Being in the Wave: Predeath Grief Experiences of Female Spousal Caregivers of Older Persons Living with Dementia and Multiple Chronic Conditions in the Community

by

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Abstract

Background: Female spousal caregivers (FSCGs) living in the community play a critical role in caring for older persons who live with dementia and multiple chronic conditions (MCCs). FSCGs experience multiple losses as their spouses' cognitive and functional abilities gradually deteriorate prior to their physical death. Experiencing these significant losses while providing care to spouses with dementia can result in predeath grief, which is "the caregiver's emotional and physical response to the perceived losses in a valued care recipient" (Lindauer & Harvath, 2014, p. 2203). The phenomenon of predeath grief that FSCGs experience is rarely recognized, but it can have a significant impact on their physiological, psychological, and emotional health.

Purpose: The purpose of this study was to explore predeath grief experiences in FSCGs living in the community and caring for older persons living with dementia and MCCs. The primary question guiding this research is, *How do female spousal caregivers of older persons living with dementia and MCCs within the community describe their predeath grief experiences?* The secondary research question is, *What factors influence female spousal caregivers' predeath grief experiences?*

Method: The author used an interpretive description approach. All of the study participants were from Alberta, Canada, and included 12 FSCGs of older persons living with dementia and MCCs in the community and three professional knowledge providers (PKPs). All participated in one-hour audio-taped telephone interviews. Concurrent data collection and data analysis involved the use of an iterative and inductive process. The findings are situated within nursing's epistemic orientation, and the author identified themes and patterns in the data. The literature augmented the data analysis in that the findings are not mainly descriptive, but interpretive.

Findings: The findings of the study focused on FSCGs' experiences of predeath grief in the context of caregiving and based on the factors that influence predeath grief. The caregiving context includes life-changing experiences, the impacts of spouses' dementia, living in a COVID-19 pandemic, and all-encompassing losses. The major overall theme of the experience of predeath grief is *being in a wave*, which includes suffering, loss of control, and moments of happiness. Suffering encompasses sadness, hopelessness, and loneliness. Loss of control is in relation to FSCGs' sleep patterns, the busyness in their daily lives, and their spouses' unexpected behaviors. Moments of happiness provided relief to FSCGs who respond negatively to predeath grief. FSCGs' previous experience of death, fear of their spouses' deaths, relationships with their spouses, support from others, and relationship with a Higher Power influence FSCGs' predeath grief experiences.

Conclusion: This study offers nurses and other professionals knowledge pertaining to FSCGs' predeath grief experiences. Subsequently, this knowledge will positively impact both their interactions with FSCGs and the services that they offer them. The findings will inform future research, care, and policy changes that will result in the development of effective interventions and programs to better support FSCGs' biopsychosocial and spiritual needs.

Keywords: *Predeath grief, female spousal caregivers, older persons, dementia, multiple chronic conditions*

Preface

This thesis is an original work by Loreen Carol Pollard. The research project, of which this thesis is a part, received research ethics approval from the University of Alberta Research Ethics Board, Project Name “Predeath Grief in Spousal Caregivers of Persons With Dementia,” No. Pro00097037, 9/23/2020.

Dedication

Although I lost three of the most incredible people in my life, I am blessed that their unconditional love and loving influence continually live on in me, and I proudly dedicate my PhD dissertation to them.

To my late grandmother (baba), Josephine Greschuk: Your love, your belief in me, your love of learning, and your role modeling of resilience have always been and will continue to be the foundation of my strength and courage to pursue my dreams in life.

To my late father, (Bob Greschuk): Your love and all that you taught me about love, faith, compassion, and life will always be my guiding light in life and in nursing. Dad, I am so very proud to be your daughter and to carry on your legacy. I promise you that I will help people who are grieving with respect, dignity, and empathy, just as you did, so that they feel seen, heard, cared for, and valued.

To my late mother-in-law, (Helen Pollard), whose love for her family continues to live on in all of us: Thank you for being an amazing role model and nurse, for your support and encouragement in my nursing education and career, and for your beautiful smile that our daughters have proudly inherited!

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CHAPTER 1: INTRODUCTION

Dementia is not a normal part of aging. It is a terminal illness and the seventh major cause of death worldwide (World Health Organization, 2022). Moreover, dementia is one of the key components of an older person's disabilities and dependency (World Health Organization, 2022). In particular, the World Health Organization (2022) stated that dementia is a universal public health challenge and priority because persons living with dementia, their caregivers, their families, and their communities are both socially and economically affected. Furthermore, as the number of people living with dementia continually escalates, so will costs to society.

Alzheimer's Disease International (2018) reported that women provide 71% of informal care hours. In 2019 the overall public cost of dementia was approximated at US$1.3 trillion worldwide; it included three types of care: informal, social, and medical (World Health Organization, 2021). With older people living longer throughout the world, it is anticipated the number of people living with dementia will increase to 78 million in 2030 (World Health Organization, 2021). In the "Prevalence and Monetary Costs of Dementia in Canada Report," the Alzheimer Society of Canada (2016) noted that in 2011 the estimated number of unpaid hours for informal caregiving was 19.2 million. The countless hours of unpaid informal caregiving can affect caregivers' financial income, as well as their mental, emotional, and physical health, because of the various challenges and obligations in their role (Ploeg et al., 2018). Additionally, "the combined Canadian healthcare system costs and out-of-pocket caregiver costs amounted to $10.4 billion in 2016. By 2031, this figure is expected to increase to $16.6 billion" (Alzheimer Society of Canada, 2016, p. 232).

Every year in Canada 76,000 Canadians are diagnosed with dementia, which alters the trajectory of not only their lives, but also the lives of their family and others who care for them

(Alzheimer Society of Canada, 2022). In fact, one in five Canadians has been a caregiver for a person living with dementia (Alzheimer Society of Canada, 2022). Typically, persons living with dementia live anywhere from 3 to 11 years after they are diagnosed; therefore, the cost of dementia can affect the Canadian economy (Alzheimer Society of Canada, 2021). Currently, the yearly cost of dementia to the Canadian health care system and economy is in excess of CAD$10.4 billion because more than 500,000 Canadians are living with dementia (Alzheimer Society of Canada, 2022). Additionally, currently in Alberta, more than 46,000 people—1% of Alberta's total population—are living with dementia. By 2043, it is anticipated 225,000 Albertans will live with dementia—nearly 3.5% of Alberta's population (Alzheimer Society of Alberta and Northwest Territories, 2022).

Notably, older Canadian adults are living longer, and the number of family members taking on caregiving roles of older persons living with dementia, especially within the community, will increase proportionately (Cranswick & Thomas, 2005; McGilton et al., 2018). Moreover, the longer that older married Canadian adults live, the longer their marital partner relationships will be, and spousal caregivers are more likely to be the primary caregivers, especially with the preference to age in place (Hong & Coogle, 2016). Many family caregivers of persons living with dementia encounter challenges, including financial loss and feelings of loneliness, isolation, loss, and grief because of the nature of the terminal illness (Kobiske et al., 2019; Lindauer & Harvath, 2014; Meichsner & Wilz, 2018). Unfortunately, they also face physical and psychological challenges associated with their caregiving role, and this can affect their mental, emotional, and physical health (Meuser & Marwit, 2001; Ploeg et al., 2018). Consequently, we can anticipate an increase in the number of spousal and adult-child caregivers who seek healthcare services associated with their caregiving role (Holley & Mast, 2009; Meuser

& Marwit, 2001; Williams et al., 2016). Hence, public-health challenges are increasing, and supporting family caregivers is a public health priority (World Health Organization, 2022).

Predeath grief is a significant part of family caregiving of persons living with dementia (Lindauer & Harvath, 2014) because care recipients' cognitive function often deteriorates before their physical functioning does, leading to a sequence of "mini-deaths" (Marwit & Meuser, 2005, p. 192). In this chapter I begin by describing characteristics associated with family caregivers of older persons living with dementia and present a general overview of grief and the concept of predeath grief in the context of caregiving of persons living with dementia. I then highlight the role of female spousal caregivers (FSCGs), who make up the majority of family caregivers of older persons living with dementia and multiple chronic conditions (MCCs) in the community, within the context of predeath grief. I conclude this chapter by outlining the purpose of the research, presenting the research questions, and describing the significance of this study.

Family Caregivers of Older Persons Living With Dementia

Over months and years of providing care, family caregivers of older persons living with dementia have diverse experiences within their role and face multiple losses because of their relationship with their care recipient (Chappell et al., 2014; Van Durme, et al., 2012). The endless losses that they experience can negatively affect caregivers' mental and physical health (Meichsner et al., 2019). Although spousal and adult-children caregivers might experience similar events, ultimately, family caregivers experience their caregiving role from their own unique perspectives (Meuser & Marwit, 2001; Pozzebon et al., 2016). For example, some caregivers are proud to assume their role, others provide caregiving out of obligation, and some consider themselves as the only person available to meet their care recipient's day-to-day needs (Crawford et al., 2015; Peacock et al., 2014; Sanders et al., 2009). Because the impetus to provide care can affect their caregiving experience, some caregivers enjoy providing personal care, whereas others face challenges and demands associated with this role (Doka, 2014; Peacock et al., 2014; Pozzebon et al., 2016).

With respect to the family caregivers of older persons living with dementia who find their role rewarding, many feel an enhanced caring connection with their care recipient (Peacock et al., 2017), feel a new appreciation for life, and discover a new spiritual awareness, which creates a more meaningful life despite the extra demands of providing personal care (Doka, 2003; Ott et al., 2007; Peacock et al., 2017). Additionally, these family caregivers are better able to cope with their caregiving responsibilities because of social support, which is an important component that augments caregivers' personal growth (Ott et al., 2007), positive relationships with their care recipient, and their independent resourcefulness (Large & Slinger, 2015). Having a positive attitude toward caregiving is vital to optimistic mental and emotional functioning among dementia caregivers because it increases their personal growth and self-efficacy and improves the quality of their caregiving relationships (Duggleby et al., 2009; Dulin & Dominy, 2008; Ghesquiere et al., 2011; Lloyd et al., 2019; Ott et al., 2007; Peacock et al., 2014).

Conversely, some family caregivers of older persons living with dementia who fulfill the extra demands of providing personal care have vastly different experiences. Many lose their independence, whereas others face a variety of stressful and challenging matters that result in anger issues and have negative effects on their physical and mental health (Bravo-Benítez et al., 2021; Caputo, 2021; Doka, 2003; Lindauer & Harvath, 2014). As these family caregivers continue to face unlimited expenditures of physical and emotional energy and increasing financial costs to provide care for their care recipients, they feel not only negative effects on their overall well-being, but also feelings of hopelessness as they experience role reversal and unmanageable caregiving roles and responsibilities (Brandstätter et al., 2014; Caputo, 2021; Crawford et al., 2015; Shanley et al., 2011). The constant daily challenges can place family caregivers at risk for chronic stress, anxiety, and depression (Ghesquiere et al., 2011; Ott et al., 2007; Sanders et al., 2008).

Notably, as the family caregivers' care recipient proceeds through the different stages of dementia, the caregivers encounter more than daily challenges; they also face a variety of significant losses (Doka, 2010; Meuser & Marwit, 2001; Moore et al., 2020). Specifically, family caregivers witness the loss of their care recipient's cognitive and functional abilities and their gradual death, and the painful impact of important losses means that they must confront grief prior to the physical death of their care recipient (Blandin & Pepin, 2017; Doka, 2010; Moore et al., 2020; Peacock et al., 2014; Sanders et al., 2009). Consequently, researchers have referred to this type of experience of family caregivers of older persons living with dementia as caring for a living dead person, because it can be many years before the actual physical death occurs (Sanders et al., 2009). Family caregivers' relational bonds with their care recipient, their experiences, and their individual perspectives shape their predeath grief experiences (Davies et al., 2014; Durepos et al., 2019; Weiss, 2001).

Grief: A General Overview

Grief is a multilayered life experience that is common to human beings as it is a natural response to loss; people may suffer, agonize, or struggle with a variety of multiple losses at various times throughout their life (Blandin & Pepin, 2017; Bonanno & Kaltman, 2001; Cowles & Rogers, 1991; Diwan et al., 2009; Meuser & Marwit, 2001; Moore et al., 2017). In spite of the universality of grief, an individual's response to grief is uniquely personal.

Historically, the word *grief* "is from the Anglo-French [word] *gref*, which is from the classic Latin *gravis*: "heavy, painful, important, . . . carrying a burden" (Klass, 2014, p. 4). For some, their burden is the death of persons who were both meaningful and connected to them, whereas for others it is any type of loss, including the loss of a hoped-for future (Klass, 2014). Many people have used the term grief in a broad and imprecise manner as a result of a variety of translations (Klass, 2014). For example, James Strachey translated the German word *Trauer* in Freud's 1915 essay "Trauer und Melancholie" to the English word *mourning*, which "can mean both the affect of grief and its outward manifestation" (Freud, 1914-1916/1957, p. 243). However, the *Collins Dictionary* (2022) defines the German term *trauer* as "mourning, sorrow, grief" (definition 1). Although the *Collins Dictionary* indicates the interchangeability of the three meanings, the *Merriam-Webster* (n.d.-a) dictionary defines *grief* as "deep and poignant distress caused by or as if by bereavement" which adds to the confusion with respect to the term.

Into the late 20th century, the definitions of *grief*, *bereavement*, and *mourning* continued to remain imprecise and inconsistent (Cowles & Rodgers, 1991). Specifically, the definition of grief also lacked unanimity in the nursing literature (Cowles & Rodgers, 1991). Furthermore, given that the terms are not clearly defined, some researchers have habitually substituted the terms, sometimes even within the same article (Cowles & Rogers, 1991; Jacob, 1993; Lindauer & Harvath, 2014). In fact, a number of the instruments that assess, describe, and define grief required revision to enhance the development of nursing diagnoses with regard to clients' grief (Cowles & Rogers, 1991). To rectify this significant situation, Cowles and Rodgers (1991) conducted a concept analysis to define the concept of grief for use in the nursing and medical literature. In their analysis they identified the principal antecedent of grief as "loss in some form"

(p. 123) and defined grief as a “dynamic, persuasive, highly individualized process with a strong normative component” (p. 121).

Grief Theories

Grief theories and models are important because they have helped psychologists, grief counselors, nurses, and many other professionals to understand a person’s reaction to loss and grief (Klass, 2014). Furthermore, grief theories and models have also augmented the understanding of the impact of grief on a person, which has helped professionals to identify the type of support that is most suitable to a person (Klass, 2014). Although many grief theories and models are valuable in their utilization, researchers have also criticized the various stage and phase models that put a person’s grief in a fairly rigid framework; for example, Dr. Kübler Ross’s theory of the five stages of grief (Fiore, 2019; Klass, 2014). I will present the dual process model (DPM) of coping with bereavement (Stroebe & Schut, 2010), ambiguous loss (Boss, 2016), anticipatory grief (Rando, 1988), and disenfranchised grief (Doka, 2016a) and explain why they are not appropriate to support research on predeath grief.

In 1999 Dr. Margaret Stroebe and Dr. Henk Schut, both professors of clinical psychology in the Netherlands, created the DPM because they observed limitations of traditional theorizing in determining the most meaningful ways to cope with bereavement (Stroebe & Schut, 1999). Specifically, they created a model of coping with loss under the assumption that coping influences adaptation to bereavement (Stroebe & Schut, 2010). In other words, effective coping should reduce the mental and physical health problems that result from bereavement (Stroebe & Schut, 2010). The DPM integrates attachment and cognitive stress theories as a foundation for constructive grief work and reorientation to life without a deceased person. Grief work and reorientation are two crucial goals for people who experience bereavement (Stroebe & Schut, 2010). In particular, the DPM "provides a framework for understanding forms of complicated grief, such as chronic, or absent, delayed, and inhibited" (Stroebe & Schut, 2010, p. 281). Although the DPM is a useful framework for people who experience bereavement, it was not an appropriate framework for me to utilize in this doctoral study because predeath grief occurs prior to the death of a person.

The theory of ambiguous loss that Dr. Pauline Boss (2016) created in the early 1970s is "a situation of unclear loss that remains unverified and thus without resolution" (p. 270). Ambiguous loss encompasses two different types of loss: Type I is a physical loss, and type II is a psychological loss (Boss, 2016). Type I physical ambiguous loss is a loss that families experience when they do not know whether their family members are alive or dead or where they are physically located. Because there is no proof of death or that the individual has not been permanently lost, physical ambiguous loss means that "a person is physically absent, yet kept psychologically present" (Boss, 2016, p. 270). Conversely, type II psychological ambiguous loss refers to a family member who is only physically present and "psychologically missing [because] of some cognitive impairment or memory loss from illness, injury, addiction or obsession" (p. 270). Ambiguous loss is a "relational phenomenon" (p. 271); in other words, some type of an attachment to the missing person is assumed (Boss, 2016). However, ambiguous loss is about "a situation of unclear loss that remains unverified and thus without resolution" (p. 270) rather than about predeath grief, which "in the context of dementia family caregiving is the caregiver's emotional and physical response to the perceived losses in a valued care recipient" (Lindauer & Harvath, 2014, p. 2203). Therefore, this theory is not suitable to study predeath grief.

Therese Rando (2000) explained that a person experiencing anticipatory grief is aware of a dying person's terminal illness and that this type of grief creates a valuable opportunity, especially for a caregiver, to implement primary prevention strategies that can lead to therapeutic interventions and result in appropriate grief work to augment healing as well as a positive bereavement experience for the caregiver (Rando, 1988). Additionally, Singer et al. (2022) stated that “anticipatory grief is *future*-oriented and defined as a family members’ grief experience while the person with the life-limiting illness is alive but that is focused on fear or anticipated losses that will occur after the person's death” (p. 22). Caregivers experiencing anticipatory grief may at the same time be able to maintain a functional relationship and therapeutic communication with their care recipient (Doka, 2016a; Lindauer & Harvath, 2014; Rogalla, 2020) “approximately 6-18 months prior to [the physical] death” of their care recipient (Lindauer & Harvath, 2014, p. 2201).

According to Lindauer and Harvath’s (2014) concept of predeath grief in the context of caregiving for a person living with dementia, the caregiver is aware of their care recipient’s terminal illness. However, they argue that a primary component within their concept is the decreased communication between care recipient and their caregiver. Since the person experiences a progressive loss of their cognitive abilities prior to their physical death, their communication with their caregiver and others is often negatively affected or even diminished prior to their physical death (Bonanno & Kaltman, 2001; Chan et al., 2013; Hovland, 2018; Lindauer & Harvath, 2014; Weiss, 2001). Furthermore, predeath grief can be experienced “over the course of a dementia illness” (Lindauer & Harvath, 2014, p. 2201). Since “communication challenges and uncertainty about the timing of the person’s living with dementia death” (p. 2200) occur within the context of predeath grief experienced when caregiving for a person living with dementia Therese Rando’s theory of anticipatory grief was not relevant to this doctoral study (Lindauer & Harvath, 2014).

Doka (2016a) described disenfranchised grief, a concept that he introduced in 1989, as a grief that is not socially sanctioned or publicly shared. For many, the root cause of their disenfranchised grief receives little support and recognition (Doka, 2016a). Disenfranchised grief can include the death of an animal companion, a divorce, a miscarriage, the loss of once-loved person, or a job loss. Although a person feels grief, societal norms might mean that they will not be offered rituals to express their grief or social support to assist with their grief process. Notably, Doka (2016a) argued that one of the most significant types of disenfranchised grief is the death of a partner whose relationship with the grieving person is held in secrecy because the larger society does not acknowledge this type of relationship. The concept of disenfranchised grief was not appropriate to utilize in this doctoral study because it refers to people who experience bereavement.

A Concept Analysis of Predeath Grief in the Context of Dementia Caregiving

With regard to the current literature, numerous researchers and healthcare professionals have used terms such as *anticipatory grief*, *ambiguous loss*, *disenfranchised grief*, *dementia grief*, and *predeath grief* to describe a person's grief experience prior to the death of a meaningful person as well as other types of significant loss (Blandin & Pepin, 2017; Boss, 2016; Bravo-Benítez et al., 2021; Doka, 2016b; Large & Slinger, 2015; Lee et al., 2017; Lindauer & Harvath, 2014). Indeed, bereavement, chronic grief, chronic sorrow, mourning, and preloss grief are also some examples of terms that researchers employ and substitute for predeath grief (Lindauer & Harvath, 2014). Although these terms are found in the literature, the terms have been substituted and interchanged at various times under the assumption that their meanings are similar (Betz & Thorngren, 2006; Bonanno & Kaltman, 2001; Chan et al., 2013; Large & Slinger, 2015; Lee et al., 2017).

Using these various terms interchangeably has resulted in inconsistent language and confusion within the scientific literature pertaining to predeath grief (Lindauer & Harvath, 2014). In the course of Lindauer and Harvath's (2014) concept analysis, the researchers examined 49 peer-reviewed papers and found that the researchers of 30 papers utilized a diversity of definitions to describe the concept of predeath grief (Lindauer & Harvath, 2014). Notably, one of the most important issues regarding predeath grief that has generated perplexity in the scientific literature is the absence of a well-defined definition of the concept (Lindauer & Harvath, 2014). Thus, this became the impetus for Lindauer and Harvath (2014) to conduct a concept analysis of predeath grief in the context of dementia caregiving. Specifically, these researchers created a definition that would endure the rigor of research, improve the ability to frame predeath grief studies, and at the same time have meaning for both family caregivers and the nurses who work with them (Lindauer & Harvath, 2014).

The design of Lindauer and Harvath's (2014) concept analysis utilized "a hybrid of Penrod and Hupceys's principle-based concept analysis and Chin and Kramer's conceptualization of meaning" (p. 2196). They collected data from 49 peer-reviewed scientific papers published from 2000 to 2013 that addressed their topic; they used the data "for the principle-based analysis. . . . [They scrutinized the papers] for epistemological, linguistic, pragmatic, and logical clarity" (p. 2196). They collected additional data from a movie and a book "for the analysis of conceptual meaning" (p. 2196). In analyzing the concept of predeath grief in the context of caregiving for a person living with dementia, Lindauer and Harvath (2014) identified primary components: (a) a vague, long, and indeterminate disease trajectory, (b) caregivers experience various emotions (e.g. yearning, sorrow, etc.) during the course of their care recipient's illness, (c) a decrease in the communication between care recipient and their caregiver, (d) caregivers experience an asynchronous loss as their care recipient’s psychological death occurs prior to their physical death, (e) variations in the quality of the caregiver and care recipient’s relationship, (f) alterations in the caregivers’ freedom, and (g) role variations occur within the family (Lindauer & Harvath, 2014). “Predeath grief can contribute to caregiver burden, depression and maladaptive coping” (Lindauer & Harvath, 2014, p. 2203).

Caregivers mourn the loss of their care recipient’s cognition in many ways, including the loss of connection with them, the loss of past memories that they enjoyed together, and the loss of life together in the future. This type of loss, although many in society do not understand or acknowledge it, exists and is a characteristic of predeath grief (Lindauer & Harvath, 2014). At times, predeath grief can feel awkward for caregivers because their care recipient remains alive. However, since their predeath grief is a response to losses in their care recipient it can be experienced at the diagnosis of dementia and continue throughout the trajectory of their care recipient’s life until their physical death (Lindauer & Harvath, 2014). From their concept analysis, Lindauer and Harvath (2014) created a definition of *predeath grief:* “the caregiver’s emotional and physical response to the perceived losses in a valued care recipient” (p. 2203). Within this doctoral study, predeath grief is in relation to the time from the care recipient’s diagnosis to end of life. Therefore, their concept analysis helps to address the misperceptions in the scientific research literature and offers a definition to frame predeath grief studies. Specifically, I have used Lindauer and Harvath’s definition of predeath grief in the context of family caregiving in this study (see Definitions section).

Predeath Grief of Family Caregivers of Older Persons Living With Dementia

Numerous family caregivers of older persons living with dementia experience predeath grief prior to the physical death of their care recipient because they experience various multiple losses over an ambiguous disease trajectory (Lindauer & Harvath, 2014; Meuser & Marwit, 2001; Moore et al., 2020). Specifically, their predeath grief is a response to the progressive losses that they have observed in their care recipient, such as the gradual loss of their care recipient's cognitive abilities which also creates "a psychological death which is asynchronous with [their] physical death" (Lindauer & Harvath, 2014, p. 2201). As their care recipients' cognitive abilities such as memory, the ability to perform daily tasks, and the competency to develop thoughts decline over time and prior to their physical decline, this creates "a chain of 'mini-deaths'" (Marwit & Meuser, 2005, p. 192). Unique to family caregivers of older persons living with dementia is the nature of their loss and the longer caregiving duration because of the progression of the dementia disease (Marwit & Meuser, 2005). In fact, Ross and Dagley (2009) not only agreed that family caregivers of older persons living with dementia experience a distinctive predeath grief, but also argued that predeath grief is more widespread in this caregiver population than in other caregiver populations. Therefore, the predeath grief experiences of family caregivers of older persons living with dementia can be a relentless, invisible companion with an undetermined length of stay that oscillates in intensity until the end of the care recipients' lives (Doka, 2010; Hovland, 2018; Lindauer & Harvath, 2014).

Female Spousal Caregivers of Older Persons Living With Dementia

According to the literature, primary caregivers of older persons living with dementia are most often FSCGs who live at home with their care recipients and provide daily care (Wong et al., 2016). These FSCGs in the role of primary caregivers are emotionally attentive to their care recipients and take a feminine relational approach when they provide care (Hong & Coogle, 2016). Moreover, they provide the most care to support their spouses' activities of daily living compared to other FSCGs whose spouse lives in long-term care or other facilities (Cranswick &

Dosman, 2008). Furthermore, the Alzheimer's Association (2022) reported that, of dementia caregivers, almost two thirds are women.

In this primary role, FSCGs are subjected to daily challenges (Egilstrød & Petersen, 2021) and face physically demanding tasks and burden, especially as they manage their spouses' difficult behaviors (Gaugler et al., 2011; Gibbons et al., 2014; Hong & Coogle, 2016). Consequently, some FSCGs feel increasingly aggravated (Gibbons et al., 2014); others might experience physical and emotional violence and isolation (Butcher et al., 2001; Rè Se et al., 2011). Specifically, they are "at risk for domestic violence, depression, and maladaptive problem-solving" (Lindauer & Harvath, 2014, p. 2202) as they provide care, all of which are associated with predeath grief.

As primary caregivers, female spouses sometimes experience anger, death anxiety, a loss of control, alterations in their personal freedom, loneliness, and the loss of their identity as they cope with the disruption of their marital relationships and the deterioration of their partners' health status (Beeson, 2003; Chan, et al., 2013; Egilstrød & Petersen, 2021; Loboprabhu et al., 2005; Pozzebon et al., 2016; Sanders & Corley, 2003; Sanders et al., 2003; Weiss, 2001). The effects of dementia challenge couples' intimacy, traditional roles, reciprocity, and communication resulting in transforming their marital relationship (Evans & Lee, 2014). Despite the fact that FSCGs encounter challenges, have altered personal experiences, and are even placed at risk, many consider their role as a new phase of life and part of their spousal commitment as they provide personal care and social support during the progression of their spouses' illness (Bédard et al., 2005; Cranswick & Dosman, 2008; Egilstrød et al., 2019; Egilstrød & Petersen, 2021; Gibbons et al., 2014; Loboprabhu et al., 2005; Yeager et al., 2010). Moreover, for numerous FSCGs, their wedding vows, cultural traditions, societal expectations, generational age, and spousal relationship underpin and influence their personal perspectives on their caregiver role and often create “a complex religious and socio-cultural significance in the context of a personalized caregiving relationship” (Loboprabhu et al., 2005, p. 172).

Most often, partners in a spousal relationship share attachment bonds and feel a sense of permanence and security in this type of connection (Weiss, 2001). At times, even though the caregiver and care recipient relationship can be tense, a bond between them has been created, underpinned by a powerful form of attachment (Ott et al., 2007). When FSCGs and their care recipients share these attachment bonds, not only do they feel a sense of security in their relationship, but any threat to their shared attachment bond can also result in an immediate and visceral response from the FSCGs (Weiss, 2001). Specifically, any sign of severing this bond as care recipients’ dementia evolves can induce feelings of intense grief for FSCGs (Ott et al., 2007; Weiss, 2001). Furthermore, Silverberg (2007) explained that any circumstances that jeopardize the attachment bond will induce protection of the bond because the purpose of the attachment behavior is to maintain a bond. Consequently, the more intense emotional, physical, and psychological attachment between spouses will result in more intense grief and loss for spousal caregivers (Sanders et al., 2008).

Although the shared attachment bond can influence FSCGs’ emotional attentiveness to their care recipients, other significant characteristics of their role can also impact the delivery of their care. For example, FSCGs of older persons living with dementia “experience significantly more burden than other types of caregivers” (Yeager et al., 2010, p. 379). Additionally, these caregivers provide more personal hours of care and social support and endure higher levels of depression than most male spousal caregivers; however, they are reluctant to use formal services for support but instead seek emotional and social support and share their experiences more often than male spousal caregivers do (Bédard et al., 2005; Cranswick & Dosman, 2008; Gibbons et al., 2014; Loboprabhu et al., 2005; Yeager et al., 2010). Notably, their new caregiver identity, personal experiences, and shared attachment bonds with their care recipients underpin the uniqueness of their caregiving role (Davies et al., 2014; Egilstrød & Petersen, 2021; Meichsner et al., 2016; Williams et al., 2016).

Living With Dementia in the Community With Multiple Chronic Conditions

As the Canadian population ages, the number of older persons living with dementia and diagnosed with MCCs will increase (McGilton et al., 2018). Particularly, MCCs in adults aged 65 years and older significantly increase with age (Ploeg et al., 2017). MCCs are diagnoses of "two or more concurrent chronic conditions, such as diabetes and dementia" (Ploeg et al., 2019, p. 1). Consider older adults with MCCs who live in the community. They are more likely to have poorer health status and be unable to provide self-care and management of their MCCs (Ploeg et al., 2020). Therefore, they will utilize the health care system more often than those with fewer medical conditions (McGilton et al., 2018; Ploeg et al., 2018). Additionally, a person with MCCs endures an "extra financial burden [regarding] costs of transportation, medication, and maintaining a healthy lifestyle" (McGilton et al., 2018, p. 33).

Caregivers who provide care to older persons living with MCCs and dementia "face many significant challenges in their caregiving journey over time that pose a threat to their physical, emotional and social health" (Ploeg et al., 2020, p. 2616). Additionally, they endure added costs; and, depending on the care recipients' stages of dementia, the increased caregiving demands increase the stress of the caregivers in their multifaceted role (McGilton et al., 2018) because the effects of dementia can be erratic (Ploeg et al., 2020). Notably, caregivers of older persons with dementia and MCCs who live in the community face various complex challenges, assume various responsibilities, and “experience high levels of burden” (Ploeg et al., 2020, p. 2602).

In a qualitative research study, Ploeg et al. (2020) demonstrated that not only do caregivers’ roles change, but also the manner in which they cope with these changes. They identified three themes regarding changes: “Everything falls on you—all of the responsibilities,” “too many feelings,” and “no time for me.” Three themes reflect how caregivers cope with change: “seeking support,” “self-caring,” and “adapting their caregiving approach” (p. 2602). Although the caregivers in their study utilized a variety of coping mechanisms, they were continually aware that their caregiving responsibilities constantly increased and became more complex as their care recipients’ dementia and MCCs progressed (Ploeg et al., 2020). Furthermore, services and supports that are not appropriately aligned with these caregivers and their recipients or do not meet their needs, significantly affect the caregivers daily lives (McGilton et al., 2018; Ploeg et al., 2017).

Caregivers feel frustrated, exhausted, and upset because they are not able to meet their own needs (Ploeg et al., 2020). Specifically, as caregivers contend with disruptions and struggles, especially with motivating their recipients to make changes, a source of tension results, and they feel that they can “see no end in sight” (McGilton et al., 2018, p. 11). Current health and social care systems that do not consistently meet the needs of older adults and family caregivers exacerbate this feeling (Ploeg et al., 2017). In fact, health care providers have a duty to connect both caregivers and recipients to various healthcare and community support services to meet their needs, especially with caregivers’ increasing complexity of care (Ploeg et al., 2020).

Understanding Predeath Grief Experiences of Female Spousal Caregivers

Living at home in the community with their spouse, FSCGs experience the constant decline of their spouse's cognitive abilities and multitude of losses and face various physical and emotional challenges. Furthermore, the quality of their relationship and communication with their spouse deteriorates, and they lose their personal freedom, all because of the effects of their spouse's dementia, which can affect their predeath grief (Lindauer & Harvath, 2014). The research literature suggested that spousal caregivers experience greater predeath grief than adult children do and that it is greater than in any other caregiver relationships (Crawley et al., 2022; Meichsner & Wilz, 2018; Meuser & Marwit, 2001). In particular, Liew et al. (2019c) discovered that being spousal caregivers and providing daily care to persons living with dementia who also have behavioral problems are key factors in grief and these caregivers might need additional assessment for elevated grief.

Rudd et al. (1999) compared grief responses between female and male spousal caregivers and found that the FSCGs experienced more anxiety, sadness, and anger. In fact, FSCGs providing care at home were the angriest group. As FSCGs witness their spouse's personhood diminish and experience the effects of dementia and multiple losses, the emotional attachment bonds that they once shared begin to unravel (Lindauer & Harvath, 2014) and cause various disruptions, such as role reversal, devastation, loss of intimacy, loneliness, hopelessness, yearning for the past, isolation, and restricted freedom, all resulting in issues of predeath grief (Sanders & Corley, 2003; Sanders et al., 2008; Shanley et al., 2011).

FSCGs of older persons living with dementia and MCCs have a critical role in providing care to their spouse. However, their role is layered with isolation and managing their spouse's difficult behaviors and attending to physically demanding tasks and new roles. FSCGs also manage the disruption of their marital relationship, the escalating complexities of care, as well as endure extra costs and caregiving hours because of their spouse's progressing dementia and MCCs. Within their critical role and multiple layers of new and challenging experiences, FSCGs experience predeath grief.

Despite the growing significance of predeath grief experiences amongst family caregivers of older persons living with dementia, no research evidence exists regarding the predeath grief experiences of FSCGs of older persons living with dementia and MCCs within the community. Therefore, the research in this doctoral study will augment the understanding of the importance of the predeath grief experiences of these FSCGs, facilitate an understanding of how predeath grief experiences influence the manner in which they provide caregiving, and assist in recognizing various gender and societal influences on predeath grief experiences. Study recommendations can potentially guide healthcare professionals to provide appropriate support to FSCGs as well as guide them to co-create appropriate predeath grief interventions with FSCGs of older persons living with dementia and MCCs in the community.

Although these caregivers have a critical role and responsibility to their spouse, it is exactly this caregiving role that can cause them to become psychologically, socially, physically, and financially vulnerable and mentally, emotionally, and physically ill (Almberg & Grafstrom, 1997; Blandin & Pepin, 2017; Madsen & Birkelund, 2013; Ott et al., 2007; Sanders et al., 2008; Wong et al., 2016). Additionally, as their spouse's cognitive impairment progresses, their predeath grief experiences will intensify (Chan et al., 2017; Meuser & Marwit, 2001). Consequently, there is a crucial need for research to understand the predeath grief experiences of FSCGs of older persons living with dementia and MCCs in the community, and this research has created new knowledge in this regard.

Purpose of the Study

The purpose of this study is to explore the predeath grief experiences of FSCGs of older persons living with dementia and MCCs within the community.

Study Research Questions

The primary question guiding this research is, *How do female spousal caregivers of older persons living with dementia and MCCs within the community describe their predeath grief experiences?* The secondary research question is, *What factors influence female spousal caregivers' predeath grief experiences?*

Significance of Study

The prevalence of female spouses who provide care for older persons living with dementia and MCCs within the community can be expected to rise because of the increased longevity of older Canadian adults (McGilton et al., 2018). The role of the FSCG involves unique issues, and predeath grief experiences can further alter the role and increase the complexity of the issues. Uncovering the factors that influence predeath grief experiences can provide substantial knowledge to understand the impact of these experiences on their daily lives, relationships, and health as they provide care to their spouse.

In the broader context, the findings of this doctoral study are useful to create specially tailored respite and counseling programs, as well as initiate dialogue with government and health officials regarding health funding to support the aforementioned programs and potentially meet FSCGs' biopsychosocial and spiritual needs. Given that nurses have a social and professional mandate to assess and acknowledge people's needs and provide appropriate interventions in collaboration with them to meet their needs, the findings of this doctoral study provide information to advance nursing knowledge and practice to understand FSCGs' predeath grief experiences.

Definition of Terms

The following are definitions of important terms that I used in this study.

Caregiver. "Lay people in a close and supportive role who share in the illness experience of the patient and who undertake vital care work and emotion management" (National Institute for Clinical Excellence, 2004).

Dementia. Dementia is an overarching term that applies to progressive behavioral and mood changes, with "memory loss, difficulties with thinking, problem solving, or language that are severe enough to reduce a person's ability to perform everyday activities" (Alzheimer Society of Canada, 2022, p. 2).

Spousal caregiver. A spouse is a person in a legal partnership with another person. The couple can be living common-law or be married and be of opposite or the same genders.

Multiple chronic conditions. MCCs are a diagnosis of "two or more concurrent chronic conditions, such as diabetes and dementia" (Ploeg et al., 2019, p. 1).

Older persons. Older persons are aged 65 years or older.

Predeath grief. Predeath grief for the purpose of this study is "the caregiver's emotional and physical response to the perceived losses in a valued care recipient" (Lindauer & Harvath, 2014, p. 2203) prior to his or her death. Marwit and Meuser (2005) claimed that predeath grief in family caregivers who care for persons living with dementia is distinctive and obvious, because recipients' cognitive function often deteriorates prior to their physical function and therefore creates a sequence of "mini-deaths" (p. 192).

CHAPTER 2: LITERATURE REVIEW

I conducted an integrated literature review on the predeath grief experiences of family caregivers of persons living with dementia. I excluded MCCs from this integrative review because a preliminary search did not yield any articles. Whittemore and Knafl's (2005) integrative review method guided the analysis of the empirical literature and resulted in a thorough understanding of predeath grief experiences of family caregivers of persons living with dementia. The aim of this literature review was to identify and critique the research studies, as well as to identify the gaps and make recommendations for future research. In this chapter I begin with a literature search of predeath grief of caregivers of persons living with dementia. Next, I present the search strategies, search, and study results; finally, I identify the gaps and make recommendations for future research.

Predeath Grief in Family Caregivers of Persons Living With Dementia

In this integrative review I utilized the Sample, Phenomenon of Interest, Design, Exploration, Research type (SPIDER) search-strategy tool (Samnani et al., 2017). The sample consisted of family caregivers (spousal, adult child, and caregivers of partners [life partner/ spouse]). The phenomenon of interest was the predeath grief experiences of family caregivers of persons living with dementia. The design was a qualitative narrative synthesis approach to explore family caregivers' experiences of predeath grief. The research types included qualitative, quantitative, and mixed-method approaches.

Search Strategies

I conducted the literature review of relevant studies by searching the following Internet-based bibliographic databases: Medline, CINAHL, Abstracts in Social Gerontology, PsycINFO, SocINDEX, Gender Studies, Scopus, and Web of Science. I used the following search terms:

((caregivers) AND (spous* OR wife) AND (dementia)) AND ((chronic AND disease) OR (chronic AND illness)) OR (long AND term AND conditions) OR (chronic AND conditions)) AND (community). Additional search terms included (dementia) AND TITLE-ABS-KEY (anticipatory AND grief OR predeath AND grief OR predeath AND (grief) AND TITLE-ABS-KEY (caregiv*)) caregiv* AND dementia AND (predeath grief OR predeath grief OR anticipatory grief).

Inclusion Criteria

- Qualitative and quantitative peer-reviewed studies published in English between 2001 and March 2022.
- Study participants who were informal family caregivers of persons living with dementia who were not paid to provide care.
- Studies in which the researchers explored family caregivers’ grief experiences prior to the physical death of their care recipients in the context of providing care to persons living with dementia.
- Studies in which the participants included FSCGs of persons living with dementia.
- Studies that included the terms *predeath grief* and *anticipatory grief* in the context of providing care to persons living with dementia.
- Studies that included the term *living in the community* in the context of providing care to persons living with dementia.

Exclusion Criteria

- Studies that included bereaved family caregivers who provided narratives on their predeath grief experiences.

- Studies that included family caregivers' bereavement experiences and predeath grief experiences that could potentially not be separated.
- Systematic reviews, concept analyses, case studies, abstracts, and dissertations.

Search Results

Following the selection process, the literature review included 31 studies that addressed some aspect of predeath grief related to family caregivers of persons living with dementia. Figure 1 illustrates the study selection procedure, and Table 1 summarizes the studies.

Data-Evaluation Stage

I utilized the Critical Appraisal Skills Programme (CASP) to evaluate each of the research studies. The checklists in the two CASP tools, one for qualitative studies (CASP, 2018a; 10 questions) and the other for quantitative studies (CASP, 2018b; 11 questions), guided my analysis of the 31 articles. The checklists were designed to help me to think systematically about research issues. Although I had selected only one randomized controlled trial (RCT) study, I utilized this checklist for all quantitative studies because it was the most suitable and enabled a consistent evaluation to compare the studies. Crowe and Sheppard (2011) explained that "the tools used are based on each appraiser's concept of research quality" (p. 87). Likewise, I chose both of these tools based on my familiarity with them, the assistance of prompts after each question, and the longevity of their utilization of over 25 years (CASP, 2018a, 2018b).

Quality Appraisal

The CASP Qualitative Checklist and Randomized Controlled Trial Checklist (CASP, 2018a, 2018b) are intended to be utilized as educational pedagogic tools rather than to score articles. However, to complete a quality appraisal of all the reviewed articles, I utilized these

Figure 1

Literature Search Flowchart

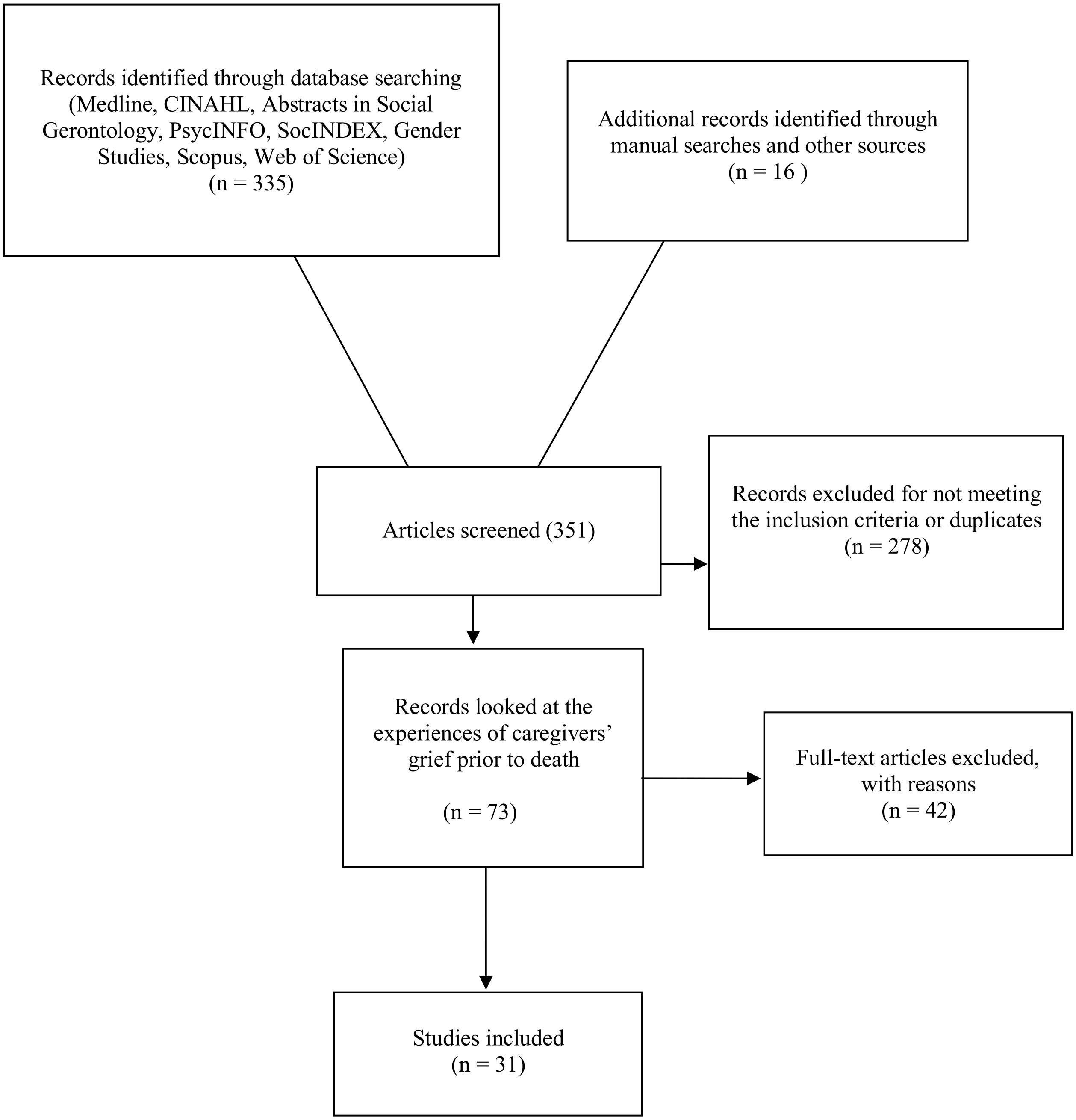

Table 1

Summary of Articles From the Literature Review

Article, location, and rating	Study purpose	Design and data-collection method	Participant demographics: Adult-child (AC), spouse (S), number (N), age-mean (SD), age range	Findings/results
Albinsson & Strang, P. (2003) Existential Concerns of Families of Late-Stage Dementia Patients: Questions of Freedom, Choices, Isolation, Death, and Meaning Sweden 23 (Qualitative CASP 24 max)	"To focus on issues of freedom/ responsibility, existential isolation, death, and issues of meaning/ meaninglessness" (p. 225).	Qualitative Positive purposive sampling. In depth, explorative interviews Analysis: Hermeneutic approach (Yalom's definition of four basic existential domains)	Caregivers N = 20 family members in regular contact with their relative with dementia. Age N = 12 AC: 42-60 N = 4 S: 68-81 N = 4 Other Family: 72-80 Care Recipients 4 with caregiver community. 1 in nursing home, all others private group dwelling. Medical Conditions None reported	Being responsible (faithfulness; paying back) was gratifying. Some felt guilt and obligation therefore provided care out of duty. Existential isolation resulted from no communication with spouse or parent. The dementia was meaningless to the caregivers. However, meaning was identified by caregivers in the past, present, and future in regard to their care recipient's life.
Alvelo et al. (2018) Validation of a Spanish Version of the Marwit–Meuser Caregiver Grief Inventory Short Form in a Puerto Rican Sample Puerto Rico, USA 15 (Non-RCT CASP max 15)	"This study was intended to adapt into Spanish and validate the short form of the Marwit–Meuser Caregiver Grief Inventory (MMCGI), an instrument for the assessment of levels of grief in caregivers of patients with dementia" (p. 507).	Quantitative Validation study "Based on cross-cultural equivalence model that included forward and backward translations, use of a bilingual committee, and a comprehension test" (p. 507).	Caregivers N = 100 N = 82 Female N = 18 *Male AC: N = 44 S: N = 47 Other: N = 9 Age N = 100 61.4 (12.5) Age range (34-88) Care Recipients Sex (Not reported) Age N = (Not reported) Medical Conditions None reported	Validated Spanish version of MM-CGI (short form).

(table continues)

Article, location, and rating	Study purpose	Design and data-collection method	Participant demographics: Adult-child (AC), spouse (S), number (N), age-mean (SD), age range	Findings/results
Chan et al., (2020) The three dimensions of caregiver grief in dementia caregiving: Validity and utility of the subscales of the Marwit-Meuser Caregiver Grief Inventory Singapore 14 (Non-RCT CASP max 15)	To "evaluate the validity and utility of [Personal-Sacrifice Burden (PSB), Heartfelt Sadness, Longing, and Worry (HSLW) and Felt Isolation (FI)] dimensions in a multiethnic Asian population" (p. 213).	Quantitative Cronbach α; test-retest reliability using intraclass correlation coefficient; and construct validity using Pearson correlation coefficient.	<u>Caregivers</u> N = 394 N = 236 Female N = Male (Not reported) AC: N = 340 S: N = 54 <u>Age</u> N = 394 53.0 (10.7) Age range (Not reported) <u>Care Recipients</u> N = 394 N = 278 Female N = Male Not reported) <u>Age</u> N = 394 79.5 (8.2) Age range (Not reported) <u>Medical Conditions</u> None reported	"MM-CGI: The three dimensions also achieved adequate test-retest reliability (ICC = .87 for *PSB*, .87 for *HSLW*, and.81 for *FI*)" (p. 216). "MM-CGI: Cronbach α = .95 for PSB, .96 for HSLW, and .78 for FI" (p. 216).

(table continues)

Article, location, and rating	Study purpose	Design and data-collection method	Participant demographics: Adult-child (AC), spouse (S), number (N), age-mean (SD), age range	Findings/results
Chan et al. (2017) Assessing Grief of Family Caregivers of People with Dementia: Validation of the Chinese Version of the Marwit–Meuser Caregiver Grief Inventory Hong Kong 13 (Non-RCT CASP max 15)	"This study aimed to validate the Chinese version of [Marwit–Meuser Caregiver Grief Inventory–Short Form] (MM- CGI-SF) among Hong Kong Chinese caregivers of PWD" (p. 152).	Quantitative Psychometric instrument testing Measures: Chinese Version of MM-CGI-SF; Chinese Version of Meaning in Life Questionnaire, The Chinese Version of Modified Caregivers' Strain Index (M-CSI), The Chinese Version of Satisfaction with Life Scale (SWL), Chinese Version of MSPSS, Chinese Version of CESD, FAST. "Psychometric properties of C-MM-CGI-SF were examined, including reliability and construct validity. Pearson's correlation, Student's t-test and one-way analysis of variance was conducted for analysis" (p. 153).	<u>Caregivers</u> N = 120 N = 80 Female N = 40 Male AC: N = 80 S: N = 30 Other = 10 <u>Age</u> N = 120 55.46 (14.89) Age range (Not reported) <u>Care Recipients</u> N = 120 N = 89 Female N = 28 Male N = 3 Missing <u>Age</u> N = 120 79.19 (9.50) Age range <u>Medical Conditions</u> None reported	"C-MM-CGI-SF was found to be a reliable and valid measure in the Hong Kong context" (p. 151). "Construct validity was demonstrated by the positive correlations with caregiving strain and depression, and negative correlations with presence of meaning and life satisfaction" (p. 151). "The discriminant validity was supported by showing that spousal caregivers' grief level was significantly higher than that of nonspousal caregivers" (p. 1151).

(table continues)

Article, location, and rating	Study purpose	Design and data-collection method	Participant demographics: Adult-child (AC), spouse (S), number (N), age-mean (SD), age range	Findings/ results
Cheng et al. (2019) A brief measure of predeath grief in dementia caregivers: the Caregiver Grief Questionnaire Hong Kong 15 (Non-RCT CASP max 15)	"Validate a new 11-item Caregiver Grief "Question-naire (CGQ) assessing two dimensions of predeath grief, namely relational deprivation, and emotional pain" (p. 1099).	Quantitative Cross-sectional survey "Caregiver predeath grief was measured using the CGQ, which consists of 11 items assembled from existing measures of caregiver grief" (p. 1101). "Besides the CGQ, measures of caregiver burden and depressive symptoms, and care-recipients' neuropsychiatric symptoms and functional impairment were assessed" (p. 1099).	<u>Caregivers</u> N = 173 N = 236 Female N = Male (Not reported) AC: N = 59% S: N = 32% Others: N = 9% <u>Age</u> N = 173 58.27 (10.42) Age range (36-84) <u>Care Recipients</u> N = 173 N = 73% Female N = Male (Not reported) <u>Age</u> N = 173 82.11 (7.48) Age range (60-104) <u>Medical Conditions</u> None reported	"Results supported the reliability and validity of the two-dimensional measure of predeath grief. As a brief measure, it can be readily added to research instruments to facilitate study of this important phenomenon along with other caregiving outcomes" (p. 1099). "Finally, no significant difference in grief was observed between spouse and adult-child caregivers: $t = -1.37$, 1.71, -0.68 for CGQ, CGQ-RD, and CGQ-EP respectively; all dfs = 160, all ps > 0.05" (p. 1103).

(table continues)

Article, location, and rating	Study purpose	Design and data-collection method	Participant demographics: Adult-child (AC), spouse (S), number (N), age-mean (SD), age range	Findings/results
Cheung et al. (2018) Anticipatory Grief of Spousal and Adult Children Caregivers of People With Dementia Hong Kong 14 (Non-RCT CASP max 15)	"To compare AG levels between spousal and adult children caregivers of people at earlier or later stages of dementia; and to explore the relationship of the level of AG with subjective caregiving burden and well-being" (p. 3).	Quantitative Cross sectional using quota sampling Measures: Demographics, MM-CGI-SF, FAST (staging of dementia), Zarit Burden Interview, Cantonese PWI scale. Recruitment through four centers providing elderly services.	Caregivers N = 108 N = 85 Female N = 23 Male AC: N = 54 S: N = 54 Age N = 108 62.9 (12.9) Age range (Not reported) Care Recipients N = 108 N = 60 Female N = 48 Male Age N = 108 81.6 (7.8) Age range (Not reported) Medical Conditions None reported	"The results showed that spousal caregivers caring for relatives in a later stage of dementia experienced the highest level of AG and subjective caregiving burden, as compared with spousal caregivers caring for relatives in an earlier stage of dementia and adult children caregivers" (p. 1). "Well-being was significantly negatively correlated with AG and subjective caregiver burden, while AG was also significantly correlated with subjective caregiver burden" (p. 1).

(table continues)

Article, location, and rating	Study purpose	Design and data-collection method	Participant demographics: Adult-child (AC), spouse (S), number (N), age-mean (SD), age range	Findings/results
Holley & Mast. (2009) The Impact of Anticipatory Grief on Caregiver Burden in Dementia Caregivers USA 14 (Non-RCT CASP max 15)	To examine "the nature of anticipatory grief (AG) in a sample of dementia caregivers and examine the relationship between AG and caregiver burden" (p. 388).	Quantitative Cross-sectional study Measures: Revised Memory and Behavior Problems Checklist, GDS, MM-CGI, AGS, Zarit Burden Interview Short Form. "Hierarchical linear regression models were used to examine whether AG is significantly associated with caregiver burden" (p. 388).	Caregivers N = 80 informal primary N = 59 Female N = 21 Male AC: N = 49 S: N = 21 Other: N = 10 Age N = 80 60.53 (12.66) Age range 25-93 Care Recipients N = 80 N = 56 Female N = 24 Male Age N = 80 81.65 (7.68) Age range 57-96 Medical Conditions None reported	AG was shown to be significantly and independently be associated with caregiver burden in this sample, "beyond the effects of known predictors such as background characteristics, behavior problems in the care recipient, and depressive symptoms" (p. 394).

(table continues)

Article, location, and rating	Study purpose	Design and data-collection method	Participant demographics: Adult-child (AC), spouse (S), number (N), age-mean (SD), age range	Findings/results
Holley & Mast (2010) Predictors of Anticipatory Grief in Dementia Caregivers USA 14 (Non-RCT CASP max 15)	"Examines several indicators of dementia severity and their relationship to anticipatory grief (AG) to investigate which aspects of the caregiving situation may lead to greater levels of AG" (p. 223).	Quantitative, cross-sectional design. Measures: Background variable, RMBPC, FAST, Index of ADL Scale, Instrumental activities of Daily Living Scale, Amount of care provided, MM-CGI (50 item).	Caregivers N = 80 primary N = 59 Female N = 21 Male AC: N = 49 S: N = 21 Other: N = 10 Age N = 80 60.53 (12.66) Age range 25-93 Care Recipients N = 80 N = 56 Female N = 24 Male Age N = 80 81.65 (7.68) Age range 57-96 Medical Conditions None reported	Results revealed that behavior problems were the only variable which was significantly associated with AG, and follow-up analyses revealed that adult child and spouse caregivers responded differently to different types of behavior problems. Disruptive behaviors of spouse cause spousal caregivers to experience greater AG and embarrassment. During the moderate stages of dementia spousal caregivers feel compassion and sadness. During the advanced stage of dementia, frustration, and uncertainty with the 'life-death limbo' are experienced by spousal caregivers.

(table continues)

Article, location, and rating	Study purpose	Design and data-collection method	Participant demographics: Adult-child (AC), spouse (S), number (N), age-mean (SD), age range	Findings/results
Jain et al. (2019). Grief, Mindfulness and Neural Predictors of Improvement in Family Dementia Caregivers USA 15 (Non-RCT CASP max 15)	"We sought to identify the clinical relationship between grief, depression and mindfulness and identify neural predictors of symptomatology and improvement" (p. 1).	Quantitative Feasibility trial – Use of functional magnetic resonance imaging. "Robust regression was used to predict changes in symptoms with longitudinal brain activation (BA) changes as the dependent variable" (p. 1).	Caregivers N = 23 AC: N = 16 (70%) S: N = 7 (30%) Age N = 60 (+/-11) Medical Conditions Depression (83%) Generalized Anxiety (35%)	"Study confirms that there is a strong inverse relationship between caregiver grief and mindfulness, and this suggests that therapies that increase mindfulness might be specifically efficacious for helping family caregivers process the serial and compound losses that result in predeath grief reactions"" (p. 10). "Neuroimaging findings indicate that the experience of caregiver grief has demonstrable neural substrates similar to those of bereavement with predominant involvement of midline cortical structures, and also identifies unique longitudinal brain changes associated with resolution of grief that may be studied for utility as treatment targets" (p. 10).

(table continues)

Article, location, and rating	Study purpose	Design and data-collection method	Participant demographics: Adult-child (AC), spouse (S), number (N), age-mean (SD), age range	Findings/results
Kiely et al. (2008) Health care proxy grief symptoms before the death of nursing home residents with advanced dementia Boston, USA 15 (Non-RCT CASP max 15)	"Identify and describe factors associated pre-death grief symptoms among health care proxies (HCPs) of nursing home (NH) residents with advanced dementia and distinguish grief symptoms from those of depression" (p. 1).	Quantitative cross-sectional "Factor analysis was used to distinguish predeath grief and depression symptoms" (p. 1). "Multivariate regression analyses identified factors associated with greater pre-death grief measured on a 10-item summary scale of grief symptoms" (p. 1).	Caregivers N = 315 health care proxies e.g., family members. AC = 70% S = 10% Age N = 315 59.9 (11.5) Care Recipients N = 315 NH residents Age N = 315 85.2 (7.6) Medical Conditions None reported	There was a difference between depression symptoms and pre- death grief. Researchers suggested HCPs experienced low levels of overall grief, separation distress, and most frequently they experienced yearning. Variables linked with more predeath grief were non-English-speaking HCPs, living with the person prior to institutionalization, HCP's that were not satisfied with the care, and had more depressive symptoms and younger resident age.

(table continues)

Article, location, and rating	Study purpose	Design and data-collection method	Participant demographics: Adult-child (AC), spouse (S), number (N), age-mean (SD), age range	Findings/results
Kobiske et al. (2019). Predeath Grief, Resourcefulness, and Perceived Stress Among Caregivers of Partners With Young-Onset Dementia USA 14 (Non-RCT CASP max 15)	"To investigate the moderating effects of both personal resourcefulness and social resourcefulness on the relationship between PDG and PS of caregivers of partners living with YOD using the theoretical framework of Resilience Theory" (p 5).	Quantitative Cross sectional, correlation design Theoretical Structure: Resilience Theory Measures: MM-CGI-SF, Perceived Stress Scale, Resourcefulness Scale Convenient sample	Quantitative Cross sectional, correlation design Theoretical Structure: Resilience Theory Measures: MM-CGI-SF, Perceived Stress Scale, Resourcefulness Scale Convenient sample <u>Caregivers</u> N = 104 Life partners/spouse of persons living with young onset dementia (YOD). <u>Medical Conditions</u> None reported	"Large positive correlation between pre-death grief and caregiver perceived stress ($r = .65$; $p < .001$). Pre-death grief, personal and social resourcefulness explained 51.5% of the variance in perceived stress. Personal resourcefulness did not moderate the relationship. Social resourcefulness did positively moderate this relationship between pre-death grief and perceived stress" (p. 1).

(table continues)

Article, location, and rating	Study purpose	Design and data-collection method	Participant demographics: Adult-child (AC), spouse (S), number (N), age-mean (SD), age range	Findings/results
Li et al. (2021) Perceived Grief Among Caregivers of Patients With Dementia in China 10 (Non-RCT CASP max 15)	"This study aims to (a) confirm the factor structure of the Mandarin version of the Marwit–Meuser Caregiver Grief Inventory–Short Form (MM-CGI-SF) (b) evaluate the levels of family caregivers' grief, and (c) explore the best predictors of family caregivers' grief" (p. 70).	Quantitative Cross sectional Purposive sampling Self-reported -2 questionnaires (The demographic questionnaire and The Mandarin version of the MM-CGI-SF)	Caregivers N = 91 N = 60 Female N = 31 Male AC: N = 38 S: N = 37 Other: N = 16 Age N = 91 Age mean,(SD) (Not reported) Age range 20-89 Care Recipients N = 91 N = 51 Female N = 40 Male Age N = 91 Age mean,(SD) (Not reported) Age range 40-99 Medical Conditions None reported	"The Mandarin version of the MM-CGI-SF possessed the same factor structure as the original English version" (p. 70). "The Chinese family caregivers experienced an average grief" (p. 70). "The multiple linear regression analysis results indicated that caregivers' monthly household income and caring time per day were significant predictors of caregivers' grief, and these variables explained 17.0% of the total grief variance of the caregivers" (p. 75). The study's post hoc test results indicated that spouse caregivers experience significantly higher worry and perceived isolation grief than other caregivers (p = .002, .043, .043, respectively, compared with children, siblings, and other caregivers)" (p. 75).

(table continues)

Article, location, and rating	Study purpose	Design and data-collection method	Participant demographics: Adult-child (AC), spouse (S), number (N), age-mean (SD), age range	Findings/results
Liew (2016) Applicability of the Pre-death Grief Concept to Dementia Family Caregivers in Asia Singapore 13 (Non-RCT CASP max 15)	To "explore the existence and the characteristics of pre-death grief in a multi-ethnic Asian population using an established pre-death grief scale—Marwit-Meuser Caregiver Grief Inventory (MM-CGI)" (p. 749).	Quantitative Cross-sectional design Psychometric testing – "internal consistency, reliability, and construct validity" (p. 749).	<u>Caregivers</u> N = 72 N = 42 Female N = Male (Not reported) AC: N = 67 S: N = 5 <u>Age</u> N = 72 50.9 (11.6) Age range (Not reported) <u>Care Recipients</u> N = 72 N = 56 Female N = Male (Not reported) <u>Age</u> N = 72 79.6 (8.5) Age range (Not reported) <u>Medical Conditions</u> None reported	"In the Asian context, pre-death grief was measurable in a reliable and valid manner" (p. 749). "Risk factors of pre-death grief included caring for patients with severe dementia, spousal relationship and secondary or below education" (p. 749). "Influence of culture was palpable—Asians had more worries and felt isolation, and certain ethnicity showed more pre-death grief" (p. 749).
Liew & Yap (2020) A brief, 6-item scale for caregiver grief in dementia caregiving Singapore 13 (Non-RCT CASP max 15)	"Develop a briefer scale that captures the essence of caregiver grief—with comparable psychometric properties and total score to MM-CGI, as well as less overlap with other caregiving constructs" (p. 1).	Quantitative Psychometric instrument testing. "Evaluated the derived scale in its reliability and validity and mapped its scores to MM-CGI using the equipercentile equating method" (p. 1).	<u>Caregivers</u> N = 394 N = 179 derivation sample N = 215 in validation sample AC: N = 340 S: N = 54 53.0 (10.7) Age range (Not reported) <u>Medical conditions</u> None reported	"A 6-item scale maintained good psychometric properties similar to those of MM-CGI, while showing lower correlation with caregiver burden and depression. It also had scores that could be mapped to MM-CGI with reasonable precision" (p. 1).

(table continues)

Article, location, and rating	Study purpose	Design and data-collection method	Participant demographics: Adult-child (AC), spouse (S), number (N), age-mean (SD), age range	Findings/results
Liew et al. (2019a) Comparing the Effects of Grief and Burden on Caregiver Depression in Dementia Caregiving: A Longitudinal Path Analysis over 2.5 Years Singapore 15 (Non-RCT CASP max 15)	"We sought to compare the effects of baseline grief and burden on caregiver depression at baseline and 2.5 years later" (p. 977).	Quantitative "A cohort study with 2.5 years of follow-up. Questionnaires with scales that assessed caregiver grief, burden, and depression. Baseline grief and burden scores were included in a path analysis to predict depression at baseline and at 2.5 years" (p. 977).	<u>Caregivers</u> Family caregivers N = 183 N = Female N = Male AC: 152 S: 31 <u>Age</u> N = 183 (Not reported) Age range (Not reported) <u>Medical Conditions</u> None reported	"The findings highlight the need to identify and address caregiver grief in dementia services. They present a window of opportunity to improve caregiving outcomes, especially during the "latent phase" when caregivers encounter loss and grief but have yet to fully experience the debilitating effects of depression" (p. 977). "Caregiver grief can amplify the effect of burden at baseline and can have an independent effect on caregiver depression over time. In addition, caregiver grief has a "latent phase" where its effect may not be fully apparent until a later time" (p. 982).

(table continues)

Article, location, and rating	Study purpose	Design and data-collection method	Participant demographics: Adult-child (AC), spouse (S), number (N), age-mean (SD), age range	Findings/results
Liew et al. (2019b) Contrasting the risk factors of grief and burden in caregivers of persons with dementia: Multivariate analysis Singapore 13 (Non-RCT CASP max 15)	"To determine whether there are differences in the risk factors of PDG and caregiver burden to aid in our understanding of the relationship between the two constructs" (p. 1).	Quantitative Multivariate linear regression Regression Analysis – factor identification.	<u>Caregivers</u> N = 394 N = 236 Female N = Male (Not reported) AC: N = 340 S: N = 54 <u>Age</u> N = 394 53.0 (10.7) Age range (Not reported) <u>Care Recipients</u> N = 394 N = 278 Female N = Male (Not reported) <u>Age</u> N = 394 79.5 (8.2) Age range (Not reported) <u>Medical Conditions</u> None reported	"Three risk factors are shared by PDG and caregiver burden (later stage of dementia, behavioral problems in PWD, and primary caregiving role), while three other risk factors are unique to PDG alone (younger age of the PWD, lower educational attainment of caregivers, and spousal caregivers)" (p. 3).

(table continues)

Article, location, and rating	Study purpose	Design and data-collection method	Participant demographics: Adult-child (AC), spouse (S), number (N), age-mean (SD), age range	Findings/results
Liew et al. (2019c) Development and validation of a simple screening tool for caregiver grief in dementia caregiving. Singapore 13 (Non-RCT CASP max 15)	Test their own "simple screening tool – based on factors associated with caregiver grief – to identify caregivers with high grief" (p. 1).	Quantitative Psychometric testing	Caregivers N = 300 N = Female (Not reported) N = 120 Male AC: N = 265 S: N = 35 Age N = 300 52.1 (11.0) Age range (Not reported) Care Recipients N = 300 N = Female (Not reported) N = 86 Male Age N = 300 79.5 (8.1) Age range (Not reported) Medical Conditions None reported	"Identified four key factors of grief and family caregivers of PWD stage of dementia, behavioral problems in PWD, spousal caregivers and caregivers who provide daily care" (p. 3). The factors "can be easily integrated into the workflow of routine services to screen for caregivers who are more likely to benefit from further grief-related assessment" (p. 1).

(table continues)

Article, location, and rating	Study purpose	Design and data-collection method	Participant demographics: Adult-child (AC), spouse (S), number (N), age-mean (SD), age range	Findings/results
Liew, Yap, et al. (2018) Detecting predeath grief in family caregivers of persons with dementia: measurement equivalence of the Mandarin- Chinese version of Marwit-Meuser caregiver grief inventory Singapore 13 (Non-RCT CASP max 15)	To test their newly developed Mandarin-Chinese version of MM-CGI against the psychometric properties to the English version.	"Quantitative Psychometric – comparison using the multiple linear regression. Family caregivers completed either the Chinese or English version. The two versions were compared in their score-difference (internal-consistency reliability and test-retest reliability known-group validity and construct validity" (p. 1).	Caregivers N = 394 N = 236 Female N = Male (Not reported) AC: N = 340 S: N = 54 Age N = 394 53.0 (10.7) Age range (Not reported) Care Recipients N = 394 N = 278 Female N = Male (Not reported) Age N = 394 79.5 (8.2) Age range (Not reported) Medical Conditions None reported	"The two versions showed similar mean scores, with the adjusted score-difference of 1.2 (90% CI -5.6 to 7.9) for MM-CGI and −0.4 (90% CI -2.9 to 2.1) for MM-CGI-SF" (p. 1). "The 90% CI for adjusted score-difference fell within predefined equivalence-margin (±8 for MM-CGI and ± 3 for MM-CGI-SF) and indicated equivalence of the scores" (p. 1). "The two versions also demonstrated similar characteristics in reliability and validity" (p. 1).

(table continues)

Article, location, and rating	Study purpose	Design and data-collection method	Participant demographics: Adult-child (AC), spouse (S), number (N), age-mean (SD), age range	Findings/results
Liew, Yeap, et al. (2018) Detecting Predeath Grief in Family Caregivers of Persons With Dementia: Validity and Utility of the Marwit-Meuser Caregiver Grief Inventory in a Multiethnic Asian Population Singapore 14 (Non-RCT CASP max 15)	"To evaluate the reliability and validity of the PDG [specifically the MM-CGI- and MM-CGI-SF] scales in a multiethnic Asian population distinct from that of United States" (p. 150).	Quantitative Psychometric testing with factor analysis. "Internal-consistency reliability was assessed by Cronbach's α, test-retest reliability by intraclass-correlation-coefficient, construct validity by Spearman's correlation-coefficient, and factorial validity by confirmatory factor analysis (CFA). Cohen's κ was used to compare the agreement between MM-CGI and a commonly-used caregiver burden scale (Zarit Burden Interview)" (p. 150).	<u>Caregivers</u> N = 300 N = 180 Female N = Male (Not reported) AC: N = 265 S: N = 35 <u>Age</u> N = 300 52.1 (11.0) Age range (Not reported) <u>Care Recipients</u> N = 300 N = 214 Female N = Male (Not reported) <u>Age</u> N = 300 79.5 (8.1) Age range (Not reported) <u>Medical Conditions</u> None reported	"MM-CGI and MM-CGI-SF demonstrated internal-consistency reliability, test-retest reliability, construct validity, and known-group validity" (p. 150). "In CFA, MM-CGI showed modest model-fit (comparative-fit-index, CFI = .80; Tucker-Lewis index, TLI = .79), whereas MM-CGI-SF showed better model-fit (CFI = .91; TLI = .90). Eighty-six percent of the caregivers reported average or high levels of PDG, with 18% reporting high PDG" (p. 150). "High scores in the caregiver burden scale only showed modest agreement with high scores in MM-CGI (κ = .47)" (p. 150).

(table continues)

Article, location, and rating	Study purpose	Design and data-collection method	Participant demographics: Adult-child (AC), spouse (S), number (N), age-mean (SD), age range	Findings/results
MacCourt et al. (2017) Effectiveness of a Grief Intervention for Caregivers of People With Dementia Canada 15 (non-RCT CASP max 15)	To examine and compare the effectiveness of five forms of a coaching intervention on participants' levels of grief, sense of empowerment, coping, and resilience.	Interventional study Participants in intervention group received a brief coaching intervention informed by Meuser's and Marwit's Caregiver Grief Model (2002). Utilized pre-and post-test for both intervention and control groups, Employed the following five data collection instruments: The Demographic and Caregiving Characteristics Questionnaire; The Caregiver Grief Inventory; The Empowerment Questionnaire; Shortened version of The Brief COPE (Carver, 1997) and The Resilience Scale (Wagnild & Young, 1993).	<u>Caregivers</u> N = 200 N = 158 Female N = 42 Male AC: N = 65 S: N = 122 Other = 10 <u>Age</u> N = 200 64.4 (SD Not reported) Age range (Not reported) <u>Care Recipients</u> N = 200 N = 90 Female N = 108 Male N = 2 Missing <u>Age</u> N = 200 78 (SD Not reported) Age range (Not reported) <u>Medical Conditions</u> None reported	"The findings indicate that coaching resulted in increased coping and resilience, and less grief for participants who received the intervention compared with those who did not" (p. 242). "Participants in the intervention group, who expressed higher coping, empowerment, and resilience levels, and lower grief levels at the outset of the study also experienced greater improvements in all areas following the intervention than did other participants" (p. 242). "The coaching intervention used in this study, regardless of delivery method, was equally effective in increasing participants' coping, empowerment, and resilience, and reducing grief" (p. 243).

(table continues)

Article, location, and rating	Study purpose	Design and data-collection method	Participant demographics: Adult-child (AC), spouse (S), number (N), age-mean (SD), age range	Findings/results
Marwit & Meuser (2002) Development and Initial Validation of an Inventory to Assess Grief in Caregivers of Persons With Alzheimer's Disease St. Louis, USA 15 (Non-RCT CASP max 15)	"To develop an empirically based, psychometrically sound instrument for the assessment of grief in caregivers of persons with Alzheimer's disease" (p. 751).	Quantitative (psychometric instrument testing with factor analysis) Used 184 statements of personal grief reactions obtained from 45 adult children and 42 spouse caregivers (obtained over 16 focus groups). These statements were rated by the participants 166 (83 adult child and 83 spouse) correspondingly to their present experience. The participants also completed the Beck Depression Inventory, Anticipatory Grief Scale, the Caregiver Strain Index, the Caregiver Well-Being Scale–Basic Needs, and the Perceived Social Support–Family Questionnaire.	Caregivers Participants (N = 166) Age N = 83 AC: 51.81 (8.05) N = 83 S-71.47 (8.93) Care Recipients Persons living with dementia. Medical Conditions None reported	Factor analysis resulted in a 50-item scale containing three factors: Personal Sacrifice Burden, Heartfelt Sadness and Longing, and Worry and Felt Isolation. Cronbach's alpha scores ranged from .90 to .96, indicating high internal consistency reliability for each factor as well as for their combined total. Correlations of each factor with other measures provide evidence of validity, especially when assessed in the context of the caregiver grief model.

(table continues)

Article, location, and rating	Study purpose	Design and data-collection method	Participant demographics: Adult-child (AC), spouse (S), number (N), age-mean (SD), age range	Findings/results
McLennon et al. (2014) Content and Face Validity of the Marwit-Meuser Caregiver Grief Inventory (Short Form) in African American Caregivers USA 22 (Qualitative CASP 24 max)	“To elicit descriptions about African American (AA) predeath grief experiences” (p. 367).	Qualitative; Content Analysis Interviews were conducted. Content and face validity to assess MMCGI-SF in AA caregivers.	Caregivers N = 19 N = 16 Female N = 3 Male AC: N = 16 S: N = 3 Age N = 19 60 (13.5) Age range 36-86 Care Recipients N = 19 N = 15 Female N = 4 Male Age N = 19 82 (6.9) Age range 74-98 Medical Conditions None reported	“Findings from study provide tangible support for content and face validity of the MMCGI-SF in AA family caregivers” (p. 371).
Meichsner et al. (2016) The Caregiver Grief Scale: Development, Exploratory and Confirmatory Factor Analysis, and Validation Germany 15 (Non-RCT CASP max 15)	“To build on previous research and develop a scale for the measurement of grief in dementia caregivers” (p. 342).	Quantitative 21-item questionnaire from existing items to for Caregiver Grief Scale (CGS)	Caregivers N = 229 N = 181 Female N = Male (Not reported) AC: N = 91 S: N = 134 Other = 4 Age N = 229 63.8 (10.5) Age range 35-87 Care Recipients N = 229 N = 120 Female N = Male (Not reported) Age N = 229 78.5 (9.4) Age range 55-104 Medical Conditions None reported	“Convincing goodness-of-fit indices emerged for a four-factor model, with factors reflecting different aspects of caregiver grief (i.e., Emotional Pain, Relational Loss, Absolute Loss, and Acceptance of Loss)” (p. 342). “The total scale and subscales yielded high internal consistency reliabilities (Cronbach’s α = .67–.89) and construct validity coefficients” (p. 342).

(table continues)

Article, location, and rating	Study purpose	Design and data-collection method	Participant demographics: Adult-child (AC), spouse (S), number (N), age-mean (SD), age range	Findings/results
Meichsner & Wilz (2018) Dementia caregivers' coping with predeath grief: effects of a CBT-based intervention Germany 27 (CASP max 33)	"Examine whether a cognitive-behavioral intervention including a grief intervention module could increase caregivers' coping with pre-death grief and whether these effects could be maintained as of a six-month follow-up assessment" (p. 218).	Quantitative RCT "Intervention group participants received 12 therapy sessions over six months; all participants completed a measure of pre-death grief The analysis was conducted using latent change models. In the first model, study group was included as a predictor of change in pre-death grief; subsequent models also included care situation and sociodemographic variables" (p. 218).	<u>Caregivers</u> N = 273 N = 139 (Intervention) N = 134 (Control group) Participants were the primary caregiver of a person living with dementia, living at home. <u>Medical Conditions</u> None reported	"The burden due to pre-death grief was reduced for intervention but not control group participants at the time of the six-month follow-up assessment (Cohen's d = −0.361). When controlling for changes in the care situation and sociodemographic variables, the treatment effect was also found in the assessment completed post intervention (Cohen's d = −0.248)" (p. 218).
Meuser & Marwit (2001) A Comprehensive, Stage-Sensitive Model of Grief in Dementia Caregiving St. Louis, USA 15 (Non-RCT CASP max 15)	To "define a model of caregiver grief to aid in clinical intervention and to support further research" (p. 658).	Quantitative Clinical Dementia Rating interview (CDR), Many Faces of Grief Questionnaires (MFG), Anticipatory Grief Scale (AGS) Qualitative approaches (N = 16 focus groups). Semi-structured interviews Exploratory study	<u>Caregivers</u> N = 87 N = 67 Female N = 20 Male AC: N = 45 Age: 51.6 (9.6) S: N = 42 Age: 71.8 (9) <u>Care Recipients</u> N = N = Female N = Male (Not reported) <u>Age</u> N = Age range (Not reported) <u>Medical Conditions</u> None reported	"Significant differences emerged between spouse and adult-child caregiver groups as a whole and as a function of Clinical Dementia Rating impairment level. Caregiver grief was found to fluctuate between intellectual, affective, and existential poles depending upon current care demands and expectations" (p. 658).

(table continues)

Article, location, and rating	Study purpose	Design and data-collection method	Participant demographics: Adult-child (AC), spouse (S), number (N), age-mean (SD), age range	Findings/results
Moore et al. (2020) Is preparation for end of life associated with pre-death grief in caregivers of people with dementia? United Kingdom 13 (Non-RCT CASP max 15)	"We hypothesized that modifiable factors indicating preparation for end of life are associated with lower pre-death grief in caregivers" (p. 753).	Quantitative Cross-sectional Primary outcome: Marwit-Meuser Caregiver Grief Inventory Short Form (MMCGI-SF). "Multiple regression to assess associations between pre-death grief and preparation for end of life while controlling for confounders" (p. 753).	<u>Caregivers</u> N = 150 N = 116 Female N = 34 Male AC: N = 72 S: N = 70 Other: N = 8 <u>Age</u> N = 150 63.0 (12.1) Age range (Not reported) <u>Care Recipients</u> N = 150 N = 82 Female N = 68 Male <u>Age</u> N = 150 80.3 (+/-9.7) <u>Medical Conditions</u> None reported	"Only one factor (reduced social support) was strongly associated with higher grief intensity along with the confounders of female gender, spouse, or adult child relationship type and reduced relationship closeness. Exploratory analyses of MMCGI-SF subscales, one additional hypothesized factor was statistically significant; higher dementia knowledge was associated with lower "heartfelt sadness"" (p. 753).
Passoni et al. (2015) Prolonged grief in caregivers of community-dwelling dementia patients Milan 13 (Non-RCT CASP max 15) Prolonged grief disorder (PGD)	"To estimate the frequency of prolonged grief disorder (PGD)… and to identify the relationship between grief intensity (GI) and other caregiver variables; another aim was to clarify the role of the objective cognitive and functional impairment of the patients and the level of deterioration perceived by caregivers" (p. 192).	Quantitative Cross-sectional study Factor analysis with logistic regression.	<u>Caregivers</u> N = 90 N = Female (Not reported) N = 30 Male AC: N = 33 S: N = 52 <u>Age</u> N = 90 63.36 (14.48) Age range (30-88) <u>Care Recipients</u> N = 90 N = Female N = Male (Both not reported) <u>Age</u> N = 90 76.28 (8.12) Age range (43-92) <u>Medical Conditions</u> None reported	"In all, 16.7% of caregivers had PGD. Caregivers of patients with dementia may experience grief symptoms that are associated with low educational level, high level of burden and anxiety, and high perceived deterioration of their demented relatives' cognitive and functional abilities" (p. 192).

(table continues)

Article, location, and rating	Study purpose	Design and data-collection method	Participant demographics: Adult-child (AC), spouse (S), number (N), age-mean (SD), age range	Findings/results
Perez-Gonzalez et al. (2021) Alzheimer's Disease Caregiver Characteristics and Their Relationship with Anticipatory Grief Spain 8 (Non-RCT CASP max 15)	"Aims to determine which characteristics of family caregivers of people with dementia, such as age, gender, educational level, relationship with the person with dementia, years with dementia or years as a caregiver, are related to the presence of anticipatory grief" (p. 1).	Quantitative A cross-sectional design "A socio-demographic data sheet and a battery of tests measure the presence of anticipatory grief, caregiver burden, and/or psychopathology" (p. 1).	Caregivers N = 129 (118) N = 80 Female N = 38 Male AC: N = 73 S: N = 3 Other: N = 7 Age N = 129 For Female Only 62.09 (10.89) Age range (32-85) Average age of caregiver 61.56 Care Recipients N = 119 N = Female N = Male (Not reported) Age N = 119 Average age of care recipient: 82.21 Age range (Not reported) Medical Conditions None reported	"The results obtained show that time dedicated to care correlates positively with symptoms of burden, sadness and isolation, fundamental constructs of anticipatory grief" (p. 12). "The results indicate that the spouses have a higher level of anticipatory grief than children. Furthermore, a long-term effort without limits and without a clear organization of resources entails a risk of burden and claudication, which proves to be one of the greatest predictors of anticipatory grief" (p. 12).

(table continues)

Article, location, and rating	Study purpose	Design and data-collection method	Participant demographics: Adult-child (AC), spouse (S), number (N), age-mean (SD), age range	Findings/results
Sanders & Corley (2003) Are They Grieving? A Qualitative Analysis Examining Grief in Caregivers of Individuals with Alzheimer's Disease USA 16 (Qualitative CASP 24 max)	There are three purposes to this study. First, "to expand the knowledge about grief and caregiving" (p. 40). Second, "develop common themes that will better define the concept of grief for caregivers of individuals with Alzheimer's disease" (p. 40). Third, "to provide information for social worker clinicians on the grief reactions of caregivers, which may be essential to examine during the assessment and intervention processes" (p. 40).	Qualitative Prior to the end of a quantitative study caregivers were asked: "Do you believe that you are grieving the loss of your loved one even though he/she is still alive? Please explain" (p. 40) Responses divided into two groups (caregivers not grieving/ caregivers grieving Organized data into familiar themes and groups utilized Padgett's (1998) recommendation for organizing data.	<u>Caregivers</u> N = 253 Caregivers from a Chapter of the Alzheimer's Association N = 178 female, N = 71 male and N = (unknown). AC: N = 112 S: N = 100 Other: N = 31 <u>Care Recipients</u> N = 139 female N = 105 male 9 did not report <u>Medical Conditions</u> none reported Receiving care: "N = 118 (49%) in their home N = 85 (35%) in a nursing home (14%) in an assisted living facility, and N = 6 (3%) in another type of location" (p+ .41).	Caregivers both grieving and not grieving reported a sense of loss in their caregiving experience. Grief is shape by multiple factors and is complex. Faith, spirituality, and religion were coping mechanisms for caregivers who reported they were not grieving. Caregivers who reported that they were grieving, had spiritual, physical, psychological, and emotional reactions during their caregiving experience.

(table continues)

Article, location, and rating	Study purpose	Design and data-collection method	Participant demographics: Adult-child (AC), spouse (S), number (N), age-mean (SD), age range	Findings/results
Sanders et al. (2008) The Experience of High Levels of Grief in Caregivers of Persons with Alzheimer's Disease and Related Dementia USA 14 (Non-RCT CASP max 15)	To examine the lived experiences of caregivers of persons with Alzheimer's disease and related dementias (ADRD) specifically those who exhibited a high level of grief as determined by the Marwit and Meuser Caregiver Grief Inventory-Short Form (MM-CGI-SF).	Mixed methods Questionnaire and interview 30 to 90 minutes conducted (at home and by telephone) per participant. MM-CGI-SF subscales used to differentiate high grief group from moderate/low grief group. Used subscales in each of the thematic areas, supported with findings from qualitative findings from constant comparative method. Triangulation of data sources. Data from larger study.	Caregivers From community N = 44 AC: N = 21 S: N = 23 Age N = 44 65.18 (13.01) Range 41-90 Care Recipients N = 44 Age: Not reported Cared for at: Home N = 24 Long term care N = 20 Medical Conditions None reported	"The qualitative analysis identified the major themes of the caregivers experiencing high levels of grief, while the quantitative data validated the majority of the themes" (p. 516). "Quantitative analysis identified major differences between caregivers with high levels of grief compared to those with moderate-low levels of grief" (p. 516-517). Themes: "Yearning for the past, regret and guilt, isolation, restricted freedom, life stressors, systemic issues, and coping strategies" (p. 495). "Quantitative analysis confirmed that these themes are unique to individuals with high levels of grief compared with those with moderate-low levels of grief, except for the coping strategies of social support and spiritual faith" (p. 495).

(table continues)

Article, location, and rating	Study purpose	Design and data-collection method	Participant demographics: Adult-child (AC), spouse (S), number (N), age-mean (SD), age range	Findings/results
Warchol-Biedermann et al. (2014) What Causes Grief in Dementia Caregivers? Poznan, Poland 15 (Non-RCT CASP max 15)	"The purpose of the article was to evaluate the Meuser and Marwit Caregiver Grief Inventory (MM-CGI-50) for use in Polish family caregivers and to find out determinants of grief of Family caregivers of AD individuals living in Poland" (p. 462).	Quantitative "Interviewed to determine the influence of such factors as caregiver's age, gender, family relation to the care recipient (CR) and caregiving-related changes in caregiver's working time, leisure time and material status to find out the impact of caregiving role on intensity of caregiver grief. Caregiver grief was measured by means of MM-CGI-50" (p. 462).	<u>Caregivers</u> N = 151 N = 95 Female N = 56 Male AC: N = 64 S: N = 84 Other: N = 3 <u>Age</u> N = 151 58.9 (10.1) Age range (Not reported) <u>Care Recipients</u> N = 151 N = Female N = Male (Both not reported) <u>Age</u> N = 151 Female 71.4 (6.2) Male 72.3 (6.7) Age range (Not reported) <u>Medical Conditions</u> None reported	"The effect of caregiver's age, gender, family relation to the CR and caregiving-related changes in caregiver's working time; leisure time and material status could not be found. To add, MM-CGI-50 can be effectively used to assess grief in Polish family caregivers of AD patients" (p. 462).

checklists and Feder et al.'s (2006) three-point rating system to calculate a score for each article. I then used the CASP RCT and qualitative checklists to appraise the RCT and qualitative articles, respectively. Because there is no checklist for non-RCT quantitative and mixed-method studies, I used the five relevant questions from the RCT CASP (questions 1, 3, 9, 10, and 11) to score each article out of a maximum of 15 points. A total of 31 articles in this review: three qualitative studies, one RCT, 26 non-RTC quantitative studies, and one mixed method studies. The three qualitative articles that I evaluated had an average CASP score of 20.3 out of a maximum score of 24. The one RCT scored 27 out of 33 on the CASP RCT checklist. The remaining non-RCT and mixed-methods studies scored 13.66 out of a maximum score of 15.

Study Results

Table 1 summarizes all of the selected articles and includes the article, location, and rating; the study purpose; the design and data-collection method; the participants' demographics; and the findings/results. The studies were located in the USA (11), Canada (1), Sweden (1), Singapore (8), Germany (2), Hong Kong (3), China (1), United Kingdom (1), Spain (1), Italy (1), and Poland (1). The sample size in each study ranged from two to 403 family caregivers and was contingent on the research design. The majority of the study participants were adult-child caregivers and females.

The researchers of two of the qualitative studies used a qualitative descriptive approach, and one was a content analysis. Ten of the non-RCT quantitative studies were validation studies in which the researchers evaluated instruments to measure predeath grief, 13 studies were cross-sectional in design, one was a cohort study, one was a feasibility study, and one was an intervention study. One study was an RCT. The researchers of one study used mixed methods, with both a thematic analysis and a cross-sectional design. I categorized the findings of all studies into major themes: family caregivers' experiences of predeath grief, the care recipient's stage of dementia and the predeath grief experiences of family caregivers, and culture and ethnicity influences on family caregivers' experiences of predeath grief.

Family Caregivers' Experiences of Predeath Grief

Family caregivers of persons living with dementia experience predeath grief during the trajectory of their care recipient's disease (Jain et al., 2019; Kobiske et al., 2019). Notably, the family caregivers' predeath grief can negatively impact their emotional, psychological, and physical well-being (Kobiske et al., 2019; Liew, 2016; Meuser & Marwit, 2001). The researchers of all of the reviewed studies reported on the family caregivers' experiences of predeath grief and used the terms *ambiguous loss*, *disenfranchised grief*, and *anticipatory grief* (Boss, 1999; Doka, 2016a; Lindauer & Harvath, 2014; Rando, 2000). Marwit and Meuser (2002) reported that family caregivers of persons living with dementia experience predeath grief in unique ways because their “grief is neither a unitary nor a static construct” (p. 751). Lindauer and Harvath (2014) explained that family caregivers’ predeath grief experience in the context of dementia family caregiving is “the caregiver’s emotional and physical response to the perceived losses in a valued care recipient” (p. 2203).

Although predeath grief is common among family caregivers of persons living with dementia, the researchers of one study (Sanders & Corley, 2003) found that 32% (n = 80) of caregivers of persons living with dementia reported that they were not grieving because they were able to spend time with their care recipient and share their lives with some level of intimacy. Similarly, these caregivers found a source of comfort in their faith, and this became a fundamental coping mechanism for them. Additionally, some caregivers did not grieve because of past relationship conflicts with the care recipient, and others because they accepted their caregiver role only because no one else wanted to do it. However, none of the researchers noted this finding.

Influences on the Predeath Grief Experience

The predeath grief experience of family caregivers of persons living with dementia is influenced by the caregivers’ unique caregiving experiences, the types of relationship with their care recipient, the living location of their care recipient, the care recipient’s behavioral problems, and the predeath grief interventions that they receive (Holley & Mast, 2009; Kiely et al., 2008; MacCourt et al., 2017; Marwit & Meuser, 2002; Meuser & Marwit, 2001). Passoni et al. (2015), in their cross-sectional study of 90 caregivers, reported that prolonged grief occurs in 16.7% of caregivers who live in the community, and they observed higher grief intensity amongst caregivers with lower education, anxiety, and the sense of a physical burden.

Caregiving Experiences and the Types of Relationships

Notably, the research literature highlighted the causes of predeath grief, the factors that influence predeath grief, predeath grief experiences, the outcomes of predeath grief, and significant differences among caregiver groups' predeath grief experiences (Holley & Mast, 2010; MacCourt et al., 2017; Meuser & Marwit, 2001). In Sanders and Corley's (2003), 68% (n = 173) of the caregivers (spouse and adult child) reported that they were grieving. Specifically, their grief resulted from feelings of hopelessness and uncertainty about their care-recipient relationships, the loss of their roles and the intimacy that they shared with their care recipient, and numerous other losses. Meuser and Marwit (2001) reported that, contingent upon multiple caregiving demands, caregivers' predeath grief oscillates with their moods, feelings, and attitudes. Although both spousal caregivers and adult-child caregivers experience predeath grief, Meuser and Marwit (2001) identified some statistically significant variations between the two caregiver groups regarding how predeath grief influences their lives. Specifically, the researchers reported that the spousal caregivers "showed greater loneliness and the loss of sexual intimacy" (p. 662) than the adult-child caregivers did.

Conversely, adult-child caregivers demonstrated higher scores on negativity, jealousy of peers who were not in the same situation, uncertainty about the meaning of life, and a loss of interest in their normal activities compared to spousal caregivers (Meuser & Marwit, 2001). Furthermore, Meuser and Marwit (2001) explained that these unique differences between the two caregiver groups are a result of the caregiver's age and life stage, education, social network, and the amount of caregiving time that they spend with their care recipient. Cheng et al. (2019) used the Caregiver Grief Questionnaire (CGQ) and found no statistically significant difference in grief measures (CGQ, CGQ-RD, & CGQ-EP) (df = 160 $p > 0.05$) between adult-child and spousal caregivers.

These differences might reflect cultural or regional differences among different populations. For example, Cheng et al. (2019) did not observe any significant difference in caregivers' predeath grief between adult children and spousal caregivers when they used the CGQ in Hong Kong. Likewise, Warchol-Biedermann et al. (2014) described similar findings (that the impact of caregiver burden is not different between adult-child and spousal caregivers) when they validated the Polish version of the MM-CGI. They attributed the differences to family living arrangements between the USA (original MM-CGI) and in Poland. Specifically in Poland, it is common for three generations of family to live together in one home, whereas the USA participants usually lived alone. This reduced the influence of the caregivers' burden that the researchers observed in the original USA study.

Finally, caregiving partners of people diagnosed with young onset dementia (YOD) also experience predeath grief in a unique manner (Kobiske et al., 2019). Because people in their 20s or 30s can be diagnosed with YOD, but more commonly in their 40s or 50s, this creates challenges for the caring partners and impacts their relationships and the household dynamics. Challenges arise as a result of the care recipients' loss of the ability to maintain jobs, assist with household responsibilities, interact socially, reciprocate within their partner relationships, and provide self-care. Caregiving partners also experience multiple losses similarly to other caregiving groups of persons living with dementia. Their losses include financial, personal identity, companionship, personal freedom, and future hopes and dreams, which result in caregiving stress (Kobiske et al., 2019). Notably, Kobiske et al. (2019) identified an association between caregiving partners' stress and predeath grief: The greater their stress, the greater their predeath grief. Moreover, Kiely et al. (2008) noted that family caregivers of persons living with dementia who are younger aged and reside in nursing homes demonstrate "greater pre-death grief symptoms" (p. 670). These differences suggest that, because younger caregivers have different experiences and responsibilities, including employment and childcare, researchers ought to study them separately.

Spouse and adult-child caregivers who experience predeath grief have also reported feelings of regret, obligation, guilt, yearning for the past, problems with formal caregiving systems, restricted freedom, and isolation (Albinsson & Strang, 2003; Kiely et al., 2008; Sanders et al., 2008). Specifically, feelings of isolation of family caregivers of persons living with dementia occurred when they were the only caregivers, had no one to whom they could express their personal feelings, or took on the role of parent to their parents (Albinsson & Strang, 2003). Likewise, they felt isolated as a result of the lack of social support and communication with their care recipients (Albinsson & Strang, 2003; Sanders et al., 2008).

Living Location of The Care Recipient

Family caregivers' emotional state and feelings of isolation can also be a result of the living location of care recipients (Kiely et al., 2008). For example, admitting care recipients to institutions or nursing homes can be difficult for many caregivers in that it forces them to acknowledge their inability to provide care in their homes (Kiely et al., 2008). Kiely et al.'s (2008) multivariate analysis revealed that family caregivers who resided with their care recipient prior to admission to nursing homes had statistically significant more predeath grief symptoms than caregivers who did not live with their care recipient. Furthermore, Sanders and Corley (2003) noted that 82% ($n = 74$) of caregivers (spouse and adult child) reported that they were grieving while they provided care in nursing homes. In addition, family caregivers can experience “anguish and grief” (p. 512) as a result of feeling that health professionals are not aware of their care recipients’ needs or that they have limited knowledge about providing care for persons living with the terminal disease of dementia (Sanders et al., 2008).

Conversely, the qualitative findings of Meuser and Marwit (2001) indicate that nursing-home placement can bring relief to both spousal and adult-child caregivers. Although spousal caregivers might feel a sense of relief, they also experience the realities of being solely responsible for themselves. Adult-child caregivers can also experience some emotional relief after their care recipients are admitted; however, as their caregiver burden is lessened, their focus of loss shifts to interpersonal regret for lost opportunities with their parents and the loss of their parental relationships.

Care Recipient’s Responsive Behaviors

Family caregivers of persons living with dementia often experience various primary stressors from their caregiving experiences; one in particular is care recipients’ responsive behaviors (Holley & Mast, 2009). Holley and Mast (2010) revealed that the regularity of care recipients’ responsive behaviors is a paramount predictor of caregivers’ anticipatory grief. For example, when spousal caregivers are affected by care recipients’ disruptive or embarrassing behavior, their anticipatory grief increases (Holley & Mast, 2010). Therese Rando (1988) defined *anticipatory grief* as grief that is inevitable prior to the death of a person with a life-limiting illness. However, people who experience anticipatory grief might also be able to maintain therapeutic communication and functional relationships with the people who are dying (Doka, 2016a; Lindauer & Harvath, 2014). Conversely, the depression-related behaviors of care recipients from loneliness and tearfulness both trigger and increase adult-child caregivers' anticipatory grief (Holley & Mast, 2010; Liew, Yeap, et al., 2018; Liew et al., 2019c).

Care Recipients' Stage of Dementia and Predeath Grief Experiences of Family Caregivers

A number of the researchers collected data on the stage of dementia of care recipients: very mild, mild, moderate, moderately severe, severe, very severe, late-stage, and advanced (Albinsson & Strang, 2003; Cheung et al., 2018; Kiely et al., 2008; Liew, Yap, et al., 2018; Liew, Yeap, et al., 2018; Liew et al., 2019b; MacCourt et al., 2017; Meichsner & Wilz, 2018; Meuser & Marwit, 2001; Sanders & Corley, 2003). They used primarily three tools. First, the Functional Assessment Staging Test evaluates the functional capabilities of people with Alzheimer's disease (Chan et al., 2017). Second, the Global Deterioration Scale measures the severity of dementia (Meichsner & Wilz, 2018). Last, the Clinical Dementia Rating (CDR) impairment level "measures six cognitive-functional domains (memory, orientation, judgment and problem-solving, community affairs, home and hobbies, and personal affairs)" (Meuser & Marwit, 2001, p. 660).

Clinicians use dementia rating scales to determine care recipients' stage of dementia, and the stage of dementia impacts every family caregiver's predeath grief experience (Cheung et al., 2018). For example, Cheung et al. (2018) reported that, compared to caregivers of persons in early-stage dementia, spousal caregivers experience the "highest level of anticipatory grief and subjective caregiving burden" (p. 1) when they care for recipients in the later stage. In fact, the later stage of dementia, a risk factor for predeath grief, is also a risk factor for caregiver burden (Liew et al., 2019b). Chan et al. (2017) explained that, as care recipients' cognitive impairment progresses through the various stages of dementia, caregivers' grief experiences increase.

Meuser and Marwit (2001) noted that as spousal and adult-child caregivers witness care recipients' cognitive deterioration, they experience different predeath grief emotions. For example, spousal caregivers feel a sense of being part of a couple in the early stage of dementia (Meuser & Marwit, 2001). In this stage, as a result of the change, spousal caregivers feel a "quieter, sadder form of grief" (p. 665) that is much different from that of adult-child caregivers. In contrast, adult-child caregivers whose parents are in the mild stage of dementia might view the disease as part of the aging process (Meuser & Marwit, 2001). As adult-child caregivers begin to experience more predeath grief, they try to suppress it by referring to these feelings as "fear, helplessness, hopelessness and anger" (p. 662).

Meuser and Marwit (2001) reported that, according to care recipients' impairment level, which the CDR measures, the perspectives of adult-children and spousal caregivers of persons living with dementia on their caregiving experiences differ. Adult-child caregivers articulate their grief as the most intense at CDR 2, and they direct their frustration and anger at their personal losses, the terminal disease, and sometimes their parents. Conversely, at CDR 2, spousal caregivers are very sad and do not want to look forward to the future. At CDR 3, adult-child caregivers move emotionally from raw to reflective emotions, and their grief is more of a deep sadness for the loss of both their parental relationships and their parents in the parental role. Meuser and Marwit (2001) discovered that, whereas the spousal caregivers at CDR 3 were not sure what path to take regarding their life's purpose, their spousal relationships as they once knew them had ended even though their spouses were still alive. They feel exhausted and know that another new type of grief is slowly approaching.

Contemporary functional magnetic resonant imaging techniques have identified neural predictors of caregiver grief, which is similar to bereavement and involves midline cortical structures in the brain (Jain et al., 2019). Jain et al.'s feasibility trial demonstrated the possibility of developing a clinical biomarker for caregivers' grief to better measure responses to their grief and depression. For example, the group demonstrated that mindfulness-based interventions are an appropriate intervention to reduce "the serial and compound losses that result in pre-death grief" (p. 10).

Predeath Grief Interventions

The researchers of two of the studies reported interventions that effectively decreased predeath grief in family caregivers of persons living with dementia. In a mixed-method study in which they evaluated the impact of grief-management coaching on caregivers of persons living with dementia, MacCourt et al. (2017) reported that grief-management coaching reduces caregivers' predeath grief measured on the Marwit-Meuser Caregiver Grief Inventory (MM-CGI). Additionally, this coaching improves the levels of coping and resilience. Registered clinical counselors with extensive knowledge and experience with coaching carried out this coaching intervention. In Meichsner and Wilz's (2018) randomized-controlled trial, they examined the effectiveness of a telephone-based cognitive-behavioral intervention that included a grief-specific intervention module for in-home family caregivers of persons living with dementia. Specifically, the intervention group demonstrated a statistically significant decrease in predeath grief scores at follow-up compared to the control group (Cohen's d = -0.361). This indicates that telephone-based cognitive-behavioral therapy interventions reduce predeath grief and might be an effective strategy to use with FSCGs of older persons living with dementia and MCCs in the community.

Increasing both caregivers' social support and resourcefulness has a positive impact on the connection between perceived stress and predeath grief (Kobiske et al., 2019). Increased role responsibilities, heightened emotions, major changes, and care recipients' behavioral problems call for caregiver support and require resources (Holley & Mast, 2010). Moore et al. (2020) demonstrated that increasing caregivers' knowledge of dementia through effective educational programs decreases the heartfelt sadness indicator of the MM-CGI/SF. Perez-Gonzalez et al. (2021) in their cross-sectional study that included 129 participants confirmed that increasing caregivers' knowledge of dementia, including Alzheimer's disease, enables caregivers to better plan for palliative care and resolve any unsettled issues. Further, Moore et al. (2020) asserted that enhancing social support and networks reduces the intensity of predeath grief.

Culture and Ethnicity Influences on Family Caregivers' Experiences of Predeath Grief

Researchers have studied and measured the predeath grief of family caregivers of persons living with dementia in Canada, China, Hong Kong, Singapore, and the United States and revealed various ethnicities and cultures that universally experience this type of grief (Liew et al., 2020). The tool that the researchers used most frequently in the reviewed studies to measure predeath grief was the MM-CGI, which Meuser and Marwit (2001) and Marwit and Meuser (2002) initially created and validated. The initial instrument measured predeath grief in caregivers of persons with Alzheimer's dementia; however, given the mixed presentation of dementia in Alzheimer's disease, researchers have increasingly used it to study predeath grief with any type of dementia. The initial MM-CGI is made up of 50 items that contain three aspects: personal sacrifice and burden, heartfelt sadness and longing, and worry and felt isolation (Marwit & Meuser, 2002). The group subsequently developed an 18-item shorter form of the MM-CGI.

Liew (2016) reported that the MM-CGI is both valid and useful in detecting predeath grief in multiethnic Asian participants (Chinese, Indian, Malay Muslim, and Eurasian). Although the scores were basically similar to caregivers' scores in the United States, the Asian caregivers reported a statistically significant higher score in the "Worry and Felt Isolation" category. Furthermore, spousal relationships, caring for recipients with severe dementia, having secondary or below education, and being of Malay ethnicity resulted in higher MM-CGI scores.

Likewise, the findings from a cross-sectional study that Cheung et al. (2018) conducted in Hong Kong reveal that spousal caregivers who live in the community with their recipients who are in later-stage dementia have the highest MM-CGI-SF total score and a greater burden. In the study, their scores were higher than those of other spousal caregivers of recipients in an earlier stage dementia or adult-child caregivers of recipients in early-/late-stage dementia. As well, spousal caregivers of care recipients in both earlier and later stages of dementia scored higher than adult-child caregivers in "the two MM-CGI-SF sub-scores of Personal Sacrifice Burden and Worry and Felt Isolation" (p. 4). The researchers stated that the influence of the Chinese culture supported the findings because the marital relationship is of vital importance to Chinese spousal caregivers. Chan et al. (2020) replicated these findings in Singapore.

In their cross-sectional study that they conducted in Southeast China, Li et al. (2021) reported that "the best predictors of caregivers' grief were caregivers' monthly household income and caring time per day" (p. 74). Although these are the two predictors, the results also indicate that caregivers' predeath grief increases when their caregiving time per day increases and decreases as their monthly household income increases. Liew et al. (2019b) conducted a study in Singapore in which the majority of the participants were Chinese adult children of community-dwelling persons living with dementia and identified three main risk factors for increased predeath grief: the age of persons with dementia, caregivers' lower educational achievement, and caregivers' relationships with the persons living with dementia.

In another study in Singapore, Liew et al. (2019c) found four key factors in the predeath grief in family caregivers of community-dwelling persons with dementia: “the stage of dementia, severe behavioral problems in [persons living with dementia], spousal caregivers and caregivers who provide daily care” (p. 3). Additionally, Liew et al. (2019a), in a cohort study that lasted 2.5 years, found that grief can, over time, have an effect on the depression of family caregivers of persons living with dementia. Notably, Cheung et al. (2018) suggested that the marital-relationship elements of emotional bonding, accountability, duties, and interdependence are vital in Chinese culture. As a result, the reviewed studies that the researchers conducted in Hong Kong, China, Southeast China, and Singapore overall demonstrated that spousal relationships, the stage of dementia, and the caregiving time per day are the major factors that affect predeath grief in the Asian population. Conversely, the Chinese culture of filial piety highlights the responsibility of adult children to honor and provide care for their ill parents in the context of intergenerational caring (Cheung et al., 2018). However, it is unclear if the tradition of filial piety benefits adult children or adds extra stress because of their other responsibilities of work, family, and other life commitments. This might increase predeath grief, but future research is needed to determine whether this is the case.

In Germany, Meichsner et al. (2016) built and tested a scale to measure predeath grief in 229 German-resident family caregivers of persons living with dementia at home. The group selected items from the original MM-CGI and developed several new items and then translated them into German. The findings revealed that both the relationship to and living with care recipients are the important predictors of the intensity of grief. Among these German participants, the values on the caregiver grief scale of the spouses who lived with their care recipients were higher.

Additionally, McLennon et al. (2014) reported evidence of the content and face validity of the 18-item MM-CGI-SF when they used it with African American caregivers of persons living with dementia. Moreover, Alvelo et al. (2018) developed and tested a Spanish version of the MM-CGI in Puerto Rico and found that it highly correlated with the English version of the MM-CGI (internal consistency = 0.91). Globally, family caregivers of persons living with dementia experience predeath grief every day. For many, their culture and ethnicity impact not only their experience of predeath grief, but also the manner in which they deliver their caregiving.

Summary and Conclusion

The literature review shows that predeath grief significantly impacts family caregivers' overall well-being, social interactions, and financial status. Although the literature focused on FSCGs of persons living with dementia, there is an absence of literature on FSCGs of older persons living with dementia and MCCs within the community. Notably, the factors that influence caregivers' predeath grief are unique caregiving experiences, the type of relationship with their care recipient, the living location of their care recipient, their care recipient's behavioral problems, culture and ethnicity, the stage of dementia, and predeath grief interventions.

Most researchers combined the predeath experiences of spousal and adult-child caregivers, with little attention to only FSCGs. All 31 of the studies on the predeath grief experiences of caregivers of persons living with dementia focused on three groups of family caregivers (spousal, adult child, and caregiving partners), and the majority included more female than male participants and more adult-child than spousal-caregiver participants. Specifically, none of the studies included FSCGs as the only participants. Therefore, it is vital to conduct research on the predeath grief experiences of FSCGs of older persons living with dementia within the community. Although a few studies included participants who lived in the community, as I noted in the introduction, none of the researchers focused on participants with MCCs. The literature identified the critical need for a comprehensive contextual understanding of the predeath grief experiences of FSCGs of older persons living with dementia and MCCs within the community. This study has added further clarity to the understanding of the predeath grief experiences of this population and identified the factors that influence FSCGs' predeath grief experiences.

CHAPTER 3: METHODOLOGY

I used interpretive description (ID) to examine the experience of predeath grief among FSCGs of older persons living with dementia and MCCs within the community. ID, an applied qualitative health-research method (Thorne, 2016a; Thorne, et al., 1997; Thorne, et al., 2004), is an appropriate approach that researchers use to discover new knowledge to advance the discipline and profession of nursing. My aim in this chapter is to discuss how I used the methodological framework of ID in this doctoral study. First, I present a brief overview of ID (Thorne, 2016a). Next, I describe the study's setting, recruitment and sampling, the data collection and analysis processes, ethical considerations, and strategies that augmented its rigor.

Interpretive Description: A General Overview

ID is an applied qualitative health-research method that researchers utilize to develop practice-oriented disciplinary knowledge (Thorne et al., 1997). Although many disciplines employ this approach, Thorne (2016a) envisioned ID as "a strategy for excavating, illuminating, articulating, and disseminating the kind of knowledge that disciplines with an application mandate tend to need in order to enact their mandate whether it be healing, educating, serving, or building something on behalf of society" (p. 11). Notably, nurse researchers who utilize ID to examine experiences of human health and illness rely on their disciplinary orientation. Therefore, nurses' disciplinary orientation influences the types of questions that they ask, the choice of literature that they review, the characteristic styles within the design, and the manner in which they analyze their data and then articulate them in their research reports (Thorne, 2016a).

The Philosophical Context of Interpretive Description

ID is philosophically aligned with a constructivist and naturalistic form of inquiry and thus recognizes that phenomena likely exist as variations of multiple constructed realities and that no *a priori* theory is likely able to predict all such variations (Hunt, 2009; Thorne, 2016a; Thorne et al., 2004). Using this form of inquiry, researchers acknowledge the constructed and contextual dispositions of people's experiences, along with the shared realities of the researcher and research participants (Hunt, 2009; Thorne, 2016a; Thorne, 2016b; Thorne et al., 2004). This means that researchers take an ID approach to develop nursing knowledge that is socially co-constructed through the transactional relationship between researcher and research participants, an inseparable interaction that impacts them in the production of research results (Thorne, 2016a; Thorne et al., 2004).

Research guided by an ID approach results in the development of knowledge aimed at broadening knowledge of the intricacies, variations, and complexities of a particular phenomenon (Thorne, 2016a; Thorne et al., 2004). As a further step, ID calls on researchers to move beyond describing a phenomenon to also interpreting the meaning of the phenomenon within the context of clinical practice (Thorne, 2016a). In this spirit, the intent of the doctoral study was both to understand the predeath grief experiences of FSCGs of older persons living with dementia and MCCs within the community and to use the findings to produce practical meaningful knowledge useful to nurses who provide care to this population (Hunt, 2009; Thorne, 2016a; Thorne et al., 2004).

The Strengths of Interpretive Description

Thorne et al. (1997) described ID as a "noncategorical research method" (p. 169). This method has been criticized for its nonprescriptive methodological format and dismissing the notion that theoretical frameworks are required in conceptualizing sound research projects. However, other researchers have written about the strengths of ID. For example, Hunt (2009) argued that ID includes precise philosophical underpinnings, a rational reasoning and structure, a focus on producing practice-relevant discoveries, and “attention to disciplinary biases and commitments” (p. 1284). Thorne et al. (1997) pointed out that ID relies on trusting in nursing’s disciplinary knowledge. Specifically, ID is “derived from an understanding of nursing’s philosophical and theoretical foundations as credible and legitimate ways to access knowledge for nursing” (p. 170). ID fills in the knowledge gaps within the clinical science of practice disciplines that traditional quantitative and qualitative research methods may not (Hunt, 2011; Thorne et al., 1997, Thorne et al., 2004). Moreover, Kalengayi et al. (2012) stated that the discoveries of an ID inquiry are presented with a combination of central themes and patterns within the situations that researchers observe. This type of presentation, especially to clinical experts, is embedded within the context of the clinical problem and enables a more reliable interpretation of the qualitative data. As a result, researchers present the discoveries of ID in a manner that “experts in the area [would] acknowledge as persuasive” (p. 15). Notably, Thorne (2016a) argued that nurses who pursue research because of their curiosity and interest in a practice-context problem might find the applied versions of methodologies, such as ID, more applicable than conventional forms. Specifically, an advantage of ID is that it illuminates gaps in knowledge that other forms of research cannot. Hence, ID contributes vital information that is required to meet the overall health needs of a person.

Researchers’ Use of Interpretive Description

ID engages researchers in the data sources. In particular, ID enables researchers to move beyond interviews and use data sources such as participant observation, documentary sources, nonempirical and empirical literature, and expert opinion to explore the complexities of the human experience (Thorne, 2016a). Additionally, ID provides researchers with the needed flexibility to design a meaningful research project by using all available tools and knowledge from other established qualitative research approaches (Thorne, 2016a). Because various kinds of design techniques create different kinds of knowledge, the utilization of borrowed methods must be appropriate to the research question to augment the research process and create a deeper understanding of the phenomenon (Thorne, 2016a). ID acknowledges that clinicians' experience results in deep knowledge of the discipline that is created through pattern recognition in clinical situations and formal learning (Thorne, 2016a; Thorne et al., 2004).

Every day, nurses use knowledge to assess their clients individually, evaluate the effects of clinical decision making, and then make further decisions. Many nurses move beyond a single description of their clients to further engage in a systematic and processual way of thinking about their clients and clinical practice that is open and reflective. Specifically, these nurses compare the commonalities of their current clients with those who came before and look for differences. Nurses refine their personal knowledge through observation subtleties and multiple variations of practice (Thorne, 2016a) and rely on this clinical knowledge when they complete an ID project. Nursing researchers see the world through a nursing lens (Thorne, 2016a) that enables them to cultivate reliable research by utilizing ID to develop nursing knowledge (Thorne, 2016a; Thorne et al., 2004). This implies that researchers who use an ID approach to research must have relevant exposure to the clinical phenomenon in practice.

Although the generic experiences of nurses are useful in creating a nursing lens, I argue that the quality of an ID project also depends on the degree to which researchers recognize common patterns in the phenomena that they are exploring. Although this is a concern in any type of research, researchers' ability and willingness to recognize patterns might be a limiting factor in ID compared to other approaches with a prescribed method.

Researcher's Reflective Statement

During my three-year traineeship I worked on a research project that involved data collection from family caregivers of older persons living with dementia and MCCs who resided in the community. Additionally, I attended meetings with the national interdisciplinary research team who worked on the research project. Throughout this valuable experience I acquired knowledge that enabled me to recognize common patterns within the population whom I interviewed. In addition, I was a family caregiver who provided care to my grandmothers, one of whom had early-stage dementia. Because I have had my own unique caregiving experience, I understand what it is like to be a family caregiver and to grieve significant multiple losses, especially prior to the deaths of my grandmothers.

Studying predeath grief experiences is my passion. As a nurse I felt that it was an honor to provide care to mothers and their families prior to the deaths of their children, both in labor and delivery and in pediatrics. As a granddaughter, it was an honor to provide care to my grandmothers prior to their deaths. As a daughter of a funeral director, it was an honor to witness my father's professional connectedness with grieving families. My father role-modeled an extraordinary way of providing care with dignity and compassion to meet the needs of these families at a very vulnerable time in their lives.

Notably, I began my study by revealing who I am and, likewise, my professional and personal experiences. This helped to develop my awareness of the need to minimize the unintended impact that I could have on the process of my research. Thorne (2016a) stated that this type of humility and insight can "determine your ability to produce a high-quality research product" (p. 79). As a result of my nursing and personal experiences, Thorne's ID approach was an appropriate choice for this study because this methodology created rich and in-depth insights into the predeath grief experiences of FSCGs and helped to answer my clinical questions.

Study Setting

The setting for the study were the homes of caregivers of persons living with dementia in Alberta, Canada. Founded on a philosophical assumption of ID, the setting respected the comfort and ethical rights of all participants and was the participants' naturalistic environment (Thorne, 2016a). Specifically, the participants' chosen environment was the ideal setting for this study because it was within this environment that they felt the most comfortable and safe to communicate with me. I chose to conduct confidential, in-depth, semi-structured individual telephone interviews.

Furthermore, this method of data collection not only respected the participants' choice of setting, but also adhered to the COVID-19 pandemic restrictions. I presented each participant with various time options for their interviews with me. Consequently, only two issues occurred with scheduling interview times, and I dealt with the issues in an ethical and competent manner. Notably, during the interviews I ensured that there was no breach of privacy, and the participants did not experience any harm in their chosen setting.

Study Participants

All of the study participants were from Alberta, Canada, and included FSCGs of older persons living with dementia and MCCs within the community and professional knowledge providers (PKP)s. I discuss the methods that I used to sample FSCGs and PKPs below in separate sections.

Female Spousal Caregivers

According to Thorne (2016a) I used both purposive and one type of theoretical sampling which was maximum variation sampling. To begin, I implemented purposive sampling based on the review of the literature prior to conducting my doctoral study and identified various conditions that I wanted to include (Thorne, 2016a). For example, the FSCGs were legally married to their spouse for different lengths of time. The FSCGs who met the inclusion criteria (see the inclusion and exclusion criteria), were interested in the phenomenon, and were motivated to communicate their experiences were included in the participant sample (Richards & Morse, 2012).

During the data collection and analysis phases patterns and themes began to emerge, financial and years of education were variables I discussed with my supervisory committee. For example, with the exception of one participant who did not share a monthly income range, the participants I had interviewed reported a monthly income range of either 1,500-3,000 CAD$ or >3,000 CAD$. No participants had reported a monthly income range of <1,000 CAD$ or 1,000-1,500 CAD$. Likewise, only three FSCGs had achieved three or more years of post-secondary education. Based on the literature, low monthly income is one key cause of caregiver burden (Chappell et al., 2014; Shanley et al., 2011) and increased predeath grief (Li et al., 2021). Likewise, lower educational achievement of caregivers is a risk factor of predeath grief (Liew 2016; Liew et al., 2019b; Passoni et al., 2015). As a result, I sought “specific types of cases” of participants with lower incomes and higher education levels to achieve maximum variation (Thorne, 2016a, p. 100).

Professional Knowledge Providers

Thorne's (2016a) methodology suggested the need for more than one source of data, such as interviewing "experiential experts" (p. 102) in the field. Thus, I interviewed professional people with comprehensive knowledge and understanding of female spouses' multifaceted caregiving experiences. I refer to these study participants as PKPs, and they functioned as secondary informants in the research. The data that I gathered from them supplemented my understanding and interpretation of the emerging patterns and themes that arose in the FSCGs' interviews (Thorne, 2016a).

Sample Size

Within the methodological framework of ID, Thorne (2016a) acknowledged that there is no ideal sample size because it is unlikely that researchers truly achieve complete data saturation. Additionally, Thorne encouraged researchers to continue to collect data until they have enough data to answer their research questions. In view of the aforementioned elements of the methodological framework of ID, I established an appropriate sample size of FSCGs and PKPs to attain their perspectives on FSCGs' predeath grief experiences by using "multiple angles of vision" (Thorne, 2016a, p. 86).

Moreover, I was aware that the number of participants in the FSCG group and the PKP group could vary depending on the quality of the preliminary findings, the informants' contributions (Thorne, 2016a), and the expert advice of my supervisory committee. With ongoing data collection, analysis, and supervisory-committee discussions, the manner in which I interviewed the participants constantly developed and improved over time, and new variations in the data continually emerged (Thorne, 2016a). Consequently, this process enhanced my understanding of the phenomenon (Thorne, 2016a).

The final sample in my research study included 12 FSCGs and three PKPs. I determined that this number was adequate because of the quality of the data that I collected and the meaningful themes and patterns that I discovered (Thorne, 2016a). Accordingly, I was able to make “a coherent and defensible claim” (Thorne, 2016a, p. 105) about the appropriate stopping point and justify the sample size in the study to ensure the validity of the results (Thorne, 2016a). Furthermore, the literature suggested that this particular sample size is appropriate in a qualitative research methodology because it facilitates a thorough examination of the phenomenon and fosters an in-depth understanding thereof (Hoskins & Mariano, 2004; Mayan, 2016; Thorne, 2016a).

Female Spousal Caregivers’ Inclusion and Exclusion Criteria

The FSCGs’ eligibility for the research study was based on the following inclusion criteria: female adult spousal caregiver of persons >60 years of age who (a) lived with dementia; (b) had two or more MCCs; (c) live in a communal home in the community with their spouse; (d) were in a legal marriage or a legal common-law relationship with their caregiver; (e) were able to speak, read, and understand English; and (f) had a telephone and a home mailing address. All FSCG participants met the aforementioned inclusion criteria. I excluded FSCGs who (a) did not provide care on a day-to-day basis to their spouse, who were >60 years of age and living with dementia and MCCs in their communal home in the community; (b) were unable to speak, read, and understand English; and (c) did not have a telephone or a home mailing address. See Table 2.

Table 2

Demographic Characteristics of Female Spousal Caregivers and Spouses

Demographic characteristics	FSCGs
FSCGs' marriage status and living location	All 12 FSCGs were married and lived with their spouses in their homes located in the community.
FSCGs' age range	65 to 82 years (M = 73.17, SD = 5.62)
Spouses' age range	71 to 86 years (M = 77.83, SD = 4.79)
FSCGs' highest level of education completed	Grade 12 (5) 6-to-12-month postsecondary education (4) 3 or more years of postsecondary education (3)
Number of years the FSCGs cared for their spouses	6 months to 15 years (180 months; M = 4.38, SD = 3.77)
FSCGs' employment	Employed part time (1) Not employed (11)
FSCGs' monthly income range (CAD $)	$1500–$3000 (5) Greater than $3000 (6) Declined to answer (1)
Number of family members in the FSCGs' households	Two family members (12)
Number of FSCGs' chronic conditions	0 to 6 (M = 1.78, SD = 1.83)
Number of spouses' chronic conditions	2 to 6 (M = 3.17. SD = 1.28)

Professional Knowledge Providers Inclusion and Exclusion Criteria

The PKPs' eligibility for the study was based on the following inclusion criteria: (a) was 18 years of age or older; (b) was exceptionally well-informed about the female spouse's multifaceted caregiving role and experiences; (c) could speak, read, and understand English; (d) had a telephone and a business email address; and (e) had assumed a professional role in any of the following: the Edmonton Chapter of the Alzheimer Society of Alberta and the Northwest Territories, Caregivers Alberta, or Pilgrims Hospice. According to the *Merriam-Webster* (n.d.-c), a professional role is “engaged in by persons receiving financial return [and] exhibiting a courteous, conscientious, and generally businesslike manner in the workplace”. All of the PKP participants met the aforementioned inclusion criteria. I excluded PKPs who (a) were not 18 years of age; (b) were not exceptionally well-informed about the female spouse’s multifaceted caregiving role and experiences; (c) could not speak, read, and understand English; (d) did not have a telephone and a business email address; and (e) were not professionally employed by the Edmonton Chapter of the Alzheimer Society of Alberta and the Northwest Territories, Caregivers Alberta, or Pilgrims Hospice. See Table 3.

Table 3

Demographic Characteristics of Professional Knowledge Providers

Demographic characteristics	PKPs
Sex	Female (2) Male (1)
PKPs’ age range	51 to 60 years
Specialized education/training	Yes (2) No (1)
Worked directly with care partners of persons living with dementia	3-5 years (2) >8 years (1)

Recruitment of Participants

Thorne (2016a) stressed that it is necessary for researchers to conduct their studies on the foundation “of some thoughtful and transparent sampling logic” (p. 98) because the findings should state what we understand our participants have revealed to us. Therefore, prior to recruitment, I considered the various types of sources from which I could possibly recruit appropriate research study participants and the manner in which I would accomplish the recruitment. I describe my recruitment of participants in the subsequent sections.

Female Spousal Caregivers

Prior to the recruitment of the FSCGs, I either met in person or spoke over the telephone with staff members who occupied managerial positions within the following organizations: the Edmonton Chapter of the Alzheimer Society of Alberta and the Northwest Territories, Caregivers Alberta, and Pilgrims Hospice. The intent of my meeting was to discuss the nature of the study, speak to the inclusion criteria of the study participants, and explain the purpose of the recruitment posters and study postcards (Appendix A). Also, I asked for their input regarding effective strategies to recruit FSCG participants at their organization because of the COVID-19 pandemic.

Since I recruited participants during the COVID-19 pandemic, I could not attend the organizations' support groups as originally planned, because they were cancelled. To rectify this problem, I emailed the recruitment posters and study postcards (Appendix A) to the managerial staff at the sites. They informed their staff about the study and the posters and postcards. Additionally, they asked their staff to discuss this information with clients with whom they communicated on the telephone or in person.

Furthermore, I executed snowball sampling, a recruitment method that leads to potential study participants based on the recommendations of the current study participants (Richards & Morse, 2012). Using this type of recruitment method, I asked participants to share the study information with others. Specifically, I asked the participants to obtain the other persons' permission for me to contact them before the participants gave me the person's contact information.

I contacted potential participants by telephone, who gave permission to be contacted by me. The Alzheimer's Society, Caregivers Alberta, and people with knowledge about the study and study participants referred these participants. At the beginning of our conversation, I introduced myself and explained the study, its length, and the processes of participation. Next, I asked them if they were interested in participating. If they were, I reviewed the inclusion criteria with them and answered their questions. If the potential participants were eligible, I obtained informed consent (Appendix B) over the telephone for their participation in the study. Last, I scheduled the first interview with each participant.

Professional Knowledge Providers

I recruited PKPs from the Edmonton Chapter of the Alzheimer Society of Alberta and the Northwest Territories. I called a member of their managerial staff to discuss the nature of the study and spoke to the PKP study participants' inclusion criteria. After our conversation, the managerial staff member stated she would call me back if she located potential participants. The recruitment was successful because she called and provided three names to contact. All three PKPs consented to participate in the study, and I did not seek any other sources.

At the initial contact I introduced myself; discussed the nature, significance, duration, and possible outcomes of the study; and explained the processes of their participation. I then asked each PKP if they were interested in participating. All were interested, and I therefore reviewed the inclusion criteria with them and answered their questions. Following this, I obtained informed consent (Appendix C) for their participation in the study. Prior to ending the meeting, I scheduled the first interview with each PKP.

Data Collection

Thorne (2016a) suggested the use of unlimited options in terms of data sources and data-collection methods to acquire essential information to answer the research question. Researchers should use valuable, creative data-collection methods and a variety of multiple sources (as well as know their shortcomings and strengths) and choose approaches that are affiliated with their disciplinary knowledge, goals, and research questions (Kalengayi et al., 2012; Thorne, 2016a; Thorne et al., 1997).

The use of multiple sources to enable triangulation of the phenomenon strengthens the trustworthiness of the findings (Hunt, 2009; Thorne, 2016a). Data collection for my doctoral study included in-depth, one-on-one, audiotaped telephone interviews with both FSCGs of older persons living with dementia and MCCs in the community, as well as the PKPs. I conducted 24 interviews with 12 FSCGs, and three interviews with the PKPs. None of the study participants withdrew. The FSCGs were the primary sources of data, and the PKPs provided supplementary data. I completed a demographic form with each FSCG and PKP and wrote fieldnotes to maintain an audit trail of my analytical decisions (Thorne, 2016a).

Demographic Forms

Appendix D includes the FSCGs' demographic form. It contains basic information that describes the participants' characteristics, such as gender; age; length of time married; length of time caregiving; the age and gender of the spouse; the spouse's number of chronic conditions; education completed; employment status; illness or disability; family members in household and monthly income range.

Appendix E includes the PKPs' demographic form. It contains basic information that describes the PKPs' characteristics, such as gender; age; position; professional designation, if applicable; specialized education/training; and years of experience working at their current places of employment and with the study participants (the FSCGs).

Interviews

Interviews are the primary sources of data in ID that researchers use most often (Hunt, 2009; Thorne, 2016a). However, they must produce high-quality data and involve more than asking questions and writing responses. According to Thorne (2016a), interviews with "a carefully thought-out frame of reference" and researchers with "attitude, and communication style designed to build rapport" (p. 139) will prompt most participants to explain their thoughts in the most complete way possible. The FSCGs' interviews focused on meaningful loss relevant to their spouse, their descriptions of predeath grief, potential circumstances, emotions, and so on that might have affected their predeath grief experiences and how their spouse's MCCs might have influenced their predeath grief experiences. In the PKPs' interviews I focused on collecting information about their observations and perspectives regarding the FSCGs' predeath grief experiences within their daily lives and the influence of spousal MCCs on the FSCGs' predeath grief experiences.

Interview Guide

I created two separate semi-structured in-depth interview guides, one for the FSCGs (Appendix F) and one for the PKPs (Appendix G) and used the appropriate interview guide to conduct confidential telephone interviews with each participant that lasted approximately 30 to 60 minutes. Subsequently, I analyzed the data to continually identify similarities and differences among the concepts (Thorne, 2016a). Based on the patterns, themes, and variations that emerged from the iterative data analysis/data collection process, I discussed with my supervisors how to improve my conversations with the participants. With their guidance and our discussions of the

FSCGs' losses, I was able to elicit rich data (Thorne, 2016a). I conducted the second interview a month after the first interview; its purpose was (a) to seek additional information and a more in-depth understanding and (b) to clarify, if necessary, what they had said in the first interview. I allowed the participants to withdraw from the study until a week after the last data collection. If they considered withdrawing, I required that they notify me as soon as possible. No participants withdrew from this study.

Fieldnotes

Fieldnotes were important to document and track my reflections, thoughts, and ideas about the FSCGs' predeath grief experiences and the PKPs' knowledge and understanding of the FSCGs' multifaceted caregiving experiences. Documentation began before I entered the field and continued throughout the research process (Thorne, 2016a). To augment my understanding of the inferences of my role, especially during the telephone interviews, I wrote fieldnotes as I engaged in data collection and construction (Thorne, 2016a). Specifically, during the data-collection and analysis phase it was important that I not only demonstrate reflexivity, but also clearly articulate what I was conceptually and emotionally experiencing (Thorne, 2016a). For example, during the interview process I felt empathy for my participants. I reflected on this emotion and asked myself about the source of this emotion. Once I identified the trigger, I became aware of my empathy during each interview with the FSCGs. "Documenting something of what is happening to you subjectively and conceptually within the research engagement becomes a core element that informs your inductive analytic process" (Thorne, 2016a, p. 199).

Data-Collection Protocol

After I received information about a potential study participant (either an FSCG and/or a PKP) who met the inclusion criteria, I contacted the person by telephone, introduced myself, and explained the length of the study and the participation process. Then I reviewed the inclusion criteria with them and answered their questions. After determining that potential participants were eligible, and after I received their permission to participate, I obtained informed consent over the telephone for their participation in the study. Last, I scheduled a time for the first interview with each participant. I mailed the potential participants a copy of the informed-consent form following the initial telephone call.

Prior to beginning the telephone interview, I told the participants that I would take notes and would respectfully honor their choice to decline to answer questions or end their interviews. Additionally, I asked all participants for their permission to record the interviews. Once they granted permission, I used an audio device to record the conversations. At the beginning of the interviews, I used the demographic form to gather information. Next, I used the appropriate interview guide to collect data. After completion of the confidential interview, I asked the participant if they had any questions and set up a time for the following interview. Finally, I respectfully terminated the interview. I then uploaded the taped interview and fieldnotes onto the University of Alberta Faculty of Nursing password-protected shared-drive secure site.

Potential Challenges for Data Collection

It was important that I anticipate challenges during the data collection, especially because FSCGs living in the community manage their spouse's behaviors daily, and their environment may involve physical and emotional violence as their care recipient's dementia progresses (Cranswick & Dosman, 2008; Gibbons et al., 2014). Because I had interviewed the FSCGs in their home environments, I anticipated the potential for an unsafe environment and risks to their safety during the interviews. Therefore, I created a resource sheet for emotional support and counselling (Appendix H) if the FSCGs required this assistance. This sheet included a list of agencies, such as 211 and HealthLink Alberta. Although there were no challenging issues during the data collection, I mailed the resource sheet to two FSCGs; one felt unsafe in her environment, and the other requested counseling.

Data Analysis

ID requires that researchers look for differences and similarities within their data and reflect on various other informative data that they have collected (Thorne, 2016a). Data analysis has no "predetermined conceptual structure," and the term *theoretical scaffolding* implies "that [researchers are] really foregrounding the study with important scholarly positioning that will influence [their] course and direction through to the end" (p. 60). Although ID does not have a definite endpoint or require theoretical saturation (Thorne, 2016a), at one point in my study my supervisors and I agreed that I had collected adequate data to report relevant findings.

After I securely uploaded the participant's taped interview, as per the previously mentioned process, I notified the transcription expert I hired. She confidentially transcribed each interview and upon completion of her transcription process, she notified me that she entered the transcript into the University of Alberta Faculty of Nursing password-protected shared-drive secure site. Following this process, I commenced the first phase of Thorne's (2016a) data analysis which involves working with the data, finding patterns among the pieces, sorting and organizing the data, and making sense of the data. Therefore, I sorted, organized and started to make sense of the data. It is important to note than I cleaned the data by listening to the audio recordings, listening for nuances and voice inflections while reading each transcription and documented my thoughts in my fieldnotes.

I immersed myself in the data as I searched for categories, patterns, and themes. Then I coded the transcript data, remaining open minded to emerging thematic patterns or reoccurring ideas (Thorne, 2016a). The initial coding process was important because it created a way for me to bring pieces of data together that might or might not be related. I focused on discerning differences and similarities within the data and used an “iterative reasoning process” (p. 163). Also, I diligently explored emerging “relationships and associations” (p. 164) and was aware of the need for precision, especially in the early stages, to avoid refuting relationships that might demonstrate significant variance. Therefore, it was essential that I used nursing epistemology and constantly asked myself, “How can [I] know what exists?” (Olson, 2011, p. 69).

By conducting my data collection and analysis concurrently, moving back and forth to clarify, and delving into the participants’ experiences, observations, and opinions to generate a greater understanding of predeath grief experiences, I identified patterns and themes that evolved from the primary data (Thorne, 2016a). I analyzed the data from the FSCG participants (primary data) first. Then I analyzed the supplementary data from the PKPs and integrated them into the findings to inform the analysis of the FSCG interviews. As part of the data-analysis process, I traced the development of new ideas, similarities, and differences, which promoted further investigation and a clearer understanding of the phenomenon under study (Thorne, 2016a).

As I simultaneously engaged in the iterative process of data collection and data analysis, themes emerged. At this point I reviewed the literature to augment my data analysis by reading what researchers had said about each specific theme. The theories in the literature informed my understanding of each theme, gave me further insights, and helped to clarify the theme. I returned to my data and determined whether my understanding of each theme was similar or different. For example, my early findings indicated that FSCGs sometimes experience hopelessness as a type of suffering within the context of predeath grief. As a result, I began to look at research and other data sources that described hopelessness to get a better understanding of whether this was what the early group of FSCGs experienced. In subsequent interviews I asked the participants specifically about hopelessness as suffering to further understand this phenomenon. The literature augmented my data analysis because it provided clarity and helped to inform my analytical interpretations of the data to inform my understanding of the phenomenon under study (Thorne, 2016a).

I integrated research articles, relevant theories, and conceptual frameworks into the analysis. Analytical notetaking inspired self-reflection and involved a process of becoming aware of and expressing my professional perceptions, personal opinions, and biases when I conducted the data collection and analysis. I maintained continual communication with my supervisors and supervisory committee during the doctoral study. Analytic notetaking was also a crucial element of the last stage of transforming patterns into findings. It enabled me to record new relationship developments, emerging linkages, variances, similarities, and differences in the data and fostered insights and an "angle of vision" (Thorne, 2016a, p. 234) with regard to the predeath grief experiences of FSCGs of older persons living with dementia and MCCs who live in the community. Therefore, I wrote memos during the process of analysis that contained my insights (Richards & Morse, 2012). Acquiring a new lens and a new perspective promoted critical thinking about the significant contributions of the creditable patterns of knowledge that I discovered (Thorne, 2016a).

It is important to note that Thorne (2016a) offered significant advice to researchers during the analytical phase of ID research studies, specifically about avoiding what she identified as common pitfalls in qualitative research. For example, Thorne cautioned researchers against premature coding, misinterpreting frequency, and the over inscription of self. Likewise, she emphasized that overly characterizing the importance of the researcher's role in co-creating knowledge can negatively impact the overall credibility of the findings. Therefore, I was aware of any development of a special bond between each participant and me because of the risk of falsely characterizing the participants' data as inherently rich (Thorne, 2016a). This did not occur during this study.

Data Management

I used Quirkos data-management software to organize and store important information such as the memos and fieldnotes that recorded the research journey, as well as the transcript data. I then calculated means, standard deviations, and frequencies from the demographical data to illustrate the participants' characteristics in the final research report. The data management involved ensuring the confidentiality of the participants' data, the transcripts, and the spreadsheets that could be easily connected to the original information about all participants. The use of a University of Alberta Faculty of Nursing password-protected shared drive was vital to ensure confidentiality and secure storage of the data. I assigned each of the participants a code number that represented them, of which they had no knowledge. After the COVID-19 government and health mandates and restrictions end, I will store all of the data from the study for 5 years in a locked file at the University of Alberta; only the research team will know where the file is located.

Because of the health mandates and restrictions, I conducted the interviews in a locked home office and ensured strict confidentiality in this office. After each interview, I immediately uploaded the interview conversations to the University of Alberta Faculty of Nursing password-protected shared drive. As a result of the COVID-19 pandemic restrictive mandates, I stored the data in a locked cabinet in a secured place, my home office, and no person has knowledge of or is privy to the data in the locked cabinet.

Credibility of the Research

Throughout the doctoral study, and particularly with the data collection, I consistently engaged in reflexivity. Each day that I was involved in the research process, I reflected (Richards & Morse, 2012) by asking myself questions regarding my affiliation with the study, my biases at that very moment and during any study interactions with the participants, and all types of data that I collected with the use of a reflexive journal.

I created records of my reflexive thoughts after I completed each individual interview. My reflexive tools included the principles that underpinned my decisions with regard to the logistics of my doctoral journey and my intellectual thoughts, as well as the activities that I performed in the study, which thereby created an audit trail (Thorne, 2016a). In the words of Olson (2011):

> Reflexivity is an important part of the analytical process; . . . part of the process for establishing the credibility of the study and the validity of its findings; [it] show[s] that the researcher is monitoring his or her standpoint as the study progresses. (p. 17)

Although I did not physically observe the participants in face-to-face interactions, I verbally communicated with them over the telephone. I was an active listener and assessed their inflections, pauses, and so on during our conversations. As a researcher, I was responsible for generating a continual process for self-feedback on my interactions with the research process and the participants (Thorne, 2016a). In my reflective fieldnotes I kept an account of my reflexivity regarding my position in and influence on what I studied (Richards & Morse, 2012; Thorne, 2016a).

Engaging in ID, I followed Thorne's (2016a) evaluation criteria. To enhance the quality and credibility of the study, at all times I adhered to evaluation criteria that included epistemological integrity, representative credibility, analytic logic, and interpretive authority. Epistemological integrity is crucial to the credibility of the study, and with confidence and integrity it was important that I demonstrate a "defensible line of reasoning from the assumptions made about the nature of knowledge through to the methodological rules" (p. 233) to explain the research process. Therefore, I was consistently immersed in the epistemological integrity of the study and aware of all processes that were happening simultaneously. I asked my supervisors and supervisory committee for guidance and wisdom with regard to aspects of the study, especially in areas that I did not understand. In doing so, I was able to declare my "defensible line of reasoning" because, while I wrote my findings, I was able to justify my analysis with quotations (Thorne, 2016a, p. 233).

I consistently assessed the representative credibility by frequently using the iterative process of analysis and constant comparison analysis and was able to identify suspicious knowledge claims in my doctoral study (Thorne, 2016a). My audit trail in the documentations in my fieldnotes and memos demonstrated my analytic logic. I consistently and frequently discussed the study with my supervisors and shared the rationale for my decisions (Thorne, 2016a). Interpretive authority is crucial to ID because the researchers' focus with this qualitative method approach is to convince the audience that their research is truthful and can be repeated because of a thorough audit trail. To accomplish this, I was accountable for consistently being aware of the need for reflexive awareness regarding the study and sharing this awareness regularly with my supervisors and supervisory committee (Thorne, 2016a).

Ethical Considerations

I adhered to ethical considerations consistently throughout the study. I obtained approval for this study from the University of Alberta Health Research Ethics Board, Edmonton, Canada (Pro00097037) on February 19, 2020 (Appendix I). The approval included information letters and consents that covered emotional distress, privacy and confidentiality, and power relations and power differential.

Information Letter and Consent

Prior to any interaction with the participants, I read the consent and information letter out loud to both the FSCGs (Appendix B) and the PKPs (Appendix C). I recorded their consent to participate in the doctoral study in my fieldnotes and audio-recorded it. Before the FSCGs and PKPs provided their oral consent, I gave them an opportunity to ask me questions about the study. Once again, I took this opportunity to record the activities that were happening at this moment in my fieldnotes and audio-taped them. I consistently obtained consent, as ethically and legally required.

I wrote the consent and information letters in English. I also included in these letters the purposes and outcomes of the study, confidentiality, privacy of the data, potential risks, potential benefits, freedom to withdraw, and future use of the data. I assured the participants that I would maintain the confidentiality and privacy of all of the information that I collected. At all times, the participants were free to ask questions or voice their concerns regarding the doctoral study. Because participation in the study was voluntary, they could withdraw at any time without penalty. After we had completed the participant-consent process, I mailed a $10.00 gift card to each participant as a thank you.

Privacy and Confidentiality

At all times I maintained the participants’ privacy and confidentiality, demonstrated respect, and maintained the dignity of the study participants and their information. I also informed them that I would always keep their data anonymous and protect their confidentiality during the dissemination of the results.

Emotional Distress

Both the participants and I as the researcher felt emotional distress at times in this study. Although, I did not need to reschedule the data collection, as per the participants' request, I did offered them a resource sheet with appropriate resources. When I needed to address my emotional distress, I wrote in my reflexive fieldnotes and debriefed with my supervisors.

Power Relations and Power Differential

I maintained respectful, professional, and trusting interactions with the participants throughout the study. At all times I encouraged them to speak openly and freely to minimize the power relations.

CHAPTER 4: FINDINGS

In this chapter I describe the predeath grief experiences of FSCGs of older persons living with dementia and MCCs in the community. The FSCGs in this study experienced predeath grief in the context of the complexities of caregiving that included life-changing events, shifting interpersonal connections with their spouse, new responsibilities related to caregiving, and the challenges of caregiving. Additionally, the FSCGs' experience of caregiving included the effects of dementia and the all-encompassing losses that the COVID-19 pandemic further complicated.

To achieve the aim of this study, I will first address my first research question: *How do FSCGs of older persons living with dementia and MCCs within the community describe their predeath grief experiences?* The overarching theme of *being in a wave* describes the FSCGs' predeath grief collectively; the subthemes include suffering, loss of control, and moments of happiness. The second research question was, *What factors influence FSCGs' predeath grief experiences?* The factors that influence FSCGs' predeath grief experiences include previous experiences of death, fear of their spouse's death, relationship with their spouse, support from others, and relationship with a Higher Power. Table 2 summarizes the themes and subthemes in the qualitative data.

Demographic Characteristics

I included two participant groups in this study: FSCGs and PKPs. I interviewed each of the 12 FSCGs twice, for a total of 24 interviews, and the three PKPs, once. All of the FSCGs were married and lived with their spouse in their home located in the community. The ages of the FSCGs ranged from 65 to 82 years (M = 73.17, SD = 5.62). The spousal age ranged from 71 to 86 years (M = 77.83, SD = 4.79). Five FSCGs completed Grade 12 as the highest level of education, four FSCGs completed a 6-to-12-month postsecondary education programs, and three FSCGs had three or more years of postsecondary education.

Table 4

Description of Themes and Subthemes

Themes	Subthemes	Description of major themes
Context of the complexities of caregiving	Life-changing experience	A description of the situations in which predeath grief occurred
	Dementia front and foremost	
	The effects of Covid--19	
	The all-encompassing loss	
Experience of predeath grief: Being in the wave	Suffering	This was the major overall theme of the findings.
	Loss of control	
	Moments of happiness	
Factors that influence caregivers' predeath grief experiences	Previous losses	A description of the factors that influenced the predeath grief experiences
	Fear of spouse's death	
	Relationship with spouse	
	Support from others	
	Relationship with a Higher Power	

The number of years that the FSCGs had cared for their spouse ranged from 6 months to 15 years (180 months; M = 4.38, SD = 3.77). Only one FSCG participant was employed part time, and the remainder of the group were not employed. Five FSCGs reported a monthly income range of CAD$1500–$3000, six reported an income range of greater than CAD$3000, and one participant declined to answer this question. Each FSCG reported two family members in the household. The number of chronic conditions of the FSCGs ranged from zero to six (M = 1.78, SD = 1.83) and the spouses' number of chronic conditions ranged from two to six (M = 3.17. SD = 1.28). I interviewed two female and one male PKP whose ages ranged from 51 to 60 years. Each participant had relevant education and/or training and worked directly with care partners of persons living with dementia. I have excluded the specific job titles to maintain the participants' confidentiality.

Context of the Complexities of Caregiving

Contextual factors are a variety of elements that influence an intricate phenomenon (Ploeg et al., 2019). Residing as a couple in the community, the FSCGs provided care to their spouse, who were living with dementia and MCCs. Their predeath grief experiences occurred within the context of the complexities of caregiving. Four themes describe this context: (a) life-changing experience, (b) dementia front and foremost, (c) the effects of COVID-19, and (d) the all-encompassing loss.

Life-Changing Experience

Many of the FSCG s described how their lives changed significantly as their spouse's cognitive and functional abilities relentlessly declined. In fact, the FSCGs agreed that "dementia is the most terrible disease" and they had no idea how caring for a loved one can be so difficult (FSCG 11). Consequently, many FSCGs felt that they had been to "hell and back" because of the multitude of uncertainties and constant challenges in their caregiving experiences (FSCG 01). This life-changing experience had three sub-subthemes: (a) shifting interpersonal connections, (b) accrued new responsibilities, and (c) an uphill battle.

Shifting Interpersonal Connections. The FSCGs explained they had dual roles in their marriage: wife (spouse) and spousal caregiver. Additionally, they all viewed the role of spouse as a lifetime commitment, legalized through the act of marriage. Moreover, within their life-changing experiences their interpersonal connection shifted. For example, one participant stated that she did not feel “as cherished anymore. I don’t feel like I am the most important thing in his life anymore. It just seems like it’s diminished. It’s lost” (FSCG 09). Another participant shared that her husband no longer kissed her goodnight, a ritual that he had never missed prior to his diagnosis.

As the interpersonal connections between the FSCGs and their spouse continually shifted, a variety of emotions emerged for the FSCGs. Some felt anxiety, fear, and sadness. Throughout one participant’s caregiving experience, she felt sad and anxious because she feared “how things will end” (FSCG 11). Another participant cherished the daily laughter that she shared with her spouse. Now, “that’s gone. And it’s really sad” (FSCG 01).

Additionally, other FSCGs felt overwhelmed, stressed, and angry because of the shift in their interpersonal connections with their spouse. Some FSCGs directed their anger at particular caregiving issues, and others directed their anger at their spouse. For example, one participant often felt overwhelmed and anxious because her interpersonal connection changed in several ways and, as a result, she stated, “Sometimes I hate him” (FSCG 08).

Accrued New Responsibilities. The PKPs confirmed that the FSCGs incorporated their spouse’s responsibilities when they no longer could accomplish them and often encountered a steep learning curve. Some of the new responsibilities included aspects of the overall daily functioning of their home, both inside and outside; the finances; and driving. One participant reported that before her spouse was diagnosed with dementia, he had done all of the yard work and household chores with her. Because he could no longer help her, she not only felt the loss of his companionship, but also the loss of sharing the burden of all of the responsibilities.

Similarly, another participant's partner was unable to help her with their home and financial responsibilities, which manifested in resentment. Her feelings of sadness, anger, and anxiety underpinned her resentment. Moreover, another participant described the frustration that she felt when she took on her spouse's previous responsibilities. She gave an example of having to shovel their very long driveway by herself: "While I'm outside plowing snow I can cry, or I can holler, or I can scream" (FSCG 09). One PKP believed that the "significant changes" in a person living with dementia and MCCs result in "the care partner increas[ing] her roles in care, that's when we definitely start to see the grief, the hurt, the anger, the loss, the sadness, the loneliness" (PKP 03). Furthermore, because of the progressive loss of their spouse's cognitive and functional abilities, the FSCG's caregiving responsibilities also continually accrued because of their spouse's increasing needs and the complexity of care.

One participant's spouse lost the ability to care for himself and to communicate verbally. Because he could not feed himself or express his thirst or hunger, she was "stressed all the time" with trying to understand when he needed something to drink or eat: "It's just horrible. He's lost all of that. And I've lost—it's harder and harder to look after him. You're just grieving every day. It never stops" (FSCG 03). As one FSCG took on "more and more things", because her spouse was unable to complete daily tasks she felt that she was losing more and more "and loss is always grief" (PKP 02).

An Uphill Battle. Most FSCG participants identified their caregiving experiences as extremely challenging which was reflected in the theme an uphill battle because of the substantial difficulties, constant uncertainties, and multiple losses they experienced. Overall, they were consumed almost every hour of the day with meeting their spouse's physical and emotional needs, managing their spouse's unpredictable behaviors, and resolving various challenges within their caregiving experience. Rarely was there any time for them to meet their own needs because providing care to their spouse was “a full-time job” (FSCG 08). It is a job with various stresses. “As things get more to handle, more to deal with, it’s more of a strain on me” (FSCG 02).

Specifically, one participant felt “more of a nurse” than a spousal caregiver because of the incessant increasing physical health demands of her spouse (FSCG 01). The FSCGs acknowledged that providing care to their spouse was their top priority. Additionally, they admitted that it takes an extraordinary amount of time and work to care for their spouse. One participant disclosed that “by the time I do have a break, all I want to do is collapse” (FSCG 11). Furthermore, another participant explained that providing care made her “plate so much fuller. I have so much extra to do because he’s not capable or has the desire to do any of it anymore” (FSCG 09). The constant uphill battle while caregiving played a vital part in their experiences of predeath grief.

Dementia First and Foremost

Although the spouses had chronic conditions, the effects of their dementia most affected the FSCGs’ lives. For example, one spouse had a chronic hearing problem for 10 years that caused numerous communicating challenges with his wife. Since his diagnosis of dementia, the FSCG participant reported, “now I’m really raising my voice so that he’ll understand, but I’ve since read that he cannot—the dementia prevents a person from understanding, computing vocabulary. [Therefore], he’s having trouble processing what I’m saying” (FSCG 08). Even though her spouse’s hearing problem had created previous communication challenges, the lack of her spouse’s understanding because of his dementia continued to intensify their communication challenges and adversely affected her caregiving experience.

Another participant stated that her spouse had a chronic obstructive pulmonary disease. She affirmed that his "sleep apnea definitely affects the dementia. If he has not had a good night's sleep the next day is not near as well" (FSCG 09). Nevertheless, she insisted that her spouse's "dementia is front and foremost" and predominantly gave rise to the many challenges that she encountered and endured while caregiving (FSCG 09).

Although the FSCGs managed and cared for their spouse's MCCs, it was evident that the MCCs were secondary to managing and caring for their dementia. For example, one participant's constant worry about the effects and trajectory of her spouse's dementia not only was a burden throughout her caregiving experience, but also underpinned her feelings of despair, especially because "there is not a cure for dementia" (FSCG 12). In fact, for the majority of the FSCGs the lack of a cure for dementia created a sense of despair.

One participant explained that her despair was a consequence of an unending frustration over her spouse's overall health. Because of his elevated blood pressure and sugar levels, she always cooked nutritionally and had "been careful" with their diet (FSCG 11). However, even though she did her best to limit her spouse's sugar intake, he ate cookies whenever he wanted them because of his lack of understanding due to his dementia, which led to her feelings of despair. Notably, a PKP revealed that a person living with dementia and MCCs compared to a person living with only MCCs might find it more difficult to communicate to his spousal caregiver how he is feeling and the type of pain that he is experiencing. It is difficult for persons living with dementia and MCCs to communicate their answers to the question, "Are you in pain?" (PKP 02). This "highlights the disabilities [and] vulnerability of the individual. He's got the physical pain, and he can barely let his caregiver know what's going on" (PKP 02). Furthermore, because his spousal caregiver is "the only one whom he trusts, . . . what happens to him if something happens to her?" (PKP 02). The despair that all FSCGs felt was a result of their spouse's dementia. This terminal illness was their top priority, and their spouses' MCCs came second.

Effects of COVID-19

The FSCGs and their spouse were living in a COVID-19 pandemic at the time of their interviews. They had to deal with newly instituted government and health regulations, enforced isolation precautions, decreased respite services, and restricted social visits. These changes gave rise to three sub-subthemes regarding the effects of COVID-19 that were important to the FSCGs: (a) emergent new challenges, (b) the generation of various losses, and (c) beneficial reprieve.

Emergent New Challenges. The majority of the FSCGs faced a variety of new challenges that increased their stress while they provided care during the COVID-19 pandemic. In particular, many participants became fearful that they or their spouse would become sick with COVID-19. One participant was "afraid" she might infect her husband (FSCG 03). Therefore, she strictly adhered to isolation precautions and constantly stayed home; thus, she felt "a prisoner in [her] stupid house" (FSCG 03). Her isolation experience made her "impatient with [her spouse]. I didn't feel I was doing the best job I could for him because I was just here all the time with him" (FSCG 03). As a result, she "want[ed] to forget this life that I'm in" (FSCG 03). Moreover, maintaining isolation was difficult for another participant as she revealed that "the total isolation is making me probably sadder than it would normally" (FSCG 11).

In particular, one participant who strictly followed pandemic restrictions to protect her spouse from getting sick stated that the effects of COVID-19 "added so much more shit" to her caregiving experience (FSCG 08). Even the simple act of handwashing with liquid soap created difficult circumstances for both because now “everything’s a fight” between her and her spouse (FSCG 08). Consequently, the effects of COVID-19 not only increased her stress within her caregiving experience, but also negatively affected her.

Because the effects of the COVID-19 pandemic brought on new challenges, a number of spouses demonstrated heightened agitation and stress. Accordingly, their required caregiving needs increased in complexity. For one participant, because her spouse did not understand COVID-19, he asked incessant questions about it, which created an additional challenge for her. As a result, she “shudder[ed] to think of what it’s going to be like as [his] disease progresses” (FSCG 05).

One PKP validated that the COVID-19 pandemic “has really increased the stress level” of the FSCGs, especially because the pandemic created an environment of isolation, which is not healthy for seniors. Specifically, seniors with dementia are at a “bigger risk” of being affected by isolation (PKP 03).

The Generation of Various Losses. COVID-19 restrictions created losses for both the participants and their spouse. For example, many day programs for the spouses were cancelled, and several programs for most FSCGs were cancelled. Consequently, the needs of both the spouses and the FSCGs were not met during the pandemic, which increased the feelings of loss. In fact, because of the COVID-19 pandemic, the coping classes of one of the FSCGs were no longer in person but were now online. Consequently, she experienced increased frustration instead of learning how to cope with caregiving. Because these classes “exist[ed only] on Zoom or Microsoft Teams or whatever the hell it might be,” this increased her stress because she had difficulty with understanding technology (FSCG 05).

The COVID-19 pandemic deprived both the participants and their spouse of spending time together as a couple outside their home. Prior to the pandemic, weekly walks at the community recreation center, dancing, and going out to eat were activities that many couples enjoyed. Specifically, one participant commented, “Because of covid, I think everything is a loss” (FSCG 11). As the FSCGs endured the effects of COVID-19 and an unhealthy living and caregiving environment, they continued to face multiple losses because their spouse’s dementia progressed. As a result, their stress escalated because it was “tied to the progression of the disease of the family member” (PKP 03). Consequently, they experienced grief from the progressively increasing losses and because their “grief is tied to [their] stress level,” this meant that as their losses increased, so did their stress and grief (PKP 03).

Beneficial Reprieve. Living during the COVID-19 pandemic not only brought on emergent new challenges and generated various losses but was also beneficial for two FSCG participants and their spouses. One participant stated, “COVID has almost made me happier in this way in that I don’t have to go out with him and get into that situation” (FSCG 06). Another participant explained that COVID-19 eliminated her spouse’s social stress because he “withdraws to himself when we are with a group of people” (FSCG 09). As a result, the two FSCGs appreciated the restrictions of COVID-19 because they were mandated to stay at home.

The All-Encompassing Loss

Three subthemes of loss that were significant to the FSCGs were (a) loss of spouse, (b) loss of self, and (c) loss of future dreams.

Loss of Spouse. Preceding their spouse’s diagnosis of dementia, all of the FSCGs witnessed a progressive decline in their spouse’s cognitive and functional abilities. At the confirmation of the diagnosis of dementia, felt disbelief and heartache. Two participants summarized the emotions of all FSCGs as their spouses' cognitive and functional abilities continued to decline: They felt "loss" (FSCG 11), and "It's just going to get worse, and then he's going to be gone" (FSCG 01). Another FSCG added, "The hobbies and activities that we shared, that's all gone. My lifestyle is totally changed. I don't have a partner anymore" (FSCG 03).

As the FSCGs lost elements of their spouse, they gradually assumed many of the responsibilities for the home, vehicles, and yard because of their spouse's inability to participate in these areas. One participant lamented:

> [I had] to learn our finances, which is something I don't enjoy. I have to understand everything about the house. I have to see to the house. My husband used to repair everything. I am not that side of the brain. I feel so self-conscious, I feel dumb. (FSCG 08)

As one FSCG's spouse's verbal communication continually decreased, it caused a major loss within their relationship. She identified feeling the loss of her spouse because "the lack of interchange or conversation at a more interesting or intellectual level, like talking about politics" was no longer taking place (FSCG 05). Likewise, another participant acknowledged that her spouse did not discuss issues with her any longer, which was "a bad loss" for her because she "always respected [his] opinion" (FSCG 07). Additionally, because of the failure to share humor with her partner, one FSCG declared that she now has "lost the ability to laugh and smile" (FSCG 11).

Notably, as the characteristics of their spouse faded away, the FSCGs agreed that they were "losing someone before [they] actually [lost] them. . . . It's like losing someone twice" (FSCG 12). Consequently, their first major loss was the decline of their spouse's cognitive and functional abilities; their second major loss would be their physical death. Sadly, between these two key losses, the FSCGs experienced constant significant multiple losses.

Loss of Self. Almost all of the FSCG participants reported that they had very minimal time available to accomplish their personal goals and meet their own needs because of the continual upsurge in their caregiving responsibilities. New challenges related to their spouse's dementia, the expansion of their spouse's unpredictable behaviors, and their spouse's increasing needs also increased their caregiving responsibilities. Specifically, one participant could not accomplish her personal goals or continue working in her profession because her spouse consumed her time: "My husband's becoming my baby, my child. I can't leave him as much as I could before" (FSCG 08).

Most FSCGs pointed out that their spouse's moods, needs, and circumstances consumed their days. Therefore, they found it difficult to run errands, meet their needs, and participate in a variety of activities about which they felt passionate. Some participants manifested resentment toward their current circumstances and occasionally toward their spouse. For instance, because of her caregiving experience, one participant felt "stifled . . . [because she lost] a bit of [her] independence [and] the inability to be able to get out" (FSCG 06). One PKP confirmed that she often heard FSCGs say, "I don't have time to do that" or "I don't do this anymore" or "I can't go and do this because of my spouse" (PKP 01). This PKP noted that the "biggest thing that I hear is that care partners are neglecting their own needs, neglecting their own health, neglecting self-care" (PKP 01). Because of their caregiving experiences, the majority of the FSCGs neglected their own needs and consequently lost aspects of themselves because they were unable to fulfill their needs.

Loss of Future Dreams. Many FSCGs felt anger, resentment, fear, and frustration because they would never achieved their planned future with their spouse. In fact, one participant described her future as "a death watch," which was something that neither she nor her spouse had planned for. Another participant was “scared” because of the loss of her and her spouse’s future dreams, even though they “were so diligent” about planning their future together. Additionally, one participant’s nonexistent future plans with her spouse created “a bit of resentment” (FSCG 05). Also, she felt sad: “It’s not how I ever planned on spending my golden years” (FSCG 05). Specifically, this participant explained her loss of future dreams as

> the beginning of a very long journey. And to be honest—and I’ve expressed it to various doctors and to my own kids—I very much hope my husband dies of physical disease like cancer or heart attack and doesn’t linger and virtually become a vegetable. (FSCG 05)

Even short-term future plans to go out for a meal or visit family were illusory for the participants and their spouse because of the COVID pandemic. Furthermore, one PKP affirmed that the FSCGs’ future plans “aren’t going to come to fruition [because] there are many, many losses that female spousal care partners would suffer” (PKP 03). The multiple losses of spouse, self, and future dreams that the FSCGs endured during their caregiving shaped their predeath grief experiences.

Overarching Theme: Being in the Wave

Prior to their spouse’s physical death, the FSCGs experienced predeath grief as “emotional and physical responses” (Lindauer & Harvath, 2014, p. 2203) to the losses that resulted from their spouse’s cognitive and functional decline. One participant described her predeath grief experiences as being in a gigantic wave:

> [Being] in the ocean and caught in a wave and you’re just upside down and backwards and just tossed. That’s just how it makes me feel. It can be frightening. It can be, oh, this is cool. It can be, whee! And it can be, I’m going to die. All of it all at once. It’s all there. That’s the end and you’re here and [there is] sand in your swimsuit. (FSCG 04)

For the majority of FSCGs their predeath grief experiences also oscillated between their responses, in a fluid like motion, moving back and forth, in various directions which was very similar to the twisting, turning, up and down motion experienced in a gigantic wave described earlier by FSCG 04. Even the action of the ocean's water slowly building up to the crest of the wave mimicked the buildup of another predeath grief experience because of a new loss. When the FSCGs believed that they were on the threshold of their predeath grief experience, they felt as though they were on the crest of the wave and then crashing with it. They felt out of control, tossed upside down, and spun around; and they were left feeling as though their heart was in their throat. Bewildered by their predeath grief experience, they felt alone. Their loneliness made them feel as though they were disoriented under the water. Trying to find a way to deal with their emotional and physical responses felt like swimming for a lighted surface area to get their head above the water and take a breath. Above the water and breathing, they felt that they were in a safe place; and this safe environment offered time for reflection on their predeath grief experiences. Even though many times the FSCGs felt that they were in gigantic waves, they occasionally experienced smaller, less turbulent waves. Above all, they wondered when the next wave would come. The theme of being in a wave during the FSCGs' predeath grief experiences has three subthemes: (a) suffering, (b) loss of control, and (c) moments of happiness.

Suffering

Living with and caring for their spouse, all of the FSCGs felt losses that caused mental and emotional pain. The majority agreed that, because of their many losses, they felt overwhelmed and suffered, which never diminished but only intensified their experiences of predeath grief. Three sub-subthemes within the subtheme of suffering that were important to the FSCGs were (a) sadness, (b) hopelessness, and (c) loneliness.

Sadness. The FSCGs' feelings of sadness were associated with their predeath grief. The sadness of one participant underpinned her thoughts about the effects of dementia on her marriage "Dementia is poisoning, is ruining our marriage: it's ruining our love" (FSCG 08).

Another participant felt both a state of shock and sadness as she felt “immediate loss upon [her spouse’s] diagnosis”:

> This just knocked the wind right out of my sails because his memory loss was very evident suddenly, and he started to deteriorate quite quickly at that point. It was heartbreaking for me. It was like going to death. I was angry. I was sad. I didn’t know sort of where to throw myself. (FSCG 06)

Numerous FSCGs also felt sad in various ways. One participant felt sad as she endured every day of her spouse’s terminal illness. Another participant explained, “[I] look after [my] husband, . . . but I don’t have a life. I just feel like I’m so sad most of the time” (FSCG 03). Another participant reported that “the loss that I’m—that we are facing and that we are experiencing” (FSCG 06) created feelings of sadness. She gained insight into her sadness and chose not to think too far into the future, “because if I did, I could be sad all the time. And I just can’t do that, because if I’m sad, he’ll be sad” (FSCG 06). Although she tried not to let her sadness impact herself or her spouse, another participant reported that she could not hold back her sadness because “the sadness and the loneliness are there all the time” (FSCG 11). All of the PKPs corroborated that the FSCGs’ experience sadness because of the multitude of losses and because every day they observed their spouse’s cognitive and functional abilities progressively deteriorate.

Hopelessness. Even though the FSCGs felt hopeless in various ways, they reported that their hopelessness was part of their mental and emotional suffering because, there is no cure for dementia. With respect to the variations in hopelessness, one participant explained that it was a result of her spouse’s lack of communication and his emotional separation from her. Moreover, another participant felt “no glimmers of hope” when her spouse did not sleep well, because his day would not be a good one (FSCG 09). Likewise, if he was not having a good day, neither would she, because her day would feel like “too much cloud in the day even if the sun is shining” (FSCG 09).

Another participant revealed that every day she felt “totally helpless [and] hopeless” as she cared for her spouse (FSCG 03). Because of her spouse’s terminal illness, she believed that they were both suffering: “It’s just hopeless, just get it over with, just hammer all those nails in [the coffin]. We know what the ending is going to be like. And it’s not going to be a happy one.”

Another participant felt despair and depression, which contributed to her hopelessness. She described her hopelessness as being in “an infinity pool, and I was near that edge, and one little breath would [put her] right over that edge” (FSCG 12). Similarly, another participant’s hopelessness was a feeling of “sinking and drowning; trying to keep [her] head above water” (FSCG 08) as she endlessly strove to survive. Notably, all of the PKPs validated the FSCGs’ frequent feeling of hopelessness because of their continual losses and knowledge that dementia has no cure.

Loneliness. At various times, nearly all the FSCGs felt lonely. As their spouse’s cognitive and functional abilities deteriorated, the FSCGs felt their loneliness amplified, especially when they were physically present with their spouse. Although the FSCGs had shared intimate connections with their spouse for decades prior to the diagnosis, the current inability of their spouse to communicate and connect created their loneliness and experience of a “failed connection” (PKP 02). The FSCGs’ failed connections with their spouse also underpinned their feelings of isolation and loneliness in their own home. Consequently, because of these feelings, they were unable to mingle within their communities or maintain other relationships, and the FSCGs viewed their world as getting smaller.

Notably, one participant’s failed connection with her spouse caused her loneliness and contributed to one of her “darkest moments, [which was] living in this house with somebody but being with myself. I feel so alone. . . That’s painful” (FSCG 12). The participants’ failed connections with their spouse were responsible for their inability to complete their life plans with their spouse even though they were physically alive. In other words, these failed connections with their spouse intensified the reality of their predeath grief experiences. In fact, a PKP who had worked with FSCGs reported they observed that “loneliness generally comes first, and then grief will follow” (PKP 02). Furthermore, a PKP noted that some FSCGs who experience predeath grief sometimes label it loneliness because they do not want to acknowledge the grief.

One FSCG described feeling alone all the time, because living with her spouse felt like living with a ghost. For example, one PKP said, “A loss [is] having your partner sitting right with you, but you [are] feeling immensely lonely” (PKP 03). Another participant felt as though she lived with a ghost because her spouse did not interact with her in any way; thus, “[my marriage] has gone just completely dead. I am a very alone person” (FSCG 02). Furthermore, another participant summarized her feeling of living with a ghost: “I have no one to talk to. I have no one to laugh with, be crazy with, enjoy a meal with, have a glass of wine with” (FSCG 12).

Loss of Control

At different times each of the FSCGs felt a loss of control. One participant considered herself a woman who could handle very challenging circumstances because she always felt in control. However, she was not in control of her spouse’s terminal illness: “I can’t do anything about it. That hurts. The loss of control is huge. And so, I’m trying to control what I can, and it’s certainly little right now” (FSCG 04). The FSCGs felt a loss of control in three areas: (a) sleep patterns, (b) busyness in their daily lives, and (c) their spouses’ unexpected behaviors.

Sleep Patterns. Many FSCGs felt a loss of control in their sleep patterns. For example, because of the effects of their spouse's dementia, some FSCGs did not sleep with their spouse, which resulted in an unrestful sleep. Not only were they physically disconnected from their spouse and their nightly routines, but they also had to be alert and aware if their spouse were awake and up during the night.

For others, their emotional suffering caused their loss of control of their sleep patterns. One participant who was with her spouse constantly developed anxiety as she observed him decline every day. As a result, she could not shut her mind down at night and have a restful sleep. Likewise, some FSCGs lacked control of their sleep patterns because in their minds at night they constantly solved the issues of their increasing responsibilities, unexpected new challenges, and what to do about the decline in their spouse's health status.

A few FSCGs admitted that they took sleeping pills or antidepressants to gain control of their sleep patterns. One participant took a sleeping pill every night because the anxiety from her losses woke her up between 12:30 a.m. and 2:00 a.m., and she laid awake, thinking. Even though she was upbeat in the morning as the day progressed, "I get a little snappier or chippier, [and I am] not as patient" (FSCG 05). Additionally, another participant revealed that her loss of control over her sleep pattern "doesn't help the whole caregiving thing" (FSCG 11). Consequently, the FSCGs' focus decreased during the day, which made them more exasperated and short-tempered.

Busyness in Their Daily Lives. Several FSCGs lacked control over the busyness in their daily lives because of their spouse's unanticipated caregiving needs and other unexpected issues. For example, a participant pointed out that the totality of her numerous responsibilities, her 24-hour-a-day, 7-day-a-week caregiving role, and unforeseen problems left very little time for herself during the day. Consequently, she felt resentful and guilty. Her loss of control over the busyness “makes me less, I’d say, tolerant [and] unable to accept what’s really happening to him” (FSCG 11).

Conversely, a participant constantly kept busy to keep her mind off her problems, especially the emotional suffering that she could not control. Often she felt resentful, felt “sorry for myself” in her role, and then felt guilty for her resentment. Her salvation was to constantly stay busy because her self-induced busyness helped her to cope and get through each hour of the day.

Spouse’s Unexpected Behaviors. Many FSCGs felt a loss of control over their spouse’s unexpected and out-of-character behaviors. One participant described her spouse as “a really kind man, and all of a sudden [the] behaviors started. And it actually really scared me” (FSCG 01). Another participant reported that, previously, her spouse “was an exceptionally brilliant person and my mentor”; now, all he wanted to do was cuddle “24 hours a day, which is making me some crazy” (FSCG 11).

Another participant revealed that her spouse “can’t do anything about [his] dementia, [but he] can quit smoking and [his] lungs will get better. They’re not going to heal. But they can get better” (FSCG 12). She claimed that he could do something about his physical health issues but refused to do so. This upset her, especially because she lacked control over his physical health, and he would not accept her help.

Moments of Happiness

Every wave has a highest point, called the *crest*. Even though the FSCGs felt that this is a place that “can be frightening. And it can be I’m going to die” (FSCG 04), it is also a place where several felt that “it can be, oh, this is cool. It can be, whee!” (FSCG 04). For one participant, “laughter and enjoyment” with her adult children (FSCG 02) when they spent time with her, and her spouse made her feel happy. Another participant felt a sense of happiness when she was a source of comfort to her “agitated” spouse (FSCG 03). Her loving act created happiness, especially because she felt a brief connection to her spouse.

A number of FSCGs enjoyed reflecting on past experiences that they shared with their spouses. Remembering the love between them that was once so special resulted in happiness, especially at this time in their lives. Moreover, a participant commented that for over 60 years she had enjoyed her spouse’s sense of humor and continued to do so. She was grateful for these moments because, when she laughed with him, “I feel I still have part of him. . . . We’re still sharing something” (FSCG 07). Likewise, another participant appreciated that her spouse “still has [his] sense of humor” (FSCG 10), because sharing laughter helped her to overcome her feelings of hopelessness and frustration. Some of the FSCGs made a conscious effort to find their inner peace and happiness. Specifically, one participant was “learning to enjoy [her] own company more than [she] used to” (FSCG 11).

At numerous times, just as ripples flank waves, so too were the FSCGs happy in between their experiences of predeath grief. Some days their happiness was like the leftover sand in a bathing suit that reminded them of the calm waters in which they swam and played. On other days their emotions felt like the leftover sand in a bathing suit that grated on their skin when a forceful wave slammed them into the sand when they only wanted to swim.

Factors that Influence Caregivers’ Predeath Grief Experiences

In this section I report the findings that answer the secondary research question, *What factors influence FSCGs’ predeath grief experiences?* Factors are parts of the circumstances that shape and contribute to an outcome. Five factors coexist with and influence the overarching theme of *being in the wave*: (a) previous losses, (b) fear of spouse's death, (c) relationship with spouse, (d) support from others, and (e) relationship with a Higher Power.

Previous Losses

Several FSCGs described how their previous losses had influenced their predeath grief experience. One participant assessed her current predeath grief in light of the sudden death of her former spouse: "The sudden death, believe it or not, is easier. It's like it was done. But this here, you're just hanging" (FSCG 03). Her ongoing predeath grief kept her continually "hanging [and] rips [her] guts out" because he is physically alive, "yet he's gone" (FSCG 03).

Notably, the teenage daughter of another participant had died. Although a "hole [remained that] never gets filled up completely," she felt a "closure to" all of the significant missed opportunities that she would have shared in her daughter's life (FSCG 09). Having previously experienced her daughter's death, this participant was aware that she would eventually have some closure when her spouse died. However, at this time in her life, as she experienced predeath grief she felt "a grief that there's no closure to" (FSCG 09). As her spouse "gets worse and worse," she described her predeath grief as "ongoing."

Likewise, one participant had suffered the death of her baby: "When I was young I actually lost a baby to crib death, and I was the one who found her" (FSCG 01). The experience of finding that her baby had passed away in her crib deeply affected her because she did not trust that her other two children were still alive while they slept quietly: "I used to go shake them to make sure they were still breathing" (FSCG 01). Because her spouse lived at home, she believed that he would pass away at home. Her experience of finding a loved one dead in her home influenced her experience of predeath grief: "I know from previous experience; I will handle it. I'll probably—I'll totally fall apart afterward" (FSCG 01).

Another participant disclosed that she had experienced the death of both of her parents. Her father passed away when she was very young, and her elderly mother passed away while she lived in a different country. As she reflected on her grief from her parents' death and her feelings from the losses that she had experienced with her spouse, she became aware of her "different feeling [of] grieving" (FSCG 11). Previously, she was

> aware of it because I've read about it, . . . but I've never really thought about it in depth. I feel a sense of loss, and I've never thought about the grieving part because it's a different feeling from grieving the loss of my parents. (FSCG 11)

Her previous losses made her aware of the difference between that loss and her predeath grief. That is, she was now in a place where she could begin to understand that her predeath grief experiences were her responses to her spouse's losses.

Fear of Spouse's Death

Witnessing their spouse's cognitive abilities progressively deteriorate prior to their physical death was an everyday reality for the FSCGs. For most, their observations reminded them of the eventual outcome of their spouse's terminal illness. Given that they all cared for their spouse at home, many FSCGs feared that their spouse's deaths would take place within their home.

For example, one participant felt very uneasy about leaving her spouse "for more than an hour, . . . two hours at the very outside, for fear that something might happen" (FSCG 05); for example, he might die at home. Likewise, another participant feared that her spouse would die or have a heart attack when she was not at home. Consequently, she began her morning routine with assessing her spouse to ensure that he was still breathing. At times "he is breathing, but he's so shallow, sometimes I'm scared" (FSCG 03).

Other FSCGs were afraid to wake up to find that their spouse had passed away. One participant described this possibility as continual fear: "Sometimes it feels like you're just waiting for that pin to drop. I'll wake up and he'll be gone" (FSCG 01). She believed that her fear was based on "the fear of not knowing" when he would pass away. Her constant fear of the unknown and the thought of her spouse passing away just magnified her ongoing fear. Therefore, she wondered how she would handle his death.

Another participant feared her spouse's impending death from dementia. Although she did not want him to die, she stated that "sometimes I wish there were some other way he would go" (FSCG 06). Even though another participant was aware of her spouse's forthcoming death, "I don't want to see the negative part of it. Like, deep down probably [I] do know but maybe don't want to face the fact" (FSCG 10). With the uncertainty of her spouse's terminal-illness trajectory, one participant felt anxious and sad rather than fearful: "I'm anxious about how things will end and sad [about] losing my partner" (FSCG 11). This heightened the experiences of predeath grief.

Relationship With Spouse

Prior to their spouse's diagnosis of dementia, the majority of FSCGs shared a mutually committed relationship with a reciprocity of a multitude of feelings such as love and respect. Even though they still had those feelings, the effect of their spouse's dementia and the multiple losses from their relationship influenced their predeath grief. For example, one FSCG described her current relationship:

> I'm grieving that our life is no longer what it used to be. I just took it for granted that he was well, and he's not well anymore. He's always been well; he's always been just so loving, just so understanding, so respectful; and I just don't have the same man I used to. Sometimes I'm afraid. Sometimes I hate him. I really do because he's not himself. It's a change. It's a gradual change in personality. I grieve every day. (FSCG 08)

The significant changes in another FSCG's relationship with her spouse led to predeath grief. Because her spouse was no longer able to go out socially and enjoy an evening of dancing, she would occasionally go out with her friends. However, on her way home, she stated, "I don't know what that feeling was in the car. Maybe that’s the feeling of grief again [as] the key went in the door” (FSCG 03). Although she enjoyed the occasional breaks and conversations with her friends, she grieved the loss of her relationship with her spouse.

Another FSCG participant felt “a grieving kind of a feeling” because, as time went on, she lost elements of her relationship with her spouse that she had cherished: “Without really losing [him], you have [him] there in person but not as a whole person. I get an overwhelming feeling like you are a couple but you’re not” (FSCG 07). The significant changes in the FSCG’s relationship made her predeath grief overwhelming.

The emotional and physical separation in their relationship with their spouse because of the effects of their dementia has resulted in losses for most of the FSCGs that were difficult to accept. Not only was the separation within their relationships a loss, but they also realized that they had not chosen this reality in their current life. This critical change in their relationship and life with their spouse influenced their predeath grief. One PKP participant explained this separation:

> Because whether you’ve actually said vows, until death do us part, or you haven’t said them in front of a spiritual person or a justice of peace or anything, you still say it like that. That’s what being a partner is; you’re in it together. And all of a sudden through wishes not of your own, but through circumstances that you haven’t made of your own choice, that separation happens. And so, to me, when I talk to people, they really feel this ripping apart of this partnership; you know, [this] great divide coming between them that wasn’t chosen. (PKP 03)

Support From Others

Relationships connect people to one another. For example, friends and family in healthy relationships with the FSCGs supported them as they experienced predeath grief. One participant reported that she had supportive friends who stayed in touch with her because they were concerned about her and her spouse. She was most grateful for their support and the respect that they gave her husband, especially when they conversed with him “on his level” (FSCG 06).

Although her friends were very supportive, her family was not. Very seldom did her husband's grandsons visit, and never did her brothers or her sons visit. Consequently, she was disappointed and resentful. She explained, "I certainly let everyone know what I needed, but they didn't do it when it was possible. Now it's not possible" (FSCG 06).

Another participant's friends and family both assisted and supported her in many ways. Although she appreciated them, she was offended when acquaintances acted judgmentally toward her spouse. For example, during the COVID-19 pandemic her spouse had difficulty breathing with a face mask on and did not understand the rationale for the mask; therefore, he did not keep it on. To protect her spouse, she did her best to help him through this issue. She shared her perspective on an acquaintance's judgments of her spouse's responsive behaviors, such as pulling off his mask: "It's up to the individual to maybe inform themselves a little bit [about] what might be going on in that other person in order to be able to be a little bit sympathetic" (FSCG 07). Although she tried her best, her acquaintance's lack of knowledge or support resulted in a sense of disappointment.

For some FSCGs, learning to accept a person's assistance was difficult and humbling. Others greatly appreciated the support they received. One participant's friend had told her numerous times to "reach out, because you're not being weak when you reach out. You're giving me the opportunity and the blessing of being able to help you" (FSCG 10). Additionally, other FSCGs felt less lonely because their families and friends were supportive in various ways. One participant appreciated that "a smiley face on my text message [from my friends] in the morning puts a smile on my face" (FSCG 12).

Many FSCGs appreciated the support of the staff of the Alzheimer Society of Alberta and Northwest Territories, who helped them in various ways. Some FSCGs claimed that the staff had changed their lives for the better. One PKP confirmed that they had supported FSCGs in a variety of ways because they "really try to help [the FSCGs] understand it's grief and loss" (PKP 03) that they were experiencing. Education and support empowered a number of FSCGs to recognize and understand their own experiences of predeath grief.

Relationship With a Higher Power

The relationship of some of the FSCG participants with a Higher Power impacted their caregiving and predeath grief experiences. One participant spoke about her faith in relation to her spouse's health. Often, she prayed to God to give her "courage to carry on and keep going" (FSCG 02). Other FSCGs reported that their inner strength and relationship with God had helped them through countless caregiving hardships and challenges, especially as they lived through their spouse's terminal illness. For example, one participant felt that God was "right beside me" and asserted that He gave her the strength to get through each day (FSCG 12).

Another participant's relationship with God had reassured her that the burden of caregiving was "not all on me" (FSCG 04). Some of the FSCGs believed that their relationship with God bolstered their inner strength, and a few believed that God planned for them to take care of their spouse living with dementia. Specifically, one participant explained that her current purpose was to care for her spouse because "this is how God planned my life" (FSCG 03). Similarly, another participant stated, "I have a very, very strong faith-based philosophy. I am a follower of God. I do; I really feel that this is part of His plan" (FSCG 09).

Although several FSCGs acknowledged that being in a relationship with God underpinned their inner strength, courage, and purpose, a few were upset with God. For example, one participant stated that being in a relationship with God enhanced her faith and inner strength; however, it "doesn't mean I still don't get ticked off at Him." She explained, "He's not a punishing God, but there are times when I just feel that, you know, he is. I don’t know what I’ve done wrong, but You’re punishing us” (FSCG 03). The relationship that some FSCGs experienced with a Higher Power not only gave them inner strength to endure their losses, challenges, and predeath grief experiences, but also helped to ease their stress.

Summary

In this doctoral study I explored the predeath grief experiences of FSCGs of older persons living in the community with dementia and MCCs. The context of the complexities of caregiving is the milieu in which the FSCGs’ predeath grief experiences occurred. The findings describe the FSCGs’ predeath grief experiences in the overarching theme of being in a wave, which means that their predeath grief experiences existed in a fluid state, moving among feelings of suffering, loss of control, and moments of happiness. The FSCGs’ predeath grief experiences were not linear, and several factors influenced them: their previous losses, fear of their spouse’s death, their relationship with their spouse, support from others, and their relationship with a Higher Power.

CHAPTER 5: DISCUSSION

In this chapter I discuss the findings of my doctoral study with a focus on the FSCGs' experiences of predeath grief. I begin with a discussion of the context of the complexities of caregiving in which I describe the milieu in which the FSCGs' predeath grief occurred. Next, I focus on the key overall theme of being in a wave and its subthemes: suffering, loss of control, and moments of happiness. Finally, I discuss the factors that influenced the FSCGs' predeath grief experiences, such as previous losses and their relationships with their spouse. Throughout this chapter I discuss these main findings in relation to existing research and theory. The chapter also includes a discussion of the study limitations.

Complexities of Caregiving

Life-Changing Experience

The FSCGs faced a shift in their interpersonal connections, accrued new responsibilities, and endured substantial challenges, uncertainties, and multiple losses because their spouse's cognitive and functional abilities continually deteriorated. Hence, their lives significantly changed. "Dealing with the massive changes in all aspects of their shared life together" (Pozzebon et al., 2016, p. 552) seems to be a common theme in the lives of spousal caregivers of persons living with dementia. For the FSCGs in this doctoral study, the significant changes in their life gave rise to feelings of being overwhelmed, stressed, resentful, and angry, which is not unusual for caregivers of persons living with dementia (Chan, et al., 2013; Kobiske et al., 2019).

Additionally, the significant changes made it very difficult for many of the FSCGs to reserve time for themselves or even to meet their own needs, which is concerning. This finding is similar to those of other qualitative studies on the caregivers of older adults with dementia and MCCs in which researchers reported that caregivers experience significant changes and, with the demands of caregiving, have little time to meet their needs (Peacock et al., 2020; Ploeg et al., 2020). As spousal caregivers of persons living with dementia continue to age, they face a greater probability of having health problems and less opportunity to look after themselves, which can increase their burden and cause adversarial feelings (Caputo, 2021; Ott et al., 2007). Creating time for self-care and ways to improve one's well-being in a caregiving role is very important, especially for female caregivers (Peacock et al., 2020), and might have been helpful to the FSCGs in this doctoral study. Future research is needed to determine whether encouraging FSCGs to create time for self-care and ways to improve their well-being effectively decreases their burden.

Besides the significant changes, many FSCGs learned that caring daily for persons living with dementia and MCCs is difficult, especially because the care that they continuously provided escalated in complexity as their spouse's dementia progressed. This is similar to the findings in other studies that many caregivers of persons living with dementia find that caregiving is challenging, time consuming, and emotionally and physically arduous (Caputo, 2021; Peacock et al., 2017; Ploeg et al., 2018) and "made even more complex by the presence of multiple chronic conditions" (Ploeg et al., 2018, p. 2). These findings suggest that FSCGs of persons living with dementia and MCC require additional support.

Alongside the significant changes that the FSCGs faced were feelings of despair because of the lack of a cure for dementia. The effects of dementia require management, and for the FSCGs, these effects took precedence over their spouse's MCCs. Similarly, the FSCGs of older adults living with Alzheimer's disease and related dementias and MCCs in the community who participated in Peacock et al.'s (2020) study also chose to manage the effects of their spouses' dementia "over [their] other chronic conditions" (p. 8). These choices might indicate that dementia adds a significant complexity to caregiving. While the spouse of each FSCG in the study lived with both dementia and multiple chronic conditions, more research is needed to determine how caring for persons living with dementia and MCCs impacts the caregivers' predeath grief experiences compared to the predeath grief experiences of caregivers who care for older persons living with dementia.

Living in a COVID-19 Pandemic

I found a limited number of studies on the effects of the COVID-19 pandemic on caregivers of persons living with dementia (Losada-Baltar et al., 2021; Maćkowiak et al., 2021). The majority of the researchers of the studies reported that the COVID-19 pandemic has adversely affected a myriad of caregivers (Parmar et al., 2021) and exacerbated challenges with regard to family caregiving (Losada et al., 2022; Parmar et al., 2021). Although Losada et al. (2022) found that the pandemic had an adverse effect on family caregivers of persons living with dementia as well as their care recipients, the researchers also stated, "It is important to highlight that a non-negligible proportion of caregivers perceived an increase in their experience of positive emotions such as happiness and hope in the context of the restrictions due to the COVID-19 pandemic" (p. 80). This is important because not only do people who have positive emotions feel good, but positive emotions also help to control negative emotions, which is important especially during the COVID-19 pandemic (Fredrickson et al., 2000).

In this doctoral study two of the FSCGs welcomed the reprieve of COVID-19 isolation regulations because it justified their need to stay at home. They no longer had to leave their homes, which was at times difficult. Also, staying home meant that they or their partners could avoid embarrassment. Embarrassment, which often resulted from their spouse's unexpected behaviors, was a common emotion. For example, Egilstrød and Petersen (2021) reported that

FSCGs are frequently embarrassed when they engage in conversation with others and their spouses add to the conversation. This finding is of interest because it might indicate that for two FSCGs their predeath grief decreased as a result of COVID-19 isolation; however, additional research is needed.

Most of the FSCGs in this doctoral study were fearful that they or their spouse would contract the COVID-19 virus. As a result, they maintained isolation to protect themselves and their spouse, faced new challenges that increased the complexity of their care, and dealt with their spouse's enhanced agitation and stress. In fact, one FSCG was so focused on protecting her spouse from COVID-19 that she was diligent about constantly handwashing with her spouse. However, because her spouse did not fully understand the need for increased hand hygiene and other protective mechanisms, the FSCG felt heightened tension and stress from having to remind him constantly to complete these safety measures. Maćkowiak et al. (2021) reported similar findings. They found that the impact of COVID-19 on the lives of informal caregivers of persons living with dementia within the community is a feeling of fear of being infected with COVID-19. Additionally, the pandemic created extra caregiving responsibilities for the participants that affected their mental health and increased their stress (Maćkowiak et al., 2021).

The All-Encompassing Loss

Another significant finding in this research is the all-encompassing loss that the FSCGs constantly experienced that involved the loss of spouse, loss of self, and loss of future dreams. Previous researchers have shown that caregivers of persons living with dementia experience and grieve multiple losses (Doka, 2010; Lindauer & Harvath, 2014; Marwit & Meuser, 2002). "Most of the risk factors of pre-death grief may possibly be conceptualized within the context of losses" (Liew et al., 2019a, p. 260).

The FSCGs continually felt the loss of their spouse, specifically the emotional closeness that they enjoyed throughout their marriage. The loss of their spouse's ability to communicate verbally and therefore to have meaningful conversations together was the most significant loss for the majority of the FSCGs. The loss of a spouse leads to additional grief reactions because of the loss of emotional closeness between the couple. Depending on their pre-existing emotional closeness, the loss of a spouse is a critical factor in predeath grief (Liew et al., 2019a; Lindauer & Harvath, 2014; Silverberg, 2007).

Over the trajectory of the FSCGs' spouse's terminal illness, they constantly provided care and dealt with new challenges as well as the effects of their spouse's dementia and MCCs. Thus, as I previously stated, they were left with minimal time for themselves and felt the loss of self, which affected their predeath grief experiences. Similarly, to the caregivers of older persons living with dementia and MCCs in their qualitative descriptive study, Ploeg et al. (2020) reported that the "caregivers often described providing care to a person with dementia and MCC as a '24/7 job'" (p. 2610); consequently, they were left with no personal time for themselves.

For most FSCGs the loss of future dreams evoked various negative emotions such as fear, resentment, and anger. The literature on the caregiving of persons living with dementia demonstrated that the loss of future dreams is a significant issue that caregivers commonly experience (Kobiske et al., 2019; Large & Slinger, 2015; Noyes et al., 2010). Moreover, because of the COVID-19 pandemic, the FSCGs also experienced the loss of short-term plans. Losing the opportunity to participate in activities with their spouse in the present moment was difficult to accept because they knew that enjoying a future with their spouse was no longer an opportunity for them. Blandin and Pepin (2017) reported that every "loss invites a state of separation from the person with dementia, from the life one has lived in the past, and from an anticipated future" (p. 73).

The FSCGs' all-encompassing loss within their predeath grief experience suggests that predeath grief is just as profound as the grief after the physical death of a spouse. After their spouses' deaths, widows/widowers experience a dramatic change in their lives and lifestyles, their relationships are different, they struggle with other losses, they assume new roles in life, and they endure social isolation (Doka, 2016a). This is similar to the experience of the FSCGs in this doctoral study.

Predeath Grief

The major overall theme of the findings in this doctoral study was the experience of predeath grief—being in a wave—which included suffering, loss of control, and moments of happiness. The suffering experienced was comparable to crashing from the crest of the wave, feeling loss of control was experienced as being tossed and spun around and moments of happiness were experienced as a feeling of being above the water and being able to breathe.

The FSCGs' experience of being in a wave seemed to oscillate among their suffering, loss of control, and moments of happiness. The idea of oscillation between negative and positive emotions in grief is also a fundamental component of the DPM (Fiore, 2019). Oscillation permits bereaved persons to move between immersion in grief and avoidance of grief, which helped them to cope (Fiore, 2019). Although the FSCGs were not in a bereaved state, oscillating between their negative and positive responses was an opportunity for respite and reflection, which can lessen the effects of predeath grief. More research is needed to examine the concept of oscillation in predeath grief.

In addition to oscillating between the negative and positive responses to multiple losses, at times the FSCGs experienced both negative and positive responses to predeath grief at the same time. This suggests the existence of a paradox in predeath grief. A *paradox* is “something (such as a situation) that is made up of two opposite things and that seems impossible but is actually true or possible” (*Merriam-Webster*, n.d.-b,). Specifically, paradoxes are “not an either/or but a both/and experience that is both complex as well as a basic component of human nature” (Raffin Bouchal et al., 2015, p. 54). In fact, Raffin Bouchal et al. (2015) suggested in their qualitative study that “the concept of the paradoxical holding of the dialectic” (p. 54) is possible because caregiving families hold on as much as they can to their loved ones and simultaneously slowly let go. I concur that the majority of FSCGs in this doctoral study had similar experiences to those of the participants in Raffin Boucal et al.’s study. Therefore, they may have experienced a paradox in their predeath grief experience. More research is needed to confirm whether this is the case.

Suffering

The FSCG s experienced various multiple losses that underpinned their suffering, which never dispelled. “Suffering is an unpleasant or even anguishing experience which can severely affect a person on a psychophysical and even existential level” (Bueno-Gomez, 2017, p. 9). According to the literature on caregivers of persons living with dementia, the experience of suffering is associated with loss, grief, and the negative effects of burden and depression, to name a few (Bravo-Benítez et al., 2021; Chan et al., 2013; Holley & Mast, 2009; Jain et al., 2019; Kiely, et al., 2008; Li et al., 2021; Marwit & Meuser, 2002; Noyes et al., 2010; Sanders et al., 2003). Although suffering affects the entire person, “a crucial aspect of [suffering] is the personal attitude and choices which are in turn influenced by cultural and social patterns”

(Bueno-Gomez, 2017, p. 9). The suffering of the FSCGs in this doctoral study was comprised of sadness, hopelessness, and loneliness.

Sadness. For most FSCGs their sadness was initiated when they heard their spouse's diagnoses and the effects of their spouse's dementia on their marriage also resulted in sadness. Others felt sadness every day along the trajectory of their spouse's terminal illness. Research on the predeath grief of caregivers of persons living with dementia has identified sadness as a standardizing symptom of grief (Ott et al., 2007) that continues throughout the caregiving (Jones & Martinson, 1992; Rudd et al., 1999), and FSCGs experience a substantially higher level of sadness than do male spousal caregivers (Rudd et al., 1999). In fact, *heartfelt sadness* is a factor in grief that measures the grief experiences of caregivers of persons living with dementia on the MM-CGI form (Marwit & Meuser, 2002). Because the physical death of a spouse is asynchronous with psychological death, caregivers feel sad (Lindauer & Harvath, 2014). An interesting finding in this doctoral study is that one FSCG believed that she would be sad all the time if she thought about the future and that if she felt sad, so would her spouse. This suggests that FSCGs and their spouse might feel sad at the same time during the predeath grief experience.

Hopelessness. At times the FSCGs felt a sense of hopelessness because of the lack of communication and emotional separation from their spouse. Additionally, their realization that dementia has no cure and is a terminal illness augmented their hopelessness (Alzheimer's Society of Alberta and Northwest Territories, 2022). The predeath grief literature on caregivers of persons living with dementia reported that the lack of a cure for dementia contributes to caregivers' feeling of hopelessness (Large & Slinger, 2015). Likewise, the literature on predeath grief revealed that caregivers also feel hopeless when they have high levels of stress, their caregiving role becomes their career, and they cannot envision a future or will ever have a future reconciliation with the care recipients, to name a few (Bravo-Benítez et al., 2021; Kobiske et al., 2019; Meuser & Marwit, 2001; Noyes et al., 2010; Rudd et al., 1999; Sanders & Corley, 2003).

Although some of the literature on the predeath grief of caregivers of persons living with dementia spoke to hopelessness, other research literature on family caregivers of persons with dementia and Alzheimer's disease focused on the concept of hope. Duggleby et al. (2009) reported in their grounded theory study of family members caring for persons living with dementia that the participants expressed hope "as the possibility of a positive future within their daily lives and in the social context of grief and loss" (p. 514). Similarly, Duggleby et al. (2011) described hope as an important "factor in all aspects of quality of life" (p. 11) in family caregivers of persons living with Alzheimer's disease. Although researchers have extensively studied the hope of various types of caregivers, including caregivers of persons living with dementia in the community, future research on hope is needed in the area of the predeath grief of FSCGs of older persons living with dementia and MCCs.

Loneliness. At various times the FSCGs felt lonely because meaningful communication with their spouse progressively declined, along with their spouse's cognitive abilities. They even felt lonely when their spouse was physically present with them. In particular, some FSCGs described living with their spouse as living with a ghost. In Li et al. (2021) cross-sectional study, the spousal caregivers also felt loneliness because they had lost their intimate relationships. Notably, intense loneliness is frequently linked with grieving, especially the emotional loneliness that often exists in the grieving process (Bonanno & Kaltman, 2001).

A surprising finding is that the PKPs in this doctoral study observed that some FSCGs who approached the Alzheimer's Society for support had often labeled their experiences of predeath grief as loneliness. The PKPs believed that these FSCGs used the term loneliness to avoid acknowledging their current reality of predeath grief. Caregivers of persons living with dementia do not always acknowledge loss and grief because they are probably struggling with the inescapable deterioration of their care recipient's cognitive abilities and relentlessly trying to maintain normalcy in their lives (Liew & Yap, 2020). Moreover, Adams and Sanders (2004) found in their quantitative study of 99 family caregivers that many caregivers who provided care for recipients in early-stage dementia did not acknowledge grief and were hopeful possibly "because the worst problems [had] not yet occurred" (p. 207). Additionally, the findings suggest that it is essential to recognize people's losses that augment their grieving as their care recipient's dementia progresses, because "there are different emotional tasks faced by caregivers" (p. 195) at each stage within the trajectory of the care recipient's disease.

The literature on the caregiving and predeath grief of older persons living with dementia frequently identified loneliness as an issue (Chan et al., 2013; Li et al., 2021; Meuser & Marwit, 2001; Shanley et al., 2011). Most of the FSCGs in this doctoral study also felt lonely and isolated because their verbal and emotional connections with their spouse continuously decreased. Lindauer and Harvath (2014) reported "a central dimension to predeath grief in dementia care is impaired communication" (p. 2202). More research is needed on the loneliness associated with the predeath grief experiences of FSCGs of persons living with dementia and MCCs in the community.

Loss of Control

Loss of control for many of the FSCGs felt as though they were in a gigantic wave, being spun around and tossed upside down. They experienced loss of control over various components in their lives that were elements entangled in the wave of predeath grief. The loss of control of the FSCGs' circumstances is consistent with that of other caregivers in the literature on predeath grief even though the type of circumstance varies according to the context of the caregivers' experiences. For example, the caregivers in the literature on predeath grief felt a loss of control over current and future losses, their burden, various responsibilities, and having to live lives that they did not choose (Durepos et al., 2020; Durepos et al., 2019; Loos & Bowd, 1997; Sanders et al., 2003). Similarly, in Sanders and Corley's (2003) qualitative research study, 173 caregivers who experienced predeath grief reported that they had no control over the changes that were happening to their care recipients. The FSCGs' loss of control in this doctoral study contributed to their emotional and physical responses of predeath grief, and they experienced loss of control in three areas: (a) sleep patterns and (b) busyness in their daily lives and their spouses' unexpected behaviors.

Sleep Patterns. Several FSCGs felt a loss of control in regard to their sleep patterns and experienced unrestful sleep for a variety of reasons. A common and significant issue for caregivers of persons living with dementia is problematic sleep (Brewster et al., 2022; Smyth et al., 2020). Some FSCGs lacked the inability to shut off their minds, their spouse's routines disrupted their nightly routines, and a few FSCGs felt physically separated from their spouse because they did not sleep with him. Furthermore, the FSCGs' emotional suffering such as anxiety and stress not only augmented the loss of control over their sleep patterns, but also resulted in poor-quality sleep. Similarly, the caregivers of persons living with dementia in the community in Smyth et al.'s (2020) study reported "poor sleep quality and high levels of . . . anxiety and stress" (p. 5).

Many of the FSCGs' in this doctoral study had difficulty sleeping because of their spouse's unexpected behaviors during the day and at night. Jiménez-Gonzalo et al.'s (2021) study, which included 246 family caregivers also reported this issue. The researchers found that “sleep problems are significantly and positively associated with care-recipients’ disruptive behaviors” (p. 640). In this doctoral study, some FSCGs took sleeping pills or antidepressants to gain control over their sleeping patterns in an attempt to get more sleep. Using pharmaceutical interventions was important for some of the FSCGs because they needed a better quality of sleep, especially in their caregiving role. Gibson and Gander (2021) reported being female family caregivers of persons living with dementia is an important predictor of increased sleep disturbances. Specifically, caregivers who have moderate to severe problematic sleep are more likely to take sleep medication (Gibson & Gander, 2021). Additional research is needed to find safer alternatives for FSCGs to regain control of their sleep patterns while they provide care and manage their predeath grief.

Busyness in Their Daily Lives and Spouse’s Unexpected Behaviors. The majority of FSCGs were busy during their daily lives primarily because of the numerous responsibilities of being caregivers. At various times their spouse’s care needs were unpredictable as a result of the often spontaneous nature of their behaviors that were related to dementia. Specifically, the FSCGs’ busyness resulted in feelings of guilt, intolerance, frustration, and resentment because of the loss of control in their daily lives. They had little time to focus on their own needs and at times had to forgo self-care activities that can be useful in reducing their stress and improving the overall experience of predeath grief. Their experiences were similar to the findings of other predeath grief studies in which the caregivers experienced loss of control in managing their spouse’s unexpected behaviors and the effects of dementia (Holley & Mast, 2010; Large & Slinger, 2015).

It is important that FSCGs use positive coping strategies to manage the busyness in their daily lives and their spouse's unexpected behaviors. Doing so will help them to feel healthy emotionally, physically, mentally, and spiritually as they experience the end of their meaningful personal relationship with their care recipient (Meichsner & Wilz, 2018). If FSCGs choose to avoid what is happening as a coping strategy, they might demonstrate unhealthy habitual and compulsive behaviors that can become barriers to managing grief (Blandin & Pepin, 2017). Consequently, this can have a substantial negative effect on the FSCGs (Bravo-Benitez et al., 2021). Therefore, it is essential to encourage FSCGs to use positive coping strategies when they feel a loss of control.

Moments of Happiness

Among the FSCGs' negative responses in their predeath grief, several FSCGs felt moments of happiness. Particularly, they were happy when they visited with family, spent time with their spouse and shared laughs, reflected on their pasts, and discovered inner peace. Nurse theorist Rosemarie Rizzo Parse (1997) found in her theory-building research study that "joy-sorrow is pleasure amid adversity" (p. 84) and that "it is a pattern of health lived as the ups and downs, the highs and lows in life, arise simultaneously in interconnections with others, ideas, objects, and situations" (p. 82). The FSCGs demonstrated that it is possible to have moments of happiness within their predeath grief experiences, which suggests that they might be living within the paradoxical experience of joy-sorrow that Parse described.

At various times most of the FSCGs in this doctoral study described their love and admiration for their spouse, but in the next breath they expressed painful emotions that accompany predeath grief. In the bereavement literature, Doka (2016a) described the journey of grief as a feeling of positive emotions mixed with complicated, sorrowful reactions. "Positive feelings are not a denial of grief but another natural response to loss, offering the promise that the memories and relationship will persist even as the pain of grief diminishes" (pp. 37-38). Likewise, in the bereavement literature Bonanno and Kaltman (1999) concurred that grief encompasses not only negative responses, but also positive feelings. Furthermore, positive emotions serve as *breathers* in a grief experience because a breather creates brief opportunities to be free from stress in the grief experience and allows caregivers to participate an enjoyable diversionary activities (Bonanno & Kaltman, 1999). More research is needed to examine FSCGs' paradoxical experience of joy-sorrow within their predeath grief experiences.

Factors That Influence Female Spousal Caregivers' Predeath Grief Experiences

The findings from this research suggest that predeath grief experiences are influenced by multiple factors such as caregivers' previous losses and their relationship with their spouse for whom they are caring.

Previous Losses

One key finding is that some FSCGs used their past experiences of the death of a loved one as a way to gain insight into their current predeath grief. Acquiring insight is possible because the experience of grief influences the way that people think (Doka, 2016a). In the bereavement literature, as people acquire insight and are able to recognize the manner in which grief manifests itself in their lives, they become more knowledgeable with regard to helping themselves to endure another grieving process (Doka, 2016a).

In a qualitative study on the existential concerns of 20 family members in frequent contact with relatives who had late-stage dementia, Albinsson and Strang (2003) found the participants' past experiences with the death of parents, spouses, or children influenced the participants' relationships with their relatives and their imminent deaths. However, their past experiences with the death of their relatives “could make the thought of the dementia patient’s impending death either easier or more difficult” (p. 231). Currently, the literature on the influence of caregivers’ previous experiences of death on their relationships with their care recipients is limited. Additional research is needed to further explore how previous experiences of death influence the predeath grief of FSCGs of persons living with dementia and MCCs in the community.

Relationship With Their Spouse

Nearly all of the FSCGs openly shared their thoughts regarding the love and respect within their marriage and partnership, as well as the intimacy and expressions of love between them that were slowly fading away. Although the FSCGs had many difficult times because of the gradual loss of their marriage and partnership, they were very slowly finding ways to accept this loss, but it was a struggle because of their commitment to their spouse and marital relationship. Similarly, to the findings of other studies, FSCGs’ honored their marital commitment that underpinned their commitment to caring for their spouse (Egilstrød & Petersen, 2021; Peacock et al., 2017).

The literature on predeath grief and caregiving demonstrated that the FSCGs, in the doctoral study, also faced similar alterations in their lives. For example, the gradual loss of connection with their spouse because of their spouse’s declining cognitive abilities, the multiple losses, and the transition from spouse to FSCG that also changed their relationship between husband and wife (Chan, et al., 2013; Egilstrød et al., 2019; Egilstrød & Petersen, 2021; Loboprabhu et al., 2005; Sanders et al., 2003). Specifically, attachment bonds and continuing bonds speak to the emotional attachment between persons living with dementia and their spousal caregivers (Doka, 2016a; Lindauer & Harvath, 2014; Meichsner et al., 2016; Pozzebon et al., 2016; Root & Exline, 2014). In this doctoral study the FSCGs were older adults, some of whom had been married for a long time. The duration of the spousal relationships become important because of the "considerable length of time available to these couples to consolidate emotional, intellectual, and physical intimacy bonds with each other" (Pozzebon et al., 2016, p. 552). As attachment bonds change between spousal caregivers and recipients, caregivers can experience more predeath grief within the changing nature of their relationships (Liew et al., 2019b); this finding is similar to the findings of this doctoral study because most of the FSCGs had difficulty with the changing emotional attachment between them and their spouse.

The emotional attachment that once provided a sense of permanence and security can slowly begin to unravel. The research indicated that FSCGs' attachment bonds unravelled at different speeds because the more passionate the emotional, physical, and psychological attachment is between the spouses, the more intense the spousal caregivers' grief and loss will be (Sanders et al., 2008). Consequently, as the bonds unravel and break, caregivers feel a loss of safety and security, which causes issues in their predeath grief (Sanders & Corley, 2003; Sanders et al., 2008; Shanley et al., 2011).

For most of the FSCGs in this doctoral study, they suffered an unraveling of their emotional bonds (separation), not by their choice but because of the effects of their spouse's dementia. Separating from their best friend, soulmate, and lover created a cognitive, emotional, and physical disconnect. The forced disconnect created emotional and physical suffering as part of their predeath grief experience, especially because they wanted to remain connected to their spouse during their terminal illness. More research is needed on the attachment and continuing bonds associated with the predeath grief experience to gain a better understanding of the implications when the emotional attachment or bond between FSCGs and spousal care recipients becomes unravelled during the trajectory of their spouse's terminal illness.

Strengths and Limitations

I used ID methodology to develop nursing knowledge, construct practice-relevant knowledge, reveal gaps in the knowledge, and contribute significant information on FSCGs' predeath grief experiences and the factors that influence these experiences. All of the participants completed the study, possibly because of their strong desire to voice their thoughts: not only to be heard, but also to help other women in this role. They generously shared their thoughts with me, which could have been the result of establishing a trusting relationship.

This study has several limitations. All FSCG study participants were female, Caucasian, older, well educated, and not employed, except for one who was employed part time. The FSCG sample was fairly homogeneous and did not reflect the experiences of other FSCGs, such as those with lower incomes, immigrants, or younger FSCGs. The majority provided care to their spouse diagnosed with dementia; two FSCGs provided care to their spouse diagnosed with Alzheimer's disease, and one FSCG provided care to her spouse diagnosed with Lewy body dementia. Stage of dementia and ethnicity were not included on the FSCGs' demographic form. These may have influenced the study findings. Future research should include a more diverse sample. I selected the PKP participants from one Alzheimer's Society site, which could have limited their perspectives to local issues. Future research should include a more diverse sample and the recruitment of PKP participants from multiple organizations.

Because of the COVID-19 pandemic, I did not attend the support groups of the Edmonton Chapter of the Alzheimer Society of Alberta and the Northwest Territories, Caregivers Alberta, and Pilgrims Hospice to recruit in person. I completed telephone interviews, which could have impacted the quality and type of data that I received from the FSCGs, including nonverbal behaviors, the home environment, and the manner in which they interacted with their spouse. Although the telephone interview data seemed to be adequately rich, the in-person interviews could have provided additional information that I listed above. However, the benefits of telephone interviewing, such as the comfort and convenience, might outweigh its limitations. The additional stressors of collecting data during a pandemic might also have resulted in different findings than if I had conducted the study during nonpandemic times.

Summary

Research on the predeath grief experiences of caregivers of persons living with dementia continues to expand in the scholarly literature (Chan et al., 2013; Doka, 2010; Lindauer & Harvath, 2014; Marwit & Meuser, 2005; Meuser & Marwit, 2001), but researchers to date have not focused on the predeath grief experiences of caregivers' of persons living with dementia and MCCs in the community. This doctoral study is the first of which I am aware in which a researcher has explored FSCGs' descriptions of their predeath grief experiences within the context of caring for older persons living with dementia and MCCs within the community during the COVID-19 pandemic.

The findings from this doctoral study can assist as a starting point for further research, a clinical predeath grief screening and grief history tool. Furthermore, the findings significantly contribute to the understanding of how FSCGs of older persons living with dementia and MCCs within the community describe their predeath grief experiences and the factors that influence them. Important contributions to the literature include (a) predeath grief within the context of COVID 19, (b) the oscillation of negative and positive responses to loss, (c) the expression of predeath grief as loneliness and (d) the influence of previous loss on predeath grief.

Even though the FSCGs' experience of predeath grief was similar to that of family caregivers of persons living with dementia, which is within the context of the complexities of caregiving, the FSCGs in this doctoral study also experienced predeath grief during a COVID-19 pandemic. Within the milieu of the pandemic, the FSCGs continued to care for their spouse during a time of greater uncertainty, the closure of community support programs, and in isolation. Knowledge from this situation offers insight into the FSCGs' experience of predeath grief in a constant crisis situation while their spouse's dementia continued to progress.

The FSCGs felt an all-encompassing loss that involved the loss of spouse, the loss of self, and the loss of future dreams, similarly to the caregivers of persons living with dementia and persons living with dementia and MCCs in the community. Although the losses are similar, a novel finding is the FSCGs' response to their multiple losses. For example, the FSCGs oscillated between negative (suffering, loss of control) and positive responses (moments of happiness), and many FSCGs experienced predeath grief as though they were in a gigantic wave, tossing, turning, and crashing down from the crest. At times, they also experienced both negative and positive responses simultaneously, which may suggest the existence of a paradoxical experience of joy-sorrow in their predeath grief.

The PKPs from the Alzheimer's Society shared an important observation regarding the FSCGs with whom they worked with at the society. These FSCGs frequently labeled their experiences of predeath grief as *loneliness*. This offers insight to various healthcare professionals and encourages them to inquire whether FSCGs are lonely or are in fact avoiding the reality of predeath grief. Doing so will open a dialogue with FSCGs that can help them acknowledge their predeath grief experiences and hopefully begin to cope in a positive way.

Several of the FSCGs acquired insights from their previous experiences of death which is a new finding from this study. Their knowledge of grief influenced and assisted the manner in which they perceived and dealt with their current predeath grief experiences. In addition, the continuing loss of the FSCGs' marriage and partnership were a struggle for them because they honored their marital commitment and their commitment to caring for their spouse. Although this finding is similar to other caregiving studies (Egilstrød & Petersen, 2021; Peacock et al., 2017), the forced disconnect and unraveling of their emotional bond that was not of their choice augmented their emotional and physical suffering during their predeath grief experiences.

The findings also have the potential to contribute to Lindauer and Harvath's (2014) predeath grief definition used in this doctoral study which states, "the caregiver's emotional and physical response to the perceived losses in a valued care recipient" (p. 2203). Since the FSCGs oscillated between their negative and positive responses to loss, and at various times experienced both responses simultaneously, an addition to the definition is possible. For example, a new definition could be stated as "the caregiver's [negative and positive] emotional and physical response[s] to the perceived losses in a valued care recipient [can be experienced moving back and forth between the negative and positive responses or experienced at the same time]" (Lindauer and Harvath, 2014, p. 2203). In other words, there is fluidity amongst the negative and positive responses or the possible existence of a paradoxical experience depending on the perceived loss.

Situation-specific "theories are designed to be pragmatic and accessible to nurses with the goal of improving patient care [and] focus on unique populations and place importance on diverse environments and cultures" (p. 2203). The findings from this doctoral study can contribute to Lindauer and Harvath's (2014) suggestion of "advancing predeath grief into a situation-specific theory" (p. 2204). At present, researchers have not explored the FSCGs' descriptions of their predeath grief experiences within the context of caring for older persons living with dementia and MCCs within the community especially during the COVID-19 pandemic. Therefore, a situation-specific theory could be customized to the isolated caregiving environment of the FSCGs.

The COVID-19 pandemic created isolation, decreased outside services and restricted social visits for the FSCGs and their spouse. The findings demonstrated living in this environment brought on increased stress and loss for a majority of FSCGs, and many spouses experienced heightened agitation, stress, and loss. Understanding the FSCGs' perspective of predeath grief in this type of environment while their spouse's dementia continues to progress is important. This knowledge could provide substantial rationale for implementing the following activities in an isolated caregiving environment: (a) safely keeping support programs open, (b) provide FSCGs appropriate guidance to deal with rising new unexpected challenges and increased complexity of care, (c) provide FSCGs effective coping skills to deal with their and their spouse's heightened stress and significant losses, and (d) provide FSCGs effective ways to meet their needs. Although, two FSCGs welcomed the reprieve of COVID-19 isolation because it provided justification to stay home, and may have lessened their predeath grief, additional research is needed.

CHAPTER 6: CONCLUSION

The focus of this doctoral study was the predeath grief experiences of FSCGs of older persons with dementia and MCCs living in the community. From the doctoral study findings, in this chapter I explore the implications for nursing practice, education, policy, and research that will further contribute to the nursing knowledge. Finally, I discuss my plan for the dissemination of the findings and my reflections on the research journey, and I offer concluding statements.

The doctoral study findings reveal FSCGs' predeath grief experiences within the context of caregiving. The impact of their spouse's dementia significantly changed their lives and underpinned their choices to prioritize the focus of their management and care on the effects of their spouse's dementia before their MCCs. Moreover, living during a COVID-19 pandemic created a new environment for the FSCGs and the spouses. Consequently, the FSCGs' new environment encompassed extra care responsibilities, increased isolation, and the fear of becoming infected. Furthermore, their all-encompassing losses included the loss of spouse, the loss of self, and the loss of future dreams, which substantially changed their lives and their relationship with their spouse, created a new role for them in life, and deprived them of their planned future with their spouse.

The doctoral study findings reveal the main overall theme of the FSCGs' experience of predeath grief of being in a wave*,* which is comprised of suffering, the loss of control, and moments of happiness. The FSCGs' suffering was a major finding that was underpinned by a multiplicity of losses that gave rise to sadness, hopelessness, and loneliness. Other key findings are the loss of control of their sleep patterns, the busyness in their daily lives, and their spouses' unexpected behaviors. The FSCGs' loss of control created extra stress and unpredictability in their predeath grief experience and denied them time to practise self-care activities and meet their own needs. Moments of happiness were also a significant finding, because the FSCGs were able to feel a sense of connection with family, their spouse, and themselves. Additionally, the FSCGs' knowledge of grief learned from their previous experiences of death was a new finding that influenced and helped them understand and deal with their current predeath grief experiences. Lastly, the FSCGs experienced a forced disconnect and unraveling of their emotional bond with their spouse which enhanced their emotional and physical suffering during their predeath grief experiences, especially because the disconnect was not their choice.

Implications for Nursing Practice

Nurses are likely to meet and provide care to people who are grieving, and others who experience predeath grief. Therefore, the findings in this doctoral study have the potential to inform nurses who work in the community, in acute care settings, and in long-term care on the specific predeath grief experiences of FSCGs of older persons living with dementia and MCCs within the community. Notably, nurses who understand the concept of predeath grief, its characteristics, and its management will be prepared to acknowledge and assess the need for and provide effective support to family caregivers.

This research did not involve assessing nurses' knowledge about predeath grief, but the new knowledge from this research will enhance the nursing care of FSCGs in such situations. Specifically, FSCGs will benefit from nurses' appropriate assessment of how they manage their predeath grief experiences, within the context they provide care, and this can lead nurses to help them access support to meet their needs.

Nurses' Assessment of Caregivers

The findings from this research and of other predeath grief research suggest that all caregivers and the persons living with dementia have their own unique, multifaceted reality of predeath grief (Perez-Gonzalez, et al., 2021; Wilson et al., 2017). Related to the foundations of nursing, it is important to assess every client individually subjectively and objectively prior to appropriate planning and implementing interventions. Indeed, "a family carers' unique clinical presentation and combination of risk factors" (Wilson et al., 2017, p. 810) should underpin the nurses' practice. For these reasons, nurses are better able to assist family caregivers with appropriate support, education, resources, and guidance when they are specifically tailored to their needs.

Therefore, the nurses' responsibility is to actively listen to caregivers' descriptions of their predeath grief because it is part of their assessment and will inform their nursing care. During assessment, nurses may identify the caregivers' predeath grief, even though the caregivers might not recognize that they are experiencing predeath grief or might call it something quite different. For example, a PKP in the study explained that some FSCGs occasionally refer to their predeath grief as loneliness, because they do not recognize their feelings as part of a predeath grief experience.

Notably, it is also essential that nurses thoroughly, subjectively, and objectively assess the caregivers' role, their responses to loss, along with their predeath grief experiences. In particular, nurses can use a validated tool such as the MM-CGI form (Marwit & Meuser, 2002): The "MM-CGI is an empirically based, psychometrically sound instrument for the assessment of grief in caregivers of persons with Alzheimer's disease" (p. 751). After the assessments, conversations between the nurses and caregivers to discuss the findings is essential and can help them to co-create an appropriate plan for effective, practical, and emotional support for caregivers' predeath grief (O'Rourke et al., 2021). MacCourt et al. (2017) stated that making "grief visible . . . is not only beneficial but necessary to the well being of these caregivers"

(p. 244). Furthermore, if caregivers or nurses do not acknowledge predeath grief, caregivers might grieve alone during the trajectory of their care recipient's terminal illness, which questions the outcomes for the caregiver (Doka, 2010; Hovland, 2018; Lindauer & Harvath, 2014). Consequently, there is a need for ongoing assessment, especially because the findings demonstrated that FSCGs experienced continual losses due to their spouse's dementia and oscillate between positive and negative responses to their losses.

Nurses' Helping Caregivers to Access Support

According to the literature on predeath grief, grief-management coaching interventions (MacCourt et al., 2017) and cognitive behavioral therapy interventions both reduce predeath grief (Meichsner & Wilz, 2018). Other supportive options include accessing Caregivers Alberta, which offers a variety of caregiver support. For example, caregiver coaches offer guidance and assistance to meet the needs of caregivers and provide educational workshops, programs, resources, and helpful links. Additionally, in their caregiver support community, peers meet virtually at various times during the week.

Likewise, the Alzheimer's Society of Alberta and Northwest Territories also offers many in-person and online supportive resources for caregivers, especially grief support, which gives caregivers an opportunity to connect with other caregivers in similar circumstances and discuss issues that are relevant to them. These are only two examples of community resources, but nurses who work with care recipients in the community, with home care, and in long-term and acute care can provide required information to caregivers. Most important, it is crucial that nurses explain why they are providing this information and encourage caregivers to ask questions regarding the resources or about any other important matters.

Very few grief focused interventions are available specifically for caregivers of persons living with dementia to ease their emotional and physical health (Arruda & Paun, 2017). However, in acute-care settings nurses can offer safe places for caregivers who are experiencing predeath grief. Specifically, a safe place to engage with one another, to share their thoughts, to support each other, and to feel a sense of connection with others who are experiencing predeath grief can help them to process their grief (Bravo-Benítez et al., 2021). Equally important, nurses can encourage caregivers to reach out to family and friends for support, connection, and moments of happiness during their experiences of predeath grief. Furthermore, nurses can also refer caregivers to grief counsellors.

Nurses focused on implementing effective supportive care to meet caregivers' needs need to know that it will be helpful to caregivers to both acquire knowledge about dementia and understand that it is a terminal illness (Arruda & Paun, 2017). This might sound simplistic; however, Moore et al. (2020) reported in their cross-sectional study of 150 caregivers of persons living with dementia either at home or in a care home that "higher dementia knowledge was associated with lower 'heartfelt sadness'" (p. 753). One factor which measures the grief experiences of caregivers of persons living with dementia on the MM-CGI form is heartfelt sadness (Marwit & Meuser, 2002). Therefore, the more knowledge that caregivers have about dementia, the less intense their predeath grief experiences might be.

The FSCGs in this doctoral study described a component of their predeath grief experiences as feeling that they had lost control, especially in the areas of sleep, the busyness in their daily lives, and their spouse's unexpected behaviors. Therefore, nurses can look for opportunities to guide and assist caregivers in these aforementioned components of their predeath grief experiences as they co-create plans to deal with these experiences. For example, nurses can assist caregivers by offering them resources such as a mindfulness program, a sleep app, or relaxing yoga movements that they can perform before they sleep. As well, nurses can look into respite programs that involve nighttime observation of care recipients to augment their sleep. Hopefully, in-person programs for the care recipients will reopen soon to decrease the caregivers' busyness in their caregiving and help them to deal with the unexpected circumstances that arise with their care recipient. Likewise, nurses can discuss foreseeable alterations that might be needed to optimize the health and functioning of FSCGs' care recipient and help caregivers to plan accordingly (Lam et al., 2020).

Crawley et al. (2022), in their systematic review, reported that caregivers who experience predeath grief receive less support than the caregivers who experience bereavement because grief services assess them less often. One way to rectify this problem would be for nurses who work with caregivers and care recipients to refer them to grief services after they have properly assessed their predeath grief experiences. Therefore, it is critical that nurses be acutely aware of and understand caregivers' experience of predeath grief. For this reason, nurses need to be able to acknowledge and assess caregivers' predeath grief and help them to manage it.

Furthermore, nurses need to inform their clients about their assessments prior to co-creating interventions with them, which might make the clients more willing to implement the interventions when they agree that it is suitable for them. It is likely that the education, support, and resources that caregivers receive from nurses will empower them and enable them to manage their predeath grief experiences effectively. As a result, they will feel more in control, which will lessen the intensity of their predeath grief.

Implications for Nursing Education

People living with dementia and their caregivers depend on nurses and others with whom they connect and understand their experiences. Therefore, nurses, nursing students, and PKPs will benefit from the findings of this doctoral study and other information related to predeath grief, grief, and grief theories. Such knowledge will promote appropriate assessment and care for FSCGs who experience predeath grief.

Enhanced Education for Practicing Nurses

Nurses who work in the community and in acute and long-term care require knowledge about FSCGs' predeath grief experiences to be able to assess them and assist them in managing their predeath grief experiences. In view of this, I therefore recommend the implementation of an educational certificate course with a standardized curriculum for practicing nurses to enable all nurses to fundamentally provide consistent predeath grief care underpinned by the philosophy and guidelines that they learn in the curriculum and then tailor their care specifically to meet their caregivers' needs. As a result of the consistent evolution of dementia and research on pre/post grief that is advancing nursing knowledge and practice, I recommend that the curriculum be constantly updated and that nurses be recertified every year to stay current in their practice. The functionality of this approach will help FSCGs to manage their predeath grief effectively. Notably, the standardized curriculum should be evaluated on a consistent basis to determine whether caregivers benefit from nurses' predeath grief knowledge and care. The findings in the doctoral study demonstrate that FSCGs' predeath grief experiences oscillate between negative (suffering and loss of control) and positive (moments of happiness) responses. Even though the DPM is best suited to people who are dealing with bereavement, this model is congruent with the findings of this study. Other models that address dementia grief (the caregiver grief model, Marwit & Meuser, 2002; the dementia grief model, Blandin & Pepin, 2017; the grief-stress model of caregiving, Noyes et al., 2010) do not address the concept of oscillation between caregivers' negative and positive responses.

However, in the 3-A grief intervention model for dementia caregivers, Silverberg (2007) incorporated Schut's (1999) DPM concept of oscillation and respite to help caregivers to manage their predeath grief. Specifically, Silverberg found that encouraging caregivers to take time for respite allows "the dynamic grieving process of oscillation to occur, . . . [resulting in] caregivers [having] some freedom to attend to restoration-oriented stressors, such as individual well being and/or social reintegration" (p. 228). This model also involves "acknowledging loss/grief, assessing, and assisting dementia caregivers in managing the grief" (p. 229). I therefore recommend more research to evaluate this model and to determine whether it is applicable to spousal and family caregivers of persons living with dementia and MCCs in the community.

Enhanced Education for Nursing Students

It is essential that nursing students understand the concepts of predeath grief, grief, and grief theories to prepare them to provide evidence-informed care for caregivers and their families. This includes education on palliative and end-of-life care because dementia is a terminal illness. In fact, educating nursing students on this care is also important, especially because "palliative care is identified internationally as a priority for efficacious dementia care" (O'Connor et al., 2022, p. 1). The Canadian Nurses Association (2015) stated, "Nurse educators are responsible for teaching nursing students and nurses (from novice to expert) about palliative and end-of-life care by explaining and modelling related competencies" (p. 1). As nursing students acquire knowledge about palliative and end-of-life care, this knowledge will help them to better understand the context in which FSCGs provide care and experience predeath grief.

Equally important is to educate nursing students on the suffering in predeath grief that encompasses sadness, hopelessness, and loneliness, which are the mental and emotional feelings of pain and the consequences of FSCGs' many losses. Likewise, engaging nursing students in grief research and giving them opportunities to reflect on and ask questions about their own experiences of loss and grief will augment their foundational knowledge on these important topics. As a result, nursing students will be more aware of grief as they provide care to caregivers. Consequently, through this progressive educational process, not only will nursing students become more prepared, but their confidence and competence will also continue to escalate, which will enable them to provide effective, focused care to caregivers, especially in relation to predeath grief.

Enhanced Preparation for Professional Knowledge Providers

I also recommend that PKPs who work with FSCGs who are caring for their spouse living with dementia and MCCs in the community receive the above-mentioned education intended for nursing students. For example, the PKPs who work at the Edmonton Chapter of the Alzheimer Society of Alberta and the Northwest Territories, Caregivers Alberta, or Pilgrims Hospice should also be included in receiving the fundamentally important information that is part of the aforementioned education, and it should be tailored to their professional needs. This recommendation is congruent with the recommendations of Warchol-Biedermann et al. (2014) in their quantitative research study in which they validated the MM-CGI-50, which assesses the grief of family caregivers of persons living with Alzheimer's disease. They emphasized the importance of "providing education and training programs" to benefit various health professionals and volunteers who are involved with caregivers to help them to understand "the phenomenon of caregiver grief and integrate the knowledge about grief into practice so that they will be able to provide adequate emotional support to grieving family caregivers” (p. 466). Educating professional nurses, nursing students, and PKPs on the predeath grief experiences of FSCGs of older persons living with dementia and MCCs within the community is critical. This knowledge will enable them to help FSCGs to understand and manage their predeath grief experiences and create meaning and peace within themselves and within their relationship with their spouse, which will help to preserve their human dignity and wholeness.

Implications for Policy

Decision makers and government planners can do much to support FSCGs’ experience of predeath grief with appropriate policies. In this section I make recommendations that could significantly impact the health of caregivers of older persons living with dementia and MCCs in the community to enhance their lives, given the situations in which they find themselves. The language that government and supportive agencies use matters. The findings from this doctoral study reveal that caregivers experience brief moments of happiness, but the majority of their experience is affected by their suffering and loss of control over various issues and their having to deal with the effects of their spouse’s dementia, the uncertainties, and the challenges. With this in mind, I recommend the consistent use of specific, clearly defined terms across Canada to define predeath grief to replace the current multiple terms currently in use. I also recommend that government and support agencies add predeath grief to their language, including in policies for pandemic and natural disasters; that they become aware that predeath grief is a common experience of the older population; and that they specifically address the needs of this population regarding predeath grief.

Add Predeath Grief to the Language of Government and Support Agencies

The family caregivers of older persons living with dementia and MCCs in the community are vital to a myriad of care recipients because they meet their biopsychosocial and spiritual needs daily. In the future, Canadians can expect an upsurge in the number of family caregivers because of the increased life expectancy of older Canadians and the fact that many older adults prefer to age in their home, where they are the most comfortable (Hong & Coogle, 2016; McGilton et al., 2018). Therefore, the potential for a primary caregiver to be a spouse is a reality. Furthermore, persons living with dementia live on average 3 to 11 years after they are diagnosed with dementia (Alzheimer Society of Canada, 2021), and during much of this time FSCGs can experience predeath grief.

In response to the losses that ensue from the FSCGs' spouse's cognitive and functional decline, the FSCGs in this doctoral study experienced predeath grief. Currently, multiple terms describe grief prior to the physical death of a care recipient: *anticipatory grief*, *disenfranchised grief*, and *ambiguous loss*, to name a few. Utilizing various terms and definitions leads to confusion and the use of inconsistent language pertaining to grief prior to the physical death of a care recipient. Although it is impossible to expect researchers and policy makers around the world to agree on one term, I advocate for the use of the term *predeath grief* by various groups such as the Alzheimer Society of Canada (2022) as an alternative to their current term of *ambiguous loss and grief*.

As an example, one of the Alzheimer Society of Canada's (2022) literature resources does not clearly explain the terms ambiguous loss and grief, the meanings of the words vary, and sometimes they melt together. To demonstrate, one resource for individuals and families states, "Ambiguous loss complicates grief. It may be hard for you to recognize this grief or know how to grieve when the abilities of the person with dementia have changed" (Ambiguous Loss and Grief in Dementia, 2019, p. 2). Dr. Pauline Boss (2016) defined ambiguous loss as "a situation of unclear loss that remains unverified and thus without resolution" (p. 270). She described this loss as a family member who is only physically present and "psychologically missing" (p. 270). Although it can be a stressful form of loss, ambiguous loss does not focus on grief, but rather on loss without closure.

The findings in this doctoral study demonstrate that FSCGs experience predeath grief because they have physical and emotional responses to the multiple losses in their spouse (Lindauer & Harvath 2014). Lindauer and Harvath's (2014) definition of predeath grief is an appropriate fit with the findings from this study, because it is uniquely suited to caregivers of persons living with dementia who experience grief prior to their care recipient's physical death. The researchers clearly explain that the nature of the loss is a "psychological death which is asynchronous with physical death" (p. 2201). To accurately support the grief of caregivers of older persons living with dementia who experience multiple losses prior to their care recipients' physical deaths, I recommend that the term *predeath grief* be defined and used according to Lindauer and Harvath's clear definition of predeath grief. "In the clinical realm, consistent use of the concept can validate caregivers experiences and facilitate effective support" (p. 2197). Furthermore, I recommend that nurse researchers use this definition to guide their research studies and "theory development and…used [it] as a foundation for measurement development" (p. 2197). In addition, I recommend the use of the findings in this doctoral study to inform governments and support agencies on the predeath grief experiences of FSCGs of older persons living with dementia and MCCs within the community.

As I previously mentioned, the Ambiguous Loss and Grief in Dementia (2019) resource states, “It may be hard for you to recognize this grief or know how to grieve when the abilities of the person with dementia have changed” (p. 2). Lindauer and Harvath (2014) clarified that dementia can lead to significant physical and psychological changes; however, “these changes are often perceived as losses to which caregivers respond with pre-death grief” (p. 2197). Their concept analysis of predeath grief is situated in the context of dementia caregiving and is a meaningful concept with a clear definition that caregivers, families, health professionals, and researchers can utilize. My future goal is to meet with the Alzheimer Society of Canada to present my doctoral study and encourage the Society to consider replacing the words and their description of ambiguous loss and grief in their resources with a more accurate term and definition of predeath grief to describe FSCGs’ actual experience.

The findings from this doctoral study offer a clearer picture of the predeath grief experience of FSCGs who care for their spouse living with dementia and MCCs. Therefore, it is important to acknowledge predeath grief as a common experience and a significant issue that needs to be addressed in this population and to advocate for changes in the language in government policy and health agencies. I will also advocate for change to the Alberta Health Services (2022) website; specifically, to the description of ambiguous grief in reference to dementia posted on the website. The description states that people might not have closure until their care recipients die. However, one FSCG in this study described her closure during the process of caregiving and how she felt after she “let him go” (FSCG 04) even though he was physically present. Accurate information will help caregivers to better understand their predeath grief experiences, which will lessen their stress and fear of the unknown and therefore enhance their caregiving experience.

Add Predeath Grief With Regard to Pandemics to the Language of Government and Support Agencies

The FSCGs in this study lived within the COVID-19 pandemic. They encountered a variety of new challenges and experienced more losses specifically related to the pandemic. For example, usual resources and support were no longer available, and mandated restrictions resulted in uncertainties and challenges and added to caregivers' workloads. Above all, the progression of their spouses' dementia did not slow down during the pandemic. The findings from this doctoral study demonstrate that as the FSCGs' losses continued to increase, so did their stress and predeath grief, except in a few situations. Alzheimer's societies across Canada and their external links provide valuable information to deal with various COVID-19 pandemic issues. I also found useful information and some deficiencies in it on various aspects of grief. Therefore, I recommend the addition of beneficial information to the language of government and support agencies, such as the association between stress and predeath grief. In fact, updating pandemic information with more predeath-grief-related information based on the findings of this doctoral study is important to meet the needs of caregivers and their care recipients during the next pandemic or natural disaster.

Implications for Research

This doctoral study has enhanced the understanding of FSCGs' predeath grief experiences and the factors that influence these experiences while they care for their spouse with MCCs who are living with dementia in the community. Although this generated unique insights into predeath grief, in this doctoral study I also highlighted areas that require additional research to further advance nursing knowledge in this practice area. This doctoral study has shown that FSCGs experience predeath grief as being in a wave and oscillate among suffering, loss of control, and moments of happiness. Overarching questions that require further research are, Do oscillations between positive and negative responses alter the predeath grief experiences of FSCGs of older persons living with dementia and MCCs in the community? If so, can interventions focused on promoting positive responses amongst FSCGs improve their predeath grief experiences?

Two FSCGs welcomed COVID isolation and restrictions because it provided some respite during the busyness of day-to-day life and sheltered them from embarrassment of unexpected behaviors in public settings. This observation of FSCGs is possibly related to decreased stress, decreased embarrassment, and the regaining of some control over their lives during the isolation period. It might also be a positive response within the wave of predeath grief. Most research indicated that caregivers generally benefit from extra social support, such as support programs, day programs, and homecare. However, this finding might indicate that such programs can simply be overwhelming to some FSCGs and can negatively impact their predeath grief experiences. This leads to the question, Can community programs focused on minimizing stress, embarrassment, and reducing FSCGs' busyness and thereby improve the predeath grief experiences of FSCGs of older persons living with dementia and MCCs within the community?

The suffering of the FSCGs in this doctoral study included aspects of sadness, hopelessness, and loneliness. These emotions intensified their experience of predeath grief. I believe that hope is an area that researchers have not yet studied within the context of predeath grief in this population. Is it possible that hope improves the experiences of predeath grief? How might hope interventions be incorporated into the care of FSCGs?

Last, the FSCGs in this research study applied their own previous experiences with the death of a loved one to give language to predeath grief and prepare themselves for the actual death of their spouse. Previous experiences with death are a fruitful area for research to learn more about how people can use past death and grief experiences as reference points to manage the death of a loved one in the future to improve their predeath grief experiences.

Dissemination of the Findings

My dissemination plan for the doctoral study's findings is based on insights from Straus et al. (2009) because they state, "knowledge translation, also known as KT,… [are] the methods for closing the gaps from knowledge to practice" (p. 165). In view of this, I will target and tailor the findings from the study to particular audiences such as FSCGs of older persons living with dementia and MCCs in the community, practicing nurses and nursing students, PKPs, and people in community services who work with and support FSCGs.

First, I will disseminate the findings from the study to my target audience of FSCGs because the findings will benefit them in some way. My plan for dissemination is also to seek funding from the Alzheimer Society of Canada and Alberta Health Services to develop a short video of various women with the same demographics who will act as FSCGs and share narratives connected to the findings from this doctoral study. The setting of the video will be a home. Stories of FSCGs' experiences have the potential to improve awareness, resonate with the audience, and make very clear the need for substantial assistance and support for FSCGs. After presentation of the video, I will encourage the FSCGs who watch it to speak to me and call the Alzheimer Society of Canada to discuss their predeath grief experiences. Additionally, I will tell them about the support group for FSCGs at the Alzheimer's Society in Edmonton, where they can share their stories, connect, and support each other.

Along with presenting the video, I will post the video on the Alzheimer Society of Canada website with permission so that FSCGs can revisit it. Furthermore, I will share the video with PKPs and policy makers because a video can make an emotional impact and can sometimes be more effective than an oral presentation. Likewise, I will create short stories in print from the video stories and distribute them to the aforementioned target population, not only to read, but to reflect on. I hope that they will pass these stories along to others so that the findings from this study have a large distribution. Last, I will advocate for nurses educated in predeath grief of caregivers living with dementia to lead support groups. Specifically, the nurses will promote effective and appropriate support for the management of the predeath grief of family caregivers of persons living with dementia and MCCs.

Furthermore, I will disseminate the findings from this study through publications in relevant journals and in policy briefs. Nursing and healthcare professionals, their students, and policymakers will be able to access the journals and apply the findings to their clinical practice and to inform further research. For example, the new knowledge will effectively enable this group to help the FSCGs of older persons living with dementia and MCCs in the community to live with predeath grief; it will also enable the development of suitable support groups and activities within the community and enhance the community's knowledge based on the findings of this doctoral study.

Possible journals for publication of the study findings include *The Journal of Advanced Nursing*, *The Journal of Gerontological Nursing*, *Aging & Mental Health,* and *The American Journal of Alzheimer's Disease & Other Dementias*. These journals inform healthcare professionals on advancing practice, the aging process, dementia research, professional development, and the practice of gerontological nursing; and researchers recommend different strategies and interventions to improve elderly persons' mental health.

I will also make presentations at scholarly conferences and to stakeholder groups. Whereas journal articles translate information to a scholarly audience in a condensed form, poster presentations or informative conference sessions impart information to others as they engage in personal interactions to discuss the most current information on the advancement of theory, patient care, and healthcare policies. The Glenrose Rehabilitation Hospital/Geriatric Rehabilitation, the Alberta Association on Gerontology, Alzheimer's associations (at the national and provincial levels), the Canadian Association on Gerontology, and the National Hartford Center of Gerontological Nursing Excellence all hold conferences for healthcare professionals and students, policymakers, stakeholders, and members of both provincial and federal governments. These are informative venues for the collegial exchange of information based on the findings of this doctoral study and to network for further dissemination of the knowledge. Additionally, this environment affords an opportunity to share valuable information with many experts and professionals.

Reflection on the Research Journey

My research journey has significantly influenced me as a nurse and as a person. I remember taking my first research course in undergraduate nursing school. The terms to which my professor introduced us to, and the various research methodologies were somewhat complicated and difficult to comprehend. However, as the course evolved, so did my curiosity, not so much about the methods of research, but more about the nurses who were doing the research. I was curious about nurses' impetus to conduct research studies that would advance nursing knowledge and practice. 36 years later, I am fascinated with the essence of research, the nurses' curiosity that underpinned the research, the rationale for the choice of method, and the interesting findings that evolved from the research. In particular, I am intrigued with how nurse researchers can advance nursing knowledge and practice, leaving their legacy for future nurses to improve nursing care.

During my experience of a three-year traineeship working on a research project, my own unique family caregiving experience, my grief over substantial multiple losses prior to the death of my grandmothers, and my passion to learn about grief influenced my thoughts about my research questions. When I interviewed caregivers for the research project, I heard a different tone in their voices when they spoke about their losses. At times, although the participants wanted to express their feelings from their losses, what they wanted to say was not a component of the interviews. After the interviews I listened to their thoughts because I wanted them to know that I cared about them, their feelings, and their losses. I never added personal advice, but I believe that my listening made a difference, because after they had voiced their thoughts, I heard a lightness in the inflections in their voices. This experience, combined with other experiences such as caregiving and loss, being present with clients as they experienced grief, and the impact of my father's role modelling as he provided care with dignity and compassion to families who were grieving the loss of loved ones, underpinned the development of my research questions.

Before I began my literature review, my knowledge about the predeath grief of caregivers of persons living with dementia and MCCs in the community evolved from my conversations with the participants in the research project. I could hear the changes in their voices and wondered whether they were experiencing grief or whether their suffering was so intense that they were grieving. As I grew up I heard people around me saying that they were suffering and grieving, which are two separate concepts. In my own experience of loss, I believe that I was suffering while grieving; or maybe I was not. I have always been curious about life, and now I was curious to discover whether caregivers grieve. If they do, I wanted to acknowledge their grief as their reality. I wanted them to feel empathy, support, and connectiveness from me and others along the trajectory of their care recipients' illness. I especially wanted to provide care with dignity and compassion as my father did, because I saw how people reacted. In fact, people would tell me that his respectful and compassionate care made their grieving journey easier, because they felt seen, heard, and cared for during a very painful time.

Initially, I chose grounded theory as my research methodology; I was privileged to meet Dr. Kathy Charmaz in person and take a seminar workshop from her. However, one afternoon Dr. Sally Thorne was at the university and invited graduate students to listen to her speak about research and ID. Dr. Thorne told us that ID is applicable if nurses are curious about something within the practice context, because it highlights gaps in knowledge that other types of research cannot. That one sentence captivated me, and I changed my research methodology because I wanted to support caregivers; make them feel seen, heard, and cared for as they experience predeath grief; and make a positive contribution to clinical knowledge and practice.

I learned a variety of important lessons in my doctoral program. For example, I always establish a therapeutic, trusting relationship and act authentically with clients, which is ethical practice whether I provide care or interview during a research project. That was the easy part, however; I could not understand why the participants' answers were not answering my research questions. My supervisors offered great wisdom, and from that time forward the participants answered my questions and provided richer data than I could have imagined.

Every step of my research project was educational. I learned about the responsibility and privilege of contributing research for nursing practice and knowledge. Furthermore, my research journey illuminated a new way of thinking about research, nursing, and life. During the research journey, I was surprised to learn how much the FSCGs' relationship with their spouse influenced their predeath grief experiences.

Also interesting was the influence of the FSCGs' previous experiences of death on their predeath grief experiences and the amount of suffering and loss of control that they felt amongst all of their losses, challenges, and uncertainties while they provided care, although they had moments of happiness. I hope that one day I will be able to expand those moments of happiness into longer periods of time for them. When people tell me that they are caregivers for someone living with either dementia or dementia and MCCs, my response is the same as before: I am empathetic, and I always ask what I can do to help. After my research experience I have added to my response by telling them that I admire their commitment and choice to become caregivers, because I know that their lives have changed forever, and sometimes not by choice.

Concluding Thoughts

The findings from this doctoral study will benefit FSCGs in various ways. For example, the findings highlight that in the context of caregiving, the impact of spouses' dementia led to escalating the complexity of care. Learning about this significant issue in the context of the complexities of caregiving in which their predeath grief occurred will heighten awareness of the need for caregiving assistance for FSCGs. This assistance will alleviate the issues that impede the management of their predeath grief.

The FSCGs' experience of predeath grief felt like being in a wave; it included suffering, the loss of control, and moments of happiness. Clearly, this major finding will promote the awareness of health care professionals and PKPs that these findings are also applicable to other FSCGs. Therefore, this finding can enhance their assessment and the co-creation of interventions with FSCGs and thus expedite the provision of assistance with managing their predeath grief.

The findings from this study will improve nursing practice and augment the knowledge of nurses, nursing students, and PKPs on FSCGs' predeath grief. Moreover, they will enhance changes in policy, offer clarity in the process of predeath grief for FSCGs, and improve their nursing care. Research is needed in a variety of areas concerning FSCGs' predeath grief in addition to my recommendations in the Implications for Research section; for example, in the areas of how to extend their moments of happiness and how to slow down the crashing of their waves to find effective ways to manage FSCGs' experience of predeath grief, just to name a few. It is important to note that I have learned about FSCGs' commitment to their spouse and their caregiving role and about their predeath grief experiences. With this in mind, it is essential to acknowledge FSCGs' predeath grief and ensure that the public is aware of their complex caregiving role and hears their narratives and requests for assistance in many areas. I hope that they will receive a generous amount of assistance from healthcare, government, and community to be able to thrive as they once did, experience smaller waves of predeath grief, and enjoy life as they commit to providing care to their spouse with a terminal illness.

REFERENCES

Adams, K. B., & Sanders, S. (2004). Alzheimer's caregiver differences in experience of loss: Grief reactions and depressive symptoms across stage of disease. *Dementia*, *3*(2), 195–210. https://doi.org/10.1177/1471301204042337

Alberta Health Services. (2022). *Dementia Advice Service*. Alberta Health Services. https://www.albertahealthservices.ca/info/page15482.aspx

Albinsson, L., & Strang, P. (2003). Existential concerns of families of late-stage dementia patients: Questions of freedom, choices, isolation, death, and meaning. *Journal of Palliative Medicine, 6*(2), 225–235. http://doi.org/10.1089/109662103764978470

Almberg, B. E., & Grafstrom, M. (1997). Major strain and coping strategies as reported by family members who care for aged demented relatives. *Journal of Advanced Nursing, 26*, 683–691. https://doi-org.login.ezproxy.library.ualberta.ca/10.1046/j.1365-2648.1997.00392.x

Alvelo, J., Cancio-Gonzalez, R., & Collazo, A. (2018). Validation of a Spanish version of the Marwit–Meuser Caregiver Grief Inventory Short Form in a Puerto Rican sample. *Research on Social Work Practice*, *28*(4), 507–518. https://doi.org/10.1177/1049731516656801

Alzheimer Society of Alberta and Northwest Territories. (2022). *About us.* https://alzheimer.ca/ab/en/about-us

Alzheimer Society of Canada. (2016). *Prevalence and monetary costs of dementia in Canada.* https://alzheimer.ca/sites/default/files/documents/Prevalence-and-costs-of-dementia-in-Canada_Alzheimer-Society-Canada.pdf

Alzheimer Society of Canada. (2019). *Ambiguous loss and grief in dementia: A resource for individuals and families.* https://alzheimer.ca/sites/default/files/documents/ambiguous-loss-and-grief_for-individuals-and-families.pdf

Alzheimer Society of Canada. (2021). *The intersection of two pandemics.* https://alzheimer.ca/sites/default/files/documents/Pre-Budget-Submission-2022_Alzheimer-Society-Canada.pdf

Alzheimer Society of Canada. (2022). *Dementia numbers in Canada.* https://alzheimer.ca/en/about-dementia/what-dementia/dementia-numbers-canada

Alzheimer's Association. (2022). 2022 Alzheimer's disease facts and figures: Special report: More than normal aging: Understanding mild cognitive impairment https://www.alz.org/media/documents/alzheimers-facts-and-figures.pdf

Alzheimer's Disease International. (2018). *World Alzheimer report: The state of the art of dementia research: New frontiers*. https://www.alzint.org/u/WorldAlzheimerReport2018.pdf

Arruda, E. H., & Paun, O. (2017). Dementia caregiver grief and bereavement: An integrative review. *Western Journal of Nursing Research, 39*(6), 825–851. https://doi.org/10.1177/0193945916658881

Bédard, M., Kuzik, R., Chambers, L., Molloy, D. W., Dubois, S., & Lever, J. A. (2005). Understanding burden differences between men and women caregivers: The contribution of care-recipient problem behaviors. *International Psychogeriatrics, 17*(1), 99–118. https://doi.org/10.1017/S1041610204000857

Beeson, R. A. (2003). Loneliness and depression in spousal caregivers of those with Alzheimer's disease versus non-caregiving spouses. *Archives of Psychiatric Nursing, 17*, 135-143. https://doi.org/10.1016/S0883-9417(03)00057-8

Betz, G., & Thorngren, J. M. (2006). Ambiguous loss and the family grieving process. *The Family Journal, 14*(4), 359–365. https://doi.org/10.1177/1066480706290052

Blandin, K., & Pepin, R. (2017). Dementia grief: A theoretical model of a unique grief experience. *Dementia, 16*(1), 67-78. https://doi.org/10.1177/1471301215581081

Bonanno, G. A., & Kaltman, S. (1999). Towards an integrative perspective on grief. *Psychological Bulletin, 125*(6), 760–776.

Bonanno, G. A., & Kaltman, S. (2001). The varieties of grief experience. *Clinical Psychology Review*, *21*(5), 705–734. https://doi.org/10.1016/S0272-7358(00)00062-3

Boss, P. (1999). *Ambiguous loss: Learning to live with unresolved grief.* Harvard University Press.

Boss, P. (2016). The context and process of theory development: The story of ambiguous loss. *Journal of Family Theory & Review*, *8*(3), 269–286. https://doi-org.login.ezproxy.library.ualberta.ca/10.1111/jftr.12152

Brandstätter, M., Kögler, M., Baumann, U., Fensterer, V., Küchenhoff, U., Domenico Borasio, G., & Johannes Fegg, M. (2014). Experience of meaning in life in bereaved informal caregivers of palliative care patients. *Support Care Cancer, 22*, 1391–1399. https://doi.org/10.1007/s00520-013-209906

Bravo-Benítez, J., Cruz-Quintana, F., Fernández-Alcántara, M., & Pérez-Marfil, M. N. (2021). Intervention program to improve grief-related symptoms in caregivers of patients diagnosed with dementia. *Frontiers in Psychology*, *12*, 1–12. https://doi.org/10.3389/fpsyg.2021.628750

Brewster, G. S., Molinari, V., McCrae, C., Beckstead, J., D'Aoust, R., & Rowe, M. (2022). Cognitive function and sleep in caregivers of persons living with dementia. *Western Journal of Nursing Research*, *44*(3), 260–268. https://doi.org/10.1177/01939459211041163

Bueno-Gómez, N. Conceptualizing suffering and pain. *Philosophy, Ethics, and Humanities in Medicine, 12*(7). https://doi.org/10.1186/s13010-017-0049-5

Butcher, H. K., Holkup, P. A., & Coen Buckwalter, K. (2001). The experience of caring for a family member with Alzheimer's disease. *Western Journal of Nursing Research, 23*(1), 33-55. https://doi.org/10.1177/019394590102300104

Canadian Nurses Association. (2015). [Home page]. http://www.cna-Aiic.ca. https://www.cna-aiic.ca/en/home

Caputo, A. (2021). The emotional experience of caregiving in dementia: Feelings of guilt and ambivalence underlying narratives of family caregivers. *Dementia, 20*(7), 2248–2260. https://doi.org/10.1177/1471301221989604

Chan, D., Livingston, G., Jones, L., & Sampson, E. L. (2013). Grief reactions in dementia carers: A systematic review. *International Journal of Geriatric Psychiatry, 28*(1), 1–17. https://doi.org/10.1002/gps.3795

Chan, I., Yap, P., Wee, S. L., & Liew, T. M. (2020). The three dimensions of caregiver grief in dementia caregiving: Validity and utility of the subscales of the Marwit-Meuser Caregiver Grief Inventory. *International Journal of Geriatric Psychiatry*, *35*(2), 213–222. https://doi.org/10.1002/gps.5238

Chan, W. C. H., Wong, B., Kwok, T., & Ho, F. (2017). Assessing grief of family caregivers of people with dementia: validation of the Chinese version of the Marwit–Meuser caregiver grief inventory. *Health & Social Work, 42*(3), 151–158. https://doi.org/10.1093/hsw/hlx022

Chappell, N., Dujela, C., & Smith, A. (2014). Spouse and adult child differences in caregiving burden. *Canadian Journal on Aging, 33*(4), 462–472. https://doi.org/10.1017/S0714980814000336

Cheng, S., Ma, D., & Lam, L. (2019). A brief measure of predeath grief in dementia caregivers: The Caregiver Grief Questionnaire. *International Psychogeriatrics, 31*(8), 1099–1107. https://doi.org/10.1017/S1041610219000309

Cheung, D. S. K., Ho, K. H. M., Cheung, T. F., Lam, S. C., & Tse, M. M. Y. (2018). Anticipatory grief of spousal and adult children caregivers of people with dementia. *BMC Palliative Care, 17*(1), 124. https://doi.org/10.1186/s12904-018-0376-3

Cowles, K. V., & Rodgers, B. L. (1991). The concept of grief: A foundation for nursing research and practice. *Research in Nursing & Health*, *14*(2), 119–127. https://doi.org/10.1002/nur.4770140206

Cranswick, K., & Dosman, D. (2008). Eldercare: What we know today. *Canadian Social Trends, 86*, 49–57. https://www. proquest.com/magazines/eldercare-what-we-know-today/docview/224100914/se-2?accountid=14474

Cranswick, K., & Thomas, D. (2005). Elder care and the complexities of social networks. *Canadian Social Trends*, *77*(11), 10-15. https://www.proquest.com/magazines/elder-care-complexities-social-networks/docview/224109923/se-2?accountid=14474

Crawford, K., Digby, R., Bloomer, M., Tan, H., & Williams, A. (2015). Transitioning from caregiver to visitor in a long-term care facility: The experience of caregivers of people with dementia. *Aging & Mental Health*, *19*(8), 739–746. https://doi-org.login.ezproxy.library.ualberta.ca/10.1080/13607863.2014.962008

Crawley, S., Sampson, E. L., Moore, K. J., Kupeli, N., & West, E. (2022). Grief in family carers of people living with dementia: A systematic review. *International Psychogeriatrics*, 1–32. https://doi.org/10.1017/S1041610221002787

Critical Appraisal Skills Programme. (2018a). *CASP Qualitative Checklist.* [Online] https://casp-uk.net/wp-content/uploads/2018/01/CASP-Qualitative-Checklist-2018.pdf

Critical Appraisal Skills Programme. (2018b). *CASP Randomised Controlled Trial Checklist.* [Online] https://casp-uk.net/wp-content/uploads/2018/01/CASP-Randomised-Controlled-Trial-Checklist-2018.pdf

Crowe, M., & Sheppard, L. (2011). A review of critical appraisal tools show they lack rigor: Alternative tool structure is proposed. *Journal of Clinical Epidemiology*, *64*(1), 79–89. https://doi.org/10.1016/j.jclinepi.2010.02.008

Davies, N., Maio, L., Rait, G., & Iliffe, S. (2014). Quality end-of-life care for dementia: What have family carers told us so far? A narrative synthesis. *Palliative Medicine, 28*(287), 919–930. https://doi.org/10.1177/0269216314526766

Diwan, S., Hougham, G., & Sachs, G. (2009). Chronological patterns and issues precipitating grieving over the course of caregiving among family caregivers of persons with dementia. *Clinical Gerontologist, 32*(4), 358–370. https://doi.org/10.1080/07317110903110179

Doka, K. J. (2003). The spiritual gifts—and burdens—of family caregiving. *Generations: Journal of the American Society on Aging*, *27*(4), 45–48. https://www.jstor.org/stable/26555267

Doka, K. J. (2010). Grief, multiple loss, and dementia. *Bereavement Care, 29*(3), 15–20. https://doi.org/10.1080/02682621.2010.522374

Doka, K. J. (2014). Caring for the carer: The lessons of research. *Progress in Palliative Care*, *22*(3), 150–154. https://doi-org.login.ezproxy.library.ualberta.ca/10.1179/1743291X13Y.0000000077

Doka, K. J. (2016a). *Grief is a journey: Finding your path through loss.* Atria.

Doka, K. J. (2016b). *Living with grief: When illness is prolonged*. Taylor & Francis.

Duggleby, W. D., Swindle, J., Peacock, S., & Ghosh, S. (2011). A mixed methods study of hope, transitions, and quality of life in family caregivers of persons with Alzheimer's disease. *BMC Geriatrics*, *11*, article 88. https://doi.org/10.1186/1471-2318-11-88

Duggleby, W., Williams, A., Wright, K., Bollinger Mn, S., & Bollinger, S. (2009). Renewing everyday hope: The hope experience of family caregivers of persons with dementia. *Issues in Mental Health Nursing*, *308*(30). https://doi.org/10.1080/01612840802641727

Dulin, P. L., & Dominy, J. B. (2008). The influence of feeling positive about helping among dementia caregivers in New Zealand: Helping attitudes predict happiness. *Dementia*, *7*(1), 55–69. https://doi-org.login.ezproxy.library.ualberta.ca/10.1177/1471301207085367

Durepos, P., Ploeg, J., Sussman, T., Akhtar-Danesh, N., & Kaasalainen, S. (2020). "A crazy roller coaster at the end": A qualitative study of death preparedness with caregivers of persons with dementia. *SAGE Open Nursing*, *6*. https://doi.org/10.1177/2377960820949111

Durepos, P., Sussman, T., Ploeg, J., Akhtar-Danesh, N., Punia, H., & Kaasalainen, S. (2019). What does death preparedness mean for family caregivers of persons with dementia? *American Journal of Hospice and Palliative Medicine®*, *36*(5), 436–446. https://doi.org/10.1177/1049909118814240

Egilstrød, B., Bay Ravn, M., & Schultz Petersen, K. (2019). Living with a partner with dementia: A systematic review and thematic synthesis of spouses' lived experiences of changes in their everyday lives. *Aging & Mental Health, 23*(5), 541–550. https://doi.org/10.1080/13607863.2018.1433634

Egilstrød, B., & Petersen, K. S. (2021). Female spouses lived experiences of living with a husband with dementia: A qualitative study on changes in everyday life. *Working with Older People*. https://doi.org/10.1108/WWOP-09-2021-0048

Evans, D., & Lee, E. (2014). Impact of dementia on marriage: A qualitative systematic review. *Dementia*, *13*(3), 330–349. https://doi.org/10.1177/1471301212473882

Feder, G. S., Hutson, M., Ramsay, J., Taket, A. R. (2006). Women exposed to intimate partner violence: expectations and experiences when they encounter health care professionals: A meta-analysis of qualitative studies. *Archives of Internal Medicine, 166*(1), 22–37. https://doi.org/10.1001/archinte.166.1.22

Fiore, J. (2019). A systematic review of the dual process model of coping with bereavement (1999–2016). *Omega*, *84*(2), 414–458. https://doi.org/10.1177/0030222819893139

Fredrickson, B. L., Mancuso, R. A., Branigan, C., & Tugade, M. M. (2000). The undoing effect of positive emotions. *Motivation and Emotion*, *24*(4), 237–258. https://doi.org/10.1023/A:1010796329158

Freud, S. (1957). *The standard edition of the complete psychological works of Sigmund Freud* (Vol. XIV; J. Strachey, Trans.). Hogarth Press. (Original work published 1914-1916)

Gaugler, J., Roth, D. L., Haley, W. E., & Mittelman, M. S. (2011). Modeling trajectories and transitions: Results from the New York University caregiver intervention. *Nursing Research, 60*(3 Suppl), S28. https://doi.org/10.1097/NNR.0b013e318216007d

Ghesquiere, A., Haidar, Y. M. M., & Shear, M. K. (2011). Risks for complicated grief in family caregivers. *Journal of Social Work in End-of-Life and Palliative Care, 7*(2-3), 216–240. https://doi.org/10.1080/15524256.2011.593158

Gibbons, C., Creese, J., Tran, M., Brazil, K., Chambers, L., Weaver, B., & Bédard, M. (2014). The psychological and health consequences of caring for a spouse with dementia: A critical comparison of husbands and wives. *Journal of Women & Aging, 26*(1), 3–21. http://10.0.4.56/08952841.2014.854571

Gibson, R., & Gander, P. (2021). Factors associated with the sleep of carers: A survey of New Zealanders supporting a family member with cognitive impairment or dementia. *Dementia*, *20*(3), 919–935. https://doi.org/10.1177/1471301220915071

Government of Canada. (2016). *Prevalence and monetary costs of dementia in Canada (2016): A report by the Alzheimer Society of Canada–HPCDP, 36*(10). https://www.canada.ca/en/public-health/services/reports-publications/health-promotion-chronic-disease-prevention-canada-research-policy-practice/vol-36-no-10-2016/report-summary-prevalence-monetary-costs-dementia-canada-2016-report-alzheimer-society-canada.html

Holley, C. K., & Mast, B. T. (2009). The impact of anticipatory grief on caregiver burden in dementia caregivers. *The Gerontologist*, *49*(3), 388–396. https://doi.org/10.1093/geront/gnp061

Holley, C. K., & Mast, B. T. (2010). Predictors of anticipatory grief in dementia caregivers. *Clinical Gerontologist*, *33*(3), 223–236. https://doi.org/10.1080/07317111003793443

Hong, S. C., & Coogle, C. L. (2016). Spousal caregiving for partners with dementia: A deductive literature review testing Calasanti's gendered view of care work. *Journal of Applied Gerontology*, *35*(7), 759–787. https://doi.org/10.1177/0733464814542246

Hoskins, C. N., & Mariano, C. (2004). Research in nursing and health: Understanding and using quantitative and qualitative methods (2nd ed.). Springer.

Hovland, C. (2018). Welcoming death: Exploring pre-death grief experiences of caregivers of older adults with dementia. *Journal of Social Work in End-of-Life & Palliative Care*, 1–17. https://doi.org/10.1080/15524256.2018.1508538

Hunt, M. R. (2009). Strengths and challenges in the use of interpretive description: Reflections arising from a study of the moral experience of health professionals in humanitarian work. *Qualitative Health Research, 19*(9), 1284-1292. https://doi-org.login.ezproxy.library.ualberta.ca/10.1177/1049732309344612

Hunt, M. R. (2011). Book review: Sally Thorne interpretive description. *Qualitative Health Research, 21,* 292–294. https://doi-org.login.ezproxy.library.ualberta.ca/10.1177/1049732310374064

Jacob, S. R. (1993). An analysis of the concept of grief. *Journal of Advanced Nursing*, *18*(11), 1787-1794. https://doi.org/10.1046/j.1365-2648.1993.18111787.x

Jain, F. A., Connolly, C. G., Moore, L. C., Leuchter, A. F., Abrams, M., Ben-Yelles, R. W., Chang, S. E., Ramirez Gomez, L. A., Huey, N., Lavretsky, H., & Iacoboni, M. (2019). Grief, mindfulness and neural predictors of improvement in family dementia caregivers. *Frontiers in Human Neuroscience*, *13*(155). https://doi.org/https://doi.org/10.3389/fnhum.2019.00155

Jiménez-Gonzalo, L., Romero-Moreno, R., Pedroso-Chaparro, M. del S., Gallego-Alberto, L., Barrera-Caballero, S., Olazarán, J., & Losada-Baltar, A. (2021). Psychometric properties of the Insomnia Severity Index in a sample of family dementia caregivers. *Sleep Medicine*, *82*, 65–70. https://doi.org/10.1016/j.sleep.2021.03.036

Jones, P. S., & Martinson, I. M. (1992). The experience of bereavement in caregivers of family members with Alzheimer's disease. *Image: The Journal of Nursing Scholarship*, *24*(3), 172–176. https://doi:&issn=0743-5150&isbn=&volume=24&is

Kalengayi, F. K. N., Hurtig, A. K., Ahlm, C., & Ahlberg, B. M. (2012). "It is a challenge to do it the right way": An interpretive description of caregivers' experiences in caring for migrant patients in Northern Sweden. *BMC Health Services Research, 12*(1), Article number 433. https://doi.org/10.1186/1472-6963-12-433

Kiely, D. K., Prigerson, H., & Mitchell, S. L. (2008). Health care proxy grief symptoms before the death of nursing home residents with advanced dementia. *American Journal of Geriatric Psychiatry*, *16*(8), 664–673. https://doi.org/10.1097/JGP.0b013e3181784143

Klass, D. (2014). Grief, consolation, and religions: A conceptual framework. *Omega*, *69*(1), 1–18. https://doi.org/10.2190/OM.69.1.a

Kobiske, K. R., Bekhet, A. K., Garnier-Villarreal, M., & Frenn, M. (2019). Predeath grief, resourcefulness, and perceived stress among caregivers of partners with young-onset dementia. *Western Journal of Nursing Research*, *41*(7), 973–989. https://doi.org/10.1177/0193945918806689

Lam, A., Ploeg, J., Carroll, S. L., Duggleby, W., McAiney, C., & Julian, P. (2020). Transition experiences of caregivers of older adults with dementia and multiple chronic conditions: An interpretive description study. *SAGE Open Nursing*, *6*. https://doi.org/10.1177/2377960820934290

Large, S., & Slinger, R. (2015). Grief in caregivers of persons with Alzheimer's disease and related dementia: A qualitative synthesis. *Dementia*, *14*(2), 164–183. https://doi.org/http://dx.doi.org/10.1177/1471301213494511

Lee, W. L., Hou, Y. C., & Lin, Y. S. (2017). Revisiting the continuing bonds theory: The cultural uniqueness of the Bei Dao phenomenon in Taiwanese widows/widowers. *Qualitative Health Research*, *27*(12), 1892–1904. https://doi.org/10.1177/1049732317697097

Li, J., Li, Y., & Li, P. (2021). Perceived grief among caregivers of patients with dementia in China. *Clinical Nursing Research*, *30*(1), 70–81. https://doi.org/10.1177/1054773819839265

Liew, T. M. (2016). Applicability of the pre-death grief concept to dementia family caregivers in Asia. *International Journal of Geriatric Psychiatry*, *31*(7), 749–754. https://doi.org/10.1002/gps.4387

Liew, T. M., Tai, B. C., Wee, S. L., Koh, G. C.-H., & Yap, P. (2020). The longitudinal effects of caregiver grief in dementia and the modifying effects of social services: A prospective cohort study. *Journal of the American Geriatrics Society*, *68*(10), 2348–2353. https://doi.org/https://dx.doi.org/10.1111/jgs.16717

Liew, T. M., Tai, B. C., Yap, P., & Koh, G. C.-H. (2019a). Comparing the effects of grief and burden on caregiver depression in dementia caregiving: A longitudinal path analysis over 2.5 years. *Journal of the American Medical Directors Association*, *20*(8), 977–983. https://doi.org/https://dx.doi.org/10.1016/j.jamda.2018.11.016

Liew, T. M., Tai, B. C., Yap, P., & Koh, G. C.-H. (2019b). Contrasting the risk factors of grief and burden in caregivers of persons with dementia: Multivariate analysis. *International Journal of Geriatric Psychiatry, 34*(2), 258–264. https://doi.org/10.1002/gps.5014

Liew, T. M., Tai, B. C., Yap, P., & Koh, G. C.-H. (2019c). Development and validation of a simple screening tool for caregiver grief in dementia caregiving. *BMC Geriatrics*, *19*(1), 54. https://doi.org/10.1186/s12877-019-1070-x

Liew, T. M., & Yap, P. (2020). A Brief, 6-Item Scale for Caregiver Grief in Dementia Caregiving. *The Gerontologist, 60*(1), e1–e10. https://doi.org/10.1093/geront/gny161

Liew, T. M., Yap, P., Luo, N., Hia, S. B., Koh, G. C. H., & Tai, B. C. (2018). Detecting pre-death grief in family caregivers of persons with dementia: Measurement equivalence of the Mandarin-Chinese version of Marwit-Meuser caregiver grief inventory. *BMC Geriatrics, 18*(1), 114. https://doi.org/10.1186/s12877-018-0804-5

Liew, T. M., Yeap, B. I., Koh, G. C. H., Gandhi, M., Tan, K. S., Luo, N., & Yap, P. (2018). Detecting predeath grief in family caregivers of persons with dementia: Validity and utility of the Marwit-Meuser Caregiver Grief Inventory in a multiethnic Asian population. *Gerontologist*, *58*(2), e150–e159. https://doi.org/10.1093/geront/gnx097

Lindauer, A., & Harvath, T. A. (2014). Pre-death grief in the context of dementia caregiving: A concept analysis. *Journal of Advanced Nursing*, *70*(10), 2196–2207. https://doi.org/10.1111/jan.12411

Lloyd, J., Muers, J., Patterson, T.G., & Marczak, M. (2019) Self-compassion, coping strategies, and caregiver burden in caregivers of people with dementia. *Clinical Gerontologist, 42*(1), 47–59. https://doi.org/10.1080/07317115.2018.1461162

Loboprabhu, S., Molinari, V., Arlinghaus, K., Barr, E., & Lomax, J. (2005). Spouses of patients with dementia: How do they stay together "till death do us part"? *Journal of Gerontological Social Work*, *44*(3–4), 161–174. https://doi.org/10.1300/J083v44n03_10

Loos, C., & Bowd, A. (1997). Caregivers of persons with Alzheimer's disease: Some neglected implications of the experience of personal loss and grief. *Death Studies*, *21*(5), 501–514. https://doi.org/10.1080/074811897201840

Losada, A., Vara-García, C., Romero-Moreno, R., Barrera-Caballero, S., Pedroso-Chaparro, M. del S., Jiménez-Gonzalo, L., Fernandes-Pires, J., Cabrera, I., Gallego-Alberto, L., Huertas-Domingo, C., Mérida-Herrera, L., Olazarán-Rodríguez, J., & Márquez-González, M. (2022). Caring for relatives with dementia in times of COVID-19: Impact on caregivers and care-recipients. *Clinical Gerontologist*, *45*(1), 71–85. https://doi.org/10.1080/07317115.2021.1928356

Losada-Baltar, A., Martínez-Huertas, J. Á., Jiménez-Gonzalo, L., Pedroso-Chaparro, M. del S., Gallego-Alberto, L., Fernandes-Pires, J., & Márquez-González, M. (2021). Longitudinal correlates of loneliness and psychological distress during the lockdown situation due to COVID-19. Effects of age and self-perceptions of aging. *The Journals of Gerontology,* Series B, 77(4), 652–660. https://doi.org/10.1093/geronb/gbab012

MacCourt, P., McLennan, M., Somers, S., & Krawczyk, M. (2017). Effectiveness of a grief intervention for caregivers of people with dementia. *Omega: Journal of Death & Dying*, *75*(3), 230–247. https://doi.org/10.1177/0030222816652802

Maćkowiak, M., Senczyszyn, A., Trypka, E., Małecka, M., Ciułkowicz, M., Mazurek, J., Świderska, R., Giebel, C., Gabbay, M., Rymaszewska, J., & Szcześniak, D. (2021). *The impact of COVID-19 on the lives of community-dwelling people with dementia and informal carers in the context of using the social and medical services: A qualitative study*. https://doi.org/10.21203/rs.3.rs-415217/v1

Madsen, R., & Birkelund, R. (2013). "The path through the unknown": The experience of being a relative of a dementia-suffering spouse or parent. *Journal of Clinical Nursing*, *22*(21–22), 3024-3031. https://doi.org/10.1111/jocn.12131

Marwit, S. J., & Meuser, T. M. (2002). Development and initial validation of an inventory to assess grief in caregivers of persons with Alzheimer's disease. *The Gerontologist*, *42*(6), 751–765. https://doi.org/10.1093/geront/42.6.751

Marwit, S. J., & Meuser, T. M. (2005). Development of a short form inventory to assess grief in caregivers of dementia patients. *Death Studies*, *29*(3), 191–205. https://doi.org/10.1080/07481180590916335

Mayan, M. J. (2016). *Essentials of qualitative inquiry.* Routledge. https://doi.org/10.4324/9781315429250

McGilton, K. S., Vellani, S., Yeung, L., Chishtie, J., Commisso, E., Ploeg, J., Andrew, M. K., Ayala, A. P., Gray, M., Morgan, D., Chow, A. F., Parrott, E., Stephens, D., Hale, L., Keatings, M., Walker, J., Wodchis, W. P., Dubé, V., McElhaney, J., & Puts, M. (2018). Identifying and understanding the health and social care needs of older adults with multiple chronic conditions and their caregivers: A scoping review. *BMC Geriatrics, 18*(1). https://doi.org/10.1186/s12877-018-0925-x

McLennon, S. M., Bakas, T., Habermann, B., & Meuser, T. M. (2014). Content and face validity of the Marwit-Meuser Caregiver Grief Inventory (Short Form) in African American caregivers. *Death Studies, 38*(6), 365–373. https://doi.org/10.1080/07481187.2013.766657

Meichsner, F., Schinköthe, D., & Wilz, G. (2016). The caregiver grief scale: Development, exploratory and confirmatory factor analysis, and validation. *Clinical Gerontologist*, *39*(4), 342–361. https://doi.org/10.1080/07317115.2015.1121947

Meichsner, F., Theurer, C., & Wilz, G. (2019). Acceptance and treatment effects of an Internet-delivered cognitive-behavioral intervention for family caregivers of people with dementia: A randomized-controlled trial. *Journal of Clinical Psychology*, *75*(4), 594–613. https://doi.org/https://dx.doi.org/10.1002/jclp.22739

Meichsner, F., & Wilz, G. (2018). Dementia caregivers' coping with pre-death grief: Effects of a CBT-based intervention. *Aging and Mental Health, 22*(2), 218–225. https://doi.org/10.1080/13607863.2016.1247428

Merriam-Webster. (n.d.-a). Grief. In *Merriam-Webster dictionary.* Retrieved April 17, 2022. https://www.merriam-webster.com/dictionary/grief

Merriam-Webster. (n.d.-b). Paradox. In *Merriam-Webster dictionary.* Retrieved April 17, 2022. https://www.merriam-webster.com/dictionary/paradox

Merriam-Webster. (n.d.-c). Professional. In *Merriam-Webster dictionary.* Retrieved April 13, 2022. https://www.merriam-webster.com/dictionary/grief

Meuser, T. M., & Marwit, S. J. (2001). A comprehensive, stage-sensitive model of grief in dementia caregiving. *Gerontologist*, *41*(5), 658–670. https://doi.org/10.1093/geront/41.5.658

Moore, K. J., Crawley, S., Vickerstaff, V., Cooper, C., King, M., & Sampson, E. L. (2020). Is preparation for end of life associated with pre-death grief in caregivers of people with dementia? *International Psychogeriatrics*, *32*(6), 753–763. https://doi.org/10.1017/S1041610220000289

Moore, K. J., Davis, S., Gola, A.. Harrington, J., Kupeli, N., Vickerstaff, V., King, M., Leavey, G., Nazareth, I., Jones, L., & Sampson, E. L. (2017). Experiences of end of life amongst family carers of people with advanced dementia: Longitudinal cohort study with mixed methods. *BMC Geriatrics, 17*, 135. https://doi.org/10.1186/s12877-017-0523-3

National Institute for Clinical Excellence. (2004). *Guidance on cancer services: Improving supportive and palliative care for adults with cancer: The manual.*

Noyes, B. B., Hill, R. D., Hicken, B. L., Luptak, M., Rupper, R., Dailey, N. K., & Bair, B. D. (2010). The role of grief in dementia caregiving. *American*

Journal of Alzheimer's Disease and other Dementias, 25(1), 9–17. https://doi.org/10.1177/1533317509333902

O'Connor, N., Fox, S., Kernohan, W. G., Drennan, J., Guerin, S., Murphy, A., & Timmons, S. (2022). A scoping review of the evidence for community-based dementia palliative care services and their related service activities. *BMC Palliative Care, 21*(1), 32. https://doi.org/10.1186/s12904-022-00922-7

Olson, K. (2011). *Essentials of qualitative interviewing.* Routledge. https://doi.org/10.4324/9781315429212

O'Rourke, G., Pentecost, C., Van Den Heuvel, E., Victor, C., Quinn, C., Hillman, A., Litherland, R., & Clare, L. (2021). Living with dementia under COVID-19 restrictions: Coping and support needs among people with dementia and carers from the IDEAL cohort. *Ageing and Society*, 1–23. https://doi.org/10.1017/S0144686X21001719

Ott, C. H., Sanders, S., & Kelber, S. T. (2007). Grief and personal growth experience of spouses and adult-child caregivers of individuals with Alzheimer's disease and related dementias. *The Gerontologist*, *47*(6), 798–809. https://doi.org/10.1093/geront/47.6.79

Parmar, J., Anderson, S., Dobbs, B., Tian, P. G. J., Charles, L., Triscott, J., Stickney-Lee, J., Brémault-Phillips, S., Sereda, S., & Poole, L. (2021). Neglected needs of family caregivers during the COVID-19 pandemic and what they need now: A qualitative Study. *Diseases*, *9*(4), 70. https://doi.org/10.3390/diseases9040070

Parse, R. R. (1997). Joy–Sorrow: A study using the Parse research method. *Nursing Science Quarterly, 10*(2), 80–87. https://doi.org/10.1177/089431849701000208

Passoni, S., Toraldo, A., Villa, B., & Bottini, G. (2015). Prolonged grief in caregivers of community-dwelling dementia patients. *American Journal of Alzheimer's Disease and Other Dementias, 30*(2), 192–200. https://doi.org/10.1177/1533317514542643

Peacock, S., Bayly, M., Duggleby, W., Ploeg, J., Pollard, L., Swindle, J., Lee, H. J., Williams, A., Markle-Reid, M., & McAiney, C. (2020). Women's caregiving experience of older persons living with Alzheimer disease and related dementias and multiple chronic conditions: Using Wuest's theory. *SAGE Open Nursing*, *6*. https://doi.org/10.1177/2377960820974816

Peacock, S., Hammond-Collins, K., & Forbes, D. A. (2014). The journey with dementia from the perspective of bereaved family caregivers: A qualitative descriptive study. *BMC Nursing, 13*(1), 42. https://doi.org/10.1186/s12912-014-0042-x

Peacock, S., Sethi, B., Williams, A., Duggleby, W., Bayly, M., Swindle, J., Ploeg, J., & Markle-Reid, M. (2017). Older adult spouses with multiple chronic conditions: Challenges, rewards, and coping strategies. *Canadian Journal on Aging*, *36*(2), 209–222. https://doi.org/10.1017/s0714980817000095

Pérez-González, A., Vilajoana-Celaya, J., Guàrdia-Olmos, J., Perez-Gonzalez, A., Vilajoana-Celaya, J., & Guardia-Olmos, J. (2021). Alzheimer's disease caregiver characteristics and their relationship with anticipatory grief. *International Journal of Environmental Research and Public Health*, *18*(16). https://doi.org/10.3390/ijerph18168838

Ploeg, J., Canesi, M., Fraser, K. D., McAiney, C., Kaasalainen, S., Markle-Reid, M., Dufour, S., Garland Baird, L., & Chambers, T. (2019). Experiences of community-dwelling older adults living with multiple chronic conditions: a qualitative study. *BMJ Open, 9*(3), e023345. https://doi.org/10.1136/bmjopen-2018-023345

Ploeg, J., Matthew-Maich, N., Fraser, K., Dufour, S., McAiney, C., Kaasalainen, S., Markle-Reid, M., Upshur, R., Cleghorn, L., & Emili, A. (2017). Managing multiple chronic conditions in the community: a Canadian qualitative study of the experiences of older adults, family caregivers and healthcare providers. *BMC Geriatrics, 17*(1), 40. https://doi.org/10.1186/s12877-017-0431-6

Ploeg, J., McAiney, C., Duggleby, W., Chambers, T., Lam, A., Peacock, S., Fisher, K., Forbes, D. A., Ghosh, S., Markle-Reid, M., Triscott, J., & Williams, A. (2018). A Web-based intervention to help caregivers of older adults with dementia and multiple chronic conditions: Qualitative study. *JMIR Aging*, *1*(1). https://doi.org/10.2196/aging.8475

Ploeg, J., Northwood, M., Duggleby, W., McAiney, C. A., Chambers, T., Peacock, S., Fisher, K., Ghosh, S., Markle-Reid, M., Swindle, J., Williams, A. M., & Triscott, J. A. C. (2020). Caregivers of older adults with dementia and multiple chronic conditions: Exploring their experiences with significant changes. *Dementia, 19*(8), 2601-2620. https://doi.org/10.1177/1471301219834423

Pozzebon, M., Douglas, J., & Ames, D. (2016). Spouses' experience of living with a partner diagnosed with a dementia: A synthesis of the qualitative research. *International Psychogeriatrics*, *28*(4), 537–556. https://doi.org/10.1017/S1041610215002239

Raffin Bouchal, S. R., Rallison, L., Moules, N. J., & Sinclair, S. (2015). Holding on and letting go: Families' experiences of anticipatory mourning in terminal cancer. *OMEGA: Journal of Death and Dying, 72*(1), 42–68. https://doi.org/10.1177/0030222815574700

Rando, T. A. (1988). *Grieving: How to go on living when someone you love dies.* Jossey-Bass.

Rando, T. A. (Ed.). (2000). *Clinical dimensions of anticipatory mourning: Theory and practice in working with the dying, their loved ones, and their caregivers.* Research Press.

Rè Se, T., Durme, V., Macq, J., Jeanmart, C., & Gobert, M. (2011). Tools for measuring the impact of informal caregiving of the elderly: A literature review. *International Journal of Nursing Studies, 49*, 490 504. https://doi.org/10.1016/j.ijnurstu.2011.10.011

Richards, L., & Morse, J. M. (2012). *README FIRST for a user's guide to qualitative methods* (3rd ed.). Sage.

Rogalla, K. B. (2020). Anticipatory grief, proactive coping, social support, and growth: Exploring positive experiences of preparing for Loss. *OMEGA: Journal of Death and Dying, 81*(1), 107–129. https://doi.org/10.1177/0030222818761461

Root, B. L., & Exline, J. J. (2014). The role of continuing bonds in coping with grief: Overview and future directions. *Death Studies*, *38*(1), 1–8. https://doi.org/10.1080/07481187.2012.712608

Ross, A., & Dagley, J. C. (2009). An assessment of anticipatory grief as experienced by family caregivers of individuals with dementia. *Alzheimer's Care Today, 10*(1), 8–21. https://doi.org/10.1097/ACQ.0b013e318197427a.

Rudd, M. G., Viney, L. L., & Preston, C. A. (1999). The grief experienced by spousal caregivers of dementia patients: The role of place of care of patient and gender of caregiver. *International Journal of Aging & Human Development*, *48*(3), 217–240. https://doi.org/10.2190/MGMP-31RQ-9N8M-2AR3

Samnani, S. S., Vaska, M., Ahmed, S., & Turin, T. C. (2017). Review typology: The basic types of reviews for synthesizing evidence for the purpose of knowledge translation. *Journal of the College of Physicians and Surgeons Pakistan, 27*(10), 635–641.

Sanders, S., Butcher, H. K., Swails, P., & Power, J. (2009). Portraits of caregivers of end-stage dementia patients receiving hospice care. *Death Studies*, *33*(6), 521-556. https://doi-org.login.ezproxy.library.ualberta.ca/10.1080/07481180902961161

Sanders, S., & Corley, C. S. (2003). Are they grieving? A qualitative analysis examining grief in caregivers of individuals with Alzheimer's disease. *Social Work in Health Care*, *37*(3), 35–53. https://doi.org/10.1300/J010v37n03_03

Sanders, S., Morano, C., & Corley, C. S. (2003). The expressions of loss and grief among male caregivers of individuals with Alzheimer's disease. *Journal of Gerontological Social Work*, *39*(4), 3–18. https://doi.org/10.1300/J083v39n04_02

Sanders, S., Ott, C. H., Kelber, S. T., & Noonan, P. (2008). The experience of high levels of grief in caregivers of persons with Alzheimer's disease and related dementia. *Death Studies*, *32*(6), 495–523. https://doi.org/10.1080/07481180802138845

Schut, M. S. H. (1999). The dual process model of coping with bereavement: rationale and description. *Death Studies, 23*(3), 197–224. https://doi-org.login.ezproxy.library.ualberta.ca/10.1080/074811899201046

Shanley, C., Russell, C., Middleton, H., & Simpson-Young, V. (2011). Living through end-stage dementia: The experiences and expressed needs of family carers. *Dementia*, *10*(3), 325–340. https://doi-org.login.ezproxy.library.ualberta.ca/10.1177/1471301211407794

Silverberg, E. (2007). Introducing the 3-A grief intervention model for dementia caregivers: Acknowledge, assess and assist. *Omega: Journal of Death and Dying*, *54*(3), 215–235. https://doi.org/http://dx.doi.org/10.2190/D1R5-0473-1922-4N70

Singer, J., Roberts, K. E., McLean, E., Fadalla, C., Coats, T., Rogers, M., Wilson, M. K., Godwin, K., & Lichtenthal, W. G. (2022). An examination and proposed definitions of family members' grief prior to the death of individuals with a life-limiting illness: A systematic review. *Palliative Medicine*, *36*(4), 581–608.

Smyth, A., Whitehead, L., Quigley, E., Vafeas, C., & Emery, L. (2020). Disrupted sleep and associated factors in Australian dementia caregivers: A cross-sectional study. *BMC Geriatrics*, *20*(1), 1–7. https://doi.org/10.1186/s12877-020-01726-1

Straus, S. E., Tetroe, J., & Graham, I. (2009). Defining knowledge translation. *CMAJ,* 181(3–4), 165–168. https://doi.org/10.1503/cmaj.081229

Stroebe, M., & Schut, H. (1999). The dual process model of coping with bereavement: Rationale and description. *Death Studies, 23,* 197–224. https://doi-org.login.ezproxy.library.ualberta.ca/10.1080/074811899201046

Stroebe, M., & Schut, H. (2010). The dual process model of coping with bereavement: A decade on. *OMEGA Journal of Death and Dying, 61*(4), 273–289. https://doi.org/10.2190/OM.61.4.b

Thorne, S. (2016a). *Interpretive description: Qualitative research for applied practice* (2nd ed.). Routledge. https://doi.org/10.4324/9781315545196

Thorne, S. (2016b). Research toward clinical wisdom. *Nursing Inquiry, 23*, 97–98. https://doi.org/10.1111/nin.12138

Thorne, S., Kirkham, S. R., & MacDonald-Emes, J. (1997). Interpretive description: A noncategorical qualitative alternative for developing nursing knowledge. *Research in Nursing & Health, 20*(2), 169–177. https://doiorg.login.ezproxy.library.ualberta.ca/10.1002/(SICI) 1098-240X(199704)20:2<169::AID-NUR9>3.0.CO;2-1

Thorne, S., Kirkham, S. R., & O'Flynn-Magee, K. (2004). The analytic challenge in interpretive description. *International Journal of Qualitative Methods, 3*(1), 1–11. https://doi.org/10.1177/160940690400300101

Trauer. (n.d.). *Collins dictionary.* Retrieved April 13, 2022.. https://www.collinsdictionary.com/dictionary/german-english/trauer

Van Durme, T., Macq, J., Jeanmart, C., & Gobert, M. (2012). Tools for measuring the impact of informal caregiving of the elderly: A literature review. *International Journal of Nursing Studies*, *49*(4), 490–504. https://doi.org/10.1016/j.ijnurstu.2011.10.011

Warchol-Biedermann, K., Mojs, E., Gregersen, R., Maibom, K., Millán-Calenti, J. C., & Maseda, A. (2014). What causes grief in dementia caregivers? *Archives of Gerontology and Geriatrics*, *59*(2), 462–467. https://doi.org/10.1016/j.archger.2014.05.013

Weiss, R. S. (2001). Grief, bonds, and relationships. In M. S. Stroebe & R. O. Hansson (Eds.), *Handbook of bereavement research: Consequences, coping, and care* (pp. 47–62). American Psychological Association. https://doi.org/10.1037/10436-002

Whittemore, R., & Knafl, K. (2005). The integrative review: updated methodology. *Journal of Advanced Nursing, 52*(5), 546–553. https://doi-org.login.ezproxy.library.ualberta.ca/10.1111/j.1365-2648.2005.03621.x

Williams, A., Sethi, B., Duggleby, W., Ploeg, J., Markle-Reid, M., Peacock, S., & Ghosh, S. (2016). A Canadian qualitative study exploring the diversity of the experience of family caregivers of older adults with multiple chronic conditions using a social location perspective. *International Journal for Equity in Health, 15*(1), 1–16. https://doi.org/10.1186/s12939-016-0328-6

Wilson, S., Toye, C., Aoun, S., Slatyer, S., Moyle, W., & Beattie, E. (2017). Effectiveness of psychosocial interventions in reducing grief experienced by family carers of people with dementia: A systematic review. *JBI Database of Systematic Reviews and Implementation Reports*, *15*(3), 809–839. https://doi.org/10.11124/JBISRIR-2016-003017

Wong, S. L., Gilmour, H., & Ramage-Morin, P. L. (2016). Alzheimer's disease and other dementias in Canada. *Health Reports, 27*(5), 11–16. https://doi.org/82-003-X

World Health Organization. (2021). *Dementia.* https://www.who.int/en/news-room/fact-sheets/detail/dementia

World Health Organization. (2022). *Dementia.* https://www.who.int/news-room/fact-sheets/detail/dementia

Yeager, C. A., Hyer, L. A., Hobbs, B., & Coyne, A. C. (2010). Alzheimer's disease and vascular dementia: The complex relationship between diagnosis and caregiver burden. *Issues in Mental Health Nursing, 31*(6), 376–384. https://doi.org/10.3109/01612840903434589

APPENDIX A: RECRUITMENT POSTER

UNIVERSITY OF ALBERTA
FACULTY OF NURSING

Contact Lori Pollard at 780-492-1316 or by email at lori.pollard@ualberta.ca

ARE YOU A FEMALE SPOUSAL CAREGIVER OF A PERSON LIVING WITH DEMENTIA AND MULTIPLE CHRONIC CONDITIONS AT HOME IN THE COMMUNITY?

We are looking for volunteers to take part in a study that will involve two to three (30–60 minute) telephone interviews. We are interested to explore pre-death grief experiences of female spousal caregivers of an older person living with dementia, who lives in the community, with multiple chronic conditions.

You will receive a $10 gift card as a thank you for your participation.

The plan for this study has been reviewed by a Research Ethics Board at the University of Alberta. If you have questions about your rights or how research should be conducted, you can call (780) 492-2615. This office is independent of the researchers.

PRO#00097037

APPENDIX B: FEMALE SPOUSAL CAREGIVER PARTICIPANTS' INFORMATION LETTER AND CONSENT

INFORMATION LETTER and CONSENT FORM

Study Title: Exploring the Predeath Grief Experiences of Female Spousal Caregivers of Older Persons Living with Dementia and Multiple Chronic Conditions, Living in the Community

Research Investigator:	**Supervisor:**
Lori Pollard RN MN	Wendy Duggleby, PhD, RN
ECHA 4-248	ECHA 5-172
University of Alberta	University of Alberta
lori.pollard@ualberta.ca	wendy.duggleby@ualberta.ca
780-492-1316	780-492-8660

Why am I being asked to take part in this research study? You are being asked to take part in this study because you are a female spousal caregiver of an older person living with dementia, who lives in the community, with multiple chronic conditions. Primary caregivers, like you, may have more difficulty providing care on a daily basis, within your home, compared to other caregivers. You may also experience predeath grief which is a response to the losses you are experiencing as a caregiver. Learning about predeath grief experiences might change how your family and nurses can support you.

What is the reason for doing the study? I am conducting this study because I want to explore predeath grief experiences of female spousal caregivers of an older person living with dementia, who lives in the community, with multiple chronic conditions. I want to know how you describe predeath grief experiences, and what factors influence them. This study will give your family and nurses more information to support you.

What will I be asked to do? If you consent to taking part in this study, you will first be asked some questions about yourself and the person you are caring for. For example, you will be asked your gender, and your age. If at any time you do not wish to answer any questions you do not need to. Taking part in this study will involve two confidential telephone interviews approximately 30 to 60 minutes in length. The approximate total time is 60 to 120 minutes for two interviews and then a possible additional 30 to 60 minutes if you are chosen for a third interview. Each interview will be over the telephone and audio-recorded and will be at a time that is convenient for you. Before each interview you will be asked if you still want to be in the study.

What are the risks and discomforts? Some people may feel sad talking about their predeath grief experiences. If this happens, you will be able to take a break in our conversation, or if you choose to stop completely, we can resume our conversation at a later date. As well, you will be offered community health resources for support.

What are the benefits to me? Taking part in this study will not provide you direct benefits. However, you may experience a sense of being heard regarding your experiences about predeath grief.

Do I have to take part in the study? Participating in this study is your choice. If you decide to be in the study, you can change your mind and leave the study, at any time, with no consequences. Just let the researcher know. Also, if you decide to leave the study, at any time, if you want, we will not use any of the information you gave us.

Will I be paid to be in the research? You will receive a $10.00 gift card honorarium for participating in the study.

Will my information be kept private? During the study, I will be collecting data regarding your predeath grief experiences. I will do everything I can to make sure that your information is kept private. Your name and information you give me will be kept confidential and kept in a secure locked drawer at the University of Alberta. Your information and interview will be assigned a code number and all identifying information will be removed from your interview transcript. Any published information will be in a group format and there will be no identifying information. I will make every effort to keep your information private. If I use the data from this study in future research, I will have to get approval from a Research Ethics Board. At the University of Alberta, we keep data securely stored for a minimum of 5 years, after the end of the study.

What if I have questions? If you have any questions about the research now or later, please contact Lori Pollard at 780-492-1316 or Dr. Wendy Duggleby at 780-492-8660.

If you have any questions regarding your rights as a research participant, you may contact the Health Research Ethics Board at 780-492-2615. This office has no affiliation with the study investigators.

UNIVERSITY OF
ALBERTA

Title of Study: Exploring the Predeath Grief Experiences of Female Spousal Caregivers of Older Persons Living with Dementia and Multiple Chronic Conditions, Living in the Community

Principal Investigator: Lori Pollard RN MN
Phone Number: 780-492-1316
Supervisor: Dr. Wendy Duggleby
Phone Number: 780-492-8660

	No	Yes
Do you understand that you have been asked to be in a research study?	☐	☐
Do you understand the information about the study?	☐	☐
Do you understand the benefits and risks involved in taking part in this study?	☐	☐
Have you had an opportunity to ask questions and discuss this study?	☐	☐
Do you understand that you are free to leave the study at any time without having to give a reason and without affecting your (future medical care/employment, or without penalty)?	☐	☐
Has the issue of confidentiality been explained to you?	☐	☐
Do you understand the conversations will be recorded?	☐	☐
Do you understand who will have access to your study records (including personally identifiable health information)?	☐	☐
Do you understand the portions of the final research may be published in professional journals or presented at conferences?	☐	☐
Do you want the investigator(s) to inform your family doctor that you are		

participating in this study? If so, give his/her name. ____________________ ☐ ☐

Future Contact

Do you agree to be contacted for follow-up or to facilitate future research? ☐ ☐
Telephone Number: ____
Home Address: ____

Do you agree for your information to be securely stored at the
University of Alberta? ☐ ☐

Who explained this study to you? __________________________________

I agree to take part in this study: ☐ ☐
Signature of Research Participant: __________________________
(Printed Name):__________________________________ Date:________________
Signature of Witness: _____________________________ Date:________________

A Witness line is only required if you anticipate that your participants will be unable to read the consent for themselves. If so, an impartial witness (i.e., not associated with the study team) must be present during the entire informed consent discussion and is witnessing that the participant understood what was discussed (i.e., not just witnessing the signature process).

I believe that the person signing this form understands what is involved in the study and voluntarily agrees to participate.

This should be signed by the person who is conducting the informed consent discussion (if that is not the Investigator – the person that obtained the consent needs to sign here)

Signature of Investigator __________________________________ Date ___________

THE INFORMATION SHEET MUST BE ATTACHED TO THIS CONSENT FORM AND A COPY GIVEN TO THE RESEARCH PARTICIPANT

APPENDIX C: PROFESSIONAL KNOWLEDGE PROVIDER INFORMATION LETTER AND CONSENT

INFORMATION LETTER and CONSENT FORM

Study Title: Exploring the Predeath Grief Experiences of Female Spousal Caregivers of Older Persons Living with Dementia and Multiple Chronic Conditions, Living in the Community

Research Investigator:	**Supervisor:**
Lori Pollard RN MN	Wendy Duggleby PhD RN
ECHA 4-248	ECHA 5-172
University of Alberta	University of Alberta
lori.pollard@ualberta.ca	wendy.duggleby@ualberta.ca
780-492-1316	780-492-8660

Why are you being asked to take part in this research study? You are being asked to take part in this study because you had been identified as a professional knowledge provider who works closely with, supports, guides, and assists female spousal caregivers of an older person living with dementia, who lives in the community, with multiple chronic conditions. You may also have observed these female spousal caregivers experience predeath grief in response to the losses they experience as a caregiver.

What is the reason for doing the study? I am conducting this study because I want to explore predeath grief experiences of female spousal caregivers of an older person living with dementia, who live in the community, with multiple chronic conditions. I want to know how you define predeath grief experiences, how you think predeath grief experiences influence their caregiving role and what you think influences their predeath grief experience. The findings of this study may give you and others working with this population more information to support female spousal caregivers of an older person living with dementia, who live in the community, with multiple chronic conditions.

What will I be asked to do? If you consent to taking part in this study, you will first be asked some questions about yourself. For example, you will be asked your gender, and your age. Taking part in this study will involve one confidential telephone interview approximately 30 to 60 minutes in length. The approximate total time is 60 minutes for one interview and then a possible additional 30 to 60 minutes if you are asked for a second interview.

Each interview will be over the telephone and audio-recorded and will be at a time that is convenient to you. Before each interview you will be asked if you still want to be in the study. During the interview, I am interested in knowing your perceptions as a professional knowledge provider regarding predeath grief experiences of female spousal caregivers of an older person living with dementia, who lives in the community, with multiple chronic conditions.

What are the risks and discomforts? There are no known risks to you for participating in this study. However, some people may feel sad talking about the predeath grief experiences of the female spousal caregivers of an older person living with dementia, who lives in the community, with multiple chronic conditions. If this happens, you will be able to take a break in our conversation, or if you choose to stop completely, we can resume our conversation at a later date. As well, you will be offered community health resources for support.

What are the benefits to me? Taking part in this study will not provide you direct benefits. However, your involvement in the study, will assist me and various others to understand predeath grief experiences of female spousal caregivers of an older person living with dementia, who lives in the community, with multiple chronic conditions.

Do I have to take part in the study? Participating in this study is your choice. If you decide to be in the study, you can change your mind and leave the study, at any time, with no consequences. Just let the researcher know. Also, if you decide to leave the study, at any time, if you want, we will not use any of the information you gave us. If at any time you do not wish to answer any questions you do not need to.

Will I be paid to be in the research? You will receive a $10.00 gift card honorarium for participating in the research study.

Will my information be kept private? During the study, I will be collecting your data and will do everything I can to make sure that your information is kept private. Your name and information you give me will be kept confidential and kept in a secure locked drawer at the University of Alberta. Your information and interview will be assigned a code number and all identifying information will be removed from your interview transcript. Any published information will be in a group format and there will be no identifying information. I will make every effort to keep your information private. If I use the data from this study in future research, I will have to get approval from a Research Ethics Board. At the University of Alberta, we keep data securely stored for a minimum of 5 years, after the end of the study.

What if I have questions? If you have any questions about the research now or later, please contact Lori Pollard at 780-492-1316 or Dr. Wendy Duggleby at 780-492-8660.

If you have any questions regarding your rights as a research participant, you may contact the Health Research Ethics Board at 780-492-2615. This office has no affiliation with the study investigators.

UNIVERSITY OF ALBERTA

Title of Study: Exploring the Predeath Grief Experiences of Female Spousal Caregivers of Older Persons Living With Dementia and Multiple Chronic Conditions, Living in the Community

Principal Investigator: Lori Pollard RN MN
Phone Number: 780-492-1316
Supervisor: Dr. Wendy Duggleby
Phone Number: 780-492-8660

	No	Yes
Do you understand that you have been asked to be in a research study?	☐	☐
Do you understand the information about the study?	☐	☐
Do you understand the benefits and risks involved in taking part in this study?	☐	☐
Have you had an opportunity to ask questions and discuss this study?	☐	☐
Do you understand that you are free to leave the study at any time without having to give a reason and without affecting your (future medical care/employment, or without penalty)?	☐	☐
Has the issue of confidentiality been explained to you?	☐	☐
Do you understand the conversations will be recorded?	☐	☐
Do you understand who will have access to your study records (including personally identifiable health information)?	☐	☐
Do you understand the portions of the final research may be published in professional journals or presented at conferences?	☐	☐
Do you want the investigator(s) to inform your family doctor that you are participating in this research study? If so, give his/her name. ______________________		

Future Contact

Do you agree to be contacted for follow-up or to facilitate future research? ☐ ☐

Telephone Number:_____________

Home Address: ________________

Do you agree for your information to be securely stored at the University of Alberta? ☐ ☐

Who explained this study to you? ___________________

I agree to take part in this study: ☐ ☐

Signature of Research Participant: ________________________

(Printed Name):________________________________ Date:_______________

Signature of Witness: ____________________________Date:_______________

A Witness line is only required if you anticipate that your participants will be unable to read the consent for themselves. If so, an impartial witness (i.e., not associated with the study team) must be present during the entire informed consent discussion and is witnessing that the participant understood what was discussed (i.e., not just witnessing the signature process).

I believe that the person signing this form understands what is involved in the study and voluntarily agrees to participate.

This should be signed by the person who is conducting the informed consent discussion (if that is not the Investigator – the person that obtained the consent needs to sign here)

Signature of Investigator ________________________________ Date __________

THE INFORMATION SHEET MUST BE ATTACHED TO THIS CONSENT FORM AND A COPY GIVEN TO THE RESEARCH PARTICIPANT

APPENDIX D: DEMOGRAPHIC DATA SHEET

FOR FEMALE SPOUSAL CAREGIVERS

Title of Study: Exploring the Predeath Grief Experiences of Female Spousal Caregivers of Older Persons Living with Dementia and Multiple Chronic Conditions, Living in the Community

The following information is required for the research study. All information will be kept confidential. The questions will take approximately 5 to 10 minutes to answer.

Code # ___________ **Gender: Female** __________

Marital Status: Married ☐ Common Law ☐ Years together _____

Age in years of Participant: _______

Age in years of Care Recipient: ________

Education: Primary ☐ Secondary ☐ Higher Education ☐ University ☐

Employed: No ☐ Yes, Part-time ☐ Yes, Full time ☐ Yes, Casual ☐ Retired ☐

How long have you been caring for your partner? (In Years) ______

How many chronic conditions does your partner have?

List them:

Do you yourself suffer from any illness/disability? _________

How many family members are there in your household? ___________

Monthly Income Range (in $CAD) <1,000 ☐ 1,000-1,500 ☐ 1,500-3,000 ☐ >3,000 ☐

APPENDIX E: DEMOGRAPHIC DATA SHEET FOR

PROFESSIONAL KNOWLEDGE PROVIDER

Title of Study: Exploring the Predeath Grief Experiences of Female Spousal Caregivers of Older Persons Living with Dementia and Multiple Chronic Conditions, Living in the Community

All of your information will be kept confidential.

Gender: Female ☐ Male ☐ Undisclosed ☐

Age range in years: 20-30☐ 31-40☐ 41-50☐ 51-60☐ 61-70☐

Position________________________________

Professional Designation If Applicable________________________________

Years of Experience Working: at your current place of employment:

1-2 years ☐ 3-5 years ☐ 6-8 years ☐ > 8 years ☐

Years of Experience Working: with female spousal caregivers of older persons living with dementia and multiple chronic conditions, living in the community:

1-2 years ☐ 3-5 years ☐ 6-8 years ☐ > 8 years ☐

Do you have specialized education/training to work with caregivers of older persons living with dementia?

Yes ☐ No ☐

If yes, please describe your education/training:

Code # ___________

APPENDIX F: INTERVIEW GUIDE FOR FEMALE SPOUSAL CAREGIVERS

- Can you tell me about a situation where you experienced a loss relevant to your spouse?
- Thinking about your caregiving role, what loss is the most meaningful to you and why?
- What does predeath grief mean to you? How would you describe it?
- What do you think influences your predeath grief experience?
- Do you think because your spouse has more than one condition, this might influence your experience of loss and predeath grief?

APPENDIX G: INTERVIEW GUIDE FOR PROFESSIONAL KNOWLEDGE PROVIDERS

As mentioned in the information letter and consent form we went over for this study, I am interested in learning about predeath grief experiences of female spousal caregivers of an older person living with dementia and multiple chronic conditions, living in the community. When you are ready, I will begin with my first question…

- Please tell me about your experiences in regard to knowing and/or supporting a female spousal caregiver of an older person living with dementia and multiple chronic conditions, living in the community who experienced a loss relevant to her spouse?
- Please describe a situation regarding a female spousal caregiver of an older person living with dementia and multiple chronic conditions, living in the community who has experienced predeath grief, while caring for her spouse? How has her predeath grief influenced her caregiving role?
- How do you think a person living in the community with multiple chronic conditions, in addition to living with dementia, impacts their female spousal caregiver's predeath grief experiences?
- What do you think influences the predeath grief experience of the female spousal caregiver of older persons living with dementia and multiple chronic conditions, living in the community?

APPENDIX H: A HELPFUL RESOURCE LIST FOR ALBERTA RESIDENTS

Helpful Resources	**Contact Information**
Advancing Dementia Care & Support in Alberta Dementia Resources Toolkit for Health Professionals, Seniors Health SCN	www.albertahealthservices.ca In the "Search AHS" box at the top of the page please type in: **Dementia in the community** Then press the "enter key"
Alzheimer Society of Calgary	1-877-569-4357
Alzheimer Society of Alberta and NWT	1-866-950-5465
Community Care Access	780-496-1300
Health Link	811
Outside the local calling area	1-866-408-LINK (5465)
Government of Alberta: Seniors and Community Supports	www.seniors.gov.ab.ca
Alberta Hospice Palliative Care Association	www.ahpca.ca
24 hour support numbers:	
Crisis line	211
Mental health help line	1-877-303-2642
Community Supports	
Alberta Aids to Daily Living: Residential	780-427-0731
Alberta Health Services- Community Care	403-943-1920
National Support Programs:	
Canada Pension Plan: Disability Benefits	1-800-277-9914
Canada Pension Plan: Survivor Benefits	1-800-277-9914
Income Tax	1-800-959-8281
Employment Insurance: Special Benefits	1-800-206-7218
Veterans Affairs Canada (VAC)	1-866-522-2111

APPENDIX I: ETHICS APPLICATION LETTER

Notification of Approval

Date: February 19, 2020

Study ID: Pro00097037

Principal Investigator: Loreen Pollard

Study Supervisor: Wendy Duggleby

Study Title: Exploring Pre-death Grief Experiences of Female Spousal Caregivers of Older Persons Living with Dementia and Multiple Chronic Conditions Living in the Community

Approval Expiry Date: February 18, 2021

Approved Consent Form:

Approval Date	Approved Document
2/19/2020	APPENDIX A - Participant Information Letter and Consent Feb. 7 2020wd (2).docx

Thank you for submitting the above study to the Research Ethics Board 1. Your application has been reviewed and approved on behalf of the committee.

Any proposed changes to the study must be submitted to the REB for approval prior to implementation. A renewal report must be submitted next year prior to the expiry of this approval if your study still requires ethics approval. If you do not renew on or before the renewal expiry date, you will have to re-submit an ethics application.

Approval by the Research Ethics Board does not encompass authorization to access the staff, students, facilities or resources of local institutions for the purposes of the research.

Sincerely,

Anne Malena, PhD
Chair, Research Ethics Board 1

Note: This correspondence includes an electronic signature (validation and approval via an online system).