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Empowering Caregivers of Persons With Alzheimer's Disease
Through Psychoeducation of Community Services

by

Lindsay S. Walker, B.A.

MSW Clinical Research Paper

Presented to the Faculty of the
School of Social Work
St. Catherine University and the University of St. Thomas
St. Paul, Minnesota
in Partial fulfillment of the Requirements for the Degree of

Master of Social Work

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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 the findings of the study. This project is neither a Master's thesis nor a dissertation.

Abstract

This qualitative study examined the ways social workers empower caregivers of persons with Alzheimer's disease (AD), through psychoeducational interventions of community services. Social workers in the field of aging may be the only informant of available support services for persons facing AD, so caregivers should not be overlooked while providing resources. Data was collected through nine semi-structured interviews to analyze the personal experience of social workers currently working with caregivers of persons with AD. This study interpreted the findings through deductive analysis of common themes from the interviews. The four themes from this study were: causes of caregiver burden, the need for psychoeducation, caregiver strengths to provide care, and social work support to caregivers. Three subthemes emerged including caregiver role identity, resiliency, and empowering caregivers. The results from this study provide strong indication for the role of social workers to provide support for caregivers in order to continue providing quality care. Implications suggest need for a caregiver assessment tool to allow social workers to further explore and discuss caregiver service expectations, awareness, and knowledge of various community-based services to encourage the caregiver to be involved in the plan of care for persons with AD.

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Empowering Caregivers of Persons With Alzheimer's Disease

Dementia among older adults is a difficult diagnosis for the person suffering from the disease, the family, and helping professionals. It is a disease that has a range of types and stages affecting each individual differently. A prevalent form of dementia is Alzheimer's disease, which is defined on the Alzheimer's Association (2014b) website as "the most common form of dementia, a general term for memory loss and other intellectual abilities serious enough to interfere with daily life" (Alzheimer's and dementia basics section, para. 1). The Alzheimer's Association (2014b) states that Alzheimer's disease (AD) accounts for 50 to 80% of dementia cases. Currently, there are an estimated 5.2 million Americans living with AD, and more than 15 million family caregivers provided unpaid care in 2013 (Alzheimer's Association, 2014a). Although the greatest known risk factor for memory loss is increasing age, as the majority of people with AD are older adults age 65 and older, memory loss is not a normal part of the aging process (Alzheimer's Association, 2014b). Those with AD live an average of eight years after dementia symptoms are diagnosed but the disease has ranged from four to 20 years, depending on the age of the individual diagnosed, along with other health conditions. The Alzheimer's Association (2014b) states that it is the sixth leading cause of death in the United States.

Families are the main provider of long-term care for older adults, particularly when caregiving is provided in the home environment. As dementia is increasing among older adults, approximately 70% of persons with dementia receive care at home from family members (Clay, Mittelman, Madan, & Roth, 2004, p. 575). The average length of caregiving lasts 4.6 years, with the large majority (86%) of caregivers taking care of a

relative, and over one-third of those caring relationships being for a parent (National Alliance for Caregiving and AARP, 2009, p. 4). Many caregivers are the spouse to the care recipient, as 62% of caregivers are married or living with the care recipient in his or her home (National Alliance for Caregiving and AARP, 2009, p. 35).

Research has shown that caregiving demands a heavy emotional, physical and financial toll. Many caregivers of persons with AD and related dementias have a full or part-time job and children to care for, so providing care in the home often conflicts between other responsibilities. Research says that 22% of caregivers are assisting two individuals, while 8% are caring for three or more (Administration on Aging, 2014). The Administration on Aging (2014) states that “almost half of all caregivers are over age 50, making them more vulnerable to a decline in their own health, and one-third describe their own health as fair to poor” (The Purpose of the Program and How it Works section, para. 2).

Without a known prevention or treatment of AD (Alzheimer’s Association, 2014b), social workers in the field of older adults can play a role in supporting caregivers of persons with memory loss living at home. Social workers should be interested in the area of caregiver support in order to effectively manage the plan of care for persons with AD by recommending various support services in the practice role of case management, care coordination, family care conferences, and discharge planning in a hospital, care center, Transitional Care Unit (TCU), or home care setting. Providing support through education of community-based resources is a psychoeducational intervention for social workers to perform with caregivers of persons with AD living in the home environment.

Social workers in the field of older adults explore care options and resources for persons with AD that allow for the greatest amount of independence and quality of life. The Administration on Aging (2014) reports that these supportive “services can reduce caregiver depression, anxiety, and stress and enable them to provide care longer, thereby avoiding or delaying the need for costly institutional care” (The Purpose of the Program and How it Works section, para. 4). Just as important as providing these community resources to reduce caregiver burden, social workers can address the stressors and attitudes towards outside services with caregivers, as this too can increase the likelihood of a person with AD staying in the home environment for a longer amount of time (Dal Santo, Scharlach, Nielsen, & Fox, 2007).

The purpose of this study is to discover the awareness of social workers working alongside persons with AD have of caregiver burden, address caregiver utilization of community-based support services, and identify social workers’ ability to assess the need for psychoeducational intervention in order to empower caregivers to continue caring for a person with AD in the home environment.

Literature Review

In order to better understand how social workers empower caregivers to continue caring for a person with Alzheimer's disease, consideration must be given to social workers' ability to assess for the need of a psychoeducational intervention of community support resources. Therefore, it is important to address caregiver burden, gain a clear understanding of utilization of community support services, and identify social work methods of psychoeducational interventions for caregivers of persons with Alzheimer's disease. The strengths perspective and value of empowerment for caregivers was used as a conceptual framework. This review of literature focused on caregiver burden, caregiver utilization of services, psychoeducational intervention of community-based resources, and a social worker's involvement to support caregivers of persons with Alzheimer's disease.

Caregiver Burden

Family caregivers caring for persons with dementia at home often experience caregiver burden. On average, caregivers spend 20.4 hours per week providing care, but "caregiving is particularly time-intensive for those who live with the care recipient" with an average of 39.3 hours per week (National Alliance for Caregiving and AARP, 2009, p. 5). Providing care for persons with a progressive disease, such as dementia of the Alzheimer's type, is a difficult task for anyone. This burden causes high levels of stress, which can lead to a lowered sense of well being, depression, diminished physical health and even early death for the caregiver (Cotrell & Engel, 1998; Sörensen, Duberstan, Gill & Pinquart, 2006). Caregivers for persons with AD have higher stress levels than other

caregivers (Sörensen et al., 2006), requiring a greater amount of support in the home to alleviate the burden of caregiving.

Caring for a person with AD is a demanding role and often presents multiple challenges. Research has shown that caregivers of persons with AD experience many day-to-day stressors and full-time caregiving contributes to burden (Dal Santo et al., 2007). The source of this burden is often from physical challenges, loss of companionship and support, social isolation, financial and legal challenges as well as decision-making requirements (Bartfay & Bartfay, 2011; Cotrell & Engel, 1998). Caregivers can cope with the burden of their role by changing the setting of care and utilize resources, such as respite services, to aide with the burden of caregiving (Dal Santo et al., 2007; Sussman & Regehr, 2009).

Supporting caregivers through community care services. When the needs of caregivers are not effectively met, caregiver burnout can result. By intervening with care services and resources and an on-going discussion of emotional support as the disease progresses, quality of life for caregivers can be improved. Efforts to reduce caregiver burden on the provider have focused on the provision of formal services by professionals in the field of aging. “Informal caregivers of dementia patients have reported that community-based services are important in fulfilling caregiving tasks” (Cotrell & Engel, 1998, p. 118). Community-based care resources are support services utilized by a family member, friend or a professional home care provider through in-home care, adult day services, and/or attending an AD support group.

The use of community-based support services can alleviate stress for the caregiver while persons with AD are living in the home environment. Through the stages of AD,

family caregivers will be in need of several resources to support the care needs of the person with AD. Gaugler, Kane, Kane, and Newcomer's (2005) findings suggest "the practical importance and cost-effectiveness implications of early community-based service use" (p. 177), in reducing stress in the dementia caregiving career. A 2002 meta-analysis that analyzed the effects of more than 77 caregiver intervention studies, found that multifaceted intervention efforts of providing more than one type of service led to significant improvements in "caregiver burden, depression, subjective well-being, perceived caregiver satisfaction, ability/knowledge, and care-receiver symptoms" (Sörenson, Pinguart, Habil, & Duberstein, 2002, p. 356).

Supporting caregivers to provide long-term care at home. Supporting family caregivers with community-based care services in the home environment early on can decrease the need for caregivers to find an alternative living arrangement for persons with AD, resulting in a longer provision of care at home. Caregivers are often appointed as agents of health care directives to make difficult decisions about care. Many caregivers feel alone in making the decision to relinquish full-time care when the time comes to move the care recipient to a care center. These caregivers experienced loss, sadness and resignation after having made this decision. Moving to a care center as an older adult has several financial and psychosocial costs (Clay et al., 2004; Gaugler et al., 2005). One-half of dementia caregivers who participated in Chene's (2006) study on residential placement were seen to be "at risk of depression that would warrant professional intervention" (p. 188). This study suggests that premature institutionalization should be avoided as long as the caregiver is in support of providing cares at home.

Continuing care by the primary caregiver, in addition to in-home support services, is beneficial to the caregiver and the person with AD. Gaugler et al. (2005) studied the use of community-based long-term care services, and found that those individuals who utilized in-home help services earlier in the dementia caregiving were more likely to avoid or delay the need for nursing home placement of the care recipient, depending on the severity of the dementia (Gaugler et al., 2005). Monahan (1993) noted that intervening with dementia-specific community resources reduces caregiver burden, allowing persons with AD to live at home longer.

Caregiver Utilization of Support Services

Historically, caregivers of persons with AD have underused community support services. Support services for persons with AD are difficult for caregivers to be aware of, as there is a reluctance to ask for help, and caregivers may not have the confidence to utilize services in the home of a vulnerable loved one with AD. “Community services such as adult day care, home health aides, and paid companions are designed to help alleviate the stress of caregivers of dementia patients” (Miller & Mukherjee, 1999, p. 162-163). Sussman and Regehr (2009) found a significant association between community service use and caregiver burden as “the more frequent[ly] a caregiver's spouse attended a day program, the less burden his or her caregiving spouse experienced” (p. 36). Yet, research indicates that community resources are considerably underused, despite care services being available and affordable. “Between 10% and 25% of families use any community services for the care of a demented relative” (Miller & Mukherjee, 1999, p. 163). This lack of service use causes more complications for the health of the person with AD if care services are not utilized at an appropriate time, therefore affecting

the caregiver. Cotrell and Engel (1998) stated that when dementia caregivers do use “formal services they often tend to delay until caregiving stress is advanced or a crisis occurs” (p. 118).

Little research has been performed on why caregivers do not use dementia resources, but researchers have questioned the possibility of not being aware of or educated on the use of formal services (Monahan, 1993; Cotrell & Engel, 1998). Cotrell and Engel (1998) found that many caregivers are unaware of potentially helpful services in the area. Caregivers have lowered expectations about formal support and, therefore, are less affected by service inadequacies. In turn, Sussman and Regehr (2009) believe that the continuity of care is also affected. Due to this, caregiver expectations regarding availability and comprehensiveness of service options are minimized. Since caregivers do not feel there is information out there, they are simply not searching for it (Sussman & Regehr, 2009). Morano and Bravo (2002) conducted a model for Hispanic caregivers of persons with AD to reduce potential resistance and barriers to the use of formal support services. The primary goals of this intervention were to increase caregivers’ knowledge of the disease, improve awareness of services, and develop better coping skills.

Caregivers reported that learning how to access services was helpful to better understand the multiple roles of supportive programs (Morano & Bravo, 2002). This was similar to Venohr, Fine, Saunders, Tenney, Vahan, and Williams’ (2001) findings of caregivers reporting the highest satisfaction with adequate support, recommendations, and awareness of “information provided to caregivers about community resources” (p. 52).

Caregiver attitudes towards service use. The underuse of support services for caregivers has led researchers to the assumption that a better understanding of the

attitudes and knowledge caregivers have of support services may improve community efforts to reach those with AD (Cotrell & Engel, 1998; Dal Santo et al., 2007; Miller & Mukherjee, 1999; Monahan, 1993). Attitudes towards service use “represent family values toward independence, autonomy, family responsibilities, and social entitlements and influence service use behavior to the extent that individuals’ beliefs and opinions about an issue influence choices” (Miller & Mukherjee, 1999, p. 163). Studies show that when older adults believe to be entitled to services, there is a greater use of services. Understanding service attitudes and beliefs is important for social workers in counseling families and developing service plans together. Miller and Mukherjee (1999) suggest that “clearer understanding of the links between caregiver attitudes and behavior may lead to more accurate estimates of how frequently families would use services if these were available” (p.163).

The ways in which attitudes, beliefs, knowledge, and personal and familial experience regarding health and social services come into being and then become expressed in behavior are enmeshed in the service use process. Miller and Mukherjee (1999) studied the correlation of caregiver attitudes towards community services, discovering that “caregivers with higher levels of caregiving mastery, lower levels of caregiver preparedness, less education, and more helpers had a greater likelihood of having confidence and trust in use of services” (p. 171). A referral to formal services may imply the “inability or unwillingness of the informal system to meet the needs” of the care recipient (Cotrell & Engel, 1998, p. 119). As the demands of caregiving increase, caregivers may be isolated from outside sources of information regarding formal services, since “social withdrawal of the caregiver is often due to shame and

concealment of the illness” (Cotrell & Engel, 1998, p. 119). This social isolation and shame is the complexity that helping professionals face when trying to improve attitudes towards community services, leading to greater use of caregiver support resources (Miller & Mukherjee, 1999).

Psychoeducational Intervention

Supporting family caregivers to alleviate the burden of caring for persons with AD can be accomplished through a psychoeducational intervention. Psychoeducation intended for caregivers and families of persons with AD is designed to provide information about the disease process, symptoms, resources, and services to equip caregivers with needed skills and open dialogue in families about the effects of AD (Morano & Bravo, 2002). Psychoeducation results in increased caregiver well-being, coping skills and delay of institutionalization of the care recipient (Sörenson et al., 2002, p. 356; Tompkins & Bell, 2009, p. 91).

How psychoeducation helps. The goals of psychoeducational interventions are to reduce caregiver burden through education about the disease and provide community resources to allow for caregivers to continue caring for persons with AD. Psychoeducation will “train caregivers to respond effectively to disease-related problems,” (Sörenson et al., 2002, p. 357) and help caregivers to establish problem-solving strategies for coping with the diagnosis. Throughout the psychoeducational intervention, support is provided to the caregiver in gaining access to services, individual counseling, support groups, caregiver training, and respite care. There are supplemental services such as home care, therapy, hospice, skilled nursing or care management provided to give the primary caregiver a break from the duties of caregiving in the home.

Caregivers often utilize help from this intervention for transportation, homemaking, meal preparation, medication management and assistance with daily living activities for the person with AD.

Studies of psychoeducational interventions with family caregivers rarely explore the long-term influence on the course of caregiving. Generally, the goals of interventions involve improving caregivers' ability to cope with stressors and to access community resources, which are expected to “reduce feelings of burden and strain” (Whitlatch, Zarit, Goodwin, & Von Eye, 1995, p. 18) and to influence caregiving ability in the home long-term.

Outcomes of psychoeducation. Research supports the beneficial outcomes of psychoeducational services. The results of a study by Sörenson et al. (2002, p. 364) suggest that when compared to various types of interventions, psychoeducational interventions had significantly beneficial effects on caregiver burden, depression, and ability/knowledge, showing the most consistent effects on all outcome variables. Fortinsky, Unson and Garcia (2002) studied the implementation of the Alzheimer’s Service Coordination Program (ASCP), which was developed to benefit family caregivers of persons with dementia “in measurable ways from a care partnership arrangement linking primary care physicians with a community organization that specializes in dementia education and support” (p. 228). Beyond raising awareness among care physicians about dementia community resources, the purpose of the ASCP program was to educate family caregivers about symptom management and how to access community services that will in turn enhance care. The positive outcomes of the impact and satisfaction of the ASCP intervention, reported by family caregivers over six

months, were changes in dementia management self-efficacy and changes in referring physicians' knowledge of dementia-related services in the local community (Fortinsky et al., 2002).

Whitlatch et al. (1995) measured patient functioning, caregivers' current use of informal and formal services, and feelings of burden and distress, by using the Memory and Behavior Problems Checklist (MBPC). Whitlatch et al. (1995) found that psychoeducational interventions of community-based care services with caregivers did have long-term positive effects related to rates of patient institutionalization. Therefore, studies on long-term caregiver outcomes do indicate that psychoeducational interventions of community resources can improve the caregiver's stress so effectively that there is an ability to delay placing the loved one in a nursing home for as long as a year following the interventions (Dal Santo et al., 2007; Mittelman, Ferris, Steinberg, Shulman, Mackell, Ambinder, & Cohen, 1993; Tompkins & Bell, 2009; Whitlatch et al., 1995).

Psychoeducation through community care services. Professionals have utilized formal methods of psychoeducation to provide information about available community-based care service options when working with older adults.

Psychoeducational interventions for caregivers of persons with AD have been used by social workers to increase satisfaction and knowledge of community services (Morano & Bravo, 2002; Venohr et al., 2001). Venohr et al. (2001) designed a model to improve linkages of caregivers to community services. This Dementia Care project was implemented through "single point informational contact, provider education, case finding, caregiver education and support, internal linkages and linkages with community services" (Venohr et al., 2001, p. 51-52).

Professionals support the relationship between the caregiver and the person with AD and how it can significantly improve as a result of service use, as caregivers begin to find it easier to provide care in the home (Monahan, 1993, p. 59). Cotrell and Engel (1998) support the idea that a professional is needed to provide information on community services and actively facilitate encouragement and influence successful service utilization. Professionals provide “emotional support by helping caregivers overcome feelings of guilt and concern about the use of respite services,” as these are common “barriers to the use of respite by caregivers, especially spouses” (Cotrell & Engel, 1998, 128-129). Cotrell and Engel (1998) also determined that the source providing information about such services was more important in determining service use of community-based resources. Psychoeducational interventions may be more effective at increasing service use among caregivers from lower socio-economic status, as caregivers may not be able to overcome obstacles without the help of a social worker (Weinberger, Gold, Divine, Cowper, Hodgson, Schreiner, & George, 1993).

Social Work Support to Caregivers

Social workers support caregivers of persons with AD in the home environment by providing psychoeducation of community-based care resources to reduce caregiver burden and the possible prevention of premature placement. Social work is a helping profession that pays attention to all aspects of the individual, family and community. Therefore, social workers helping persons with AD take time to recognize the support caregivers may need when providing care in the home. Community resources for caregivers of persons with AD are underutilized, which can increase problems for persons with AD and caregivers alike (Weinberger et al., 1993). Older adults with

dementia are disenfranchised due to cognitive impairment, age, and accessibility to available resources, but social workers have access to community-based service resources in order to be the advocate persons with AD need to assist the primary caregiver.

Recommendations by professional social workers to use community resources are more likely to be acted upon if in-home care is mentioned as an alternative to the provision of care by the caregiver (Cotrell & Engel, 1998).

It is necessary for social workers to provide information on substantial care and resources for caregivers of persons with AD at an early stage as the person's condition deteriorates over time. The Alzheimer's Association (2014b) explains that it is a progressive disease, where dementia symptoms gradually worsen over a number of years as the disease advances through its seven stages. Early stages display mild memory loss, but with late-stage AD, individuals lose the ability to converse with others and respond to outside factors of the environment, eventually losing the ability to complete daily tasks to live independently. Factors contributing to service utilization may "require more frequent contact by social workers to account for changing needs" (Weinberger et al., 1993).

Social workers support caregivers by knowing the best time to approach caregivers about using available care resources. Caregivers cannot process all of the resource information upon diagnosis, or at a time in crisis. The National Family Caregivers Association (NFCA) report 84% positive reactions, of the 1,579 family caregivers surveyed, to simply knowing that someone is there when the need arises (Getz, 2012). Social workers can then assess care responsibilities and the impact that those duties have on caregiver well-being to "identify the specific types of caregiver support services which are most appropriate for particular caregiver coping styles or needs" (Dal

Santo et al., 2007, p. 46). By facilitating appropriate service use and access, caregivers increase self-awareness, manage stress, assert communication skills and expand the support network to have the capacity to provide care longer. Social workers help to embrace the disease's ambiguity by working alongside caregivers to "discover choices and make decisions about how to find some continuity in the midst of chaos and change" (Boss, 2011, p. 6). Boss (2011) suggests being aware of differences between caregivers, as there may be varying beliefs and cultural values when determining the level of care the care receiver is in need of, in addition to disparities in the caregiver's ability to find resilience.

Implications for social work practice include identifying at-risk caregiver groups and acknowledging the need for appropriate community supports for AD caregivers at all stages of the caring process. Due to the increase risk for depression, anxiety, physical health issues, and social isolation, social workers can make an impact on assessing a caregiver's bio-psycho-social-spiritual wellbeing. Since it is unknown why caregivers do not often utilize dementia resources, some researchers assume that caregivers of older adults are not receiving this education (Monahan, 1993). Social workers can provide a psychoeducational intervention to inform caregivers of services that are "aimed at improving the caregiver's well-being and coping skills" (Sörenson et al., 2002, p. 356). Caregivers are commonly challenged by not knowing enough about service options, yet have a need for additional skills and resources, lacking the ability to match services and resources with needs and goals. Many caregivers are not able to effectively match the need with known community resource services without the assistance of a professional acting as a mediator to clarify formal service use (Cotrell & Engel, 1998). Social

workers can “match specific needs as defined by the caregiver with the available service through improved intake procedures, more training of service providers, and public education campaigns” (Miller & Mukherjee, 1999, p. 174).

The current literature does not explore caregivers' expectations of community service resources options and how that affects caregiver burden and service use.

Exploring caregivers' expectations toward service utilization and satisfaction over time might have provided more knowledge base for social workers to understand how psychoeducation can affect caregivers of persons with AD in various ways. By addressing caregiver utilization of community-based support services, social workers can empower caregivers to continue caring for a person with Alzheimer's disease in the home environment. Furthermore, exploring how caregivers' service expectations differ at various stages of the caregiving career could highlight important changes in caregivers' attitudes, beliefs, awareness and knowledge toward service utilization (Sussman & Regehr, 2009, p. 37).

Considering what the literature says about caregiver burden and psychoeducational interventions for caregivers, it is worth further study to discover how social workers can play an integral role in empowering caregivers of persons with AD to utilize community service resources.

The research question for this study is: How do social workers empower and support caregivers of persons with Alzheimer's disease through the use of psychoeducational interventions?

Conceptual Framework

The use of psychoeducational interventions focuses on caregiver burden, increases knowledge of the disease, improves awareness of support services, and develops better coping skills for caregivers (Morano & Bravo, 2002; Sörenson et al., 2002, p. 364). When a caregiver of a person with AD has experienced a crisis, it is important for social workers to provide support during this time, by assessing the strengths the caregiver brings to providing care for the person with AD. It is then the social worker's role to empower the caregiver to make the changes needed to decrease caregiver burden, increase awareness of support options, and better cope with the situation of caring for a person with AD. Therefore, this study looks to the strengths perspective and empowerment models as the theoretical frameworks to guide the research methodology.

Strengths Perspective

The strengths perspective implies that the social work practice approach should utilize client strengths as resources when focusing on change and overcoming problems. This perspective assumes that everyone has the capacity for growth, heightened well-being and the ability to create lasting change, by focusing on one's own strengths rather than limitations (Miley, O'Melia, & Dubois, 2010). Sheafor and Horejsi (2006) define strength as "anything important and positive that the client is doing, can do, or wants to do" (p. 93).

Many researchers have recognized this framework as a beneficial method of practice when working with older adults. The strengths perspective places importance on self-determination and maximizing consumer choices in long-term care settings and

within the community (Nelson-Becker, Chapin, & Fast, 2006). Lamb, Brady, and Lohman (2009) reviewed the strengths-based perspective “as an ideal fit for gerontological social workers in that it provides a focus for identifying and encouraging coping strategies and life enhancing alternatives rather than dwelling on deficit management” (p. 714). Acknowledging strengths will help caregivers “strive toward the development of their potential, mastery, and self-actualization” in caregiving for persons with AD (Miley et al., 2010, p. 76). This in turn can assist caregivers to overcome challenges by possessing the capability to problem-solve, cope and thrive, being encouraged to continue caring for this individual.

Empowerment Theory

The empowerment theory is also an effective framework when working with older adults and caregivers. Personal empowerment refers to “a subjective state of mind, feeling competent and experiencing a sense of control” (Miley et al., 2010, p. 80). Empowerment can also be experienced on an interpersonal level, which suggests “a sense of interdependence, support and respected status” (Miley et al., 2010, p. 80). Cox (2002) describes the empowerment process by a social worker as an analysis of an individual’s outlook and opinions in regard to problems, the provision of mutual support for the individual’s experiences, increasing one’s knowledge and skills that are pertinent to the situation, and taking action.

The use of the empowerment model in long-term care settings has been found to be beneficial in helping older adults learn new ways to cope with facing many changes (Cox, 2002). Using this orientation with older adult caregivers helps affirm the ability to be involved in the process of setting and determining goals for the person with AD

(Chapin & Cox, 2001). The practice of empowering another individual allows for the expansion of one's ability to make decisions. When an older adult has AD, the loss of the sense of independence and ability to have self-determination diminishes, without the assistance of a stable caregiver. Therefore, caregivers of persons with AD are in need of empowerment to feel supported and in control to make decisions about care according to their personal experience and knowledge.

Strengths Perspective and Empowerment for Caregivers

The strengths perspective and empowerment theory provide a strong framework for working with caregivers of persons with AD. When the social worker is able to acknowledge an individual's strengths, he or she will better be able to understand the day-to-day challenges that are affecting the person with AD and the caregiver, as caregivers are ultimately the 'expert' of the situation. This deeper understanding then allows the social worker to empower the caregiver to make necessary changes in care. Gutheil and Congress (2000) studied the natural tendency for these two theories to be practiced together. Focusing in on strengths makes way for clients to discover and utilize the resources within and around them (Gutheil & Congress, 2000).

The strengths perspective and empowerment theory are applicable to the current research regarding social workers' effectiveness in using psychoeducation to support caregivers of persons with Alzheimer's disease. It is expected that social workers have knowledge and skills to detect the need for psychoeducation and therefore locate adequate resources and support services. Utilizing these two perspectives helps to develop a solid framework to gather data on the use of psychoeducation by social workers to empower caregivers of persons with AD to provide care longer.

The strengths perspective and empowerment-based practice theories guide this study in developing the questions used to interview social workers working with caregivers of persons with AD. The questions developed for the qualitative semi-structured interviews in this study seek to gain reflection of how social workers empower and support caregivers of persons with AD through the use of psychoeducational interventions.

Methods

Research Design

The purpose of this study was to discover how social workers in the field of aging empower and support caregivers of person with Alzheimer's disease through the use of psychoeducational interventions. This descriptive study utilized a qualitative method in order to receive an in-depth understanding from professional social workers' practice role with caregivers of persons with AD, as this topic "requires empathy and understanding" (Padgett, 2008, p. 15). This qualitative study relied on using a semi-structured interview design of open-ended questions. The researcher found nine social workers as participants, who work with older adults and caregivers of persons with Alzheimer's disease. The interviews lasted approximately 45 minutes in quiet meeting rooms. A series of twelve interview questions (see Appendix B) was asked while the interview was audiotaped. The researcher kept field notes to document observations and important insights. The interviews were transcribed then analyzed using content analysis to understand social workers' responses. The researcher then coded each response or phrase. After reviewing the field notes and interview transcriptions, four overall themes were discovered through the coding process of content analysis.

Sample

This inquiry was to determine how social workers empower caregivers when working with persons with AD. The audience for this question was licensed social workers in the field of aging. These social workers primarily worked in a hospital, residential care facility, community, or home care setting where persons with Alzheimer's disease often reside or receive care services. The participants in this study

were licensed social workers who were chosen based on the position held as a social worker in the aging field within the Minneapolis and St. Paul area. Social workers were recruited to participate in this study by a probability sample method of contacting possible participants by email from a list provided by the MN Association of Home Care Social Workers (MAHCSW). The researcher selected every other name on the list to email, ordered alphabetically by last name. Each email included a flyer invitation (see Appendix C) asking for willingness to participate in this study, along with the assistance to recruit at least two other social workers in the field of older adults. Once the researcher contacted the potential social work participants by email, the researcher asked these contacts to either forward the email on and/or hand out the flyers to other colleagues.

The second method used in this study relied on the snowball effect, where recipients shared the flyer by forwarding the email to fellow social workers in the aging field. The researcher was made aware that this email was forwarded on to a team of social workers in at least two agencies. By allowing emailed contacts to recruit colleagues, the interview opportunity was provided to a greater amount of potential participants who were willing and interested in this study by receiving the informational flyer by email. The researcher offered a \$10 gift card to a coffee shop as an incentive benefit. The flyer allowed the participants to contact the researcher voluntarily to make the researcher aware of their interest and willingness to participate in the study. Participants with scheduled interviews were told they would receive the \$10 gift card benefit, regardless of whether or not they completed the interview.

The researcher interviewed nine participants overall for this study. Two of the licensed social workers work for a home care agency, one works in a residential care facility, two work for a social services community program for seniors, three work for a hospice agency, and one is a medical social worker in a hospital setting.

Protection of Human Subjects

The researcher made every effort to conduct the semi-structured interview with respectful questions, reducing as much risk as possible for the participant. The interviews were confidential in nature held in quiet and private meeting rooms, therefore this study had no risk for the participating social workers. The benefit provided for participating in this study was a \$10 gift card to a local coffee shop.

Before beginning the interviews, an IRB consent form from the University of St. Thomas was presented to the participants to describe the purpose of the study, the reason for being selected, the process of the interview and how the data would be used (see Appendix A). In addition, the researcher explained to each participant that there were no risks to participating in this study. Before signing the consent form, participants were told that this study is voluntary and that it would be audiotaped, but the recording of the interview would be destroyed immediately after transcribing. Participants were also informed that if they would like to withdraw from this study, participants were allowed to do so up to one week after the interview was completed, and that any identifying information of the participant is enclosed on a password-protected computer to ensure confidentiality. They were given the \$10 gift card before the interview as a benefit for participating in the interview. After the researcher discussed the consent form, participants were asked to sign the consent form prior to the interview.

Data Collection

This qualitative study relied on using a semi-structured interview design to collect data from its participants. In order to address the research question, twelve open-ended questions were asked of the participants with additional follow-up exploratory questions. These additional questions were asked to help clarify or obtain further detail regarding the response the participants provided. The questions were developed to answer the research question in this study. These questions were asked about social workers' practice and the use of strengths and empowerment for caregivers of persons with Alzheimer's disease. Questions covered social workers' perspectives of caregiver burden, the use of community-based support services, and how social workers use this knowledge and perceptions to provide psychoeducational interventions in practice. The questions were simply stated in jargon-free language, and are reliable as evidenced by utilizing the language existing in prior research on the topic of caregiving for persons with AD. Questions were pre-tested by peer review, to ensure no bias was revealed. The researcher's committee members also reviewed the interview questions to increase validity of matching the study's overall research question.

Data collection occurred by audiotaping the participants' interview responses on the researcher's iPhone 'voice memo' app. Twelve open-ended questions were gathered, along with follow-up exploratory questions as needed throughout. The interviews lasted approximately 45 minutes in a quiet meeting room. The interview questions below were developed after carefully considering the limitations and barriers of the literature review on empowering caregivers of persons with AD through community-based services and the social workers' role in providing support. The researcher's main concern was to gain

knowledge on the participants' ability to empower and support caregivers of persons with Alzheimer's disease through the use of a psychoeducational intervention.

Interview Questions for Social Workers working with Older Adults

- 1. How long have you worked as a social worker with older adults (persons 65+)?**
- 2. Tell me about your roles and responsibilities as a social worker in your current agency?**
- 3. Approximately, what percentage of the clients you are currently working with have Alzheimer's disease or related dementias?**
- 4. When working with a client with Alzheimer's disease, how frequently do you work with the primary caregiver? *Can you describe what this work looks like, and how you might assist these caregivers?***
- 5. What are some of the needs or challenges faced by the caregivers you work with?**
- 6. What strengths do you commonly see in caregivers who seek services? How do you assess for caregiver strengths?**
- 7. What prior skills, abilities and/or knowledge do you notice caregivers have that aide in providing care for individuals with Alzheimer's disease?**
- 8. What kind of education do you provide for caregivers regarding AD? *How do you assess what information to provide and when?***
- 9. What community-based care resources do you educate caregivers on in your role as a social worker? *How? Do you match this information to their needs as they move through the disease process?***
- 10. What types of community-based services for persons with Alzheimer's disease are supportive to the caregivers? *How do you get a sense for their willingness to utilize your suggestions for services?***
- 11. How do you empower caregivers of persons with Alzheimer's disease? *What does empowering caregivers mean to you?***
- 12. Do you believe your role as a social worker empowers these caregivers to continue caring for the older adult with Alzheimer's disease in the home environment? *If so, how?***

Data Analysis

The researcher considered the use of psychoeducation by social workers to empower caregivers of persons with AD. The researcher analyzed the data retrieved from the interviews by transcribing the recordings, typing up the interviewer's questions and interviewees' responses word for word. Then the researcher performed content analysis on the transcription of interview data. The approach to content analysis was conventional, coding each response or phrase in the interview data separately to find categories. Throughout the analysis, the researcher looked for evidence of empowerment and strength to discover codes in the interview content, by counting the times the respondent talked about caregiver empowerment and assessing for strengths. These codes helped in identifying the four main themes or patterns to describe the participants' responses. Deductive analysis approach was then utilized by moving from more general themes to specific, helping to discover meaning that the coded themes presented. Then a research chair provided feedback to ensure similar response patterns from the transcript as a reliability check. Field notes were also gathered to assist the researcher in clarifying the meaning behind the participants' responses.

Strengths and Limitations

The strength of this study came from formulating quality questions for the participants to answer that were clearly written and pre-tested with peer review. The researcher slowly asked one question at a time to each participant. This careful process assisted in gathering clear data within each interview before performing content analysis. The use of open-ended questions, rather than leading questions, was obtained to refrain from the possible presence of the researcher's bias upon interviewing. The validity and

relevance of the questions allowed the researcher to receive transparent face validity when looking at the content results of this study, after transcribing the nine interviews. The use of a snowball method was also a strength as offering a gift card was expected to be helpful in gaining participants, as social workers often know many others in the field of aging and enjoy working as a team towards a common goal.

In addition to the strengths of this study, the researcher found some limitations to address. The main limitations to this study were the variety of experience and total number of participants received due to the restriction of time. The potential for a small sample size was a disadvantage due to utilizing a snowball effect method to gather participants. This method limits the variety of participants to be chosen at complete random, as the social workers are likely to know each other and hold similar experiences and ideals. By utilizing a snowball sample and receiving a low number of participants, this study is limited to the inability to generalize the data retrieved across all social workers working with older adults.

Personal biases possessed by the researcher for this qualitative study affected the gathering and analyzing of data. The researcher has a family member with AD. This personal connection to caregiving for persons with AD was assumed to impact the research conducted in this study. The researcher also has past work experience in the field of older adults, working directly with and in service of persons with AD. This work was performed in an agency that provides home care services to older adults. Therefore, the researcher has seen the influence and benefits of providing community-based care services to older adults in order to continue supporting the caregiver as the person with AD is living at home. To limit these biases from getting in the way of the data analysis

process, the researcher used content analysis to uphold the codes and themes that arose in the raw transcribed interview data. The researcher utilized a research chair and research committee to ensure this bias was monitored while analyzing the data and formulating themes. It is assumed that by utilizing the empowerment theory to gather and analyze data, each participant provided adequate knowledge and experience to contribute to this study.

Findings

This study demonstrated the experience of social workers working alongside caregivers of persons with AD. By interviewing nine licensed social workers in the field of aging, a deeper understanding was gained of the role of social work in empowering caregivers to continue caring for a person with Alzheimer's disease, by using psychoeducational interventions. The findings for this study were situated in support of the literature review, using this as content validity to discover similar answers across participant responses that reflected the research. There were four overall themes found through deductive data analysis of utilizing the themes within existing research to explain the outcome of psychoeducational interventions and how social workers empower caregivers. The four themes found in the study were: causes of caregiver burden, the need for psychoeducation, caregiver strengths to provide care, and social work support to caregivers.

Caregiver Burden

Each of the nine participants effortlessly responded with reflections of caregiver burden and stress when asked about the needs or challenges commonly seen in the caregivers of persons with AD in their role as a social worker. Three subthemes arose when asking participants about the causes of caregiver burden: time, change in the caregiver's role identity, and a lack of supportive resources.

Time. Five out of the nine participants responded with the caregiver's burden of finding time to care for the person with AD, and having the ability to care for their own health at the same time. Two participants responded with experiential stories of providing care:

It's just such an intense job as far as number of hours when memory care is needed. Frequently they [persons with AD] need daily or long hours of service. We have some that need help every night or overnight or round-the-clock care. If they have a spouse who's providing that care, it's very draining. (Participant 1, Page 1, Lines 19-22)

Exhaustion, or just being tired is common [among caregivers]. I'll tell them about support groups, but they say that if they had extra time, they'd nap, go shopping or go to a movie. While a caregiver support group is a great idea, most caregivers have so little time. Especially if you're at home taking care of someone with dementia and their sleep patterns are off, and you don't know if they're going to wander and leave. (Participant 5, Page 1, Lines 34-37)

The amount of time spent on caregiving is very tiring, as participant 8 reported on sleep deprivation when caring for someone at all hours of the day. Participant 6 spoke of how the loss of sleep can result in a loss of patience and increased frustration, causing a heightened risk for caregiver fatigue and burnout. Another participant described this burden as, “*when you're exhausted, emotionally you're raw and you don't react right and it's kind of hard to sit and appreciate the person, especially when you don't understand the person's dementia*” (Participant 5, Page 1, Lines 40-42).

Caregiver role identity. Six out of nine participants discussed the burden of a new role that caregivers take on in caring for persons with AD. With this new role of being a caregiver, family members are also slowly losing identity in a former role they played, such as a spouse, sibling or child. “*So many don't see themselves as caregivers. When it's family, they say 'of course I'd be doing this for her'!*” (Participant 8, Page 3,

Lines 126-127). With this identity change or confusion, many caregivers do not view themselves as being a part of a new role, and therefore are unable to fully understand the importance of the role of caregiving.

The following two quotes demonstrate this burden of caregiver role identity:

It can be a challenge to make caregivers understand that this is a full-time role.

To take care of yourself too, which can be hard sometimes [for caregivers] to practice self-care. (Participant 7, Page 2, Lines 70-72)

I think [caregivers need] education about the fact that they are a caregiver. And that this is a job and it's a very important role. It's interesting because I work with people that are both low education and income, as well as some that are highly educated. I had a client with the daughter who was a professor of a local college and she had no idea that she was a caregiver for her mom, not knowing that there were resources out there. (Participant 9, Page 1-2, Lines 44-50)

While caregiving can be a challenging role, when the participants of this study recounted assessing the caregivers they work with, many of the caregivers denied experiencing any burden. This is assumed to be due to an inability to identify as a caregiver, as a close relative often fulfills the caregiving role. Caregivers caring for a loved one reply that it is their 'duty' or an 'honor' as a spouse, child, family member or friend to provide care. Two respondents discussed the possible reasons for the burden of caregiver role identity in respect to the caregiver's ability to accept the loved one's disease and the loss that comes with AD. Participant 4 described the difficulty in accepting AD may be due to a form of denial that the caregiver is experiencing after

losing the emotional connection and psychological relationship with a loved one who has AD.

Lack of supportive resources. To address the many challenges faced by caregivers, social workers reported the lack of resources used and outside help available to provide support to the unmet needs of caregivers of persons with AD. These supportive resources include formal community-based services and informal family help accessible to assist with caregiving duties.

The following three quotes demonstrate this theme of a lack of resources:

Caregivers need to have good support and back up systems. They have to realize that they can't necessarily do it all, so they need to see what other kinds of help we can find. Like through their other family members, church or friends if they can't afford private caregivers. (Participant 5, Page 1, Lines 37-40)

Caregivers experience burnout and stress. Even when they're having their loved one move into a more structured setting, it's still stressful for them. Just making sure that you are there to be a support for them and help them understand the resources that would be available to them. (Participant 7, Page 2, Lines 63-65)

People can't work with somebody with cognitive impairment all on their own and think that they can do it all. The biggest [caregiver] challenge is when people don't have resources, such as other family members or friends, or if they don't belong to a church. Or if they don't have financial assistance. (Participant 3, Page 2, Lines 50-53)

Psychoeducation

This study utilized two questions for the participants to recall community-based care resources in which they educate caregivers on and those that they notice to be a support to caregivers through a psychoeducational intervention. These two questions found similar answers across the collection of nine social workers. Each participant agreed with the need for and benefit of providing psychoeducation of community-based services for persons with AD to support the caregiver.

Community resources. Many of the types of community resources overlapped among the participants. When providing a psychoeducational intervention, participants stated that the resources provided to caregivers often depended on the individual need, as caring for someone with AD looks different for every individual and family.

I provide resources on everything from the county services, depending on income and assets, to paid caregivers. I often have provide Care Options Network information about the Medicare and private pay home care agencies and then talk about the different levels of the agencies and what they can provide. If it's getting too hard at home, then I talk about housing options. [I explain] everything from assisted living options to nursing home level of care. (Participant 3, Page 3, Lines 123-128)

There is a broad continuum of care out there. So I'm educating, depending on what the need is, whether its long-term care, skilled nursing care, secure memory care units, residential housing, home health and companion care services, adult day programs, support groups, and church volunteers. I also share information about specialty doctors, regarding Alzheimer's and dementia,

if they have behaviors. There's really a wide gamut of services, and obviously only talking about what they need. You wouldn't want to overwhelm them with all of that information. (Participant 7, Page 3-4, Lines 142-147)

Supportive services to caregivers. Each participant in this study shared how many of the resources in the community to educate caregivers, give support to the caregiver in that they provide them with respite care, a much needed break from their caregiving duties. The most common resource provided by participant responses was adult day programs.

The following response is an example of supportive resources for caregivers:

I provide resources on adult day programs, home health and companion care, and those that give respite; financial help, if they qualify for waiver services; transportation if the spouse isn't comfortable driving; meals so that the caregiver doesn't have to cook; support groups through the Alzheimer's Association and local churches. We do back-up planning together. Some people have a wealth of information on what they're going to do when they can't care for their loved one anymore, where others are so definitive that their [loved one is] never going to leave, and then that's just a process [to talk through] depending on the level of dementia. With some that are milder dementias in the beginning who can function great in their homes, it's when you take them out that they fall apart. I have so many patients where that's been the case, so we get services that can come to them, like Meals on Wheels or companion care in to the home, rather than having to move. Sometimes it's just nice [for the caregiver] to know that they're not going to have to clean the house today, but can put their energy into

something different. I feel like the resources are endless! It just depends on what they need and how much financial resources are available. (Participant 6, Page 4, Lines 135-149 & 168-171)

Caregiver Strength

Two questions in this study asked the participants about caregiver strengths and how the social worker assesses or notices the strengths each caregiver has that he or she works with. One participant described her assessment of caregiver strengths through asking questions:

During the assessment process, I use questions like, 'What are the things that help you care for your loved one?' and, 'What do you think the strengths are that you bring to in this role in your life and this work?' If they can't answer that directly, then I assume strength and say, 'Wow, how do you find the strength?' 'What do you think it is in you to help you deal what that crisis after your dad fell the other day?' Trying to pull it out of them, so that they can self identify their strengths. (Participant 9, Page 2, Lines 69-76)

Responses to caregiver strengths vary according to participants' role in the community and the stage of the disease in which they commonly work with caregivers. At the beginning stages of AD, the social worker may take more time to assess the person with AD, whereas at the later stages the hospice social workers report more involvement with the caregiver and the person with AD's entire care team. The subthemes of caregiver strengths are knowledge of resources and skills, utilization of support services, and the strength of resiliency to continue providing care for persons with AD.

Knowledge of resources and skills. A strength that participants commonly reported in caregivers of persons with AD is knowledge of both community resources and ability to confidently use their own skills as a resource. Similarly to how a lack of supportive resources available was reported under caregiver burden, it is a strength when a caregiver is aware of, seeking and willing to learn about what resources are accessible for persons with AD. Participant 4 spoke of a caregiver she has recently worked with and how this caregiver has “*taken it upon herself to become educated on Alzheimer’s, and what’s available for support and extra services*” (Page 2, Lines 73-75).

Three participants report knowledge of resources as a caregiver strength:

Caregivers are so amazing! I’m not kidding you! They’re resilient, willing to learn and understand. They talk to their doctors about what they may or may not see going forward. They have the heart and strength to be willing to accept the changes that are coming. (Participant 8, Page 2, Lines 56-60)

I’ve noticed more [caregivers] that have had another family member and are kind of familiar with it. If they are seeking out support, that makes a big difference. It shows they have the skills to seek help and a willingness. They are familiar with various services and are asking for more information. (Participant 3, Page 2, Lines 87-90)

I think that it varies depending on the caregiver of course. For example the caregiver that had been a stay-at-home parent full time to his infant children, he learned a lot from doing that, and calling upon other areas in life. One caregiver, who is a musician and his dad really loved music, so he pulled that into the caregiver relationship. Music was something his dad could still relate to,

even after he was nonverbal. I think pulling skills from loving relationships in the past, whether it's a child, parent, spouse or partner, are definitely helpful in that area. Then whatever skills they may have as a person, like a college professor was really good at documenting things and keeping track of paperwork. She had to do a lot on her mom's behalf. So she pulled some of her own skills into the caregiving relationship. (Participant 9, Page 2, Lines 80-89)

Participant 7 also shared about the skill some caregivers present with of resourcefulness and how this is a strength to provide caregivers with the willingness to seek out, learn, understand and accept the disease. *"The education piece of what their diagnosis is, those that do learn and question. I think there is a strength in having that knowledge"* (Participant 8, Page 2, Lines 71-72). Other resource knowledge mentioned as caregiver strengths were finances, past experience, ability to problem solve, decision-making skills, emotional support and social skills.

Utilization of support services. The participants of this study were asked about the types of community-based resources for persons with AD that are supportive to the caregiver. Participants reported the importance of gaining a sense for the caregiver's willingness to utilize the social worker's suggestions, as many caregivers do not have access to a family system as an outside support network. Utilizing supportive services allows caregivers to receive respite, in hopes of continuing to provide care for the person with AD. It is a strength to be able to simply ask for help and receive a break from the caregiving role.

Three quotes clarify this theme of caregiver utilization of support services:

Most people have been at it for a long time before they get around to asking for help, if they've never experienced this before. Those who do reach out for help, that's huge. I think our society kind of teaches us to do it on your own, but it's ok to ask for help. So often people are pushed to pure exhaustion, or their loved one has wandered away, then they're kind of forced to face it. (Participant 5, Pages 1-2, Lines 50-54)

I think a good strength when I work with a caregiver is knowing their limits, when they need a break, and allowing themselves to take that break. A strength of just being able to take care of their loved one, and their willingness to do that [provide care]. Not everybody can do that. Another strength would be just honoring the person who has Alzheimer's. Giving them dignity the best way that they can and that they know how. Or how the person with Alzheimer's might have wanted towards the end of their life or while they're in this disease. (Participant 4, Page 2, Lines 57-63)

I applaud caregivers that realize that they can't do it on their own. Home care and hospice agencies are really good at finding ways to try to have the caregiver be involved to some degree and then there's a nice transition so that they feel that they're still a piece of the care. I've seen how [care professionals] do this really lovely dance of honoring the caregiver in what they've done all this time, but then also kind of gently taking the reigns, letting them know that they are still a part of the care. These caregivers have a positive outlook on life typically and they're able to just hold on deep when things are hard and hang in there. I love to see it when people have support in their life and they're able to access it.

For me, it's not how much support or who's your support, it's whether you can call them when you need it. (Participant 6, Pages 1-2, Lines 48-64)

Resiliency. Respondents reported that many caregivers have a strong long-lasting relationship with the person they are caring for. Due to this loving familial relationship, caregivers wish to provide the person with AD honor, dignity and respect through the care they provide sacrificially. Because of this admiration or bond with the person with AD, participants reported dedication to having a positive outlook on caregiving duties, which provides a high level of resiliency and the most common caregiver strength noted among participants in this study.

Three respondents illustrate resiliency as a strength for caregivers:

Most of the [caregiver] strengths I see are that they're really dedicated to caring for their family member. They want to do right by them. And typically they will do anything they can to make the right decision. You just have to assure them that you know they're doing everything they can, that sort of thing. They're pretty resilient they kind of, ya know, 'pull up your boot straps' and keep moving. (Participant 2, Page 2, Lines 61-66)

If the caregiver has a base of a real strong and positive relationship [with the person with AD], the caregiver will say, 'it's an honor to provide care!' I don't know if it's a basic love for their family member, but there sure is a strong bond. And I see others that have that, and I don't know if it's just because I'm seeing people in their homes, and those are the ones getting cared for that type of person, I don't know but there is some type of an admiration or a commitment to

caring for them. To some it's their family obligation. (Participant 8, Page 2, Lines 72-78)

A real love for their family member, and a desire to ensure that their family member is still valued and has a good quality of life, in spite of the level of their dementia. ...a willingness to learn, and be open minded about learning ways to care differently that might be more effective and helpful for them.

(Participant 9, Page 2, Lines 63-67)

Social Work Support to Caregivers

At the end of the interviews the participants were given time to share how their role as a social worker is supportive to caregivers when working with persons with AD. All nine participants stressed the importance of providing education on service resources available in order to provide support and empower caregivers to continue caring for persons with AD.

Social work role. Each participant was asked to share about his or her role as a social worker with caregivers of persons with AD. The ways in which social workers assist and support caregivers and assess the need for psychoeducation of community services for AD was discussed. Participant 4 described the social work role as “*providing support and validating what [caregivers] are talking about in their journey*” (Page 1, Lines 29-30).

Three participants shared about the social work role supporting caregivers:

I work quite intensely [with the caregiver] in the beginning, but as time goes on they involve us more for level of care changes or increased care, such as a hospitalization, crisis, or behavior issue. There are different kinds of resources

[for persons with AD], and a lot more empathy and sympathy with dementia caregivers as it has daily struggles. Families are so grateful for a simple piece of information that makes such a huge impact on the care of their loved one.

(Participant 1, Page 1, Lines 10-17)

At our initial home visits, we provide teaching on the stages of dementia as well various community resources that could be helpful to their home environment. By listening to the caregiver and seeing the daily routines and where they need most help during the day. I start slow...to gain their trust.

(Participant 1, Page 2, Lines 82-101)

Most of the time people are wanting to remain in their homes until death, and so my job is to help make sure that they have the community resources, services and problem solving to help make sure they can stay home as long as possible. Then if they can't stay home, helping them transition to the other placements like hospice homes or nursing homes. [I do] a lot of grief counseling and emotional support for caregivers. (Participant 3, Page 1, Lines 9-14)

Other respondents explained the importance of their role with caregivers through spending time listening, asking exploratory questions, normalizing feelings, problem solving, and then ensuring follow-up with continued questions for further understanding of each individual caregiver and person with AD to provide education and support. “*I spend a lot of time listening and providing education on the disease process and normalizing dementia behaviors for family. I help [caregivers] with resources for those that live at home, such as private home care and support groups. My main roles are listening, educating and advocating*” (Participant 5, Page 1, Lines 6-10).

Empowering caregivers. Each of the nine respondents in this study overwhelmingly believed that his or her role as a social worker with older adults empowers and supports the caregivers of their clients to continue providing care for the loved one with AD. The result of social workers providing education, encouragement, validation, positive feedback, gratitude, purpose, and support to caregivers is empowerment. The three main responses on empowerment were education, validation and support for the caregiver. *“I think [caregivers need] encouragement and reassurance that they’re doing a good job because a lot of times they don’t hear that anywhere, that [caregiving] is a job and it’s a very important role”* (Participant 9, Page 1-2, Lines 44-50).

Two respondents shared this belief in empowering caregivers:

I think [empowering means] giving them resources and information, to feel like you’re meeting their needs. Plus, as social workers we’re experts at this, we do this [sharing resources] every day with several families. They’re walking this road for the first time. We’ve walked this road a thousand times and that’s comforting to them that we’ve seen it all! I think it helps to give them the support to walk this road. ...We get to encourage them to use a break from all the duties they’re taking on as a caregiver. I like to say that it takes a village to help someone with Alzheimer’s disease!

As social workers, a lot of what we do is teaching... and giving ideas and resources to support the caregiver. We keep communication open and encourage caregiver that they’re doing it right. I believe this information and relationship as a social worker provides them with comfort, hope, support, encouragement,

and joy! I think we can truly bring them back to a place of enjoyment in their last days. (Participant 1, Page 3-4, Lines 134-151 & 177-182)

Validate what they're doing. Recognize what they're doing. Pointing out their strengths. Saying 'wow you've done such a good job caring for him all these years.' That goes a long way. I've had women get welled up because they said, 'no one's ever said that to me. I've just been doing this because this is what I'm supposed to do.' That's probably the biggest way I try to empower and encourage them to think about what you need. This isn't just about your loved one, this is about you. How can we make sure you get what you need so that you can be the best caregiver you can be. I think that's a message that can be received well. Because people want to be the best caregiver they can be. They want to do a good job.

Genuine validation. Nothing develops rapport and trust with how we're going to move forward in the future than, of course we're assessing everything as a social worker when we come in, but honoring the role of the caregiver is really important. When you honor the role, you develop the rapport and you can move down that path together. (Participant 6, Page 4, Lines 186-201)

Discussion

The results from this study provided strong support for existing literature regarding social workers in the field of aging perspectives on the role of empowering and supporting caregivers of person with Alzheimer's disease. A focus on the use of psychoeducational interventions through community services was of shared importance in previous research as well as this study (Morano & Bravo, 2002; Sussman & Regehr, 2009). In this discussion the researcher will interpret the findings of this study, compare and contrast to existing research, then determine implications for social work practice and future research on the topic of empowering caregivers for persons with Alzheimer's disease.

Interpretation of Findings

The findings of this study were among four themes; caregiver burden, psychoeducation, caregiver strength, and social work support to caregivers. Three of the four themes were found within existing literature. Aligning with the conceptual framework of this study, the strengths perspective brought up an emerging theme of caregiver strength to continue providing care for persons with AD. Several subthemes found were also in support of the existing literature, with three emerging subthemes mentioned; caregiver role identity, resiliency and empowering caregivers.

Caregiver Burden

There are several challenges that caregivers face along the course of the caregiving career. When caring for someone with AD, these challenges turn into stressors, which make caregiving a difficult task for any one person to take on. Research indicates that caregivers have a heavy burden and each of the nine participants responded

with experience that reflected this current research when asked about the needs or challenges that they commonly notice in the caregivers they work with. Caregiver burden and stress was often a result of unmet needs or a lack of supportive resources, as supported by the research in this study's literature review (Cotrell & Engel, 1998; Sörensen et al., 2006; Sussman & Regehr, 2009).

Time. Caregivers are burdened by finding time to care for the person with AD. The results of this study show how a lack of time to perform caregiving duties does not allow caregivers to take time to care for their own physical and emotional health. Prior research mentions the need for a break from caregiving duties (Dal Santo et al., 2007), and the importance of receiving respite care services for the person with AD (Monahan, 1993), but current research does not mention this inability to have time to take a break when caring for persons with AD, as it is a role that has constant needs at all hours of the day.

Caregiver role identity. Caregivers are burdened by the need to transform into a new role of caring for a loved one with AD. This role presents a change in identity in the relationship for many caregivers. This finding subtheme of caregivers not fully understanding the importance of the full-time role of caregiving was not mentioned in existing literature on caregiver burden. Therefore, caregiver role identity is an emerging theme due to the denial of experiencing any burden when caring for a family member.

Many participants of this study recounted how caregivers who are caring for a loved one report that it is an 'honor', rather than a burden, to provide care to the family member displaying the caregiver's coping strategy and inability to identify as serving in the role of a caregiver. Participant 9 shared how she assesses for caregiver identity by

asking how the caregiver, “*finds time for the different roles in life, such as working and caregiving... or [how they are doing] caring for three different people at a time*” (Page 2, Lines 52-54). This same participant shared the isolation felt by those she works with in a caregiver role, perhaps this isolation is the reason for being unaware that they are fulfilling a new role as a caregiver with their loved one.

Lack of supportive resources. Previous research on caregiver burden indicates the use of support groups and day programs as a resource that supports caregivers of persons with AD (Cotrell & Engel, 1998; Sörenson et al., 2002). The findings of this study report similar results in that emotional support and the use of outside resources are a support to alleviate caregiver burden and stress. When asked about the common needs caregivers have, participants reported the lack of resources used and outside help available to provide support to the challenges of caregiving. In addition to the formal community-based services, results displayed the importance of having informal family help accessible to assist the primary caregiver with the caregiving duties. Having access to supportive resources is crucial to alleviating caregiver burden, as many caregivers have a fear to utilize outside help in the early phases of their caregiving career.

Psychoeducational Intervention

This study affirmed existing research in regards to the need for and benefit of providing psychoeducational interventions to caregivers of persons with AD.

Respondents agreed with the current literature on the importance of community resources when educating caregivers (Morano & Bravo, 2002; Sörenson et al., 2002). Additionally, the ways to utilize these resources as a respite service to support the caregiver with day-to-day care duties, and to help caregivers understand the disease process (Fortinsky et al.,

2002; Whitlatch et al., 1995). Participants reported that by providing a psychoeducational intervention of care services, the caregiver will be able to separate the person with AD's needs from the meaning of the relationship.

Community resources. The findings of this study were in support of the existing literature on the need for community resources specific to caring for persons with AD. Participants shared the benefit of caregivers receiving education on outside support resources in the community. Each participant was a licensed social worker, and so much of their role in working with caregivers of persons with AD is providing necessary resources. Many respondents noted that it goes beyond providing a list of community resources, it takes educating the caregiver to ensure the resources are helpful in meeting the needs of the caregiver.

Supportive resources to caregivers. The use of a psychoeducational interventions of community resources for persons with AD was found to be most effective when the resource provided support to the caregiver. By utilizing a service resource for the person with AD, it helps the caregiver to realize that they are not able to do the job of caregiving completely alone. A service that offers a break for the caregiver from caregiving duties is supportive in meeting the needs of the caregiver as it displays the need to utilize care services in order to continue providing care for the person with AD. Participants reported that by educating caregivers about the role of caregiving, it offers less guilt to use outside resources and upholds the importance of the relationship.

Caregiver Strength

Aligning with the conceptual framework of this study, the strengths perspective brought up an emerging theme of caregiver strength in the findings of this study. The

strengths perspective implies that the social work practice approach should utilize client strengths as resources when focusing on change and overcoming problems (Miley et al., 2010). When working with a person with AD who has cognitive impairment, it is vital that the social worker acknowledges and utilizes the strengths of the caregiver to approach any necessary change (Nelson-Becker et al., 2006).

Knowledge of resources and skills. This study has discovered the importance of educating caregivers on service resources to aide in caring for persons with AD. As a social worker, the participants of this study have to determine the existing knowledge of resources and the skills caregiving requires to be able to fully understand the day-to-day challenges that are affecting both the person with AD and the caregiver. Without taking time to acknowledge what strengths the caregiver has, a social worker will not be able to benefit the caregiver, and the caregiver may not feel able to continue providing care without the knowledge of how to access existing resources and skills. Participants recognized caregiver strength through knowledge and skills, then utilized this strength as a resource to help provide better care for the person with AD. Acknowledging that caregivers have existing knowledge and skills to help care providers better understand the person with AD places the caregiver as a resource for social workers to access when setting up care services for clients with AD.

Caregiver utilization of support services. Participants of this study shared understanding with existing literature how the strength of having knowledge of resources is not adequate unless caregivers also have the strength to utilize the support services (Miller & Mukherjee, 1999; Monahan, 1993). Participants share how this goes beyond accessing a support network, but looking to the strength to have the willingness to seek

services out when support is not readily available (Gutheil & Congress, 2000). To discover this form of caregiver strength, participants discuss and assess for an ability to ask for help. Participant 6 spoke about this as a help-seeking skill that all caregivers will need when considering placement for the person with AD, as they will need assistance in making the right decision for care. The results of this study discovered that caregivers who do have family to access, or are utilizing community services for help, seem to have more strength to overcome the challenges of caregiving, with a decreased outcome of disappointment or guilt in their caregiving duties.

Resiliency. The most common response, and emerging theme not mentioned in prior research, was the caregiver strength of resiliency in providing care for persons with AD. Social workers observe resiliency through the caregiver's dedication to caring for the loved one. The results of this study provide strong support for this emerging theme as participants effortlessly recalled several accounts of caregivers displaying resiliency in the caregiver role. Most caregivers have an established, long-standing and positive relationship with the person they are providing care for. This strong relationship allows caregivers to have a positive outlook, learn ways to support themselves, and view this new role as an 'honor' to provide care for the person with AD.

Social Work Support to Caregivers

The purpose of this study was to discover the awareness of social workers working alongside persons with AD have of caregiver burden, utilization of community-based support services, and ability to assess the need for psychoeducational intervention in order to empower caregivers to continue caring for a person with AD in the home environment. The findings of this study supported the importance of social worker's role

in providing education on service resources to discuss need for support and empower caregivers caring for persons with AD.

Social work role. Results supported current research on social worker's role in providing psychoeducation with caregivers of persons with AD (Cotrell & Engel, 1998). With findings supporting the role of educating caregivers on the available service resource and the disease process, one can come to the conclusion that sufficient training and education for social workers is needed. This education to support social worker's role would be on available resources in the community and what the progression of Alzheimer's disease looks like and its need for care services. Additionally, this education allows the social worker to confidently discuss the caregiver's strengths through current and potential knowledge and abilities to provide care.

Empowering caregivers. The role of a social worker empowering caregivers of persons with AD to utilize community services was not mentioned in existing literature. The results of this study support empowering caregivers, through social workers providing education, encouragement, validation, positive feedback, gratitude, and purpose. Utilizing education, validation and support for the caregiver were the three most common responses on empowering caregivers. Participants believed that this empowerment results in uplifting caregiver's attitudes to bring joy back to the role, and meaning into the relationship with the care recipient. This support of empowerment also reaffirms caregiver strengths, normalizes the experience, shows understanding of the important role, and increases hope in caregivers to no longer feel alone or isolated. Participants often spoke when they provide validation and gratitude for the importance of a caregiver's role, they are acknowledging the significance of what the caregiver is

sacrificing. The use of empowerment to allow the caregivers to take care of themselves, as they play an integral role in the care of the loved one with AD was also reported by participants. By receiving this personal validation and education on community-based resources, participants believed that caregivers are better equipped to accept the disease process, and empowered to keep their loved one home longer with a supportive team behind them.

Implications for Social Work Practice

This study interpreted the findings of social workers working with caregivers of persons with AD. With results of emerging topics of caregiver role identity challenges, caregiver strengths, and empowering caregivers, it is evident that the social work profession is in need of a thorough discussion guideline, checklist or assessment tool that includes these three emerging themes to utilize when working with caregivers.

Implications for future social work practice suggest an assessment tool of caregiver strengths for social workers to use as a guideline during care plan discussions with caregivers.

This emerging research on social work practice suggests that professionals should be knowledgeable and well trained on AD care resources in order to educate caregivers, ensuring quality care is provided in the home of persons with AD. Implications of this study for social work practice point to the need for quality educational material that is relevant to caregiver role identity throughout the caregiver's career. Educational material on caregiving for persons with AD would improve training for social workers about caregiver strengths, and the importance of the role of social workers to empower

caregivers through supportive validation. Additionally, social workers will be better equipped to provide psychoeducation of care resources in the community.

Current research displays how social workers are aware of caregivers' experience of burden and stress throughout the role of caring for persons with AD (Cotrell & Engel, 1998; Sörensen et al., 2006; Sussman & Regehr, 2009). Participants in this study shared how lack of time is a source of this burden on the caregiver's physical and emotional health. A lack of sleep is part of this burden, which can cause mental health challenges for caregivers that could be discovered by a clinical social worker through an assessment tool. Another cause of caregiver burden is the change in the caregiver's identity as he or she takes on the new relationship to the care recipient. This theme of role identity confusion causes denial of a caregiver's important job of caring, and unwillingness to ask for help, ultimately causing a lack of utilization of support services. Caregivers can employ the help of a clinical social worker to process this identity change. This implication for social work displays the need for an assessment of a caregivers' diverse causes of burden, allowing the social worker to fully support a caregiver in the journey of caring for persons with AD. Social workers can acknowledge this role confusion through an assessment tool, and work together with the caregiver to discuss and educate on the new role, providing community services as respite.

In addition to recognizing caregiver burdens, social workers should practice discussing and acknowledging caregiver strengths. Validating any present caregiver strengths of knowledge and ability to care for persons with AD is a crucial role of social workers. This practice also points to the need for an on-going caregiver assessment to evaluate caregiver strengths present at all stages of the caregiver's career during their

loved one's disease. When asked about an assessment of caregiver strengths in question 6 of this study's survey (Appendix B), some participants' admitted to not inquiring with specific questions or utilizing a guideline in their work setting to ask the caregiver about strengths, but stay focused on asking about the care receiver. This finding displays that many social workers in this field are assuming that caregivers have knowledge and skills to follow up on the social worker's recommendations, in addition to an ability to confidently provide quality care for the loved one with AD.

Based on the findings in this study, an assessment tool was needed for social workers working caregivers of persons with AD. Therefore, the researcher created a checklist tool with field instructor, Denise Morcomb. They adapted a discussion tool Denise had developed to assess knowledge and abilities of abuse victims. The purpose of this instrument was to discover areas of growth needed for follow-up conversations or visits by the social worker, in hopes to validate current competencies, and assess what to do next. The Caregiver Strengths Assessment Tool (see Appendix D) was then created from this framework, utilizing the researcher's findings in this study. The caregiver assessment asks questions to identify individual needs and strengths to not only validate the caregiver's current knowledge and ability strengths, but also measure the caregivers' desire to be open to learn or possible willingness to change. The outcome of this knowledge and skill assessment tool will discover the caregiver's attitudes towards service use allowing the social worker to recommend appropriate community resources, ultimately affecting future service utilization. Understanding a caregiver's service attitudes and beliefs is important for social workers in counseling families and developing long-term service plans together. Being mindful of the care plan as an on-going service

will require the social worker to follow-up with the caregiver, as the care plan will have a likelihood for change as the care recipient's disease progresses. Additionally, the assessment tool will serve as a discussion guideline or reminder for future engagements or care conferences with caregivers.

Client Name _____ **Initial Assessment Date** _____
Caregiver _____ **Follow-up Dates** _____, _____, _____

Assessment of Caregiver Strengths: Knowledge and Ability

	Confident	Some	Minimal	None
Knowledge of Alzheimer's disease, symptoms, and normal aging process				
Knowledge of role and responsibilities of caregiving (such as power of attorney)				
Knowledge of health insurance, Medicare, Medicaid, elderly waiver and VA benefit				
Knowledge of health care directive, advance planning and/or wishes of care recipient				
Able and willing to collaborate on care plan with various care professional disciplines				
Able to read, write, and use computer to search the internet to provide care				
Able and willing to access community resources (home care, day program, etc.)				
Able and willing to provide care in the home (ADLs/IADLs, safe transfers)				
Understands importance of medication reminders, nutrition and hydration needs				
Able and willing to utilize informal emotional, social, or familial support system				
Comfort in navigating and resolving family conflict in relation to care recipient				
Knowledge of outside formal supports (therapy, support groups, respite care, etc.)				
Knowledge of personal well-being, stress management and coping strategies				
• Able to utilize internal strengths: faith, spirituality, meaning and purpose in life				
• Able to identify values and preferences in				

life, acknowledging belief in self				
• Willing to seek help and share care responsibilities with others				
Knowledge of ambiguous loss, anticipatory grief and end-of-life process of relationship				
Knowledge of plans for life after caregiving, and able to recognize new self identity				

The result of social workers providing education and support to caregivers is a form of empowerment. This finding supported prior literature in this study for the needs of the caregiver and the role of the social worker to fulfill a caregiver's need through a psychoeducational intervention (Bartfay & Bartfay, 2011; Cotrell & Engel, 1998). Social work is a profession that empowers others through recognizing strengths. When social workers empower caregivers to overcome challenges, they are encouraging and validating caregivers to continue caring for the person with AD to the best of their ability. Chapin and Cox (2001) discuss how the practice of empowering another individual allows for the expansion of one's ability to make decisions. Caregivers of persons with AD are in need of empowerment to feel supported and in control of making decisions about care according to their personal experience and knowledge.

There are several service options available in most communities for persons with AD, and it is the role of the social worker to accurately assess each caregiver's need and provide community resources according to both caregiver burden and strengths. The results of this study indicate various knowledge and skill levels for caregivers and social workers of different service backgrounds in the aging field. When a social worker takes time to assess for a caregiver's needs and strengths, in addition to the person with AD, the social worker can validate, support and ultimately empower what the caregiver is currently doing well to care for his or her loved one. This caregiver strengths assessment,

shown in Appendix D, will also allow the social worker to continue to provide empowerment to the caregiver throughout the various stages of the care receiver's disease process. This involvement encourages the caregiver to actively participate in the plan of care, rather than having the social worker only provide education from one perspective.

Implications for Future Research

The results of this study had three emerging themes about supporting caregivers in order to continue providing quality care to persons with AD. Respondents shared the first theme of caregiver struggle with role identity, while the second theme was caregivers with strong resiliency. Leading to the third emerging theme of the opportunity for social workers in the field of aging to empower caregivers of persons with AD. These results show how each caregiver is different in the way they face the duty of caregiving, equally in need of support in this role through education of available and suitable community resources. Due to these emerging topics of caregiver role identity, resiliency and empowering caregivers, it is evident that future research should include looking into the reasons for why each caregiver is so different in the way they view the role of caregiving, asking caregivers what their needs are from professionals in the field of older adults.

Social workers are often providing resources to caregivers at the initial stages of the care recipient's diagnosis or at another time of crisis. Social workers have to be aware that the caregiver may not be able to process all of the resource information during this time. Future research could use caregivers of persons with AD as subjects, asking their impressions of the challenges of caregiving, what gives them strength, what a social worker's role should entail to empower caregivers to continue providing care throughout

the disease process, how often and when is the most beneficial time in the caregiver's career to utilizing a psychoeducational intervention. Future research from a caregiver's perspective can also take a look at the variety of diverse caregivers caring for persons with AD. An individual factor such as the age, gender or cultural background could impact the needs, strengths and view of the caregiving role.

Future research on empowering caregivers of persons with AD should utilize other health care discipline's opinions, in addition to social work. Many health care providers are integrated within the social workers' use of psychoeducation of community resources. In relation to this health care team approach to caring for persons with AD, another topic for research on social workers empowering caregivers could be how social workers share their knowledge of a caregivers' burden and strengths with an interdisciplinary team. When a caregiver assessment tool is in place, future research could ask whether the results being shared with other health care professionals to collaborate on providing the best quality of care for persons with AD.

Too often, social workers are unable to take the time to provide more than one community resource referral, not modifying the support of service resources to the care recipient's stage of the disease and educating their caregiver on appropriate community options. Future research is suggested to assess new intervention materials to include an implementation manual for further training for health care professionals working with AD caregivers and families. A multi-component method could be considered, including more psychosocial interventions and the caregiver assessment tools. Further research can be done on whether an intervention or tool to assess and discuss caregiver strengths has a positive outcome to empower caregivers to have a higher sense of well-being, lower

levels of burden, and an overall outcome of increased quality of life for both the caregiver and care recipient. A practice evaluation study in a specific older adult work setting could evaluate the impact a caregiver assessment has on the plan of care for the provider to serve both the client with AD and the caregiver. This future research could display the benefit of investing more time and money to community services that are supportive to caregivers.

Finally, further research could be performed on discovering the appropriateness of types of assessment tools in various settings, with differing levels of caregiving abilities in response to the stage of AD. Because many participants in this study did not use a particular caregiver assessment tool or discussion guideline, a possible study could look at the available resource tools in working with caregivers and discover the effectiveness they have on caregiver outcomes. Due to the varied amounts of time social workers are able to spend with caregivers, the assessment tool may prove to be simply taking time to hear the caregiver's story, find strengths, and create a plan of action or service recommendations together from the narrative. This future research could discover what the advantages and disadvantages of using a caregiver assessment tool for varied settings and types of caregivers. Caregivers of persons with AD make up a diverse group of people with varying ages, culture, involvement and relation to the care receiver. They also have a variety of skills and understanding of service options and supports in the community. All of this provides abundant opportunity for social workers to be involved in the caring process of persons with Alzheimer's disease.

Conclusion

In conclusion, research indicates evidence that caregivers of persons with AD need the assistance of social workers to access service resources by informing the primary caregivers of community-based support options. Without a known prevention or treatment of AD (Alzheimer's Association, 2014b), social workers play an vital role in supporting family caregivers as the main provider of care for persons with AD. Past and present literature indicates a heavy burden aligning with this care role, therefore, social workers can play an important role in providing a psychoeducational intervention as a support for caregivers. There is often an assumption that social workers should be interested in the area of caregiver support to reduce caregiver burden, recommending various community-based care resources to effectively manage the plan of care for persons with AD. However, there has been a lack of attention on empowerment of caregiver resiliency, through validation and support of possible caregiver strengths, in addition to apparent caregiver burden.

This study found the need for social workers to have a good understanding of both the burden and strengths that caregivers present, a knowledge base of the resources that the community offers to educate and empower caregivers. A psychoeducational intervention will help caregivers of persons with AD to feel supported and more capable of providing adequate care. Participants in this study believed that empowering caregivers results in uplifting caregivers' attitudes to bring joy back to the role, and meaning into the relationship with the care recipient. This empowerment also reaffirms caregiver strengths, shows understanding of the important role, and increases hope and resiliency in caregivers. Social work practice implications suggest a caregiver

assessment tool to further explore a caregiver's service expectations, awareness, and knowledge throughout the caregiving career. With knowledge of various community-based services for persons with AD caregivers are expected to be able to provide a greater quality of care, as the caregiver is encouraged to be involved and supported by social workers during the disease process of the care recipient.

References

- Administration on Aging. (2014). *National Family Caregiver Support Program (OAA Title III E)*. Older Americans Act (1965). Section 371. Retrieved on July 26, 2014 from http://www.aoa.gov/aoaroot/aoa_programs/hcltc/caregiver/index.aspx
- Alzheimer's Association. (2014a). *Alzheimer's facts and figures*. Retrieved on September 13, 2014 from http://www.alz.org/alzheimers_disease_facts_and_figures.asp#impact
- Alzheimer's Association. (2014b). *What is Alzheimer's?*. Retrieved on July 26, 2014 from http://www.alz.org/alzheimers_disease_what_is_alzheimers.asp?type=carecenter_footer
- Bartfay, E., & Bartfay, W.J., (2011). Quality of life outcomes among Alzheimer's disease family caregivers following community-based intervention. *Western Journal of Nursing Research*, 35, 98-116. doi: 10.1177/0193945911400763
- Boss, P. (2011). *Loving Someone Who Has Dementia: How to Find Hope While Coping With Stress and Grief*. Hoboken, NJ: Jossey-Bass.
- Chapin R., & Cox, E. O. (2001). Changing the paradigm: Strengths-based and empowerment-oriented social work with frail elders. *Journal of Gerontological Social Work*, 36(3/4), 165-179. doi: 10.1300/J083v36n03_13
- Chene, B. (2006). Dementia and residential placement: A view from the carers' perspective. *Qualitative Social Work*, 5(2), 187-215.
doi:10.1177/1473325006064257

- Clay, O., Mittelman, M., Madan, A., & Roth, D. (2004). Effectiveness of a multicomponent psychosocial intervention for dementia caregivers in delaying nursing home placement. *The Gerontologist, 44*(1), 575. Abstract retrieved from Social Services Abstracts database. (Accession No. 61349338; 06OP07579)
- Cotrell, V., & Engel, R. J. (1998). The role of secondary supports in mediating formal services to dementia caregivers. *Journal of Gerontological Social Work, 30*(3), 117-132. doi: 10.1300/J083v30n03_10
- Cox, E. O. (2002). Empowerment-oriented practice applied to long-term care. *Journal of Social Work in Long-Term Care, 1*(2), 27-46.
- Dal Santo, T. S., Scharlach, A. E., Nielsen, J., & Fox, P. J. (2007). A stress process model of family caregiver service utilization: Factors associated with respite and counseling service use. *Journal of Gerontological Social Work, 49*(4), 29-49. doi: 10.1300/J083v49n04_03
- Fortinsky, R. H., Unson, C. G., & Garcia, R. I. (2002). Helping family caregivers by linking primary care physicians with community-based dementia care services: The alzheimers service coordination program. *Dementia, 1*(2), 227-240. Retrieved from <http://search.proquest.com.ezproxy.stthomas.edu/docview/61496318?accountid=14756>
- Gaugler, J. E., Kane, R. L., Kane, R. A., & Newcomer, R. C. (2005). Early community-based service utilization and its effects on institutionalization in dementia caregiving. *The Gerontologist, 45*(2), 177-185. Retrieved from

<http://search.proquest.com.ezproxy.stthomas.edu/docview/61522611?accountid=14756>

Getz, L. (2012). Listening to family caregivers what matters most? *Social Work Today*, 12 (2), 28.

Gutheil, I. A. & Congress, E. (2000). Resiliency in older people: A paradigm for practice. In E. Norman (Ed.), *Resiliency enhancement: Putting the strengths perspective into social work practice* (pp. 40-52). New York: Columbia University Press.

Lamb, F. F., Brady, E. M., & Lohman, C. (2009). Lifelong resiliency learning: A strengths-based synergy for gerontological social work. *Journal of Gerontological Social Work*, 52, 713-728. doi: 10.1080/01634370802716216

Miley, K., O'Melia, M. & Dubois, B. (2010). *Generalist social work practice: An empowering approach*. Boston, MA: Pearson/Allyn & Bacon.

Miller, B., & Mukherjee, S. (1999). Service use, caregiving mastery, and attitudes toward community services. *Journal of Applied Gerontology*, 18(2), 162-176. Retrieved from <http://search.proquest.com.ezproxy.stthomas.edu/docview/61622147?accountid=14756>

Mittelman, M.S., Ferris, S.H., Steinberg, G., Shulman, E., Mackell, J.A., Ambinder, A., & Cohen, J. (1993). An intervention that delays institutionalization of Alzheimer's disease patients: Treatment of spouse-caregivers. *The Gerontologist*, 6, 730-740.

- Monahan, D.J. (1993). Utilization of dementia specific respite day care for clients and their caregivers in a social model program. *Journal of Gerontological Social Work*, 20: 3/ 4, 57-70.
- Morano, C. L., & Bravo, M. (2002). A psychoeducational model for hispanic alzheimer's disease caregivers. *Gerontologist*, 42(1), 122-126. Retrieved from <http://search.proquest.com.ezproxy.stthomas.edu/docview/61308496?accountid=14756>
- National Alliance for Caregiving and AARP. (2009). *Caregiving in the U.S. 2009*. NAC and AARP: Mathew Greenwald & Associates. Retrieved from http://www.caregiving.org/pdf/research/Caregiving_in_the_US_2009_full_report.pdf
- Nelson-Becker, H., Chapin, R., & Fast, B. (2006). The strengths model with older adults: Clinical components. In D. Saleebey (Ed.), *The strengths perspective in social work practice* (4th ed.) (pp. 148-170). Boston: Pearson Education, Inc.
- Padgett, D. K. (2008). *Qualitative methods in social work research* (2nd Ed.). Thousand Oaks, CA: Sage. (ISBN 978-1-4129-5193-7).
- Sheafor, B. W. & Horejsi, C. R. (2006). *Techniques and guidelines for social work practice* (7th ed.). Boston: Pearson Education, Inc.
- Sörensen, S., Duberstein P., Gill D., & Pinquart M. (2006). Dementia care: mental health effects, intervention strategies, and clinical implications. *Lancet neurology*. 5(11), 961-73.

Sörenson, S., Pinqart, M., Habil, D., & Duberstein, P. (2002) How effective are interventions with caregivers? An updated meta-analysis. *The Gerontologist*, 42: 3, 356-372.

Sussman, T., & Regehr, C. (2009). The influence of community-based services on the burden of spouses caring for their partners with dementia. *Health & Social Work*, 34(1), 29-40. Retrieved from <http://ezproxy.stthomas.edu/login?url=http://search.ebscohost.com/login.aspx?direct=true&db=swh&AN=59275&site=ehost-live>

Tompkins, S. A., & Bell, P. A. (2009). Examination of a psychoeducational intervention and a respite grant in relieving psychosocial stressors associated with being an alzheimer's caregiver. *Journal of Gerontological Social Work*, 52(2), 89-104. Retrieved from <http://ezproxy.stthomas.edu/login?url=http://search.ebscohost.com/login.aspx?direct=true&db=swh&AN=59572&site=ehost-live>

Venohr, I., Fine, R., Saunders, V., Tenney, E., Vahan, V., & Williams, M. (2001). Improving dementia care through community linkages: A multi-site demonstration project. *Home Health Care Services Quarterly*, 19(4), 51-63. Retrieved from <http://search.proquest.com.ezproxy.stthomas.edu/docview/61476670?accountid=14756>

Weinberger, M., Gold, D. T., Divine, G. W., Cowper, P. A., Hodgson, L. G., Schreiner, P. J., & George, L. K. (1993). Social service interventions for caregivers of patients with dementia: Impact on health care utilization and expenditures.

Journal of the American Geriatrics Society, 41(2), 153-156. Retrieved from

<http://search.proquest.com.ezproxy.stthomas.edu/docview/61599120?accountid=1>

[4756](#)

Whitlatch, C. J., Zarit, S. H., Goodwin, P. E., & Von Eye, A. (1995). Influence of the

success of psychoeducational interventions on the course of family care. *Clinical*

Gerontologist, 16(1), 17-30. Retrieved from

<http://search.proquest.com.ezproxy.stthomas.edu/docview/61602968?accountid=1>

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Appendices

Appendix A. Consent Form

Appendix B. Interview Questions

Appendix C. Interview Flyer

Appendix D. Caregiver Strengths Assessment Tool

APPENDIX A**Consent Form for Interview of Social Workers working with Older Adults****CONSENT FORM****UNIVERSITY OF ST. THOMAS**

Empowering Caregivers of Persons with Alzheimer's Disease
through Psychoeducation of Community Services

IRB Log Number: 690183-1

I am conducting a study about how social workers empower caregivers of persons with Alzheimer's disease through education. I invite you to participate in this research. You were selected as a possible participant because of your current work experience with older adults as a social worker. Please read this form and ask any questions you may have before agreeing to be in the study.

This study is being conducted by: Lindsay Walker, under the advisement of Kendra Garrett, Ph.D., within the University of St. Thomas Social Work Department.

Background Information:

The research question for this study is: How do social workers empower and support caregivers of persons with Alzheimer's disease through the use of a psychoeducational intervention, in response to the awareness of caregiver burden and assessment of the need for community-based support services in the home environment?

Procedures:

If you agree to be in this study, I will ask you to do the following things: Participate in a one-time audio-recorded and transcribed interview, lasting approximately 45 minutes.

Risks and Benefits of Being in the Study:

There are no risks for participants in this study.

The direct benefit you will receive for participating is: A \$10 gift card to a coffee shop for participating in this study.

Confidentiality:

The records of this study will be kept confidential. In any sort of report I publish, I will not include information that will make it possible to identify you in any way. The types of records I will create include a transcribed audio recording of the interview and it will be securely stored

on both my password protected iphone and personal laptop. After the interviews are transcribed, they will be destroyed, along with the recording and any notes taken during the interviews to ensure confidentiality. The transcripts will be kept until May 18, 2015, without any identifying data.

Voluntary Nature of the Study:

Your participation in this study is entirely voluntary. Your decision whether or not to participate will not affect your current or future relations with the University of St. Thomas or myself. If you decide to participate, you are free to withdraw up to one week after the interview. Should you decide to withdraw in that time, I will not use the data and destroy anything collected immediately. You are also free to skip any questions I may ask.

Contacts and Questions

My name is Lindsay Walker. You may ask any questions you have now. If you have questions later, you may contact me at #(763) 300-1317. Kendra Garrett, at #(651) 962-5808. You may also contact the University of St. Thomas Institutional Review Board at #(651) 962-5341 with any questions or concerns.

You will be given a copy of this form to keep for your records.

Statement of Consent:

I have read the above information. My questions have been answered to my satisfaction. I consent to participate in the study. I am at least 18 years of age. I consent to being audio-recorded.

Signature of Study Participant

Date

Print Name of Study Participant

Signature of Researcher

Date

APPENDIX B**Interview Questions for Social Workers working with Older Adults**

- 1. How long have you worked as a social worker with older adults (persons 65+)?**
- 2. Tell me about your roles and responsibilities as a social worker in your current agency?**
- 3. Approximately, what percentage of the clients you are currently working with have Alzheimer's disease or related dementias?**
- 4. When working with a client with Alzheimer's disease, how frequently do you work with the primary caregiver? *Can you describe what this work looks like, and how you might assist these caregivers?***
- 5. What are some of the needs or challenges faced by the caregivers you work with?**
- 6. What strengths do you commonly see in caregivers who seek services? How do you assess for caregiver strengths?**
- 7. What prior skills, abilities and/or knowledge do you notice caregivers have that aide in providing care for individuals with Alzheimer's disease?**
- 8. What kind of education do you provide for caregivers regarding AD? *How do you assess what information to provide and when?***
- 9. What community-based care resources do you educate caregivers on in your role as a social worker? *How? Do you match this information to their needs as they move through the disease process?***
- 10. What types of community-based services for persons with Alzheimer's disease are supportive to the caregivers? *How do you get a sense for their willingness to utilize your suggestions for services?***
- 11. How do you empower caregivers of persons with Alzheimer's disease? *What does empowering caregivers mean to you?***
- 12. Do you believe your role as a social worker empowers these caregivers to continue caring for the older adult with Alzheimer's disease in the home environment? *If so, how?***

APPENDIX C

Interview Flyer for Social Workers working with Older Adults

Recruiting Social Workers for a Research Study on Empowering Caregivers

Support the growth of research on the role social workers play in empowering caregivers of persons with Alzheimer's disease, by providing your personal experience and perspective!

What is the study about?

Psychoeducational interventions of community-based support services for caregivers to continue providing care at home. I would like to learn more about social workers' perspectives regarding the role they play in assessing the need for this intervention to foster empowerment among caregivers facing the burden of caring for persons with Alzheimer's disease in the home environment.

What do I have to do?

You will be requested to participate in a face-to-face interview with the researcher at a meeting location of your choice. Interviews will be in January or February of 2015. The interview should take approximately 30-45 minutes, and will be audio-recorded.

For participating, you will receive a **\$10 gift card** to a local coffee shop!

Am I eligible?

You are eligible if..

- . You are a Licensed Social Worker.
- . You work primarily with older adults and have at least 1-year experience.
- . You are currently working in a setting that provides care for persons with Alzheimer's disease.

For more information or to participate, please contact:

Lindsay Walker – MSW student at the University of St. Thomas

#xxx-xxx-xxxx or xxxxxxx@stthomas.edu

Appendix D

Client Name _____ Initial Assessment Date _____

Caregiver _____ Follow-up Dates _____, _____, _____

Assessment of Caregiver Strengths: Knowledge and Ability

	Confident	Some	Minimal	None
Knowledge of Alzheimer's disease, symptoms, and normal aging process				
Knowledge of role and responsibilities of caregiving (such as power of attorney)				
Knowledge of health insurance, Medicare, Medicaid, elderly waiver and VA benefit				
Knowledge of health care directive, advance planning and/or wishes of care recipient				
Able and willing to collaborate on care plan with various care professional disciplines				
Able to read, write, and use computer to search the internet to provide care				
Able and willing to access community resources (home care, day program, etc.)				
Able and willing to provide care in the home (ADLs/IADLs, safe transfers)				
Understands importance of medication reminders, nutrition and hydration needs				
Able and willing to utilize informal emotional, social, or familial support system				
Comfort in navigating and resolving family conflict in relation to care recipient				
Knowledge of outside formal supports (therapy, support groups, respite care, etc.)				
Knowledge of personal well-being, stress management and coping strategies				
<ul style="list-style-type: none"> • Able to utilize internal strengths: faith, spirituality, meaning and purpose in life 				
<ul style="list-style-type: none"> • Able to identify values and preferences in life, acknowledging belief in self 				
<ul style="list-style-type: none"> • Willing to seek help and share care responsibilities with others 				
Knowledge of ambiguous loss, anticipatory grief and end-of-life process of relationship				
Knowledge of plans for life after caregiving, and able to recognize new self identity				