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Ambiguous Loss For Caregivers of Family Members With Dementia

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A thesis submitted in partial fulfillment of the requirements for the Master of Education degree in Psychology

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AMBIGUOUS LOSS FOR CAREGIVERS OF FAMILY MEMBERS WITH DEMENTIA

(Thesis format: Monograph)

by

Ashleigh E. Vella

Graduate Program in Education

A thesis submitted in partial fulfillment of the requirements for the degree of
Master of Education

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Abstract

This study examined the grief of spousal caregivers, specifically pertaining to how grief reactions and losses shift over the progression of Alzheimer's disease and related dementias, and how caregivers experience ambiguous loss. Five caregivers of spouses with Alzheimer's disease or related dementias participated in this study, recruited from the Alzheimer's Society of London and Middlesex and the Alzheimer Outreach Services of McCormick Home. This was a descriptive field study using a qualitative approach to discover each participant's experiences, which was complimented by two quantitative measures. The findings of this study were consistent with previous research regarding the changes in grief and the existence of ambiguous loss, however, the phases of ambiguous loss, as described in previous research, were expressed as characteristics of the caregiving experience. This study identified a need for a quantitative measure of ambiguous loss to determine how to support caregivers through this distressing feature of caregiving.

Keywords: Alzheimer's disease, dementia, loss, grief, caregiver, spouse, ambiguous loss

Acknowledgements

I would like to thank my supervisor, Dr. Alan Leschied, for his unwavering support and encouragement. Alan's genuine enthusiasm fueled this process and pushed me to reach farther than I believed possible. I would also like to acknowledge and thank the other advisory members involved throughout this process – Dr. Jason Brown, Dr. Susan Rodger, and Dr. Darcy Harris.

I would like to express a deep gratitude to the participants of this study, for their courage and willingness to share their personal and meaningful experiences. It was a privilege to witness. Thank you to the Alzheimer Society London and Middlesex and the Alzheimer Outreach Service of McCormick Home for supporting my research goals. A special thank you to the Alzheimer Society and their donors for the generous support of the Graduate Research Award.

Finally, I would like to thank my fiancé, Ryan Lerch, for his daily support, patience, and love. Without you, Ryan, none of this would be possible.

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Chapter 1: Introduction

According to the Alzheimer Society of Canada (2011), dementia is the term used for a broad class of brain disorders characterized by loss of memory, judgment and reasoning, and changes in mood and behaviour. According to a study commissioned by the Alzheimer Society of Canada (2010), almost 500,000 Canadians were living with dementia in 2008 and this figure is expected to increase to over 1.1 million by 2038. Globally, more than 35.6 million people were living with dementia as of 2010, and this figure is expected to double every 20 years, amounting to 65.7 million in 2030 (World Health Organization, 2012). Alzheimer's disease is the most common form of dementia, accounting for 63% of dementia cases (Alzheimer Society London and Middlesex, 2010).

Dementia is a progressive disease that affects the afflicted person's memory, language skills, ability to comprehend, reason, concentrate, and know where they are in time and space (Rentz, Krikorian, & Keys, 2005). There are several types of dementia, but across dementia types in general, there are three broad stages referred to as early, middle, and late stage. In the early stage of dementia, symptoms include forgetfulness and loss of concentration that only the individual may be aware of that are typically attributed to the normal signs of aging (Mayer, 2001). In the middle stage of dementia, there is severe memory loss for recent events but the individual may remember past events (Mayer, 2001). This stage is also associated with disorientation, dysphasia (the inability to find the right word), and unpredictable or sudden mood changes (Mayer, 2001). In the late stage of dementia, there is severe confusion, disorientation, and hallucinations or delusions (Mayer, 2001). Some people with dementia may become violent or angry in this stage, or docile and helpless, and may experience wandering without purpose, incontinence, and neglect of personal hygiene (Mayer, 2001).

Chapter 2: Literature Review

Scope of Dementia

The Transitional Process

Prediagnostic phase. The experience of living with dementia is a highly individualized and complex process that begins before the diagnosis is made (Steeman, de Casterlé, Godderis, & Grypdonck, 2006). During the prediagnostic phase, individuals with dementia will gradually become aware that there is a problem as memory failures become more severe (Steeman et al., 2006). Initially, memory problems may be interpreted as normal signs of aging (Mayer, 2001; Steeman et al., 2006). Others may experience critical events that alert them to the fact that something is wrong, such as having a driver's license revoked (Steeman et al., 2006). Another condition in the prediagnostic phase is that other people point out the person's memory failures, yet they themselves lack an awareness that there is something medically wrong (Steeman et al., 2006). In this case, there is a discrepancy between others' perceptions and the person's experiences, which may result in suspecting that there is something wrong (Steeman et al., 2006).

Sensing that one has a problem may produce feelings of frustration, uncertainty, and fear, which stem from a lack of self-assurance, feelings of being out of control, and an inability to understand the perceived changes (Steeman et al., 2006). In the prediagnostic phase, individuals with dementia may develop strategies to monitor themselves for signs of deterioration, including strategies of vigilance and avoidance to maintain control and concealment of their memory problems (Steeman et al., 2006). These attempts to keep the problem hidden will become increasingly difficult, cause psychological strain, and eventually fail (Steeman et al., 2006).

In some cases, family members who notice these failed strategies will acknowledge the memory impairment and accept their loved one's need for professional help (Steeman et al., 2006). In other cases, the person with dementia will acknowledge the problem due to a need for an explanation, a desire to relieve the strain of maintaining a normal appearance, and a need to feel supported (Steeman et al., 2006).

Diagnostic phase. The diagnostic phase may bring a sense of relief and fear as people who suspect that they have dementia seek neurological assessment and a diagnosis (Steeman et al., 2006). This phase involves reflecting on the prospect of a diagnosis, considering possible causes for memory impairment, what the reactions of others may be, and accompanying feelings of threat, uncertainty, and anxiety (Steeman et al., 2006). When the diagnosis of dementia is confirmed, the individual may feel validated as it provides an explanation for their experiences (Steeman et al., 2006). On the other hand, a diagnosis of dementia to an individual who is unaware of their cognitive problems will cause distress as this causes a discrepancy between their perceived self-image and reality (Steeman et al., 2006). Regardless, a diagnosis of dementia may threaten the individual's sense of existence, causing shock, anger, depression, disbelief, and a fear of an inability to retain their personal identity in the future (Steeman et al., 2006).

Postdiagnostic phase. Accepting a diagnosis of dementia may cause the individual to consider present or future losses, and a desire to live life despite the dementia (Steeman et al., 2006). Impaired cognition is the most prominent loss, which has several interrelated aspects that may be experienced (i.e., loss of thinking ability, decision-making difficulties, problem-solving difficulties, getting lost; Steeman et al., 2006). Cognitive loss causes their reality to become

unpredictable and unfamiliar, resulting in a perceived loss of control (Steeman, 2006). Coping with the changes and threats that accompany living with dementia produces a challenge in itself.

Loss

The losses for the person afflicted with dementia are different from the losses that the caregiver will experience. The person with dementia will likely experience anticipatory grief with the diagnosis. However, it is unclear how their perception of loss progresses with the disease. Few studies have addressed the loss and grief experience from the perspective of the person with dementia. In the early stage of dementia, some individuals may have an awareness of their symptoms and insight into how their impairments affect their ability to function (Rentz et al., 2005). Coping strategies may still be available to these individuals in the early stage, but as they become more cognitively impaired, their ability to self regulate emotional responses may decline (Rentz et al., 2005). The challenge is when individuals with dementia are experiencing grief but lack the ability to express and manage their feelings in a coherent way (Rentz et al., 2005).

Caregiver Loss. The losses for the caregiver are of a different nature as they may include the loss of their future, affection, social interactions, and companionship (Lindgren, Connelly, & Gaspar, 1999). These losses are due to the changes in relationship they once had with the person with dementia, or from other activities that caregivers can no longer participate in due to the increased responsibilities of caregiving. It has been identified that the losses for caregivers will vary depending on the relationship with the individual with dementia. For example, spousal caregivers experience loss associated with the marital relationship and social connections. The loss for an adult child caregiver is characterized as regret over the lost parent (Meuser & Marwit, 2001). It has also been noted that “spouses have a higher sense of duty or obligation than

children of caregivers. Spousal caregiving in later life is seen as an expression of love and influences the meaning and quality of the care that occurs” (Mayer, 2001, p. 54). Other studies, however, have noted that there is no significant difference between spouse caregivers and adult child caregivers (e.g., Lindgren et al., 1999).

In addition to the differences between spouse and adult child caregivers, the experiences of the caregiver will also be unique to each individual. One commonality is that it will be an emotionally distressing experience. According to Lindgren and colleagues (1999), “family caregivers are burdened and manifest significant levels of depression, burnout, poorer levels of health, and decreased life satisfaction” (p. 521). Caring for a family member with dementia has been referred to as a ‘career’ in itself because of the impact that it can have on the family and daily life (Frank, 2008), lasting for many years. A number of studies have examined the impact of stress and burden on caregivers, but it is also important to include an examination of the impact on caregiver grief.

Overview of Bereavement Research

Classical Grief Theory

Task-Based Theories

Grief work hypothesis. The “grief work hypothesis” originally postulated by Sigmund Freud, refers to the notion that one has to come to terms with loss by confronting the experience of bereavement and working towards a detachment from the lost person (Stroebe & Shut, 1999). As a task-based theory of grief, the goal of grief is to disengage from the deceased individual. Grief does not automatically resolve with the passage of time, rather, the bereaved individual needs to actively “work through” his or her pain (Hadad, 2009). Freud viewed an ongoing emotional connection with the deceased as being pathological (Rothaupt & Becker, 2007).

Current research challenges this theory as (1) predominately based upon research with older widows, (2) not accounting for variation in grieving style and needs, and (3) the inaccurate assumption that one must ‘let go’ of the deceased person as a goal of the grieving process.

Erich Lindemann. Lindemann (1944) was another early pioneer in the area of bereavement research, describing grief work as the process of confronting the reality of the loss and severing the emotional connection with the deceased (Rothaupt & Becker, 2007). The task of severing emotional bonds is the ultimate goal of grief work as it allows the bereaved individual to build new relationships (Rothaupt & Becker, 2007).

William Worden. Worden’s (1991) model of bereavement included four tasks of mourning that can be completed and revisited in any given order (Rothaupt & Becker, 2007). The tasks to be completed are: (1) acceptance of the reality of the loss, (2) experiencing the pain of the loss, (3) adjustment to an environment without the deceased, and (4) emotional relocation of the deceased individual and moving on with life (Hadad, 2009). It was proposed that when these tasks were completed, the bereaved individual would be ready to move on with life and his or her grief would be resolved (Rothaupt & Becker, 2007). In Worden’s earlier model of bereavement, the fourth task involved “withdrawing emotional energy from the deceased and reinvesting it in another relationship” (Worden, 1982, p. 15). The current revision is a break from earlier grief theories, recognizing that emotional connections with the deceased are transformed rather than ‘let go’.

Stage/Phase-Based Theories

Kübler-Ross. Elizabeth Kübler-Ross (1969) published the results of her interviews with patients who were dying of a terminal illness. Kübler-Ross’s observations provide the basis of her stages of adjustment to the emotional trajectory of dying: (1) denial and isolation, (2) anger,

(3) bargaining, (4) depression, and (5) acceptance. These stages were intended as a very general guide to the psychological reactions of an individual when confronted with a terminal diagnosis, rather than in a step-wise progression (Hadad, 2009). According to Kübler-Ross's stage model, elements of each stage can be found at any point in the dying trajectory. Kübler-Ross also applied the stages to the family members of the dying patient, as she observed families experienced a similar process through the dying trajectory and after the death (Hadad, 2009).

Attachment theory. Developed by John Bowlby (1980), attachment theory describes the bonds that tie children to their primary caregivers early in life (Hadad, 2009). Attachment bonds are instinctual in nature and exist to ensure safety and survival. Bowlby used attachment theory as the basis for a formulation of loss and recognized that attachment can also occur between adults (Hadad, 2009). Grief is seen as the result of a disruption to an attachment bond; it is an innate response to loss and is an adaptive process. Bowlby described bereavement by the following phases: (1) numbness – shocked and stunned, not as denial, (2) yearning and searching – an alternating state of despair and denial, (3) disorganization and despair – an attempt to recognize the loss and develop a “new normal”, and (3) reorganization – the bereaved is viewed as moving through this phase when there is no thought of the deceased's return and they are able to form new aspects of life and relationships with others (Walter & McCoyd, 2009).

Postmodern Grief Theory

Meaning-Making in Bereavement. The process of making meaning involves imposing a structure on life so it is coherent, organized, understandable, and predictable (Hadad, 2009). When there is the loss of a loved one, the assumptions that once gave meaning to life are often shattered. The grieving process is essentially a way to make meaning of the loss and thus integrate the loss into a new way of being in the world. Neimeyer (2000) stated that meaning

restructuring includes: (1) finding or creating meaning in the death of the loved one and in the life of the bereaved, (2) integrating and constructing meaning within a framework of life beyond the death, (3) an interpersonal process, and (4) a cultural process (Hadad, 2009).

Dual Process Model. The Dual Process Model was developed to examine what bereaved individuals actually do when coping with grief (Hadad, 2009). According to this model, the bereaved individual moves between times of actively experiencing the grief and focusing on the loss (“loss-orientation”) to times of avoiding the grief through focusing on daily activities and functioning (“restoration-orientation”). This oscillation allows the bereaved individual to both recognize the loss and experience the grief, and time away from active grieving to focus on rebuilding one’s life.

Continuing Bonds Theory. Current research is embracing the idea that one can remain emotionally connected to a deceased loved-one through a continued and transformed relationship that still recognizes and acknowledges the death (Rothaupt & Becker, 2007). Based on attachment theory, Klass, Silverman, and Nickman’s (1996) continuing bonds theory challenges the notion that disengagement from the deceased is a part of successful mourning. Grief can be seen as a reaction to having lost someone with whom there was an attachment, in childhood or in adulthood (Hadad, 2009). Klass and colleagues (1996) emphasize that resolving grief does not mean severing the attachment, suggesting that the relationship to the deceased does not end with death.

Concerning dementia, the caregiver can continue a bond with their loved one throughout the stages of dementia. As the disease progresses, the caregiver can transform their relationship with their loved one, while recognizing the loss.

Grief Trajectory

Adams and Sanders (2004) assessed loss and grief reactions experienced by dementia caregivers in the early, middle, and later stages of dementia. They found that caregivers for those in the later stages of dementia reported significantly more symptoms of grief than caregivers of those in the early and middle stages of dementia. Ponder and Pomeroy (1996) also reported that grief shifts for caregivers as the disease progresses, with the intensity of grief being higher in the earlier stages of the disease, declining in the middle stage, and then rising again in the later stage. These findings support the premise that grief for caregivers changes over the course of the disease. The grief associated with caring for a family member will be unique for each caregiver, but the literature illustrates how grief responses to caring for a family member with dementia can change over the progression of the disease as new losses occur at each stage.

Meuser and Marwit (2001) examined caregiver grief at mild, moderate, and severe stages of dementia (stages were determined by cognitive-functional impairment status), and noted some differences between spouse and adult child caregivers. For both these groups of caregivers, the perception of losses shifted with the progression of the disease (Meuser & Marwit, 2001).

At the mild stage of dementia, adult child caregivers are reported to be in denial of the situation by attributing early dementia to the normal aging process or depression. This is illustrated in the minimization of their feelings, and avoidance of discussions regarding the future. Expressed grief is minimal at this stage. Spouse caregivers are more open, accepting, and realistic about the disease, and exhibit feelings of sadness. Expressed grief is a linear progression for spouse caregivers, with the least intense grief experience at the mild stage and increasing with the disease severity. Also noted by Meuser and Marwit (2001), at the mild stage of dementia there are differences between adult child and spouse caregivers' focus of their

losses. The focus of loss for adult children is on their personal losses, such as the loss of freedom and support from siblings. Spouse caregivers' losses are focused on their partners' losses, and on the loss of companionship.

At the moderate stage of dementia, the denial that adult child caregivers maintained at the mild stage is replaced with intense emotions such as sadness, anger, frustration, jealousy of others who do not have to be caregivers, and guilt over the wish that their parent would die (Meuser & Marwit, 2001). Grief is highest at this stage for adult child caregivers, with the focus of loss still being within themselves. For spouse caregivers, their emotions of sadness increase from the earlier stage along with an increase in empathy and compassion, with the focus of loss remaining on their spouse. Meuser and Marwit (2001) account for the differences in responses to caregiving responsibilities simply by the nature of the relationship; adult children see caregiving as an unwanted burden whereas spouses prepare for this eventual caregiving role.

Finally, at the severe stage of dementia, Meuser and Marwit (2001) noted that both groups of caregivers are faced with the task of placing their loved one in a nursing home. At this stage, adult child caregivers experience the mixed sense of relief along with sadness, and the focus of loss is now on the parent and the relationship. Grief is moderate at this stage of dementia. In contrast, grief is highest at this stage for spouse caregivers as they experience anger and frustration, and the focus of loss shifts from their spouses to themselves.

Frank (2007) addressed the question of how to measure levels of grief among dementia caregivers, by reporting on a measure that was developed to be sensitive to the differences in caregivers. The Marwit-Meuser Caregiver Grief Inventory (MM-CGI; Marwit & Meuser, 2002) differed from other grief measures because it was designed to specifically address the grief experienced by dementia caregivers. The MM-CGI items are empirically derived,

psychometrically supported, and representative of spouse and adult children caregivers across mild to severe stages of dementia (Marwit & Meuser, 2002). This measure is intended to be used by clinicians to help caregivers understand the nature of their grief. It consists of three grief-related factors: Personal Sacrifice and Burden (18 items), Heartfelt Sadness and Longing (15 items), and Worry and Felt Isolation (17 items). With the use of this measure, Frank (2007) found that the grief experienced by dementia caregivers can actually serve as a barrier, meaning that it is not the hands-on care issues that are most distressing to caregivers. This further supports the need to examine caregiver grief.

Ambiguous Loss

Another dimension to the experience of grief for caregivers is the concept of ambiguous loss [AL]. AL refers to a situation where the loss is incomplete or uncertain. There are two types of ambiguous loss (Boss, 1999). The first represents the person who is perceived to be psychologically present but physically absent. This is the case in situations of missing persons, where the person is believed to be alive (i.e., kidnappings, military service) but not physically present. The second type of AL reflects when the person is perceived to be physically present but psychologically unavailable. This is the case in dementia, where the person is physically alive but psychology absent. It presents confusion to family members whether the person with dementia is 'truly alive'. Due to the ambiguous nature of the losses associated with dementia, grief responses in caregivers are characterized as being disenfranchised. The disenfranchisement of grief makes support for coping with the significant loss unavailable to caregivers (Rentz et al., 2005). The degenerative nature of dementia brings with it losses that will change over the course of the disease, and these losses are ongoing and ambiguous.

Dupuis (2002) examined the experiences of AL for adult children caring for a parent living in a long-term care facility due to dementia. She explored the meaning of loss for the adult children in describing the stages of ambiguous loss in the context of dementia. There are a few key concepts that Dupuis (2002) describes which add to how we consider the losses caregivers experience when they have a loved one with dementia.

It is important to recognize that there are differences amongst how family members will experience the same loss. This is a point that needs to be considered further, and will become important when understanding AL. As an example, the participants in Dupuis' (2002) study were all adult children of residents with dementia. Although the participants were selectively sampled based on a set criteria, there could be considerable differences between the participants in the study, and even differences that need to be accounted for between siblings.

Phases of ambiguous loss. In support of the paradigm that grief shifts with the progression of dementia, Dupuis (2002) proposed that caregivers think about their losses differently across the course of the disease. Dupuis (2002) described AL as a gradual process rather than the previous conceptualization as a stable event or situation. The first phase in the ambiguous loss process is referred to by Dupuis (2002) as anticipatory loss, where the care recipient is perceived to still be psychologically present and involved in the family unit but ambiguity exists regarding the future. Adult child caregivers in this phase describe their loss in terms of difficulties they may experience when their parents' disease progresses. The next phase of the ambiguous loss process is progressive loss and "involves living through and dealing with the gradual loss of loved ones" (Dupuis, 2002, p. 102). The ambiguity shifts from the previous phase of uncertainty about the future to a confusion regarding the existence of the loved one with

dementia. The final phase of ambiguous loss is acknowledged loss, where the caregiver perceives that their loved one no longer psychologically exists.

Dupuis (2002) describes the phases of AL as being concurrent with the stages of dementia, where the phases of loss follow the same time line as the stages of the disease. This conceptualization of AL as a process is useful because AL can be measured according to phases including anticipatory loss, progressive loss, and acknowledged loss, in direct association with the stages of the dementia. However, this contradicts the previous notion that caregivers, even siblings, may not experience loss in the same way. To account for this, Dupuis (2002) described caregiving as a career and described three phases of the career based on the length of caregiving: the early career is 1-9 months by the caregiver, the mid-career is 10 months to 2 years, and later career is over 2 years. Caregivers can differ on variables for the phases of the experience of AL, the phase of caregiving, and the stage of the disease. Lindgren and colleagues (1999) examined the relationship of grief and the length of caregiving, and found that grief did not vary across the time of caregiving except for the component of guilt. However, grief was reported by the caregivers retrospectively following the death of their family member, so the validity of these results is questionable.

AL has been described as “one of the greatest stressors associated with caring for a person with dementia” (Dupuis, 2002, p. 95). A final contribution of Dupuis (2002) is a potential solution for how to manage caregiver ambiguous loss. She described two coping mechanisms (acceptance and avoidance) that were typically used by her participants to cope with acknowledged loss, the last phase of AL. However, how caregivers cope with AL during the previous phases has not been addressed.

Summary

To summarize, there are several questions that need to be addressed in future research. Dupuis (2002) distinguished between different phases of ambiguous loss, dementia, and the caregiver career. This is useful for professionals in determining where a caregiver may be in their grief process. One coping mechanism was identified as being helpful for caregivers in the acknowledgement phase of AL. It is unclear what coping mechanisms, if any, would be useful for caregivers in the earlier phases of ambiguous loss.

Caregiving for a loved one with dementia can be an emotionally painful and stressful experience. Helping caregivers understand their grief will be useful in providing the needed support. Evidence suggests that grief reactions are not significantly different between the caregivers of those with dementia who are cared for in their homes or institutions, or for bereaved caregivers (Lindgren et al., 1999). However, this does not address the support they would require to cope with loss at all of the stages of dementia. Some caregivers report a sense of meaning and purpose for caring in a loved-one with dementia.

The Present Study

The purpose of this study is to examine the grief of caregivers at the early, middle, and later stages of dementia. There are a limited number of studies that examine the grief of caregivers and how grief reactions and losses shift over the progression of the disease. Few studies have examined how dementia caregivers experience AL and how AL can also shift with the progression of dementia. This review did not generate any formal measures in characterizing AL. Qualitative research will be a useful means to identify the themes of AL as they shift with the progression of dementia. AL has been previously described as a gradual process, but this has been demonstrated solely with adult child caregivers following their family member being placed

in a long-term care facility. Further research on spouse caregivers is needed to support the hypothesis that phases of AL progress with the stages of dementia, as well as research that examines ambiguous loss for caregivers before the care recipient is placed in a long-term care facility.

In gathering this information on grief and losses for caregivers, a secondary goal of this study will be to determine what caregivers find useful in support such that recommendations may be made for on-going care. Noyes, Hill, Hicken, Luptak, Rupper, Dailey, and Bair (2010) capture the difficulty of AL and illustrate that dementia caregivers need to be supported in ways that bereavement support cannot address:

“It is this kind of unstable pattern of loss that makes applying coping resources to offset the impact of grief on the caregiver difficult. In some instances, the degree of ambiguity may be so great that it renders a dementia caregiver’s coping resources less effective than a person who is engaged in postdeath grieving.” (p.11).

The questions of this research are:

- (1) Does grief change with the progression of dementia?
- (2) How will caregivers think about their losses differently at each stage?
- (3) Is AL a gradual process that progresses with the stages of dementia?

Chapter 3: Methodology

Participants and Procedure

Five caregivers of spouses with Alzheimer's disease or related dementia participated in this study. Participants were comprised of a convenience sample recruited from the Alzheimer's Society of London and Middlesex and the Alzheimer Outreach Services of McCormick Home. The recruitment procedure consisted of a poster containing a call for participants with a brief description of the research study and the inclusion criteria (Appendix A and Appendix B), which was posted in counselling offices and/or circulated at support group meetings. A brief presentation to the attending members of a spousal caregiver support meeting was completed at one recruitment site, where potential participants had the opportunity to ask the researcher questions related to the study. All participants received a letter of information outlining the purpose, confidentiality, and risks of the study (Appendix C and Appendix D). Participants had the opportunity to address their questions or concerns. Written informed consent was obtained to participate in the study (Appendix E).

Inclusion Criteria

The inclusion criteria outlined that participants self-identified as being a primary caregiver, without reimbursement, for their spouse with Alzheimer's disease or related dementia. Primary caregiving included sharing caregiving responsibilities with another family member, and involved having to make major decisions for the care recipient, although not necessarily the power of attorney for personal care. This study was not restricted to caregivers based on the number of hours for which they provide direct physical care. Spousal caregivers were selected because previous research showed differences between spouse and adult child caregiver groups, therefore, only spousal caregivers were accepted.

Design

This was a descriptive field study using a qualitative approach to discover each participant's experiences. A quantitative measure complimented the interview questions in order to help identify which stage of grief and loss each participant represented, and to determine each participant's perception of their spouse's cognitive impairment.

Measures

The Caregiver Grief Inventory (MM-CGI; Marwit & Meuser, 2002), as described earlier and presented in Appendix F, was designed specifically to measure the grief of dementia caregivers.

The stage of dementia of the caregiver's spouse was measured by administering the Clinical Dementia Rating (CDR; Morris, 1993) to the caregiver participants (Appendix G). Participants were asked to read each functional domain and choose which description best fit his or her spouse. This measure verified the perceived level of dementia according to the caregiver.

Open-ended questions about grief and loss were queried in an in-person semi-structured interview (Appendix H). Questions were developed in an effort to answer the following: (1) Do dementia caregivers experience ambiguous loss, and if so, what is the essence of their experience?, (2) What caused the feelings of grief, or what are their experiences of grief?, (3) What losses have they experienced?, (4) How do caregivers cope with their grief?, and (5) What types of support are helpful to dementia caregivers? Interviews were audio recorded and transcribed, verbatim.

Inter-rater Reliability

A subset of the qualitative data was coded by an impartial coder to measure the consistency of observed themes. Table 1 outlines the summed frequency of endorsements for the

subset of data, by theme and by coder (i.e., researcher and second coder). A percentage of agreement was calculated for each theme, giving an inter-rater reliability ranging from 66.7% - 97.1%. An inter-rater reliability of 86.9% was calculated when the percentage of agreement by theme was averaged. This accounts for the low percentage of agreement for the themes that were not frequently endorsed (i.e., theme 8).

Table 1: Inter-rater Reliability

	Theme 1	Theme 2	Theme 3	Theme 4	Theme 5	Theme 6	Theme 7	Theme 8	Total
Researcher	25	35	9	17	19	15	29	6	150
Second Coder	24	34	7	18	16	14	34	4	151
% agreement	96.0	97.1	77.8	94.4	84.2	93.3	85.3	66.7	

Ethical Considerations

Consent was informed and voluntary. There was minimal risk to participants. Participation in this study was voluntary, and potential participants were informed prior to signing up that they would be required to talk about their grief experiences as caregivers. Discussing one's personal losses and grief may be an emotional experience, but in the context of this research, participants were only queried on the caregiving experiences of their daily lives. For some participants, this may be the first time they were given the opportunity to express their experiences of caregiving to a nonbiased empathic listener. After the interview, participants were debriefed before they left the interview location.

This study was approved both by Western's *Research Ethics Board* (Appendix I) and the *Alzheimer Society London Middlesex Research Committee*.

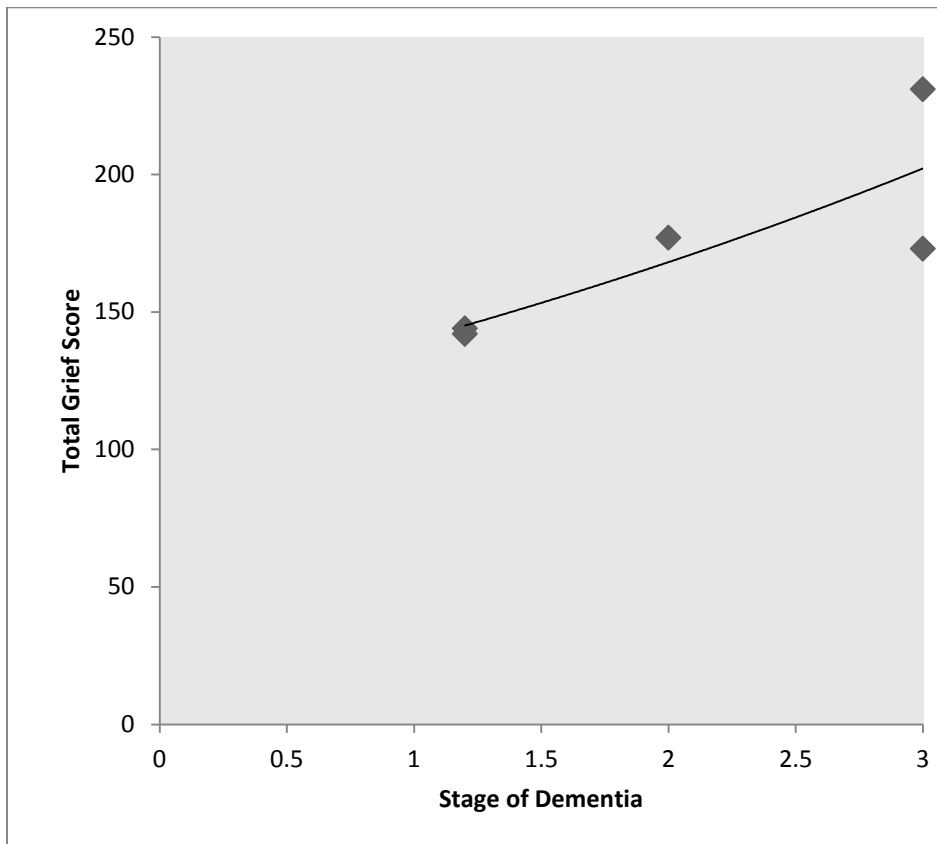
Chapter 4: Results

This study examined the grief experiences of spousal caregivers at the early, middle, and late stages of Alzheimer's disease and related dementias. A review of the literature revealed that there are a limited number of studies that examine how caregiver grief and perceived losses shift over the progression of the disease, and how caregivers experience ambiguous loss. The goal of this study was to gain insight into how grief changes with the progression of the disease, how caregivers think about their losses at each stage of the disease, and whether ambiguous loss is a gradual process. A secondary goal of this study was to gain insight into the coping mechanisms of caregivers and the available supports.

Quantitative Measures

Two qualitative measures were used to assess the reported grief of caregivers (MM-CGI), and the stage of dementia of caregiver's spouse (CDR). These measures were intended to compliment the interview questions, to identify the intensity of grief experienced by each participant, and to determine each participant's perception of their spouse's stage in the disease. Figure 1 illustrates the relationship between the perceived stage of dementia and the total grief scores on the MM-CGI. Table 2 outlines the participants' scores on the CDR, indicating the perceived stage of dementia of their spouse, and the scores on each of the subscales and total grief scores of the MM-CGI.

Figure 1: Relationship Between Stage of Dementia (CDR) and Total Grief Scores (MM-CGI).



Note: Stage of dementia; 0 = no impairment, 0.5 = very mild, 1 = mild, 2 = moderate, 3 = severe.

Table 2: Stage of Dementia and MM-CGI Subscale Scores.

Participant	CDRS	MM-CGI			Total Grief Score
		Personal Sacrifice Burden	Heartfelt Sadness and Longing	Worry and Felt Isolation	
P1	2 (Moderate)	65 (Average)	55 (Average)	57 (High)	177
P2	3 (Severe)	87 (High)	74 (High)	70 (High)	231
P3	3 (Severe)	61 (Average)	70 (High)	42 (Average)	173
P4	1.2 (Mild)	51 (Average)	46 (Average)	47 (Average)	144
P5	1.2 (Mild)	60 (Average)	42 (Average)	40 (Average)	142

Themes

Eight themes were identified in the qualitative analysis of the interview content: (1) Spousal characteristics; (2) Experience of caregiving; (3) Spousal losses; (4) Anticipation of future events; (5) Caregiver losses; (6) Experience of grief; (7) Coping; and (8) Ambiguous loss.

Table 3 outlines the frequency with which each theme was endorsed by the spousal caregiver participants, the total number of endorsements across themes and participants, and the percentage that each theme was endorsed. Appendix J summarizes the above themes with the corresponding meaning codes, as outlined below.

Table 3: Theme Endorsement Summary

Participant	Theme 1: Spousal Characteristics	Theme 2: Experience of Caregiving	Theme 3: Spousal Losses	Theme 4: Anticipation of Future Events	Theme 5: Caregiver Losses	Theme 6: Experience of Grief	Theme 7: Coping	Theme 8: Ambiguous Loss	Total # of endorsed themes
P1	15	19	3	10	6	7	13	1	74
P2	4	16	1	7	9	9	7	2	55
P3	20	20	9	2	11	10	17	3	92
P4	21	33	10	14	17	26	29	1	151
P5	10	16	6	7	13	8	16	5	81
Total # of endorsed themes	70	104	29	40	56	60	82	12	453
% of total endorsements	15.5	23.0	6.4	8.8	12.4	13.2	18.1	2.7	

Theme 1: Spousal characteristics. This theme represents the extent to which caregivers discussed specific characteristics of their spouse. Participants endorsed this theme on 70 occasions, accounting for 15.5% of all endorsements. Three meaning codes were identified within the theme of spousal characteristics: (1) Personality characteristics; (2) Spousal activities; and (3) Changes in spouse. Participant quotes to illustrate these meaning codes are provided in the following passages.

Meaning code 1: Personality characteristics. Participants described their spouses in terms of his or her personality characteristics, including aspects of personality that have not changed, and how personality relates to the experience of caregiving. These descriptions provide depth to the experience of caregiving by illustrating the day to day experience of living with an individual diagnosed with Alzheimer's disease or related dementia. Five of the participants described a spouse who was relatively easy to get along with and did not exhibit difficult personality characteristics related to the disease. For example:

"My wife is very amiable and she's very affectionate and she doesn't give me any trouble at all...she is very cooperative. But she is rather childlike...She's an amiable warm body in the house is what she is. She's affectionate, charming, she likes a lot of hugs and kisses, so that's a great thing."

"He was very, he was a very loving person, and he even up until the time he went into hospital, he would, if I had something on, he would say 'oh you look nice today'. He was very complimentary...that was what he was like, very complimentary person."

"He never complained that I would go out and do it but I know he didn't like sitting there, I mean nobody would. He used to sort of come around and apologize for what was happening which he couldn't help."

"But he didn't have that nastiness...he still had his sense of humour a little bit."

"He's at the stage where he's pretty calm and so it's not that he's much trouble...but he's a pretty easy guy...he loves to go shopping with me. He loves to push the cart around and

he's very patient. He never asks are we going home soon. He loves to go to the mall and walk around and do things like that...he's not difficult, he's not difficult."

"And he always thanks me, if I do anything, or if a meal is especially good, you know, he'll say 'oh, this is really good'. So, you know, he's still, that part of him, he still appreciates things."

"He loves me. He loves to go out for a drive in the car, like he's so easy going."

"He's remarkably good natured if he's not angry. He still has a strong spirit."

Two of the participants described characteristics that were more negative in nature, neutral or absent of positive characteristics, which were presented in very brief comments by the participants:

"I think he, I don't know what emotions he feels now."

"But he got really mad back at me of course."

"He gets angry easily and that's partly him. That's just pre-Alzheimer's, tendency to flare."

Meaning code 2: Spousal activities. Participants described the activities with which their spouses were engaged, including household chores, personal hygiene activities, and leisure activities. These descriptions illustrated the spouse's abilities and capabilities while living with the disease. For example:

"She sleeps a lot of the time and she's obsessed with doing word search puzzles so she spends a lot of time doing word search puzzles, and when she's not doing that, as I said, she sleeps a lot of the time."

"So she'll eat, she gets her lunch for herself and every day it's the same thing, and this is a typical thing for people with Alzheimer's, if they, she can make toast and put margarine on the bread and she likes these cheese slices and has that for lunch just about every day."

“She can dress herself, it’s just that she often doesn’t know what to chose for the occasion, what shoes she’s supposed to wear or something, but she’ll dress herself.”

“He still offers to help with the chores, he does. When there’s dishes to be done and we don’t have a dishwasher, so everything is hand done. But he’ll come in the kitchen, and say ‘is there anything I can help you with?’ And I’ll say, ‘Sure, you put your hands in the soapy water here and we’ll do the dishes together.’ So he’ll wash them and I’ll dry them...Now he used to do all the vacuuming. Now he doesn’t. But you know what he does, he’ll hold the cord of the vacuum and kind of let it out when I need to let it out and, you know, reign it in so that’s a help too. So he helps in any little way, you know, that I ask him to do...I think that makes him feel good too that he’s still able to do things like that.”

“He works on jigsaw puzzles and it goes really slowly but he loves it.”

“What he does is make the bed, and shower, shave, and dress himself. Although I often have to say ‘no, you’ve worn that too many days in a row, give that to me for the laundry, wear this instead’. So I make more suggestions as time goes by for what he should wear. But he showers and shaves with a little prompting from me but he does it himself, so that’s good.”

Meaning code 3: Changes in spouse. This meaning code included the participant’s descriptions of how their spouses have changed, including the progression of the disease, and new behaviours their spouse engage in as the disease progressesbehaviours of their spouse that they would not have done before the disease. For example:

“She can fold the laundry. She has some eccentricity in that respect because after the laundry is finished and in the dryer, down in basement where it is rather cool she thinks they’re damp. She goes to my bedroom and takes my clothes hangers and hangs them all over the place. Supposedly till they’re dry. She has gradually lost interest in television. She can’t keep up with the hour programs she used to watch, such as Bones or NCIS. She used to love those programs. She cannot follow the plots anymore. She doesn’t take much interest in half hour situation comedy except the ones in which it’s lots of slapstick.”

“She has not much concept of time or place anymore so she worries about things I don’t tell her yesterday that she’s going to the we call it the club, She’s going to the club today cause if I did she’d keep going on about it. Worrying about what to wear, what time she has to go.”

“The only thing she’ll eat, she’s very restrictive in what she wants to eat. She’s seemed to go back to childhood. She doesn’t like milk, she won’t eat tomatoes, she takes the seeds out of bananas, tiny tiny little seeds of bananas.”

“The first thing was some years ago when we were driving Adelaide Street and she wanted to know what route we were taking so I said we’re going down Cheapside Street toward Waterloo and she said ‘where’s Waterloo?’. Now she worked at a school on Waterloo Street and Waterloo Street is one of the pretty well known streets to get downtown and I thought, that’s rather strange. And that was the beginning of it. That was the first time it happened. Then there were little things. Even now things get a little weird sometimes. She’ll think, sometimes she’ll think...I called her name, and a couple times she’ll come in the room in the middle of the night and stood by the bed and made me jump out my skin, think I’ve fallen out of bed and was worried about me because she’s heard a thump. So the odd little things have happened.”

“She seems to like being waited on and not having anything to do. In fact, having to do, getting out of the house, getting dressed to go to the club as they call it, she likes it when she gets there but she doesn’t like getting out of the house.”

“I don’t know if he knows me anymore, sometimes I think he does, sometimes I think he doesn’t, and it’s certainly getting worse.”

“Over the last 12 months it became that he couldn’t dress himself or do personal hygiene or bathroom or that sort of thing. It did come on sort of fast.”

“He gradually, over the last 12 months, he gradually started talking to like a pillow, a cushion on the other side of the room, that kind of thing, and he’d think he was talking to me. He would also see animals that we didn’t have. We used to have a dog up until 2 years ago and he used to drop food on the floor for the animal and I used to say ‘don’t do that’ and he used to say ‘oh that’s ok the dog will pick it up’. This was part of the Alzheimer’s getting him. He also used to, at this point, he knew me and he used to love Seinfeld. And he used to, there was one program where George was getting shouted out so he stood up and went to the television and told the person to leave George alone cause he liked him...he said ‘leave George alone’, he said ‘he’s a nice guy or you’ll have me to deal with’.”

“And then we moved, we’re in a one floor condo now so he would never, every time he went to go to the bathroom he would complain that somebody had moved it. And ‘why is it in here, why isn’t where it was yesterday’.”

“Like every time he, if in the morning he, I try to let him fix his own oatmeal in the bowl, put raisins in and he puts it in the microwave and he knows minute and 30 seconds, he still does that. But there are some days he doesn’t even know where the microwave is or he’ll put the cereal in the microwave and he’ll come sit at the kitchen table the dining room table and he’ll sit there and wait and I’ll say, ‘Where’s your cereal?’. I say ‘You’ve probably left it in the microwave’, so he’ll get up and go into the bedroom and that.”

“His understanding of certain jokes or what’s funny has somehow changed. He’ll laugh wildly at something on the TV that actually isn’t funny at all, but he misunderstood it and thought it was, or he’ll just be deadpan during a very funny sitcom.”

Theme 2: Experience of Caregiving. This theme represents how caregivers viewed their role as a caregiver for their spouse. Participants endorsed this theme on 104 occasions, accounting for 23% of all endorsements, which was the highest endorsed theme in this study. Nine meaning codes were identified within the theme of the caregiving experience; (1) Rewarding experiences; (2) Difficult experiences; (3) New responsibilities; (4) Practical aspects of caregiving; (5) Decision making; (6) Maintaining connections to spouse’s family; (7) What has not changed for the caregiver/going well; (8) Projecting feelings onto spouse; and (9) Relationship between caregiver and spouse. Participant quotes to illustrate these meaning codes are provided in the following passages.

Meaning code 1: Rewarding experiences. This code represents the aspects of being a caregiver for their spouse that participants reported they found rewarding, or conversely, that they did not find caring for their spouse an innately rewarding experience. For example:

“I take some pride in managing things. Now, I really do, I take some pride in that. I take pride in keeping my wife happy.”

“It’s been rewarding, I guess, possibly.”

I’d say that it’s, there’s nothing rewarding about it... Not positive in any way that I can think of.”

Meaning code 2: Difficult experiences. This code represents the extent to which participants found caring for their spouse difficult, challenging, or overwhelming. For example:

“I mean, every now and again it overwhelms me and something will set me off quite trying, quite frankly.”

“The other problem I have is, this is a big problem for me right now. I can’t say I’m a great cook, but I think I cook reasonably well. Yesterday I took the easy way out and got hamburger helper, followed the directions and made a meal, and my wife barely touched it, and in fact turned her nose up, and this is a problem every night...and I’m a little worried about her nutrition because I’m not that bad a cook.”

“It’s been difficult more than anything. It’s got gradually worse of course, and it’s got to the point now that I find it very difficult.”

“It was getting more difficult for me. I was getting, finding it way more difficult. Little by little, and then just over the holidays I thought I just can’t handle this.”

“You get frustrated because you, I mean, you have to think for somebody else all the time and that becomes a habit so that really, you don’t think ‘I’ve got to put [husband] in the car’, you just do it.”

“The older I get, like the time. Well it just makes me tired, like I’m more tired. More, the patience and having the patience to stop and take the time to do everything for him, and everything. Not that I think that I’m losing part of my time it’s just that I’ve added on time for him. I don’t resent that. I don’t resent it. I just sometimes I feel as if, kinda overwhelming at times. To have to think for two people.”

Meaning code 3: New responsibilities. This code represents the extent to which participants had to learn new tasks or the roles which their spouse had previously been responsible for, but could no longer do due to the disease. For example:

“I do the laundry now as far as things I had to learn to do...I had to learn how to use the washing machine and how to cook, and there’s an art to buying groceries.”

“But now I have to do everything, I have to do with the Christmas cards and any social contact we have.”

“The lawn was always my husband’s job, everything else outside was mine. And I’ve sort of kept it up. Last year I got a neighbour kid to start cutting the lawn because I had never ever used the riding lawn mower before. But I found out I could, in a pinch, I could do it. It’s funny when you have to do things, you learned how to do things.”

“We used to share and talk about the financial stuff. He has no clue about that stuff anymore so it’s my responsibility to do the best for us both of us.”

Meaning code 4: Practical aspects of caregiving. This code represents the hands-on aspects of caregiving, and the day-to-day activities that participants reported was required for caring for their spouse in their home. For example:

“The last 12 months I had to help him with his walking because his depth perception was gone, so he could only go anywhere with me, in the car.”

“And he would say to me, ‘Can I have [gesture around the waist]’, and I would say ‘What do you want, a belt for your trousers?’, because he motioned for a belt, where the belt would go. And he would say, ‘No you know what I mean’, and I said ‘No I don’t’, and I got to learn that this meant candies. Don’t tell me how, but I said ‘Is it a candy you’re looking for?’, and he said ‘Yes, you know, one of these a candy that I like to eat’. I have no idea how that came but that was the sign for candies in the end.”

“It’s hard to, it’s hard, like getting dressed and getting undressed for bed, things like that. He used to say ‘Well I don’t take this off to go to bed’. It used to be, you have quite a few little fights in the beginning. Not fights, raising of the voices. And he used to sleep in his underwear and t-shirt and to get his other sweater off and golf shirt off and trousers, he couldn’t understand why I had to do this to him. You know, ‘Why can’t you just leave me alone?’. And then he’d have fresh stuff in the morning of course.”

“I mean, when I used to shower [husband] because he didn’t want the lady who came in to do it. At that time he could stand in to the bath and we have the handles and everything and he could stand very well, and that’s 6 months ago even. I used to do it twice or three times a week, it was a chore to do it, it’s very hard on him and me, but I did it.”

“The last 6 months was hard going to the restaurant because of the washroom situation, I couldn’t let him go on his own. So we would go to older restaurants where they would have single men and women and I’d just take him in the women’s and lock the door cause no one’s going to come in anyway. And I found that a hard situation of where to go. Like the malls aren’t too bad cause they’ve got a family one. But if you’re going to the family

restaurants there's usually men and woman and there's 3 toilettes so you can't lock the door. And that was a hard thing for the personal sort of part of it."

"But the caregiving part, except for the part it's time consuming at times because, like, I have to prompt him at most of the things like his hygiene or make sure that he gets in the shower and you know...but I have to, there's your body wash, there's your, I have to direct. I have to put the tap, the faucet on for him cause he doesn't remember how to do that. So it's more time consuming."

"I certainly make all his doctor and dental appointments and I end up going with him which almost always involves my being with him and speaking for him....So really I speak for him almost always. So at restaurants I order for him and at the doctors and I explain that he's here and that he's seeing so and so at such and such a time, and I explain to the doctor everything he's there for. So I speak for him."

"Now, I'm it seems like I'm constantly doing housework, cooking, financial, arranging his doctors appointments, going to pick up his medication."

"I get his meds together each day and give them to him, and he can certainly pick them up and swallow them, but I get them together for him."

"I buy all the gifts for his family for Christmas and birthdays and send all the cards. And I pretty much do everything."

Meaning code 5: Decision making. This code represents the role of the caregiver as the primary decision-maker in the relationship. For example:

"I am very tired. All of this making every decision, maybe that kind of thing is more tiring than doing all the house work. I used to have to do all the housework when I lived alone. Having, knowing that every decision is on you and having to think through what will work for that person and then for me because his language, having to explain everything to him so carefully over and over again and trying to guess what he's saying back to me. I think all those things just really wear me out."

Meaning code 6: Maintaining connections to spouse's family. This code represents the extent to which the caregiver initiates contact with, or puts effort into maintaining the relationships with the spouse's family. For example:

“I’m trying to keep her in touch with her family, but that involves me calling them and me speaking to them and keeping them up to date and chatting with them, then handing the phone over to [wife], and then I have to tell [wife] who they are. But I sometimes tell them, when I call them myself, to remind her of who they are.”

“I’ve sent them all information packets from the Alzheimer Society last year for Christmas, that’s what they got, a packet of information, and some of his children responded and said ‘We never knew all about, we never knew what it was all about’, and I said I thought all the family members should know what is going on... So once a month I get on the computer and I send them all a blanket email about what’s going on and what we’re doing and how he’s doing and how we’re keeping busy and stuff like that, and they appreciate that.”

Meaning code 7: What has not changed for the caregiver/going well. This code represents aspects of the caregiving experience that participants reported had not changed regarding how they live their lives, or aspects that they perceived to be going well. For example:

“I’m fortunate I’m kind of a dull fellow. Give me a book and a computer and I’m quite happy. I’ve got an iPad, my computer, the whole world is there for me on the computer and I just love to read and I don’t, and another thing is I kind of like to shop. I don’t mind going grocery shopping.”

“He eats anything I put in front of him, honestly, honestly. I don’t have to worry about what I’m going to make or will he like this. That’s a great help, you know. And he’s a good eater. I don’t have to worry about him not eating or things like that. That part is good. We get along, we get along great. He’s a good guy.”

Meaning code 8: Projecting feelings onto spouse. This code represents the extent to which participants felt the emotions that they believed their spouse would be experiencing had they not been afflicted with the disease, or if they had any awareness of the disease, the emotions which the caregivers took on as their own. For example:

“...so I suspect she’s being bored. And I tend to put my emotions on to her, I tend to, how can she do that? How can she sit that length of time doing word search puzzles.”

“This is another thing, I’m trying to put my emotions on her because I think if that was happening to me, she knows she has Alzheimer’s, doesn’t seem to bother her.”

“Sometimes I’ll just look at him, this feeling just comes over me, this, like how badly I feel about him, you know, what he’s going through. I think the grief is for him rather than for me. Yeah, I think I’m grieving instead of him grieving, I’m grieving for him.”

“I feel just a tremendous sadness for him, knowing that his life is changing so drastically and will slowly get worse and that he probably won’t live as long as he had hoped.”

Meaning code 9: Relationship between caregiver and spouse. This code represents the relationship that the caregivers reported having with their spouse, as it pertains to their marital relationship, and as caregiver to care recipient. For example:

“But otherwise we get along fairly well.”

“Then you sometimes feel that you get irritated with your spouse, some of the things she does.”

“I, he really just, really gets my, gets me agitated because he doesn’t understand anything that I say to him, and I don’t under, he’ll say the few odd words that I do understand but they don’t make sense at all, so it’s very difficult to see him go like that.”

“There is still love certainly there I think on both sides.”

“We both still have our sense of humour and that helps a lot too.”

Theme 3: Spousal Losses. This theme represents the specific losses that the participants have identified as directly experienced by their spouse. Participants endorsed this theme on 29 occasions, accounting for 6.4% of all endorsements. For example:

“She used to take on a lot of responsibilities such as doing the clothes washing and doing the cooking every evening and sending the Christmas cards. She was more of the social secretary at the time.”

“My wife was a really practical person and she loved her house. She wasn’t overly fond of cooking or housework but she did it in a competent manner. She used to be a teacher. She was a fairly intelligent person.”

“But in the end, [the doctor] wouldn’t let him drive home so that was a real slap in the face...So from then on he wasn’t able to drive.”

“He was slowly over the first, this is 3 years ago, and he slowly lost memory for words.”

“So then from there he couldn’t read or write so that’s where it sort of started.”

“But he lost memory for words when he wanted to say something. He just couldn’t find the right word.”

“And he used to have moments when he used to say he was jealous of other people and I say ‘what do you mean’, and he said ‘well you can talk to them and we can’t talk like that anymore’.”

“He would start to say something and he just went, just could not get the word, and he was a very intelligent man. He had quite a big job in his youth and so this was hard for him too.”

“I was talking to the man in the next bed ...and I looked over and first time that I ever seen my husband in I don’t know how long, he had tears streaming down his face. And then I realized that sometimes they hear you. They hear what you’re saying and I think he was upset again because I could talk to this person and couldn’t talk to him.”

“But he never liked going in the wheelchair naturally. Nobody would. But I think that, and another thing he didn’t like doing was going in company very much because he knew he would be embarrassed. He was always embarrassed of what he couldn’t do anymore. Like having help getting out of a chair, and stuff like that.”

“[Husband] didn’t have any close friends living in, the closest one was [another city] and again he was embarrassed as to what was happening to him, so he didn’t really want to go and meet people.”

“...his family, he doesn’t know their names, he doesn’t know how many children he has or their names.”

“...when he had to lose, when he lost his license. That was really that was a bad time for him. He went on for about a year after that he was very upset. And he was angry.”

“He had a very close group of friends, but I think the guys have more trouble maybe more than women do, knowing how to try to relate to him now. He won’t recognize them when he sees them now. And they’ve mostly dropped off. They just have dropped off.”

“For him, he’s well aware that he has Alzheimer’s and what he’s losing. So it’s often that, ‘oh my god I used to do that all the time’ and he was a very intelligent and talented man...and was really well educated, and an athlete, and on and on and on. He was quite phenomenal. So there are many many things that he used to do that he doesn’t do now and he really excelled at the things that he did. So this is very difficult loss for him and he’s aware of it.”

Theme 4: Anticipation of Future Events. This theme represents the extent to which caregivers reported concerns, thoughts, worries, or expectations for the future. Participants endorsed this theme on 40 occasions, accounting for 8.8% of all endorsements. Five meaning codes were identified within the theme of anticipation for future events: (1) Concern for the future; (2) Anticipated losses/grief; (3) What happens to the spouse if something happens to the caregiver; (4) Placing spouse in long term care; and (5) Life after spouse dies. Participant quotes to illustrate these meaning codes are provided in the following passages.

Meaning code 1: Concern for the future. This code represents how the progression of the disease will impact caregiving for their spouse. For example:

“But I’m concerned about the future. I sometime, rather, I’m going to have to contact CCAC and get some assistance. I know when I can no longer shower her the way I am now, the time when I have to feed her. Wipe her bottom or something like that is something that I’m not really looking forward to in any way shape or form, and I’ll have to contact CCAS and get some assistances. That’s down the line.”

“I have nothing to be optimistic about the rest of my time with him because I know he isn’t going to get any better than he is, he’s going to get worse. And as it gets worse it’s going to be harder on me with dealing with it.”

Meaning code 2: Anticipated losses/grief. This code represents the losses that caregivers believe could potentially occur or they will have to face, related to the progression of the disease, and the grief that they expect to experience in response to upcoming losses. For example:

“I can foresee in the future, I know roughly the way this is going to go and there may come a time when she doesn’t recognize me and that will be a real blow. A terrible emotional blow.”

“I don’t know how long my wife will stay on this plateau. She’s been given a pill that is supposed to keep her, that was from a couple years, year and a half has gone now, maybe there will be a slide downwards.”

“The time she doesn’t recognize me that’s going to be a really, I don’t anticipate that... Well you can imagine when people that you know they suddenly didn’t know who you are.”

“I try not to think of the future, as I said before, but sometimes it does come into mind. It’s not that I, I feel sorry for myself, you kind of you think, oh dear it’s going to worse, I’m going to lose out on a lot more, and everything.”

“And I keep thinking will it get worse, will I, I shouldn’t say will I, I will feel the grief more as time goes by. I try not to, I try not to have too many quiet moments when I look at him and think about, you know, think about what’s coming and what’s going to happen.”

Meaning code 3: What happens to spouse is something happens to caregiver. This code represents the caregivers concerns if they are no longer able to provide care, or be the primary caregiver, for their spouse. For example:

“And another problem I have is my wife is 78 and I’m 81 and have angina. I have a form a cancer too, and I also worry about if something happens to me, what’s going to happen to her...I’m sure my wife will finish up in a long term nursing home which she’s certainly not ready for yet. So that’s a worry as well.”

“So sometimes I think, oh gosh what would happen to him if something happened to me.”

Meaning code 4: Placing spouse in long-term care. This code represents the caregiver’s decision process or concerns regarding placing their spouse in a long-term care facility. For example:

“The only support that I can get is to get him in long-term care. That’s my only solution now. There’s no, I can’t think of any other person that could come into the house to, you

know, think they were helping us out and everything. That is my only solution is to get him into long-term care. And as difficult as it has been up to this point, I know I have to.”

“It was about two weeks after that, they found the nursing home. I couldn’t take him back home because I couldn’t handle, and I knew he was going.”

Meaning code 5: Life after spouse dies. This code represents the caregiver’s expectations that their spouse will ultimately die or be placed in a long-term care facility as a result of the disease, and their expectations of life following this event. For example:

“I’ve got a few more years left surely to goodness, and if he’s in here [long-term care facility], he’ll be well looked after.”

“I did go to bed at night I wonder how many years I have ahead of me, and yet, you don’t want to lose them either.”

Theme 5: Caregiver Losses. This theme represents the losses that the caregivers reported experiencing as a direct result of caring for a spouse with dementia. Participants endorsed this theme on 56 occasions, accounting for 12.4% of all endorsements. Nine meaning codes were identified within the theme of caregiver losses: (1) Aspects of who spouse was; (2) Conversation; (3) Companionship; (4) Personal activities/time; (5) Social connection; (6) Shared memories with spouse; (7) Intimacy; (8) Shared activities; and (9) Family time. Participant quotes to illustrate these meaning codes are provided in the following passages.

Meaning code 1: Aspects of who spouse was. This code represents the extent to which the caregivers perceived that they had lost their spouse as a husband/wife, and the specific characteristics of their spouse that they have lost as a direct effect of the disease. For example:

“I already lost a good deal of what my wife was before.”

“You know, he’s just not the person he was 5 years ago...Just the loss of the man he used to be, my husband.”

“So they basically took him off all the medication and then after that it was about well, about a month after being in the hospital that he didn’t know me then.”

“Like he would not, the real husband wouldn’t have done anything like that, you know.”

Meaning code 2: Conversation. This code represents the extent to which the caregiver reported not being able to converse with their spouse due to the effects of the disease. For example:

“I’ve lost conversation, I can’t converse with her. Sometimes when I talk to her she just goes off on a tangent, talks about something else...I could discuss things with her, I can’t now.”

“Once you’ve talked about here we are having coffee, or something like that, we can’t talk about anything.... And, but to sit and chat about different things it just doesn’t happen anymore.”

“So things I want to share I so often just don’t because he, it would just be too much work and in the end he might not get it. So more and more it seems I don’t talk to him as much, and it’s partly because he can’t respond as much, but also because he less and less, he is less and less likely to understand what I am saying to him.

“A lot of loss, just plain old talking to each other and sharing ideas and thoughts, cause we just did that hours on end. Totally changed.”

Meaning code 3: Companionship. This code represents the extent to which the caregiver perceived that they have lost their spouse as their main source of companionship. For example:

“The companionship is gone.”

“Loss of just having company...He, there’s no empathy on his part. Like if something sad has happened, like say to a friend that passed away, he really, that we were really good friends with or something. And I’ll say so and so passed away. He’ll say ‘oh that’s too bad’, but there’s no sense of, it’s almost as if he’s not feeling it, there’s no feeling left. Now maybe there is there probably is on his part but. So losing him that way is difficult.”

“I feel a real loss of companionship and that’s probably the main loss.”

“Well, most of all, I’ve lost the very enjoyable companionship of someone that I love a lot. Companionship in terms of being able to talk about things, to appreciate the same things.”

Meaning code 4: Personal activities/time. This code represents the extent to which the caregiver reported that they cannot participate in their leisure activities, or have the personal time they had prior to caregiving for their spouse. For example:

“Well, I used to sing with the [singing group]...so I used to go there. I can’t go there anymore.”

“When he’s home I have none because I’m constantly watching what he’s getting into.”

“I love to read and I feel like that’s something that can’t play a big role in my life now because so often if I try to sit down with a book he needs something pretty quickly.”

Meaning code 5: Social connection. This code represents the connections with friends and social groups that the caregiver has lost due to caregiving for their spouse or the progression of the disease. For example:

“But friends just disappear. I guess they just can’t cope with seeing someone like that, that was a friend cause they can’t talk to them anymore and stuff like that. So it’s very lonely, very lonely. And very quiet and very lonely. My evenings are spent really by myself.”

“So my social life which was very very active has changed really drastically”

“I’ve lost, not lost friendships, but lost the frequency of friendships by a long shot. And lost a number of couples friendships, mostly cases where the men were his good friends, mostly from colleagues...who he got to be close to and their wives let’s say, in fact that’s mostly it. ... And so there’s been a loss of, and I had become good friends with these couples too, and I do feel a loss there.”

“I don’t go out in the evening, I used to go with a girlfriend to the movies or have dinner and go to the movies or anything, and I don’t do any of that anymore. So there’s a lot of loss there.”

Meaning code 6: Shared memories with spouse. This code represents the memories that the caregiver had created with their spouse that the spouse can no longer recall. For example:

“And the other thing that they don’t, my wife doesn’t remember things at all. I’ve got reams of photographs, we took a trip to visit my parents in England and we took a bus tour through Europe in 1963, I got lots of photographs from then. Photographs from when we drove out West, we’ve been to Calgary several times, we’ve been down to Florida, all those things I’ve got on sets. But I can show those to her and she doesn’t remember anymore. You lose your memories. This is, you lose her memories so you can’t share your memories with her anymore because she doesn’t have them.”

Meaning code 7: Intimacy. This code represents the extent to which the caregiver has lost their spouse as a lover. For example:

“The touching and stuff like that, and a hug now and then, it’s gone...I have lost him. As a husband and as a lover and as everything.”

“Our romance at times its still there, you know, and I can hug him or dance together and its very nice, but certainly the sexual and romantic components changes a fair bit. So that, there’s not the quite, it’s not the same just major connecting.”

Meaning code 8: Shared activities. This code represents the extent to which the caregiver reported that they were no longer able to participate in activities that they used to do with their spouse. For example:

“We were very active, we played cards a lot. At one point we would play cards every day. Then it got to the point where it was getting too much because we have a big yard and garden and stuff, so we cut back on that a little bit. And we were still playing cards two or three times a day and we, you know, didn’t go out once and a while, and there were parties and stuff that we would go to, and we had to give that up little by little.”

“We would go out, we used to go to sports events, we’d play cards in the evening too. We’d have company over, we have no company over any more.”

“The only thing that I lost was the things we did together. We used to swim a lot. We lived in an apartment with an indoor pool and that was good but then it became too cold, he used to feel cold, so then we couldn’t do that.”

“There’s a lot of things that we used to do. We had a camper van and used to go coast to coast in the States and Canada. We travelled, he loved to travel and he loved to fish and do things like that, and we’ve stopped doing that”

“The sense of loss is what we had, what we did, what we don’t have any more, what we don’t do anymore, and it’s hard to replace that with something else when the other person isn’t on the same wavelength.”

“A lot of things we had planned for our retirement including continuing to go to Mexico every winter, which was just part of our life blood. We have relatives down there, we love the place, we don’t go to the resorts, we go to a city in Mexico where we have relatives. And we just can’t go anymore, like the travelling and the possibility of getting lost in this very large city that we go to and so on. Has made us have to end that.”

“Some of the entertainment that we would enjoy together, going to a movie or a play, or Stratford, we used to do that, or even watching TV in the evening. Part of my enjoyment always came from his enjoyment and discussing it afterwards. All that’s pretty much gone, that doesn’t happen. That’s a real loss to me.”

Meaning code 9: Family time. This code represents the time that the caregiver is no longer able to spend with their immediate and extended family, due to the complications of caregiving for their spouse. For example:

“We used to go to my daughter’s in [another city] and stay overnight on weekends and that. We don’t do that, we just go for day trips now and come home.”

“We used to have his four grandchildren overnight when we lived at the house almost once a month and they loved it, we loved it, it got so that one was having trouble putting up with the noise and stuff ...So we don’t have them, it’s just an apartment and we don’t have room for them to spend the night. And so they aren’t around as much and they don’t relate to him as much, they love him, but they’re not sure what to say to him so in a funny way there’s kind of a loss of that too.”

Theme 6: Caregiver Grief. This theme represents the caregiver’s experience of grief in response to the incurred losses. Participants endorsed this theme on 60 occasions, accounting for 13.2% of all endorsements. Five meaning codes were identified within the theme of caregiver

grief: (1) Guilt; (2) Sadness; (3) Anger; (4) Suppressed feelings; and (5) Changes in grief over time. Participant quotes to illustrate these meaning codes are provided in the following passages.

Meaning code 1: Guilt. This code represents the extent to which caregivers felt guilt in response to caregiving for their spouse, such as spending time away from their spouse, their feelings towards their spouse or situation, feelings of burdening family members, and self-blame for events related to their spouses wellbeing. For example:

“I feel that I can’t leave my wife for something that is a frivolous occasion. If I have to go shopping, there are things that I have to do. If there was something frivolous, I wouldn’t be able to forgive myself if something happened to her. Earlier this year she fell down the stairs, for instance, and broke her leg and arm and I was outside for some reason. When I came in, I heard her calling. She spent time in the hospital. As I say, I had to cut out frivolous things that like that. If I spend time away from her, it’s time I have to spend away from her.”

“And then I feel guilty after. Like yesterday if he could have known what I was saying to him through that door when I was locked out in the cold, he wouldn’t have been pleased (laugh).”

“Cause it’s funny, when he went into hospital and he knew me, and you’ve got this thing, if I hadn’t of taken him in he’d still be here. But who knows, he went down so fast when he went into hospital.”

“When I come home he’ll say ‘oh you’re right on time’ and if I’m not he’ll say ‘you’re ten minutes late’. But then I kind of feel guilty about that so I try to make sure I’m home. There is a bit of guilt when I first started to go out, when I still go to my bazaar and my coffee with the girls like I usually do. It used to bother me to leave him at home.”

“Sometimes I feel guilty because sometimes there’s long periods of silence, even if we’re having coffee at the mall or something, just long periods of silence.”

“...that is a loss, it’s just one I feel a little bit guilty saying because he didn’t cause me to lose that independence, the illness did.”

Meaning code 2: Sadness. This code represents the extent to which caregivers experienced feelings of sadness in response to loss and their spouse’s situation. For example:

“Sometimes if I’m on the television and I see a, I’m watching a video that might touch me a little bit, I probably get overly emotional and cry and break down, and cry and sob a little. So I tend to sublimate whatever feelings of sadness I have. You know, we all have to do that I suppose.”

“I found it, it’s sad. That you have to do this. Particularly...particularly when you know they know.”

“Basically, when you’re husband and wife you’re just sad that you’re not the same as you used to be.”

“I feel sad about it. I feel sad for him rather than me.”

“I just felt so, you know, seeing him get on that bus. Made me sad. It makes me sad when we’re in the company of other friends and that and he can’t seem to carry on a conversation anymore.”

“But that makes me sad too, that he’s not able to communicate. He still asks me, ‘Do you still love me?’. And that makes me sad too.”

“Sometimes I do just sit and cry. Often that’s sparked by something that has gone wrong, that he hasn’t understood or been angry about, but I realize when it happens, that I’m crying because so much is gone. So certainly it’s a grieving and a reaction to difficulties all tied together.”

Meaning code 3: Anger. This code represents the extent to which caregivers experienced anger in response to losses related to the disease. For example:

“I lose my temper a lot and I know that that’s not good.”

“Yeah, I’m mad, I’m mad, I’m really mad at the disease. I’m not mad at him but I’m mad at the disease. What it’s done to him, just ruined him completely.”

“Everyone’s different in the time they progress in this stupid disease.”

“If I can be angry, it takes away the sadness. I don’t know if that makes any sense or not.”

“I was angry, I wasn’t angry at him, I was angry at the disease. ...But there was a lot of anger at the beginning for the first few years. The last two years haven’t been, not that much anger.”

Meaning code 4: Suppressed feelings. This code represents the extent to which caregivers reported an inability to express their feelings of grief, and either intentionally or unintentionally avoid experiencing their grief. For example:

“Well, I suppose I keep [my grief] down most of the time.”

“You keep it bottled up as much as you can, I don’t like to cry if I can help it. And it probably would be good for me if I did do more crying.”

Meaning code 5: Changes in grief over time. This code represents the extent to which caregivers reflected on how their grief has changed or felt differently throughout their caregiving experiences. For example:

“It’s become, yeah I think I’m grieving more now than I was in the beginning. Someone with Alzheimer’s is a thin end of the wedge. When, you don’t really know, it happens so gradually that I had to ask my son and daughter, ‘you notice anything with your mother?’. They both said oh yeah, definitely, but they didn’t want to say anything to me. But when your living with her you don’t quite notice it at first...I just think it’s a gradual increase and there will be a further increase I would imagine.”

“I think it’s become more intense that I feel that way...because I never anticipated it being this bad, so I wasn’t aware of what I was going to have to deal with down the road or had badly it was going to get. Just, you know, no comprehension or anything. I never dreamt that he was going to get like that.”

Well, I don’t think I even felt grief then [when first learned of diagnosis]. I felt this can’t be happening and I had no idea. I didn’t feel grief at the start because I had no idea what was going to happen. I’ve never been around somebody like this before ...So I really didn’t grieve at first at all.”

“Yeah, cause I think in the beginning, as I said, I think it was anger. So there was no time for grief. There was just anger. Eventually it did turn into grief, the loss.”

“Now as the years go by, I keep thinking about grief, and grief, it’ll be different as the years go by, and it changes.”

“I will feel the grief more as time goes by.”

“There is a loss, there is some grief there and I know the grief process began when he was diagnosed, and it will go on.”

“I remember early on when I really realized what was happening and what was ahead, but we were earlier in the stage that I was still able to be very connected to him, even talking to him and so on. I think I grieved more then because he still was really him, and now he’s a different person.”

Theme 7: Coping. This theme represents the coping strategies employed by caregivers, both adaptive and maladaptive. This theme also represents the obstacles caregivers experienced that contributed to difficulties in coping. Participants endorsed this theme on 82 occasions, accounting for 18.1% of all endorsements. Five meaning codes were identified as adaptive coping strategies for caregivers: (1) Meaning making; (2) Support groups/community services; (3) Information gathering; (4) Religion/prayer; and (5) Social support. Four meaning codes were identified as barriers to adaptive coping: (6) Unable to cope; (7) Denial; (8) Lack of family support/involvement; and (9) Lack of understanding from others. Participant quotes to illustrate these meaning codes are provided in the following passages.

Meaning code 1: Meaning making. This code represents the extent to which caregivers attempted to make meaning out of their situation by, for instance, accepting the disease, feeling thankful, and comparing themselves to others. For example:

“I mean, life is random. I have long accepted the randomness of life. I was 30 years of police work and you see life in all its shapes and forms when you are a policeman. Random things happen to people. People get into a car accident for instance and they die. People marry and think that things are going to be great and spouse turns out to be a brute or nag. They live in beautiful house somewhere and they think they have everything and get neighbours from hell, all these things happen to people, it’s just random, so I don’t get angry about the fact that this has happened. It happened to her mother as well, her mother had senile dementia herself later in life. But in lots of ways I think I’m lucky. I’m lucky I have enough money to get by. I’m lucky my house is paid for, my car is paid for. Car will probably last the rest of my life as far as it goes. And I’m lucky I have a son and a daughter that I get on great with. There’s lots of things I feel I’m lucky about,

living in this lovely country in this lovely province. There's lots of things to be thankful for, and I have to keep reminding myself of that."

"And then it's a bit, tend to feel sorry for those that have worse problems, but then it makes you feel good that you don't have those problems. For one thing, my wife now is 78, can't tell you exactly when it started, but these poor people who have early onset Alzheimer's, middle age couple where the husband for instance get Alzheimer's and the wife is still working and he can't work anymore so she's working, so it's a tough thing from two points of view. She has to go to work all day and has to tippy toe around him because men are more aggressive and they're resentful. My wife asked me permission to do things but men, not all women are like her of course, but men tend to get pretty touchy. If they think their wife is trying to boss them around, some women have problems with the men. So I'm lucky that way."

"And I'm giggling, you know. But I mean it isn't funny, but it is. You have to joke about it."

"I mean, with the group here, some of them have had people six or seven years, and to me, it's, I'm a younger, I was ten years younger than my husband and I don't know how some of the ladies cope, I really don't, in their eighties, and it's just so hard."

"No, because you take every day at a time. You take every day and try and make the best of every day. I mean, as far as I'm concerned I had it easier than a lot of the others in the outreach group. I didn't have the abuse, which is a lot of it too. He never swore at me, he never said anything. The only time is when he might argue about getting undressed for bed or something like that, but nothing abusive. No, I think it's every day you think to yourself here we go again, but you make the best, what else can you do. You can either be miserable, but I'm upset now, but I have to go on with my life."

"I am still really able to find everything that does still happen that feels good. And I think you have to keep your eyes out for that stuff and really celebrate it as much as you can. So I try to come up with fun things for us to do or point out something pretty when we're taking a drive or anything that I can think of that's positive, because it helps me and I think it helps him."

Meaning code 2: Support groups/community services. This code represents the extent to which caregivers accessed services in the community, and to which they were aware of additional services that may be needed in the future. For example:

"I didn't realize how much I would depend on [caregiver support groups]. I go to the caregivers' meetings and, in fact, I'm going to start going to two different caregiver

meetings. So one I'm going to now, we recently had a Christmas party there and one of the social workers said there's man...who's in a similar situation to me with his wife. So I'm going to start going to his caregiver's meetings too because it's a great blessing to be sitting there with people who have the same kind of problems you do. They're all different in some ways, but there are some basic things that are common to all Alzheimer's patients. So I'm ready to learn more about it from them, I learn ways to cope. And it's helped me a lot with my wife."

"He was here at the day program more than he was at home. That has been a big help, and the caregivers group, you know, where we just talk, we laugh, we cry, we just tell each other what we've experienced over the last two weeks."

"Like I said, we don't get any hands on [support], I don't feel as if we need it now. But I know there is support at different places, Alzheimer's Society, CCAC [Community Care Access Centre], got all the information and if I ever need anything I know where to call and, you know, what our needs are, and I know somebody's going to respond. I know I'm not alone."

"I think I'm very very lucky. All of us in that [caregiver's support] group are very lucky. That's wonderful, and it's the spousal support group, so everyone in there's a caregiver, the spouses, so we're really in the same boat. We're living every day with that person and I can't tell you how much good solid support there is in that group and the friendships that form. So sometimes we all get together for lunch or coffee. I mean, it's just amazing how helpful that group is and I feel so fortunate. The people in this program over here [Alzheimer Outreach Service], they are wonderful. They are absolutely wonderful people. So even though I am not in the day program, I feel supported because they always greet me when I come in, they know my name right, they learn everyone's name right away. "Oh hi [participant's name], how are you? [Husband] had a good day", whatever, that feels supportive."

Meaning code 3: Information gathering. This code represents the extent to which caregivers seek and collect information related to Alzheimer's disease in order to facilitate understanding of their spouse's experience, and what to expect. This also includes seeking information for available services and supports. For example:

"Yeah, there's plenty of information on Alzheimer's on the internet. The only one that has a community board, I like the community boards, is the Canadian National Alzheimer's Society, as far as I have found anyway. The American one does and the British one does. The British, American, and Canadian one are big organizations so you get information there. That helps."

“I’ve read a lot about Alzheimer’s and dementia and I keep myself informed, and so I know that everybody is different, everyone who’s going through that journey will go through it differently.”

Meaning code 4: Religion/prayer. This code represents the extent to which the caregiver reported religious beliefs and prayer as a way to get through difficult experiences related to their spouse’s disease. For example:

“Well I pray, I pray a lot. I’ve always prayed. I went through a bad time with my first husband...So I prayed. I was praying before then, but I prayed hard then and it got me through, and I pray now.”

Meaning code 5: Social support. This code represents the extent to which the caregiver was able to access emotional or instrumental support from their family and friends. For example:

“Our church is very good. He loves going to church on Sundays and all our friends there have patience of Job (laugh), speaking of church. They’ll listen to him talk and sometimes it doesn’t make sense what he’s saying, it’s kind of, he has a hard time getting words out of his mouth. But they’ll listen and he’ll talk. He has a good friend that takes him out for coffee, and I know it gets more difficult for the friend to converse with him, and I said just let him talk, just sit down and say ‘tell me about it’ and he’ll tell you, he’ll just talk to you.”

“When I’m feeling down I pick up the phone and I call [my grandson] and he is just, he is beyond his age, and he is so, he’s a little compassionate little fellow, honestly...So I always call and say to my daughter I need a [grandson] fix. So he’ll come on the phone and we’ll talk and it lifts my spirits.”

“But if I’m going for more than two hours, and even that’s rare, but if I am, I would have usually his daughter, one of his two daughters, watch him. He would go visit them, I’d drop him off, he’d stay with them and I’d pick him up.”

“He has two daughters in town. They’re very helpful, and I have 2 kids in town who would help out if they could. They’re both working full time, as is one of his daughters. But still, they would do it if they possibly could. So I have a lot of support that way.”

“I’ve got two children in town and one in [another city] who all want to know how [husband] is doing, and talk to me about what it feels like, and always offer to help out. [Husband] has three daughters, but one’s in [another city]. The two here are willing to have him come over or come over. Last night...his one daughter, who doesn’t have kids, came over and sat with him, talked with him, and watched TV with him, basically watched TV with him last night for two hours. That was great.”

“So I feel, the friends that I still see, and I have friends that I still see that are long term friends, are very supportive to me. They just, always, how I am, how he is, so I’m just so lucky that way. Very lucky. I’m so glad that I’ve got them and he’s got me and his family and no one in this whole thing is really on their own and not knowing what to do.”

Meaning code 6: Unable to cope. This code represents the caregiver’s experience of feeling that they are no longer able to cope with their situation. For example:

“I’ve been able to cope with it pretty well up until fairly recently and I just can’t anymore, I just cannot deal with it. Having to give up, and I do not begrudge giving up cause I’m hoping, and I know he would have done the same for me if the tables were turned. You give up everything.”

Meaning code 7: Denial. This code represents the extent to which the caregiver engages in denial to avoid acknowledging realities of the disease. For example:

“At the moment I’m in a fool’s paradise...the moment I’m in a fool’s paradise cause my wife is easy to get along with.”

“I kind of avoided the, the word Alzheimer’s and dementia with him. I don’t know why...But we didn’t talk about it. We didn’t say the word, the ‘A’ word or the ‘D’ word.”

“So there was no time for grief. There was just anger. Eventually it did turn into grief, the loss and the, I try not to dwell on that part, I don’t, I try not to dwell on that. I don’t know if there’s part denial there or not, you know. I wish it would go away. I know it won’t.”

Meaning code 8: Lack of family support/involvement. This code represents the extent to which the caregiver reported feeling isolated from, or that they are not supported by, family or friends. For example:

“And in my case also, my son lives in [another city] and my daughter lives in [another city], and they have families, and my daughter’s on shift work and my son’s a police officer. He and his wife are police officers and have four children. I’m pretty well isolated. I can’t rely on anybody else in this city. All my relatives are in [another country]. All my wife’s relatives come from [another] area. So there’s just me. So it’s a little, I have a sense of being sometimes deserted in a way.”

“Another thing I’d like, but it’s not going to happen, but I’d like my son and daughter to spend some time with my wife.”

“But, I’m very disappointed with his side of family because we were very close. He has some nieces that we were very close to at one point, his brother’s children. And it’s almost that they’ve sort of given up on us, I don’t know if they’re afraid to see him like this or what, but they’ll call occasionally, but they’ve never come to see us, never. And we used to drive to [city] where they’re from, and we used to drive there, but I can’t drive that far anymore. And it’s almost as if they’ve given up and, what the heck, if he doesn’t know them anyway. And it really hurts that they’ve done that to him.”

“We don’t get much support from our family because they’re all out of town.”

Meaning code 9: Lack of understanding from others. This code represents the extent to which the caregiver reported that significant people in their lives do not appreciate the reality of caregiving for a spouse with dementia. For example:

“One of the things that you resent is the fact that people don’t really know what frustrations are of having a spouse with Alzheimer’s. They don’t really, they may think they know, but they don’t. Really, they don’t know because it’s all the time, it’s not just something that takes two hours or something, you’re with that person pretty well all the time.”

“She doesn’t understand, she hasn’t been through this herself and nobody does unless they’ve been through it themselves.”

Theme 8: Ambiguous Loss. This theme represents the extent to which the caregiver identified losing their spouse prior to death. Participants endorsed this theme on 12 occasions, accounting for 2.7% of all endorsements, which was the least endorsed theme. Participant quotes to illustrate this theme is presented in the following passages.

“I’ve had other people close, like my parents, and I had a nephew that died and I really thought I knew what grief was. But seeing someone actually die and you saw the body, they were gone, they were dead. But it’s a different type of grief all together, I don’t know how to explain it. Because really they’re, you might say, brain dead pretty near. Their body is functioning but their brain is not.”

“It’s hard how you feel. This is harder than I thought...Because you lose them twice.”

“His mind had gone. And that’s one of the hardest things.”

“And you feel that you lose them once, and you lose them again.”

“So there is like a, when there’s an illness, the grief begins and then it goes on and then even after death, you know. [My sister] was more, she’s been mourning for years, the loss of her husband, her child. The mourning will go on but it’s almost as if we’re privileged because we can begin earlier before the person dies. I don’t know if that makes any sense or not.”

“So I think I am, all of this stuff I’m telling you is stuff I’m so aware, that I know what I’m really doing is grieving this loss after this one after this one. Not the same kind of grieving that I would feel when he died.”

“Definitely some anger. And some sadness. For sure. I think still not the same as what I would feel, what I’m sure I would feel when he dies, assuming he goes first. Which is just a total loss of that person being with me. As long as he’s alive, he’s still there, he’s still with me so it’s, as much as people say, it is, it is grieving, but it is not like that person has already died.”

“And so the thought of his dying of Alzheimer’s, cause we had watched his mother go through horrible years of not knowing a soul and still being alive, and how sad it was for all of us, that that was always in my mind and I cried a lot.”

Chapter 5: Discussion

The purpose of this research was to examine the grief experiences of the caregivers of spouses with Alzheimer's disease or related dementias, at the early, middle, and late stages of the disease. There is limited research that examines the grief experiences of caregivers and their perceived losses throughout the progression of the disease. The questions of this study aimed to explore whether grief changes with the progression of the disease, how caregivers think about their losses, and whether ambiguous loss is a gradual process that progresses with the disease. Furthermore, this study explored the coping mechanisms of caregivers, with a particular interest in how these strategies relate to coping with ambiguous loss.

Through a qualitative analysis of the participant interview content, eight themes were identified: (1) Spousal characteristics; (2) Experience of caregiving; (3) Spousal losses; (4) Anticipation of future events; (5) Caregiver losses; (6) Experience of grief; (7) Coping; and (8) Ambiguous loss. The overall findings of this study suggest that spousal caregivers experience a gradual increase in their grief over the progression of the disease, with lowest levels of reported grief at the mild stage of disease, and highest levels of grief at the severe stage of the disease. There was a tendency for caregivers to focus their perception of loss on their spouses, specifically with what their spouse was losing and with losing their spouse as a marital companion. Ambiguous loss was not explicitly identified by caregivers, rather, the concept of ambiguous loss and the individual phases were endorsed. Participants' dominant coping mechanisms were meaning making and receiving support from community and social sources.

Links to Previous Research

The transitional process. The caregivers in this study were asked to describe their experiences of caring for their spouse. Interestingly, participants responded with a detailed

description of their spouse, rather than a description of the actual caregiving experience. In this initial description, some caregivers discussed how their spouse was diagnosed with Alzheimer's disease or a related dementia, including specific events in the prediagnostic phase. Caregivers described changes in behaviour or unusual lapses in their spouse's memory that prompted them to pursue a medical explanation. Caregivers reported feelings of anger, disbelief, and grief at the diagnostic phase, with anger being the predominantly reported experience of their spouse. At the postdiagnostic phase, which all caregiver participants were in, there was an expressed acceptance of the disease and a common desire to live one day at a time.

Loss. Spousal losses, as described by caregiver participants, were an identified theme in this research. Interestingly, caregivers did not focus on describing their spouse's losses from the perspective of their spouse, rather, spousal losses were indirectly described in terms of shared losses between the caregiver and spouse (as described in theme 5), characteristics of the spouse (as described in theme 1), and the responsibilities of caregiving (as described in theme 2).

The spouse's losses that were described related to the general loss of cognitive function that caused a drastic change in the spouse's life. It was unclear to what extent these losses were perceptions of the caregiver or if the spouses had awareness of these losses.

Caregiver Loss. Theme 5 was dedicated to caregiver loss, as loss is a significant aspect of caregiving for a spouse with dementia. Not only do caregivers experience losses related to their spouse, but caregivers face multiple losses in their individual lives.

The findings of this study were consistent with previous research, in that caregiver losses comprised the relationship and social connections they once had with their spouse, and related to the increased responsibilities of caregiving. As the scope of this study was not to compare the experiences of spousal and adult child caregivers, there was no gathered information regarding

the perceived obligation of the caregivers. It was noted, however, that spouses did not expect other family members, such as their children, to play an active role in caregiving, and they expressed the desire to have their spouse live at home for as long as possible, as opposed to seeking long-term care accommodations as an option. The reported affection that caregivers expressed towards their spouse is an indication that caregiving was a natural extension of the marital relationship. Interestingly, three of the five participants were married to their spouse later in life, and in some cases, the decision to marry followed the diagnosis. This evidence suggests that caregivers wanted to ensure their spouse received the highest quality of care.

Consistent with the literature is the finding that all caregiver participants reported a unique experience of caring for their spouse, yet all described it as an emotionally distressing experience, at least some of the time. It is consistent with the literature to infer caring for a spouse with Alzheimer's disease or a related dementia as a career, as all participants commented on the time consuming nature of caregiving. All participants were retired, therefore, all participants were able to devote their full time to caregiving responsibilities. Despite the availability of time, however, all caregivers reported that the level of care required was an exhausting experience. It would be accurate, therefore, to label caregiving as a *career*, due to the countless responsibilities, the impact that their caregiving has on their spouse, and the dependence of the care recipients on the caregivers.

Regarding Dupuis' (2002) description of caregiving as a career, this study did not collect information from participants regarding the length of caregiving. However, it was clear from the interview content that all participants were in the later career of caregiving, which is a duration of over 2 years. As previous research indicated that grief and the length of caregiving did not

vary, except for reported guilt, the length of caregiving was not considered as a relevant factor in this study. Regarding the reported guilt, see meaning code 1 in theme 6 for a report on guilt.

Caregivers did not report the hands-on aspects of caregiving as the most distressing; rather, caregivers reported that the time and attention devoted to caring for their spouse and losing the essence of their spouse were the most distressing aspects. For instance, all participants reported the challenges of having to think for their spouse during the entire day as a challenge, and that they were losing their spouse as their main companion and partner in life.

Also noteworthy were some of the acknowledged caregiver losses that were reported as aspects that the caregiver did not mind giving up. For instance, some caregivers reported an acceptance of losing personal time or social activities because they enjoyed being with their spouse, despite their role as the caregiver. All of the caregiver losses, except for personal time/activities were losses related to the relationship with the spouse. For example, losses were described as losing aspects of who their spouse was, and losing companionship and conversation with their spouse. Therefore, caregiver losses were heavily focused on their spouse, as opposed to losses concerning their personal loss.

Postmodern Grief Theory

Meaning-making was a strong coping tendency for the spousal caregiver participants. Participants were confronted with losing their spouse, a person with whom they were expecting to share the rest of their lives. Instead, participants were placed in the role of caregiver for their spouse, and were losing many aspects of their lives, including their spouse. Such losses are accompanied by the shattered assumptions of what once gave meaning to their lives.

Meaning-making in bereavement is a grieving process following the death of a loved one, but can also be applied to the grieving associated with losing a loved one in the progression of

Alzheimer's disease and related dementias, as in the cases within this study. For instance, caregivers in this study reported a tendency to accept the disease and their role as the caregiver as a 'new' way of life, living one day at a time, appreciating what they are grateful for, and comparing themselves to others who, in their perspective, are in less fortunate circumstances. All of these strategies to create meaning of their losses appear to be an attempt by caregivers to rebuild the structure of their lives in a way that is organized and understandable.

The Dual Process Model of bereavement was observed in participants in two ways. First, the oscillation between loss-orientation and restoration-orientation was frequent throughout a given day. For instance, caregivers reported single days where they would actively experience grief related to their losses, and focus on the daily activities of caregiving. Second, the oscillation seemed to be suspended in the loss-orientation for an extended period of days or weeks, without a clear indication of time away from active grieving. In these cases, the caregivers had experienced significant losses related to the disease, such as deciding to place their spouse in a long-term care facility or the death of their spouse.

Continuing Bonds Theory was present among the caregivers, as they continued to recognize their primary role as a spouse and the relationship they had with their spouse, despite the progression of the disease. Caregivers were reporting how the relationship with their spouse had changed, but also reported aspects that remained the same, such as the love they shared with their spouse. Caregivers were transforming their relationship with their spouse from partner to caregiver, while recognizing their losses along the way. It was noted that the severity of the disease did not impact the caregiver's identity as the spouse in the relationship.

Grief Trajectory

Consistent with previous research (i.e., Adams and Sanders, 2004), this study found that caregivers for those in the later stages of Alzheimer's disease and related dementias reported higher levels of grief than caregivers of those in early and middle stages of the disease. This was measured with the CDR, in which caregivers reported their perception of their spouses functioning, and the MM-CGI (Marwit & Meuser, 2002), which measured the caregivers level of grief. The findings of this study were consistent with previous research, in that spouse caregivers experienced grief in a linear progression, with the least intense grief reported at the mild stage and increasing with disease severity.

As illustrated in Figure 1, there was a linear progression of reported grief amongst caregivers, with lowest levels of grief reported among participants in the early stage of caregiving, moderate levels of grief reported among caregivers in the middle stage of caregiving, and highest levels of grief reported by caregivers in the late stage of caregiving. This supports the premise that grief changes in time with the progression of the disease. The caregivers in this study were focused on their spouse's losses, which then shifted to focus on their personal losses.

At the mild stage of the disease, and also consistent with the literature, is the reported focus of loss on their spouse's losses, and on the loss of companionship.

At the moderate stage of the disease, the focus of loss remained on the caregiver's spouses, and reports of sadness increased from the earlier stage. This is consistent with the literature. All participants reported feelings of sadness in their interviews, and described their grief as feeling sad for what their spouse was losing, and feeling the loss of companionship with their spouse.

At the more severe stage of the disease, participants were in the process of placing their spouse in a long-term care facility or already had done so, which is a characteristic milestone at this stage of the disease. Consistent with the literature, grief was highest at this stage for the spousal caregivers. Anger and frustration were strongly reported by the participant who was in the process of placing their spouse in a long-term care facility, in addition to feelings of sadness. Loss was more focused on the participant's personal losses at this stage rather than the spouses, as the caregivers were now in the position to consider their life outside of the caregiving role, and the physical loss of their spouse is predominant, for instance with their spouse either moving out of the home or physically dying. That is, the caregivers were no longer actively providing the day-to-day care for their spouse.

The MM-CGI (Marwit & Meuser, 2002) is composed of a total grief score and three subscales: (1) Personal Sacrifice Burden; (2) Heartfelt Sadness and Longing; and (3) Worry and Felt Isolation. Table 2 outlined the participants scores on the CDR, indicating the perceived stage of dementia of their spouse, and scores on each of the subscales and total grief score of the MM-CGI. An average score on any subscale indicates grief reactions that are common among caregivers, whereas high scores may indicate that there is a need for formal support or there is poor coping (Marwit & Meuser, 2002). The purpose of the subscales are to facilitate a dialogue between the caregiver and the support worker so that the caregiver can gain a deeper understanding of their grief experience and receive the support that is needed.

According to Marwit and Meuser (2002), placing a spouse in a long-term care facility brings high levels on the subscales of Heartfelt Sadness and Longing, and Worry and Felt Isolation, which was representative for the participant in this study who had recently made that decision. For the participant whose spouse had recently passed away after time in a long-term

care facility, it comes as no surprise that there was a high score on the heartfelt sadness and longing subscale.

Ambiguous Loss

As ambiguous loss refers to a situation where the loss is incomplete or uncertain, it was evident that participants did not possess the language to express their experiences of ambiguous loss, although they did refer to ambiguous loss through their descriptions of their caregiving experiences. For instance, participants reported experiencing the loss of their spouse twice, once through the disease and again at death. Participants also reported losing the mental capacity of their spouse, which defines ambiguous loss. This could be an indication that the caregivers are more focused on the aspects of what remains of their spouse rather than the aspects that are lost, and that perhaps it takes a reflective period after the death of their spouse to recount how their loss experiences were ambiguous in nature.

As previously described, it was proposed by Dupuis (2002) that ambiguous loss be conceptualized as a gradual process, rather than a stable event or situation, and that each phase of ambiguous loss parallels the stage of dementia. The phases of ambiguous loss as described by Dupuis (2002), anticipatory loss, progressive loss, and acknowledged loss, were reported by the participants in this study. For instance, participants reported anticipatory loss and grief, as described in theme 4, in which they reported concerns for the future and the expected losses related to the progression of their spouses' disease. Participants reported progressive loss, in which they described living with a spouse with dementia and the associated losses. The final phase of ambiguous loss, acknowledged loss, was also reported by caregivers as they related to aspects of the psychological losses of their spouse.

Although all participants reported experiences that are consistent with the three phases of ambiguous loss as described above, participants experienced these simultaneously, rather than in phases. There was no indication that the phases of ambiguous loss progressed with the severity of the disease. Considering these as features of ambiguous loss rather than phases, it is clear that participants are experiencing ambiguous loss, even though they are not describing it with the related terminology.

Relevance to the Counselling Profession

Recognizing the loss experiences of caregivers is important to the counselling profession, as there was a reported desire from participants to receive formal supports. Participants reported accepting the available services, and did not express any forms of support that they were not receiving, except through family members. That being said, it was hypothesized that the participants in this study would accept counselling services if offered, under the assumption that other service providers are not providing informal counselling to caregivers. For instance, one participant reported knowledge of grief counselling, and the perceived benefits of such counselling while experiencing the gradual loss of a spouse to Alzheimer's disease, both during active caregiving and following death. With a deeper understanding of the grief experience of caregivers, caregivers could be assisted to understand their experience of grief and identify the areas in which they need further support.

A professional counsellor would be able to offer formal grief support, for instance, with the use of the MM-CGI subscales. Participants in this study appeared very open and candid when sharing their experiences. However, their participation was an interview and in no way was there an interaction between the participant and the interviewer consistent with a counselling session. With that, participants were provided the opportunity to express their feelings and experiences to

a willing listener. The eagerness of participants to share their experiences indicates that there is a need for counselling among the caregiving population.

Participants reported positive experiences in the support groups they attended. However, there was also a reported ambivalence regarding the nature of these groups, such as disapproving of certain content shared by other members. For this reason, it appears that individual counselling could be beneficial in addition to group support, so that the experience is completely free of judgement and solely focused on the individual experience. Individual grief counselling would give the individual a place to express and feel their grief, understand their grief, and have their grief acknowledged by an empathic trained professional, especially regarding the ambiguous loss and disenfranchisement of grief. If there are complications in coping with grief, such as with denial, avoidance, or barriers to coping, the counsellor can effectively support the individual. Following the death of their spouse, the counsellor can monitor the situation so that the caregiver continues to process the loss in a supportive environment.

Grief is often perceived as a reaction to the death of a loved one. However, this research further supports the prevalence of ongoing grief and ambiguous loss in this population. Spousal caregivers will continue to grow in numbers as the prevalence of Alzheimer's disease and related dementias are expected to increase significantly. The demands on community services will be taxed and will experience significant pressure to increase available resources given the numbers of individuals who are in need of service. Unfortunately, this could potentially result in an increase in the number of individuals who do not receive needed services. Given that grief and ambiguous loss are distressing experiences related to caregiving for a loved one with dementia, it is evident that funding will need to be increased for community and counselling services to meet the needs of caregivers. This will be even truer if caregivers continue to extend the length of

time that they attempt to care for their spouse in their homes, and the increase of grief that will be experienced when they have to place their spouse in a long-term care facility or hospital.

Relevance to future research

The findings of this study were consistent with previous research regarding the changes in grief and the existence of ambiguous loss. This study contributed to the existing literature in that it described the grief experiences of spousal caregivers and the unique experiences of loss and grief over the progression of the disease.

The participants in this study represented a convenience sample of individuals who were receiving services from the Alzheimer's Society London & Middlesex and/or the Alzheimer Outreach Service of McCormick Home. It was evident from the interview content that all participants reported feeling very well supported by these community services and services from CCAC (Community Care Access Centre).

A question for future research would be to investigate those caregivers who are not receiving community support, are not participating in support groups to the extent that the participants in this study were, and the caregivers who experience financial or location barriers to receiving community support. Are there unique challenges to the caregiver population who are not regular recipients of community services, and how do they cope?

Future research could also benefit from the development of a quantitative measure for ambiguous loss. Using the three components of ambiguous loss as described above, this measure could be developed similarly to the MM-CGI, in that there would be a total ambiguous loss score and three subscales, one for each of the defining components. Such a measure would be helpful to identify the extent to which caregivers are experiencing ambiguous loss, to open the dialogue

for extended support, and to increase the language regarding ambiguous loss for caregivers and those who support them.

Limitations

A limitation of this study was the small sample size of five participants. This study utilized a convenience sample, and given the time restraints, the sample goal was six participants.

With a small sample size, the distribution of caregivers among the three stages of disease progression was short one participant in the moderate stage of disease.

Another limitation of this study was the unequal distribution of male and female participants, as it has been noted in previous literature that male caregivers, especially older male caregivers, do not express their grief in the same way that female caregivers express their grief. In this study, there were no noted differences between male and female participants, however, further comparison could be beneficial to future research.

Summary

Notwithstanding the limitations identified above, the findings of this study support the premise that caregiver grief progresses with the stages of Alzheimer's disease and related dementias, and that caregivers think about their losses differently throughout the progression of the disease. This study examined the grief experiences of the caregivers of spouses with Alzheimer's disease or related dementias, at the early, middle, and late stages of the disease, finding that spousal caregivers experienced grief in a linear progression, with the least intense grief reported at the mild stage and increasing with disease severity. Caregivers focused their losses predominately on their spouse until the later stage of the disease, when identified losses became more focused on personal losses of the caregiver. This study identified eight unique

themes common to all participants, which provides new clarity about the grief experience of caregivers. Ambiguous loss was not identified as phases that progress with the disease, as hypothesized in previous research. This study supports three components of ambiguous loss, rather than phases, which caregivers experienced at all stages of the disease. Meaning-making and continuing bonds were found to be dominant in the caregiver's experiences, which provides a reference for how professionals involved with grief and bereavement work can interpret non-death and ambiguous loss experiences.

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Research Participation Opportunity

“Ambiguous Loss for Caregivers of Family Members with Dementia”

Seeking participants for a research study conducted by a graduate student from the University of Western Ontario. The purpose of this study is to gain understanding into the experiences of adults who are caring for a spouse with dementia, and to explore how caregivers need or want to be supported.

If you agree to participate in this study you will be asked to complete 2 questionnaires, and an in-person interview. Questions will ask participants to discuss their losses and experiences of grief associated with caring for a spouse with dementia. Participation will take place at the Faculty of Education at Western University (Althouse College) and will take approximately 1-2 hours of your time. Parking will be provided.

Eligible participants must be the spouse of the individual with dementia. Any form of dementia is eligible. Participants must identify as being the primary caregiver of their spouse, meaning that they are involved in making major decisions about their spouse's care. Participants do not necessarily have to be the power of attorney for their spouse or be the sole care provider, however, participants who receive monetary compensation for caring for their spouse are not eligible to participate.

Participation in this study, or refusal to participate, will in no way affect the support services received by ASLM clients from the Society.

The information collected will be used for research purposes only, and neither your name nor information which could identify you will be used in any publication or presentation of the study results. All information collected for the study will be kept confidential.

For questions about the study, or to volunteer to participate, please contact Ashleigh at [contact information redacted] or by email at [contact information redacted].

Research Participation Opportunity

“Ambiguous Loss for Caregivers of Family Members with Dementia”

Seeking participants for a research study conducted by a graduate student from the University of Western Ontario. The purpose of this study is to gain understanding into the experiences of adults who are caring for a spouse with dementia, and to explore how caregivers need or want to be supported.

If you agree to participate in this study you will be asked to complete 2 questionnaires, and an in-person interview. Questions will ask participants to discuss their losses and experiences of grief associated with caring for a spouse with dementia. Participation will take place at the Alzheimer Outreach Services of McCormick Home and will take approximately 1-2 hours of your time.

Eligible participants must be the spouse of the individual with dementia. Any form of dementia is eligible. Participants must identify as being the primary caregiver of their spouse, meaning that they are involved in making major decisions about their spouse's care. Participants do not necessarily have to be the power of attorney for their spouse or be the sole care provider, however, participants who receive monetary compensation for caring for their spouse are not eligible to participate.

Participation in this study, or refusal to participate, will in no way affect the support services received by caregivers or clients from McCormick Home or Alzheimer Outreach Service.

The information collected will be used for research purposes only, and neither your name nor information which could identify you will be used in any publication or presentation of the study results. All information collected for the study will be kept confidential.

For questions about the study, or to volunteer to participate, please contact Ashleigh at [contact information redacted] or by email at [contact information redacted].

APPENDIX C: Letter of Information Alzheimer's Society

***AMBIGUOUS LOSS FOR CAREGIVERS OF FAMILY MEMBERS WITH DEMENTIA***

LETTER OF INFORMATION

Introduction

My name is Ashleigh Vella and I am a graduate student at the Faculty of Education at Western University. I am currently conducting research into the grief experienced by dementia caregivers and would like to invite you to participate in this study.

Purpose of the study

The aims of this study are to gain understanding into the experiences of adults who are caring for a spouse with dementia, and to explore how caregivers need to or want to be supported.

If you agree to participate

If you agree to participate in this study you will be asked to complete 2 questionnaires, and an in-person interview. Participation will take place at the Faculty of Education at Western University and will take approximately 1-2 hours of your time. Interviews will be audio-recorded and transcribed into written format.

Confidentiality

The information collected will be used for research purposes only, and neither your name nor information which could identify you will be used in any publication or presentation of the study results. All information collected for the study will be kept confidential. Research data will be retained for 7 years and will be stored in a locked cabinet in the office of Dr. Alan Leschied and will then be destroyed confidentially. Please note that if you report any abuse against you, the caregiver, or the individual with dementia, including perceptions of feeling unsafe, I must report this to the Alzheimer Society staff.

Risks & Benefits

There are no known risks to participating in this study. If responding to the interview questions causes you to feel very uncomfortable or anxious, please inform the researcher so that we can provide assistance.

Voluntary Participation

Participation in this study is voluntary. You may refuse to participate, refuse to answer any questions or withdraw from the study at any time with no effect on the services provided to you and your spouse from the Alzheimer's Society.

Questions

If you have any questions about the conduct of this study or your rights as a research participant you may contact the Office of Research Ethics, Western University at [contact information redacted]. If you have any questions about this study, please contact me at [contact information redacted] or my faculty advisor Alan Leschied at [contact information redacted].

If you would like to receive the results of the study please let the researcher know.

This letter is yours to keep for future reference.

[Signature]

Ashleigh Vella

APPENDIX D: Letter of Information Alzheimer Outreach Service

***AMBIGUOUS LOSS FOR CAREGIVERS OF FAMILY MEMBERS WITH DEMENTIA***

LETTER OF INFORMATION

Introduction

My name is Ashleigh Vella and I am a graduate student at the Faculty of Education at Western University. I am currently conducting research into the grief experienced by dementia caregivers and would like to invite you to participate in this study.

Purpose of the study

The aims of this study are to gain understanding into the experiences of adults who are caring for a spouse with dementia, and to explore how caregivers need to or want to be supported.

If you agree to participate

If you agree to participate in this study you will be asked to complete 2 questionnaires, and an in-person interview. Participation will take place at McCormick Home and will take approximately 1-2 hours of your time. Interviews will be audio-recorded and transcribed into written format.

Confidentiality

The information collected will be used for research purposes only, and neither your name nor information which could identify you will be used in any publication or presentation of the study results. All information collected for the study will be kept confidential. Research data will be retained for 7 years and will be stored in a locked cabinet in the office of Dr. Alan Leschied and will then be destroyed confidentially. Please note that if you report any abuse against you, the caregiver, or the individual with dementia, including perceptions of feeling unsafe, I must report this to the Alzheimer Outreach Services social worker staff.

Risks & Benefits

There are no known risks to participating in this study. If responding to the interview questions causes you to feel very uncomfortable or anxious, please inform the researcher so that we can provide assistance.

Voluntary Participation

Participation in this study is voluntary. You may refuse to participate, refuse to answer any questions or withdraw from the study at any time with no effect on the services provided to you and your spouse from the Alzheimer Outreach Services of McCormick Home.

Questions

If you have any questions about the conduct of this study or your rights as a research participant you may contact the Office of Research Ethics, Western University at [contact information redacted]. If you have any questions about this study, please contact me at [contact information redacted] or my faculty advisor Alan Leschied at [contact information redacted].

If you would like to receive the results of the study please let the researcher know.

This letter is yours to keep for future reference.

[Signature]

Ashleigh Vella

APPENDIX E: Consent Form

AMBIGUOUS LOSS FOR CAREGIVERS OF FAMILY MEMBERS WITH DEMENTIA*Ashleigh Vella, University of Western Ontario*

CONSENT FORM

I have read the Letter of Information, have had the nature of the study explained to me and I agree to participate. All questions have been answered to my satisfaction.

Name (please print): _____

Signature: _____ Date: _____

Name of Person Obtaining Informed Consent: _____

Signature of Person Obtaining Informed Consent: _____

Date: _____

APPENDIX F: Marwit-Meuser Caregiver Grief Inventory (MM-CGI)

Instructions: This inventory is designed to measure the grief experience of current family caregivers of persons living with progressive dementia (e.g., Alzheimer's disease). Read each statement carefully, then decide how much you agree or disagree with what is said. Circle a number 1-5 to the right using the answer key below (for example, 5 = strongly agree).

ANSWER KEY					
1 = Strongly Disagree 2 = Disagree 3 = Somewhat Agree 4 = Agree 5 = Strongly Agree					
1	I have to give up a great deal to be a caregiver.	1	2	3	4 5
2	I miss so many of the activities we used to share.	1	2	3	4 5
3	I feel I am losing my freedom.	1	2	3	4 5
4	My physical health has declined from the stress of being a caregiver.	1	2	3	4 5
5	I have nobody to communicate with.	1	2	3	4 5
6	I don't know what is happening. I feel confused and unsure.	1	2	3	4 5
7	I carry a lot of stress as a caregiver.	1	2	3	4 5
8	I receive enough emotional support from others.	1	2	3	4 5
9	I have this empty, sick feeling knowing that my loved one is "gone".	1	2	3	4 5
10	I feel anxious and scared.	1	2	3	4 5
11	My personal life has changed a great deal.	1	2	3	4 5
12	I spend a lot of time worrying about the bad things to come.	1	2	3	4 5
13	Dementia is like a double loss...I've lost the closeness with my loved one and connectedness with my family.	1	2	3	4 5
14	I feel terrific sadness.	1	2	3	4 5
15	The situation is totally unacceptable in my heart.	1	2	3	4 5
16	My friends simply don't understand what I'm going through.	1	2	3	4 5
17	I feel this constant sense of responsibility, and it just never leaves.	1	2	3	4 5
18	I long for what was, what we had and shared in the past.	1	2	3	4 5
19	I could deal with other serious disabilities better than with this.	1	2	3	4 5
20	I can't feel free in this situation.	1	2	3	4 5
21	I'm having trouble sleeping.	1	2	3	4 5
22	I'm at peace with myself and my situation in life.	1	2	3	4 5
23	It's a life phase, and I know I will get through it.	1	2	3	4 5

24	My extended family has no idea what I go through in caring for him/her.	1	2	3	4	5
25	I feel so frustrated that I often tune him/her out.	1	2	3	4	5
26	I am always worrying.	1	2	3	4	5
27	I'm angry at the disease for robbing me of so much.	1	2	3	4	5
28	This is requiring more emotional energy and determination than I ever expected.	1	2	3	4	5
29	I will be tied up with this for who knows how long.	1	2	3	4	5
30	It hurts to put him/her to bed at night and realize that he/she is "gone".	1	2	3	4	5
31	I feel very sad about what this disease has done.	1	2	3	4	5
32	I feel severe depression.	1	2	3	4	5
33	I lay awake most nights worrying about what's happening and how I'll manage tomorrow.	1	2	3	4	5
34	The people closest to me do not understand what I'm going through.	1	2	3	4	5
35	His/her death will bring me renewed personal freedom to live my life.	1	2	3	4	5
36	I feel powerless.	1	2	3	4	5
37	It's frightening because you know doctors can't cure this disease, so things only get worse.	1	2	3	4	5
38	I've lost other people close to me, but the losses I'm experiencing now are much more troubling.	1	2	3	4	5
39	Independence is what I've lost...I don't have the freedom to go and do what I want.	1	2	3	4	5
40	I've had to make some drastic changes in my life as a result of becoming a caregiver.	1	2	3	4	5
41	I wish I had an hour or two to myself each day to pursue personal interests.	1	2	3	4	5
42	I'm stuck in this caregiving world, and there's nothing I can do about it.	1	2	3	4	5
43	I can't contain my sadness about all that's happening.	1	2	3	4	5
44	What upsets me most is what I've had to give up.	1	2	3	4	5
45	I'm managing pretty well overall.	1	2	3	4	5
46	I think I'm denying the full implications of this for my life.	1	2	3	4	5
47	I get excellent support from members of my family.	1	2	3	4	5
48	I've had a hard time accepting what is happening.	1	2	3	4	5
49	The demands on me are growing faster than I ever expected.	1	2	3	4	5
50	I wish this was all a dream and I could wake up back in my old life.	1	2	3	4	5

APPENDIX G: Clinical Dementia Rating (CDR)

Functional Domain	Normal/No Impairment (0)	Very Mild (0.5)	Mild (1)	Moderate (2)	Severe (3)
1. Memory	No memory loss or slight inconsistent forgetfulness	Consistent slight forgetfulness; partial recollection of events; "benign" forgetfulness	Moderate memory loss; more marked for recent events; defect interferes with everyday activities	Severe memory loss; only highly learned material retained; new material rapidly lost	Severe memory loss; only fragments remain
2. Orientation	Fully oriented	Fully oriented except for slight difficulty with time relationships	Moderate difficulty with time relationships; oriented for place at examination; may have geographic disorientation elsewhere	Severe difficulty with time relationships; usually disoriented to time, often to place	Oriented to person only
3. Judgment & problem solving	Solves everyday problems & handles business & financial affairs well; judgment good in relation to past performance	Slight impairment in solving problems, similarities, and differences	Moderate difficulty in handling problems, similarities, and differences; social judgment usually maintained	Severely impaired in handling problems, similarities, and differences; social judgment usually impaired	Unable to make judgments or solve problems
4. Community affairs	Independent function at usual level in job, shopping, volunteer and social groups	Slight impairment in these activities	Unable to function independently at these activities although may still be engaged in some; appears normal to casual inspection	No pretense of independent function outside home; appears well enough to be taken to functions outside of family home	No pretense of independent function outside of home; appears too ill to be taken to functions outside a family home
5. Home and hobbies	Life at home, hobbies, and intellectual interests well maintained	Life at home, hobbies, and intellectual interests slightly impaired	Mild but definite impairment of function at home; more difficult chores abandoned; more complicated hobbies and interests abandoned	Only simple chores preserved; very restricted interests, poorly maintained	No significant function in home
6. Personal care	Fully capable of self-care		Needs prompting	Requires assistance in dressing, hygiene, keeping of personal effects	Requires much help with personal care; frequent incontinence

APPENDIX H: Semi-structured Interview Questions

- 1) Can you describe your experience of caring for your spouse? (Probe: For instance, has it been difficult or rewarding?)
- 2) What has been your experience of grief while caring for your spouse? (Probe: For instance, have you felt sad, regretful, angry, or compassionate?)
- 3) Has your grief changed or felt differently over time? (Probe: For instance, when you first suspected or learned of the diagnosis to now?)
- 4) What losses have you experienced? (Probe: For instance, have you lost your social connections, personal time, income, or companionship with your spouse?)
- 5) How have you coped with your grief? (Probe: For instance, have you depended on friends and family to help, or have you been optimistic about the time you have with your spouse?)
- 6) Is there any support you have found helpful, or think would be helpful to you? (Probe: For instance, with family members or community services/programs?)

APPENDIX I: Ethics Approval Notice

Western Education
WESTERN UNIVERSITY
FACULTY OF EDUCATION
USE OF HUMAN SUBJECTS - ETHICS APPROVAL NOTICE

Review Number: 1304-4
 Principal Investigator: Alan Leschied
 Student Name: Ashleigh Vella
 Title: *Ambiguous Loss for Caregivers of Family Members with Dementia*
 Expiry Date: April 30, 2014
 Type: M.Ed. Thesis
 Ethics Approval Date: June 10, 2013.
 Revision #:
 Documents Reviewed &
 Approved: Western Protocol, Letter of Information & Consent, Advertisement

This is to notify you that the Faculty of Education Sub-Research Ethics Board (REB), which operates under the authority of the Western University Research Ethics Board for Non-Medical Research Involving Human Subjects, according to the Tri-Council Policy Statement and the applicable laws and regulations of Ontario has granted approval to the above named research study on the date noted above. The approval shall remain valid until the expiry date noted above assuming timely and acceptable responses to the REB's periodic requests for surveillance and monitoring information.

During the course of the research, no deviations from, or changes to, the study or information/consent documents may be initiated without prior written approval from the REB, except for minor administrative aspects. Participants must receive a copy of the signed information/consent documentation. Investigators must promptly report to the Chair of the Faculty Sub-REB any adverse or unexpected experiences or events that are both serious and unexpected, and any new information which may adversely affect the safety of the subjects or the conduct of the study. In the event that any changes require a change in the information/consent documentation and/or recruitment advertisement, newly revised documents must be submitted to the Sub-REB for approval.

Dr. Alan Edmunds (Chair)

2012-2013 Faculty of Education Sub-Research Ethics Board

Dr. Alan Edmunds	Faculty of Education (Chair)
Dr. John Barnett	Faculty of Education
Dr. Wayne Martino	Faculty of Education
Dr. George Gadanidis	Faculty of Education
Dr. Elizabeth Nowicki	Faculty of Education
Dr. Julie Byrd Clark	Faculty of Education
Dr. Kari Vebleu	Faculty of Music
Dr. Jason Brown	Faculty of Education
Dr. Suzan Rodger	Faculty of Education, Associate Dean, Research (<i>ex officio</i>)
Dr. Ruth Wright	Faculty of Music, Western Non-Medical Research Ethics Board (<i>ex officio</i>)
Dr. Kevin Watson	Faculty of Music, Western Non-Medical Research Ethics Board (<i>ex officio</i>)

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APPENDIX J: Themes and Meaning Codes

THEME	MEANING CODES
1: Spousal Characteristics	<ul style="list-style-type: none"> • Personality/behavioural characteristics • Spousal activities • Changes in spouse
2: Experience of Caregiving	<ul style="list-style-type: none"> • Rewarding experiences • Difficult experiences • New responsibilities • Practical aspects of caregiving • Decision making • Maintaining connections to spouse's family • What has not changed for the caregiver/going well • Projecting feelings onto spouse • Relationship between caregiver and spouse
3: Spousal Losses	<ul style="list-style-type: none"> • Specific losses of the spouse
4: Anticipation of Future Events	<ul style="list-style-type: none"> • Concern for the future • Anticipated losses/grief • What happens to spouse if something happens to caregiver • Placing spouse in long-term care • Life after spouse dies
5: Caregiver Losses	<ul style="list-style-type: none"> • Aspects of who spouse was • Conversation • Companionship • Personal activities/time • Social connection • Shared memories with spouse • Intimacy • Shared activities • Family time • Home
6: Experience of Grief	<ul style="list-style-type: none"> • Guilt • Sadness • Anger • Suppressed feelings • Changes in grief over time
7: Coping	<ul style="list-style-type: none"> • Meaning making • Support groups/community services • Information gathering • Hope • Religion/prayer • Social support • Unable to cope • Denial • Lack of family support/involvement • Lack of understanding from others
8: Ambiguous Loss	<ul style="list-style-type: none"> • Loss of spouse prior to death

Curriculum Vitae

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