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Running Head: ALZHEIMER'S DISEASE, SPOUSAL CAREGIVING
RELATIONSHIPS, AND ATTACHMENT

Alzheimer's Disease, Spousal Caregiving Relationships, and Attachment

By Mary G. Sherman

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MSW Clinical Research Paper

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Master of Social Work

Committee Members

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This 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

Alzheimer's disease is the most common cause of dementia in older adults. Due to increased life expectancy and the lack of a current effective treatment or prevention for this disease, a growing number of older couples will face the transition to a caregiving relationship in which one partner has dementia. Studies have shown that spousal caregivers experience a greater strain than adult children in the caregiving role, and that spousal caregivers who are providing care for Alzheimer's related dementia experience the greatest strain of any other caregiving group due to the nature of the Alzheimer's disease process. Studies also suggest that there is significant individual variation in the level of emotional support and distress experienced by the dementia spousal caregiver that can impact the health and well-being of each partner. The aim of this qualitative, exploratory study was to explore if and to what extent Master of Social Work professional use an attachment framework to guide and inform their practice when working with dementia caregiving spouses. Three primary findings resulted from this study. First, MSW professionals noted specific caregiving characteristics that enhanced responsive caregiving. Second, these professionals stated that they did not directly use Attachment Theory, but that components of this were built into their assessment process, thus, indirectly guiding their interventions. Third, MSW professionals felt that applying a more direct attachment lens could add additional dimensionality to inform and guide their practice at least in some situations. Implications for the broader practice of Social Work are discussed, as an attachment lens has the potential to help social workers proactively tailor their counseling or support recommendations for caregivers. Targeted support for caregivers has the potential to decrease caregiving burden and increase well-being. This

in turn has the potential to decrease early institutionalization of the partner with dementia which places further burdens on the health care system.

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Table of Contents

I.	Introduction	5
II.	Literature Review	10
III.	Conceptual Framework	30
IV	Methodology	39
V	Findings	45
VI	Discussion	62
VII	References	72
VIII	Appendices	80

Introduction

Statement of the Problem

Alzheimer's disease (AD) is a specific type of brain disease that is permanent, worsens over time, and is fatal (Alzheimer's Association Report, 2014; National Institute of Aging, 2011). Alzheimer's disease is the most common form of dementia and causes brain cells to degenerate and die (Mayo Clinic, n.d.). The most frequent early symptom of AD is a gradual inability to remember new information because the first areas of the brain to be affected are the regions involved in forming new memories (Alzheimer's Association Report, 2014). As the disease progresses individuals lose their capacity to function independently in every area of their lives (Mayo Clinic, n.d.).

Although age is the primary risk factor for getting AD, the disease is not considered a normal part of the aging process; indeed, ethnicity and gender also represent significant factors that increase risk for getting AD (Alzheimer's Association Report, 2014). African Americans and Latinos are at greater risk than whites for developing Alzheimer's disease due to social, economic and racial inequalities (Fiscella, Franks, Gold, & Clancy, 2000; Alzheimer's Association, 2002; Alzheimer's Association, 2004). In addition, by age sixty, for reasons that are not completely understood, women are more likely to develop Alzheimer's disease during the remainder of their lives than men are (Alzheimer's Association and National Alliance for Caregiving, 2004; Alzheimer's Association Report, 2014; Skelton & Geiger, n.d.; Viña & Lloret, 2010). This gender related phenomenon "cannot be simply attributed to the higher longevity of women versus men" (Viña & Lloret, 2010, p.S527).

The increase in life expectancy, particularly in the United States and Europe, “has been associated with a parallel increase in age-related diseases” (Vina & Lloret, 2010, p.527). The prevalence of AD will continue to expand because of the continuing aging of the population as a whole (United Nations, 2013). Due to the increased frequency and the nature of the Alzheimer's disease itself, a growing number of older married couples will face major changes in their relationships when one partner develops AD and the other takes on a caregiver role.

Caring for individuals with Alzheimer's disease is challenging because of how the disease progresses. People with AD lose the ability to understand their environment; they frequently become disoriented and misinterpret the environment, and can also have increasing difficulty with speaking and writing as well as with thinking and reasoning. People with AD also progressively lose the ability to make sound judgments and decisions, as well as planning for and performing familiar tasks. Moreover, changes in personality and behavior are also common as a result of AD and may lead to neuropsychiatric problems such as paranoia, delusions, hallucinations, and aggressive, even violent, behaviors (Mayo Clinic, n.d.).

A transition from a traditional relationship to an AD caregiving role is often difficult and especially stressful because the type of care provided is more physically and emotionally demanding and more time-consuming than other kinds of caregiving (Alzheimer's Association & National Alliance for Caregiving, 2004). In addition, this transition is difficult because it drastically changes the historic roles, responsibilities, and ways of relating the couples previously experienced, and can threaten the emotional connection that spouses may feel with each other (Dankoski, Davies, Gregory, 2007).

The shift from a traditional relationship to a caregiving and care-receiving role is often linked with negative outcomes for the caregiver as well as for the marital relationship as a whole (Braun, Scholz, Bailey, Perren, Hornung, & Martin, 2009).

Caregiving situations may also have external, positive and negative influences. Risk factors that influence individual caregiver outcomes include gender, being the spouse of the person with dementia, having a lower level of education, having fewer social skills thus being more socially isolated, and having fewer financial resources to pay for needed support services (Pinquart & Sorensen, 2003). Individual factors that appear to have a protective effect on caregiver outcomes include the ability to think in a positive way when faced with challenging situations, having a sense of competence, and a belief in one's own ability to provide care (Bekhet, 2013).

Couples face complex relationships to begin with, but AD complicates things to a much greater extent. As a direct result of the Alzheimer's disease process spouses with dementia are less able to maintain their emotional connection within the relationship. Spousal caregivers to individuals with dementia experience a significant decline in happiness, feel the relationship is no longer equal, and experience a deterioration in the sexual aspects in the marital relationship (Braun et al., 2009; Gallagher-Thompson, Dal Canto, Jacob, & Thompson, 2001; Eloniemi-Sulkava, Notkola, Hamalainen, Rahkonen, Viramo, & Hentinen, 2002). However, some spouses also report caregiving as self-fulfilling and affirming at the same time as they are experiencing negative changes in the relationship (Braun et al., 2009; Gallagher-Thompson, Dal Canto, Jacob, & Thompson, 2001).

Even considering the challenges of external impacts on relationships, and the unpredictable changes that AD can bring to couples, there are factors that are protective to the relationship. These factors may enhance caregiver resiliency and include the quality of past and present relationship, the amount of affection the caregiver feels for the care recipient, and having engaging activities that can be enjoyed by each spouse (Beckhet, 2013). Indeed, effective caregiving requires a number of skills and abilities as well as the emotional resources to perceive, evaluate, understand and control emotions. Individual differences appear to exist for triggering burden and ability to cope with caregiving responsibilities. Attachment Theory may help identify factors that explain the difference in thresholds that trigger burden and caregiving outcomes because attachment beliefs about the self seem linked to beliefs about providing care to others (Feeney & Collins, 2001, p.974).

Theoretical Framework

A psychological model called Attachment Theory provides the framework used in this research study to shed light on the caregiving process. Attachment Theory states that the need for security is a fundamental need for humans, and provides a way to understand the complex attachment-caregiving bond (Feeney & Collins, 2001). Attachment is believed to be a behavioral system that starts in infancy and extends throughout life. The function of attachment is to assure that reliable relationships will be established that can be counted on for emotional support and physical protection in times of distress (Sable, 2008). The primary goal of this behavioral system is to maintain a feeling of security (Feeney and Collins, 2001). Thus it is heavily influenced by early life caregiving experiences. Through these experiences, individual expectations, responses,

interpretations, and beliefs about oneself and relationships are shaped (Besser & Priel, 2008) and impact a wide range of social and emotional outcomes later in life (Carpenter, 2001; Feeney & Noller, 1996; Rothbard & Shaver, 1994). Research also suggests that attachment behaviors are most likely to be triggered and experienced during the beginning and end of life, the two time periods generally depicted as having the greatest dependency and need (Magai & Consedine, 2004).

According to Attachment Theory, caregiving like attachment is identified as another safety-regulating system that is intended to reduce the risk of harm (Feeney & Collins, 2001). Caregiving includes a wide range of behaviors designed to provide comfort and reassurance (Feeney & Collins, 2001; Bowlby, 1980, 1982; Kunce & Shaver, 1994). Attachment Theory suggests that beliefs about providing care to others are built on previous experiences of receiving care (Feeney & Collins, 2001). Thus, the quality of effective caregiving will be influenced by the quality of previously experienced caregiving interactions.

Research has shown that effective caregiving requires a number of skills and emotional resources that individuals have in varying degrees. These skills and emotional resources may be helpful in predicting the quality and effectiveness of caregivers as they provide care (Feeney, Collins, 2001). Attachment Theory is one way to understand the variation that is seen in the ability of caregivers to provide support, and in the levels of distress they experience during the dementia caregiving journey.

Purpose of the Study

The purpose of this research study was to explore professional thoughts of attachment within spousal caregiving dyads when one partner had Alzheimer's disease. My specific research question was twofold: First, do clinicians use an attachment framework when working with couples when one partner has dementia? And second, do clinicians think that Attachment Theory helps to inform their practice?

Research Question and Hypothesis

My hypothesis was that in general, clinicians do not consciously use an attachment framework during their assessment and treatment process. However typical information gathered during the assessment phase can be linked back to client attachment beliefs about self and others. Clinician interventions may be therefore be enhanced by a more direct and conscious use of an attachment framework to tease apart individual variation in the level of emotional support and distress experienced within the marriage relationship during their journey through the course of the disease.

Literature Review

For this study, the literature review was focused on three major areas: the impact of Alzheimer's disease on the care receiver, the impact of Alzheimer's disease on the caregiver, and the impact of Alzheimer's disease on the spousal relationship as a whole.

The Impact of Alzheimer's Disease on the Care Receiver

What is Alzheimer's Disease?

Alzheimer's disease is a specific form of dementia. It is a brain disease that is "irreversible and progressive . . . and slowly destroys memory and thinking skills and

eventually even the ability to carry out the simplest tasks” (National Institute on Aging, 2011, p.1). AD is caused by an accumulation of proteins called “beta-amyloid” plaques within the brain. As more plaques form, healthy neurons work less efficiently, and eventually lose their ability to function and communicate with each other and die (UCSF Memory and Aging Center, n.d.). Researchers still don’t know what starts the disease process, but they believe that damage to the brain begins as many as ten to twenty years before any problems are noted (Alzheimer’s Association Report, 2014).

Alzheimer’s disease is the most prevalent type of dementia and most frequently diagnosed type of dementia (Alzheimer’s Association Report, 2014). It accounts for 60-80 percent of those with dementia and is “officially listed as the sixth-leading cause of death in the United States” (Alzheimer’s Association Report, 2014, p. e58; US Department of Health and Human Services, 2014). Although the primary risk factor for getting Alzheimer’s disease is age, it is not a normal part of the aging process and age alone does not cause the disease (Alzheimer’s Association Report, 2014). At this time there is no known cure for Alzheimer’s disease, no treatment that can slow the progression, and is ultimately fatal (Alzheimer’s Association Report, 2014).

Symptoms of Alzheimer’s Disease

Although the symptoms related to Alzheimer’s disease may emerge differently in different people, the most common early symptom is a gradual inability to remember new information, such as recent conversations and names or events and which worsens over time. “This occurs because the first neurons to malfunction and die are usually neurons in brain regions involved in forming new memories” (Alzheimer’s Association Report,

2014, p.e48). Lack of interest, feeling, or concern as well as symptoms of depression are also often early symptoms of Alzheimer's disease (Alzheimer's Association Report, 2014).

As the disease progresses, symptoms frequently include disorientation and misinterpreting the environment, increased difficulty with speaking and writing, and difficulty with thinking and reasoning, especially about abstract concepts (Mayo Clinic, n.d.). AD also affects the ability to make sound judgments and decisions, as well as planning and performing familiar tasks (Mayo Clinic, n.d.). Changes in personality and behavior are also common as a result of the brain damage caused by AD and may lead to psychiatric behavior problems such as paranoia, delusions and hallucinations (Mayo Clinic, n.d.).

Risk Factors for Developing Alzheimer's Disease

Age is the leading risk factor for developing Alzheimer's disease, and the population of the United States as well as the world is aging rapidly. (Alzheimer's Association Report, 2014; Alzheimer's Disease International, 2013). It is estimated that the number of individuals age 65 and older in the United States is expected to more than double from 43 million to 92 million between 2012 and 2060 (United States Census Bureau, 2012). This magnitude of an aging population is unprecedented in human history (United Nations, 2013). In the United States, the growth in the population is due to the 'baby boom' generation beginning to reach retirement age however population aging is a global phenomenon (United Nations, 2013). According to the United Nations World

Population Aging Report (2013), the young-to-old balance is shifting throughout the world and the trend will last because people are increasingly likely to live longer.

In the United States, it is currently estimated that 5.2 million Americans have Alzheimer's disease and related dementias, and this number is projected to be 13.8 million by 2050 (Alzheimer's Association Report, 2014; Herbert, Weuve, Scherr, & Evans, 2013). In addition, it is believed that 26.6 million individuals had Alzheimer's worldwide in 2006, and by 2050 it is estimated that this number will quadruple to over 100 million (Brookmeyer, Johnson, Ziegler-Graham, & Arrighi, 2007). Of this 100 million individuals projected to be diagnosed with Alzheimer's by 2050, it is estimated that forty-three percent will need a high level of care, such as what is typically provided in a long-term care facility (Centers for Disease Control and Prevention, 2013). These numbers suggest that AD will place an enormous burden on the United States' and the global health care systems.

Generally, Alzheimer's type symptoms first appear after age 60 (National Institute on Aging, 2011), but up to five percent or 200,000 are younger than 65, and may be as young as their 40s or 50s when diagnosed with younger-onset AD (Alzheimer's Association Report, 2014). Of the Americans age 65 and over, 1 in 9 has AD, and of those 85 and older, 1 in 3 has the disease (Alzheimer's Association Report, 2014). Projections of the further prevalence of Alzheimer's disease and related dementias within the next 50 years is expected to nearly triple to an estimated 13 million in the United States with some estimates as high as 16 million (American Journal of Public Health, 1998; Bekhet, 2013; Bredesen, 2014; Robertson et al., 2007).

Gender is also a risk factor for developing AD. Recent research indicates that the prevalence of AD is higher in women than in men (Viña & Lloret, 2010). Some research appears to indicate that the higher percentage of AD in women can be related to the fact that women live longer than men in general (Alzheimer's Association Report, 2014; Seshadri, Beiser, Au, McNulty, & White, 1997; Scherr, McCann, Beckett, & Evans, 2001). However, other research indicates that the higher prevalence of AD in women cannot be "simply attributed to the higher longevity of women versus men" (Viña & Lloret, 2010, p.527).

Race is an additional risk factor for developing AD. The Alzheimer's Association indicated in its 2010 Alzheimer's Disease Facts and Figures report, that African Americans are about 2 times more likely and Latinos are about 1.5 times more likely to have AD and other dementias than whites (Alzheimer's Association Facts and Figures, 2010). In addition the Alzheimer's Association released a report *African-Americans and Alzheimer's disease: The silent epidemic* (2002) indicating that there is a "growing body of evidence that vascular disease may be a key mechanism in triggering the manifestation of AD" (p.1). African-Americans have a higher risk for developing vascular disease than whites. The prevalence of AD in African-Americans is estimated to range from fourteen percent to almost one-hundred percent higher than whites (Alzheimer's Association, 2002). Similar findings have been found in regards to Latinos/Hispanics. Latinos have high rates of diabetes, sixty-four percent higher than non-Hispanic white Americans, and "diabetes is the one vascular risk factor related to risk of Alzheimer's disease in the absence of stroke" (Alzheimer's Association, 2004, p.3). Research suggests that "high

blood pressure, heart disease, diabetes, and stroke are known risk factors for Alzheimer's disease" (Alzheimer's Association, 2010, p.55)

Finally social and economic factors, such as having a "low level of education and low income are also associated with greater risk for AD" and African-Americans and Latinos are overly represented among these disadvantaged groups in the United States (Alzheimer's Association, 2010, p. 57; Williams, 2010). Although African-Americans and Latinos are more likely than whites to have AD, they are less likely to be diagnosed, ultimately resulting in less treatment and planning (Alzheimer's Disease Facts and Figures, 2010). Research suggests that African-American and Hispanics recognize the value of having a diagnosis, but there are often long delays between the recognition of the symptoms of dementia onset and the scheduling of a medical evaluation (Alzheimer's Association, 2010; Williams, 2010). Delays in diagnosis translate into less treatment during the earlier stages of the AD process, when possible treatments are more likely to be useful (Alzheimer's Association, 2010; Williams, 2010).

Impact of Alzheimer's Disease on the Caregivers

Who are the Caregivers

Spouses and adult children primarily female are the principal providers of care. According to the National Alliance for Caregiving (2004), families are the primary long term care providers for individuals living with Alzheimer's disease in the United States, with spouses and adult children making up approximately seventy-five percent of those providing care (Gallup Healthways Well-being Survey, 2011; Family Caregiver Alliance, n.d.). In addition, more than 3 in 5 unpaid Alzheimer's caregivers are women, and there

are 2.5 times more women than men who provide on-duty care 24-hours a day for an individual with AD (Alzheimer's Association Factsheet, 2014).

Spouses suffer a greater strain than adult children in the process of providing care (Braun et al., 2009). According to a study conducted by Horowitz and Shindelman (1983) adult children caregivers showed a trend towards a closer emotional bond to the care recipient during the process of providing care. However, spousal caregivers were negatively influenced by the need to provide care and showed a tendency towards a less close emotional bond (Braun et al., 2009; Howowitz & Shindelman, 1983). This negative trend appeared to be related to the impact of AD on the marital relationship (Braun et al., 2009).

The Caregiving Experience

The strains that caregivers experience have been termed caregiver burden (Pinqart & Sorensen, 2003). Caregiver burden has been described as "the negative reaction to the impact of providing care on the caregiver's social, occupational, and personal roles and appears to be a precursor to depressive symptoms" (Reinhard, Giver, Petlick, & Bernis, 2008, p. 1-344). This definition emphasizes the multidimensional way that caregiving may affect those providing care and how individualized the caregiving role is experienced (Adelman et al., 2014).

Caregivers of persons with Alzheimer's disease experience a particularly heavy burden of care compared with other caregivers due to the global, progressive and permanent nature of the AD process (National Alliance for Caregiving, 2004). Research has shown that Alzheimer's caregiving is more physically and emotionally demanding

and more time-consuming than other kinds of caregiving (National Alliance for Caregiving, 2004; Alzheimer's Association Report, 2014). Due to the nature of AD and the progressive and permanent decline in physical and cognitive functioning, individuals with Alzheimer's dementia require ongoing and increasingly intense support in all areas of daily functioning both physically and emotionally.

Types of Caregiver Burden

Based on a meta-analysis of caregiver burden and depressive mood, Pinquart and Sorensen (2003) suggest that caregiver burden has two dimensions: objective burden which relates to the difficulty of the specific responsibilities of caregiving tasks, and subjective burden which relates to the psychological emotional reactions of the caregiver such as worry, anxiety, frustration and fatigue (Crispi, Schiaffino, & Berman, 1997).

Time Consuming Nature of Dementia Caregiving

According to the 2014 Alzheimer's Association poll, about half of all caregivers spent twenty hours or less each week performing caregiving duties. However, there is a distinct group of caregivers who provide care twenty-four hours a day (National Alliance for Caregiving, 2004; Alzheimer's Association, 2014) This group, which makes up twenty-three percent of Alzheimer's caregivers, provides forty or more hours of care per week (National Alliance for Caregiving, 2004; Alzheimer's Association Report, 2014).

Duration of Caregiving

Duration of caregiving is type of burden. Caregiving for someone with Alzheimer's disease, on average, lasts for a longer time period than caregiving for older

adults with other conditions (Alzheimer's Association Report, 2014). According to the Alzheimer's Association Report (2014), "forty-three percent of caregivers of people with Alzheimer's and other dementias provide care for one to four years compared with thirty-three percent of caregivers of people without dementia." (p. e63) In addition, "thirty-two percent of dementia caregivers provide care for over five years compared with twenty-eight percent of caregivers of people without dementia" (Alzheimer's Association Report, 2014, p.e63). According to the Alzheimer's Association individuals age 65 and older live for an average of four to eight years after a diagnosis of Alzheimer's, with some living as long as twenty years (Alzheimer's Association Report, 2014). Ott, Sanders, and Kelber (2007) found a somewhat different result, and indicate that caregiving for someone with dementia lasts an average of eight years.

Rate of Deterioration in Functional and Cognitive Abilities

The physical aspects of caregiving are an additional type of burden. The type of care provided to persons with Alzheimer's disease is often more physically draining than caring for other types of diseases and conditions (National Alliance for Caregiving, 2004). Two-thirds of Alzheimer's caregivers help with one or more Activities of Daily Living (ADL's). ADL's can include tasks such as getting out of bed, getting dressed, getting to and from the toilet, bathing, and feeding (National Alliance for Caregiving, 2004). Alzheimer's caregivers are significantly more likely than other caregivers to help with the most difficult ADL tasks such as incontinence, bathing and feeding. In addition, Alzheimer's caregivers are more likely to provide assistance with Instrumental Activities of Daily Living (IADL's) such as managing medicines, finances, grocery shopping, housework, preparing meals, transportation, as well as arranging or supervising other

caregiving support services (National Alliance for Caregiving, 2004). According to Yeager, Hyer, Hobbs, and Coyne (2010) IADLs increase caregiver burden significantly.

Caregiver Perception of the Severity of Problematic Behaviors

Subjective dimensions of caregiving are related to emotional reactions. The type of care provided to persons with AD is more emotionally draining than with other long term caregiving. Forty-one percent of Alzheimer's caregivers state they have a "great deal of emotional stress," compared to thirty-one percent of all other caregivers (National Alliance for Caregiving, 2004, p. 2). Psychiatric behavior problems such as paranoia, delusions and hallucinations significantly increase caregiver burden more than poor cognition according to research by Yeager and others (2010). Other psychiatric behavior symptoms that may also need to be managed when caring for someone with Alzheimer's include agitation, restlessness, disturbed sleep, aggression and depression (Yeager et al., 2010). According to Yeager and others (2010), studies have documented an Alzheimer's prevalence of psychosis related behaviors between 10-73 percent, and prevalence of depression in those with Alzheimer's disease ranging from 10-50 percent depending on the sample, dementia stage, and psychological measurement instrument used (Yeager et al., 2010).

Perception of Caregiving Adequacy

Psychological perceptions of caregiving adequacy and caregiving coping style are variables that impact caregiver burden (Crispi et al., 1997). Caregivers who perceive distress in the care recipient are more likely to experience caregiver burden (Adelman et al., 2014). Coping strategies can either exacerbate or reduce burden. Examples of coping

strategies that have the potential to reduce burden could include, seeking advice, problem-solving to determine solutions, engaging in relaxing activities and seeking active support from others. Having fewer coping strategies was associated with caregiver burden (Adelman et al., 2014; Kim, Chang, Rose, & Kim, 2012). Lack of coping skills was a significant predictor of depression (Crispi et al., 1997). Social isolation and decreased social activity are variables that impact caregiver burden (Adelman et al., 2014; Rodakowski, Skidmore, Rogers, & Schulz, 2012). Depression, depressive symptoms and anxiety are risk factors for caregiver outcome as well as caregiver burden (Adelman et al., 2014; Gallagher, Rose, Rivera, Lovett, & Thompson, 1989). Finally, chronic stress related to being a dementia care provider is a risk factor for level of burden. This chronic stress has been shown to have significant consequences on the caregiver's physical and mental health, and overall well-being (Crispi et al., 1997) and often leads to high levels of anxiety and depression and more physical ailments (Crispi et al., 1997; Braun et al., 2009; Pinquart & Soerensen, 2003).

In summary, the time consuming nature of AD caregiving along with the rate of overall physical decline, the deterioration in cognitive abilities and the ability to perform basic tasks, the severity of problematic behaviors, and perceptions of the caregiving experience, all influence caregiver burden (Perren, Schmid, Hermann, & Wettstein, 2007; Braun et al., 2009; Crispi et al., 1997).

Risk Factors for Caregiver Burden

Research has suggested that there are numerous variables and risk factors that may influence caregiver burden. Gender is a risk factor for becoming a caregiver and

studies suggest that women are more likely than men to take on a caregiving role and to be providing care to individuals with greater cognitive and physical limitations (Crispi et al., 1997; Ory, Yee, Tennstedt, & Schulz, 2000). The type of relationship is also a risk factor for caregiver burden, and being a spouse is a more significant risk factor for caregiver burden than being an adult child care provider (Pinquart & Sorensen, 2003). This is likely due to the fact that spousal caregivers live with the care recipient, frequently have little choice in becoming the caregiver, are less aware of the toll that caregiving is taking on them, and often suffer from age-associated chronic illness (Pinquart & Sorensen, 2003; Connell, Janevic, & Gallant, 2001; Adelman et al., 2014). Low educational attainment is a risk factor for caregiver burden due to the link between socioeconomic status and poor health (Burton, Zdaniuk, Schulz, Jackson, & Hirsch, 2003; Mechanic, 2000). Social isolation is yet another risk factor for caregiver burden: the time consuming nature of caregiving responsibilities, fear of a care receiver's inappropriate behavior, and the level of family support can add to and affect caregiver burden (Adelman et al., 2014). Finally, financial stress is also a risk factor for, and an outcome of, caregiver burden. Formal caregiving services can be expensive and are frequently not covered by insurance (Adelman et al., 2014).

Protective Factors for Caregiving

As a counterbalance to the risk factors for caregiving burden discussed in the section above, Feeney and Collins (2000) talk about three essential skills that are necessary for effective caregiving, and which provide some protection from the burdens that are likely to be felt by caregivers. The first relevant skill is to have flexibility to provide care to a range of needs. Flexibility includes the knowledge about how, and what

type of care is needed, as well as the ability to empathize and take the perspective of the other individual, and the social skills to recognize their needs. The second skill is the ability to have adequate emotional and material resources. This means having the self-insight to be aware of emotions and slow down to remain calm. When emotions are calm the brain is more able to access information, have empathy, and identify creative strategies that all help to enhance the caregiver's responsiveness to address needs. The third skill is the motivation to provide care. Caregiving involves a lot of responsibilities, as well as a number of cognitive and emotional skills and abilities. Caregivers must be motivated to accept that responsibility and put in the effort and time required to provide effective support. (Feeney and Collins, 2001, p. 974).

Impact of Alzheimer's Disease on the Marriage Relationship

There has been relatively little research regarding the impact of AD on the marriage relationship, although some qualitative studies exist (Baikie, 2002; Braun et al., 2009; Perren et al., 2007). From the perspective of the dementia caregiving spouse, Alzheimer's disease negatively impacts the marriage relationship. Dementia caregiving spouses experienced a significant decline in happiness, believed the relationship was no longer equal, and felt there was deterioration of the marital sexual relationship (Braun et al., 2009; Gallagher-Thompson et al., 2001; Eloniemi-Sulkava et al., 2002). Wright (1991) did a study comparing caregiving and noncaregiving spouses' perceptions of the marital relationship. He found that caregivers and care receivers showed a greater difference in how they answered questions about their perceived marital quality when compared to healthy couples. Individuals with dementia perceived marital quality higher and reported more sexual activity than their caregiving partner (Braun et al., 2009).

In 2001, Gallagher-Thompson and others studied spousal interactions within the marriage relationship. This study compared communication patterns between caregiving and noncaregiving couples. Core differences were found between caregiving and noncaregiving wives. "Noncaregiving spouses were more interactive and expressed more support to each other" compared with caregiving spouses (Braun et al., 2009, p. 432). The authors of this study used a cross-sectional research design and observational methods to "capture the dyadic interaction and to compare communication patterns between caregiving and noncaregiving dyads" (Braun et al., 2009, p. 432; Gallagher-Thompson et al., 2001). Since this study was cross-sectional, future research is needed to better understand communication patterns in couples with dementia.

An additional study by Perren, Schmid, Herrmann, and Wettstein (2007) assessed the impact of dementia on the marriage relationship by specifically looking at attachment styles of caregiving spouses and their partners (Braun et al., 2009). The authors of this study found that "the attachment styles of both spouses were significantly associated" (Perren et al., 2007, p. 163). The more the caregiver avoided closeness and dependency from the care receiver, the more the care receiver displayed agitation and aggression (Perren et al., 2007, p. 174) Research by Perren and others (2007) suggested the quality of the caregiving interactions were significant. They also suggested that caregiving spouses who provide care out of obligation, but prefer to avoid emotional closeness, may display ineffective caregiving behavior that fuels the care receiver's resistance to being helped (Perren et al., 2007). This is significant since agitation, aggression, and delusions are strongly associated with caregiver burden and the decision to institutionalize (Perren

et al., 2007). This may result in an additional threat to the attachment relationship for both spouses (Perren et al., 2007).

In summary, the strains of caregiving will be the most intensely felt by African-Americans (Alzheimer's Association, 2010; Alzheimer's Association, 2002), Hispanics (Alzheimer's Association, 2004), females (Alzheimer's Association Report, 2014; Viña & Lloret, 2010), and the spouse of the person with dementia (Pinquart & Sorenson, 2003; Horowitz & Shindelman, 1983). Caregivers who are less educated (Alzheimer's Association, 2010; Burton et al., 2003; Mechanic, 2000; Adelman et al., 2014), more socially isolated (Adelman et al., 2014; Alzheimer's Association, 2010), and less financially secure (Alzheimer's Association, 2010; Williams, 2010) will also feel the strains of caregiving more intensely.

The demands of caregiving will be felt in physical and emotional ways because dementia caregiving is more labor and time intensive than any other type of caregiving (Alzheimer's Association Report, 2014; National Alliance for Caregiving, 2004). Alzheimer's caregivers are most likely to help with the most difficult and time-consuming ADL tasks (Alzheimer's Association Report, 2014, National Alliance for Caregiving, 2004). They are also more likely to manage and assist with time consuming and labor intensive instrumental activities of daily living (Alzheimer's Association Report, 2014; National Alliance for Caregiving, 2004) and manage behavior problems (Yeager et al., 2010). Spouses are more likely to provide on-duty care twenty-four hours a day (Alzheimer's Association Report, 2014; Braun et al., 2009). The duration of Alzheimer's caregiving lasts longer than other types of caregiving, and on average will last four to eight years (Alzheimer's Association Report, 2014).

Protective Factors for the Marriage Relationship

Although caregiving spouses experienced negative changes in their marital relationship, they also reported aspects of caregiving as self-fulfilling and affirming (Braun et al., 2009; Gallagher-Thompson et al., 2001). Protective factors that may enhance caregiver resiliency include the quality of the past and present relationship, and amount of affection the caregiver felt for the care recipient (Braun et al., 2009; Horowitz & Shindelman, 1983). Spousal caregivers with a good past and present relationship are “more committed less depressed and more likely to find gratification in caring for their spouse” (Braun et al., 2009, p. 430; Horowitz & Shindelman, 1983). Affection helps build or enhance caregiver resiliency, and may result in less negative perceptions of caregiving demands (Braun et al., 2009; Horowitz & Shindelman, 1983).

In addition, activities that can be shared and enjoyed by both partners help to protect the marriage relationship. A study conducted by Searson, Hendry, Ramachandran, Burns, and Purandare, (2008) researched whether activities enjoyed by both the caregiving and care receiving spouse influence caregiver strain. Results indicated that activities enjoyed by the spouses together enhanced caregiver well-being (Searson et al., 2008). Examples of activities that could be enjoyed by both partners included reminiscing about childhood events, engaging in regular exercise, listening to music, putting together puzzles, folding laundry, and looking at old photographs.

A new type of activity – Memory Café – that can be enjoyed by both caregiving and care receiving individuals was developed in 1997 in the Netherlands. The activity involves neighborhood based meeting places where individuals and their caregivers can

meet, have conversation, find support, share concerns, and celebrate without feeling embarrassed or misunderstood; they are organized, maintained, and sustained by the people who attend the Memory Café (Third Age Services, n.d.). The goal of the Memory Café is to provide a safe place to socialize, and to promote and restore a sense of “normalcy” for the person with a dementia related diagnosis, family members, and caregivers (Third Age Services, n.d.). The United Kingdom started offering Memory Cafés in 2000, and the first Memory Café opened in the United States in 2008.

From the findings of research designed to study both the caregiver and care receiver perspectives, Braun and others (2009) concluded that it is important to examine how both partners experience the caregiving-receiving relationship, and that “consideration of the ‘couplehood’ is essential to attain a better understanding of how spouses live with dementia” (p. 432). Furthermore, understanding how the partners’ perspectives are similar and different is relevant for research questions, theory building, and practical interventions (Braun et al., 2009).

In summary, the quality of the relationship, the amount of affection the caregiver feels for the care recipient, and a continued commitment to the caregiving role appear to be important factors in the caregiver experiencing greater well-being, lower burden, lower depression and higher caregiver competence (Braun et al., 2009; Horowitz & Shindelman, 1983; Searson et al., 2008).

Perceptions of caregiving adequacy impact the emotional burden of the caregiver (Crispi et al., 1997). Effective caregiving requires three essential elements: relevant skills and abilities, adequate emotional and material resources, and the motivation to provide

care (Feeney & Collins, 2001). Having fewer coping strategies, being socially isolated, experiencing depression and anxiety are risk factors for caregiver outcome as well and have a significant impact on the caregiver's physical health, mental health, and overall well-being (Adelman et al., 2014; Kim et al., 2012; Crispi et al., 1997; Rodakowski et al., 2012; Gallagher-Thompson et al., 2001; Braun et al., 2009).

Implications for Clinical Social Workers

The aging of the population will be the most significant factor increasing the demand for social work supportive services over the next half century (National Institute of Aging, 2011). According to the US Department of Health and Human Services (2006) the number of persons aged 85 and over is projected to increase five-fold by 2050. As the population ages, the prevalence of Alzheimer's disease will also rise. The need for social workers with a knowledge and expertise in the area of aging, and more specifically with Alzheimer's disease and related dementia, will also continue to grow. Since spouses provide the bulk of caregiving support at least in the early stages of the dementia, it is important for social workers to understand the caregiving dynamics created in spousal relationships since these dynamics are different than the dynamics created when adult children provide caregiving to a parent with dementia.

As the prevalence of AD grows and is coupled with an aging population, social workers will likely be called upon to more frequently provide assessments of couples experiencing dementia, in order to help them function better in their environment, preserve and enhance physical and social functions, and promote an optimal quality of life (National Institute on Aging, 2011; Davies, 2008). Understanding how to achieve this

goal of promoting an optimal quality of life will require the social worker to have insights about how each couple's unique set of strengths and vulnerabilities may affect the caregiving journey.

Achieving this goal of promoting an optimal quality of life for caregiving couples when one spouse has Alzheimer's disease appears to be complex and clinically challenging. This literature review would seem to indicate that it is important for clinicians to understand the past and present relationship in terms of the 'couple' since interactions are a two way process, and each affects the other. In addition, the care receiver's perception of safety and emotional security will be altered by the progressive and debilitation nature of Alzheimer's disease. These altered perceptions and will lead to greater physical and emotional dependency on the caregiver and may cause a number of behavioral problems.

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Alzheimer's disease is one of the most costly diseases in the United States (Alzheimer's Association Report, 2014). People with Alzheimer's disease have more hospital stays, nursing home stays and home health-care visits than other patients (Alzheimer's Association Report, 2014, p. e69). In addition, persons with AD tend to have more coexisting medical conditions than others without dementia, and "have higher

average per-person payments for most health-care services” that those who have the “same medical condition without dementia” (Alzheimer’s Association Report, 2014, p. e71). Alzheimer’s disease will continue to put an enormous strain on the United States health care system (Herbert, et al., 2013). It is projected that there will be a six-fold increase in government spending under Medicare and Medicaid within the next forty years (Alzheimer’s Association Report, 2014, p. e75). Social workers will be part of the multidisciplinary team trying to help informal caregivers maintain in their role as the primary caregiver to persons with Alzheimer’s dementia and thus contain costs associated with care. Social workers will continue to evaluate, anticipate, and facilitate discussions with caregivers and their spouse with dementia, and family members regarding changes in the plan of care with each stage of Alzheimer’s related decline. Discussions will involve providing information regarding the nature of Alzheimer’s decline, issues that are generally seen, and facilitating discussions about how to provide appropriate physical and emotional support, avoid hospitalizations, and maintain comfort. As the numbers of individuals diagnosed with Alzheimer’s disease continues to rise, the social worker’s role will only continue to increase in importance in helping to address these personal and interpersonal dynamics.

How Does Theory Guide Social Work Practice?

In more recent years, dementia research has begun to suggest that understanding the role of family caregiving means placing the caregiver role in its “historical context and recognizing the complexity of relationships between and among family members and the person with dementia” (Morhardt & Spira, 2013, p. 39). This historical and contextual relationship “influences the quality of life of the person with dementia as well as the

experience of caring” (Davies, 2008, p. 16). The quality of the marriage relationship, specifically the commitment to the marriage, personal attributes, the couples’ understanding of dementia, as well as social support, all influence how dementia is encountered and lived (Davies, 2008, p. 16). Caregiving occurs in a social as well as relational context and “each relationship has pre-existing dynamics, strengths, and vulnerabilities to the challenge of dementia that will likely affect the patient and the family’s adjustment and ability to cope” (Morhardt & Spira, 2013, p. 39). Individual characteristics, such as attachment style, personality and identification with the relationship can shape how caregivers experience their responsibilities (Carpenter, & Mak, 2007).

Since dementia caregiving occurs in a social as well as a relationship context, where the dynamics both past and present shape how caregiving and care receiving is perceived, Attachment Theory appears to be useful lens to tease apart how certain characteristics of the individual members in the relationship affect outcomes at the individual as well as relationship levels (McCarthy, Lyons, & Powers, 2011). The attachment model allows one to consider how couples’ interdependent relationships affect their experience of the dementia journey and caregiving outcomes.

Conceptual Framework

Attachment Theory provided the lens by which this paper was analyzed, and provided a background and basis for the research study.

Attachment Theory

Over 40 years ago, John Bowlby proposed an attachment theory to explain individual differences in behavior, emotion and understanding about others in close relationships (Chopik, Edelstein, & Fraley, 2013). He introduced the term “attachment” to describe certain emotional relationships that individuals form with others and try to maintain because they are crucial to having a sense of belonging, as well as security and protection in times of fear (Sable, 2008). He called these emotional relationships with others “attachment figures” and believed the stability of these attachment bonds were related to mental and physical well-being throughout the entire lifespan (Sable, 2008). Bowlby theorized that “human beings have a natural inclination to make and maintain lasting affectional bonds – or attachments – to familiar, irreplaceable others, and, once established, the quality, security and stability of these ties was related to emotional health and well-being throughout life” (Sable, 2008, p. 22).

In times of fear, Bowlby identified attachment behaviors as distress during unwanted separation and loss, and contact-seeking behaviors when feeling vulnerable (Magai & Considine, 2004). Early theory and research regarding these attachment behaviors was focused on infancy and childhood. Through observation, Mary Ainsworth identified within this context specific behaviors by mothers that lead to individual differences in infant attachment (Cassidy, Jones, & Shaver, 2013). These individual differences in attachment were based on caregiving experiences. Ainsworth's creation of the term “Strange Situation provided a gold standard for identifying and classifying individual differences in infant attachment security and insecurity”, which led to decades of research examining caregiving behaviors and its impact on differences in infant attachment (Cassidy et al., 2013, p. 1415).

Infant attachment security and insecurity remains a critical area of ongoing research given that attachment bonds impact relationships throughout life. In the book *From Neurons to Neighborhoods: The Science of Early Childhood Development* (Shonkoff & Phillips, & Children, 2000) The National Research Council and the Institute of Medicine's Committee on Integrating the Science of Early Childhood Development "based its policy and practice conclusions and recommendations on four themes" (Shonkoff & Phillips, 2000, p. 4). One of the themes states that:

"Early environments matter and nurturing relationships are essential. Children grow and thrive in the context of close and dependable relationships that provide love and nurturance, security, responsive interaction, and encouragement for exploration. Without at least one such relationship, development is disrupted, and the consequences can be severe and long-lasting" (Shonkoff & Phillips, 2000, p. 4).

These statements are based in part, on the research inspired by Bowlby's theory of attachment and Ainsworth's research methods (Cassidy et al., 2013).

Mary Main and colleagues studied the ways that attachment patterns are passed from one generation to another (Cassidy et al., 2013). They and other researchers found that a "parent's state of mind with respect to attachment" predicted the infant's pattern of attachment (Cassidy et al., 2013, p. 1415). These attachment findings led to research examining attachment process beyond the parent and child relationship, to look at attachment in adult romantic relationships. This research again was based on Bowlby's (1979) belief that "attachment is a process that characterizes humans from cradle to the

grave” (Cassidy et al., 2013, p. 1415; Bolby, 1979, p.129). Thus, adult attachment research is largely based the infant attachment process in relation to parental behaviors that affect the quality of infant attachment (Cassidy et al., 2013).

Elements of Attachment Theory

One of the core ideas of Attachment Theory is that “proximity to an attachment figure reduces fear in the presence of a possible or actual threat” (Cassidy et al., 2013, p. 1418). For Bowlby, this proximity was defined as the concept of a secure base. The secure base concept contained two linked components: a secure base from which a child could explore, and a safe place that a child could return to in times of distress. Within the concept of a secure base, how physically present, emotionally available, and responsive the caregiver was to a child’s needs affected how a child came to understand a situation, the level of threat created by the situation, and how well the child could manage and respond to that threat (Cassidy et al., 2013).

Over time these experiences became “internal working models” or attachment related beliefs used to guide an individual’s behavior (attachment style) towards others. The individual attachment style reflected general beliefs about themselves and others. These beliefs about self included how worthy they felt to receive care and affection from the caregiver, as well as beliefs about how available and responsive the caregiver will be to them when needed (Feeney & Collins, 2001, p. 973). Different attachment styles or patterns of behavior also represented different ways individuals learned to regulate emotion and provided rules that guided an individual’s responses to stressful situations (Feeney & Collins, 2001). Thus, level of caregiver responsiveness over time played an

important role in shaping behavioral responses to threats and how well a child learned to cope and regulate internal emotions in distressing situations (Cassidy et al., 2013).

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Jeffrey Webster (1998) in his research about attachment styles referenced Berman and Sperling's (1994) definition of adult attachment:

"The stable tendency of an individual to make substantial efforts to seek and maintain proximity to and contact with one or a few specific individuals who provide the subjective potential for physical and/or psychological safety and security. This stable tendency is regulated by internal working models of attachment, which are cognitive-affective-motivational schemata built from the individual's experience in his or her interpersonal world" (p. 8).

Attachment Theory and the Caregiving Process

From the perspective of an Attachment Theory framework, it would seem that dementia represents a significant threat to the attachment relationship between spouses (Perren et al., 2007). Relationship threats may include a loss of "emotional support and intimacy, having a helpmate, mental stimulation, and companionship" (Perren et al.,

2007, p.163). These losses may threaten the relationship security that each spouse has traditionally experienced. Since the need for security is a fundamental need for individuals across the lifespan, Attachment Theory provides an ideal framework for understanding the complicated attachment-caregiving bond (Feeney & Collins, 2001; Bradley & Cafferty, 2001).

Caregiving has been broadly defined as “behaviors that complement a partner’s attachment behavior and may include a wide range of responsibilities, such as providing help or assistance, offering comfort and reassurance, providing a secure base, and encouraging autonomy” (Feeney & Collins, 2001, p. 973). Within the Attachment Theory framework, caregiving is considered a normal approach to providing safety and security to reduce the risk of harm coming to someone the caregiver is close to emotionally (Feeney & Collins, 2001).

Kunce and Shaver (1994) were the first to identify the links between attachment styles and how style affects caregiving patterns in adult intimate relationships (Feeney & Collins, 2001). Feeney and Collins (2001) expanded upon this research and suggested that “unique patterns of motives, skills and resources” influence why “people with different attachment styles care for their partners in particular ways that they do” (Feeney and Collins, 2001, p. 981).

According to Attachment Theory, memories from one’s past attachment-related experiences are likely to be stored, remembered and reorganized in a way that uphold existing beliefs about self and others. Beliefs about the likelihood of receiving care from

others are prone to be linked to caregiving beliefs about providing care to others (Feeney & Collins, 2001, p. 973; Kuncze & Shaver, 1994).

Research also suggests that the quality of caregiving may be related to type of attachment. Securely attached caregivers were able to cope more easily with the changes associated with dementia, and felt capable of maintaining a connection with, and caring for, their spouse (Perren et al., 2007). Secure attachment appears to buffer spousal caregivers against the stresses associated with caregiving and enhance the amount and quality of perceived support (Perren et al., 2007). Anxious and ambivalently attached caregiving spouses “showed more negative emotional reactions to their spouses’ cognitive impairment and problem behavior” and reported less satisfying support from others (Perren et al., 2007, p. 175).

Memories from one’s past attachment-related experiences are also likely to impact one’s sense of happiness and well-being. In research conducted by Webster (1998) results suggest that older adults with a positive sense of self were happier than those with a negative sense of self. Webster also found that Attachment style predicted happiness, not marital status. Finally, the mental belief about attachment relationships was a more powerful predictor of happiness than the actual relationship (Webster, 1998). In a study by Andersson and Stevens (1993) findings suggested that when currently unattached respondents recalled earlier parental care as cold and inattentive, they experienced higher levels of anxiety and loneliness compared to currently unattached individuals who recalled their parent as warm and attentive (Webster, 1998).

Adult attachment researchers have generally viewed attachment behavior as dimensions of behavior along a continuum where differences are identified based on significant behavior differences when compared to secure attachment behavior (Feeney & Collins, 2001; Karantzas & Cole, 2011). Individuals identified as having a secure behavior style display a “comfort with closeness and a confidence in depending on others to fulfill attachment needs, while also demonstrating the ability to self-help or assist others in times of need” (Karantzas & Cole, 2011, p. 405). This comfort and confidence reflects attachment histories where “attachment needs were met through sensitive and responsive caregiving from attachment figures” (Karantzas & Cole, 2011, p.406).

Individuals who display a high level of avoidance or anxiety are regarded as having an insecure attachment style, while individuals who display low avoidance and anxiety are thought to be securely attached (Karantzas & Cole, 2011). While numerous studies have found links between attachment style and how one seeks support, some research has resulted in inconsistent findings (Karantzas & Cole, 2011). For instance, the outcomes of some attachment studies have shown no link between attachment avoidance and attachment care-seeking behavior, particularly in men (Karantzas & Cole, 2011, p. 407; Simpson, Roles, Orina, & Grich, 2002). Other studies report negative or no significant links between attachment anxiety and support-seeking behavior (Karantzas & Cole, 2011; Simpson, Rholes, & Nelligan, 1992; Simpson et al., 2002; Vogel & Wei, 2005). Research by Feeney and Collins (2001) suggests that avoidant individuals “may be unresponsive and controlling caregivers at least partly because they lack knowledge about how to support others”; they lack an orientation towards empathy and focusing on others, and they “fail to develop the deep sense of relationship closeness, commitment,

and trust that appear to be critical for the motivation of caregiving behavior” (p. 990).

Thus, findings suggest that “avoidant individuals have deficits in caregiving because they lack both the skills and motivation necessary to be good caregivers” (Feeney and Collins, 2001, p. 990). This is because they experienced caregivers who were rejecting so they did not see caregiving modeled, and because of this avoidant individuals have limited knowledge about effective caregiving strategies (Feeney & Collins, 2001, p.990).

Avoidant individuals are also motivated to keep the attachment system suppressed, and as a result they move away from others who seek emotional or physical support (Feeney & Collins, 2001, p. 990). Feeney and Collins (2001) speculate that factors such as empathy and orientation towards others “conflict with avoidant adult’s broader goal of keeping the attachment and caregiving systems in a deactivated state” (p. 990).

The anxiety dimension of adult attachment represents the “degree to which an individual behaves that reflects an incessant need for approval, a need to merge with relationship partners, a sense of low self-worth, and a fear of abandonment and rejection” (Karantzas & Cole, 2011, p.406; Brennan, Clark, & Shaver, 1998). Per Karantzas and Cole (2011), Mikulincer and Shaver (2003, 2007) argue that these “behavioral tendencies result from anxious individual’s experiences of inconsistent or inept caregiving by the attachment figure; consequently, these individuals engage in hyperactivating strategies that increase distress as a means of forcing the attachment figure to attend to the anxious individual’s needs for attention, love and support” (p. 406). Because of these hyperactivating strategies, it comes to no surprise that attachment anxiety is associated with “care seeking, and placing excessive demands on attachment figures to meet one’s

needs” (Karantzas & Cole, 2011, p. 406; Mikulincer & Florian, 1995; Ognibene & Collins, 1998).

The findings of Feeney & Collins (2001) also describe caregiving tendencies in anxious adults. Analysis suggests that anxious adults may be “compulsive and controlling caregivers” at least partly because they feel close and committed to their partners, but at the same time, “they distrusted their spouse, and were selfishly motivated in their caregiving attempts” (p. 990). Findings suggest that anxious adults do possess some of the skills required for effective caregiving and have motivation to provide care based on their partner’s needs, “but that other conflicting, perhaps more selfish motives may cause them to care for their partners in a compulsive, controlling, and inconsistent manner” (p. 990).

Feeney and Collins (2001) are, however quick to point out limitations in their analysis. Conclusions may “do a better job of predicting general caregiving patterns than of predicting specific caregiving behavior.” (p. 991). The authors also suggest that factors that drive behavior may not be present in every caregiving situation. More research is needed in this area to identify the contexts in which various factors are likely to be important, and to identify other factors that were not measured in this study (Feeney & Collins, 2001).

Methods

The research questions for the present study were: Do clinicians use an attachment framework when working with couples when one partner has dementia? Do clinicians think that Attachment Theory helps to inform their practice?

Research Design

This study used a qualitative exploratory research design. Data was collected qualitatively by interviewing Master of Social Work (MSW) clinicians who support individuals diagnosed with Alzheimer's type dementia, their spouses, and families, in order to gain insights as to the potential role an attachment lens may play during the assessment phase that guides some intervention goals.

Subject Selection

The researcher recruited MSW professionals using convenience and snowball sampling. Five such professionals were successfully recruited to participate in a single 60-minute interview discussing their work with spousal caregiving dyads when one partner has Alzheimer's disease (AD), including their thoughts about whether Attachment Theory helped inform their practice when working with spousal caregiving dyads. The subjects were selected based on their MSW degree, and their expertise with dementia issues in an older adult population.

Recruitment for participants was initiated by the researcher using publicly listed website contact information for MSW social workers with practice emphasis in aging issues. The researcher contacted 10 MSW professionals using publicly listed contact information and a recruitment letter. Attached to the recruitment letter were the consent form, interview protocol, and interview questions (see Appendix A). Consent and questions were included to assure that potential participants were fully aware of the interview questions, and the voluntary nature of their participation. In addition, to ensure participation was voluntary, MSW professionals were asked to contact the researcher of

the study using the email address or telephone number provided in the email. This method did not result in any participant contact.

The researcher then contacted MSW professionals from the Twin City area, via a recruitment email, based on recommendations from the researcher's personal network of social work contacts. Attached to the recruitment letter were, again, the consent form, interview protocol, and interview questions. Recruitment also included participant recommendations of others who might have been willing to participate in this study. The researcher also followed up the recruitment email with the same recruitment letter if no contact had been received after one week. This combined recruitment method resulted in seven participants that expressed interest in this research study. One individual was unable to participate due to scheduling conflicts and time constraints, and another declined due to agency policy. A total of five MSW professionals participated in this study.

Data Collection

The five participants met with the researcher for a one hour in-person interview at a location chosen by the participant. The data was collected using a list of nine semi-structured questions prepared by the researcher, and approved by the Institutional Review Board. Questions were developed and formulated with input from the researcher's committee members. A physical copy of the interview questions and summary of Attachment theory was provided at the beginning of the interview. The researcher followed the interview protocol (Appendix A). The first six semi-structured questions were designed to capture the type of work and expertise each participant provided and

then more specifically their work with individuals experiencing Alzheimer's related dementia and their spouses. After the first six semi-structured questions, the researcher paused to discuss the Attachment Theory summary provided at the beginning of the interview. After participants had a few minutes to review Attachment Theory concepts, the last three attachment specific-questions were discussed. The research questions and participant responses were audio-taped on the researcher's personal iPhone. Once the researcher completed the interview, the interview data was transferred from the iPhone to the researcher's personal password protected computer for later transcription and data analysis.

Confidentiality and Consent

To protect the privacy of the participants and minimize risk associated with participation, information including name, agency each participant was affiliated with, and any other identifying factors were excluded from the transcripts. In addition, the transcriptionist signed a confidentiality agreement with the researcher regarding participant information as well as participant data. Signed consent was obtained from each participant prior to the interview including information concerning confidentiality and their rights as a participant. Participants received a copy of the consent form for their own records, which also contained contact information should they have further questions for the researcher or supervising faculty member, or choose to withdraw their interview data at any time during the research process.

All participant interview responses were downloaded to the researcher's password protected computer within 24 hours of the interview, and then deleted from the

researcher's iPhone. During the data analysis period, transcripts of the interviews were locked in a lockbox in the researcher's home and only the researcher had access to the data. Additionally, all participant interview responses were deleted from the researcher's computer following completion of this research study in May 2015, and all hard copies of research data were shredded to further protect the confidentiality and rights of each participant.

Risks and Benefits of Being in the Study

Participants were informed at the beginning of the interview that they did not have to answer any questions they did not feel comfortable with, in addition to the option of withdrawing from the research process at any time. The researcher also offered participants a list of resources should they experience any emotional discomfort related to the interview topic. At either the beginning or end of the interview, the researcher also provided each participant a \$10.00 coffee shop gift card as a token of the researcher's appreciation for providing an hour of their time to meet with the researcher and be interviewed, regardless of their level of participation.

Voluntary Nature of the Study and Human Subjects

Participation in the present study was completely voluntary. Participants were informed that they could skip any questions they did not wish to answer and could end the interview at any time. In addition, each participant was informed that whether or not they completed the interview or later withdrew from the research study, this would not affect their current or future relations with St. Catherine University, the University of St. Thomas, or the School of Social Work.

To protect human subjects, the researcher completed the Collaborative Institutional Training Initiative (CITI Program), and developed a semi-structured interview protocol that was reviewed and approved by the Institutional Review Board at the University of St. Catherine.

Setting

The settings for the interviews were varied depending on the wishes of each participant. Interviews were held in private or semi-private meeting spaces at locations such as coffee shops, libraries, and private offices at the participant's place of employment. The researcher traveled to each preferred meeting place for each interview.

Analysis Technique

The analytic strategy for the present qualitative study was for the researcher to perform content analysis by coding and categorizing data, to allow themes to emerge. Content analysis, as described by Monette, Sullivan, Dejong and Hilton (2014), refers to "a method of transforming the symbolic content of a document, such as words or other images, from a qualitative, unsystematic form into a quantitative, systematic form (p. 203).

The researcher began by reading and re-reading the interview transcripts in order to code and categorize the type of information participants discussed. The researcher first focused on participant observations regarding qualities of caregivers that enhanced or limited caregiving outcomes. The researcher developed categories to identify these qualities based on previous research by Feeney and Collins (2001) although the researcher remained flexible regarding how the categories were ultimately defined.

Next, the researcher coded and categorized information regarding participant thoughts about their current use of an attachment framework and why they did or did not use an attachment lens. Lastly, the researcher coded and categorized participant observations about whether an attachment lens could inform their practice, and if so, in what ways.

Findings

The Findings section is divided into three parts. Part one of findings section is related to participant observations of effective and ineffective caregiving as a prelude to their thoughts of Attachment Theory.

In part two of this section, participants answer the first research question: Do clinicians use an attachment framework when working with couples in which one partner has dementia? All five participants indicated they did not use an attachment lens directly. Participants observed that the various caregiving traits, motivations, skills and abilities are generally identified in the assessment process that social workers are trained to use. These assessments provide the necessary information to develop strategies and goals to support Alzheimer's spousal relationships. Although participants did not explicitly use an attachment framework, some of the language the participants used in part one of the findings to describe caregiving traits reflected attachment ways of thinking and suggest that participants were already applying an attachment lens in some situations.

Finally, part three of this section answers the second research question: Do clinicians think that elements of the Attachment Theory help to inform their practice? All five participants indicated that an attachment lens could inform their practice in at least

some situations. Participants identified that an attachment lens could add dimensionality to their assessment and insight; could help inform and guide information during the assessment process; and could help the clinician interpret and gain deeper meaning from the assessment information.

Part One

Participants observed two primary caregiving qualities that enhanced the caregiver's ability to provide a sense of security, comfort and support to their spouses with dementia: the motivation and commitment to provide care to their spouses with dementia, and having skills and abilities that promoted responsive and safe caregiving.

All five participants observed that spouses who were more successful in the caregiving role were motivated to provide care in order to maintain their interpersonal connection to their spouse with dementia. However, caregiver motivation to provide care was either enhanced or limited by the following factors: historic roles and interpersonal dynamics within the relationship; the ability of the caregiver to cope with the stress and anxiety experienced in the caregiving role; and the length of the relationship prior to dementia. Participants noted that the loss of the care receiver's recognition of the spousal caregiver limited motivation and commitment to the caregiving role.

Commitment to Provide Care

The first quality of successful caregiving identified by the study participants was the motivation to provide care in order to maintain their interpersonal connection to the spouse with dementia. All participants observed that maintaining interpersonal

connection was most successful when caregivers were able to modify their identity within the relationship to align with the new caregiving roles and responsibilities.

Ability to Adjust Identity and Roles within the Relationship

Participants identified that the most successful caregivers were able to recognize the dementia process and define their role within the disease process. This trait enhanced the caregiver's ability to utilize resources for support, learn and integrate new knowledge to respond in more effective and compassionate ways; increase their ability to tolerate their own distress and not take things personally; trust others who may provide supplemental caregiving support; be attuned to the spouse's feelings and needs; and maintain emotional connection within the relationship. These traits had the general effect of promoting care receiver trust and sense of security.

One participant described the most important trait of a successful caregiver in the following way:

"I think the caregiver's ability to recognize the disease and kind of define their role within that. Obviously it's a devastating disease, but the folks that I see doing the best are those that can kind of just say alright this is the situation . . . so the strengths would be the caregiver's ability to be able to withstand, to tolerate distress, and not taking it personally."

Likewise, all five participants observed that the motivation and commitment to provide care was limited when the caregiver was unable to adequately align their identity with the new roles and responsibilities. Participants observed that when identity and roles were not aligned, caregivers provided less effective caregiving because they were less

likely to identify their spouse's needs; caregivers were more frustrated and angry; and displayed less empathy for what their spouse with dementia was experiencing.

Historic Roles and Interpersonal Dynamics

All of the participants observed that historic roles and interpersonal dynamics within the relationship could enhance or limit caregiver motivation and commitment to provide care. Two participants identified positive outcomes related to historic roles and interpersonal dynamics. Early in the dementia process caregivers and care receivers who felt a general sense of positive historic roles and interpersonal dynamics were more likely to communicate, anticipate, and plan for their future through the dementia journey. Another participant identified that trusting historic roles and interpersonal dynamics enhanced the tendency that spouses with dementia would continue to trust throughout the dementia journey. This participant was quick to note that sometimes this tendency towards their pre-dementia disposition did not always happen due to the nature of the brain damage caused by the dementia process.

The majority of participants identified that historic roles and interpersonal dynamics can complicate the caregiver's ability to take on new roles, and the care receiver's ability to accept the help. Participants noted that spouses who were demanding, dominating, controlling and abusive before their dementia, were less likely to have spouses that were committed to provide ongoing care.

Participants also noted that caregiving spouses had greater difficulty taking on the caregiving duties when they had personalities that were more subservient to, and dependent on, their spouse prior to the onset of dementia. This resulted in spouses with

dementia who were less willing to accept the caregiver's help after dementia onset and made it difficult for the caregiver to step into a leadership role within the relationship. Participants identified that these caregivers tended to cling to their pre-dementia roles, which limited their ability to think in flexible ways because their identity was not aligned to their roles and responsibilities. Participants also noted that this inflexibility affected the caregiver's ability to take in and integrate new information since their identity was not aligned to their new caregiving tasks, and this ultimately led to greater caregiver stress.

Caregiver Ability to Cope with Stress and Anxiety

All five participants observed that the caregiver's ability to cope with the stress and anxiety experienced in the caregiving role either enhanced or limited the commitment to provide care. Participants identified that behavioral problems such as suspicious behavior, paranoia, wandering at night, and physical aggression were significant factors that limited motivation to provide care. One participant also noted that the caregiver's inability to cope with the stress and anxiety experienced in the caregiving role led to the overuse of antipsychotic medication use as a way to manage behaviors instead of implementing caregiving information that could provide alternative ways to manage these behaviors. Participants also noted that caregivers who had the ability to cope with the stress and anxiety within the caregiving role were more attuned to the emotional needs of the spouse with dementia, were able to think in flexible ways and try new strategies, and remain calm in stressful situations.

Length of Relationship

Two participants observed that the length of the spousal relationship could enhance or limit the caregiver's commitment to provide care. Both participants identified

that long-term relationships generally strengthened the commitment to the caregiving role and provided the 'glue' to help the caregiver maintain their role when experiencing caregiving stress. Both participants noted that caregivers in long-term relationships were more likely to maintain their caregiving role than caregivers in relationships of a shorter length. One participant noted this was especially true for spouses from second and third marriages. This participant observed that these caregivers frequently just didn't have enough history and glue to help them remain in their role. This same participant was quick to point out that this is not always true, and she described some caregivers from shorter-term relationships as being *remarkable* in the continuation of their caregiving role. The other participant observed that the length of the relationship was less of a factor in the motivation to provide care when there was a history of abuse.

Loss of Recognition

Two participants observed that when the spouse with dementia no longer recognized their caregiving spouse, the motivation and commitment to provide care diminished. Both participants noted how emotionally painful this was for the caregiver. Participants noted that the loss of recognition helped the caregiver take a step back and evaluate their role, identify that a transition to institutional care may not do emotional harm to their spouse with dementia, and helped caregiving spouses feel like they had honored their spouse when it mattered most during the earlier part of the dementia journey.

Skills and Abilities

The second quality of effective caregiving was identified as having the right skills and abilities in order to be responsive and provide a sense of comfort and support.

Participants observed that the right skills and abilities included the ability to think in a flexible way, the ability to learn new caregiving information and implement new approaches; the ability to be empathic with sensitivity towards what their spouse would want; and the ability to remain calm in stressful situations.

Ability to Think in Flexible Ways

All five participants had different observations that suggested that caregivers who had the ability to think in flexible ways helped the caregiver provide a sense of comfort and support. Participant observations included: flexible thinking helped the caregiver adapt to new situations and roles; helped the caregiver focus on the positive and use their sense of humor to reduce stress; increased ability to utilize resources for support; enhanced ability to take in new information and integrate to try new strategies for care; fostered ability to tolerate distress and remain calm; and enhanced caregiver ability to maintain the emotional connection.

“I had a [man in the support] group from the age of 85 to 88. What a thoughtful, thoughtful man. He tried everything to come up with ways to provide meaning to her life. How can I help her feel like she's part of life?”

Participants observed a variety of ways that inflexible thinking limited caregiver's ability to provide comfort and support. Participants noted that inflexible thinking limited caregiver's ability to plan ahead, led to more rigidity in caregiving roles, reduced the ability of the caregiver to identify the need for help, limited the ability to stay calm, and also reduced empathy to the perspective of the spouse with dementia; and for some

caregivers, inflexible thinking led to the belief that no one could care for their spouse with dementia as well as they could; it was noted that this particular caregiver belief led to increased anxiety, stress and over-involvement when others were providing the care.

Ability to Learn and Integrate New Information

In general all five participants observed that the ability to learn and integrate new information was beneficial to successful caregiving. Participants noted that the ability to learn and integrate new knowledge helped caregivers adjust their traditional ways of thinking and acting and so that they could provide the necessary care when needed. Participants stated that the inability to learn and integrate new knowledge limited the safety, health and well-being of spouses with dementia. Two participants specifically noted how important it was for the caregiver to learn more compassionate ways to communicate since engaging in logic-based reasoning leads to more stress and conflict and exhausts everyone when dementia limits the care receiver's judgment and insight.

Ability to Empathize With Their Spouse

Three participants observed that the caregiver's ability to empathize with their spouse enhanced responsive caregiving. These participants noted that caregivers who displayed empathy showed more compassion towards their spouse with dementia and were more easily able to provide the support, were more tolerant towards behaviors displayed by their spouse with dementia, and showed a greater ability to take situations in stride.

Ability to Stay Calm

Lastly, two participants observed that an important skill for caregivers was the

ability to remain calm in stressful situations. Participants noted that the ability to remain calm enhanced the caregiver's ability to be responsive and provide a sense of comfort and support to their spouse with dementia. One participant described the ability to remain calm in stressful situations the following way:

“Being able to go with the flow a bit more, or at least not react hysterically, I hope that it's more of a neutral reaction.”

Part Two

Part two of the research findings answers the first research question: Do participants use an attachment framework when working with couples when one partner has dementia? The major theme of this section is that none of the five participants consciously used an attachment lens when working with couples where one partner had dementia. However, some participants noted indirect ways that an attachment lens was used in some situations. Some participants noted: attachment information was frequently discovered even though it was not the focus of conversation; an attachment lens was indirectly applied to some assessments to enhance understanding of the marriage relationship; and an attachment lens was indirectly use to guide interventions in some situations.

Attachment Theory is not Directly Used

Participants indicated they did not directly use an attachment lens. Instead, participants described various assessment processes that were specific to their clinician role. Three participants described assessments that were quite involved covering medical issues and implications, psychological components, social aspects, and spiritual

dimensions. The other two participants noted that their assessments and roles were focused only on one or a few presenting problem due to the short-term nature of their role, which changed and limited the type of information they assessed. However, all participants observed that their assessment process was based on their social work training, and provided the general information necessary to develop strategies and goals with their client or clients.

“I think we’re trained in the bio-psycho-social-spiritual assessment, and it’s such a starting point for working with anyone. So it just seems like everywhere I worked there’s been an assessment process built in. And that’s one of the delightful parts about being a social worker is you get to have those questions or probe a little bit . . . thinking about the Attachment Theory itself, I don’t recall any specific questions that come to mind that would address some of those things. But within a typical assessment you do ask about mental health. You get to ask hobbies, and so you get a sense of personality and style of communication. You know what their baselines are, which is always helpful. But not about the relationship itself. Not so much about that I’d say. But you’re certainly working around it.”

In the above quote, the participant suggested that information identified in the assessment process could indirectly be applied to an attachment lens since the focus of the assessment may overlap with attachment related issues.

Attachment Information is Often Indirectly Uncovered

For instance, the participant quoted below did not ask about any attachment or relationship history. However, she often gleaned pre-dementia relationship information during her specific assessment related to care receiver symptoms and caregiver reactions to symptoms.

“Our assessment is very here and now. So we assess what the person’s needs are as well as the caregiver’s reactions to symptoms. What we do is kind of have a long list of symptoms and the caregiver lists out the frequency that they’re seeing those symptoms and then their reaction on a scale of one to four about how just stressful those symptoms are to the caregiver. And we focus on that. But we don’t take any family history. And sometimes that comes up working with the family . . . so they might say well it’s complicated because you know the relationship has always been like this or other family history pieces that people will just share contemporaneously.”

Attachment Lens is Indirectly Applied to Assessments

One participant indicated that she asked dementia caregiving couples questions about the pre-dementia relationship to help her understand the historic roles and areas of disagreements within the relationship.

“Early attachment, no. Pre-dementia marriage, yes. So that might come up just in terms of how did you handle disagreements? Or how did you handle making decisions before? . . . And it probably depends on what role as a social worker you’re going in . . . [and] the purpose of your working with these clients.”

Attachment Lens is Indirectly Applied to Guide Interventions

One participant indicated she did not ask about attachment or pre-dementia spousal relationships. However, in certain circumstances she would ask more background about the pre-dementia relationship due to behaviors the spouse exhibited towards the institutional staff who were now caring for the spouse with dementia. This background information was then used to develop strategies and goals to support the spouse as well as the staff providing the direct care.

“The assessments that we do, we don’t specifically look at what was the marriage relationship prior. But I do think, depending on who you’re working with, that that is probably an important part which you usually can feel out depending on the involvement of the spouse. But we don’t specifically look at it. But in situations such as the gentleman that I’ve given examples on, I did go more in depth with the wife – whether it was intentional or not, but just to help understand their past relationships to help guide us as caregivers for her husband now. Which was found to be helpful. Especially in situations where spouses are very involved and it can become stressful for caregivers when you have kind of the spouse overlooking your shoulder and you know maybe nitpicking a little bit – regarding how they do things. And that can be stressful for caregivers. So it’s important for them to understand that history and where that relationship was before, so they can learn how to work with her better and not personalize her interactions with them regarding how they provide care. I would say that’s the biggest way I would use that information.”

Part Three

The second research question for this study was: Do clinicians think that Attachment Theory helps to inform their practice? All five participants stated that an attachment lens could, in some situations, help inform their practice. Three themes emerged regarding the use of Attachment Theory to inform clinician practice: Attachment Theory could add dimensionality, Attachment Theory could help inform and guide information gathered, and Attachment examples increased the application of the theory.

Dimensionality

Two participants stated that an attachment lens could add dimensionality. The

first participant said that an attachment lens could inform their practice by adding dimensionality to the personality strengths and weaknesses of the caregiver and care receiver as well as those who may or may not seek or follow up on support services.

In this example, the participant observed that caregivers who displayed a more anxious personality type had a tendency to focus on smaller issues that created frustration, and were limited in their ability to take a step back in order to gain perspective.

“When I was reading through the attachment styles and thinking about anxious attachment[s][and]different personality types, one thing that’s interesting to observe just how you know with dementia there’s a wide range of behaviors. And some, many of the behaviors are not a safety risk for the person with the memory loss or their caregiver. And our general view on that is – if it’s not jeopardizing anyone’s safety is it worth addressing? Or, is it worth becoming upset about? Sometimes there’s a lot of caregivers where all the quirks and idiosyncrasies of memory loss, just the little things, kind of grate them and cause anger and frustration.”

This same participant went on to note that given the nature of her work as a short term information, education and referral clinician, she tended to see more anxious caregivers.

“Thinking about someone with an anxious attachment - that over caregiving, I think that’s some of the folks that I hear from a lot too. It can be challenging when there’s such a high level of anxiety and detail orientedness. I’m on the level of is everyone safe and healthy? Not nit-picking every little piece. That helps me understand what might be going on for them.”

This same participant noted that Attachment Theory could add dimensionality to the care receiver's strengths and weaknesses and how these factors affected the caregiving relationship.

“Some of the successful dyads that I see are where the person with the disease is very trusting of the [caregiver] and has an easy going nature. I just feel . . . that people that are more predisposed naturally to be suspicious and distrustful before the disease, after the diagnosis those attributes really become significant . . . it's so difficult because the disease can cause personality changes . . . [that] are starkly different from who they were before the diagnosis. But I've also worked with many more folks where it's really exacerbated some of these things like suspicion and distrust. And you know that sense of feeling judged or put down. And I can't help but think that has to come from their background . . . imagine growing up in a family where you didn't have secure attachment. You live your whole life kind of coping in different ways, and then you get a diagnosis that can exacerbate some of those things.”

Finally, this same participant also stated that Attachment Theory could add dimensionality to help her understand who may or may not seek support services, and what caregivers are more likely to follow up on referrals.

“One thing that I'm thinking is about avoidant caregivers and how that might be someone we would see more because the adult children are saying this isn't working well . . . please help the caregiver understand the disease or change their communication . . . an avoidant caregiver would be someone brought in by other people . . . and so those might be some of the folks who [might] not take initiative or follow up on our referral.”

In addition, a second participant also agreed that Attachment Theory could add dimensionality to the clinician's understanding of a caregiver's struggles.

“I’m not sure how I would approach it. I guess it depends on the situation that it arises in . . . in a support group [role it] could help me just try to recognize where this person is coming from . . . even though I may not be able to really address it . . . I can understand that person better.”

Inform and Guide the Assessment Process

Two participants observed that Attachment Theory could help inform and guide the information gathering and assessment process. The first participant observed that an attachment lens could help guide information gathered on the social history which might then help inform the plan of care.

“I think if you’re in this setting, if you’re aware of Attachment Theory and thinking about it, I think it can inform the way that you work. Especially with residents who have Alzheimer’s and spouses. So looking at what style of attachment they may be coming from, and if you’re able to differentiate that, I think it could help inform how much information you get on the social history so that can help guide the care that you provide them.”

The second participant observed that an attachment lens could potentially inform her work with older adults at the stage of life where they are doing a life review. Information gleaned from life review reflection, had the potential to inform the social worker’s assessment and plan of care.

“It’s kind of like who’s the client? You know a lot of places social workers work, it isn’t always the caregiver who is the client, it’s just the care receiver. So that changes it too. But it certainly is part of life review, it’s part of the conversations you have with seniors as they age and get the opportunity just to sit and chat and then follow-up and do assessments and do care conferences and planning ahead and things like that with people.”

Attachment Theory Examples Increased Application

Towards the end of the interview meeting, the researcher provided additional information about attachment research regarding dementia related caregiving relationships in order to facilitate further discussion. The researcher specifically highlighted research suggesting that more problematic behaviors were noted in relationships where the person with dementia exhibited an insecure attachment style and the caregiving spouse displayed an avoidant attachment style. The more the person with dementia sought out the avoidant caregiver for support, the more the avoidant caregiver needed to pull away. This example facilitated further reflection and discussion with all five participants.

Upon Reflection Saw a Potential Link

Four participants immediately reflected on caregiving situations that were similar to the information provided by the researcher an insecure attachment style of the spouse with dementia and an avoidant attachment style of the caregiving partner were correlated with higher levels of problematic behaviors.

The first participant reflected that she just had not put a similar situation within her practice, within an attachment framework.

“You saying it is what did that for me. Because the minute you’re describing what that looks like, I think oh yes, I put their faces in that story immediately. But I hadn’t put it in that context prior to that.”

The second participant immediately reflected on a caregiving situation that was similar to the information provided by the researcher about styles of attachment and behavior. This participant reflected that the attachment styles of the caregiver and spouse

with dementia may have played a role in the caregiver prematurely placing the spouse with dementia in a long term care setting.

“Gosh, that describes another situation perfectly . . . where the gentleman had the disease and he wanted to be near his wife at all times, and trailed her around. And that happens a lot. But for this particular caregiver, she didn't want to be needed like that. She resented being a caregiver, so it was just a bad, bad match. In fact he ended up [being placed] while he was late early stage. And some of the members in the support group [were] questioning, you placed him already? And she's like yes, and I don't go visit him that much. She needed out. She needed out.”

The third participant indicated that the research example regarding different attachment styles and the negative impact on dementia related behaviors helped her look back and see certain situations in a new way by using the attachment lens.

“I think you've done a really good job of planting that seed. I mean because just in this brief hour I'm already thinking well yeah, I guess it does more than I thought it did, I can see that here or there . . . I guess again looking at it backwards, which I usually do, I have had quite a few experiences [with] attachment meaning.”

The fourth participant indicated that the research example regarding different attachment styles and the negative impact on dementia related behaviors made a lot of sense to her. She then reflected on some articles she had previously read regarding the use of Attachment Theory, Alzheimer's dementia, and sexuality. This reflection appeared to infer some credibility to the validity of Attachment Theory.

“Mh,. Mhm. Yeah. You know that makes a lot of sense . . . Last year about this time, I read some articles about . . . sexuality and dementia . . . and

there [were a]couple of articles [that] referenced Attachment Theory as a basis for their research or their writings that they were doing.”

Raised Awareness

The participant quoted below indicated that the discussion on Attachment Theory helped raise her awareness of the potential usefulness of an attachment lens especially in situations where the caregiver was struggling to cope in their caregiving role.

“Everything you said . . . put a different lens on looking at this for me. And not that those haven't come up, I just haven't put them in that lens. And so I think it might actually be a lens that I would look at. I mean purposely look at in terms of why someone is coping or not coping.”

Discussion

The research questions for the present study were: Do clinicians use an attachment framework when working with couples when one partner had dementia? Do clinicians think that Attachment Theory helps to inform their practice? In this section, findings will be explained as to why clinicians did not use an attachment framework when working with couples when one partner had dementia, and why clinicians thought that an attachment lens could provide dimensionality to their understanding of client behaviors, even if it did not affect the treatment approach. In addition, participant observations about traits of a successful caregiver will be explained.

Findings from the present study are: 1) Successful caregiving requires the commitment to provide care as well as having certain skills and abilities. These skills and abilities include: flexible thinking; the ability to learn new information and integrate that knowledge to respond in different ways; the ability to empathize with their spouse; and

the ability to stay calm in stressful situations. 2) Clinicians do not use an attachment framework when working with couples when one partner has dementia because the type of assessments used already captures the information needed to develop interventions in the participant settings. 3) Attachment Theory could provide further dimensionality to clinician understanding regarding the difficulties that some caregivers experience.

Caregiving Requires the Commitment to Provide Care

Previous research as well as the present study, suggest that in general spouses are committed to providing care. They engage in the caregiving process despite the challenging nature of caregiving, and at great personal sacrifice. Attachment Theory suggests that humans are hardwired through evolution to seek affectionate emotional connections and physical contact with important others throughout life for security and protection when afraid. The core idea of Attachment Theory is that being close to an irreplaceable attachment figure reduces stress. Like attachment, caregiving is considered a normal approach to providing safety and security.

Individuals spend their whole lives seeking, building and repairing attachment relationships. Spousal relationships are one of the most significant attachment relationships in adulthood, and dementia is considered a threat to that adult attachment relationship. It appears that the stronger the spousal attachment relationship prior to the onset of Alzheimer's disease, the stronger the motivation to provide care. This appeared to be based on the desire to maintain the attachment relationship. Previous research suggests that spousal caregivers with positive past and present relationships were "more committed, less depressed, and more likely to find gratification in caring for their spouse" (Braun et al., 2009, p. 430). Participants in the present study reported similar observations

that the commitment to provide support was based, at least in part, on the motivation to maintain the spousal relationship.

Previous research also suggested that caregivers who did not feel a strong emotional attachment bond appeared to be motivated more by duty than by a spousal bond (Pinquart & Sorensen, 2003). Participants in the present study reported similar observations that spouses from second and third marriages did not generally last as long in the caregiving role because they did not have enough glue and history to keep them going through the hard parts of caregiving. This would suggest the attachment bond was not as strong. However, previous research also suggests that the emotional bond felt by the spousal caregiver declines during the caregiving process because of the impact that Alzheimer's disease has on the marital relationship (Braun et al., 2009).

Successful Caregivers Have the Right Skills and Abilities.

Having the motivation to provide caregiving support to a spouse with dementia is not enough to be a successful caregiver. Caregivers also must have the right skills and abilities to carry out their roles and responsibilities.

Previous research suggests that the type of care that Alzheimer's caregivers provide is more physically and emotionally demanding and more time-consuming than other kind of caregiving because of the nature of the disease (National Alliance for Caregiving, 2004). Alzheimer's caregivers are significantly more likely to provide assistance with the most difficult Activities of Daily Living (ADL) tasks such as incontinence, bathing and feeding. Alzheimer's caregivers are also very likely to experience behavior problems in their spouse with AD dementia such as paranoia,

hallucinations, agitation, disturbed sleep, and depression (Yeager et al., 2010). Studies have documented that the prevalence of these types of behaviors ranges between ten to fifty percent (Yeager et al., 2010). One research study specifically noted that delusions around themes of theft are common in the middle stage of AD (Yeager et al., 2010).

Given the types and intensity of caregiving duties, having the right skills and abilities seems crucial to be a successful caregiver. Previous research found that important skills and abilities for caregivers included flexibility to provide care to a variety of needs; having the knowledge about how to provide the appropriate type and amount of support that is needed; the ability to empathize and take the perspective of the person with dementia; and the social skills necessary to recognize the needs of the person with dementia (Feeney & Collins, 2001). These same skills and abilities are protective factors and help sustain the changing process of caregiving (Feeney & Collins, 2001).

The current study found similar themes in that participants described both positive and negative characteristics of caregivers. The skills and abilities themes fell into the same general categories although some skills and abilities were emphasized more than others. The two most prominent skills and abilities emphasized by the participants in the current study were regarding the caregiver's ability to shift identity and roles to align with the necessary caregiving duties, and the ability to learn and integrate new caregiving knowledge especially as it related to communication skills.

Looking at these skills and abilities using an attachment lens, they appear to be similar to qualities associated with securely attached caregivers. Perren and others (2007) suggested that securely attached caregivers were able to cope more easily with changes

associated with dementia, and felt capable of maintaining a connection with their spouse, as well as providing care for their spouse. Karantzas and Cole (2011) described individuals with a secure behavior style as displaying a “comfort with closeness and a confidence in depending on others to fulfill attachment needs, while also demonstrating the ability to self-help or assist others in times of need” (p. 405). The same researchers went on to indicate that this comfort and confidence reflected attachment histories where “attachment needs were met through sensitive and responsive caregiving from attachment figures (Karantzas & Cole, p.406). Perren and others (2007) also suggested that secure attachments appeared to buffer spousal caregivers against the stress associated with caregiving, and enhanced the amount and quality of perceived support.

Adult attachment researchers have generally viewed attachment behavior as dimensions of behavior along a continuum where differences are identified based on significant behavior differences when compared to secure attachment behavior (Feeney & Collins 2001; Karantzas & Cole, 2011). There are two basic types of insecure attachments, avoidant and anxious attachment. Avoidantly attached individuals generally have a strong need to be self sufficient. Although all individuals seek close emotional bonds, avoidant individuals are motivated to restrain their attachment needs and caregiving patterns (Fraley & Shaver, 1997). Feeney and Collins (2001) speculate that factors such as empathy and wanting to be close to others “conflict with the avoidant adult’s broader goal of keeping the attachment and caregiving systems in a deactivated state” (p.990).

Previous research also described some characteristics of behaviors associated with anxiously attached caregivers. Research analysis by Feeney and Collins (2001) suggests

that anxious caregivers feel close and committed to their partners and have motivation to provide care based on their partner's needs, but other "perhaps more selfish motives may cause them to care for their partners in compulsive, controlling and inconsistent" ways (p. 990). However they also suggest that factors that drive behavior may not be present in every caregiving situation.

Participants in This Study Did Not Directly Use an Attachment Lens

This research study indicated that the participants did not directly use an Attachment lens when working with dementia caregiving couples. Participants observed that the type of assessments that social workers were trained to do provided the necessary information. Participants also noted that social workers were frequently not working with the couple together as a unit, but were more likely to only work with one member of the relationship as the identified client. However, previous research suggests that individual differences in adult attachment styles may help predict caregiving behavior in close adult relationships (Feeney & Collins, 2001).

Attachment Theory May Provide Dimensionality

The results of this study suggest that an attachment lens could add dimensionality for the clinician during their assessment process. This dimensionality might be as simple as what type of caregiver is likely to seek support and follow up on referrals, or what type of caregiver is likely to be brought in by a third party for help when the caregiver does not see that there is any problem.

Attachment Theory May Provide Additional Insight

The attachment lens could also add insight as to why a caregiver might be

displaying specific behaviors, why they might be struggling to take on new caregiving roles and responsibilities, and why some caregivers may prematurely transition their spouse with dementia to a supported care setting.

In addition the results of this study suggest that an attachment lens could help when working with older adults when they were reflecting back on their life as they sought to interpret and create meaning through life review.

Attachment Theory Examples Increase Application

When given a specific research finding regarding different attachment styles and the impact different styles had on each spouse within the relationship, four participants identified examples from their own case histories that were very similar to the example provided by the researcher. Upon reflection, these participants appeared to have an easier time using an attachment lens to identify a potential link between styles of attachment and behaviors. The researcher's example appeared to further raise awareness to the potential usefulness of the attachment lens in certain situations.

Suggestions and Implications for Social Workers

Taking an Attachment Theory perspective may help social workers identify dementia caregiving couples who may not be able to seek or provide support as effectively as caregivers who have more secure attachments. This insight could help the social worker proactively tailor their counseling or specific support recommendations to the anticipated areas in which dementia caregiving couples may struggle. Although the current assessment process that social workers use, already helps to individualize the plan of care, an attachment lens may help to tweak the tailored support by adding

dimensionality to personal and interpersonal skills and struggles. Understanding and anticipating attachment related patterns of behavior and caregiving, helps the clinician's ability to support the dementia caregiver and thereby support both members of the relationship to successfully remain together in their home environment for longer periods of time. This has the potential to save millions of dollars for federal and state health care programs such as Medicare and Medicaid. Although many partners with dementia ultimately transition to a supported care setting due to changes in health and physical abilities, delaying this transition until those changes are more significant may help both the caregiver and spouse with dementia make an easier transition to a supported care setting.

Strengths and Limitations of Present Research

The strength of the present study was that the participants had a variety of social work focused roles and worked across a variety of settings. The diversity in clinician roles helped to provide a broader understanding from different perspectives of participant observation of successful caregiving, the use of Attachment Theory within their role, and the potential ways they believe that an attachment lens could inform their practice.

Limitations for the present study include: a small sample size of five participants, all participants were Caucasian and female, and all were from one geographical area. Each of these limitations restricts broader generalizations from the research findings.

A limitation common to qualitative research is that the researchers bring their own particular lens to the study, so another researcher with a different lens may interpret different meanings into the findings. Also, it is likely that there are other variables not

identified in prior research or by this researcher that could change the results. In addition, the attachment styles are likely to have further complicating aspects in correlating with caregiving patterns, which this study did not look at.

Emerging Themes

One theme that emerged in this study that has also been uncovered in previous research is that attachment styles may have certain characteristics that affect caregiving patterns of behavior. Understanding these dynamics within the framework of spousal relationships is difficult due to the multiple factors that affect each partner in the relationship. However this perspective helps to capture the dynamics within the relationship instead of reducing the caregiving relationship to a more one sided description of the stress and burden experienced while caregiving.

Suggestions for Future Research

Further research is needed to understand the specific needs and strengths of caregivers throughout the entire caregiving process since the sources of caregiver distress are likely to change along with the Alzheimer's stages of decline. In addition, further research regarding the factors that influence the caregiver's motivation to provide care appears to be multidimensional and complex. More research regarding the influence of both partners' attachment characteristics on the physical and emotional well-being of individuals with dementia would again help tailor support programs for both partners in the dementia caregiving relationship. In addition, further research is needed to understand if caregiving partners other than heterosexual spousal caregivers, such as in same sex partner dementia caregiving relationships, have unique challenges and strengths.

Conclusion

The overall finding from this study was that Attachment Theory is not typically used among social workers working with caregiving couples when one spouse has dementia. However, it could broaden a clinician's perspective regarding the underlying history of couples both personally and interpersonally as well as provide insights into how that history may be exhibited both behaviorally and emotionally in patterns of spousal caregiving when one spouse has dementia. Although this broadened perspective may not change the treatment approaches, it may provide a perspective that enhances clinician empathy towards the difficulties that caregivers struggle to overcome. An attachment perspective may also be a helpful approach to provide a broader context when trying to help the caregiver understand their specific dementia caregiving struggles, and tailor therapeutic approaches accordingly.

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Appendix A

Interview Protocol

Interview Introduction

Thank you for being willing to meet with me today.

I am a social work graduate student at St. Thomas – University of St. Catherine. As part of my graduate school experience, I am conducting a qualitative research project. The focus of my study is to explore clinician thoughts of attachment within spousal caregiving dyads when one partner has dementia.

I have brought along with me today a participant consent form which I would like to go over with you before you sign. It is important to know that participation in my research project is completely optional and that all data used will be presented only as group data, and no individual will be identifiable. Do you have any questions before I go over the consent form?

Thank you for agreeing to be interviewed by me today.

Before I ask more specific questions related to your thoughts of Attachment Theory, I would like to start with a little background information about your work.

- 1 Can you tell me about the type of work you do with older adults?
 - What is your work setting?
 - Practice area? (therapy or support)
 - What is the service you are providing?
- 2 Where do your referrals come from?
- 3 How often do you work with spousal caregiving dyads when one partner has dementia? What factors do you think influence the frequency of your answer?
- 4 What are the most difficult aspects of your clinical practice when working with couples when one partner has dementia? Can you give me an example?
- 5 Describe some positive attributes you have seen displayed in dementia caregiving relationships that appear to sustain the emotional connection between spouses.
- 6 What are the most common factors driving the caregiver to transition the care receiver to a supported living setting?

Next, I'd like to ask you some questions about attachment. To get started I would like to offer an overview of Attachment Theory. Here is a brief written summary of Attachment Theory to reflect on as I'm asking you questions.

The basic concept of Attachment Theory is that it is an emotional behavioral system that guides how individuals manage their need for emotional security especially during times of distress.

Adult attachment theory suggests that the attachment figure may change during different periods in life but it is the same behavioral system designed to maintain a feeling of security and emotional support.

There are three basic attachment styles: Secure, avoidant, and anxious. Individuals with a secure behavior style display a comfort with closeness and a confidence in depending on others to fulfill attachment needs, while also demonstrating the ability to self-help or assist others in times of need.

Individuals with an avoidant attachment style have a discomfort with closeness, are extremely self-reliance, and a lack of confidence in depending on caregivers to meet attachment needs.

Individuals with an anxious attachment style have a high a need for approval, low self-worth, and a fear of abandonment and rejection.

According to attachment theory, caregiving is identified as a safety-regulating system, like attachment, that is intended to reduce the risk of harm. Attachment theory suggests that caregiving behaviors are linked to past emotionally based attachment experiences that are used as a template for how care is provided by the caregiver. It is from this attachment orientation that I am approaching this research project.

- 7 In your assessment process, do you look at early attachment history and/or the pre-dementia marriage relationship when working with couples when one partner is the caregiver and the other is the care receiver with dementia?
 - If the answer is no, what kind of questions do you routinely ask, and why?
 - How do you use this information to inform your practice?
 - Can you give me an example of a typical referral?

- If the answer is yes, what kinds of questions do you ask about the early and adult relationship history, and why?
 - How do you use this information to inform your practice?
 - In more general terms, what kind of information do you routinely gather in the assessment process?
 - How might Attachment Theory enhance the work you are currently doing? Examples?
- 8 Prior to this interview, had you thought about your assessment and treatment process in an attachment framework? Why or why not?
- 9 Does this discussion about Attachment Theory change in any way your thoughts about how this theory could benefit your practice at least in some situations?

End of Interview

Thank you for meeting with me today. I appreciate your time and willingness to share your insights with me. Would you like a copy of this transcript interview once it is transcribed? If so, I would be happy to send it to you. If you have any other questions that come up later, feel free to contact me or the other individuals listed on the back of this consent form.

As a token of my appreciation for your time to participate in this research here is a \$10 visa gift card.