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Grief, Loss and Stress Burden among Spouse Caregivers of the Person with Young-onset Dementia

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Grief, Loss and Stress Burden among Spouse Caregivers of

the Person with Young-onset Dementia

(TITLE)

BY

Sharbari Ganguly

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Running Head: GRIEF LOSS AND STRESS BURDEN

Grief, Loss, and Stress Burden among Spouse Caregivers of the Person with
Young-onset dementia

Sharbari Ganguly

Gerontology Master's Thesis

Eastern Illinois University

Abstract

The effects of young/early-onset dementia are devastating not only for the person who has been diagnosed with young/early-onset dementia, but also for their primary caregivers (de Vugt & Verhey, 2013). The major aim of this study is to focus on the level of grief, loss, and stress burden that are associated with the partner or the spouse caregivers of someone with young-onset dementia. This study has used a previously unanalyzed set of data consisting of 55 partner or spouse young-onset dementia caregivers. Three instruments were used for data collection including the Marwit-Meuser Caregiver Grief Inventory (MMCGI), the Zarit Burden Interview (ZBI) and a self-designed questionnaire. Pearson's product moment Correlation- coefficient (Pearson's r) and Regression analysis were used as the fundamental quantitative methods for data analysis in this study. Results show the major predictors of increasing the level of spouse caregivers' stress burden are changes in caregivers' life due to the caregiving activities combined with a constant sense of responsibility where the Pearson's $r=0.83$ and 0.87 respectively. Caregivers' emotional loss is strongly correlated with their loss of freedom ($r=0.82$). The findings indicate that most caregivers are grieving for several reasons most in the study population agreed that these feelings accumulated together and initiated feelings of depression and anxiety among themselves.

Keywords: Young-onset dementia, Spouse caregiver, MMCGI, Emotional grief, Emotional loss

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Chapter One

Introduction

One of the social objectives of every society is to increase life expectancy and promote healthy aging. With the advancement of science and technology the medical world has progressed enormously. One of the remarkable boons of this scientific advancement is the higher life expectancy which has become a worldwide phenomenon (Zhang & Franklin , 2006). Almost every developed or developing nation is now experiencing an increasing number of older adults and with that an unavoidable prevalence of health related difficulties (Gupta & Sankar, 2003). There are physical and cognitive changes that occur when a person ages. When these unprecedented changes become impairments, they can threaten the quality of life as a whole. Among many cognitive disorders, dementia has been documented as one of the most severe and incurable cognitive disorders among the elderly (ALZ, 2010). However, dementia is not an old age disorder. A disease called younger onset or early onset dementia exists and it affects people who are younger than 65 years of age (ALZ, 2010).

Statement of the Problem

Dementia denotes a decline in mental ability that becomes severe enough to interfere in the daily life of an individual. It encompasses a wide range of signs and symptoms that are associated with the deterioration of memory or the thinking ability of an individual (ALZ, 2010). Currently, it is estimated that there are 30 million people affected by dementia all over the world and this population is likely to double every 20 years (Brodaty & Donkin, 2009). There are numerous studies that have documented the difficulties faced by the informal caregivers of the people with dementia. However, there are very few studies the examining informal caregivers of

the persons who are affected by dementia prior to the age 65, that is early onset dementia or younger onset dementia (Ducharme, Kergoat, Antoine, Pasquire, & Coulombe, 2013).

The effects of dementia are devastating not only for the victims but also to their surrounding world. Their marital life and the life of their primary caregivers are significantly affected due to the effects of dementia. A caregiver provides care due to various reasons such as, someone needs help, their empathy or love for the person, or a sense of moral duty. Informal and primary caregivers often provide years of extensive care and that require a wide range of skills, such as: supervising, taking over daily tasks, interpreting and managing behavioral changes and adapting to new social and economic circumstances (de Vugt & Verhey, 2013).

The majority of people affected by dementia live in their local community and their care is provided by their family members (Schulz & Martire, 2004). The largest proportions of these caregivers are spouses and children (Brodaty & Donkin, 2009). In the United State, at least 70 percent of unpaid family caregivers are wives, daughters, daughters-in-law, granddaughters, and other kin relatives (Alzheimer's Association and National Alliance for Caregiving, 2004; MetLife Mature Market Institute, 2006). As dementia progresses, the quality of the spousal relationship and the intimacy level often diminish remarkably (De Vugt, et al., 2003).

In the current study, the level of grief and loss of caregiver spouses was studied through various methods. For this study a secondary set of data were used that was comprised of spouse caregivers of the person with young-onset dementia. Participants came from more than twenty states of the United States through a purposive sampling method. The methods of collecting samples and the background of the participants will be discussed in Chapter 3.

Purpose of the study

Studies and literature indicate that the various effects of dementia not only change the life and behavior of the affected individuals but also affect the life of informal or primary caregivers. Sometimes while caring for and serving a loved one with dementia, caregivers themselves acquire emotional burden and some form of emotional disorder. The aim of this study was to explore the level of grief and emotional loss associated with the spouse caregivers of a person with early/young onset dementia. The principle/major objectives of this study were as follows:

1. To examine the emotional losses experienced by caregivers while providing care to a spouse with young-onset dementia.
2. To evaluate the level of stress among the spouse caregivers of the people with young-onset dementia.
3. To assess the different forms of caregivers' burden associated with caring for a spouse with young-onset dementia.
4. To examine potential interventions that are associated with the challenges of caring for the caregivers and their needs.

Limitations of the Study

This study has the potential to make a significant contribution in the socio-psychological knowledge about young-onset dementia caregivers, but has several limitations. The limited sample size is insufficient for broad generalization. Another important limitation of this study was, that the researcher had limited control over the data set, since this study utilized a previously collected yet unanalyzed set of data. Another limitation is that the present researcher did not consider other important independent variables such as, gender of the caregivers and the years of marriage. Previous research has shown that Male caregivers react differently than

female caregivers (Diehl-Schmid, et al., 2013). Other factors such as financial status should also be considered while talking about caregivers of people with young-onset dementia. Apart from the limitations, the present study opened up several avenues for future research on the level of grief and stress of the caregivers. In future studies, the researchers would definitely focus on several other components that might be the contributory factors of increasing the level of grief, loss and stress burden of the caregivers, such as gender of caregivers, financial factors and length of marriage with the care recipient and the issue of social relationship.

Terminology

Young-onset dementia- Dementia that affects people under age 65 (ALZ, 2010).

Anticipatory grief- A person is grieving or mourning for his or her foreseen loss for the person or the care recipient who is still alive (Rando, 1986).

Ambiguous loss- When a loved one or close relative is physically present but no longer cognitively present (Boss, 1999).

Informal Caregiver- Relatives or others closely involved in taking care for the person with dementia but who do not receive payment for their caregiving. (Peeters, Van Beek, Meerveld, Spreeuwenberg, & Francke, 2010)

Caregiver Burden- It is defined as the stress, burden and other multidimensional responses that arises due to caring for a person diagnosed with a disease (Kim, Chang, Rose, & Kim, 2012).

Research Question

How are grief, loss and stress burden associated among spouse caregivers of the person with young-onset dementia?

Chapter Two

Review of the Literature

There is a limited number of studies focusing on the issue of caregivers' stress and burden for the people caring for someone with young-onset dementia. In all of the studies, through various dimensions, researchers have concluded that a significantly higher level of burden has been experienced by the caregivers a person with young-onset dementia. These studies showed that the young age and shorter period of married life significantly increases the caregivers' challenges associated with caring for their loved one diagnosed with young-onset dementia. Also, young age relates to the financial struggle which further increase the caregivers' burden as the person with young-onset dementia may no longer be able to contribute financially and the entire financial burden for the family becomes the caregivers' responsibility. The caregiver takes the responsibility of raising the children in the family without much support from the spouse with dementia and this also increases the caregivers' burden.

This present study reviewed literature in three distinct areas: 1) The effects of young-onset dementia on marital life, 2) The burden of caregiving; and 3) Caregiver's feelings of loss and grief due to the recent changes taking place as the effects of young-onset dementia.

Effects of dementia in the marital relationship

The experience of spouses caring for a husband or wife with young-onset dementia has been studied to determine the impact of this disorder on the marital relationship (young-onset dementia occurs in people before the age of 65). Ducharme et al. (2013) designed a qualitative study to focus on the experience of spouse caregivers with respect to the first symptoms of the disease, the evolution of their relationship and diagnosis. Eight women and four men participated in the study and were interviewed. Participants were required to meet the selection criteria, they

had to be spouse of a person diagnosed with dementia before age of 65 and had to be the self-defined as the primary caregiver.

Ducharme et al. (2013) identified six recurring themes from the results: 1) Difficulty managing behavioral and psychological symptoms of life partner, 2) Length of time before diagnosis, 3) Stigma and taboo associated with this disorder that led nondisclosure to others and denial of diagnosis, 4) Grieving for the relationship that existed prior to the disorder and craving for a “normal” life, 5) Difficulty juggling unexpected role and daily life responsibilities, and 6) Difficulty planning for their future (Ducharme, Kergoat, Antoine, Pasquire, & Coulombe, 2013). The Ducharme et al. (2013) study opens up several avenues for evaluating and developing professional interventions for the spouses dealing with a partner with young-onset dementia.

Clare et al. (2012) sought to explore the perception of present marital relationship quality when one partner was diagnosed with young-onset dementia and their study specifically focused on the effects of congruence or incongruence within the relationship. Clare et al. included both the caregivers and the person with dementia in the data analysis and obtained ratings regarding their relationship quality. Clare et al. conducted a cross-sectional quantitative data analysis for 108 married couples and equally distributed for clinical and control groups (54 couples each group). They used the Positive Affect Index (PAI) to assess the relationship quality in terms of five areas of their conjugal life that are associated with closeness, communication quality, engagement in joint activities, similarity of views about life and overall relationship quality. This was rated on a 6 point Likert scale where possible range of score from 5 to 30 and higher scores indicate better relationship quality. The findings showed that the relationship quality of the clinical group was significantly lower than the control group where lower ratings indicated higher levels of stress.

Clare et al. (2012) observed significant discrepancies in the scores between the caregiver and the care recipient, and suggested such discrepancies were extensively related to the impact of dementia in terms of awareness of functioning. These incompatibilities demonstrated that people with dementia (PwD) showed a tendency to overestimate themselves regarding their functioning compared to their caregiver, specifically, in the domains of memory and activities of daily living. Clare et al. also found sex discrepancies as a major indicator to perceive the relationship quality considering the lower rate given by the male caregivers than female caregivers. On the other hand, female PwD's gave higher ratings for declining relationship quality whereas male PwD gave higher ratings for improving relationship quality over time.

Clare et al. (2012) aimed to recognize the perspectives of both the person with dementia and their caregivers. Their study considered the extent of similarity and discrepancy of the views of both the members of a couple and the sex dichotomy, whereas Ducharme et al. (2013) studied only the experiences the caregiving spouses and their views on the affects of dementia on their relationship.

De Vugt et al. (2003) investigated whether the Behavioral and Psychological Symptoms of Dementia (BPSD) were related to the quality of marital relationship. Sixty-four spouse caregivers participated in this study and the researchers used both qualitative and quantitative methodology. Multiple regression analysis was conducted to examine the relationship between the variables considering care recipient functioning as the independent variable and relationship change as the dependent variable. Qualitative data analysis helped them to assess the expected relationship between the variables.

Through the data analysis, De Vugt et al. (2003) found a combination of negative and positive outcomes. The spouses were experiencing a deterioration in their relationship whereas at

the same time they were feeling a stronger emotional bond with their spouse. This outcome was noted as a positive change due to dementia. Results also indicated that since the spouse caregivers and the person with dementia were dealing with a difficult situation this sharing of difficult experiences may build up a strong bond between the couples. Also, taking care of the partner was seen as spending time with their spouse and togetherness that reinforced their bond. Regarding the negative outcomes in terms of deterioration of marital relationship, the researchers found a correlation with care recipients' behavioral problems due to the functional impairment or cognitive status. Caregivers' experience of declining marital relationship was greatly associated with apathetic and withdrawn behavior by the person with dementia. The apathetic or active disturbed behavior had a negative impact on their marital relationship.

A comparative review should be considered from the above three studies. De Vugt et al. (2003) and Clare et al. (2012) focused in the same area although it should be considered that both the studies have significant differences. For example De Vugt et al. (2003) conducted their study on the spouse caregivers whereas Clare et al. (2012) conducted research on both the caregivers and the person with dementia. But the results of De Vugt et al. (2003) study resembles the study of Ducharme et. al. (2013) where researchers have focused on the experiences of spouse caregivers.

There are very limited research studies and literature that document the sexual relationship between married couples while one partner is suffering from dementia. Ballard et al. (1997) conducted a study to determine the proportion of married couples continuing sexual life and their level of satisfaction when one partner was suffering from dementia. The caregiver partners were interviewed through Geriatric Mental State Schedule (GMSS) and the level of depression was diagnosed through the Research Diagnostic Criteria (RDC). Ballard et al.

excluded the people with severe dementia. Forty-seven spouse caregivers living with their dementia partners participated in this study, while forty participants agreed to answer the questionnaire regarding their sexual relationship. The caregivers were asked about their present sexual relationship, satisfaction, understanding of their spouse's satisfaction, and if they were more interested in sexual activities compared to the person with dementia. The study showed that 22.5% of the couples had active sexual relationships, and 38.7% were sexually inactive and dissatisfied with the absence of a sexual relationship. The couples that were not sexually active were associated with person diagnosed with vascular dementia. Ballard et al. concluded that since the present study was conducted using a small sample size, the hypothesis presented also needed to be verified using larger sample sizes.

Effects of dementia in the life of informal caregivers

The term primary or informal caregivers has been used to signify a close relative who takes the major role of caregiving for a person with dementia who resides at home. If the person with dementia is married, a spouse is the person who most likely to take on the caregiving role (de Vugt & Verhey, 2013). Dementia has diverse effects on both (Brodaty & Donkin, 2009). Studies and literature indicate that the various effects of dementia not only change that person's life and behavior but also affects their informal or primary caregivers.

Mioshi et al. (2013) conducted a comparative study on the caregivers' burden in the variants of frontotemporal dementia (FTD) and Alzheimer disease (AD) and identified the key contributing variables to the caregivers' burden. Information was collected from three different variants of FTD. The number of participants for behavioral frontotemporal dementia (bvFTD), semantic dementia (SemDem) and progressive non-fluent aphasia (PNFA) and Alzheimer disease (AD) were 17, 20, 20 and 19, respectively. Mioshi et al. used several instruments,

including the Zarit Burden Inventory scale, Depression, Anxiety and Stress scale for data analysis.

Mioshi et al. (2013) analyzed the data through regression analysis and findings revealed a significant group difference in caregivers' burden scores. The Zarit Burden Inventory score indicated that bvFTD caregivers had significantly higher level of burden than other groups ($p < .05$) whereas caregivers of PNFA individuals had significantly lower levels of burden than the others. Furthermore, researchers found that the severity of the disease was the key factor in determining the caregivers' burden in dementia subtypes.

Since the life expectancy for human beings has increased remarkably, so have age related diseases and disorders (Byers , Yaffe, Covinsky, Friedman, & Bruce, 2010). Mioshi et. al. (2013) conducted a study to identify caregivers' burden in four subtypes of dementia selecting the samples from Sydney, Australia. Similarly, Liu et al. (2012) conducted a comparative study on caregivers of dementia and non-dementia in Beijing, China. The purpose of Liu et al.'s study was to evaluate the levels of depression and anxiety that are associated with caregiving. The equal number of participants (90 for each group) were selected via convenience sampling, whereas caregivers of people having disease other than dementia were selected through random sampling. According to the Liu et al. study, 90% of are cared for by their spouses at home, and 50% of those caregivers suffered from anxiety and depression (Liu, et al., 2012).

To determine the level of burden, anxiety and depression Liu et al. (2012) used the CBI, SDS and SAS scales for data analysis. The authors observed that the mean scores for the CBI, SAS and SDS measures steadily increased from non-dementia to dementia groups. Also, patients' CDR scores were positively correlated with the caregivers' burden. In Liu et al. study,

the authors concluded that the time and burden score was the highest because it represented the daily care time, which was positively correlated with the burden of caregivers.

A high level of care is a general requirement for people with dementia and in most cases care is provided by family caregivers who are also known as 'informal caregivers'. Without the service of family caregivers the quality of life for the people with dementia would be worse. However, this support comes at a high cost of distress and inferior quality of life for the caregivers (Brodaty & Donkin, 2009). Diehl-Schmid et al. (2013) looked at the problem of frontotemporal dementia (FTD) on caregivers and examined the contributory factors for strain and depression. Diehl-Schmid et al. also explored the needs of caregivers and investigated the support of different interventions and strategies by interviewing 94 care givers. The results showed that 60% of the caregivers scored >7 in the CSI scale, which indicated that caregivers had excessive strain. From the results it was determined that about half of the caregivers had clinically significant levels of depressive symptoms.

Diehl-Schmid et al. (2013) also identified changes in the personality of people with dementia, specifically aggression, lack of manners, inflexibility, and egocentric behaviors as they were the most burdensome for the caregivers. Findings indicated that with behavioral symptoms and physical impairments, such as swallowing difficulties and walking disability together, were the most burdensome for the caregivers. The caregivers' strain was associated with several factors, such as the need for supervision at home, too much dependency on the caregiver, physical impairments including lack of self-restraint and the need for care. Cognitive impairments like speech problems and spatial disorientation, apathy and compulsive behavior were the major contributors of caregivers' strain (Diehl-Schmid, et al., 2013). Financial problems

were another important component that had the potential to increase the level of caregivers' strain.

The research conducted by Mioshi et. al. (2013), Liu et. al. (2012) and Diehl-Schmid, et al. (2013) showed that there are a few common findings that need to be considered. Behavioral changes in are considered a critical component that can increase the level of burden for caregivers, whereas Diehl-Schmid, et al. (2013) also noted that physical impairment can cause extra burden to the caregivers.

How the partners or spouses make sense and negotiate transition of their normal life into caregiver role, in addition to how they interpret the changes into their dementia affected partner was the main objective of the study conducted by Quinn et al. (2008). In Quinn et al.'s study, the researchers explored the subjective (psychological) experiences of the spouses during the early stage of their caregiving career. Quinn et al. interviewed 34 partners of individuals diagnosed with young onset dementia. Four different themes emerged from their study such as, 1) difficulties that the caregivers experienced trying to understand what was happening with their partners, 2) changes in the caregivers' relationship with the care-recipient and new emerging restrictions in their lifestyle, 3) developing new strategies to cope with the new situation, and 4) emotional strain and anxiety experienced by the caregivers.

Quinn et al. (2008) indicated that the caregivers were experiencing significant level of stress due to the new shift in their life that occurred undesirably. In consequence, the caregiver's main objective was to focus predominantly on coping day by day, and they occasionally discussed the situation with the care recipients. Since the caregivers were in the primary stages of their caregiving career, they were struggling with gradually taking over the roles and responsibilities as time passes and they noticed further changes in their partner. Other interesting

findings from this study included that, some of the caregivers were trying to minimize the problems of their partners, whereas others were trying to deny that their partners had dementia. Interestingly, the caregivers found it is very beneficial to talk to somebody about the situation, preferably, the informal support group such as close friends and fellow feelings.

Anticipatory Grief and Ambiguous Loss

Family members experience the deterioration of ability to work and love. It is extremely sorrowful for the family members and close relatives to experience the fragments and the glimpses of familiar personality and behavior that has been lost (Robins, 1982). Robins (1982) explained that the life of healthy spouses and family members of a person with dementia can be described as an ongoing funeral or a long good bye because the person they knew before is dying every moment. Currently, there are no formal rituals that exist for mourning like this, but the family grieves for their loved one regardless. This psychological death can have a profound impact on the entire family. Literature on the mourning process that is experienced by the family members of a dying person defines a course of development with distinct phases such as denial, anger, bargaining, depression and acceptance (Ross, 1969). These are the usual stages of the mourning process and include a psychological closure and acceptance at the end and that helps to decrease the level of grief. Closure is impossible for the families of person with dementia and this can result in an extended and prolonged process of grief (Robins, 1982).

Sanders et. al. (2008) focused their study on the life experiences of 44 spouses and adult children as caregivers of persons with dementia. The mixed method approach examined the experiences of caregivers who had exhibited an extensive level of grief. Researchers used the Marwit and Meuser Caregiver Grief Inventory-Short Form (MM-CGI-SF) to examine the grief level of caregivers. Participants had to be an adult child or spouse of a person who has been

diagnosed with Alzheimer's disease or related dementia and that person had to be the primary or secondary caregiver with a wide range of assistance (Sanders, Ott, Kelber, & Noonan, 2008).

Sanders et. al. (2008) identified seven themes that emerged from their qualitative data analysis, including yearning for the past, isolation, regret and guilt, life stress, restricted freedom, systemic issues and coping strategies. Results indicated that caregivers have an enormous sense of yearning for the past in terms of their relationship with the person with dementia that has been lost due to the disease. It is not only the past that they are yearning for, but also the past dreams they had shared together for themselves, for their children and for other kin. Researchers have found a significant number of caregivers have a strong feelings of regret and guilt commonly towards the long term care facility where the patients are admitted. The caregivers felt that their loved one has not been treated as well as they deserve or if they could arrange home care for the care recipient. Caregivers experienced high levels of grief due to the isolation. They expressed their feelings about having less contact with friends and community. Conversely, some of the friends and relatives refrained from keeping relationships with the caregiver and person with dementia, which made the caregivers feel even more isolated. Above all, twenty-four hour care and attention for the care recipient takes its toll on caregivers' freedom and social involvement. Sanders et. al. (2008) concluded that all these adverse themes in caregivers' lives accumulate together and increase the levels of stress and burden.

Few studies have been conducted to understand the impact of grief on spouse and adult children who are considered as the two most common primary caregivers. Meuser and Marwit (2001) systematically investigated the grief responses from the spouse and adult caregivers of people diagnosed with dementia. Meuser and Marwit hypothesized that spouse and adult child caregivers would establish distinctly different forms of grief as the disorder progressed. The

objective of the study was to develop a constructive psychometric instrument that would measure the range of grief responses from the caregivers of people with dementia. Forty two spouse and forty five adult caregivers participated in the study.

In Meuser and Marwit's (2001) study, the participants were recruited from the St. Louis Chapter of the Alzheimer's Association, the Memory Clinic and Aging Project at Washington University's School of Medicine. Out of 121 caregivers, 87 were selected for the study. The investigators conducted a semi structured interview for the focus group that consisted of six major areas: participants' background, that included their family, work and other aspects, questions related to the dementia affected person in terms of their past role in the family and caregiver's life, participants' reaction to the early recognition of the disease, questions related the changes in caregiver's life and major losses, grief experience, and questions related to coping the situation.

The result of Meuser and Marwit's (2001) study showed the fundamental differences in the grief responses of spouse caregivers versus adult children caregivers. Adult children caregivers pointed the condition of dementia as part of normal aging. Adult children caregivers focused on the capacity of their parents instead of the signs of dementia. As a result of that they minimized their feelings and they were not interested in discussing the future. On the other hand, spouse caregivers clearly expressed their sadness and they were realistic about the potential future. This study has also explored the distinction in loss issue experiences between children and spousal caregivers. As adult child caregivers kept their denial regarding their parents' dementia, they expressed their loss issue in terms of loss of personal freedom. In contrast, spouse caregivers expressed the loss issue largely in terms of change, burden and grief of losing the past life.

Family caregivers of people with dementia experience anticipatory grief and ambiguous loss that becomes an unbreakable barrier into the role of caregiving. Frank (2008), conducted a study with 353 caregiver participants from the state of Indiana to explore an association between anticipatory grief, ambiguous loss and major barriers that family caregivers of person with dementia experience. In this study 38% of participants were spouse caregivers, whereas 53% of participants were adult child caregivers and only 9% of participants of the study were classified as “other close” relatives.

Frank (2008) used open-ended surveys in the study and the Marwit-Measure Caregiver Grief Inventory scale to explore the direct association between barriers to the caregiving role and the various aspects of grief. The level of grief was measured in terms of “personal sacrifice burden,” “worry and felt isolation” and “heartfelt sadness and longing” (Frank, 2008). The findings revealed five distinct categories of grief expression: caregiving role versus personal life, patient related challenges, heartfelt sadness and longing, lack of support, and communication. Frank’s study suggests the inevitable and unavoidable linkage between grief and loss with the caregiving role for a family member with dementia. The study explored and highlighted the loss and grief of the caregivers in a way that would help to implement and focus possible interventions for the caregivers to neutralize the coping capabilities and reduce stress, burden and depression (Frank, 2008).

As the life expectancy of individual increases, the prevalence of dementia along with other disorders has also been increasing (Wimo & Prince, 2010). The effects of dementia in the caregiver’s life have been upsetting through various ways, such as the effect on the marital relationship, intimacy and even sexual activity. On the other hand, serving or caring for a partner with early onset or late onset dementia is always challenging and devastating. The unprecedented

changes in their partner are not only shocking but coping with the situation is also difficult and stressful. Since dementia is an incurable disease (ALZ, 2010), the findings and the conclusion of all of these studies have suggested the systematic need, support and intervention for informal care givers who are caring for people with dementia, regardless of age.

Chapter Three

Methodology

Numerous research studies have concluded that dementia has multidimensional effects. It is not only devastating for the person who suffers from it, but also presents as an enormous strain and burden on their caregivers. This pressure can lead to chronic stress, fatigue, irritability and depression (Gort, et al., 2007). Caregiver burden is defined as the stress and other multidimensional responses that can arise due to caring for a person diagnosed with a disease (Kim, Chang, Rose, & Kim, 2012).

The current study explored the association between stress burden, grief and loss with the spouse caregivers of the individuals with young-onset dementia using a secondary data set. The current study also examined the level of stress and burden on the spouse caregivers and explored the areas of anticipatory grief and loss that can be associated with the caregiving and changes in the spouse due to the effects of dementia.

Research Design and Instrumentation

A burgeoning level of research on caregivers' stress and burden has become well known in the field of social-psychology, although researchers in this field remain uncertain about the ways to measure the level of stress and the health risk (Schreiner, Morimoto, Arai, & Zarit, 2006). Marwit and Meuser (2002) developed a model for measuring the level of caregivers' grief experiences that is known as the Marwit-Meuser Caregiver Grief Inventory (MM-CGI). The measure consists of three subscales that record various grief related issues associated with Alzheimer's caregivers. Although there are various scales and methods to measure the level of burden of caregivers in terms of psychological, physical and emotional implications, the Zarit

scale is widely used to assess caregivers' burden and predict the psychological risk factors (Gort, et al., 2007). The study utilized a secondary data set where the MM-CGI and Zarit Burden interview methods had been used to explore both grief and levels of stress among spouse caregivers.

Sample

In 2009, Frank conducted an empirical study and collected data on spouse primary caregivers of the people with young-onset dementia. Fifty five young-onset caregivers from all over the US participated in Frank's study. Through a purposive sampling method, the potential participants were contacted via postal mail and email and a total of 55 completed surveys were received. Frank did not have the opportunity to analyze the data and complete her study based on her research questions. The present study utilized Frank's unanalyzed data set to specifically examine the degree of grief and loss and level of stress on spouse caregivers using quantitative analysis.

The age range of the participants in the data set was 34-67 years. Most (98.2%) of the participants were primary caregivers of their spouses with young-onset dementia while only 1.8% of caregivers were siblings. All of the participants were Caucasian. Frank collected the basic information about the participants through the Indiana University Alzheimer's Disease Center, the Greater Indiana Chapter of the Alzheimer's Association and the Washington University Alzheimer's List.

Description of Previous Data Collection Procedure

The original study conducted by Frank used the following instruments to gather data:

- 1) The Marwit-Meuser Caregiver Grief Inventory (MMCGI) (Appendix-A)
- 2) The Zarit Burden Interview (ZBI) (Appendix-B)

- 3) A self-designed questionnaire (Appendix-C) examining demographics, employment, relationship with the care recipient as well as amount of time spend with the care recipient, and length of care history.

Data Analysis

The present researcher used statistical analyses on the secondary data set to determine the relationships between the variables from the MMCGI and ZBI. The dependent variables were defined using a combination of independent variables. The present researcher used the caregiving role and progression of the disease as the independent variables and stress burden, grief and loss were the dependent variables. The variable stress burden is dependent on the caregiving role such as life change, and constant sense of responsibility. The variable emotional loss is directly correlated with the freedom of their life. The variable grief was analyzed based on the percentage of the caregivers experiencing various emotional strains such as anger, craving for their past life and feeling of their loved one is gone.

The Pearson product-moment correlation coefficient (Pearson's correlation) statistic was used to determine the relationships between the variables. The Pearson's correlation provides a clear picture of the strength and the direction of an association between two variables when the variables are continuous.

Statistical significance of the results was examined by calculating the *p*-value. A *p*-value of less than 0.05 is indicative of statistically significant relationships. Multiple regression analysis were conducted to examine the relationship between the dependent variable stress and the predictor variables. The data obtained from the Zarit Burden Interview was used to determine the level of stress and burden of the caregivers due to their care giving role. In the Zarit Burden interview a Likert scale of 0-4 were used, whereas 0 and 4 were considered as "never" and

“nearly always,” respectively. All the quantitative data were analyzed using SPSS software (IBM SPSS Software, Version 22, New York, USA).

The data obtained from the Marwit-Meuser Caregiver Grief Inventory (MMCGI) interview was used to determine stress burden, grief and loss due to the intensity of the disease in the person suffering from young-onset dementia. In MMCGI a Likert scale of 1-5 were used, where 1 and 5 were labeled as “strongly disagree” and “strongly agree,” respectively. Percentages were calculated to illustrate the stress burden, grief and loss experienced by the participants. Based on the data analysis the possible intervention methods are discussed in the Chapter 5.

This study predominantly focused on three distinct areas resulting due to the caregiving activities, such as the level of stress, level of the feeling of emotional loss and the feeling of the emotional grief. These three variables and the predictors were measured from the MMCGI and ZBI scales. Meuser and Marwit subdivided the MMCGI questionnaire into three different subgroups as A) Personal Sacrifice Burden, B) Heartfelt Sadness & Longing , C) Worry & Felt Isolation (Mesure & Marwit, 2001; Marwit & Meuser, 2002), also shown Appendix A in the MMCGI answer key. Referring to the subscale “Personal Sacrifice burden” (subgroup A) participants were asked to mention their level of stress for the statement “I carry a lot of stress as caregiver” (MMCGI7) using the Likert scale which was considered as the level of stress of the spouse caregivers for this study. In the domain of “personal sacrifice burden”, MMCGI scale measured life changes and the sense of responsibilities of caregivers by asking “my personal life has changed a great deal” (MMCGI11) and “I feel this constant sense of responsibility and it just never leaves” (MMCGI17). These three variables under the subscale “personal sacrifice burden” of MMCGI (subgroup A) were analyzed to determine their relationship with the level of stress.

In this study the level of emotional loss among the spouse caregivers were determined by the MMCGI scale “Worry and Felt Isolation” (subgroup C). Under this domain, participants were asked to indicate their level of emotional loss in terms of “dementia is like a double loss, I have lost the closeness with my loved one and connectedness with my family” (MMCGI13). In this study the above statement was considered as the feeling of emotional loss.

The Zarit Burden Interview (ZBI) has focused on the areas that is related with caregivers’ burden (Appendix B). In the ZBI scale participants were asked “do you feel that because of the time you spend with your relative that you don’t have enough time for yourself?” and this question was considered as the variable time spent (Zarit2). The answers to these two above statements given by the participants were then analyzed for correlation.

The feeling of emotional grief of the spouse caregivers was determined by the domain of MMCGI “heartfelt sadness and longing” (subgroup B). In this subscale participants were asked to indicate their feelings in terms of “I have this empty, sick feeling knowing that my loved one is gone” (MMCGI9) and “I long for what was, what we had and shared in the past” (MMCGI18). These two variables, were analyzed to determine their correlation. The statistical analysis of these three areas that is the level of stress, the emotional loss and the emotional grief would be explained in the chapter 4 Results.

Chapter Four

Results

The present study focused on a quantitative data analysis to determine the level of stress burden and emotional grief and loss among the spouse caregivers of persons diagnosed with young-onset dementia. In this research study, Pearson's product moment Correlation- coefficient was used for the data analysis. Correlation-coefficient is one of the most extensively used statistical analytical methods in scientific research studies (Richard, 1990). Usually, correlation-coefficients explore the potential linear traits and relationships between two continuous variables (Puth, Neuheuser, & Ruxton, 2014). In this present study the level of stress was one of the continuous and dependent variables, whereas life change due to the caregiving activities, and a constant sense of responsibility were the two independent and continuous variables to determine the stress level of the caregivers.

Fifty five spouse caregivers participated in this study. The participants were asked to determine their level of stress burden, emotional grief and loss due to their caregiving activities. Pearson's correlation coefficient was used to determine the association between the variables level of stress (MMCGI7), life change due to the caregiving activities (MMCGI11) and a constant sense of responsibility (MMCGI17). The value of Pearson's r close to 1 indicates a strong relationship between two variables and also indicates that changes in one variable was strongly associated and correlated with the changes in the other variable. A multivariate correlation analysis was performed to understand the level of stress due to the life change and a constant sense of responsibility while caregiving.

In the present study, life change due to the caregiving activities (MMCGI11) was greatly correlated with the level of stress. The results were significant ($r = 0.83$, $p = 0.00$) indicating that as the changes occur in the caregiver's life due to the caregiving role and activities, the level of stress would be increasing as well (shown in Table 1). This result shows a strong positive relationship between changes in caregivers' life due to the caregiving activities and their level of stress.

Table 1.

Summary of intercorrelation, means (M), and standard deviations (SD) for scores between stress (MMCGI7), life changes (MMCGI11) and constant sense of responsibility (MMCGI17).

	Stress	Life changes	Responsibility	<i>M</i>	<i>SD</i>
Stress	1.00	0.83*	0.87*	4.15	1.09
Life changes	0.83*	1.00	0.73*	4.20	1.04
Responsibility	0.87*	0.73*	1.00	4.35	1.06

Note. *Correlation is significant at the 0.05 level (2-tailed).

In the present study the constant sense of responsibility (MMCGI17) was found to be another important variable responsible for the increasing level of stress among the spouse caregivers. The MMCGI scale had an important component to measure the caregivers' sense of responsibility. Sense of responsibility among the caregivers was defined in the MMCGI scale as "I feel this constant sense of responsibility and it just never leaves" (MMCGI17). The results were significant ($r = 0.87$, $p = 0.00$) indicating that an increase in sense of responsibility linearly increased the level of stress. As a result of the disease, the person affected with the young-onset dementia lost his/her capabilities of taking on responsibilities. This affects the life of his/her spouse in terms of being required to take on more responsibilities and this accumulation of responsibilities increased the level of stress among the spouse caregivers.

The analysis also showed a significant correlation ($r = 0.73$, $p = 0.00$) between life change (MMCGI11) and the constant sense of responsibility (MMCGI17) among the spouse caregivers for person diagnosed with young-onset dementia. The spouse caregivers typically experienced increases in sense of responsibility due to the cognitive deterioration of their demented partners which significantly also changed their level of stress. This situation forced them to take on more responsibilities including those usually taken by their partner before they were diagnosed with young-onset dementia. These unprecedented responsibilities along with caregiving roles and activities changed their life in an undesired manner. The combined effect of life change and constant sense of responsibility significantly affected the level of stress burden experienced by the spouse caregivers.

Multiple regression analysis were conducted to examine the relationship between the level of stress (MMCGI7), with life change (MMCGI11) and constant sense of responsibility (MMCGI17) in the spouse caregivers of person with young-onset dementia. Table 2 summarizes the result of the regression analysis. The results indicated that the increase in either life change or constant sense of responsibilities increased the level of stress in spouse caregivers.

The multiple regression model with these two predictors produced $R^2 = 0.84$, $F(2, 52) = 135.33$, $p < 0.05$. The R^2 value also known as the coefficient of determination, is the proportion of variance in the dependent variable that can be explained by the independent variables. The result indicates that the independent variables (life change and constant sense of responsibility) explained 84% of the variability of the dependent variable stress burden in the spouse caregivers.

Using the B values estimated by the multiple regression analysis the regression model can be defined as

$$\text{Stress Level} = -0.025 + 0.45 \times (\text{Life Change}) + 0.57 \times (\text{Sense of Responsibility}).$$

The results clearly indicated that the positive correlation between life change and constant sense of responsibility caused changes in the level of stress in the spouse caregivers. Small differences in the coefficients of the model for life change ($B = 0.45$) and constant sense of responsibility ($B = 0.57$) were observed indicating that both the predictor variables equally contributed to the changes in the level of stress experienced by the spouse caregivers.

Table 2

Regression analysis of predictors of level of stress burden among the spouse caregivers

Variable	Level of Stress Burden		
	Unstandardized Coefficient	95% Confidence Interval for B	Standardized Coefficient β
	B	Std. Error	
Constant	-0.25	0.27	
life change	0.45	0.09	0.43
sense of responsibility	0.57	0.08	0.56
R^2		0.84	
F		135.33	

Note. $N = 55$. Level of stress burden, the life change and sense of responsibility are denoted as MMCGI7, MMCGI11 and MMCGI17, respectively.

In the present study, the grief and emotional loss due to the caring for a spouse with young-onset dementia was investigated. The level of emotional loss was estimated by responding to the statement, "I feel I am losing my freedom," which was coded as MMCGI3. The percentage of the spouse caregiver participants going through emotional loss was estimated from the answer given for MMCGI3 and graphically presented in a histogram.

Generally histograms are used to show the distribution of a quantitative variable by its relative frequency of data (Leech, Barret, & Morgan, 2005). The histogram's shape is approximately a bell-curve histogram which suggests that the data have come from a normal

distribution where the mean value is 3.82 and the Standard Deviation is 1.2 as shown in Fig. 1. The graph suggests that most of the participants in this study were going through a high level of emotional loss. Specifically, 80% of the participants either agreed or strongly agreed that they were experiencing emotional loss in terms of losing their freedom due to their caregiving responsibilities.

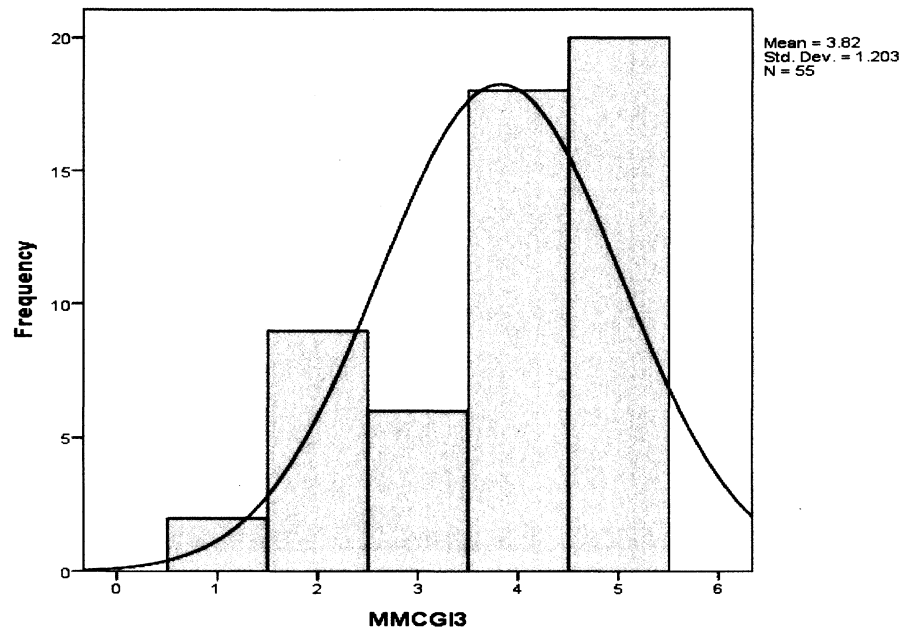


Figure 1. Histogram of the level of emotional loss experienced by the spouse caregiver (MMCGI3).

A few important variables were found to be responsible for increasing the level of emotional loss among the spouse caregivers, such as the amount of time the caregivers were spending on caregiving that reflects on the freedom of their life. Time spent was coded as Zarit2 and the emotional loss was coded as MMCGI3. The correlation coefficient indicated a strong

positive correlation between the time spent and emotional loss as shown in Table 3. The results were significant ($r = 0.82$, $p = 0.00$) indicating that an increase in spending time for the caregiving activities linearly increased the level of emotional loss. As much the caregivers would be spending time for the caregiving role, they would seldom receive time for themselves and as a result of that they would be inevitably suffering from lack of freedom in their life.

Table 3

Summary of correlation, Means (M), and Standard Deviations (SD) for Scores between emotional loss (MMCGI3) and time spent for caregiving (Zarit2).

	MMCG3	Zarit2	M	SD
MMCGI3	1.00	0.82*	3.78	1.01
Zarit2	0.82*	1.00	2.35	1.19

Note. *Correlation is significant at the 0.05 level (2-tailed).

In the present study most of the participants were grieving for their present situation. The results showed that the spouse caregivers of the individuals with young-onset dementia were grieving for multiple reasons. For example, most of the participants were grieving that his/her loved one is was “gone,” the person he/she knew had changed or become a completely different personality. The feeling of a loved one being gone was coded as MMCGI9 and 78.2% of the spouse caregiver participants agreed that their loved one had changed significantly and that they had a deep feeling that their loved one was gone. At the same time, more than 90% of the spouse caregiver participants were longing for their past life.

Changes in the personality of a person due to the fatal effects of dementia was correlated with the grief for their past happy life that they used to share together. The results were significant ($r = 0.90$, $p = 0.00$) indicating that changes in one variable predicted changes in the other variable. In other words, as the personality of the person with dementia changed or

deteriorated in contrast with his/her past, the longing for the past life among the spouse caregivers was increasing as well.

The correlation between longings for the past life (MMCGI18) and the feeling of knowing that the loved one was gone (MMCGI9) was strongly correlated ($r = 0.90$, $p = 0.00$). A scatter plot of longings for the past life (MMCGI18) versus feeling of knowing that the loved one is gone (MMCGI9) is shown in Fig. 2. All the dots are positioned in a same direction from zero to upward and the slope indicates an extremely strong and positive correlation between the variables longings for the past life (MMCGI18) and feeling of knowing that the loved one is gone (MMCGI9).

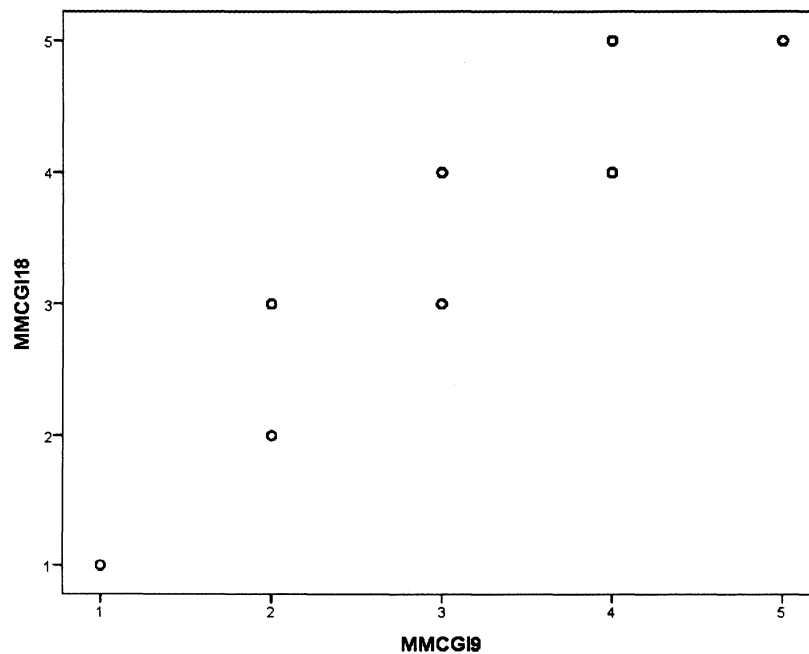


Figure 2. Scatter plot of the longings for the past life (MMCGI18) parameter versus feeling of knowing that the loved one is gone (MMCGI9) parameter.

The majority (85.5%) of the participants in the current study believed that the disease robbed them of their past life (MMCHI27) and more than 65 % of the participants felt that dementia was like a “double loss” (MMCGI13), as the spouse caregivers had lost the closeness they had with their loved one prior to the onset of dementia and at the same time he/she lost the connectedness with friends and family. These results indicated that the participants were going through the process of emotional grief and the major responsible factors included feeling the loss of their loved one (MMCGI9), longing for their past life (MMCGI18), feeling that the disease robbed their past life (MMCHI27) and grieving for losing the closeness of the loved one and connectedness with friends and family.

Chapter Five

Discussion

According to the Alzheimer's Association (2010), Dementia denotes a wide range of deterioration in cognitive ability and it is severe enough to interfere in the daily life of an individual. Studies that are associated with dementia and the family caregivers' of the person with dementia are substantial in the research literature. However, there are few studies that have focused on the spouse caregivers of persons diagnosed with young-onset dementia (Kaiser & Panegyres, 2007). The present study has focused on the psychological status, specifically the hurdles faced by the spouse caregivers of people diagnosed with young-onset dementia. This study is based on an unanalyzed secondary data set that was collected by a Frank in the year 2009. In this study, the participants were selected through purposive sampling method from the Indiana University Alzheimer's Disease Center, the Greater Indiana Chapter of the Alzheimer's Association and the Washington University Alzheimer's List.

The present study has utilized quantitative methods to analyze the data. Three major instruments were used for the data collection including the Marwit-Meuser Caregiver Grief Inventory (MMCGI), the Zarit Burden Interview scale (ZBI) and self-designed questionnaire related to the demographics of the participants. To focus on the psychological status of the spouse caregivers, this study mainly focused on the level of emotional grief and feelings of emotional loss and the level of stress burden. Pearson's product moment Correlation- coefficient and the regression analysis were used to find the responsible factors that are associated with grief, loss and stress burden.

Stress Burden

In this study the level of stress was categorized as one of the continuous and dependent variables. The spouse caregivers were experiencing stress burden due to their life change that was the result of an unprecedented caregiving activities for their spouse or partner diagnosed with young onset dementia. The caregivers expressed that they carried a great deal of stress as a caregiver which is substantiated from the answer given by the participants to the question in the MMCGI scale “I carry a lot of stress as a caregiver”. The major predictors of the level of stress burden were changes in the caregivers’ life and a constant sense of responsibility. Result indicated that 89.1% participants mentioned that they were experiencing a great level of stress as a caregiver and 92.7% participants agreed about rigorous changes in their life style due to their caregiving role. The result of the Pearson’s product moment Correlation- coefficient $r=0.83$, indicates a strong positive correlation between the stress level and life change. This outcome directs as the caregivers would experience changes in their life due to caring and serving for their dementia affected partner, the level of stress would be intensifying as well. This trend shows a linear increase in stress with increasing caregiving responsibilities.

A constant sense of responsibility made the caregivers’ life harder as stated by 90.9% of the participants. As a part of the unprecedented life changes, a high level of responsibility was placed on the spouse caregiver since his/her partner has been diagnosed with young onset dementia. In the past, caregivers used to share their responsibilities with their partners in terms of household activities, financial responsibilities and child rearing jobs and other miscellaneous decision making processes. But the capability of sharing these responsibilities was stolen by the disease – young-onset dementia – from the affected person and the all these responsibilities were accumulated on the spouse caregiver. In some cases the caregiver is responsible for helping the

partner in his/her Activities of Daily Living (ADLs). As a result of that the caregivers experience a high level of stress. In this study, the result of Pearson's product moment Correlation-coefficient $r = 0.87$ indicates a strong positive correlation between stress and constant sense of responsibility. As the level of responsibilities would be accumulated on caregivers' life they would be experiencing higher level of stress burden.

Multiple regression analysis examined the relationship between the level of stress with life change and constant sense of responsibility due to the caregiving activities of the spouse caregivers. The result indicates that the independent variables (life change and constant sense of responsibility) explained 84% of the variability of the dependent variable stress burden in the spouse caregivers. The results of regression analysis clearly indicated a positive correlation of life change and constant sense of responsibility due to the caregiving activities were the two major responsible factors to increase the level of stress in the spouse caregivers.

Emotional/Ambiguous Loss

It is always painful for the family members to experience an undesirable change and the glimpse of familiar personality and behavior that has been lost in their loved one. This ambiguity continues among the family members of the person with dementia as the disease progresses. It is a sorrowful experience and completely unacceptable from a spouse's point of view. In this study a great number of participants have expressed their situation as a "double loss" because they lost the closeness with their loved one and at the same time they lost connectedness with their family due to the time occupied by their caregiving activities. The result suggests that 80% of the participants are experiencing strong feeling of emotional loss due to the loss of their freedom in their life and lack of time for themselves. The correlation coefficient $r = 0.82$ indicates a strong positive association between the emotional loss and their loss of freedom. As the caregivers

would be occupied with their caregiving activities they would hardly find any room for their own activities and that would cause a deep feeling of emotional loss. Several caregivers expressed that they feel anxious and scared and worried about upcoming bad things and negative feelings as time progresses. This negative feelings can lead to deterioration of caregivers' psychological and physiological health.

Anticipatory Grief

Grieving is very natural when we lose our loved one. But grieving for a person who is still alive is very common for those whose loved one has been diagnosed with dementia. The family members of a demented person grieve for various reasons. They predominantly grieve for their past and their "normal" life. Most importantly the family members grieve for their loved one's changed personality. In the present study most of the participants are grieving for losing their past life. The result shows that several participants have expressed their grief for multiple reasons in which most (78.2%) of the participants have strong feelings that his/her loved one is "gone", due to behavioral change, deterioration of mental ability, problems in decision making and disorientation. Changes in the personality of a person due to the devastating effects of dementia was highly correlated ($r = 0.90, p = 0.00$) with the grief and longing for their past happy life that they used to share together. As the personality of the person with dementia changed or deteriorated in contrast with his/her past, the longing for the past life among the spouse caregivers was increasing as well.

Caring for a demented spouse was conveyed by several caregivers as a robber who robbed them of their past, healthy and happy life. Sometimes this emotional grief is manifested in different forms with some of the participants mentioning that they are experiencing a never ending sad phase of life and other participants mentioning that they cannot control their

frustration and often it becomes outbursts aimed at the care recipient. More than an average number of caregivers agreed that these feelings accumulate together and initiate feelings of depression and anxiety among themselves.

Caregivers' Support Group

There are many studies that have focused on the needs of dementia family caregivers. This study suggests that the family caregiver of a person with dementia needs special help because the effects of the disease would be severe enough as time progresses. In this study, caregivers' level of stress burden and emotional loss and grief suggest that they should attend and receive help from caregivers' support group. Surprisingly, only 61.8% of the participants receive help and emotional support from caregiver' support group, although the results indicate that more than 80% of the caregivers are experiencing a high level of stress and feelings of emotional loss and grief. Additionally, 73.3% of the participants mentioned that their health is declining from the stress due to the caregiving activities and 76.4% participants conveyed that they have a severe feeling of depression due to their present situation.

Attending a caregiver support group is helpful for the caregivers because they share their own experience with people who are going through the same situation and the caregivers get a friend network. Caregiver support group leaders provide efficient support and discusses several issues that helps caregivers for future planning (Caregiver Support Groups, 2014). However a significant number of caregivers do not attend caregiver's support group programs. Studies have documented several reasons behind the reluctance to attend support groups. Caregivers with low family income seldom afford the expenses of support group programs (Biegel, Shafran, & Johnsen, 2004). Not all the neighborhoods have the same availability of caregivers support programs and that prevents many caregivers to access the support group (Goelitz, 2003).

Sometimes an unintended disclosure of the dementia status and fear of stigma and social rejection are the responsible factors for not attending the caregivers' support group programs (Madiba & Canti-Sigaqa, 2012).

Since the person with dementia needs fulltime care, and the caregivers too need care for themselves, this study recommends caregivers to attend caregivers' support group to improve their own psychological and physiological status. Studies suggest that there is a common tendency for the caregivers to experience psychological and physiological strains while caregiving for a loved one. Studies have also suggested that the stress burden and feelings of grief and loss are higher for the caregivers of person with dementia than other long term diseases (Clipp & George, 1993). Therefore, by accepting help from a support group the caregivers can improve their health and also simultaneously improve the caregiving quality.

Recommendation for future research

The present study, "Grief, Loss and Stress Burden among Spouse Caregivers of the with Young-onset Dementia" revealed the factors and the predictors that are responsible for the increased levels of grief, loss and stress burden among the spouse caregivers due to their caregiving activities. This research study has opened up several avenues for future research studies in the same area. The researcher recommends conducting a qualitative study to understand participants' point of view through face-to-face interviews and participant observation. Face-to-face interviews can help the researcher to understand why a participant answered a question in a certain manner and can assist the researcher in gleaning more information than what is included in the instrument. Such information can help significantly when an answer on a survey instrument is out of the norm.

In this study the length of marriage was not considered. In the future, the researcher would like to consider the length of marriage as an important variable to correlate with stress burden in caregivers. Often the length of marriage correlates with the quality of the bond between the couple. Therefore, it would be critical to investigate if it has any correlation with the level of stress, grief and emotional loss. Such information may help in developing interventions and support groups for caregivers.

Stress level differs from person to person and also differs between men and women. In the future, the researcher would like to investigate any potential correlation between gender differences among the caregivers with the level of stress experienced by them. Such a study will help dementia scholars to understand how the stress level may differ between male and female caregivers while caregiving for their partner diagnosed with young-onset dementia.

This research study indicates that caregivers of spouses with young-onset dementia experience significant levels of stress, burden and emotional grief and loss. More research is needed to understand the psychological and physiological deterioration of the caregivers so that we can help them with their caregiving responsibilities. Such research will help in developing intervention strategies to help caregivers to overcome the daily life hurdles.

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Appendix A

MM Caregiver Grief Inventory

Thomas M. Meuser, Ph.D., University of Missouri – St. Louis
 Samuel J. Marwit, Ph.D., University of Missouri-St. Louis (Emeritus)

Instructions: This inventory is designed to measure the grief experience of current family caregivers of persons living with progressive dementia (e.g., Alzheimer's disease). Read each statement carefully, then decide how much you agree or disagree with what is said. Circle a number 1-5 to the right using the answer key below (For example 5 = Strongly Agree). It is important that you respond to all items so that the scores are accurate. Scoring rules are listed at the end.

ANSWER KEY						
1 = Strongly Disagree // 2 = Disagree // 3 = Somewhat Agree // 4 = Agree // 5 = Strongly Agree						
1	I've had to give up a great deal to be a caregiver.	1	2	3	4	5 A
2	I miss so many of the activities we used to share.	1	2	3	4	5 B
3	I feel I am losing my freedom.	1	2	3	4	5 A
4	My physical health has declined from the stress of being a caregiver.	1	2	3	4	5 A
5	I have nobody to communicate with.	1	2	3	4	5 C
6	I don't know what is happening. I feel confused and unsure.	1	2	3	4	5 C
7	I carry a lot of stress as a caregiver.	1	2	3	4	5 A
8	I receive enough emotional support from others.	1	2	3	4	5 Cr
9	I have this empty, sick feeling knowing that my loved one is "gone".	1	2	3	4	5 B
10	I feel anxious and scared.	1	2	3	4	5 C
11	My personal life has changed a great deal.	1	2	3	4	5 A
12	I spend a lot of time worrying about the bad things to come.	1	2	3	4	5 C
13	Dementia is like a double loss...I've lost the closeness with my loved one and connectedness with my family.	1	2	3	4	5 C
14	I feel terrific sadness	1	2	3	4	5 B
15	This situation is totally unacceptable in my heart.	1	2	3	4	5 B
16	My friends simply don't understand what I'm going through.	1	2	3	4	5 C
17	I feel this constant sense of responsibility and it just never leaves.	1	2	3	4	5 A
18	I long for what was, what we had and shared in the past.	1	2	3	4	5 B
19	I could deal with other serious disabilities better than with this.	1	2	3	4	5 B
20	I can't feel free in this situation.	1	2	3	4	5 A
21	I'm having trouble sleeping.	1	2	3	4	5 A
22	I'm at peace with myself and my situation in life.	1	2	3	4	5 Cr
23	It's a life phase and I know we'll get through it.	1	2	3	4	5 Cr
24	My extended family has no idea what I go through in caring for him/her.	1	2	3	4	5 C
25	I feel so frustrated that I often tune him/her out.	1	2	3	4	5 A
26	I am always worrying.	1	2	3	4	5 C
27	I'm angry at the disease for robbing me of so much.	1	2	3	4	5 B
28	This is requiring more emotional energy and determination than I ever expected.	1	2	3	4	5 A
29	I will be tied up with this for who knows how long.	1	2	3	4	5 A
30	It hurts to put her/him to bed at night and realize that she/he is "gone"	1	2	3	4	5 B
31	I feel very sad about what this disease has done.	1	2	3	4	5 B
32	I feel severe depression.	1	2	3	4	5 C

ANSWER KEY							
1 = Strongly Disagree // 2 = Disagree // 3 = Somewhat Agree // 4 = Agree // 5 = Strongly Agree							
33	I lay awake most nights worrying about what's happening and how I'll manage tomorrow.	1	2	3	4	5	C
34	The people closest to me do not understand what I'm going through.	1	2	3	4	5	C
35	His/her death will bring me renewed personal freedom to live my life.	1	2	3	4	5	A
36	I feel powerless.	1	2	3	4	5	B
37	It's frightening because you know doctors can't cure this disease, so things only get worse.	1	2	3	4	5	B
38	I've lost other people close to me, but the losses I'm experiencing now are much more troubling.	1	2	3	4	5	B
39	Independence is what I've lost...I don't have the freedom to go and do what I want.	1	2	3	4	5	A
40	I've had to make some drastic changes in my life as a result of becoming a caregiver.	1	2	3	4	5	A
41	I wish I had an hour or two to myself each day to pursue personal interests.	1	2	3	4	5	A
42	I'm stuck in this caregiving world and there's nothing I can do about it.	1	2	3	4	5	A
43	I can't contain my sadness about all that's happening.	1	2	3	4	5	B
44	What upsets me most is what I've had to give up.	1	2	3	4	5	A
45	I'm managing pretty well overall.	1	2	3	4	5	Cr
46	I think I'm denying the full implications of this for my life.	1	2	3	4	5	C
47	I get excellent support from members of my family.	1	2	3	4	5	Cr
48	I've had a hard time accepting what is happening.	1	2	3	4	5	B
49	The demands on me are growing faster than I ever expected.	1	2	3	4	5	A
50	I wish this was all a dream and I could wake up back in my old life.	1	2	3	4	5	B

FAIR USE OF THE MM-CGI: The inventory was developed and pilot tested on two samples of dementia caregivers, 87 caregivers (45 adult child, 42 spouse) in the development phase and 166 (83 of each type) for pilot testing. Funding support came from the Alzheimer's Association (Grant 1999-PRG-1730). A 3-factor solution materialized (KMO = .889) and these factors are listed below. The authors consider this instrument to be part of the public domain. The authors would appreciate hearing feedback on how the scale is used. Researchers who wish to administer the inventory and/or modify it as part of a formal study are asked to notify the authors of their plans (Tom Meuser, Ph.D., meuser@umsl.edu, 314-516-5421).

Meuser, T.M., & Marwit, S.J. (2001). A comprehensive, stage-sensitive model of grief in dementia caregiving. *The Gerontologist*, Vol 41(5), 658-770.
 Marwit, S.J., & Meuser, T.M. (2002). Development and Initial Validation of an Inventory to Assess Grief in Caregivers of Persons with Alzheimer's Disease. *The Gerontologist*, 42(6), 751-765.

Self-Scoring Procedure: Add the numbers you circled to derive the following sub-scale and total grief scores. Use the letters to the right of each score to guide you. C Items with "r" afterwards must first be reverse scored (1→5, 2→4, 3→3, 4→2, 5→1) before adding to calculate your scores.

Personal Sacrifice Burden (A Items) = _____
 (18 Items, M = 54.3, SD = 14.1, Alpha = .93, Split-Half = .91)

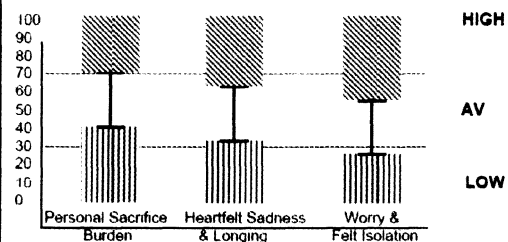
Heartfelt Sadness & Longing (B Items) = _____
 (15 Items, M = 48.2, SD = 11.1, Alpha = .90, Split-Half = .86)

Worry & Felt Isolation (C Items) = _____
 (17 Items, M = 40.6, SD = 11.9, Alpha = .91, Split-Half = .91)

Total Grief Level (Sum A + B + C) = _____
 (50 Items, M = 144, SD = 31.6, Alpha = .96, Split-Half = .87)

Plot your scores using the grid to the right. Make an "X" in the shaded section nearest to your numeric score for each sub-scale. This is your grief profile. Discuss this profile with your support group leader or counselor.

MM-CGI Personal Grief Profile



What do these scores mean?

Scores in the top area are higher than average based validation sample statistics (1 SD above the Mean). High scores may indicate a need for formal intervention or support assistance to enhance coping. Low scores in the bottom lined section (1 SD below the Mean) may indicate denial or a downplaying of distress. Low scores may also indicate positive adaptation if the individual is not showing other signs of suppressed grief. Average scores in the center indicate common reactions. These are general guides for discussion and support only – more research is needed on more specific interpretation issues.

Appendix-B

THE ZARIT BURDEN INTERVIEW

Please circle the response the best describes how you feel.

	Never	Rarely	Sometimes	Quite Frequently	Nearly Always	Score
1. Do you feel that your relative asks for more help than he/she needs?	0	1	2	3	4	
2. Do you feel that because of the time you spend with your relative that you don't have enough time for yourself?	0	1	2	3	4	
3. Do you feel stressed between caring for your relative and trying to meet other responsibilities for your family or work?	0	1	2	3	4	
4. Do you feel embarrassed over your relative's behaviour?	0	1	2	3	4	
5. Do you feel angry when you are around your relative?	0	1	2	3	4	
6. Do you feel that your relative currently affects our relationships with other family members or friends in a negative way?	0	1	2	3	4	
7. Are you afraid what the future holds for your relative?	0	1	2	3	4	
8. Do you feel your relative is dependent on you?	0	1	2	3	4	
9. Do you feel strained when you are around your relative?	0	1	2	3	4	
10. Do you feel your health has suffered because of your involvement with your relative?	0	1	2	3	4	
11. Do you feel that you don't have as much privacy as you would like because of your relative?	0	1	2	3	4	
12. Do you feel that your social life has suffered because you are caring for your relative?	0	1	2	3	4	
13. Do you feel uncomfortable about having friends over because of your relative?	0	1	2	3	4	

14. Do you feel that your relative seems to expect you to take care of him/her as if you were the only one he/she could depend on?	0	1	2	3	4	
15. Do you feel that you don't have enough money to take care of your relative in addition to the rest of your expenses?	0	1	2	3	4	
16. Do you feel that you will be unable to take care of your relative much longer?	0	1	2	3	4	
17. Do you feel you have lost control of your life since your relative's illness?	0	1	2	3	4	
18. Do you wish you could leave the care of your relative to someone else?	0	1	2	3	4	
19. Do you feel uncertain about what to do about your relative?	0	1	2	3	4	
20. Do you feel you should be doing more for your relative?	0	1	2	3	4	
21. Do you feel you could do a better job in caring for your relative?	0	1	2	3	4	
22. Overall, how burdened do you feel in caring for your relative?	0	1	2	3	4	
Total Score (out of 88)						

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Interpretation of Score:	
0 – 21	little or no burden
21 – 40	mild to moderate burden
41 – 60	moderate to severe burden
61 – 88	severe burden

Score values and interpretation are guidelines only, as discussed in:
 Hebert R, Bravo G, and Preville M (2000). *Canadian J Aging* 19: 494-507.

Appendix-C

IRB Protocol # 0162

Caregivers please complete the following list of general questions about you and your care partner. Then send this form back with the three completed survey instruments in the postage-paid envelope provided. ***Thank you very much!***

1. What is your gender? ☐F ☐M
2. What is your age? _____
3. What is your race/ethnicity? (check all that apply)

☐ African-American	☐ Asian
☐ Caucasian	☐ Hispanic/Latino
☐ Other _____	
4. What is your employment status?

☐ I work full time, 40+ hours a week
☐ I work part-time, 20-40 hours a week
☐ I do not work due to caregiving responsibilities
☐ Other. Please explain _____
5. What is your relationship to the person you are caring for?

☐ I am his/her spouse/significant other
☐ " " sibling
☐ " " parent
☐ Other. Please explain _____
6. On average, what percentage of time is the person you are caring for able to understand questions that you ask, and respond appropriately to your question?

☐ 75% of the time or more
☐ at least 50% of the time
☐ at least 25% of the time
☐ less than 25% of the time
7. How long have you been caring for your family member with early-onset dementia? _____
8. When was your family member diagnosed with early-onset dementia? _____
_____
9. Where does the care-recipient live

☐ With me	☐ with another family member
☐ In assisted living	☐ in a nursing home
☐ Other. Please explain _____	

10. What is the age of the care-recipient? _____
11. On the scale from 1-10, how would you rate your stress level TODAY in relationship to your caregiving responsibilities. (1=lowest stress level, 10=highest).
1   2   3   4   5   6   7   8   9   10
- 11.a. Is there anything in particular that is causing your stress today? _____
_____
12. Do you attend a caregiver support group? ____ Yes   ____No
13. Does your family member with early-onset attend a support group for people with dementia? ____ Yes   ____No
If yes, how often? _____
14. Does your family member with early-onset ever talk about feelings of sadness or loss about having dementia?
____ Yes   ____No
If yes, how often? _____
15. What is your zip code? _____