

IMPACT OF GRIEF ON FORMAL AND INFORMAL CAREGIVERS

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Abstract

The purpose of this study is to determine whether paid caregivers of Alzheimer's patients are impacted by grief following the death of their patients. The Marwit-Meuser Caregiver Grief Inventory was utilized with four memory care facilities in Lincoln, Nebraska in order to measure grief levels of paid caregivers. Following Pearson's Correlation analyses, null hypotheses were retained and there was no linear relationship found between number of years employed as an Alzheimer's caregiver and grief scale scores. Future studies would benefit from more participants and a different instrument. Memory care facility administrators can benefit from looking at the impact of grief on their employees, as it may affect the quality of care to patients, and overall well being of caregivers.

Introduction

With the expected rise of the older adult population due to the baby-boomers, caring for these individuals will require more services and caregivers. Specifically, with Alzheimer's disease and related dementias, there is a unique set of challenges presented to the caregivers. According to the Centers for Disease Control and Prevention, Alzheimer's disease is the sixth leading cause of death in the United States (NCHS, 2016). The high mortality rate associated with Alzheimer's disease results in caregivers experiencing more deaths, more so in long-term care settings. More than 5 million Americans have Alzheimer's, with a new diagnosis taking place every 66 seconds (2016 Alzheimer's Disease Facts and Figures, 2016). With the increasing incidences of Alzheimer's, as well as the projected growth of the disease, caregiving plays a vital role in the daily lives of these individuals. Caring for individuals with Alzheimer's and related dementias can come informally, through unpaid family members and friends, or formally, through a care facility or a paid caregiver. The Alzheimer's Association reports that 18.1 billion hours of unpaid caregiving were provided by informal caregivers to friends and family with Alzheimer's and related dementias (2016 Alzheimer's Disease Facts and Figures, 2016).

Unsurprisingly, therefore, the act of caregiving, as well as the effects of Alzheimer's, can take a drastic toll on caregivers. Specifically, the grief caregivers experience can be exceptionally difficult given that they are grieving both the loss of the cognitive abilities of a loved one, as well as the eventual physical loss of the individual. This can also be true for formal caregivers, due to the intense level of interaction and care they provide for their patients, which could in turn lead caregivers to develop family-like emotional bonds to those that they care for. While the relationships may be similar, it is yet to be determined whether the grief reactions are similar for formal and informal caregivers of Alzheimer's and dementia patients.

Many times, the caregiver for the person with Alzheimer's is an adult child. Montgomery and Kosloski have developed a caregiver identity theory, in which the role of caregiving is an extension of a pre-existing relationship, such as a family relationship (Montgomery & Kosloski, 2009). Also according to the caregiver identity theory, caregiver identity is influenced and driven by social norms and rules, such as daughters typically being responsible for caring for older parents, or other cultural backgrounds governing who is responsible for caregiving (Montgomery & Kosloski, 2009). In addition to the social norms guiding the caregiving role, each individual family has its own ideology of what care is expected, who delivers the care, and when outside care should be sought out (Montgomery & Kosloski, 2009). This can make the identity of a caregiver confusing and constantly shifting, due to changes in the care recipient's health and medical needs; for family caregivers of people with dementias, these changes can be slow and erratic, ultimately changing the identity the family caregivers once had as a family member and not a caregiver (Montgomery & Kosloski, 2009). Regardless of how slow or fast changes in the identity of the family caregiver are made, there is nonetheless a shift in how the family member views their responsibilities to the care recipient, both as a family member and as a caregiver.

The identity a family caregiver takes on as their responsibilities shift can have implications for his or her grieving process. Bowlby's attachment theory explains that grief occurs when the person feels as though the security and safety they have with a relationship is threatened (Bowlby, 1969). The caregiver child already shares a strong emotional bond with their parent, and now faces the potential threat of the safety and security of that bond due to Alzheimer's disease, resulting in feelings of grief. The safety and security of the child-parent bond is threatened as a result of loss in the quality of their relationship, as well as losses in communication, social interaction, and overall health status (Ott, Sanders, & Kelber, 2007). In

assuming the caregiving role, the child witnesses first-hand the effects of Alzheimer's while trying to maintain separate roles of caregiver and child. However, there is another relationship that is compromised when family members take on the role of caregivers: spouses. If the person with Alzheimer's has no children who are able or willing to care for them, many times the spouse becomes the primary caregiver. Spouses tend to experience sadness as a result of the impact of the disease on their partner in the initial stages, while adult children tend to experience denial, avoidance, and anger in the initial stages of the disease (Ott, Sanders, & Kelber, 2007). While there are differences in the experiences of grief between adult children and spouses, both tend to experience intensified grief as the disease progresses (Ott, Sanders, & Kelber, 2007).

In order to measure grief of Alzheimer's caregivers, Marwit and Meuser developed an instrument to assess grief according to 50 different statements regarding personal grief reactions (Marwit & Meuser, 2002). The resulting instrument is the Marwit-Meuser Caregiver Grief Inventory (MM-CGI), and contains three subsections within the 50 statements: 1) personal sacrifice burden, 2) heartfelt sadness and longing, and 3) worry and felt isolation (Marwit & Meuser, 2002).

A study done in 2004 using the MM-CGI with family caregivers found that scores in the subscales of heartfelt sadness and longing, and worry and isolation tend to increase as the dementia progresses. Moreover, the highest scores of total grief were reported in the late stages of the disease (Adams & Sanders, 2004). Fifty-nine percent of the participants reported that they were actively grieving for their family member despite them still being alive, as well as grieving the loss of communication and relationship they once shared with the family member (Adams & Sanders, 2004)

Aside from the original MM-CGI, Marwit and Meuser also developed an abbreviated version of the assessment. To develop the Marwit-Meuser Caregiver Grief Inventory, Short Form (MM-CGI-SF), spouse and child Alzheimer's caregivers were administered the MM-CGI, and the results were reviewed to condense the 50-item questionnaire to an 18-item questionnaire (Marwit & Meuser, 2005). The 18-items include six items for each of the three subsections that are also measured in the original MM-CGI: personal sacrifice and burden, heartfelt sadness and longing, and worry and isolation (Marwit & Meuser, 2005). By using the Marwit-Meuser Caregiver Grief Inventory, Short Form (MM-CGI-SF), researchers have interviewed informal family Alzheimer's caregivers and revealed nine themes from the caregiving experience: isolation, longing for the past, guilt, limited freedom, feeling stressed, barriers to obtaining help, unresolved issues, social support, and coping (Sanders, Ott, Kelber, & Noonan, 2008). The double loss that many Alzheimer's and dementia family caregivers feel they face is highlighted by the theme of 'longing for the past'. One of the caregivers from the 2008 study said, "I grieve the relationship I lost with my mom, I grieve when I see her not be able to dial a phone, not be able to use a microwave...She doesn't tell the stories, she just not my mom anymore. And yet it doesn't end, so you can't, you can't finish the grieving...it just goes on and on," (Sanders, Ott, Kelber, & Noonan, 2008). Caregivers experience the loss of the personality and cognitive abilities while also experiencing the loss of physical abilities. Caregivers in this same study who scored high on the MM-CGI-SF also commonly reported feeling regret and guilt, more so when they admitted their family member into a long-term care facility (Sanders, Ott, Kelber, & Noonan, 2008).

Watching the progression of the disease and knowing the eventual outcome is death can lead to grieving before the actual death. Lindemann first described this idea of anticipatory grief

in 1944 when noticing people were experiencing grief as a result of a separation of a relationship, such as a family member going to war (Lindemann, 1944). While there was no death of the person going to war, family members were grieving over the fact that death was very likely the outcome. Someone who is experiencing anticipatory grief is doing so because they are concerned with the future adjustment following the death and go through the phases of grief in order to anticipate the adjustment (Lindemann, 1944). Lindemann found that anticipatory grief has profound effects, including wives of soldiers saying they did not love their husband anymore and wanted a divorce upon the arrival home of their husbands (Lindemann, 1944).

In order to measure levels of anticipatory grief, Susan Theut developed the Anticipatory Greif Scale (AGS), which consists of twenty-seven items scored on level of agreement by the participants (Theut, Jordan, Ross, & Deutsch, 1991). Originally designed for use by wives whose spouses were diagnosed with dementia, the items on the AGS were selected based on experiences of guilt, anger, sadness, and feelings of loss associated with the wives' grief responses (Theut, Jordan, Ross, & Deutsch, 1991). Using the AGS, one study found that levels of anticipatory grief are highest during the earliest stages of Alzheimer's, as the family member is just beginning to care for the individual (Garand, Lingler, Deardorf, DeKosky, Schulz, Reynolds, & Dew, 2012). This same study also found that anticipatory grief can negatively affect mood, physical health, productivity, and social relationships. A different study used the MM-CGI (Marwit-Meuser Caregiver Grief Inventory) as well as the Anticipatory Grief Scale (AGS) to measure levels of grief within informal caregivers. The study found that personal sacrifice and caregiving burden were associated with anticipatory grief, along with heartfelt longing and sadness (Holley & Mast, 2009).

Anticipatory grief can make coping with the death of a loved one or patient either better or worse, and is heavily influenced by ambiguous loss and disenfranchised grief (Shuter, Beattie, & Edwards, 2013), each of which will be discussed in turn. Boss describes ambiguous loss as an unsettled loss in which a loved one is either physically or psychologically present or absent (Boss, 2004). An example of physical ambiguous loss is a kidnapped child or a remote plane crash, whereas psychological ambiguous loss is when someone has lost emotional or cognitive abilities but is still physically present (Boss, 2004). While ambiguous loss was first used to describe the grieving process of families and spouses of missing soldiers in the 1970s, the model has implications for a variety of ambiguous losses (Boss, 2004) relating to Alzheimer's and other dementias – primarily psychological. There is the ambiguous loss in the decreased communication and social interaction with the person, the loss of personality traits and demeanor, as well as the loss in memories of a past life.

The other influence of anticipatory grief is disenfranchised grief, which is grief from a loss that is “not, or cannot be, openly acknowledged, publicly mourned, or socially supported” (Doka, 1999). Disenfranchised grief can happen to someone who has a friend die but is not recognized as a socially accepted griever. While everyone asks how the husband of the deceased individual is handling the loss, they fail to ask the friend about their grief. Disenfranchised grief can also occur when a child no longer spends time with one parent following a divorce but the other parent does not recognize it as a ‘death’ of the relationship for the child and parent (Doka, 1999). An Alzheimer's caregiver may experience disenfranchised grief because his or her peers may not recognize or acknowledge the anticipatory grief that the family member is experiencing. The family member may not openly discuss their anticipatory grief making it difficult to cope with those feelings. For those whom Alzheimer's does not affect or who have not witnessed the

disease progress, they may be unaware of the double loss and anticipatory grief family caregivers experience. When examining informal family Alzheimer's caregivers, it appears that the grieving process is far more complicated than usual, as caregivers grieve over the psychological losses, physical losses, as well as potentially dealing with a lack of social understanding by others of the grief they face. Due to the lack of social support and acknowledgment of disenfranchised grief, it may result in grief being private (Doka, 1999). This leads to the question of whether paid Alzheimer's caregivers exhibit a more complex grief response as well, or if they are able to separate the bonds they share with their patients from their responsibilities as a formal caregiver.

When examining the results of the MM-CGI, anticipatory grief and ambiguous loss are major barriers to Alzheimer's caregivers, rather than the actual physical hands-on care issues (Frank, 2008). Family caregivers in one study reported that hands-on care issues are not the biggest barriers they face in regard to caregiving, but the aspects of grief measured by the MM-CGI are connected to the burden of the physical care (Frank, 2008). Many of the participants in the study said that one of the biggest barriers they faced was being able to differentiate between their caregiving role and their family role; responses in relation to this barrier focused on loss of time and freedom, which is related to ambiguous loss because Alzheimer's offers uncertainty in caregiving demands as well as loss of communication with the relative, which can result in psychological ambiguous loss (Frank, 2008). Anticipatory grief was another widely reported barrier by the participants, describing the act of having to 'let go' of the person they used to know, and being aware of the fact that one day their family member will no longer know who they are (Frank, 2008). While the hands-on care such as dressing and bathing may be draining on the caregiver, it is ultimately the anticipatory grief and ambiguous loss that the family caregivers perceive as being the biggest barriers they face.

For family caregivers, the death of their loved one can be emotionally confusing. Doka explains a type of “liberating loss”, in which the family caregiver feels relieved of their duties and responsibilities following the death of the person they cared for (Doka, 2010). This view of the death being a type of relief can lead to disenfranchised grief, particularly because many times people will expect the grieving to be done throughout the progression of the illness, rather than at the death of the person (Doka, 2010). In contrast, the death of the person may also spark grieving of the loss of the caregiving role the family member once had, as they have possibly lost part of meaning in their lives (Doka, 2010).

While the death of an individual with Alzheimer’s can be seen as a ‘relief’ for the family caregiver, it may be seen as a different experience for a paid caregiver in which the individual is a client, and not a family member. In long-term care facilities and nursing homes, death is a common occurrence, which may in turn desensitize the caregiver. This could lead to an absence of feeling of ‘relief’ or a liberating loss when the patient dies because the formal caregivers have several other patients to care for. The death of one patient allows for new patients with new care needs; the death does not always signify a relief of duties.

In comparing family caregivers to paid caregivers in long-term care facilities, Boerner, Burack, Jopp, and Mock (2015) reported that formal paid caregivers tend to show similar grief symptoms to those of family members, such as missing the deceased, and experiencing the recall of painful memories (Boerner, Burack, Jopp, & Mock, 2015). It was also found that the grief symptoms of the formal caregiver were more likely to be intense if they had a closer and longer relationship with the client who passed (Boerner, Burack, Jopp, & Mock, 2015). Further, many of the caregivers reported struggling with the acceptance of death and felt unprepared for the death, which may be due to the fact that many caregivers may distance themselves from death as

a self-protection from the reality of the situation (Boerner, Burack, Jopp, & Mock, 2015). It is not clear whether distancing themselves from death is a conscious decision but regardless, this study highlights the idea that many formal caregivers develop family-like bonds to their patients, and may show grief symptoms similar to bereaved family members as a result (Boerner, Burack, Jopp, & Mock, 2015).

Though caregivers and residents may recognize and acknowledge their relationship with each other, it may not be recognized by everyone. Anderson and Gaugler sampled CNAs from nursing homes and found that they had greater personal growth from their grief if their relationship with the nursing home resident was acknowledged by others (Anderson & Gaugler, 2007). It was also reported that CNAs who experienced more resident deaths per year also tended to report lower levels of grief (Anderson & Gaugler, 2007). This could potentially be due to CNAs distancing themselves from the deaths of residents as a type of self-protection that Boerner et al. (2015) suggest, or due to CNAs experience with more resident deaths, resulting in them becoming more desensitized to the death itself. Death becomes an expected part of their job duties, rather than a disruption to their responsibility. However, CNAs who had a higher fear of death tended to also experience higher levels of grief, perhaps due to the death or residents causing CNAs to think about their own mortality (Anderson & Gaugler, 2007).

In 2010, Anderson and Ewen used the Texas Revised Inventory of Grief (TRIG), a 21-item self-report grief assessment, in order to measure grief of CNAs in nursing homes. Results from 380 CNAs completing the TRIG show that those who reported higher levels of distress from grief also reported higher levels of emotional exhaustions as well as had less personal relationships with the nursing home residents (Anderson & Ewen, 2010). Anderson and Ewen indicated emotional exhaustion can result in greater use of employee sick days, substance abuse

within employees, staff turnover, as well as conflict between staff, residents, and family members of residents. Further, results of the study by Anderson and Ewen found that CNAs who had higher levels of grief also had lower levels of psychological and physical well being (Anderson & Ewen, 2010).

Similar to CNAs working in nursing homes, registered nurses (RNs) working in hospitals also experience grief as a result of the death of their patients. A study conducted with 11 RNs found that a “curtain of protection” was created by the RNs in order to alleviate the grieving process and be able to continue to provide quality care (Gerow, Conejo, Alonzo, Davis, Rodgers, & Domian, 2010). One aspect of this ‘curtain’ was composed of the relationship shared by the RN and the patient; many of the nurses become involved with the patients and family past the professional expectations, which the RNs felt made the grieving possible to occur and be acknowledged (Gerow, Conejo, Alonzo, Davis, Rodgers, & Domian, 2010). Another aspect of the curtain was the past patient death experiences of the RNs; those who felt they were supported and mentored through their initial patient death experiences tended to have healthier and more positive experiences with future patient deaths (Gerow, Conejo, Alonzo, Davis, Rodgers, & Domian, 2010). The majority of the nurses also recognized that grieving is a natural response to death, especially when working in the healthcare field; however, many of the RNs also felt that they needed to be able to differentiate between their professional duties and their personal grief responses in order to continue their work with other patients (Gerow, Conejo, Alonzo, Davis, Rodgers, & Domian, 2010).

In a similar study of nurse grief of patient death, pediatric nurses were given the Revised Grief Experience Inventory (RGEI), a 22-question self-report assessment of grief experiences designed originally for family caregivers; results from 120 pediatric nurses showed that the

nurses experienced grief in a similar way compared to that of a family member of the patient (Adwan, 2014). Despite being similar grief experiences, those of the pediatric nurses tended to be less intense compared to family member grief (Adwan, 2014). It was also found that the more patient deaths the nurses experienced, the higher they scored on the RGEI; interestingly, the fewer number of patients a nurse had to care for on or around the day a particular patient died, the higher their RGEI score (Adwan, 2014). Further, the study also found that higher levels of grief of pediatric nurses tended to explain part of employee burnout and emotional exhaustion; there also appears to be a relationship between higher levels of nurse grief and the nurses' intention to leave the pediatric unit (Adwan, 2014).

When comparing family to paid caregivers, a common theme that emerges is relationships. Undoubtedly, some caregivers do develop intense and strong emotional bonds with the individual(s) they care for. Sometimes this may also include a relationship with the family of the patient. When family caregivers, residents in long-term care (LTC) facilities, and paid caregivers of LTC are asked about their opinions of death within LTC, the central theme that emerges from their responses is closeness (Munn, Dobbs, Meier, Williams, Biola, & Zimmerman, 2008). Not only does closeness entail the physical closeness a caregiver has with the resident, but also the closeness of the psychological relationship between resident and caregiver in terms of trust and empathy (Munn, Dobbs, Meier, Williams, Biola, & Zimmerman, 2008). The level of closeness has implications for the caregiver and the resident, as less closeness leads to less empathy and different expectations of care (Munn, Dobbs, Meier, Williams, Biola, & Zimmerman, 2008). The caregivers, family members, and residents also reported a 'good death' in LTC would include "comfort, dignity, and closure", all of which could not be possible without the caregiver providing quality care (Munn, Dobbs, Meier, Williams,

Biola, & Zimmerman, 2008). The closeness a paid caregiver experiences with the residents in LTC could aid in the caregiver providing the same level of care and interaction they would want for their own family member.

Caregiving for individuals, regardless of the reason for needing the care, can take a physical, mental, and emotional toll on for the caregivers. Family caregivers may only have one individual to care for, while formal caregivers may have several individuals to care for at one time and the stress of the job can have a profound impact on the caregiver. In hospice care professionals, stress typically stems from death and dying, family and personal grief, emotional and physical exhaustion, experiencing strong emotions such as anger and depression, as well as observing pain in their patients (Alkema, Linton, & Davies, 2008). Stress relating to one's job has the potential to lead to a lack of motivation and interest. However, within the care setting specifically, stress can lead to compassion fatigue, which is defined as "a deep physical, emotional, and spiritual exhaustion accompanied by acute emotional pain" (Alkema, Linton, & Davis, 2008). Compassionate fatigue has been linked to a lower quality of care for patients, and thus becomes an important aspect of the caregiving role in order to maintain a certain quality of care for the patients (Alkema, Linto, & Davis, 2008). As mentioned earlier, grief - both from families and personally - can impact compassionate fatigue. The importance of examining the grief of paid caregivers could in part help to reduce compassionate fatigue, although it may not be the ultimate solution to this issue.

Looking further into compassionate fatigue, Ward-Griffin, St-Amant, and Brown (2011) conducted a study examining the experiences of compassionate fatigue for registered nurses who were also caring for their own elderly parents, which they term 'double duty caregiving'. The researchers found that one of the reasons these 'double duty caregiving' nurses experienced

compassionate fatigue is due to a constant mediation between professional and personal roles as a caregiver, as well as being heavily focused on their own parents' health concerns (Ward-Griffin, St-Amant, & Brown, 2011). Many of the nurse-daughters in the study said they took on the caregiving role for their parent because they wanted to make sure their parent had quality care, however, they also indicated feeling an obligation to be the caregiver because they already had the skills to do so in their professional life (Ward-Griffin, St-Amant, & Brown, 2011).

Several of the nurse-daughters also mentioned they felt a dramatic difference emotionally when caring for their parent relative to their patients because while at work they are able to put up a type of boundary that allows them to be less emotionally invested in the patients (Ward-Griffin, St-Amant, & Brown, 2011). As previously mentioned, many paid caregivers develop family-like ties to their patients due to the amount of involvement their job calls for. When comparing this to the comments of the nurse-daughters, it seems to create two types of paid caregivers: those who are able to view patients only as patients, and those who view patients through the lens of a family member or close friend. The caregivers might be subconsciously or actively deciding on how to view their patients, which could ultimately affect how they experience the death of their patients.

The effects of compassionate fatigue can be detrimental to both the caregiver as well as the work environment and quality of care. Higher numbers of sick days and turnover rates, as well as decreased workplace productivity can result from compassionate fatigue (Potter, Deshields, Divanbeigi, Berger, Cipriano, Norris, & Olsen, 2010). Oncology nurses face similar challenges to caregivers of Alzheimer's and dementia persons in the fact that death of patients as well as being closely involved with the patients are aspects of the job. Oncology nurses are susceptible to burnout and compassion fatigue in part due to the death of patients, heightened

involvement with patients and families, as well as the nature of the disease (Potter, Deshields, Divanbeigi, Berger, Cipriano, Norris, & Olsen, 2010). Alzheimer's caregivers and oncology nurses face similar challenges due to the nature of their work: both give care to patients where death is commonly the ultimate outcome. While causes of death are different in each case of caregiving, both oncology nurses and dementia caregivers nonetheless see the decline in the patients, whether physical or psychological. For these reasons, it can be beneficial to look at oncology nurse grief reactions to offer insight to Alzheimer's caregiver grief reactions. Oncology nurses tend to conceal expressions of grief in front of the families of the patients as well as their peers; additionally, many nurses have the impression that showing emotion or crying in response to patient death is unprofessional and implies they are too involved with the patient and their patient's family (Brown & Wood, 2009). Another reason for the suppression of grief reactions in the caregiving workplace is because the nurses feel they do not have time to grieve due to staffing shortages; however, the consistent suppressions of emotions can lead to "compassion overload and workplace burnout" (Brown & Wood, 2009).

Dementia and cancer caregivers exhibit similar behaviors as it relates to compassionate fatigue, but may offer differences with anticipatory grief. Using the Anticipatory Grief Scale (AGS), the anticipatory grief experiences of close relatives of someone diagnosed with either cancer or dementia were compared in 2012 by Johansson, Sundh, Wijk, and Grimby. The study found that more children than spouses were respondents for the dementia group, while more spouses than children were respondents for the cancer group; while this may have caused slight variation in the results of the AGS, there were still a large number of similarities in the responses (Johansson, Sundh, Wijk, & Grimby, 2012). Similarities between the groups include daydreaming about their life before their relative was diagnosed with the illness, missing the way

their relative use to be, tearfulness, and feeling it is unfair that their relative was diagnosed with the illness (Johansson, Sundh, Wijk, & Grimby, 2012). Despite similarities in the AGS, Johansson et al. (2012) suggest that spouses may feel closer to the ill person compared to other relatives, as well as seeing a relative in physical pain from cancer may increase the amount of stress and grief.

In further comparison of cancer and dementia caregivers, the MM-CGI has been used to evaluate grief of cancer caregivers. In a study by Marwit et al. (2008), the use of the MM-CGI led to similar reports relative to when the assessment is used with dementia caregivers (Marwit, Chibnall, Dougherty, Jenkins, & Shawgo, 2008). Dementia caregivers tend to report more personal sacrifice and burden, and heartfelt sadness and longing in comparison to cancer caregivers, however, the MM-CGI scores of total grief and worry and isolation were similar for the two types of caregivers (Marwit, Chibnall, Dougherty, Jenkins, & Shawgo, 2008). This study reveals the possibility of using the MM-CGI for people other than family Alzheimer's caregivers.

Occupational stress and burnout are likely to occur for caregivers of both cancer and Alzheimer's patients. Cancer and Alzheimer's formal caregivers experience a work environment surrounded by dying patients, which can lead to the caregivers feeling frustrated or powerless by the pain and suffering their patients experience (Plante & Bouchard, 1995). In addition to being witnesses to the pain of the patients, formal caregivers such as nurses also must support the family of the patient in terms of providing information and advice regarding end of life issues (Plante & Bouchard, 1995). A study done in 1995 by Plante and Bouchard used the Occupational Stress of Nurses Working with Dying Patients Questionnaire with 76 oncology and palliative care nurses in order to assess the effects of stress and workplace burnout. The study reported that

the stress related to working with dying patients had a high positive correlation with workplace burnout, as well as reports of a negative correlation between professional support and burnout (Plante & Bouchard, 1995). Nurses who felt they had support between other nurses and doctors, as well as had adequate training regarding working with dying patients tended to be able to avoid nurse burnout due to working with dying cancer patients (Plante & Bouchard, 1995).

While literature exists examining grief responses by informal Alzheimer's caregivers as well as research examining grief responses of formal caregivers, there exists far less literature on the grief of formal Alzheimer's caregivers. Although LTC and nursing homes will more likely than not include residents who have some type of dementia or memory loss, but the studies presented are not primarily concerned with this type of caregiving. Caring for people with Alzheimer's presents different needs and obstacles. Family caregiving reactions to death are helpful in understanding the experiences of paid caregivers of death because of the family-like bonds that are formed many times between the formal caregiver and the patient. With regard to Alzheimer's disease caregiver, more research is needed in order to determine if formal caregivers exhibit grief responses, as well as how the grief affects their quality of work and life.

The Present Study

The literature review has highlighted a gap in research regarding the grieving process of paid caregivers of Alzheimer's and related dementias. Research exists examining grief of family Alzheimer's caregivers, which is of importance due to the family-like ties that can exist between a patient and a paid caregiver. There are substantially fewer studies that have examined the grief process in paid caregivers, and most of these studies are related to pediatric and oncology nurses, rather than with Alzheimer's patients. The existing literature of family caregivers can provide a

basis for comparison of paid caregiving grief but it is also useful to directly study grief in paid caregivers. Memory care facilities can benefit from research of the grief of paid caregivers, as it has been shown that grief has led to caregiver burnout and a decline in physical and emotional well being (Anderson & Ewen, 2010). By providing additional investigation into this topic, it can further the discussion of a need for bereavement services and support for paid caregivers in memory care facilities.

Due to the specific dedication of the Marwit-Meuser Caregiver Grief Inventory (MM-CGI) to caregivers of persons with Alzheimer's, the use of the assessment in the current study appears to be appropriate. Alteration of the MM-CGI may help the applicability of the instrument for paid caregivers, rather than the original target population of family caregivers. The study done in 2008 by Marwit et al. with cancer caregivers suggests versatility with the use of the MM-CGI.

The purpose of this study is to determine if there is significant grief experienced by paid Alzheimer's caregivers. Four hypotheses will be tested. The first hypothesis is that the longer the participant has been employed as a paid Alzheimer's caregiver, the higher their total grief score on the MM-CGI. This hypothesis is based on the results of the 2014 study done by Adwan, which found that the greater number of patient deaths the nurses experienced, the higher their scores on the grief assessment. Paid caregivers who have been working longer are likely to experience more patient deaths compared to newer employed caregivers. The second hypothesis is that the longer the participant has been employed as a paid Alzheimer's caregiver, the higher their Personal Sacrifice Burden subscale score. The third hypothesis is that the longer the participant has been employed as a paid Alzheimer's caregiver, the higher Heartfelt Sadness &

Longing subscale score. The fourth hypothesis is that the longer the participant has been employed as a paid Alzheimer's caregiver, the higher Worry & Felt Isolation subscale score.

Method

Participants

Before recruiting participants for this study, IRB approval through the University of Nebraska Lincoln was obtained. 35 paid caregivers of persons with Alzheimer's disease and related dementias participated in this study. The participants were recruited from four memory care facilities in Lincoln, Nebraska. All of the participants were female. 27 (77.1%) of the participants identified as white/Caucasian, 3 (8.6%) identified as black/African American, 3 (8.6%) identified as Asian, 1 (2.9%) identified as Native American, and 1 (2.9%) identified as "Other". The average age range of the participants was 25 – 34 years of age. The average length of time employed as a caregiver was 0 – 5 years. The average length of time employed as a caregiver in memory care was 0 – 5 years.

Materials

The Marwit-Meuser Caregiver Grief Inventory (MM-CGI) was used in this study. The MM-CGI is a 50-item questionnaire that measures three areas related to grief: Personal Sacrifice Burden, Heartfelt Sadness & Longing, and Worry & Isolation. The three subareas are combined to calculate the Total Grief Level. Higher scores on each of the scales indicate higher levels of grief. Due to the MM-CGI's original purpose to measure grief of family caregivers, some items on the assessment were revised to be better suited to measure grief of paid caregivers. Item 13 was revised from 'Dementia is like a double loss...I've lost the closeness with my loved one and connectedness with my family' to 'Dementia is like a double loss...I've lost the closeness with

my patient and connectedness with their family'. Item 24 was revised from 'My extended family has no idea what I go through in caring for him/her' to 'My extended family has no idea what I go through in caring for patients'. A demographic page collecting data regarding age, gender, race, length of time employed as a caregiver, as well as use of grief counseling was also utilized in this study.

Procedures

After obtaining informed consent, participants completed the MM-CGI and demographic form in their respective locations of employment. The assessments were scored and entered into a database of data from all of the participants. Data was entered and analyzed using SPSS. Pearson's Correlation tests were run on data to test the hypotheses.

Results

Table 1.1 shows the univariate statistics collected for this study. Figure 1.1 shows the distribution of lengths of time employed as caregivers. Figure 1.2. shows the distribution of lengths of time caregiving for memory care specifically.

The first hypothesis was that the longer the participant has been employed as a paid Alzheimer's caregiver, the higher their total grief score. Pearson's Correlation with a 95% confidence interval was run between number of years employed as an Alzheimer's caregiver and total grief score of the MM-CGI. The null hypothesis was retained; there is no linear relationship between years employed as an Alzheimer's caregiver and total grief score on the MM-CGI, $r(35) = .065$, $p = .710$, which does not support the research hypothesis. Refer to Figure 1.3 for a means plot of years employed versus total grief score.

The second hypothesis was that the longer the participant has been employed as a paid Alzheimer's caregiver, the higher their Personal Sacrifice Burden subscale score. Pearson's Correlation with a 95% confidence interval was run between number of years employed as an Alzheimer's caregiver and Personal Sacrifice Burden subscale score. The null hypothesis was retained; there is no linear relationship between years employed as an Alzheimer's caregiver and Personal Sacrifice Burden subscale score on the MM-CGI, $r(35) = .021, p = .903$, which does not support the research hypothesis. Refer to Figure 1.4 for a means plot of years employed versus Personal Sacrifice Burden subscale score.

The third hypothesis was that the longer the participant has been employed as a paid Alzheimer's caregiver, the higher their Heartfelt Sadness & Longing subscale score. Pearson's Correlation with a 95% confidence interval was run between number of years employed as an Alzheimer's caregiver and Heartfelt Sadness & Longing subscale score. The null hypothesis was retained; there is no linear relationship between years employed as an Alzheimer's caregiver and Heartfelt Sadness & Longing subscale score on the MM-CGI, $r(35) = -.054, p = .903$, which does not support the research hypothesis. Refer to figure 1.5 for a means plot of years employed versus Heartfelt Sadness & Longing subscale score.

The fourth hypothesis was that the longer the participant has been employed as a paid Alzheimer's caregiver, the higher their Worry & Felt Isolation subscale score. Pearson's Correlation with a 95% confidence interval was run between years employed as an Alzheimer's caregiver and Worry & Felt Isolation subscale score. The null hypothesis was retained; there is no linear relationship between years employed as an Alzheimer's caregiver and Worry & Felt Isolation subscale score on the MM-CGI, $r(35) = .231, p = .757$, which does not support the

research hypothesis. Refer to figure 1.6 for a means plot of years employed versus Worry & Felt Isolation subscale score.

Discussion

This study examined the grief levels of formal Alzheimer's caregivers employed by memory care facilities in Lincoln, Nebraska. Following data collection and analysis, all null hypotheses were retained for all four of the research hypotheses. No linear relationships were found between years of employment as an Alzheimer's caregiver and total grief score, as well as the subscale scores of the MM-CGI. This does not support the findings of Adwan (2014) of a linear relationship between number of patient deaths and grief scores. However, the study done by Adwan uses the Revised Grief Experience Inventory (RGEI), rather than the MM-CGI; the RGEI is similar to the MM-CGI due to its intended purpose to measure grief levels of primary family caregivers.

In contrast to the study done by Adwan, results of the Anderson and Gaugler (2007) suggest that the more patient deaths CNAs experience, the lower their grief levels. The 2007 study utilized the 19-item Inventory of Complicated Grief scale to measure the grief levels of the CNAs (Anderson & Gaugler, 2007). Although the current research study retained all null hypotheses of grief score levels, it could be beneficial to recreate the study done by Anderson and Gaugler to determine if there is a linear relationship between number of years employed as a caregiver and grief levels.

Despite not being able to accept the alternative hypotheses, the means plots for each hypothesis offer an interesting observation. In Figures 1.3, 1.4, and 1.5, the highest mean subscale and total grief scores were for paid caregivers who have been employed as Alzheimer's

caregivers for 16 – 20 years. Only 3 (8.6%) of the participants indicated they have been employed as Alzheimer’s caregivers. In contrast, participants who indicated they had been employed as Alzheimer’s caregivers for 0 – 5 years tended to have the lowest or second to lowest grief scores and subscale scores. 14 (40%) of the participants indicated they have been employed as Alzheimer’s caregivers for 0 – 5 years. It is important to not conclude too much based on a trend. This does suggest that in a larger sample with a greater range of experience, a relationship between grief levels and years of experience may manifest.

The MM-CGI gives a range of scales that are considered to be normal levels of grief for each of the three subscales. For Personal Sacrifice Burden, scores between 40 – 70 are considered to be normal. For Heartfelt Sadness & Longing, scores between 35 – 65 are considered to be normal. For Worry & Felt Isolation, scores between 25 – 55 are considered to be normal. Of the 35 participants, all had subscale scores within the normal range. Only one participant had a score on the upper level of Worry & Felt Isolation subscale, with a score of 55. For the remainder of the participants, all subscale scores were well within the normal range.

A lack of abnormal levels of grief scores could indicate that paid caregivers of Alzheimer’s patients do not experience grief in a similar fashion to family members of the Alzheimer’s patients. However, this would be in disagreement with the findings that paid caregivers share family-like bonds with their patients, and therefore can develop grief reactions similar to that of the family members (Boerner, Burack, Jopp, & Mock, 2015). Although none of the research reviewed in the introduction indicated how long it takes for the family-like bond to form between the paid caregiver and the patient, it could be possible that the participants in the current study did not interact with the patients long enough to form a bond. A majority of the participants had been caregiving for 0 – 5 years, which may be too short of a time period to form

close and emotional bonds with the people they care for. Furthermore, it could be that the caregivers were not developing close bonds with the care recipients because they did not experience a connection with their patients, or because the progression of the disease made it difficult to develop the bonds. Length of time employed as a memory caregiver may not fully determine if a relationship is formed.

Gender could all be affecting the results of this study. All 35 of the participants were female. Due to the lack of male participants, the results could be skewed. In the future, it will be important to obtain a more representative sample that also includes male participants.

Upon completion of this study, it became apparent that more questions should have been asked of the participants. It would have been beneficial to have the participants rate the level of emotional closeness they feel they have with the people they care for. Correlational analyses could be done to determine if there is a relationship between perceived emotional attachment and levels of grief. Another applicable question to ask participants is how long had they known the resident with whom they felt the closest to. It could be argued that the longer you know and physically care for an individual, the more able you are to develop the family-like bonds that may lead to higher levels of grief following death.

Furthermore, it would have been beneficial to ask the participants how long they have been employed at their current memory care facility, as well as how many care facilities they have been employed at. Low levels of grief in the paid caregivers could be due to the fact that turnover rates of caregivers tend to be high; there is not enough opportunity for the caregivers to grieve the death of their patients because they are frequently changing locations of employment. Employment changes may be a defense mechanism of the paid caregivers, whether conscious or

subconscious. By actively ensuring they do not get too connected or attached to the patients or care facility, the emotional bonds will not form and the grief will likely be less.

Utilization of counseling services for grieving the loss of a patient was asked of the participants. Only one participant indicated they had sought out grief support services, and consequently believes the services were beneficial. If this study were to be repeated, it should also include a question of if the paid caregivers ever go to funerals or rituals following the death of the patients. End of life services may be able to offer closure for the paid caregivers. Further, paid caregivers may be off duty when one of the patients they shared a bond with passes away. Attending funeral services could potentially be beneficial to the grief experiences of paid caregivers who are not present at the time of death.

In future studies, it will be important to ask participants if they feel as though their relationships with patients are recognized and supported by family members of the patient. Studies done by both Anderson and Gaugler, as well as Gerow et al., have indicated that paid caregivers who felt their patient relationships were acknowledged by family members tended to have better grief experiences. In the study by Gerow et al. (2010), the nurses who had relationships not only with the patient but also with the family members felt it was more appropriate and accepted to grieve the death of the patient. In future studies, comparisons can be made of the grief experiences of paid caregivers who have patient relationships acknowledged by family members versus the paid caregivers who do not indicated this acknowledgment.

Financial considerations could also be a cause for low levels of grief within paid caregivers. For family caregivers of loved ones with Alzheimer's or related dementias, there is no financial reimbursement whereas for paid caregivers of Alzheimer's patients, perhaps monetary motivation is a large driving force behind the choice to be a caregiver. While money

may not be the biggest motivation for all caregivers, it could be for some. When one resident dies in the care facility, it opens up a bed for another resident, which could mean more work and thus more money for the paid caregiver. On the other hand, the high caregiver turnover rates could be due to caregivers finding higher wages at a different care facility. Caregiving may simply be a way of making a living for some people, and emotional bonds and grief are in no way a part of earning their salary.

Several limitations exist for this study. The most prominent limitation is the use of the MM-CGI to measure grief for paid caregivers. The assessment was intended to be used with family caregivers, rather than paid caregivers, which may have led to inaccurate measures of grief of the participants. The MM-CGI has been used in previous studies with cancer caregivers rather than Alzheimer's caregivers, such as the study done by Marwit et al. (2008) with cancer caregivers. However, it cannot be determined from the current study whether the MM-CGI is the best assessment for use with paid caregivers. This reveals a need for the development of an assessment tool for detecting levels of anticipatory grief in paid caregivers, regardless of caring for Alzheimer's or another specific diagnosis. Paid caregivers face similar challenges to family caregivers, yet there are many drastic differences such as paid caregivers caring for more than one person at a time. By developing a paid caregiving grief assessment, specific challenges not encountered by family caregivers can be addressed.

When looking at the use of the MM-CGI in this study, the alteration of two of the fifty items may lead to inaccurate measurements of grief levels. However, this does not seem likely, as the statements were changed only in the context in which they should be thought of, and not in the meaning of the statement. The results of this study could be used as the initial planning stages of a grief assessment tool for paid caregivers. Items on the MM-CGI that the participants tended

to rate higher can be assessed to determine if the statements can be altered to address paid caregivers rather than family caregivers.

Another limitation of this study is the relatively small number of participants which prevents sufficient generalizability to the larger population. While Lincoln, Nebraska offered several memory care facilities, only four of the facilities contact agreed to participate in the study. In order to recruit more participants, future studies could expand the location of memory care units to also include the surrounding areas of Lincoln, such as Omaha. A larger participant pool could help results of the study be generalized to the population of paid Alzheimer's caregivers.

In continuing this investigation, future studies could include discussions with the memory care facility administrators. It would be helpful to ask specific questions regarding how or if the administration and facility provide bereavement services to the caregivers following the death of patients. An investigation of whether facilities provide education regarding grief, as well as if they offer a certain amount of time-off for grieving caregivers would also be beneficial to determine. Paid caregivers may not know the appropriate reactions or expressions of grief following patient death, which could possibly lead to employee turnover. Discussions with the administrators or directors of memory care facilities regarding the grief of their employees may offer insight as to whether they are prepared to support their caregivers effectively. Furthermore, it may reveal gaps where grief support is lacking within care facilities.

Caregiving will continue to be an important aspect to healthcare, even more so with the increasing incidences of Alzheimer's disease and related dementias. Long-term care facilities will need to be prepared for the baby-boomer generation to enter the market for specialized care. By providing caregivers with the necessary education, bereavement, and grief support services,

care facility administrators can better ensure quality care for their residents. While the current study did not find any results indicating high levels of grief from paid Alzheimer's caregivers, it did indicate a need for the development of a grief assessment tool for paid caregivers. There still exists a large gap in research regarding paid caregiving, particularly with Alzheimer's and related dementias. The growing population of older adults prompts the question of are we prepared to care for the older adults, and are we prepared to care for the caregivers.

Table 1.1
Summary of Univariate Statistics

Variable	Univariate Statistic	
Gender	Female	35 (100%)
	Male	0 (0%)
Age Range	19 – 24	8 (22.9%)
	25 – 34	10 (28.6 %)
	35 – 44	6 (17.1%)
	45 – 54	6 (17.1%)
	55 – 64	5 (14.3%)
Race	African American	3 (8.6%)
	Asian	3 (8.6%)
	Caucasian	27 (77.1%)
	Other	1 (2.9%)
Have you missed work due to grieving the death of a patient?	Yes	2 (5.7%)
	No	31 (88.6%)
	Prefer Not to Answer	2 (5.7%)
Have you sought out counseling/grief services following the death of a patient?	Yes	1 (2.9%)
	No	34 (97.1%)
If you sought out counseling/grief services, were the helpful?	Yes	1 (100%)

Figure 1.1 Percentages of Years as Paid Caregiver

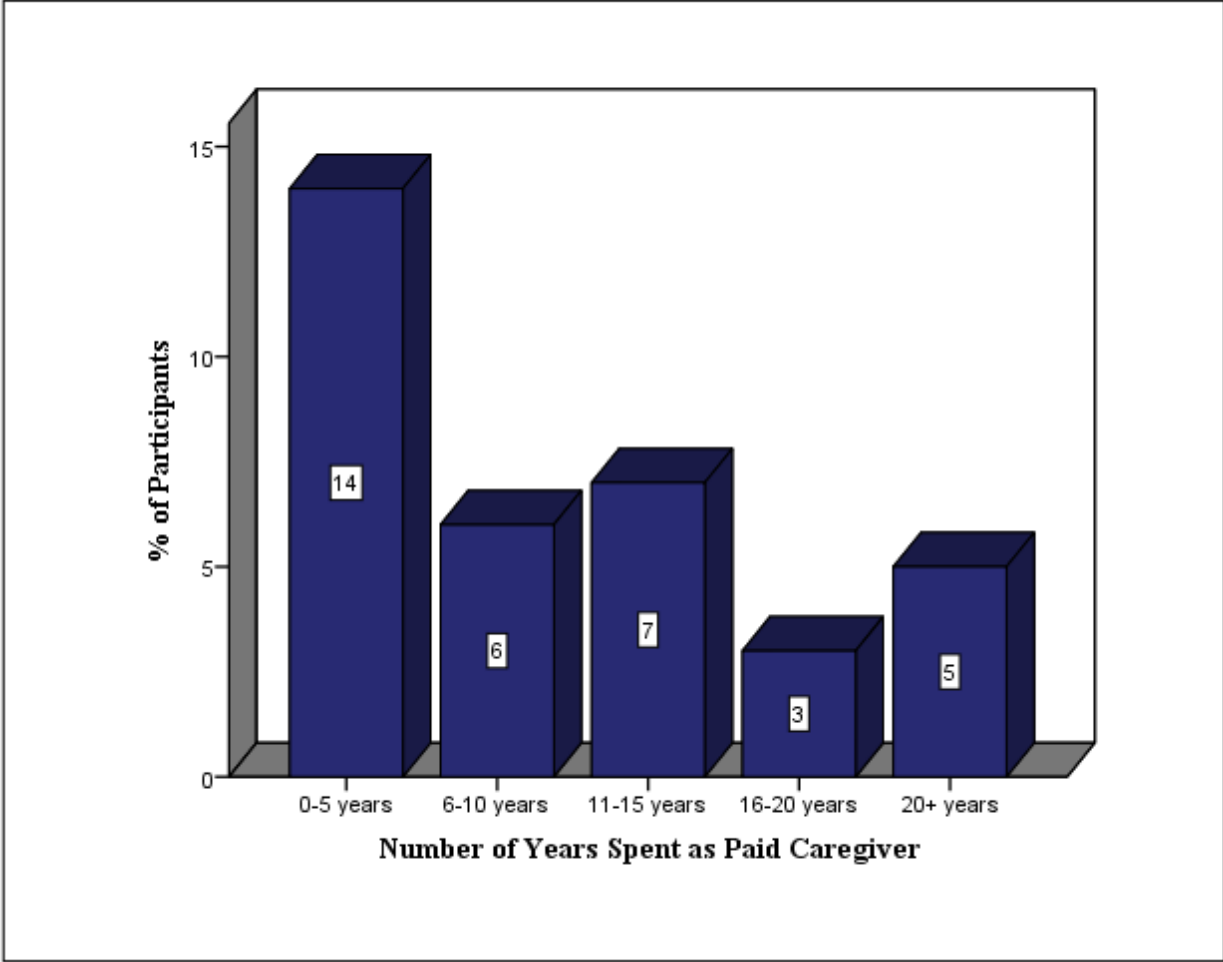


Figure 1.2 Percentages of Years as Paid Memory Caregiver

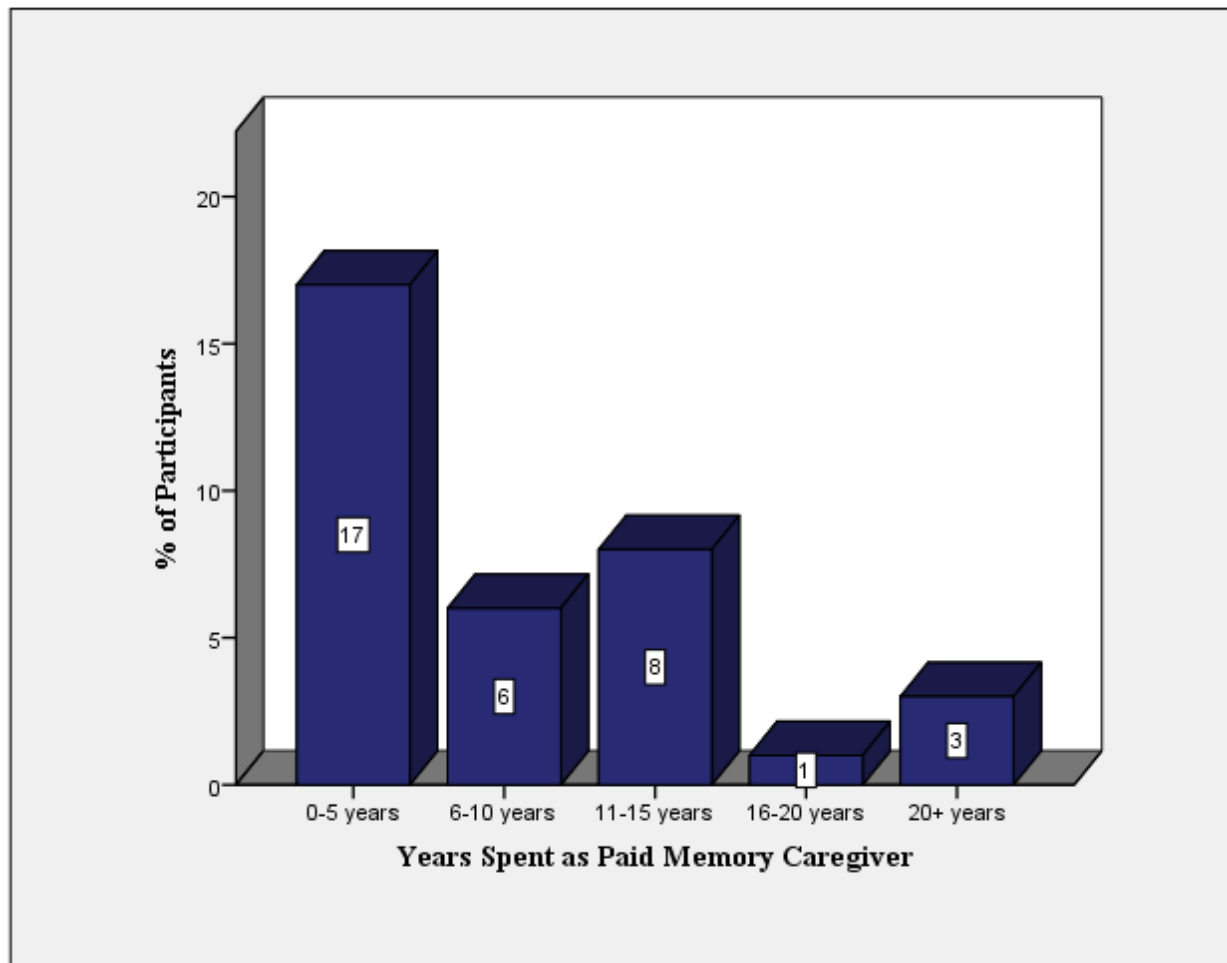


Figure 1.3 Means Plot: Years as Memory Caregiver versus Total Grief Score

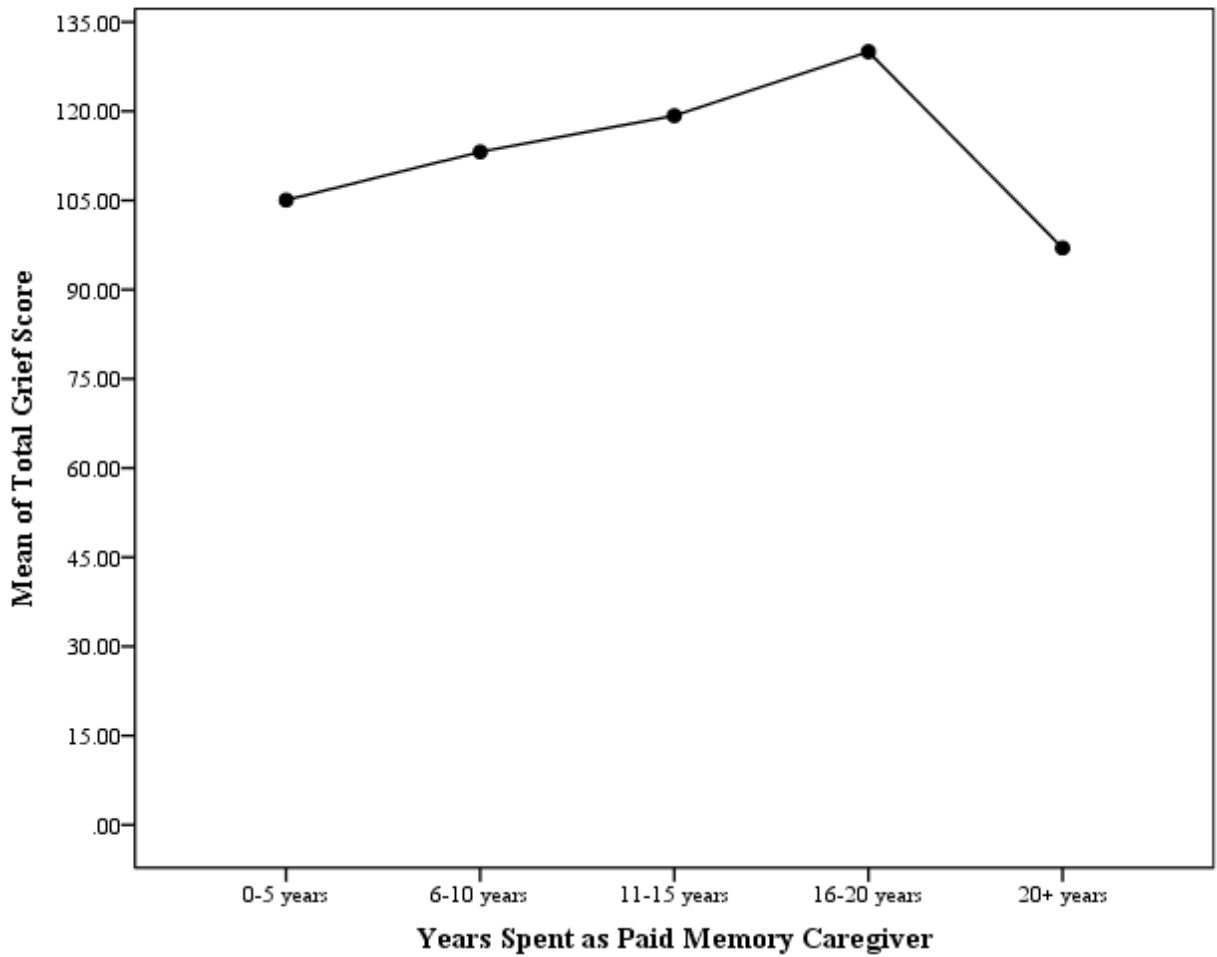


Figure 1.4 Means Plot: Years as Memory Caregiver versus Personal Sacrifice Burden Score

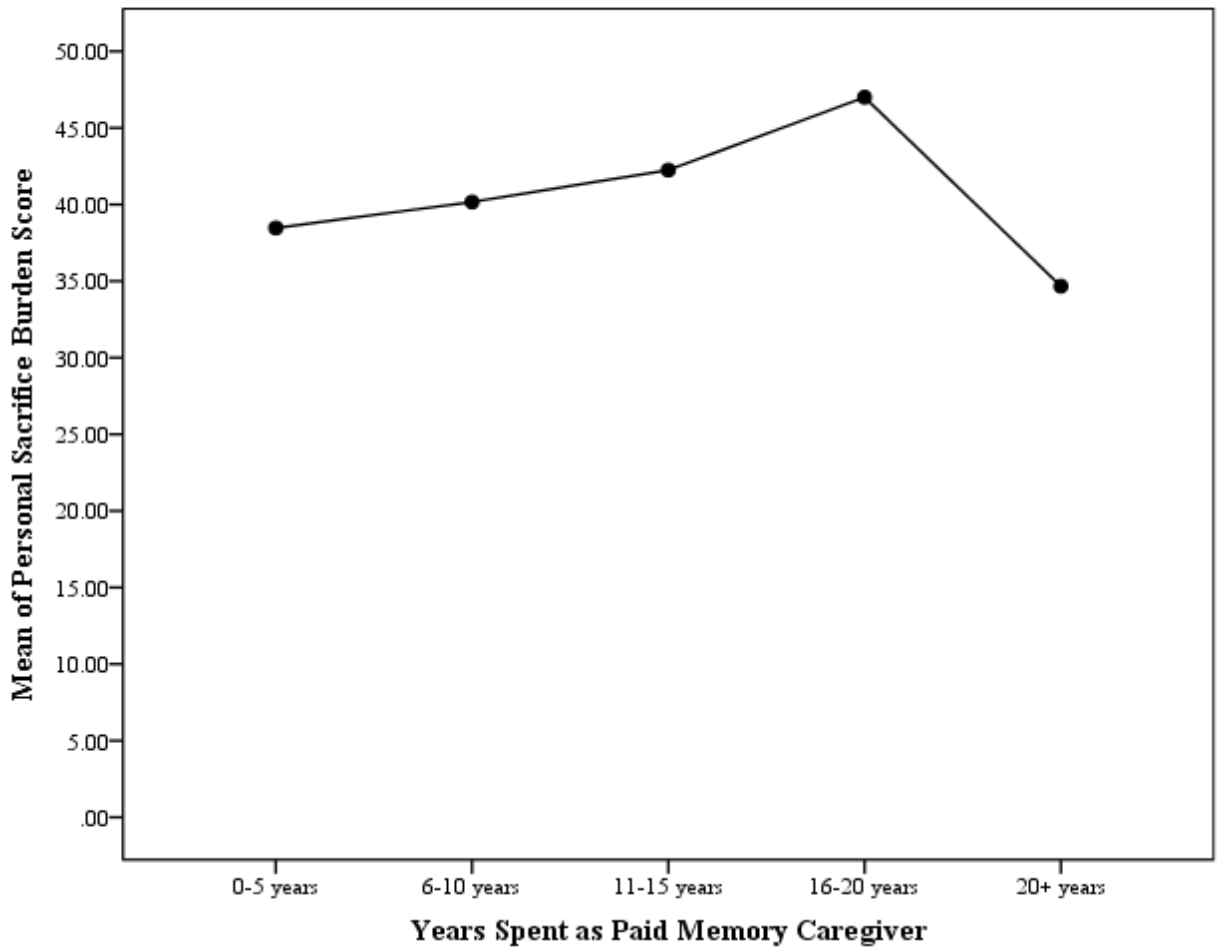


Figure 1.5 Means Plot: Years as Memory Caregiver versus Heartfelt Sadness & Longing Score

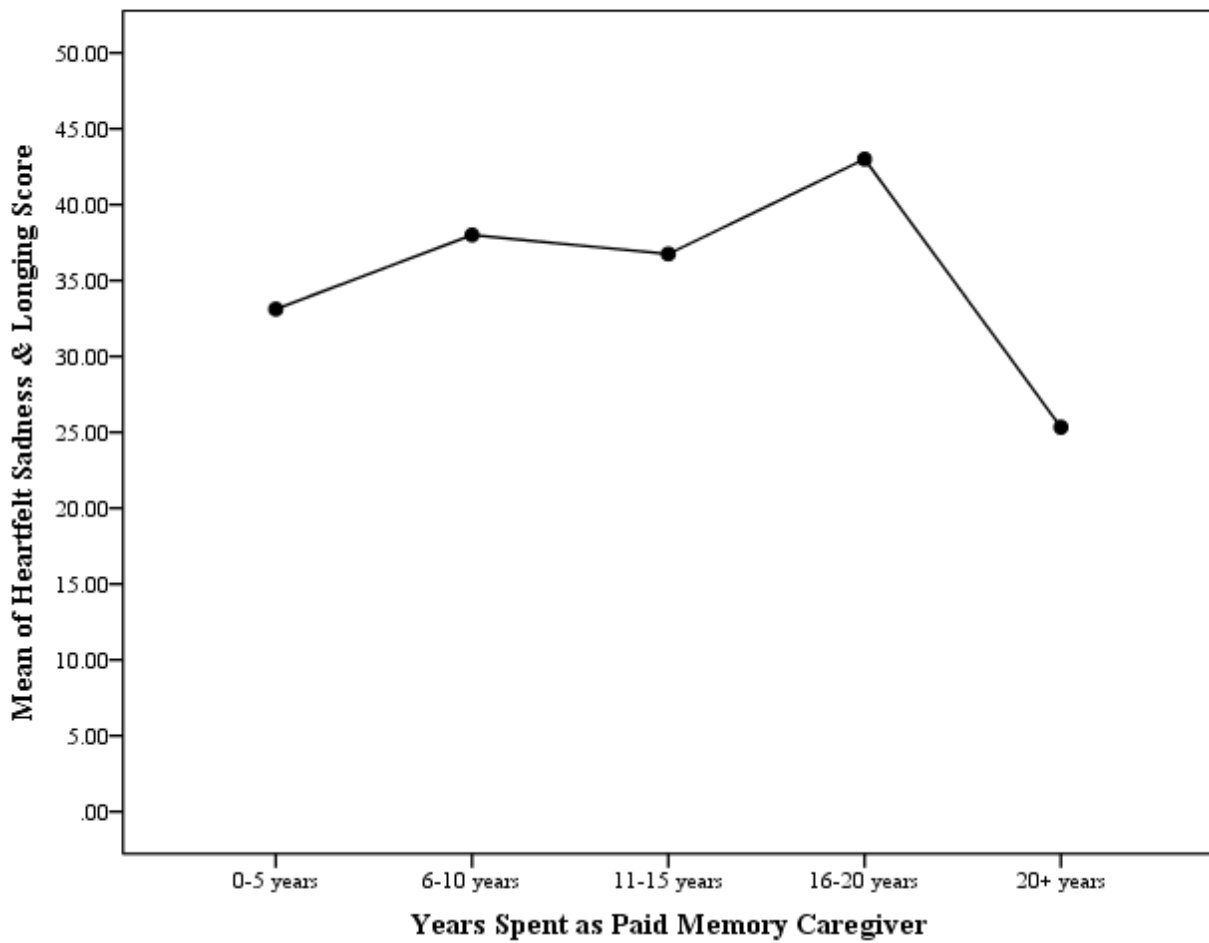
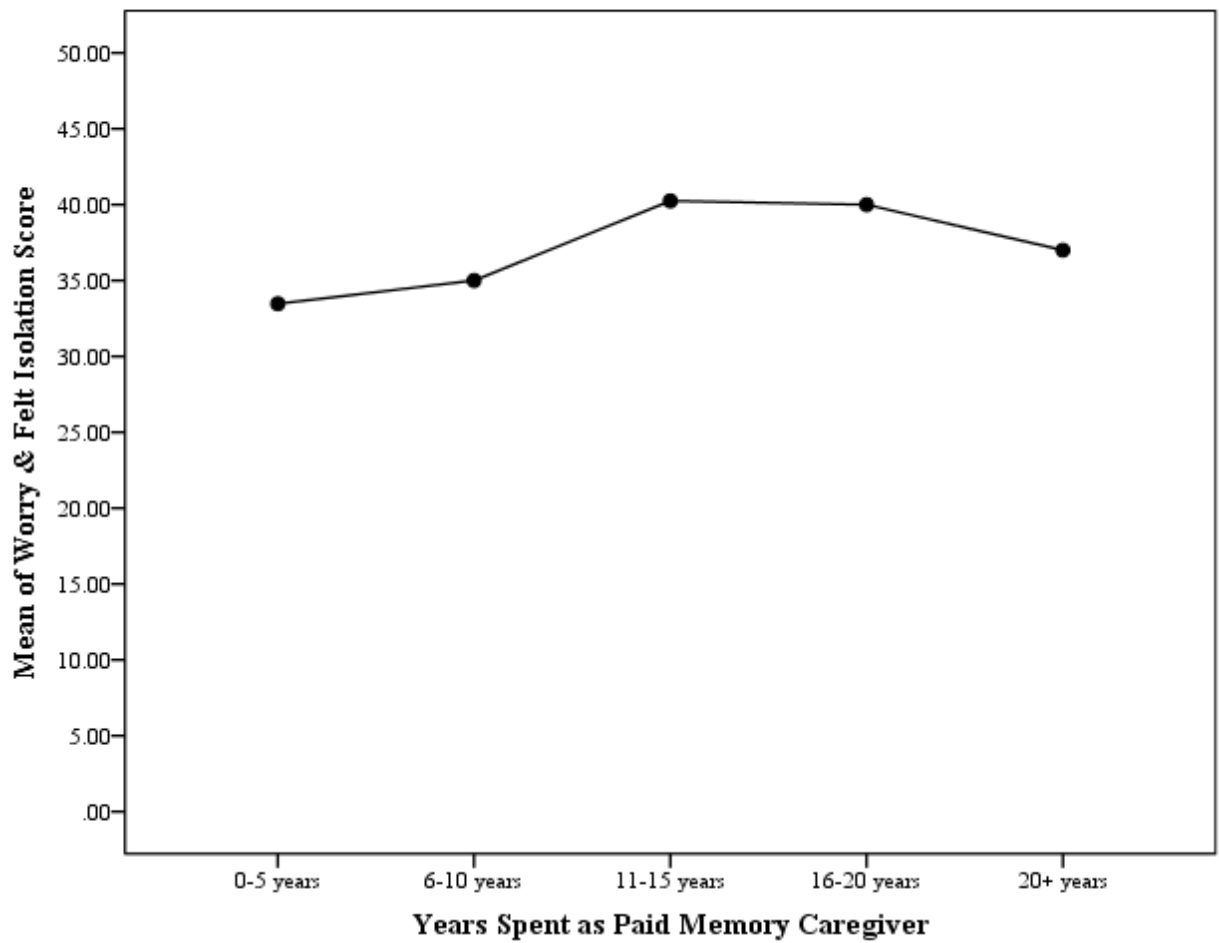


Figure 1.6 Means Plot: Years as Memory Caregiver versus Worry & Felt Isolation Score



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