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Investigating the Theory of Ambiguous Loss: The Role of Ambiguity Tolerance in Pre-Death Grief for Caregivers of Individuals with Dementia

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Investigating the Theory of Ambiguous Loss: The Role of Ambiguity Tolerance in Pre-Death
Grief for Caregivers of Individuals with Dementia

Investigating the Theory of Ambiguous Loss: The Role of Ambiguity Tolerance in Pre-Death
Grief for Caregivers of Individuals with Dementia

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

by

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Abstract

This thesis sought to investigate the relationship between ambiguity tolerance and caregiver grief within the framework of ambiguous loss theory. Thirty-one family caregivers completed a quantitative survey comprising two pre-existing scales and several demographic questions designed to assess level of ambiguity tolerance, level of grief, caregiver age and gender, type of relationship to the care recipient, living situation, length of caregiving career, level of social support and frequency of difficult behaviors. Quantitative data analysis revealed that while no relationship existed between total ambiguity tolerance and total caregiver grief, a modest, inverse relationship exists between tolerance toward general-type ambiguity and burden, which is one identified aspect of caregiver grief.

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I would also like to acknowledge the support of my family, without whose love and assistance I would not have been able to get through this project.

Dedication

This thesis is dedicated to Pippa, who inspires me with her passion for life, her resilience, and her joy.

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CHAPTER 1

INTRODUCTION

Background of the Study

Over 5 million Americans are living with Alzheimer's disease, including approximately 100,000 Arkansans (Alzheimer's Association, 2014). Approximately ten percent of all individuals over age 65 and 50% of those over age 85 are impacted by Alzheimer's disease (Ross & Dagley, 2009). As dementia currently has no preventative treatment and is strongly associated with advancing age, it is estimated that the number of new cases is doubling each year (Bynum, 2014). Due to the exponential growth of the number of older adults in the United States, estimates are that as many as 14 million Americans may be affected by dementia in the coming decades (Ross & Dagley, 2009).

Alzheimer's disease and other dementias cause both physical and cognitive impairments that render the affected individual increasingly dependent on supportive care (Bynum, 2014). The most common symptoms experienced by individuals with dementia include memory loss, struggles with problem solving, difficulty with familiar tasks, disorientation with time or place, difficulty with speaking or writing, poor judgment, and changes in personality or temperament (Alzheimer's Association, 2014). During moderate stage dementia, the affected person may require assistance with activities such as driving or paying bills and may experience behavioral or personality changes that impact her relationships with others; during late stage dementia, the impacted individual is often completely dependent on others for assistance with personal care and may lose the ability to communicate entirely (Bynum, 2014). Seventy percent of individuals with dementia live at home and receive care from family or friends (Putnam, Pickard, Rodriguez,

& Shear, 2010). In fact, it is estimated that 80% of dementia caregiving is provided by unpaid, informal in-home caregivers, often spouses or adult children (Alzheimer's Association, 2006, as cited in Etters, Harrison, & Goodall, 2008).

Implications for Caregivers

Dementia-related changes in cognition and function are progressive in nature and have been referred to as a series of “mini-deaths” for the caregiver, who not only witnesses the decline of the person with dementia but also experiences the gradual loss of a relationship with that individual (Meuser & Marwit, 2001). This may culminate in what has been referred to as the “psychosocial death” of the individual affected by the disease (Lindauer & Harvath, 2014; Meuser, Marwit, & Sanders, 2004). In addition to the loss of physical health and independence, she loses the ability to sustain previous communication patterns, to engage in meaningful relationships, and to fulfill previously held social and familial roles.

Dementia-related losses hold several implications for caregivers. First, these losses create confusion and ambiguity in the life of the caregiver. The individual with dementia may be altered so much in personality, cognition, and function that she may seem to be both “here” and “gone,” “alive” and “dead,” at the same time (Boss 2007, 2010, 2012; Boss & Carnes 2012; Boss et al., 2011). The care recipient looks physically unchanged, but is psychologically “lost.” The caregiver, too, loses a sense of identity, shifting from being an adult child to almost a parental figure, or from being a spouse to an unrecognized stranger. These paradoxes are difficult to comprehend and accept for the caregiver. In addition, dementia-related changes do not progress in a strictly linear fashion; the cognitive and behavioral changes often fluctuate. Individuals with dementia may have days in which they exhibit more cognizance and emotional stability, overshadowed by days filled with anxiety, suspiciousness, and aggression. This variability in

behavior may create more uncertainty and ambiguity for caregivers, producing anxiety, confusion, and an inability to adapt to or cope with the losses (Boss 2007, 2010, 2012; Boss & Carnes 2012; Boss et al., 2011).

A second outcome of dementia-related losses is pre-death grief for the caregiver, also known as caregiver grief. Caregiver grief is a term used to describe emotional reactions to the losses associated with the caregiving experience, loosely comprising feelings of sadness, burden, and isolation (Marwit & Meuser, 2002). Caregiver grief carries ramifications for both the caregiver and the care recipient. Caregiver grief can have profound negative effects on the caregiver's mood, health, social life, and performance at work and at home (Meuser & Marwit, 2005). Psychological distress related to caregiving has been associated with poor nutrition and sleep habits, as well as increased vulnerability to infectious illnesses (Pinquart and Sörenson, 2007). Caregiver grief has also been associated with depression and anxiety (Holley & Mast, 2010). Increased burden, one aspect of caregiver grief, may contribute to premature institutionalization of the care recipient (Etters, Goodall, & Harrison, 2007). Studies also show that higher levels of caregiver grief are linked to difficulties with problem solving and decision-making regarding management of the care recipient's medical needs (Fowler, Hansen, Barnato, and Garand, 2013). Caregiver grief, then, has strong implications for the health and well being of both caregivers and the individuals they support.

Rationale for Studying Ambiguity Tolerance and Caregiver Grief

Much of the literature on caregiver grief has focused relational and external factors that contribute to caregiver grief. For instance, there is a wealth of literature pertaining to the impact of behavioral changes or severity of dementia (Clyburn, Stones, Hadjistavropoulous, & Toukko, 2000; Frank, 2007; Ott et al., 2007; Ponder & Pomeroy, 1997; Sanders & Corley, 2003;

Warchol-Biedermann, Mojs, Gregersen, Maibom, Millán-Calenti, & Maseda, 2014), differences in the grief of spousal and adult child caregivers (Holley & Mast, 2010; Meuser & Marwit, 2001, Warchol-Biedermann et al., 2014) the living situation of the care recipient (Clyburn et al., 2000; Frank, 2007; Loos & Bowd, 1997; Marwit & Meuser, 2001; Ott et al., 2007; Rudd, Viney, & Preston, 1999), social support felt by the caregiver (Frank, 2007; Loos & Bowd, 1997; Ott et al., 2007), and the length of the caregiver's career (Lindren, Connelly, & Gaspar, 1999; Ponder & Pomeroy, 1999).

Only one study to date, however, has sought to understand the involvement of specific personality traits of the caregiver on her experience of psychological distress. The authors of that study found that neuroticism increased both burden and depression in caregivers, concluding that personality plays a significant role in outcomes for both caregivers and care recipients (Melo, Maroco, and de Mendonça, 2011).

Another such personality trait of interest, and the focus of this study, is tolerance for ambiguity, which describes an individual's reaction to complex, novel, or insoluble stimuli (Budner, 1962; MacDonald, 1970; McLain, 1993; McLain, 2009). While individuals with a high ambiguity tolerance may be attracted to new and complex situations, those individuals with a low tolerance for ambiguity may react to equivocal stimuli with distress, anxiety, avoidance, and denial (McLain, 2009).

Statement of the Problem

Considering the uncertainties and ambiguities involved in dementia caregiving, do caregivers with a higher tolerance for ambiguity experience a lower level of grief than those with a lower tolerance for ambiguity? Boss, who coined the term "ambiguous loss" to describe the specific grief experienced as a result of the an indefinite loss or the psychosocial death of a loved

one, suggested that tolerance for ambiguity, in particular, may allow caregivers to thrive in the midst of confusion and insolubility (Boss, 2007; Boss et al., 2011). Indeed, several studies suggest that individuals with a higher tolerance for ambiguity perform better on vague or complex tasks (MacDonald, 1970; Shaffer & Hendrick 1974) and derive more enjoyment from those tasks (Shaffer & Hendrick, 1974; Wittenberg & Norcross, 2001). Conversely, those with a lower tolerance for ambiguity have been shown to disdain complex, unclear tasks (Shaffer & Hendrick, 1974) and to experience anxiety in the midst of uncertain or unclear situations (Bardi, Guerra & Ramdeny, 2009; Frone, 1990).

However, Boss's assertion regarding the relationship between ambiguity tolerance and grief (2007) has yet to be supported by any empirical studies. Thus, this study sought to understand the association between ambiguity tolerance and grief in family or friend caregivers of individuals with dementia.

Purpose of the Study

Using a cross-sectional, correlational analysis, this study investigated the relationship between a caregiver's level of ambiguity tolerance (AT) and that person's feelings of grief in response to caregiving. Specifically, this study aimed to understand the association between AT (overall AT as well as distinct types of AT including general, novel, insoluble, and uncertain) and grief (overall grief as well as specific aspects of grief, namely feelings of burden, sadness, and future worry and social isolation) (Meuser & Marwit, 2001).

Significance of the Study

The significance of the study is unequivocal, as it is the first study to date investigating ambiguity tolerance and its relationship to caregiver grief. Boss (2007) asserts that ambiguity tolerance is a factor of resilience in caregivers of individuals with dementia and should be a

target for intervention when working with individuals who are experiencing ambiguous loss. In fact, it has been contended that improving an individual's tolerance for ambiguity through exercises in paradoxical thinking and acceptance of contradictions will help to alleviate some distress associated with ambiguous losses (Boss, 2010; Boss et al., 2011).

Therefore, the results of this study may provide preliminary evidence to support the theory that ambiguity tolerance provides a buffering effect against the grief associated with dementia caregiving. In doing so, the study may direct future research in the area of ambiguous loss theory that may be applied to dementia caregivers as well as other populations who experience ambiguous loss, such as family members dealing with addiction, mental illness, or a traumatic brain injury (Boss, 2007; Boss, 2010; Boss, 2012; Boss & Carnes, 2012; Boss et al., 2011). In addition, confirming ambiguity tolerance as a factor of influence with regard to grief may help clinicians identify individuals who may be in need of specific intervention and even help to inform interventions aimed at helping individuals cope with ambiguous loss.

Definition of Terms

Ambiguity Tolerance

Ambiguity tolerance is defined as an individual's response to stimuli that are ambiguous, and includes such factors as general, uncertain, insoluble, or novel ambiguity (Budner, 1962; McLain, 2001; 2009). An individual's reaction to an ambiguous situation can include submission or denial and is either phenomenological or operative (Budner, 1962).

Ambiguous Loss Theory

Ambiguous loss theory, within the context of this study, is defined as a theory pertaining to a type of grief reaction seen in the loved ones of individuals who experience cognitive and behavioral changes due to dementia. This theory holds that the ambiguities associated to a loved

one being both “here” and “gone” at the same time causes a frozen grief that is difficult to resolve (Boss, 2007; 2010; 2012; Boss, Roos, & Harris, 2011). Boss (2007) also postulates that increasing an individual’s tolerance for ambiguity may improve her ability to cope with this grief.

Care

Care, within the context of this study, is left to the interpretation of the caregiver. It may refer to assisting with activities of daily living, providing emotional support, or any interaction in which the caregiver feels he or she is providing time or attention to the individual who is affected by dementia.

Care Recipient

A care recipient is defined as a person who is on the receiving end of the caregiver’s attentions. Within the context of this study, a care recipient is an adult who has been diagnosed with dementia and is being cared for by either a family member or friend. A care recipient may be living individually, with the primary caregiver, or within an institutional setting.

Caregiver

A caregiver is defined as a person who defines herself or himself as providing care for an individual who has been diagnosed with dementia. Within the context of this study, a caregiver may be providing unpaid care for a friend or family member who is living independently, within the caregiver’s home, or within an institutional setting.

Caregiver Grief

Caregiver grief is defined as feelings of emotional loss, specifically sadness, burden, or worry experienced by a family member or friend of an individual with dementia and who defines himself or herself as the primary caregiver for that individual. These dimensions of grief are

based on the findings of Meuser and Marwit (2001), whose work with focus groups laid the foundation for the caregiver grief scale utilized in this study.

Dementia

Dementia in this study was defined largely by the caregivers, who were asked to self-report that their care recipient had been diagnosed with a form of dementia.

Research Questions

The predominant question guiding this study was to investigate the relationship between ambiguity tolerance and pre-death grief in caregivers of individuals with dementia. The specific research question addressed is:

Question 1. Is there an association between ambiguity tolerance and caregiver grief?

In order to answer the above question fully, it was necessary to examine the question using several hypotheses. The hypotheses delineated below were intended to provide a complete understanding of the relationship between each specific aspect of ambiguity tolerance and each specific aspect of caregiver grief (Marwit & Meuser, 2002).

Hypothesis 1. Individuals with a higher tolerance for each type ambiguity (total, general, novel, uncertain, and insoluble) will experience a lower level of overall grief.

Hypothesis 2. Individuals with a higher tolerance each type ambiguity (total, general, novel, uncertain, and insoluble) will report a lower level of burden.

Hypothesis 3. Individuals with a higher tolerance for each type ambiguity (total, general, novel, uncertain, and insoluble) will report a lower level of sadness.

Hypothesis 4. Individuals with a higher tolerance for each type ambiguity (total, general, novel, uncertain, and insoluble) will report a lower level of worry and isolation.

Limitations

The study has the following limitations:

1. The sample of caregivers was recruited mainly through the use agency contacts, and therefore represents a convenience sample of individuals who were seeking services. Therefore, the results of the study may not be generalizable to other populations.
2. The sample recruited was too small to conduct an effective multivariate analysis; therefore only bivariate analysis was conducted, and confounding variables could not be controlled for in the study.
3. The study relies on two self-report measures that have not been validated for social desirability bias (Marwit & Meuser, 2005; McLain, 2009).
4. The study is correlational in nature; therefore causation cannot be inferred.

Assumptions

The study included the following assumptions: (a) all participants understood the vocabulary associated with the measures utilized, (b) all participants answered the survey instrument honestly and accurately.

Organization of the Study

This research study is organized into six chapters. Chapter I includes the background of the study, statement of the problem, purpose of the study, significance of the study, definition of terms, theoretical framework, research questions, limitations, and the assumptions of the study.

Chapter II provides a review of the literature, which includes ambiguous loss theory, ambiguity tolerance, and caregiver grief. Chapter III presents the theoretical framework of the study. Chapter IV outlines the methodology used for the study. This chapter includes the selection of participants, instrumentation, data collection, and data analysis procedures.

Chapter V offers the study's findings. This includes demographic information, testing of the research questions, and data analysis results for hypothesis testing. Chapter VI comprises a summary, discussion of the findings, implications for theory, practice, and research, and a conclusion.

CHAPTER II

THEORY

Introduction

This chapter serves to justify the use of Ambiguous Loss Theory as the theoretical framework study. The chapter will orient the reader to the concept of ambiguous loss, to the assumptions held by the theory, to the relevant causes and impacts of ambiguous loss, and to the rationale for the research question posted by the study.

Defining Ambiguous Loss

Ambiguous loss is a term coined in the 1970s to describe a certain type of loss reaction observed by Pauline Boss while doing family therapy (Boss, 2007). Boss worked with families in which she noticed that fathers were physically present, but psychologically and emotionally absent, causing feelings of loss in other family members (Boss, 2007). Continuing in her work, she used the term ambiguous loss to more inclusively describe two specific types of loss – physical loss in the midst of psychological presence (as in the case of kidnapping, adoption, or incarceration) or psychological loss in the midst of physical presence (as in the case of dementia, traumatic brain injury, or other cognitive impairment) (Boss, 2007, 2010, 2011; Boss & Carnes, 2012). In these cases, there is no clear understanding of family or social roles. Restructuring and renegotiating roles is often warranted, but it is unclear to what extent the “lost” person is truly “gone” or whether that person may return. Because social and familial roles become blurred, those who are left behind may question their sense of identity as well (Blieszner, Roberto, Wilcox, Barham, & Winston, 2007; Boss, Roos, & Harris, 2011; Dempsey & Baago, 1998).

This study focuses on ambiguous loss within the unique context of dementia caregiving, during which the caregiver experiences an unstable pattern of losses culminating in the psychosocial death of their loved one. The psychosocial death of an individual with dementia is slow, progressive, and unpredictable, and it is marked by losses of memory, language, independence, and emotion regulation, interspersed with periods of lucidity (Boss, 2010; Dempsey & Baago, 1998; Dupuis, 2008), which disrupts the relationship between caregiver and care recipient. The phenomenology of the loss of the relationship, paired with the intermittent periods of hopefulness, makes dementia caregiving a multifaceted and nuanced experience (Noyes, Hicken, Luptak, Rupper, Dailey, & Blair, & 2010). Ambiguity, uncertainty, and confusion abound for the caregiver. These losses are difficult to delineate and understand; they are unclear and uncertain. Because there is no finality, they are seemingly endless and provide no closure.

Ambiguous Loss Theory

Ambiguous loss theory holds several major assumptions (Boss, 2007). First, it assumes that family exists outside the traditional definition, or rather, that familial bonds are psychological rather than biological. As such, losses experienced are based on the changes or threats to the emotional and psychological relationship, or attachment, between individuals. Ambiguous loss theory, then, follows from Bowlby's attachment theory, which states that threats to the attachment between individuals can result in anxiety, sadness, anger, and feelings of grief (Bowlby, 1989; Worden, 1998).

Second, while the loss itself is neutral, the caregiver's interpretation of the loss determines how the caregiver will react emotionally and behaviorally (Boss, 2007). Dementia-related losses, then, are not inherently negative for all caregivers. Some caregivers may

experience growth as a part of their caregiving role, deriving meaning from providing attention and support to the care recipient during the physical and mental decline. Third, tolerance for ambiguity, which has salience for how a loss is perceived by a caregiver, is influenced by values and cultural beliefs (Boss, 2007).

Fourth, tolerance for ambiguity creates a natural resiliency that allows families and caregivers to cope and succeed in the midst of uncertainty (Boss, 2007). Paradoxical thinking, the ability to hold contrary ideas, can help caregivers cope with the often-disparate daily realities of dementia caregiving (Boss 2007, 2012; Boss & Carnes, 2012).

Ambiguity in Dementia Caregiving

Feelings of loss can be attributed to the uncertainties and ambiguities involved in dementia caregiving (Boss, 2007; 2012; 2010; Boss et al., 2011; Boss & Carnes, 2012; Dupuis, 2008; Frank, 2007; Sanders & Corley, 2003). These uncertainties are past, present and future oriented (Dupuis, 2008) and relate to the disease process and its impact upon the care recipient and the relationship between caregiver and care recipient (Boss, 2007; 2012; 2010; Boss et al., 2011; Boss & Carnes, 2012; Dupuis, 2008; Frank, 2007; Sanders & Corley, 2003).

Several qualitative studies investigating loss in dementia caregiving have reported significant themes of ambiguity as a part of a caregiver's career, including uncertainty of future, relational losses in the present, ambiguous past losses, as well as loss of role clarity and identity (Dupuis, 2002; Frank, 2007; Sanders & Corley, 2003). Their findings support Boss's argument that ambiguous loss is a relational condition caused by threats and disruptions to the attachment between caregiver and care recipient and to the caregiver's identity (2012).

Several studies remarked that ambiguity produced uniquely past-, present-, and future-oriented losses for dementia caregivers (Frank, 2007; Dupuis, 2002). In a study of adult child

caregivers of parents living in long term care facilities, Dupuis (2002) found that ambiguity played a large role in the grief of caregivers throughout the caregiving career. In the early stages of caregiving, feelings of loss and grief manifest as anticipatory in nature, as caregivers worry about the uncertainties of what the future will hold (Dupuis, 2002). Frank (2007) reported a similar finding, as distress and uncertainty over the future loss of a loved one's memory or ability to recognize the caregiver was prominent among her sample. During the middle phases of dementia caregiving, losses appeared to become more present-oriented, and caregivers reported more emotional upset related to communication difficulties and progressive deterioration of their loved one (Dupuis, 2002; Frank, 2007). Caregivers remarked that their loved one looked the same, but was not really *there*, or was alive but dead at the same time. During the late stages of dementia caregiving, losses felt were oriented toward the past, as caregivers longed for what was shared prior to the onset of the disease (Dupuis, 2002; Frank 2007).

Sanders and Corley (2003) also conducted a qualitative study regarding the lived experiences of dementia caregivers and found ambiguity to be a large component of the process. Confusion and ambivalence were prominent emotions among the sample. Caregivers in the study remarked that while their loved ones looked the same, they were cognitively and emotionally quite different. There were significant themes of role reversal for adult children (Sanders & Corley, 2003). Adult children reported that their parents were becoming more "child-like" (Sanders & Corley, 2003). This group of caregivers struggled with the conflict involved in taking responsibility for the care of their parent. While some adult children experienced growth as a part of this process, many others reported emotional distress and burden as a result (Sanders & Corley, 2003). Spouses reported more difficulty with role confusion. As care recipients became increasingly unable to fulfill their social and familial roles, spouses

struggled to restructure their own identities as both caregiver and spouse. Loss of intimacy was a common theme among spousal caregivers, with several caregivers expressing frustration, anger, and rejection at being treated as a stranger rather than a spouse (Sanders & Corley, 2003).

Blieszner and colleagues (2007) investigated ambiguous loss in spouses of individuals with mild cognitive impairment (MCI), a population they termed “care partners,” suggesting that they are distinct from caregivers, in that the individual with MCI maintains a higher degree of independence. The authors concluded that, despite the mild impairments in the spouses in their sample, themes of ambiguous loss were still present and caused by changes in the relationship between partners (Blieszner et al., 2007). For instance, prior to diagnosis, care partners experienced uncertainty regarding differences in the cognition of their spouses. Some partners misattributed memory or repetition issues to lack of concentration on the part of their spouse and found the unpredictability of these moments to be upsetting (Blieszner et al., 2007).

Multi-Systems Life Course Perspective

Multi-Systems Life-Course Perspective integrates four distinct theories and perspectives that allow for a broader understanding of the client system impacted by caregiver grief: ecological systems perspective, life course theory, symbolic interactionism and social change theory (Murphy-Erby, Christy-McMullin, Stauss, & Schriver, 2010). These four theories allow researchers to have holistic understanding of caregivers. From a symbolic interactionism perspective, beliefs are to some extent socially constructed, resulting from the meanings an individual attaches to social roles and other concepts built throughout the life course. The social environment, made up of various systems, including family, work, and the larger societal structure, informs the beliefs individuals apply to those roles. These socially constructed roles, whether between spouses or between parent and child, become blurred because of dementia-

related behavioral and psychological changes. The resulting ambiguity may threaten the symbolic meanings caregivers attach to those roles, as well as the caregivers' own self-perceptions. Future uncertainty and ambiguity may impact what a caregiver had projected for the life course, causing feelings of loss. Adult children may lose a sense of freedom to provide care for an ill parent, while spouses experience the loss of longstanding retirement plans. From an ecological systems perspective, which emphasizes the exchange of energy between systems in a caregiver's life, caregivers often become isolated as a result of the dementia-related losses described above. Communication is damaged; social roles are confused and often reversed. Loss of intimacy and feelings of social support are common among caregivers (Sanders & Corley, 2003). As the care recipient becomes increasingly more dependent, more time investment is required of caregivers, leading to disconnect from previously established social systems, including friends, places of employment (Meuser & Marwit, 2001). There is a strong sense of obligation to care for family members throughout American society, though many caregivers report that they feel disenfranchised and unsupported by both society at large (Frank, 2007; Loos & Bowd, 2007) and by social support structures, which are often unaffordable and inaccessible (Putnam, Pickard, Rodriguez, & Shear, 2010). From a social change perspective, policies and programs to support caregivers must be more person-centered and family-oriented to adequately and effectively support caregivers (Putnam et al., 2010).

Rationale for the Study

It has been postulated that tolerance for ambiguity provides natural resiliency for families experiencing ambiguous loss (Boss, 2007), though this has never been empirically tested. Blieszner et al. (2007) found that some individuals in their study were more adept than others at tolerating the uncertainties that are inherent in caring for a spouse with mild cognitive

impairment (MCI). They suggested that individual appraisals impact whether a caregiver is able to adapt or adjust to a new or ambiguous situation, which was supported in their findings (Blieszner et al., 2007). Certain care partners in their sample were better able to tolerate ambiguities than others. While few couples in their sample had made any preparations for their future care, the responses regarding this reality were mixed. Some care partners stated they were accepting challenges as they came, while others experienced worry and stress about the future (Blieszner et al., 2007). The authors extrapolated that the ambiguities associated with supporting a spouse with MCI are better tolerated by care partners who may not be inclined toward “control” (Blieszner et al., 2007). However, this study was merely observational and did not use any quantitative measure to assess level of ambiguity tolerance; neither did the study discuss its rationale for defining individuals as being inclined toward “control.”

Despite the lack of quantitative evidence for ambiguity tolerance as a factor of resilience among dementia caregivers, it has been found to be a factor of resilience in other empirical studies, promoting successful performance on difficult or unclear tasks (MacDonald, 1970), promoting enjoyment of those tasks (Shaffer & Hendrick, 1974; Wittenberg & Norcross, 2001), and supporting decision-making efficiency (Xu & Tracey, 2014). Lower ambiguity tolerance in the presence of ambiguous stimuli, on the other hand, has been associated with increased anxiety and stress (Bardi et al., 2009; Frone, 1990).

Considering Boss’s theory of ambiguous loss and the literature encompassing ambiguity tolerance, pursuing a greater understanding of the relationship between ambiguity tolerance and a caregiver’s experience of grief is warranted. Utilizing a quantitative methodology will allow the researcher to precisely measure each construct and use bivariate analysis to determine if, indeed, there is a significant relationship between ambiguity tolerance and pre-death grief.

Conclusion

Boss's concept of ambiguous loss, which holds that relational losses and grief occur in caregivers as a result of the psychosocial death of the care recipient prior to physical death, is well supported by the caregiving literature. Numerous studies describe the ambiguities that arise during the course of the caregiving career (Dupuis, 2008; Frank, 2007; Loos & Bowd, 1997; Sanders & Corley, 2003) as a result of behavioral and psychological changes that impact the attachment between caregiver and care recipient (Sanders & Corley, 2003) and cause role confusion and reversal (Sanders & Corley, 2003), loss of identity and control (Frank, 2007; Loos & Bowd, 1997; Rudd et al., 1999), and loss of and uncertainty of future (Dupuis, 2002; Frank, 2007). These ambiguities, particularly the psychosocial death of the care recipient as evidenced by emotional and behavioral changes, carry a substantial emotional toll, resulting in pre-death grief reactions in the caregiver (Clyburn, Stones, Hadjistavropoulos, & Toukko, 2000; Frank, 2007; Holley & Mast, 2010; Ott, Sanders & Kelber, 2007; Ponder & Pomeroy, 1997; Warchol-Biedermann et al., 2014). These ambiguities also prevent the caregiver from adapting to the caregiving role (Boss, 2010; Dupuis, 2002; Sanders & Corley, 2003).

If ambiguity tolerance is associated with better performance on complex tasks, emotional wellbeing despite ambiguous circumstances, and even ability to make decisions, then it stands to reason that caregivers of individuals with dementia with higher AT will experience less emotional distress, despite the ambiguities inherent to dementia caregiver, than caregivers with lower AT. This study seeks to understand the relationship between an individual caregiver's level of AT and the pre-death grief experienced by that person.

CHAPTER III

REVIEW OF LITERATURE

Introduction

This chapter offers the justification for conducting a study to investigate the relationship between a caregiver's tolerance for ambiguity, including the specific stimuli, and that individual's grief response to their care recipient's dementia: in total, and specifically in burden, worry, and sadness.

The trait of ambiguity tolerance (AT) has not been empirically connected to emotional outcomes when individuals face complex, confusing, and indefinite losses. While Boss's theory of ambiguous loss claims that ambiguity tolerance creates a natural resiliency in caregivers (Boss, 2007), this has not been demonstrated through any empirical study related to grief and loss. Instead, social psychologists have investigated ambiguity tolerance and its impact upon emotional wellbeing by using such outcome variables as depression and anxiety (Andersen & Schwartz, 1992; Bardi, Guerra, & Ramdeny, 2009). Organizational psychologists have investigated ambiguity tolerance within an organizational setting to determine if role ambiguity in the workplace causes psychological strain in individuals with low AT (Frone, 1990). While these studies are suggestive of the impact ambiguity has on individuals with low AT, there is a need for empirical study on the direct association between ambiguity tolerance and grief reactions in caregivers of individuals with dementia.

The following review of the literature represents literature relevant to this research study, specifically AT and caregiver grief. Therefore, this chapter contains a section for each.

Ambiguity Tolerance

Ambiguity tolerance (AT), as a personality trait, has been investigated in the psychological literature since the early twentieth century and defined as an individual's reaction to a nebulous stimulus. One of the earliest scholars to investigate this concept, Frenkel-Brunswik (1947) tied AT to the authoritarian personality. She described AT as the ability of an individual to acknowledge both positive and negative attributes of the same entity without making premature black and white value judgments about that entity. She described individuals with low AT as being rigid and unable to view situations in more than one way. As a result, Frenkel-Brunswik (1947) argued, low AT individuals experience anxiety as a result of confusion arising from complex situations, engaging in either denial of these situations or seeking for premature closure by relying on all-or-nothing judgments. Budner (1962) expanded on this notion by enumerating differential reactions of low AT individual in response to ambiguous situations. He stated that individuals could either submit to these situations or deny them, and they could do so either phenomenologically or operatively. Budner concluded that AT is not a "lever for manipulating the environment" (1962, p. 48) and viewed AT as a largely contextual trait that becomes relevant for an individual only when that person comes into contact with an ambiguous or complex situation; as a result, Budner differentiated between rigidity and AT. MacDonald (1970) further differentiated the concepts, stating that rigidity is a persistent, unique state, whereas intolerance for ambiguity is a tendency to respond in diverse ways to ambiguous or complex ideas or situations. He argued that those who were intolerant of ambiguity could still be adaptable when presented with changing information or stimuli (MacDonald, 1970).

As a Resilience Factor

Several studies have shown AT to be a factor of resilience, allowing higher AT individuals to thrive in the midst of uncertainty and to perform better in uncertain and ambiguous

situations. Several studies have linked AT to enjoyment of complex or ambiguous work or tasks (Shaffer & Hendrick, 1974; Wittenberg & Norcross, 2001) and to performance quality on those tasks (MacDonald, 1970). MacDonald (1970) found an association between AT and performance on complex tasks by pairing a word scramble test with his own Ambiguity Tolerance-20 scale in a sample of students at Cornell University. Shaffer and Hendrick (1974) sought to understand to what extent high and low AT individuals enjoyed complex and ambiguous tasks and to what extent their participants would seek to enhance the tasks. Their findings revealed that higher AT individuals experienced less mental discomfort resulting from the more complex and effortful task and that those individuals mentally enhanced the tasks; conversely, lower AT individuals experienced greater discomfort resulting from the study's tasks and disdained the task afterward (Shaffer & Hendrick, 1974). A more recent study by Wittenberg & Norcross (2001) employed a sample of 212 psychologists to investigate AT and the enjoyment of conducting psychotherapy. They found that intolerance of ambiguity was resulted in reduced enjoyment of conducting psychotherapy, while individuals with higher AT enjoyed conducted psychotherapy (Wittenberg & Norcross, 2001). Brandi-Brown, Bello, and Ragsdale (2010) investigated the impact of AT on the interpretation of marital repair messages among remarried individuals at a Southern university. The authors found that higher AT individuals had more positive perceptions of the competence of marital repair messages, leading the authors to believe that higher AT individuals have a broader acceptance and toleration of repair message uncertainty and interpretation (Brandi-Brown et al., 2010).

Overall, then, individuals with a higher AT are able to function and even thrive in the midst of ambiguity and uncertainty (Brandi-Brown et al., 2010; Shaffer & Hendrick, 1974; Wittenberg & Norcross, 2001), whereas their lower AT counterparts experienced discomfort

when faced with complexity and performed poorly on tasks that were considered to be insoluble (MacDonald, 1970; Shaffer & Hendrick, 1974).

As an Emotional Wellbeing Factor

Ambiguity tolerance has been associated with indicators of emotional wellbeing, including anxiety, depression, and psychological strain, resulting from the individual's difficulty coping with situations that are unfamiliar or complex. One study concluded that intolerance of ambiguity increases an individual's risk of developing emotional difficulties (Andersen & Schwartz, 1992). For instance, in a ten-week study of college students, Anderson and Schwartz (1992) sought to understand the association between ambiguity intolerance (AI) and depression. They measured AI, depression, and depressive certainty (defined as the number of negative events that students anticipated would occur). The results supported their hypothesis, which was that AI predicted both depression and depressive certainty, even when depression was controlled for at the first time of measurement (Andersen & Schwartz, 1992). The authors concluded individuals who were higher in AI accepted depressive certainties in order to relieve the tension of an ambiguous situation (Andersen & Schwartz, 1992).

Several studies have found that the influence of AI upon emotional wellbeing is situational (Bardi, Guerra, and Ramdeny 2009; Frone, 1990). Bardi and colleagues (2009) investigated wellbeing and AI within the context of a life transition by comparing first year college students to upper level college students. The authors observed that wellbeing was correlated with AI only in first-year students and thus concluded that the construct of AI is contextual in nature. Their findings support Budner's (1962) conclusion that AI is situational. Frone (1990) conducted a meta-analysis of occupational role stress studies in order to determine whether AI moderates the relationship between role ambiguity and psychological strain within an

occupational setting. While hypothesis was preliminarily confirmed, the author cautioned that more research was needed due to limitations in research design (Frone, 1990). Frone noted that the only one study included in his analysis used a stressor other than role ambiguity and that assessments of psychological strain were very narrow in scope in the studies he included (1990).

AT and curiosity and information-seeking behaviors. Several studies have investigated whether individuals vary in curiosity and information-seeking behaviors, based on their levels of ambiguity tolerance (Bennett, Herold, & Ashford, 1990; Littman, 2010; Xu & Tracey, 2014). It has established above that individuals who have lower AT struggle with complexity, ambiguity, and a lack of clarity of information. Ambiguity tolerance also plays a role in an individual's desire to seek out more information (Bennett et al., 1990; Littman, 2010) and ability to make decisions based solely on the information that is presently available (Xu & Tracey, 2014).

Several studies have investigated the role of information seeking with regard to ambiguity tolerance (Bennett et al., 1990; Litman, 2010). Bennett and colleagues investigated feedback-seeking behaviors within the context of the workplace, finding that individuals with higher TA seek job-related feedback less often than individuals with lower TA in order to reduce anxiety related to career. However, like Budner (1962) and Bardi et al. (2009), Bennett and colleagues concluded that AT is contextual. Tolerance for ambiguity in problem solving did not predict feedback-seeking, specifically; only job-related tolerance for ambiguity was associated with feedback-seeking behaviors in the workplace (Bennett et al., 2009). Litman (2010) investigated information-seeking from a slightly different perspective, seeking to understand the motivation behind information-seeking behaviors. Litman (2010) therefore investigated the relationship between AT and two separate types of information seeking: Interest-type curiosity

(motivated by the desire to produce feelings of interest) and Deprivation-type (motivated by the desire to reduce negative feelings associated with a deficiency of knowledge). As hypothesized, ambiguity tolerance was inversely correlated with D-type curiosity, indicating that individuals with lower AT seek information out of a desire to reduce negative feelings associated with lack of clarity or with ambiguity.

Xu and Tracey's (2014) study of career indecision among college students in the southwest found ambiguity tolerance plays a powerful role in decision-making with regard to careers. Ambiguity tolerance was found to be inversely associated general indecisiveness and indecisiveness attributed specifically to flawed beliefs, incomplete information, and conflicting information (Xu & Tracey, 2014). Therefore, individuals who have higher AT are less likely to experience career indecision. Interestingly, rather than seeking for premature closure, low AT individuals can become caught up the need to determine the optimal career decision, becoming increasingly indecisive due to distorted and conflicting information about their choices (Xu & Tracey, 2014). Combined with the results of Fouad, Cotter & Kantamneni's study (as cited in Xu & Tracey, 2014), which found that simply acquiring more information is not sufficient for reducing career indecision, it would appear that ambiguity tolerance plays a significant role in an individual's decision-making capability.

Caregiver grief

History of the Concept

Caregiver grief refers to pre-death grief experienced by those who provide assistance to loved ones living with dementia in response to past, present and future relational losses. However, research on caregiver grief has been plagued by a lack of clarity as to the definition and operationalization of the term "caregiver grief" (Lindauer & Harvath, 2014). While caregiver

grief is sometimes referred to as *anticipatory grief*, it is important for the purposes of this study to draw a distinction between the concept of pre-death grief and anticipatory grief. While there are some similarities between the concepts, Lindauer and Harvath (2014) argue that there are important differences that differentiate the two and offer helpful clarifying points that may help to guide future research on both anticipatory grief and pre-death grief.

First, whereas anticipatory grief specifically refers to feelings of anxiety and loss in anticipation of the future (such as impending death of a loved one with a terminal illness), pre-death grief, which is the focus of this study, refers to losses that take place throughout the course of dementia and result from disruptions or threats to the attachment between the two involved persons (Lindauer & Harvath, 2014; Ott et al., 2007).

Because anticipatory grief is in response to the loss of a *future*, it is considered to be an irretrievable loss. For instance, the diagnosis of terminal cancer in a loved one may be construed as the loss of years spent together, the loss of future possibilities, the loss of opportunities – in other words, anticipated or future losses (Lindauer & Harvath, 2014). Pre-death grief results from changes in the relationship between two individuals – impaired communication, disturbances in behavior, emotional instability. Pre-death grief is often more intermittent in nature, in that the affected individual may at times seem to improve and recover some of her former health and lucidity. These periods of improvement can cause confusion and anxiety for the caregiver. Second, pre-death grief includes the loss of personhood, or a psychosocial death (Lindauer & Harvath, 2014; Meuser, Marwit, & Sanders, 2004). Therefore, for the caregiver, the full extent of grief is felt in the present, unlike with anticipatory grief, in which grief is not fully experienced until the death of the individual.

The pre-death grief associated with dementia caregiving is often referred to as a series of mini-deaths, due to the progressive impairments associated with the disease (Lindauer & Harvath, 2014; Marwit et al., 2004; Ross & Dagley, 2009). All aspects of personhood are impacted: communication, emotion regulation, memory, sleep, and behavior, such that the affected individual becomes increasingly dependent upon the care of another individual (or perhaps an agency).

Pre-death grief in caregivers of individuals with dementia results from the attachment between the caregiver and care recipient. Bowlby's theory of attachment explains the tendency of all human beings to form emotional bonds to others, as well as the emotional reaction of individuals when those bonds are challenged or broken (1989; Worden, 2009). This theory holds that individuals, from the time they are children, form attachments to those who are older, wiser, and stronger, beginning with their primary caregiver, often the mother. This is due to the child's need for protection, sustenance, and security. While attachments formed in childhood persist into adulthood, they often wane to some extent and are appended by new attachments, such as those to spouses or partners. The attachment figure is sought out due to a desire for a sense of security. These roles provide safety and a sense of purpose for both individuals (Bowlby, 1989; Worden, 2009).

How Grief Manifests

When there is a disturbance or threat to the attachment, as a result of death, separation, or illness, feelings of grief manifest in a range of emotions (Bowlby, 1989; Worden, 2009). These emotions mirror the bond between the two individuals and can range from anxiety and fear to anger and frustration to depression and sadness. Behavioral disturbances can also occur due to grief, including poor sleep, loss of appetite, and social isolation (Worden, 2009). Grief can also

manifest in feelings of burden, which has been associated with loss of health status (Papastavrou, Kalokerinou, Papacostas, Tsangari, & Sourtzi, 2007).

As mentioned above, the caregiver grief literature has struggled to define and to measure the concept of pre-death grief. Due to the insensitivity of quantitative instruments, many researchers have chosen to investigate the experience of caregivers using a qualitative or mixed methods approach (Frank, 2007; Loos & Bowd, 1997; Marwit & Meuser, 2001; Rudd, Viney & Preston, 1999; Sanders & Corley, 2003; Sanders, Ott, Kelber, & Noonan, 2008). Findings from these studies indicate that while caregivers have a diverse range of phenomenological reactions to their daily circumstances, common themes abound, including loss of control and burden, isolation, and longing for the past.

Loss of control over life and increased burden were prominent themes among the studies (Frank, 2007; Loos & Bowd, 1997; Marwit & Meuser, 2001; Rudd et al., 1999; Sanders & Corley, 2003; Sanders et al., 2008). This loss of autonomy was connected to the uncertainty of the disease, and caregivers felt immobilized by the constant threat of being needed by the care recipient at all hours (Loos & Bowd, 1997; Sanders et al., 2008). The emotional toll resulting from such burden is high, with many caregivers reporting frustration, anger, anxiety, and sadness over the day-to-day demands (Loos & Bowd, 1997; Marwit & Meuser, 2001; Rudd et al., 1999).

Isolation was also a common experience for caregivers with some reporting that they had had to give up social interaction (Loos & Bowd, 1997), and others stating that friends had simply ceased to approach them, causing the caregiver to feel stigmatized by their care recipients' illness (Sanders et al., 2008). The sense of isolation had a negative impact on the caregiver's grief, particularly when coupled with the loss of intimacy, increasing feelings of sadness and loneliness (Sanders & Corley, 2003). Caregivers report both a loss of social interaction and a

loss of relationship with the care recipient simultaneously, compounding their sense of isolation (Sanders & Corley, 2003). Grief over loss of various interpersonal relationships was a prominent theme in the several studies (Marwit & Meuser, 2005; Meuser & Marwit, 2001; Sanders & Corley, 2003).

Yearning for the past was another common theme in qualitative studies (Frank, 2007; Loos & Bowd, 1997; Marwit & Meuser, 2001; Sanders et al; 2008), revealing that caregivers experience loss prior to the death of the care recipient. Caregivers expressed sadness over changes in the care recipient's affect and behavior, reporting that the individual acted in unfamiliar ways or did things that would never have done prior to the onset of the disease (Frank, 2007; Sanders & Corley, 2003; Sanders et al., 2008). Care recipients became like strangers to the caregiver as a result, producing feelings of ambivalence and confusion (Sanders & Corley, 2003). Caregivers mourned the loss of the relationship that was previously shared between themselves and the care recipient and had been damaged due to the disease (Marwit & Meuser, 2001).

Ambiguities in Caregiving

As discussed in the previous chapter, several studies have specifically investigated themes of ambiguity in dementia caregiving (Blieszner et al., 2007; Dupuis, 2002; Frank, 2007; Sanders & Corley, 2003). Various factors associated with dementia caregiving produce uncertainty, complexity, and confusion for caregivers. While this study is limited in its ability to consider the influence of such factors, their influence warrants discussion here in order to justify the design of the study.

Behavioral issues/severity of dementia. The behavioral and psychosocial changes associated with dementia create confusion and ambiguity for caregivers. As individuals affected

by dementia become increasingly impaired by the disease, they become more dependent on their caregivers and less able to fulfill social roles, but are still unchanged in physical appearance. These changes are often gradual in nature, which adds to the confusion and ambiguity for caregivers. Blieszner and colleagues (2007), whose qualitative study focused on spouses of individuals with mild cognitive impairments resulting from the early stages of dementia, noted that misattribution of symptoms was common among their sample, due to the gradual nature of the disease. Even so, role ambiguity, due to behavioral changes and needs, was common among the sample. Other qualitative studies drew similar conclusions about the ambiguities and grief resulting from dementia-related impairments. Blocked communication that occurred during the course of the disease caused complex emotional reactions for many caregivers (Dupuis, 2002; Frank, 2007).

Behavioral issues and severity of dementia, which produce ambiguity as discussed above, are also directly correlated with increased grief in caregivers (Clyburn et al., 2000; Frank, 2007; Ott et al., 2007; Ponder & Pomeroy, 1997; Warchol-Biedermann et al., 2014), largely due to the disruptions these cause in the relationship between caregiver and care recipient (Frank, 2007; Ott et al., 2007; Warchol-Biedermann et al., 2014). Behavioral problems can take the form of disruption to communication patterns (Frank, 2007), depressive symptoms (Holley & Mast, 2010), memory difficulties (Holley & Mast, 2010; Ott et al., 2007), repetition of words (Frank, 2007), aggression (Sanders & Corley, 2003), etc.

Both qualitative and quantitative methods have been employed to investigate the association between severity of dementia and grief. One aspect of caregiver grief as identified by Marwit and Meuser (2001), burden, has been linked to frequency of disturbing behaviors in a quantitative study of both adult child and spousal caregivers (Clyburn et al., 2000). Another

study had conflicting results, concluding that while burden was not increased in caregivers of severely impaired individuals, sadness and longing were elevated in the sample (Ott et al., 2007). Similarly, Warchol-Biedermann and colleagues (2014) found that individuals who supported care recipients with severe dementia scored significantly higher on a grief measure than those whose care recipients were less severely impaired by dementia. Ponder and Pomeroy (1997) drew a similar conclusion, attributing approximately 12% of the variance of the intensity of the caregiver's grief to the severity of the care recipient's dementia. Frank (2007) utilized a mixed methods approach to determine the greatest barrier faced by caregivers and concluded that grief attributed to behavioral difficulties in the care recipient was a prominent theme among her sample.

Several studies refute this strong and direct association, however (Holley & Mast, 2010; Lindgren, Connelly, & Gaspar, 1999). A study of emotional grief expression conducted by Lindgren and colleagues (1999) found no association between severity of dementia (measured as functional and cognitive ability). However, one possible explanation for this result is that the clinical rating of dementia was performed by researchers; other studies have established that a caregiver's subjective assessment of the care recipient's disease progression is a better predictor of grief (Clyburn et al., 2000; Ott et al., 2007; Warchol-Biedermann et al., 2014). Holley and Mast (2010) concluded that severity of dementia alone played little or no role in grief as a whole. Using a qualitative design, the authors instead found that specific types of behaviors triggered grief reactions in adult child and spousal caregivers, respectively. For instance, adult child caregivers were most distressed by depressive and tearful behaviors in their parent care recipients, whereas disruptive behaviors produced grief reactions in spousal caregivers (Holley & Mast, 2010). This finding speaks to the unique nature of attachments between adult children and

parents and between spouses and also lends support to the theory that pre-death grief in caregivers is a relational loss.

Length of caregiving career. Despite the association between severity of dementia, which increases with time, and grief, studies have shown that there is no association between grief and the length of time a caregiver has been providing assistance (Lindgren et al., 1999; Ponder & Pomeroy, 1997). Lindgren et al. (1999) used a survey methodology to investigate grief in both spousal and adult child at-home caregivers of individuals with dementia, concluding that grief remained constant throughout the caregiving career. Ponder and Pomeroy (1997) found evidence for a very slightly curvilinear relationship between number of years caregiving and grief, showing that grief may increase in the early years of caregiving, decrease slightly during the middle years, and increase again near the care recipient's death. However, they were unable to substantiate this with enough data to produce a significant result (Ponder & Pomeroy, 1997).

This lack of association between length of caregiving career and grief supports Boss's assertion that the ambiguities inherent in dementia caregiving block coping mechanisms and freeze grief (Boss, 2007, 2010, 2011, 2012; Boss & Carnes, 2012). Without a definitive loss and due to the progressive nature of the dementia illness, the caregiver exists in a state of confusion and constant adjustment to which there is no adapting.

Social support and isolation. Findings related to social support and grief in caregivers of individuals with dementia are diverse and conflicting, as social isolation has been investigated as both a cause of increased grief and a consequence of dementia caregiving. In that respect, social isolation related to dementia caregiving is somewhat cyclical in nature. For instance, dementia-related behavioral changes cause a sense of grief and social isolation as communication

with the care recipient becomes increasingly more difficult (Frank, 2007; Lindauer & Harvath, 2014; Ott et al, 2007) and as social interactions with others become less frequent due to increased caregiving demands (Frank, 2007; Lindauer & Harvath, 2014). However, Ott et al. (2007) found that the existence of social support did not provide an effective buffer against loss in caregivers with high levels of grief. Additionally, Clyburn et al. (2000) found that low levels of informal help actually led to increased levels of burden. However, several qualitative studies found that lack of social support can be a source of grief and stress for caregivers (Frank, 2007; Loos & Bowd, 1997). Frank (2007) reported that social isolation was a barrier to coping with grief and stress, as non-caregiving family members had divested themselves of any responsibility and friends were incapable of understanding. Caregivers within this sample felt that others were pushing them toward early institutionalization due to insensitivity toward their emotional attachments (Frank, 2007). Loos and Bowd (1997), whose sample was derived from rural Canada, reported that caregivers felt friends within their social networks were insensitive to their personal sacrifices.

Demographic Factors

Nature of relationship to care recipient. There are conflicting results regarding the nature of pre-death grief in spouses and adult child caregivers of individuals with dementia, though most studies indicate that adult children and spouses perceive and react to dementia-related losses differently (Holley & Mast, 2010; Meuser & Marwit, 2001). Quantitative and qualitative approaches produce differing results, and it is necessary to examine both types of studies to gain a more shrewd perspective into the experiences of adult child and spousal caregivers.

Adult children and spouses each have different triggers for their grief (Holley & Mast, 2010) and experience grief differently throughout the caregiving career (Meuser & Marwit, 2001). Meuser and Marwit (2001) used a mixed methods approach, employing focus groups to better understand the diverse emotional experiences of adult child and spousal caregiver. Their findings revealed that pre-death grief differs significantly based on the nature of the relationship between caregiver and care recipient, particularly at different stages of the illness. Adult children began the caregiving career with a sense of denial, attributing any changes in their older parents' behavior to "normal" aging processes rather than to the diagnosis of dementia; spousal caregivers, on the other hand were more accepting and open regarding the dementia-related changes (Meuser & Marwit, 2001). Whereas spousal caregivers responded with empathy and sadness as their loved ones' dementia progressed, adult child caregiver reported anger and frustration at the burden and sacrifices that are an intrinsic part of dementia caregiving (Meuser & Marwit, 2001). The adult children reported a sense of relief upon placing their parents in an institutional setting during late stage dementia, spousal caregivers experienced a rise in grief at this point (Meuser & Marwit, 2001).

Quantitative approaches have produced mixed results (Holley & Mast, 2010; Warchol-Biedermann et al., 2014). Warchol-Biedermann et al. (2014) found no significant difference in the grief experiences of spousal and adult child caregivers. Holley and Mast's quantitative approach was able to capture the nuanced emotional reaction of spousal and adult child caregivers due to their use of a sensitive scale for dementia-related behavioral changes (2010). They concluded that distinct behavioral changes elicit grief in adult children and spousal caregivers. For instance, spousal caregivers experienced more grief in response to disruptive

behavioral changes in their care recipient, whereas adult child caregivers' grief reactions were more prominent when their care recipients exhibited depressive-type behavioral changes.

Warchol-Biedermann et al. (2014) surveyed a sample of 151 Polish family caregivers using a quantitative scale to measure the intensity and level of grief in spouse and adult caregivers, finding no difference between the two groups. There are perhaps several explanations for the differences found in these studies. First, while the quantitative methodology employed by Warchol-Biedermann et al. (2014) was able to measure intensity of grief, it may not have been suitable for revealing disparities in the emotional experiences of the spousal and adult child caregivers. Second, there may be cultural differences in family structure and caregiving expectations in Poland that inform children's reactions to providing care for their aging parent (Warchol-Biedermann et al., 2014).

Placement/living arrangement. The literature regarding the placement of care recipients has been nuanced. The findings of studies are highly contingent upon the population of interest (adult child versus spousal) and upon which outcome measure of grief is being measured (burden, longing, or isolation). Clyburn et al. (2000) performed a quantitative study linking caregiver burden to community residence of care recipient in a mixed sample of adult child and spousal caregivers. Marwit and Meuser's (2001) study seems to support this finding, as, within their sample, adult children, conversely, reported a sense of relief and reduction in burden upon institutionalization. The results of Loos and Bowd's (1997) study contradict this finding, as many caregivers within their sample reported that they still felt burdened with daily care, despite having institutionalized the care recipient.

Several studies that compared spousal and adult child caregivers were able to discover differences between the two groups (Marwit & Meuser, 2001; Ott et al., 2007). Marwit &

Meuser (2001) argue that spousal caregivers experience tremendous emotional distress upon placing the care recipient within an institutional setting, which is supported by Ott and colleagues' finding (2007) that caregiving spouses of nursing home residents scored higher on grief measures. Rudd et al. (1999) employed a qualitative methodology to better understand the emotional experience of spousal caregivers, drawing the conclusion that nursing home caregivers experience more anxiety, sadness, and guilt, whereas at-home caregivers report more anger and bitterness resulting from the burden of caregiving.

Influence of Personality

As demonstrated above, pre-death grief is well documented in the literature in terms of its causes and its emotional toll. However, only one study to this author's knowledge has investigated the influence of a caregiver's personality traits on the experience of depression and burden in dementia caregivers. (Melo et al., 2011). In a sample of 105 Portuguese dementia patients and their family caregivers, the authors investigated the influence of the Big 5 personality traits (openness to experience, agreeableness, conscientiousness, extraversion, and neuroticism) on depressive symptoms and the caregivers' perception of burden (Melo et al., 2011). The authors concluded that three personality traits were significantly associated with the dependent variables measured in the study. Neuroticism was correlated with increased burden and depressive symptoms, while Extraversion was associated with decreased burden and depressive symptoms. Agreeableness, meanwhile, was related to reduced burden. On the whole, Melo and colleagues (2011) concluded that increased attention should be paid to the influence of a caregiver's personality during intervention and in directing future research endeavors.

Conclusion and Gaps

The literature concerning caregiver grief has extensively explored the vast experiences of those providing support and assistance to an individual with dementia. Both qualitative and quantitative studies attempted to capture the grief reactions that surface throughout the course of caregiving, as well as the factors that influence that grief, including the ambiguities that surface throughout the caregiving career. One of the most profound influencing factors includes caregiver's perception of the severity of the care recipient's dementia, which has been linked with confusion, ambiguity, and the overall intensity of the caregiver's grief (Blieszner et al., 2007; Clyburn et al., 2000; Dupuis, 2002; Frank, 2007; Ott et al., 2007; Sanders & Corley, 2003; Warchol-Biedermann et al., 2014). However, length of caregiving career has not been associated with any increases in caregiver grief, which supports Boss's theory of ambiguous loss (Boss, 2007; 2010; 2012). Only one study to date has investigated the relationship between a caregiver's personality traits and any aspect of grief, and that study found that three personality traits influence caregiver grief. The authors concluded that more research should be conducted on the influence of personality on caregiver grief and that more clinical attention should be paid to the personality of individual caregivers.

Research applications of the ambiguity tolerance trait have been diverse. Ambiguity tolerance has been investigated within the context of workplace role ambiguity (Frone, 1990), informational deprivation (Bennett et al., 1990; Litman, 2010; Xu & Tracey, 2014), academic life transition (Bardi et al., 2009), and marital repair (Brandi-Brown et al., 2010). Despite the diversity of these applications, conclusions from the studies shared several themes. Individuals with lower ambiguity tolerance experience more stress in situations that lack clarity (Bardi et al., 2009; Frone, 1990), experience reduced enjoyment of and increased frustration with ambiguous tasks (Shaffer & Hendrick, 1974; Wittenberg & Norcross, 2001), and do not perform as well at

tasks that are unclear or are difficult to construe (MacDonald, 1970). Individuals with low ambiguity tolerance may be motivated to seek out ways to reduce this stress by seeking certainty, including coming to premature depressive conclusions (Andersen & Schwartz, 1992) or seeking out information in an attempt to reduce uncertainty and ambiguity (Bennett et al., 1990; Litman, 2010).

While caregiver grief and ambiguity tolerance have each been investigated separately, there have been no studies investigating this relationship from the perspective of ambiguous loss theory. This study aims to investigate the relationship between the two in caregivers of individuals with dementia. The study takes into account the different aspects of grief identified here, including burden, sadness, and social isolation, and whether these different outcomes are influenced by several different types of ambiguity tolerance as well. The following chapter will outline the specific methodology employed by the study, including participant selection, instrumentation, data collection, and data analysis.

CHAPTER IV

METHODOLOGY

Introduction

The primary aim of this study was to test the research questions, as stated in Chapter I, regarding the relationship between overall ambiguity tolerance (as well as reactions to stimuli that are generally ambiguous, novel, insoluble, and uncertain) and overall grief (as well as grief factors of burden, sadness, and isolation). To this end, a survey was constructed comprising two separate instruments and seven additional questions. This chapter details the methodology utilized to test the research question and includes the following sections: (1) selection of participants, (2) instrumentation, (3) data collection, and (4) data analysis.

Selection of Participants

The study targeted family caregivers of individuals with diagnosed with dementia in Arkansas. In order to recruit participants most effectively, the researcher approached agencies comprising adult day centers, assisted living facilities, and memory care units, as well as support group facilitators in west and northwest Arkansas for interest in assisting with the research. Agencies were chosen based on their self-reported interaction with dementia caregivers. A total of 13 agencies were approached about participating in the study; eleven agreed to participate. Upon consenting to participate, each agency or support group facilitator was given a box of survey packets according to the approximate number of caregivers served by the organization. Agencies and facilitators were asked to distribute a survey packet to all family caregivers served by the agency, in order to limit bias. One hundred-ninety surveys were distributed to agencies; fourteen surveys were returned, yielding a 7.4% return rate.

In addition to paper survey distribution, participants were also recruited using an online posting to a university news site due to the ability to reach a large number of potential participants through electronic means. An online version of the survey was created so that potential participants could easily access it. A description of the study and requirements for participation were posted to the university news site. Seventeen caregivers were recruited in this manner.

Instrumentation

The survey instrument comprised two pre-existing scales to measure ambiguity tolerance and overall caregiver grief and seven additional questions to collect other data, including demographic information and several factors indicated in the literature to influence caregiver grief and ambiguity in dementia caregiving. A copy of the survey instrument can be found in Appendix A.

Demographic questions. Participants self-identified their own gender as male, female, or “prefer not to say.” This was treated as a nominal variable. Age of participant, also self-reported, was measured in years and treated as an interval variable.

Other factors. Participants were asked to identify the type of relationship between themselves and the care recipient (“I am caring for...” [left open-ended to allow for non-traditional relationships]), producing a nominal variable. A third demographic nominal variable included the living situation of the care recipient (in-home, independently, in an assisted living or nursing home facility, or other [open-ended]). Participants reported the length of time they had been providing care since the care recipient’s diagnosis of dementia in months or years, which was treated as an interval variable. Level of social support was assessed using a five-point Likert-scale, asking caregivers to choose level of agreement, from “strongly disagree” to

“strongly agree,” with a statement expressing fully supported by others in caregiving efforts. Perceived frequency of difficult behaviors in the care recipient was also assessed using a five-point Likert scale, from “hardly ever” to “almost always.” Both questions were treated as interval measures.

Meuser-Marwit Caregiver Grief Inventory. The Meuser-Marwit Caregiver Grief Inventory Short Form (MM-CGI-SF) (Marwit & Meuser, 2005), which was derived from the original 50-item scale (Meuser & Marwit, 2001) was used to measure caregiver grief. Marwit and Meuser (2002) developed their original scale from the results of the focus groups conducted in their 2001 study of caregiver grief (Meuser & Marwit, 2001). Based on these results, the authors developed a 50-item scale consisting of three subscales, which they titled Personal Sacrifice Burden, Heartfelt Sadness and Longing, and Worry and Felt Isolation (Marwit & Meuser, 2002; 2005). The MM-CGI-SF consists of the six best correlating items from each factor on the original scale, totaling 18 items. The selected items demonstrate item-to-scale correlations of $r = .915 - .928$, $p < .01$, when compared to the original 50-item scale. The Cronbach’s alpha for this scale ranges from .80 to .83 (Marwit & Meuser, 2005), demonstrating good internal consistency for a short form scale. For the present study, Cronbach’s alpha for the MM-CGI-SF was .874. Item-to-scale correlations ranged from .239 to .711; removal of the lowest two correlating items, items 7 (“My friends simply don’t understand what I am going through”) and 12 (“I feel very sad about what this disease has done” at $r = .239$ and $r = .247$, respectively, would have improved the scale’s overall performance.

In its initial validation, the MM-CGI-SF was presented with the following measures to test its construct validity: the Caregiver Strain Index (Robinson, 1983), the Anticipatory Grief Scale (AGS, Theut et al., 1991), and Perceived Social Support Family Questionnaire (PSS-FQ;

Procidano & Heller, 1983) (Marwit & Meuser, 2005). The MM-CGI-SF demonstrated convergent validity with the Anticipatory Grief Scale ($r = .760, p < .01$) and the Caregiver Strain Index ($r = .640, p < .01$), as well as discriminant validity with the Perceived Social Support Family Questionnaire ($r = -.353, p < .01$) (Meuser-Marwit, 2005).

The authors named the three subscales of the MM-CGI-SF for identified themes of loss in the qualitative literature. Each subscale contains six items. The Personal Sacrifice Burden subscale identifies losses related to autonomy and personal freedom due to the demands of caregiving and consists of items such as “Independence is what I’ve lost...I don’t have the freedom to go and do what I want.” Within the present sample, this subscale performed with an internal consistency of $\alpha = .789$. The Heartfelt Sadness and Longing subscale is more closely connected to conventional understandings of grief and describes intrapersonal feelings relating to sorrow and yearning for the past. It consists of statements such as “I long for what was, what we had and shared in the past.” Within the present sample, reliability for this subscale was found to be $\alpha = .788$. The Worry and Felt Isolation subscale expresses loss of social connections and support as a result of caregiving, as well as concern regarding future losses. It consists of items such as “I lay awake most nights worrying about what’s happening and how I’ll manage tomorrow” and “The people closest to me do not understand what I’m going through.” For the present sample, reliability analysis showed that internal consistency for this subscale was slightly lower at $\alpha = .697$.

On the MM-CGI-SF, participants are asked to respond to each statement on a scale ranging from 1 (strongly disagree) to 5 (strong agree). According to Marwit and Meuser (2005), scores above 25 may be indicative of a need for clinical intervention. Scores below 13 may be

indicative of either advantageous coping mechanisms or denial, and attention in such cases may be warranted (Marwit & Meuser, 2005).

Multiple Stimulus Types Ambiguity Tolerance Scale. This construct was measured by the 13-item Multiple Stimulus Types Ambiguity Tolerance Scale II (MSTAT-II), developed by McLain (2009) as a shortened form of the original 22-item Multiple Stimulus Types Ambiguity Tolerance Scale (McLain, 1993). The scale is intended to measure an individual's response to several types of ambiguous stimuli: novel, insoluble, uncertain, or general ambiguity. Items were chosen for the shortened scale based on item-to-scale correlation and comprehensibility for individuals of diverse backgrounds (McLain, 2009).

The general-type ambiguity subscale of five items, such as "I don't tolerate ambiguous situations well." The insoluble-type ambiguity subscale is designed to measure stimuli that are complex or contradictory and consists of five items, such as "Problems that cannot be considered from just one point of view are a little threatening." The novel-type ambiguity subscale measures a participant's response to stimuli that are new or unfamiliar and consists of only two items, including "I prefer familiar situations to new ones." The uncertain-type subscale only contains one item, which is "I find it hard to make a choice when the outcome is uncertain."

Participants are asked to respond to each statement on a scale ranging from 1 (strongly disagree) to 5 (strong agree). Four items are reverse scored, and when totaled and reversed, higher scores indicate a higher degree of tolerance for ambiguity.

The scale has demonstrated moderate concurrent validity with the MacDonald AT-20 Ambiguity Tolerance Scale ($r = .41, p < .01$) and moderate convergent validity with the related constructs of sensation seeking ($r = .33, p < .001$) and perceived uncertainty ($r = .19, p < .001$), but reports better internal consistency ($\alpha = .83$) than other ambiguity tolerance scales (McLain,

2009). For the present study, Cronbach's alpha for the MSTAT-II was .854. Item-to-scale correlations ranged from .267 to .688 for the MSTAT-II; removal of item 13 ("I prefer a situation in which there is ambiguity") at $r = .267$ would have improved the scale's overall performance.

Data Collection

Data collection included delivering survey packets to participating agencies that previously agreed to distribute the packets to caregivers. Each copy of the survey instrument was numbered 1 to 190 and packed into a correspondingly numbered, postage-paid return envelope. Each agency that consented to participate was provided with packets of the survey instrument to distribute to family caregivers, according to the approximate number of caregivers it serves. The corresponding numbers on the survey instruments were recorded so that it was possible to determine from which agencies completed surveys had originated. Approximately 15 paper flyers containing a link to an online version of the survey were also distributed to agencies to support the recruitment effort.

Employees at participating agencies and support group facilitators distributed individual packets to family caregivers. Individuals who consented to participate filled out the survey instrument and mailed it back using the addressed, stamped envelope.

Follow-up calls were made to each agency approximately two weeks after survey packets were initially delivered in order to ascertain how distribution was progressing. At follow-up, it was discovered that survey distribution was not progressing as effectively as had been anticipated. Two support group facilitators reported they had had no attendance; one agency director reported that her employees only distributed the survey if a caregiver asked about it after having seen the flyer or to caregivers she felt certain would complete it. Fourteen packets were

returned out of 190 that were distributed to agencies, yielding a 7.4% return rate. However, it is unknown how many surveys out of 190 were successfully distributed from agencies to caregivers.

A second strategy included advertising the study on a university electronic news posting. A description of the study's purpose and a link to the online survey were posted for one day on a campus news posting. Seventeen online survey respondents participated by clicking the link in the electronic news posting, providing electronic consent, then completing an electronic version of the same survey instrument. Responses were stored in an online database.

Data Analysis

The study employed a quantitative methodology of data analysis. Responses from completed surveys, including both the MSTAT-II and MM-CGI-SF, as well as demographic data, relationship to care recipient, placement of care recipient, level of social support, and frequency of behavioral problems, were coded into SPSS Version 22.

Univariate statistical analyses were conducted on demographic data, relationship to care recipient, placement, length of caregiving career, level of social support, and frequency of behavioral problems. Descriptive statistics and tables in the SPSS program presented findings regarding frequency and percentage of each response.

Next, nine items on the MSTAT-II were reverse-scored. Resulting scores and the four original items on the MSTAT-II were tallied into a new variable to assess *total ambiguity tolerance* for each participant. Scores for responses to the MSTAT-II subscales of general ambiguity, novelty, insolubility, and uncertainty were also calculated into new interval variables, resulting in a total of five independent variables. Participant responses on the MM-CGI-SF were calculated to assess *total caregiver grief*. MM-CGI-SF subscale scores for Personal Sacrifice

Burden, Heartfelt Sadness and Longing, and Worry and Felt Isolation were likewise calculated and stored as individual interval variables. This resulted in a total of four dependent variables.

Pearson's correlations were run between all nine variables described above in order to analyze relationships between them. Bivariate correlations were chosen to test the research question because both independent and dependent variables were interval measures.

Furthermore, due to the small sample size, multivariate analysis was not an option for the study, and as a result, it was impossible to control for confounding variables. Due to the small sample size, correlations at the $p < .1$ level were flagged as statistically significant, (Rubin & Babbie, 2011). For significant relationships, effect size was calculated to determine the strength of the relationship between the relevant variables.

Summary

This chapter reiterated the purpose of the study and research question. The participants of the study were chosen through the use of purposive sampling by approaching agencies that serve family caregivers of individuals with dementia in western and northwest Arkansas. As discussed, fourteen surveys paper surveys and seventeen online surveys were collected for a total of thirty-one participants. In addition, the reliability and validity of both the MSTAT-II and MM-CGI-SF were presented as evidence of their appropriate choice for the study. Procedures for data collection, as well as the participation rate for the study, were also discussed above. Lastly, data analysis methodology was offered, including both hypothesis testing and univariate analysis. In the following chapter, results of the data analysis will be presented.

CHAPTER V

RESULTS

Introduction

This study primarily aimed to investigate the relationship between levels of ambiguity tolerance and grief in caregivers of individuals with dementia. In order to achieve this aim, the study measured ambiguity tolerance and grief in a sample of caregivers in Northwest Arkansas. As mentioned in the Methodology chapter, due to the small sample size, it was impossible to confounding variables during data analysis. Instead, bivariate analysis was utilized to analyze the relationship between ambiguity tolerance and caregiver grief. This chapter offers the results of statistical analysis, including univariate and bivariate analysis of data collected.

First, a sample description is offered to provide an understanding of the characteristics of those who participated in the study. Next, descriptive statistics of interval data collected are provided, including ambiguity tolerance (and subscales), caregiver grief (and subscales), frequency of perceived behavioral difficulties, level of social support, and length of time caregiving. Lastly, the chapter presents the results of hypothesis testing using bivariate analysis.

Univariate Statistics

Sample Description

One hundred-ninety surveys were distributed to agencies. Fourteen surveys were returned, yielding in a 7.4% return rate. Seventeen surveys were completed online for a total of thirty-one respondents. Demographic information, including age and gender of caregiver, relationship to care recipient, and placement of care recipient were collected in order to ascertain a distinct representation of caregivers in the sample.

As noted in Table B1, 87% of caregivers sampled reported their gender as female ($n = 27$). Caregivers ranged in age from 20 years to 82 years with a mean of 61.61 years ($SD = 14.47$) and a median of 63 years (see Table B2).

Diverse relationships between caregiver and care recipient were reported. Spousal and adult-child caregivers were nearly evenly represented in the sample at 38.7% ($n = 12$) and 41.9% ($n = 13$), respectively. Other relationships reported include those caring for the parent of committed partner (6.5%, $n = 2$), for multiple persons (6.5%, $n = 2$), for a friend (3.2%, $n = 1$), and for another relative (3.2%, $n = 1$). Most of the caregivers in the sample stated that their care recipient lived either in the same home (48%, $n = 15$) or in an assisted living or nursing home facility (35.5%, $n = 11$). Four respondents said their care recipient lived independently (12.9%); one respondent responded “other” without elaborating. Demographic information and statistics are provided in Table B1.

Interval Variables

Interval data. The mean response for perceived frequency of difficult behavior exhibited by the care recipient was 3.29 ($SD = .902$). Responses ranged from 1 (“Very Rarely”) to 5 (“Almost Always,”) with a median and mode of 3 (“Occasionally.”) Agreement with the statement “I feel supported in my efforts caring for this person” also ranged from 1 (“Strongly Disagree”) to 5 (“Strongly Agree”). The mean response was 3.73 ($SD = 1.34$). The median and mode for this variable were both 4 (“Agree”). The length of time spent caregiving since the care recipient’s diagnosis of dementia ranged widely in the sample from 4 months to 10 years, with a mean of 3.57 years ($SD = 2.42$). The median was 3 years. These results are highlighted in Table B2.

Ambiguity tolerance. Total scores on the MSTAT-II ranged from 26 and 58, with a mean of 41.44 (SD = 7.26) and a median of 43. These statistics, as well as participant scores in response to the four distinct types of ambiguous stimuli (general ambiguity, insolubility, novelty, and uncertainty) can be seen in Table B3.

Caregiver grief. Participant scores on the MM-CGI-SF ranged from 35 to 73, with a mean of 52 (SD = 9.56) and a median of 51. Scores on the Personal Sacrifice Burden subscale ranged from 11 to 24, with a mean of 18 (SD = 3.83) and median of 18. Scores ranged from 10 to 30 on the Heartfelt Sadness and Longing subscale, with a mean of 21.48 (SD = 4.20) and median of 21. On the Worry and Felt Isolation subscale, participant scores ranged from 10 to 27, with a mean of 15.87 (SD = 4.16) and median of 15. These results can also be seen in Table B4.

Hypothesis Testing

Research Question: Is there an association between ambiguity tolerance and caregiver grief?

The overarching research question sought to determine if there is a relationship between ambiguity tolerance and grief in caregivers of individuals with dementia. The survey instrument utilized one scale to measure each construct. First, the MSTAT-II asked participants to identify their level of comfort with ambiguous situations or stimuli, including stimuli that were generally ambiguous, novel, insoluble, or uncertain. Next, the MM-CGI asked participants to indicate the degree to which they experience different aspects of grief associated with providing care for an individual with dementia.

Data for each scale were transformed into sub-scores and totaled. A Pearson's correlation matrix was then produced utilizing total ambiguity tolerance score on the MSTAT-II, scores in response to four subscales of ambiguity tolerance, total grief score on the MM-CGI-SF, and

scores on the three grief subscales. Statistically significant relationships at the $p = .1$ level were flagged. A p -value of .1 was determined to be adequate for the study due to the small sample size (Rubin & Babbie, 2011).

Table B5 illustrates the results of the correlations. No relationship was found to exist between total ambiguity tolerance and total caregiver grief ($r = -.003, p = .988$), which is illustrated in Figure B1. In addition, no relationships were found to exist between total ambiguity tolerance and Personal Sacrifice Burden ($r = -.089, p = .635$), Heartfelt Sadness and Longing, ($r = .096, p = .607$), and Worry and Felt Isolation ($r = -.051, p = .785$).

However, a weak, inverse relationship was found to exist between response to general-type ambiguous stimuli and Personal Sacrifice Burden ($r = -.349, p = .054$). As general-type ambiguity tolerance increased, Personal Sacrifice Burden decreased. The effect size of this relationship is modest ($r^2 = .122$). Approximately 12% of the variance of Personal Sacrifice Burden can attributed to a caregiver's reaction to general-type ambiguity. The results of this correlation are illustrated in Figure B2. No other statistically significant relationships were found to exist between any type of grief and any subscale of ambiguity tolerance.

Summary

In this chapter, the results of statistical tests were presented, including a sample description, univariate analysis, and hypothesis testing using bivariate correlational analysis between participant scores on the MSTAT-II and the MM-CGI.

The sample was predominantly female and split between adult child and spousal caregivers. Nearly all caregivers sampled were between the ages of 51 and 80, with the care recipient living primarily either in the same home or in an assisted living or nursing home facility.

Length of time providing care ranged widely within the sample, with the majority of participants having provided care for between 2 and 4 years.

Results of hypothesis testing revealed that no relationship was found to exist between total ambiguity tolerance and either total grief or any subscale thereof. However, a modest, inverse relationship was found to exist between a caregiver's response to general-type ambiguous stimuli and feelings of Personal Sacrifice Burden.

The next chapter will present a discussion of these findings in order to expand the understanding of the concepts presented within this study. Also discussed will be relevant implications for theory, direct social work practice, and policy practice, as well as future recommendations for research.

CHAPTER VI

DISCUSSION

Introduction

The preceding chapter presented the results of statistical analysis of data collected. This chapter comprises a summary of the study, a discussion of the findings, implications for direct and policy practice, recommendations for research, and conclusions. The aim of this chapter is to develop a broader understanding of the concepts presented by the study, including the influence of ambiguity tolerance on the experience of pre-death grief in dementia caregivers.

Summary of the Study

The purpose of this study was to investigate the association between ambiguity tolerance and grief in family caregivers of individuals with dementia. In order to achieve this aim, the study utilized a quantitative design. The Multiple Stimulus Types Ambiguity Tolerance Scale-II (McLain, 2009) and the Meuser-Marwit Caregiver Grief Inventory Short Form (Marwit & Meuser, 2005) were employed to measure ambiguity tolerance and caregiver grief, respectively.

The study included 31 participants recruited by agencies, support group facilitators, online news postings, and paper flyers. A demographic breakdown was provided for this sample, including age, gender, relationship to the care recipient, and placement of the care recipient.

The study investigated the following research question:

1. Is there an association between ambiguity tolerance and caregiver grief?

This question was answered using the results of a Pearson's correlation matrix between participants' scores for ambiguity tolerance (total, general ambiguity, insolubility, novelty, and

uncertainty) and caregiver grief (total, Personal Sacrifice Burden, Heartfelt Sadness and Longing, and Worry and Felt Isolation).

Discussion of the Findings

Previous researchers have studied themes of ambiguity in the dementia caregiving experience (Sanders & Corley, 2003), as well as the impact of ambiguity tolerance within various contexts, including life transitions (Bardi et al., 2009) and job-related role ambiguity (Frone, 1990). The central aim of this study was to determine if ambiguity tolerance as a personality trait might provide any buffering effect for family caregivers against loss that has been previously identified in the literature. The research hypotheses stated that an inverse correlation would be found between ambiguity tolerance (overall, as well as response to specific stimuli – general ambiguity, novelty, insolubility, and uncertainty) and grief (again, over, as well as each identified factor – burden, sadness, and perceived social isolation). The next section discusses the findings of the statistical analyses presented in the previous chapter in order to provide a broader understanding of the concepts offered here.

Total Ambiguity Tolerance and Caregiver Grief

Contrary to expectations, the results revealed that there is no relationship between total ambiguity tolerance and total caregiver grief. Participants with a higher total ambiguity tolerance did not experience any difference in level of total grief than participants with a lower ambiguity tolerance. Therefore it can be inferred that total ambiguity tolerance (meaning reaction to all types of ambiguous stimuli) did not have any impact upon overall grief for the caregivers in the study. As a result the researcher was not able to reject the null hypothesis.

Furthermore, no relationship was found to exist between total ambiguity tolerance and each of the three distinct facets of caregiver grief: Personal Sacrifice Burden, Heartfelt Sadness

and Longing, and Worry and Felt Isolation. As discussed in Chapter IV, total ambiguity tolerance, as measured by the MSTAT-II, comprises an individual's reaction to stimuli that are generally ambiguous, insoluble (complex or without an obvious solution), novel (new or unfamiliar), and uncertain (unable to be predicted). The results of the data analysis indicate that all of these types of ambiguity tolerance combined do not have the predicted inverse relationship with grief. Therefore, it can be said that total ambiguity tolerance does not buffer a caregiver's experience of Personal Sacrifice Burden, Heartfelt Sadness and Longing, and Worry and Felt Isolation, individually or in total.

While this finding contradicts the hypothesis in the study, it partially supports what has been shown in some of the literature on ambiguity tolerance. As previously mentioned in the literature review, ambiguity tolerance is believed to be a contextual and situational trait rather than a rigid pattern of behavior (Bardi et al., 2009; Bennett et al., 1990; Budner, 1962; MacDonald, 1970). For instance, Bennett and colleagues specifically compared job-related ambiguity tolerance and insolubility-type ambiguity tolerance to determine their relationship with feedback-seeking behaviors in the work place. They found that only job-related ambiguity tolerance was shown to induce behaviors aimed at reducing ambiguity; complex-type, problem-solving ambiguity tolerance had no impact (Bennett et al., 1990). For this reason, they concluded that ambiguity tolerance may be very a situation-specific trait. The scale used to measure ambiguity tolerance in the present study, however, the MSTAT-II, is composed of items that are designed to measure response to certain types of ambiguous stimuli and to particularly avoid situation-specific language (McLain, 2009). In doing so, it may not be appropriately measuring ambiguity tolerance within the context of dementia caregiving. In future studies, it

may be beneficial to devise and validate a scale designed to measure ambiguity tolerance specific to dementia caregiving.

General-Type Ambiguity Tolerance and Burden

Despite the lack of relationship between total ambiguity tolerance and total grief, the results revealed a modest and statistically significant inverse relationship between response to general ambiguity and Personal Sacrifice Burden. Participants who showed a higher tolerance for generally ambiguous stimuli on the MSTAT-II tended to score slightly lower on the Personal Sacrifice Burden subscale than other participants, suggesting that individuals with a higher tolerance for general-type ambiguous stimuli experience feel less burdened by caregiving than individuals with a lower tolerance for this type of ambiguity. This result partially supports the second research hypothesis, suggesting that an inverse association exists between ambiguity tolerance and feelings of burden.

This finding supports what has been shown in the ambiguity tolerance literature, namely, that individuals with a higher tolerance for ambiguity tend to report a higher enjoyment of tasks and situations that are marked by a lack of clarity than individuals with a lower ambiguity tolerance (Shaffer & Hendrick, 1974; Wittenberg & Norcross, 2001). (It is worth noting that the scales employed by these studies did not differentiate between types of ambiguous stimuli). Individuals with a lower tolerance for ambiguity, on the other hand, have been shown to become distressed by such situations and to even disparage them afterward (Shaffer & Hendrick, 1974). The results of the present study add to these findings by suggesting that the caregivers who demonstrate a higher tolerance for general-type ambiguous stimuli experienced less burden regarding their caregiving efforts than their counterparts with a lower tolerance for that type of ambiguity.

As discussed in the literature review, dementia causes a slow decline for those impacted by the illness, which impacts those individuals' abilities to fulfill social and familial roles. Dementia disrupts communication patterns between caregiver and care recipient (Dupuis, 2002; Sanders & Corley, 2003) and may fundamentally alter the emotional and psychological temperament of the affected individual (Dupuis, 2002; Frank 2007) that creates uncertainty and ambiguity for the caregiver. Caregivers with a higher tolerance for general ambiguity may more easily accept the confusion and the uncertainties that accompany dementia caregiving, including the blurring of social roles and loss of identity. This ability to tolerate general ambiguities allows these caregivers to transition to the caregiving role and provide assistance, accepting some the tasks that accompany that role with less burden than caregivers who lack the same level of ambiguity tolerance.

Alternative Explanations for the Findings

While the MSTAT-II measures responses to specific types of ambiguous stimuli, it is unknown what types of ambiguous stimuli are experienced by caregivers. While caregivers in the literature describe frustration and ambiguities surrounding role confusion and loss of identity (Blieszner et al., 2007), future uncertainties (Blieszner et al., 2007; Dempsey & Baago, 1998), ambivalent and confusing emotions (Dempsey & Baago, 1998; Sanders & Corley, 2003), fluctuations in the health status of the care recipient (Dupuis, 2002; Frank, 2007; Noyes et al., 2010; Sanders & Corley, 2003), and loss of the care recipient's personhood (Dempsey & Baago, 1998), several uncertainties remain. First, it is uncertain if any of the ambiguities described above align with the subscales of the MSTAT-II. Second, because the study utilized only quantitative methodology and did not investigate the participants' experiences of ambiguities

related to caregiving, it is uncertain whether the caregivers within the present sample experience the ambiguities described in the literature during the course of their caregiving careers.

Furthermore, the author of the MSTAT-II argues that the scale measures ambiguity tolerance that is not situation specific and therefore applicable for many areas of interest. However, certain items on the scale may not have resonated with caregivers, making it an inappropriate measure to assess dementia-specific ambiguity tolerance. For instance, the item designed to measure tolerance for uncertain stimuli, for example, reads, “I find it hard to make a choice when the outcome is uncertain.” While themes of uncertainty have been identified in the caregiving literature, particularly in the literature related to ambiguous loss, those themes do not relate to decision-making but rather to future uncertainty regarding the health and status of the care recipient (Dupuis, 2002; Frank, 2007; Sanders & Corley, 2003). Therefore, this statement may not appropriately assess caregivers’ tolerance for uncertain stimuli. As discussed above and following from the ambiguity tolerance literature (Bennett et al., 2009), it may be necessary to devise a scale measuring caregiving-specific ambiguity tolerance in order to ascertain whether the trait truly impacts influences the experience of grief.

Another explanation for the findings may have been the inability to control for confounding variables. Due to the small sample size, only bivariate analysis was conducted, and the study was unable to control for several confounding variables that have been shown to impact grief in family caregivers, such as perceived level of social support (Clyburn et al., 2014; Frank, 2007; Loos & Bowd, 1997) and overall frequency of behavioral problems (Clyburn et al., 2000; Frank, 2007; Lindgren et al., 1999; Ott et al., 2007; Ponder & Pomeroy, 1997; Warchol-Biedermann et al., 2014). For instance, as discussed in the literature review, low levels of social support have been associated with increased levels of burden (Clyburn et al., 2014) and grief

(Frank, 2007; Loos & Bowd, 1997) in both quantitative and qualitative studies. Frequency of behavioral problems, too, has been linked to increased levels of grief (Clyburn et al., 2000; Frank, 2007; Ott et al., 2007; Ponder & Pomeroy, 1997; Sanders & Corley, 2003; Warchol-Biedermann et al., 2014). As a result, it is not possible to know to what extent any other factors may have interfered with the results of the data analysis.

Implications

Theory

Ambiguous Loss Theory. Ambiguous loss theory states that the psychosocial death of an individual creates a lack of clarity surrounding that person's status as being both "here" and "gone" at the same time (Boss, 2007; 2010; 2012). The psychosocial death results in role confusion, feelings of ambivalence, and uncertainty about the future (Boss 2010; 2012; Boss et al., 2011). The lack of clarity about the "lost" individual's status prevents closure and forestalls coping. However, it has been asserted that ambiguity tolerance promotes resilience for families and caregivers experiencing this phenomenon (Boss, 2007).

The findings of the study support Boss's ambiguous loss theory in several respects. While total ambiguity tolerance was not related to total grief, an inverse correlation was found to exist between general-type ambiguity tolerance and Personal Sacrifice Burden. This suggests that one type of ambiguity tolerance may buffer caregivers from burden associated with ambiguous loss. This finding does support Boss's assertion regarding tolerance for ambiguity as a factor of resilience, as ambiguity tolerance may allow caregivers to thrive in spite of the ambiguities inherent in the caregiving experience. However, as discussed in Chapter 2 of this study, Boss also espoused that ambiguous loss is a neutral phenomenon and an individual's appraisal of the loss is what determines its meaning for that individual (Boss, 2007). The

findings of the present study may imply that the individual's interpretation of the loss may be more salient than ambiguity tolerance for determining such grief outcomes as sadness and social isolation.

Multi-Systems Life Course Perspective. The findings of the study have several implications for Multi-Systems Life Course Perspective. First, due to the established inverse relationship between general-type ambiguity tolerance and burden caregivers with a low tolerance for general ambiguity may be at risk for higher burden. From a social change perspective, those caregivers should be a target for support and social work intervention through both direct and policy practice. Evidence-based interventions and programs should be developed and implemented for caregivers of individuals with dementia.

Next, while tolerance for general-type ambiguity was associated with Personal Sacrifice Burden, neither total ambiguity tolerance nor any specific type of ambiguity tolerance was associated with either Heartfelt Sadness and Longing or Worry and Felt Isolation. Tolerance for ambiguity, then, did not impact a caregiver's experience of losses related to the relationship to the care recipient. This would imply that, from a symbolic interactionist perspective, the meaning of the relationship between caregiver and care recipient, that is developed throughout the life course, may be more influential than a personality trait like ambiguity tolerance. Furthermore, tolerance for ambiguity did not impact a caregiver's experience of losses related to social connections. From an ecological systems perspective, then, it seems that other factors may be more impactful than tolerance for ambiguity for determining a caregiver's experience of interpersonal losses or feelings of social isolation.

Direct Practice

The findings of this study bear several implications for direct social work practice. Because general-type ambiguity tolerance is associated with lower burden in family caregivers, caregivers who score high in the Personal Sacrifice Burden subscale of the MM-CGI-SF may benefit from interventions designed to target general-type ambiguity tolerance. Therefore, effective interventions that focus on increasing general-type ambiguity tolerance should be developed and evaluated. Boss and colleagues make suggestions for some possible interventions to address tolerance for ambiguity, such as teaching paradoxical thinking (Boss, 2012; Boss & Carnes, 2012), normalizing ambivalence, revising and restructuring relational attachments, and attempting to lighten the individual's need for control (Boss, 2010; Boss et al., 2011). However, to this researcher's knowledge, none of these interventions has been investigated empirically.

Next, social workers should assess both a caregiver's tolerance for general-type ambiguity and level of burden when working with a family caregiver. Assessment using instruments such as the ones employed in this study may be useful in assessing grief and assessing tolerance for general-type ambiguity. When employing exploratory interventions to increase tolerance for general-type ambiguity, such as those described above, utilizing assessment instruments will allow the social worker to determine if the intervention is achieving the predetermined goals.

Policy

Likewise, agencies should consider policies designed to both identify and support individuals who are experiencing burden-specific grief related to their dementia caregiving responsibilities. Agency policies to educate social workers about the concepts discussed in this study are warranted, including the concepts of ambiguous loss, pre-death grief, and general-type ambiguity tolerance. Such education would prepare social workers to meet the needs to

caregivers. In addition, agency-wide use of assessment instruments like the MM-CGI-SF and the MSTAT-II may help to identify individuals who could benefit from services and interventions described above.

In order for such services to be effective, funding must be made available and services must be accessible for caregivers. Advocacy for funding to support caregivers will be of paramount importance in the coming decades, as the population of adults age 65 and older in the United States will nearly double by 2050 (U.S. Census Bureau, 2014). Considering that approximately 10% of those over age 65 and 50% of those over age 85 are affected by Alzheimer's disease (Ross & Dagley, 2009), and that 70% of those individuals are cared for by family and friends (Putnam et al., 2010), it will be imperative to develop and fund effective programs to support informal caregivers.

According to the AARP Public Policy Institute, the typical family caregiver in the United States is approximately 50 years of age, female, working outside the home, and providing almost 20 hours a week of care to a parent for nearly five years (Williams, Devaux, Petrac, & Feinberg, 2012). Many caregivers are forced to reduce working hours in order to provide support to the care recipient, causing financial hardship and decreasing the likelihood of seeking services. Due to the difficulty of caregivers accessing (Sanders et al., 2008) and affording support services (Putnam, Pickard, Rodriguez, & Shear, 2010), states should increase funding for programs to support caregivers. As discussed above, programs designed to increase general-type ambiguity tolerance may reduce feelings of burden, which have been linked to health and psychological problems in caregivers, as well as premature institutionalization (Papastavrou et al., 2007). Caregiver support programs, then, may reduce health care costs over the long term.

Recommendations for Further Research

Several suggestions can be made for further research. First and foremost, a similar study should be conducted using a larger and more diverse sample and a more sophisticated data analysis methodology that will allow the investigator to control for other variables known to impact grief, such as severity of dementia and perceived social support.

Second, the findings warrant consideration of the development and validation of a caregiver-specific ambiguity tolerance measure. Using the qualitative caregiving literature as a foundation, researchers may be better able to develop items that would resonate with caregivers, without becoming overly situation-specific. Social workers, then, would be able to assess a caregiver's tolerance for ambiguity specifically related to their experiences and responsibilities as caregivers. In conjunction with a grief measure like the MM-CGI-SF, the instrument could act as a basis for the development of interventions to address caregiver needs and concerns.

Third, other outcome measures aside from grief should be considered in order to consider caregiver resilience. While Boss discusses ambiguity tolerance as a natural resilience for families experiencing ambiguous loss (2007), the outcome for such resilience is never specifically mentioned or defined. While this study chose to investigate the potential that ambiguity tolerance may result in lower levels of caregiver grief, it may be possible that ambiguity tolerance provides other benefits to caregivers that were not explored here. Exploratory research, then, should be conducted to determine other ways that ambiguity tolerance may aid dementia caregivers. One such possibility is personal growth, which was investigated by Ott and colleagues (2007), as a part of their investigation of factors related caregiver grief and personal growth. Other possibilities include wellbeing, emotional health, and coping strategies. Such investigations would provide more insight into the connection between ambiguity tolerance and ambiguous loss.

Strengths and Limitations

Strengths

The study relied on quantitative data from two established instruments. As discussed in a previous chapter, the MM-CGI-SF, which is composed of three subscales (Personal Sacrifice Burden, Heartfelt Sadness and Longing, and Worry and Felt Isolation) has been proven to be both a reliable and valid measure of three separate but related aspects of caregiver grief – burden and loss of autonomy, sadness and loss of interpersonal connection, and worry for the future and isolation from social connections (Marwit & Meurser, 2005). Likewise, the MSTAT-II has been proven as one of the most reliable and valid measure of ambiguity tolerance (McLain, 2009). Employing these instruments to measure the constructs examined here lends credence to the study's findings, as the data obtained are precise. Furthermore, utilizing a quantitative data analysis allowed the researcher to efficiently and effectively evaluate the relationships between variables in order to draw definitive conclusions. While several studies have presented themes of ambiguity in caregiving, no study to date has investigated the relationship between ambiguity tolerance and caregiver grief. Therefore, the present study fills a significant gap in the literature related to both ambiguity tolerance and ambiguous loss.

Limitations

While the use of purposive sampling is well established in the caregiving literature, it limits the generalizability of the study (Rubin & Babbie, 2011). The caregivers in the sample were recruited mainly from two sources: first, agencies and support group facilitators, and second, through a university news listing. As a result, the sample is more likely to be representative of those two sources and less likely to be representative of the caregiving population as a whole. For instance, participants who were recruited from agencies and support

groups are representative of caregivers who are seeking services and may be experiencing a greater degree of grief than caregivers who were not reached by recruitment efforts. Caregivers recruited from the university news list, likewise, are representative of a segment of the population who are more likely to have access to higher education and affluence than the general population of caregivers. Therefore, readers of the study should be cautious when generalizing these findings to other populations. Despite the use of purposive sampling, however, it should be noted that the sample in the present study bears resemblance to the samples of other studies in the caregiving literature, in terms of both gender frequency and median age.

In addition, the quantitative design employed by the study may have been too simplistic to explain the complex issues experienced by caregivers. As discussed above, the MSTAT-II may not be sensitive enough to detect the types of ambiguities faced by dementia caregivers and therefore may not have been an appropriate measure for this study. A qualitative or mixed methodology may have provided more robust and nuanced data, allowing the researcher to discover what types of ambiguities were experienced by the sample and which types of ambiguity tolerance are specific and relevant to dementia caregivers, offering a more conclusive and comprehensive answer to the research question.

Conclusions

The caregiving literature abounds with studies examining factors linked to caregiver grief. Most researchers have focused on interpersonal factors specific to the caregiving relationship (Collins et al., 1993; Holley & Mast, 2010; Meuser & Marwit, 2001). Some researchers have acknowledged the phenomenon of ambiguous loss as grief over the loss of a relationship without any sort of definite, physical loss, as in the case of death. Other researchers are beginning to

recognize the importance of individual personality traits as a factor in the experience of dementia caregiving (Melo et al., 2011).

The present study sought to investigate tolerance for ambiguity as one such personality trait that may be associated with caregiver grief. Using bivariate analysis, ambiguity tolerance was found to be moderately inversely associated with caregiver grief. These findings add to literature related to ambiguity tolerance. However, consumers of this study should bear in mind the use of purposive sampling, as the findings of this study may not be generalizable to other populations.

However, the significance of the study is discernible. It is the first study to examine tolerance for various types of ambiguity as a factor related to an individual's ability to cope with the complexities of dementia caregiving. Therefore, the study addresses a gap in the literature with regard to the impact of general ambiguity tolerance on one type of ambiguous loss. The findings of this study provide tentative support for Boss's (2012) assertion that increasing general ambiguity tolerance may enhance a caregiver's ability to thrive in the midst of confusion and uncertainty. The study furthermore lays the groundwork for larger and more diverse studies that may offer additional evidence to support or refute Ambiguous Loss Theory, as well as the role social workers should take in developing interventions to target this trait.

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APPENDIX A.

Survey Instrument

Ambiguity Tolerance and Feelings of Loss in Caregivers of Individuals with Dementia

Please answer the following questions to the best of your ability. Only provide one answer for each question.

1. I am _____ years of age.

2. I am:
 - Female
 - Male
 - Prefer not to say

3. The person I am caring for lives (check one):
 - In my home
 - Independently
 - In an assisted living or nursing home facility
 - Other _____

4. I am caring for my _____.
(mother, husband, grandmother, aunt, etc.)

5. Since his/her diagnosis of dementia, I have been caring for this person for
_____.
(6 months, 1 year, 2 years, etc.)

6. I feel supported by others in caring for this person. **(Please circle.)**

Strongly disagree	Disagree	Neutral	Agree	Strongly Agree
-------------------	----------	---------	-------	----------------

7. My care recipient's behavior is difficult for me to deal with... **(Please circle.)**

Hardly ever	Rarely	Occasionally	Frequently	Almost always
-------------	--------	--------------	------------	---------------

Please circle the response that **BEST** describes your reaction to the following statements.

1. I don't tolerate ambiguous situations well.

Strongly disagree	Disagree	Neutral	Agree	Strongly Agree
-------------------	----------	---------	-------	----------------

2. I would rather avoid solving a problem that must be viewed from several different perspectives.

Strongly disagree	Disagree	Neutral	Agree	Strongly Agree
-------------------	----------	---------	-------	----------------

3. I try to avoid situations that are ambiguous.

Strongly disagree	Disagree	Neutral	Agree	Strongly Agree
-------------------	----------	---------	-------	----------------

4. I prefer familiar situations to new ones.

Strongly disagree	Disagree	Neutral	Agree	Strongly Agree
-------------------	----------	---------	-------	----------------

5. Problems that cannot be considered from just one point of view are a little threatening.

Strongly disagree	Disagree	Neutral	Agree	Strongly Agree
-------------------	----------	---------	-------	----------------

6. I avoid situations that are too complicated for me to easily understand.

Strongly disagree	Disagree	Neutral	Agree	Strongly Agree
-------------------	----------	---------	-------	----------------

7. I am tolerant of ambiguous situations.

Strongly disagree	Disagree	Neutral	Agree	Strongly Agree
-------------------	----------	---------	-------	----------------

8. I enjoy tackling problems that are complex enough to be ambiguous.

Strongly disagree	Disagree	Neutral	Agree	Strongly Agree
-------------------	----------	---------	-------	----------------

9. I try to avoid problems that don't seem to have only one "best" solution.

Strongly disagree	Disagree	Neutral	Agree	Strongly Agree
-------------------	----------	---------	-------	----------------

10. I generally prefer novelty over familiarity.

Strongly disagree	Disagree	Neutral	Agree	Strongly Agree
-------------------	----------	---------	-------	----------------

11. I dislike ambiguous situations.

Strongly disagree	Disagree	Neutral	Agree	Strongly Agree
-------------------	----------	---------	-------	----------------

12. I find it hard to make a choice when the outcome is uncertain.

Strongly disagree	Disagree	Neutral	Agree	Strongly Agree
-------------------	----------	---------	-------	----------------

13. I prefer a situation in which there is ambiguity.

Strongly disagree	Disagree	Neutral	Agree	Strongly Agree
-------------------	----------	---------	-------	----------------

Please circle the response that BEST describes your reaction to the following statements.

1. I have had to give up a great deal to be a caregiver

Strongly disagree	Disagree	Neutral	Agree	Strongly Agree
-------------------	----------	---------	-------	----------------

2. I feel I am losing my freedom.

Strongly disagree	Disagree	Neutral	Agree	Strongly Agree
-------------------	----------	---------	-------	----------------

3. I have nobody to communicate with.

Strongly disagree	Disagree	Neutral	Agree	Strongly Agree
-------------------	----------	---------	-------	----------------

4. I have this empty, sick feeling knowing that my loved one is “gone.”

Strongly disagree	Disagree	Neutral	Agree	Strongly Agree
-------------------	----------	---------	-------	----------------

5. I spend a lot of time worrying about the bad things to come.

Strongly disagree	Disagree	Neutral	Agree	Strongly Agree
-------------------	----------	---------	-------	----------------

6. Dementia is like a double loss. I’ve lost the closeness with my loved one and connectedness with my family.

Strongly disagree	Disagree	Neutral	Agree	Strongly Agree
-------------------	----------	---------	-------	----------------

7. My friends simply don’t understand what I am going through.

Strongly disagree	Disagree	Neutral	Agree	Strongly Agree
-------------------	----------	---------	-------	----------------

8. I long for what was, what we had and shared in the past.

Strongly disagree	Disagree	Neutral	Agree	Strongly Agree
-------------------	----------	---------	-------	----------------

9. I could deal with other serious disabilities better than this.

Strongly disagree	Disagree	Neutral	Agree	Strongly Agree
-------------------	----------	---------	-------	----------------

10. I will be tied up with this for who knows how long.

Strongly disagree	Disagree	Neutral	Agree	Strongly Agree
-------------------	----------	---------	-------	----------------

11. It hurts to put her/him to bed at night and realize that she/he is “gone.”

Strongly disagree	Disagree	Neutral	Agree	Strongly Agree
-------------------	----------	---------	-------	----------------

12. I feel very sad about what this disease has done.

Strongly disagree	Disagree	Neutral	Agree	Strongly Agree
-------------------	----------	---------	-------	----------------

13. I lay awake most nights worrying about what's happening and how I'll manage tomorrow.

Strongly disagree	Disagree	Neutral	Agree	Strongly Agree
-------------------	----------	---------	-------	----------------

14. The people closest to me do not understand what I'm going through.

Strongly disagree	Disagree	Neutral	Agree	Strongly Agree
-------------------	----------	---------	-------	----------------

15. I've lost other people close to me, but the losses I'm experiencing now are much more troubling.

Strongly disagree	Disagree	Neutral	Agree	Strongly Agree
-------------------	----------	---------	-------	----------------

16. Independence is what I've lost. I don't have the freedom to go and do what I want.

Strongly disagree	Disagree	Neutral	Agree	Strongly Agree
-------------------	----------	---------	-------	----------------

17. I wish I had an hour or two to myself each day to pursue personal interest.

Strongly disagree	Disagree	Neutral	Agree	Strongly Agree
-------------------	----------	---------	-------	----------------

18. I'm stuck in this caregiving world and there's nothing I can do about it.

Strongly disagree	Disagree	Neutral	Agree	Strongly Agree
-------------------	----------	---------	-------	----------------

APPENDIX B.

Table 1.

Sample Description, Nominal Variables

Characteristic	n	%
Gender of Caregiver		
Female	27	87.1
Male	4	12.9
Placement of Care Recipient		
Same Home	14	48.4
Independently	4	12.9
Facility	11	35.5
Other	1	3.2
Relationship to Care Recipient		
Spouse	12	41.9
Adult Child	13	38.7
Parent of Committed Partner	2	6.5
Caring for multiple persons	2	6.5
Friend	1	3.2
Another Relative	1	3.2

Table 2.

Descriptive Statistics for Frequency of Continuous Variables

Variable	Min.	Max.	Median	Mean	S.D.
Age	20	82	63	61.61	14.48
Frequency of Difficult Behaviors	1	5	3	3.29	0.902
Perceived Social support	1	5	4	3.73	1.34
Years Spent Caregiving	0.33	10	3	3.572	2.6

Table 3.

Descriptive Statistics for Participant Scores on the MSTAT-II, including Sub-Scales

Factor	Min.	Max.	Median	Mean	S.D.
MSTAT-II Total	26	58	43	41.44	7.26
General Ambiguity	10	22	15	15.68	3.06
Insolubility	10	24	18	17.47	3.34
Novelty	2	7	5	5.1	1.25
Uncertainty	2	4	4	3.5	.76

Table 4.

Descriptive Statistics for Participant Scores on the MM-CGI, including Sub-Scales

Scale	Min.	Max.	Median	Mean	S.D.
MM-CGI-SF Total	35	73	51	52.03	9.56
Personal Sacrifice Burden	11	24	18	18.03	3.83
Heartfelt Sadness and Longing	10	30	21	21.48	4.2
Worry and Felt Isolation	10	27	15	15.87	4.16

Table 5.

Relationships between Total Grief, Grief Subscales, Total Ambiguity Tolerance, and Ambiguity Tolerance Subscales

	1	2	3	4	5	6	7	8
1. MM-CGI Total	–							
2. Personal Sacrifice Burden	.781***	–						
3. Heartfelt Sadness & Longing	.806***	.493***	–					
4. Worry and Felt Isolation	.853***	.582***	.486***	–				
5. MSTAT-II Total	-.003	-.089	.096	-.051	–			
6. General Ambiguity	-.207	-.349*	-.034	-.163	.876***	–		
7. Insolubility	.105	.059	.099	.045	0.756***	.534***	–	
8. Novelty	.153	.153	.188	.035	0.623***	.454**	.244	–
9. Uncertainty	.113	.121	.105	.083	.712***	.507***	.459***	.423*

*Correlation is significant at the .1-level (2-tailed).

**Correlation is significant at the .05-level (2-tailed).

***Correlation is significant at the .01-level (2-tailed).

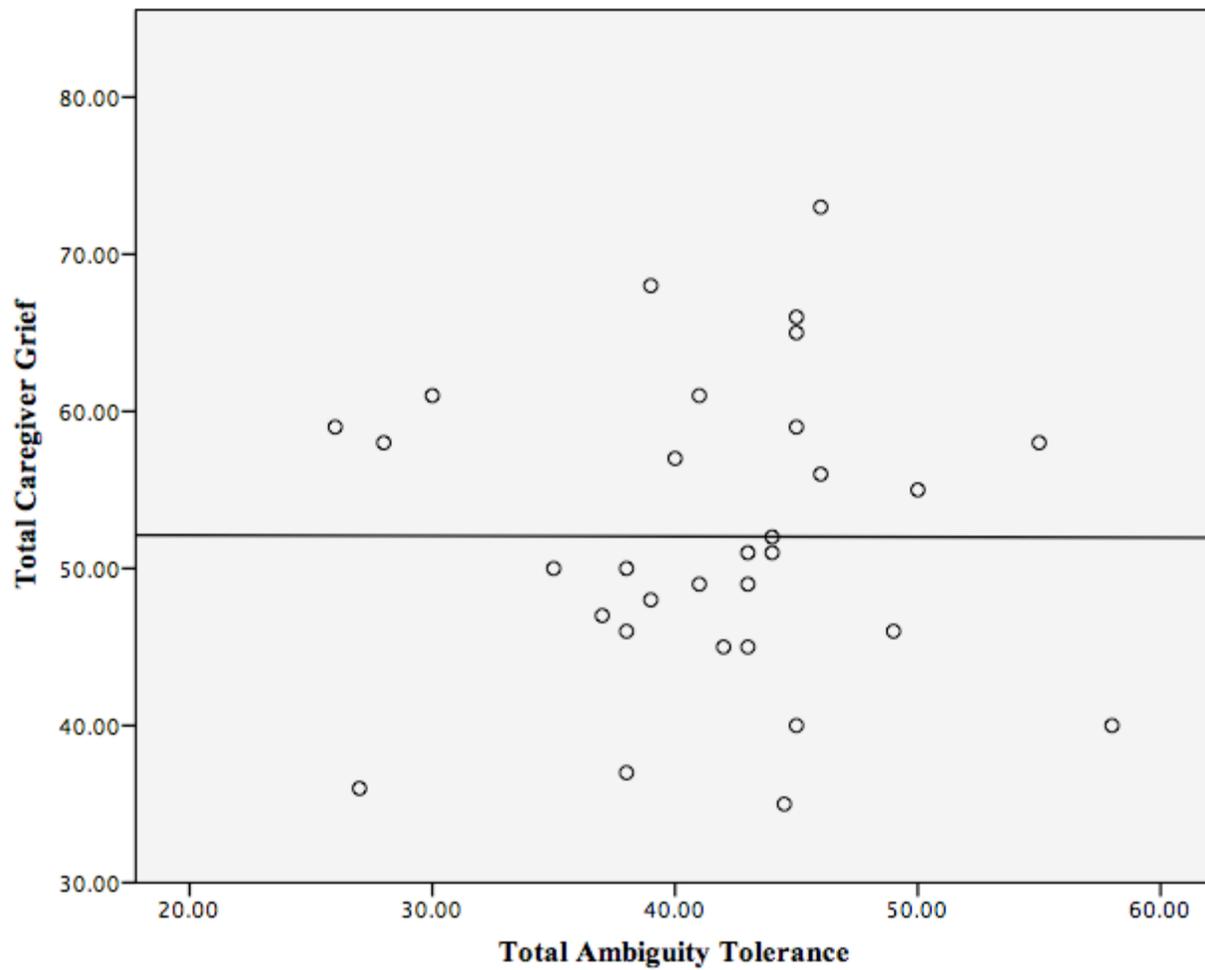


Figure 1. The relationship between total ambiguity tolerance score on the MSTAT-II and total caregiver grief score on the MM-CGI-SF.

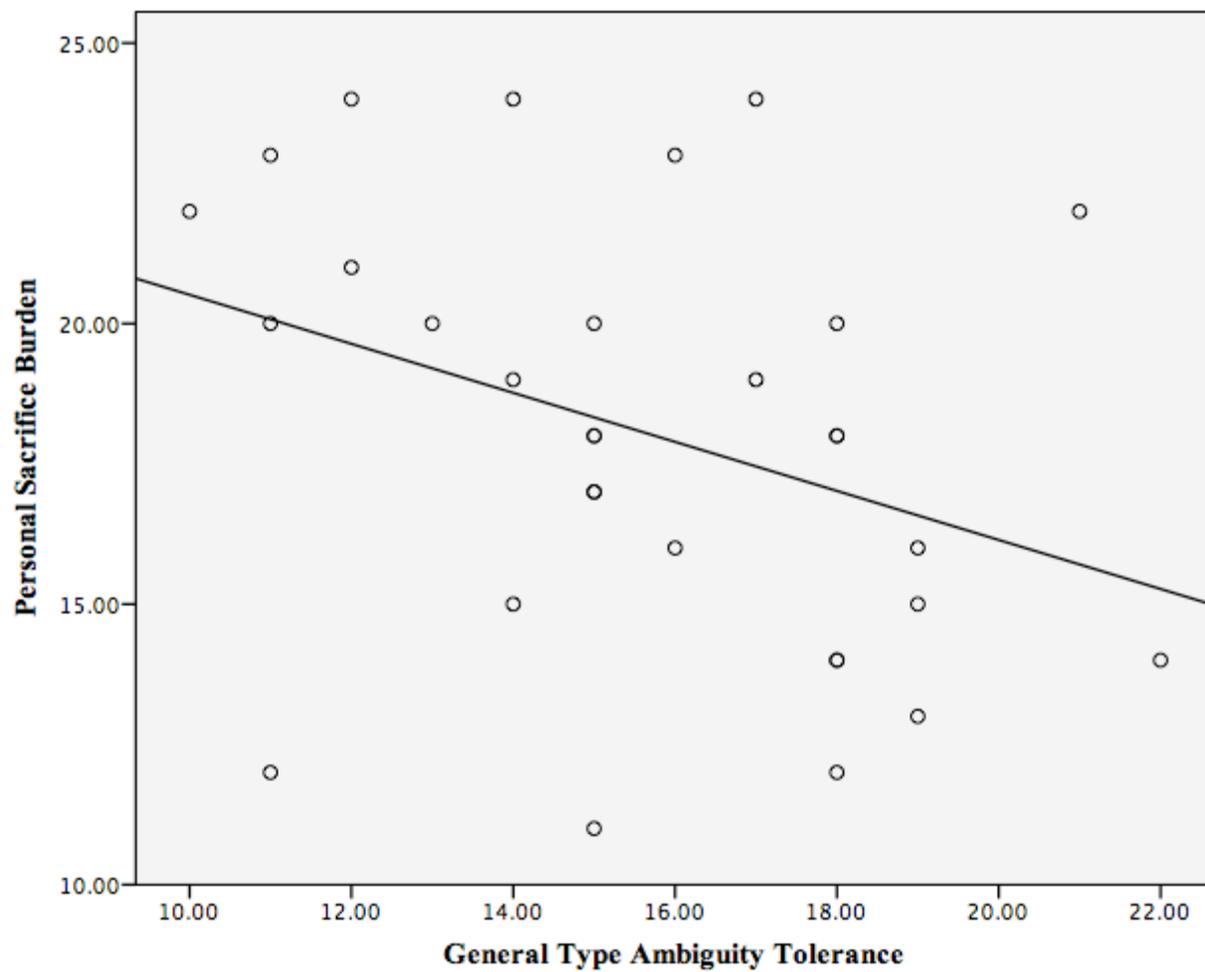


Figure 2. The relationship between the general-type ambiguity tolerance subscale of the MSTAT-II and the Personal Sacrifice Burden subscale on the MM-CGI-SF.

APPENDIX C.

Institutional Review Board Approval



Office of Research Compliance
Institutional Review Board

December 15, 2014

MEMORANDUM

TO: Megan Kale-Cheever
Alishia Ferguson

FROM: Ro Windwalker
IRB Coordinator

RE: New Protocol Approval

IRB Protocol #: 14-12-372

Protocol Title: *Multivariate Analysis of the Association between Ambiguity Tolerance and Caregiver Grief*

Review Type: EXEMPT EXPEDITED FULL IRB

Approved Project Period: Start Date: 12/15/2014 Expiration Date: 12/14/2015

Your protocol has been approved by the IRB. Protocols are approved for a maximum period of one year. If you wish to continue the project past the approved project period (see above), you must submit a request, using the form *Continuing Review for IRB Approved Projects*, prior to the expiration date. This form is available from the IRB Coordinator or on the Research Compliance website (<https://vpred.uark.edu/units/rscp/index.php>). As a courtesy, you will be sent a reminder two months in advance of that date. However, failure to receive a reminder does not negate your obligation to make the request in sufficient time for review and approval. Federal regulations prohibit retroactive approval of continuation. Failure to receive approval to continue the project prior to the expiration date will result in Termination of the protocol approval. The IRB Coordinator can give you guidance on submission times.

This protocol has been approved for 150 participants. If you wish to make *any* modifications in the approved protocol, including enrolling more than this number, you must seek approval *prior to* implementing those changes. All modifications should be requested in writing (email is acceptable) and must provide sufficient detail to assess the impact of the change.

If you have questions or need any assistance from the IRB, please contact me at 210 Administration Building, 5-2208, or irb@uark.edu.

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