

2012

## The effects of coping strategies on burden among Louisiana Alzheimer's disease caregivers

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THE EFFECTS OF COPING STRATEGIES ON BURDEN AMONG LOUISIANA  
ALZHEIMER'S DISEASE CAREGIVERS

A Thesis

Submitted to the Graduate Faculty of the  
Louisiana State University and  
Agricultural and Mechanical College  
In partial fulfillment of the  
requirements for the degree of  
Master in Social Work

in

The School of Social Work

by  
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B. A., Thomas A. Edison State College, 2009  
May 2012

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## ABSTRACT

The purpose of this study was to examine the relationship between three coping strategies—emotion-focused, task-focused, and avoidance-focused—and the perceived burden among Louisiana Alzheimer’s disease caregivers. This study was a secondary data analysis. The target population was Alzheimer’s disease caregivers in Louisiana. The design for this study was cross-sectional. The instrument was a survey consisting of a demographic section, the *Revised Memory and Behavior Problems Checklist*, the shortened *Zarit Burden Interview*, and the Coping in Task questionnaire. Most caregivers reported engaging in task-focused coping. Emotion-focused coping and avoidance-focused coping were positively related to burden. No significant relationship existed between task-focused coping and burden. The implication for social work was to inform clients of coping techniques less related to burden.

## CHAPTER ONE

### INTRODUCTION

Two out of every five older adults over the age of 85 have Alzheimer's disease (Alzheimer's Association [AA], 2011b). Louisiana is expected to increase in the number of individuals with Alzheimer's disease by at least 31% by 2025 (AA, 2011b; Hebert, Scherr, Bienias, Bennett, & Evans, 2003). Currently, Louisiana has approximately 83,000 individuals with Alzheimer's disease (AD; AA, 2011b; Hebert, et al., 2003). Ten percent of the nation's caregivers are AD caregivers (National Alliance for Caregiving [NAC] & American Association for Retired Persons [AARP], 2009). With 560,000 caregivers total, Louisiana's total AD caregiver population is estimated at 56,000 (Feinberg, Newman, Gray, & Kolb, 2007; NAC & AARP, 2009).

Because the focus of this study is on caregivers, this paper refers to individuals with AD as *care recipients*. The majority of scholarly literature refers to the caregivers of individuals with AD as *Alzheimer's caregivers*. As a researcher, this author recognizes the importance of keeping the same, easily understood term in order to bring into focus the purpose of this paper. For that reason, this paper refers to caregivers of individuals with AD as AD caregivers.

Burden is reported in a little under half of AD caregivers (AA, 2011b). Burden is positively related to depression and anxiety (Phillips, Gallagher, Hunt, Der, & Carroll, 2009). The techniques for alleviating burden in this study are grouped as emotion-focused coping, task-focused coping, and avoidance-focused coping. Some coping techniques are related to increased levels of depression (Billings & Moos, 1984).

The purpose of this study is to examine the effects of coping strategies on burden among Louisiana AD caregivers. This paper reviews the literature including the topics of AD,

caregivers, theoretical implications, and purpose and research questions; discusses methods including design and sampling, instrumentation, and data analysis; reports results including descriptive statistics, correlation analysis, and stepwise regression; and gives a discussion including review of results, social work implications, and limitations and future results.

## CHAPTER TWO

### LITERATURE REVIEW

This section reviews the current literature on AD, caregivers, theoretical implications, and purpose and research question. In order to understand the effects of coping strategies on burden among caregivers of individuals with AD, one must have a thorough understanding of AD. The following section on AD goes over the history; overview; prevalence, incidence, and cultural considerations; stages; and treatment options. The next section, caregiving, discusses caregivers and their caregiving, scope, burden, positives of caregiving, coping, and coping strategies. Following caregiving are the theoretical implications and the purpose and research questions sections.

#### **Alzheimer's Disease**

**History.** Alois Alzheimer, a German who lived in the late 1800s to early 1900s, discovered the biological etiology of Alzheimer's disease (AD) in 1906 (Lage, 2006). The name of the patient with dementia-like symptoms that Alois Alzheimer studied, and on whom later he did an autopsy, was Auguste D. (Lage, 2006). During the autopsy, he discovered the association of plaques and tangles with AD (Delacourte, 2006). The previous name for the illness was *presenile dementia*, but it changed to *Alzheimer's disease* in 1910 (Lage, 2006).

**Overview.** While AD is one out of a dozen types of dementia (American Psychiatric Association [APA], 2000), it constitutes up to 70% of dementia cases (Austrian, 2005). Although the only guaranteed way to diagnose AD is to do an autopsy, a diagnosis may be given after it is determined that the symptoms are not caused by any other illness (APA, 2000; Austrian, 2005). There are two types of onsets, early and late, defined by whether the symptoms started before or after age 65 (APA, 2000).

AD is associated with plaques, which is a gathering of beta-amyloid in the brain (Shier, Butler, & Lewis, 2004) and neurofibrillary tangles, which develop in the nerve (Mader, 2003). Neurofibrillary tangles develop when tau, a protein, begins to latch to more tau proteins (Mader, 2003). Delacourte (2006) reported that these problems with the tau proteins were found in all of the participants in his study, indicating that it is a normal aging process. Because of the amount of plaque, neurons begin to die (Mader, 2003). The loss of memory in care recipients seems to be caused by a decrease in nerve action and the beta-amyloid residue collected on the brain (Hooyman & Kiyak, 2005). AD is also associated with a decreased amount of acetylcholine, which is a neurotransmitter that helps the functioning of muscles (Sheir et al., 2004). The reduced amount of acetylcholine decreases the ability of the cells to communicate, resulting in memory loss (Hooyman & Kiyak, 2005).

Genes related to AD are more evident in early-onset AD (Austrian, 2005). Chromosomes 1, 14, 19, and 21 have been found to have some possible genetic relationship with AD (Hooyman & Kiyak, 2005). Apolipoprotein (APOE) is a protein found on chromosome 19 and involved in ensuring the beta-amyloid reaches the brain (Hooyman & Kiyak, 2005). One variant, APOE<sub>4</sub>, is seen in 65% of individuals with AD (Hooyman & Kiyak, 2005; Mader, 2003). Once the disease starts, a person may have up to 10 years before death (APA, 2000; Austrian, 2005). Secondary health complications typically cause death in the care recipient (Mader, 2003).

**Prevalence, Incidence, and Culture Considerations.** The older a person is, the more likely he or she will develop AD, with the highest prevalence rate at 43% among individuals age 85 and older (AA, 2011b; Hebert et al., 2003). Hebert et al. (2003) found the prevalence to be approximately 4.5 million. They also estimated a prevalence rate of up to 13.2 million by 2050 (Hebert et al., 2003). Fitzpatrick et al. (2004) found the incidence rate per 1,000 years for white

patients with AD was 19.2, and for black patients it was 34.7. On hindsight, Fitzpatrick et al. (2004) reported that dismissing many white participants that were less likely to have dementia may have distorted the numbers, a mistake in their methodology. Fitzpatrick et al. (2004) adjusted this by increasing the number of whites with dementia by 56. The incidence rates were consequently more even (Fitzpatrick et al., 2004).

Women have a higher chance, albeit not by much, than men to develop AD (APA, 2000). Fitzpatrick et al. (2004) found that differences of prevalence rates between men and women were not significant until the participants were much older. A positive relationship exists between diagnosis of dementia such as AD and less educational attainment (Fitzpatrick et al., 2004; McDowell, Xi, Lindsey, & Tierney 2007).

**Stages.** AD can be divided into three stages, including early stage, middle stage, and advanced (or late) stage (Hooyman & Kiyak, 2005). In the early stage, the care recipient may experience some memory problems, have difficulty staying on-task, and experience mood problems (Hooyman & Kiyak, 2005). This is caused by the plaques beginning to gather on the hippocampus (Hooyman & Kiyak, 2005). The early stage is estimated to be inclusive of 48% of the patient population with AD (Hebert et al., 2003). Because care recipients in this stage show fewer symptoms, and the symptoms they show are of a lesser degree, the standard for determining whether or not an individual has AD should be re-evaluated in order to ensure proper, early intervention (Storandt, 2008).

In the middle stage, the care recipient may have recognition and recall difficulties, caused by the plaques gathering on the neocortex (Hooyman & Kiyak, 2005). This stage is estimated to include 31% of the patient population with AD (Hebert et al., 2003). Care recipients in this stage

begin to be more dependent on others and experience behavioral problems, making caregiving for patients in this stage harder (APA, 2000; Voisin & Vellas, 2009).

In the advanced stage, or late stage, the care recipient may lose the ability to provide an appropriate level of self-care, caused by the decrease in neurons (Hooyman & Kiyak, 2005). The care recipient may lose control over the musculoskeletal functions and may no longer be able to mobilize (APA, 2000). This stage is estimated to be inclusive of 21% of the care recipients (Hebert et al., 2003). Care recipients in this stage continue to have increased behavior symptoms (Voisin & Vellas, 2009).

Recently, the National Institutes of Health, the National Institute on Aging and the Alzheimer's Association (NIH, NIA, & AA, 2011) have redefined the stages of AD and called them preclinical stage, mild cognitive impairment stage, and AD stage. The NIH, NIA and AA (2011) reported that the biomarkers (biological changes) in the preclinical stage are not ready to be defined, as more research is needed. The NIH, NIA and AA (2011) reported that the biomarkers of the mild cognitive impairment stage, including plaques, tangles, decreased glucose, and brain mass decrease, may be used by experts to determine the etiology of the cognitive problems. The NIH, NIA and AA (2011) reported that tests may be used in the Alzheimer's disease stage to help the diagnosis, although the tests may not be accurate. For the purpose of this study, the stages are considered as early, middle, and advanced (or late).

**Treatment Options.** The brain has a protective defense that prevents some substances, including medication, from getting into the brain (Sheir et al., 2004). Some medications have been found helpful, however, including medication that increases the effectiveness of neurotransmitters (such as acetylcholine), medication that retards the growth of plaques, and medication that reduces inflammation (Hooyman & Kiyak, 2005). Some medications have been

found to decrease burdensome behaviors in patients with AD, but not without side effects (Hooyman & Kiyak, 2005). The Food and Drug Administration (FDA, 2005) warns against the use of atypical antipsychotic drugs, a medication that relieves burdensome behaviors, among patients with dementia because they found that the occurrence of death rose up to 1.7 times for this population. Acetylcholinesterase inhibitors, otherwise known as AChEIs, work by reversing the decline of acetylcholine (Lleo, 2007). AChEIs, along with memantine, is a popular medication treatment to reduce symptoms with minimal side effects (Lleo, 2007; Smith, 2009).

Non-medication treatment options include making life changes, such as scheduling the day and improving the atmosphere (Hooyman & Kiyak, 2005). This can help a care recipient to stay involved and interactive (Hooyman & Kiyak, 2005). Improving the atmosphere to remove anything that makes the care recipient feel restless, fearful, or agitated may help stop behavioral problems (AA, 2011c). Note-taking on the details of when, where, and how often behavioral problems occur can help identify triggers (Curtin, 2010). Removing those triggers may reduce the behavioral problems (Curtin, 2010). Exercising is also important for the care recipient because it encourages healthy sleeping habits (Hooyman & Kiyak, 2005). A number of organic supplements are on the market that supposedly fight and reduce the effects of AD (AA, 2011a). Among some of these, however, a lack of appropriate research and regulation exists (AA, 2011a).

Nursing homes and other care facilities should have special accommodations to provide the best treatment for patients with AD (Hooyman & Kiyak, 2005). For care recipients monitored in the home, helping to relieve caregiving burden boosts the level of appropriate care (Voisin & Vellas, 2009). Sink et al. (2004) found that non-white patients had more behavior problems, possibly due to a possible higher prevalence of Caucasian care recipients to be placed in a long-

term care facility. Caucasian caregivers may also report burdensome behaviors differently than other ethnicities (Sink et al., 2004). Regardless of the cause for the difference, concern about easing caregiving burden should not neglect non-white caregivers (Sink et al., 2004).

## **Caregiving**

**Caregivers and Their Caregiving.** Caregiving functions are known as activities of daily living (ADL) and instrumental activities of daily living (IADL) (AA & NAC, 2004a). ADLs include sitting, standing, dressing, walking, and eating (AA & NAC, 2004a). AD caregivers provide assistance with complex ADLs more so than caregivers of individuals without AD (AA & NAC, 2004a). IADLs include buying groceries, balancing the checkbook, making dinner, and cleaning the house (AA & NAC, 2004a). IADLs are the largest part of all caregiving responsibilities (AA & NAC, 2004a).

The NAC and AARP (2009) defined caregivers as individuals who care for others with mental or physical disabilities and do not receive monetary compensation for that assistance. The AA and NAC (2004a) defined caregivers as those who, without monetary compensation, assist one or more adults over the age of 50 with necessary functions of living. Others refer to caregivers who do not receive monetary compensation as informal caregivers (Feinberg et al., 2007). For the purpose of this paper, *caregivers* are defined as individuals assisting with ADLs or IADLs without monetary compensation, and *AD caregivers* are defined as the same except exclusively caring for care recipients with AD.

**Scope.** Looking at all types of caregivers, the United States contains over 65 million caregivers (NAC & AARP, 2009). This national data reported that caregivers are more likely to be middle-aged, and two-thirds of caregivers are female (NAC & AARP, 2009). Caucasian caregivers make up 72% of all caregivers, followed by 13% African American caregivers, 2%

Hispanic caregivers, and 2% Asian American caregivers (NAC & AARP, 2009). These percentages follow the ethnic diversity percentages of the United States except the ethnicity of caregivers is 2% below the national percentage of Asian Americans and 14% below the national percentage of Hispanic/Latinos Americans (U. S. Census Bureau, 2010b). Caregivers are more likely to have attended some form of higher education (NAC & AARP, 2009). They are also more likely to be working at least some of the time, with 46% being full time (NAC & AARP, 2009). The majority of caregivers are married (58%), followed by single, divorced, or separated caregivers (30%) and cohabitating caregivers (5%) (NAC & AARP, 2009). Finally, caregivers are slightly more likely to live in a suburban area (37%), closely followed by urban (33%) and rural (28%) areas (NAC & AARP, 2009).

Narrowing the scope, Louisiana contains 560,000 of the United States' caregivers (Feinberg et al., 2007). Louisiana's average for Caucasians is nearly 20% less than the average for the nation, and Louisiana's average for African Americans is twice the national average (United States Census Bureau [USCB], 2010 & 2012). All other ethnicities are less represented in Louisiana than for the nation (USCB, 2010 & 2012). Therefore, one may assume that Louisiana has less Caucasian caregivers and more African American caregivers than reported by the NAC and AARP (2009).

Ten percent of total caregivers in the United States care for individuals with AD (NAC & AARP, 2009). Caregivers are mostly women, composing 59% of AD caregivers (AA & NAC, 2004a). However, more male, AD caregivers exist than male caregivers of individuals without AD (AA & NAC, 2004a). AD Caregivers are also 10% more likely to be older than 49 years of age than caregivers of individuals without AD (AA & NAC, 2004a). Fifty-eight percent of AD caregivers are older than 54 (AA, 2011b). At least two-thirds of AD caregivers are Caucasian

(AA, 2011b). African Americans make up 15% of AD caregivers, Hispanic caregivers make up 12%, and Asian Americans make up 1% (AA & NAC, 2004b). A majority of AD caregivers have attended college, with 39% having completed college (AA & NAC, 2004a). Fifty-five percent of AD caregivers have the responsibility to earn the main income for the household (AA, 2011b). Approximately 50% of AD caregivers have full time jobs, and 7% have part time jobs (AA & NAC, 2004a). Income of working AD caregivers varies widely (AA & NAC, 2004a). Sixty percent of AD caregivers are married or cohabitating (AA & NAC, 2004a). AD caregivers are more likely to be related to the care recipient (87%), with children being the most likely AD caregiver (AA & NAC, 2004a). However, in Louisiana, Wilks and Vonk (2008) sampled 304 caregivers and found spouses to be 4% more likely than children to be caregivers.

**Burden.** AD caregivers have overwhelmingly more burden than other types of caregivers (AA & NAC, 2004a). Burden may be *objective* or *subjective* (Brodaty & Donkin, 2009). The former is associated with the tasks of caregiving and burden itself, and the latter is associated with the manner in which the caregiver perceives the burden (Brodaty & Donkin, 2009). This section describes the following types of burden: physical, psychological, financial, and time.

A little under half of AD caregivers report high physical burden (AA, 2011b). AD caregivers may experience physical burdens if their caregiving causes illnesses. One-fourth of AD caregivers self-report to be in excellent health, and over half self-report as being in good or close to excellent health (AA & NAC, 2004a). Seventy-three percent of AD caregivers do not think that their caregiving is related to their health status; however, more AD caregivers than other types of caregivers report a breakdown in health due to caregiving (AA & NAC, 2004a). Seventeen percent of all caregivers see a connection between caregiving and a decline in health (NAC & AARP, 2009). AD caregivers may also experience physical burden if their caregiving

prevents them from engaging in healthy behaviors, as few caregivers utilize exercise and otherwise active outlets (AA, 2011b).

AD caregivers may experience a psychological burden if their caregiving is related to a stress or depressive disorder. Up to 21% of AD caregivers experience psychological problems (Carrasco et al., 2002). In a study of 5,627 dementia caregivers in seven different states, 32% were found to have depression (Covinsky et al., 2003). Almost two-thirds of AD caregivers described their responsibilities as highly stressful (AA, 2011b). Women are more likely than men to report this (NAC & AARP, 2009). Contributing factors may be care recipient aggression, increased caregiving responsibilities, financial status, and health of caregiver (Covinsky et al., 2003). Ten percent more AD caregivers than other types of caregivers view their caregiving circumstances as nearly or highly stressful (AA & NAC, 2004a). Several things have been found linked to a greater chance of getting depressed while caregiving, including being older, being female, having a lower socioeconomic status, having a lower education, being a spouse to the care recipient, having poor health, and assisting with more ADLs and IADLs (Covinsky et al., 2003). In a longitudinal study of all types of caregivers, Phillips et al. (2009) found that the higher the score for perceived burden, the higher the scores for depression and anxiety.

AD caregivers may experience a financial burden if their caregiving is related to a depletion of funds. Nearly half of AD caregivers spend around \$2,616 a year on the care recipient (AA & NAC, 2004a). NAC and AARP (2009) found that the higher the perceived burden, the higher the perceived financial burden. Individuals with lower financial status tend to report higher financial burden (NAC & AARP, 2009). Sixty-six percent of AD caregivers have to arrive late, take off early, or not go into work due to their caregiving (AA, 2011b; AA & NAC, 2004a). Eight percent have to quit their job (AA & NAC, 2004a).

AD caregivers may experience a time burden if their caregiving takes time away from other things. Over half of all caregivers report having less time with friends (NAC & AARP, 2009). For all caregivers, over 20 hours are spent caregiving in a week (NAC & AARP, 2009). Thirteen percent spend over 40 hours a week (NAC & AARP, 2009). In a study of caregivers of patients with dementia, Covinsky et al. (2003) found that about 28% participants spent under 40 hours per week, 38% spent between 40 and 119 hours per week, and around 33% spent over 119 hours per week caregiving.

**Positives of Caregiving.** This researcher did not find empirical research looking at the positives of caregiving specifically for AD caregivers; therefore, for the purpose of this paper, the positives of caregiving for other types of caregivers (especially dementia caregivers) are discussed. Except for caregivers of low functioning individuals, dementia caregivers are more likely to report satisfaction in their role as a caregiver than displeasure (Heru, Ryan, & Iqbal, 2004). Hogstel, Curry, and Walker (2005) found that caregiving for older adults improves a person's character. After completing the same tiresome chores day after day, some caregivers of older adults find gratefulness for the often overlooked things in life (Hogstel et al., 2005). Relationship stress between a caregiver and the older adult care recipient will be accentuated at some point during caregiving, opening an opportunity for reconciliation (Hogstel et al., 2005). Andren and Elmstahl (2005) reported that 58% of dementia caregivers are satisfied that caregiving improves their relationship with the care recipient. Caregivers of older adults increase in stamina as they learn to balance their different roles (Hogstel et al., 2005). Andren and Elmstahl (2005) found that 61% of dementia caregivers are satisfied that caregiving increases competency in difficult situations.

Just as a giver feels happy to give to someone in need, a caregiver feels happy to care for someone in need, as Andren and Elmstahl (2005) found, 90% of dementia caregivers enjoy pleasing the care recipient. Ninety-one percent of dementia caregivers enjoy the happiness of the care recipient (Andren & Elmstahl, 2005). Over four-fifths of dementia caregivers are satisfied because they enjoy helping people (Andren & Elmstahl, 2005). The large majority of dementia caregivers find satisfaction in being appreciated and needed (Andren & Elmstahl, 2005). Over half of dementia caregivers are satisfied that caregiving increases their essentiality (Andren & Elmstahl, 2005). Eighty-three percent of dementia caregivers are satisfied that the care recipient views them as essential (Andren & Elmstahl, 2005). Eighty-two percent of dementia caregivers are satisfied that the care recipient is grateful for the care provided to them (Andren & Elmstahl, 2005). Sixty-four percent of dementia caregivers are satisfied that others are grateful for the care the caregivers are providing (Andren & Elmstahl, 2005).

Comradeship and spirituality are often positively related to caregiving (Andren & Elmstahl, 2005; Farran, Paun, & Elliot, 2003; Hogstel et al., 2005). The caregiver and older adult care recipient may enjoy a reciprocal relationship as they discuss past experiences and form new ones (Hogstel et al., 2005). Caregiving is a form of demonstrating love and faith (Andren & Elmstahl, 2005). Eighty percent of dementia caregivers are satisfied that their caregiving is a show of love for the care recipient (Andren & Elmstahl, 2005). Fifty-seven percent of dementia caregivers show faith through their caregiving (Andren & Elmstahl, 2005). Farran et al. (2003) found that faith improved the quality of caregiving, and caregiving in turn augmented faith.

**Coping.** This researcher did not find empirical research looking at the coping techniques of solely AD caregivers; therefore, for the purpose of this paper, the coping techniques for other types of caregivers (especially dementia caregivers) are discussed. AD caregivers develop ways

to alleviate burden, or more efficiently stated, cope. Exterior relationships, such as religion (Sun, Kosberg, Kaufman, & Leeper, 2010), or friends (AA & NAC, 2004a), have been found effective coping techniques. Seventy nine percent of AD caregivers pray as a means of coping (AA & NAC, 2004a). As much as 95% of AD caregivers pray (Wilks & Vonk, 2008). In a rural Alabama study, caregivers of individuals with dementia reported their most commonly used coping methods were religion-related (Sun et al., 2010). Seventy percent of AD caregivers enjoy relations to others (AA & NAC, 2004a). Better support from family and friends is associated with better coping (Wilks, 2009). Telephoning friends and family is way of feeding the relationship and helping with coping (Upton & Reed, 2006). Nearly three-fourths of dementia caregivers use social support as a coping mechanism (Sun et al., 2010).

Another common coping technique is resource gathering (AA & NAC, 2004a). Fifty-eight percent of AD caregivers educate themselves about caregiving with paper-based resources, and 48% of AD caregivers do the same with the Internet (AA & NAC, 2004a). This is different for caregivers of patients with other illnesses, with 16% less using paper-based resources and 14% less using Internet resources (AA & NAC, 2004a). Most AD caregivers use the Internet for education of the disease, with less than half using it for networking (AA & NAC, 2004a). In fact, the AA and NAC (2004a) found that more AD caregivers reported they would turn to the Internet for assistance before doctors, counselors, and others.

More than 70% of all caregivers engage in exercise as a means of reducing stress (Salin, Kaunonen, & Astedt-Kurki, 2009). The AA and NAC (2004a) reported that 44% of AD caregivers exercise as a means of coping. Mere distraction with a different activity is a coping technique found in 80% of all caregivers (Salin et al., 2009). Another coping technique is humor (Heinemann, 2009; Sun et al., 2010). A little over half of dementia caregivers use humor to aid

in coping (Sun et al., 2010). Having humor during unpleasant caregiving tasks helps a caregiver for an older adult care recipient to cope by making the task go by quicker and improving the caregiver—care recipient relationship (Heinemann, 2009).

AD caregivers are 11% more likely (33% total) to seek counseling due to their responsibilities than non-AD caregivers (AA & NAC, 2004a). Salin et al. (2009) found that 89% of all caregivers do not use groups (such as self-help or counseling groups) as a means for coping. An intervention that combined social support, activities, counseling, and information about the disease was found successful in helping AD caregivers cope (Sorensen, Waldorff, & Waldemar, 2008). A telephone intervention, consisting of a series of phone calls between a therapist and the caregiver, was shown to be effective in helping dementia caregivers cope, as 94% were pleased with the outcome as evidenced by client satisfaction (Tremont, Davis, Bishop, & Fortinsky, 2008). The telephone intervention further showed lower rates of burden and depression among caregivers as evidenced by one measure of depression and two measures of burden (Tremont et al., 2008). Morano and King (2010) had African American dementia caregivers critique a new, informative intervention designed to improve coping. The intervention included 12 points and contained information about the disease, caregiving, safety concerns, and collaboration with doctors and social supports (Morano & King, 2010). Although the study was limited to less than 15 participants due to recruiting complications, the participants spoke highly of the intervention (Morano & King, 2010).

Sun et al. (2010) explored subjective burdens and found the coping skills developed from those burdens among dementia caregivers. Sun et al. (2010) found that three-fourths of dementia caregivers cope by from their caregiving responsibilities and growing from that learning. For all types of caregivers, 84% look for positive things as a way of coping (Salin et al., 2009). Eighty-

five percent of all caregivers find that pacing their life day-by-day is a good coping technique (Salin et al., 2009). Over three-fourths for both dementia caregivers and non-dementia caregivers cope by accepting the unchangeable situation (Salin et al., 2009; Sun et al., 2010). Seventy-nine percent of caregivers cope by finding confidence in their self-efficacy (Salin et al., 2009). Seventy-nine percent cope by coming to terms with the fact that no one is at fault for the current circumstances (Salin et al., 2009).

**Coping Strategies.** This researcher did not find empirical research looking at the coping strategies specifically for AD caregivers; therefore, for the purpose of this paper, the coping strategies for other types of caregivers or other groups of people are discussed. Coping strategies encompass the type of response one has toward stress (Folkman & Lazarus, 1980). Coping strategies differ from the afore mentioned coping techniques in that coping strategies are categories in which coping techniques may be classified (Folkman & Lazarus, 1980). The following three types of coping strategies are discussed in this paper: emotion-focused, task-focused, and avoidance-focused. These coping strategies are used interchangeably or separately (Ali & Askari, 2011). Coping strategies may also change during the course of the stressor (Ali & Askari, 2011). Nearly every caregiver combines strategies (Folkman & Lazarus, 1980).

Emotional control is a part of emotion-focused coping (Green, Choi, & Kane, 2010). Compton et al. (2011) reported that emotion-focused coping involves blaming and condemning self-actions and self-decisions (see also Endler & Parker, 1990 & 1994). DeGraff and Schaffer (2008) reported that emotion-focused coping is about making the problem seem smaller, and finding positive aspects of the problem (DeGraff & Schaffer, 2008). Either way, emotion-focused coping focuses on the feelings that come with stressful situations (DeGraff & Schaffer, 2008). It involves the letting go of emotions (Johnsen, Eid, Laberg, & Thayer, 2002). Emotion-

focused coping helps a person get his or her psychological bearings and cope with past disappointments (Lilly & Graham-Bermann, 2010). It does not focus on altering the stressor, but rather altering the significance of the stressor's impact (Ekwall, Sivberg, & Hallberg, 2007).

Emotion-focused coping may manifest as anger management, relaxation techniques, or activities that encourage the let-out of restrained emotions (Ali & Askari, 2011). It also involves looking at the situation in a different light (Morano & King, 2010). An example of emotion-focused coping would be a person engaging in a spiritual activity that allows him or her to release emotions to a spiritual Being (Lilly & Graham-Bermann, 2010). Lilly and Graham-Bermann (2010) found emotion-focused coping to positively correlate with depression but did not know whether or not the depression came first. Using a self-created scale, Endler and Parker (1990) studied 599 college students and found that as the likelihood of utilizing emotion-focused coping increased, so did the likelihood of having anxiety. The same was found true for depression, with similar results in a later study using a different scale (Endler & Parker, 1990 & 1994). Billings and Moos (1984) found that emotion-controlling, a technique classified as emotion-focused coping, was related to lower levels of depression. Therefore, not all individual techniques classified as emotion-focused coping are positively related to depression, despite the overall coping strategy's positive relationship with depression (Billings & Moos, 1984; Endler & Parker, 1990 & 1994; Lilly & Graham-Bermann, 2010).

Task-focused coping strategies involve physical actions (Di Mattei et al., 2008). Task-focused coping strategies focus on the doing most important things first, managing all aspects of each problem, and studying a situation before acting in response (Compton et al., 2011). Analyzing the stressful situation and finding a way to relieve that stress is a part of task-focused coping (Green et al., 2010). Those who engage in task-focused coping strategies plan each step

and possible scenario (Johnsen et al., 2002). It is not solely making a plan, but also carrying it out (Billings & Moos, 1984). Task-focused coping tends to involve rationality, unhurriedness, and determination (Billings & Moos, 1984).

Examples of task-focused coping include utilizing social support, utilizing outside help, engaging in health practices, and concentration on other obligations (Kartalova-O'Doherty & Doherty, 2008). The benefits of task-focused coping include decreased burden among caregivers (Di Mattei et al., 2008). Task-focused coping is inversely related to depression and is associated with healthy self-esteem (Billings & Moos, 1984). Anxiety and depression tend not to be found among those with task-focused coping (Endler & Parker, 1994).

Avoidance-focused coping is the non-acceptance of stressing events (Johnsen et al., 2002). A person with avoidance-focused coping may be focusing on what he or she wishes for that particular situation, instead of the actual reality (Glidden, Billings, & Jobe, 2006).

Examples of avoidance-focused coping include avoidance of everything related to the stressor and the use of pharmaceuticals (Kartalova-O'Doherty & Doherty, 2008). Those who engage in avoidance-focused coping strategies ignore the problems causing them tension (Green et al., 2010). Risks associated with it include drinking and isolation (Di Mattei et al., 2008). Avoidance-focus coping is also associated with increased burden among dementia caregivers (Di Mattei et al., 2008; Sun et al., 2010). Endler and Parker (1994), however, found that depression and anxiety tend not to be found among those with avoidance-focused coping. For dementia caregivers, Sun et al. (2010) found that avoiding the stressor alleviated the effects that physical problems usually have on burden.

The subject of gender and coping strategy usage is contradicted between studies (see Folkman & Lazarus, 1980; Endler & Parker, 1994). Therefore, for the purpose of this paper, the

studies are discussed here separately and in detail. Ali and Askari (2011) reported that women use emotion-focused coping more and that men used task-focused coping more, but they did not report statistics to support their claim. Billings and Moos (1984) studied 424 adults with depression. They used a cross-sectional research design made up of 55.4% women. This percentage was nearly 5% higher than the national percentage of women (U. S. Census Bureau, 2010b). They used a 32-item scale in Likert format to gather information about coping strategies used. They further reported that the Cronbach's alpha for the varying facets of the scale ranged from .41 to .66. Billings and Moos (1984) reported a non-significant difference between men and women utilizing emotion-focused coping, with a Hotelling's  $T$  statistic of .03. When contrasted using one-variable analysis, women were found to be more likely to release emotions (Billings & Moos, 1984).

Folkman and Lazarus (1980) studied 100 middle-aged individuals, and 52% were women. Their research design was cross-sectional, and their instrumentation consisted of *Ways of Coping*, a 68-question survey divided between two coping strategies (Folkman & Lazarus, 1980). The Cronbach's alpha for the 41 questions regarding emotion-focused coping was .81 (Folkman & Lazarus, 1980). They found that men and women used emotion-focused coping at the same rate (Folkman & Lazarus, 1980). They further found that men were more likely to use task-focused coping while at their job. Folkman and Lazarus (1980) reported that the results may be distorted because the men participants had different jobs than the women participants had. They reported that future researchers should look at participants with closer to the same jobs (Folkman & Lazarus, 1980).

Endler and Parker (1994) did not have the same results with their study of 483 participants. With 55% female and using a cross-sectional design, Endler and Parker (1994) used

the *Coping Inventory for Stressful Situations* to study the differences in men and women's coping strategies. They reported that women used emotion-focused coping and avoidance-focused coping more so than men (Endler & Parker, 1994). In an earlier study of 559 college students (50.8% female), they reported that men and women use task-focus coping at the same rate (Endler & Parker, 1990). They further reported that task-focused coping was the most utilized strategy among men and women (Endler & Parker, 1990).

### **Theoretical Implications**

This section sets the foundation of the current research study on a theory. For the purpose of this study, the appraisal theory is used to enhance understanding of the relationship between AD caregiver coping strategies and AD caregiver burden. This section gives a brief history of the appraisal theory, explains the basic ideas of the theory, and relates the theory to this study.

*Appraisal*, according to Lazarus (2006), is attributing the relational aspect to one's life and letting that affect one's emotions. The relational aspect refers to the connection of an individual to his or her surroundings (Lazarus, 2006). Scherer (1995) reported that Lazarus is among the leaders in the study of stress. Lazarus, along with some others, conducted an experiment that involved films showing emotion-evoking scenes, such as skin cutting and accidental finger amputation (Lazarus, 1993). Neither Lazarus (1993) nor Lazarus (2006) mentioned the research design used in this study. Lazarus (2006) realized that a film that once elicited an emotional response from him no longer did due to his learned coping. He encountered several problems, including not having the variety of films he needed, and the rejection of his proposal to make films (Lazarus, 2006). He ended up changing the appraisals by allowing the participants to hear either a professional or an emotional pre-film explanation (Hyman, 2002). This paper uses the resulting appraisal theory.

Smith and Kirby (2009) reported that people react differently to stress because their appraisals are different. According to Lazarus and Folkman (1987), *appraisal* can be either *primary* or *secondary*. Primary involves the type of stress, whether it may be harm, challenge, or threat (Lazarus & Folkman, 1987). Secondary involves the reasoning of whether or not things can be done by the individual in the situation (Lazarus & Folkman, 1987). Appraisal can be viewed at either *harm-loss appraisal*, *challenge appraisal*, or *threat appraisal* (Folkman & Lazarus, 1980; Lazarus & Folkman, 1987). Harm-loss appraisal is the interpretation of a stressor that has caused impairment or destruction (Folkman & Lazarus, 1980). Challenge appraisal is the interpretation of a stressor that is expected to encourage personal growth (Folkman & Lazarus, 1980). Threat appraisal is the interpretation of a stressor highly likely to cause impairment or destruction (Folkman & Lazarus, 1980).

Smith and Kirby (2009) furthered appraisal theory with the following three ideas: *motivational relevance*, *problem-focused coping potential*, and *emotion-focused coping potential*. Motivational relevance indicates the impact of the stress on an individual, problem-focused coping potential indicates the potentiality of a person using problem-focused coping, and emotion-focused coping potential indicates the potentiality of a person to use emotion-focus coping (Smith & Kirby, 2009). Problem-focused coping is the same as task-focused coping as evidenced by the focus being on problem-solving (Smith & Kirby, 2009). Smith and Kirby (2009) did not discuss avoidance-focused coping or avoidance-focused coping potential.

This theory is important because by studying how a person reacts in a situation, social workers may identify a person's wishes (Lazarus, 2006). Social workers may also identify how a person may appraise and react to a situation by studying what people want (Lazarus, 2006). Appraisal influences coping, thus is why appraisal is important in studying coping and coping

strategies (Folkman & Lazarus, 1980). It is important to look at a person holistically in order to understand the reasoning for how he or she appraises a stressor (Smith & Kirby, 2009).

For the purpose of this study, the appraisal theory is the theoretical framework for two reasons. The first is because it helps explain the cyclical relationship of stressors, coping strategies, and the resulting emotions (Endler & Parker, 1990; Endler & Parker, 1994; Lazarus, 2006). Appraisal is used to define coping style during stress, influencing the impact of that stress (Smith & Kirby, 2009). The second reason is because caregivers appraise their situations differently, develop a coping strategy based on that appraisal, and have a certain degree of stress (or burden) due to that coping strategy (see Endler & Parker, 1990; Endler & Parker, 1994; Lazarus, 2006). By changing the appraisal of a stressful situation, the adverse feelings from the previous appraisal will decrease (Lazarus, 1993). Using the appraisal theory in this study of coping strategies and burden is essential for explaining the relationship between the two, as appraisal affects coping strategies, which affects burden (Lazarus, 1993).

### **Purpose and Research Questions**

The purpose of this current study is to examine the relationship between coping strategies (emotion-focused, task-focused, and avoidance-focused) and the perceived burden among Louisiana AD caregivers. Perceived burden is looked at two ways: prevalence of burden felt and the degree of bother. For the purpose of this paper, the degree of bother refers to the extremity of bother from the burdensome behaviors engaged in by the care recipient. This study focuses on seven questions. Because it is important to understand the descriptive statistics of each item before looking at their interrelationships, the first four questions focus on the descriptive statistics for each coping strategy and the perceived burden. The last three questions focus on relationships between variables.

The following are the research questions put forth by this study:

1. What is the prevalence of emotion-focused coping among AD caregivers?
2. What is the prevalence of task-focused coping among AD caregivers?
3. What is the prevalence of avoidance-focused coping among AD caregivers?
4. What is the prevalence of perceived burden among AD caregivers?
  - (a) What is the prevalence of burden felt among AD caregivers according to the *Zarit Burden Interview*?
  - (b) What is the prevalence of burden felt among AD caregivers according to the *Revised Memory and Behavior Problems Checklist (RMBPC)* bother subscale?
5. What is the relationship between emotion-focused coping and perceived burden?
  - (a) What is the relationship between emotion-focused coping and burden felt according to the ZBI?
  - (b) What is the relationship between emotion-focused coping and burden felt according to the RMBPC bother subscale (see instrumentation)?
6. What is the relationship between task-focused coping and perceived burden?
  - (a) What is the relationship between task-focused coping and burden felt according to the ZBI?
  - (b) What is the relationship between task-focused coping and burden felt according to the RMBPC bother subscale?
7. What is the relationship between avoidance-focused coping and perceived burden?
  - (a) What is the relationship between avoidance-focused coping and burden felt according to the ZBI?

(b) What is the relationship between avoidance-focused coping and burden felt according to the RMBPC bother subscale?

Based on the preceding questions, the primary independent variables are emotion-focused coping, task-focused coping, and avoidance-focused coping. The primary dependent variables are prevalence of burden felt and the degree of bother.

## **CHAPTER THREE**

### **METHODS**

This study is a secondary data analysis based on a study by Wilks, Little, Gough & Spurlock (2011). The methodology comes from this previous study, which was approved by the Louisiana State University Institutional Review Board (LSU IRB). The LSU IRB also approved this present study.

#### **Design and Sampling**

This study took place at Louisiana State University School of Social work (Wilks et al., 2011). The Alzheimer's Services of the Capital Area, a not-for-profit 501 (C)3 organization in south Louisiana, took part in the study. The target population was AD caregivers in Louisiana. The cross-sectional design was used to analyze data from the survey (Wilks et al., 2011).

This study consisted of two parts (Wilks et al., 2011). The first part consisted of completion and thorough critique of the survey by caregivers and the staff of Alzheimer's Services of the Capital Area. These volunteers made up focus groups that also suggested ways to recruit participants for the study. The focus groups critiqued the survey for things such as simplicity and brevity. The second part consisted of sending the survey throughout Louisiana to the target population. The survey was given in packets to the director of the Alzheimer's Services of the Capital Area. The directors distributed the packets to AD caregivers affiliated in support groups and outreach programs. The packets came with prepared envelopes in which the leaders and staff could send the finished survey back. Each survey came with a cover letter. This study was voluntary, and AD caregivers that finished the survey were compensated in the amount of five dollars. The sample included all volunteers that completed the survey. The

information provided by participants was kept confidential (Wilks et al., 2011). This present study holds to the same confidentiality of participants.

### **Instrumentation**

The instrument used in the original study was a survey. Because this present study is a secondary data analysis, only selective pieces of the original survey are used: demographics, burden, and focus of coping strategy. In the demographic section, the survey asked for gender, ethnicity, stage of care recipient's disease, and AD caregiver's relationship to the care recipient. Age was obtained at a time interval prior to the remaining data. The level of measurement for each item except age was non-parametric. The level of measurement for age was parametric.

In the burden section, the survey utilized the following two scales: the *Revised Memory and Behavior Problems Checklist* (RMBPC), and the shortened *Zarit Burden Interview* (ZBI). The RMBPC measured the extent of burdensome behaviors of individuals with AD and the intensity to which those behaviors bother the AD caregiver (Teri et al., 1992). For the purpose of this present study, only the measure for the intensity to which the burdensome behaviors bother the AD caregiver was used (RMBPC bother subscale). The RMBPC bother subscale has 24 items in Likert format ranging from 0 to 4, with the overall higher score indicating a higher degree of burden felt (Teri et al., 1992). The Cronbach's alpha has been found to be .90 (Teri et al., 1992). The overall global score's level of measurement was parametric. The ZBI measured whether the AD caregiver feels burdened (Bedard et al., 2001). It had four items in Likert format, each ranging from 0 to 4 (Little & Wilks, 2011). A higher overall score indicated AD caregiver burden, with scores higher than 8 indicating high burden (Bedard et al., 2001). The Cronbach's alpha has been found to be between .78 in an earlier study (Bedard et al., 2001). The overall global score's level of measurement was parametric.

The focus of coping strategy section contained the *Coping in Task* questionnaire. The *Coping in Task* questionnaire contains 21 ordinal items in Likert format from 0 to 4 (Matthews & Campbell, 1998). The overall global score's level of measurement was parametric. The questionnaire evaluated the participant's tendency towards emotion-focused coping (seven items), task-focused coping (seven items), and avoidance-focused coping (seven items; Matthews & Campbell, 1998). Higher scores for each coping strategy suggested a higher tendency towards that coping strategy (Matthews & Campbell, 1998). Cronbach's alpha is moderately strong for each coping strategy (Matthews & Campbell, 1998). Each scale has been tested for consistency using Spearman-Brown coefficients and Cronbach's alpha with a cut-off point of .80 to ensure reliability (Rentz, 1980; Wilks et al., 2011).

### **Data Analysis**

**Descriptive Analysis.** Descriptive statistics for all non-parametric variables will be reported in percentages and frequencies. Descriptive statistics for all parametric variables will be reported in means and standard deviations. These statistics will address research questions 1—4 because the variables are descriptive.

**Bivariate Correlation Analysis.** As one variable increases, another variable may increase or decrease at the same time (Royse, Thyer, & Padgett, 2010). Bivariate correlations show directional similarities or dissimilarities of any two variables (Royse et al., 2010). This study examines each coping focus and burden correlation. Each correlation will be reported using Pearson's  $r$  because all variables are parametric.

**Tests for Research Questions Five through Seven.** Simple linear regression will be used to see if the independent variables predict the dependent variables. Simple linear regression will be used because the independent variables and dependent variables are parametric. After

simple linear regression, stepwise regression will be used to determine the effect size with the inclusion of demographic variables. The beta statistic will be the test coefficient, along with its p-value. The p-value will be set at 0.05.

## CHAPTER FOUR

### RESULTS

#### Descriptive Statistics

**Sample Characteristics.** The average age of the participants was 61 years. Female participants made up 79.8% (n=546) of the participants. The majority (61.9%; n=424) of the participants indicated *Caucasian/White* ethnicity, followed by *African American/Black* ethnicity (35.9%; n=246).

The stage of the care recipient's disease was mostly reported as *late*, making up 41.5% (n=260). This was followed by *middle* stage of care recipient's disease with 36.1% (n=226). The participants were mostly a child of the care recipient, amounting to 51.5% (n=350) of the total. The second most frequent answer for relationship to care recipient was *other* (16.9%; n=115). An interpretation of these results is discussed in Chapter Five: Discussion. A detailed outline of the comprehensive sample characteristics can be found in Table 1.

Table 1

*Sample Characteristics*

Characteristic	n=	Valid %	M
<b>Gender</b>			
Female	546	79.8	
Male	138	20.2	
<b>Ethnicity</b>			
African American/Black	246	35.9	
Hispanic/Latino	6	.9	
Caucasian/White	424	61.9	
Other	9	1.3	
<b>Stage of care recipient's disease</b>			
Early	140	22.4	
Middle	226	36.1	
Late	260	41.5	
<b>AD caregiver's relationship to the care recipient</b>			
Spouse/partner	114	16.8	
Child	350	51.5	
Grandchild	45	6.6	
Sibling	30	4.4	
Friend	26	3.8	
	30		

Other

115

16.9

Age\*

61

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\*Age was obtained at a time interval before the rest of the data

**Descriptive Statistics for Primary Variables.** For the emotion-focused coping, the mean score was 12.4 (SD=6.53; range=0—28). This answered research question one. The task-focused coping mean score was 20.1 (SD=5.00; range=0—28). This answered research question two. The avoidance-focused coping mean score was 7.98 (SD=5.44; range=0—28). This answered research question three. The global mean score on the ZBI was 12.2 (SD=3.11; range=4—20). This answered research question 4a. The global mean score on the RMBPC bother subscale was 33.3 (standard deviation [SD]=23.24; range=0—96). This answered research question 4b. An interpretation of these results is discussed in Chapter Five: Discussion.

### **Correlation Analysis**

When looking at the relationships between the primary variables, a strong, positive relationship ( $r=.43, p<.01$ ) existed between the scores on the ZBI and the scores on the RMBPC bother subscale. The score on the RMBPC bother subscale had a strong, positive relationship ( $r=.45, p<.01$ ) with the score on the emotion-focused coping subscale. This answered research question 5b. The score on the RMBPC bother subscale had a moderately strong, positive relationship with the score on the avoidance-focused coping subscale ( $r=.37; p<.01$ ). This answered research question 7b. The score on the ZBI had a moderately strong, positive relationship ( $r=.36, p<.01$ ) with the score on the emotion-focused coping subscale. This answered research question 5a. The positive relationship between the scores on the avoidance-focused coping subscale and the score on the task-focused coping subscale was strong ( $r=.47,$

$p < .01$ ). An interpretation of these results is discussed in Chapter Five: Discussion. Table 2 contains all correlation findings.

Table 2

*Correlation Findings*

		ZBI	RMBPC	Emotion- focused	Task- focused	Avoidance- focused
ZBI		-				
RMBPC	<i>r</i>	.434**	-			
Emotion-focused	<i>r</i>	.357**	.450**	-		
Task-focused	<i>r</i>	-.020	.024	.115*	-	
Avoidance-focused	<i>r</i>	.076	.368**	.091*	.466**	-

\* $p < .05$

\*\* $p < .01$

**Stepwise Regression**

The global scores of the ZBI significantly regressed on the global scores of the emotion-focused coping subscale ( $\beta = .366$ ;  $p < .01$ ). With the inclusion of the demographic variables in the stepwise regression, the significance of the scores of the emotion-focused coping subscale remained the same ( $\beta = .339$ ;  $p < .01$ ). Ethnicity showed significance within the stepwise regression ( $\beta = .128$ ,  $p < .01$ ). An interpretation of these results is discussed in Chapter Five: Discussion. Table 3 gives a comprehensible outline of the stepwise regression for the global scores of the emotion-focused coping subscale with the scores on the ZBI.

Table 3

*Stepwise Regression on the Global Scores of the Emotion-focused Coping Subscale with the ZBI*

*Outcome*

	$\beta$	$R^2$
Step 1		
Emotion-focused coping	.366**	
$R^2$		.134
Step 2		
Emotion-focused coping	.339**	
Gender	-.026	
Ethnicity	.128**	
Relationship to care recipient	-.074	
Care recipient's stage of AD	.056	
$R^2\Delta$		.029

\*\* $p < .01$

The global scores of the ZBI did not significantly regress on the global scores of the task-focused coping subscale. An interpretation of these results is discussed in Chapter Five: Discussion. Table 4 outlines the stepwise regression for the global scores of the task-focused coping subscale with the scores on the ZBI.

Table 4

*Stepwise Regression on the Global Scores of the Task-focused Coping Subscale with the ZBI**Outcome*

	$\beta$	$R^2$
Step 1		
Task-focused coping	.001	
$R^2$		.000
Step 2		
Task-focused coping	-.008	
Gender	-.027	
Ethnicity	.148**	
Relationship to care recipient	-.109**	
Care recipient's stage of AD	.077	
$R^2\Delta$		.047

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\*\* $p < .01$

The global scores of the ZBI did not significantly regress on the global scores of the avoidant-focused coping subscale, though near-significance was noted with the inclusion of the demographic variables ( $\beta = .080$ ). Table 5 outlines the stepwise regression for the global scores of the avoidant-focused coping subscale with the scores on the ZBI.

Table 5

*Stepwise Regression on the Global Scores of the Avoidant-focused Coping Subscale with the ZBI*

*Outcome*

	$\beta$	$R^2$
Step 1		
Avoidant-focused coping	.067	
$R^2$		.004
Step 2		
Avoidant-focused coping	.080	
Gender	-.029	
Ethnicity	.161**	
Relationship to care recipient	-.099*	
Care recipient's stage of AD	.082*	
$R^2\Delta$		.049

\* $p < .05$

\*\* $p < .01$

The global scores of the RMBPC bother subscale significantly regressed on the global scores of the emotion-focused coping subscale ( $\beta = .445$ ;  $p < .01$ ). With the inclusion of the demographic variables in the stepwise regression, the significance of the regressed scores of the emotion-focused coping subscale remained the same ( $\beta = .443$ ;  $p < .01$ ). The following two demographics showed significance within the stepwise regression: ethnicity ( $\beta = -.212$ ;  $p < .01$ ), and the care recipient's stage of AD ( $\beta = .111$ ;  $p < .05$ ). An interpretation of these results is

discussed in Chapter Five: Discussion. Table 6 outlines the stepwise regression for the global scores of the emotion-focused coping subscale with the scores on the RMBPC bother subscale.

Table 6

*Stepwise Regression on the Global Scores of the Emotion-focused Coping Subscale with the RMBPC Bother Subscale Outcome*

	$\beta$	$R^2$
Step 1		
Emotion-focused coping	.445**	
$R^2$		.198
Step 2		
Emotion-focused coping	.443**	
Gender	-.016	
Ethnicity	-.212**	
Relationship to care recipient	-.042	
Care recipient's stage of AD	.111*	
$R^2\Delta$		.055

\* $p < .05$

\*\* $p < .01$

The global scores of the RMBPC bother subscale did not significantly regress on the global scores of the task-focused coping subscale. An interpretation of these results is discussed in Chapter Five: Discussion. Table 7 outlines the stepwise regression for the global scores of the task-focused coping subscale with the scores on the RMBPC bother subscale.

Table 7

*Stepwise Regression on the Global Scores of the Task-focused Coping Subscale with the RMBPC*

*Bother Subscale Outcome*

	$\beta$	$R^2$
Step 1		
Task-focused coping	.011	
$R^2$		.000
Step 2		
Task-focused coping	-.031	
Gender	.031	
Ethnicity	-.192**	
Relationship to care recipient	.054	
Care recipient's stage of AD	-.194**	
$R^2\Delta$		.071

\*\* $p < .01$

The global scores of the RMBPC bother subscale significantly regressed on the global scores of the avoidant-focused coping subscale ( $\beta = .339$ ;  $p < .01$ ). With the inclusion of the demographic variables in the stepwise regression, the significance of the regressed scores of the avoidant-focused coping subscale remained the same. The following two demographics showed significance within the stepwise regression: ethnicity ( $\beta = -.157$ ;  $p < .01$ ), and care recipient's stage of AD ( $\beta = .160$ ;  $p < .01$ ). An interpretation of these results is discussed in Chapter Five:

Discussion. Table 8 outlines the stepwise regression for the global scores of the avoidant-focused coping subscale with the scores on the RMBPC bother subscale.

Table 8

*Stepwise Regression on the Global Scores of the Avoidant-focused Coping Subscale with the RMBPC Bother Subscale Outcome*

	$\beta$	$R^2$
Step 1		
Avoidant-focused coping	.339**	
$R^2$		.115
Step 2		
Avoidant-focused coping	.323**	
Gender	-.050	
Ethnicity	-.157**	
Relationship to care recipient	-.077	
Care recipient's stage of AD	.160**	
$R^2\Delta$		.055

\*\* $p < .01$

## CHAPTER FIVE

### DISCUSSION

#### Review of Results

The typical AD caregiver was 61 years of age, female, Caucasian, and a child of the care recipient. The average age in this current study was much older than the average age (48) found by previous studies of AD caregivers (AA & NAC, 2004a; NCA & AARP, 2009). This present study found a greater female-to-male ratio (4:1) than did previous AD caregiver studies (3:2; AA & NAC, 2004a; NAC & AARP, 2009). The participants' ethnic diversity was similar to that of previous studies (AA & NAC, 2004a; NAC & AARP, 2009) except for the percentage of African American AD caregivers. The present study intended to reflect the proportion of African Americans in south Louisiana. According to the 2010 census, African Americans made up 32% of the population in Louisiana, while making up only slightly higher than 12% of the national population (USCB, 2012). The percentage of African American AD caregivers in this present study was twice the percentage found for a national survey (AA & NAC, 2004a).

For this Louisiana study, relatives were found more likely to be AD caregivers similar to prior finding of a national study of AD caregivers (AA & NAC, 2004a). Children were found to be the most likely AD caregiver similar to the previous study by AA and the NAC (2004a). The finding was different than the finding of Wilks and Vonk (2008), who found spouses to be slightly more likely AD caregivers among their sample of participants from seven different southern states (excluding Louisiana). The second most likely relationship to the care recipient reported by participants was other. This group may include aunts, uncles, cousins, in-laws, and others not specifically mentioned on the survey. Care recipients in this present study had a greater likelihood of being considered late stage (41.5%) than reported by Hebert et al. (2003),

who reported that the least amount of individuals with AD were in the late stage (21%; Hebert et al., 2003). This difference in prevalence rates of disease reported by participants of this study could be attributed to the increased need for a caregiver as the disease progresses, as evidenced by an increased need for assistance with ADLs (AA & NAC, 2004a).

The average global score of the RMBPC bother subscale indicated the overall score of participants and the amount of bother from care recipient behaviors (Teri et al., 1992). According to the average global scores, this present study's participants were *moderately* burdened by the care recipient's negative behaviors. This was determined since the global average score was between the sums of all the questions answered with a one (*a little* bothered) and all the questions answered with a two (*moderately* bothered). The fact that the sample did not report higher level of burden from this measure may be explained by the prior research that reported that dementia caregivers were more likely to report satisfaction than displeasure (Heru et al., 2004). The average global score for the ZBI in this present study was higher than that which is considered a high level of burden (8; Bedard et al., 2001). This reinforced the prior research that found that AD caregivers experience more burden than other caregivers (AA & NAC, 2004a).

The highest possible score for each subscale (28) was divided into low (0—9.3), medium (9.4—18.6), or high (18.7—28) to determine the prevalence of engaging in each coping strategy. The average global score for this present study for the emotion-focused coping subscale showed a medium prevalence level. This study's finding was similar to some studies (Billings & Moos, 1984; Compton et al., 2011; Glidden et al., 2006; Lilly & Graham-Bermann, 2010) and dissimilar to others (DeGraff & Schaffer, 2008; Ekwall et al., 2007; Kartalova-O'Doherty & Doherty). The average global score on the task-focused subscale showed a high level of prevalence. This score was also the highest among the three coping strategy subscales' average

global scores. This finding reinforced the prior finding that task-focused coping is the most utilized strategy, although the prior findings were among individuals with depression, anxiety, and PTSD (Billings & Moos, 1984; Compton et al., 2011; Endler & Parker, 1990; Glidden et al., 2006; Lilly & Graham-Bermann, 2010). The average global score for the avoidance-focused subscale showed a low prevalence level. This score was the lowest of the three coping strategy subscales' average global scores. This finding was similar to prior studies (Ekwall et al., 2007; Glidden et al., 2006; Lilly & Graham-Bermann, 2010).

Emotion-focused coping was significantly, positively related to burden. As the likelihood to utilize emotion-focused coping increased, so did the likelihood of burden. The effect size is the extent to which the relationship between the independent variable and the dependant variable is explained by the independent variable (College of Humanities & Social & Behavioral Sciences, n. d.). Based on Cohen (1998, as cited in College of Humanities & Social & Behavioral Sciences, n. d.), the effect size of emotion-focused coping was rather weak for one measure of burden (ZBI) and small for the other measure of burden (RMBPC bother subscale). For both regression models with emotion-focused coping and burden, the influence of the demographics appeared minimal. Prior studies showed that emotion-focused coping was linked to depression (Endler & Parker, 1990; Endler & Parker, 1994; Lilly & Graham-Bermann, 2010). Depression is a type of psychological burden that many AD caregivers reported on previous studies (Carrasco et al., 2002; Covinsky et al., 2008).

Task-focused coping did not significantly influence either measure of burden. This is a remarkable contrast from prior research that reported that task-focused coping was related to decreased burden (Di Mattei et al., 2008). It is also in contrast to prior research that reported that

many of the coping techniques AD caregivers use to combat the heavy burden load are task-focused (AA & NAC, 2004a).

Avoidant-focused coping was significantly related to burden (RMBPC bother subscale). The effect size was rather minimal. Because the change in effect size was minimal with the inclusion of demographic variables, the influence of these demographics appeared nominal. Prior research found avoidance-focused coping to be associated with increased burden (Di Mattei et al., 2008; Sun et al., 2010).

### **Social Work Implications**

Several key findings of this study provide implications for the social work practitioner, and in particular, the gerontological social work practitioner. The relationship between emotion-focused coping and burden may imply that gerontological social workers should provide information of less burden-inducing coping techniques to clients. The same is true for the relationship between avoidance-focused coping and burden. These coping strategies often add to burden or put the caregiver's mental health at risk as reported in prior research (Di Mattei et al., 2008; Endler & Parker, 1990; Endler & Parker, 1994; Lilly & Graham-Bermann, 2010; Sun et al., 2010). Social work practitioners may help AD caregivers find coping strategies related to decreased burden, such as task-focused coping (Di Mattei et al., 2008). Some examples of task-focused coping techniques includes help-seeking, planning, determining to get responsibilities done, and studying educational resources (AA & NAC, 2004a; Billings & Moos, 1984; Johnsen et al., 2002; Kartalova-O'Doherty & Doherty, 2008).

The high percentage of African American AD caregivers in this Louisiana study reminds social work practitioners to recognize the cultural differences of caregivers in order to have cultural competence in practice (National Association of Social Workers [NASW], 2001).

Culturally competent social work practitioners practice with sensitivity to the needs of African American families (Bullock, Crawford, & Tennstedt, 2003). An example of this is recognizing the cultural expectation for the family to assume the primary caregiving role to the extent that African American caregivers may quit their jobs because the caregiving role is too demanding (Bullock et al., 2003). Culturally competent social work practitioners are also aware that African American caregivers may also experience difficulty accessing helpful services, for example, African Americans may not be aware such services exist due to lack of social service outreach among African American populations (Bullock et al., 2003). Social workers should also work to ensure African American AD caregivers are able to continue working by utilizing outside help, while remaining sensitive to the African American cultural expectation to maintain the primary caregiver role (Bullock et al., 2003).

Social work educators may help students become more aware of clientele diversity by assigning reading material that was written by diverse authors such as women, ethnic minority, and LGBT authors (Gabbard, Starks, Jagers, & Cappiccie, 2011). Critical race theory may help combat varying teaching problems such as the student's denial of biased attitudes, the student's and the instructor's ignorance of diversity, and the instructor's lack of comprehensive course objectives (Abrams & Moio, 2009). Social work educators and practitioners should meet the demand for cultural competence as the increase in life expectancy and well-being among diverse groups means an increase in the number caregivers in those populations (Bullock et al., 2003).

The care recipient's higher likelihood in this study to be in the late stage of AD, contrasting a prior study with most care recipients in the early stage (Hebert et al., 2003), could indicate that caregivers are not being reached by human service practitioners earlier in the disease progress. The implication from this finding may be that social work and other human

service practitioners should be more assertive in reaching out to families not aware of available services. In a study of caregivers of individuals with a variety of health issues, Casado, van Vulpen and Davis (2010) found that the majority of the participants did not know some of the helpful services existed. Forty percent of the participants were not aware of support group services, and 14% experienced difficulties accessing support groups (Casado et al., 2010). Alternatives to traditional services may be considered, such as group therapy conducted on the telephone (Goelitzo, 2008). Other services may be difficult to access, as Li (2006) found that 84% of caregivers of older adult care recipients experienced problems accessing respite services, and 75% of the caregivers experienced problems accessing transportation services. Programs such as the AD Knowledge Building Program (Kuhn & Fulton, 2004) may help caregivers of care recipients in the early stage of AD. The program was found related to less burden among early-stage AD caregivers (Kuhn & Fulton, 2004), reinforcing the possible benefit of caregivers seeking help early in the disease process. Early-stage AD caregivers benefit from these types of services because other services are specifically directed toward helping later-stage AD caregivers (Kuhn & Fulton, 2004).

### **Limitations and Future Research**

Several limitations existed in this study. Because age was obtained at a time interval prior to the remaining demographic data, it was not included in the stepwise regression. Furthermore, age cannot be used as a controlling factor for this present study or future secondary analysis of this survey. Age, like burden, is higher among AD caregivers than other types of caregivers (AA & NAC, 2004a). Future studies should include age with the rest of the demographics to enable focus on the age differences in coping techniques and burden.

Kenny (2004) defined spuriousness as the relationship between two variables affected by another variable. The relationship between emotion-focused coping and burden was spurious because, although its correlation was significant, the effect size was only moderate. The relationship between avoidant-focused coping and burden was spurious because although the correlation was significant, the effect size was nominal. This brings to question the factor or factors connecting the variables together. Future studies may identify the confounding factor or factors by controlling for them (Kenny, 2004). Possible confounding factors include the likelihood of the care recipient to engage in bothersome behaviors, educational attainment of the caregiver, caregiver health, time spent caregiving, financial stability of the caregiver, and the caregiver's other roles and responsibilities (NAC & AARP, 2009; Okabayashi et al., 2008).

Finally, the generalizability of this study is limited due to the participants being only from Louisiana as opposed to other states as well. Because Louisiana has more African Americans than the national average (USCB, 2012), the results may be different than a study with participants more closely aligned with the national average. Because this study involved caregivers of care recipients more likely in the late stage, the results may not apply for caregivers of care recipients in the earlier stages. This study also had a higher ration of females (4:1) than found in previous studies (3:2; AA & NAC, 2004a; NAC & AARP, 2009). Future research should involve a higher number of AD caregivers for care recipients in the earlier stages and a smaller ratio of females-to-males.

## CHAPTER SIX

### CONCLUSION

This paper reviewed the current literature regarding AD, including its history; overview; prevalence, incidence, and culture considerations; stages; and treatment options. AD has been studied for over a hundred years (Lage, 2006). One of a dozen types of dementia (APA, 2000), AD is associated with beta-amyloid build-up and neurofibrillary tangles (Mader, 2003). A decrease in nerve action causes memory loss (Hooyman & Kiyak, 2005). *Preclinical stage, mild cognitive impairment stage, and AD stage* are the three stages of AD as defined by NIH, NIA, and AA (2011). The highest prevalence rate is 45% among individuals aged 75 years and older (AA, 2011; Hebert et al., 2003). The earliest stage of AD is characterized by memory problems, difficulty staying on-task, and mood problems (Hooyman & Kiyak, 2005). The middle stage of AD is characterized by increased dependence on others and behavioral problems (APA, 2000, Voisin & Vellas, 2009). The advanced stage of AD is characterized by loss of musculoskeletal function and decrease in self-care (APA, 2000; Hooyman & Kiyak, 2005). Although atypical antipsychotic drugs have been found helpful (Hooyman & Kiyak, 2005), it is associated with an increase in the occurrence of death (FDA, 2005). Non-medication alternatives exist that involve changing the atmosphere (Hooyman & Kiyak, 2005).

This present study also discussed caregiving, including caregivers and their caregiving; scope; burden; positives of caregiving; coping; and coping strategies. Any type of caregiving functions are known as ADLs and IADLs (AA & NAC, 2004a). Caregivers care for others with disabilities without monetary compensation (NAC & AARP, 2009). Louisiana contains 560,000 of over 65 million total caregivers in the United States (Feinber et al., 2007; NAC & AARP, 2009). AD caregivers report more burden than other caregivers (AA & NAC, 2004a),

constituting a little under half of all of AD caregivers (AA, 2011b). Burden may be considered physical, psychological, financial, or time (Carrasco et al., 2002; Covinsky et al., 2003; NAC & AARP, 2009). Caregivers of older adult care recipients also experience positive aspects of caregiving responsibilities (Heru et al., 2004). Positive aspects include gratefulness, relationship improvement with care recipient, increased stamina, an opportunity to please the care recipient, the feeling of being needed, and an opportunity to show love and faith (Andren & Elmstahl, 2005; Hogstel et al., 2005).

AD caregivers utilize a variety of coping techniques. Techniques include engaging in exterior relationships, praying, resource gathering, exercising, using humor, counseling, learning from caregiving responsibilities, looking on the bright side of things, pacing life, accepting the situation, and increasing self-efficacy (AA & NAC, 2004a; Heinemann, 2009; Salin et al., 2009; Sun et al., 2010). Coping strategies may be emotion-focused, task-focused, and avoidance-focused (Parker & Endler, 1992). Coping strategies are used during coping, and caregivers often utilize more than one strategy (Ali & Askari, 2011; Folkman & Lazarus, 1980). Emotion-focused coping focuses on emotional control (Green et al., 2010). Anger management, relaxation techniques, and praying are examples of emotion-focused coping (Ali & Askari, 2011; Lilly & Graham-Bermann, 2010). Emotion-focused coping has been found associated with depression and anxiety (Endler & Parker, 1990; Lilly & Graham-Bermann, 2010). Task-focused coping focuses on physical actions (Di Mattei et al., 2008). Examples of task-focused coping include planning, utilizing social support, and concentrating on other obligations (Johnsen et al., 2002; Kartalova-O'Doherty & Doherty, 2008). Task-focused coping has been found associated with decreased burden and healthy self-esteem (Billings & Moos, 1984; Di Mattei et al., 2008). Avoidance-focused coping focuses on the non-acceptance of stressing events (Johnsen et al.,

2002). Examples of avoidance-focused coping include avoiding reality, using pharmaceuticals, and ignoring the problem (Glidden et al., 2006; Green et al., 2010; Kartalova-O'Doherty & Doherty, 2008). Avoidance-focused coping has been found associated with increased risk of drinking, increased risk of isolation, and increased burden (Di Mattei et al., 2008; Sun et al., 2010).

This present study further discussed the theoretical implications. The appraisal theory was used in this study to understand the relationship between coping and burden. Instituted by Lazarus, appraisal theory explains the different reactions to stress and the effect on burden (Lazarus, 2006; Smith & Kirby, 2009). A cyclical relationship exists between stressors, appraisal, coping strategies, and emotions (Endler & Parker, 1990; Endler & Parker, 1994; Lazarus, 2006). If the appraisal of a particular stressor causes adverse feelings, changing the appraisal may decrease those feelings (Lazarus, 1993).

This present study discussed the purpose and research questions. The first question was as follows: What is the prevalence of emotion-focused coping among AD caregivers? The results from this study revealed that emotion-focused coping was the second to the most used strategy. The second question was as follows: What is the prevalence of task-focused coping among AD caregivers? The results indicated that caregivers were most likely to utilize task-focused coping than other types of coping strategies. The third question was as follows: What is the prevalence of avoidance-focused coping among AD caregivers? The results indicated that caregivers were least likely to engage in avoidance-focused coping. The fourth question was as follows: What is the prevalence of perceived burden among AD caregivers? The results revealed that caregivers had medium levels of burden according to one measure (RMBPC bother subscale) and high levels of burden according to the other measure (ZBI). The fifth question was as follows: What is

the relationship between emotion-focused coping and perceived burden? The results showed that emotion-focused coping had a significant, positive association with burden. The sixth question was as follows: What is the relationship between task-focused coping and perceived burden? The results showed that task-focused coping did not have a significant relationship with burden. The seventh question was as follows: What is the relationship between avoidance-focused coping and perceived burden? The results showed that avoidance-focused coping had a significant, positive association with burden according to one measure of burden (RMBPC) but not the other measure of burden (ZBI).

This present study discussed the methods used, including the design and sampling, instrumentation, and the data analysis. This study was a secondary data analysis based on a study by Wilks et al. (2011). Using a cross-sectional design, this study's sample were caregivers affiliated with the Alzheimer's Services of the Capital Area. The RMBPC bother subscale, the shortened ZBI, and the *Coping in Task* questionnaire were the instruments for this study. This study used descriptive statistics for all non-parametric variables. The results reported the sample characteristics and the descriptive statistics for primary variables. The average AD caregiver was 61 years of age, female, Caucasian, child of the care recipient, and caregiving for a care recipient in the late stage of AD. The descriptive statistics for primary variables answered research questions 1—4. This study used bivariate correlation analysis using Pearson's  $r$  to analyze similarities between two variables. The results reported the correlation analysis that answered research questions 5—7. This study used simple linear regression to see if the independent variables predicted the dependent variables. The results reported the stepwise regression findings that yielding an understanding of the effect size of the variables. The results were spurious.

This present study reported the discussion, including review of results; social work implications; and limitations and future results. The review of results revealed that this present study's participants had a higher percentage of African American caregivers than a previous study (AA & NAC, 2004a). Care recipients in this study also had a higher likelihood of being in the late stage than reported in a prior study (Hebert et al., 2003). Task-focused coping did not influence burden, contrary to the findings of prior studies (AA & NAC, 2004a; Di Mattei et al., 2008). The social work implications included the need to inform clients of less burden-inducing coping techniques, the need for culturally competent social workers, and the need to increase outreach to AD caregivers earlier in the care recipient's disease progress. The limitations of this study included age being obtained at a time interval prior to the remaining demographic data, the spuriousness of the effect sizes, and the limited generalizability of the study.

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## **VITA**

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