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Impact of Caregiving Role in the Quality of Life of Family Caregivers for Persons with Alzheimer's Disease

Supriya Sarkar
Minnesota State University - Mankato

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Impact of Caregiving Role in the Quality of Life of Family Caregivers for Persons with Alzheimer’s Disease

By
Supriya Sarkar

A Thesis Submitted in Partial Fulfillment of the Requirements for the Degree of Master of Science in Gerontology

Minnesota State University, Mankato

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Impact of Caregiving Role in the Quality of Life of Family Caregivers for persons with Alzheimer’s Disease

(Supriya Sarkar)

This thesis has been examined and approved by the following members of the committee.

________________________________
Dr. Donald J. Ebel, PhD
Advisor

________________________________
Dr. Judith K. Luebke, PhD

________________________________
Dr. Mark Windschitl, PhD
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Dedication

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Abstract

Impact of Caregiving Role in the Quality of Life of Family Caregivers for persons with Alzheimer’s Disease

Supriya Sarkar, MS in Gerontology, Minnesota State University, Mankato, MN. 2015.

This study investigated quality of life of family caregivers of persons with Alzheimer’s disease (AD). Caregiving is a strenuous and challenging job. Family caregivers experience poor quality of life after they take the role of caregiving which might be related to depression. Purpose of this study was to find if caregiving duration and depression has any role in affecting family caregivers’ emotional, physical, and general health.

Data for this study were collected through electronic and mailed survey methods. The questionnaires completed by subjects: Medical Outcomes Study Short Form 36 (MOS-36) and Center for Epidemiologic Studies Depression Scale (CES-D). Descriptive statistics including mean, standard deviation, minimum and maximum values were calculated on demographics. Correlation statistics were calculated for emotional health, physical health, general health, depression and caregiving duration in the target population to find if there is presence or absence of any significant relationship that affects quality of life of family caregivers of persons with AD.
Data were collected in Minnesota through Alzheimer’s Association Minnesota-North Dakota Chapter, Lyngblomsten Care Center, St. Paul, MN, Lyngblomsten Home and Community Based Services, St. Paul, MN and Ecumen Seasons at Apple Valley, MN. The agencies were contacted in-person for recruitment of subjects. Total of 207 family caregivers responded where 25 were males and 182 females. Statistical analyses were computed which resulted in four statistically significant findings: emotional and physical health was significantly related to each other; emotional and physical health was significantly related to depression; general health was significantly related to depression; and caregiving duration was significantly related to depression. Study presented new information on family caregivers’ quality of life. The conclusion drawn from the current study may help future researchers to investigate improvement in quality of life of family caregivers with AD. It is hoped that the data will help health professionals and support groups to plan and develop better programs to improve quality of life of family caregivers for persons with Alzheimer’s disease.
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Chapter I—Introduction

Several studies reported that poor quality of life affects family caregivers of persons with Alzheimer's disease (AD) (Deimling & Bass, 1986; Pruchno & Resch, 1989; Schulz, Boerner, Shear, Zhang, & Gitlin, 2006). According to Schulz and colleagues (2006), caregiving stress is linked with poor outcomes for caregivers such as depression, illness, and decreased quality of life. Schulz and Beach (1999) specified that stressed caregivers experienced a 63% greater risk for mortality when compared to non-caregivers. Further, family caregivers suffer from increased depression when compared to non-caregivers (Given, Given, Stommel, & Azzouz, 1999). Similarly, caregivers for spouses with dementia experience greater risks of emotional stress, depression, and other health related problems or issues (Adams, 2008; Mills et al., 2009; von Kanel et al., 2008). Higher levels of depression and distress among caregivers are associated with care recipients’ functional and behavioral features such as need for assistance with personal care and status of cognitive or behavioral impairment (Clipp & George, 1993; Deimling & Bass, 1986; Miller, McFall, & Montgomery, 1991; Pruchno & Resch, 1989; Schulz & Williamson, 1991; Sheehan & Nuttall, 1988).

Statement of the problem

Emotional health and depression are the leading detriments of family caregiving (Schulz & Beach, 1999). Authors have found that a variety of emotions, including feelings of guilt, anger, anxiety, depression, and continued burden are associated with the placement of an elderly family member in a nursing home (Gaugler, Anderson, Zarit &
Pearlin, 2004; Zarit & Whitlatch, 1992). The study by Gaugler and colleagues (2004) suggested institutionalization as the end of caregiving but recent research has highlighted the persistent effects of tension following nursing home placement.

According to the Alzheimer’s Disease and Education Referral Center (ADERC, 2005), family caregivers themselves may end up with depression and other illnesses from the act of caregiving. Higher levels of depression and poor emotional health among family caregivers are associated with the care recipient’s functional and behavioral status such as need for assistance with personal care and level of cognitive or behavioral impairment such as memory loss, wandering, or aggressive behavior (Clipp & George, 1993; Deimling & Bass, 1986; Miller, McFall, & Montgomery, 1991; Pruchno & Resch, 1989; Schulz & Williamson, 1991; Sheehan & Nuttall, 1988). Many studies have stated that female caregivers usually suffer more with depression than male caregivers and wives are said to be more distressed than husbands (Whitlatch, Schur, Noelker, Ejaz, & Looman, 2001). Majerovitz (2007) found that caregiver burden and depression are correlated with one another. Factors associated with higher caregiver burden and depression and which could be expected to have an influence on the family caregiver includes: contextual factors such as demographics and prior family closeness, memory and behavior problems of the resident, greater involvement in caregiving tasks following placement, dissatisfaction with nursing home care, and lack of social support (Majerovitz, 2007).

The present study is based on the life transition model that helps to understand and describe family caregivers’ health and well-being through their role shift, life events
or crisis situation, and focus on the nature of the change. According to Kramer and Lambert (1999), the life transitions approach offers an alternative framework in which the caregiving experience may be construed. Transition psychology was first hypothesized on bereavement, family crisis, and depression by Hill (1958), Kubler Ross (1969), Parkes (1964) and others. These researchers have recognized that transition is the primary cause of poor health. Models of transition help to describe how people should react to change, either in their own lives or environment. Transition such as caregiving is associated with significant life events that bring change to caregivers’ role or environment that needs thorough restructuring of the caregivers’ view of self and in the setting they live. It is believed that transition to caregiving role encompasses emotional, psychological, and physical disruptions which act as negative events in a person’s life (Kramer & Lambert, 1999).

**Purpose of the study**

The purpose of this study was to assess factors which are associated with the caregiving role and that affect quality of life of family caregivers of persons with Alzheimer’s disease (AD). Four factors were studied in this research namely, emotional health, physical health, general health and depression.

**Significance of the problem**

Family members caring for their loved ones often narrate the caregiving experience as “enduring stress and frustration” (Etters, Debbie, & Barbara, 2008).
Emotional anxiety and depression amongst family caregivers impact their health and also affect the relationship between them and care recipients (Etters et al., 2008).

This study uses the transitional model to find and understand caregiving which influences the quality of life of the family caregivers of persons with Alzheimer’s disease (AD). The study helped to identify the unfavorable circumstances caused by caregiving role and depression. The transitional model leads to recognition of underlying issues in caregiving while encouraging improvement in the quality of life of family caregivers particularly from emotional and physical health perspectives. The findings may also be used to improve and develop caregivers’ health programs, while enhancing the body of literature in aging studies pertaining to the quality of life of family caregivers.

**Research question**

How caregiving duration and depression affect emotional health, physical health and general health of family caregivers for persons with Alzheimer’s disease during caregiving role?

Five variables namely, caregiving duration, depression, emotional health, physical health and general health of family caregivers were studied. Caregiving plays an important role in the health of family caregivers, so it is believed that caregiving duration might also have a critical role in the health and well-being of family caregivers. The project studied how much caregiving duration impacts a family caregivers’ emotional, physical and general health. The project also studied depression and how it impacted emotional, physical and general health of family caregivers of persons with AD.
Definitions

Following are the terms and their definitions used widely in the chapters—

Activities of daily living (ADL): Activities that are usually performed in the course of a normal day such as bathing, toileting, eating, dressing, and transferring (Rogers, Meyer, Walker, & Fisk, 1998; Wagner, 1997).


Burden: Something that is difficult to bear which refers to a high level of stress that may be experienced by people who are caring for another person such as financial strain, managing the person's symptoms, dealing with crises, loss of friends, or loss of intimacy (Tull, 2008).

Caregiver: A family or significant other who is responsible for taking care of the elderly with Alzheimer’s disease (Mayo Clinic, 2012).

Caregiving: Caregiving refers to attending to another individual’s health needs.

Caregiving often includes assistance with one or more activities of daily living (ADL) such as bathing and dressing (Alzheimer’s Association Facts and Figures, 2014). This includes both emotional support and instrumental assistance for an older person (Wagner & Hunt, 1994). Caregiving covers a range of responsibilities and commitments, from occasional assistance with transport or shopping through 24-hour invalid care (Lee, 1999).
Care recipient: The person who receives care. A person who is suffering from Alzheimer’s disease and receives care from family or significant other or health care organization.

Depression: A condition of mental disturbances and difficulty in maintaining concentration or interest in life (Mayo Clinic, 2012).

Eldercare: Provision of assistance with daily living to aging or disabled family members or friends suffering with Alzheimer’s disease (Mayo Clinic, 2012).

Emotional health: A state of well-being in which the individual realizes his or her own abilities, can cope with the normal stresses of life, can work productively and fruitfully, and is able to make a contribution to his or her community (Segen’s Medical Dictionary, 2012).

Emotional stress: Emotional stress can be defined as an additional burden on one’s mental well-being or a condition that occurs when an individual is under stress affecting their emotions (Segen’s Medical Dictionary, 2012).

General health: The condition of being “sound in body, mind or spirit”, especially, freedom from physical disease or pain (Merriam-Webster’s online dictionary).

Nursing home: Nursing home is a long term care facility licensed by the state which provides residential accommodations with health care, especially for elders (Centers for Medicare & Medicaid Services (CMS), 2012).

Nursing home resident: Residents who live in nursing home for continued or custodial care (CMS, 2012).
Physical health: Physical health can be defined as an essential part of overall health of an individual, which includes everything from physical fitness to overall wellbeing (Segen’s Medical Dictionary, 2012).

Primary family caregiver: The individual (family member or significant other) identified as being the most responsible for the care of the elder and would be called on to make decisions for an elder if he/ she became unable to do so. (CDPH, 2010).
Chapter II— Literature Review

Literature on the quality of life of family caregivers with Alzheimer’s disease (AD) is both deep and complex. Perspectives offered within this chapter include defining family caregivers for AD patients; identifying responsibilities of family caregivers towards care recipients with AD; explaining the relationship between family caregivers and care recipients; impact of caregiving role on family caregivers’ emotional, physical and general health; and suggesting ways to improve quality of life of family caregivers and measures to reduce depression amongst family caregivers.

Epidemiology of Alzheimer's disease

Alzheimer's disease (AD) is a progressive neurological disease that, over time, results in the brain’s inability to function correctly. Alzheimer's disease causes lapses in memory, communication, judgment and overall functioning. AD is the sixth-leading cause of death in the United States and the fifth-leading cause of death for individuals age 65 and older (National Center for Health Statistics (NCHS), 2010). According to Alzheimer's Association Facts and Figures (2014), 1 in 9 people age 65 and older (11 percent) has AD. About one-third of people age 85 and older (32 percent) have Alzheimer’s disease. In the population affected with Alzheimer's disease, an estimated 4 percent are under age 65, 13 percent are 65 to 74, 44 percent are 75 to 84, and 38 percent are 85 or older. As the population ages, the number of individuals with AD and other related disorders are expected to increase, from nearly two million to nearly three million by the year 2015 (U.S. General Accounting Office, 1998). Alzheimer's Association Facts
and Figures (2014) predicts that the number of Americans with Alzheimer’s disease and other dementias will grow each year because the number and proportion of the U.S. population age 65 and older is increasing. Data suggests that the number will escalate rapidly as the baby boom generation ages (Alzheimer’s Association Facts and Figures, 2014). Because of the increasing number of people age 65 and older in the United States, the annual number of new cases of Alzheimer’s and other dementias is projected to double by 2050 (Hebert, Beckett, Scherr & Evans, 2002). Hebert et al. (2002) found that in every 68 seconds, someone in the US develops Alzheimer’s disease. Alzheimer’s Association Facts and Figures (2013) proposes that projection of total number of Americans age 65 and older with Alzheimer’s in the state of Minnesota will be 110,000 in the year 2025 from 94,000 in the year 2010. Percentage increase in 2025 compared to 2010 is projected to be close to 17%. The increasing number of individuals with Alzheimer’s will have a marked impact not only on states’ health care systems, but on families and caregivers health (Alzheimer’s Association Facts and Figures, 2013).

**Family caregivers for AD patients**

Family caregivers could be primarily immediate family members, but they also may be other relatives and friends (Alzheimer’s Association Facts and Figures, 2013). Family caregivers are the individuals who help care recipients with essential activities of daily living (ADL) such as dressing, personal hygiene, feeding, movement and toileting (Alzheimer’s Association Facts and Figures, 2013). Sometimes the caregivers may also help with tasks that are less essential also known as instrumental activities of daily living.
(IADLs) for basic functioning that help the care recipients to lead their lives independently — such tasks include housework, managing medications, shopping, managing money and providing transportation (Alzheimer’s Association Facts and Figures, 2013). Schumacher, Beck, and Marren (2006) have broadly defined family caregiving as a wide range of unpaid care provided in response to illness or functional impairment to a chronically ill or functionally impaired older family member, partner, friend, or neighbor that advances the support usually provided in family relationships. More than 15 million Americans provide unpaid care for people with Alzheimer’s disease and other dementias (Alzheimer’s Association Facts and Figures, 2013).

Eighty percent of care provided in the community is provided by unpaid caregivers (most often family members), while fewer than 10 percent of older adults receive all of their care from paid caregivers (Alzheimer’s Association Facts and Figures, 2013). Data from the 2010 Behavioral Risk Factor Surveillance System (BRFSS) survey conducted in Connecticut, New Hampshire, New Jersey, New York and Tennessee concluded that “62 percent of family caregivers of people with Alzheimer’s disease and other dementias were women; 23 percent were 65 years of age and older; 50 percent had some college education or beyond; 59 percent were currently employed, a student or homemaker; and 70 percent were married or in a long-term relationship” (Bouldin & Andresen, 2010). The National Alliance for Caregiving and AARP (NAC, 2009) found that 30 percent of family caregivers had children under 18 years old living with them, such caregivers are sometimes also known as “sandwich caregivers” because they simultaneously provide care for two generations.
Roles and responsibilities of family caregivers for AD patients

The care provided to people with AD and other dementias is believed to be challenging both physically and mentally (Alzheimer’s Association Facts and Figures, 2013). The role of the primary caregiver is often taken by the spouse, son or daughter (Alzheimer’s Association Facts and Figures, 2013). Acton (2002) stated that AD or other dementia family caregivers spend more hours in caring and assisting care recipients with activities of daily living (ADL) and instrumental activities of daily living (IADL) tasks. Assisting with personal activities of daily living, such as bathing, dressing, grooming, feeding and helping the person walk, transfer from bed to chair, use the toilet and manage incontinence. Activities also include managing behavioral symptoms of the disease such as aggressive behavior, wandering, depressive mood, agitation, anxiety, repetitive activity and nighttime disturbances (Ornstein & Gaugler, 2012). Assistance with instrumental activities of daily living includes household chores, shopping, preparing meals, providing transportation, arranging for doctor’s appointments, helping the person take medications correctly, managing finances and legal affairs and answering the telephone. This seems consistent with results found by Scharlach (1989) that caregivers for AD or other dementias were significantly more likely to do the laundry, provide transportation, coordinate outside help, shop, clean, cook, and make telephone calls for the person. Other responsibilities entails finding and using support services such as support groups and adult day service programs, making appropriate arrangements for paid in-home, nursing home or assisted living care, hiring and supervising others who provide care (Alzheimer’s Association Facts and Figures, 2013). There are also some supplementary
responsibilities that are not necessarily specific tasks such as providing overall management of getting through the day and addressing family issues related to caring for a relative with Alzheimer’s disease, including communication with other family members about care plans (Alzheimer’s Association Facts and Figures, 2013). Caregivers have also been reported to be more likely to co-reside with the care receiver (Acton, 2002). Study by Ory, Yee, Tennstedt, and Schultz (2000) found that co-residence is more likely for the caregivers, especially at later stages of the disease. This may account for the greater caregiving involvement and responsibility on caregivers’ part.

Findings by National Alliance for Caregiving and AARP (2009) advocate that more than half of AD caregivers report providing help with getting in and out of bed, and about one-third of family caregivers provide help to their care recipients with getting to and from the toilet, bathing, managing incontinence and feeding. These findings suggest the elevated degree of dependency experienced by some people with Alzheimer’s disease and other dementias. In addition to assisting with ADLs, almost two-thirds of caregivers (64%) of people with Alzheimer’s and other dementia advocate for their care recipient with government agencies and service providers, and nearly half (46%) arrange and supervise paid caregivers from community agencies. Family caregivers for persons with AD or other dementia need to manage other symptoms such as neuropsychiatric issues and severe behavioral problems that family caregivers of individuals with other diseases may not experience (NAC and AARP, 2009).
Quality of life of family caregivers of persons with AD

Extensive review of primary research studies reveal that individuals who provide care to persons with AD may be at risk for more emotional and physical problems due to their caregiving responsibilities (Schulz & Beach, 1999). The authors have concluded that caregivers with AD patients face extreme level of stress. They are less likely to report being employed and more likely to be retired, and they consider caregiving as their full time job. Family members caring for their loved ones often narrate the caregiving experience as “enduring stress and frustration” (Etters, Debbie, & Barbara, 2008).

Alzheimer's disease is known for placing great burden and stress on caregivers from emotional, social, psychological, physical, and economic or financial perspectives. A noted study found that family caregivers for persons with Alzheimer’s disease suffer from increased levels of depression (Given, Given, Stommel, & Azzouz, 1999).

Generally, caregiving for family members with cognitive impairment is stressful and time consuming (Acton, 2002). Caregivers as part of their duties often try to engage in intellectual activities such as reading, playing board games, completing crossword puzzles, playing musical instruments or regular social interactions. It has been found that AD or other dementia caregivers are subject to high rates of physical and mental disorders (Acton, 2002). No doubt caring for a person with Alzheimer’s and other dementias poses special challenges. Individuals with AD may require increasing levels of supervision and personal care as the disease progresses. Family caregivers experience increased emotional stress, depression, impaired immune system response, health impairments, lost wages due to disruptions in employment, and depleted income
and finances with worsening symptoms that occurs with the progression of the disease (Kiecolt-Glaser, Glaser, Gravenstein, Malarkey, & Sheridan, 1996; Schulz & Beach, 1999; Vitaliano, Zhang, & Scanlan, 2003; Liu & Gallagher-Thompson, 2009; Pinquart & Sörensen, 2003; Sörensen, Duberstein, Gill, & Pinquart, 2006).

Furthermore, spouse caregivers report more depression symptoms, greater financial and physical burden, and lower levels of emotional well-being when compared to adult children (Pinquart & Sorensen, 2011). Spouse caregivers show “higher levels of care provision” than adult children (Pinquart & Sorensen, 2011). According to Conde-Sala, Garre-Olmo, Turró-Garriga, Vilalta-Franch, and López-Pousa (2003), spouse caregivers have a more positive perception of the patient’s quality of life than adult child caregivers. Quality of life of women caregivers is more distressful than men caregivers and their perception shows the strongest association with mental health and burden of caregiving (Conde-Sala et al., 2003). Schulz, Boerner, Shear, Zhang, and Gitlin (2006) suggest that caregiving stress is linked with poor outcomes for caregivers such as depression, illness, and decreased quality of life. Schulz and Beach (1999) specified that stressed family caregivers experienced a 63% greater risk of death when compared to non-caregivers. Acton (2002) stated that family caregivers pay little attention to their own health needs due to the lack of time. Most of their time is spent on managing memory and behavior problems of the patient which often leads to poor health and increases severe health issues. Specifically, caregivers for spouses with dementia experience greater risks of emotional stress, depression, and other health related problems or issues (Adams, 2008; Mills et al., 2009; von Kanel et al., 2008). Similarly, it is also confirmed by Takai
and associates (2011) that lower caregiver quality of life are associated with higher levels of depressive symptoms and burnout.

It was found that higher levels of depression and distress among caregivers are linked with care recipient’s functional and behavioral features such as, need for assistance with personal care and status of cognitive or behavioral impairment (Clipp & George, 1993; Deimling & Bass, 1986; Miller, McFall, & Montgomery, 1991; Pruchno & Resch, 1989; Schulz & Williamson, 1991; Sheehan & Nuttall, 1988). Furthermore, studies prove that women experience greater negative consequences of caregiving than men, such as burden and stress (Blasisnky, 1998; Jones & Peters, 1992; Stone, Cafferata, & Sangl, 1987). According to Conde-Sala and colleagues (2003), daughter caregivers are hugely affected by caregiving and show the strongest association with mental ill health and burden.

Factors associated with greater psychosocial problems of the family caregivers include patient being a spouse, demanding behaviors of the care recipient such as depression, behavioral disturbances, hallucinations, sleep problems or walking disruptions and social isolation (Alzheimer’s Association Facts and Figures, 2011). The physical and emotional impact of AD caregiving is estimated to have resulted in $9.1 billion in health care costs in the United States in 2012 (Alzheimer’s Association Facts and Figures, 2013). It is assumed that the dementia or AD caregivers are more likely to visit the emergency department or be hospitalized in the preceding six months if the care recipient is depressed, and has low functional status or behavioral disturbances (Schubert et al., 2008). According to Alzheimer’s Association Facts and Figures (2011), 50% of
caregivers report depression within 12 months of initiating care and 80% indicate emotional or physical disorders due to caregiving loads.

The health of a person with AD may also affect caregivers’ risk of dying, though studies have reported mixed results on this subject (Christakis & Allison, 2006; Fredman, Cauley, Hochberg, Ensrud, & Doros, 2010). In the study done by Christakis and Allison (2006), it was found that caregivers of spouses who were hospitalized and had medical records of dementia were more likely to die in the following year than caregivers whose spouses were hospitalized but did not have dementia, even after accounting for the age of caregivers. In a different study it was reported that higher levels of stress and depression were associated with higher rates of mortality in family caregivers for person with AD (Fredman et al., 2010). These findings suggest that high pressure in caregiving role is the leading cause that increases risk of mortality among family caregivers (Fredman et al., 2010). The pressure of AD caregiving is influenced by a number of other factors, such as disease severity, caregiver’s ability to accept the challenge of caregiving, available social support and caregiver personality. All of these aspects are essential to note to comprehend the health impact of caregiving for a person with AD (Aneshensel, Pearlin, Mullan, Zarit, & Whitlatch, 1995). Based on the above discussed research studies it is believed that family caregivers for persons with AD experience poor quality of life.

**Caregiver emotional health**

Caregiving has some benefits where caregivers enjoy togetherness and the satisfaction of helping others, but at the same time the caregivers report high levels of
caregiving stress over the course of providing care (Alzheimer’s Association 2010 Women and Alzheimer’s Poll, 2010). Based on Alzheimer’s Association 2010 Women and Alzheimer’s Poll (2010), sixty-one percent of family caregivers of people with Alzheimer’s and other dementias rated the emotional stress of caregiving as high or very high. Most family caregivers report “a good amount” to “a great deal” of caregiving strain concerning financial issues (56 percent) and family relationships (53 percent). In the NAC/AARP survey (2009), older women caregivers White or Hispanic ethnic background residing with the care recipient, indicated caregiving as stress and they believed there was no choice left in taking on the role of caregiver.

Institutionalization is surrounded with mixed emotions in the family caregivers’ life (Gaugler & Teaster, 2006). Ryan and Scullion (2000) found that the decision to place a relative in the nursing home is a long and agonizing issue for the caregiver. These researchers have also found that caregivers often feel a sense of failure to perform their duty when they place their relative in a nursing home. Based on NAC/AARP (2009) study result, seventy-seven percent of family caregivers of people with Alzheimer’s disease and other dementias reported that they somewhat agree to strongly agree that there is no “right or wrong” when families decide to place their family member in a nursing home. However, many such caregivers experience feelings of guilt, emotional upheaval and difficulties in acknowledging the nursing home admission transition (Alzheimer’s Association Facts and Figures, 2013). Rashkis (1981) stated that the decision to place a relative in the nursing home needs to be made on the basis of reason and not emotion so that the act of placement could be positive. In a similar study by
Dellasaga and Mastrian (1995), it was found that all family caregivers who were interviewed experienced emotional turmoil due to the placement. Similarly, Lieberman and Fisher (2001) found that caregiver health and well-being did not improve over time following the placement. It was noted by these researchers that the act of placing the relative in the nursing home did relieve some aspects of caregiving burden, but did not relieve the emotional aspect that often accompanies caring for someone with AD. Numerous studies have found that emotional distress and psychological well-being remain relatively constant for dementia caregivers after institutionalization (Dellasaga & Mastrian, 1995; Gaugler & Teaster, 2006; Lieberman & Fisher, 2001). Moreover, institutionalization brings new responsibilities and roles for the family caregivers, and sometimes, negative interactions between family caregivers and institution staff triggers negative impacts on family caregivers’ stress and well-being (Gaugler & Teaster, 2006).

Demands of caregiving may get intense and challenging for caregivers when care recipients approaches near the end of life. In one of the studies done by Schulz and associates (2004), it was found that in the year before the person’s death, 59 percent of caregivers felt they were “on duty” 24 hours a day, and many felt that caregiving during this time was extremely stressful. The same study also found that 72 percent of family caregivers said they experienced relief when the person with Alzheimer’s disease died.

**Caregiver physical health**

Often caregivers perceive that demands of caregiving may cause decline in their own health (Alzheimer’s Association Facts and Figures, 2013). Family caregivers of
people with AD may experience greater risk of chronic disease, physiological impairments, increased health care utilization and mortality than those who are non-caregivers (Vitaliano, Zhang, & Scanlan, 2003). Sleep disturbances, which can occur often while taking care for a relative with Alzheimer’s disease or dementia have also been said to negatively influence family caregivers’ health (Peng & Chang, 2012). Forty three percent of caregivers of people with Alzheimer’s disease and other dementias reported that the physical impact of caregiving was high to very high (Alzheimer’s Association, Women and Alzheimer’s Poll, 2010).

The chronic stress of caregiving is associated with physiological changes that indicate risk of developing chronic conditions. Recent studies found that under certain conditions some AD caregivers are more likely to have prominent biomarkers of cardiovascular disease risk and impaired kidney function risk than those who are not caregivers (Chattillion et al., 2012; Vitaliano et al., 2002). Caregivers of a spouse with Alzheimer’s or other dementias are more likely to have physiological changes that may reflect declining physical health, including high levels of stress hormones (von Kanel et al., 2006) reduced immune function (Kiecolt-Glaser, Glaser, Gravenstein, Malarkey, & Sheridan, 1996) slow wound healing (Kiecolt-Glaser, Marucha, Mercado, Malarkey, & Glaser, 1995) increased incidence of hypertension (Shaw et al., 1999) and coronary heart disease (Vitaliano et al., 2002) than married non-caregivers. Some of these changes might be linked to an increased risk of cardiovascular disease (Mills et al., 2009). The literature reviewed provides evidences that chronic stress of caregiving for person with AD can have potentially negative influences on caregivers’ health.
Caregiver general health

Vitaliano, Zhang, and Scanlan (2003) reported that AD or other dementia caregivers have fair to poor general health status. Caregiving was thought to be a reason for their worsening health (NAC & AARP, 2009; MetLife Mature Market Institute, 2006). Data from the 2010 BRFSS caregiver survey found that seven percent of AD or other dementia caregivers say that the greatest difficulty of caregiving is that it creates or aggravates their own health problems compared with two percent of other caregivers (Bouldin & Andresen, 2010). A study suggested that caregiving tasks have the negative effect on caregivers’ health (Fredman et al., 2006).

Caregiver depression

AD caregiving is all consuming and challenging, it can lead to feelings of stress, guilt, anger, sadness, isolation, and depression (Pinquart & Sörensen, 2003). AD caregiving is different from other types of caregiving (Pinquart & Sörensen, 2003). Not only do caregivers spend significantly more hours per week providing care, they report more employment problems, personal stress, mental and physical health problems, less time to do the things they enjoy, less time to spend with other family members, and more family conflict than non-dementia caregivers (Pinquart & Sörensen, 2003). Literature reviewed that depression affects different family caregivers in different ways and at different times (Alzheimer’s Association Facts and Figures, 2011). Someone may experience depression after their family member show symptoms of AD progression and the cognitive abilities also diminish, while other caregivers may experience depression.
due to heavy caregiving duties (Alzheimer’s Association Facts and Figures, 2011).

Caregivers may also lack sleep due to heavy caregiving responsibilities that contributes to depression (Ory et al., 1999). Further, depression can persist after placing dear ones in a care facility (Gaugler & Teaster, 2006). Many caregivers feel depressed at the time of placement and some continue to feel depressed for a longer time (Ryan & Scullion, 2000). Researchers have found that a person who provides care for an individual with AD or dementia is twice as likely to suffer from depression as a person providing care for an individual without dementia. The more severe the case of the care recipient, the more likely the caregiver is to experience depression (Ory et al., 1999).

It was found that higher levels of depression and distress among caregivers are linked with care recipient’s functional and behavioral features such as, need for assistance with personal care and status of cognitive or behavioral impairment (Clipp & George, 1993; Deimling & Bass, 1986; Miller et al., 1991; Pruchno & Resch, 1989; Schulz & Williamson, 1991; Sheehan & Nuttall, 1988). Earlier research in smaller samples found that over one-third (39 percent) of caregivers of people with AD suffered from depression compared with 17 percent of non-caregivers (Schulz, O’Brien, Bookwala, & Fleissner, 1995; Baumgarten et al., 1992). A meta-analysis of research comparing caregivers confirmed the difference in the prevalence of depression between caregivers of people with AD and non-caregivers (Pinquart & Sörensen, 2003). In the study conducted by Fisher and colleagues (2011), it was found that 44 percent of caregivers of people with AD indicated depressive symptoms, compared with 27 percent of caregivers of people who had cognitive impairment but no dementia. Similarly, Gitlin
and associates (2003) found that female caregivers, on average, provide more direct care and report higher levels of burden and depression. Mahoney, Regan, Katona, and Livingston (2005) stated that high rates of anxiety as well as depressive symptoms in family caregivers of people with AD, especially in female caregivers are very common. Pinquart & Sorensen (2006) and Vitaliano and colleagues (2003) found that just being a caregiver for a person with AD puts an individual at increased risk for higher levels of stress and depression and lower levels of subjective well-being and physical health. Caucasian caregivers for AD patients exhibit more depression when compared to African-Americans, Asian-Americans and Hispanics (Gitlin et al., 2003; Pinquart & Sorensen, 2004). Less-educated caregivers also report more depression (Gitlin et al., 2003; Pinquart & Sorensen, 2004). In contrast, spouse caregivers report higher levels of depression than non-spouse caregivers (Pinquart & Sorensen, 2004). Spouse caregivers report more depression symptoms, greater financial and physical burden, and lower levels of psychological well-being compared to adult children (Sörensen, 2011). Flannery (2002) believed caregivers who have poor relationship with the care recipient report more strain and suffers increased level of depression. The author also found that caregivers who lack preparedness for the caregiving role had more complaints of depression and presents with increased health problems.

**Relationship between family caregivers and care recipients with AD**

AD causes significant social and economic consequences for the patient and his/her family (Alzheimer’s Association Facts and Figures, 2013). Apart from
neuropsychiatric effects of specific therapies for dementia, one of today's challenges is the quality of life for care recipients and their family caregivers. The close bonding and memories which are the essential component of the relationship between a caregiver and care recipient might be threatened due to the memory loss, functional impairment and psychiatric/behavioral disturbances that can accompany the progression of AD (Alzheimer’s Association Facts and Figures, 2013). Quality of health of nursing home residents is based on the relationship status with their caregiving family (Whitlatch, Dorothy, Noelker, Farida, & Looman, 2001). The relationship between the care recipient and family caregiver is affected by the worries and burden associated with the care recipient. Emotional well-being and other behavioral changes amongst family caregivers affect the relationship. Findings of Thomas and colleagues (2006) suggest that caregivers' and care recipients’ quality of life are interrelated and both share distress. The findings by Quinn, Clare, and Woods (2009) show that caregiving has an impact on the quality of the relationship between family caregiver and care-recipient. Pre-caregiving and current relationship quality has an impact on caregiver's well-being. The care-recipient's needs for help with activities of daily living (ADL) and level of behavioral problems were found to influence the caregiver's perceptions of relationship quality (Quinn et al. 2009).

**Strategies to improve quality of life of family caregivers**

According to Duggleby, Swindle, Peacock, and Ghosh (2011) and Duggleby, Wright, and Bollinger (2009), poor quality of life of family caregivers can be a result of many factors such as demographic variables, their transition to caregiving, and hope. The
authors’ findings suggest that hope plays a significant role in individuals’ perceptions of overall quality of life and the active engagement of families in seeking information and help. Irvin and Acton (1997) also emphasized that hope mediates the relationship between stress and well-being. Acton and Kang (2001) have found that multicomponent interventions work considerably better in reducing family caregivers’ depression and other related issues than single interventions such as support groups, education and hope as types of coping strategies to overcome stress, depression and improving quality of life of family caregivers for AD patient. The authors found that these interventions help in improving quality of life from emotional, psychological and physiological perspectives (Acton & Kang, 2001; Irvin & Acton, 1997). Caregiving for a person with Alzheimer’s disease is believed to be a challenging job. The job becomes more intense with the advancement of the disease and consequently, it starts affecting family caregivers’ health. If family caregivers do not take right step from the beginning then the situation could be detrimental that might affect the relationship between caregiver and care recipient and also affect the quality of life of the care recipient.

Chappell and Reid (2002) emphasized that two factors, namely, well-being and burden are strongly associated with the quality of life of family caregivers. Their findings suggest that social support is highly associated with wellbeing but unrelated to burden. According to them, quality of life of caregivers could be improved even with burden in their lives and thorough research on caregiving should be enhanced with an emphasis on quality of life. Connell, Janevic, and Gallant (2001) have stated that socio-demographic characteristics, caregiver resources such as coping, social support and personal
characteristics can change the AD or dementia caregiving experience and can help to reduce the emotional stress and burden of family caregivers in performing their role of caregiving.

According to Takai, Takahashi, Iwamitshu, Oishi, and Miyaoka (2011), depressive symptoms, burnout, and the cognitive impairment of patients are linked with caregiver’s quality of life. However, Brodaty, Draper, and Low (2003) found that caregivers were significantly less distressed in relation to behavioral disturbance of the patient immediately after attending the “Making Memories” program but no improvement was recorded in psychological distress or depression of the caregiver. The “Making Memories” program decreases psychological distress in people with dementia, has short-term positive effect on caregiver reactions to behavioral disturbance (Brodaty et al., 2003). According to Leslie and colleagues (2009), if polarized therapy (PT) which is basically a touch therapy, could be delivered to family caregivers and it might result as an important approach in reducing stress, depression, and pain and would help to improve quality of life of the family caregivers. Additionally, Montgomery, Gonyea, and Hooyman (1985) have stated some ways to reduce the level of burden through the introduction of personal aid services, supportive equipment that enables greater self-care, and respite services. To summarize, findings of Takai and colleagues (2011) suggested that both objective and subjective experiences of family caregivers are associated with the caregiver quality of life.

Different studies by Liew and associates (2010); Diwan, Hougham, and Sachs (2004); Adams (2006) suggest that in order to maintain mental well-being of the AD or
other dementia caregivers certain encouragement is needed, such as participation in educational and support programs, training for coping with memory loss, and specific management strategies. Garcia-Alberca and colleagues (2012) found that family caregivers with anxiety and depression should use disengagement coping strategies. However, Gaugler, Roth, Haley, and Mittelman (2008) claimed that institutionalization is the only option to reduce caregiver burden and other symptoms related to depression. Acton (2002) suggests that health-promoting self-care behavior has a positive impact on the relationship of caregivers’ emotional health and their well-being. The author claims that health-promoting self-care behaviors perform as a mediator to lessen the effect of caregiver stress on general well-being. Furthermore, Arango-Lasprilla et al., (2010) have emphasized on the need for rehabilitation health professionals to develop and implement culturally appropriate interventions to improve the quality of life of family caregivers for individuals with memory loss. Similarly, Jansen and associates (2011) have pointed out that case management could help those family caregivers who are suffering from extreme distress and severe problems associated with caregiving. Based on Diwan and colleagues (2004) findings, it has been suggested that the palliative care programs should—

- Help to localize the factors and types of family caregiver stress
- Support caregivers for coping with problem behaviors
- Provide counseling to help cope with disease progression
- Help to communicate with the health care team

Similarly, Thomas and colleagues (2006) have found that information and support interventions could improve the quality of life of the caregiver. Many studies reviewed
suggested support groups and education as the best types of coping strategies (Chappell & Reid, 2002; Brodaty et al., 2003; Leslie et al., 2009). Sorenson and colleagues (2002) have found that the interventions dealing with individual works better than dealing with people in a group in improving their well-being. Zarit and associates (1998) and Sorenson and colleagues (2002) explained that respite/ adult day care services help caregivers in reducing stress, depression and burden within 3 months and maintaining/ improving wellbeing.

**Summary**

This chapter describes the impact on quality of life of family caregivers’ for persons with AD and how caregivers’ emotional health, physical health and depression are affected by caregiving responsibilities. Caregiving not only negatively impacts caregivers’ health but also leads to depression. This literature review presented findings of studies on chronic stress of caregiving that affects family caregivers’ quality of life. The researcher discussed evidence from different literatures on caregivers’ mortality, relationship between family caregiver and care recipient, roles of family caregiver, quality of life of family caregivers, their emotional, physical and general health, possible reasons that leads to depression and ways to improve quality of life of family caregivers.

Current literature reviewed do not provide information if length of caregiving duration has any role in the deterioration of caregivers’ health. This study will help to identify factors leading to poor quality of life of family caregivers of persons with AD. The study hopes to recognize underlying issues, factors affecting quality of life of family
caregivers from emotional, physical and general health perspectives and if depression causes reduced quality of life.
Chapter III—Methodology

Introduction

This research focused on identifying the factors that affect quality of life of family caregivers for persons with Alzheimer’s disease (AD). The chapter discusses in detail the research question, aims and hypotheses, research design, population and sample selection, data collection, instrumentation, data processing and analyses for this research.

Research question

How caregiving duration and depression affect emotional health, physical health and general health of family caregivers for persons with Alzheimer’s disease during caregiving role?

To address these issues, three aims including eight hypotheses were proposed.

Aims and hypotheses:

Aim 1: To understand if caregiving duration affects emotional, physical and general health in family caregivers while performing caregiving responsibilities.

Hypotheses:

H.1.a. Increase in caregiving duration will significantly increase family caregivers’ emotional health.

H.1.b. Increase in caregiving duration will significantly increase family caregivers’ physical health.
H.1.c. Increase in caregiving duration will significantly increase family caregivers’
general health.

H.1.d. Emotional health is significantly related to physical health in family caregivers.

**Aim 2**: To understand if caregiving duration and caregiver age affect level of depression
in family caregivers.

Hypotheses:

H.2.a. Increase in caregiving duration will significantly increase level of depression in
family caregivers.

H.2.b. Increase in caregiver age will significantly increase level of depression in family
caregivers.

**Aim 3**: To understand if emotional/ physical health and general health affects depression
in family caregivers.

Hypotheses:

H.3.a. Emotional and physical health is significantly related to depression in family
caregivers.

H.3.b. General health is significantly related to depression in family caregivers.

**Research design**

The data for this study were collected through quantitative technique using
electronic (online) and mailed survey methods. A third party, SurveyMonkey
organization was used to design and conduct the electronic survey questionnaire.
Electronic survey was done considering certain elements from participants’ and
researchers’ perspectives. It is fast and less time consuming, therefore participants could easily respond anytime according to their choice convenience and flexibility. A mailed, hard copy version of the survey was provided to the family caregivers for whom an electronic survey proved difficulty in responding. Mailed survey method was used due to variability in age group and participant comfort with writing rather than typing responses.

The study utilizes a cross-sectional method of data collection to determine the effects of caregiving responsibilities. The participants were given two questionnaires that helped to measure their emotional health, physical health and general health and depression on the basis of factors which majorly affects individual’s quality of life. The two questionnaires were: Medical Outcomes Study (MOS): 36- Item Short form survey instrument (Appendix 1) and Center for Epidemiologic Studies Depression Scale (CES-D), NIMH (Appendix 2). The maximum time needed to complete the questionnaire was 15-20 minutes.

**Subject selection**

The population for this study was primary family caregivers of persons with Alzheimer’s disease (AD) in Minnesota. The inclusion criteria were: the participants were primary family caregivers, able to understand, read and write English, and have an access to computer/ internet (for those choosing electronic survey). Alzheimer’s Association Minnesota-North Dakota Chapter, Lyngblomsten Care Center, St. Paul, MN, Lyngblomsten Home and Community Based Services, St. Paul, MN and Ecumen Seasons at Apple Valley, MN were contacted in person for the recruitment of the subjects. Family
caregivers of persons with Alzheimer’s disease were contacted through these above mentioned organizations. Alzheimer’s Association Minnesota-North Dakota Chapter was approached to reach potential family caregivers from rural as well as urban areas in the state of Minnesota. The family caregivers were spouse or adult child or friend. To reduce sampling bias and to protect HIPPA regulations, participating facilities were requested to send the potential family caregivers the survey parcel that included cover letter, consent form and survey questionnaire. The family caregivers returned the survey responses to their respective organization/facilities. The organization/facilities anonymized the surveys and sent them to the researcher.

**Data collection**

Data was collected by the researcher through electronic and mailed survey questionnaires. Prior to the survey the subjects were informed about the research purpose, confidentiality status, participants’ rights, and contact information of the researcher. Participants were informed that by continuing to do the study they will be consenting to participate and must abide by the MSU Institutional Review Board (IRB) and University policies. Participants who were contacted through electronically received email from the organization/ facilities containing a cover letter that briefly explained the overview of the study and why they receive the email including a copy of electronic consent form and a link to the survey questionnaire. [https://www.surveymonkey.com/s/CGVDTCK](https://www.surveymonkey.com/s/CGVDTCK). Data collection started after MSU IRB approval on December 3, 2013 (Appendix 14).
**Instrumentation**

The data collection instruments for the current study were two survey questionnaires: Medical Outcomes Study (MOS): 36- Item Short form survey instrument (Appendix 1) and Center for Epidemiologic Studies Depression Scale (CES-D), NIMH (Appendix 2). Survey was conducted through electronic (online) and mailed survey method by the researcher. The total time to complete the entire survey questionnaire was 15-20 minutes (Appendix 3). Emotional, physical health and general health of family caregivers are the dependent variables and these were tested through Medical Outcomes Study (MOS): 36- Item Short form survey instrument (Appendix 1).

The Center for Epidemiologic Studies Depression Scale (CES-D), NIMH (Appendix 2) was used to measure depression. The scale is a valid instrument to diagnose individuals with depression (Almeida & Almeida, 1999). Participants answered 20 questions measuring affective characteristics of depression. Scores ranged from 0-60 with higher scores indicating greater depressed mood. The reliability coefficient of the scale is 0.81 (Almeida & Almeida, 1999).

Medical Outcomes Study Short Form 36 (MOS-36) is a widely used reliable and generic scale to measure health status (Hopman et al., 2000). It includes eight subscale measuring different health dimensions including physical abilities, social activities, physical health, mental health, and limitations in usual role due to emotional problems. Each subscale is rated 0-100 with higher scores indicating better health status. According to Turner-Bowker, Bartley & Ware (2002), SF-36 has been documented in nearly 5,000 publications and 2060 citations for those published in 1988 through 2000 are documented in a
bibliography covering the SF-36 and other instruments in the “SF” family of tools. The reliability coefficient of the scale is 0.93-0.95 (Ware, Kosinski, & Dewey, 2003).

Table 1 below shows the different outcome measures that were used to determine and understand the status of emotional, physical health, general health and level of depression (outcome variables) of family caregivers.

<table>
<thead>
<tr>
<th>Variable</th>
<th>Outcome Measure</th>
<th>Type of Variable</th>
</tr>
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<tbody>
<tr>
<td>Emotional, Physical &amp; General Health</td>
<td>MOS-36</td>
<td>Continuous</td>
</tr>
<tr>
<td>Depression</td>
<td>CES-D</td>
<td>Continuous</td>
</tr>
</tbody>
</table>

The two questionnaires (MOS-36 and CES-D) have 36 and 20 questions respectively. These two questionnaires were combined to make it easier for caregivers to respond and have lower attrition rate. Participants might get frustrated looking at so many questions and might ignore answering the questions leading to reduction in data quality and reliability. Keeping in mind the interest and comfort zone of the participants the revised questionnaire was designed so that it appears to have fewer questions and the researcher made sure that all the questions based on the two questionnaires were intact. Demographic information was also added to the study questionnaire as it was absent in the MOS-36 and CES-D, and demographics might play a critical role in the findings of the study. Therefore, the two questionnaires were combined with additional questions on their age, gender, ethnicity, caregiving duration, and income were asked. Study questionnaire is comprised of a total of 10 questions (Appendix 3).
**Data processing and analyses**

The data were analyzed quantitatively. Descriptive statistics including mean, standard deviation, minimum and maximum values of demographics such as age, gender, income, ethnicity and caregiving duration were calculated. Correlation statistics was calculated for emotional health, physical health, general health, caregiving duration, and depression in the sample to find if there is presence or absence of any statistically significant relationships that affects quality of life of family caregivers of persons with Alzheimer’s disease and how caregiving duration and depression affect the quality of life of family caregivers of persons with Alzheimer’s disease.

The most common measure of correlation in statistics is the Pearson Correlation which is a short form of Pearson Product Moment Correlation (PPMC) (Cohen, Cohen, West, & Aiken, 2003). Correlation is done between two variables to measure how well they are related and to show their linear relationship. Values of the correlation coefficient are always between -1 and +1. A correlation coefficient of +1 indicates that two variables have positive linear relation. A correlation coefficient of -1 indicates that two variables have negative linear relation, and a correlation coefficient of 0 indicates that there is no linear relationship between the two variables (Cohen et al., 2003). The authors also mentioned in the book that Pearson correlation is also used for testing significance of relationships between two variables. It focuses on two factors:

- **Strength of the relationship:** Pearson correlation is used as a measure of the strength of a relationship between two variables and is indicated by the correlation coefficient ‘r’.
• Significance of the relationship: Any relationship between the two variables should be assessed for its significance as well as its strength. Significance of the relationship is expressed in probability levels ‘p’, if p is ≤ 0.05 is considered to be significant. This means that 95% of the time there will be a presence of correlation between the two variables.

Correlation analyses cannot be interpreted as indicating cause-and-effect relationships. They can only specify how or to what extent variables are associated with each other (Cohen et al., 2003).

Pearson correlation was a good fit for the current study because it helps to know the strength of the relationship as well as the significance of the relationship of the dependent and independent variables present in the study. All the hypotheses were tested on the basis of Pearson correlation. The method measured if there was any statistically significant relationship between caregiving duration and emotional, physical, and general health of family caregivers. The method also measured if there was any statistically significant relationship between depression and emotional, physical, and general health of family caregivers. Findings indicate how or to what extent these variables are associated with each other and which also means how these variables impact each other. Pearson correlation was used to find if there is any relationship between two variables (caregiving duration and emotional/physical/general health; depression and emotional/physical/general health) present in the target population.
Chapter IV—Results

Subjects

The study was completed in Minnesota through Alzheimer’s Association Minnesota-North Dakota Chapter (Appendix 10), Lyngblomsten Care Center, St. Paul, MN (Appendix 11), Lyngblomsten Home and Community Based Services, St. Paul, MN (Appendix 12) and Ecumen Seasons at Apple Valley, MN (Appendix 13). These organizations were contacted in person for the recruitment of the subjects. Each organization has given their written consent to conduct the study within their facility. To reach potential participants in the rural and urban areas in the state of Minnesota Alzheimer’s Association Minnesota-North Dakota Chapter was approached. Family caregivers of persons with Alzheimer’s disease were contacted through the above mentioned four organizations. To reduce sampling bias and to protect HIPPA regulations, participating facilities were requested to send the potential family caregivers the survey parcel that included cover letter, consent form and survey questionnaire.

A total of 207 family caregivers responded and answered survey questionnaire for the study where 44 were online respondents and 163 responded to mailed survey method. Demographic distribution of total subjects is presented in the Table 2. Among 207 respondents, 44 family caregivers did not record their age. Therefore Table 2 represents mean age of 163 family caregivers which is 58.9. All 207 family caregivers belong to White ethnic background. Income of 2 family caregivers is missing. The table represents average income of 205 family caregivers out of 207 which is $50,001-$75,000. Average caregiving duration is 4 years.
Table 2: Demographic distribution

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<table>
<thead>
<tr>
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</thead>
<tbody>
<tr>
<td>Total Subjects</td>
<td>207</td>
</tr>
<tr>
<td>Mean Age (Years)</td>
<td>58.9</td>
</tr>
<tr>
<td>Mean Income</td>
<td>$50,001-$75,000</td>
</tr>
<tr>
<td>Mean Caregiving Duration (Years)</td>
<td>4</td>
</tr>
</tbody>
</table>

Demographic distribution based on gender is presented in Table 3. Total male family caregivers who have responded are 25 and total female family caregivers are 182. Four male family caregivers and 40 female family caregivers did not report their age. Table 3 represents average age of 21 male family caregivers which is 61 years and average mean age of 40 female family caregivers which is 58.6. Average income of 24 male family caregivers is $50,001-$75,000. Average income of 181 female caregivers is $50,001-$75,000. Average caregiving duration for male family caregivers is 3 years and for female family caregivers is 4 years.

Table 3: Demographic distribution based on gender

<table>
<thead>
<tr>
<th></th>
<th>Male</th>
<th>Female</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total Subjects</td>
<td>25</td>
<td>182</td>
</tr>
<tr>
<td>Mean Age (Years)</td>
<td>61.00</td>
<td>58.60</td>
</tr>
<tr>
<td>Mean Income</td>
<td>$50,001-$75,000</td>
<td>$50,001-$75,000</td>
</tr>
<tr>
<td>Mean Caregiving Duration (Years)</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>

Analyses of the survey instruments

The Medical Outcomes Study (MOS): 36- Item Short form survey instrument (Appendix 1) is comprised of questions regarding an individual’s emotional, physical and general health. Emotional health is divided in three components shown in Figure 1. The components are role limitations due to emotional problems, emotional well-being and
social functioning. The first component of emotional health is role limitations due to emotional problems include a set of three questions. Each question has a score of 100, totaling to 300 points. The other component measuring emotional well-being is a set of five questions. Each question has a score of 100, totaling to 500 points. The last component social functioning is a set of two questions. Each question has a score of 100, totaling to 200 points. Therefore, emotional health comprises of a total of ten questions. Each question has a score 100, totaling to 1000 points. Higher scores refer to better health status (Appendix 4).

Figure 1: Components of emotional health

Physical health for the MOS-36 is divided in four components presented in Figure 2. The components are physical functioning, role limitations due to physical health, energy/fatigue and pain. The first component physical functioning is a set of ten questions. Each question has a score of 100, totaling to 1000 points. The other component role limitations due to physical health is a set of four questions. Each question has a score of 100, totaling to 400 points. Energy/fatigue is a set of four questions. Each question has a score of 100, totaling to 400 points. The last component, pain, is a set of two questions. Each question has a score of 100, totaling to 200 points. Therefore, physical health
comprises of a total of twenty questions. Each question has a score of 100, totaling to 2000 points. Higher scores refer to better health status (Appendix 4).

Figure 2: Components of physical health

General Health consists of six questions. Each question has a score of 100, totaling to 600 points. Higher scores refer to better health status (Appendix 4).

The Center for Epidemiologic Studies Depression Scale (CES-D), NIMH (Appendix 2) consists of twenty questions. The instrument is scored between 0 and 60. Higher scores indicate the presence of more symptoms related to depression. Scoring was done based on CES-D reference (Appendix 5).

Data analyses

Descriptive statistics for the data presented in Table 4 represents minimum, maximum, average and standard deviation of family caregivers’ age, caregiving duration, emotional health, physical health, general health and depression score. Data indicates the minimum age of family caregivers is 36 years and maximum age is 82 years. Mean age is 58.90 years and standard deviation is 10.08 years. Minimum caregiving duration is 1 year and maximum caregiving duration is 40 years. Mean caregiving duration is 4.00 years.
and standard deviation is 3.43 years. Minimum emotional health score is 235.00 and maximum is 980.00. Mean emotional health score is 528.59 and standard deviation is 188.28. Minimum physical health score is 209.00 and maximum is 1923.00. Mean physical health score is 1004.25 and standard deviation is 426.33. Minimum general health score is 50.00 and maximum is 600.00. Mean general health score is 275.97 and standard deviation is 93.41. Minimum depression score is 0.00 and maximum is 46.00. Mean depression score is 27.12 and standard deviation is 9.79.

Table 4: Descriptive statistics

<table>
<thead>
<tr>
<th></th>
<th>Number of Subjects Responded</th>
<th>Minimum</th>
<th>Maximum</th>
<th>Mean</th>
<th>Standard Deviation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age (Years)</td>
<td>163</td>
<td>36.00</td>
<td>82.00</td>
<td>58.90</td>
<td>10.08</td>
</tr>
<tr>
<td>Caregiving Duration (Years)</td>
<td>207</td>
<td>1.00</td>
<td>40.00</td>
<td>4.00</td>
<td>3.43</td>
</tr>
<tr>
<td>Emotional Health</td>
<td>207</td>
<td>235.00</td>
<td>980.00</td>
<td>528.59</td>
<td>188.28</td>
</tr>
<tr>
<td>Physical Health</td>
<td>207</td>
<td>209.00</td>
<td>1923.00</td>
<td>1004.25</td>
<td>426.33</td>
</tr>
<tr>
<td>General Health</td>
<td>207</td>
<td>50.00</td>
<td>600.00</td>
<td>275.97</td>
<td>93.41</td>
</tr>
<tr>
<td>Depression Score</td>
<td>207</td>
<td>0.00</td>
<td>46.00</td>
<td>27.12</td>
<td>9.79</td>
</tr>
</tbody>
</table>

Percentage of scores of health status for the four factors that measured the quality of life of family caregivers are: Physical health= 50.21%, emotional health= 52.86%, general health= 46.54% and depression= 45.20%. For physical, emotional and general health higher percentage indicates better health of family caregivers. Depression scores are reversed, meaning higher the number, worse is the status of health. A graphical representation of percentage of scores of health status for the four factors is shown in Figure 3.
Hypotheses testing

The eight hypotheses were tested according to Pearson’s correlation model:

Aim 1: To understand if caregiving duration affects emotional, physical and general health in family caregivers while performing caregiving responsibilities.

Hypotheses:

H.1.a. Increase in caregiving duration will significantly increase family caregivers’ emotional health.

Statistical correlation was performed to understand the relationship of caregiving duration with emotional health. Table 5 represents the findings of the two variables. r is 0.02 and the p-value is 0.82. The two variables are not significantly related to each other.

Figure 3: Percentage of scores of health status
Table 5: Relation of caregiving duration with emotional health

<table>
<thead>
<tr>
<th>Pearson Correlation (r)</th>
<th>0.02</th>
</tr>
</thead>
<tbody>
<tr>
<td>p-value</td>
<td>0.82</td>
</tr>
</tbody>
</table>

H.1.b. Increase in caregiving duration will significantly increase family caregivers’ physical health.
Statistical correlation was performed to understand the relationship of caregiving duration with physical health. Table 6 represents the findings of the two variables. r is 0.04 and the p-value is 0.57. The two variables are not significantly related to each other.

Table 6: Relation of caregiving duration with physical health

<table>
<thead>
<tr>
<th>Pearson Correlation (r)</th>
<th>0.04</th>
</tr>
</thead>
<tbody>
<tr>
<td>p-value</td>
<td>0.57</td>
</tr>
</tbody>
</table>

H.1.c. Increase in caregiving duration will significantly increase family caregivers’ general health.
Statistical correlation was performed to understand the relationship of caregiving duration with general health. Table 7 represents the findings of the two variables. r is 0.08 and the p-value is 0.81. The two variables are not significantly related to each other.

Table 7: Relation of caregiving duration with general health

<table>
<thead>
<tr>
<th>Pearson Correlation (r)</th>
<th>0.08</th>
</tr>
</thead>
<tbody>
<tr>
<td>p-value</td>
<td>0.81</td>
</tr>
</tbody>
</table>

H.1.d. Emotional health is significantly related to physical health in family caregivers.
Statistical correlation was performed to understand the relationship of emotional health with physical health. Table 8 represents the findings of the two variables. r is 0.69 and the
p-value ≤ 0.05. ‘r’ value is considered to have stronger relation between the variables if the value is between 0.50 and 0.75 (Portney & Watkins, 2009). The two variables (emotional health, physical health) show statistically significant relationship with each other. Since the association is positive, this result indicates that if emotional health increases, physical health also increases.

**Table 8: Relation of emotional health with physical health**

<table>
<thead>
<tr>
<th>Pearson Correlation (r)</th>
<th>0.69</th>
</tr>
</thead>
<tbody>
<tr>
<td>p-value</td>
<td>&lt;0.05*</td>
</tr>
</tbody>
</table>

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

A graphical representation in Figure 4 suggests emotional health and physical health have a strong positive relationship. As presented in this scatterplot, the trend line visually illustrates the strong, linear, and positive association between emotional health and physical health for family caregivers of persons with AD.

**Figure 4: Linear graph of relation between emotional health and physical health**
**Aim 2:** To understand if caregiving duration and caregiver age affect level of depression in family caregivers.

Hypotheses:

H.2.a. Increase in caregiving duration will significantly increase level of depression in family caregivers.

Statistical correlation was performed to understand the relationship of caregiving duration with depression. Table 9 represents the findings of the two variables. $r$ is -0.14 and the $p$-value $\leq 0.05$. The two variables show statistically significant association with each other. This finding suggests that as caregiving duration increases, depression level decreases.

**Table 9: Relation of caregiving duration with depression**

<table>
<thead>
<tr>
<th>Pearson Correlation (r)</th>
<th>-0.14</th>
</tr>
</thead>
<tbody>
<tr>
<td>p-value</td>
<td>0.05*</td>
</tr>
</tbody>
</table>

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

A graphical representation in Figure 5 suggests caregiving duration and depression have a weak negative relationship. The trend line in this scatterplot visually illustrates a slight negative association between caregiving duration and depression level for family caregivers of persons with AD.
H.2.b. Increase in caregiver age will significantly increase level of depression in family caregivers.

Statistical correlation was performed to understand the relationship of caregiver age with depression. Table 10 represents the findings of the two variables. $r$ is 0.08 and the p-value is 0.29. The two variables are not significantly related to each other.

Table 10: Relation of age with depression

<table>
<thead>
<tr>
<th>Pearson Correlation (r)</th>
<th>0.08</th>
</tr>
</thead>
<tbody>
<tr>
<td>p-value</td>
<td>0.29</td>
</tr>
</tbody>
</table>

Aim 3: To understand if emotional/ physical health and general health affects depression in family caregivers.

Hypotheses:
H.3.a. Emotional and physical health is significantly related to depression in family caregivers.

Statistical correlation was performed to understand the relationship of emotional and physical health with depression. Table 11 represents the findings of the two variables. \( r \) is -0.60 and the p-value ≤ 0.05. ‘\( r \)’ value is considered to have stronger relation between the variables if the value is between 0.50 and 0.75 (Portney & Watkins, 2009). The two variables (emotional and physical health, depression) show statistically significant relationship with each other. The negative sign indicates that higher the score of emotional and physical health, lower is the level of depression.

Table 11: Relation of emotional and physical health with depression

<table>
<thead>
<tr>
<th>Pearson Correlation (r)</th>
<th>-0.60</th>
</tr>
</thead>
<tbody>
<tr>
<td>p-value</td>
<td>&lt;0.05*</td>
</tr>
</tbody>
</table>

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

A graphical representation in Figure 6 suggests emotional & physical health and depression have a strong negative relationship. This finding suggests that as emotional & physical health increases, depression level decreases. The trend line in this scatterplot illustrates the strong, linear and negative association between emotional & physical health and depression level for family caregivers of persons with AD.
H.3.b. General health is significantly related to depression in family caregivers.

Statistical correlation was performed to understand the relationship of general health with depression. Table 12 represents the findings of the two variables. \( r \) is -0.48 and the p-value \( \leq 0.05 \). ‘\( r \)’ value is considered to have stronger relation between the variables if the value is between 0.50 and 0.75 (Portney & Watkins, 2009). The two variables (general health, depression) show statistically significant association with each other. The negative sign indicates that higher the score of general health, lower is the level of depression.
Table 12: Relation of general health with depression

<table>
<thead>
<tr>
<th>Pearson Correlation (r)</th>
<th>-0.48</th>
</tr>
</thead>
<tbody>
<tr>
<td>p-value</td>
<td>&lt;0.05*</td>
</tr>
</tbody>
</table>

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

A graphical representation in Figure 7 suggests general health and depression have a weak negative relationship. This finding suggests that as general health increases, depression level decreases. The trend line in this scatterplot illustrates the slight weak, linear and negative association between general health and depression level for family caregivers of persons with AD.

Figure 7: Linear graph of relation between general health and depression
Chapter V—Discussion and Conclusion

Interpretation of findings

The quality of life study received responses from two hundred and seven family caregivers of persons with Alzheimer’s disease. This study of family caregivers is based on 4 different health factors: physical health, emotional health, general health and depression. The findings are based on individual averages and total averages of the status of health of each participant on the basis of 4 different factors namely, physical health, emotional health, general health and depression that measured the quality of life of family caregivers.

Eight hypotheses were tested according to Pearson’s correlation model to check if there were any statistically significant relationships between the variables which were influencing the health status of family caregivers. Table 13 presented the list of eight hypotheses where four hypotheses shows statistically significant relationship with each other and the rest four hypotheses shows not statistically significant relationship with each other.

Table 13: Hypotheses testing results

<table>
<thead>
<tr>
<th>Significantly related hypotheses</th>
<th>Not significantly related hypotheses</th>
</tr>
</thead>
<tbody>
<tr>
<td>Relationship of emotional health with physical health</td>
<td>Relationship of caregiving duration with emotional health</td>
</tr>
<tr>
<td>Relationship of caregiving duration with depression</td>
<td>Relationship of caregiving duration with physical health</td>
</tr>
<tr>
<td>Relationship of emotional and physical health with depression</td>
<td>Relationship of caregiving duration with general health</td>
</tr>
<tr>
<td>Relationship of general health with depression</td>
<td>Relationship of age with depression</td>
</tr>
</tbody>
</table>
Correlation was performed to find if caregiving duration was related to emotional health but the model did not show statistically significant relationship between the two variables. Between the two variables r was 0.02 and the p-value was 0.82. Even though there were no statistically significant findings but it is believed that there might be a possibility of finding a relationship between the two variables based on the studies done by different authors (Ryan & Scullion, 2000; Schulz et al., 2004; Alzheimer’s Association Facts and Figures, 2011). According to these authors there is impact on caregivers’ emotional health due to caregiving.

Correlation was performed to find if caregiving duration was related to physical health where r was 0.04 and the p-value of 0.57. The two variables did not show statistically significant relationship between each other. The study result did not match with the result of other studies (Alzheimer’s Association Facts and Figures, 2013; Vitaliano et al., 2003; Peng & Chang, 2012) where the researchers claimed that caregiving impacts a person’s physical health.

Correlation was performed to find if caregiving duration was related to general health. The r was 0.08 and p-value was 0.81. The two variables did not show statistically significant relationship between each other. The result did not confirm findings of other studies done by Fredman et al. (2006), NAC and AARP (2009), MetLife Mature Market Institute (2006) and Vitaliano et al. (2003). These authors have found that caregiving impacts general health.
Correlation was performed to find if emotional health was related to physical health and the model show statistically significantly relationship between them. The r was 0.69 and the p-value ≤0.05. ‘r’ value is considered to have stronger relationship between the variables if the value is between 0.50 and 0.75 (Portney & Watkins, 2009). Therefore, the two variables (emotional health and physical health) show strong, statistically significant association between each other. The correlation indicates that higher the score of emotional health better is the status of physical health. The finding matched with the findings of other studies done by Alzheimer’s Association 2010 Women and Alzheimer’s Poll (2010), Adams (2008), Chattillion et al. (2012), Mills et al. (2009), Peng and Chang (2012), and von Kanel et al. (2008) which found that both emotional and physical health are inter related, so if one becomes better the other will also be better.

Correlation was performed to find if there was any relationship between caregiving duration and depression, the model shows statistically significant association between these variables. The r was -0.14 and the p-value ≤0.05. These variables show weak and negative relationship with each other meaning that with the increased caregiving duration there is reduction in depression. Based on studies by Ory and associates (1999), Schubert and colleagues (2008) and Alzheimer’s Association Facts and Figures (2011), a person who provides care for an individual with AD or dementia is twice as likely to suffer from depression as a person providing care for an individual without dementia. According to these authors, the more severe the case of the care recipient, the more likely the caregiver is to experience depression. Based on these
authors’ statement, it could be interpreted that based on the negative association between the variables in the current study the care recipient may have less severe health status so probably less likely family caregivers will experience depression.

Correlation was performed to find if family caregivers’ age is related to depression but the analysis did not show that these variables have any significant relationship with each other. The r value was 0.08 and the p-value was 0.29.

Correlation was performed to find if there was any relationship between emotional and physical health with depression. The r value was -0.60 and the p-value ≤0.05. ‘r’ value was considered to have stronger relation between the variables if the value is between 0.50 and 0.75 (Portney & Watkins, 2009). The two variables (emotional and physical health, depression) have statistically significant relationship with each other. The association show strong and negative relationship. The negative value indicates that higher the score of emotional and physical health, the lower the level of depression. The statistical analysis shows similar result to other studies (Clipp & George, 1993; Deimling & Bass, 1986; Miller et al., 1991; Pinquart & Sörensen, 2003; Pruchno & Resch, 1989; Schulz & Williamson, 1991; Sheehan & Nuttall, 1988) where researchers interpreted that physical and emotional health impacts caregiver and leads to depression.

Correlation was performed to find if general health was related to depression. The r was -0.48 and the p-value ≤0.05. ‘r’ value was considered to have stronger association between the variables if the value is between 0.50 and 0.75 (Portney & Watkins, 2009). The two variables (general health, depression) show slight weak and negative statistically significant relationship with each other. The negative sign indicates that higher the score
of general health, lower is the level of depression. The finding implies that if a caregiver has good general health, his/ her depression will be less. The statistical analysis shows similar result to other studies (Baumgarten et al., 1992; Bouldin & Andresen, 2010; Schulz et al., 1995) where the researchers have described that general health and depression of family caregivers will affect each other negatively.

The current study measured the quality of life of family caregivers on the basis of emotional health, physical health, general health and depression score. Findings suggest that there are strong significant relationships between the following variables:

- Emotional health and physical health
- Caregiving duration and depression
- Emotional and physical health with depression
- General health and depression

The conclusion drawn from the current study is that the factors are interrelated and the effect in one has an impact on the other variable. Emotional and physical health of family caregivers of persons with AD are highly correlated, meaning if one factor improves the other factor will also improve. The present study did not find a statistically significant relationship between caregiving duration and family caregivers’ emotional, physical and general health. Findings show that caregiving duration has statistically significant influence on depression level in family caregivers. Results from this study also show that depression significantly influences emotional, physical and general health of family caregivers’ of persons with AD. Overall findings show that longer the duration
of depression, greater is the impact on family caregivers’ health which negatively affects their quality of life.

**Limitations of the study**

Possible limitations of this research that may affect the findings may be: higher variance in age between subjects was absent, caregiving duration was less, and no information collected on family caregivers’ health status. It may be possible to find more statistically significant findings between variables if these limitations will be taken into account. The data has mean caregiving duration of four years. If caregiving duration was more then there may be possibility of finding different results. Probably some of the relationships which were not statistically significant currently might have confirmed other studies. Only three subjects had caregiving duration of 18, 23 and 40 years; for the remaining subjects caregiving duration was between four to 10 years. Likewise, the mean age was 58.9 years and very few caregivers were beyond 70 years with one subject who was 82 years old. It may be possible that health situation of that caregiver may be different from others. The study did not collect information on the stage or level of disease progression of the AD patients. It can be assumed that caregivers’ health will vary based on the type of AD patients they are caring. And it is believed caregiving experience might be different between stage 1, stage 2 and stage 3 AD individuals.

**Future directions**

Future studies should take into account this important variable to find the effect of quality of life on family caregivers while reducing the limitations discussed. Application
of regression model can be used to find the cause and effect between the study variables. Effect of potential outliers can be tested to check for statistically significant relationship between study variables. A longitudinal study can be performed to better predict changes in family caregivers’ quality of life considering all the 4 study factors.

**Summary and conclusion**

The study is based on quality of life of family caregivers for persons with AD. AD is the sixth leading cause of death in the U.S. One in three seniors dies with AD (Alzheimer’s Association Facts & Figures, 2013). Caregiving is a strenuous and challenging job. Family caregivers report poor quality of life after they take the role of caregiving and it may also lead to depression. The study describes impact on quality of life of family caregivers’ for persons with AD and how caregivers’ emotional health, physical health, general health and depression are affected due to caregiving responsibilities. The study received four statistically significant findings which indicate that caregiving duration and depression has roles in caregivers’ quality of life. The findings show that emotional health and physical health have statistically significant relationship with each other. In the study sample, caregiving duration and depression have statistically significant relationship with each other. The association of emotional health and physical health show statistically significant relationship with depression. General health and depression show statistically significant relationship with each other. These findings support past research on impact of caregiving on family caregivers’ health (Adams, 2008; Alzheimer’s Association Facts and Figures, 2011; Alzheimer’s Association 2010 Women and
Alzheimer’s Poll, 2010; Baumgarten et al., 1992; Bouldin & Andresen, 2010; Chattillion et al., 2012; Clipp & George, 1993; Deimling & Bass, 1986; Miller et al., 1991; Mills et al., 2009; Ory et al., 1999; Peng & Chang, 2012; Pinquart & Sörensen, 2003; Pruchno & Resch, 1989; Schubert et al., 2008; Schulz & Williamson, 1991; Schulz et al., 1995; Sheehan & Nuttall, 1988; von Kanel et al., 2008).

It is hoped that this study shared new information on the effects of depression on quality of life of family caregivers for persons with AD. The findings may help future researchers to study and conduct research to improve quality of life of family caregivers. The data collected in this study may help health professionals and support groups to plan and develop better programs for improving quality of life of family caregivers of persons with Alzheimer’s disease.
References


National Alliance for Caregiving and AARP. (2004). Caregiving in the U.S. National Alliance for Caregiving and AARP. NAC.


von Kanel, R., Mills, P. J., Mausbach, B. T.,Dimsdale, J. E., Patterson, T. L., Ziegler, M. G., et al. (2012). Effect of Alzheimer caregiving on circulating levels of C-


Appendix 1

MOS-36 Survey Questionnaire

1. In general, would you say your health is:
   - Good
   - Very good
   - Excellent
   - Fair
   - Poor

2. Compared to one year ago, how would you rate your health in general now?
   - Much better
   - Somewhat better
   - About the same
   - Somewhat worse
   - Much worse

The following items are about activities you might do during a typical day. Does your health affect you in these activities? If so, how much?

<table>
<thead>
<tr>
<th></th>
<th>Yes, A Lot</th>
<th>Yes, A Little</th>
<th>No, Not Limited at All</th>
</tr>
</thead>
<tbody>
<tr>
<td>3. Vigorous activities, such as running, lifting heavy objects, participating in strenuous sports</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
</tr>
<tr>
<td>4. Moderate activities, such as raking leaves, lifting a vacuum cleaner, bending, or playing golf</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
</tr>
<tr>
<td>5. Lifting or carrying groceries</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
</tr>
<tr>
<td>6. Climbing several flights of stairs</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
</tr>
<tr>
<td>7. Climbing one flight of stairs</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
</tr>
<tr>
<td>8. Bundling, tending, or stretching</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
</tr>
<tr>
<td>9. Walking more than a mile</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
</tr>
<tr>
<td>10. Walking several blocks</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
</tr>
<tr>
<td>11. Walking one block</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
</tr>
<tr>
<td>12. Picking up objects from the floor</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
</tr>
</tbody>
</table>

During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of your health problems?

<table>
<thead>
<tr>
<th></th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>13. Cut down the amount of time you spent on work or other activities</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>14. Slowed down more than you would like</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>15. Felt too weak or tired to do the work or other activities you usually do</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>16. Had difficulty performing the work or other activities (for example, it took extra effort)</td>
<td>1</td>
<td>2</td>
</tr>
</tbody>
</table>

During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?

<table>
<thead>
<tr>
<th></th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>17. Cut down the amount of time you spent on work or other activities</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>18. Accomplished less than you would like</td>
<td>1</td>
<td>2</td>
</tr>
</tbody>
</table>
21. How much difficulty pain have you had during the past 6 weeks?

(Circle one number)

None 1
Very slight 2
Mild 3
Moderate 4
Severe 5
Very severe 6

22. During the past 6 weeks, how much did pain interfere with your normal work (including both work outside the home and household)?

(Circle one number)

None 1
A little bit 2
Moderate 3
Quite a bit 4
Extremely 5

These questions are about how you feel and how things have been with you during the past 6 weeks. For each question, please give the one answer that comes closest to how you have been feeling.

23. How much of the time during the past 6 weeks did you feel sad or depressed?

(Circle one number on each line)

All of the time 1
Most of the time 2
A good bit of the time 3
Some of the time 4
None of the time 5

24. How much of the time did you feel downhearted or blue?

(Circle one number on each line)

All of the time 1
Most of the time 2
A good bit of the time 3
Some of the time 4
None of the time 5

25. How much of the time did you feel restless or keyed up?

(Circle one number on each line)

All of the time 1
Most of the time 2
A good bit of the time 3
Some of the time 4
None of the time 5

26. How much of the time did you feel that you couldn't control your life?

(Circle one number on each line)

All of the time 1
Most of the time 2
A good bit of the time 3
Some of the time 4
None of the time 5

27. How much of the time did you feel that you were a happy person?

(Circle one number on each line)

All of the time 1
Most of the time 2
A good bit of the time 3
Some of the time 4
None of the time 5

28. How much of the time did you feel your health or physical problems interfered with your social activities? (Do you have the following right now?)

(Circle one number on each line)

All of the time 1
Most of the time 2
A good bit of the time 3
Some of the time 4
None of the time 5

29. How much of the time did you feel that you were able to do the things you were used to doing? (Do you have the following right now?)

(Circle one number on each line)

All of the time 1
Most of the time 2
A good bit of the time 3
Some of the time 4
None of the time 5

30. How true or false is each of the following statements for you?

(Circle one number on each line)

Definitely True 1
Mostly True 2
Don't Know 3
Mostly False 4
Definitely False 5

31. I usually get sick as often as other people

32. I have as much energy as anybody I know

33. I expect my health to get worse

<table>
<thead>
<tr>
<th>5</th>
<th>4</th>
<th>3</th>
<th>2</th>
<th>1</th>
<th>0</th>
</tr>
</thead>
<tbody>
<tr>
<td>My health is excellent</td>
<td>Good</td>
<td>Fair</td>
<td>Poor</td>
<td>Very poor</td>
<td>Unmeasured</td>
</tr>
</tbody>
</table>

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Appendix 2

CESD Survey Questionnaire

Center for Epidemiologic Studies Depression Scale (CES-D), NIMH

Below is a list of the ways you might have felt or behaved. Please tell me how often you have felt this way during the past week.

<table>
<thead>
<tr>
<th>Week</th>
<th>During the Past</th>
</tr>
</thead>
<tbody>
<tr>
<td>Rarely or none of the time (less than 1 day)</td>
<td>Some or a little of the time (1-2 days)</td>
</tr>
<tr>
<td>1. I was bothered by things that usually don't bother me.</td>
<td>[ ]</td>
</tr>
<tr>
<td>2. I did not feel like eating; my appetite was poor.</td>
<td>[ ]</td>
</tr>
<tr>
<td>3. I felt that I could not shake off the blues even with help from my family or friends.</td>
<td>[ ]</td>
</tr>
<tr>
<td>4. I felt I was just as good as other people.</td>
<td>[ ]</td>
</tr>
<tr>
<td>5. I had trouble keeping my mind on what I was doing.</td>
<td>[ ]</td>
</tr>
<tr>
<td>6. I felt depressed.</td>
<td>[ ]</td>
</tr>
<tr>
<td>7. I felt that everything I did was an effort.</td>
<td>[ ]</td>
</tr>
<tr>
<td>8. I felt hopeful about the future.</td>
<td>[ ]</td>
</tr>
<tr>
<td>9. I thought my life had been a failure.</td>
<td>[ ]</td>
</tr>
<tr>
<td>10. I felt fearful.</td>
<td>[ ]</td>
</tr>
<tr>
<td>11. My sleep was restless.</td>
<td>[ ]</td>
</tr>
<tr>
<td>12. I was happy.</td>
<td>[ ]</td>
</tr>
<tr>
<td>13. I talked less than usual.</td>
<td>[ ]</td>
</tr>
<tr>
<td>14. I felt lonely.</td>
<td>[ ]</td>
</tr>
<tr>
<td>15. People were unfriendly.</td>
<td>[ ]</td>
</tr>
<tr>
<td>16. I enjoyed life.</td>
<td>[ ]</td>
</tr>
<tr>
<td>17. I had crying spells.</td>
<td>[ ]</td>
</tr>
<tr>
<td>18. I felt sad.</td>
<td>[ ]</td>
</tr>
<tr>
<td>19. I felt that people dislike me.</td>
<td>[ ]</td>
</tr>
<tr>
<td>20. I could not get “going.”</td>
<td>[ ]</td>
</tr>
</tbody>
</table>

SCORING: zero for answers in the first column, 1 for answers in the second column, 2 for answers in the third column, 3 for answers in the fourth column. The scoring of positive items is reversed. Possible range of scores is zero to 60, with the higher scores indicating the presence of more symptoms of depression.
Appendix 3

Survey Questionnaire for the participants

---

**Survey Questionnaire**
*(To be filled out by the Family Caregiver)*

1. Compared to one year ago, how would you rate your health in general now?
   - [ ] Much better
   - [ ] Somewhat better
   - [ ] About the same
   - [ ] Somewhat worse
   - [ ] Much worse

2. The following items are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much? (Check the one that you agree with)

<table>
<thead>
<tr>
<th>Vigorous activities, such as running, lifting heavy objects, participating in strenuous sports</th>
<th>Yes, Limited a Lot</th>
<th>Yes, Limited a Little</th>
<th>No, Not Limited at All</th>
</tr>
</thead>
<tbody>
<tr>
<td>Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling or playing golf</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lifting or carrying groceries</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Climbing several flights of stairs</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Climbing one flight of stairs</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Bending, kneeling, or stooping</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Walking more than a mile</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Walking several blocks</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Walking one block</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Bathing or dressing yourself</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

3. During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of your physical health? (Check the one that you agree with)

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cut down the amount of time you spent on work or other activities:</td>
<td></td>
</tr>
<tr>
<td>Accomplished less than you would like</td>
<td></td>
</tr>
</tbody>
</table>
Were limited in the kind of work or other activities: [ ]

Had difficulty performing the work or other activities (for example, it took extra effort): [ ]

4. During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)? (Check the one that you agree with)

<table>
<thead>
<tr>
<th>Problem</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cut down the amount of time you spent on work or other activities</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Accomplished less than you would like</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Didn’t do work or other activities as carefully as usual</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

5. Answer the following questions: During the past 4 weeks.

<table>
<thead>
<tr>
<th>Question</th>
<th>Not at all</th>
<th>Slightly</th>
<th>Moderately</th>
<th>Quite a bit</th>
<th>Extremely</th>
</tr>
</thead>
<tbody>
<tr>
<td>To what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbors, or groups?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>How much bodily pain have you had during the past 4 weeks?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>How much did pain interfere with your normal work (including both work outside the home and housework)?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

6. Following questions are about how you feel and how things have been with you during the past 4 weeks. For each question, please give the one answer that comes closest to the way you have been feeling.
How much of the time during the past 4 weeks...

<table>
<thead>
<tr>
<th>Did you feel full of pep?</th>
<th>All of the time</th>
<th>Most of the time</th>
<th>A Good bit of the time</th>
<th>Some of the time</th>
<th>A Little of the time</th>
<th>None of the time</th>
</tr>
</thead>
<tbody>
<tr>
<td>Have you been a very nervous person?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Have you felt so down in the dumps that nothing could cheer you up?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Have you felt calm and peaceful</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Did you have a lot of energy?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Have you felt downhearted and blue?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Did you feel worn out?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Have you been a happy person?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Did you feel tired?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting with family, friends, etc.)?

7. How TRUE or FALSE is each of the following statements for you. (Check the one that you agree with)

<table>
<thead>
<tr>
<th>Definitely True</th>
<th>Mostly True</th>
<th>Don't Know</th>
<th>Mostly False</th>
<th>Definitely False</th>
</tr>
</thead>
<tbody>
<tr>
<td>I seem to get sick a little easier than other people</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I am as healthy as anybody I know</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I expect to get my health worse</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>My health is excellent</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
8. Below is a list of the ways you might have felt or behaved. Please tell me how often you have felt this way during the past week.

<table>
<thead>
<tr>
<th></th>
<th>Rarely or none of the time (less than 1 day)</th>
<th>Some or a little of the time (1-2 days)</th>
<th>Occasionally or a moderate amount of time (3-4 days)</th>
<th>Most or all of the time (5-7 days)</th>
</tr>
</thead>
<tbody>
<tr>
<td>I was bothered by things that usually don’t bother me.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I did not feel like eating; my appetite was poor.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I felt that I could not shake off the blues even with help from my family or friends.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I felt I was just as good as other people.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I had trouble keeping my mind on what I was doing.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I felt depressed.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I felt that everything I did was an effort.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I felt hopeful about the future.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I thought my life had been a failure.</td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>I felt fearful.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>My sleep was restless.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I was happy.</td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I talked less than usual.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I felt lonely.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>People were unfriendly.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I enjoyed life.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I had crying spells.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I felt sad.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I felt that people dislike me.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I could not get “going”</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
5. Following questions are about general information. If you do not wish to answer, you can skip these questions.

For how many years are you caring as a family caregiver?
- [ ] Less than 1 year
- [ ] 1-2 years
- [ ] 2-4 years
- [ ] 4-6 years
- [ ] 6-10 years
- [ ] More than 10 years

Gender?
- [ ] Male
- [ ] Female

Ethnicity?
- [ ] Asian/Pacific Islander
- [ ] Black
- [ ] Hispanic
- [ ] Native American
- [ ] White

Age: __________

10. What is your yearly average income? (If you do not wish to answer, you can skip the question)
- [ ] Less than $25,000
- [ ] $25,001-$50,000
- [ ] $50,001-$75,000
- [ ] $75,001-$100,000
- [ ] More than $100,000
Appendix 4

MOS-36 Survey Questionnaire Scoring

INTRODUCTION

The RAND 36-Item Health Survey (Version 1.0) taps eight health concepts: physical functioning, bodily pain, role limitations due to physical health problems, role limitations due to personal or emotional problems, emotional well-being, social functioning, energy/fatigue, and general health perceptions. It also includes a single item that provides an indication of perceived change in health. These 36 items, presented here, are identical to the MOS SF-36 described in Ware and Sherbourne (1992). They were adapted from longer instruments completed by patients participating in the Medical Outcomes Study (MOS), an observational study of variations in physician practice styles and patient outcomes in different systems of health care delivery (Hays & Shapiro, 1992; Stewart, Sherbourne, Hays, et al., 1992). A revised version of the RAND 36-Item Health Survey (Version 1.1) that differs slightly from Version 1.0 in terms of item wording is currently in development.

SCORING RULES FOR THE RAND 36-ITEM HEALTH SURVEY (VERSION 1.0)

We recommend that responses be scored as described below. A somewhat different scoring procedure for the MOS SF-36 has been distributed by the International Resource Center for Health Care Assessment (located in Boston, MA). Because the scoring method described here (a simpler and more straightforward procedure) differs from that of the MOS SF-36, persons using this scoring method should refer to the instrument as the RAND 36-Item Health Survey 1.0.

Scoring the RAND 36-Item Health Survey is a two-step process. First, precoded numeric values are recorded for the scoring key given in Table 1. Note that all items are scored so that a high score defines a more favorable health state. In addition, each item is scored on a 0 to 100 range so that the lowest and highest possible scores are set at 0 and 100, respectively. Scores represent the percentage of total possible score achieved. In step 2, items in the same scale are averaged together to create the 8 scale scores. Table 2 lists the items averaged together to create each scale. Items that are left blank (missing data) are not taken into account when calculating the scale scores. Hence, scale scores represent the average for all items in the scale that the respondent answered.

Example: Items 20 and 32 are used to score the measure of social functioning. Each of the two items has 5 response choices. However, a high score
(response choice 5) on item 20 indicates extreme limitations in social functioning, while a high score (response choice 5) on item 32 indicates the absence of limitations in social functioning. To score both items in the same direction, Table 1 shows that responses 1 through 5 for item 20 should be recoded to values of 100, 75, 50, 25, and 0, respectively. Responses 1 through 5 for item 32 should be recoded to values of 0, 25, 50, 75, and 100, respectively. Table 2 shows that these two recoded items should be averaged together to form the social functioning scale. If the respondent is missing one of the two items, the person's score will be equal to that of the nonmissing item.

Table 3 presents information on the reliability, central tendency and variability of the scales scored using this method.

References


Table 1  
STEP 1: RECODING ITEMS

<table>
<thead>
<tr>
<th>ITEM NUMBERS</th>
<th>Change original response category (a)</th>
<th>To recoded value of</th>
</tr>
</thead>
<tbody>
<tr>
<td>1,2,20,22,34,36</td>
<td>1 ———— &gt;</td>
<td>100</td>
</tr>
<tr>
<td></td>
<td>2 ———— &gt;</td>
<td>75</td>
</tr>
<tr>
<td></td>
<td>3 ———— &gt;</td>
<td>50</td>
</tr>
<tr>
<td></td>
<td>4 ———— &gt;</td>
<td>25</td>
</tr>
<tr>
<td></td>
<td>5 ———— &gt;</td>
<td>0</td>
</tr>
<tr>
<td>3,4,5,6,7,8,9,10,11,12</td>
<td>1 ———— &gt;</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>2 ———— &gt;</td>
<td>50</td>
</tr>
<tr>
<td></td>
<td>3 ———— &gt;</td>
<td>100</td>
</tr>
<tr>
<td>13,14,15,16,17,18,19</td>
<td>1 ———— &gt;</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>2 ———— &gt;</td>
<td>100</td>
</tr>
<tr>
<td>21,22,26,27,30</td>
<td>1 ———— &gt;</td>
<td>100</td>
</tr>
<tr>
<td></td>
<td>2 ———— &gt;</td>
<td>80</td>
</tr>
<tr>
<td></td>
<td>3 ———— &gt;</td>
<td>60</td>
</tr>
<tr>
<td></td>
<td>4 ———— &gt;</td>
<td>40</td>
</tr>
<tr>
<td></td>
<td>5 ———— &gt;</td>
<td>20</td>
</tr>
<tr>
<td></td>
<td>6 ———— &gt;</td>
<td>0</td>
</tr>
<tr>
<td>24,25,28,29,31</td>
<td>1 ———— &gt;</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>2 ———— &gt;</td>
<td>20</td>
</tr>
<tr>
<td></td>
<td>3 ———— &gt;</td>
<td>40</td>
</tr>
<tr>
<td></td>
<td>4 ———— &gt;</td>
<td>60</td>
</tr>
<tr>
<td></td>
<td>5 ———— &gt;</td>
<td>80</td>
</tr>
<tr>
<td></td>
<td>6 ———— &gt;</td>
<td>100</td>
</tr>
<tr>
<td>32,33,35</td>
<td>1 ———— &gt;</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>2 ———— &gt;</td>
<td>25</td>
</tr>
<tr>
<td></td>
<td>3 ———— &gt;</td>
<td>50</td>
</tr>
<tr>
<td></td>
<td>4 ———— &gt;</td>
<td>75</td>
</tr>
<tr>
<td></td>
<td>5 ———— &gt;</td>
<td>100</td>
</tr>
</tbody>
</table>

(a) Precoded response choices as printed in the questionnaire.
### Table 2

**STEP 2: AVERAGING ITEMS TO FORM SCALES**

<table>
<thead>
<tr>
<th>Scale</th>
<th>Number Of Items</th>
<th>After Recoding Per Table 1, Average The Following Items</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical functioning</td>
<td>10</td>
<td>3 4 5 6 7 8 9 10 11 12</td>
</tr>
<tr>
<td>Role limitations due to physical health</td>
<td>4</td>
<td>13 14 15 16</td>
</tr>
<tr>
<td>Role limitations due to emotional problems</td>
<td>3</td>
<td>17 18 19</td>
</tr>
<tr>
<td>Energy/fatigue</td>
<td>4</td>
<td>23 27 28 29</td>
</tr>
<tr>
<td>Emotional well-being</td>
<td>5</td>
<td>24 25 26 28 30</td>
</tr>
<tr>
<td>Social functioning</td>
<td>2</td>
<td>20 22</td>
</tr>
<tr>
<td>Pain</td>
<td>2</td>
<td>21 22</td>
</tr>
<tr>
<td>General health</td>
<td>5</td>
<td>1 3 3 3 4 3 5 3 6</td>
</tr>
</tbody>
</table>

### Table 3

**RELIABILITY, CENTRAL TENDENCY AND VARIABILITY OF SCALES IN THE MEDICAL OUTCOMES STUDY**

<table>
<thead>
<tr>
<th>Scale</th>
<th>Items</th>
<th>Alpha</th>
<th>Mean</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical functioning</td>
<td>10</td>
<td>0.93</td>
<td>70.61</td>
<td>27.42</td>
</tr>
<tr>
<td>Role functioning/physical</td>
<td>4</td>
<td>0.64</td>
<td>52.97</td>
<td>40.78</td>
</tr>
<tr>
<td>Role functioning/emotional</td>
<td>3</td>
<td>0.83</td>
<td>65.78</td>
<td>40.71</td>
</tr>
<tr>
<td>Energy/fatigue</td>
<td>4</td>
<td>0.66</td>
<td>52.15</td>
<td>22.39</td>
</tr>
<tr>
<td>Emotional well-being</td>
<td>5</td>
<td>0.90</td>
<td>70.38</td>
<td>21.97</td>
</tr>
<tr>
<td>Social functioning</td>
<td>2</td>
<td>0.85</td>
<td>78.77</td>
<td>25.43</td>
</tr>
<tr>
<td>Pain</td>
<td>2</td>
<td>0.78</td>
<td>70.77</td>
<td>25.46</td>
</tr>
<tr>
<td>General health</td>
<td>5</td>
<td>0.78</td>
<td>56.39</td>
<td>21.11</td>
</tr>
<tr>
<td>Health change</td>
<td>1</td>
<td>---</td>
<td>59.14</td>
<td>23.12</td>
</tr>
</tbody>
</table>

**Note:** Data is from baseline of the Medical Outcomes Study (N = 2471), except for Health change, which was obtained one-year later.
Appendix 5

CESD Survey Questionnaire Scoring

Center for Epidemiologic Studies Depression Scale (CES-D), NIMH
Below is a list of the ways you might have felt or behaved. Please tell me how often you have felt this way during the past week.

<table>
<thead>
<tr>
<th>Week</th>
<th>During the Past</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Rarely or none of the time (less than 1 day)</td>
</tr>
<tr>
<td>1. I was bothered by things that usually don't bother me.</td>
<td>[ ]</td>
</tr>
<tr>
<td>2. I did not feel like eating, my appetite was poor.</td>
<td>[ ]</td>
</tr>
<tr>
<td>3. I felt that I could not shake off the blues even with help from my family or friends.</td>
<td>[ ]</td>
</tr>
<tr>
<td>4. I felt I was just as good as other people.</td>
<td>[ ]</td>
</tr>
<tr>
<td>5. I had trouble keeping my mind on what I was doing.</td>
<td>[ ]</td>
</tr>
<tr>
<td>6. I felt depressed.</td>
<td>[ ]</td>
</tr>
<tr>
<td>7. I felt that everything I did was an effort.</td>
<td>[ ]</td>
</tr>
<tr>
<td>8. I felt hopeful about the future.</td>
<td>[ ]</td>
</tr>
<tr>
<td>9. I thought my life had been a failure.</td>
<td>[ ]</td>
</tr>
<tr>
<td>10. I felt fearful.</td>
<td>[ ]</td>
</tr>
<tr>
<td>11. My sleep was restless.</td>
<td>[ ]</td>
</tr>
<tr>
<td>12. I was happy.</td>
<td>[ ]</td>
</tr>
<tr>
<td>13. I talked less than usual.</td>
<td>[ ]</td>
</tr>
<tr>
<td>14. I felt lonely.</td>
<td>[ ]</td>
</tr>
<tr>
<td>15. People were unfriendly.</td>
<td>[ ]</td>
</tr>
<tr>
<td>16. I enjoyed life.</td>
<td>[ ]</td>
</tr>
<tr>
<td>17. I had crying spells.</td>
<td>[ ]</td>
</tr>
<tr>
<td>18. I felt sad.</td>
<td>[ ]</td>
</tr>
<tr>
<td>19. I felt that people dislike me.</td>
<td>[ ]</td>
</tr>
<tr>
<td>20. I could not get ‘going.’</td>
<td>[ ]</td>
</tr>
</tbody>
</table>

SCORING: see for answers in the first column. 1 for answers in the second column, 2 for answers in the third column, 3 for answers in the fourth column. The scoring of positive items is reversed. Decent range of scores is zero to 60, with the higher score indicating the presence of more symptomatology.
Appendix 6

Cover Letter for Facility Care Provider

Cover Letter

February 19, 2014

Dear Care Provider,

My name is Donald Ebel, Ph.D. and I am an Assistant Professor and Director of Gerontology at Minnesota State University, Mankato. Supriya Sarkar, a graduate student who works with me, and I are conducting a research study.

The purpose of the study is to find factors associated with the caregiving role and how it affects quality of life of family caregivers of persons with Alzheimer’s disease (AD). The family caregivers could be spouse or adult child or friend.

The participants have to be family caregiver, able to understand and read and write English, and have access to computer/Internet (not compulsory for everyone). The family caregivers could be spouse or adult child or friend. Both mail and electronic options have been opted for this research to reach maximum family caregivers and get better response from the participants. The participant can reach to the link to complete the survey electronically https://www.surveymonkey.com/s/CGVDTCK. Participants need not have to sign the consent form. Their consent will automatically be obtained as soon as they complete and submit the survey.

The survey needs to be completed in one sitting. Responses cannot be saved to complete the survey at a later time. Also, it is not possible to re-enter the survey page (from the link sent to you) if you hit “Done” button at the end.

The participants will be given a questionnaire which will help to measure their emotional, psychological, physical health and quality of life on the basis of factors which may or may not affect individual’s lifestyle. The maximum time needed to complete the survey questionnaire will be 10-15 minutes. The survey for the study could be done either electronically or through mailed survey methods keeping in mind the participant’s choice and flexibility because of the variability in age.

If you are willing to support us with the research, kindly forward the message to staff, family, friends and family caregivers of persons with Alzheimer’s disease from your facility and your neighborhood.

Please call Donald Ebel at 507.389.5188 or Supriya Sarkar at 507.779.6188 if you have questions. We appreciate your time and willingness to be part of the study.

Sincerely,

Donald Ebel, Ph.D. (Principal Investigator), Director of Gerontology, AH 113
Supriya Sarkar (Student Investigator)
Minnesota State University, Mankato
Mankato, MN 56001
Appendix 7

Cover Letter for Family Caregiver

Cover Letter

February 19, 2014

Dear Family Caregiver,

My name is Donald Ebel, Ph.D and I am an Assistant Professor and Director of Gerontology at Minnesota State University, Mankato. Supriya Sarkar, a graduate student who works with me, and I are conducting a research study. The purpose of the study is to find factors associated with the caregiving role and how it affects quality of life of family caregivers of persons with Alzheimer’s disease (AD). The family caregiver could be spouse or adult child or friend.

You will be given one survey questionnaire which will help us measure the emotional, psychological, physical health and quality of life on the basis of factors which majority affects individual's lifestyle. The maximum time needed to complete the survey questionnaire will be 10-15 minutes. The survey for the study could be done either through electronic or mailed survey methods keeping in mind the participant's choice and flexibility.

Here is an internet link that will take you to the survey questionnaire
https://www.surveymonkey.com/r/CGV0DCK. If you prefer to complete the survey either electronically or mailed, you do not need to return the signed consent letter. Your consent will automatically be obtained as soon as you complete and submit the survey.

Kindly complete the survey in one sitting. You cannot save your responses to complete the survey at a later time. Also, you will not be able to re-enter the survey page (from the link sent to you) if you hit “Done” button at the end.

Would you share this internet link with others who also assist you in any way? Examples could include: picking up groceries, getting prescriptions, mowing the lawn, bringing in meals, paying the bills, managing the finances, taking the person with Alzheimer’s disease for outings or overnight, etc. If you are willing to support us with the research, kindly forward the message to family, friends and neighborhood.

The information learned from the survey will provide valuable feedback to know and understand how certain factors could be detrimental to the caregiver’s health and how these factors affect the overall health of that individual emotionally, psychologically and physically. The result of the study will also help future researchers to do advance studies on the areas related to quality of life of the family caregivers.

If you are willing to participate, please answer the survey questionnaire and send in the return envelope to us. Please call Donald Ebel at 507-389-5188 or Supriya Sarkar at 507-779-6188 if you have questions. We appreciate your time and willingness to be part of the study.

Sincerely,

Donald Ebel, Ph.D (Principal Investigator), Director of Gerontology, All 1113
Supriya Sarkar (Student Investigator)
Minnesota State University, Mankato, MN 56001
Appendix 8

Mailed Survey Consent Form

CONSENT FORM

We invite you to participate in a research study involving a survey about the “Impact of caregiving role in the quality of life of family caregivers for a person with Alzheimer’s disease”. Poor quality of life affects family caregivers of persons with Alzheimer’s disease (AD). The purpose of this study is to find factors which are associated with the caregiving role and that affect quality of life of family caregivers of persons with Alzheimer’s disease (AD). If you agree to participate in this research study you will be asked questions about your emotional and physical health status. All of your information will be kept private, and can be viewed only by authorized research staff members. The survey takes about 10-15 minutes to complete.

This research project is being directed by Dr. Donald Ebel. You can contact Dr. Ebel at 507-389-5188 or Donald.ebel@mnmsu.edu (principal investigator) and Supriya.Sarkar@mnmsu.edu (student investigator) about any concerns you have about this project. You may also contact the Minnesota State University, Mankato Institutional Review Board Administrator, Dr. Barry Rae at 507-389-2321 or barry.rae@mnmsu.edu with any questions about research with human participants at Minnesota State University, Mankato.

Participation in this project is voluntary and you have the right to refuse to be in the study or stop at any time. Your decision whether or not to participate will not affect your relationship with Minnesota State University, Mankato nor will a refusal to participate involve a penalty. There are no direct benefits to you as a result of participation in this research.

None of your answers will be released and no names will be recorded. Survey responses will be kept for 3 years in a safe location by Dr. Donald Ebel (Principal Investigator) and then will be destroyed.

The risks of participating in this research study are about the same as are encountered in daily life. Participating in this study will help the researchers to better understand the challenges related to the quality of life that family caregivers for a person with Alzheimer’s disease face during their caregiving role. Your responses would be helpful in understanding the emotional health and physical health of a family caregiver. The result which will be drawn from the responses would help to find a solution and plan a program to maintain better quality of life of family caregivers.

To participate in this research, no signature is required and the completed survey should be mailed back with no return address on the envelope.

Submitting the completed survey will indicate your informed consent to participate and indicate your assurance that you are at least 18 years of age.

Please keep a copy of this consent for your future reference.

MSU IRB Net ID #: 53732-4
Date of MSU IRB approval: December 3, 2013
Appendix 9

Online Survey Consent Form

ONLINE ANONYMOUS SURVEY CONSENT

We invite you to participate in a research study involving a survey about the “Impact of caregiving role on the quality of life of family caregivers for a person with Alzheimer’s disease”. Poor quality of life affects family caregivers of persons with Alzheimer’s disease (AD). The purpose of this study is to find factors which are associated with the caregiving role and that affect quality of life of family caregivers of persons with Alzheimer’s disease (AD). If you agree to participate in this research study you will be asked questions about your emotional and physical health status. All of your information will be kept private, and can be viewed only by authorized research staff members. The survey takes about 10-15 minutes to complete.

This research project is being directed by Dr. Donald Ebel. You can contact Dr. Ebel at 307-389-5188 or Donald.ebel@msu.edu (principal investigator) and Srinivasa sarma@msu.edu (student investigator) about any concerns you have about this project. You may contact the Minnesota State University, Mankato Institutional Review Board Administrator, Dr. Barry Rieh at 307-389-2221 or barry.rieh@msu.edu with any questions about research with human participants at Minnesota State University, Mankato.

Participation in this project is voluntary and you have the right to refuse to be in the study or stop at any time by closing your web browser. Participation or nonparticipation will not impact your relationship with Minnesota State University, Mankato.

The risks of participating in this research study are about the same as are encountered in daily life. Responses will be anonymous. However, whenever one works with online technology there is always the risk of compromising privacy, confidentiality, and/or anonymity. If you would like more information about the specific privacy and anonymity risks posed by online surveys, please contact the Minnesota State University, Mankato Information and Technology Services Help Desk at 307-389-6224 or you may speak to the MSU Information Security Manager (ITS) at itsecurity@msu.edu.

There are no direct benefits to you as a result of participation in this research. Participating in this study will help the researchers better understand the challenges related to the quality of life that family caregivers for a person with Alzheimer’s disease faces during their caregiving role. Your responses would be helpful in understanding the emotional health and physical health of a family caregiver. The result which will be drawn from the responses would help to find a solution and plan a program to maintain better quality of life of family caregivers.

Submitting the completed survey will indicate your informed consent to participate and indicate your assurance that you are at least 18 years of age.

Please print a copy of this page for your future reference.

MSU IRB/Net ID# 537522-4

Date of MSU IRB approval: December 3, 2013
Appendix 10

Agency Permission Letter from Alzheimer’s Association Minnesota-North Dakota Chapter

February 27, 2014

Dear Dr. Emdl,

I am familiar with your research project titled “Impact of Caregiving Role in the Quality of Life of Family Caregivers for People with Alzheimer’s Disease” and your desire to have the Alzheimer’s Association Minnesota-North Dakota involved with it. I understand the role of Alzheimer’s Association Minnesota-North Dakota, such as allowing employees to participate in the research if they wish to, forward the message to staff, family and friends and family caregivers of people with Alzheimer’s disease and neighborhoods.

We have also discussed the role of Minnesota State University, Mankato and I am satisfied that their (participant) safety and well being are adequately protected as described in the research protocol. In addition, I understand that this research will be carried out following sound ethical principles and that involvement in this research, for Alzheimer’s Association Minnesota-North Dakota and Minnesota State University, Mankato, is strictly voluntary and guarantees the protection of participant’s privacy. In particular, I understand that the investigator cannot provide me with data that might allow anyone other than the research team to identify anyone’s answers unless permission has been specifically given by the subject. I agree that there will be no negative consequences for potential participants based on whether or not they choose to participate in the study.

Therefore, as a representative of Alzheimer’s Association Minnesota-North Dakota, I agree to allow you to conduct your research at our facility.

Sincerely,

[Signature]

Dennis Winkler
Support Group Manager
dwinkler@ain.org

OUR VISION IS A WORLD WITHOUT ALZHEIMER’S DISEASE.
December 18, 2013

Dear Dr. Bel,

I am familiar with your research project titled “Impact of Caregiving Role in the Quality of Life of Family Caregivers for People with Alzheimer’s disease” and your desire to have Lyngblomsten Care Center involved with it. I understand the role of Lyngblomsten Care Center, such as allowing employees to participate in the research if they wish to, forward the message to staff, family, friends and family members of people with Alzheimer’s disease and their families.

We have also discussed the role of Minnesota State University, Mankato and I am satisfied that the participants’ safety and welfare are adequately protected as described in the research protocol. In addition, I understand that this research will be carried on, following sound ethical principles and that involvement in this research for Lyngblomsten Care Center and Minnesota State University, Mankato is strictly voluntary and guarantees the protection of participants’ privacy. In particular, I understand that the investigator cannot provide me with data that might allow anyone other than the research team to identify anyone’s answers unless permission has been specifically given by the subject. I agree that there will be no negative consequences for potential participants based on whether or not they choose to participate in the study.

Therefore, as a representative of Lyngblomsten Care Center, I agree to allow you to conduct your research at our facility.

Sincerely,

[signature]

[Name]
CEO/President

Agency Permission Letter from Lyngblomsten Care Center, St.Paul, MN
Appendix 12
Agency Permission Letter from Lyngblomsten Home and Community Based Services, St. Paul, MN

Dear Dr. Lebel,

I am familiar with your research project titled "Impact of Caregiving Role in the Quality of Life of Family Caregivers for People with Alzheimer's Disease," and your desire to have Lyngblomsten involved with it. I understand the role of The Gathering and allowing employees to participate in the research if they wish to, because the research is staff, family, friends and family caregivers of people with Alzheimer's disease and neighborhoods.

We have also discussed the role of Minnesota State University, Mankato once. I am satisfied that their (participants) safety and welfare are adequately protected as described in the research protocol. In addition, I understand that this research will be carried out following sound ethical principles and that involvement in this research, for The Gathering and Minnesota State University, Mankato, is strictly voluntary and guarantees the protection of participant anonymity. In particular, I understand that the investigator cannot provide me with data that might allow anyone other than the researcher to identify anyone's answers unless permission has been specifically given by the subject. I agree that there will be no negative consequences for potential participants based on whether or not they choose to participate in the study.

Therefore, as a representative of Lyngblomsten, I agree to allow you to conduct your research at our facility and in our community programs.

Sincerely,

[Signature]

Julie Pahl
Director of Home and Community Based Services
Lyngblomsten Services, Inc.
Appendix 13

Agency Permission Letter from Ecumen Seasons at Apple Valley, MN

ECUMEN

Seasons at Apple Valley

ECUMEN

Seasons at Apple Valley

August 16, 2015

Dear Dr. Sheld,

I am familiar with your research project titled "Impact of Caring Role in the Quality of Life of Family Caregivers for People with Alzheimer's Disease" and your desire to have Ecumen Seasons at Apple Valley involved with it. I understand the role of Ecumen Seasons at Apple Valley, such as allowing employees to participate in the research if they wish to, forward the message to staff, family, clients, and family caregivers of people with Alzheimer's disease and neighborhoods.

We have also discussed the role of Minnesota State University, Mankato and I am satisfied that their (participants) safety and welfare are adequately protected as described in the research protocol. In addition, I understand that this research will be carried out following sound ethical principles and that involvement in this research, for Ecumen Seasons at Apple Valley and Minnesota State University, Mankato is strictly voluntary and guarantees the protection of participant's privacy. In particular, I understand that the investigator cannot provide me with data that might allow anyone other than the research team to identify anyone's answers unless permission has been specifically given by the subject. I agree that there will be no negative consequences for potential participants based on whether or not they choose to participate in the study. Therefore, as a representative of Ecumen Seasons at Apple Valley, I agree to allow you to conduct your research at our facility.

Sincerely,

Katie Bauer
Housing Manager
Ecumen Seasons at Apple Valley
Appendix 14

IRB Approval Letter

December 3, 2013

Dear Donald Ebel, Ph.D:

Re: IRB Proposal entitled "Impact of Caregiving Role in the Quality of Life of Family Caregivers for People with Alzheimer's Disease"

Review Level: Level [I]

Please be sure to change the MSU IRBNNet ID# to 557322-4 in your consent forms. The number you have is not correct.

Your IRB Proposal has been approved as of December 3, 2013. On behalf of the Minnesota State University, Mankato IRB, I wish you success with your study. Remember that you must seek approval for any changes in your study, its design, funding source, consent process, or any part of the study that may affect participants in the study. Should any of the participants in your study suffer a research-related injury or other harmful outcome, you are required to report them to the IRB as soon as possible.

When you complete your data collection or should you discontinue your study, you must notify the IRB. Please include your log number with any correspondence with the IRB.

This approval is considered final when the full IRB approves the monthly decisions and active log. The IRB reserves the right to review each study as part of its continuing review process. Continuing reviews are usually scheduled. However, under some conditions the IRB may choose not to announce a continuing review. If you have any questions, feel free to contact me at irb@msu.edu or 507-389-5102.

The Principal Investigator (PI) is responsible for maintaining signed consent forms in a secure location at MSU for 3 years. If the PI leaves MSU before the end of the 3-year timeline, he/she is responsible for following "Consent Form Maintenance" procedures posted online.

Cordially,

Mary Hadley, Ph.D.
IRB Coordinator

Sarah Sifers, Ph.D.
IRB Co-Chair
Richard Auger, Ph.D.
IRB Co-Chair

This letter has been electronically signed in accordance with all applicable regulations, and a copy is retained within Minnesota State University, Mankato IRBs records.