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Spirituality and Coping: Caregivers of Spouses Afflicted with Alzheimer's

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SPIRITUALITY AND COPING:
CAREGIVERS OF SPOUSES AFFLICTED WITH ALZHEIMER'S

by

Khalil A. Sakalla
Master of Arts, University of North Dakota

A Dissertation

Submitted to the Graduate Faculty

of the

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for the degree of

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This dissertation, submitted by Khalil A. Sakalla in partial fulfillment of the requirements for the Degree of Doctor of Philosophy from the University of North Dakota, has been read by the Faculty Advisory Committee under whom the work has been done and is hereby approved.

(Chairperson)

F Richard Ferraro

This dissertation meets the standards for appearance, confirms to the style and format requirements of the Graduate School of the University of North Dakota, and is hereby approved.

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For my family, especially my father

ABSTRACT

Caring for a loved one with Alzheimer's disease can be one of the biggest commitments a spouse will make and the most difficult experience to undertake. Undesired surprises of old age such as a spouse's affliction with Alzheimer's disease can increase the individual's psychological distress and hinder his or her ability to cope with stressful situations. Religious and spiritual beliefs, activities and experience are believed to help distressed individuals bring emotional equilibrium into their lives.

In this study, I explored the influence of spiritual well-being, also religious well-being and existential well-being, on task-, emotion-, and avoidance-oriented coping among caregivers challenged by their loved one's affliction with Alzheimer's. I examined the caregivers' (*N* = 35) perceived strain or burden using the Zarit Burden Interview (*M* = 37.09, *SD* = 12.05) and depression using the Center for Epidemiologic Studies for Depression Scale-Revised 20 (*M* = 111.57, *SD* = 11.63). I assessed their spiritual (*M* = 91.46, *SD* = 19.94), religious (*M* = 46.37, *SD* = 19.91), and existential (*M* = 45.09, *SD* = 8.98) well-being utilizing the Spiritual Well-Being Scale (SWBS). To determine their level of coping, I administered participants the Coping Inventory for Stressful Situations: Situation Specific Version (CISS: SSC) with its three subscales: Task-Oriented (*M* = 46.11, *SD* = 10.68), Emotion-Oriented (*M* = 44.40, *SD* = 9.26), and Avoidance-Oriented (*M* = 48.97, *SD* = 11.36).

A multivariate three-way Analysis of Variance (ANOVA) revealed non-significant difference among caregivers' task-oriented, emotion-oriented, or avoidance-oriented coping and their level of spiritual well-being ($F = 1.504$, $p = .241$), religious well-being ($F = 1.198$, $p = .327$), or existential well-being ($F = 2.175$, $p = .120$). Given the small sample of this study, further research is encouraged before making any conclusion about the effects of spirituality well-being on coping and enhancing caregivers' quality of life and adjustment.

CHAPTER I

INTRODUCTION

Alzheimer's Disease (AD) is a prevalent, neurological disease of the brain that causes cognitive functioning to deteriorate progressively, afflicting older people at a rate estimated at about 360,000 cases a year. In the United States, the number of cases doubles every five years, raising the current number of individuals with Alzheimer's to four million Americans (Brookmeyer, Gray, & Kawas, 1998). Approximately 19 million Americans have a family member with Alzheimer's, and 37 million Americans know someone with the disease. It is also projected that 14 million Americans will have Alzheimer's by the middle of the next century, given no cure or prevention thus far (United States Department of Health and Human Services, 2002). It is estimated that by the year 2025, approximately 22 million individuals worldwide will be afflicted with Alzheimer's (Alzheimer's Association, 2001).

The National Institute of Health (2000) estimated that half of patients are cared for at home by spouses, family members or friends while the remaining half are cared for at nursing homes and related dementia and Alzheimer's units. Currently, seven out of 10 people (or 75%) with AD live at home, cared for by family members or friends (United States Department of Health and Human Services, 2002). The increasing number of Alzheimer's caregivers calls for research inquiring into their well-being.

The economic burden and psychological strains are significant on the individual caregiver and on the country as a whole. Ernst and Hay (1994) indicated that both the direct and indirect national cost of caring for AD patients was $100 billion dollars. The continued growth of the aging population is expected to accelerate, such that people aged 65 and older are likely to number 70 million individuals by the year 2050 (US Bureau of Census, 2000). Ten percent of people aged 65 years or older and about 50% of individuals aged 85 years or older are likely to become afflicted with Alzheimer's (Kumar & Eisdorfer, 1998).

Psychological and emotional strain, in addition to economical burden, results in shortening the caregiving spouse's lifespan. "Elderly spouses strained by caregiving are 63 percent more likely to die during a given 4-year period than other spouses their age" (U.S. Department of Health and Human Services, 2002, p. 2). Caring for older individuals is an experience that can awaken certain fears within the caregiver. Jones (2000) describes the symbolization-avoidance theory in which the "aging person, ailing and pitiful, functions as a symbol of our own fate: death" (p. 8). Caring for an individual with Alzheimer's can be a constant reminder of our limitations and fragility, an experience that many caregivers wish to avoid. It is the intention of this research to aid caregivers on their journey of caregiving while they are struggling with their own cognitive and physical decline.

Cognitive Functioning, Aging, and Alzheimer's

Cognitive functioning is a contextual process influenced by more than aging. Aging is distinguished by the interaction among three factors: biological, social and psychological (Thompson, 1997; see also Koenig, 1994). It is necessary to examine this interaction to determine normal from abnormal cognitive functioning in older adults. Thompson (1997) illustrated the process of aging by using the example of an older person with arthritis that resulted in physical limitations. This individual's physical limitations impacted his social interaction and lessened enjoyment of previous activities. Such changes resulted in psychological distress and a decline in cognitive functioning that could be linked to the interaction of the three factors. To determine the individual's level of functioning, the author suggests that "a range around the middle of a dimension with two extremes at opposite ends" (Thompson, 1997, p. 4) will determine normal from abnormal deterioration. Therefore, in order to evaluate this man's cognitive functioning, it is important to include his ability prior to and after his arthritis. Likewise, in determining cognitive functioning in old age, it is important to determine whether cognitive decline is a result of a cognitive disorder such as dementia, other physical limitations, and/or impaired social interaction.

In normal aging, individuals differ on various aspects that define their level of functioning. Personality aspects and experience contribute to how well individuals adapt to their new physiological and environmental changes. Cognitive functioning is impacted by how well an individual adapts to the new changes that often result in an alteration of how the aging adult receives, processes and recalls new information and learning. "Generally, older people can learn as much as younger people, but more time is needed for them to achieve the same level of learning" (Thompson, 1997, p. 4). Thus, it is not surprising that cognitive functioning slows down at old age, showing normal deterioration that can be confused with dementing disorders (Huppert & Brayne, 1994; Roth, 1994).

Dementia of the Alzheimer's Type

The most common dementia is the Alzheimer's type that causes gradual and irreversible degeneration of the brain (Parks, Zec, & Wilson, 1993). Dementia can be related to depression, drug interaction, thyroid problems, and certain vitamin deficiencies. Under these circumstances, dementia can be reversible if detected early. Other causes of dementia include stroke, Huntington's disease, and Parkinson's disease. In these particular circumstances, dementia is not reversible (Kumar & Eisdorfer, 1998). Dementia alone may not necessarily account for Alzheimer's disease. Dementia of the Alzheimer's type is distinct from normal aging deterioration by the presence of multiple cognitive deficits. One deficit is memory and other deficits are one or more of four other cognitive disturbances: aphasia (language disturbance), apraxia (motor activity disturbances), agnosia (inability to identify objects), or disturbance in executive functioning such as planning and other abstract thinking (DSM-IV-R, 2001).

Alzheimer's disease is "a progressive neurodegenerative disease leading to severe cognitive impairment accompanied by the development of neurofibrillary tangles and neuritic plaques, and neuronal loss" (Gilman, 1997, p. 230). Alzheimer's disease was named after a German physician, Alios Alzheimer, who identified it in 1907 (Thompson, 1997). Alzheimer first described the characteristics of the disease of a 51-year-old woman who had a progressive dementing disorder. Alzheimer described the disease to include that of normal aging senile plaques and structures termed neurofibrillary tangles, also known as Alzheimer's neurofibrillary tangles or Alzheimer's neurofibrillary changes (Iqbal & Wisniewski, 1983; see also Reisberg, 1983). Alios Alzheimer combined these characteristics to diagnose the patient whose symptoms were only seen in older individuals (Berrios, 1994).

The nature of the disease involves a progressive deterioration of neurons of the central nervous system resulting in dementia, which is a global cognitive impairment including impaired ability to recall previously learned information. It is believed that "some type of aberrant immune system in the brain that unleashes inflammation and cell death may underlie Alzheimer's disease" (Stephenson, 1999, p. 502). The neuropathological changes occur first in the cortex and progress to an important region of memory formation, the hippocampus. As a result of this cognitive deterioration, patients' social and occupational functioning starts to deteriorate as well.

Alzheimer's Causes and Risk Factors

Mortimer and Hutton (1985) suggested that the pathogenesis of Alzheimer's disease, like other diseases, to be:

> an interaction among agents (infectious or toxic), the environment (the extent of exposure to etiologic agents), and the host (inherited or acquired susceptibility to a certain agent). It is likely that these three factors play an important role in determining who becomes afflicted with Alzheimer's disease. (p. 192).

One leading hypothesis of the causes of AD relates to neurochemical imbalances and neurotransmitter deficits. Other hypotheses of the causes of Alzheimer's disease suggest that selective brain cells might be destroyed from viral infection and exposure to toxic agents such as aluminum and zinc and to individual genetic makeup (Torak, 1983). Deficits in the immune system and autoimmune process can also bring the affliction of dementia and Alzheimer's disease. Speculations about the causes and risk factors are inconclusive, "because AD can be diagnosed with certainty only at autopsy, [and] …currently available epidemiologic data are often used based on a presumed clinical diagnosis" (Rocca, 1987, p. 3). However, recent technology such as MRI and CAT scans were able to detect AD-related lesions in the brain, a promising screening technique in progress.

There are several risk factors and possible causes for Alzheimer's disease. Demirovic (1998) presented five risk factors that seemed to be consistent across several studies (Parks et al., 1993; Jorm, 1990; Hutton & Kenny, 1985; Reisberg, 1983; Mortimer, 1994; Torak, 1983): sociodemographic characteristics, family history, genetic makeup, the environment, and lifestyle factors.

Sociodemographic characteristics such as age, gender, ethnicity, and education are risk factors of developing AD. Incidents of chronological age and AD increase exponentially (Hodges, 1994; Parks et al., 1993; Iqbal, Wisniewski, & Winblad, 1989). As chronological age increases, a number of neurons die and the remains collect around a central core of amyloid, forming abnormal "hard tissues referred to as senile, neuritic or amyloid plaques" (Whitbourne, 1996, p. 157). This normal aging process slows down the neural communication in the brain, especially since the number of neurotransmitters and synapses decrease as well (Roth, 1994). Autopsies of Alzheimer's patients have indicated that plaque tissues were prevalent, accounting for deterioration of cognitive functioning. No significant difference was found among male and female AD afflicted individuals (Jorm, 1990). However, since the female older population is larger than the male population, it is likely that females afflicted with AD slightly outnumber male patients (Reisberg, 1983).

Race and ethnicity studies are scarce to determine specific differences (Kumar & Eisdorfer, 1998). The authors found AD prevalence to be 16% among blacks versus 3% among whites. Demirovic (1998) explains that in the same study "blacks were found more likely than whites to have a history of hypertension, stroke, and other chronic diseases that might contribute to the development of dementia" (p. 11). Researchers (Gilman, 1997; Mortimer, 1994) found a low level of education to be a risk factor, as the number of people afflicted with Alzheimer's was high for individuals with little or no education.

Family history of dementia, Down's syndrome, and Parkinson's disease are also risk factors (Demirovic, 1998). Richards and Broeckhoven (1994) explained that aggregation of dementia of the Alzheimer's type in specific families is well documented, linking AD and family history of dementia. A strong association was found between blood relatives of both Alzheimer's disease and Down's syndrome (DS) patients. Studies (see Huppert, Brayne, & O'Connor, 1994) indicate that almost all individuals with DS who survive to at least the age of 40 years and come to autopsy have AD lesions. Those with Down's syndrome who live past the age of 40 develop brain lesions similar to that of Alzheimer's (Mortimer & Hutton, 1985). A family history of Parkinson's disease is also a risk factor, as Parkinson's disease shares similar cognitive deficits as those of Alzheimer's (Mahurin, Feher, Nance, Levy, & Pirozzolo, 1993).

Demirovic (1998) and Mortimer (1994) presented other risk factors that pertain to "genetic deficit on chromosomes 14, 19, 21, …and the e4 allele of apolipoprotien" (Dermirovic, 1998, p. 13). A medical history of head trauma, hypothyroidism, epilepsy, and depression are other risk factors due to their impact on the nervous system and neurological outgrowth. The researchers also reported different studies linking head trauma and AD, as severe head trauma "can result in a post-traumatic encephalopathy dementia syndrome. Second, several individual case reports have described pathologically confirmed Alzheimer's disease following a single head trauma" (Mortimer, 1994, p. 215).

Finally, environmental and lifestyle factors were linked to the prevalence of Alzheimer's. Excessive exposure to aluminum (Kumar & Eisdorfer, 1998; Mortimer, 1994; Mortimer & Hutton, 1985; Reisberg, 1983) and/or zinc (Gilman, 1997) was found to be a risk factor, but such findings were not supported in other studies (see Huppert et al., 1994). Lifestyle, diet, and smoking (also nicotine intake) were also factors for AD (Ott, Slooter, & Hofman, 1998). Demirovic (1998) found studies supporting Vitamin C and beta-carotene to be a positive influence on cognitive functioning. The author also found linoleic acid intake to be positively associated with cognitive impairment in older adults. Mixed results were found linking Vitamin C and beta-carotene to impair or enhance cognitive functioning.

Researchers (Salomon, Marcinowski, Friedland, & Zagorski, 1996; van Duijn & Hofman, 1991) found AD cases to be fewer among smokers and nicotine intake compared to a control group. On the other hand, Ott, Slooter, & Hofman (1998) found smoking to double the risk of both dementia and Alzheimer's disease. The authors suggested that smoking and nicotine studies advocating protection against Alzheimer's disease are inconclusive. Other studies (Boyd, Calinas-Correia, & Peto, 2000; Wang, Fratiglioni, Frisoni, Viitanen, & Windblad, 1999; Creasey et al., 1998) found no direct impact of nicotine to protect against Alzheimer's disease.

Alzheimer's disease appears to be a result of interaction among the individual's genetic composition, drug effects, and other environmental influences. However, much research is still needed to determine appropriate causes and effects. Regardless of the causes and risk factors, Alzheimer's affliction is an experience that has degenerative effects on the ill individual as well as on his or her caregiver.

Impact of Alzheimer's on Caregivers

Caregiving for family members with chronic illness, dementia, or non-dementia illnesses has been found to have a great impact on the caregiver's psychical and psychological well-being (Ory, Yee, Tennstedt, & Schulz, 2000; Schulz, O'Brien, Bookwala, & Fleissner, 1995; Cochrane, Georing, & Rogers, 1997; see also Haley, 1996; Zarit & Knight, 1996). Ory et al. (2000) found dementia caregivers to experience more stress and have a more powerful negative impact than caregivers of non-dementia caregivers. "[C]aring for someone with dementia is assumed to be more difficult and burdensome than caring for loved ones with chronic conditions and disabilities" (p. 2). Others (Koenig, 1994) indicated that dementia caregivers in a number of studies consistently reported an increased rate of depression and anxiety as well as poorer health conditions than non-caregivers.

Schulz et al. (1995) assessed the prevalence and magnitude of psychiatric and physical morbidity effects among caregivers and found a high correlation between morbidity and reported health effects and their underlying causes. The researchers indicated that psychiatric morbidity in caregiving was linked to the patient's problem behaviors, and caregiver's income, self-rated health, perceived stress, and life satisfaction. Physical morbidity was linked to patient's behavioral and cognitive deficits as well as caregiver's perceived social support, and level of anxiety and depression. Cochrane et al. (1997) supported these findings as they found a positive relationship between caregiving and the presence of disabilities, physical symptoms and illness. The researchers also indicated that caregivers had higher rates of affective and anxiety disorders than non-caregivers. Caregivers were also found to utilize health services for mental health problems at almost double the rate of non-caregivers.

Religion, Spirituality, and Well-Being

There is a large body of research studies demonstrating that religious activities such as faith and prayer are a common resource utilized by elderly men and women to cope with threat or loss (Hover, 2000), indicating that "there is a positive relationship between religious activities and health" (Wotherspoon, 2000, p. 69). Others (Koenig, 1994) found religion to facilitate a reformation of the patient's as well as the caregiver's attitude and perspective of their affliction. Moberg (1970) captured the positive relationship in his definition of religion as "the personal beliefs, values, and activities pertinent to that which is supernatural, mysterious and awesome, which transcends immediate situations, and pertains to questions of final causes and ultimate ends of man and the universe" (p.175).

Koenig (1994) listed five ways religion facilitates the transcendence of stressful circumstances and change in patients' and caregivers' outlook of their situation. First, there is a place and meaning for suffering in the framework of religion. Second, religion instills in individuals the hope of a better hereafter in place of suffering in the here and now. Third, religion provides individuals with a sense of worthiness and eternal value through personal faith and the experience of a loving God. Fourth, an individual's religious faith often serves as a source of motivation to reach out to others and fulfill God's purpose in their lives. "Finally, religion can motivate other people (family, staff, friends, other patients) to provide the elder with a sense of being important and cared for" (Koenig, 1994, p. 357). Hover (2000) indicated that religion provides believers with a sense of having some power over their circumstance and that religious rituals, beliefs and sentiments provide vital support in difficult situations (see also Koenig, Smiley, & Gonzales, 1988).

However, Thoroson (2000), also Moberg (2002), suggested that the religious terms and definitions employed in many of the studies investigating religion influence on well-being might be limiting. Religion-related terms often imply a restricted system of doctrine or faith in an organized or formal knowledge whereas spirituality is more of a multidimensional concept that refers to the individual's search for meaning. Stuckey (2001) contrasted the two concepts of religion and spirituality. Stuckey referred to religion as a guiding paradigm or doctrine with defined, collective practices that structure how people worship. The author referred to spirituality as more personally established beliefs and practices that bond the individual with a higher being than themselves. The relationship through one's own beliefs and practices give meaning and purpose to life. "Although they are not mutually exclusive, religion emphasizes a communal type of worship and spirituality emphasizes a personal or meditative worship experience" (Stuckey, 2001, p. 70).

Seifert (2002), in an attempt to clarify the meaning and definition of spirituality, suggested that the word "spirituality" in the literature has more reference to struggles within the individual as he or she searches for meaning, whereas religiosity was more of an external search for significance. The author found empirical ground that a crisis such as the death of a loved one, illness, and a similar unfortunate event fosters an individual's meaning-searches and/or spirituality. Seifert (2002) suggested that meaning-search and meaning-discovery are a spiritual struggle common in the older population. The author concluded that with respect to issues of aging, spiritual reformation might be indirectly related to advancing age, "because one has more opportunity to have experienced life crises the longer one lives" (p. 64). In the current study, my aim was to determine whether a resolution to the individual's internal struggle and search for meaning (spiritual well-being) had any influence on individual's coping with a stressful event, caregiving of a spouse afflicted with Alzheimer's. Thus, it is essential to understand and finely define spiritual well-being to better understand the findings.

Fairchild (2000) provided two constructs that are important to understand spiritual well-being: self-concept and perception of a personal future. In the first construct of self-concept, "the sense of persisting personal identity and the sense of personal worth or control would seem to be two important components" (p. 40). In the second construct of perception of personal future, the individual's insight into his or her future is embedded with a sense of hope and satisfaction in the three time dimensions: past, present, and future. In 1975, the National Interfaith Coalition on Aging (NICA) yielded a definition of spiritual well-being as "the affirmation of life in a relationship with God, self, community, and the environment that nurtures and celebrates wholeness" (Clingan, 2000, p. xiii).

The NICA's definition indicates that the concept of spiritual well-being reflects a comprehensive and interactive relationship with the natural and the supernatural that brings wholeness in one's life. Being spiritual reflects a relationship with a supernatural source, often but not limited to, God the Creator. The relationship provides strength, which nourishes relationships with others and the surroundings to achieve and maintain wholeness (Thoroson, 2000). Spirituality may provide a paradigm for one's life. "One's spirituality ideally provides a guide and framework for decisions and choices made throughout one's life" (Hover, 2000, p. 25). Spirituality from the wholeness paradigm may be a source of strength and wisdom in individual's challenges. Moberg (1968) demonstrated that deeply held traditional Christian beliefs and church participation are related to a good personal adjustment in old age. Koenig, Smiley, et al. (1988) extended the support for higher level of adjustment and coping in old age due to involvement in organized religious community, activities and beliefs (see also Seifert, 2002). However, there are several studies that concluded no direct impact of religion and spirituality on well-being.

Not everyone believes in the positive association between religion/spirituality and well-being (Koenig, 1994). Freud believed that religion was a universal obsessional neurosis that man created to help him cope with crushingly uncontrollable forces of nature (Strachey, 1962). Ellis (1980) believed that people disturb themselves with religious beliefs. He proposed that the devoutly religious person "tends to be inflexible, closed, intolerant, and unchanging. Religiosity, therefore, is in many respects equivalent to irrational thinking and emotional disturbance" (p. 637). Although I have not found studies that support Ellis' view, there are studies that found little or no support for an association between religion/spirituality and the level of adjustment, anxiety, or depression among older population (Koenig, 1994; Koenig, Smiley, et al., 1988). Koenig

(1994) in a study of over 1,000 inpatients (65 years of age and older) found 56% to report 7.5 on a scale from 0 to 10 describing how religion was helpful in their situations. Koenig (1994) found 20% of the patients to report that religion was most helpful in their coping process. I am inspired by the positive findings linking religion/spirituality to well-being of the older population and set out to determine the direction of effect, if at all, that spirituality has on caregiver's coping with the burden of a loved one's affliction of Alzheimer's.

Statement of the Problem

With the advances of science, many people are fortunate to live many years beyond the expected lifespan. With this blessing comes a price, as in later years, the individual is more vulnerable to illness or disease. As a result, many family members and older adult spouses find themselves in a new, often unexpected and undesired role of caregiving that necessitates a helping power beyond the caregiver's natural resources. Stone, Cafferata, & Sangl (1987) found the mean age for husbands in a caregiver role to be 73, and the mean age for caregiving wives to be 69. Caring for a spouse with Alzheimer's disease in the home is an increasingly common experience among families due to economic, social, emotional, and medical demands (Connell & Gallant, 1999; Bedini & Phoenix, 1999; Schulz, 2000). Caring for a loved one can be just as demanding and burdening even when the caregiving is facilitated away from the home. The changing social demographics, family size, financial, psychological and physical strains associated with caregiving contribute to the burden already afflicting caregivers who are grieving their losses.

Schulz et al. (1995) found caregivers to be in poorer physical condition than their age-related peers, attributing their own physical deterioration to caregiving demands and responsibilities of their afflicted spouses. Zarit (1996) indicated that most likely caregivers are spouses who "themselves are older and may be suffering from limitations attributed to chronic problems of their own" (p. 140). Research on the impact of caregiving on psychiatric and physical well-being (Schulz et al., 1995; Cochrane et al., 1997; Schulz, 2000) found depression and anxiety rates to be higher among caregivers compared to the general population with higher reports of symptoms as well. Aneshensel, Pearlin, Mullan, Zarit, & Whitlatch (1995) found coping, among other factors such as social support and a feeling mastery of caregiving, to be effective in containing the caregiver's stressors. Four factors were found to facilitate coping and adjustment for caregivers: a sense of humor; the support of good friends and family; old-fashioned ingenuity; and "the grace of God" (Koenig, 1994). Investigation in the present study (effects of spirituality) is relevant to the fourth factor, the grace of God.

There is a need to help older population in caregiving roles find ways to cope with their challenges. The older population is increasing and with advanced age many friends and family members are lost to death or geographic relocation so that social and emotional support becomes scarce. With lack of support, the burden of caregiving is more challenging, which creates a need for helping caregivers to enhance their coping potential in order to combat the strains bestowed upon them as they care for their loved ones. Creative intervention and support is needed to alleviate the stress afflicting caregivers, facilitate their adjustment, and lighten their burden by finding the power to cope well amidst their peril and pain.

Purpose of the Study

In this study, I explored whether spiritual (also religious or existential) well-being enhanced burdened caregivers' coping (task, emotion, and/or avoidance) with stressful situations such as a loved one's affliction of Alzheimer's. Caregiving for an AD afflicted spouse has been found burdensome (Zarit, 1994). Aneshensel et al. (1995) found coping to help contain caregiver's stressors that contribute to feeling burdened and overwhelmed. Other researchers (Forbs, 1994; Thorson & Cook, 1980; Wotherspoon, 2000; Koenig, 1994; Levin & Markides, 1987; Koenig, Kvale, & Ferrel, 1988; Koenig, Smiley, et al., 1988) found spirituality to enhance well-being. However, other studies (Levin & Markides, 1987) found no significant evidence linking religious attendance and health. The aim of this study was to determine further support of the enhancing effects of spiritual well-being on the individual's coping ability in stressful circumstances as that of the spouse's affliction with Alzheimer's.

It is the hypothesis in this study that spiritual well-being enhances coping with stressful situations by helping the individual to contain stressors and, in turn, alleviate his or her burden. This research was inspired by the need of the rising number of the older population in caregiving roles of spouses with Alzheimer's. Insights into the influence of spirituality on caregiver's coping will direct future research into specific techniques to include aspects of spirituality in intervention programs.

By understanding the influence of spirituality on the coping process of caregivers, I hope to contribute to the body of research on effective intervention strategies to enhance caregivers' quality of life. A positive relationship between spirituality and the caregiver's emotion-oriented coping can serve as bases for future research to enhance the caregiver's coping and containment of their stressors. Spiritually-oriented intervention programs may also be designed in order to enhance caregivers' quality of life by facilitating their coping, and therefore, their containment of stressors.

CHAPTER II

LITERATURE REVIEW

The burden of caring for a loved one afflicted with Alzheimer's is a challenge that brings with it high levels of depressive symptomatology, anxiety, and other psychiatric and/or physical morbidity (Schulz et. al, 1995; Schulz, 2000). To capture the impact of caregiving of an Alzheimer's afflicted spouse, it essential to better understand the impact of the disease on the afflicted person. In this part of my review, I intend to explore the degenerative effects of Alzheimer's affliction. Then, I plan to review the literature that examined the effect on the caregivers and the burden they bear during the journey of caregiving. Finally, I will follow with a review of literature on spirituality and well-being in coping with difficult situations.

Alzheimer's Affliction

Alzheimer's and the Patient

The onset of the disease is "usually so insidious" (Forsythe, 1991, p. 24) that it is hard to determine when it starts. It is marked by memory impairment including the inability to recall newly learned information. Other deficits may include language, speech and/or spatial orientation. Poor judgment is a characteristic of early stages of the disease, which often leads to personal, financial and/or physical disaster (Jorm, 1990; Alzheimer's Association, 2001). Behavioral disturbances develop over time such as visual and auditory hallucinations, paranoia and suspiciousness. Patients may become more aggressive and act inappropriately. Wright (1993) found the cognitive degeneration in

AD patients to result in desensitization to the emotional needs of others. Some patients become unusually sexually aggressive (Duffy, 1995; Ballard, 1995). Patients may also experience "agitation, reversal of day and night with nighttime wandering, affective disorder usually depressed mood and tearfulness, unexplained anxiety and phobias including fear of being left alone, and in late stages incontinence of both urine and stool" (Gilman, 1997, p. 231).

Cammermeyer and Prendergast (1997) examined deterioration of memory. The researchers found cognitive functioning deficits to include impairment of short-term memory, or an increase in forgetfulness and decrease in long-term memory. Recent research (Huppert, 1994) also indicated that although some of these deficits are apparent in normal aging, the rate of decrements for AD patients is much faster than in normal aging. Several intervention methods and drugs are used to control the progression of the disease. Some interventions to control this disease involve drugs using anti-inflammatory agents or newer drugs used to regenerate neurotransmitters (Gauthier, 1998). More recent medical studies (Raskind, Peskind, Wessel, & Yuan, 2000; Tariot, Solomon, Morris, Kershaw, Lilienfeld, & Ding, 2000) demonstrated beneficial effects of Galantamine on cognitive, functional, and behavioral symptoms on patients with mild to moderate AD. Although the medication does not reverse the affliction, it appears beneficial in slowing down the progression and maintaining cognitive and behavioral functioning.

Other impairments are related to attention, visual scanning, sleep pattern, and unawareness or failure to acknowledge deficits (Cammermeyer & Prendergast, 1997; Cortell, 1997). The unawareness of Alzheimer's patients' own deficits add more challenge and distress to the spouse and/or caregiver. Cortell (1997) used the term "anosognosia," which is defined as a "lack of knowledge of the disease ...a failure to acknowledge a particular deficit" (p. 71) to describe in general the patient's unawareness of intellectual deficits. The researchers investigated the possibility of helping patients to maintain some of their functioning by raising their insight and self-awareness. Unawareness of deficits aggravates cognitive dysfunction associated with the disease and often contributes to a heightened intensity of personal catastrophe such as financial, physical and/or emotional crises. The unawareness and its negative effects on the afflicted individual impact interpersonal communication, as well as the relationship with the caregiving spouse or family member, further contributing to the caregiver's burden (National Institute of Health, 2000).

Patient's Stages of Affliction

Reisberg et al. (1993) described 16 levels of functioning decrements corresponding to seven global stages of the Central Nervous System (CNS) and Alzheimer's disease functional disabilities. The researchers identified these stages as Functional Assessment Stages or "FAST stages" (p. 28) to determine the level of disability of aged CNS and AD-related decrements. In FAST stage 1, there appear no subjective or objective functional decrements as the aged individual shows a competent level of functioning occupationally as well as a similar level of social functioning in the previous five to seven years. In FAST stage 2, the individual experiences subjective but not objective decrements, such as forgetting appointments and location of objects. Reisberg et al. (1993) suggested that it is difficult for others to detect these subjective decrements.

In the following stages, the decrements are more prevalent and noticeable. In FAST stage 3, the individual experiences objective decrements that interfere with occupational and social functioning. It becomes hard for individuals to finish a task they had mastered for many years. Reisberg et al. (1993) provided the example of a professor who is used to writing several articles at the same time and who at this stage may not be able to finish a single report. Decrements of a retired individual in this stage may be harder to detect. In FAST stage 4, the decrements relate to complex tasks such as managing financing and related functions. The authors indicated that the individual at this stage may be unable to work with numbers, balance their checkbooks or make sound financial decisions. In FAST stage 5, the individual may need assistance, as he or she experiences difficulty with coordinating own clothes. The individual may also wear the same garments for several successive days if not reminded to change.

In FAST stage 6, Reisberg et al. (1993) described the individual's decrements in clothing, bathing, and using the toilet. The researchers identified five substages to describe the acquired decrements. In substage (a), the patient is unable to put on clothes properly. He or she may wear garments over their nightgowns. The individual may have difficulty zipping or buttoning clothes, tying shoelaces or neckties. In substage (b), the patient is unable to bathe, adjust water temperature, or safely get in and out of the bathtub or shower. In substage (c), the patient experiences decrements in the ability to use the toilet, wipe oneself, or flush the toilet. The patient in the process of using the toilet may forget to put their clothes back on. In substages (d) and (e), the patient experiences difficulty containing urine and feces when he or she does not have any infection or other impacting pathology other than the cognitive decrements of AD.

Finally, Reisberg et al. (1993) described FAST stage 7 in which the patient's decrements relate to loss of speech and motor abilities in six distinct substages. In substage (a), the patient's vocabulary appears to be limited and speech reticence and paucity become more frequent. In substage (b), the patient vocabulary is severely limited to a single word. The patient, for example, may use "yes," "no," or "okay" to respond to everything they hear. In substage (c), the decrements become increasingly motor-related. The patient may walk too fast or too slow. He or she may tilt backward or forward. In substage (d), the patient loses the ability to sit up and may not be able to stay in a seat without falling. In substage (e), the patient loses the ability to smile, although retains other facial movement. However, in substage (f), the AD patient loses his or her ability to independently hold up his or her head (Iqbal et al., 1989).

Alzheimer's and the Older Caregiver

Watching the loved one progress through the different stages of this illness is a stressful experience. With the deterioration of Alzheimer's afflicted individuals, their caregiver spouses "are faced with an ever increasing burden of responsibilities, ...and experience severe emotional turmoil and/or physical exhaustion, as they witness the loved one change into a different person before their eyes" (Koenig, 1994, p. 369). Caregivers are found to participate less in social activities and experience conflict at work and with family members. Caregivers may experience "erosion of self [or] the feeling of becoming trapped or that one's identity has been completely submerged into the caregiving role" (Zarit, 1996, p. 142).

Aneshensel et al. (1995) developed a stress model of caregiving in which they identified two key concepts: stress proliferation and stress containment. The first key concept, stress proliferation, refers to the overflow of primary stressors in the life of the caregivers into other areas of life such as work and family. Primary stressors are identified as objective or subjective. Objective stressors pertain to direct activities of care whereas the subjective stressors pertain to the caregiver's own feelings of being overwhelmed with caregiving. Subjective stressors are also called "secondary role stressors" (Aneshensel et al., 1995, p. 36).

The second key concept in the stress process model of caregiving is stress containment. Containment refers to the process of utilizing available resources to combat primary and secondary stressors that contribute to the caregiver's erosion of self-concept (Zarit, 1996). There are two identified resources that caregivers can utilize in the process of containment: material and psychological resources. Material resources refer to caregiver's financial and social support. Psychological resources are the style and the self-concept of the caregiver, how he or she copes with and responds to stressors, and views or feels own level of mastery (Aneshensel et al., 1995; see also Stephens, Crowther, Hobfoll, Tennenbaum, 1990). It was the intent of the present study to establish groundwork for a third resource available to caregivers in order to aid them in the process of containment of their stressors. Beyond material and psychological resources, the potential third resource expected to help the burdened caregiver is spiritual resources.

The burden of caregiving for a spouse of Alzheimer's disease is far more unique than the burden of caregiving of terminally ill spouses as AD is "a good deal more insidious [as] with other fatal sickness, there is a built-in time limit" (Carroll, 1989, p. 175). With a terminal illness, patients physically suffer faster than an Alzheimer's patient whose physical deterioration starts out slow and may progress as long as 20 years, a long time to care for a loved one with whom the caregiver once shared a life, family, finances and responsibilities. The caregiver of a terminally ill spouse mourns the dead faster than the caregiver of a spouse afflicted with Alzheimer's. With Alzheimer's afflicted spouses, mourning is chronologically and emotionally amplified in that the caregiver is mourning the afflicted spouse while he or she is still alive (Carroll, 1989). The caregiver advances through a number of stages in adjusting to the role of caregiver while comprehending the ongoing loss that both the caregiver and the spouse experience.

Caregiver's Stages of Adjustment

The caregiver progresses through various stages in the journey of caregiving: denial, overinvolvement, anger, guilt, and acceptance (Gruetzner, 1988). At the beginning, when the first signs of Alzheimer's appear in the spouse, denial is common as the spouse's forgetfulness is excused and the seeking of help and/or treatment is postponed. Denial of the problem often leads to family conflict as members disagree on the course of action or type of care necessary, which can create barriers within the family and/or the couples. Gruetzner (1988) described the next stage, overinvolvement, in which the caregiver admits the existence of illness and attempts to meet the patient's every need to compensate for the loss the illness brings. As the ill spouse continues to deteriorate, the physical and emotional burden of the caregiving spouse advances to the third stage, anger.

The anger stems from feelings of abandonment when the caregiver is left helpless in the relationship, widowed while the partner is still alive. The caregiving spouse is endowed with a role change as the caregiver, assuming many other responsibilities such as managing finances, making everyday decisions for both self and afflicted spouse, and in some cases also taking on the role of breadwinner. The caregiver is also robbed of their spouse's love, emotional support along with intimate and sexual connection, as well as long anticipated plans for a comfortable retirement. Anger may also be a result of misbehavior of the ill spouse as a result of deteriorating cognitive functioning. Gruetzner (1988) indicated that anger behavior on the part of the caregiver and feeling of losing control of one's emotions precipitate guilt, the next stage of caregiver's adjustment.

In the guilt stage, the caregiver is reacting to his or her own loss of control as well as anger. The caregiver may wish that the spouse be relieved of the pain and die. In turn, the caregiver feels guilty for having these thoughts and wishes. It is common that "the powerful combination of unresolved anger and guilt they [the caregivers] feel ...becomes overwhelming and develops into serious depression" (Gruetzner, 1988, p. 92). As the caregiver struggles through the different stages, he or she comes to acceptance, realizing that the ill spouse may need care away from the home. Acceptance, the final stage, often comes when the caregiver fully understands the process, development and effects of the disease.

Beyond the acceptance stage, as well as throughout the stages of adjustment to such a heartbreaking and burdening life circumstance, the caregiver wrestles with existential queries. Life and death issues are blurred and a deeper meaning for living with the dead becomes evermore desired as the older caregiver struggles to comprehend one loss after the other in the different stages of the spouse's deterioration, as well as within the caregiver's deterioration. Seifert (2002) describes the internal struggle and search for meaning as spirituality.

Religious/Spiritual Well-being and Coping

The older caregiver for a spouse with Alzheimer's is faced with the existential dilemma of searching for meaning and purpose in the loved one's affliction as well as one's own insecurities and fears that arise during the spouse's decline and the caregiving experience. The caregiver's way of life is stripped from its normal routine and a sense of emotional poise suddenly vanishes. Koenig (1994) suggested that during this difficult experience "religion may be turned to by either the patient or the family caregiver as a source of comfort" (p. 369). The internal struggle, or spirituality as Seifert (2002) described, arouses the caregiver's "spiritual needs" that Koenig (1994) indicated to stem from our knowledge that life is finite and that we are called to a higher purpose. Spiritual needs are "conscious and unconscious striving that arise from the influence of human spirit on the biopsychosocial nature. They are a consequence of an inherent human impulse to relate to humanity" (p. 283).

Koenig (1994) listed 14 spiritual needs that he identified while working with physically ill veterans. The 14 needs are as follows: a need for meaning, purpose and hope; a need to transcend circumstances; a need for support in dealing with loss; a need for continuity; a need for validation and support of religious behavior; a need to engage in religious behavior; a need for personal dignity and sense of worthiness; a need for unconditional love; a need to express anger and doubt; a need to feel that God is on their side; a need to love and serve others; a need to be thankful; a need to forgive and be forgiven; and a need to prepare for death and dying (Koenig, 1994). I propose that a caregiver of a spouse afflicted with Alzheimer's may also experience these needs in their internal struggle to cope with their stressful circumstances. The continuous and successful process of meeting these needs may bring about emotional equilibrium and spiritual well-being. My goal in this study was to determine whether this equilibrium or spiritual well-being has any effects on the caregiver's coping with their spouse's affliction.

Coping with caregiving of a spouse's illness is the managing of internal and external demands, involving the caregiver's thoughts, feelings and behavior. "Coping is a process of adaptation… conscious volitional efforts to regulate emotion, cognition, behavior, physiology, and the environment in response to stressful events or circumstances" (Compas, Connor-Smith, Saltzman, Thomsen, & Wadsworth, 2001, p. 89). Coping in the event of Alzheimer's caregiving is process-oriented, and is aimed at processing feelings, minimizing or avoiding stressful conditions, and accepting the unfortunate circumstances. It is important to distinguish between coping and other constructs such as stress, depression, or anxiety. In this study, coping is an ability to function in the face of stress rather than a state or trait (being stressed or anxious). It involves behaviors, feelings and cognitions pertaining to the individual him- or herself in dealing with stressful and anxiety-provoking events. In the present study, I assessed coping by looking at the construct as process-oriented, examining individuals' behavior (task-oriented), feelings (emotion-oriented), and cognitions (avoidance-oriented).

Lazarus and Folkman (1984) defined coping as "constantly changing cognitive and behavioral efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person" (p. 141). Coping in the present study is consistent with this definition, as I am examining manners or characteristics of individuals confronting or dealing with the stress of caregiving of their loved ones. Individuals may resort to religious and/or spiritual resources to cope with the unchangeable circumstances and irreversible health conditions of the spouse. These resources could influence how one appraises the situation, conceptualize and react to stress, accept the burden, and believe in higher helping sources in seeking a change (Koenig, 1994).

Lazarus and Folkman (1984) reflected on avoidance-focused coping, avoiding sources of distress, to be the coping preference for individuals who cannot modify their environment or their circumstances, as opposed to emotion- or problem-focused coping in more manageable situations. In situations of caregiving of a spouse afflicted with Alzheimer's, the caregiver is likely to utilize avoidance-oriented coping and adapt to tolerating and accepting stressful conditions by also utilizing emotion-focused coping. Emotion-focused coping involves regulating emotional responses to the stressful situation by seeking higher powers such as God, religion, or other human sources of support in order to process their emotions. Emotion-oriented coping can be negative in which individuals tend to blame themselves and others, as well as become angry, for their misfortune.

Problem-focused coping is less utilized in caregiving situations for the inability to reverse the loved one's affliction. In problem-focused coping, individuals seek solutions aimed at altering the existing problem to manage distress. However, Alzheimer's caregivers are likely to benefit from both emotion-oriented and problem-focused coping in accommodating oneself to the external as well as internal demands of caregiving. For example, the caregiver can seek information on the spouse's progression, self-help resources, innovative treatment and other possible solutions. The caregiver becomes task-oriented or action-oriented in his or her coping style and proactive in dealing with stress. By tapping into religious/spiritual resources, the individual may find emotional balance by becoming able to conceptualize and accept the affliction. In the present study, I investigated the effect of spiritual well-being on the different coping styles: task-oriented, emotion-oriented, and avoidance-oriented.

Research investigation on the effects of religion and/or spirituality on well-being has recently increased (Stuckey, 2001) and many studies support a positive relationship suggesting that religion and spirituality are important resources for coping with life stressors (Pargament, 1997; Aneshensel et al., 1995). Chang, Noonan, and Tennstedt (1998) indicated that despite differences in the religious/spiritual dimensions used in the various studies "the overall picture points to a positive association between religion and both physical and mental health" (p. 463). Koenig, Smiley et al. (1988) provided a comprehensive review of religion and well-being, reporting a positive association between religious beliefs and activities and successful adjustment in the older population. The researchers also report studies that found no significance in the relationship between religion, spirituality and overall well-being. Koenig, Kvale, et al. (1988) explained that, "due to methodological diversity, ambiguity in definitions, and use of closely related variables, numerous reasons exist for the disparity in results between studies" (p. 14).

In this part of my review, I will reflect on relevant studies linking religion and spirituality to overall well-being of elder caregivers and noncaregivers. Stuckey (2001) explored how people of faith cope with traumatic life events and transcend crisis with a sense of hope and purpose rather than fall into despair. Stuckey proposed that the roots of hope for individuals in stressful life events are religion. The author based this proposal on previous studies (Farran, Herth, & Popovich, 1995) that found those who reconcile life perspectives of religion, spirituality and stressful events and remain hopeful in hopeless situations were able to develop basic roots of hope. Stuckey (2001) interviewed caregivers and matched them with noncaregivers to clarify the connection among religion, spirituality, and significant life events. The author used the following definitions: "Religion is a particular doctrinal framework that guides sacred beliefs and practices in ways that are sanctioned by a broader faith community... Spirituality refers to beliefs and practices that connect persons with sacred and meaningful entities beyond themselves" (p. 70). Stuckey used the Life Reflection Interview and the Reconciled Life Perspective measures to assess religious and spiritual beliefs and how the individual reconciled the two beliefs when facing stressful life events.

Utilizing data analysis and qualitative thematic design, Stuckey (2001) aimed to identify spiritual and religious elements that people rely on in stressful situations. The author identified five common patterns among the participants' responses: "attributes of God and faith, spiritual growth, values, definitions and details, and caregiving and other significant life events" (p. 75). Participants' responses yielded interchangeability of the use of terms and definitions of religion and spirituality. All participants ($N = 20$) were found to turn to their religious and spiritual beliefs during stressful events in their lives. Religion and spirituality were the main source of comfort for all the participants as well.

Chang et al. (1998) investigated the possible indirect effect of religious and spiritual coping on psychological distress through the quality of relationship between elders and caregivers. The researchers indicated that the indirect relationship was posited for three reasons. First, religious and spiritual beliefs foster values of caring for others and serve as a resource for coping with stressful situations such as caregiving. Second, religion and spirituality influence the individual's evaluation and perception of the quality of relationships. Third, "religion/spirituality has been shown to be associated with more specific issues, for example, higher marital quality" (p. 464). To test their hypothesis, Chang et al. utilized path analysis starting with stressor variables of elders' heath status (functional disability, cognitive impairment, and behavioral problems). Then the authors examined how the caregivers' religious/spiritual coping helped them conceptualize their caregiving experience. The next pathway of the researchers' analysis was the quality of the relationship with the loved one being cared for. The researchers examined both global distress by assessing depressive symptoms and role specific distress by assessing role submersion reports.

In their study, Chang et al. (1998) used the Instrumental Activity of Daily Living (IADL) measure to assess the three stressors of caregiving by evaluating the condition of the loved one cared for. The researchers utilized the Meaning in Caregiving scale to assess religious/spiritual beliefs involvement in coping with caregiving. To assess the quality of relationship with the loved one cared for, Chang et al. (1998) utilized questions from the positive effect measure used in the University of Southern California Longitudinal Study of the Three-Generation Families. This item examined "general closeness, how well the caregiver can exchange ideas or talk about things that really concern the caregiver, similarity of views about life, and how well they get along together" (p. 466). To measure the psychological distress, Chang et al. utilized Center for Epidemiologic Studies-Depression (CES-D) scale and two of Pearlin's model intrapsychic strain measures: role capacity and loss of self.

In their results, Chang et al. (1998) found those who utilized religious/spiritual coping more likely to have a good quality of relationship with the care recipient ($\beta = .24$, $p < .01$). A good quality of relationship was linked to lower levels of depression ($\beta = -.30$, $p < .01$) and lower level of role submersion ($\beta = -.40$, $p < .001$). When controlling for relationship quality, religious/spiritual coping had no direct impact on distress. Overall, the authors found "the effects of religious/spiritual coping in reducing the level of depression symptoms and role submersion are mainly attributed to higher relationship quality" (p. 468). Others (Koenig, Smiley, et al., 1988) employed a different model that I hoped to partly emulate in the present study.

In the Religion and Social Stress Model, Koenig, Smiley, et al. (1988) investigated how religious beliefs, activities and experience might enhance older people's coping with stressful situations associated with aging. The authors assumed a causal direction between religiosity and coping and hypothesized that "religion acts directly at a variety of points in this schema to cushion the impact of social, psychological, and biological stressors" (p. 93). In order to achieve successful coping, the older individual must have adequate internal and external resources and able to execute appropriate coping behavior. Internal resources for coping refer to three components: heredity or biological aspects; personality or interaction between biological aspects and the environment and life experience that relates to the type and degree of exposure to stressful life events. External resources for coping refer to health and financial stability that can promote autonomy, dignity, and an active lifestyle. A third aspect of external resources is the older individual's social support that helps prevent loneliness and enhances active lifestyle with meaningful contacts.

Finally, coping behavior refers to strategies employed in handling stress, which can be instrumental or palliative behaviors. Instrumental strategies are action-oriented with the goal of modifying external strenuous factors contributing to stress. Palliative strategies are intrapsychic in nature, which is often the positive internal conceptualization of the stressful event. Palliative strategies aim to bring emotional equilibrium when faced with stressful circumstances. "Coping strategies, personal resources, heredity factors, and life experience, then, interact to determine how well an older person will adapt to stressful life changes" (Koenig, Smiley, et al., 1988, p. 95). In later life, internal and external resources become harder to control. In a major life event, such as a spouse's affliction with Alzheimer's, internal and external resources are often diminished and coping behaviors start to decline. A goal of the present study was to identify spiritual influence as an aspect that would enhance coping in the face a major life event as a spouse's affliction with Alzheimer's.

Religious beliefs, activities, and experience (RBAE) may have their impact on the model (Koenig, Smiley, et al., 1988) serving as both internal and external resources, and as intrapsychic, cognitive coping strategies. Religion can be an internal resource through socializing experiences that prepare individuals for possible or anticipated stressful situations, and through promotion and modification of different personality traits. Religion can also be an external source for its richness in social support through participation, financial security for the reinforced value of having concern for the needs of others, and health-promoting guidelines such as teaching against drugs, smoking, and alcohol use. As an intrapsychic, cognitive resource, RBAE may help individuals alter their perception of their situation or actively seek the change. Finding a purpose in suffering may facilitate coping at the cognitive level. At a behavioral level, the individual may consult and seek support from a religious authority and/or social contacts through one's place(s) of religious activities. Therefore, RBAE "may moderate the effects of stressors by functioning as conditioning variables and may directly impact… coping through intrapsychic and behavioral responses that alter perception of stressors" (Koenig, Smiley, et al., 1988, p. 100).

Based on the Religion and Social Stress Model above, I replaced the construct of religion with a more multidimensional concept of spirituality, examining the individual's spiritual well-being during a specific major life event as that of caring for a spouse with Alzheimer's. I investigated the hypothesis that there is a positive relationship between spirituality and coping using a one-way ANOVA by exploring three main effects of spiritual well-being on caregiver's emotion-oriented coping. To better understand the results, it is important to clarify the constructs utilized in this research.

Definition of Terms

Caregiver Burden

I have utilized Zarit, Todd, and Zarit's (1986) definition of a caregiver's burden: "The extent to which caregivers perceive their emotional or physical health, social life, and financial status suffering as a result of caring for their relative" (p. 261). A score on the Zarit Burden Interview determines the caregiver's burden. High scores indicate a higher sense of burden.

Spirituality

I have used Stukey's (2002) definition of spirituality: "Spirituality refers to beliefs and practices that connect persons with sacred and meaningful entities beyond themselves. These beliefs and practices often create and sustain a personal relationship with a supreme being as defined according to one's own beliefs, and give meaning and purpose to life... It emphasizes a personal meditative worship experience" (p. 70).

Spiritual Well-being

I have employed the National Interfaith Coalition on Aging (NICA, 1975) definition of spiritual well-being: "Spiritual well-being is the affirmation of life in a relationship with God [whoever the individual believes God to be], self, community, and the environment that nurtures and celebrates wholeness" (Clingan, 2000, p. xiii). Scores on the Spiritual Well-Being Scale determine spiritual well-being. High scores indicate high spiritual well-being.

Coping

Coping is the individual's ability to function and experience emotional equilibrium in the face of major life events. It is the ability to utilize internal and external resources to execute external or palliative coping behavior (Koenig, 1994; Koenig, Smiley, et al., 1988). The score on the Emotion-Oriented coping subscale of the Coping Inventory for Stressful Situations: Situation Specific Version determines caregivers' emotional level of coping. Higher scores suggest enhanced coping style.

Hypotheses

In this study, four hypotheses were developed and tested based on the review of the literature as follows:

The Main Hypothesis

There are significant differences of mean scores across the coping subscales (Task-Oriented, Emotion-Oriented, and Avoidance-Oriented) of the Coping Inventory for

Stressful Situations: Situation Specific Version (CISS: SSC). The difference is based on participants' overall level of Spiritual Well-Being (SWB) of the Spiritual Well-Being scale, or its subscale components, Religious Well-Being (RWB) and Existential Well-Being (EWB) levels, when caregivers' levels of burden and depression are accounted for in the mean differences. In particular, there is significant influence of mean scores on the Emotion-Oriented coping (EC) subscale of the CISS: SSC across participants' levels of SWB.

The Second Hypothesis

The average scores across the Task-Oriented and Emotion-Oriented subscales of the CISS: SSC support previous research (Koenig, Smiley, et al., 1988) that suggests a decline in older adult populations' palliative (emotion-oriented) and instrumental (task-oriented) coping.

The Third Hypothesis

Caregivers' level of burden positively correlates with their level of depression while both caregivers' levels of burden and depression positively correlate with their emotion-oriented coping, scores on the EC of the CISS: SSC.

The Fourth Hypothesis

The number of spiritual activities practiced positively correlates with total scores on EC of the CISS: SSC as well as the total scores on the SWB. However, the number of activities practiced negatively correlates with both the level of burden and level of depression.

CHAPTER III

METHOD

Participants

Approximately 250 men and women 55 years of age or older who are primary caregivers of a spouse afflicted with Alzheimer's were invited to participate. Invitations were made through direct contact with regional and local Support Group leaders and Adult Day Care facilities, Nursing Homes, and Special-Care Units' directors in 20 states on the East and West coasts, and in the Midwestern states including Manitoba Province of Canada. Programs were targeted in metropolitan and rural areas. The group leaders and program directors, in turn, passed on the research materials to random, interested caregivers. Invitations were also made through media advertisement: local television and newspaper, various older communities' newsletters, websites of at least two Alzheimer's Associations (Northern California and North Dakota), support group email listserv for caregivers, support group email listserv for Alzheimer's patients, and through personal and professional contacts throughout the states. Despite this effort, approximately 14% of the 250 surveys (N = 35) completed the materials. Cohen (1998) recommended that in order to detect a large population effect size (*ES* = .80) at a statistical power of alpha = .05, 26 participants are needed to execute a three-way MANOVA intended in this study.

Participants were expected to meet four criterions. First, participants were to be the primary caregivers of a spouse afflicted with Alzheimer's. The spouse was to be living at home or at a special care unit if the caregiver still provided direct and primary care. The spouse has been diagnosed with the dementing disorder of the Alzheimer's type or other dementing disorder for a minimum of three months. Second, the participants were to be 55 years of age or older. Third, participants were expected to be fluent in English (speak, read, and write). Fourth, participants agreed to participate in the study. The volunteer participants then received a check of $5 for their participation.

Descriptive statistical analyses revealed the following distributions of participants. Geographically, participants responded from 13 different states: Alabama (2.9%, *n* = 1), Arizona (5.7%, *n* = 2), California (8.6%, *n* = 3), Florida (11.4%, *n* = 4), Maine (2.9%, *n* = 1), Minnesota (11.4%, *n* = 4), Montana (2.9%, *n* = 1), North Dakota (31.4%, *n* = 11), New Mexico (2.9%, *n* = 1), New York (2.9%, *n* = 1), Texas (5.7%, *n* = 2), Virginia (2.9%, *n* = 1), Wisconsin (2.9%, *n* = 1), and from Manitoba, Canada (5.7%, *n* = 2). More than half of the participants were over the age of 71 (57.1%, *n* = 20). Despite the potential that female AD-afflicted individuals may outnumber males (Reisberg, 1983, see Chapter 1), female caregivers represented the majority of this sample (62.9%, *n* = 22). Most of the participants were married (91.4%, *n* = 22), had lived with their spouses well over 11 years (except for one participant 1-3 years), some indicating as many as 59 years. Education and occupational demographics reveal that 40% (*n* = 14) of participants had high school education or less, 25.7% (*n* = 9) had a 2-year degree, 20% (*n* = 7) had a 4-year degree, and 14.3% (*n* = 5) had more than a 4-year degree. The majority of participants reported no current occupation (82.9%, *n* = 29), while 11.4% (*n* = 4) had a part-time job and 5.7% (*n* = 2) had full-time jobs. Statistical analyses of participants' annual income revealed that 40% (*n* = 14) made $20,000-$40,000, 37.1% (*n* = 13) made over \$40,000, 20% (n = 7) made \$10,000-\$20,000, and 2.9% (n = 1) made less than \$10,000 per year.

Frequency distributions also revealed that most participants lived independently (91.4%, n = 32), practiced organized religion (82.9%, n = 29), and all practiced more than one spiritual activity such as prayer, meditation, reading, and/or fasting. Participants reported 11 different religious affiliations or denominations: Baptist (2.9%, n = 1), Catholic (17.1%, n = 6), Christian (2.9%, n = 1), Episcopal (2.9%, n = 1), Jewish (8.6%, n = 3), Lutheran (37.1%, n = 13), Mormon (2.9%, n = 1), Protestant (5.7%, n = 2), United Church of Christ (2.9%, n = 1), United Methodist (8.6%, n = 3), while the remaining participants (8.6%, n = 3) indicated no religious affiliation with only one of whom indicated no spiritual practices.

Further frequency analyses of participants' demographics revealed the following. Most caregivers (88.6%, n = 31) cared for partners at home; the majority diagnosis was dementia of the Alzheimer's type (80%, n = 28) while the remaining (20%, n = 7) had additional diagnosis (Parkinson's) and/or other types of dementia. A little over half of the participants (57.1%, n = 20) were diagnosed within one to three years, 40% (n = 14) were diagnosed 4-7 years past, and 2.9% (n = 1) was diagnosed over 7 years past. Most of the caregivers (65.7%, n = 23) cared for spouses who needed moderate assistance as in help eating, bathing, and dressing, 14% (n = 5) provided care to spouses who were totally dependent, while 20% (n = 7) provided little to no assistance. Close to half the caregivers in this study (48.6%, n = 17) were in the final Acceptance stage, still experiencing some anger and guilt feelings, 34.4% (n = 12) were in the Awareness, Anger, and Guilt stages of caregiver's stages of adjustment, while 17.1% ($n = 6$) while still in the denial stage of caregiving based on data obtained from the Caregiving Activities and Adjustment Index.

Frequency distributions of the dependent and independent variables of the participants revealed the following. More than half the participants (51.4%, $n = 18$) reported moderate level of burden. About 17.1% ($n = 6$) experienced low burden while 31.4 ($n = 11$) reported high level of burden in their caregiving. The majority of participants in this sample (82.9%, $n = 29$) reported no depression. One participant or 2.9% reported low depression, three or 8.6% reported moderate depression, and two or 5.7% met the criteria for major depression. On the spiritual well-being scale, participants had two levels moderate (62.9%, $n = 22$) and high (37.1%, $n = 13$). None of the participants had a low spiritual well-being level. Participants varied on the coping subscales of the Coping Inventory for Stressful Situation: Situation Specific Version (see *Materials* below). On the Task-Oriented coping subscale, participants ranged between 30 and 70 ($M = 46.11$, $SD = 10.68$), on the Emotion-Oriented coping subscale scale between 30 and 66 ($M = 44.40$, $SD = 9.26$), and on the Avoidance-Oriented coping subscale between 32 and 78 ($M = 49.87$, $SD = 11.36$).

Materials

Zarit Burden Interview (BI)

The BI (Appendix A-4) was developed by Zarit, Reever, & Bach-Peterson (1980) to assess the stress perceived by family caregivers of elderly and disabled individuals. It renders the caregiver's evaluation of the burden acquired in the caregiving process. The BI is a 22-item instrument that assesses the caregiver's perceived impact of caregiving on his or her physical and emotional well-being, social activities and financial status

(Kaszniak, 1996; Zarit & Zarit, 1990). The BI is a self-report inventory that can be utilized as a paper-pencil measure or can be completed during an interview. Each of the 22 items has a 5-point scale: 0 = never, 1 = rarely, 2 = sometimes, 3 = quite frequently, and 4 = almost always. Participants were asked to indicate how much each statement applies to their lives in the caregiving experience. They inquired into rating caregiving chores, degree of stress felt, emotional impact, physical concerns, and social and financial strains (see Appendix A-4). The total score is the sum of all 22 items. Higher scores indicate a higher sense of burden and greater distress (Zarit & Zarit, 1990).

The Burden Interview has high internal reliability estimated using Chronbach alpha at .88 and .91 (Zatit & Zarit, 1990). It has test-retest reliability of .71 (Gallager, Rappaport, Benedict, Lovett, & Silven, 1985). The BI total score was correlated with a single global rating of burden (*r* = .71) to estimate its construct validity. It was also correlated with the total score of the Brief Symptoms Inventory (*r* = .41) and with subscales of the Brief Symptoms Inventory (Zarit & Zarit, 1990). Kaszniak (1996) found the following:

> The BI validity is supported by various observations, such as significant correlation with an index of social support, ...prediction ...of dementia patient nursing home placement..., sensitivity to the effects of group support programs for the family members of patients with dementia..., and sensitivity to the effects of a 2-week respite care program. (p. 174).

Whitlatch, Zarit, & von Eye (1991) derived two scales from the Burden Interview using confirmatory factor analysis. Two dimensions are represented in the scales: Personal Strain (*alpha* = .80) and Role Strain (*alpha* = .81). The sum of items 1, 4, 5, 8, 9, 14, 16, 17, 18, 19, 20, and 21 constitute the Personal Strain scale. The sum of items 2, 3, 6, 11, 12, and 13 constitute the Role Strain scale. In this study, the BI was utilized to assess the overall sense of burden felt by the caregiver by considering the total score of all items. High reliability coefficient for this sample ($N = 35$) was obtained (*alpha* = .8925). Scale statistics were also computed revealing a scale mean of 37.0857 and standard deviation of 12.0547 for 22 items of the scale.

Spiritual Well-Being Scale (SWBS)

The Spiritual Well-being Scale (Appendix A-6) is a well-researched, 20-item paper-pencil measure that inquires into the individual's perception of the quality of his or her spiritual life, a valid and direct measure of spiritual well-being (Ellison & Paloutzian, 1991). The items have a Likert response scale ranging from Strongly Agree to Strongly Disagree with no mid-point option. The SWBS has positively and negatively worded items to elicit respondents' attentiveness and minimize possible response-set bias, which renders the scale as highly face valid. "It has good reliability, reasonable validity, and a sound conceptual basis" (D'Costa, 1995, p. 984). The authors designated 10 questions for each of the two domains of the measure: Religious Well-being (RWB) and Existential Well-being (SWB). The RWB assesses for the individual's own well-being in a religious sense while the EWB assesses for the individual's sense of purpose and satisfaction of life. The two domains comprise the total score of the instrument reflecting the individual's spiritual well-being. The total score of the SWB scale can be categorized to reflect the individual's level of spiritual well-being. Scores ranging from 20-40 means that the individual has low spiritual well-being, 41-99 means the individual has moderate spiritual well-being, and a range from 100-120 indicates that the individual has high spiritual well-being. Paloutzian and Ellison (1991) reported various Means and Standard Deviations for several populations. The authors found caregivers' SWB *M* = 93.91 and *SD* = 17.68, RWB *M* = 48.00 and *SD* = 11.03, and EWB *M* = 46.94 and *SD* = 8.21. In this sample (*N* = 35) of caregivers of AD-afflicted spouses, participants' mean and standard deviation on the different measures were consistent: SWB *M* = 91.46 and *SD* = 19.94, RWB *M* = 46.37 and *SD* = 13.91, and EWB *M* = 45.09 and *SD* = 8.98.

Bufford, Paloutzian, and Ellison (1991) reported test-retest reliability coefficients ranging from .82 to .99, a test-retest interval ranging from 1-10 weeks. It has internal consistency coefficients ranging from .78 to .82 for the RWB and .82 to .94 for the EWB. The scale has high face validity for its reverse scores. Items 3, 4, 7, 8, 10, 11, 14, 15, 17, 19, and 20 are positively scored while the rest of the items are negatively scored. Schoenrade (1995) reported correlations of the SWBS with other measures such as Crumbaught's (1969) Purpose in Life Test (for the EWB, *r* = .68) and Allport and Ross's (1967) measure of Intrinsic Religion (for the RWB, *r* = .79). Wotherspoon (2000) reported the RWB to correlate well with Religious Orientation Scale (*r* = .77), and the Moral Object subscale of the Reason for Living Inventory (*r* = .56). The author also reported that the constructs of SWBS correlates in predictive ways with UCLA Loneliness Scale (*r* = .37), the Abbreviated Loneliness Scale (*r* = .41), the Purpose in Life Scale (*r* = .52), the Intrinsic Religious Orientation Scale (*r* = .67), and the Extrinsic Religious Orientation Scale (*r* = .26). In this study, I utilized the total score on the SWB to assess the overall spiritual well-being in order to be inclusive of both religiousness and spirituality. High reliability coefficient for this sample (*N* = 35) was obtained (*alpha* =

.9355, *Standardized item alpha* = .9350). Scale statistics were also computed revealing a scale mean of 91.4571 and standard deviation of 19.9401 for 20 items of the scale.

Center for Epidemiologic Studies Depression Scale-Revised 20 (CESD-R2)

The original CES-D was first developed in 1977 as a self-report measure of depression (Radloff, 1977) by the National Institute of Mental Health for epidemiological research. It has since been revised from a self-report measure to telephone and self-administration (both on paper and through the web or a software program). The latest revisions are the Long Form (CESD-R35) and the Short Form (CESD-R20) by Dr. William Eaton of John Hopkins University (both are public domains). The Short Form is a 20-item measure that was developed especially for the older population to alleviate potential confusion and emotional stress that the original form might have on the older population experiencing emotional and physical strain (Sheikh & Yesavage, 1986). It was intended to facilitate administration for the older population (Irwin, Artin, & Oxman, 1999). The latest revision (Eaton, Muntaner, and Smith, 1998) was intended to better predict depression utilizing the DSM-IV criteria for major depression.

In the CESD-R20, known also as the HRCESD-20 (Appendix A-5), the participants were asked to indicate how they felt or behaved in the "past week or so" relevant to each of the 20 items provided. The items explore the following aspects of the individual's life: sadness, interests, appetite, sleep, thinking, guilt, fatigue, movement, death, hopelessness, friends, and happiness. Responses are indicated on a Likert scale from 0 being "Not at all or less than 1 day" to 5 being "Nearly everyday for 2 weeks". Scores range from 0-60 on the original as well as on the short form. There is no cutoff score for depression on the revised forms. Higher depressive symptoms are not always associated with higher scores, nor lower depressive symptoms always associated with lower scores. Depression in this revised version is mainly based on symptoms according to the DSM-IV criteria.

The CESD-R20 scale has four separate factors: Depressive Affect, Somatic Symptoms, Positive Affect, and Interpersonal Relations (original scale). Gupta and Yick (1987) indicated that the CES-D has "very good" internal consistency with an Alpha of .85 for the general population and alpha of .90 for psychiatric patients. Radloff (1977) reported split-half and coefficient alpha estimates of internal consistency ranging between .85 and .92.

For the short form, Edelstein, Kalish, Drozdick, and McKee (1999) reported test-retest reliability to be "good" ($r = .70$). Eaton et al. (1998) correlated revision scores with the scores of the original measure and found high correlation (r = .89) with almost identical standard deviation (9.97 and 9.92). Edelstein et al. (1999) indicated that the strength of this measure is its widespread use in epidemiological studies and availability of norm samples. The author also recommended that the measure is more suitable for screening older adults. However, the author cautioned against using the scale solely for diagnosing major depression (see also Eaton et al., 1998; Matschinger, Schork, Riedel-Keller, & Angermeyer, 2002). In this study, the CESD-R20 was intended for screening purposes to determine participants' level of depressive symptomology and control for depression as a potential confounding variable.

Coping Inventory for Stressful Situations: Situation Specific Version (CISS: SSC)

The Coping Inventory for Stressful Situation (CISS), as well as the short form CISS: SSC, is an empirically and theoretically validated, multidimensional measure used to assess an individual's coping style. The CISS is a 48-item measure with a five-point Likert scale ranging form 1 (Not at all) to 5 (Very much) used for adolescents and for adults. The participants are asked to indicate their involvement in activities described in the various statements inquiring into the individual's coping behavior and style. The scale has three coping dimensions: Task-Oriented, Emotion-Oriented, and Avoidance-Oriented coping. The Avoidance-oriented scale has two subscales: Distraction and Social Aversion.

The Situation Specific Version (CISS: SSC) is a 21-item measure (Appendix A-7) used to assess adults coping with the specific stressful situation in mind. Norms are provided for situations such as social evaluation, change in social situations, relationship or interpersonal conflict, and general stress (Multi-Health System, 1999). Similar to the CISS, the CISS:SSC is a multidimensional measure that has three scales: Task-Oriented, Emotion-Oriented, and Avoidance-Oriented coping. The Task dimension describes specific coping behavior utilized in problem solving and solution planning. It involves cognitive restructuring the problem or attempt to change the situation. The emphasis in Task-Oriented coping is on efforts to solve the problem. The Emotion-Oriented dimension describes emotional reactions and personal perception of self such as self-blame, and getting angry and tense in self-oriented reaction to the situation. Self-preoccupation and fantasying such as daydreaming are other self-oriented reactions experienced. Emotion-Oriented coping may not always be successful. In fact it may increase stress in some cases when reactions are oriented towards the person who often becomes very upset and tense. The Avoidance-Oriented dimension describes cognitive changes aimed at stress avoidance as a coping style in a stressful situation. Avoidance is possible when the individual distracts him- or herself with other situations or tasks. Avoidance may be person-oriented as in social deviation as a means to alleviate stress (Endler & Parker, 1999). Non-significant or low correlations were found among Task, Emotion and Avoidance subscales ($r = .00$ to $r = .46$) supporting the multidimensionality of the instrument.

Endler, Speer, Johnson, & Flett (1998) established validity for the CISS: SSC when they assessed the relationship between control over a stressful situation and the resultant coping strategies in reacting to the stressful situation. The researchers found validity when examining "goodness of fit" hypothesis (high-low control versus congruent coping) and predicted Task-Oriented and Emotion-Oriented coping dimensions. The researchers also found "very good alpha levels for each of the Task and Emotion-Oriented coping subscales" (Multi-Health Systems, 1999, p. 62). The scale generates raw scores that are converted into standard *T*-scores based on data provided from individuals coping with General Stress, one of four possible scenarios and their relevant data: Social Evaluation, Change in Social Situation, and Relationship or Interpersonal Conflict. Data used in profiling the CISS: SSC General Stress Scenario is based on the largest pool of the four groups (N = 537). The average score for Task was higher (M = 25.86, SD = 4.63, alpha = .81) than Emotion (M = 18.95, SD = 6.03, alpha = ,.84) and Avoidance (M = 18.60, SD = 5.72, alpha = .76). For testing the hypothesis in this study, participants were administered the short form, CISS: SSC, with "caregiving" as the specific situation in mind and standardized scores based on the General Stress database.

Additional Forms

Two more forms were utilized: the Demographic Form, and the Caregiving Activities and Caregiving Adjustment Index. The Demographic Form (Appendix A-2) included information regarding the caregiver's age, gender, marital status, length of marriage, education, occupation, income, and living arrangement. The form also included questions about the caregiver's religious and spiritual practices, information regarding the spouse's residence, diagnosis, and length of diagnosis. Participants checked the provided answers that applied to their demographic information as well as their spouse's conditions. The items and answers were coded and interred SPSS for Windows software for analyses to reflect sample demographics.

The Caregiving Activities and Adjustment Stages Index (Appendix A-3) inquired into the spouse's (patient's) needs and the type of caregiving activities provided by the caregiver. This form assessed for caregiver's beliefs about spouse's conditions as well as the caregiver's own emotional reactions. The form is based on the Activities of Daily Living instrument (ADL) published in the Journal of American Medical Association (185:914-19), and on Gruetzner's (1988) Caregiver's Stages of Adjustment. The first part, caregiving activities, assessed whether the caregiver provided "little to no assistance," "moderate assistance," or "assistance to a totally dependent spouse." Each of these three categories was scored on a continuous scale and coded to match the level of caregiving activities. The questions in the second part addressed each stage Gruetzner proposed. The questions were intended to be scored utilizing a continuous scale that would reflect the caregiver's stages of adjustment. However, caregivers answered in a way that indicated multiple levels of adjustment that it was more appropriate to group the different stages into three categories: denial, awareness/anger/guilt, and acceptance.

Design and Procedure

To conduct this study, approval from the Institutional Review Board (IRB) of the University of North Dakota (UND) was obtained. In the process of accessing the population intended, Caregivers Support Group listings from Alzheimer's Association, as well as listings of Adult Day Care Programs and Special Alzheimer's Units, were obtained from the internet, regional, and local Alzheimer's Chapters. Prior to contacting Support Group leaders, whose contact information was provided by the Alzheimer's Association, permission was obtained from the Directors of the different Associations to contact the group leaders. Most Directors granted verbal permission over the telephone, others via email messages with the list of contact information, while others requested a copy of the IRB form that was submitted to UND before they granted permission.

Once permission was obtained to contact group leaders, initial contact with leaders and relevant professionals was made. Some group leaders adapted the permission granted by the Alzheimer's Chapters and passed the information to their members. Other leaders initiated their own IRB process and documentation before they presented the idea to their members. A follow-up contact was made and support group leaders requested a specific number of research packets for their interested members who met the criteria. Other group leaders requested various numbers of the research packets and passed them on to their members who met the criteria and indicated their willingness to complete them. An agreement was made that leaders would give research packets to members who would volunteer to complete the surveys, and that the leaders would remind participants to complete and send the materials as soon as possible in later group meetings. Other follow-up calls, emails, and/or printed matter materials were made on a weekly basis, or upon an agreement with the leaders to contact them at scheduled intervals (three weeks being the maximum interval).

A total of 250 research packets were distributed. Initially, 150 research packets were sent out. One hundred and forty eight packets were mailed to group leaders and directors of various care units. Two caregivers contacted me directly, one caregiver learning of the study through UND Channel 3 while the other learning about it from a local ad in the Grand Forks Herald. Only eight completed research packets were received. Approximately 50 were returned either unfilled to group leaders who sent them back to me or were sent directly back to me by the caregivers. The 50 research packets were re-prepared and re-sent to other group leaders. I urged the group leaders to remind participants often. Later, I received seven more completed packets (*N* = 15). Another round of searching for participants was initiated through new groups, special units, and through personal and professional contacts. A third round of research packets were prepared and sent out that raised the total number of research packets to 250. Out of the 250 mailed surveys, the total number of caregivers who sent completed packets was 35, giving a response rate of 14%.

Each spouse caregiver who voluntarily agreed to participate received a research packet that contained an instruction sheet, an addressed and stamped envelope to mail back a copy of the signed consent form, and two copies of the consent form which explained the purpose of the study, confidentiality, voluntary participation, and contact information should the participant have any questions or experience any potential lowgrade stress associated with the strain of completing the forms. The packets also included an addressed and stamped manila envelope containing the instruments to be filled out and returned to me. The instruments consisted of six forms. First, the demographic form inquired into participants' gender, education, socioeconomic status, spouse's diagnosis information, spiritual practices, and other demographic questions (See Appendix A-2). Second, the Caregiving Activities and Adjustment Index form (see Appendix A-3) inquired into the spouse's needs and the type of caregiving activities provided, and assessed caregiver's beliefs about spouse's condition as well as the caregiver's own emotional reactions. The form is based on the Activities of Daily Living instrument (ADL) published in the Journal of American Medical Association (185:914-19) and on Gruetzner Caregiver's Stages of Adjustment.

The remaining four forms included the instruments described in the Material section above: the Zarit Burden Interview (Appendix A-4), the Hopkins Revised Center for Epidemiologic Studies Depression Scale – 20 (Appendix A-5), the Spiritual Well-being Scale (Appendix A-6), and the Coping Inventory for Stressful Situations: Situation Specific Form (Appendix A-7). The instruments were number-coded to assure confidentiality. Participants mailed the signed consent form in the designated envelope, separate from the data as instructed. A Thank You note (Appendix B) and a check of $5.00 were sent as a follow-up (some participants declined receiving the $5.00). The Thank You note also served as a reminder or request for participants to pass on information to other caregivers to participate in this study.

Data Analyses

All data analyses were conducted by utilizing the SPSS software package for Windows version 10.0. The analyses included descriptive, hypothesis-testing, and exploratory statistical procedures. In determining the level of significance, all analyses were conducted at an alpha level of .05 and an effect size of .80.

Descriptive statistical analyses were conducted in order to describe the sample characteristics. Frequencies, percentages, mean scores, and standard deviations were computed when appropriate for demographic data, such as age, gender, marital status, years of living together, education, occupation, income, living arrangement, religious and spiritual practices, and spouse's diagnosis and its duration.

Other relevant descriptive statistical analyses were conducted. Means, frequencies, and/or percentages were conducted to describe participants' caregiving activities and level of adjustment to caregiving. Further descriptive analyses included participants' level of burden, level of depression, level of spiritual well-being, and total scores of SWB scale and the CISS: SSC.

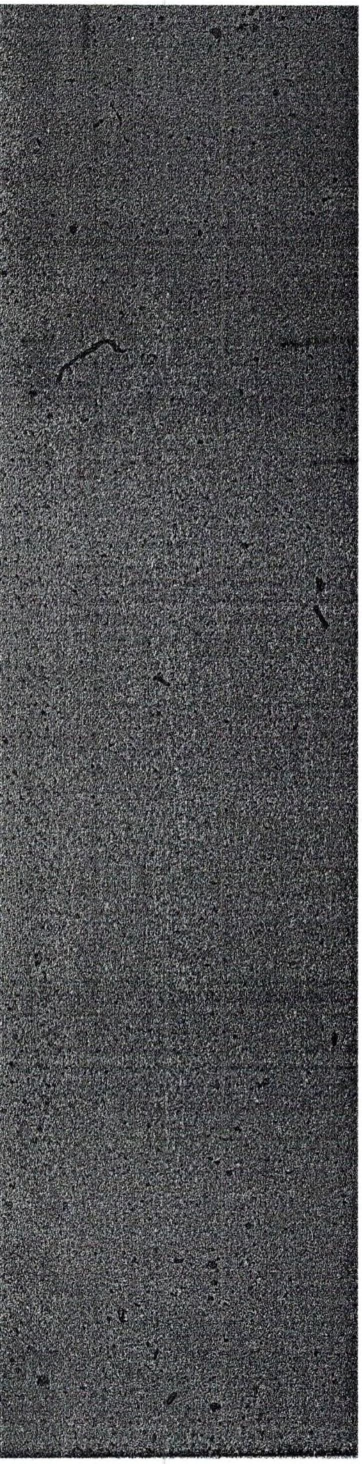
Correlations were conducted between the demographic variables and scores on the measures of depression, spiritual well-being, and coping. A Pearson product moment correlation matrix was computed for the total of the different coping subscales (Task-Oriented, Emotion-Oriented, and Avoidance-Oriented). Similar matrices were also obtained for emotion-oriented coping, spiritual well-being, depression, and other demographic data.

To test the main hypothesis, data of the CISS: SSC and SWB scale were analyzed using multivariate (three-way MANOVA) and univariate (three-way ANOVA) to determine mean differences on the coping subscales of the CISS: SSC across caregivers' levels of SWB, RWB, and EWB in conjunction with participants' levels of caregiving burden and depression. Using a multivariate approach was intended to detect effects on a single dependent variable (one subscale of the CISS: SSC) or a linear combination of the dependent variables (two or more of the subscales of the CISS: SSC).

To test the second hypothesis, a series of *t*-tests were conducted to determine whether older caregivers' average scores on the task-oriented and emotion-oriented coping declined, as suggested by Koenig, Smiley, et al., (1988), below adult mean scores on the two subscales of the CISS: SSC: Task (for men $M = 58.56$, $SD = 9.95$; for women $M = 58.60$, $SD = 8.65$) and Emotion (for men $M = 39.21$, $SD = 11.54$; for women $M = 42.47$, $SD = 11.35$) found in previous research (Endler & James, 1999).

Regarding the third and fourth hypotheses, Pearson product-moment correlation coefficients were computed to determine the relationship, if any, among caregivers' burden, depression, and emotion-oriented coping (third hypothesis), and between the number of spiritual activities practiced and the total scores on EC of the CISS: SSC as well as the total scores on the SWB (fourth hypothesis). The same analysis was utilized to examine the relationship between the number of spiritual activities and caregivers' level of burden and depression (fourth hypothesis).

Further exploratory analyses such as descriptive statistics, univariate, and multivariate analyses were conducted to examine several other relationships. For example, descriptive statistics were computed to examine links of caregiver's age, income, education and depression. A two-way ANOVA was computed to examine the



CHAPTER IV

RESULTS

The results of this study are presented in seven sections. The first three sections pertain to the main hypotheses regarding coping and spirituality. The following three sections pertain to the following areas: palliative and instrumental coping, burden and depression, and spiritual practices relationship with caregivers' spiritual well-being and their emotion-oriented coping. The final seventh section presents results of exploratory analyses.

The Main Hypothesis

The main hypothesis of the study was that caregivers' mean scores on the three subscales of CISS: SSC, Task-Oriented, Emotion-Oriented, and Avoidance-Oriented coping differ significantly based on caregivers' level of spiritual well-being (SWB) determined by the total score of the Spiritual Well-Being scale, as well as the levels of religious well-being (RWB) and existential well-being (EWB) subscales of the SWB scale. Factors such as caregiving burden and depression are likely to influence coping as well. Therefore, I examined the main hypothesis by conducting several multivariate and univariate analyses combining the possible confounds of burden (measured by the BI) and depression (measured by the CESD-R20) with spiritual well-being, then religious well-being, and finally existential well-being levels.

I started with a three-way MANOVA to determine the effects of the three independent variables' (BI, CESD-R20, and SWB) levels on the dependent variables, the

Task-Oriented, Emotion-Oriented, and Avoidance-Oriented coping subscales of the CISS: SSC. I replaced the SWB (determined by the SWB scale total score) with RWB, and later with EWB subscales of the SWB scale and conducted the same analysis. Three-way MANOVA was chosen to assess mean differences across each of the three dependent variables that account for caregivers' coping. The MANOVA was also chosen to assess any significant effects on any linear combinations of the dependent variables. Significance was determined by setting alpha at .05 given the small sample size and large effect size expected. To evaluate significance, the statistical numbers reported for Wilks' Lambda was considered, being most frequently used in social science literature (Green, Salkind, & Akey, 2000).

Spiritual Well-Being (SWB)

Table 1

Multivariate Tests of Significance for Coping Using SWB (Wilks' Lambda)

Source	Λ	*df*	*F*	η2	*p*
Intercept	.975	3 , 22	284,353	.975	.000
SWB	.830	3 , 22	1.504	.170	.241
CESD-R20	.671	9 , 53.693	1.063	.125	.405
Burden	.861	6 , 44	.571	.072	.751

The MANOVA results using SWB yielded non-significant effects among the three independent variables (spiritual well-being, burden, and depression) on the dependent measures (Task, Emotion, Avoidance): for SWB, Wilk's $\Lambda = .830$, $F\,(3, 22) = 1.504$, $p = .241$; for depression, Wilk's $\Lambda = .671$, $F\,(9, 53.693) = 1.063$, $p = .405$; and for burden, Wilk's $\Lambda = .861$, $F\,(6, 44) = .571$, $p = .751$. The multivariate η2 based on Wilk's

Λ was non-significant: SWB $\eta 2 = .170$ or approximately 17% of the total variance, depression $\eta 2 = .125$ or approximately 13% of the total variance, and burden $\eta 2 = .072$ or about 7% of the total variance. Results of MANOVA are presented in Table 1.

Post hoc analyses to the MANOVA for SWB, depression, and burden consisted of conducting pairwise comparisons to find which level of the above independent variables affected coping most strongly. Pairwise comparisons revealed significant differences in the means among the moderate, and high level combinations of caregivers' spiritual well-being ($M = 11.278, p = .003$) on the Emotion-Oriented subscale of the CISS: SSC. The variance between the two groups ranged from 4.272 to 18.283. Pairwise comparisons also revealed significant differences in the means across the Emotion-Oriented subscale of the CISS: SSC among the level combinations of "moderate depression" and "not depressed" ($M = 11.694, p = .030$), and the "high depression" and "not depressed" ($M = 14.694, p = .018$). The variance between the "moderate depression" and "not depressed" ranged from 22.192 to 1.197. The variance between the "high depression" and "not depressed" ranged from 26.654 to 2.735.

Pairwise comparisons also revealed significant differences in the means across the Emotion-Oriented subscale of the CISS: SSC among the level combinations of "moderate" and "low" burden ($M = 10.167, p = .026$), and the "high" and "low" burden ($M = -9.083, p = .046$). The variance between the moderate and low levels of burden ranged from 19.005 to 1.328. The variance between the high and low levels of burden ranged from 17.991 to .175.

In reviewing the multivariate three-way MANOVA including SWB, results revealed no significant interaction among the independent variables or significant differences in the means across the three dependent variables as a result of the interaction. Univariate follow-up tests of pairwise comparisons (using estimated marginal means) detected significant differences in the means of caregiver's emotion-oriented coping scores across the two spiritual well-being levels (moderate and high), three depression levels (not depressed, moderate, and high), and three burden levels (low, moderate, and high).

Table 2

Descriptive Statistics of Emotion-Oriented Coping Using SWB

	M	SD	N
SWB			
Moderate	47.73	8.78	22
High	38.77	7.33	13
CESD-R20			
Not D.	42.48	8.19	29
Low D.	44.00		1
Moderate	54.67	8.33	3
High D.	57.00	12.73	2
Burden			
Low	39.33	9.61	6
Moderate	44.44	8.53	18
High	47.09	9.93	11
Total	44.40	9.26	35

The results suggest that caregivers utilized emotion-oriented coping when they experienced a moderate level of spiritual well-being more than caregivers who experienced high spiritual well-being. Caregivers who experienced high level of depression utilized emotion-oriented coping more than those who experienced moderate level of depression. Finally, caregivers who experienced high level of burden utilized emotion-oriented coping more than those who experienced lower levels of burden. The results indicate that those who had higher spiritual well-being level, higher depression and/or burden levels were able to maintain better emotional equilibrium by being less blaming of themselves and more positive about their stressful situations (lower scores on Emotion-Oriented subscale of the CISS: SSC). Means and standard deviations of caregivers' emotion-oriented coping across the independent variables are presented in Table 2.

Religious Well-being (RWB)

Table 3

Multivariate Tests of Significance for Coping Using RWB (Wilks' Lambda)

Source	Λ	*df*	*F*	$\eta 2$	*p*
Intercept	.973	3 , 20	242,454	.973	.000
RWB	.718	6 , 40	1.198	.152	.327
CESD-R20	.626	9 , 48.825	1.149	.144	.348
Burden	.942	6 , 40	.973	.029	.975

The MANOVA results using RWB also yielded non-significant effects when RWB (religious well-being) was entered as the independent variable: for RWB, Wilk's $\Lambda = .718$, F (6, 40) = 1.198, $p = .327$; for depression, Wilk's $\Lambda = .626$, F (9, 48.825) =

1.148, $p = .348$; and for burden, Wilk's $\Lambda = .942$, $F(6, 40) = .201$, $p = .975$. The multivariate $\eta 2$ based on Wilk's Λ was non-significant: RWB $\eta 2 = .152$ or approximately 15% of the total variance, depression $\eta 2 = .144$ or approximately 14% of the total variance, and burden $\eta 2 = .029$ or about 3% of the total variance. Results of MANOVA are presented in Table 3.

Post hoc analyses to the MANOVA for RWB, depression, and burden consisted of conducting pairwise comparisons to find which level of the above independent variables affected coping most strongly. Pairwise comparisons revealed significant differences in the means across the Avoidance-Oriented subscale of the CISS: SSC between the "low" and "moderate" level combinations of caregivers' religious well-being ($M = 18.567$, $p = .025$). Th variance between the two groups ranged from 2.610 to 34.523. Means and standard deviations of caregivers' Avoidance-Oriented coping across the different levels of religious well-being are presented in Table 4.

Table 4

Descriptive Statistics of Avoidance-Oriented Coping Using RWB

RWB	M	SD	N
Low	62	13.11	3
Moderate	45.71	9.98	14
High	49.33	11.08	18
Total	48.97	11.36	35

Pairwise comparisons also revealed significant differences in the means across Emotion-Oriented coping subscale of the CISS: SSC between the combination levels of "high depression" and "not depressed" ($M = 14.143$, $p = .032$). The variance ranged from

1.313 to 26.973 (see Table 3 above for means and standard deviations of caregivers' emotion-oriented coping across the different levels of depression). Pairwise comparisons revealed non-significant differences in the means among the burden level combinations across the three subscales of the CISS: SSC.

In reviewing the multivariate three-way MANOVA including RWB, results revealed no significant interaction effects among the independent variables or significant differences in the means across the three dependent variables as a result of the interaction. Univariate follow-up tests of pairwise comparisons (using estimated marginal means) detected significant differences in the means of caregivers' Avoidance-Oriented coping scores across the two religious well-being levels, low and moderate. Significant differences were also detected in the means of caregivers' emotion-oriented coping between the "high depressed" and "not depressed" levels. The results suggest that caregivers who experienced low levels of religious well-being utilized less avoidance behavior as they coped compared to those who experienced higher levels. Caregivers also utilized emotion-oriented coping when they experienced high level of depression more than caregivers who were less depressed.

Existential Well-being (EWB)

The MANOVA results using EWB yielded non-significant effects among the three independent variables (existential well-being, burden, and depression) on the dependent measures (Task, Emotion, Avoidance): for EWB, Wilk's $\Lambda = .771$, $F\,(3, 22) = 2.175$, $p = .120$; for depression, Wilk's $\Lambda = .699$, $F\,(9, 53.693) = .946$, $p = .494$; and for burden, Wilk's $\Lambda = .863$, $F\,(6, 44) = .559$, $p = .761$. The multivariate $\eta 2$ based on Wilk's Λ was non-significant: EWB $\eta 2 = .229$ or approximately 23% of the total variance, depression η2 = .113 or approximately 11% of the total variance, and burden η2 = .071 or about 7% of the total variance. Results of MANOVA are presented in Table 5.

Table 5

Multivariate Tests of Significance for Coping Using EWB (Wilks' Lambda)

Source	Λ	*df*	*F*	η2	*p*
Intercept	.028	3 , 22	252.627	.972	.000
EWB	.771	3 , 22	2.175	.229	.120
CESD-R20	.699	9 , 53.693	.946	.113	.494
Burden	.863	6 , 44	.559	.071	.761

Post hoc analyses to the MANOVA for EWB, depression, and burden consisted of conducting pairwise comparisons to find which level of the above independent variables affected coping most strongly. Pairwise comparisons revealed significant differences in the means across the Emotion-Oriented subscale of the CISS: SSC between the "moderate" and "high" level combinations of caregivers' existential well-being (M = 9.641, p = .014). The variance between the two groups ranged from 2.100 to 17.183. Means and standard deviations of caregivers' Emotion-Oriented coping across the EWB levels are presented in Table 6.

Table 6

Descriptive Statistics of Emotion-Oriented Coping Using EWB

EWB	M	SD	N
Moderate	47.73	8.78	22
High	38.77	7.33	13

Pairwise comparisons also revealed significant differences in the means across the Emotion-Oriented subscale of the CISS: SSC among the level combinations of "moderate depression" and "not depressed" (*M* = 12.301, *p* = .025), and the "high depression" and "not depressed" (*M* = 15.301, *p* = .015). The variance between the "moderate depression" and "not depressed" ranged from 1.709 to 22.892. The variance between the "high depression" and "not depressed" ranged from 3.240 to 27.361.

Pairwise comparisons also revealed significant differences in the means across the Emotion-Oriented subscale of the CISS: SSC among the level combinations of "moderate" and "low" burden (*M* = 9.439, *p* = .039), and the "high" and "low" burden (*M* = 9.083, *p* = .047). The variance between the "moderate" and "low" levels of burden ranged from .499 to 18.379. The variance between the "high" and "low" levels of burden ranged from .117 to 18.050.

In reviewing the multivariate three-way MANOVA including EWB, results revealed no significant interaction effects among the independent variables or significant differences in the means across the three dependent variables as a result of the interaction. Univariate follow-up tests of pairwise comparisons (using estimated marginal means) detected significant differences in the means of caregiver's emotion-oriented coping scores across the two existential well-being levels (moderate and high), three depression levels (no depressed, moderate, and high), and three burden levels (low, moderate, and high).

The results suggest that caregivers utilized emotion-oriented coping when they experienced a moderate level of existential well-being more than caregivers who experienced a high level of existential well-being. Caregivers who experienced a high level of depression utilized emotion-oriented coping more than those who experienced a moderate level of depression. Finally, caregivers who experienced a high level of burden utilized emotion-oriented coping more than those who experienced lower levels of burden. The results indicate that those who had a higher existential well-being level, higher depression and/or burden levels were able to maintain better emotional equilibrium by being less blaming of themselves and more positive about their stressful situations (lower scores on Emotion-Oriented subscale of the CISS: SSC).

Palliative and Instrumental Coping

In examining the Second Hypothesis, a series of one-sample *t* tests was conducted to determine whether the mean scores on the two subscales of the CISS: SSC (Emotion and Task) support previous research (Koenig, Smilely, et al., 1988), which suggested that palliative (emotion-oriented) and instrumental (task-oriented) coping decline in older populations. One-sample *t*-tests comparisons were conducted to compare this sample's mean with mean scores of college students and adults from the community (249 males; 288 females) in stressful situations provide by Endler and Parker (1999).

A one-sample *t* test was conducted on the emotion-oriented coping for men to evaluate whether their mean was significantly different from 39.21, the accepted mean for male adults emotion-oriented/palliative coping in general stressful situations. The sample mean of 43.23 ($SD = 6.71$) was not significantly different from 39.21, $t\ (12) = 2.160$, $p = .052$. Another one-sample *t* test was conducted on task-oriented coping for men to evaluate whether their mean was significantly different from 58.56, the accepted mean for male adults' instrumental coping in general stressful situations (task-oriented).

The sample mean of 42.00 (*SD* = 7.92) was significantly different from 58.56, *t* (12) = -7.542, *p* = .000.

In examining mean scores of female older adults in this sample, a one-sample *t* test was conducted on the emotion-oriented coping for women to evaluate whether their mean was significantly different from 42.47, the accepted mean for female adults emotion-oriented/palliative coping in general stressful situations. The sample mean of 45.09 (*SD* = 10.58) was not significantly different from 42.47, *t* (21) = 1.162, *p* = .258. Another one-sample *t* test was conducted on task-oriented coping for women to evaluate whether their mean was significantly different from 58.60, the accepted mean for female adults instrumental coping in general stressful situations (task-oriented). The sample mean of 45.09 (*SD* = 10.58) was significantly different from 58.60, *t* (21) = -5.990, *p* = .000.

Table 7

Descriptive Statistics of Emotion-Oriented Coping (EC)Using Gender

EC	M	SD	N
Male	43.23	6.71	13
Female	45.09	10.58	22
Total	44.40	9.26	35

The *t* tests series comparing this sample's means of emotion-oriented/palliative and task-oriented/instrumental coping with means of adults in general stressful situations found by Endler and Parker (1999) partially support the decline in palliative and instrumental coping suggested by Koenig, Smiley, et al. (1988). There seems to be a decline only in instrumental coping for both men and women in this sample, consistent with previous research. However, male and female older adults in this sample did not seem to decline in their ability to utilize emotion-oriented coping. Mean and standard deviations of male and female emotion-oriented coping are presented in Table 7.

Exploratory univariate analyses of one-way ANOVA evaluating mean differences of emotion-oriented and task-oriented coping across male and female older adults of this sample revealed non-significant results. Using Emotion-Oriented coping as a dependent variable and gender as an independent variable in a one-way ANOVA revealed non-significant results, $F(1, 33) = .323, p = .574$. The $\eta2$ of .010 indicates a very weak relationship that accounts for approximately 1% of the total variance on the dependent variable. Replacing Emotion-Oriented with Task-Oriented as a dependent variable in another one-way ANOVA was also non-significant, $F(1, 33) = 3.273, p = .080$. The $\eta2$ of .090 indicates a weak relationship that accounts for approximately 9% of the total variance on the dependent variable. ANOVA results of emotion-oriented coping across gender are presented in Table 8.

Table 8

Analysis of Variance for Emotion-Oriented Coping Using Gender

	Source	*df*	*F*	$\eta2$	*p*
Task-Oriented	Corrected Model	1	.323	.10	.574
	Gender	1	.323	.10	.574
	Error	33			

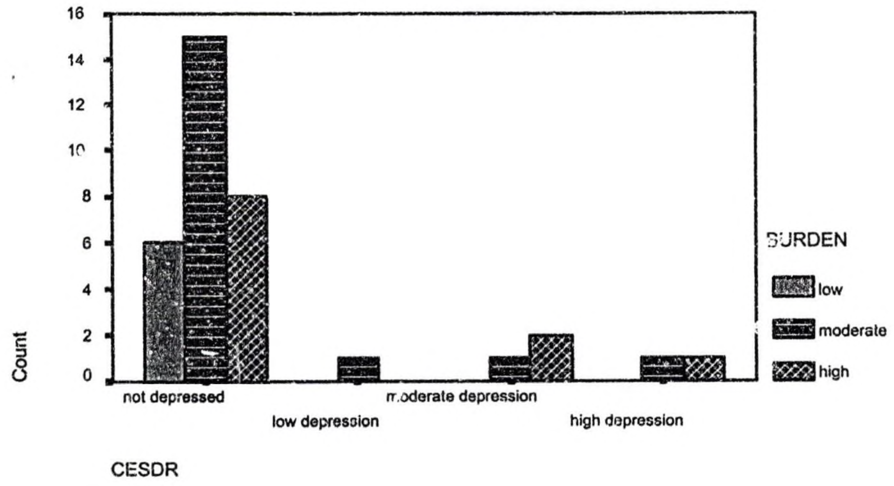
R Squared = .010 (Adjusted R Squared = .020)

Burden and Depression

To better understand the relationship between the individual's burden and their depression, and how depression might influence the caregiver's emotion-oriented coping, both descriptive statistics and Pearson product-moment correlation coefficients were computed (Third Hypothesis). Figure 1 displays the number of burdened participants (low, moderate, and high burden) across the four levels of depression (not depressed, low, moderate, and high depression).

Figure 1

Frequency Distribution of Burden and Depression



As can be seen in Figure 1, the majority of participants (*n* = 18) had a moderate level of burden and was not depressed (*n* = 15), one moderate-level burdened participant had low depression, another had moderate depression, and a third moderate-level burdened participant had a high level of depression. Those with a low level of burden were in the "not depressed" category (*n* = 6). Caregivers with a high level of burden (n = 11) were in the following categories: not depressed (*n* = 8), moderate depression (*n* = 2), and high depression (*n* = 1). A one-way ANOVA was also computed to determine the

.275 $p = .110$). The results confirm the hypothesis that depression positively correlates with caregiver's emotion-oriented coping. The results suggest that caregivers who reported higher levels of depression utilized emotion-oriented coping in their stressful situations more than caregivers who reported lower levels of depression. Intercorrelations among Burden, CESD-R20, and Emotion-Oriented Coping are presented in Table 9.

Spiritual Activities, SWB, and Emotion-Oriented Coping

Examining the Fourth Hypothesis, Pearson Product-moment correlation coefficients were computed among caregivers' number of spiritual practices, emotion-oriented coping, and total score on the SWB scale. Similar correlations were also computed for the number of spiritual activities practiced and caregivers' level of burden and depression. Significance was expected based on 2-tailed alpha at .05 and .01 levels.

Table 10

Intercorrelations Among Spiritual Activities, SWB Total, and Emotion-Oriented Coping

	1	2	3
1. Spiritual Activities	—		
2. SWB Total Score	.32	—	
3. Emotion-Oriented Coping	-.05	-.37*	—

Note. $N = 35$. * $p < .05$

The results of correlating spiritual activities practiced and caregivers' emotion-oriented coping and their SWB did not support the hypothesis that higher spiritual practiced activities increase caregivers' emotion-oriented coping (total scores on the Emotion-Oriented coping subscale of the CISS: SSC) and their SWB (total scores on the SWB scale). Correlations between caregivers' spiritual activities practiced and their emotion-oriented coping was non-significant ($r = -.053, p = .761$). Likewise, non-significant correlations were found between caregivers' spiritual practices and their SWB ($r = .316, p = .064$). However, the intercorrelations among the variables revealed significant negative correlations between total scores on the Spiritual Well-Being scale and emotion-oriented coping subscale of the CISS: SSC. The results suggest that caregivers who had higher SWB utilized emotion-oriented coping less than those who had lower SWB scores. Caregivers who had higher SWB tended to blame themselves less for their stressful situations and less angry about their experience. The intercorrelations among spiritual activities practice, and total scores of SWB and emotions-oriented coping (EC) are presented in Table 10.

Pearson product-moment correlation coefficients computed for spiritual activities practiced and caregivers' levels of burden and depression also revealed non-significant correlations. Correlation coefficients between spiritual activities practiced and caregivers' level of burden were non-significant ($r = .029, p = .869$). Correlation coefficients between spiritual activities practiced and the caregivers' level of depression were non-significant as well ($r = -.105, p = .869$).

Table 11

Intercorrelations Among Spiritual Activities, Burden and CESD-R20

	1	2	3
1. Spiritual Activities	—		
2. Burden	.03	—	
3. CESD-R20	-.11	.25	—

Note. $N = 35$.

The results did not confirm the Fourth Hypothesis, as the number of spiritual activities practiced did not correlate with scores on Emotion-Oriented scores of the CISS: SSC, the total score on the SWB scale, or caregivers' level of burden or depression. The intercorrelations among spiritual activities practices, Burden and Depression (CESD-R20) are presented in Table 11.

Exploratory Statistical Analyses

Exploratory descriptive statistics, multivariate and univariate analyses were conducted to determine several relationships. Descriptive statistics among the demographic variables of caregiver's age, gender, marital status, education, and socioeconomic status were non-significant when correlated to their levels of burden, depression, SWB, or scores on the coping inventories.

A two-way ANOVA was computed to determine the relationship between individuals' caregiving activities performed and their caregiving stage (measured by the Caregiving Activities and Adjustment Index) and their burden (measured by BI). The dependent variable was the total score on the BI while the independent variables were caregivers' activities of caregiving performed (three levels: minimal, moderate, and totally dependent) and their stages of caregiving development (three stages: denial, awareness/guilt/anger, and acceptance).

The results of the ANOVA were non-significant. The main effect, interaction of caregiving activities and caregiving stages, was non-significant: F (3, 27) = 2.380, p = .092. The $\eta 2$ of .209 indicates a moderate relationship between caregivers' burden and the caregiving activities and stages of caregivers' development, accounting for approximately

21% of the total variance of the dependent variable. The ANOVA results of Caregiving Activities, Caregiving Stages, and Burden are presented in Table 12.

Table 12

Analysis of Variance for Caregiving Activities, Stages, and Burden

Source	*df*	*F*	η2	*p*
Corrected Model	7	1.530	.285	.197
Activities (A)	2	.825	.058	.449
Stages (S)	2	.927	.062	.408
A X S	3	2.380	.209	.092
Error	27			

R Squared = .285 (Adjusted R Squared = .100)

To determine the effect of caregiving activities and stages on caregivers' depression, a two-way ANOVA was computed. The dependent variable was depression as measured by the CESD-R20 while the independent variables were caregivers' activities of caregiving performed (three levels: minimal, moderate, and total dependent) and their stages of caregiving development (three stages: denial, awareness/guilt/anger, and acceptance).

The main effect of the ANOVA, interaction of caregiving activities and caregiving stages, was significant: *F* (3, 27) = 6.330, *p* = .002. The η2 of .419 indicates a strong relationship between caregivers' depression and the caregiving activities and stages of caregivers' development, accounting for approximately 42% of the total variance of the dependent variable. The significant interaction indicates that the combination of low to moderate caregiving activities and lower caregiving stages increased the caregiver's level of reported depression. The ANOVA results of Caregiving Activities, Caregiving Stages, and Depression (CESD-R20) are presented in Table 13.

Table 13

Analysis of Variance for Caregiving Activities, Stages, and CESD-R20

Source	*df*	*F*	η2	*p*
Corrected Model	7	3.145	.440	.015
Activities (A)	2	2.404	.151	.109
Stages (S)	2	1.577	.105	.225
A X S	3	6.330	.413	.002
Error	27			

R Squared = .449 (Adjusted R Squared = .306)

CHAPTER V

DISCUSSION

The main goal of the present study was to explore the effect of individuals' spiritual well-being on their coping amidst the perils and pain of caregiving for a spouse afflicted with Alzheimer's. In old age, several events produce stress for individuals such as their own physical and cognitive decline (Zarit, 1996), social and economic challenges (Ernst & Hay, 1994), and losing their social network of friends and family to both geographical relocation and/or death. One very stressful event is caring for a spouse afflicted with Alzheimer's as it involves constant care and attention as well as a continuous reminder of the caregiver's own mortality (Jones, 2000).

Alzheimer's caregivers are found to experience more stress (Ory et al., 2000), burden (Zarit & Knight, 1996), increased rates of anxiety and depression (Koenig, 1994; Schulz et al., 1995), and the presence of disabilities, physical symptoms and illness (Cochrane et al., 1997) than non-caregivers. Socioeconomic stressors and personal challenges often accompany caregiving in these circumstances (Ernst & Hay, 1994), intensifying burden, and hindering the ability to cope well with stress. Older adult populations are increasing. As individuals grow past the age of 65, their risk of being afflicted with Alzheimer's is approximately 10%, but it increases to 50% at age 85 (Kumar & Eisdorfer, 1998). Caring for a spouse with Alzheimer's is relatively high as seven out of 10 people with AD are cared for at home (United States Department of Health and Human Services, 2002).

The purpose of this study is to identify spiritual well-being as a source for caregivers to better cope with their burden of caregiving, building on previous research. Hover (2000) found faith, prayer, religious rituals, beliefs and sentiments to provide vital support in difficult situations for older men and women. Other research supported a positive influence of religious activities and health (Wotherspoon, 2000), and attitude and perception of affliction (Koenig, 1994). Thorson & Cook (1980) found spirituality to enhance well-being. With previous research support for the positive influence of spirituality on well-being, and expected findings of the present study, the long-term notion of this project is to eventually incorporate individuals' spirituality into intervention programs for those struggling to cope with their loved one's affliction of Alzheimer's.

I expected a strong influence of individuals' spiritual well-being on their overall coping, in particular, emotion-oriented coping. I also expected that the spiritual well-being level of caregivers would decrease their burden and depression, which would enhance their ability to cope with their stressful life event of caring for their AD-afflicted spouses. I explored older adults' level of palliative and instrumental coping in this sample to determine a decline, if at all, suggested in previous research (Koenig, Smiley, et al., 1988). Furthermore, I examined other relationships among burden, depression, and spiritual practices. In addition, I explored correlations among various variables to provide suggestions for future research on enhancing intervention for caregiver populations. The following is a list of the major findings of the present study:

1. Spiritual well-being, when combined with caregiver's level of burden and depression, had no significant effects on individuals' coping styles: Task, Emotion, or

Avoidance. In fact, compared to caregivers with high spiritual well-being, those who had a moderate spiritual well-being level utilized more emotion-oriented coping (significant difference of means in pairwise comparisons).

2. Religious well-being when combined with caregivers' levels of burden and depression, had no significant effect on individuals' coping abilities. However, caregivers who experienced low levels of religious well-being utilized less avoidance-oriented coping behavior compared to those who experienced higher levels or RWB. Caregivers also utilized emotion-oriented coping when they experienced a high level of depression more than those who were less depressed.

3. Existential well-being, when combined with caregivers' levels of burden and depression, has no significant effects on caregivers' coping. However, in comparing means of caregivers with different levels of EWB, caregivers utilized emotion-oriented coping when they experienced a moderate level of existential well-being more than caregivers who experienced a high level of existential well-being.

4. Caregivers with moderate and low depression levels, when EWB is combined with burden and depression, utilized emotion-oriented coping more than caregivers who had a high level of depression. In the same combination of EWB, depression, and burden, caregivers who experienced a high level of burden utilized emotion-oriented coping more than those who experienced lower levels of burden.

5. Older caregivers' ability to utilize task-oriented coping in stressful situations declined, yet their ability to utilize emotion-oriented coping was similar to younger adults in stressful circumstances.

6. The majority of caregivers in this sample experienced low levels of burden and depression.

7. Caregivers who practiced more spiritual and religious activities appeared to have experienced similar or more depression than those who practiced fewer activities.

8. Caregivers' level of burden increased as both their caregiving activities and their caregiving developmental stages increased.

Interpretations

The majority of this sample of caregivers of spouses afflicted with Alzheimer's reported moderate to high levels of spiritual, religious, and existential well-being. These caregivers also reported mostly being "not depressed." Caregivers' emotion-oriented and avoidance-oriented ability to cope was well within the expected mean for adults in stressful situations. However, the majority of these caregivers (88.6%) fell below the mean score average adults in their ability to instrumentally cope facing stressful circumstances. Since caregiving of a spouse afflicted with Alzheimer's is a stressful event (Zarit, 1996), the decline in caregivers' coping is expected. In fact, general decline across the coping subscales of the CISS: SSC was expected given the stress of caregiving and the emotional strains experienced as the caregivers witness their loved one fade away, cognitively, emotionally, and physically. Decline in palliative and instrumental coping was particularly expected as demonstrated in previous research (Koenig, Smiley, et al., 1988). However, caregivers' emotion-oriented coping in this sample was within the expected mean but a decline was confirmed in their instrumental coping.

Using a multivariate approach was beneficial to test the effects of the caregivers' levels of spiritual, religious and existential well-being on their task, emotion, and avoidance coping styles and behaviors. The multivariate approach also allowed for the examination of interaction effects among burden, depression and the SWB, RWB, or EWB measures on each of the coping measures (task, emotion, or avoidance), and/or interaction on a linear combination of coping measures. The MANOVA is a valuable design for the intended study, as examining the effect of SWB alone might discount the confounding effects of either burden and/or depression, possibly producing false impressions of significant effect that may not exist (Type I error).

The results of the present study indicated that a moderate level of spiritual well-being was associated with better ability to utilize emotion-oriented coping with stress. The results also indicated that a moderate level of religious well-being was associated with better ability to exercise avoidance-oriented coping in stressful situations, an ability to minimize stress by cognitive changes aimed at avoiding stress as a coping style in stressful situations. The results did not support the hypothesis that spiritual well-being, religious well-being, or existential well-being would enhance caregivers' coping. However, caution is advised against concluding a non-significant relationship between spirituality and coping given the small number of participants in the present study, especially since previous research has found significant effects of spirituality and religion on well-being (Moberg, 1968; Koenig, Smiley, et. al., 1988; Fairchild, 2000; Thoroson, 2000; Moberg, 2002). Further research is encouraged to determine the potential influence of spirituality among a large sample of AD caregivers, especially since most of the caregivers in this sample were at "moderate" to "high" levels of spiritual well-being and were mostly "not depressed" in as stressful a life event as a spouse's affliction with Alzheimer's.

The results were rather surprising that there was no statistical or scientific explanation of the phenomenon that caregivers in this sample were adjusted to their stress and able to cope relatively well given no attribution of significant effects to a single factor. I suggest two theoretical hypotheses to explain the findings of lack of significance among the different variables. One possible explanation is that moderate levels of spiritual and religious well-being were serving to both suppress depression below a significant level and maintain an average level of coping. Maintaining an average level of coping, on the other hand, resulted in containing caregivers' levels of burden, stress, and depression as found in previous research (Aneshensel, et al., 1995). The second possible explanation for lack of significance, other than the small sample size, is that most of participants in this study were members of support groups who had been receiving some support, which may account for psychological and emotional well-being of this sample. The results, though unexpected, provide new ground for future research to determine the formula of success of these caregivers, who were able to maintain their ability to cope with their stress and remain at a desirable "low" to "no" burden and/or depression. Research is especially encouraged to investigate the effect of support group participation on AD-caregivers' coping and levels of depression and burden.

In examining the possible decline in caregivers' palliative and instrumental coping compared to findings of Koenig, Smiley, et al. (1988), the results indicated optimism regarding caregivers' ability to maintain their emotion-oriented coping although their instrumental coping appeared to decline. These results are particularly encouraging for the hopeful picture portrayed of the course of the caregiving journey given minimal indication of high burden and depression by maintaining a desirable level of adjustment, and by exercising an average ability to cope amidst the difficult circumstances.

The results of examining the relationship between spiritual activity practices did not support the hypothesis of enhancing emotion-oriented coping or spiritual well-being. Caregivers who practiced less spiritual and religious activities such as reading, prayer, meditation, and/or fasting, did as well or better than those who practiced more activities. In fact, the increase of these practices did not necessarily increase individuals' level of spiritual well-being. Those who practiced more spiritual and religious activities appear to have lower levels of spiritual well-being. These findings are contrary to the hypothesis as well as to previous research (Wotherspoon, 2000). A possible explanation is that caregivers who practiced more spiritual activities struggled with higher levels of burden or depression and were seeking spiritual balance by increasing their practices. It is possible that those who practiced fewer activities had less depression and existential struggle, thus a lesser need to seek higher power and help though increasing spiritual activities. The present study did not assess for detailed information regarding the spiritual activities or their nature or duration to conclude with confidence the direction of effects of spiritual activities practiced on caregivers' well-being.

In examination of other relationships, such as caregiving activities as well as caregivers' developmental stages and level of burden, it was apparent that more caregiving activities, combined with caregivers' developmental stages of caregiving, contributed to a higher level of burden. However, the increase of activities of caregiving did not affect their level of depression. It is possible that received support and average coping ability helped caregivers contain depression. Neither depression nor burden was correlated with demographic variables of caregivers such as age, gender, marital status, and income.

Limitations

There are several limitations for this study given the nature of survey research, the study design, and one of the instruments used. Among the limitations is sample size and sample selection. Sample size (*N* = 35) was well below my expectation despite extensive advertisement and recruitment. Participants were invited through several means in order to recruit as high a number as possible and to be as representative as possible of the general population of caregivers of Alzheimer's afflicted spouses. However, the majority of participants responded from support groups for caregivers despite the effort for a true random selection, resulting in potential sample bias. The sample in this study may be biased because many of the participants were receiving support in support groups, which could have contributed to the overall quality of coping and psychological well-being among the sample members. As noted earlier, the majority of the sample had "low" to "moderate" levels of burden and "low" to "no" depression at all, contrary to expectations based on previous research of high burden and depression for this population (Zarit, 1996; Schulz, 2000).

A second potential limitation in this study pertains to the design and nature of the inability of survey studies to control for all possible confounds. In the present study, social support may have been a very strong confounding variable, given that the majority of participants are support group members. Efforts were made throughout the study to control for various confounds such as burden and depression using assessment instruments, and other variables using the Demographic form (Appendix A-2) and

Caregiving Activities and Adjustment Index form (Appendix A-3). However, social support was overlooked in this study, which may have contributed to the decrease in burden, stress, and depression. Support may have also accounted for a higher level of coping, a variable worthy of further investigation and inclusion in future analysis. Research including experimental studies and survey designs examining support was scarce, an area in need of research with AD-caregiver populations.

Another limitation in this study is the operational definition of depression and the CESD-R20. Using the CESD-R20 was expected to produce a total score consistent with the level of depression. Indeed, it examined a variety of areas affected by depression such as sadness, interests, appetite, sleep, thinking, guilt, fatigue, movement, death, hopelessness, friends, and happiness, which makes it a unique depression assessment instrument. Perhaps the instrument was too unique, in that it was based on DSM criteria for major depression, as the total score was not a continuous score as expected. In scoring the instrument, individuals varied on the total score and their level of depression without a specific correlation. For example, one participant had a score of 32 and depression for that participant "was not a problem" according to the results' profile provided by the computer scoring system associated with this measure. Another participant had a score of 18 and the profile indicated "possible depression." The difference between the two is that the latter may have answered questions regarding suicidal ideation in a way that could have raised the level of concern and met specific criteria for major depression according to the DSM. Given the discrepancy of the total score and possible categorization of the depression continuum, the operational definition of depression was not as clear as the definition of burden, spiritual well-being, and coping, each having corresponding continuous and categorical scoring systems.

Other instrument-related limitations pertain to some questions on the demographic form. Certain questions provided a range of potential answers. The question of age, for example, provided several options of age ranges to choose from: 55-60, 61-70, and over 71 years of age. Using this categorization instead of using exact age did not allow for age-specific descriptive statistics. A similar limiting question was "Spouse Diagnosis (duration)," which had a range of years as options (within 1-3 years, 4-7 years, and 8 or more years) similar to the question of age. The range limited descriptive statistics exploring correlations of the length of illness and various variables, such as burden and/or depression.

The question regarding "practicing spiritual activities" may have lacked clear instructions as well. The options to choose from were: "prayer, reading, mediation, and fasting" without indication to choose if more than one applies. An optional category, "other activities," was given. It is possible that some participants treated this question like the rest of the questions by choosing one option or limiting their selection. However, it is important to note that some participants indicated more than one while others provided different activities not on the list.

Finally, limitations may pertain to questions on the Caregiving Activities and Adjustment Index form. While the first part of the form was based on the Index of Activities of Daily Living, the second part was based on Gruetzner (1988) Caregiver's Stages of Adjustment. Limitations are relevant to the second part. Although the questions addressed each stage, a continuous score was not feasible as participants clearly belonged to more than one stage. Thus, stages were summed up in three categories, with each containing more than one stage of Gruetzner. The categorization, rather a total score, limited descriptive statistics and specific correlations to determine the stage of adjustment influence with other variables.

Implications

Implications for this study pertain to research more than practice given the early exploration of the possible influence of spiritual well-being on coping among caregivers. It was the short-term goal of the study to establish a link between spiritual well-being and coping to allow for further research on the potential effect of utilizing spiritually-based interventions for caregiver populations. The long-term objectives were to design and implement effective intervention strategies and programs that would enhance caregivers' coping ability with the challenges of caregiving. The results of the study suggested no direct link between spiritual well-being and coping. Given sample size limitations and possible bias, it is premature to discount the existence of a relationship. Thus, at the present, the goals of the study were adjusted to a short-term objective to conduct further investigations instead of the proposed long-term objectives recommending design and implementation of spiritually-based intervention programs for caregivers.

The results of descriptive analyses of participants reveal a sample with "low" levels of depression and "low" to "moderate" levels of burden. Given that the majority of participants were recruited from support groups. social support and intervention strategies used in support groups appear to be highly valuable in helping caregivers maintain their ability to cope and contain their burden and depression. Thus, participation in support groups may be among the first steps towards better coping with burden and depression.

The results of the study also associated "moderate" levels of spirituality with "low" levels of burden and "no" depression. Thus, it may be helpful to encourage caregivers to maintain their spiritual support and well-being as relevant to their own beliefs while further research continues to explore this phenomenon.

Implementations for research were the priority of the current study. It was intended that this project would lend support to the notion that implementing spiritually-based intervention would be valuable in helping caregivers cope with their challenges. Although the hypothesis was not confirmed in establishing a link between coping and spiritual well-being, conducting an experimental design testing spiritually-based intervention with caregivers may better answer the question of this study regarding SWB effect on coping. A design that would include all potential variables such as burden, depression, support, and financial strain would produce more reliable results explaining the effect, if any, of spiritually-based interventions with caregiver populations.

Another research implication is considering longitudinal research projects and case-study designs exploring cohort as well as the individual's journey of caregiving from early stages of the spouse's diagnoses. Long-term studies from early stages of the journey would provide better understanding of the development of challenges and steps utilized in the process of coping. Step-by-step observation of the sojourner's coping behaviors and examination of sources of stress would produce specific research questions and new research designs to test the most effective intervention and treatment. Given the results of this study, it is not feasible to recommend specific intervention design to be tested. However, recommendations for further exploratory investigations of the effect of spirituality are encouraged with larger sample size to confirm or rule out any effect of spiritual well-being and coping. Further investigations should include caregiver's support as a variable. Research inquiring into the effect of social support and support groups can be valuable for this population and as equally important as investigation the effect of spirituality on caregivers' well-being.

Conclusion

The main aim of the study was to detect possible effect of caregivers' spiritual well-being on their coping ability amidst the challenges of caregiving. The results did not support the hypothesis, indicating no significant effects of individuals' spiritual well-being on coping when examined in combination of confounding variables, both burden and depression. Significant differences were found comparing means of individuals' coping and depression across levels of spiritual, religious, and existential well-being. The significance indicates that moderate levels of spiritual, religious, or existential well-being were associated with better caregivers' ability to cope with their stress. Caregivers who had higher levels of depression and burden were also found to cope as well as others with a lower level of distress. Given the limited number of participants, caution is advised before concluding that a relationship does not exist between individuals' spiritual well-being and coping, especially that previous research indicated positive effects of spirituality and religion on individuals' well-being.

The results of the present study is hoped to improve future research investigating the possible effects of spiritual well-being on the psychological well-being of caregivers of Alzheimer's afflicted spouses and implementing spiritually-based interventions. Research improvement could include "support" as a variable for the possibility of the positive influence of support groups moderating caregiver's levels of burden and depression in the present sample. A more balanced coping measure assessing both negative and positive coping behaviors may also help clarify the direction of the influence of SWB on coping, as the CISS: SSC of the present study focused heavily on negative emotion-oriented coping behaviors.

Finally, in order to avoid bias in sample selection, future researchers may benefit from tapping into participants from cognitive assessment clinics where caregivers first acknowledge spouses' limitations and identify spouses as AD afflicted. At this early stage of caregiving, individuals are less likely to have received support. Although recruiting caregivers for research participation was one of the challenges of this study, consideration of larger number of participants for future studies is encouraged for stronger conclusions.

1. Participant Consent

Code_____

Information about And Consent to Participate in Research

My name is Khalil Sakalla, a graduate student at the University of North Dakota. I am investigating the possible effects of spiritual well-being on the coping process of individuals caring for a spouse with Alzheimer's. I am being supervised by Dr. Cindy Juntunen from the UND Department of Counseling.

The selection of participants is based on age and caregiving status of a spouse with Alzheimer's. Only caregivers (age 55 and older) whose Alzheimer's afflicted spouse is living at home are invited to participate. The selection of participants is limited in order to understand spiritual influences on the coping process of older adult caregivers of a spouse afflicted with Alzheimer's.

The procedure and duration of the study is as follows. You will be asked to fill out six short forms: The Demographic Form that includes demographic information, the Caregiving Activities and Adjustment Index that includes information regarding your spouses caregiving needs and your adjustment to caregiving, the Zarit Burden Interview to assess your perception of the impact of caregiving on your life, the Center for Epidemiologic Studies Depression Scale: Short Form (Revised) to evaluate the quality of your mood and emotions, the Spiritual Well-being Scale to assess your spiritual well-being; and the Coping Inventory for Stressful Situations: Situation Specific Version to assess your coping level in your caregiving situation. The process may take 20-30 minutes.

You may feel uncomfortable disclosing demographic information and responding to questions regarding spiritual and emotional feelings. To minimize such risks, I will be checking with you periodically throughout the procedure and encourage you to stop if you experience any stress. You are free to abandon the study at any time without any negative consequences. All data collected will remain confidential. The names provided on this form will not be matched with the data collected. The questionnaires and consent forms will be kept in separate, locked file cabinets. Interpretation of results and description of the study will not reveal the identity of any of the participants. Complete records of participants will be destroyed three years after the study. The study will examine spiritual influence of the coping process of caregivers in order to design prevention programs and activities that facilitate the coping process. All information will remain confidential and will not be released without your permission. Description of the study will not include identity of participants. Data will be disseminated in aggregate form.

Should you prefer to complete the forms at your home and feel uncomfortable at any point during participation, you are free to abandon the study. To process your feelings and any distress regarding the procedure and wish to speak with a counselor, please leave your name and number on the UND Clinic Voice Mail System at (701) 777-3745 and a trained counselor will return your call. You can also contact me at (701) 777-9317, or my advisor, Dr. Juntunen, at (701) 777-2729 regarding the procedure and/or the study. Nothing will be held against you should you decide to stop and abandon the process. You will receive a cash amount of $5 for completing all the forms.

If you have other questions or concerns, please call the Office of Research & Program Development at (701) 777-4279.

Please sign and return one copy of this form and keep the second copy for your records.

ALL OF MY QUESTIONS HAVE BEEN ANSWERED AND I WAS ENCOURAGED TO ASK ANY QUESTIONS THAT MAY HAVE CONCERNING THIS STUDY IN THE FUTURE.

I AGREE TO PARTICIPATE.

Name (print): ______________________________
Signature and Date: ______________________________
Witness: ______________________________

2. Demographic Form

Code: _____

In order to investigate the influence of spirituality on the coping process of caregivers, we would like you to answer the following questions:

1 . Age: ☐ 55-60 ☐ 61-70 ☐ 71 and older

2. Gender: ☐ Male ☐ Female

3. Marital Status: ☐ Single ☐ Married ☐ Divorced ☐ Cohabitant

4. Have been living together for: ☐ 1-5 years ☐ 6-10 years
☐ More than 11 years

5. Education: ☐ High School or less ☐ 2-year degree
☐ 4-year degree ☐ More than 4-year degree

6. Current Occupation: ☐ None ☐ Part-Time ☐ Full-Time

7. Income level per year: ☐ Under $10,000 ☐ $10,00-20,000
☐ $20,000-40,000 ☐ $ Over $40,000

8. Living arrangement: ☐ Independent Home ☐ Retirement Community

9. Practice Organized Religion ☐ Yes ☐ No

10. Religion/Denomination ________________________

11. Practice Spiritual Activity: ☐ Meditation ☐ Prayer ☐ Fasting
☐ Reading ☐ Other Activities_____________

12. Spouse's Residence: ☐ With me ☐ Nursing home/Care Facilities

13. Spouse's Diagnosis: ☐ Alzheimer's ☐ Other Types of Dementia

14. Spouse Diagnosed: ☐ Within 1-3 years ☐ 4-7 years ☐ 8 or more years

3. Caregiving Activities and Adjustment Index

Spouse's Activities	**Needs no Assistance or Supervision**	**Needs Some Assistance or Supervision**	**Totally Dependent/ Cannot do at all**
Eating	☐	☐	☐
Toileting	☐	☐	☐
Bathing (Sponge, shower, or tub)	☐	☐	☐
Dressing	☐	☐	☐
Grooming (Combing, shampooing hair, shaving, trimming)	☐	☐	☐
Transferring (Moving in and out of bed and/or chair or using a cane or a walker)	☐	☐	☐

Caregiver/Your Beliefs/Activities	**YES**	**NO**
I am concerned that my spouse has or is developing serious cognitive and physical limitations........................	☐	☐
I am hopeful that my spouse's limitations will not increase and my spouse will get better.......................	☐	☐
I am involved in my spouse's life and make decisions for both of us (or our family) more than ever before, and re-check activities my spouse often does.....................	☐	☐
I become angry at my spouse for being ill and/or behaving in an embarrassing manner..............................	☐	☐
I become angry at myself and/or guilty for having unpleasant thoughts about myself and/or my spouse............	☐	☐
I have considered professional care for my spouse..............	☐	☐

Based on Activities of Daily Living published in Journal of American Medical Association (185:914-19), Index of Activities of Daily Living published in The Gerontologist (1:20-301), and Gruetzner (1988) Caregiver's Stages of Adjustment.

4. Zarit Burden Interview (BI)

Code:________

BURDEN INTERVIEW

INSTRUCTIONS: The following is a list of statements, which reflect how people sometimes feel when taking care of another person. After each statement, indicate how often you feel that way; never, rarely, sometimes, quite frequently, or nearly always. There are no right or wrong answers.

1. Do you feel that your relative asks for more help than he/she needs?

   0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always

2. Do you feel that because of the time you spend with your relative that you don't have enough time for yourself?

   0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always

3. Do you feel stressed between caring for your relative and trying to meet other responsibilities for your family or work?

   0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always

4. Do you feel embarrassed over your relative's behavior?

   0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always

5. Do you feel angry when you are around your relative?

   0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always

6. Do you feel that your relative currently affects your relationship with other family members or friends in a negative way?

   0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always

7. Are you afraid what the future holds for your relative?

   0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always

8. Do you feel your relative is dependent upon you?

   0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always

9. Do you feel strained when you are around your relative?

   0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always

10. Do you feel your health has suffered because of your involvement with your relative?

0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always

11. Do you feel that you don't have as much privacy as you would like, because of your relative?

0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always

12. Do you feel that your social life has suffered because you are caring for your relative?

0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always

13. Do you feel uncomfortable about having friends over, because of your relative?

0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always

14. Do you feel that your relative seems to expect you to take care of him/her, as if you were the only one he/she could depend on?

0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always

15. Do you feel that you don't have enough money to care for your relative, in addition to the rest of your expenses?

0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always

16. Do you feel that you will be unable to take care of your relative much longer?

0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always

17. Do you feel you have lost control of your life since your relative's illness?

0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always

18. Do you wish you could just leave the care of your relative to someone else?

0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always

19. Do you feel uncertain about what to do about your relative?

0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always

20. Do you feel you should be doing more for your relative?

0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always

21. Do you feel you could do a better job in caring for your relative?

0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always

22. Overall, how burdened do you feel in caring for your relative?

0. Not at all 1. A little 2. Moderately 3. Quite a bit 4. Extremely

5. Spiritual Well-Being Scale

Code: ________

SWB Scale

For each of the following statements, circle the choice that best indicates the extent of your agreement or disagreement as it describes your personal experience:

SA =Strongly Agree
MA =Moderately Agree
A = Agree

D = Disagree
MD = Moderately Disagree
SD =Strongly Disagree

I don't find much satisfaction in private prayer with God. SA MA A D
MD SD

I don't know who I am, where I came from, or where I am going. SA MA A D MD SD
I believe that God loves me and cares about me. SA MA A D MD SD
I feel that life is a positive experience. SA MA A D MD SD
I believe that God is impersonal and not interested in daily situations. SA MA A D MD SD
I feel unsettled about my future. SA MA A D MD SD
I have a personally meaningful relationship with God. SA MA A D MD SD
I feel very fulfilled and satisfied with life. SA MA A D MD SD
I don't get much personal strength and support from my God. SA MA A D MD SD
I feel a sense of well-being about the direction my life is headed in. SA MA A D MD SD
I believe that God is concerned about my problems. SA MA A D MD SD
I don't enjoy much about life. SA MA A D MD SD
I don't have a personally satisfying relationship with God. SA MA A D MD SD
I feel good about my future. SA MA A D MD SD
My relationship with God helps me not to feel lonely. SA MA A D MD SD
I feel that life is full of conflict and unhappiness. SA MA A D MD SD
I feel most fulfilled when I'm in close communion with God. SA MA A D MD SD
Life doesn't have much meaning. SA MA A D MD SD
My relationship with God contributes to my sense of well-being. SA MA A D MD SD
I believe there is some real purpose for my life. SA MA A D MD SD

6. Center for Epidemiologic Scale for Depression, Revised 20

CESD-R20

Code:________

HRCESD-20

Below is a list of the ways you might have felt or behaved. Please check the boxes to tell me how often you have felt this way in the past week or so.	**LAST WEEK**				**Nearly every day for 2 weeks**
	Not at all *or* Less than 1 day	**1-2 days**	**3-4 days**	**5-7 days**	
My appetite was poor.					
I could not shake off the blues.					
I had trouble keeping my mind on what I was doing.					
I felt depressed.					
My sleep was restless.					
I felt sad.					
I could not get going.					
Nothing made me happy.					
I felt like a bad person.					
I lost interest in my usual activities.					
I slept much more than usual.					
I felt like I was moving too slowly.					
I felt fidgety.					
I wished I were dead.					
I wanted to hurt myself.					
I was tired all the time.					
I did not like myself.					
I lost a lot of weight without trying to.					
I had a lot of trouble getting to sleep.					
I could not focus on the important things.					

7. Coping Inventory for Stressful Situations: Situation Specific Version

CISS:SSC

CISS:SSC by Norman S. Endler, Ph.D., F.R.S.C. & James D. A. Parker, Ph.D.

Name or ID #: ________________ Age: _______ Gender: M F Date: __________
Occupation: ______________ Education: ______________ Marital Status: _______

Instructions: The following are ways people react to various difficult, or upsetting situations. Please circle a number from 1 to 5 for each item. Indicate how much you engaged in these types of activities during this specific situation

This situation was: Caregiving

1.	*Take sometime off and get away from the situation*	*1*	*2*	*3*	*4*	*5*
2.	Focus on the problem and see how I can solve it	1	2	3	4	5
3.	Blame myself for having gotten into this situation	1	2	3	4	5
4.	Treat myself to a favorite food or snack	1	2	3	4	5
5.	Fell anxious about not being able to cope	1	2	3	4	5
6.	Think about how I can solve similar problems	1	2	3	4	5
7.	Visit a friend	1	2	3	4	5
8.	Determine a course of action and follow it	1	2	3	4	5
9.	Buy myself something	1	2	3	4	5
10.	Blame myself for being too emotional about the situation	1	2	3	4	5
11.	Work to understand the situation	1	2	3	4	5
12.	Become very upset	1	2	3	4	5
13.	Take corrective action immediately	1	2	3	4	5
14.	Blame myself for not knowing what to do	1	2	3	4	5
15.	Spending time with a special person	1	2	3	4	5
16.	Think about the event and learn from my mistakes	1	2	3	4	5
17.	Wish that I could change what had happened or how I felt	1	2	3	4	5
18.	Go out for a snack or a meal	1	2	3	4	5
19.	Analyze the problem before reacting	1	2	3	4	5
20.	Focus on my general inadequacies	1	2	3	4	5
21.	Phone a friend	1	2	3	4	5

[redacted]

Participants' Thank-You Note

KHALIL A. SAKALLA
P. O. BOX 14592
GRAND FORKS, ND 58208-4592
(701) 777-9317
KH_SAKALLA@YAHOO.COM

Date_____

Dear Participant:

I wish to express my gratitude for your participating in my study. I enclosed a check of five US dollars as promised. Although I wish to have offered you more than this modest amount, I hope my real contribution will be an effective intervention program for caregivers like you. My thoughts are with you. I hope that you will have all the strength you need to go about your caregiving activities. If you have any questions about the study, please feel free to contact me. I also appreciate it if you know of any one in caregiving situations that meets the criteria for this study that you would give them my contact information. I thank you again for your help. Be Blessed.

Sincerely,

Khalil A. Sakalla
Doctoral Candidate

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