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Spiritual support as coping among Alzheimer's caregivers

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SPIRITUAL SUPPORT AS COPING AMONG ALZHEIMER'S CAREGIVERS

A Thesis

Submitted to the Graduate Faculty of the
Louisiana State University and
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by
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Abstract

The purpose of this study is to identify the effect of spiritual support on Alzheimer's caregiver's perceived burden. This study will examine the relationship between spiritual support and burden among Alzheimer's caregivers. The collection of data was accomplished by a packet of surveys mailed to Alzheimer's caregivers. For this study the population is separated and difficult to survey as a whole, therefore, a smaller cluster sample is surveyed from a specific organization. The global score of the burden measure is negatively correlated with the global score of the Spiritual Support Scale. In this study, spiritual support is not the sole reason for perceived burden to be low; rather, spiritual support causes a more positive outlook on the burden, triggering the caregivers to report lower levels of perceived burden. A social worker must be confident in the knowledge of supports used by clients and how to accommodate each client in achieving the ability to cope with stress when caring for a loved one with Alzheimer's disease.

Introduction

Alzheimer's disease can be a devastating condition for anyone experiencing the symptoms. This disease can also affect the family of the person who is experiencing the symptoms, particularly the main caregiver. The symptoms of the Alzheimer's disease are felt by the person who is suffering from the disease and witnessed by the caregiver. While observing a loved one experience the symptoms of the Alzheimer's disease the caregiver can develop an overwhelming sense of burden. Alzheimer's disease and the symptoms witnessed by the caregiver will be better understood by understanding the burden felt by the caregiver.

Dementia is an ancient concept; derived from a Latin term demens, meaning without mind, and the prefix de, meaning off (Cipriani, Dolciotti, Picchi, & Bonuccelli, 2011). Dementia is a broad term with the most common form of dementia being Alzheimer's disease which includes characteristics such as memory decline and decline in other cognitive areas such as language (Taner, 2010). Dementia slowly destroys the ability to carry out simple tasks due to toxic changes that occur in the brain causing cells in the brain to die (Islam, Alam, Ferdousy, & Chowdhury, 2010).

This study will examine Alzheimer's disease and the caregivers who provide care for loved ones with the Alzheimer's disease. The study will begin with the history of Alzheimer's disease followed by the demographics reporting individuals affected by the disease. The study will then describe Alzheimer's disease, the risk and protective factors, and the treatment options. Next, the study will define and discuss caregivers. The many functions caregivers are responsible for will be thoroughly discussed in this study. The demographics regarding caregivers in the United States and more specifically in Louisiana will be reported.

The different types of burden caregivers experience will be discussed in this study. Beginning with physical burden, financial burden, and burden related to the lack of time and finally emotional burden associated with caring for a loved one with Alzheimer's disease. Both emotional-focused coping strategies and problem-focused coping strategies will be generally defined, followed by a more specific examination, pertaining to spiritual coping strategies. A theoretical foundation will be applied to the issue of perceived burden from caregivers. The theoretical foundation will be followed by the results. Finally, the discussion will explain the results before the conclusion of the study.

Literature Review

History

Over one hundred years has passed since Alois Alzheimer first described the clinical features of a unique brain disease during the meeting of the Society of Southwest German Psychiatrists in Tubingen, Germany (Cipriani et al., 2011). The first diagnosed patient, a female, by the name of Auguste Deter, showed signs of memory loss, delusions, hallucinations and disorientations (Cipriani et al., 2011). Deter died at fifty-five years of age (Cipriani et al., 2011). These symptoms were developed over four and a half years before Deter was treated (García-Albea & Trullen, 2003). Other reported symptoms included attacks of jealousy, progressive aphasia (language disturbance), agnosia (failure to identify or recognize objects), and apraxia (impaired ability to complete motor activities) (García-Albea & Trullen, 2003).

Alois Alzheimer's attention was caught by Deter's symptoms during early onset (García-Albea & Trullen, 2003). At the time Alois Alzheimer was working at Munich under the direction of Emil Kraepelin; however, Deter, his fifty-five year old patient continued to remain on Alzheimer's mind (Cipriani et al., 2011). After Deter's death, Alzheimer requested her records and actual brain to be sent to him for research purposes (Cipriani et al., 2011). On examination he found intensely coiled and thick masses of fibres in the cytoplasm of numerous neurons (García-Albea & Trullen, 2003). Emil Kraepelin, in 1910, named the condition after Alois Alzheimer (Cipriani et al., 2011). Today the massive loss of neurons and the presence of amyloid plaques and neurofibrillary tangles are associated with Alzheimer's disease (Cipriani et al., 2011).

The first American case of Alzheimer's disease was described by Nicolas Achucarro in the National Library of Medicine (García-Albea & Trullen, 2003). Achucarro reported a patient

who was seventy-seven years old at the time of her death (García-Albea & Trullen, 2003). The patient had resided in an institution for nineteen years and at the time of her death, she had the diagnosis of chronic dementia (García-Albea & Trullen, 2003). At the patient's autopsy, Achucarro reported finding plaques and pathologies corresponding with the description given by Alois Alzheimer (García-Albea & Trullen, 2003).

Demographics

There are more than 25 million cases across the world, making Alzheimer's disease the most common neurodegenerative disease (Cipriani et al., 2011). In the United States there are an estimated 5.3 million people with Alzheimer's disease (Sabbagh & Cummings, 2011). More than half of the total Alzheimer's patient population may be classified as having moderate or severe symptoms of the disease (Sabbagh & Cummings, 2011).

As the United States population ages, more than 33% of all women, age sixty-five and older are expected to develop this disease during their lifetime (Potyk, 2005). Men are possibly less affected with a predicted percentage of 20% of men, aged sixty-five and older, who are expected to experience dementia during their lifetime (Potyk, 2005). Unless therapies are identified, the number of patients with dementia is expected to exceed one hundred and fifteen million (Taner, 2010). There is a lack of effective treatments for this disease causing much frustration for patients diagnosed with Alzheimer's disease. (Potyk, 2005).

Describing the Disease

The onset of Alzheimer's is gradual and involves continuing cognitive decline (American Psychiatric Association, 2000). Alzheimer's disease is an ultimate diagnosis after years of experiencing minor compromise of one specific cognitive territory- memory (Buscema, Grossi, Capriotti, Babiloni, & Rossini, 2010). The age of onset of Alzheimer's disease is categorized as

either early onset, sixty-five years of age or before; or late onset, which is after the age of 65 (American Psychiatric Association, 2000). The condition of a minor compromise of cognitive processing is referred to as mild cognitive impairment (Buscema et al., 2010). As more plaques and tangles form in the brain of an Alzheimer's patient, healthy neurons begin to work less efficiently, losing their ability to communicate and function together and eventually dying (Islam et al., 2010).

The hippocampus is vital in developing memories, however as the process of the disease spreads, the neurons continue to die in different structures of the brain such as the hippocampus (Islam et al., 2010). Regions of the patient's brain shrink as the death of neurons continue to increase (Islam et al., 2010). By the final stage of the Alzheimer's disease, damage is widespread and brain tissue has shrunk significantly (Islam et al., 2010) which ultimately leads to the death of the patient (García-Albea & Trullen, 2003).

A common pattern in the early stages of the disease is memory loss several years later this is followed by the development of aphasia, apraxia, and agnosia (American Psychiatric Association, 2000). The earliest symptom of the Alzheimer's disease is usually memory loss. However, other early noticeable symptoms include problems with language, reasoning, or spatial perception or mood changes (Belluck, 2011). The most frequent symptoms of Alzheimer's disease include tearfulness, delusions, tremors, lack of concentration with the most common being depression and lack of cooperation (Fernández, Gobartt, & Balañá, 2010). In many individuals behavioral signs and symptoms begin in the early stage and become increasingly pronounced in later stages (American Psychiatric Association, 2000). These behavioral symptoms include increased irritability and personality changes (American Psychiatric Association, 2000).

During the course of Alzheimer's disease, most patients experience agitation and depression (Cohen, 2002). Agitation in the patients is often provoked by delusions or an unstructured environment (Cohen, 2002). In later stages patients may develop motor disturbances and eventually may become bedridden and mute (American Psychiatric Association, 2000). The duration of Alzheimer's disease from onset of symptoms to death on average is eight to ten years (American Psychiatric Association, 2000).

There is no specific biological marker currently accepted as the diagnostic feature of Alzheimer's in a living individual; however, in the majority of cases, brain atrophy is the only completely accepted determining factor to diagnose Alzheimer's disease (American Psychiatric Association, 2000). Upon atrophy examination the hallmarks of Alzheimer's disease can be seen, including senile plaques, neurofibrillary tangles, neuronal loss, granuovascular degeneration, amyloid angiopathy, and astrocytic gliosis (American Psychiatric Association, 2000). In reflection of a deeper understanding of Alzheimer's disease, diagnostic criteria for the disease have been revised for the first time in over twenty-five years (Vaughn, 2011). The new criteria divides the disease into three stages: early phase in which symptoms are not evident and the beginnings of the disease can only be seen in the brain, middle phase in which daily function is still possible but mild problems have emerged, and lastly, the late phase where dementia is developed and eventually ability to function is lost (Belluck, 2011).

Risk and Protective Factors

Risk factors for Alzheimer's disease include: age, female sex, African-American ethnicity, Hispanic ethnicity, hypertension, high cholesterol, diabetes, smoking, head trauma, poor socioeconomic status, low education, environmental or occupational exposures (Taner, 2010). The foundation evidence of a genetic risk for developing Alzheimer's disease comes from

three positions of studies: familial aggregation, transmission pattern, and twin studies (Taner, 2010). Exercise, higher education, alcohol in moderation, diet, mental activity, social activity, medication, vitamins, and estrogen are possible protective factors (Taner, 2010).

Alzheimer's disease is a progressive disease that cannot be terminated or reversed; however, some treatments can ease suffering, improve coping, and enhance patients' dignity as they live with the disease (Cohen, 2002). Buscema et al. (2010) stated rehabilitative treatments are more effective when started earlier in the development of the disease. Holt, Stiltner, and Wallace (2009) suggested treating Alzheimer's disease in early stages produce statistically significant improvements in cognition and global function. Holt, Stiltner, and Wallace (2009) also stated non-pharmaceutical treatments for Alzheimer's disease includes cognitive stimulation, exercise, amplified socialization, and enhanced nutrition.

There is a growing knowledge that cognitive activity and social engagement may be protective against the development of Alzheimer's disease (Potyk, 2005). Holt, Stiltner, and Wallace (2009) encouraged exercise, cognitive stimulation, and increased socialization, which may assist in preventing functional decline in the very elderly. Exercise suggested for this population is moderate in scale for thirty minutes three days a week (Holt, Stiltner, & Wallace, 2009). For some individuals, who have developed Alzheimer's disease, an emotion-oriented psychotherapy is being tested, such as reminiscence therapy (Potyk, 2005). Reminiscence therapy requires the recollection of events, places and people in the patient's life (Potyk, 2005). Alzheimer's patients are encouraged to reminisce about early memories, family, jobs, transitions and/or other meaningful memories (Potyk, 2005). Cohen (2002) stated behavioral issues may be more easily managed by including Alzheimer's patients in meaningful activities that are

supervised and structured by an authority such as an institute like an adult day treatment program.

Treatment

Common medications that are FDA-approved for the treatment of Alzheimer's disease are Haloperidol (Haldol), Perphenazine (Trilafon), and Thioridazine HCl (Mellaril), which are typical neuroleptics (Cohen, 2002). Atypical neuroleptics include medications such as Olanzapine (Zyprexa), Quetiapine fumarate (Seroquel), and Risperidone (Risperdal) (Cohen, 2002). The atypical neuroleptics have fewer side effects and are newer medications that have, by and large, replaced the older typical neuroleptics which are used specifically for psychotic symptoms of Alzheimer's disease (Cohen, 2002). Evidence shows cholinergic deficits correlate with the decline of cognition of Alzheimer's patients (Sabbagh & Cummings, 2011). As the severity of the disease amplifies, cholinergic activity shows deficiencies (Sabbagh & Cummings, 2011). Hence, Holt (2009) stated patients in the later stages of Alzheimer's disease would likely benefit from cholinesterase inhibitors.

Caregivers

The phrase *care recipient* will be substituted for the term *patient* because this work focuses on the perspective of the caregiver. The care recipient who suffers with Alzheimer's disease personally experiences these symptoms. The caregiver must witness the suffering which can have a major impact on the observing caregiver. As mentioned before, for the care recipient, Alzheimer's disease is a gradual decline of cognition. The caregiver must watch as a possible loved one slowly disappears from reality; therefore, the study of caregivers is important in making an attempt to alleviate the many stressors experienced by the caregivers because of their multitude of responsibilities.

Definition

The Alzheimer's Association (AA, 2004) defined *caregiving* as care provided to a friend or relative, usually unpaid. The caregiver is usually 50 years of age or older and focus on performing tasks associated with assisting the care recipient in caring for themselves. The care recipient may or may not live with the care provider. The care provided may include assistance with personal and/or household needs and chores. The care may also include arranging outside services, regular visits to check on the care recipient, and/or assuming the responsibility of the care recipient's finances.

Traits associated with the Alzheimer's caregivers include successful coping skills, the ability to problem solve, and flexibility throughout life (Farcnik & Persyko, 2002). These traits and others would be considered significant assets for caregivers (Farcnik & Persyko, 2002). Routine stressors associated with caregivers of Alzheimer's care recipients consist of the caregivers' responsibilities and the caregivers' attitude towards these responsibilities (Farcnik & Persyko, 2002). The professional guidelines and legislation, the organizational aspects and the

socio-cultural aspects of the caregiver all dictate the role of caregivers in the decision-making process on issues associated with the Alzheimer's care recipient (Pazart et al., 2011).

Functions

Tasks associated with caregiving may include, but are not limited to, handling finances, performing household chores, preparing of meals, toileting, dressing, communication and supervision (Marin et al., 2000). The time a caregiver spends caring for a care recipient with the Alzheimer's disease varies widely but tends to correlate with the severity of the disease (Marin et al., 2000). The caregiver may become disheartened if no benefit to the care recipient is observed, which may lead to a caregiver's disappointment and anger (Brodaty & Green, 2002).

The caregiving role occupies an enormous amount of time for the caregiver; therefore, the caregiver is left with little time to attend to his or her own personal needs, socially and/or physically (Elliott, Burgio, & DeCoster, 2010). Caring for Alzheimer's care recipients tends to cause a more prevalent disturbance on the work and family life of the caregiver (Wilks & Croom, 2008). The reason for this negative toll on the caregiver is because the type of care provided is more physically, emotionally, and time demanding (Wilks & Croom, 2008). Caregivers may be forced to deal with other family members' opinions about the care of their loved one (Farcnik & Persyko, 2002). A spouse may experience difficulties when attempting to balance caregiving duties with outside work (Farcnik & Persyko, 2002). Both experiences plus many more may lead to caregiver burden (Farcnik & Persyko, 2002).

United States Caregivers

In the United States more than 70% of people suffering with the Alzheimer's disease live at home with 75% of the care provided to these Alzheimer's care recipients is provided by friends and family members (Martin-Carrasco et al., 2009). Female caregivers make up three-

fourths of the caregiver population (Wilks & Vonk, 2008). One-third of the caregivers have children or grandchildren who are under 18 years of age and living at home (Wilks & Vonk, 2008).

There are an estimated 5.3 million people living in the United States who are suffering the symptoms of the Alzheimer's disease (Alzheimer's Association, 2011). Cherry (2008) stated there are millions of professionals, friends, and family members providing care to people with the Alzheimer's disease. To be specific, Cherry (2008) quotes about one to three caregivers for each person with the Alzheimer's disease, approximately 10 million Americans.

The Alzheimer's Association (2011) stated there are close to 15 million Alzheimer's caregivers in the United States. These caregivers provide around 17 billion hours of care, valued at \$202 billion; however, most of the care provided is unpaid (Alzheimer's Association, 2011). Due to the prolonged duration of caring for an Alzheimer's care recipient, high levels of stress are reported by more than 60% of family caregivers (Alzheimer's Association, 2011). The negative health effect of caring for an Alzheimer's patient causes an additional \$7.9 billion in 2010 (Alzheimer's Association, 2011).

Symptoms of the Alzheimer's disease cause stress in caregivers no matter the cultural background of the caregiver or the person suffering from the Alzheimer's disease (Pang et al., 2002). However, American caregivers reported higher distress than Chinese caregivers at certain times (Pang et al., 2002). For American caregivers, these highly stressful times were caused by the care recipient exhibiting agitation, delusions, euphoria, anxiety, hallucinations, depression, and other severe symptoms associated with the Alzheimer's disease (Pang et al., 2002).

Louisiana Caregivers

The Alzheimer's Association (2011) verified Louisiana to be one of the most affected states by Alzheimer's. In 2010 the number of people 65 years of age and older who are living with the Alzheimer's disease in Louisiana is 83,000 (Alzheimer's Association, 2011). For 2025 the estimated total number of people age 65 years or older in Louisiana who have the Alzheimer's disease is 100,000 (Alzheimer's Association, 2011). If a cure for this disease is not found, allowing the numbers to continue as estimated, by the year 2025, 37% of Louisiana's population will be suffering with the Alzheimer's disease (Alzheimer's Association, 2011).

The number of people who have the Alzheimer's disease is astounding; however, the number of caregivers who are and will be affected by this disease is simply overwhelming. In 2008 there were a total of 160,914 caregivers in Louisiana, caring for a care recipient with the Alzheimer's disease (Alzheimer's Association, 2011). In Louisiana, the total number of hours of unpaid care provided by caregivers of people with the Alzheimer's disease was 138,900,565 valued at \$1,541,796,269 (Alzheimer's Association, 2011). By 2010, all of the numbers, in Louisiana, have risen substantially and the reasonable conclusion is the same will continue each year unless change happens. The number of unpaid Louisiana caregivers in 2010 was 218,965 (Alzheimer's Association, 2011). These caregivers were providing a total of 206,237,562 hours of care to Alzheimer's care recipients, valued at \$2,974,831,052, almost doubling the value from 2008 (Alzheimer's Association, 2011).

Caregiving Burden

Caring for a person with Alzheimer's disease is a stressful activity which often leads to high levels of burden experienced by caregivers (Germain et al., 2009). The reaction of a caregiver to stress has a major impact on perceived caregiver burden (Robinson, Adkisson, & Weinrich, 2001). Caregiver's burden may correlate with the amount of problems exhibited by the care recipient (Robinson et al., 2001). The burden of caregivers includes a wide variety of undesirable consequences including physical, financial, time, and emotional (Croog, Burleson, Sudilovsky, & Baume, 2006).

The toll that is laid upon the caregiver due to day-to-day responsibilities may manifest itself negatively on the caregiver, psychologically, financially, socially, and/or physically (Brodaty & Green, 2002). Symptoms of depression are reported by 33% of caregivers due to the unprecedented demands the Alzheimer's care recipient requires (Alzheimer's Association, 2011). Considerable financial costs can be the responsibility of the caregiver, placing the caregiver in a financial crisis (Brodaty & Green, 2002). To combat this financial issue some caregivers may contemplate nursing home care as an option that would lower their personal costs. The contemplation of this decision alone can add a considerable amount of burden on the caregiver (Brodaty & Green, 2002). As the progression of the disease persists the caregiver must focus more time toward the care recipient decreasing or possibly eliminating social activities for the caregiver (Brodaty & Green, 2002).

Physical problems may be experienced and worsened while the caregivers focus is on the care recipient (Brodaty & Green, 2002). As Alzheimer's disease progresses, the supervision and care given by the caregiver must increase (Martin-Carrasco et al., 2009). The number of caregivers who experiences stress related health problems such as a weakened immune system as

a direct result of caregiving is almost 15% (Wilks & Vonk, 2008). Over half of the caregivers are over the age of 50 years and 14% are over 65 years of age, these caregivers at this advanced age are more likely to experience health problems associated with the care they provide (Wilks & Vonk, 2008).

The perception of the burden by the caregiver is parallel to the care recipient's impairment and the impact the impairment causes on the caregiver (Annerstedt, Elmstahl, Ingvad, & Samuelsson, 2000). Annerstedt et al. (2000) identified three factors involved in the caregiver's burden. The first factor is the burden associated with the care recipient; such as activities of daily living, behavior, and health status (Annerstedt et al., 2000, Germain et al., 2009). The second factor is the burden associated with the caregiver; including the relationship with the care recipient, the age of the caregiver, and the health status of both the caregiver and the care recipient (Annerstedt et al., 2000, Germain et al., 2009). The final factor is the responsibilities assumed by the caregiver, such as the time consumed by the tasks and the type of tasks (Annerstedt et al., 2000, Germain et al., 2009).

Physical

The appraisal of personal burden by the caregiver correlates with personality which is a predictor of their own physical health (Hayslip, Han, & Anderson, 2008). Caregivers usually experience increased demands on efficiency which may lead to work overload (Takano & Arai, 2005). Depression (crying, feeling hopeless or feeling like a burden) and disruptive behavior (speaking loudly, arguing, or showing aggression) are two main behaviors of care recipients that warrant a negative reaction from caregivers increasing the perceived burden (Robinson et al., 2001). Robinson et al. (2001) stated that the knowledge of possible behaviors that the care recipient may display can alleviate some burden that is perceived by the caregiver. Decreased

behaviors deemed problematic for caregivers will lessen the burden and increase self-care abilities in the caregivers (Robinson et al., 2001).

Caregivers may feel committed and energized to providing the best care to the care recipient; however, caregivers also feel their daily activities are significantly affected by the assumed responsibilities (Hwang, Rivas, Fremming, Rivas, & Crane, 2009). The caregiver's energy can be quickly consumed by the demands of caring for the care recipients which can lead to participation in their own life being restricted (Hwang et al., 2009). The social well-being of the caregiver can be affected when the caregiver begins to withdraw from society because of the overwhelming responsibilities (Hwang et al., 2009). Withdrawing from society may include reducing participation in social activities, loss of friends, and other activities, contributing to the caregiver's social isolation (Hwang et al., 2009).

Financial

Financial challenges can be some of the heaviest burdens to accept for a caregiver (Lai, 2009). While caring for a loved one, a caregiver may be on high demand as a caregiver, alleviating time and energy to devote to an occupation (Hwang et al., 2009). Employment may be something a caregiver must give up in order to provide the needed care (Hwang et al., 2009). As a caregiver surrenders employment, financial problems can quickly become a heavy part of the burden the caregiver must shoulder (Hwang et al., 2009).

Results from Takano and Arai (2005) stated caregivers, especially female caregivers, are personally affected by the economic cost of caregiving. Financial support is lacking for elderly people and their caregivers, but the situation is worse when trying to meet the extra cost for specific dementia care (Takano & Arai, 2005). This lack in financial assistance may increase caregivers' perceived burden (Takano & Arai, 2005).

Time

Annerstedt et al. (2000) suggested high burden for a caregiver can be predicted by the amount of time a caregiver must spend caring for the care recipient. Germain et al. (2009) stated the number of hours caregivers spend attending to the activities of daily living were one of the most important factors in predicting burden of the caregiver. The greater the number of hours spent caring, the greater the impact and perceived caregiver burden (Germain et al., 2009).

Assistance from family members can help to alleviate responsibilities but even with support from others, caregivers still have little time to devote to self-care, social activities, employment and other meaningful occupations (Hwang et al., 2009). A care recipient living home alone may require more attention by the caregiver (Annerstedt et al., 2000). However, it is evident in studies done over a long period of time that caregivers are not relinquished of responsibilities after the institutionalization of the care recipient (Gaugler, Roth, Haley, & Mittelman, 2008).

Emotional

One of the most complex consequences of caregiving is the emotional strain. The onset and the progression of symptoms of the Alzheimer's disease are gradual; therefore caregivers assume caregiving responsibilities without identifying themselves as caregivers of an Alzheimer's care recipient until later in the progression of the disease (Garand, Dew, Eazor, DeKosky, & Reynolds, 2005). The uncertainty of the prognoses, the unclear affect the disease will have on the care recipient, and the undefined timeline the disease will progress all cause the caregiver stress and increase the burden as the caregiver attempts to anticipate the future needs of the loved one (Garand et al., 2005). Hayslip et al. (2008) speculated the caregiver is highly burdened by the lack of control over the situation as a whole.

The coping abilities and the adaptability of the caregiver may also be a determining factor in the caregiver's perceived burden (Annerstedt et al., 2000). The caregiving role is diverse, even in the early stages of the Alzheimer's disease, and requires the caregiver to assume many new responsibilities that may be unfamiliar to a new caregiver (Garand et al., 2005). High depression levels in caregivers are associated with the increased nursing tasks such as the administration of medication which may serve as a daily reminder of the suffering of the loved one related to this disease (Garand et al., 2005).

When a care recipient is experiencing hallucinations and delusions a caregiver can be seriously affected by witnessing such a decline in their loved one's cognitive ability (Germain et al., 2009). Watching the slow deterioration of a loved one is associated with a struggle with depression by the caregiver (Lai, 2009). The total perceived burden a caregiver feels can be affected by the caregiver's opinion of the care recipient's dependency in social functioning (Annerstedt et al., 2000). A high level of social dependency on the caregiver by the care recipient may increase the level of burden that is felt by the caregiver (Annerstedt et al., 2000).

Coping Strategies

Caregivers experience many emotions during their time as a caregiver. Their feelings range from sadness, anxiety, fear, frustration, to relief directly following a diagnosis, also shock may occur because the caregiver never assumed they would become a caregiver (Sanders & McFarland, 2002). To combat these feelings caregivers employ their own coping strategies. Coping strategies are efforts, psychological or behavioral, made to reduce, tolerate, or overcome stressful events such as becoming the primary caregiver of a loved one with Alzheimer's disease (Cooper, Katona, Orrell, & Livingston, 2008). When faced with caring for a care recipient with Alzheimer's disease a caregiver may use three different styles of coping: emotion-focused, problem-focused, or dysfunctional.

Emotional-focused

Emotional-focused strategies focus on the caregivers' ability to psychologically manage the meaning of their own caregiving experience (Morano, 2003). A caregiver using this style of coping focuses on the appraisal of burden, which can discourage problematic behaviors and negative psychological outcomes (Morano, 2003). Cooper et al. (2008) stated caregivers who employ emotional-focused coping strategies during their time of crisis, demonstrate less anxious qualities one year following the beginning of their caregiving role.

Cooper et al. (2008) identified five approaches to emotion-focused coping strategies. Accepting the caregiver role as a fact of life and learning to live with the new role can be difficult but is an emotion-focused response to this stressful event. The second emotion-focused strategy is positive reframing. This is the attempt of a caregiver to reframe the stressful event into a positive event. A caregiver may view caregiving as a chance to honor the care recipient by giving back to them or the chance to spend precious time with the loved one.

Cooper et al. (2008) identified the third strategy as emotional support, which is allowing others to comfort the caregiver. Caregivers may seek conversation with someone who will understand the caregiver's situation. Humor is the fourth coping strategy that is classified as emotional-focused. Using humor to cope with a situation may seem strange to others but making fun of the situation can lighten the perceived burden for some caregivers. Lastly, Cooper et al. (2008) viewed religion as an emotional-focused coping strategy, which will be explained more thoroughly later in this discussion.

Problem-focused

Problem-focused coping strategies focus on the attempts of the caregiver to manage the situation (Morano, 2003). The appraisal of satisfaction in the management of the situation is made evident on the effects of the behavior and the outcomes (Morano, 2003). Cooper et al. (2008) identified three types of problem-focused coping strategies. The first is active coping. The caregiver concentrates all efforts on taking action to make the situation better. The second is instrumental support, which includes obtaining help and advice from others as social supports, such as local Alzheimer Service organizations. Finally there is planning, which is determining steps that must be taken to better the current situation of the caregiver.

The most common coping strategies identified by caregivers are problem-focused and in particular seeking social supports (Wilcox, O'Sullivan, & King, 2001). Sanders and McFarland (2002) stated sons who care for parents with Alzheimer's disease emphasized the success of problem-focused coping strategies. Problem-focused coping strategies most used by caregiving sons were home aides, support groups, Alzheimer's Association, long-term care, adult day care, and respite care (Sanders & McFarland, 2002). Daughters who provide care for a parent with Alzheimer's disease are the most likely to use problem-focused coping strategies (Wilcox,

O'Sullivan, & King, 2001). Caregivers who are wives of the care recipient associate problem solving and seeking help with the well-being of themselves and the care recipient (Wilcox, O'Sullivan, & King, 2001).

Spiritual Coping Strategy

In this discussion the belief that spiritual coping strategies can be seen as emotional-focused or problem-focused will be explained. Cooper et al. (2008) stated religion is an emotional-focused coping strategy because religion may assist in psychologically managing the meaning of a caregivers experience, which is the definition of emotional-focused coping strategy provided by Morano (2003). However, spirituality can also be beneficial in the attempts to manage the caregiving situation, which is the definition of problem-focused coping strategy.

Spiritual coping strategies are consistently important to caregivers caring for loved ones with Alzheimer's disease, involving activities which focus on the caregivers' spiritual beliefs (Stuckey, 2001). Stuckey defined spirituality as involving the practices and beliefs that link a person to meaningful and often holy entities beyond them; creating and often sustaining a relationship with a supreme being which gives meaning and purpose to one's own life. Pearce (2005) stated caregivers reporting involvement in religion also report frequent involvement in religious coping strategies.

Emotional-focused. The caregivers reporting high involvement in religious coping strategies reported depression at lower levels (Morano & King, 2005). Caregivers with only a basic understanding of religion and who do not actively participate in any religious activities report burden at a higher level (Herrera, Lee, Nanyonjo, Laufman, & Torres-Vigil, 2009). Choi, Tirrito, and Mills (2008) stated African American caregivers are more social, and this may indicate these caregivers utilize support from spiritual communities more often by participating

in religious activities. Choi, Tirrito, and Mills also found White caregivers to report more depression than African American caregivers.

Spiritual caregivers may experience fewer problems in accepting themselves and their situation (Morano & King, 2005). Morano and King (2005) stated spiritual growth in a caregiver can serve as a protective factor against burden. Instead of caregivers focusing on the despair experienced from the disease, caregivers who have spiritual growth focus on faith and positive consequences despite loss from the disease (Stuckey, 2001). Stuckey stated caregivers reported spiritual beliefs and practices were supportive roles when coping with caregiving. Spiritually focused caregivers stated events in life, such as caregiving, are never random; rather God is the protector and provider (Stuckey, 2001).

Stuckey (2001) reported many caregivers believe God is always in control and has a plan for each life regardless of whether or not the reason for an event was clear. No matter the difficult trials experienced by emotional-focused caregivers, belief in God is non-wavering and the belief God has their best interest in mind (Stuckey, 2001). DePalo and Brennan (2004) stated hope is a prevalent human value, allowing for a sense of stability and positive thinking even in the face of an uncertainty caused by caregiving for a loved one with Alzheimer's disease. Hope is a value that spiritual caregivers possess, confirming vitality of life even in the face of death (DePalo & Brennan, 2004). Prayer is another human value when using spirituality to cope (Stuckey, 2001). However, Stuckey (2001) reported emotional-focused caregivers did not pray for a cure, rather for comfort and assistance in coping.

Caregivers using spirituality as an emotional-focused coping strategy uniquely define the event of caregiving. Herrera et al. (2009) research indicated caregivers reporting high levels of spirituality were less likely to report caregiving as a negative or burdensome role. Stuckey's

(2001) research stated caregivers caring for loved ones with Alzheimer's disease and using spirituality to cope with the stress did not report the situation as burdensome rather focused on the support provided by spiritual beliefs and the plan God has for caregivers and care recipients.

Choi, Tirrito, and Mills (2008) stated caregivers using spiritual coping strategies were successful in lowering stress caused by caregiving burden, which resulted in lower depression rates among caregivers. Morano and King's (2005) data indicated significant differences among three groups varying by race and ethnicity. Morano and King (2005) reported African American caregivers reported coping with caregiving using spiritual coping strategies at the highest rate, followed by Hispanics, and then White non-Hispanics. This suggests using religion as a coping strategy varies by race and ethnicity (Morano & King, 2005).

Problem-focused. Interest in coping with caregiving using spirituality is widespread which has led to a surge of scientific investigations on this topic (DePalo & Brennan, 2004). In the care of older adults, problem-focused spirituality coping strategy is a vital requirement in assessments and planning interventions (DePalo & Brennan, 2004). Stuckey (2001) identified a theme that has emerged from research on caregivers using spirituality to cope with caregiving. The theme identified by Stuckey is focused on caregivers using the church or the synagogue as a support network. Herrera et al. (2009) stated 69%, the majority, of caregivers report Roman Catholic background. Herrera et al. (2009) also stated 22% of caregivers were other Christian background and 7% were unaffiliated.

Choi, Tirrito, and Mills (2008) stated caregivers' ability to care for their loved ones is significantly supported by the caregivers' place of worship. A caregiver receives support from their own place of worship, which influences decision making and allows less stress and less likelihood of an overloaded caregiver (Choi, Tirrito, & Mills 2008). Religious institutions can be

partners in delivering services which may aid in bridging trust in social services, address the importance of seeking help, and expedite referrals and follow-up communication with social services (Stuckey, 2001). Actively seeking support is a direct linkage from spirituality to a problem-focused coping strategy.

Choi, Tirrito, and Mills (2008) stated caregivers are likely to give better care when religious beliefs are strengthened by spiritual support, which may be provided by the caregivers' church. Turning to spirituality to cope with caregiving represents a relationship with God that is secure (Pearce, 2005). Belief that meaning can be found in life and a sense of connection to others spiritually lead to healthy psychological adjustment, better self-esteem, and spiritual growth (Pearce, 2005). Stuckey (2001) identified five patterns common in caregivers who use spirituality to cope with burden from caring for a loved one with Alzheimer's. These patterns are spiritual growth, caregiving, attributes of God and faith, values, and defining the stressor (Stuckey, 2001).

Pearce (2005) stated conversely some caregivers concentrate on a negative religious coping strategy; however, this style tends to come from a condensed relationship with a higher power causing the caregiver to view the world as more of a struggle. Herrera et al. (2009) reported caregivers experience a negative sentiment from their spiritual beliefs only when caregiving is viewed as a punishment. These caregivers felt abandoned by God and were more likely to report higher levels of burden (Herrera et al., 2009). The stress felt from the burden of caring for anyone can be overwhelming; however, as an adult child transitions into the caregiving role and a parent becomes the care recipient the stress is quite unique.

Using spirituality to cope is a multidimensional coping strategy, which involves emotions, behaviors, relationships with a congregation, and a relationship with a higher power

(Pearce, 2005). Spirituality involves a highly sensitive emotion for most people allowing the caregiver to increase faith in a higher power and allow for positive reframing when faced with a problem. Spirituality also creates readily available support systems through religious congregation allowing the caregiver to focus on making the situation better. For these reasons the spiritual coping strategy can be viewed as an emotional-focused or as a problem-focused coping strategy.

Theoretical Foundation

It is understood for a person to experience devastating stress when a loved one is diagnosed with an incurable disease. It is understood a child may be distraught when a parent experiences pain. It is understood a parent no longer capable of caring for anyone, even self-care, may begin feeling unbearable stress. This section will highlight social role theory, describe the role of parent and child, and discuss the stress experienced by both during a reversal of roles due to a diagnosis of Alzheimer's. The idea of this section is to better understand the specific stress which causes the overwhelming sense of burden in adult child caregivers and the Alzheimer's patients.

George Mead made a contribution positively toward social role theory when he initiated an idea which made it possible to connect human impulses to a rule defined by society (Joas, 1990). This theory defines the role each person subscribes to in life. The role identified is accompanied by scripts, which explain how each role should be portrayed in public. For example, a parent's role is defined as the activities and relationship related to being a mother or father (James & Mullen, 2002). Similarly, a child's role describes how a child is supposed to behave toward a parent. For another example, Teitelman and Watts (2004) reported a case where the wife who had lived her life as a full-time homemaker spent several years caring for her husband. During this caregiving time she reports an overwhelming feeling because her relationship with her husband had gone from a partnership to a place where she felt she had to do it all by herself (Teitelman & Watts, 2004).

The majority of the caregivers are wives, husbands, daughters, and sons (Papastavrou, Kalokerinou, Papacostas, Tsangeri, & Sourtzi, 2007). The theory section will explain the unique circumstances that tend to create a stressful environment for Alzheimer's patients and their

caregiver. Principles of social role theory will be provided along with a discussion regarding the application of the theory toward the distinctive relationship of an adult child caregiver and a parent with Alzheimer's.

Principles

Social role theory says there is a certain way each individual should act in public based on his or her role. Continuing with the example of a mother and child relationship, a mother takes on the role as a mother once society views her as such (Martin, 2005). As a child grows he or she learns the role given by society. Within the roles there are rules to follow, which are taught by society's reactions to behaviors. For instance, a child should learn to obey parents because of the understanding of negative consequences when this rule is not followed. A parent should learn encouraging a child is a rule of the parent role by witnessing the positive effect from society and the child (Hill, Kondryn, Mackie, McNally, & Eden, 2003).

Once a role is learned and established, it becomes imprinted and difficult to change. However, as a child grows and matures it becomes necessary for the role to change which can cause stress to mother and/or child (Hill et al., 2003). A spouse caregiver may also experience a great deal of perceived burden due to role change. A spouse may seek support throughout the caregiving role and specifically targeting the transition period into the role (Gaugler, Roth, Haley, & Mittelman, 2008). The social role theory can be applied to any role a person chooses to subscribe to during their life. Other roles consist of grandparent, teacher, preacher, car driver and many others. Each of these roles has a set of rules that are put in place and monitored by society.

Applying Theory to Caregiving

When focusing on caregivers and care recipients specifically with Alzheimer's disease, there may be role reversal issues (Sanders & McFarland, 2002). When an older adult is

diagnosed with Alzheimer's disease a person must step out of the previous subscribed role and into the role of caregiver. At this point there is an immediate role change. Either when the parent becomes the care recipient and the adult child becomes the caregiver or when a spouse must become more than a partner, roles change and the primary caregiver must be responsible for all decision making. The caregiver must now learn a new role in which not only are the responsibilities great but the focus has changed from the caregiver's own life, to giving care to one who once was independent which may lead to a unique burden (Martin, 2005 & Sanders & McFarland, 2002).

Not only must the caregiver reorganize the role portrayed, but also the care recipient is also reestablishing their role as well. A care recipient is the parent or spouse who now has an Alzheimer's diagnosis. The previous role of parent was to provide care and mentor their child, but now he or she must relinquish most of what has become identity. No longer will the parent be the provider, now the parent must rely on the child who is now the caregiver for all tasks of daily living. The previous role of a spouse was to walk hand in hand with a spouse, completely equal, or with roles established at the beginning of a relationship. No longer is the relationship equal but one spouse must be responsible for caregiving and all other responsibilities for life to continue. This reversal of roles may be extremely stressful for both caregiver and care recipient (Sanders & McFarland, 2002). Each is giving up a familiar role to take on a new, possibly more challenging role with all new rules from society. During the reorganization period a supportive role is crucial for each (Hill et al., 2003).

Perceived burden is different for every person. Social role theory explains the specific burden involved in reversing original roles to establish new roles. The burden of caring for a parent is difficult on a child in any case. Specifically when the parent is diagnosed with

Alzheimer's the adult child must step up into a caregiving role which explains a unique sense of burden (Sanders & McFarland, 2002). Sanders and McFarland (2002) also stated the parent with Alzheimer's must face unique burden as well. The Alzheimer's patient must cease in his or her role of caregiving and adjust to being dependent on the caregiver which explains a burden that is unique to Alzheimer's patient being cared for by adult children.

The theory George Mead suggested attempts to explain roles society gives to each individual (Joas, 1990). Each role has a script which dictates the actions of individuals. An individual learns the role given by society and it becomes permanent and nearly impossible to change. After an Alzheimer's diagnoses, the established role must change, which causes stress for the relationship and individual. The reestablished roles of Alzheimer's patient and caregiver are both quite unique (Sanders & McFarland, 2002). Hill et al. (2003) stated the period of reorganization is a crucial time which may benefit from a strong coping strategy. Thus, the researcher selected the population of caregivers caring for a loved one with Alzheimer's disease.

The independent variable in this study will be spirituality. Hill et al. (2003) stated the need for a uniquely strong coping strategy to manage the burden perceived by Alzheimer's caregivers. Therefore the researcher was led to focus on spirituality as the main coping strategy.

Purpose and Research Questions

The purpose of this study is to identify the effect of spiritual support on Alzheimer's caregiver's perceived burden. This methodology and data originated from a previous study by Wilks, Little, Gough, and Spurlock (2011).

Research questions are as followed:

1. What is the level of spiritual support among Alzheimer's caregivers?
2. What is the level of burden reported by caregivers of Alzheimer's patients?
 - a. What is the level of burden reported by Alzheimer's caregivers using the Revised Memory and Behavior Problems Checklist by Alzheimer's caregivers?
 - b. What is the level of burden reported by Alzheimer's caregivers using the shortened Zarit Burden Interview?
3. What is the relationship between spiritual support and burden among Alzheimer's caregivers?
 - a. What is the relationship between the Spiritual Support Scale and the Revised Memory and Behavior Problems Checklist?
 - b. What is the relationship between the Spiritual Support Scale and the score of the shortened Zarit Burden Interview?

Methods

Design

This study is based on secondary data analysis originally gathered by Wilks et al. (2011). The original data analysis was approved by the Louisiana State University (LSU), Institutional Review Board (IRB), therefore, approving this secondary analysis from the original Wilks et al. (2011) study. This project is a cross-sectional analysis of data reported by Alzheimer's caregivers in Louisiana. The study completed by Wilks et al. (2011) began in September 2008 and was completed in August 2010.

The study by Wilks et al. (2011) contained a packet of surveys that were administered by the LSU School of Social Work with the assistance of the Alzheimer's Services of the Capital Area (ASCA). ASCA is a non-profit, 501c3, institution. This institution provides families, in Louisiana, affected by the Alzheimer's disease, with awareness, education, and support (Wilks et al., 2011).

Sampling

The information for this project is taken from a previous study by Wilks et al. (2011). The collection of data was accomplished by a packet of surveys, preceded by a cover letter and self-addressed, postage-paid envelopes being distributed to the directors of the ASCA who mailed the packets to Alzheimer's caregivers whose addresses are known. Cluster sampling methods is used in this study. The population is separated and difficult to survey as a whole, therefore, a smaller cluster sample is surveyed from a specific organization. Trusted facilitators collected the completed surveys. A compensation of \$20 was offered to participants for their time and effort. All completed surveys were maintained in a secure, locked environment and a secure, password-protected computer maintained the electronic data.

Measures

Demographics. The data collection that will be discussed in this thesis project is data from collected quantitative, self-report surveys by Wilks et al. (2011). Demographics collected in the surveys include non-parametric measures of gender, ethnicity, relation to care recipient, and the stage of the Alzheimer's disease as estimated by the caregiver. The parametric measure of age will also be reported in this study.

Spiritual Support. The spiritual support data is collected from the Spiritual Support Scale (Ai, Tice, Peerson, & Huang, 2005). This 12-item scale with a possible range of 1 to 48, measures perceived support from a spiritual relationship. The results of this scale will be given in parametric terms. An example of a statement on this scale is *I have an inner resource from my spiritual relationship with God that helps me face difficulties*. Responses range from 1-*strongly disagree* to 4-*strongly agree*; the higher the sum of responses indicate greater perceived spiritual support. Psychometric properties are established in the Ai et al. (2005) study. In this study the primary independent variable is spiritual support.

Burden. The dependent variable in this study is burden. In this study there will be two scales used to measure burden in Alzheimer's caregivers. The first is the Revised Memory and Behavior Problems Checklist (Teri et al., 1992). This scale is an in-depth 19-point scale ranking the frequency of a possibly disturbing event acted out by the Alzheimer's patient (in subscale A) (Teri et al., 1992). An example of a statement on this scale is, *Asking the same question over and over*. Subscale B is the focus of this study. Subscale B has a possible range of 0 to 96 and measures how disturbing the event is for the caregiver, essentially how burdensome (Teri et al., 1992). Global scores on subscale B of this scale will be reported in parametric terms. The range of response is from 0-*not at all* to 4-*extremely*, with 5-*don't know/not applicable*. The greater the

Table 1. Descriptive statistics of demographic information. (N=691)

Variable	Valid %	(n)	Mean
<i>Gender</i>			
Female	79.8	(546)	
Male	20.2	(138)	
<i>Ethnicity</i>			
Caucasian	61.8	(424)	
African American	35.9	(246)	
Other	1.3	(9)	
Hispanic/Latina(o)	.9	(6)	
<i>Relation to Care Recipient</i>			
Child	51.3	(350)	
Other	16.9	(115)	
Spouse/Partner	16.7	(114)	
Grandchild	6.6	(45)	
Sibling	4.4	(30)	
Friend	3.8	(26)	
<i>Stage of Alzheimer's Disease</i>			
Late	41.3	(260)	
Middle	35.9	(226)	
Early	22.3	(140)	
<i>Age</i>			61

sum of the scores the greater the event disturbs the caregiver. Strong psychometric properties were revealed in past studies (Teri et al., 1992).

The second burden measure is the shortened Zarit Burden Interview (Bedard et al., 2001). This scale is a shorter version of the original Zarit Burden Interview identifying the burden experienced by the caregiver of an Alzheimer's patient through the feelings of the caregiver in parametric terms (Bedard et al., 2001). An example of a question on this scale is as followed, *Because of your caregiving, you don't have enough time for yourself.* This is a 4-item scale with responses ranging from 0-*never* to 4-*nearly always* with a possible response range from 0 to 16. The greater the sum of the scores the greater the burden is perceived by the caregiver. Positive psychometric properties were evident in past studies (Bedard et al., 2001).

Data Analysis

In this study, all non-parametric measures will be reported using frequencies and percentages. Non-parametric measures in this study include gender, ethnicity, relation to care recipient, and the stage of the Alzheimer's disease. Numeric representation will be assigned to all non-parametric variables (Rubin & Babbie, 2010). Parametric measures include the age of participants as well as the global scores of the Spiritual Support Scale, Revised Memory and Behavior Problems Checklist subscale B, and the shortened Zarit Burden Interview. Research questions 1 and 2 will address descriptive statistics and be reported as means and standard deviations.

The correlation statistic describes the strength of the bivariate relationship between all primary variables. In this study, the primary variables include the global score on the Spiritual Support Scale, the global score on the Revised Memory and Behavior Problems Checklist

subscale B, and the global score on the shortened Zarit Burden Interview. The correlations among these variables will be reported using Pearson's correlation coefficient.

Research question 3, including 3a and 3b, will be tested using linear regression because the variables are parametric (Rubin & Babbie, 2010). Linear regression assists in the understanding of the predictability of the influence of the independent variable, or predictor, on the dependent variable. The relationship between the dependent and independent variables will be described by the linear regression.

Results

Descriptive Statistics

Sample Characteristics. The total sample includes 691 caregivers. Female caregivers were the majority (79.8%, $n = 546$). Over half of caregivers reported their ethnicity as Caucasian (61.8%, $n = 424$). The next largest ethnicity group reported was African American (35.9%, $n = 246$). The majority of reported caregivers were the child of the care recipient (51.3%, $n = 350$). The next largest group reported their relationship as *other* (16.9%, $n = 115$). The two most common stages of the Alzheimer's disease was first *late* (41.3%, $n = 260$) followed by *middle* (35.9%, $n = 226$). The mean age of the caregivers in the total sample was 61 years. Table 1 provides complete details of all demographic information.

Primary Variables. The caregivers reported a mean of 12.2 (SD = 3.11) on the ZBI global score. On the RMBPC subscale B global score, caregivers reported a mean of 33.3 (SD = 23.23). The mean of the global score reported by caregivers on the Spiritual Support Scale was 41.8 (SD = 7.48). Table 2 provides details on the primary variables.

Correlation Analysis

Pearson correlation coefficients were calculated to show the significant relationships between the primary variables. The global scores between the ZBI and the RMBPC subscale B are positively and significantly correlated ($r = .434$, $p = .01$). The global score of the ZBI is negatively correlated with the global score of the Spiritual Support Scale ($r = -.140$, $p = .01$). Table 2 displays correlations between all primary variables.

Regression Analysis

The dependent variable, ZBI, negatively and significantly regressed on independent variable, Spiritual Support Scale ($\beta = -.126$; $p = .002$). With the inclusion of demographics the

change in beta in that same relationship was minimal ($\beta = -.104$; $p = .012$). The ZBI significantly regressed on the demographic variable *ethnicity* ($\beta = .127$; $p = .002$) and the demographic variable, *relation to the care recipient* ($\beta = -.115$; $p = .005$). Table 3 provides complete details regarding the relationship between the ZBI and the Spiritual Support Scale.

The dependent variable, RMBPC subscale B, significantly regressed on independent variable, Spiritual Support Scale ($\beta = -.089$; $p = .071$). The inclusion of demographics, the dependent variable, and RMBPC, significantly regressed on the Spiritual Support Scale ($\beta = -.140$; $p = .005$). The RMBPC significantly regressed on the demographic variable *ethnicity* ($\beta = -.198$; $p = .000$) and the demographic variable, *stage of Alzheimer's disease* ($\beta = .177$; $p = .000$). Table 4 provides complete details regarding the relationship between the RMBPC subscale B and the Spiritual Support Scale.

Table 2. Correlation of the global score of each primary variable.

	ZBI global score	RMBPC global score	Spiritual Support Scale global score	<i>M</i>	<i>SD</i>
ZBI global score	--			12.2	3.11
RMBPC global score	.434**	--		33.3	23.23
Spiritual Support Scale global score	-.140**	-.077	--	41.8	7.48

**correlation is significant at the 0.01 level

Table 3: Linear regression using the ZBI

	β	p-value	R ²
Step 1			
Spiritual Support Scale	-.126	.002	
R ²			.016
Step 2			
Spiritual Support Scale	-.104	.012	
Gender	.043	.290	
Ethnicity	.127	.002	
Relation to care recipient	-.115	.005	
Stage of Alzheimer's Disease	.082	.043	
R ² Δ			.042

Table 4: Linear Regression using RMBPC

	β	p-value	R ²
Step 1			
Spiritual Support Scale	-.089	.071	
R ²			.008
Step 2			
Spiritual Support Scale	-.140	.005	
Gender	-.066	.174	
Ethnicity	-.198	.000	
Relation to care recipient	-.073	.132	
Stage of Alzheimer's Disease	.177	.000	
R ² Δ			.072

Discussion

Review of Results

This study focused on individuals caring for loved ones with Alzheimer's disease. The goal was to relate perceived burden to perceived spiritual support to observe effects spiritual support has on burden perceived by the caregiver. In this study the typical caregiver was a Caucasian female, age 61, caring for her parent in the late stages of Alzheimer's disease. In previous articles the majority of caregivers were females around the age of 60 years (Germain et al., 2009; Marin et al., 2000; Wilks & Vonk, 2008) and of Caucasian ethnicity (Germain et al. 2009; Wilks & Vonk 2008).

In previous studies (Marin et al., 2000; Wilks & Vonk, 2008) the majority of caregivers were the care recipients' spouse. In contrast, this study identified the majority of caregivers as the care recipients' adult children. This sample also reported majority of caregivers were caring for loved ones in the late stages of Alzheimer's disease. This finding is similar to the findings of Sabbagh and Cummings (2011).

The study by Germain et al. (2009) found 55% of the caregivers experience absent or mild burden. Wilks and Vonk (2008) found the majority of caregivers report a mild-to-moderate degree of burden. According to two measures in the current study a moderate level of burden was perceived by caregivers which is comparable to previous studies.

The sample in this study reported high levels of perceived spiritual support. These results coincide with results from previous research such as Wilks and Vonk (2008). Prior research by Wilks and Vonk (2008) and Stuckey (2001) reported the majority of Alzheimer's caregivers utilize prayer and other spiritual activities to cope with perceived burden.

This sample reported spiritual support related to one measure of burden. Identified in the linear regression is the effect size in which the independent variable, spiritual support, helps to explain the dependent variable, burden. The effect size identified between the spiritual support and one measure of burden was small but the relationship was significant.

The second step of the linear regression was the addition of the demographic variables. The change in the effect size identified the extent to which the dependent variable, burden, can be explained by the independent variable, spiritual support, along with the total demographic variables. The change in effect size expressed between one measure of burden (ZBI) and spiritual support once demographics were added to the model was nominal. The change in effect size expressed between the second burden measure (RMBPC subscale B) and spiritual support once demographics were added was nominal. The increase between the effect size and the change after adding the demographic variables on each regression suggests demographic variables have little or no predictability to the outcome.

Practice Implications

According to Wilks and Vonk (2008), 78% of caregivers report praying on a daily basis to reduce burden. To speculate, strongly perceived spiritual support could predict lower levels of perceived burden, may be common. However, in this study, the most significant statistical result was found when demographics were added to the linear regression between spiritual support and burden, which may suggest a conclusion similar to Germain et al. (2009). Germain et al. found statistical difference may be explained by a difference in cohort beliefs. Previously stated, other studies have reported the majority of caregivers are care recipients' spouse. However, this sample reports a majority of caregivers are the adult children of the care recipient. A difference

in generation may be the reason for the difference in the utilization of spiritual support as a coping strategy in this study.

The sample reported moderate burden and high spirituality. Also, in this study, the two variables correlated to a smaller degree than expected based on prior research indicating prayer as a main coping strategy (Wilks & Vonk, 2008). The two variables show a spurious relationship indicating that there may be a confounding factor that is a more specific influencing variable. To be certain of this lurking variable more studies must be done in the specific area of using spiritual support to cope with burden among Alzheimer's caregivers. An additional variable possibility may be the idea stated earlier by Stuckey (2001), which is that persons with mature spiritual focus may simply have a more positive outlook on the consequences of the Alzheimer's disease. In this idea, spiritual support is not the sole reason for perceived burden to be low; rather, spiritual support causes a more positive outlook on the burden, triggering the caregivers to report lower levels of perceived burden.

A goal of many social work practitioners is to help clients cope successfully with crisis. There are many ways to cope with crises, and as written in this study, many ways to cope with perceived burden of caring for a loved one with Alzheimer's disease. As previously stated, spiritual support is an emotional focused coping strategy because the aim is to psychologically manage the meaning of caregiving. Also, spiritual support is a problem-focused coping strategy aiming to assess and plan tasks to lessen the burden of caregivers. A significant, negative relationship was reported in the correlation between spiritual support and burden. The results reveal that as spiritual support increased burden decreased. The majority of the sample did report a strong sense of spiritual support.

Social workers meet each client as an individual and at the client's mental, emotional and spiritual level (Sheridan, 2001). Each client exhibits their own strengths and areas of growth. The goal of the social worker is to assist the client in finding comfort in a stressful situation, such as caring for a loved one with Alzheimer's disease, by using the client's strengths. Spirituality is reported in many studies as a main coping strategy such as Wilks and Vonk (2008) and Choi, Tirrito, and Mills (2008). Social workers should be aware of this and be able to assist a client using spiritual support as a method to reduce burden.

Social work educators must be aware of the high levels of spiritual support reported by many Alzheimer's caregivers. Social work educators strive to prepare social work students for diversity among clients. Students may be open to spiritual support conversations or may be closed to the idea of spirituality. Sheridan (2009) stated the importance of allowing the client to educate the social worker on the relevance religion and spirituality play in their own life. The goal of educators is to educate the social work students on the wide variety of clients and the wide variety of coping strategies. Sheridan (2001) stated social work students must be sensitive to the culture of the client no matter the personal belief of the social worker. A social work student must be confident in the knowledge of coping strategies used by clients and how to accommodate each client, no matter their background, in achieving the ability to cope with stressful situation such as caring for a loved one with Alzheimer's disease.

This study concluded as an increase in spiritual support is reported a decrease in burden is reported with a slight effect size. Moreover, the sample in this study reported high levels of spiritual support. Spiritual support is an important coping mechanism reported by the majority of caregivers in this study. Therefore, the conclusion can be made that spiritual support is an

important factor to the majority of caregivers and therefore is important to professional, the caregiver, and the family as a whole.

Limitation and Future Research

The data used in this study originated from a project by Wilks, Little, Gough, and Spurlock (2011). As such, some limitations remain the same for this research. Due to the strong female majority caregivers, the limit of male caregivers in this sample is apparent. Future research is needed to address the unique contributions of male Alzheimer's caregivers.

Cluster sampling, as used in this study, adds a limitation to the sample. A cluster sample is a small sample relative to the entire population (Rubin & Babbie, 2010). While cluster sampling may be less financially troublesome, the increase in errors may increase due to the small sample size. To remedy this limitation, future research may use quota sampling, to cover the population of Alzheimer's disease caregiving more evenly.

Another limitation in this study is due to the self-reported responses on each scale used to measure burden and caregivers' perceived spiritual support. All three scales are self-administered surveys making the survey a measurement of the caregiver's individual perception. For instance, each caregiver may have a different perception of the terms *burden* and *spiritual support*, causing the answers to vary among caregivers. Some activities may be seen as burdensome to one caregiver; however, to another caregiver the same activities may be more accepted and less burdensome. Therefore, each item of the survey is subject to the opinion of caregivers. To decrease the effects of this limitation, future research may use a neutral third party's observation to report burden and spiritual support. The same third party observer would be used to survey participants, possibly illuminated the difference in perception and definitions varying among individual.

Conclusion

Alzheimer's disease has affected people since before Auguste Deter was diagnosed by Alois Alzheimer. Today, Alzheimer's disease affects numerous individuals while the families of the Alzheimer's patients struggle to cope (Garand et al., 2005). To watch a loved one suffer from any disease is distressing, but the Alzheimer's disease progression can be an extensive process and even more alarming for families. Families must watch as the disease slowly robs individuals of each memory, body function, brain function, and the individual's personality (Hayslip et al., 2008). While the family must observe the decline of the loved one, there is typically a primary caregiver who must assist the patient in every way, every day.

The spouse, adult child, or other loved one, who becomes the primary caregiver usually does not have a choice and if given a choice would not choose this disease for a loved one. A caregiver is strained physically, financially, socially, and emotionally. The caregiver may become overwhelmed with the responsibilities. The feeling of being overwhelmed may lead to stress and unprecedented amounts of burden. Coping with this burden can be difficult for caregivers and may lead to a decline in the caregivers' physical and mental stability.

Caregivers have many strategies to cope with the burden from caring for a loved one with Alzheimer's disease. Some coping strategies used by caregivers may consist of reframing the perceivably negative situation, seeking out people in similar situations, hiring aides to assist in day to day responsibilities, and adult day care programs. Caregivers may also report spiritual support as a coping strategy. Some caregivers report spiritual support assists in the outlook of the situation and/or a religious institution assists in finding services which gives aid to the caregiver; either task is considered spiritual support in this study.

As the burden of caregivers continues to be studied the change in roles must be considered as a factor leading to stress for individuals giving care and care recipients. Each care recipient, suffering from the Alzheimer's disease, may have been a caregiver by being a parent. Stress can be created by learning the new roles demanded by the disease for both caregivers and care recipients. The caregiver is learning how to provide care and the care recipient must eventually give up control and learn to be cared for by another individual, in a society which praises and pushes independent living.

This study focused on a sample of caregivers who completed surveys containing two scales measuring perceived burden and one scale measuring perceived spiritual support. The sample reported a moderate level of burden related to the care provided to the loved one suffering with the Alzheimer's disease. The caregivers in this sample perceived a high degree of spiritual support. This study suggested a possible difference in cohort beliefs between spouse caregivers and adult child caregivers in regards to perceived spiritual support and burden. Additionally, this study suggested spiritual support influences the degree of burden an individual perceives by affecting the attitude of the caregiver to be more positive. If a caregiver has a positive attitude toward caregiving because of spiritual support, burden may be perceived as lower.

Alzheimer's caregiving is a lofty responsibility for a family member. Some individuals, who take on this responsibility are in desperate need of assistance. Professionals must seek out these caregivers because the time to search for support is extremely limited. Caregivers in search of logistical help may rely on spiritual support. Caregivers in search of emotional or mental help may rely on spiritual support. Caregivers in search of financial help may rely on spiritual support. More specific research is needed to provide professionals with insight into the coping

improvements individuals are gaining from reported spiritual support. Professionals must be aware of spiritual support resources and the prevalence of reliance of caregivers on spiritual support.

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Vita

Mary Katherine Schillings is the daughter of two extraordinary parents, Melinda and Juliet Schillings. Katherine's parents raised her in Kentwood, Louisiana with a focus on Christian morals and family values. Katherine credits her close friends and family for the love and support and love, which has enabled her to be successful. Katherine's grandmother, Bette Brown is the inspiration for her life ambition of supporting caregivers and the topic of this thesis. Katherine attended high school at Oak Forest Academy in Amite, Louisiana. In Oak Forest she met her best friend and was taught by many exceptional people.

While working toward her undergraduate degree in human ecology, family and child consumer science at Louisiana State University, Katherine worked for the Louisiana Extension Service. She had the pleasure of meeting many of her mentors during both her undergraduate classes and employment with Louisiana 4-H Youth Development. Katherine graduated from Louisiana State University with her B.A. in 2010 and immediately entered the Social Work Masters Program at the Louisiana State University.

During Katherine's master's program, she completed two internships. Katherine has met many wonderful people and two inspirational supervisors during her internships. She especially acknowledges Dr. Scott Wilks for his encouragement and his willingness to be thesis chair. His constructive criticism and many patient hours of teaching allowed her to complete this study. Katherine also credits Dr. Michelle Livermore and Dean Daphne Cain for the positive criticism and support provided while on her thesis committee. Katherine is most proud of her thesis, titled, *Spiritual Support as Coping among Caregivers*. Immediately following her graduation she will work full time at Alzheimer's Services of the Capital Area in Baton Rouge, Louisiana.