

Dementia Spousal Caregivers:

An Exploration of Pre-Loss Grief Interventions to Mitigate Post-Loss Complicated Grief

by

Jude Weir

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APPROVED BY

Maria Stella, Ph.D., R.C.C., Thesis Supervisor, Counsellor Education Faculty

Glen Grigg, Ph.D., R.C.C., Faculty Reader, Counsellor Education Faculty

Division of Arts and Sciences

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Dedication

This thesis is dedicated to my mother, Louise Capton, whose dementia journey began my own journey towards working with families living with dementia and this thesis topic. And to my partner Ian whose insight, patience, humour, and unflagging support carries me through.

Abstract

The aim of this thesis is to synthesize the existing evidence regarding spousal dementia caregivers' pre-death grief experiences and grief variables linked with caregiver post-death complicated or prolonged grief. Dementia grief models that take dementia caregivers' pre and post-loss grief in account are examined. The evidence regarding the efficacy of psycho-social interventions to alleviate distress, assist with pre-loss grief adjustment, and mitigate complicated grief in bereavement is also discussed. Findings reveal that the perception of dementia caregiver grief as a critical component of the caregiving experience which may be detrimental to caregivers' mental and physical health is relatively new. Also revealed is the scarcity of quality studies and studies that use consistent categorizations of interventions when reporting on the efficacy of interventions for dementia caregiver's pre-loss grief. Conclusions include the acknowledgment of the pressing need to assist caregivers as more and more spouses find themselves in a caregiving role that may exceed their skill level and capacity to cope. Recommendations for pre-loss interventions are offered.

Key Words: Dementia Caregivers, Dementia Grief, Anticipatory Grief, Pre-loss Grief, Dementia Grief Models

Table of Contents

Acknowledgements.....	ii
Dedication.....	ii
Abstract.....	iii
Chapter 1: Introduction.....	6
Background and Scholarly Context	6
Purpose of this Study	8
Importance of this Study.....	9
Scope of Study	13
Research Questions.....	13
Definition of Terms.....	13
Ambiguous Grief	13
Anticipatory Grief.....	14
Bereavement	14
Care Recipient.....	14
Complicated Grief.....	14
Dementia.....	15
Dementia Caregivers.....	15
Dementia Grief.....	15
Disenfranchised Grief.....	16

Grief.....	16
Mourning.....	16
Chapter 2: Literature Review.....	17
Introduction.....	17
Dementia Caregiving: The Costs.....	17
Grief in Dementia Caregiving.....	18
Connections: Dementia Grief and Complicated Grief in Bereavement.....	27
Perceived Burden.....	31
Caregiver Characteristics – Demographics.....	32
Depression and Preparedness.....	33
Chapter 3: Grief Models Framework, Summary, Recommendations.....	37
Grief Models, Frameworks, Assessment Tool.....	37
Grief Intervention Studies.....	42
Summary.....	47
Intervention Recommendations.....	49
References.....	51

Spousal Dementia Caregivers:

Interventions in Pre-Loss Grief to Mitigate Post-Loss Complicated Grief

Chapter 1: Introduction

Background and Scholarly Context

Dementia is a neurological disorder that affects cognitive functioning. While there are reversible dementias Alzheimer disease, which accounts for 60% of dementia diagnoses, is irreversible (Alzheimer Society of BC, 2017). As of 2016, there are an estimated 564,000 Canadians living with Alzheimer or other related dementia (ADRD) with 85% of them depending on family members, friends, or neighbours for informal care. Each year, 25,000 new cases of dementia are diagnosed, which increases the number of dementia sufferers by 66% every 12 months (Alzheimer Society of Canada, 2017). Alzheimer disease and related dementias are the eighth leading cause of death in Canada (Statistics Canada, 2017).

While Alzheimer disease is the dementia with the most name recognition, there are over 50 different types of dementias, terminal brain diseases all, that greatly affect everyone involved, the diagnosed, family members, and friends on emotional, social, physical, relational, psychological, and economic levels (Madsen, Birkelund, 2013, Alzheimer Society of Canada, 2017, Blandin & Pepin, 2016).

There is no cure for ADRD and the course of a dementia can span 20 years or more although the average length of time between diagnosis and death runs four to eight years (Alzheimer Society of Canada). ADRD have been described as “death through a thousand subtractions” (Anderson, 2008, in Alzheimer Society of Canada brochure, 2015, p. 2), which aptly describes the stripping away process Dementia caregiver witness as the disease slowly shuts down the dementia patient’s brain and robs them of their ability to reason, speak, or locate

their memories. They become absent yet present, in need of care and nourishment yet no longer able to grow or interact with those around them; it is no wonder that for many caregivers and family members grief is an embedded part of their experience (Alzheimer Society of Canada, 2017). The dementia caregiver experience has previously been identified as being unique from other long-term caregiving experiences owing to the ongoing and unpredictable emotional upheavals and losses all along the disease trajectory (Alzheimer Society of Canada, 2017; Supiano, Andersen & Haynes, 2015; Richardson, 2010, Robinson, Clare, & Evens, 2005; Madsen & Birkelund, 2013), but researchers have only recently started to look closely at the impact pre-death losses and grief have on dementia caregiver' experience and connect those impacts with caregiver's ability to make post-death adaptations (Silverberg, 2017). Tomarken et al (2008) add that to understand the dementia caregiver experience all phases of the disease from pre-diagnosis to post-death and beyond must be considered in a context where pre and post-death grief are understood to be phenomena unique from each other and from other psychiatric diagnoses.

Poor post-death adaptation has been conceptualised as complicated grief (Boss, 1999) and, more recently, as prolonged grief disorder (PGD) (Prigerson, 2010, 2011) which approximately 20- 30% of dementia caregivers experience after the death of their care recipient (CR) (Holland, Currier, & Gallagher-Thompson, 2009; Schulz, Boerner, Shear, Zhang, & Gitlin, 2006; Supiano, Haynes, Pond, 2016). Several elements of pre-loss grief have been identified in the literature as being connected to, or part of, complicated grief outcomes including anticipatory grief, ambiguous loss, chronic sorrow, disenfranchised grief, non-finite loss (Schultz & Harris, 2011), and prolonged grief (Peacock, Hammond, Forbes, 2014; Tomarken, Holland, Schachter, Vanderwerker, Zuckerman, Nelson, Coups, Ramirez, & Prigerson, 2008; Shear, Boelen, &

Niemeyer, 2011; Supiano, Burns, Haynes & Pond, 2017). Higher levels of pre-death grief have been linked to post-death complicated grief outcomes for dementia caregivers (Blandin & Pepin, 2016; Boss, Roos, & Harris, 2011) suggesting that dementia caregiving and post-death bereavement adaptation would benefit from clinical interventions that address “caregiving and bereavement as one, continuous, chronic, stressful situation” (Silverberg, 2017, p. 217), aimed at reducing levels of burden and stress pre-death in order to reduce levels of post-death complications in grief and depression (Hebert, Dang, & Schulz, 2006; Tomarken et al, 2008).

Purpose of this Study

The ultimate goal of this thesis is to put forth informed and well-supported recommendations for dementia grief interventions that are aimed at alleviating the impact of the unique pre-death grief and loss experiences dementia caregiving that, for some, contribute to problematic bereavement outcomes. To do this several topics of investigation are included in a review of the present literature to discover what is presently known about dementia caregiver experiences of grief and loss during the course of their caregiving “career” - a trajectory that can run from pre-diagnosis to three years after the death of the CR (Arruda & Paun, 2017; Boss, Roos & Harris, 2011; Madsen & Birkelund, 2013); how grief affects caregivers’ psychosocial, emotional, physical, and financial well-being; how pre-death grief may be connected to caregiver post-death grief difficulties such as complicated grief (Prigerson, 2010, 2011); what dementia caregiver grief models exist and how or if they have been utilized in determining best practices for caregiver pre-loss grief interventions.

In addition to offering therapeutic intervention recommendations for practice this thesis also aims to raise the awareness of counsellors, dementia support workers, and dementia

caregivers and partners in the roles and responsibilities, stressors, and possible bereavement outcomes involved in dementia caregiving.

Importance of this Study

As of 2017 there are approximately 500,000 Canadians with dementia and 85% of them are being cared for at home by family members (Alzheimer Society of Canada, 2010). As McCourt, McLennan, Somers and Krawczyk (2017) report, professional services for support are “fragmented and not evenly available across the country” (p. 231) while health-care professionals may be limited in their training and understanding of dementia and dementia care. Meanwhile dementia caregiver report a higher rate of chronic physical and psychological distress than non-caregivers including a decrease in life satisfaction and well-being due to increased depression, fatigue, stress, burden, family conflict, guilt, anger, isolation, loneliness, and grief due to experiencing nearly twice the amount of loss caregivers to those with a non-dementing diseases experience (Ross & Dagney in MacCourt et al, 2017).

My own experience as a Support and Education Coordinator (SEC) and First Link Coordinator for the Alzheimer Society of BC confirmed, for me, the need for therapeutic services targeted at dementia caregiver grief as I and other staff were at a loss when a grief referral was needed prior to the death of the CR. Interestingly, while Alzheimer Society SECs are trained as support workers rather than therapeutic counsellors, mental health professionals and physicians often refer caregivers in need of mental health support to the society for lack of knowing where to find trained and knowledgeable therapeutic counsellors and services for this demographic.

In my personal life as my mother’s primary caregiver after her AD/DRD diagnosis I realized, long after her passing, that there was little information, discussion, or recognition of the

grief running through and beneath my caregiving experience. MacCourt et al (2017) acknowledge this when they point out the absence of policies and practices detailing best practices for supporting dementia caregivers as does Silverberg (2017) when she speaks of her own discovery, as a dementia caregiver and clinical social worker working with caregivers, that grief is often not addressed nor are grief interventions used in practice with dementia caregivers. Silverberg and others have observed that social workers and medical personnel often neglect grief when assessing dementia caregivers for depression and stress (Sanders and Saltz in Silverberg, 2017; Tomarken et al, 2008; Chan et al, 2010).

Government services such as Health BC and the Ministry of Health acknowledge that dementia caregiving can be a very a difficult, stressful, and tiring job where “the demands of caring for a person who has dementia may cut off caregivers from friends, leisure activities, and other responsibilities ... [while] the physical and emotional strain of caregiving can make [caregiver’s existing health] problems worse. Fatigue, depression, and sleep problems commonly develop, and caregivers often carry an added emotional burden of feeling worried, guilty, and angry about taking care of the person.” (Healthlink BC, 2016, para. 1). It is unfortunate but not unusual that grief, a central feature of dementia caregiving, is not mentioned in this description.

In recognition of dementia caregiver’ needs and the lack of targeted services one of the main objectives of the Canadian National Dementia Research plan is to explore services and therapies for dementia caregivers and others to improve or maintain their health and wellbeing and/or quality of life (Alzheimer Canada, 2017). This thesis aims to contribute to this initiative through a literature review of dementia caregiver grief and loss experiences with an emphasis on the pre-death grief factors and possible links to post-death complicated grief or prolonged grief

disorder (PGD). The importance of addressing complicated grief/PGD is reflected in Parkes and Prigerson's (2009) findings that PGD is more common than delayed, inhibited, or distorted grief, meets all criteria for a mental disorder, and has been shown to respond to the right treatment. Their study contributed to the inclusion of PGD in the DSM-V (2013).

A review of current caregiver grief model frameworks along with discussion as to their suitability as guidelines for dementia caregiver pre-death grief interventions can also be found in this document. This is in aid of the intent for this document to increase the knowledge and awareness of counsellors, dementia support workers, and dementia caregivers of issues around grief, loss, and bereavement over the dementia disease trajectory and interventions that may help caregiver's process pre-loss grief and, perhaps, decrease the incidence of post-death complicated grief or PGD.

Situating the Author

I have long been aware of the emotional, physical, cognitive, and practical intricacies involved in dementia care. For 10 years I was the primary caregiver for my mother who was diagnosed with vascular dementia in her late 60s. At that time I did not seek out the advice or services of professionals or the Alzheimer Society of BC but later, after my mother had died from complications of her brain disease, I began to volunteer with the society as a way to share the knowledge I had gained as a caregiver and I continued to do this as a Support and Education Coordinator, First Link Coordinator for the Alzheimer Society of BC. Accumulatively I spent eight years working directly with dementia caregivers and their CRs in one-to-one meetings, support groups, doing phone support, and in psycho-education classes where I observed, and was told by caregivers themselves, that in some areas the needs of these caregivers were not being

adequately met. One area in particular that resonated with me was grief and loss—in part because my own caregiving years were marked by a series of losses I did not know then how to understand, process, or contextualize, and in part due to the frequency with which the topic came up or there were recognisable symptoms of grief in the caregivers I was seeing.

At the same time as I began to work with the Alzheimer Society I also began to volunteer at my local Hospice Society facilitating bereavement groups. I now realize I was looking for ways to understand my own dementia caregiver experiences in relation to my losses and grieving processes. Working with a variety of people struggling with their grief as well as with dementia caregivers before and after the death of their CR gave me a depth of understanding I am grateful for. During this time I was also studying grief and loss as part of my Master's program in counselling psychology which gave me a solid understanding of the history of thinking on the topic of grief. When I came across the Two-Track Bereavement Model (Rubin, 1999) I recognised it as a possible framework for treating dementia caregiver pre-death grief despite it being a post-death grief model. Further research revealed that others had had similar thoughts and that the dementia caregiver literature had recently moved beyond looking to post-death bereavement models such as the Two-Track model to newly-developed grief models that directly address the elements involved in caregiver's pre-death grief. As my post-graduate plans include working with dementia caregivers I could not pass up the opportunity to use my thesis to increase my awareness about caregivers pre-loss grief, connections to complicated grief in bereavement, and possible pre-loss interventions that could mitigate both pre and post-death complicated grief.

Scope of Study

While this literature review focusses on spousal dementia caregiver grief before and after the death of the CR it is not within the scope of this thesis to examine dementia caregiver grief as it particularly pertains to gender, culture, orientation, or relationship status with care recipient (although gender and relationship is touched on). It must also be said that this document does not seek to pathologize grief. While for many of us losing a loved will be the most stressful experience we will have most of us will not suffer any lasting mental or physical impairments (Worden, 2009, Parkes, 2011). However, 20 - 25% of dementia caregivers will experience grief complications before and/or after their charges' death and it is this phenomenon that is addressed here in an attempt to understand and therapeutically address these complications (Holland, Currier, & Gallagher-Thompson, 2009; Schulz, Boerner, Shear, Zhang, & Gitlin, 2006).

Research Questions

The questions that guide this literature review are:

- 1) What do we know about dementia caregiver grief prior to after the death of the care recipient?
- 2) What pre-death grief factors may be linked with dementia caregiver's post-death complicated or prolonged grief?
- 3) Are there grief models that include the dementia caregiver's experience?
- 4) What do we know about the efficacy of interventions for the therapeutic treatment of pre-death grief in dementia caregivers?

Definition of Terms

Ambiguous Grief

Defined here as a type of caregiver grief reaction arising from the experience of witnessing the ever-declining changes in a care-recipient's cognitive and behavioural abilities due to dementia. When a loved one is both "here" and "gone" at the same time, the inherent ambiguity of the situation causes a frozen grief that is difficult to resolve (Boss, Roos, & Harris, 2011). What's more, when there is no "official verification of death" there is no closure, rituals of support, or resolution of grief (Boss, 1999, p. 137).

Anticipatory Grief

Anticipatory grief has been used interchangeably with pre-death grief and pre-loss grief but is used here as a particular concept referring to the complex "phenomenon encompassing the processes of mourning, coping, interaction, planning, and psychosocial reorganization" arising out of the awareness of impending loss or losses as well as associated "losses in the past, present, and future" (Rando, 1986, p. 24).

Bereavement

Bereavement has historically been conceptualized as a reaction to the death of a loved one (Zisook & Shear, 2009) but is often paired with the word "grief" or, as in this document, bereavement is used interchangeably with the word grief when referring to post-death grief. Recently bereavement before death in dementia caregiving has been captured in the term "pre-death grief" (see definition of this term below).

Care Recipient

Care recipient (CR) here refers to those with a dementia diagnosis whose spouse, partner, family member, or friend is their primary caregiver and, often, advocate.

Complicated Grief

Also referred to as Prolonged Grief Disorder and pathological or traumatic grief in the literature (Jordan & Litz, 2014). In this document the term complicated grief is used to refer to both pre and post-death grief involving intense yearning, difficulty accepting the disease or the death, excessive bitterness, numbness, emptiness, feeling uneasy about moving on, and a depressive outlook (the future is bleak); symptoms are understood to be distinct from depression and anxiety (Tomarken et al, 2008).

Dementia

Dementia ADRD (Alzheimer Disease and Related Dementias) are general terms used in the literature and in this paper to denote the many diseases that can cause dementia symptoms, including Alzheimer's disease, Vascular dementia, Lewy Body disease, head trauma, Frontotemporal dementia, Creutzfeldt-Jakob disease, Parkinson's disease, and Huntington's disease - all of which can have similar and overlapping symptoms. The term dementia is also used here to capture the many symptoms experienced by those with progressive brain disorders that may or may not include difficulties with language, thinking, problem-solving, memory losses, and changes in mood or behaviour severe enough to affect the ability to perform everyday activities.

Dementia Caregivers

Dementia caregivers can be family members or friends, formal, informal, or paid professionals. This paper is primarily concerned with informal spousal dementia caregivers. Dementia caregivers or care partners are most often unpaid family members who identify themselves as the care recipient's primary care support and advocate when the diagnosed person lives at home and, for many, after they have been placed in a care facility.

Dementia Grief

The term dementia grief refers specifically to dementia caregiver' pre-death grief and refers to the wide range of emotional and physical responses caregivers may have in response to real or "perceived losses" in the CR over the course of the disease and before the death of the recipient due to "(a) care recipient's psychological death, which is asynchronous with physical death; (b) a lengthy and uncertain disease trajectory; (c) compromised communication between the person with dementia and the family caregiver; and (d) changes in relationship quality, family roles and caregiver freedom" which all contribute to caregiver burden, depression and maladaptive coping (Lindauer and Harvath, 2014, p. 8).

Disenfranchised Grief

Greif experienced when a person sustains a loss that is not or cannot be socially sanctioned or recognized, or mourned publicly which, in effect, complicates the griever's ability to mourn her or his loss (Doka, 2017).

Grief

Greif is generally understood to be a normal and multifaceted emotional reaction to real or perceived losses that can involve physical, emotional, and cognitive symptoms for the griever (Boss, 1999, Schut & Stroebe, 2008, Arruda & Paun, 2016). In this document grief is used as a general term to describe caregiver's emotional responses to post-death losses while *dementia grief* is used to refer to the pre-death losses specific to the dementia disease trajectory.

Mourning

Mourning differs from grief (internal cognitive and emotional reactions) in that it is the outward expression of grief. Mourning is the active, often public, expression of grief through ritual, ceremony, monument creation, and such that serve to help the mourner and their community process a loss and reconcile grief (Wolfelt, 2014).

Chapter 2: Literature Review

Introduction

This chapter is divided into three discussion sections: Section I looks at what is known about dementia caregiver' experiences in general; Section II moves on to grief and loss specifically, focusing on differences between general caregiver grief and grief relating to dementia caregiver experience including specific types of grief; Section III looks at the variables in caregiving that have been found to contribute to grief complications.

Dementia Caregiving: The Costs

Spousal dementia caregivers experience a myriad of emotional, physical, financial, and relational upheavals, reversals, and losses over the trajectory of their partner's brain disease (Chan et al, 2010; Doka, 2016; MacCourt et al, 2017). While Young Onset or Early Onset Dementia can be diagnosed in people as young as 55 years old, most dementias are diagnosed in people 65 years and older (Alzheimer Society, 2017). What's more, the average span of time between a dementia diagnosis and the death of the CR can stretch out over eight to 10 years (Alzheimer Society of Canada, 2017), which means caregiving may well become a later-in-life "career" that unexpectedly takes caregivers away from their paid or volunteer work, their families, friends, and life as they know it as they head into their senior years (Aneshensel, Pearlin, Mullan, Zarit, & Whitlatch, 1995 in McCourt et al, 2017). The personal costs associated with caregiving a family member with a terminal illness have been well documented and while family caregivers share many experiences across caregiving spectrums, dementia presents caregivers with unique challenges (MacCourt et al, 2017; Blandin & Pepin, 2016; Chan et al, 2013; Noyes et al, 2010). These include experiencing pre-death levels of stress equal to or greater than those in post-death bereavement (Noyes et al, 2010), an elevated risk of developing chronic physical and

psychological symptoms, increased family conflict, fatigue, anger, guilt, frustration, depression, sense of burden, and isolation—all of which can lead to a decrease in life satisfaction and well-being (Arruda and Paun, 2017; Chan et al, 2013; Blandin and Pepin, 2016; MacCourt et al, 2017; Noyes et al, 2010, Meuser and Marwitt, 2001). In addition to the prolonged caregiving demands of a progressive illness for which there is no cure, and the lack of services such as Hospice or affordable private care, placing a loved one into long-term care also leads to emotional turmoil, grief and bereavement (Arruda & Paun, 2017).

For a dementia caregiver emotional and psychological upheaval and grief can be constant companions throughout day to day life and last from before diagnosis to as many as three years after the death of the CR (Arruda & Paun, 2017; Blandin & Pepin, 2016; MacCourt, McLennan, Somers, & Krawczyk, 2017; Meuser & Marwit, 2001). This means that many dementia caregivers exist in the realm of chronic grief for years (Noyes et al, 2010, Arruda & Paun, 2017). To get some understanding of the dementia caregiver journey and of how we might better support them we must delve into caregiver grief so as to fully appreciate both the role grief plays before the death of the CR and the impact it can have on bereavement outcomes afterwards. It is to this complex and newly emerging topic we turn next.

Grief in Dementia Caregiving

When we think of grief and loss we often think in terms of finite losses, as when we lose someone through death, rather than in terms of living losses such as life-altering changes and the ongoing adaptations they call for (Harris, 2009). In much the same way many of the studies on caregiver burden, stress, and coping written since the early 1980's fail to consider grief in any meaningful way (Meuser & Marwitt, 2001; Blandin & Pepin, 2016; Arruda & Paun, 2017). Only recently have theoretical grief models and the literature on caregiver grief moved beyond post-

death bereavement models such as the Dual-Process Model of Bereavement (Stroebe & Schut, 1999) and stress-process models of caregiving that conceptualize elements of caregiver burden, such as grief, as symptoms rising out of “characteristics inherent in dementia and stress in the course of caregiving” (Noyes et al, 2010, abstract). More recent caregiver grief models such as Meuser & Marwitt’s (2001) Stage Sensitive Model, Silverberg’s (2007) 3-A Grief Intervention Model, Noyes et al (2010) Stress Model of Dementia Caregiving, and Blandin & Pepin’s (2016) Dementia Grief Model consider grief a process separate from, but related to, caregiver burden. A discussion of these grief models can be found in Chapter 3.

Lindauer & Harvath (2014) added to grief recognition when they tested and defined an emerging concept: dementia caregiver pre-death grief, or dementia grief – which they found to be a robust and “maturing concept meaningful for the scientific community and general public” (p. 2203). Here caregiver pre-death grief in dementia is defined as “the emotional and physical response to the perceived losses in a valued CR [where] caregivers experience a variety of emotions...that can wax and wane over the course of a dementing disease, from diagnosis to end of life” (p. 2203). Dementia grief overlaps with anticipatory grief but is different from anticipatory grief in that it captures the disruptions in communication, awareness impairments, and lack of opportunity for conflict resolution and/or co-grieving that are unique in dementia caregiving (Chan et al, 2013; Blandin & Pepin, 2016; Lindauer & Harvath, 2014). In this way the term dementia grief captures reactions to the living losses of dementia in a way that the other five identified grief patterns common to dementia caregiving do not. These grief and loss patterns, or reactions are: Chronic Sorrow, Ambiguous Grief, Relational Deprivation, Anticipatory Grief, and Disenfranchised Grief and all been identified as being particularly salient

to problematic grief trajectories for some caregivers (Noyes et al, 2010; Harris & Gorman, 2011; Boss, 2012; Lindauer & Harvath, 2014; Blandin & Pepin, 2016; MacCourt et al, 2017).

Before we look closer at each of these grief patterns it is important to bring the concept of nonfinite loss into the picture. While it is not included here as a main topic it must be acknowledged that each of the above grief/loss patterns are related to, or fit under, the umbrella term of nonfinite loss - a critical concept in grief literature that “refers to losses that are contingent on development; the passage of time; and on a lack of synchrony with [the] hopes, wishes, ideals, and expectations” a CR and/or caregiver may have developed over a lifetime (Bruce & Schultz, 2001, p. 7). As we will see chronic sorrow is considered to be a common response to nonfinite loss (Bruce & Schultz, 2001; Schultz & Harris, 2011) and ambiguous loss is also connected in that it involves a lack of clarity or awareness of the nature of loss or losses (Boss, 2010, Boss, Roos, Harris, 2011). Relational deprivation involves changes in the quality and substance of the emotional relationship between caregiver and recipient over time which, as the disease progresses, involves a lack of clarity and understanding around relational and social roles (Boss, 2010, Braun, Scholz, Bailey, Hornung, Martin, 2009). Disenfranchised grief is grief over losses that cannot be “openly acknowledged, socially sanctioned, or publicly shared” (Doka, 2016, p. 7) which can block understanding, validation, and acceptance. Although anticipatory grief is not considered a response to nonfinite loss *per se* it is related to nonfinite losses in ADRD due to the long and often unpredictable trajectory of the illness that increases ambiguity around guilt, anger, frustration and the future – all primary features of anticipatory grief (Chan et al, 2010).

Clearly, the ADRD trajectory presents a caregiver with multiple loss conundrums around how, when, and the extent to which the other is present or is lost leaving caregivers unsure and

unsettled about the nature of their relationship to their partner and to themselves (Boss, Roos, & Harris, 2011). Therefore the impact of nonfinite losses should not be minimized. As Bruce and Harris (2001) warn, nonfinite losses can have a powerful negative effect on one's personal narratives about the meaning of life and disrupt a lifetime of expectations shaped by family values, societal expectations, and personal decisions which requires adaptation and the creation of a new narrative.

Returning to the five non-death or living-loss grief concepts that are the focus of this section the question arises - why these grief concepts? Suffice it to say here that these concepts have been identified in the literature as pre-death aspects of grief and loss that have been linked to post-death complicated grief and therefore should be targeted for interventions aimed at mitigating complicated grief post-death (Nielsen et al, 2016; MacCourt et al, 2017; Chan et al, 2010; Boss et al, 2011; Kale, 2015; Tomarken et al, 2008; Silverberg, 2008). Things are not as clear cut as this sounds however as the literature reveals varying findings/discussions on which elements of these five themes has the greatest impact on caregiver grief outcomes.

Chronic sorrow. In the context of caregiver dementia grief chronic sorrow refers not only to the previously discussed prolonged timeframe of a long-term dementing disease but also to the distinct grief reaction that arises from losses that are not finite but change in such a way as to disable a caregiver's ability to concretely mourn losses as they occur. In most post-death grief situations grief dissipates over time, but in dementia caregiving the "repeating pattern of recurring and new losses of increasing severity" (Rossheim & McAdams, 2010, p. 478) can continually trigger grief while simultaneously hindering a finite resolution of non-death losses which leads, for some, to ongoing grief, depression, and anxiety. Also feeding into this negative grief loop are the overwhelming responsibilities and endless tasks involved in caregiving which

may be taken on incrementally without the conscious decision to “give up my life for his” as one caregiver put it to this writer (personal communication, 2016). These tasks are often performed without boundaries, breaks, or the training, skills, awareness, and support necessary for psychological, emotional, and physical well-being (Rossheim & McAdams, 2010).

A specific aspect of chronic sorrow as it relates to dementia care has to do with the ambiguous nature of loss with this disease. Boss, Roos, and Harris (2011) found that while ambiguous grief and chronic sorrow are similarly described in the literature and are found in similar loss experiences, there is a trajectory where ambiguous loss may lead to chronic sorrow since it is the “lack of clarity” as to exactly what has been lost - a hallmark of dementia loss - that leads to the “unrelenting cycle of disequilibrium and despair, temporary adaptation and re-entry into uncertainty” that marks chronic sorrow (Boss, Roos, Harris, 2011, p. 166). Ambiguous grief and its relationship to chronic sorrow are explored further below.

As previously stated, depression and anxiety are distinct aspects of chronic sorrow but it should also be noted that these conditions, when associated with chronic sorrow, may present differently than in more typical contexts (Rossheim & McAdams, 2010). For example, as a psychiatric disorder depression is identified by symptoms such as sadness, self-deprecation, irritability, hopelessness, apathy, insomnia, social withdrawal, and impaired functioning (DSM-V-TR, 2000), but a depressed caregiver may present as high-functioning due to the nature of caregiving and the inherent responsibility involved. Rather than withdrawn the carer may be an energetic and high-profile advocate for the loved one yet also be depressed. As this example suggests, the combined features of grief, anxiety, and depression in the context of chronic sorrow can present in distinctive ways that call for insight and specialized counselling approaches (Roos, 2002, as in Rossheim & McAdams, 2010).

Ambiguous Loss. The term ambiguous loss was coined in the 1970s by Pauline Boss to describe a certain type of loss reaction she observed while doing family therapy. In families where the father was physically present but psychologically and emotionally absent, family members reported feelings of loss related to the juxtaposition of physical absence with psychological presence (as with kidnapping, adoption, or incarceration) and/or their physical presence existing alongside psychological absence (as with dementia or other cognitive impairments) (Boss, 2010, 2011). The ambiguity arises out of the absence of a clear understanding of relational or social roles when the extent to which the other is present or is lost is unclear or changes over time, leading others to question their own sense of identity (Boss, Roos, & Harris, 2011).

Both ambiguous loss and chronic sorrow arise out of losses that are ongoing, not easily defined or recognized, and are often “intangible in manifestation” (Boss, Roos, Harris, 2011, p. 169) as when a loved one is psychologically absent but physically present, or when there is role confusion as when the care recipient’s cognitive abilities and awareness change to a degree that creates conflict and uncertainty for the dementia carer - are they a parent or a spouse? A protector or a partner? If they are no longer recognised does a relationship still exist? And each time the recipient’s functioning returns to (near) normal hope for re-connection and recovery may be renewed, holding grief at bay and making it less likely it will be expressed or processed; possibly preventing the caregiver from reaching closure through mourning rituals and supports (Boss, 2010, Holley & Mast, 2009; Boss, Roos, Harris, 2011).

Although ambiguous loss and chronic sorrow are two separate concepts—the focus of ambiguous loss being losses in another and the focus of chronic sorrow being on one’s self or on the loss of another—the two can and do overlap in the case of dementia caregiving with

ambiguous loss often leading to chronic sorrow as ongoing losses create cycles of upheaval, confusion, sadness, and acclimatization (Peterson & Bredow, 2004). Because this paper is concerned with dementia caregiver non-death grief and connections to post-death complicated or prolonged grief disorder (Prigerson et al, 2010) it's important to note that ambiguous loss and chronic sorrow also align with prolonged grief disorder in that the three concepts encompass somatic symptoms, depression, anxiety, and persistent and ongoing relationship difficulties – although length of time is not a criteria for ambiguous loss or chronic sorrow as it is for prolonged grief disorder (Okun & Nowinski in Boss et al, 2011).

In addition, because ambiguous loss is a relationally-based condition caused by disruptions, or the threat of disruptions, to the attachment between caregiver and recipient and to the caregiver's identity (Boss, 2012), there is a strong connection between ambiguous grief and relational deprivation (discussed later in this chapter). Harris (2011) also connects symbolic loss – losses arising out of lost hopes and dreams, dashed expectations about life and relationships, and realities that corrupt personal myths about identity – with ambiguous grief and disenfranchised grief.

Disenfranchised Grief. Has to do with losses that are hard to explain, understand, or define but essentially refers to grief that is inhibited on any or all of three counts:

- 1) Social rules, folkways, and formal statements (company policies for example) that dictate what is acceptable in grief, which losses can be grieved, how they can be grieved, who they can be legitimately grieved by, and who can receive sympathy and support (McCourt et al, 2017, Doka, 2107). These rules typically don't include the psychological and non-death losses that come with ADRD so these losses are often discounted or go unrecognized.

- 2) A main source of disenfranchised grief in ADRD has to do with the erosion of the quality of the relationship between care giver and recipient which, at some point, prevents caregivers and care partners from grieving together or resolving past and current issues (Meuser & Marwit, 2001). Coping with the ensuing confusion and chaos around “critical sources of identity and support” (McCourt et al, p. 232) such as changing role definitions, intimacy, control, social interaction, transparency with self and others, health status, and communication can be overwhelmingly distressing yet difficult to recognize before the bodily death of the care receiver, therefore grief symptoms are often treated medically or identified as something else, such as depression.
- 3) Grief is also disenfranchised due to the shame, secrecy, death anxiety and stigma associated with ADRD (Nielsen, Neergaard, Jensen, Bro, & Guldin, 2016; Silverberg, 2007; Doka, 2017).

Again, clarity about a grief concept is muddled when Ponder & Pomeroy (1996) point out that many aspects of disenfranchised grief relate to anticipated losses and should properly be considered anticipatory grief and MacCourt et al (2017) argue that witnessing the “gradual death of a loved one’s personality and memory” creates a form of grief that is unique and “distinct” from anticipatory grief (p. 321). Silverberg notes that while disenfranchisement is a concept separate from anticipatory grief, it does impede caregivers’ normal anticipatory grief trajectory and Nielsen et al (2016) agree when they say that disenfranchisement of anticipatory grief (conceptualized in their review as low levels of pre-preparedness) along with high levels of grief are associated with complicated grief after bereavement.

Anticipatory Grief. Anticipation and ambiguity about the future, anger, frustration and guilt are core features of anticipatory grief with dementia caregiver experiencing “a particularly tragic

variant of' anticipatory grief (Holley & Mast, 2009, p. 388) owing to the dual decline of cognitive and physical abilities of loved ones. In their exhaustive literature review Chan et al (2010) found that anticipatory grief for dementia caregiver is greatest in moderate to severe stage dementia when the person with dementia is often institutionalized, but Garand et al (2012) in their study examining anticipatory grief in a sample of relatively new family caregivers, found that new caregivers who were living with the CR were not only experiencing high levels of anticipatory grief but also had a higher level than caregivers who did not live with the diagnosed. This suggests that for some anticipatory grief is also infused at the earlier stages of dementia.

Anticipatory grief is often triggered when a terminal illness has been diagnosed. AD/DRD are not only terminal but there are no known treatments to stop the disease trajectory, nor is it possible to be sure how long the patient will live (Alzheimer Society of BC, 2017) which brings anticipatory grief and ambiguous loss together in a very difficult combination. As described previously, cognitive decline, flat affect, and the lack of insight the CR usually experiences along with the caregiver's loss of personal autonomy and needing to cope with increasingly difficult, often startling, behaviours makes their grieving together difficult and, at the same time can thwart completion of individual tasks of grieving (Worden, 1991) due to a lack of clarity as to exactly what is being anticipated. Given the situation it is not surprising that Chan et al (2010) found several studies citing a connection between anticipatory grief and caregiver's increasing depression which underlines the importance of targeting distressing anticipatory grief for intervention.

Relational Deprivation is a concept that acknowledges the loss of relational reciprocity between caregiver and partner as the disease progresses. Caregiver's level of relational deprivation typically increases with the recipient's decreasing level of cognitive impairment

which, in turn, can elevate caregiver levels of loneliness, depression, stress, alexithymia, and anxiety (Bauer, Maddox, Kirk, Burns, & Kuskowski, 2001; Floyd, 2014). While the concept is grounded in a caregiver stress/burden model rather than a grief model this description helps us to understand it in terms of grief and loss and how it relates to both ambiguous loss and disenfranchised grief (Bauer et al, 2001; Garand et al, 2012). For example, on professional, antidotal, and personal experience levels, it has been demonstrated to me that a person with dementia can alternate between engaged, resistant, passive, aggressive, and apathetic relational behaviours. This complicates relationship status while adding ambiguity and stress. Meanwhile these types of changes, or losses, can be difficult to identify, particularly by those outside the relationship, making it possible for the impacts of these losses to be disregarded and/or disenfranchised as well. Changes in sexual intimacy, whether it be a lack thereof, an unwanted increase in demand, or confusion as to whether a partner is still able to responsibly consent may also be difficult to disclose to others or admit to self (Alzheimer Society of BC, 2016).

Connections: Dementia Grief and Complicated Grief in Bereavement

When accounting for these five identified grief patterns and the emotional, psychological, physical and instrumental impact they can have on dementia caregiver it is important to repeat that grief in dementia is a normal but complex reaction to losses before and after death and most caregivers are able to adapt and “recover” with little help. However, it is also the case that for many caregivers "the right help, given at the right time, for the right problem, will reduce the risk of lasting physical and mental damage” (Parkes, 2011, p. 2; Chan et al, 2010; McCourt et al, 2017). When it comes to helping these grievers it makes sense to this writer that matching the solution to the problem, as Parkes (2011) suggests, can be a valuable approach. Therefore not only do we need to understand pre-death grief processes we must also understand if and/or how

these processes contribute to or predict complicated post-death grief outcomes. It is to this topic we turn to now.

It is significant that up to 30% of dementia caregivers experience poor bereavement outcomes (Holland, Currier, & Gallagher-Thompson, 2009; Schulz, Boerner, Shear, Zhang, & Gitlin, 2006; Supiano, Haynes, Pond, 2016). At least one study found that surviving caregivers of those with dementia, lung cancer, and renal failure consistently (at least 50% of the time) required increased bereavement services after the death of their loved (Jones, 2010). To reiterate, poor post-death adaptations have been conceptualized as complicated grief (Boss, 1999) and prolonged grief disorder (PGD) which Prigerson et al (2010; 2011) describe as intense yearning for the lost person, numbness, emptiness, difficulty accepting the death, excessive bitterness, difficulty moving on, and hopeless about the future; it is more common than delayed, distorted, or inhibited grief (Parkes & Prigerson, 2009). In this document the single term *complicated grief* is used to signify both complicated grief and prolonged grief disorder.

Caregivers from a wide range of caregiving situations who have difficulty with post-death adjustments have been well studied but pre-death complicated grief experiences received little attention prior to Tomarken et al's 2008 study of 248 caregivers of terminally ill patients where caregiver complicated grief is described as being distinct from depression and anxiety and independently associated with substantial morbidity. While there is no suggestion in the general caregiving grief literature that caregivers present with complicated grief any differently than any other bereaved individual there are variables specific to the dementia caregiving experience that are associated with a higher likelihood of complicated grief in bereavement. Identifying those in dementia caregiving roles who are at higher risk of developing complicated grief in bereavement enables appropriate pre-death interventions to reduce that risk (Hebert, Dang, & Schulz, 2006;

Tomarken et al, 2008; Boss, Roos, & Harris, 2011; Chan et al, 2012; Blandin & Pepin, 2016; Silverberg, 2017).

In their systemic review of 40 articles from the literature on predictors of complicated grief prior to the death of a significant other, Lobb, Janson, Aoun, Monterosso, Halkett, & Davies (2010) found that previous losses, trauma, psychiatric history, attachment style, and relationship to the deceased (marital closeness and dependency, kinship relationship) were primary predictors. In addition, factors associated with the death such as quality of caregiving, the dying experience, lack of preparation for the death, and high distress at the time of the death were identified as being significant predictors of complicated grief in the general caregiving population. These findings can be generalized to all caregivers and so to dementia caregivers. However, the focus of this literature review is on dementia caregiver variables that contribute to complicated grief in bereavement which offers a much smaller number of studies to draw upon. A search for studies on caregiver pre-loss grief and pre and post-loss complicated grief completed between 1997 to 2016 captured 31 studies in total: 11 account for caregivers of terminally ill family members, five look at caregivers in general, and 13 focus specifically on dementia caregivers. Of the 31 studies only 12 are concerned with pre-and-post death complicated grief variables specifically. This is not only reflective of the relative newness of complicated grief being defined as a distinct disorder it also demonstrates that caregiver research in the areas of dementia and grief is an emerging topic (Lobb et al, 2010). In general, studies that measured complicated grief used the Inventory of Complicated Grief (Prigerson et al., 1995) or the Prolonged Grief Disorder -12 (Prigerson et al., 2008) while the Meuser and Marwitt Caregiver Grief Inventory (2002) was the most often used tool for grief, although four studies used Sanders' et al (1985) Grief Experience Inventory (Chan et al, 2012).

Research on caregiver grief and bereavement outcomes generally prescribe to one of three theoretical perspectives: the resource depletion/cumulative stress or “wear & tear hypothesis” (Boerner & Schulz, 2009, p. 2) where an accumulation of stressors - be they emotional, physical, psychological, and/or economic - over the course of caregiving deplete coping resources and result in poorer adjustment in bereavement. The relief/stress reduction perspective (Burton et al, 2008) comes from the opposite direction positing that the death of the care receiver brings relief and improved mental health and health to the caregiver due to reduced responsibility and stress. The anticipatory grief theory is predicated on research identifying grief as a significant concern for caregivers before death and that grief work, or anticipatory processing of the death, while increasing stress before the death decreases stress afterwards which benefits the caregiver (Worden, 2009; Meuser & Marwit, 2002). While many dementia caregivers report feelings of relief after the death this is not generalizable to dementia caregivers in general as a subgroup of caregivers who report higher levels of psychopathology in bereavement consistently come up in studies (Holland, Currier, Gallagher-Thompson, 2009). Even so, research on caregiver grief seems to support the relief/stress reduction and anticipatory grief perspectives for the bulk of caregivers whose symptoms decline after the death indicating that more research is needed to determine how well these perspectives fit for the 30% of dementia caregivers at risk for clinical depression one year post-death as well as those who experience complicated grief (Schulz et al, 2006).

As has been said, dementia caregivers differ from those caring for people with other terminal illnesses due to the greater emotional impact of, for example, an uncertain trajectory, the withering away of a significant other’s autonomy and independence and the need to make life-changing decisions for, and at times, despite, the CR (Shuter, Beattie, Edwards, 2014).

Complicated grief risk variables relate to caregiver characteristics, psychological and emotional wellbeing, existential anxieties, and attachment style. An overview of the literature reviewed here suggests that the strongest predictors of complicated grief for dementia caregivers in bereavement have to do with caregivers' perceived burden, preparedness for the death, being a spousal caregiver, the level of care recipient's cognitive impairment, family conflict, depressive symptoms pre-death, and religiosity/spirituality. Of these perceived burden, caregiver characteristics, preparedness, and depressive symptoms seem most salient.

Perceived Burden

For example, in their study of 1,222 family caregivers (217 of whom experienced the death of their CR during the study), Schulz et al (2006) found that those who had high levels of pre-loss depressive symptoms and reported caregiver burden, including a more cognitively impaired CR, were more likely to report higher levels of complicated grief post-loss. These findings are in accordance with others who found aspects of burden such as higher levels of CR impairment (Baurer et al, 2001; Shuter et al, 2008), intensity of care (Shuter et al, 2008; Almborg, Grafstrom & Winbland, 2000), and changes in role function (Beery, 1997) were significantly associated with complicated bereavement outcomes. Interestingly, some studies found that those reporting more positive features of caregiving also experienced complicated grief (Beery, 1997; Bonnano et al, 2002; Schulz et al, 2006). These findings may indicate that positive and negative aspects of caregiving can coexist for some caregivers but another explanation may be found in studies where overly dependent caregivers or those with unstable or insecure attachment styles were found to be at risk of complicated grief (Lobb et al, 2010; Bonnano, 2012).

Another aspect of perceived burden has to do with professional and personal support. One 2008 study of complicated grief in dementia caregivers found that those who reported their

professional care as lacking and who felt unsupported or ignored were at higher risk (Shuter, Edwards, Sacres as in Ghesquiere et al, 2011). Similarly, a study focusing on 41 next-of-kin pre-death decision makers in an ICU were at greater risk of complicated grief if they did not feel their CR's physicians were supportive. This study also found that burden related psychological disorders were more common in spouse caregivers than in other next-of-kin relationships (Siegel et al, 2008). Caregivers with little family support or experiencing family conflict during CR illness (particularly if none existed before diagnoses) or whose family members did not accept the illness had more intense grief and increased complicated grief symptoms (Shuter et al, 2008; Kramer, 2010; Chiu, 2010). Looking at it from another perspective Vanderwerker and Prigerson (2004) found that caregivers with a good support network were at lower risk of bereavement complications.

Beery et al (1997) and others have found caregiver burden to be significantly associated with caregiver levels of depression and complicated grief. In their study comparing dementia caregivers who experience burden and burnout with those who do not, Almberg, Grafstrom and Winblad (2000) found that those reporting high burden and exhaustion had more depressive and complicated grief symptoms. Other contributors to burden that increase complicated grief include intensity of care and high caregiving involvement (Shuter et al, 2008) and higher CR level of cognitive impairment (Schulz et al, 2006; Shuter et al, 2008; Boerner et al, 2009).

Caregiver Characteristics – Demographics

Caregiver's individual characteristics also contribute to burden including whether caregiving is perceived as a burden or not. Pessimistic thinking and having experienced severely stressful events in life were predictors of complicated grief in a study of cancer caregivers (Tomarken et al, 2008) while in other studies caregivers' general psychological distress pre-

death, including anxiety and depression, led to higher bereavement grief symptoms (Kelly et al, 1999; Boerner, Schulz & Horowitz, 2004). Female spousal caregivers have shown higher risk for complicated bereavement than males (Siegel et al, 2008; Chiu et al, 2010; Gilbar, Ben-Zur, 2002) as do caregivers with lower education and income levels (Schulz et al, 2006). Caregiver attachment style is closely aligned with complicated grief. As Lobb et al (2010) discuss, complicated grief is considered to be an attachment disorder where “insults to a sense of security caused by weak parental bonding in childhood” present a vulnerability to the onset of complicated grief later in life (p. 690). Studies by both Silverman et al., 2001 and Vanderwerker et al., 2006 validate this view.

Existential issues such as a fear of death and religiosity or spirituality have been found to have an impact on grief reactions. Kramer et al (2010) found that CR’s fear of death did not affect caregiver’s complicated grief when hospice services were used but did so when they were not. Studies have also found that that religious beliefs and practices are very important to bereavement outcomes with more frequent attendance at services, meetings, or activities leading to less depression and fewer complicated grief symptoms (Herbert, Dang, Schulz, 2007; Kramer et al, 2010, Lobb et al, 2010). Metzger and Grey (2008) found that those able to make sense of the death experienced less distress following bereavement than those persons who were unable to make meaning or come to terms with the illness or death.

Depression and Preparedness

An important distinction to make is that coming to terms with the CR’s illness and/or death is not the same as feeling prepared for the death. Despite very long-term caregiving, dementia carers often report not being or feeling prepared. This finding is supported by a National REACH (Resources for Enhancing Alzheimer's Caregiver Health, 2006) study where

23% of caregiver participants indicated that they were not prepared for the death which was highly associated with complicated grief. Another study, looking at caregivers of terminally ill patients, also reported that 23% of participants felt the death was unexpected (Teno et al., 2004). Other studies have found that pre-loss depressive symptoms and low levels of pre-preparedness not only complicated grief outcomes but depressed and unprepared caregivers were in worse health, exhibited more depressive and anxiety symptoms, and were at higher risk of bereavement-associated morbidity than those who felt prepared (Barry, Kasl, & Prigerson, 2004; Herbert, Dang, & Schulz, 2006; Schulz et al, 2015; Nielsen et al, 2016).

While these findings surely indicate that a lack of preparedness takes a toll on caregivers' grief an important awareness piece is that it is often unclear as to what type of preparedness - instrumental, emotional, or psychological - is being measured or reported on. For example, in two studies preparedness was measured through the single self-report interview question: "to what extent were you prepared for the death?" with possible response choices of: "not at all, somewhat, and very much" (Barry, Stanislav & Prigerson, 2002, p. 450; Herbert, Dang & Shultz, 2006, p. 685). A clearer picture as to what a caregiver might mean when they report being unprepared, as well as what the associated variables might be (high levels of depression, ethnicity, education levels, income, CR pain levels) would increase the value of these findings and allow more clearly targeted grief interventions.

Overall, what we can take away from the literature an understanding that the dementia caregiver trajectory over time is often that as the disease advances so does dementia grief. The caregiver's health declines and their sense of burden increases (Holly & Mast, 2007). That pre-death grief is generally understood to be a psychological response to disruption in significant relationships (with the CR, family, friends, spiritual, and self-identity) and depression

(Silverberg, 2007; Blandin & Pepin, 2016). Risk factors for complicated post-death grief can be predicted prior to the death including situational factors related to preparedness and burden, caregiver characteristics such as gender and attachment history, interpersonal factors such as level of cognitive impairment of CR and level of social, emotional, spiritual, and professional supports. Although fixed variables such as age, gender, and some health trajectories cannot be modified the literature tells us that caregiver outcomes and adjustments in bereavement can be influenced by the quality of caregivers' experience and their ability to manage their pre-death grief reactions (Silverberg, 2007).

Limitations of this Literature Review

As has been stated, there have been few studies involving interventions for dementia caregiver grief, but a more serious limitation to reportage of the existing literature has to do with depth of studies, consistency, and categorization of interventions. For example, a recent review of the state of caregiver research in palliative care concluded that it is currently at a descriptive level with few interventions tested or found superior to usual care or control conditions (McGuire et al., 2012). In their 2017 systematic review and meta-analyses of the literature on dementia caregiver grief interventions Gaugler et al found that although there have been many attempts to translate evidence-based interventions for dementia caregivers into practice, the current state of the evidence for efficacy is problematic. Their look at 22 systematic reviews of the recent literature (2001-2015) revealed there is little consistency in how reviews are labeled or how interventions are categorized with varying or multiple categorizations of studies in some reviews and non-inclusion in others. In addition they found little uniformity in the levels of rigor involved in conducting these reviews as well as a low quality of evidence in the included studies.

An example of this is Selwood et al's (2006) review of grief interventions where only 10 of the 62 studies meeting their inclusion criteria was rated as being of top level quality.

Not only do these issues make overall assessments of intervention efficacy very challenging but they also work against accountability as to how or why interventions have met or not met efficacy goals (Gaugler et al, 2017). An attempt by this writer to determine how many of the 466 interventions described in the 22 studies included in Gaugler et al's review addressed caregiver grief, psychosocial support, or counselling directly was stymied due to there being insufficient information provided in intervention descriptions. Of those descriptions that are clear, or clear enough, only 64 interventions involved psychosocial and/or counselling elements and none are directly described as grief interventions. Clearly, as Gaugler and colleagues point out, there is a need for higher quality evidence as to the efficacy of dementia caregiver interventions. In the meantime, despite their limitations and "opaqueness" (p. 28) as to the actual effectiveness of individual interventions, professionals looking to translate or implement interventions for their clients must work with the study results, indications and conclusions we have to date. Towards that goal we move on to Chapter 3 where we first consider grief models or frameworks that particularly address dementia caregiver pre-loss grief and then move on to studies based on these models or frameworks. Interventions are identified, efficacy and outcomes are discussed. Section three brings the chapter to a close with discussion and intervention recommendations for practice.

Chapter 3: Grief Models Framework, Summary, Recommendations

Grief Models, Frameworks, Assessment Tool

Previously in this paper it was stated that early theoretical grief models were post-death bereavement models such as Rubin's (1981) Two-Track Model of Bereavement, which concentrates on the reorganisation of the relationship to the deceased, and the Dual-Process model of Coping in Bereavement which concentrates on coming to terms with a loss (Stroebe & Schut, 1999). Models addressing the pre-loss experience and subsequent reactions are dominated by stress-process models that account for the stress, burden, depression, and health changes caregivers experience in their caregiving role but largely neglect the impact of grief (Sanders et al, 2008). An example would be Pearlin et al's (1990) Stress Model of Dementia Caregiving where caregiver burden and stress-processing are the primary focus and grief is addressed as an element of burden which is considered an inherent feature of dementia caregiving and resulting stress (Blandin & Pepin, 2016). In 2004 Marwit, Meuser, and Sanders were among the first to argue that grief may be a causal factor contributing to the stress, depression, and burden experienced by caregivers (as in Sander, Marwit, Meuser & Harrison, 2007). To this writer's knowledge, to date there are only five models that specifically address dementia grief: Ponder and Pomeroy (1996) is briefly mentioned here, Noyes et al's (2010), Meuser and Marwit (2001, 2002), Silverberg (2007), and Blandin and Pepin (2016). Although Noyes et al's model came after Meuser and Marwit's they are included here out of chronological order since this model builds on Pearlin et al's (1990) earlier Stress model.

Reflecting on Pearlin et al's stress model Noyes et al (2010) noted that while relational deprivation was included in the model as a variable of burden, the concept received little subsequent attention in relation to other stress variables. Explicating the concept they argued that

relational deprivation is a valid descriptive term for the caregiver grief process and that caregivers were more likely to experience grief from relationship losses than caregiving losses leading them to add relational losses to Pearlin et al's model to create the Grief/Stress Model of Caregiving (2010).

One of the first models to focus on caregiver grief was Ponder and Pomeroy's (1996) which presented a curvilinear model of the grief experience where grief changes over the course of the disease leading off with high intensity in the earliest stages, a decreased level in the middle stages, and increases again in later stages. Meuser and Marwit's (2001) Stage Sensitive Model of Grief in Dementia Caregiving, a descriptive grief model based on the study of adult-children and spousal dementia caregiver's grief responses over three stages of the disease, also found that grief increased with each stage of the disease but at different rates depending on caregiver type. Substantial and definable differences in the grief responses between adult-child and spousal caregivers were found at every stage of the disease suggesting that appropriate interventions need to be both caregiver type and stage-based. More will be said about the findings of study in the next section.

In 2004 Marwit, Meuser, & Sanders developed a Dementia Caregiver Grief Model (as in Doka, 2004) which served as the basis for Marwit and Meuser's 2004 empirically-based psychometrically sound inventory for assessment of grief in dementia caregivers, the Marwit and Meuser Caregiver Grief Inventory (MM-CGI) and later, the shortened version, the MM-CGI-SF (2005) – an assessment tool that can be used a variety of settings to help caregivers identify the impact grief is having on their lives and assist in developing appropriate interventions to address their grief (Sander et al, 2007). High scores on the subscales can indicate a need for intervention and further examination while low scores indicate appropriate coping or denial of grief related issues. Questions are utilized to assess caregivers at risk on three different subscales: *Personal Sacrifice*

Burden assesses caregiver's perception of burden and the losses they have experienced due to the caregiving role. The question "What have you given up or postponed in order to care for the care recipient?" is designed to help the professional examine current issues which impact the caregiver as well as issues from the past that have not been reconciled. The *Heartfelt Longing and Sadness* subscale addresses grief-related sadness and a longing for the life before the onset of memory losses. The key question, "What changes in the care recipient or your relationship with him/her evoke feelings of sadness?" helps to assess caregiver strategies being used to maintain connection with the care recipient as well as assist in exploring areas where grief may be more complex than the caregiver can handle alone. The third subscale, *Worry and Felt Isolation*, addresses the "aleness" Marwit, Meuser & Sanders found caregivers experience alongside grief and loss (Sanders et al, 2007). Two questions, "How has your situation (caregiving) impacted your relationship with others?" and "What are your worries?" are aimed at assessing caregiver's involvement in meaningful activities and interpersonal relationships with a focus on symptoms of isolation and whether these feelings are acceptable to the caregiver or if a clinical level of depression exists that requires professional assistance. Suggested interventions stemming from an MM-CGI assessment are covered in the next section of this document.

Silverberg's (2007) 3-A Grief Intervention Model for family dementia caregivers takes different grieving styles into account and recognizes the important role denial and respite play in a caregiver's ability to cope and adapt (Stroebe & Schut, 1999). This model is predicated upon Silverberg's personal experience as a dementia caregiver, substantiating data taken from her clinical practice with over 500 dementia involved families, a literature review including assessment of caregiver grief accounts within it, and informal, open-ended interviews with one male and two female spousal caregivers. The model utilizes an ongoing process of:

Acknowledging grief and multiple losses, Assessing grieving style (intuitive/instrumental,

adaptive/maladaptive), attachment issues and/or resistance to assistance, and/or over-responsibility, and Assisting family caregivers with ongoing support, empathy, practical support, and therapeutic grief resolution strategies to help caregivers let go of the past and adapt to a new relationship that “accommodates the [ongoing] changes brought on by the disease” (p. 229). The model can be adapted to suit individual caregivers and prevent co-existing problems, such as depression, from arising or increasing (Silverberg, 2007). In developing the model elements of Worden’s (1991) grief work, Stroebe and Schut’s (1999) Dual Process Model for coping in bereavement (DPM), and Attachment Theory (Bowlby, 1969) are applied to the caregiving experience to aid intervention development. An important element of this perspective is that it links pre-death grief with post-death adaption in bereavement which suggests that they can be treated as part of the same “chronic, stressful continuum” rather than as separate and unconnected experiences (p. 217).

Of particular note to this writer is the 3A model’s emphasis on the DPM as an acceptable model for pre-loss grief as I, too, recognized this possibility which became the primary catalyst for this thesis on caregiver pre-loss grief. Like the DPM Silverberg’s intervention model stresses that an essential aspect of grief adaptation is the need for relief from stressor, both loss-oriented and restoration-oriented. Like Stroebe and Schut (1999), Silverberg, and others I found that the grieving movement described for bereavement – alternating between loss-oriented stressors and restoration-oriented stressors to achieve respite from continual focus on one or the other – also aptly described my own pre-death grieving process as a caregiver as well as the grieving process of many caregiving and bereavement clients. While the DPM was originally meant to assist the bereaved I have observed, as Silverberg describes, that explicating this model to those experiencing pre-death grief allows them to recognize the pattern and normalizes the act of

taking time away from one set of stressors to attend to the other. In this way emotional support and a rationale is offered for the movement which in turn allows caregivers to mindfully continue attending to, for example, restoration-oriented stressors, such as social interaction or self-care, with less guilt and worry, giving them a chance for true respite and resiliency building before the return to loss-oriented stressors.

Blandin and Pepin's (2016) Dementia Grief Model describes the dementia grief process as a normal grief process involving anticipatory grief in response to compound losses (Lindauer & Harvath, 2104) but with the addition of the "unique properties" (p. 5) of dementing illnesses that create cognitive and awareness impairments and disruptions in communication, sometimes even before diagnosis. This theoretical model of dementia grief is centered on three distinct characteristics of dementia grief (compounded loss, ambiguity, and receding of the known self), and is informed by "current understanding of the dynamic and iterative trajectory of grief" (p. 5) as represented by the DPMCB (1999). The unique dementia grief process is described as an iterative process cycling through three separate physiological states – Separation (due to compound serial losses), Liminal (being between previous and emerging situations), and Re-emergence (acceptance and adaptation). Each state has its' own dynamic mechanism that facilitates or, if not achieved, hinders movement through the grief process: for separation it is acknowledging losses, for liminality it is tolerating difficult feelings, for re-emergence it is adaptation. As adaptation in dementia caregiving is temporary and cyclical state of being, the cycle is repeated until physical death.

In this section we have traced the development of caregiver grief models and frameworks and conceptions of caregiver pre-loss grief beginning with Pearlin et al's stress model that does not deal directly with grief but did include general losses experienced in dementia caregiving as

symptoms of burden. Recognizing relational losses as a discrete grief dynamic Noyes et al (2010) amended Pearlin' et al's model by separating the concepts of relational losses and burden. Meuser and Marwit's (2001) Stage Sensitive model was the first to correlate the stages of the disease with grief symptom intensity and caregiver type while Silverberg (2007) developed a 3-pronged plan to address grief symptoms. In each of these models grief is presented as one of many dementia caregiver symptoms (Blandin & Pepin, 2016). In what seems like large steps forward Marwit and Meuser's (2004) MM-CGI tool and Blandin and Pepin's model interpret caregiver grief as a process related to, but separate from, burden and other grief-related symptoms. This, it seems to this writer, is the way towards interventions that are specifically and appropriately aimed at caregiver pre-loss grief.

Grief Intervention Studies

Given the aforementioned issues around clarity of intervention intent (what intervention is meant to alleviate) and categorization of individual interventions in the literature, and the very recent conceptualization of caregiver grief as a process that is separate from, but overlaps with, burden related variables there are few studies clearly aimed at dementia grief interventions to offer here. After careful consideration of the above points a criteria was developed whereby only intervention studies that are based on a clear framework or model of caregiver pre-loss grief and feature intervention targets that are, at least in part, specifically grief related are included here. This gives us three studies and one caregiver grief assessment tool to consider.

In the study that defined their Stage-Sensitive Model of Grief in Dementia Caregiving Meuser and Marwit systematically investigated grief responses of 42 spouse and 45 adult-children mixed male/female caregivers of people in mild, moderate, severe, and post-death stages of dementia. Response data were gathered through questionnaires and qualitative data through 16 semi-

structured focus group interviews which revealed significant differences between the two groups of caregivers both as a whole and as a function of CR's impairment level.

In the early, low impairment, stages of the disease adult-children presented with denial while spouses were more realistic, accepting, and sad suggesting that spouses might benefit more from a support group early on while adult-children would benefit more from psycho-education about the disease and what to expect. In the middle stages adult-children were at their highest level of grief and were "almost crippled with intense raw emotions" (p. 667) presenting with burden, frustration, anger and guilt. Spouse's emotions increased at a slower pace than the other group as they reported more extreme sadness than anger, guilt, or burden. This group experienced increased empathy and compassion at this point and grief had more to do with their CR's losses than their own. For adult-children in the middle stages therapeutic interventions, anger management techniques, and support group involvement may be most helpful while continued group support, including home service referrals, would best serve spouses. Sometime during the third stage of dementia the CR will likely be placed into care which can bring a sense of relief for adult-children whose focus of loss now goes to the other rather than being about the self. For spouses this stage brings grief to its highest level; sadness gives way to frustration and anger, internalized grief, and fears about the future. The death of the care recipient occurs in the third stage. Here Meuser and Marwit suggest adult-children would benefit most from philosophical integration while spouses are best served by addressing individual concerns and planning for a future without the CR.

The MM-CGI assessment tool was included in the previous section due to it being based on Marwit, Meuser, and Sander's 2004 Caregiver Grief Model, it is included here due to the suggested grief interventions for each of the assessment tool's exploratory subscales *Personal*

Sacrifice, Heartfelt Sadness and Longing, and *Worry and Felt Isolation*. When intervention is indicated on the *Personal Sacrifice* subscale the recommendation is for brief therapy aimed at exploring feelings of loss, education on self-care strategies, and referrals to appropriate services (home help, support groups, hospice services) and professionals. On the *Heartfelt Sadness and Longing* subscale encouraging caregivers to tell the story of CR's process, educating them on activities that may increase connection with CR (touch, music, reminiscing), grief and loss counselling, and making appropriate referrals are advised while the *Worry and Felt Isolation* subscale interventions focus more on physician and clinical therapist referrals to address depression or deliver more intensive interventions. Education on depression and its relation to grief is also recommended.

MacCourt et al's (2017) intervention study was also informed by Marwit and Meuser's Caregiver Grief Model although their focus was on a coaching intervention delivered by trained counsellors rather than a psychotherapy intervention. Therefore, while treatment is individualized and person-centered, interventions are aimed more towards skills building and problem-solving than therapy might be. However, as the intervention was delivered by trained counselling professionals it can be argued that the core conditions for therapeutic change – congruence, empathy, and unconditional regard – were met, adding a therapeutic dimension to the coaching intervention.

The intervention measured levels of grief (CG Grief Inventory, 2002), sense of empowerment (Empowerment Questionnaire, 2005), coping (The COPE 1977), and resilience (The Resilience Scale, 1993). Five different modes were used for intervention delivery: individual face-to-face, individual by phone, face-to-face group, telephone group, and online group. Six sessions with an option for two more were offered participants and topics covered in

sessions were: Introduction to Transitions, Dimensions of Grief, Living with grief, Honouring Grief, Maintaining Self, and Enhancing Resilience. Additionally, two follow up/check in sessions were offered. Participants were BC residents caring for someone with dementia and were placed into intervention (123 participants) or control (77 participants) groups based on time of recruitment. Participants of both groups were encouraged to attend all available support and education programs in their communities. Participants were further divided into one of five delivery methods according to proximity, timing, and access to/ability to use technology. Results indicate that the intervention had significant positive effects on caregivers' levels of grief and increased their levels of empowerment, coping, and resilience. There were differences in efficacy between spouses and adult-children and while spouses reported significantly lower grief at the end of the intervention it was still higher than adult-children reported. All delivery methods were equally effective in raising levels of coping, resiliency, and empowerment and decreasing grief. The authors point out that a crucial aspect of the intervention was that it was delivered by skilled professionals who tailored the intervention to each participant/group which may be difficult to replicate elsewhere.

Also based on Meuser and Marwit's caregiver grief model, the Easing the Way Intervention pilot feasibility study (Ott et al, 2010) targeted three components of grief that correspond with the MM-CGI subscales: *Heartfelt Sadness and Longing*, *Worry and Isolation*, and *Personal Sacrifice*. In this single-group repeated measures study 20 spousal caregivers living with their CR in the U.S. received the intervention composed of supportive counselling and emotional support, education and skill building, and referral to community resources delivered via telephone or one-to-one meetings over, on average, 4-8 months. Meuser and Marwit's (2002) general principles for working with dementia caregiver grief were utilized including: realizing

that grief is a unique experience for each person; using individualized approaches while considering the caregiver's grief response and coping resources; considering that men may express less of an emotional response while needing similar levels of support as women; listening more than talking while also addressing emotions such as anger and guilt; proceeding at a comfortable pace that corresponds to the caregiver's openness and coping abilities (as in Ott et al, 2010).

Changes in grief and mental health were measured at baseline and at completion (5 months on average), 3 months post intervention and then a follow up at 8 months. Results showed a significant decrease in the mean grief score from baseline to completion. Between completion and 8 month follow up grief scores returned to baseline for caregiver's whose CR were moved into care during that time. The authors hypothesize that placement into care triggers further losses and recommend that the intervention period last through placement and beyond to maintain intervention benefits.

In considering the findings above it is important to notice that the assessments and interventions in each of the four examples are aimed at the identified pre-death risk variables for complicated grief in bereavement identified in the Chapter two literature review: preparedness, sense of burden, depression, and relational losses. Counselling, coaching, and education were utilized to help caregivers recognize, make sense of, and accept their grief and to acknowledge, grieve, and make-meaning of the illness and the changes/disruptions in their relationships with the CR, with family and friends, and with their own changing role(s). Perceived burden was addressed by increasing awareness and through referrals to other professionals for practical, physical and mental health needs, particularly depression as the literature has shown that improvements in these areas particularly lead to improvement in perceptions of burden. All four

interventions addressed preparation through discussion and education around life transitions and the dementia trajectory and by increasing coping skills while increasing social, emotional, spiritual, and professional supports where possible thereby increasing resilience.

A vital aspect of each of these studies lies in the recognition that dementia grief is unique to each caregiver and, accordingly, assessments of caregiver (and in one case CR) needs were completed in or before the first session and interventions were tailored for individual caregivers as well as for groups. Of note are Meuser and Marwit and Ott et al's findings that while spousal caregiver's grief decreased overall it was still higher than adult-children caregivers' grief when their CR was placed into care or died suggesting that longer-term treatment, perhaps extending beyond the death of the CR, might be most helpful for spouses.

Summary

Spousal dementia caregivers offer practical and emotional support to some of societies' most vulnerable and dependent individuals but to do this effectively they, themselves, need practical and emotional support. The overall aim of this document was to synthesize the existing evidence regarding spousal dementia caregivers' pre-death grief experiences and grief variables linked with caregivers' post-death complicated or prolonged grief, grief models that take into account dementia caregivers' pre and post-loss grief, and the evidence regarding the efficacy of psychosocial interventions to alleviate distress and assist with pre-loss grief adjustment in order to mitigate complicated grief in bereavement. A prevalent theme throughout discovery has been the relative newness of the perception of dementia caregiver grief as a critical component of their experience that may be detrimental to caregivers' mental and physical health. The most recent literature challenges the notion of caregiver grief being solely a function of caregiver burden while new terms, such as dementia grief, and the evolution of related and established terms, such

as complicated grief now recognized as a distinct disorder, also reveal that research in the areas of dementia caregivers, grief, and interventions to relieve grief are emerging topics.

As we have seen, existing research on caregiver pre-loss grief addresses its' anticipatory, ambiguous, and disenfranchised nature as well as the cycle of chronic sorrow, the intangibles of nonfinite losses, and the often wide-ranging relational deprivations involved in caring for someone with a long-term terminal brain disease with no set symptom trajectory or timeline. In tracing this literature connections between these grief processes and the ways in which they contribute to, or predict, complicated post-death grief outcomes have been highlighted – for some, non-finite losses, ambiguous, anticipatory and disenfranchised grief can keep caregivers locked in a cycle of chronic sorrow, disrupting caregivers' ability to come to terms with ongoing losses which, in turn, can prevent or postpone adaptation and preparation for the CR's death. As the CR's cognitive function decreases caregiver's perceived burden often increases as do depressive symptoms which, in turn, can lead to decreased well-being in physical, emotional, social, and spiritual realms. Of the many risk factors for complicated grief in bereavement perceived burden, depressive symptoms, and lack of preparedness for the death have been identified as being the most significant predictors of negative bereavement outcomes.

Given this it is vital to identify those in caregiving roles who are at a high risk of developing complicated grief before the death of their CR so that appropriate risk reduction interventions can be administered to address situational factors related to preparedness and burden, caregiver characteristics factors such as gender and attachment history, and situational factors including CR's level of cognitive impairment and caregiver's social, emotional, spiritual and professional support levels. To date Meuser and Marwitt's Caregiver Grief Inventory (2002), Sander's et al's (1985) Grief Experience Inventory, Prigerson et al's (1995) Inventory of

Complicated Grief are the most often used tools to assess risk. However, for more accurate assessment tools, more research is needed to determine how well each the three theoretical perspectives on caregiver grief and bereavement (resource depletion/cumulative stress hypothesis, relief/stress reduction perspective, anticipatory grief theory) apply to or describe those most at risk for complicated grief and depressive symptoms.

Intervention Recommendations

While there is a scarcity of quality studies and studies using consistent categorizations of interventions that report on the efficacy of psychosocial interventions for dementia caregiver's pre-loss grief there is little doubt about the pressing need to assist caregivers as more and more spouses find themselves in a caregiving role that may exceed their skill level and capacity to cope. Interventions are needed to address grief associated with the dementia caregiver role particularly for the 30% at risk for complicated grief. Until there is a higher level of evidence to draw upon I offer the following recommendations, drawn from the literature for assessment and intervention (Meuser & Marwitt, 2001; Silverberg, 2007; Blandin & Pepin, 2016; McCourt et al, 2017; Meichsner & Gabriele, 2018):

- Identifying and (re)activating personal resources - to foster positive emotions and spotlight caregiver's own positive characteristics and abilities to increase self-efficacy and an awareness of their own needs.
- Identifying and activating professional, social, and spiritual resources/services – increasing emotional support and feelings of well-being of caregiver and, by extension, CR.

- Increase cognitive and caregiving skills – increase caregiver confidence, improve caregiving, increase awareness and allowance to share caregiving duties (family/professionals) - associated with decrease in depressive symptoms.
- Identification and expression of painful thoughts and emotions - validation and normalization of pre-death grief, psychosocial support and interventions to decrease depression.
- Management and acceptance of painful emotions – recognition and expression of avoided or suppressed emotions, acceptance of the disease and progressive losses. Address unhelpful assumptions that obstruct identification, expression, and acceptance of painful emotions. Support and education for preparation of CR’s death, bereavement, time afterwards and associated emotions.
- Redefining relationship with CR – ongoing exploration of changes in the relationship between caregiver and care recipient, redefinition of caregiver’s role.

Planning to meet the mental health needs of our aging population has placed more focus on community care options including a “better at home” philosophy of care for those with a dementia diagnosis. For many spousal caregivers dementia care demands exceed their knowledge, capacity, and skill sets putting some at high risk for emotional and physical breakdown before the death of the CR. Evidence informed interventions are needed to support and promote the health and well-being of caregivers - including addressing the grief associated with the long-term care of a loved one with an unpredictable and terminal disease and possible complicated, long-term grief in bereavement.

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