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## The Experiences of Caregivers Caring for Loved Ones with Dementia

Molly E. Wassman  
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# The Experiences of Caregivers Caring for Loved Ones with Dementia

Submitted by Molly E. Wassman  
May, 2012

## MSW Clinical Research Paper

The Clinical Research Project is a graduation requirement for MSW students at St. Catherine University/University of St. Thomas School of Social Work in St. Paul, Minnesota and is conducted within a nine-month time frame to demonstrate facility with basic social research methods. Students must independently conceptualize a research problem, formulate a research design that is approved by a research committee and the university Institutional Review Board, implement the project, and publicly present their findings. This project is neither a Master's thesis nor a dissertation.

School of Social Work  
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## THE EXPERIENCES OF CAREGIVERS CARING FOR LOVED ONES

### **Abstract**

The Alzheimer's Association indicates there are almost 15 million caregivers providing care to those diagnosed with Alzheimer's disease and dementia (2011). Oftentimes family members willingly assume the role of caregiver for their loved ones as dementia progresses and cognitive abilities begin to fail. As a result, this qualitative research sought to explore the experiences of caregivers caring for a loved one with dementia. Seven participants were asked open-ended questions designed to elicit responses that explained their experiences caring for a loved one with dementia. The research participants were the primary caregivers for their loved ones for whom they were either providing in-home care or were the primary contact for the facility where their loved one was residing. Research participants' loved ones had a diagnosis of dementia of the Alzheimer's type, frontotemporal dementia, or dementia - unknown, and participants were the primary caregiver caring for their loved one for a time period of two to five years. The findings indicated caregiving does contribute to relationship and life changes and has its challenges; however, it was found that caregiving can also be a rewarding experience and caregivers do continue to participate in self-care activities, despite their important responsibilities. It was also found that caregivers today are still in need of help and support from other family members and friends.

*Keywords:* Alzheimer's, dementia, caregivers, qualitative, rewards, challenges

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# THE EXPERIENCES OF CAREGIVERS CARING FOR LOVED ONES

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### The Experiences of Caregivers Caring for Loved Ones with Dementia

Caring for a loved one with a debilitating disease can cause psychological, physical, and financial stressors for those in the caregiving role. Consequently, caregiver burden is a likely outcome and significant problem of the caregiving experience. One disease in particular, Alzheimer's disease, creates memory, thinking, and behavioral problems that cause problems in daily living and eventually may require around-the-clock care for individuals with the disease (Alzheimer's Association, 2011). Alzheimer's disease falls under the umbrella term dementia, which is "the name given to a group of symptoms which result from failing brain functions" (Rudd, Viney, & Preston, 1999). While Alzheimer's is the most common cause of dementia in people age 65 and older, there are other types of dementia, including Parkinson's disease, vascular dementia, Lewy body dementia, and frontotemporal dementia or FTD (National Institute of Neurological Disorders and Stroke, 2011). FTD is characterized by degeneration of nerve cells, specifically those in the frontal and temporal lobes of the brain (National Institute of Neurological Disorders and Stroke, 2011).

As dementia progresses and cognitive abilities begin to fail in individuals with a disease of the brain, oftentimes family members willingly assume the role of caregiver for their loved ones. The Alzheimer's Association indicates there are almost 15 million caregivers providing care to those diagnosed with Alzheimer's disease and dementia (2011). Caregiving takes an emotional as well as physical toll on caregivers, resulting in more medical bills and increased stress for the caregiver (Alzheimer's Association, 2011). Specifically, the Alzheimer's Association indicates 33% of caregivers report symptoms of depression as the result of their caregiving role (2011). Others report the

percentage of primary caregivers living with a relative with dementia who experience clinical depression themselves is as high as 50% (Monahan, 1995), which indicates some caregivers are managing fine in their caregiving role but others are not. Caregiver burnout is a major predictor for placing loved ones in nursing homes; particularly, strain has been identified as one of four predictors of placement in a care facility (Monahan, 1995). Consequently, in order for individuals with dementia to stay in their homes versus being placed in a care facility, their caregivers must feel supported and validated in their caregiving role. The need for caregiver support is apparent in order to reduce overall caregiver burden as well as reducing adverse health effects in caregivers caring for their loved ones with dementia. Furthermore, more information is needed about what caregivers experience and what kind of support is essential for caregivers in order for them to be successful in their role as caregiver.

### **Purpose of Study**

The primary purpose of this study is to examine the experiences of caregivers with the intention of understanding their role and learning what it is like to care for a loved one with dementia. Themes of both caregiver resiliency and caregiver burden will be assessed. With this knowledge, solutions and supportive interventions can be expanded upon based on what caregivers are already using to alleviate their stress. The rationale for this research is to determine how social workers can help ease some of the burden that caregivers experience and the difficulties they face via listening to personal accounts from the caregivers themselves. The topic is relevant to social work particularly because the “baby boomer” generation is aging out and the number one risk factor for Alzheimer’s disease is age (Alzheimer’s Association, 2011). With more individuals

developing Alzheimer's or other diseases resulting from failing brain functions, there will be more caregivers needing to take on the important role of caregiving, and social workers must be able to assist and support individuals in the process of caring for their loved ones (Rudd et al., 1999). With the help of this research, supportive interventions can be developed that will be based on testimonies of what caregivers' most pressing needs and concerns are. If the profession of social work is well-informed by research, then clinicians will be in a better position to support caregivers in their roles. As a result, if caregivers have the support they need, they will be in a healthier place to provide ongoing care for their loved ones.

This study seeks to answer the following overarching research question: What are the experiences of family members caring for their loved ones with dementia? The study seeks to have a better understanding of what it is like to care for a family member with dementia and to understand how the relationship with the person who has it changes as well as how the lives of caregivers change. The goal of the overarching research question and its sub-questions is to provide a better idea of what types of supports are needed to assist caregivers in their caregiving role.

### **Literature Review**

The existing literature on caregiver burden was reviewed in order to gain a better understanding of what has been researched and written by other researchers on the topic. A review of the literature on caring for loved ones with dementia has revealed that, stated mildly, caregivers struggle when caring for a loved one who has a disease of the brain. The umbrella phrase for the problems experienced by caregivers is caregiver burden, which is defined as "an all-encompassing term used to describe the physical, emotional,



and financial toll of providing care” (American Academy of Family Physicians, 2000). The existing literature contains information about the types of familial caregivers, adverse effects of caregiving, gender’s influence on caregiving, populations that are considered to be at-risk or vulnerable to caregiving, and a few positive aspects of caregiving. Additionally, the research provides examples of interventions that have been tested and services that are still needed to assist caregivers. Controversy exists among researchers about each topic and the effectiveness of reducing feelings of burden, strain, and stress in caregivers. However, with the existing knowledge and ideas of other researchers being situated within this research, the experiences of caregivers may be better defined and a gap may be filled where more research is needed on the overall issue of caregiver burden.

### **Types of Familial Caregivers**

Although there are many types of caregivers, such as doctors, nurses, and other healthcare professionals that are paid for their work, familial caregivers, including siblings, adult children, and spouses, often willingly take on the role even though they are not monetarily or emotionally compensated for their time and energy. Among individuals diagnosed with dementia of the Alzheimer’s type, the majority of those in the caregiving role were found to be spouses or adult children, and the majority of the literature focused on these types of familial caregivers (Holley & Mast, 2009). There was limited information on siblings caring for their siblings with dementia. The idea that caregiving is taken on by family members is summed up by Kuhn (1990) who describes the role of caregiving as a normal family stressor that begins in the home and continues even after a loved one is placed in a care facility (Monahan, 1995). Few studies provided

a breakdown of the number of familial caregivers; however, some researchers did provide exact percentages of those taking on the familial caregiving role. In terms of the number of spouses caring for a loved one with dementia, studies ranged from 38 to 50% (Sussman & Regehr, 2009; Conwell & Gallant, 1998). Whether the caregiver of a loved one with dementia was the individual's spouse or adult child, the research indicated that the role of caregiver is a difficult, ongoing task.

### **Adverse Effects Associated with Caregiving**

The research indicated a number of negative effects as the result of taking on the role of caregiver. These adverse effects included psychological, physical, and financial stressors that begin with the diagnosis and increase as the disease progresses and cognitive abilities become more impaired. As many as 50% of caregivers feel their role as caregiver is a 24-hour job, an indication of the challenges associated with this role (Schulz, Mendelsohn, Haley, Mahoney, Allen, Zhang, Thompson, & Belle, 2003). In their study on caregivers caring for loved ones with four different types of ailments, Kim and Schulz (2008) found that out of all the caregivers, those caring for loved ones with cancer and dementia reported the highest level of psychological concerns. This is congruent with other studies in that the major theme in the literature focuses on psychological problems as the result of caregiving.

**Psychological effects.** Common emotional difficulties when caring for a loved one with Alzheimer's disease included stress, depression or sadness, grief, and sometimes anger toward their loved one and, consequently, feelings of guilt for having such feelings. In their study of 193 pairs of caregivers and loved ones with dementia, Brodaty and Luscombe (1998) found associations between psychological problems in the caregivers

and the severity of the dementia in their loved ones. Battista, Pate, Hierholzer, Howsepian, and Mogelof (2004) indicated that cognitive and behavioral problems in loved ones with dementia were associated with feelings of burden in their caregivers. Nichols, Martindale-Adams, Greene, Burns, Graney, and Lummus (2009) found that the top four topics requested by caregivers in their Enhanced Care intervention group (i.e., an intervention targeted at managing stress levels in caregivers) included information on living a healthy lifestyle, grief, relaxation, and depression. These topics were requested to help alleviate stress levels and to help caregivers cope with the psychological effects of their caregiving role.

***Stress.*** One psychological effect of caregiving found in the literature is increased stress levels. In their study of 349 caregivers, who were either caring for an individual with or without dementia, Bertrand, Fredman, and Saczynski (2006) found that stress was higher for caregivers caring for an individual with dementia versus someone without a dementia diagnosis. For participants in Burns, Nichols, Martindale-Adams, Graney, and Lummus' (2003) study, caregivers in the intervention group were provided with Enhanced Care in order to manage stress and decrease psychological problems. Findings indicated that the Enhanced Care intervention did improve caregivers' general well-being and reduce stress. Rudd, Viney, and Preston (1999) found a ripple effect in that female spousal caregivers with high stress levels also tended to have higher levels of anxiety in their role as caregiver. The anxiety was found to be more significant for women due to having to take over some of the duties previously carried out by their husbands (Rudd et al., 1999). In spousal caregivers, Sussman and Regehr (2009) found relatively high levels of "service-related stress," meaning in addition to the stress caused by the

caregiving role, community services that were supposed to assist them in their role actually caused additional stress (p. 33). As demonstrated in the literature, stress permeates the lives of caregivers and more support is needed in relieving this effect of caregiving.

***Depression.*** Depression was also very prevalent in the literature on caregivers. Cohen and Eisdorfer (1986) found that 50% or more of caregivers living with a relative with dementia experienced clinical depression, just as Nichols et al. (2009) found that in terms of educational material, the top four of the most commonly requested topics by caregivers were related to coping with depression and grief.

***Grief.*** As mentioned, grief was also a prevailing theme in the literature, which indicates that coping with loss is an integral part of the caregiving experience. Holley and Mast (2009), Sanders, Ott, Kelber, and Noonan (2008), Meuser and Marwit (2001), and Rudd et al. (1999) included grief or sadness in their studies. Rudd et al. (1999) described the process in which caregivers caring for a loved one with dementia experience the stages of grief. Initially, family members may be in denial, which is followed by anger then guilt as the result of getting angry with their loved one. After denial, anger, and guilt there may be intense loneliness and sadness. Rudd et al. (1999) found sadness to be the most common emotion that emerged from their qualitative research on 60 spousal caregivers. Grief and loss came up especially for spouses of loved ones with dementia. Those spousal caregivers who end up having to place their partners in a nursing facility have to face the reality that even though they are married, they will be living like a single person; the “marital relationship [that includes] intimacy, affection, sharing, and mutuality” ends (Meuser & Marwit, 2001, p. 666).

Many researchers included specific terminology to describe the type of grief that caregivers caring for loved ones with dementia experience. Jones and Martinson indicated that grief increases as the disease progresses and included the concept of “dual dying,” which means there is pre-death grief and then additional grief once the loved one is physically gone (as cited in Sanders et al., 2008, p. 497). The pre-death grief is similar to “anticipatory grief,” meaning there is grief in *anticipation* of the upcoming loss of the loved one with an Alzheimer’s disease diagnosis (Rando, 1986, p. 24). Meuser and Marwit (2001) also indicated that grief in anticipation of a loved one’s death is very real and is comparable to grief from a physical death. They concluded that even though grief is often overlooked in caregivers, it is a significant part of the caregiving experience (Meuser & Marwit, 2001). Holley and Mast (2009) indicate grief is more prevalent in family caregivers, and they believe it plays a key role in understanding caregiver burden.

Despite there being no physical loss when a loved one is diagnosed with dementia, researchers stress the necessity of providing support to caregivers because society does not recognize the diagnosis as a loss of their loved ones (Rudd, Viney, & Preston, 1999). Doka (1989) finds “disenfranchised grief” especially troublesome because family members with a loved one with dementia have grief, yet society does not recognize the grief or provide the same amount of support and comfort as when an actual death occurs (p. 4). Similarly, Boss (2011) describes the concept of “ambiguous loss” as having a loved one who is physically present, but psychologically absent. Ambiguous loss does not provide validation of feelings of grief and loss or support for caregivers because the person with dementia is still alive (Boss, 2011).

In addition to grief over the progressive loss of their loved ones, the idea that there is a loss of personal freedom for caregivers was prevalent throughout the literature as well. For example, one adult-child caregiver in Meuser and Marwit's (2001) study commented, "I was forced in one day to quit my job and go get her. I'm grieving more for myself and the loss of my life. I'm 43 years old and I can't leave my house" (p. 663). Summarily, the theme of grief and loss was apparent throughout the literature, which demonstrates a need for providing ongoing support for caregivers as they grieve the progressive loss of their loved ones.

*Anger.* In addition to negative psychological effects such as depression, grief, stress, and sadness, Rudd, Viney and Preston (1999) found guilt and anger to be among the effects of caregiving. They found nursing home caregivers to have more guilt than home caregivers, whereas home caregivers were found to have more anger, especially wives of husbands with dementia (Rudd et al., 1999). The wives' anger was typically found to be the result of negative, violent behaviors in their husbands, which, prior to the dementia diagnoses, was uncharacteristic of their husbands (Rudd et al., 1999). Anger in women also resulted from the perception that they had been deprived of freedom in their old age due to taking on the caregiving role (Rudd et al., 1999). In Meuser and Marwit's (2001) study of 42 spousal caregivers and 45 adult-child caregivers, they found the adult children to be angrier than the spousal caregivers. Connell and Gallant (1998) indicated there is a cause and effect relationship between mental and physical health. Caregivers who feel depressed, sad, or angry are less likely to take care of themselves, leading to physical health problems, another negative effect of caregiving.

**Physical effects.** Caregivers who took care of their loved ones were generally found to neglect their own health and physical well-being. Conwell and Gallant (1998) found that health is adversely affected for both genders as the result of taking on the role of caregiver. Due to the demands of caregiving, healthy activities are compromised, such as exercising, sleeping, and eating nutritiously (Conwell & Gallant, 1998). Increased alcohol consumption and cigarette smoking were also associated with caregiving, which consequently caused poorer health outcomes (Conwell & Gallant, 1998). Specifically, Conwell and Gallant found that high levels of depression in the caregivers were correlated with an increase of changes to the caregivers' health. Son, Erno, Shea, Femia, Zarit, and Stephens (2007) found associations between high levels of burden in caregivers and three different measures of health. Caregivers reported poorer health, had more unhealthy behaviors, and used health care services more often (Son et al., 2007). Similarly, in their study of 90 spousal caregivers and 111 adult-child caregivers, Ott, Sanders, and Kelber (2007) found significant health changes in spousal caregivers after their loved ones were diagnosed with Alzheimer's disease. Overall, 57.7% of the total sample experienced health changes, with 65.6% of the 90 spousal caregivers and 51.4% of the 111 adult-child caregivers experiencing health changes (Ott et al., 2007).

**Financial effects.** In addition to psychological and physical problems associated with caregiving, financial burden is also typical of the caregiving experience. Services within and outside the home cost money, and oftentimes if long-term care options are not available, family members will likely assist financially. Despite the importance of the financial aspect and topic, limited information was found in the literature. Therefore, research on the negative financial effects of caregiving is important to examine.

**Gender's Influence on Caregiving.** While keeping in mind the adverse effects of caregiving, distinctions were also found in the literature between male and female familial caregivers. Gender's influence on caregiving frequently was examined in the existing research. Most studies focused on differences; however, a few studies demonstrated similarities between genders, and two studies focused on specific beliefs that are held about male caregivers.

**Differences.** Because gender roles and widely-held beliefs about what each gender can or cannot do are still prevalent in US society, it is not surprising that gender differences also existed in the literature in terms of the experiences of caregivers. Collins, Stommel, Wang, and Given (1994) found that female caregivers tended to experience more depressive symptoms and feelings of burden than male caregivers. Similarly, Sanders et al. (2008) indicated that female caregivers experience higher levels of grief than men. Chadiha, Rafferty, and Pickard (2003) found that wives of husbands with dementia have multiple roles, which suggests women do have more stress as the result of managing many different aspects of their lives. Rudd et al. (1999) indicated female spousal caregivers in their study were found to have higher levels of anxiety and anger and were more sad and depressed than male spousal caregivers in their study. Male caregivers kept living their lives and continued pursuing their hobbies, whereas women felt their lives were over and had been "robbed of all their retirement plans" with their husbands (Rudd et al., 1999, p. 235). Despite studies that indicate women have more feelings of grief and depressive symptoms, some researchers found women to be better at coping than their male counterparts (O'Rourke & Wenaus, 1998).



**Similarities.** Despite the literature focusing mainly on gender differences, a few studies found none at all. In contrast to studies focused on gender differences, Conwell and Gallant (1998) found that the stress process does not differ by gender and that health is negatively affected equally for both male and female caregivers, which is similar to Fitzpatrick and Vacha-Haase (2010) in that marital satisfaction and caregiver burden were similar for both male and female spouses when caring for a spouse with Alzheimer's disease.

**Specific perspectives on male caregivers.** Perspectives on male caregivers may also be the result of the gender roles that are still apparent in society today. Overall, Russell (2001) demonstrated that male caregivers are underrepresented in the literature, and there are generally two perspectives about male caregivers. One perception is that male caregivers are ineffective and not capable of providing a loved one with care, and the other viewpoint is that men are fully capable of providing competent care to their loved ones (Russell, 2001). From the negative perspective on the abilities of male caregivers, Thompson (1997) indicates there is a sense of "double jeopardy" because if men behave like female caregivers, they are seen as "unnatural" or not masculine, but if they act unlike women, they are perceived as incompetent (as cited in Russell, 2001, p. 354). In Russell's qualitative study of 14 male spousal caregivers, he found the following three major themes in his research: male caregivers feel isolated and feel their work is invisible, males have a style of caregiving that utilizes a combination of management, task-focused skills and nurturing skills, and male caregivers do feel committed, responsible, and devoted in their caregiving role.

**At-Risk or Vulnerable Populations.** The literature included information on populations that are at-risk or more vulnerable to psychological or physical problems as the result of caregiving. Controversy existed among researchers about which types of caregivers are the most vulnerable and what populations are more at risk for problems associated with caregiving.

**Spouses.** One type of caregiver that appeared in the literature as being vulnerable to the demands of caregiving was spouses. Sussman and Regehr (2009), Sorensen and Conwell (2011), Ott et al. (2007) found spousal caregivers to be the most susceptible to problems. Spousal caregivers are at high risk for financial and health problems and are the least likely to ask for help (LoboPrabhu, Molinari, Arlinghaus, Barr, & Lomax, 2005; Ade-Ridder & Kaplan, 1993).

**Caregivers with lower socioeconomic status and less education.** A population that was considered to be at-risk was those with lower socioeconomic status or less education. Sorensen and Conwell (2011), Connell and Gallant (1998), and Sun, Kosberg, Kauf, and Leeper (2010) found those with lower socioeconomic status to be more at risk. Specifically, those with less education were found to be more vulnerable to the negative effects of caregiving and to have more subjective burden overall (Connell & Gallant, 1998). Sun et al. (2010) found that socioeconomic factors of rural-dwelling Alabama caregivers did affect how well caregivers coped with their caregiving role.

**Caregivers in rural communities.** Another population that was considered to be vulnerable to the effects of caregiving was individuals in rural communities with fewer resources. In their study on 141 familial caregivers in rural Alabama, Sun et al. (2010) found that this population of caregivers is “invisible and understudied” (p. 548). The

authors indicate that services in rural areas are lacking and, therefore, caregivers in rural areas are at risk for caregiver burnout and emotional and physical problems.

**Minority populations.** Populations in the literature that needed more resources and culturally-competent tools and services to assist in the caregiving role were minority populations and persons of color. Some studies indicated that there needs to be more research on minority caregivers, while other researchers expressed that studies on caregivers need to be conducted using more diverse samples. Sorensen & Conwell (2011) found Latinos and Asian Americans to be at risk for more depressive symptoms and health problems. In their qualitative study Ranney and Aranda (2001) found moderate levels of depression and fair to poor health in 97 Latino familial caregivers. The moderate levels of depression in the Latino caregivers were considered “clinically significant symptoms that interfere with daily functioning” (Ranney & Aranda, 2001, p. 14).

Monahan (1995) also indicated “non-white, married caregivers” were found to have higher burden levels (p. 77). In a study that included 89 caregiver-care recipient dyads, 39 of which were Latino and 50 were European American, Valle, Yamada, and Barrio (2004) found that Latino caregivers were less likely than European American caregivers to ask for help, even under high levels of stress. Latino caregivers “were less willing than Euro-Americans to seek out advice from or to talk about their feelings with available persons of their social network,” whereas Euro American caregivers sought emotional support from friends or professionals (Valle et al., 2004, p. 540). Furthermore, even when under “slightly higher distress,” Latino caregivers were less likely to seek out formal services, such as professional help (Valle et al., 2004, p. 541). In their study on

coping styles of African American and white caregivers, Sun et al. (2010) found no differences between race/ethnicity and coping in the caregiving role. Overall, the existing research highlights the need for more services geared towards specific populations and culturally-competent tools to assist caregivers in their roles.

**Younger versus older caregivers.** Controversy existed in the literature about whether younger or older caregivers are more at risk to the adverse effects of caregiving. Fitzpatrick and Vacha-Haase (2010) found age to be a “protective buffer” when an older person is caring for their spouse with dementia (p. 177). They found that younger caregivers may actually be at more risk and need more resources. This is in contrast to Monahan (1995) who indicated older male caregivers have higher levels of burden and that more research needs to be conducted on older male caregivers.

### **Positive Aspects of Caregiving**

Despite the majority of the literature focusing on the negative effects of caregiving, research was found that suggests the caregiving experience can be positive and enriching. Ott et al. (2007) found that caregivers do experience positive effects like personal growth and meaningful self-reflection, which is more apparent for adult-child caregivers. Russell (2001) also found the caregiving experience to provide personal growth for spouses with loved ones with dementia. In their study on 30 spousal caregivers, Fitzpatrick and Vacha-Haase (2010) indicated that older spousal caregivers experienced more marital satisfaction than their younger counterparts.

Despite the morose nature of their research finding, Haley, Bergman, Roth, McVie, Gaugler, and Mittelman (2008) found that the death of a caregiver’s loved one led to a decrease in depressive symptoms, which was apparent in both the intervention

and control groups of their study on 254 spousal caregivers who experienced the death of their loved one while participating in the study. Schulz et al. (2003) also found a significant decrease in depression among former caregivers even a year after the death of their loved one. In terms of the caregivers' experience, it was demonstrated that death of their loved ones with dementia may actually bring relief and closure, which can be viewed as a positive aspect of the caregiving experience.

### **Interventions**

There are a number of interventions that have been found to decrease feelings of stress and burden for caregivers. Contrarily, other interventions have been found to be ineffective or to have no apparent effect in reducing stress and burden for caregivers. There are varying theories about what works and what does not. Variation also exists about what types of problems are reduced by certain interventions.

**Respite for the caregiver.** Respite care or a break for the caregiver from their loved one had mixed results in the literature. In their study of 85 spousal caregivers caring for their loved ones with dementia, Sussman and Regehr (2009) found adult day programs for the partners with dementia to be the most effective at reducing *perceptions* of burden for their caregivers. The caregivers in the study were allowed alone time while having the "peace of mind" that their loved ones were being cared for and socially-stimulated at a day program approximately two days per week (p. 36). Respite care was also found to be effective at reducing burden, especially for men, according to Sorensen and Conwell (2011) and Russell (2001). Russell (2001) indicated men utilize respite care "in order to conserve their physical and emotional strength" (p. 361). In a study providing care-assisted vacations to caregivers and their loved ones with dementia, Wilz

and Fink-Heitz (2008) found that such vacations helped decrease physical and emotional problems months after caregivers returned home from the vacations. Improvements in the intervention group were found three months after the first interview in overall emotional and physical states of the participants in comparison with those in the control group (Wilz & Fink-Heitz, 2008). In everyday life, Wilz and Fink-Heitz (2008) contended that positive social activities away from the care recipient reduce depression and stress in the caregiver. Unlike Sorensen and Conwell (2011) and Russell (2001), Wilz and Fink-Heitz (2008) found that respite care may actually aggravate memory and behavioral problems in individuals with Alzheimer's disease. Similarly, Sussman and Regehr (2009) indicated that giving caregivers a break by offering in-home services may actually increase stress; it creates a sense of "invasion" that can be overwhelming for families (p. 36).

**Education.** Overall, providing education to caregivers seemed to be helpful across studies. Sorensen and Conwell (2011), Holley and Mast (2009), and Monahan (1995) all found psychoeducation to be the most effective at improving caregiver knowledge and reducing high levels of burden. Specifically, Haley et al. (2008) found that enhanced caregiver support early on leads to improvements. In their study of 167 caregiver-care recipient dyads, Burns et al. (2003) found that brief interventions for caregivers that included educational material on managing stress and coping with Alzheimer's disease reduced feelings of burden for the caregivers.

**Caregiver support.** Social and emotional support as an intervention for the caregiver provided mainly positive results among researchers' findings. A number of studies argued that social and emotional support as well as validation and attention to

caregivers' frustrations are all important for caregivers (Haley et al., 2008; Holley & Mast, 2009; LoboPrabhu et al., 2005; Monahan, 1995; Ott et al., 2007; Rudd, Viney, & Preston, 1999; Sorensen & Conwell, 2011; Sussman & Regehr, 2009). Haley et al. (2008) provided enhanced caregiver support to spousal caregivers and found it worked especially well if started early on in the caregiving experience. In a study conducted in Miami, Florida using telephone support groups, 81% of English- and Spanish-speaking caregivers found the group to be helpful, mainly because of the social and emotional support from other caregivers (Bank, Arguelles, Rubert, Eisdorfer, & Czaja, 2006). Monahan (1995) argued that caregivers need to be recognized and then offered support based on their own unique needs. The idea that caregivers are not alone in the process of caregiving may be comforting to those in the caregiving role and reduce some feelings of burden. On the contrary, Connell and Gallant (1998) found that social support, by itself, does not reduce depression or feelings of burden in caregivers. The authors argue that more is needed to assist caregivers than just support.

**Religion or spiritual outlet.** Having a belief in God or a belief in a higher power was found to be useful for caregivers in only some studies. In order to simultaneously decrease grief and increase a sense of personal growth, LoboPrabhu et al. (2005) and Sanders et al. (2008) found religion or a spiritual connection to be helpful. One participant stated, "I pray a lot. God, help me to come out of this situation that I'm in and then I pray, I pray hard" (Sanders et al., 2008, p. 514). In a study combining spirituality, problem-solving methods, and the Serenity Prayer from Alcoholics Anonymous, seven adult-child caregivers reported more self-confidence in their ability to solve problems and more happiness after a series of eight weekly caregiver meetings (Sistler & Washington,

1999). Unlike LoboPrabhu et al. (2005) and Sanders et al. (2008), Ott et al. (2007) found that religion and social support do not decrease grief.

**Specific programs.** Two studies indicated specific interventions for reducing stress levels in caregivers. The Enhanced Care intervention, which provided educational pamphlets on topics that caregivers self-identified as most helpful for reducing stress, allowed caregivers to specify what was important for them in the caregiving process. The Enhanced Care intervention was more useful to caregivers than the Behavior Care intervention and helped with controlling behaviors in their loved ones (Nichols et al., 2009). The implication of the study is that not only are strategies for controlling difficult behaviors in the person with dementia important, but paying attention to and providing support for caregivers' emotional needs is also critical. Hepburn, Lewis, Narayan, Center, Tornatore, Lindstrom Bremer, and Nelson Kirk (2005) found that a psychoeducation program similar to cognitive behavioral therapy, which provided caregivers with knowledge and skills for caregiving based on a clinical perspective, reduced distress and improved caregiver attitudes for about six months; however, the same intervention was not as beneficial after one year following treatment.

**Coping techniques.** In order to relieve feelings of burden in caregivers, some researchers focused on the coping techniques that are most beneficial and detrimental to caregivers. Self-efficacy or the belief in oneself to be able to manage the diagnosis and care for a loved one with Alzheimer's disease competently was found to decrease both depressive symptoms and feelings of burden in caregivers (Connell & Gallant, 1998). In their study on coping styles of 67 African American and 71 white familial caregivers in rural Alabama, Sun, Kosberg, Kauf, and Leeper (2010) found that caregivers with high



scores on deliberate coping were more likely to report more happiness and life satisfaction. Deliberate coping was described as “growth, seeking emotional help, seeking instrumental support, suppressing competing demands, active coping, and planning” (p. 556). Participants’ coping style was labeled as deliberate coping when they were actively dealing with challenges. In contrast, both Sun et al. (2010) and Ashley (2002) found that an avoidance style of coping tended not to work; specifically, Ashley found a significant positive correlation between an avoidance style of coping and depression in caregivers. Sun et al. (2010) defined avoidance coping as a “focus on and venting emotions, denial, behavior disengagement, and mental disengagement” (p. 557). Participants’ coping style in the Sun et al. (2010) study was labeled as avoidance coping when they were withdrawing from dealing with challenges. Sun et al. (2010) found associations between avoidance coping and higher caregiver burden and lower scores on life satisfaction.

### **Services Needed**

Within the existing literature, there were various ideas about what resources are currently lacking and where services could be added. General themes throughout the literature included tailoring supportive services to each caregiver’s unique needs and providing more education about the progression of the disease, screening for grief, depression, or negative coping skills in psychosocial assessments and subsequently providing help based on the results, and providing more gender-sensitive and culturally-competent services (Conwell & Gallant, 1998; Haley et al., 2008; Ott et al., 2007; Ranney & Aranda, 2001; Rudd et al., 1999; Russell, 2007; Sanders et al., 2008; Schultz et al., 2003; Sussman & Regehr, 2009).

**Tailored supportive services and educational tools.** Sussman & Regehr (2009) indicate that services and programs that can best support spousal caregivers at home are needed without a sense of intrusion. As evidenced in the Haley et al. (2008) study, enhanced caregiver support early on results in less depression before and after the death of their loved one. Schultz et al. (2003) emphasized the need for support before the death of a loved one with dementia. Interventions that target health and psychological distress are needed in order to maintain healthy behaviors in caregivers (Conwell & Gallant, 1998). Sun et al. (2010) demonstrated a need for more programs and services in rural communities. Ott et al. (2007) would like to see more education for caregivers about the progression of the disease in their loved ones. Ranney and Aranda (2001) stressed the importance of distributing self-care techniques to Latino caregivers.

**Special screenings.** Researchers have indicated the importance of screening for grief, depression, and/or negative coping styles.

**Grief.** Ott et al. (2007) indicated that caregivers need to be screened for levels of grief using the Marwit and Meuser Caregiver Grief Inventory. Rudd et al. (1999) stressed including assessments of grief in caregivers and providing extra support and validation for their losses. Holley and Mast (2009) and Sanders et al. (2008) also stressed the importance of grief services being included in interventions for caregivers. Sanders et al. (2008) argued that even if grief is not explicitly expressed by the caregiver, it is likely a part of their experience.

**Depression.** Ranney and Aranda (2001) recommended that depression screening tools be included as part of the psychosocial assessment of Latino caregivers. Burns et al. (2003) indicated that depression and stress are simply part of the caregiving process,

and as clinicians, it may be more reasonable to focus on providing assistance and improving emotional coping skills in caregivers rather than trying to eliminate stress or depression altogether.

*Negative coping styles.* Sun et al. (2010) stressed the need to pay attention to caregivers who use avoidance coping because it is associated with poor health outcomes.

**Gender-sensitive and culturally-competent services.** Russell (2007) would like gender-sensitive services and male caregiver styles to be recognized as strengths. Russell also stresses the importance of ongoing support for men to participate in groups and to receive encouragement and support for seeking outside respite. Additionally, as the baby boomers get older, Russell would like to see an increased awareness of gender differences in familial care. In addition to gender-sensitivity, Conwell and Gallant (1998) recommend more awareness and cultural competency about specific populations. In addition, they suggest greater representation of minority caregivers in the research as well as culturally-appropriate services targeted at minority populations.

Overall, there is much debate about caregiver burden and the best interventions to use when working with someone who is caring for a loved one with dementia. This study will add to the existing literature regarding caregiver burden and caregivers' experiences caring for loved ones. In this study, qualitative interviews will be conducted with familial caregivers and the following questions will be examined: What are the experiences of family members caring for their loved ones with dementia? How does the relationship with the person who has dementia change? What is the most rewarding aspect of caregiving? What is the most challenging aspect? How do the lives of caregivers change after a diagnosis of dementia in their loved ones? How do caregivers

cope in their roles? How do caregivers rank the following stressors as they relate to their caregiving role: psychological, physical, and financial? Do caregivers rely more on informal support systems or formal, community resources? What do caregivers presently need in order to continue successfully in their role without burning out? These are the questions this research seeks to explore. In the following section, the conceptual framework for this research will be discussed.

### **Conceptual Framework**

This research was guided by two theoretical perspectives with an emphasis on empowerment. It was viewed through the lenses of the ecological framework or person-in-environment (PIE) and a strengths-based perspective. In the proceeding paragraphs, each theory will be discussed in detail and then an explanation will be provided of how each theory was applicable to this research.

The ecological framework is sometimes referred to as the ecosystems perspective; however, both concepts are generally alike and seek to answer the same question: How does one's environment affect their behavior in any given situation? This perspective puts the responsibility on gaps between persons and environments, rather than just on the environment alone or by simply labeling someone dysfunctional (Miley, O'Melia, & DuBois, 2011). The ecosystems view asserts that "dysfunctional behavior is transitory, changeable, and related to the responsiveness of the environment" (Miley et al., 2011, p. 33).

The ecological framework fits well with the strengths perspective because it explains how people can develop both strengths and weaknesses based on the environments they are in (Miley et al., 2011). A strengths-based perspective is based on

the following assumptions: 1) individuals have existing competencies to draw upon, 2) individuals have unique capacities for growth and change, 3) positive change is built on a vision of future possibilities, and 4) the supportive process focuses on competencies rather than deficits (Miley et al., 2011).

It is important to keep the ecological framework and the strengths perspective in mind when caring for a loved one with a progressive disease like dementia. The ecological framework is important because one major principle of the theory indicates that changing one thing in the environment may have a chain like effect on the rest of a person's life (Miley et al., 2011). Miley et al. (2011) states, "Prompting one productive change initiates a cycle that may have subsequent benefits throughout the entire transactional system" (p. 34). Therefore, if one aspect of a caregiver's life can be improved, if a positive alteration of the environment can be made, the caregiver's overall outlook and caregiving experience may change for the better. Based on this perspective, the goal of this research, then, was to find at least one aspect of each caregiver's environment that could be altered in order to improve their overall caregiving role. A strengths-based perspective was also pertinent because the focus needs to remain on the caregiver's strengths and what is going well. Using a strengths perspective keeps the skills and the potential of each caregiver at the forefront (Miley et al., 2011). Focusing on the unique strengths of each caregiver helps clinicians individualize plans or interventions that can build on a person's positive characteristics and provide potential for growth.

The ecological framework and the strengths perspective compliment one another. "Because human beings naturally evolve to work in harmony with their environments, it

is likely that client systems are actually doing a lot right” (Miley et al., 2011, p. 34). By focusing on existing strengths within caregivers, clinicians can assist with eliminating practices or mindsets that are not effective while caregiving. Miley et al. (2011) state that when the inherent mental, physical, emotional, social, and spiritual abilities of individuals are supported, positive growth can occur. Using the strengths perspective allows individuals and social workers to focus on what is going well in the present to determine what resources or positive characteristics can be used to better the future (Miley et al., 2011). Working within the ecological framework and from a strengths-based orientation also brings feelings of empowerment to individuals. Personal empowerment allows individuals to feel more in control of their personality, thinking, and behavior; it represents a “sense of competence, mastery, strength, and ability to effect change” (Miley et al., 2011, p. 79).

For the reasons previously discussed, the ecological framework and a strengths-based perspective were used to guide this research. The research was conducted with the idea that an individual’s environment predicts how he or she will behave in any given situation and by tapping into competencies an individual already has will provide opportunities for growth and positive changes for the future.

## **Methods**

### **Research Design**

In this qualitative research, participants were asked questions designed to elicit responses that explain their experiences caring for a loved one with dementia. Qualitative research “refers to the meanings, concepts, definitions, characteristics, metaphors, symbols, and descriptions of things” (Berg, 2007, p. 3). Through a qualitative

approach, meaning was ascribed to participants' experiences through words and provided the researcher with a greater understanding of what it is like to be a caregiver.

The research participants were asked qualitative and open-ended questions. The rationale for why this research required a qualitative interview is because the data sought was based on words and narratives, not numbers (Monette, Sullivan, & DeJong, 2011). The goal of the overall research question was to capture the participants' experiences and "what they think and feel about what is happening to them," which is referred to as *verstehen*, a subjective understanding (Monette et al., 2011, p. 225).

### **Sample**

This study consisted of a sample size of seven participants. The research participants were the primary caregivers for their loved ones for whom they were either providing in-home care or were the primary contact for the facility where their loved one was residing. Research participants' loved ones had a diagnosis of dementia of the Alzheimer's type, frontotemporal dementia, or dementia - unknown, and participants were the primary caregiver caring for their loved one for a time period of two to five years. The recruitment process was supported by a Midwestern, nonprofit, health organization (Appendix A). Research participants were recruited via flyers posted at the agency. Flyers were also disseminated by support group facilitators working under the guidance of the health organization. A copy of the flyer can be found in Appendix B. Participants for this research were drawn using purposive or judgmental sampling because participants were selected as the result of their participation in caregiver support groups. Purposive sampling is a type of nonprobability sampling that is based on the researcher's knowledge of some group that will provide the researcher with participants

that represent a certain population (Berg, 2007). In this case the researcher had knowledge that the health organization hosts support groups for caregivers and, thus, the agency provided a population in which to recruit participants.

### **Protection of Human Subjects**

Participants in this research were asked to read over a consent form that was reviewed by St. Catherine University's institutional review board (Appendix C). Their participation in the study was completely voluntary, and there were no direct benefits to participants and minimal risk. Possible discomfort and feelings of grief and loss may have come up as participants discussed their caregiving experiences. Participants were asked to agree to the study and answer 10 questions related to their experiences as caregivers in a 45-minute to one-hour interview. Participants were also asked to agree to an audio-taping of the interview and to allow the information to be reviewed by and presented to colleagues in a non-identifying way. Upon completion of their interviews, each participant received a \$10.00 gift card for a local coffee shop as a small token of the researcher's appreciation. Participants were asked on the day of their scheduled interviews whether they wished to receive the final results of the study upon completion of the research.

This research was conducted under the supervision of Dr. Catherine Marrs Fuchsel, Assistant Professor in the School of Social Work at St. Catherine University and the University of St. Thomas. Research participants' participation in the study was entirely voluntary and information that was shared by the participants was kept completely confidential and anonymous. Since participants were able to choose whether to participate in this research after informed consent, the risk to participants was



relatively low to nonexistent. The stories and information provided was used for purposes of this research only. Names of participants were not disclosed. If participants had any questions about their rights as research subjects, they were encouraged to contact the chair of the Human Subjects Institutional Review Board through St. Catherine University (see Appendix C).

While the research was being conducted, audio tapes and documents containing personal information of participants were kept in a locked filing cabinet in the researcher's home. Upon completion of the data analysis portion of the research project, all documents and audio tapes containing participants' personal information were destroyed in April, 2012.

### **Data Collection**

The research questions required a qualitative approach in order to understand the participants' personal experiences in a more general, abstract way (Monette et al., 2011). The structure of the interviews followed a semistandardized format. In this type of interviewing, the researcher asked participants a number of questions that were chosen beforehand, but the interviews remained fairly conversational throughout, and the researcher was free to digress in order to get more information or clarification from participants' initial responses (Berg, 2007). The study focused on approximately 10 predetermined sub-questions to answer the overarching research question. The sub-questions that participants were asked can be found in Appendix D.

Prior to the interviews, the questions were subject to several analyses by the researcher, the researcher's committee members, and members of the public in order to test their reliability and validity. Overall, the 10 questions were analyzed for reliability to

ensure they were dependable and would elicit similar *types* of answers, although not similar in *content* due to their subjective nature, from various caregivers caring for loved ones with dementia. The questions needed to be reviewed for validity to make certain they asked what was intended by the researcher. The goal was to have interview questions that were appropriately designed to elicit responses which accurately measured participants' caregiving experiences (Berg, 2007).

After each participant signed a consent form and agreed to the study, interviews were conducted at the location of each participant's choice or via telephone call on speaker phone. In the event that participants did not have a private space in which to meet and conduct the interviews, rooms were reserved at a university library. The interviews were audio-recorded using an Olympus handheld audio-recording device, and there were no outside interruptions during the course of the interviews. Throughout the interviews, brief field notes were taken; however, the majority of the data was collected by audio-recording.

### **Data Analysis**

After completing the interviews, all the data from each interview was transcribed verbatim by the researcher. A filing system was created to sort the data into coded classifications when analyzing the data; the analysis method of thematic clustering was utilized (Berg, 2007). Index sheets were used to organize the data into broad themes and then gradually narrowed down to smaller ideas and key words. Different colored highlighters were used to categorize the data in a meaningful way for the researcher. Upon completion of the initial assessment for emerging themes, a colleague provided a secondary review of the data as a reliability check to ensure the data was interpreted as

accurately as possible and was free of coding bias. The secondary analysis was sought to provide an additional opinion about the conclusions of the qualitative data. Since the data was interpreted similarly during the secondary review, the data analysis and conclusions are considered valid and reliable.

### **Strengths and Limitations**

This study was designed to elicit the subjective experiences of caregivers caring for their loved ones with dementia and contributed to the existing literature on the experiences of caregivers. Through this research, the field of social can have a better understanding of caregivers' needs and may be better equipped to assist caregivers in their important, yet strenuous roles. However, since the sample in this research only consisted of seven participants, the experiences and beliefs are not representative of all caregivers' points of view. Although there were similarities and common themes across the interviews, the experiences were unique to each individual caregiver and did not allow a generalization of findings. Furthermore, since the sample was drawn using a nonprobable, purposive technique, the pool of research participants was somewhat homogenous. Their individual characteristics and demographics varied, but all research participants in this research were included based on their participation in support groups and connection to a Midwestern health organization. Despite these limitations, purposive sampling was a straightforward method for gathering data for this research.

### **Findings**

In this section, the characteristics of participants as well as the findings of the study based on the participants' responses will be described. A discussion of the findings and implications for the research will be discussed in later sections. In order to protect

their identities and maintain confidentiality, participants were assigned a letter from “A” through “G.” The participants reported on their relationships with their loved ones and life changes, the rewards and challenges of caregiving, self-care activities, and coping mechanisms they utilized in their role as caregivers. Helpful community resources, surprises along their journeys, and the supports caregivers need today will be explored. Within each topic, major themes among participants will be discussed.

### **Characteristics of Participants**

Out of the seven total participants recruited, four were female and three were male. Four were caring for loved ones with Alzheimer’s disease, two with frontal temporal dementia, and one defined the loved one’s diagnosis as dementia – unknown. All participants were married and had some type of education or training beyond high school. Three had Bachelor of Science degrees, two had doctorate degrees, and two had attended a vocational college. Four participants were employed, one defined herself as a homemaker, and two were retired. Six participants were Caucasian and one was Chinese American. Of the seven participants, three were caring for their mothers, two for their wives; one was caring for her sister, and one for her mother-in-law. One of the seven participants had been primary caregiver for both her mother and father (at the same time) up until her father’s death approximately two years ago. Five of the participants were in their 50s and two were in their late 70s or early 80s. Participants had been caring for their loved one anywhere between two and five years. Three of the participants’ loved ones were placed in care facilities, two were still living at home, and two had been living at home for approximately a year and a half, but were then placed in a care facility. In the following paragraphs, topics the participants reported on will be discussed.

### **Relationship Changes**

Participants described changes in their relationships with the loved one they are caring for as well as relationship changes with other family members and friends. In terms of changes in their relationship with their loved ones, the theme of role reversal appeared frequently. Participants reported that either they felt less support from family and friends or the disease brought them closer to friends and family when describing how their relationships changed with people other than their loved ones.

**Role reversal.** A theme that came up consistently throughout the data was caregivers felt a role reversal in their relationship with their loved one. Participant A reported on how initially she had very little contact with her loved one, but then she began having frequent contact with her sibling and began coordinating appointments after taking on the caregiving role. As a result of caregiving for her loved one, she had assumed the role of personal planner. Participant D felt more like a coach. He defined caregiving as follows: “One of the main jobs of a caregiver has got to be to shift from seeing that other subject as an equal to becoming more like an object that you need to act upon.” Several participants felt like instead of being the child, they had to take on more of a parental role. In response to whether her relationship with her mother had changed, participant G stated, “Definitely, in that she’s more like the child, and I’m more like the parent.” Similarly, participant B stated, “You wouldn’t think you’d have to ask a 70 year old, adult woman – Did you change your underwear? Did you throw your clothes down the shoot, or are you going to wear them for five days straight?” One husband commented that since his wife’s diagnosis, he had to assume all the cooking and household chores, which was something she had previously done throughout their

marriage. The same participant reflected that his relationship with his wife changed in that they communicate less than they did prior to her diagnosis.

**Support.** Five out of the seven participants reported that their loved ones' diagnosis affected their relationships with other family members and friends in a negative way. In contrast, the other two participants felt it strengthened their support system. Both participants B and E reported that after their loved ones' diagnosis, friends and family stopped calling and coming over. Participant B stated, "People wouldn't come or didn't come to our house...my sister would drop in every once in a great while, my friend, ya know, those kinds of things, but nobody did that because they didn't want to intrude." Participant G cried when she talked about the effect that her mother's diagnosis has had on her family. She reported:

I have two older siblings who live in the same city as I do and my parents and they both take kind of a hands-off approach. And it felt to me as the youngest in the family to take responsibility to make sure Mom and Dad had what they needed. And the one sibling, when I asked her for help with taking them to appointments, she got very angry and that started a decline in our relationship, which I feel like I don't have a sister anymore.

Participant B described the increased stress and strain on her marriage when her mother-in-law was living in their home. She reported the following regarding challenges with her husband: "We almost ended up in a divorce court because I would get very mad at him, because I'd say, ya know, in respecting the woman, in respecting that she's my mother-in-law, but yet she's acting kind of childish." Similarly, participant A reported

that due to the stresses of caregiving, she felt more irritable and less patient with other family members.

In contrast, two participants reported that caregiving had brought them closer to other family members. Participant D reported that his two children were “very supportive” and noted that he and his wife still maintain phone contact with other family members and friends. Participant F stated the following:

I’m also fortunate that I’m not a single child...but I have two sisters and a brother, and my older sister has power of attorney, and she takes care of all her financial needs... I feel pretty lucky, very blessed, that I have resources, that I don’t have a burden... I mean my sisters are my first line [of support], but ya know, part of that is because we’ve grown up together, my siblings. They’re the easiest ones because I’ve been in support group [with them], just in general, because we all know Mom, how she operates; it’s easier to talk to each other, vent, sit there and say, ‘don’t take it personal.’

### **Life Changes**

Themes among participants in terms of life changes included increased stress and feeling more restricted due to spending more time with their loved one directly or in coordinating their loved ones’ activities or appointments.

**Increased stress.** Participant A reported having great difficulty with the care facility where her loved one was living. The stress of having to coordinate her sister’s appointments and visitors at the facility was overwhelming. The facility was far from her home, which required considerable drive time when taking her loved one back and forth to appointments. She mentioned receiving frequent calls from the facility anytime there

was a problem, including calls in the middle of the night. Participant G described a similar type of stress when her mother and father were first placed in a care facility. She reported:

At that place where they were it, it required a lot of oversight on my part as far as medications, making sure they were getting what they needed, close contact with the nurses and the people at the assisted living. It was a place that wasn't really staffed wonderfully so there were a lot of issues, and I would get a lot of phone calls in the middle of the night, notifying me of things that had happened.

**Less freedom.** Regardless of whether their loved one was living with them or in a care facility, several participants stated their lives had become more restricted. Participants felt they had less freedom to travel and do things they used to do because of the time it took to coordinate things for their loved one or to provide direct care. As the result of his mother moving into their home, participant C reported dedicating more time to her and having less time for he and his wife to socialize with other couples. Similarly, participant E stated, "Well, I'd say 90% of my day-to-day activity is doing stuff for [my wife], so that's changed a lot."

### **Rewards of Caregiving**

Spending time with their loved one and witnessing the occasional glimpses of their former personality were two themes that developed in the data. In addition, feelings that it was their "turn" to return the caregiving favor were also evident.

**Spending time with loved one.** Participants F and G reported on how they cherish the time they get to spend with their mothers. Participant F indicated that



caregiving is worth the stress when she is able to see her mother smile on good days.

Participant G reported the following:

I think the most rewarding is definitely just spending time with her because even at this stage in her life and with her limitations, I just have so many wonderful memories of adventures; that's what I call them when I take my mom out somewhere. Ya know, I guess I like to look at it as an adventure, rather than a negative thing, because it is a lot of work; it takes time and it can be very tiring, but just to see how much she appreciates being able to get out of the place that she's living and do some of the things that we've done makes it all worthwhile.

Due to their loved ones becoming increasingly less like their former selves, both participants B and C reported on how they enjoy the times when they can catch a glimpse of their loved ones' former personality. Participant B stated, "You see this sweetness...like I say, little moments; it's like she's back again..."

**'My turn.'** As part of the rewards of caregiving, two caregivers mentioned that they were happy to be able to return the favor after so many years of their loved one taking care of them. Participant F stated, "[My mother] was there for me when I was growing up, so it's my turn to be there for her during this time." Similarly, in reference to his wife who he is now caregiving for, participant E stated:

When I got my PhD from the University of \_\_\_\_\_, she got a 'PhT' – 'pushing hubby through' degree, and I'm sure her certificate was fancier than mine, but she really deserved it. And so, even when we were first married, I was just starting graduate work and she worked...and she's done much more in raising our three children. I was always preoccupied with going back to my lab in the evenings

and getting lectures ready, working to do the right thing to get tenured... So now I just feel this is my turn.

### **Challenges of Caregiving**

A majority of the participants described their loved ones' decline as the most challenging aspect of caregiving. A second major challenge was having loved ones in facilities with poor staff-to-resident ratios and not enough training or education regarding dementia care. As part of the potential challenges of caregiving, participants were asked to rank three possible stressors from most distressing to least distressing.

**Decline in loved one.** Decline was described by caregivers as their loved one not seeming like their old self anymore or as behavioral changes. Participant D indicated that the most challenging part about caring for his wife was his emotional coping in witnessing her decline. Similarly, participant G became tearful when discussing having to watch her mother's condition worsen. Participants B, C, and F reported difficulty with observing uncharacteristic behaviors and personality changes in their loved ones. Participant B described her mother-in-law as being "conceited" and "child-like" since her diagnosis, whereas participant E stated his wife had become "apathetic." One male participant commented that in the past, his mother "wouldn't say a bad word about anybody," but now he often catches her talking openly and loudly in a negative way about other residents at her care facility.

**Unreliable facilities.** Another major challenge was having to deal with facilities that either are not prepared to care for persons with dementia or do not have enough staff to meet the needs of all residents. One caregiver related how uneasy she felt when her mother was in a care facility with a low number of staff. She stated, "[My mother] fell 11

times in one year and, thankfully, never broke a bone, but it was a lot of situations that shouldn't have occurred." Another caregiver expressed great frustration with the facility where her sister is residing. She described medication errors, frequent phone calls from the facility, and staff being unfamiliar with the needs or behaviors of residents with dementia. One caregiver who finally switched her mother to a different facility stated, "The right facility makes all the difference in the world."

**Emotional, physical, financial stressors.** All participants but one ranked emotional stress as most distressing when asked to rank the preceding stressors from most distressing to least distressing. The participant who did not rate emotional as most distressing listed financial as most distressing due to the initial stress of getting her mother's finances in order by having to meet with an elder law attorney and financial advisor. Of the six participants who answered whether caregiving had affected their own health, three said yes, and three said no. (In error, the researcher failed to ask the seventh participant whether caregiving had affected his health.) Of the three who answered yes to having negative health changes, one suffered from a hormonal imbalance (i.e., having a high level of the stress hormone, cortisol, and a lack of sleep). Another participant had suffered from diabetes and heart problems since beginning caring for his mother. He was also put on an antidepressant over the last 4 years. The third participant noted changes to his health. For example, participant E reported sleep disturbances, increased tension in his neck and shoulders, and clouded thinking. He, too, was put on an antidepressant. In summary, three participants noted adverse effects to their health as the result of caregiving, and two, specifically, had been put on antidepressants.

### **Self-Care Activities**

All seven participants reported continuing to enjoy activities. Five of the seven participants attended caregiver support groups in their community. One participant stated the following regarding support groups:

I highly recommend it because you know the old saying, 'I used to be unhappy because I had no shoes 'til I met somebody who had no feet.' And I kinda feel that way when I go in because some of the people are having a much rougher time than I am right now.

Participant E related a similar feeling in that other peoples' stories provide perspective to his situation. In addition to support groups, participants reported hobbies such as exercising, reading, gardening, volunteering, and attending sports events as a means to care for themselves. Participant F stated:

I love to read, so I belong to a book club. My husband and I like to motorcycle, so we do that when the weather is nice. Ya know, I just take the time if I want to watch a movie or a show or do something that I want to do...go to the spa and get a massage or get my nails and toenails done. Yeah, I still do that, take time for myself, to balance out both work and taking care of my mom and family in general.

### **Coping Mechanisms**

**Daily coping.** Participants cope with caring for their loved ones on a daily basis in a variety of ways. Two participants reported they cope by believing that the supports they have in place are keeping their loved ones safe. Both expressed satisfaction with having technological devices (i.e., a wristband or necklace) to track their loved ones whereabouts and to address any potential emergency situations that may arise. One

participant remarked that the facility where her loved one lives gives her peace of mind because she knows her mother is receiving excellent care. Participant D uses what he calls “fiblets” to get through each day as he cares for his wife. He stated:

Being a caregiver has many opportunities for frustration and you really need to keep your cool because you do not confront somebody with dementia. It just makes it worse. When they come up with something that’s a little bit off the wall, taking about their dead parents, like taking them out to lunch or something like that, and it happens; you don’t tell them they’re dead, you simply go along with it. You try to enter their world almost. It’s not going to make any difference if you lie to them about such things. I call it ‘fiblets’ sometimes, keep it smooth...

Distraction is a major, major technique to use with dementia patients. You’re not going to change their minds; you’re not going to bring them back to reality. You need to work with it. And I’m learning that slowly.

**General coping.** Many participants reported turning to support groups and psychoeducation for guidance when coping, generally, in the caregiver role. In reference to the support group she attends, one participant stated she would be “dead without it.” Another common theme was caregivers’ self-education about their loved ones disease or the experiences of other caregivers. Gaining knowledge through reading books or attending community events seemed to help participants cope with their loved ones’ diagnosis and the progression of their diseases. Two participants reported that they turn to their faith community when they feel overwhelmed by their responsibilities.

**Someone to turn to.** Five out of the seven participants reported a specific person who they can rely on when things get particularly difficult. In contrast, one participant

reported how she felt isolated and requested a referral to speak with a therapist knowledgeable about dementia. The other participant stated he has been “pretty independent so far,” but appeared to have supports in place that he could turn to in the future.

### **Most Helpful Community Resource**

Three participants ranked caregiver support groups as the community resource that has been the most beneficial to them. The other participants found adult day programs for their loved ones (i.e., respite for caregivers) and reliable care facilities as the most helpful community resource. Participant F stated, “I would say the facility because it’s the combination [facility, staff, and resources]. They’re just so good about engaging with all the residents in general. They’re able to kinda work through what’s really going on.”

### **Surprises along the Way**

Five of the seven participants reported *how* the disease has progressed and manifested in their loved one has been surprising. Participants F and G both reflected that they had read about their mothers’ diagnoses in the beginning, but they did not realize how hard it would be to see the disease actually play out in real life, in *their* lives. As she wiped away tears, participant G stated, “Yeah, well, ya know I kinda knew it in my head, but I guess I wasn’t really prepared for how that would make me feel.” Similarly, Participant F stated, “Besides reading up about it, reading some books and stuff on it, it’s like ‘Wow, this really does happen. This really is true.’”

Participants A and B reported on the difference between caregiving for someone with dementia (i.e., a disease of the brain) versus caring for someone with a physical

ailment. In reference to caring for her mom with heart disease versus caring for her sister with Alzheimer's disease, participant A stated, "While I was stressed caring for my mom, it was nothing compared to this." In a poignant explanation of her experiences with caregiving, participant B stated the following:

Ya know, [my husband's] dad died of an aneurism... He was okay today, he had it tonight, and he died tomorrow...it was quick, sweet, shocking. My mom had leukemia. She took, what, two weeks, devastating. We lived in the hospital, yeah, hope, please God, ya know... Going through this, this long damn goodbye, I wouldn't wish it on a dog, nobody. For as shocking and hard as it is to lose somebody, this is worse, this is worse. Because you're mourning for God-damn years, excuse my mouth, but years. And I wouldn't wish it on nobody.

Similarly, participant C was surprised at his desire to see his mom die just to relieve her from her suffering and his own emotional anguish. He stated, "I sometimes think that, and I know this sounds so mean and so cruel, but that something else would take her than the disease because it does mentally draw you out."

### **Support Still Needed**

Participants named a variety of supports still needed when asked what would help them today in caring for their loved one with dementia. However, support from family and friends was a major, recurring theme among participants. Participants E and G both reported wanting more social stimulation for their loved ones from other family members or friends. Participant E stated he would like friends to "visit with [his wife] to increase the interaction she has with people" other than himself. Similarly, participant G said, "I so often wish that I didn't have to be the only one providing opportunities for my mom to

experience life...because that stimulation is so important.” Participant B expressed frustration with family members who claim to know what it is like to be a caregiver, but who are not caring for a loved one on a regular basis. Participant B stated, “I get so pissed off at people when they say, ‘we know how it is, don’t we, because her sister had it,’ and I say, ‘No, *we* do, you don’t.” A few participants felt like they could benefit from more psychoeducation and updates about the progression of the disease in their loved one.

In contrast, the two participants who had maintained their memberships on committees and boards on aging seemed to feel they were doing the best they could with the knowledge they gained. Both seemed to have a strong belief in their ability to manage in the caregiving role. One of the participants reported that there was nothing he really needed because he felt confident in the supports he already had in place.

### **Discussion**

A number of similarities and differences were found when comparing and contrasting the literature review with the data from the qualitative interviews, including major themes within each topic. Among the topics compared and contrasted in this section were, (a) characteristics or types of caregivers, (b) challenges or adverse effects associated with caregiving, (c) rewards or positive aspects of caregiving, (d) coping techniques or interventions utilized by caregivers, and (e) support or services still needed.

#### **Characteristics or Types of Caregivers**

In terms of familial caregivers, the majority of previous research studies explored in the literature review focused on spouses and adult children (Holley & Mast, 2009). There was little to no previous research data on siblings caring for their siblings with



dementia. The data in this research is consistent with this finding because only one participant was caring for her sister with dementia. The other caregivers were either the spouses or adult children of their loved ones.

### **Challenges or Adverse Effects Associated with Caregiving**

A number of similarities and differences were found between the literature review and findings in this research in terms of the challenges or negative effects of caregiving. Similarities included caregivers felt stressed by the demands of caregiving; caregivers experienced grief in terms of losing certain aspects of either their life or components of their loved ones' personality, and caregivers experienced some type of adverse health effect as the result of caregiving. Differences included the types and extent of the negative emotional effects of caregiving. Furthermore, this research found that caregiving is not as big of a burden as previous research studies indicated (Alzheimer's Association, 2011; Monahan, 1995).

**Emotional effects.** Kim and Schulz (2008) found that out of all the caregivers, those caring for loved ones with cancer and dementia reported the highest level of psychological problems. Because this research only explored the experiences of caregivers with dementia and not other diseases, this finding was not addressed in the research. However, out of all the stressors of caregiving, emotional stress was ranked as the most distressing for the majority of participants. Rudd et al. (1999) found sadness to be the most common emotion from their study. Similar to previous research, the theme of grief and loss was apparent in this research as evidenced by participants reporting relationship changes, life changes, worsening of symptoms in their loved ones, and loss of support from family members and friends. Caregivers in this research specifically

discussed the difficulty of seeing the disease progress in their loved ones as well as personality changes along the way. As previously discussed, participant B reported how when caring for a loved one with dementia, a person is “mourning for God-damn years.” This is similar to Pauline Boss’ concept of “ambiguous loss,” meaning a loved one may be physically present, but psychologically absent, which makes the grieving process that much more difficult (2011).

Although it varied from caregiver to caregiver, stress was apparent in participants in this research. Similar to Sussman and Regehr (2009) who found “service-related stress” in caregivers as the result of community services that were supposed to assist caregivers in their roles, participants A and G found unreliable facilities to be an additional source of stress.

In terms of other negative emotions associated with caregiving, Rudd et al. (1999) found guilt and anger to be among the effects of caregiving. However, unlike previous research, feelings of guilt and anger were not evident among caregivers in this research. Furthermore, high rates of depression were not apparent in this research. Only two of the seven participants reported taking an antidepressant, whereas Cohen and Eisdorfer (1986) found that 50% or more of caregivers living with a relative with dementia experience clinical depression.

**Physical effects.** Conwell and Gallant (1998) and Ott et al. (2007) found that caregivers’ health was negatively affected by the demands of caregiving. Similarly, caregiving did have an adverse effect on caregivers in this research. Approximately 50% had in some way experienced changes to their health as the result of caregiving.

**Financial effects.** As previously discussed, one participant in this research rated financial stress as the most distressing due to having to get her mother's financial matters in order. However, the majority of participants did not report financial stress as the result of caregiving. This came as a surprise to the researcher because many caregivers the researcher has come into contact with as the result of work within a memory loss clinic have expressed financial hardship when trying to pay for services and long-term care for their loved ones. Previous research studies explored also did not focus on this aspect of caregiving. Financial stress may be a burden for some caregivers, but existing research still continues to lack data in this area.

### **Rewards or Positive Aspects Associated with Caregiving**

Schulz et al. (2003) reported that caregiving is a 24-hour job for as many as 50% of caregivers. Although caregivers in this study did struggle in their caregiving role, the data did not support the finding that 50% found it to be a 24-hour job. Many caregivers still found time to participate in activities they enjoy, and many expressed that caregiving is not always stressful and demanding, as previous research seems to imply. Participants also reported the joy of spending time with their loved ones and seemed to take pride in their ability to care for their loved ones. Previous research appeared to only focus on caregiving being rewarding in terms of it being a reflective experience and time for personal growth (Ott et al., 2007; Russell, 2001). While that may have been true for many caregivers in this research, other rewards were reported.

### **Coping Techniques or Interventions Utilized by Caregivers**

A number of studies argued that social and emotional support as well as validation and attention to caregivers' frustrations are all important for caregivers (Haley

et al., 2008; Holley & Mast, 2009; LoboPrabhu et al., 2005; Monahan, 1995; Ott et al., 2007; Rudd, Viney, & Preston, 1999; Sorensen & Conwell, 2011; Sussman & Regehr, 2009). Similar to many previous research studies, caregiver support groups were an important coping mechanism for participants in this research. Three participants rated support groups as the most helpful community resource. Contrary to many participants in this research who expressed that more support from other family members and friends would reduce their feelings of burden, Conwell and Gallant (1998) found that more is needed to assist caregivers than just support.

Psychoeducation was also very important for participants in this research, which is similar to Sorensen and Conwell (2011), Holley and Mast (2009), and Monahan (1995), as they found psychoeducation to be the most effective at improving caregiver knowledge and reducing high levels of burden. The benefits of respite for caregivers had mixed results in previous studies; however, adult day programs and reliable care facilities were found to be beneficial for participants in this research (Russell, 2001; Sorensen & Conwell, 2011; Sussman & Regehr, 2009; Wilz & Fink-Heitz, 2008). Having a belief in God or a belief in a higher power was found to be useful for caregivers in some studies, just as a faith community was important for two participants in this research (LoboPrabhu et al., 2005; Sanders et al., 2008). Self-efficacy or the belief in oneself to be able to manage the diagnosis and care of their loved one was found to reduce feelings of burden in caregivers, which was true for two participants in this research who maintained their membership on boards on aging and were confident in their abilities (Connell & Gallant, 1998).

### **Support or Services Still Needed**

In terms of support or services still needed, themes throughout the literature review included tailoring supportive services to each caregiver's unique needs and providing more education about the progression of the disease, screening for specific things such as grief, depression, or negative coping skills in psychosocial assessments and subsequently providing help based on the results, and providing more gender-sensitive and culturally-competent services. Similarly, participants in this study reported needing more education about the progression of the disease in their loved one. The major theme within this research was caregivers need more support from family and friends, which was not designated as a support still needed by caregivers in previous studies.

### **Topics Not Addressed**

In contrast with previous research, this research did not address gender's influence on caregiving or at-risk or vulnerable populations, such as caregivers with lower socioeconomic status and less education, caregivers in rural communities, or minority populations. Due to a lack of services, caregivers from these populations may be more at risk for caregiver burnout and other adverse effects (Sun et al., 2010). Previous research indicated a need for gender-sensitive and culturally-competent services due to gender's influence on caregiving as well as attention being given to certain at-risk or vulnerable populations (Conwell & Gallant, 1998; Russell, 2007).

### **Strengths and Limitations**

This study was designed to elicit the subjective experiences of caregivers caring for their loved ones with dementia and contributed to the existing literature on the experiences of caregivers. The goal of the overall research question was met in that the

participants' experiences or "what they think and feel about what is happening to them," was captured by the findings of the study (Monette et al., 2011, p. 225). Through this research, the field of social work can have a better understanding of caregivers' needs and may be better equipped to assist caregivers in their important, yet strenuous roles. However, since the sample in this research only consisted of seven participants, the experiences and beliefs are not representative of all caregivers' points of view. Although there were similarities and common themes across the interviews, the experiences were unique to each individual caregiver and did not allow a generalization of findings. Additionally, the researcher's personal experience working in a memory loss clinic with families caring for loved ones with dementia may have resulted in a personal bias or preconceived notions about what the experiences of caregivers in this study would be, which may have skewed the direction of the study. Furthermore, since the sample was drawn using a nonprobable, purposive technique, the pool of research participants was somewhat homogenous. Their individual characteristics and demographics varied, but all research participants in this research were included based on their participation in support groups and connection to a Midwestern health organization. Despite these limitations, purposive sampling was a straightforward method for gathering data for this research.

### **Implications for Social Work Practice**

Given the knowledge gleaned from the literature review and findings of this research, caregivers caring for loved ones with dementia are still in need of support, especially from other family members and friends. Social workers can assist caregivers by providing disease and caregiver education via family care conferences. It is important that family members of caregivers know what the full scope of dementia is and how

different it is to care for someone with a disease of the mind, versus a disease of the body, so they can better support caregivers in caring for a loved one with dementia. More family members and friends need to be more supportive and respectful of the work that caregivers do; they also need to know how critical it is to remain a constant in both the caregiver's life and the loved one's life. Social workers can assist caregivers by acting as a neutral, third party to other family members while providing education and care direction to the entire family.

Social workers can assist caregivers directly by providing disease education and helpful community resources and by ensuring caregivers know what the progression of the disease could look like in their loved one. Social workers should encourage caregivers to seek caregiver support groups and to continue self-care, as these activities help to alleviate stress and feelings of burden. Special attention should be given to siblings caring for their siblings with dementia, as sibling caregivers appear to be a population that is overlooked. Short-term respite services should also be encouraged in order for caregivers to feel less stressed and less restricted. Social workers, in general, should become more familiar with dementia and clinical social workers providing psychotherapy should become trained in "ambiguous loss" and the grief process that is unique to caregivers caring for a loved one with dementia.

### **Implications for Policy**

Additionally, there needs to be more educational programs aimed at family and friends of caregivers caring for loved ones with dementia. General educational programs and public awareness about dementia are also important. Free caregiver conferences offering guest speakers, self-care activities, and respite for the day for their loved ones

need to occur more often. There needs to be sliding fee costs associated with short-term placements, so that caregivers from all economic backgrounds can afford respite care for their loved one as needed. Dementia training programs, including training in dementia grief work, need to be directed towards clinicians providing psychotherapy.

Additionally, more oversight is needed for care facilities. If facilities claim they can provide dementia care, staff need to be fully trained and understand the unique needs and behaviors of residents with dementia.

### **Implications for Future Research**

Future research should focus on sibling caregivers because, although there may be fewer sibling caregivers, it is a population that may have unique needs that require more attention. Research focused on the behind-the-scenes work of completing paperwork and managing loved ones' financial matters, resulting in additional stress and potential financial burden, also needs to be further addressed. Future studies could compare male and female caregivers to determine whether gender socialization does, in fact, influence the caregiving experience. Studies explored in the literature review indicated a need for more culturally-competent caregiver services and attention to at-risk or vulnerable populations, including caregivers with lower socioeconomic status and less education, caregivers in rural communities, and minority populations. Future research studies could also explore these topics in greater detail.

### **Conclusion**

While caregiving for a loved one with a debilitating disease like dementia can be challenging and cause emotional, physical, and potential financial stress, it is not and does not have to be the entire experience for caregivers who willingly assume the role.



With the support of their family and friends as well as additional support from social workers and policy makers, caregivers can and should feel validated and supported in their roles without sacrificing their own health, well-being, and freedom while continuing to do the important job of caring for a loved one with dementia. Support groups, self-care activities, and psychoeducation are all useful tools in helping to alleviate stress and ease some of the burden of caregiving as well.

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**APPENDIX A****Letter of Cooperation for Research Project**

Institutional Review Board  
St. Catherine University  
St. Paul Campus  
2004 Randolph Avenue  
St. Paul, MN 55105

RE: The Experiences of Caregivers Caring for Loved Ones with Dementia

Lead Researcher: Molly E. Wassman  
MSW Clinical Research Student  
St. Catherine University and the University of St. Thomas  
School of Social Work; Joint Program

Student Advisor and Chair of Research Project:  
Dr. Catherine Marrs Fuchsel, PhD., LICSW  
St. Catherine University and the University of St. Thomas  
School of Social Work; Joint Program

To Whom It May Concern:

We have agreed to assist Molly E. Wassman in recruiting participants for her research project. Ms. Wassman's research project will be a study on the experiences of caregivers caring for a loved one with dementia. The research will be qualitative in nature and will seek to answer the question: What are the experiences of caregivers caring for a loved one with dementia? In order for her to recruit participants, we will allow Ms. Wassman to post a flyer at our agency until Ms. Wassman recruits all potential participants for the research project. We will also distribute Ms. Wassman's flyer to support group facilitators who are associated with the organization.

Ms. Wassman will make it clear to potential participants that their participation is entirely voluntary, and the information they share in their interviews with Ms. Wassman will only be used for research purposes. Ms. Wassman will also make it clear that research participants' names will not be identified. Furthermore, upon completion of the study, Ms. Wassman will destroy copies of the audio-taped interviews with research participants.

We will inform potential participants to contact Ms. Wassman by telephone or by email if they are interested in the research project. We will inform the participant's that they will give their verbal consent to participate in the research project after Ms. Wassman has answered all of their questions. Ms. Wassman will make it clear to potential participants when she speaks to participants on the phone or by email that any

information they share during the research project will be kept confidential to the full extent permitted by the law.

Ms. Wassman will make it clear to potential participants that they are free to refuse to participate in Ms. Wassman's research project and that this will not affect their relationship to the organization in any way.

Sincerely,

---

Signature and Title

---

Date

---

Print Name

**APPENDIX B****Recruitment Flyer**

Are you the primary caregiver for a family member who has been diagnosed with dementia?

Share your story in a qualitative research study on the experiences of caregivers and the potential for caregiver burnout when caregiving for a loved one with dementia.

Criteria for participation:

- ❖ Primary caregiver for a family member
- ❖ Loved one has a diagnosis of dementia
- ❖ Caregiving for at least 6 months, but preferably for 2 or more years

**\*As a small token of appreciation, all research participants who complete an in-person or phone interview will receive a \$10.00 gift card redeemable at a local coffee shop.\***

If interested in participating in this study, please contact Molly, 2012 MSW candidate in the School of Social Work at St. Catherine University and the University of St. Thomas.

This study is being conducted under the supervision of Dr. Catherine Marrs Fuchsel, who is an assistant professor in the School of Social Work at St. Catherine University.

Your participation in the study would be entirely voluntary and information that you share would be kept completely confidential, including your name. The stories and information you provide will be used for research purposes only.

If you have any questions about your rights as a subject/participant in this research, or if you feel you have been placed at risk, you can contact the Chair of the Human Subjects Institutional Review Board through St. Catherine University at (651) 690-7739.

## APPENDIX C

### The Experiences of Caregivers Caring for Loved Ones with Dementia RESEARCH INFORMATION AND CONSENT FORM

**Introduction:**

You are invited to participate in a research study investigating the experiences of caregivers caring for loved ones with dementia. This study is being conducted by Molly Wassman, student in the School of Social Work Program at St. Catherine University and the University of St. Thomas, under the supervision of Dr. Catherine Marrs Fuchsel. You were selected as a possible participant in this research because you have been the primary caregiver for your loved one with dementia for at least six months. Please read this form and ask questions before you decide whether to participate in the study.

**Background Information:**

The purpose of this study is to discover the experiences of caregivers caring for a loved one with dementia and, in turn, provide the profession of social work with ways to better assist caregivers in their role. Approximately 8-10 people are expected to participate in this research.

**Procedures:**

If you decide to participate, you will be asked to answer approximately 10 questions related to your experiences as a caregiver in a 45-minute to one-hour interview, agree to an audio-taping of the interview that will be used for this research only, agree to allow the information to be presented to the public in a non-identifying way, and agree to allow colleagues to review the data and transcript of the interview for a reliability check. The interview will take place in a private place of your choice or via telephone on speaker phone with no one else present but the researcher. In the event that a private space is needed, rooms will be available for the interview at the university library. This study will take approximately one hour of your time.

**Risks and Benefits:**

The study has minimal risk. Due to the nature of dementia, you may feel discomfort when talking about your experiences, especially feelings of grief and loss. If your feelings become too overwhelming, you may ask to terminate the interview early.

There are no direct benefits to you for participating in this research.

**Compensation:**

If you participate, you will receive a \$10.00 gift card redeemable at a local coffee shop. You will receive the gift card upon completion of the one-hour interview.

**Confidentiality:**

Any information obtained in connection with this research study that could identify you will be kept confidential. In any written reports or publications, no one will be identified or identifiable and only group data will be presented.

I will keep the research results in a password protected computer and a locked file cabinet in my home and only I will have access to the records while I work on this project. I will finish analyzing the data by April, 2012. I will then destroy all original reports and identifying information that can be linked back to you.

**Voluntary nature of the study:**

Participation in this research study is voluntary. You are also free to pass on some of the interview questions. However, you must answer the majority of the interview questions in order for you to participate and receive the gift card at the end of the interview.

**New Information:**

If during course of this research study I learn about new findings that might influence your willingness to continue participating in the study, I will inform you of these findings.

**Contacts and questions:**

If you have any questions, please feel free to contact me, Molly Wassman. You may ask questions now, or if you have any additional questions later, the faculty advisor, Dr. Catherine Marrs Fuchsel can be reached at 651-690-6146. She will be happy to answer any questions you may have. If you have other questions or concerns regarding the study and would like to talk to someone other than the researcher, you may also contact Lynne Linder, Institutional Review Board Assistant of the St. Catherine Institutional Review Board, at (651) 690-6203.

You may keep a copy of this form for your records.

**Statement of Consent:**

You are making a decision whether or not to participate. Your signature indicates that you have read this information and your questions have been answered. Even after signing this form, please know that you may withdraw from the study at any time and no further data will be collected.

I consent to participate in the study and I agree to an audio-taping of my interview.

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Signature of Participant

Date

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Signature of Researcher

Date

**APPENDIX D****Qualitative Research Questions**

1. How long have you been caring for your loved one?
2. How has your *relationship* with your loved one changed since s/he was diagnosed with dementia?
3. How has *your life* changed since your loved one was diagnosed with dementia?
4. What is the most rewarding aspect of being a caregiver? What is the most challenging?
5. Do you take time for self-care? If yes, what types of things do you like to do for yourself? If no, please explain (what you would like to do and what would need to change for you to be able to do those activities).
6. Can you tell me how you cope with caring for your loved one with dementia on a daily basis? How do you cope with caregiving overall?
7. When things get difficult, do you feel you have someone other than your loved one who you can talk to about your feelings?
8. What community resource (outside of support from your family and close friends) has been most helpful?
9. Can you rank the following stressors from the most distressing to the least distressing: psychological or emotional stress, physical (health-related) stress, or financial stress?
10. What type of support would help you right now, today, in caring for your loved one?

The sub-questions should seek to answer the overarching research question: What are the experiences of caregivers caring for a loved one with dementia? (What is it *like* to care for a mother/father/spouse/sibling with dementia?)