications for social work practice.

Chapter Two

Literature Review

Overview

This literature review focuses on the major conceptual grief theorists, theoretical frameworks of grief and the grief process for elderly caregivers whose spouses have died. There are many conceptual theories that can be applied to the grieving process for these elderly former caregivers. This literature review discusses several of the early theorists as well as several more recent theories. The literature review also discusses studies conducted on grieving caregivers to better understand the grieving process and what factors affect the intensity and duration of the grieving process.

Definition of Terms

The terms grief, bereavement and mourning are often used interchangeably, but in order to better understand the losses caused by the death of a loved one, it is important to know the precise definitions of each term. Grief is the psychological and physical reactions that are experienced due to the loss. These include the emotional reactions such as denial, anger and guilt as well as the physical reactions such as sleeplessness and loss of appetite. Bereavement is defined as the state of having suffered a loss. The term bereavement encompasses the emotions, experiences and changes an individual experiences as a result of the loss. Mourning refers to the customs or mourning rituals performed after the death. These rituals differ from culture to culture. (Sanders, 1986).

The terms "complicated bereavement" and "life marker events" also need to be defined for the scope of this literature review. Complicated bereavement occurs when the individual either experiences multiple losses at the time of the loss of the loved one or the

individual has been diagnosed with mental health complications. Life marker events are anniversaries, holidays, birthdays or events that were shared by the couple prior to the death of the husband.

In addition, the term "anticipatory grief" needs to be defined. Erich Lindemann was the first to use this phrase in 1944 (Walker, Pomeroy, McNeil & Franklin, 1994).

According to Lindmann, anticipatory grief is the progression through the phases of grief prior to the death of a loved one.

Conceptual Theorists

This literature review focuses on several major conceptual grief theorists. The early theorists, Freud and Bowlby provide the groundwork for grief theories. Worden, Parkes and Lindemann provide the more recent concepts of the grief process.

In 1917, Sigmund Freud proposed the first intrapsychic theory of grief in his treatise "Mourning and Melancholia" (Sanders, 1989). Freud explained that the amount of energy invested in a loved one must be retrieved before the individual can reinvest and love again. Freud referred to the process of retrieving the energy invested in the loved one as the work of mourning. Although, in his initial theory, Freud wrote of a final detachment from the loved one and a total resolution, in his later years he recognized that some losses are never totally resolved. Sigmund Freud's daughter, Anna Freud, who was forty-four in 1939 when her father died, spent a number of years working through the loss of her father. She struggled with the theory of detaching from her father and her own sense of needing some connection to her father (Gaines, 1997).

John Bowlby used his attachment theory and human information processing to explain loss and bereavement. He examined grief as a characteristic not only in humans,

but also in animals. Bowlby identified four phases in bereavement. He described the initial numbing phase as a defensive mechanism outside the conscious awareness that blocks processing of difficult information. His second phase is the process of yearning and searching for the lost person. Bowlby viewed searching and crying as an adaptive mechanism used to retrieve the lost attachment figure. The last two phases, disorganization and despair, and reorganization are tasks to reconcile the belief and disbelief of the loss. The individual must learn new skills to redefine himself or herself.

J. William Worden (1991) expands on Bowlby's attachment theory by defining four tasks of mourning. His tasks are, to accept the reality of the loss, to work through the pain of grief, to adjust to an environment in which the deceased is missing and to relocate the deceased and move on with life. Worden describes mourning as a process not a state. According to Worden, the tasks do not necessarily follow a specific order, however, there is some ordering by definition.

Another major contributor to understanding grief is Erich Lindemann. He interviewed the surviving family members in the Boston Coconut Grove restaurant fire in 1944. He proposed five characteristics for grief that are still used today; somatic distress, preoccupation with the image of the deceased, guilt, hostile reactions and a loss of the usual patterns of conduct (Sanders, 1989). However, although Lindemann accurately described five characteristics of grief, he believed that recovery from grief happened within a few weeks after the grief work was accomplished. More recent literature shows that even a year after a loss, grief is prominent (Glick, Weiss & Parkes, 1974).

In 1972, Colin Murray Parkes described grief as similar to a physical injury.

Parkes studied 22 London widows (1972) and found that grief is a major stressor that has

implications on the health of the individual. Parkes identified four stages of grief: numbness, searching and pining, depression and recovery, but pointed out that the stages vary from individual to individual and overlap and replace one another (Sanders, 1986).

Studies Regarding Elderly Caregiver Grief

In the context of this study, caregiving in our culture includes providing emotional and physical support to the ill person. Research shows that the elderly receive most of their support from informal support networks (LaGory, Sherman & Ward, 1989). While the role of informal caregivers is filled by children, siblings, friends and other relatives, the majority of the burden of caregiving falls to the spouse (Keefe & Snyder, 1985). Most of the literature on elderly caregiver grief has been conducted on widows and widowers of Alzheimer's patients. Anticipatory grief has been studied over the past fifty years, yet studies have been inconclusive on whether anticipatory grief is helpful to successful grieving or whether it causes complications to the grieving process (Rando, 1986). Few studies focus on whether life marker events result in a regression in the grieving process for elderly caregivers.

A study by Hyrkas, Kaunonen and Paunonen (1996) examined the experiences of widows and widowers in Finland between the ages of twenty five and sixty five years of age eight months after the death of their spouses. The purpose of the study was to compare two sub-groups of grieving women and men who had lost their spouses. The study described the intensity of grief experienced after eight months to two years and over two years after the death of the spouse. The subjects were divided into two groups according to the length of time that had passed since the death of the spouse. The findings of the researchers showed that the intensity of grief diminished over time.

Gender was found to have no effect on the intensity of grief. The study concluded that every individual experiences the grieving process differently. Hyrkas, Kaunonen and Paunonen found that the grieving process is diverse and multidimensional and that it cannot be viewed from a static, linear or single perspective. In addition, the findings showed that grief can be seen as a limitless phenomenon in regard to time with certain events, i.e. anniversaries, holidays and other events. These special events reminded the widow or widower of the loss and renewed aspects of grief recurrently for several years (Hyrkas, Kaunonen & Paunonen, 1996).

A qualitative longitudinal study of spousal bereavement among older adults was conducted by Anderson and Dimond (1995). The purpose of the study was to describe the experiences of older bereaved people within the first two years after the death of their spouses. The spouses ranged from fifty years of age to ninety three years of age. The categories of questions asked through interviews and questionnaires included feelings, physical symptoms, special hardships and ways to cope. Participants reported shock and disbelief as the first response to the death regardless of the length of the spouse's illness. Few subjects expressed anger toward their spouse, God, fate or toward the health care professionals. After the first year, they still expressed sadness and loneliness, though the pain was less. In the first three weeks of bereavement, nine of the twelve subjects reported nausea, loss of appetite, sleep disturbances dizziness, heart palpitations, headache and fatigue. One year after the death these symptoms had resolved. Loneliness was described as the greatest hardship even two years after their spouses' death. When asked to identify what had been most difficult for them since the death of their spouse, the widows identified a number of challenges. Anderson and Dimond categorized the

challenges into six categories; a) loneliness, b) daily reminders, c) anniversaries, d)learning new skills, e) learning to socialize as a single person and f) events or conflicts experienced concurrently with their loss.

In the anniversaries category, Anderson and Dimond found that over a two year period, the surviving spouses found holidays, anniversaries and birthdays particularly difficult. The widowed spouses reported that the first anniversary after the death was most painful. In addition, if the spouse died around a holiday, that time of the year remained especially sad for the widowed spouse even two years after the death.

Jones and Martinson (1992) studied the experience of bereavement in caregivers of Alzheimer's patients. In their research, Jones and Martinson found that due to the daily challenge of providing care to a child-like adult, the caregivers were both physically and emotionally exhausted. After the family member died, relief was obvious and natural. Clear relief was experienced most often in caregivers who felt comfortable with decisions made and care given during the illness of the family member. However, some caregivers experienced different types of relief that were mixed with other feelings such as ambivalence, sorrow or guilt. Jones and Martinson (1992) identified three patterns of relief: sorrowful relief, guilty relief and grateful relief. Caregivers of family members who still had some communication skills and who still showed affection to the caregivers, experienced more sorrowful relief. The grieving process was less complete prior to the death than for other caregivers. Some caregivers experienced feelings of guilt. In some cases the caregiver felt guilty for feeling relieved by the death. In other cases, the caregiver felt guilty about decisions made during the caregiving period. For example, caregivers often felt guilty for placing their loved one in a nursing home. Some

caregivers felt guilty for expressing anger or frustration to the family member (Jones & Martinson, 1992). Grateful relief was felt by caregivers who had lost all communication with the Alzheimer's patient. Most of these caregivers had already grieved a lot. Their grief following the death of their relative resolved quickly.

A study conducted by Collins, King, Liken, and Kokinakis (1993) researched six themes in the experience of death of a relative with dementia. The themes are, loss of person and relationship, loss of hope, grief before death, expectancy of death, post-death relief and care giving reflections. The study was a five year qualitative longitudinal study that focused on social, emotional and financial changes that the caregivers experienced since the death of their relative. Over half of the participants identified changes in the relative's personality that led to a loss of person they had known. Loss of hope for recovery was reported by only 46% of the participants. This left the caregiver with a sense of helplessness. Grief before death was experienced by 47% of the participants. Most described the experience as wrenching and overwhelming. Expectancy of death was experienced by 28%. Even though there was no cure, the caregiver did not expect the death at the time it occurred. Post-death relief was cited by 51% of the sample. Feelings of relief were accompanied by feelings of loneliness and grief. Caregivers often stated that they missed the person as he or she was before the Alzheimer's disease.

Jacob (1996) explored the grief experience of older women whose husbands had hospice care. The study asked women over a sixteen month period following the death of their husbands to describe their grief experience. In his study, Jacob (1996) identified the concept of facing new realities which he defined as becoming aware of the loss, confronting the loss and adjusting to the loss. Although the women began to face reality

when they became aware of the terminal diagnosis, it was not until the reality of the actual death that grieving could begin. Loneliness and dissatisfaction with socialization were the major stressors. The widows expressed feelings of guilt, wondering if they had done enough during the caregiving period and also anger toward their husbands for not seeking medical care sooner. Keeping busy was an important coping strategy, however, remembering also was a strategy frequently used. The remembering included both positive and negative aspects of the spouse, however, over the sixteen month period of time, the remembering became more focused on the positive aspects of the spouse.

Summary

The literature shows that while a number of studies have been conducted on the grief process of elderly caregivers who have lost their spouses, few have focused on whether life marker events affect their grieving process. However, several common themes are evident in the research.

Two of the studies, Hyrkas, Kaunonen and Paunonen (1996) and Anderson and Dimond (1995), addressed the effect of life marker events on the grieving process on elderly caregivers who had lost their spouses. Both studies found that holidays, birthdays and anniversaries were painful reminders of the loss. However, only Hyrkas, Kaunonen and Paunonen (1996) stated that the life marker events renewed aspects of grief recurrently for several years.

Loneliness was a common theme in the studies. Anderson and Dimond (1995) found that at the first year anniversary of the spouse's death, the widows still expressed sadness and loneliness. The study by Collins, King, Liken and Kokinakis (1993) found that the widows experienced feelings of relief, but the feelings of relief were

accompanied by feelings of loneliness. Jacobs (1996) found that loneliness and dissatisfaction with socialization continued to be the major stressor at the end of the sixteen month study. Jacobs also found that widows frequently used remembering as a coping mechanism during their grieving. His study showed that shortly after the death of the spouse, the widows remembered both positive and negative aspects of their spouses. However, over time the widows remembered fewer negative aspects and more positive aspects of their spouses.

Guilt was another common theme for the elderly caregivers. The research conducted by Jones and Martinson (1992) shows that caregivers often experience feelings of guilt after the death of the spouse. The caregiver may feel guilty about decisions made during the caregiving period or may feel guilty for feeling relieved when the spouse dies.

Jacob (1996) found that widows expressed feelings of guilt, wondering if they had done enough during the caregiving period.

Several studies showed that the pain of loss lessened over time. Hyrkas,
Kaunonen and Paunonen (1996) found that the intensity of grief diminished over time.
The study by Anderson and Dimond (1995) showed that though the participants still expressed sadness and loneliness, after the first year, the pain was less.

Theoretical Framework

I focus on several theoretical frameworks that can be applied to the grieving process for the elderly caregivers who have lost their spouses. The frameworks outline stages or phases of grief that can be used to identify the process of grieving. The frameworks have commonalties, but the underlying concepts of the process are different.

One of the most well known authorities on death and dying is Elisabeth Kubler-Ross, MD. Her model (1969) is based on the stages of dying, but is also translated into the grieving process for people suffering any type of loss. Her stages are, denial and isolation, anger, bargaining, depression and acceptance. Denial and isolation is characterized by shock, numbness and disbelief. Anger, the second stage of the model, often includes anger directed at the deceased for deserting his or her loved ones, or anger at God for the unfairness of the individual's loss. The third stage, bargaining, often occurs when a terminally ill individual attempts to strike a bargain with God to regain health or physical function. In the fourth stage, depression, the individual understands the loss and feels loneliness and despair. In the final stage, acceptance, the individual acknowledges the loss and begins to work on alternatives to cope with the loss.

The Westberg model of grieving identifies ten reactions to loss. The first stage, shock and denial (Zastrow & Kirst-Ashmann, 1993), is similar to the Kubler-Ross model. Numbness and disbelief cause the individual to act as if nothing has happened. The second stage is when emotions erupt and the individual expresses the pain of the loss (Zastrow & Kirst-Ashmann, 1993). The third stage is anger (Zastrow & Kirst-Ashmann, 1993). This stage is similar to the Kubler-Ross model in that the individual expresses anger at the deceased for deserting his or her loved ones or the anger may be directed at God for causing or allowing the loss. In the fourth stage, Westberg identifies the illnesses caused by the stress of the loss (Zastrow & Kirst-Ashmann, 1993). The illnesses include insomnia, headaches, rashes, colds and ulcers, to name a few. In Westberg's fifth stage, the characteristics are uncontrollable emotions and difficulty in concentrating (Zastrow & Kirst-Ashmann, 1993). The bereaved individual may worry about going

insane. Guilt is the sixth stage(Zastrow & Kirst-Ashmann, 1993). The bereaved individual may believe that he or she contributed to the loss or that he or she may have been able to prevent the loss. In Westberg's seventh stage, depression and loneliness set in(Zastrow & Kirst-Ashmann, 1993). The bereaved individual may feel isolated and lonely, and may withdraw from others who are not perceived as being helpful or supportive. In the eighth stage, the bereaved individual may attempt to reenter his or her old life. Old attachments to the past and loyalties to memories may interfere with the individual pursuing new interest and activities. Westberg calls his next stage "hope" (Zastrow & Kirst-Ashmann, 1993). At this stage, the individual begins to gain hope in putting his or her life back together. The tenth and final stage of the Westberg model is reaffirming reality (Zastrow & Kirst-Ashmann, 1993). The individual begins to feel in control of his or her life again. The new life is different from the old life, but the grieving individual finds satisfaction in his or her new life (Zastrow & Kirst-Ashmann, 1993).

In 1991, Marge Hegge adapted a model from William Lamers (1978) that is based on the work of Parkes (1970, 1975), and Caplan (1974). Hegge identifies four phases in her grieving model. Unlike the Kubler-Ross and the Westberg models, Hegge refers to the grieving process in phases rather than in stages. The first phase, shock and numbness, is similar to both the Kubler-Ross and Westberg models. Hegge (1991) lists insomnia, nausea and restlessness as characteristics of the first phase. The second phase is the alarm reaction. Anger, guilt, panic, irritability and emotional exhaustion are characteristics of this phase. Disorganization and despair is the third phase of the model adapted from Lamers by Hegge (Hegge, 1991). The grieving individual experiences profound loneliness, self-doubt, hopelessness and dependency. The fourth and final

phase of this model is acceptance. During this phase, the individual emerges with a new role and new identity. Self-confidence increases as the individual begins a new life (Hegge, 1991). This model is circular, with the individual moving freely between the phases rather than in a linear pattern.

While the stage models are well accepted, the models do not allow for the grieving process to be a free-flowing process. Westberg believes that individuals move back and forth in the stages (Zastrow & Kirst-Ashmann, 1993); however, the Lamers' model adapted by Hegge recognizes that a number of conflicting emotions often are experienced at the same time and are part of the same phase of grieving. The Lamers' model allows more flexibility for the elderly widowed caregivers to accurately identify their emotions during their grieving process.

Summary

The death of a spouse is usually the most profound loss that a person experiences in his or her lifetime (Schuchter, 1986). It is a pain that affects the surviving spouse in every area of his or her daily activities. There are conflicting views on whether life marker events result in a regression to previous stages or phases of the grief process or whether the life marker event days are days when the individual identifies some emotions more strongly. Sanders (1986) states that some widows who thought their grief was over, have become anxious and disheartened when they experienced a strong reaction to a life marker day. Stage model theories would suggest that this is unresolved grief, however, the free flowing model suggests that this would be an anticipated response to a life marker event. In my study, I assume that grief follows the free flowing model and that strong emotional reactions to life marker events are a normal part of the grieving

process. Research on the effect of life marker events will provide a greater understanding of the grieving process.

Chapter Three

Methodology

Overview

The methodology section discusses the research design, states the research question, provides operational definitions, explains how the sample population was selected and describes the method of data collection. The procedure used to protect the participants is included as well as a copy of the interview guide.

Research Design

This was an exploratory study using the open-ended interview design. The open-ended interview was used to ensure that the interviews are conducted in a consistent manner with a minimum of biases (Rubin & Babbie, 1997). The study used qualitative data collected to answer the research question. The purpose of the study was to better understand how life markers affect the grief process of elderly caregivers after the death of their spouse. The open-ended interviews allowed the participants each to tell their own stories and describe their experiences.

Terms and Definitions

The terms grief, bereavement and mourning are often used interchangeably, but in order to better understand the losses caused by the death of a loved one, it is important to know the definitions of each term. Grief is the reactions that are experienced due to the loss. These include the emotional reactions such as denial, anger and guilt as well as the physical reactions such as sleeplessness and loss of appetite. Bereavement refers to the state caused by suffering a loss. The term bereavement encompasses the emotions,

experiences and changes an individual experiences as a result of the loss. Mourning refers to the customs or rituals performed after the death. These rituals differ from culture to culture, (Sanders, 1986). The terms complicated bereavement and life marker events also need to be defined for the scope of this research. Complicated bereavement encompasses the emotions, experiences and changes an individual experiences as a result of the loss. Life marker events are anniversaries, holidays, birthdays or events that were shared by the couple prior to the death of the husband. In addition, elderly spouse caregiver refers to a caregiver between the ages of seventy and eighty five who cared for his or her spouse.

Population/Sample Selection

The sample selection was a nonrandom convenience procedure. Participants for the study were recruited through the Senior Outreach Program of Senior Community Services which is located in a large metropolitan area. Former clients or current clients who met the study criteria first received a phone call from the Senior Community Services' Program Administrator to let them know that the study was worthy of their attention and then received a letter explaining the research study. Those who responded positively to the letter were contacted to schedule an interview. Out of the five letters sent, four responses were received. The four widows met the criteria of the study. They were between 70 and 85 years of age and had lost their husbands between 18 and 24 months prior to the interview. All of the participants had experienced uncomplicated grief (did not experience multiple losses or have mental heath issues) and successfully had completed the grieving process at the time of the interview. The women were Caucasian, lived in the southern and western suburbs and were of the Christian faith.

Three of the participants were low income (under \$24,000.00 per year) and one participant was high income (over \$40,000.00 per year). All of the women had been married to their husbands for over 35 years at the time of the husbands' death.

Data Collection

An interview guide was developed to ensure that the interviews were consistent for each participant. The interview questions were developed using my knowledge of grief theories, symptoms of grief and life marker events. The participants were interviewed for two hours in their own homes. Introductory questions were asked to open the interviewing process. All participants were asked the name of their deceased spouses and how long they cared for the spouse. In addition participants were asked how the past year had gone for them and if they had been involved in any formal grief group counseling.

The second step of the interview was to establish a baseline of the participants' feelings following the loss of the spouse in first year of bereavement. For example, participants were asked to think back to the first months after their loss and describe any dominant feelings or emotions they experienced. Names of feelings associated with grief theories were used as prompts when needed. After the participants described their feelings, they were asked to remember how long each feeling lasted and to choose an intensity of the feeling from an intensity chart.

The next set of questions focused on the participants' feelings on the first life marker event after the first anniversary of the death of the spouse. Participants were asked about their daily routine at that time and what, if anything, was different on the day

of the life marker event. Prompting questions regarding phone calls received or social activities and conversations they had on that day were used to help participants describe the events on that day. Participants then were asked what dominant feelings they remembered having on that day; the intensity of each feeling and how long the feeling lasted.

Each participant was asked to remember three life marker event days over the approximately one year period since the first anniversary of the death of her spouse.

Participants were asked to compare their feelings, longevity of the feeling and intensity of the feeling on that day with the experiences they described on the first life marker event.

At the end of each interview, the participant was thanked for her willingness to share her experiences.

Reliability/Validity

To reduce the amount of bias, the question guide for the interviews was reviewed by the Senior Outreach Program Administrator and a facilitator of a grief support group. However, due to the way the questions were phrased, some bias may have occurred. The term of life marker events was explained to the participants as anniversaries, holidays or birthdays, however, some participants may not have understood or remembered all qualifying events. Also, some participants may not have accurately remembered the emotions or the intensity of their feelings during the specific time periods. The interviews were tape recorded and later transcribed. In order to ensure an accurate transcription of the interviews, the transcripts were checked against the tape recordings three times.

Protection of Human Subjects

The study was approved by the Augsburg College Institutional Review Board Committee, IRB approval number 99-99-9. Participation was completely voluntary. Each participant was informed at the beginning of the session of her right to stop the interview at any time, skip a question or terminate the interview. The participants were assured that their responses would be kept confidential.

Strengths/Limitations

The major strength of this study is the exploration of four homogeneous participants' experiences during their time of bereavement. The open-ended interview allowed each participant to describe her experiences in her own words. A second strength of the study is the comparison of each woman's experiences during the first year of bereavement and the second year of bereavement. One limitation of the study is the small sample size. Also, the sample did not include men, or people of different diverse backgrounds. Further study could be done to compare the impact of life markers on the grieving process on men to better understand the differences in gender.

Data Analysis

The data were analyzed by qualitative methods. The responses to the open-ended questions was organized into categories, themes, ideas and concepts. This information is reported in the findings chapter of this paper.

Summary

This chapter described an exploratory descriptive study which used interviews consisting of open-ended questions to gather qualitative data to answer the research

question. Terms used in this chapter were defined for the scope of this paper. Subject selection and criteria for the participants were defined for the scope of this paper. The interview process was described and examples of the interview questions were provided to illustrate how the interview was conducted.

Chapter Four

Findings

Introduction

This chapter presents the findings of the study. It contains biographical information on each of the participants as well as the responses to the interview questions.

Overview

The interviews with the four participants each lasted approximately two hours. Prior to beginning the interview, some time was spent getting to know the participants and understanding their current life circumstances. In the first part of the interview, the participants were asked to think back to the first months after the death of their husbands. Participants were asked to describe dominant feelings or emotions they experienced. A prompt of feelings was used to help when appropriate. The prompts consisted of two to four words to assist in naming their dominant feelings. For example, the terms, shock, denial, disbelief, numbness or sadness were used as prompts. After the participant described the feelings or emotions she experienced, she was asked how long she experienced the feeling or emotion and to choose an intensity rating from the intensity chart I provided.

The second part of the interview included questions regarding the participants' experiences on life marker event days after the one year anniversary of the death of the spouse. In order to establish a baseline, participants were asked to describe their normal daily routine at the time of each life marker event.

Participants were asked to describe their feelings on three life marker event days.

Their feelings, intensity and duration at each life marker day was compared to the feelings, intensity and duration of the first months after the death of their husband.

The participants in the study were four women between the ages of 75 – 85 who had cared for their husbands in their homes between 2 – 4 years prior to the husbands' deaths. All of the husbands suffered from increasing dementia as well as physical illnesses. Three of the four husbands were placed in nursing homes between 2 - 18 months prior to their deaths. One husband was not placed in a nursing home, however, he was hospitalized for several weeks prior to his death. Each of the four women has created her own way of coping with the loss of her husband.

Biographies of Participants

Each of the four participants have been given pseudo names to aid in maintaining their anonymity.

Respondent #1

The first respondent will be known as Lilly for the purpose of this paper. Lilly has faced a number of challenges, first as a child and later as an adult. When Lilly was five years old, her mother became so ill with the flu that she was unable to care for her children. She placed Lilly, her younger sister and her two older brothers in an orphanage, When Lilly's mother recovered from her illness and returned to the orphanage to take her children home, she found that Lilly and her younger sister had been adopted by two different families. Lilly's mother was able to take her two sons home. Lilly was raised in a loving home by her adopted parents, however, when she was twenty years old, she was successful in finding her sister. Later the two girls located their brother and their

mother. Lilly's mother was very ill at the time and died shortly after she was reunited with her daughters.

Lilly later was married, had a son and was divorced. She raised her son alone for many years before marrying her second husband. Her husband was a musician, playing with the big bands evenings and weekends, and Lilly always went with him when he played.

Lilly cared for her husband who suffered from Parkinson's Disease in their home until she was no longer physically or emotionally able to care for him. He was placed in a nursing home where she visited him almost daily until he died of cancer about a year after he entered the nursing home.

At present, according to Lilly, "life is never dull, but, not always enjoyable."

Respondent #2

The second respondent will be known as Bertha for the purpose of this paper.

Bertha cared for her husband who suffered from dementia in their home for four years.

His illness came on gradually over time. He would go for walks and get lost and she would go out to find him. As his illness progressed, he "became more difficult to keep track of." Once the police had to help find him. When he became ill with pneumonia, he was hospitalized and within two weeks passed away in the hospital.

Bertha and her husband were unable to have children so they adopted two boys. When the sons married, they joined a religious organization that does not celebrate Christmas, birthdays and other holidays. This is difficult for Bertha, however, she "respects their wishes."

According to Bertha regarding the loss of her husband, she has "learned to live with and make the best of the situation."

Respondent # 3

The third respondent will be known as Ruth for the purpose of this paper. Ruth and her husband experienced a major loss early in their marriage. They lost a five year old daughter when she was hit by a car. Ruth stated she still feels sad when she remembers her daughter.

Ruth cared for her husband at home for several years, however, when he needed twenty-four hour care, she placed him in a nursing home. He was in the nursing home about one year when he died of pneumonia.

According to Ruth, you "don't get over the loss of a loved one."

Respondent #4

The fourth respondent will be known as Mary for the purpose of this paper.

Mary's husband was an engineer who traveled frequently. She cared for the children and the home when he was gone. Mary also stated that she was the oldest of ten children and helped raise her brothers and sisters.

Mary cared for her husband in the home for two years. He died two weeks after being admitted into the nursing home. When he was in the nursing home she visited him twice every day. She remembered how he had taken care of her once when she was ill and she wanted to do the same for him.

Mary remembers once saying she want to "be alone for 6 months". In the interview, Mary stated she is "sorry I ever wanted that."

First Months After the Death

When asked to think back to the first months after their husbands' deaths and describe any dominant feelings or emotions, all four participants denied experiencing shock, denial or disbelief. Only Ruth expressed being surprised at hearing the news of the death of her husband. Lilly was the only participant who expressed experiencing numbness when first told of her husband's death. The feeling or emotion most strongly expressed by all four participants was relief for their spouses. Each participant was careful to explain that the relief she experienced was not relief for herself, but relief that her husband's suffering was over. None of the women expressed feelings of relief for themselves, only relief for their husbands. Mary explained her feeling by saying, she was "happy that he was out of pain." Lilly stated that she "didn't think it would be right to wish him back."

Another feeling or emotion expressed by three participants was sadness. Bertha stated she felt intense sadness for the first few months. Ruth stated she experienced sadness to the point of feeling hopeless. According to Ruth, sadness is something, "You can't do anything about." "You can't change the way you feel." Lilly described the feeling of sadness as "your heart never get light." Mary denied experiencing sadness, stating she was only "happy he was out of pain."

All four participants denied experiencing feelings of anger during the first few months after the death of their husbands. The only emotions that all the participants remembered at the time of the death were relief for their spouses and sadness.

Next Life Marker Event After the First Anniversary of the Death of the Spouse

Mary and Lilly named their late spouse's birthday as the first life marker event after the first anniversary of their husband's death. Mary denied experiencing sadness or other feelings of grief on her late husband's birthday. She stated that she, her son and a friend from the nursing home celebrated the birthday with a birthday cake.

Lilly also named her late spouse's birthday as the first life marker event after the first anniversary of her husband's death and stated that she put flowers on her husband's grave, but she also denied experiencing feelings of sadness or other emotions of grief.

Ruth and Bertha named Christmas as the first life marker event after the first anniversary of the deaths of their husbands. Bertha stated she experienced more sadness on the Christmas holiday. It must be pointed out that the children of this participant are members of a religious organization that does not celebrate holidays. Bertha spent Christmas with other relatives, but spent a significant amount of time reflecting on past Christmases that she had shared with her husband. Although Bertha experienced more sadness on Christmas, the sadness was less intense and lasted a shorter amount of time than the initial sadness she experienced during the first few months after her husband's death. According to the Bertha, she has "learned to live with the situation and make the best of it."

Ruth, also identifying Christmas as the first life marker event after the first anniversary of her husband's death, stated that the Christmas celebration was held at her daughter's house instead of her house. This participant denied feeling more sadness on

this day. She stated "there are always reminders." The holidays are not worse because "the kids are around."

All participants denied experiencing other emotions or problems on the first life marker event after the first anniversary of their husband's death. Three of the participants were sleeping well and continuing with their social activities. One participant stated that she was still uncomfortable sleeping; however, on the day of the life marker event, she did not experience any more problems than usual. The participants did not remember feelings of relief for their spouses at the first life marker event.

Second Next Life Marker Events

The participants selected a variety of occasions as their next life marker events.

Lilly identified New Year's Eve as the next life marker event. Lilly experienced more intense feelings of sadness on New Year's Eve. She explained that her husband played in a band and she "always went with him on New Year's Eve." The sadness experienced by Lilly was more intense than she had been feeling in her normal routine. The intensity was less than the intensity of sadness she experienced during the first few months after her husband's death and the stronger feelings of sadness ended after the holiday.

However, the sadness was more intense than the sadness that she had experienced at her first life marker event.

Two participants chose their wedding anniversary as the next life marker event.

Bertha expressed feeling more sad on the date of their wedding anniversary. The other participant who chose her wedding anniversary as the next life mark event was Mary.

Mary denied feeling more sad on this day.

One participant, Ruth, chose the second anniversary of her husband's death as her next life marker event. Ruth stated that she received calls from family, but "not sure if remembering or ignoring is best." Ruth stated she experienced more sadness on this day than experienced in her normal routine. She stated her sadness was about the same as on her first life marker event day.

The participants denied other feelings of the grieving process including relief for their spouses that they had discussed experiencing during the first few months after the death.

Third Next Life Marker Event

Responses to questions regarding the next life marker event became more difficult for the participants. Defining the third life marker event appeared to be more difficult for the participants. Two participants, Mary and Ruth, identified Christmas as their third life marker event, but each stated that she did not experience more sadness on this day. Both spent Christmas with their children. Bertha identified her husband's birthday as her third life marker event. She denied feeling more sad on this day. Lilly identified her wedding anniversary as the next life marker event. According to Lilly, "life should always be with two, not just one." The sadness was less intense than during the first few months after the death of her husband, however the sadness again was more intense than the sadness at her first life marker event. The stronger feelings of sadness ended the day after the wedding anniversary date.

The participants denied other feelings of the grieving process, again including relief for their spouses that they remembered at the baseline of the first few months after the death.

Summary

In this exploratory study, the findings suggest that the participants denied experiencing shock, disbelief, denial or anger within the baseline time period of the first few months after the death. The participants identified two dominant feelings during the baseline time period. The first feeling described by all participants was relief that their spouse was no longer suffering. Each participant also made the point that her relief was not for herself, but relief for her husband. A second dominant feeling, sadness, was identified by three participants during the baseline time period and on specific life marker events.

On the first life marker event, three of the participants denied experiencing any dominant feelings outside their normal routine. One participant remembered experiencing more sadness. She described the feeling as less intense and of a shorter duration than she experienced during the first few months after her husband's death.

At the second life marker event, three participants remembered experiencing a more intense sadness than at the first life marker event, but the feeling of sadness was less intense and of a shorter duration than during the first few months after their husbands' death. The three participants reported experiencing more sadness at the second life marker event than at the first life marker event. One participant denied experiencing more sadness or other grief emotions on the second life marker event than during the baseline time period or at the first life marker event.

Responses to the question regarding the third life marker event appeared more difficult for the participants. Two identified their husbands' birthdays, one identified

Christmas and one identified her birthday. All participants denied experiencing more sadness on the third life marker event.

The findings also can be viewed from the perspective of events that are shared with family and events that are meaningful only to the couple rather than the events in chronological order. Most of the participants reported that the events previously shared with family were less intense than the events shared only with their spouses. Wedding anniversaries or special celebrations for the couple appeared to cause more sadness than Christmas or events when family had always been involved in the event. This finding may warrant more study, but may help social workers and families provide better support to caregivers who have lost their spouses.

Another finding in this study is that the four participants can be separated into two groups based on their history of independence prior to the loss and the degree to which the participants were affected by their loss. Questions regarding independence were not asked in the interview, however, the participants talked about their current lives and activities. The women who had been more independent during their marriage were more successful in keeping busy. The participants who had been more dependent during their marriages were more dependent on children and friends for transportation and help with finances.

The challenge of keeping the participants on task was difficult. They were gracious and wanted to be helpful, but they were anxious to share their life stories as well as the experiences of their grieving process. The death of their husbands was an important part of their stories; however, they wanted to share the other events they had experienced.

Chapter Five

Discussion

Overview

This exploratory study was developed to better understand how life marker events affect the grieving process of elderly caregivers who have lost their spouses. The four participants in the study were between seventy-five and eighty-five years of age. They had lost their spouses between eighteen months and twenty-four months prior to the interview. Interviews were conducted in the participants' homes and lasted approximately two hours.

The baseline of dominant feelings or emotions experienced during the first few months after the death of the participant's spouse established the intensity and duration for each participant. The second part of the interview identified the feelings or emotions experienced on life marker events and compared the feelings or emotions as well as the intensity and duration of the feelings and emotions to the baseline.

One challenge of this study was keeping the interview structured and focused on the interview questions. Participants were open and wanted to be helpful to the interview process. However, a significant amount of time was spent by the participants reviewing their personal histories, including their happy times and their tragedies.

Discussion

The four participants can be separated into two groups based on their history of independence prior to the loss and the degree to which the participants were affected by their loss. The two participants who appeared to be more affected by their loss appeared more dependent prior to their loss, while the two participants who appeared more

independent prior to their loss reported being less affected. While the women who were more independent prior to the death expressed feelings of sadness, they brought up keeping busy as helping.

The two more independent participants stated that because of personal tragedies, (i.e. death of their child, given up for adoption at the age of four,) they were stronger and more realistic about life. These participants stated that they accept their situation and do not "dwell on it." It is interesting to note that the two participants who talked about these tragedies in their lives also had been more independent during their earlier years and in their marriages. One participant had been divorced, raising her son alone until her second marriage in her forties. The other participant's husband traveled weekly for his job. She was responsible for the family during her husband's absence while her children were growing up.

I found in this study that the participants did not experience or did not remember experiencing several of the emotions usually associated with the Kubler-Ross, Westberg or Hegge grief models. There are several possible explanations that could be attributed to the participants denying experiencing shock, denial, disbelief and anger. One possible explanation is that the participants did not accurately remember the feelings or emotions they experienced during the first few months after their husbands' deaths and on the life marker events. The age of the participants may have played a role in the responses I received. Another possible explanation is that all of the participants experienced anticipatory grief during their husbands' illnesses. The participants may have instead chosen not to share some of the feelings or emotions that they experienced. The responses by the participants may have been affected by the bias for social desirability

(Rubin & Babbie, 1997). The participants may have filtered their responses rather than to acknowledge that they may have experienced emotions that can be perceived as negative in our society. Only one participant reported experiencing surprise at hearing of the death of her husband and one other participant remembered feeling numbness. The feeling of numbness is consistent with Bowlby's first phase of bereavement Worden (1991). According to Bowlby, numbness is the defensive mechanism outside the conscious awareness that blocks processing of difficult information. The other participants denied feelings of numbness. Using Bowlby's theory that numbness is outside the conscious awareness of the individual, the three widows who denied feelings of numbness may not have been able to identify these feelings. In reality, they may have experienced these feelings.

At the first life marker event, only one participant reported feeling more sadness than during her normal routine at that time. Two of the participants identified Christmas as the first life marker event and two participants identified their spouses' birthdays.

Only the one participant whose children belong to a religious organization that does not celebrate Christmas felt more sad on the first life marker event. The other three participants denied experiencing more sadness.

Three of the participants stated that they experienced more sadness at the second life marker event than the first life marker event. The life marker events identified by two participants were a wedding anniversary and New Year's Eve. One possible explanation for the participants experiencing more sadness on these life marker events is that the events had been special times, shared by the husband and wife only. On the other hand, Christmas, birthdays and other holidays usually included other family members.

While their spouse may be gone, the other family members continue to celebrate the occasion. Family support and activities appear to play a role in how the life marker events affect the grieving process for elderly caregivers who have lost their spouses. The third participant who stated that she experienced more sadness at the second life marker event than the first life marker event, identified the second anniversary of the death of her spouse. The anniversary of the death of a spouse can be a time of reflection for the surviving spouse resulting in more sadness.

One participant denied ever experiencing sadness after the death of her husband. This participant focused on the relief she felt that her husband's suffering was over. It is difficult to understand why she denied ever experiencing feeling sadness.

One common theme in the findings of the study is the relief that the participants experienced that their spouses were no longer suffering. The relief for their husbands may be one reason the participants denied experiencing feelings of shock, denial, disbelief or anger. The emotional pain the participants experienced while watching their husbands suffer may have resulted in the absence of some of the feelings named in grief theories. Ruth stated "there was nothing I could do for him" and Lilly stated that she "didn't think it was right to wish him back".

Another reason the widows may not have remembered feelings of shock, denial, disbelief or anger may be related to the age of the participants and the losses they had already experienced in their lives. The participants had all experienced the death of parents, friends or siblings. The experience of death was not unknown to them.

Sadness was the overwhelming feeling or emotion that three of the four participants spoke about most often. Sadness was the emotion that they could identify

and measure with the intensity scale I provided. This may be because the women were more comfortable discussing sadness than other emotions. Sadness may be the emotion they remembered most during the time period of eighteen to twenty-fours months after the death of their spouse or sadness may be the emotion the participants are still experiencing.

Social Work Implications

The findings of the study have several implications for social work practice. One commonalty among all of the participants was their eagerness to tell their life stories. While trying to keep the interviews on task was challenging, the women wanted to talk about their life experiences as well as their lives with their husbands. Interviews that were scheduled to last one hour, lasted from one and one half to two hours. It is important for social workers to take the time to listen to the stories told by the elderly.

Social workers also can learn from this study that even after a widow appears to have successfully completed the grieving process, some occasions may cause the widow to experience more intense sadness again. Widows and their families and friend need to recognize that these feelings are valid and not outside the norm.

The findings of this study also can help social workers better understand that the elderly caregivers may not relate to some of the terms used by professionals to describe the grieving process. Whether the elderly did not relate to some of the terms because of generational or cultural mores, social workers should provide examples of feelings or behaviors to help the worker and the client obtain a better understanding.

Limitations and implications of study

Several limitations of the study can be identified. The language of the interview may not have been clear to the participants. For example, one of the emotions used as a prompt was the feeling of shock. Providing the definition of shock may have resulted in the participants relating this emotion to their experience rather than denying experiencing the emotion. Using direct language of emotion also may not have been meaningful to the participants. The participants interviewed are from a generation that may have been uncomfortable discussing their emotional experiences.

Another limitation of the study is that the women may not have accurately remembered the life marker events in chronological order and may not have accurately remembered the feelings or emotions they experienced. The interviews were conducted eighteen to twenty four months after the death of their spouses. Time may have been a factor in how they remembered the death and the later events.

Future Research

The findings of this study provide some insight into the grieving process for elderly caregivers, however, additional research needs to be done in order to continue to develop greater understanding of the grief process for elderly caregivers.

The size of the study was small, four participants, and interviews with a larger sample of caregivers who have lost their spouses may provide more insight into the grieving process for this population. Larger studies could provide addition insight and other concepts not identified by the four participants of this study.

Future studies could include men as well as women to identify differences related to the gender of the bereaved. This study suggests that women who were more independent during their marriage were more successful in keeping busy. A future study could look at how men, who are usually more independent in a marriage, experience the grieving process.

Studies that include participants who are minorities, participants who have different religious beliefs and participants who come from different cultural backgrounds would provide information to assist the growing diversified populations. The possible impact of cultural and racial differences in the bereaved elderly should be studied so that better and appropriate support and assistance can be provided by social workers and families.

The findings of the study appear to show that life marker events that the participants celebrated as couples caused more sadness that events where family usually was involved. This finding can be used to educate family members as well as social workers on the effect of these special events on the grieving process. Family members and friends can be more sensitive and understanding of the more intense sadness experienced by the grieving caregivers on these event days. Also more support and activities could be planned to attempt to lessen the sadness experienced by the grieving caregivers.

References

Anderson, K. & Dimond, M. (1995). The experience of bereavement in older adults. <u>Journal of Advanced Nursing</u>. 22, 308-315.

Caine, L. (1988). Being a widow. New York: Arbor House

Collins, C., Liken, M., King, S., & Kokinakis, C. (1993). Loss and grief among family caregivers of relatives with dementia. Qualitative Health Research. 3, 236-253.

Gaines, R. (1997). Detachment and Continuity. <u>Contemporary Psychoanalysis</u>. 33, 549-571.

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

Hegge, M. (1991). A qualitative retrospective study of coping strategies of newly widowed elderly. American Journal of Hospice and Palliative Care. 4, 28-34.

Hyrkas, K., Kaunonen, M., & Paunonen, M. (1997). Recovering from the death of a spouse. Journal of Advanced Nursing. 25, 775-779.

Jacob, S. (1996). The grief experience of older women whose husbands had hospice care. <u>Journal of Advanced Nursing</u>. 24, 280-286.

Jones, P. & Martinson, I. (1992). The experience of bereavement in caregivers of family members with Alzheimer's Disease. <u>Journal of Nursing Scholarship</u>. 24, 172-176.

Keefe, K. & Snyder, B. (1985). The unmet needs of family caregivers for frail and disabled adults. Social Work in Health Care. 10, 1-13.

LaGory, M., Sherman, S., & Ward, R. (1988). Women as caregivers of the elderly: Instrumental and expressive support. Social Work. March-April, 164-166.

Parkes, C. (1972). <u>Bereavement: studies of grief in adult life</u>. Madison, Connecticut: International Universities Press.

Rando, T. (1986). <u>Loss and anticipatory grief</u>. Lexington, MA, Lexington Books.

Rubin, A. & Babbie, E. (1997). <u>Research methods for social work.</u> (3rd Ed).

Pacific Grove: Brooks/Cole.

Sanders, C. (1989). <u>Grief: The mourning after.</u> New York: John Wiley & Sons. Schuchter, S. (1986). <u>Dimensions of grief.</u> San Francisco: Jossey-Bass Walker, R., Pomeroy, E., McNeil, J., Franklin, C. (1994). Anticipatory grief and Alzheimer's Disease: Strategies for Intervention. <u>Journal of Gerontological Social</u>

Work. 22(3/4), 21-39.

Worden, J. (1991). <u>Grief counseling and grief therapy.</u> New York: Springer Zastrow, C., Kirst-Ashmann, K. (1993). <u>Understanding human behavior and the social environment</u>. Chicago: Nelson-Hall.

Interview Guide

I would like to start by asking you some introductory questions. What was your husband's/ wife's name? How long did you care for him/her? How has this past year gone for you? Have you been involved in any formal grief group counseling? (Chronology of Grief Experience) Baseline Now, I'd like to ask you some questions about the first year following the death of I would like you to think back to the first months after 's death. 1. Can you describe any dominant feelings or emotions you had? Prompts: Shock Denial Disbelief Numbness Sadness Guilt Relief Anger A. В. C. D. (Begin with first stated feeling or emotion) 2. How long do you remember feeling ? See attached intensity scale. (Scale will 3. At first, how intense was your be placed on 5" X 7" Card) 4 Strongly intense 3 Very intense 2 Somewhat intense 1 Mildly intense (Repeat for each feeling) (Life Marker Events)

Now, if we fast forward to one year following the death of your husband. I would like to ask you questions about anniversaries, holidays and birthdays.

First Life Marker Event -Anniversary of death							
Let's start at the anniversary of's death:							
1. Tell me about your normal daily routine during this time period. (Prompts:)							
Do you remember changes in your sleeping pattern?							
Do you remember changes in your appetite?							
Can we talk about your social activities?							
2. On this day, what if anything did you do that was different than your normal daily routine?							
(Prompts:)							
What phone calls did you receive?							
What happened when friends or family called?							
What did you talk about?							
3. Can you tell me what dominant feelings or emotions you remember having that day? A.							
B.							
C.							
D.							
4. How long do you remember feeling?							
4. How long do you remember feeling?5. What was the intensity of your? (See attached scale)							
(Repeat with each feeling)							
I noticed that you remember experiencing both following the death of and on the anniversary of his/her death.							
6. Can you compare your feeling of immediately following the death of							
with your feeling of on the anniversary of his/her death?							
(Repeat with each feeling)							
Next Life Marker Event							
1. Following the one year anniversary of your husband's/wife's death, what was the next significant anniversary, holiday or birthday you experienced?							
2. Tell me about your normal daily routine during this time period. (Prompts:)							
Do you remember any changes in your sleep pattern?							
Do you remember changes in your appetite?							
Can you tell me about your social activities?							

Were you seeing your friends and family more often?

3. On this day, what if anything did you do that was different than your normal daily routine?
(Prompts:)
What phone calls did you receive?
What happened when friends or family called?
What did you talk about?
4. What dominant feelings or emotions you remember on that day? A.
B.
C.
D.
5. How long do you remember feeling?6. What was the intensity of your? (See attached scale)
6. What was the intensity of your? (See attached scale) (Repeat with each feeling)
I noticed that you remember experiencing both on the first anniversary of's death and on this (anniversary, holiday, birthday).
7. Can you compare your feeling of on this day with the feeling of that you had on the first anniversary of his/her death? (Repeat with each feeling)
Next Life Marker Event What was the next significant anniversary, holiday, birthday that you experienced?
(Repeat questions listed above.)
Thank you for taking the time to meet with me. Do you have any questions for me? I appreciate your participation in my research and I'm happy you were able to share your experiences with me.

Intensity Rating

Strongly Intense Very Intense Somewhat Intense Mildly Intense



SENIOR COMMUNITY SERVICES

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January 29, 1999

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Dr. Lucie Ferrell Institutional Review Board Augsburg College #118 2211 Riverside Avenue South Minneapolis, MN 55454

Dear Dr. Ferrell:

I am writing on behalf of Gayle Galarneau, MSW graduate student, at Augsburg College. Gayle has requested the opportunity to interview clients of Senior Community Services for her research study.

Gayle has my permission to conduct personal interviews with approximately four clients of our agency. In order to assure our elderly clients that the research study is legitimate and supported by our agency, I will contact the individuals to inform them that they will be receiving a letter from Gayle explaining her research study.

Sincerely,

Adele Mehta

Program Administrator

Adule Mehta



Script

Adele

This is Adele from Senior Community Services. I'm calling to let you know that you will be receiving a letter from Gayle Galarneau in a few days. Gayle is a graduate student in the Masters of Social Work program at Augsburg College and is working as an intern at the agency this year. The letter you receive from Gayle is requesting your participation in her research study for her Masters thesis. I just want you to know that the agency has reviewed her study and that the study is worthy of your attention.

Gayle

My name is Gayle Galarneau. I received notification in the mail that you are interested in my research study. I would like to set up an appointment with you. At the appointment, we will talk one on one and I will ask you a series of questions pertaining to my research. The interview will take about one and one half hours. We can meet either in your home or at another location. Again, I want to assure you that you may skip any questions which make you uncomfortable and still remain in the study or you may end the interview at any time. Do you have any questions for me?

Exploratory Study on Grief and Elderly Caregivers

My name is Gayle Galarneau. I am a graduate student working toward a Master's Degree in Social Work at Augsburg College in Minneapolis, Minnesota. For my thesis, I am studying grief and loss among elderly former caregivers. I am focusing on how life marker events such as birthdays, anniversaries and holidays affect the recovery from the loss of a spouse. This research study has been approved by and is being done in cooperation with Senior Community Services. You have been chosen as a possible participant in my research because you are a client or a former client of Senior Community Services whose husband died between 18 – 24 months ago and you were a caregiver for your husband. The findings from this study may be used to better understand the processes we all experience following the loss of a spouse.

I want to assure you that participation in this research study is voluntary. Your decision whether to participate or not will not affect your current or future relations with Senior Community Services or Augsburg College. If you choose to participate, you may choose any questions which make you feel uncomfortable and still remain in the study. Also, you can stop the interview at any time.

You received a letter from Senior Community Services. No agency staff will know whether you do or do not participate in this study. Participants in my study will be asked to discuss their feelings and related experiences following the death of their husband or wife. Participant names will not be attached to the interviews and answers will be kept confidential. Direct quotes from your interview will be used only with your written consent. However, because the number of participants in the study is small,

anonymity cannot be promised. The information participants provide will only be used in my Masters thesis. Data collected from the interview and the audio tapes will be kept in a locked file at my home until my thesis is completed, approximately, December, 1999, and then will be destroyed.

The potential risk to participating in this study is that it may evoke strong memories or strong emotions. Counseling at Pyramid Mental Health Center, (phone number 612-546-1866), is available to you if you would like to talk to someone. You will be financially responsible for any counseling services provided.

While there is no direct benefit to you, the study is designed to increase our understanding of the recovery process following the death of a spouse. It will be a one time commitment and should take no longer than one to two hours of your time. If you choose to participate, I also will ask you to sign this consent form and ask permission to use direct quotes from the interview and to audio-tape the interview.

Thank you in advance for considering this research study. You may contact me at (612) 993-7570 with questions about the research or about your rights. You may also speak with my thesis advisor at Augsburg College, Dr. Michael Schock at (612) 330-1725.

You will receive a copy of this consent form for your records.

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I have read the above information.	I have asked questions and have received							
answers. I hereby consent to participate in the study.								
Signature:	Date:							
Signature of Investigator:	Date:							
I consent to be quoted directly.								
Signature:	Date:							
I consent to be audio-taped.								
Signature:	Date:							

Augsburg IRB Approval # 99-18-3

Augsburg College Lindell Library Minneapolis, MN 55454