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APPENDIX E

Comparison of Caregiver Burden among Types and Stages of Dementia

Submitted by Jeanette J. Foizie

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.

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Abstract

The purpose of this study was to better understand the effects of caregiver burden as they relate to different dementia diagnoses and the stage of the disease in order to discover appropriate supports and interventions. Potential participants were identified through their use of a specialty memory loss clinic. Using a mixed methodology, respondents completed a survey which included a quantitative measure and qualitative open ended response questions designed to allow the caregiver to expand on their experience. The quantitative portion of this research used the Zarit Burden Interview (ZBI), a caregiver self-report measure. Diagnosis information and the patient's Allen Cognitive Level (ACL) were supplied by the clinic in order to confirm appropriate diagnosis and stage of disease. Moderate ACL scores of 3.5-4.5 appear to increase burden. Caregiving daughters in this study were found to have the highest total ZBI scores, indicative of a higher level of burden than other caregivers. Husbands and wives in this study had identical mean total ZBI scores. The findings indicated several areas of caregiver burden in which social work supports could be valuable. Role transitions, isolation, a lack of social support, and the need for adult day centers equipped to handle patients with dementia related behaviors were all identified as areas of concern.

Acknowledgements

It is a pleasure to thank those who made this project possible. My research committee, Dr. Alvin Holm and Tanya Rand, LICSW for their professional expertise, knowledge of dementia and for helping me craft a research project which met all the needed requirements while still focusing on my primary objectives. I would also like to thank my research advisor, Jessica Toft, Ph.D., LISW for her expertise in navigating the research process and her skillful assistance in identifying areas of my paper for revision.

My family was also of vital support during this research process. I would like to thank my Mom for all of her “Cinderella” services, Hazel and Bob for all of their support – both tangible and intangible, Morgan for her proofreading and statistical abilities, and Brooke for her moral support and cooking on all of those “fend for yourself” dinner nights. Last, but certainly not least, I’d like to thank my husband, Gordy, for his unwavering belief in me, willingness to embark on this new journey and his unending encouragement throughout the process.

Dedication

For Hazel, and all the other caregivers who embrace caregiving with warmth, humor and love.

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Introduction

It is widely recognized that the population of the United States over age 65 is increasing due to the aging of the baby boomer generation. By the year 2030 it is anticipated that the population over the age of 65 will double (Alzheimer's Association, 2011). According to the Alzheimer's Association (2011), along with the aging process incidence of memory loss and dementia are also escalating. Approximately 5.4 million Americans currently suffer from Alzheimer's disease (AD); including one in eight people over the age of 65 and 43% of those over 85. Currently, every 69 seconds someone in America develops AD. It is anticipated that by 2050 this will have increased to one person every 33 seconds. In fact, AD, the most commonly recognized form of dementia, is the sixth leading cause of death in the United States (Alzheimer's Association, 2011). This increase may cause a correlated rise in the number of family caregivers. Family caregivers are unpaid individuals who provide care to family members or other loved ones who are suffering from a chronic incapacitating illness or injury.

In 2010, there were nearly 15 million family caregivers providing support to a family member with dementia (Alzheimer's Association, 2011). In Minnesota alone, there are more than 500,000 family members providing informal care to their loved one (National Family Caregivers Association, 2010). Sixty percent of caregivers nationwide are women and the majority of them, 56%, are over age 55 (Alzheimer's Association, 2011). According to Ramnarace (2011), caregivers supplied the equivalent of \$450 billion worth of services to loved ones in 2009, a necessary form of assistance that "makes caregivers one of the largest and most overlooked pillars of the U.S. health care system"

(p. 1). The cost of providing this care can be seen not only in monetary terms, but also in the physical and mental toll on the caregivers.

Family caregiving appears to be a chronically stressful and anxiety provoking task. Caregiver burden has been defined as an adverse reaction to the responsibilities associated with providing care to a dementia patient which affects the caregiver's social, relational, and occupational roles (Papastavrou, Kalokerinou, Papacostas, Tsangari, & Sourtzi, 2007). The severe burden of caregiving takes its toll with mental and physical health concerns (Robinson, Adkisson, & Weinrich, 2001; Papastavrou et al, 2007; Ostwald, Hepburn, Caron, Burns, & Mantell, 1999; Berger, Bernhardt, Weimer, Peters, Kratzsch, & Frolich, 2005). Research indicates that 30-40% of family caregivers suffer from depression, have increased blood pressure, are at increased risk for cardiovascular events, and have a 63% higher mortality rate than non-caregivers of the same age (Family Caregiver Alliance, 2005; National Family Caregivers Association, 2010; Alzheimer's Association, 2011). According to the Alzheimer's Association (2011), caregiver burden results in additional medical expenses for the carer, approximately \$7.9 billion of increased healthcare costs in the United States. From the perspective of the caregiver, the chronic stress and fatigue of providing care to a loved one with dementia may continue indefinitely, and can lead to severe physical and mental health issues.

Dementia is an umbrella term that encompasses a variety of disorders with a similar set of symptoms. Deficits must be seen in at least two domains in order for dementia to be diagnosed. These symptoms include memory loss and other cognitive changes, behavioral manifestations, mood and personality alterations, speech and language abnormalities, changes in visual-spatial, abstract reasoning, and executive functions (National Institutes

of Health, 2011). The most well-known of these disorders is Alzheimer's disease (AD), but the dementia diagnosis also includes a multitude of other diagnosis including Frontotemporal Dementia (FTD) and Dementia with Lewy Bodies (DLB). These conditions are progressive in nature and the patient eventually requires assistance with all activities of daily living. This care may be provided in a professional setting or, very commonly, by family caregivers.

Social workers, in particular, are ideally situated to work with dementia families. Their ability to perceive systems perspectives and apply person-in-environment techniques may allow them to assist in these situations. Social work interventions could be utilized that may lessen the emotional and physical strain that caregiving may cause. It is of critical importance that social workers are able to identify behaviors and symptoms of dementia that cause excess stress to caregivers so that they may offer interventions that will decrease this burden.

The purpose of this research is to better understand the effects of caregiver burden as it relates to different dementia diagnoses and stage of the disease in order to discover appropriate supports and interventions.

Literature Review

A review of the literature was conducted to understand the main elements of caregiver burden as it relates to various types of dementia. This literature review will focus on two specific areas. First, it will identify three of the most common forms of dementia: Alzheimer's disease (AD), Dementia with Lewy Bodies (DLB) and Frontotemporal Dementia (FTD). Specific features of each dementia and their effects on

caregivers will be explored. Next, it will describe how caregiver burden affects the physical and emotional wellbeing of the caregiver.

Alzheimer's Disease

AD, the most common of these disorders, affects approximately 5.4 million Americans and is responsible for 50-80% of dementia cases (Alzheimer's Association, 2011). Although it is initially characterized by trouble remembering recently learned information or short term memory loss, new evidence has shown that biological changes may be taking place in the body for years before diagnosis (National Institutes of Health, 2011). AD gradually advances and begins to involve various symptoms which may include: disorientation, mood and behavior changes; deepening confusion about events, time and place; unfounded suspicions about family, friends and professional caregivers; more serious memory loss and behavior changes; and difficulty speaking, swallowing and walking (Alzheimer's Association, 2011). These symptoms, and the associated changes in functioning, may make caregiving a challenging task.

In a study conducted by Vugt et al (2006), it was found that although FTD caregivers have an overall higher level of distress, AD caregivers experienced higher levels of caregiver burden in the areas of reduced time for self and necessary constant supervision of their loved one. They found that AD caregivers often had to provide continuous supervision for safety reasons and consequently had little time for themselves. Apathy on the part of the patient was also reported by AD caregivers as "highly distressing". This may be due to fact that the decrease in interaction between the patient and caregiver can impair their relationship and lead to a lack of intimacy and a change in roles (Vugt, et al 2006; Alzheimer's Association, 2011). Psychiatric and behavioral symptoms, along with

the need for increasing amounts of assistance with activities of daily living (ADL's) commonly occur later in the AD progression and also may cause an increase in burden.

Dementia with Lewy Bodies

DLB, the second most common form of dementia, affects about 1.3 million individuals in the United States (Lewy Body Demetia Association, Inc., 2011). DLB is actually a term that includes a diagnosis of dementia with Lewy bodies, or Parkinson's disease dementia. Although both diagnoses have similar long term symptoms, diagnosis is based on whether motor or cognitive symptoms appeared first (Galvin & Tarawneh, 2007). If motor symptoms appear a year or more before the onset of cognitive symptoms, the disease is diagnosed as Parkinson's disease, if cognitive symptoms appear simultaneously or before motor symptoms, dementia with Lewy bodies is diagnosed. Both diagnoses are within the DLB spectrum of diseases. Symptoms of DLB typically include psychiatric as well as cognitive manifestations. When diagnosing DLB, certain symptoms are frequently present. These symptoms may include: dementia, unpredictable fluctuations in cognitive function, Parkinson's related motor symptoms such as rigidity, tremors, or shuffling gate, auditory or visual hallucinations, REM sleep disorders which may cause acting out of dreams – sometimes violently, and severe sensitivity to antipsychotic medications (Lewy Body Demetia Association, Inc., 2011). Other symptoms may occur and are related to changes in the autonomic nervous system. The changes may include: difficulty regulating temperature, blood pressure and digestion, dizziness, fainting, sensitivity to heat and cold, sexual dysfunction, early urinary incontinence, or constipation. Other symptoms can include repeated falls attributed to dizziness or fainting, excessive daytime sleepiness or transient loss of consciousness, other mood disorders and psychiatric symptoms such as

depression, and delusions; or hallucinations in other senses, like touch or smell (Lewy Body Demetia Association, Inc., 2011).

Behavioral and emotional challenges are often seen earlier in DLB than in AD (Leggett, Zarit, Taylor, & Galvin, 2010). Because behavioral and emotional symptoms are unpredictable, difficult to manage, and often unsettling for the caregiver, they are among the most stressful of caregiving burdens. According to Leggett, et al (2010), the increased perception of burden caused by behavioral and emotional symptoms over an extended length of time leads to increased burden and emotional distress in the caregiver.

Psychiatric symptoms, including hallucinations which occur in up to 77% of DLB patients and delusions which occur in 46% of those diagnosed with DLB, cause an increase in caregiver burden and are associated with reduced quality of life for the patient and the carer (Bhat & Rockwood, 2011).

Isolation has also been identified as a probable cause for caregiver burden in DLB carers. In a 2008 study by the Dementia with Lewy Bodies Association, it was found that patients saw an average of three physicians before receiving the correct diagnosis and 50% of respondents said it took longer than one year for them to be diagnosed (Dementia with Lewy Bodies Association, Inc, 2008). Seventy eight percent indicated that DLB was not their original diagnosis. These barriers to care, along with a perceived lack of empathy from family and friends regarding their caregiving duties, may lead to a sense of isolation (Leggett, Zarit, Taylor, & Galvin, 2010; Dementia with Lewy Bodies Association, Inc, 2008). Over 80% of DLB caregivers surveyed by the Dementia with Lewy Bodies Association said they felt somewhat or very isolated by their caregiving duties.

Frontotemporal Dementia

According to the Association for Frontal Temporal Degeneration (2011), FTD affects approximately 50,000-60,000 Americans. They are typically diagnosed at an earlier age than AD patients, on average in the mid-fifties to early sixties, although there have been cases as young as 21 years of age (The Association for Frontal Temporal Degeneration, 2011). Symptoms of FTD usually include a decline in behavior and language skills which make it progressively more difficult for people to plan or organize activities, behave appropriately in social or work settings, interact with others, and care for themselves. These behavior changes may include changes in personality, loss of empathy and increasingly inappropriate behaviors including hyper-sexuality, impulsive behaviors, swearing, aggression, overeating, drinking, and/or a decline in self-care (The Association for Frontal Temporal Degeneration, 2011; Yeaworth & Burke, 2000). FTD is differentiated from AD by its primary symptoms, a profound alteration in personality, social conduct, and behavioral symptoms (Yeaworth & Burke, 2000; Bhat & Rockwood, 2011). According to Yeaworth and Burke (2000), FTD may often be mistaken as a psychiatric disorder due to the initial symptoms of changes in personality and disinhibition. Psychiatric symptoms are a part of the core diagnosis criteria of FTD (Bhat & Rockwood, 2011). Memory loss symptoms usually appear later in this disorder.

A study by Davis and Tremont (2007) discussed the impact of frontal systems behaviors on caregiver burden. They found that behavior associated with executive function and disinhibition is predictive of caregiver burden. As discovered by Yeaworth and Burke (2000), aggressive behaviors by the care recipients, along with unpredictable behavior, also increase family caregiver distress. They found that most community

services are designed around caring for AD patients and are not equipped to accept FTD patients who are often younger and suffer more problematic behaviors.

Caregiver Burden

A review of the literature identifies several aspects of dementia that appear to increase caregiver distress. A caregiver's perception of the severity of the symptoms may be more important to consider than the actual problem behavior itself. Dementia brings about many changes in the physical and cognitive capacity of the sufferer. The changes in global functioning that are taking place in the brain, such as personality changes, loss of capacity to reason and plan, and behavioral symptoms - are all common issues which may affect the patient and their caregiver. These symptoms may create a change to the intimacy of the marriage partnership and all other family dynamics. The patient and caregiver may be forced to alter their past relationship and forge a new path.

Relationship adjustments. Research has found that changes in family dynamics, family disharmony, and a lack of social support contribute to increased caregiver burden (Ostwald et al, 1999; Robinson et al, 2001). These changes in relationships, a role reversal from spouse or child to caregiver can be extremely challenging for the carer (Holley & Mast, 2009). One of their primary social supports may be unable to provide emotional and psychological sustenance. These caregivers are challenged by a loss of meaningful conversation, emotional closeness, and changes in the patient's personality (Holley & Mast, 2009). The caregiver may be forced to rely on social supports outside of this relationship. Andren and Elmstahl (2008) found that spouses of dementia patients experienced significantly higher burden, strain, isolation and disappointment than a control group. This was especially true of caregivers providing support to a loved one with a high

level of disability. These changes, and the variety and scope of the consequent role adjustments, may bring stress and suffering to the patient and the caregivers.

Role ambiguity, when aspects of a role are unclear, can amplify the stress burden (Garvin, 1991; Greenberg, 2009). Reassigning tasks that were typically completed by the patient to the primary caregiver or other loved ones in a clear manner can help alleviate some of this distress (Boss, 2006). Holly and Mast (2009) found that role reversals, and the accompanying feelings of disrespect or reluctance to accept that the patient is no longer able to complete tasks, were extremely distressing to caregivers.

Role discontinuity (Garvin, 1991) or role insufficiency as it is identified by Greenberg (2009), occurs when a caregiver is unprepared or inexperienced in the task to be completed. For dementia caregivers, taking on tasks such as financial management, specific household chores, or driving, which they may never have been responsible for in their historical relationship, may cause feelings of insufficiency. Garvin (1991, p. 162) proposes “anticipatory socialization” in which an individual is able to practice their new role before taking it on as a solution to some of the stress the new role creates. For dementia caregivers, this would mean identifying the roles in which they will eventually participate early on in the disease process in order to be comfortable with them later on. If the dementia process is already well under way, another possibility for reducing caregiver burden created by role discontinuity is to provide psychoeducational training, which could be offered by a social worker in the clinic setting.

Role insufficiency and role discontinuity may be closely related to role captivity. Aneshensel, Pearlin, and Schuler define role captivity as “situations in which people are unwilling incumbents of social roles” (1993, p. 56). Role captivity is not due to the

inability to perform the role, but attributable to their lack of desire to be in this role.

Caregivers may feel they are gradually losing their sense of self and being overcome by the role of caregiver. As a social role, caregiving is not a responsibility most individuals are socialized to seek out. Role captivity may increase feelings of powerlessness which increases the perception of burden (Aneshensel, Pearlin, & Schuler, 1993). Many caregivers willingly step forward to take on the role of caregiving for a loved one, but some are chosen by default. Perhaps they are a female, live closest to the care recipient, or are not employed outside of the home. Regardless of how one becomes a caregiver, the length and duration of dementia, along with its progressive nature can become exhausting. Caregivers, particularly adult children or those who care for younger care recipients, may feel role captivity.

Role overload, or the cumulative demands of numerous roles, has been found in some studies to mentally and physically exhaust some individuals (Garvin, 1991; Greenberg, 2009; Berger, 2005). If the multitude of roles leads to a situation in which the caregiver feels overwhelmed and unable to cope with the demands, then burden could result. Recent research into Role Theory (Nordenmark, 2004) and research into multiple roles on caregiver stress (Bainbridge, Cregan, & Kulik, 2006) have found that caregivers who are caring for a person with a mental disability experienced a reduction in stress when they worked outside of the home. This may be due to the stress buffering effect discussed by Berger (2005) in relation to employed parents. She found that adults who achieve in one role create a "buffer," reducing the stress of other roles. Bainbridge et al (2006) reports similar findings. In their research into caregivers of patients with mental disabilities, they found that caregivers who worked outside of the home experienced

significantly fewer stress outcomes. They speculate this may be due to expanded resources including: autonomy, self acceptance, social interaction, respite opportunities, and financial income. Nordenmark (2004), in a study which examined social roles and well-being found that participating in multiple roles reduced the rates of insomnia and lingering illness in the respondents.

For dementia caregivers, role overload may come in the form of unanticipated roles and excess responsibilities. “Quality” (Nordenmark, 2004) of roles plays an important part in reducing stress. Improving the quality of caregiver roles, as well as allowing time for roles that are unrelated to caregiving may reduce burden and increase well-being.

In home or facility living and caregiver burden. Whether care is provided in the home or at a facility, research has shown that levels of burden remain similar (Caron, Ducharme, & Griffith, 2006; Majerovitz, 2007). Caregivers providing support at home suffer burden from providing a variety of physical supports, 24 hour supervision, and a loss of emotional connection. For these caregivers, the decision to transition to facility care may be one of the most difficult decisions they make regarding the care of their loved one. In fact, many times these transitions occur as the result of a crisis. Caron, Ducharme, and Griffith (2006) found that this decision is often put off as long as possible, poorly planned or unplanned, and fraught with anticipated feelings of guilt and shame. The reasons for the transition to facility care are multifactorial and may include physical strain, sleep disturbance, problem behaviors, and a decline in caregiver health (Spillman & Long, 2009). Gaugler et al (2010) found that role captivity, the feeling of being trapped in a role, contributed to nursing home placements. This could explain why other studies have found an increase in the number of placements when the primary caretaker is a child of the

patient (Caron, Ducharme, & Griffith, 2006; Spillman & Long, 2009). Cultural factors may also play a role. Stevens, et al (2003 as cited in Caron, Ducharme, & Griffith 2006) found that African American caregivers take twice as long to place their loved ones as Caucasian caregivers. Once the decision to place the patient in a facility is made, the transition to a new caretaking role begins.

Caregivers providing support to a loved one in a facility experience different stressors. Primary sources of burden associated with caring for a loved one in a facility may include family conflict over the decision to place, travel to and from the facility, monitoring the resident's care at the facility, financial stressors, conflict with nursing home staff, and the adoption of new roles (Majerovitz, 2007; Nikzad-Terhune, Anderson, Newcomer, & Gaugler, 2010). Although some studies have found a decrease in burden at nursing home placement, Gaugler et al (2010) found that clinically significant burden persisted for wives and daughters, while husbands were more likely to suffer from clinically significant depression. This could be due to the wives' and daughters' investment in their role as caregivers, which may be a major component of their personal identity. It may be more difficult for them to give up their daily interaction and care of their loved one. Placing their loved one may lead to difficulty managing the transition to new caretaking roles.

Ambiguous loss. The stress of losing their historical relationship with their loved ones can cause ambiguous or anticipatory grief. This type of grief is a "complex concept that encompasses grief in anticipation of a future loss of a loved one, in addition to previously experienced and current losses as a result of the terminal illness" (Holley & Mast, 2009, p. 388). Caregivers are processing the decline in both the physical and

cognitive wellbeing of their loved ones as well as taking on an increasingly difficult caregiving role. Their worries about the future, loss of personal freedoms, changes in roles and the loss of the person they once knew along with the reduction in intimacy and the loss of the ability to have meaningful conversations may cause ambiguity about their relationships (Holley & Mast, 2009; Boss, 2006). Caring for a person who is physically present yet psychologically absent troubles even resilient caregivers (Boss, 2006). Identifying ambiguous grief, and providing support to caregivers who are experiencing it, may be one way to reduce the burden of caring for their loved one and minimizing the feelings of isolation and distress that may lead to depression.

In a study of 87 dementia caregivers, 42 spouses and 45 adult child caregivers, it was found that spouse caregivers and adult child caregivers experienced the anticipatory grief process in different manners (Meuser & Marwit, 2001). Spouse caregivers appear to initially be more accepting of the illness with a feeling of sadness and a focus on the care recipient. As the disease progresses towards the middle stages the spouses feelings may shift towards anger and frustration. In the final stages, nursing home placements sometimes bring a sense of relief but also the realization that they are “uncoupled”. For adult child caregivers, they start out in what Meuser and Marwit (2001) call the approach-avoidance conflict. The adult child caregiver tends to seek information in order to make concrete decisions while at the same time minimizing the inevitable difficulties of the future. The adult child caregiver may focus on their own losses of personal freedom and familial support. In the middle stages the adult child caregiver is no longer able to deny the disease and now may be overwhelmed by emotion. In the final stages, often at nursing home placement, there is a sense of emotional relief and their feelings change from

focusing on themselves to focusing on their loved one. They may “mellow and become reflective and philosophical” (Meuser & Marwit, 2001, p. 669).

Depression. Grief and depression have both been associated with the stress of caregiving. Research has found that there is a strong correlation between family caregiving and depression in the carer (Robinson et al, 2001; Papastavrou et al, 2007; Berger et al, 2005). Robinson et al. (2001) found that caregiver depression is positively related to the number and severity of patient behaviors, negative social supports, and financial concerns. The quality of past relationships was also a factor. The primary stressors that appear to be linked with depression in caregivers are: increased restrictions on caregiver activities, role strain, and aggressive behaviors. Previous research seemed to identify a link between female caregivers and a higher incidence of depression but current research appears to indicate that this could be due to the higher levels of informal support male caregivers receive from outside of the dyad (Robinson et al, 2001; Papastavrou et al, 2007). This increase in informal support may reduce caregiver burden and in conjunction reduce their susceptibility to depression.

In a study conducted in Australia, researchers found that FTD caregivers scored significantly higher on stress and depression scales than AD caregivers (Moishi, Bristow, Cook, & Hodges, 2009). Research has found that chronic stress, such as the burden experienced by caregivers, may be linked to depression. Greenberg (2009), discusses how the long term physiological effects of stress affect both the mind and the body, and often lead to depression, anxiety, hypertension, Rheumatoid arthritis, and possibly cancer. Dementia is a progressive, long term, chronic illness in which the duties of caregivers

continue to expand over time. In 30% - 40% of cases this may lead to depression in family caregivers (National Family Caregivers Association, 2010).

Education and Social Support

The informal style of family caregiving leads carers into territory they may not be equipped to handle. Unlike medical professionals, family caregivers may not have the knowledge and skills to manage a chronic illness. Education in the form of psychoeducational interventions and various types of social supports have been shown to reduce caregiver burden, decrease episodes of depression, and increase positive perceptions of caregiving (Andren & Elmstahl, 2008; Holley & Mast, 2009; Robinson et al, 2001). In a study of 308 family caregivers, 153 received a psychosocial intervention composed of general education with group discussion, strategies for mobilizing assistance, reducing social isolation, and coping methods (Andren & Elmstahl, 2008). The remaining 155 participants did not receive the intervention and were considered a control group. This research, which used the the Caregiver Burden Scale and the Carers' Assessment of Satisfaction Index, found that spouses, in particular, showed a significant decrease in strain. This reduction remained even at the one year follow up.

In other research, Ostwald et al (1999) found in a 3 year randomized study that pairing interventions, for example social support and education about disease processes and possible symptoms or behaviors, appears to be more successful in alleviating caregiver burden and depression. Their study used repeated 3 year Analysis of Variance (ANOVA) results to test for significant differences between family caregivers in the Minneapolis/St. Paul, MN metropolitan area who received seven weekly, 2 hour multi-media training sessions and a waiting list control group. This study found a significant decrease in

caregiver burden on the Zarit Burden Inventory. They also identified a reduction in caregivers negative reactions both during the intervention and at follow up. Learning techniques that are designed to prevent specific behaviors, such as redirecting or validating, have also been shown to decrease caregiver stress (Alzheimer's Association, 2011). Social workers are ideally positioned to offer the multi-prong psychoeducational and social support method of interventions. Clinics who serve the dementia population often offer support groups and these groups could encompass both an educational and support component.

Research Questions

Does the specific diagnosis of Alzheimer's disease (AD), Dementia with Lewy Bodies (DLB), or Frontotemporal Dementia (FTD) impact the level of caregiver burden? While the end results of each disease are cognitive impairment, the symptoms and behaviors associated with each specific diagnosis can be very different. These differences may influence the perceived level of burden placed upon caregivers. The purpose of this research is to better understand these effects as they relate to different dementia diagnoses in order to discover appropriate supports and interventions. This will be accomplished through the use of the Zarit Burden Interview (ZBI) and a survey which includes open ended questions.

The secondary research question aims to discover if stage of the disease impacts the level of caregiver burden. Different stages of dementia present with a variety of symptoms and behaviors which may cause elevated caregiver burden. The purpose of this research is to better understand these effects as they relate to stage of dementia in order to discover

appropriate supports and interventions. This will be accomplished through the use of the ZBI, as discussed in the primary question, and the Allen Cognitive Level (ACL).

Conceptual Framework

Role Theory

According to Garvin (1991), Role Theory “seeks to explain behavior-environment interaction by examining how the social environment creates roles” (p. 151) A role is a social construct that defines the way a person acts in any given position. These roles can be understood as an interaction between the person and their environment. Much of the information on Role Theory refers to an individual's career (Garvin, 1991; Greenberg, 2009; Berger, 2005). Although a career generally refers to someone in the workforce, the theory seems uniquely able to adjust to a variety of roles, including that of caregiver. In the case of dementia caregivers, boundaries regarding roles may be blurred or changed as the disease progresses. A variety of challenges may arise when role problems occur.

As discussed previously, role ambiguity, role discontinuity or insufficiency, and role captivity may increase the burden of caregiving. Role overload, the demands from numerous roles, may mentally and/or physically exhaust some individuals but may also create a buffering effect for others. As Nordenmark (2004) found in his study of 9,000 randomly selected Swedes, quality of roles is an important factor in the buffering effect. For the dementia caregiver, identifying ways to improve the quality of their many roles could establish a safeguard against caregiver burden.

Family Systems Theory

Family Systems theory grew out of the General Systems theory which originated in the 1960's (Greene, 1991; International Encyclopedia of Marriage and Family, 2003).

General Systems theory is a “set of assumptions or rules which can be applied to many fields of study to understand systemic change” (Greene, 1991, p. 227). Systems theory was instrumental in moving social work from a purely medical model to a holistic framework for understanding behavior. Family Systems theory studies the organizational framework of a family in order to identify existing patterns.

Family Systems theory compels us to look at the family as a whole. Relationships within the family are based on “mutual caring and reciprocal exchanges” of support and affection (Aneshensel et al, 1993). These relationships within each family, and their sub-systems, are unique in regard to their rules, humor, and communication methods (International Encyclopedia of Marriage and Family, 2003). Anything that changes one member influences the behavior of all the members. Identifying how they arrange themselves to manage tasks and take on challenges as a whole provides insight into their family structure. There are several concepts imbedded in Family Systems theory which will be discussed: hierarchies, boundaries, equilibrium, and feedback loops.

Hierarchies refer to the “sub-systems” such as couple, parent, or siblings which inhabit the family system (International Encyclopedia of Marriage and Family, 2003). The sub-systems correspond to various daily tasks and responsibilities of each group. When responsibilities that are normally undertaken by one sub-system, for example the father, have to be completed by another family member difficulties may emerge. If the father has always provided financial management for the family and his spouse has not been involved in the process it may be difficult for the spouse to take on these responsibilities.

Boundaries are closely related to hierarchies (International Encyclopedia of Marriage and Family, 2003). Boundaries are found between the family and the outside

world, but also between the various sub-systems of the family. Rules are in place that indicate who may or may not be allowed to cross into the family boundary. Rules also function as an unspoken guide for information access and topics open for discussion. Hooyman and Kramer (2006), discuss the impact of loss, such as the diagnosis of dementia, on Family Systems. They state that loss can be a “normative transition” or create “immediate distress and long term problems” (p. 82) depending on the family’s level of functioning. The family’s unspoken rules which allow or deny discussion regarding the loss are in place to protect them in times of trouble.

Equilibrium refers to a family’s desire to have a sense of balance (International Encyclopedia of Marriage and Family, 2003). Families are constantly changing and adapting. The ability to provide resources to meet challenges is an important part of the family dynamic. When a family member is diagnosed with dementia, their equilibrium may be threatened. The relationships between caregiver and care recipient will eventually change from one of mutual support and affection to a more unilateral relationship (Aneshensel et al, 1993). As the disease progresses, the dementia patient will lose the ability to offer social exchanges such as affection and support. Patterns of positive or negative behavior within the family system may be magnified and resources, such as social supports, may be perceived as scarce.

Feedback loops within Family Systems Theory are patterns of family behaviors (International Encyclopedia of Marriage and Family, 2003). Negative feedback loops maintain stability and dependability within the family. Positive feedback loops promote change, either positive or negative within the family system. When a family member is diagnosed with dementia, the negative feedback loops attempt to provide stability to the

family and to help them maintain the status quo. Expectations may remain that the patient will still be available for his routine matters and will still respond as usual. At the same time, positive feedback loops are initiating due to the fact that the patient will change. His or her ability to function as they did before the dementia will be compromised. Behaviors and communications of family members will need to adjust to the new feedback loop for a negative loop to reform. As dementia is a progressive illness, creating new positive feedback loops may be a continual process that the family needs to accept.

Methods

Research Design

The research design for this study consisted of a mixed methodology including a one-time quantitative survey and a qualitative questionnaire. The quantitative survey included 22 questions in which the respondent is asked to make a selection from a Likert scale. The qualitative questionnaire was comprised of open-ended questions designed to allow the caregiver to expand on their experience as a caregiver and to assist the researcher in understanding their experience and identifying appropriate social work supports and interventions.

Sample

Participants included informal family caregivers who provide care for persons with AD, DLB, or FTD. Potential respondents in the Minneapolis/St. Paul, MN metropolitan area were identified through their use of a specialty memory loss clinic. Non-probability, convenience sampling was used to access the potential candidates. Eligibility for inclusion in this study required that the respondent be a family member or loved one of an adult with dementia.

The agency provided the names and addresses of memory loss caregivers who were qualified to participate in this study. The researcher mailed a copy of the research packet including a pre-addressed, stamped return envelope to each prospective participant. The United States Postal Service (USPS) was selected as the delivery method for this survey in order to reach participants who, due to age or other factors, may not be familiar with technology, and therefore would be unlikely to participate in online data collection. It was the goal of this researcher to use the least restrictive method of data collection for the participants in order to make this survey available to all members of the caregiving population.

Protection of Human Subjects

This research study was approved by the University of St. Thomas Institutional Review Board (IRB) and the HealthEast IRB prior to data collection. Participants were assured that participation in this study was completely voluntary and that neither the staff at the clinic, support group leaders, nor this researcher were aware of their participation status. A Letter of Informed Consent was provided with each survey packet so that candidates were fully informed on the scope of their participation before beginning the survey. Along with the Letter of Informed Consent, prospective participants were advised that information from the study could be shared with the clinic but all results shared would be de-identified. Additionally, participants in the study were specifically informed that participating would have no bearing on their relationship with the clinic or the support group. Their responses were mailed directly to the home of the researcher, kept in a locked cabinet and on a password protected computer. By June 1, 2012 all completed surveys will be destroyed. There were no direct benefits to participating in this study.

Although participants in this research were not considered vulnerable, their status as a caregiver could cause them to be considered more vulnerable than the general population. If the caregiver did feel worried or upset, there was a list of resources available in the Minneapolis/St. Paul metropolitan area with options for respite care and caregiver counseling included in the research packet.

Data Collection Instrument and Process

The quantitative portion of this research used the Zarit Burden Interview (ZBI), a caregiver self-report measure. This instrument is a shortened version of the original 29 question scale which was developed by Zarit, Reever, and Bach-Peterson in 1980 (APA, 2011). It has been used in different formats since that time, including the 22 question version that was used in this study. The ZBI is a 22 question survey which uses a five point Likert scale with zero meaning “never” and four being “nearly always”. Caregiver scores on the ZBI range from 0 to 88 with lower scores indicating little or no burden and higher scores showing increased levels of burden. The ZBI has been found to have good internal reliability and validity across a variety of populations (APA, 2011). The ZBI addresses personal strain as well as role strain.

The qualitative portion of this research was made up of open ended questions designed to allow the caregivers to expand on their experience as caregivers and to assist the researcher in understanding their experiences and identifying appropriate social work supports and interventions.

Another component of the research packet was the demographic information relating to age of the caregiver, age of the recipient, relationship to the recipient, specific

dementia diagnosis, stage of disease, income, and race. Information on the frequency and type of respite care accessed was also requested.

Data Analysis

The data was analyzed using Minitab 15 data analysis software. Descriptive statistics were used to identify demographic characteristics of the respondents and to identify any possible sub-groups. Inferential statistics, such as a Chi Square, scatterplot and an Analysis of Variance (ANOVA), were applied to compare and contrast responses obtained from the ZBI with the demographic information.

The open ended questions were analyzed using content analysis. According to Berg (2009), content analysis is the “careful, detailed, systematic examination and interpretation of a particular body of material in an effort to identify patterns, themes, biases, and meanings” (p. 338). The researcher identified themes based on specific “criteria of selection” which were determined before the data was analyzed. After the first review, identified themes were compared across the population and collated to discover commonalities. Properly creating and consistently maintaining criteria of selection improves the reliability and validity of the findings.

Sample and Methods

Participants included informal family caregivers who provide care for persons with AD, DLB, or FTD. Respondents in the Minneapolis/St. Paul, MN metropolitan area were identified through their use of a specialty memory loss clinic. Non-probability, convenience sampling was used to access the potential candidates. Eligibility for inclusion in this study required that the respondent be a family member or loved one of an adult with dementia.

The agency provided the names and addresses of memory loss caregivers, along with the diagnosis and Allen Cognitive Level (ACL) of the patient. It was determined that to accurately define the stage of the disease a standard measurement was necessary. The ACL is a diagnostic tool used to measure the “functional cognition” of a person (Allen, et al., 2009). Results include information on the patient’s ability to function in several areas including: living alone in the community, transportation (the ability to drive), medication management, nutrition and cooking, money management and safety. The ACL was developed in order to assess adults with psychiatric disorders or dementia and is one measure of global cognitive processing capacity. As the participating clinic regularly uses the ACL as one of their diagnostic tools, it was selected as the standard measure of dementia staging for this project. The researcher coded each survey with the diagnosis code and the ACL score of the patient before they were mailed to potential respondents. In cases where the survey was returned with a diagnosis or ACL score that differed from the code, the information from the medical record was used. The research packets, including a pre-addressed, stamped return envelope, were then mailed to the prospective participants. A total of 162 research packets were mailed.

Results

The purpose of this research was to better understand the effects of caregiver burden as they relate to different dementia diagnoses and stage of the disease in order to discover appropriate supports and interventions. The findings below provide a snapshot of the caregiver burden experienced by the caregivers who responded to this survey.

Demographics of Respondents

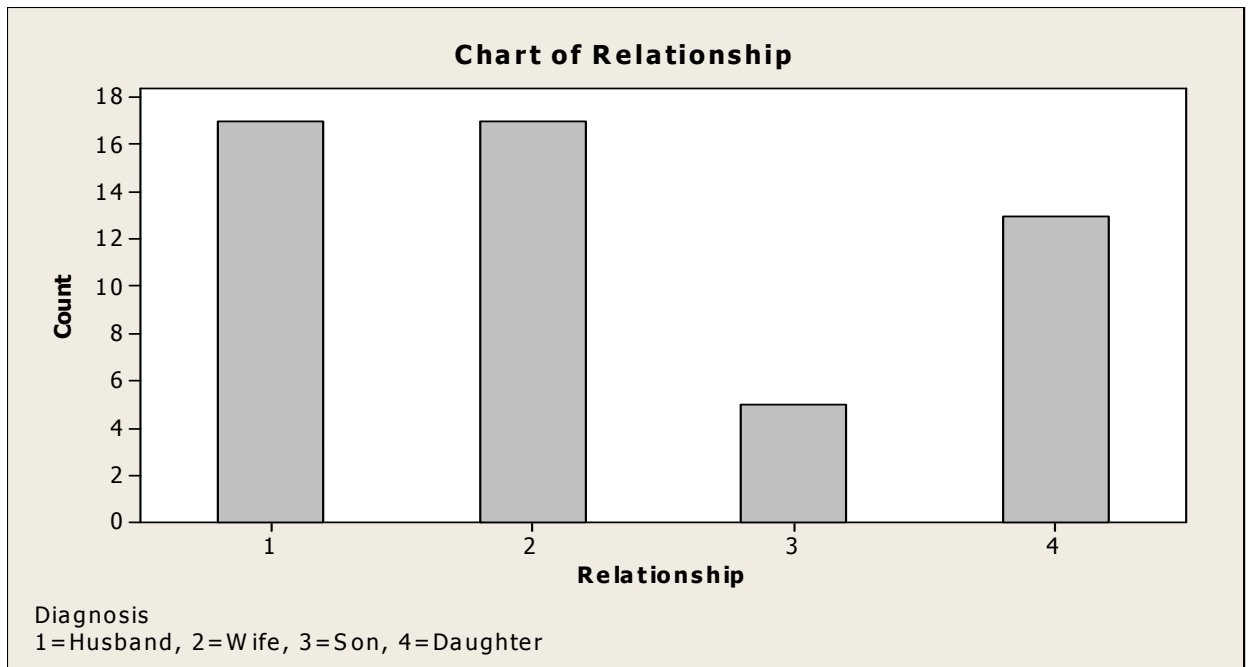


Figure 1 Relationship of Caregiver to Person with Dementia

A total of 52 caregivers completed the survey packet and returned it to the researcher. The respondents include 23 men and 30 women who are the primary caregiver of a loved one with dementia. In this research, most of the respondents were caregivers to spouses. Thirty four of the respondents are married to the patient, 13 are a daughter and 5 are a son of the patient. The researcher did not receive any surveys in which the caregiver was unrelated to the patient. The caregivers included 32 carers of AD patients, 15 of DLB and 5 of FTD.

Caregiver Burden and Dementia Diagnosis

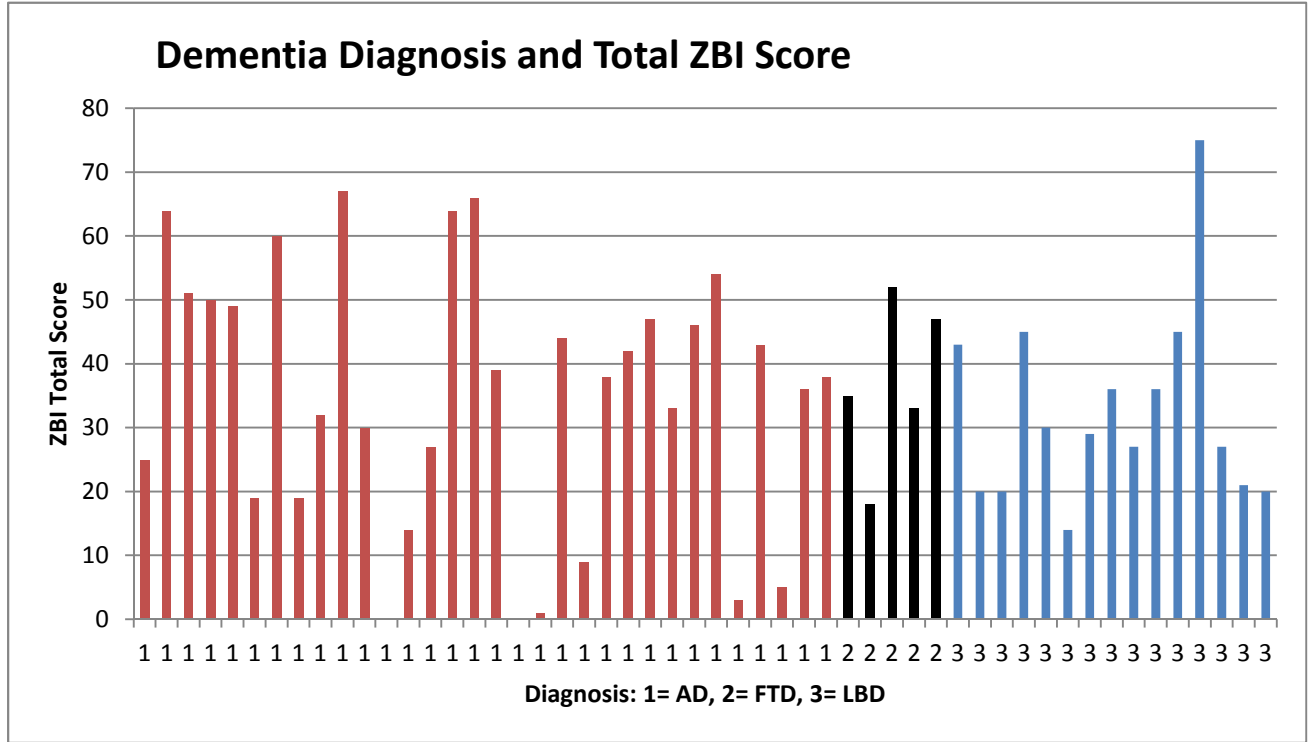


Figure 2 Dementia Diagnosis Compared with Total ZBI Score

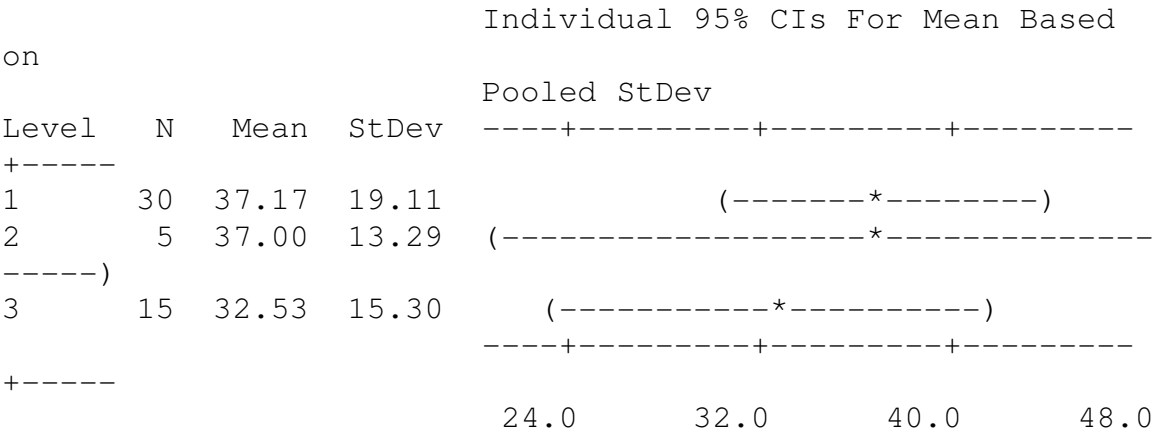
In response to the primary research question, does the specific diagnosis of Alzheimer’s disease (AD), Dementia with Lewy Bodies (DLB), or Frontotemporal Dementia (FTD) impact the level of caregiver burden, the mean values for the ZBI score for the diagnosis were calculated. The diagnosis responses were categorized by numeric code in order to perform statistical analysis. AD was assigned number 1. FTD was assigned number 2, and DLB was assigned number 3. The mean for AD was 37.17, for FTD it was 37.00, and for DLB it was 32.53. In order to determine whether or not there was a statistical difference between the three mean values, an ANOVA test was performed.

Table 1 Caregiver Burden Score and Dementia Diagnosis
1= AD, 2=FTD, 3=DLB

One-way ANOVA:

Source	DF	SS	MS	F	P
DX	2	223	112	0.36	0.700
Error	47	14576	310		
Total	49	14799			

S = 17.61 R-Sq = 1.51% R-Sq(adj) = 0.00%



Pooled StDev = 17.61

The p-value was calculated to be 0.700, which indicated no significant difference among mean scores of burden for the three types of dementia. Although there was no statistical difference, AD caregivers with a mean total ZBI score of 37.17 and FTD caregivers with a mean total ZBI score of 37.00, scored five points higher on the burden scale than DLB caregivers who had a mean total ZBI of 32.53. The range of scores for DLB caregivers, from 14 to 75 is quite large. More knowledge is needed in this area to determine if AD and FTD caregivers suffer higher levels of caregiver burden than DLB caregivers or if that finding is unique to this study.

Caregiver Burden and ACL

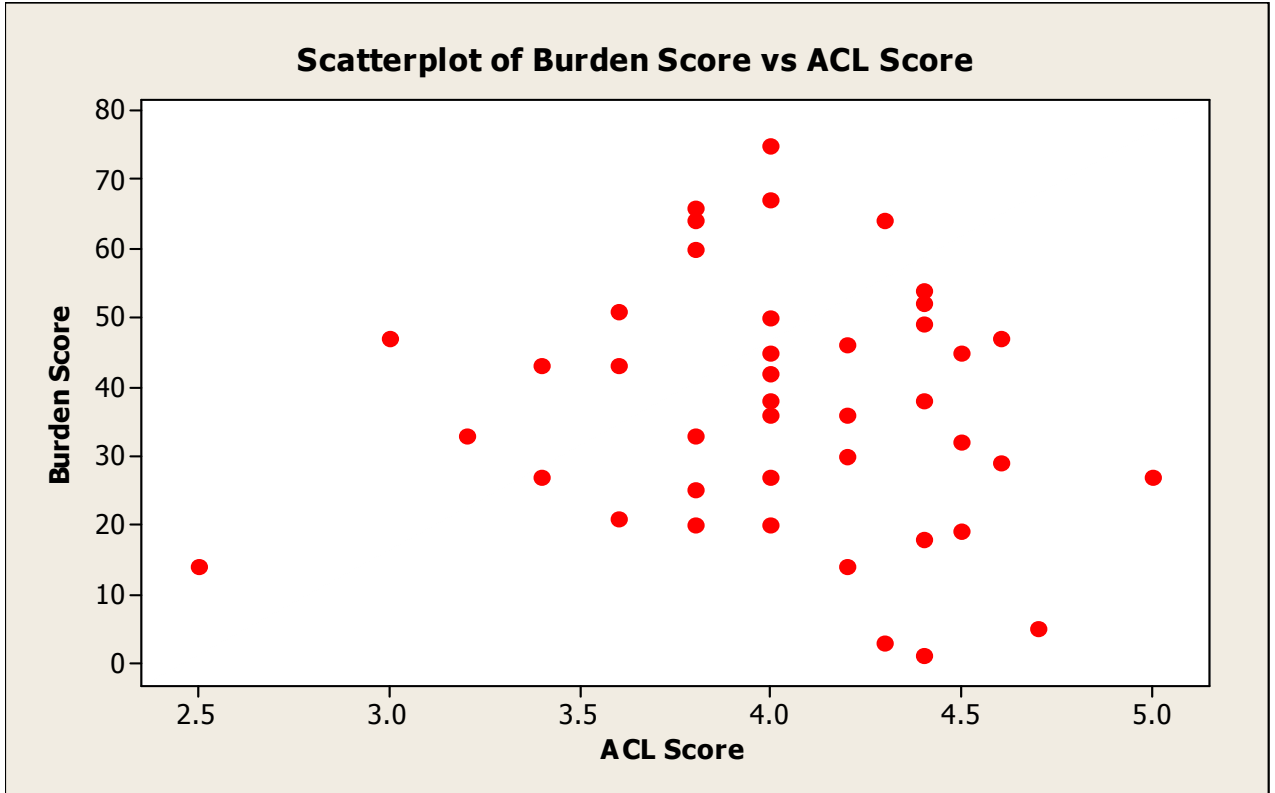


Figure 3 Caregiver Burden Score compared with ACL Score

The secondary research question aimed to discover if stage of the disease impacts the level of caregiver burden. The mean values for the total ZBI score were compared to the ACL score of the patient. The caregivers in this study cared for dementia patients with a wide range of ACL scores. The ACL scores range from 2.5 to 5.0. The mean ZBI total scores were calculated for each ACL score. The scatterplot in figure 3 shows a Bell Curve with lower ZBI scores early in the disease process and then again later in the process. Mid-range ACL scores, 3.5-4.5, appear to be associated with an increase in caregiver burden.

responsibilities the caregiver was undertaking at this time. At the ACL 4.0, cognitive functioning and performance abilities are diminished to the degree that it is recommended that the patient have 24 hour supervision, no longer drive, and have assistance with medication management, finances, and identifying safety hazards (Allen, et al, 2009). The dementia patient may still be functioning well socially and their verbal skills may lead the caregiver to underestimate the level of impairment. This could lead to frustration on the part of the caregiver when the care recipient agrees to complete tasks and then is unable to adequately perform them. At the ACL 3.8 the care recipient requires 24 hour on site supervision. He or she will need assistance with medication management, nutrition, hygiene, and identifying safety hazards. The caregiver will need to allow extra time for all activities and may need to prompt the dementia patient and give cues as the dementia patient may not “ask for help or even recognize the need for it” (Allen, et al, 2009).

Place of Residence and Total Zarit Burden Interview Score

Respondents in this study include 30 in-home caregivers and 22 caregivers of a loved one who resides in a facility. The in-home group contains 18 caregivers providing care for a loved one with AD, 8 with DLB, and 4 with FTD. The facility placement group contains 14 who are providing care for a loved one with AD, 7 with DLB, and 1 with FTD. For the purpose of this study, patients residing in a nursing home or a memory care facility are considered as an out of home placement.

Table 3 Total ZBI Score compared with Residence
1=in home, 2= facility placement

Two-Sample T-Test and CI: ZBI Total, residence

Two-sample T for ZBI Total

residence	N	Mean	StDev	SE Mean
1	30	35.0	16.1	2.9
2	18	38.9	18.6	4.4

Difference = mu (1) - mu (2)
 Estimate for difference: -3.94
 95% CI for difference: (-14.71, 6.82)
 T-Test of difference = 0 (vs not =): T-Value = -0.75
 P-Value = 0.460 DF = 31

In order to compare the total ZBI scores of in-home and out-of-home caregivers, a t-test was calculated. The p-value of the t-test was 0.460 indicating there is not a statistical difference between burden scores for in-home caregivers and caregivers of a loved one in a facility. The in-home caregivers had a mean total ZBI score of 35 and the facility based caregivers had a mean total ZBI of 38.9. These scores are on the high end of the mild to moderate category of the ZBI, which implies a moderate level of burden for both subsets of caregivers. Some specific causes of the high level of stress for out of home caregivers were found in the qualitative questionnaire:

“I feel guilty for not visiting as much (since nursing home placement) which is stressful. I wrestle for days until I get up the courage to see her again”

“I get calls from the home that they are having problems handling her”

“Visiting spouse and then leaving – it makes for much sadness”

“Visits when my wife is not responsive”

“I think of my mom’s decline and wonder if she will be able to stay in her facility due to the cost”

“Micromanaging staff, correcting them”

“Having no one ‘need’ me”

“Not being able to care for him myself. I’ve had a stroke and have limited walking ability.”

The causes of burden for caregivers of loved ones in a facility appear to be diverse and vary by the individual. They seem to include guilt, patient behaviors, financial resources, conflict with staff, and role changes.

Relationship and Total Zarit Burden Interview Score

The relationship of the caregiver and the mean total ZBI scores were analyzed using an ANOVA. The relationships were assigned a numeric code in order to process the statistical analysis. The relationships were coded as: 1= husband, 2=wife, 3=son, 4=daughter. According to the calculated data, daughters caring for a parent appear to have the highest level of burden, with an average score of 43.33 on the ZBI. This score is indicative of moderate to severe burden on the caregiver. Sons, with a mean score of 36, fall into the mild to moderate burden category.

Husbands and wives both scored an average ZBI of 33.06 which is considered mild to moderate burden. Although the relationship and burden scores show no significant difference, it is remarkable to note that the means of the husband and wife caregiver category total ZBI scores are exactly the same. Because they are exactly the same, there is

no statistical difference between them. This indicates that husbands and wives in this study experience an equal amount of burden.

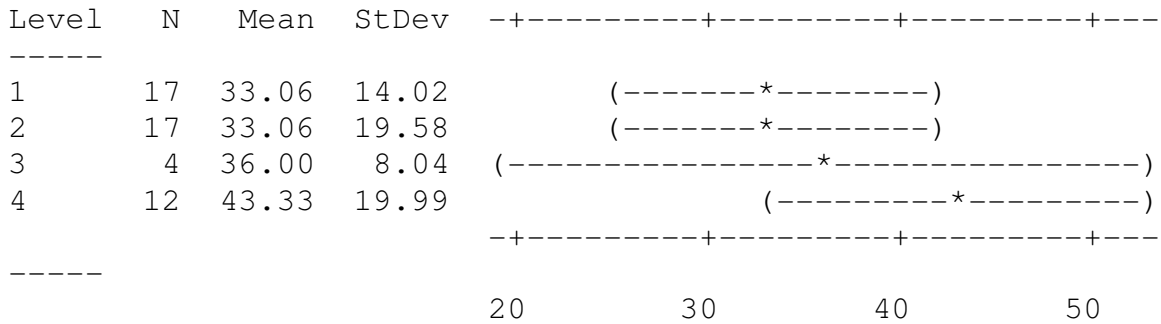
Table 4 Total ZBI Score and the Caregivers Relationship to the Care Recipient
1=Husband, 2=Wife, 3=Son, 4=Daughter

One-way ANOVA:

Source	DF	SS	MS	F	P
Relationship	3	937	312	1.04	0.386
Error	46	13863	301		
Total	49	14799			

S = 17.36 R-Sq = 6.33% R-Sq(adj) = 0.22%

Individual 95% CIs For Mean Based on Pooled StDev



Pooled StDev = 17.36

Support Groups and Adult Day Centers

Psychoeducational interventions and various types of social supports have been shown to reduce caregiver burden, decrease episodes of depression, and increase positive perceptions of caregiving. Support groups often provide social support, encouragement and psychoeducational training which may help normalize experiences and help caregivers feel more confidence and satisfaction. Adult day programs offer structure and social interactions for the patient which may decrease problematic dementia behaviors. Problematic dementia behaviors have been shown to increase caregiver distress. Adult day programs also provide much needed respite for the caregiver.

Table 5 Support Group Attendance and Adult Day Usage
Support Group 1=Yes, 2=No: Adult Day 1=Yes, 2=No

Rows: Support Group		Columns: Adult Day		
	1	2	All	
1	6	9	15	
	40.00	60.00	100.00	
	66.67	20.93	28.85	
	11.54	17.31	28.85	
2	3	34	37	
	8.11	91.89	100.00	
	33.33	79.07	71.15	
	5.77	65.38	71.15	
All	9	43	52	
	17.31	82.69	100.00	
	100.00	100.00	100.00	
	17.31	82.69	100.00	

Cell Contents: Count
 % of Row
 % of Column
 % of Total

Pearson Chi-Square = 7.585, DF = 1, P-value = 0.006
 Likelihood Ratio Chi-Square = 6.902, DF = 1, P-value = 0.009

* NOTE * 1 cells with expected counts less than 5

The use of support groups by dementia care providers was directly associated to their use of adult day programs. Twenty eight percent of respondents report they attend a dementia caregiver support group. While 11.5% of those who attend support groups also use an adult day program, only 5.7% of those who do not attend a support group use adult day programs. The statistical analysis of the Chi Square supports the association between the use of adult day programs and the use of support groups by the same respondents. The

p-value of .006 indicates a significant correlation between attending a support group and the use of adult day programs.

Qualitative comments underscored that although only nine respondents in the survey used adult day services, many others would like to use this service if it was more accessible. Responses from the open ended questions indicate that caregivers would like to use adult day programs but either lack financial resources, feel that choices in this area are, in the words of one respondent, “*quite limited,*” or have found that the adult day centers are not equipped to handle patients with behaviors related to dementia. One respondent stated he has tried three different adult day centers and they “*could not or would not deal with her agitation, wandering and attempts to leave*” and another stated they wished there was an adult day “*designed to handle my wife’s behaviors.*”

Another barrier to the use of adult day programs is resistance on the part of the patient. Some caregivers would like the respite provided by adult day but are reluctant to force a resistant loved one into participating. Respondents from the survey wrote:

“I use daycare once a week, if he will go”

“I would like to use adult day services and some of the resources of our neighborhood, but my husband is unwilling to participate.”

“We tried it once and he won’t go, the others were worse off than him.”

These comments signal an awareness of adult day programs and the caregiver’s desire for respite but also suggest various barriers to care including financial resources, lack of appropriate programming and resistance by the care recipient.

Kinds of Help Respondents Need

In response to the question “What kind of help do you feel you need that is not available to you?” many of the respondents indicated they were in need of emotional supports. 28% of participants explicitly stated they suffered from a lack of support as established from the following quotes:

“I need family support from 3 siblings and 1 wife.”

“The constant loneliness and feeling left out, alone. Social life non-existent, very lonesome.”

“I need someone else to help me. I am tired constantly...managing poorly.”

“More concern for my feelings from people.”

“Someone to talk to.”

“Need a 24/7 Angel that talks back to me”

The theme of needing additional support was easily identified due to the number of respondents who felt it was unavailable. This need was universal and spanned all diagnoses, relationship types and living environments.

Stress

From the perspective of the caregiver, the chronic stress and fatigue of providing care to a loved one with dementia is evident by the following statements:

“I only actually care for my mother for 18 hours a week. The rest is paid caregivers. But she is rarely not in my mind. I don’t know how others who are constant caregivers survive”

“Need more stress control help”

“Coping with all the duties with no days off”

“Overwhelmed at times”

“the helpless feeling that there is not too much I can do”

“Juggling work and personal time presents challenges”

“Handle all finances, medication management, advocate for services, problem solver. Too stressed, emotional/mental burden”

“Simply being constantly aware of this situation is a source of stress for me”

“It gets progressively more difficult...never having a moment to yourself, care recipient following you from room to room”

“I feel I have to be 1-2 or 5 steps ahead in planning”

The respondents presented a variety of causes of caregiver stress including coping with caregiving duties, lack of time for respite, juggling responsibilities, guilt, and constant awareness of their caregiving responsibilities. These stressors are fluid and may change over the course of the disease. The variety of responses indicates that stress may continue indefinitely. Since research has shown that chronic exposure to the stress of caregiving may lead to severe physical and mental health issues it is important to identify the specific causes of stress and solutions to those stressors.

Role Reversals

As stated earlier, research has shown that role reversal may be a major component of caregiver burden. Respondents in this project expressed these changes in the following ways:

“I’m the mother of my mother now!”

“We’ve both (2 sisters) had to interrupt our careers to manage the crisis caused by both our parents Alzheimer’s”

“Full responsibility for all decisions...with doubts that the decisions are the right ones”

“Confident decision making has been difficult.”

“I’d like to get a house and run my own life but my mother has grown dependent on me”

“Every aspect of her life is now a part of mine. It is like having a special needs child”

“Well, it has been a total role reversal for me. I feel like I am the parent and she is the child now.”

“Our roles have almost 100% flipped.”

“More of a parenting role than a spousal role”

“I have to be coach, safety provider and ‘police’”

Respondents overwhelmingly identified this sense of role reversal in their comments. As the disease of dementia progresses, role changes become more obvious and more extreme. Many of the above respondents indicate they feel the change has moved them from a child or spouse role into that of the parent. This may be difficult due

to a sense of losing respect for their loved one and a reluctance to accept that the care recipient is unable to complete familiar tasks. It may also be stressful as a result of the changes in emotional closeness and reciprocity in relationships. As symptoms of the disease progress, the personality of the patient may change, inhibiting the intimacy and reciprocity of past relationships.

Challenges and Stressful Aspects of the Day

The most challenging/stressful aspect of the day for the majority of the caregivers in this study is first thing in the morning when their loved one needs help with Activities of Daily Living (ADL) to get ready for the day, and in the evening when they are tired and preparing for bed. 29 participants, or 55% of respondents, found that morning and evening were the most difficult.

“Bath time and hygiene are the biggest challenges.”

“Evenings and mornings – there seems to be more confusion at these times.”

“It is stressful to get her up, dressed, fed and ready to go...bedtime is the most stressful.”

“Mornings and late evenings after dinner.”

“Most challenging, bathing, convincing her to get out of bed, taking medications and assisting with using the toilet.”

“Dealing with combativeness. Bathing and shaving. Afternoons – he starts to forget who I am and wants to leave.”

These comments emphasize the challenges faced by caregivers during the morning and evening hours. As dementia progresses, the amount of care needed by the patient may increase. The addition of ADL's, a more physical level of assistance, may be perceived as

a more stressful form of care. The volume of caregiving needed first thing in the morning and right before bed may also be a factor. ‘Sundowning’, problematic dementia behaviors and a sense of confusion that often occur in dementia patients late in the day, may also create a more stressful caregiving situation.

Discussion

In 2010, there were nearly 15 million family caregivers providing support to a family member with dementia (Alzheimer's Association, 2011). Research shows that there are a multitude of stressors related to the role of caregiving. The purpose of this research was to better understand these effects as they relate to different dementia diagnoses, and stages of the disease process, in order to discover appropriate supports and interventions.

In response to the primary research question, does the specific diagnosis of Alzheimer’s disease (AD), Dementia with Lewy Bodies (DLB), or Frontotemporal Dementia (FTD) impact the level of caregiver burden the ANOVA showed no statistical difference between the different diagnoses. While the overall caregiver burden means of all diagnoses ranged from 32.53 – 37.17, the p-value of 0.7 indicated there was not a statistically significant difference between the levels of burden. According to the ZBI, all of these means fall within the category of mild to moderate burden. This indicates that, while the burden is not significantly different between the diseases, it is present for caregivers of all diagnoses. Although AD and FTD caregivers have previously been compared in a study conducted by Vugt et al (2006), no research was found comparing all three diagnoses. Most research has focused on caregivers as a group without identifying diagnosis. Future research into the particular stresses of each disorder could be helpful in identifying appropriate social work supports and interventions.

In this study, a wide range of caregiver burden scores fell within the FTD diagnosis with total ZBI scores ranging from 18, little or no burden, to 52, moderate to severe burden. It is interesting to note that all of the respondents who cared for a loved one with FTD and participated in this survey were husbands who cared for a wife with FTD. These couples had been married a minimum of 38 years and the ages of the patients ranged from 62-79 years. FTD is often diagnosed in the mid-fifties to early sixties and may often be mistaken as a psychiatric disorder due to the initial symptoms of changes in personality and disinhibition (Yeaworth & Burke, 2000). The wide range of scores found in this research may suggest that there is a variance in the number and severity of the psychiatric symptoms suffered by each individual patient. Research conducted by Vugt et al (2006) found that FTD caregivers have an overall higher level of distress in the areas of caregiver burden associated with psychiatric behaviors than caregivers of AD patients. It is possible that the variation in psychiatric symptoms has in some way influenced the wide range of scores in this study. Since FTD is thought to occur equally in both men and women, and often has a younger age of onset, the sample from this population may not be representative of the FTD caregiver population as a whole.

The secondary research question aimed to discover if stage of the disease impacted the level of caregiver burden. Stage of the disease was identified in this study by the ACL score of the patient. The majority of the respondents, 31 out of the 53 respondents, had an ACL of 3.8 - 4.4. The mean total ZBI score for all categories was 35.76 and the mean ACL score was 4.025. The p-value for the calculated ANOVA was 0.842, indicating there was no statistical difference in the mean total ZBI scores and the ACL of the patient. The total ZBI scores appear to peak with ACL scores of 3.8-4.0. This peak correlates with the

overall increase in burden between an ACL of 3.5-4.5 that is seen in figure 3. The increase in burden seen at the moderate ACL levels could be due to the added responsibilities the caregiver is undertaking at this time or possibly to the severity of the dementia and the symptomology that is occurring at this stage of the disease. Research has shown that psychiatric and behavioral symptoms may cause an increase in caregiver burden (Bhat & Rockwood, 2011; Leggett et al, 2010). It is possible that patients in the middle stages of dementia exhibit more psychiatric and behavioral symptoms which correlate with the increase in burden shown here. It is important to note that, despite the lack of statistical significance between the ACL scores and level of caregiver burden in this study, trends of higher burden in the moderate ACL ranges indicate the need for further research into this area.

An item of interest in this study is the difference, or lack thereof, in burden levels when they are compared by relationship. According to the calculated data, daughters caring for a parent appear to have the highest level of burden, with an average score of 43.33 on the ZBI. This score is indicative of moderate to severe burden on the caregiver. Caregivers, particularly adult children, may feel they are gradually losing their sense of self and being overcome by the role of caregiver. Role captivity may increase feelings of powerlessness which increases the perception of burden (Aneshensel, Pearlin, & Schuler, 1993). It is unclear whether the daughters in this study suffer from a feeling of role captivity. According to Garvin (1991) and Greenberg (2009) role ambiguity, when aspects of a role are unclear, can also amplify the stress burden. Throughout the dementia process, daughters may have suffered more role ambiguity than spouses. Many of the respondents indicated they were now "*the mother of their mother*" or stated "*I'm the*

parent now” which indicates that there may have been a time during the course of the disease when this transition occurred. The transition itself, and the resulting change in relationship could be a major cause of burden.

Another possible explanation for the higher burden level for the caregiving daughters is the possibility that they are part of the “Sandwich Generation”. Bogolea (2012), describes the Sandwich Generation caregiver as a women, usually in her mid-forties, married, employed, and caring for her family and an elderly parent. In this study, the average age of the caregiving daughters was 54.5 years. Although the caregiving daughters in this study are older than the traditional Sandwich Generation caregiver, role overload, or the cumulative demands of numerous roles, could be mentally and physically exhausting the caregiving daughters (Garvin, 1991; Greenberg, 2009; Berger, 2005). This is an area where further study is needed in order to determine why daughters appear to experience greater burden.

Another fascinating aspect of this research is the identical mean burden level of 33.06 between the husband and wife caregivers who responded to this research. A total ZBI score of 33.06 is indicative of mild to moderate burden. There were an equal number of husband and wife respondents, 17 apiece, which may indicate an unusual sample as previous research has indicated there are typically more female caregivers. The caregivers in this sample also had loved ones of varying diagnoses and ACL levels. The number of married years, a mean of 49.82, could also be a factor due to their lengthy relationship. Family Systems theory informs us that relationships within the family are based on “mutual caring and reciprocal exchanges” of support and affection (Aneshensel et al, 1993). These couples had many years of reciprocal exchanges before the dementia

diagnosis and may have built in some relational hardiness during this time which is providing a protective factor for the caregiver. While husbands and wives in this study showed identical levels of burden, further research into the similarities and differences of husband or wife burden is necessary to identify if they experience burden from the same aspects of caregiving or if they encounter different challenges and the overall level of burden is the same due to different facets of caregiving.

Place of residence in this study was not shown to create a difference in levels of caregiver burden. At-home caregivers and those with a loved one in a facility had remarkably similar total ZBI scores. Although their scores are comparable, it is likely that the stressors which create the burden are different. At-home caregivers experience burden from isolation, a lack of emotional closeness, and the dementia symptomology of their loved one including a decline in executive function, behavioral issues, and the need for assistance with ADL's (Holley & Mast, 2009; Majerovitz, 2007). Caregivers of a loved one in a facility may incur burden from other areas which may include family conflict over the decision to place, travel to and from the facility, monitoring the resident's care at the facility, financial stressors, dissatisfaction with nursing home care, conflict with nursing home staff, and the adoption of new roles (Majerovitz, 2007; Nikzad-Terhune, Anderson, Newcomer, & Gaugler, 2010).

Role transitions from at-home caregiver to facility based have been shown to increase levels of burden. Exchanging home based care, which is familiar to the caregiver, with the new tasks associated with the transition to facility living may be stressful. The caregiver will need to learn new tasks, such as interacting with staff and advocating for the type of care they expect for their loved one. Behavioral issues may also continue after

placement and remain a source of stress. Gaugler et al (2010) speculates that care recipients with severe functional or behavioral impairments continue to require high levels of care from the family as they are more difficult for facilities to manage than other dementia patients. In their study, they also found that there may be a misconception within professional and social circles that the need for support is lessened by facility placement when in reality this may be a time of great need for the caregiver. Majerovitz (2007) also found that social support was a key resource in caring for a facility based loved one.

The use of support groups by dementia care providers was directly correlated to their use of adult day programs. The p-value of .006 indicates a significant correlation between attending a support group and the use of adult day. While only nine of the respondents were actively using adult day programs as a form of respite, many others were aware of the programs and were unable to participate for a variety of reasons. The barriers included insufficient financial means, a lack of appropriate programs, and resistance on the part of the patient.

Research has shown that respite care and support systems allow caregivers to provide care longer, identify less stress and greater satisfaction from their caregiving responsibilities (Family Caregiver Alliance, 2012). The benefits of respite care and support groups may be seen in reduced medical costs for the patient and the caregiver, social interaction and structure for the patient and stress reduction for the caregiver. The value of respite care and social supports for the caregiver lie in their ability to reduce caregiver burden and improve the caregiver/care recipient relationship. A lack of respite could lead to health problems for the caregiver and the absence of structured daytime

activity could lead to dementia behaviors in the patient, which may then lead to increased caregiver burden.

The lack of programming for dementia patients who are experiencing problematic dementia behaviors identified by this study has been previously noted. In a study of FTD caregivers, Yeaworth and Burke (2000) found that most adult day centers were designed for AD patients who were older and did not suffer from problematic behaviors. Adult day centers equipped to handle dementia patients with these behaviors appear to be needed in this area. Research has shown that since problematic behaviors and emotional symptoms are unpredictable, difficult to manage, and often unsettling for the caregiver, they are among the most stressful of caregiving burdens (Leggett, et al, 2010; Yeaworth & Burke, 2000). Respite for caregivers of patients who are exhibiting problematic dementia behaviors is an important component of self-care. When caregivers are unable to find respite services, they may burn out from their caregiving responsibilities sooner or have a health crisis themselves.

As the burden of chronic stress may cause 30-40% of caregivers to develop health problems and since research indicates that family caregivers have a 63% higher mortality rate than non caregivers of the same age, it is important for social workers to advocate for change on the macro level (National Family Caregivers Association, 2010). Although congress passed the Lifespan Respite Care Act in 2006 to provide funds to improve the quality and delivery of respite services, the program is woefully underfunded. In 2006 it received funding of \$30 million, but over the past three years only a total of \$2.5 million was allocated towards the Lifespan Respite Care Act (Edwards-Tate, 2012). Fully funding

this program could provide the respite services so desperately needed by the 15 million family caregivers providing support to a family member with dementia.

Twenty-eight percent of respondents in this study also indicate a desire for increased social/emotional support. Research supports the belief that dementia caregivers experience a feeling of isolation (Dementia with Lewy Bodies Association, Inc, 2008), reduced time for self, a decrease in communication with their loved one, and an increase in time spent supervising their loved one (Vugt et al, 2006). On the ZBI 20 respondents in this study, or 38%, scored a 3 (quite frequently) and an additional 15 respondents, or 29% scored a 2 (sometimes) for the question “do you feel that your social life has suffered because you are caring for your relative?” This shows that almost 70% of respondents feel that their social life is sometimes or frequently impacted by their caregiving duties. Further examination of this issue may reveal social work interventions that could help caregivers reconnect with their social support systems, and for those in extreme stress, to connect them with mental health counseling.

The idea of improving social support connections may also be helpful for the constant stress caregivers identify. When asked on the open-ended questions to discuss how their roles have changed and which aspects of caregiving were most challenging, the majority of caregivers volunteered that they were stressed. The mean total ZBI score for all respondents was 35.76. This score is on the higher end of the mild to moderate burden interpretation which ranges from 21-40, indicating that the majority of caregivers experience a moderate level of caregiver burden. The causes of this burden are multiple, but social workers could be instrumental in reducing caregiver burden through psychoeducational training and support groups. By means of caregiver coaching, social

workers could also assist caregivers in identifying sources of social/emotional support, learning stress reduction techniques, and identifying the roles in which they will eventually participate early on in the disease process in order for the caregiver to be comfortable with them later on. Involving the extended family through education could also improve the caregiving experience by decreasing isolation and increasing options for respite.

Strengths and Limitations of this Study

There were a variety of strengths associated with this research. One of the strengths of this research was the high percentage of respondents to the survey. Over a third of those who received a mailed research packet responded with a completed survey. Some of the potential participants who did not complete the survey called the researcher to explain why they would not be taking part in this project. This seems to indicate a willingness on the part of caregivers to share their experiences in order to help social work professionals identify areas in need of support and intervention. This may also indicate that this topic is relevant and important to the caregivers.

Another strength is the historic validity and reliability of the ZBI. Using an established instrument which has been previously vetted lends a degree of confidence to the results of this survey. Also, the dementia diagnosis of the participants sampled was similar to the diagnosis content within the general dementia population.

A total of 52 caregivers completed the survey packet and returned it to the researcher. The respondents include 23 men and 29 women who are the primary caregiver of a loved one with dementia. Limitations of this research included the small homogenous sample. The respondents of the survey were primarily urban, Catholic, and retirement age.

The mean age of caregivers was 68.75 years, which may or may not be similar to the majority of caregivers.

Also, this sample may not be representative of the larger population of caregivers. The patients were all treated in a specialty memory loss clinic which includes access to social work services for all of their patients. The clinic also offers support groups and psycho-educational classes on a regular basis. It is unclear how this access to social work services may affect the level of burden experienced by the caregivers of these patients as compared to patients in a primary care setting. The small sample size also makes it difficult to generalize to the overall population of dementia care providers. A larger, more diverse sample would improve the likelihood of identifying differences in burden based on the patient's diagnosis and stage of disease.

Conclusion

As the population ages and dementia diagnoses become more common, the number of caregivers will increase. The issues facing these caregivers are diverse and may change throughout the course of the disease. Research has identified numerous causes of caregiver burden including: role transitions, isolation, emotional separation, grief or depression, financial concerns, and global changes in the care recipient's personality, behaviors, and executive function. It is critical that we identify services and supports that will reduce caregiver burden and improve the physical and mental health of caregivers.

This research discovered that the majority of caregivers feel a need for additional social supports to reduce isolation and provide respite. Social workers could help fill this void by offering support groups and psychoeducational classes designed for the caregiver and their extended family. Including the extended family may increase their understanding

of dementia and the stressors the primary caregiver is experiencing and encourage them to be more involved in the care of their loved one.

The desire for affordable adult day programs which are equipped to handle patients with behaviors related to their dementia was also identified. Macro level change is needed to provide funding for the Lifespan Respite Care Act of 2006 which was signed to provide enhanced levels of respite and other services for caregivers. Fully funding this Act could offer a wider variety of adult day centers and potentially help defray costs associated with this service.

Role transitions appear to increase caregiver burden throughout the disease progression. The caregiver must gradually assume responsibility for all aspects of their loved ones care. Role reversals were a common theme among participants in this study. May have referred to themselves as taking on a parental role as opposed to their typical role of spouse or child. Role overload may have led to the higher burden levels experienced by the daughter caregivers as they may be part of the sandwich generation and taking on the multiple roles of wife, mother, wage earner, and caregiver. Social workers could be instrumental in improving the quality of the roles and smoothing the transitions between roles by helping the caregiver identify upcoming roles and providing psychoeducational training on the anticipated transitions.

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THE ZARIT BURDEN INTERVIEW

Please circle the response the best describes how you feel.

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

12. Do you feel that your social life has suffered because you are caring for your relative?	0	1	2	3	4
13. Do you feel uncomfortable about having friends over because of your relative?	0	1	2	3	4

Survey continues on the next page.

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

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Interpretation of Score:

0 – 21 little or no burden

21 – 40 mild to moderate burden

41 – 60 moderate to severe burden

61 – 88 severe burden

Score values and interpretation are guidelines only, as discussed in:

Hebert R, Bravo G, and Preville M (2000). *Canadian J Aging* 19: 494-507

Please answer the questions below with a check mark in the appropriate slot.

1. What is your loved one's primary dementia diagnosis?

Alzheimer's Disease (AD)

Frontal Temporal Dementia (FTD)

Lewy Body Dementia (LBD)

Other _____

Unknown

2. How long ago was your loved one diagnosed with dementia?

< 1 year

2-4 years

5 - 7 years

8 - 10 years

> 10 years

3. What is the primary residence of the care recipient?

Independent living in home

Assisted living

Assisted living memory care

Adult foster care

Nursing home

other (please identify) _____

4. Do you know the Allen Cognitive Level (ACL) of your loved one?

Y N

If yes, what is the ACL score? _____

If no, what stage of disease is your loved one currently in?

Mild_____ Moderate_____ Severe _____ Unknown _____

5. Gender of care recipient: M_____ F_____

6. Gender of caregiver M_____ F_____

7. Caregiver relationship to recipient:

_____ husband

_____ wife

_____ son

_____ daughter

_____ Other (please identify)_____

8. If married to care recipient, number of years? _____

9. Age of caregiver _____

10. Age of care recipient_____

11. Gross annual household income of the care recipient?

_____ <\$15,000

_____ \$15,001 - \$25,000

_____ \$25,001 - \$35,000

_____ \$35,001 - \$50,000

_____ \$50,001 - \$75,0000

_____ >\$75,001

12. What is your spiritual preference?

_____ Catholic

_____ Protestant

_____ Jewish

_____ Muslim

_____ Other _____

_____ None

13. How important would you say spirituality is in your life?

_____ very important

_____ fairly important

_____ not very important

14. Do you currently attend a support group for dementia caregivers?

Y_____ N_____

15. Do you currently use an adult day program?

Y_____ N_____

Please answer the questions below. If you need additional space for your answers, please feel free to write on the back or use an additional sheet of paper.

16. Which community resources do you currently use (ie: adult day center, block nurse, Safe Return)?

17. What kind of help do you feel you need that is not available to you?

Informed Consent to Participate in a Research Study

Caregiver Burden in Alzheimer's Disease, Lewy Body Dementia,
and Frontal Temporal Dementia

Jeanette Foizie, Master of Social Work Student
HealthEast Bethesda Memory Loss Clinic

INTRODUCTION

The purpose of this document is to invite your participation in a research study developed by Jeanette Foizie and to inform you of the possible benefits and risks that may be associated with your experience if you decide to participate. Please read this form carefully and ask any questions that you may have before agreeing to participate.

PURPOSE AND DESCRIPTION OF THIS RESEARCH

The purpose of this research is to better understand the effect of caregiver burden as it relates to different dementia diagnoses and stages of disease in order to identify appropriate support services and resources for caregivers.

This will be accomplished by asking individuals who care for people with memory loss to complete a survey. This survey will ask demographic questions about your age, the age of your loved one, their specific dementia diagnosis, and stage of their disease. You will also be asked to respond to questions about your experiences as a caregiver and to complete the Zarit Burden Interview, which is a standardized tool designed to assess caregiver burden.

This is a student research project that is being done for academic purposes. The results of this study will be reported in a clinical research paper which will be presented at the University of St. Thomas and available in the University of St. Thomas library.

BENEFITS AND RISKS

There are no direct benefits to you for participating in this research. The results of this study may help to identify support services and resources that could be beneficial to future caregivers.

The risks associated with this study may include an emotional reaction to answering questions that are personal and sensitive in nature. You do not have to answer any question. Included with the survey is a list of caregiver resources available in the Minneapolis/St. Paul Metropolitan area, including options for

caregiver counseling. The researcher, Jeanette Foizie, Master of Social Work student, is available by phone or email foiz5670@stthomas.edu to answer any questions or discuss any concerns you have about this study. The Research Supervisor, Jessica Toft, PhD., is available at 651-962-5803. You may also contact Dr. Alvin Holm or Tanya Rand, LICSW, from the Bethesda Memory Loss Clinic.

CONFIDENTIALITY

By completing and mailing the enclosed survey in the included postage paid envelope, you agree to participate in this research study.

The information collected will be analyzed and the results will be presented to the University of St. Thomas in May 2012. Also, the bound clinical research paper will be available at the University of St. Thomas and Saint Catherine University libraries. You and your loved one will not be identified by name in any written report.

The information collected will be kept in a secure and confidential form by the researcher. The privacy of your information will be carefully guarded and no information that can identify you will be released or published. The United States Food and Drug Administration (FDA) and the HealthEast Institutional Review Board (the committee that oversees the rights of people in research studies) may inspect the research records to ensure that the study is being conducted appropriately.

COMPENSATION/COST

There is no cost to you to participate in this study. You will not be paid to participate in this study.

NEW INFORMATION

Any new information that is learned while this study is in progress that may influence your willingness to continue to participate will be provided to you.

CONTACT PERSONS

The person conducting the study, Jeanette Foizie, can answer any questions you might have. You may also contact Dr. Alvin Holm or Tanya Rand, LICSW, from the Bethesda Memory Loss Clinic at or Jessica Toft, PhD. LISW, Research Supervisor from the University of St. Thomas at 651-962-5803 with questions about the study. In addition, you may also contact Dean Huska, Chair person of

HealthEast Institutional Review Board at (651) 232-3234 or dhuska@healtheast.org with questions regarding your rights as a participant in a research study.

VOLUNTARY PARTICIPATION

Participation in this study is entirely voluntary. You may choose not to participate or you may participate and then decide to stop at any time. Your refusal to participate in this study will not affect the care your loved one receives, or their relationship with their physician, Bethesda Hospital, or HealthEast and will not involve any penalty or loss of benefits to which they are entitled. Your refusal to participate will not affect your relationship with Bethesda Hospital or HealthEast.

CONSENT

I have read all of the above information, asked questions, and received answers to things I did not understand. The completion and mailing of this survey will serve as documentation of my consent to participate in this research.

Please keep this form for your records.