

Patterns of Coping:
Differences between Latina and Non-Hispanic White ADRD Caregivers

by
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ABSTRACT

While the literature on caregivers of loved ones with Alzheimer's Disease and Related Disorders (ADRD) has continued to grow, the relationship of ethnicity and acculturation factors with regards to the coping strategies used by caregivers has not been extensively explored. The current study included participants from the Palo Alto site of the Resources for Enhancing Alzheimer's Caregiver Health (REACH) project. The study examined differences in coping strategies between 140 non-Hispanic White, 45 less acculturated Latina, and 61 more acculturated Latina caregivers. Univariate and Multivariate Analysis of Variance, as well as post hoc analyses, were conducted to determine the differences among the three groups. Results indicated less acculturated Latina caregivers employ more avoidant coping strategies compared to non-Hispanic White caregivers. However, no differences were found among the other groups in their use of avoidance coping. Moreover, there were no differences found in the use of social support seeking, count your blessings, problem focused, and blaming others coping among the three groups. These findings have important implications for the design of culturally relevant psychoeducational and therapeutic interventions aimed towards meeting the individual needs of these three populations. In addition, the findings expand on the understanding of maladaptive coping strategies that may be potentially exacerbating caregiver distress among Latina caregivers.

DEDICATION

This thesis is dedicated to my mother, my husband, and my sister who have zealously supported and encouraged me. My mother has inspired me to be a life long learner and inculcated that there are no invincible quests when one really desires something. My husband's ardent belief in me and academically prolific example have served as motivation through challenging times. I also feel privileged for my little sister's interest in my endeavors. Her exuberance and humor have provided me with energy. This thesis would not have been possible without their love, company, and all of the big and little things that they have incessantly done to facilitate the process.

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Chapter 1

INTRODUCTION

Overview of the problem

By the year 2030, adults aged 65 and older will reach approximately 72.1 million people, which translates to almost one out of every five people; thus, making up approximately 20% of the general population in contrast to 12.8% in 2008 (Administration on Aging, 2009). The oldest old (85 and older) will more than triple, from 5.4 million to 19 million between 2008 and 2050 (Smith & Baltes, 2007; U.S. Census Bureau, 2008).

Furthermore, according to the U.S. Census Bureau, the U.S. will become “an older and more diverse nation by midcentury (2008).” Minorities currently make up approximately one-third of the U.S. population and are expected to become the majority by 2050, making up a little over half of the entire population. In 2050, non-Hispanic Whites are projected to make up 46 percent of the population, Latinos will make up 30 percent, African Americans will make up 14 percent, Asians will make up 9.2 percent, and American Indians, Alaska Natives, Native Hawaiians, and other Pacific Islanders will make up approximately 3 percent (U.S. Census Bureau, 2008).

In regards to the older adult population, non-Hispanic Whites presently constitute 80 percent, African Americans make up 9 percent and Latinos make up 7 percent, other racial groups constitute the remaining 4

percent (Alzheimer's Association, 2010). However, with Latinos among the fastest growing minority, the growth rate of older adults in this group is expected to increase by 322% compared to 81% for older non-Hispanic Whites (Administration on Aging, 2009). In 2050, Latinos will make up 20 percent of the older adult population, non-Hispanic Whites will constitute 59 percent, African Americans will make up 12 percent, and other racial groups will make up the remaining 9 percent (Alzheimer's Association, 2010).

Overall, as the older adult population continues to grow and experience increased longevity, they will also be at-risk not only for developing Alzheimer's Disease and Related Disorders (ADRD), which increase in incidence with age and presently have no cure, but they will also be at risk for developing other leading causes of death among older adults (Centers for Disease Control and Prevention, 2010). Moreover, a five year longitudinal study which included a total of 1079 Medicare recipients, without AD or a related disorder at baseline, revealed that although Latinos with an *APOE-4* allele were as likely as whites with an *APOE-4* allele to develop AD by age 90, in the absence of that specific allele older Latinos were 2 to 4 times more likely than older non-Hispanic Whites to develop ADRD. These results suggest that even though no clear link between genetic factors and developing ADRD have been found, there are several risk factors to developing ADRD that are prevalent among Latinos which include a history of stroke, heart disease, diabetes,

high blood pressure, and level of education (Tang, Stern, Marder, Bell, Gurland, Lantigua, Andrews, Feng, Tycko, & Mayeux, 1998).

The growing older adult population and the rise in morbidity of ADRD will have a significant impact on the U.S. healthcare system. The implications are that the number of both formal and informal caregivers will increase as well. Patients with ADRD receive care primarily from informal caregivers such as spouses and adult children (Steadman, Tremont, & Davis, 2007). Fortunately, the assistance of informal caregivers provides some relief to a healthcare system that would otherwise struggle to meet the needs of the growing adult population. For example, in 2008, informal caregivers provided an approximated 12.5 billion hours of unpaid care, saving the healthcare system an estimated value of \$144 billion dollars a year (Alzheimer's Association, 2010).

Unfortunately, caregivers for persons with dementia experience higher stress levels and are at high risk for poor psychological and physical health when compared to the overall population and caregivers of other illnesses (Sorensen & Pinquart, 2003). Furthermore, Latino caregivers not only report more depressed symptomatology and higher levels of distress than non-Hispanic White caregivers, but are also susceptible to additional 'high stress' indicators such as linguistic/communication barriers and other stresses of acculturation such as experiencing hostility and prejudice (Sorensen et al., 2005). These high stress indicators along with emotional and cultural barriers contribute to

their underutilization of services even though research suggests they may actually be in more need of these services (American Psychiatric Association, 2007). Such findings not only emphasize the importance of addressing the needs of a growing aging and multiculturally diverse population, but also the significance of expanding on the information available about ADRD caregivers in order to more effectively address their unique caregiving needs thereby potentially improving the quality of care provided to the care recipient (Beach et al., 2005; Lewis, Lewis, Daniels, & D'Andrea, 2003, pp.20).

A Call to Action

Despite the growing body of literature on ADRD caregiving, very little research has focused on Latino caregivers. Therefore, it is essential to further explore and learn about the caregiving experience of both non-Hispanic White and Latino caregivers in an effort to determine culturally competent and efficient approaches for providing services (Gallagher-Thompson et al., 2005). In addition, Latino caregivers endorse more depressed symptomatology than non-Hispanic White caregivers (Sorensen et al., 2005). It may be helpful to gain additional insight into various coping strategies used by non-Hispanic White and Latino family caregivers, as both positive and negative coping strategies have been associated with caregiver distress and have been found to be effectively impacted by intervention (Coon et al., 2003). Identifying potential differences may assist in the development or strengthening of

interventions in order to decrease caregiver distress for both non-Hispanic White and Latino caregivers.

The purpose of the present study is to explore the differences in coping strategies employed by non-Hispanic White, less acculturated Latina, and more acculturated Latina caregivers of family members with ADRD. This exploration will help inform whether female ADRD caregivers, regardless of race or ethnicity, cope in different ways. Thus clarifying whether current interventions which include all race/ethnicities are appropriate, can be strengthened, or the development of interventions geared towards addressing the coping strategies particularly needed by a particular racial/ethnic group are warranted.

If differences in coping strategies between non-Hispanic White, less acculturated, and more acculturated Latina caregivers are found, the next step would be to determine whether there is a relationship between coping strategies utilized (i.e. negative or positive) and levels of distress by ethnicity/acculturation. The relationship between coping strategies and distress will not be examined as part of this thesis. However, investigating the potential differences and similarities in the utilization of coping strategies as well as the relationship between coping strategies and level of distress would provide rationale for the development or strengthening of interventions to decrease caregiver distress.

Chapter 2

AN EMERGING CRISIS

The rapid growth of both the older adult and Latino populations highlight the need to address the needs of Alzheimer's Disease and Related Disorders (ADRD) caregivers, as the probability of developing a type of dementia not only increases with age but the Latino population also appears to be at higher risk for developing it than the non-Hispanic White population (Centers for Disease Control and Prevention, 2010). Unlike other degenerative illnesses, the onset and progression of Alzheimer's Disease and Related Disorders (ADRD) is insidious and often attributed to the normal aging process (Allen, 2007). Therefore, patients of ADRD tend to be taken care of primarily at home and by family caregivers (Schulz, 2000). ADRD caregivers not only report higher levels of distress associated to caregiving than caregivers of other illnesses, but also have a higher mortality and morbidity rate (Vitaliano, Zhang, & Scanian, 2003). This means that ADRD caregivers tend to die at a higher rate and tend to have poorer health or co-occurring illnesses than caregivers of other illnesses.

The healthcare system benefits greatly from ADRD caregivers, as it is increasingly unable to efficiently meet the health needs of a rapidly growing older adult population (Alzheimer's Association, 2010). In addition, the mental health of ADRD caregivers has been found to be linked to the quality of care provided to ADRD patients. ADRD caregivers

who have poor mental health are at higher risk for exhibiting abusive behavior towards their care recipients, it is critical that attention is given to improving interventions that decrease ADRD caregiver distress (Beach, Schulz, Williamson, Miller, Weiner, & Lance, 2005).

Lastly, there is a scarcity of literature with regards to the particular needs and challenges faced by Latino ADRD caregivers. Therefore, it is essential to explore the potential differences in coping strategies utilized by non-Hispanic White and Latino ADRD caregivers in an effort to strengthen and develop culturally relevant interventions that decrease distress symptomatology by addressing coping strategies which have been found to be amenable to intervention and significantly decrease distress.

In order to understand the physical and emotional challenges faced by ADRD caregivers, it is important to first establish what constitutes normal aging and normal physiological health as well as comprehend how Alzheimer's Disease and Related Disorders deviate from the normal aging process.

Normal Aging and Physiological Health

Throughout the years, the literature on aging has utilized the terms "elderly," "older persons," "older adults," "seniors," and "elders" interchangeably to refer to adults over 64 years of age. Recent literature along with leading organizations on aging issues, such as the Alzheimer's Association and the Administration on Aging, have referred to this group

as “older persons” or “older adults.” Thus, the term “older adult” will be utilized to refer to this population. Furthermore, as a result of the heterogeneity in the older adult population, gerontologists and research on aging utilize the following categories to classify older adults: young old (65-75 years old), old old (75-85 years old), oldest old (85-99 years old), and centenarian (100 years old) (Administration on Aging, 2009; Alzheimer’s Association, 2010; Area Agency on Aging, 2010).

Aging is defined as a process in which progressive functional decline occurs and includes the following components: 1) a constant increase in mortality with age; 2) physiological changes that usually lead to a decline in functioning with age; and 3) increased vulnerability to diseases with age (Integrative Genomics of Ageing Group, 2008).

Normal aging involves a linear decline in most aspects of human physiology such as immune function, organ function, bone density, and cognitive function. In normal aging, the physiological changes that occur (in the absence of disease) are significantly heterogeneous among older adults. Therefore, normal aging can be categorized into two subtypes: usual aging and successful aging. The usual aging adults have significant impairments in some functions, compared to their younger counterparts, but do not qualify as having a disease and are considered to be “aging as expected.” The successful aging adults make up a small but growing portion of adults from the usual aging subtype. Successful aging adults show minimal age-associated declines in a given physiological function

and typically show minimal age-associated declines in a group of physiological functions. Thus, successful aging adults are in better physiological health than usual aging adults. Many factors such as genetics, environmental influences, personal habits, and diet are responsible for inter-individual differences in aging (Rowe & Devons, pp. 25-45, 1996).

Adults aging normally experience changes in the five senses: audition (hearing), gustation (taste), vision, olfaction (smell), and tactition (touch). Some common physiological declines that can be observed in the senses include: diminished hearing acuity, decreased ability to taste and produce saliva, loss of peripheral vision and ability to perceive depth, and decreased sensitivity to touch and smell. Older adults may also experience a slowing down of functions or organs such as the bladder, heart, and lungs, which may increase the frequency of urination (urinary disorders), increase the likelihood of a heart attack, and increase difficulty breathing respectively (respiratory diseases). Lastly, older adult's vulnerability to diseases such as dementia (Alzheimer's and Parkinson's disease), osteoporosis, arthritis, cardiovascular diseases (heart disease and blood pressure), cerebrovascular (stroke), and diabetes increase with age (Area Agency on Aging, 2010).

Currently, the leading causes of death for adults over 65 years are: heart disease (28%), cancer (22%), stroke (7%), chronic lower respiratory diseases (6%), and Alzheimer's disease (4%) (Center for Disease Control,

2009). However, there have been significant declines in major causes of death such as heart disease (-11.1%), prostate cancer (-8.7%), breast cancer (-2.6%), and stroke (-18.2%), but Alzheimer's disease related deaths have continued to rise (+18.2%) (Alzheimer's Association, 2010).

Normal Aging and Cognitive Health

Along with the previously mentioned physiological declines, research suggests that some cognitive decline is also a normal part of aging. Although much is still unknown about the course of cognitive functioning in normal aging, research suggests that there is no regular or predictable pattern of age-related changes in cognitive abilities before the age of 60, due to substantial variability in cognitive aging from individual to individual. As with physiological aging, inter-individual variability in normal cognitive aging can be attributed to diverse factors such as gender, ethnicity, environmental circumstances, and individual health (physiological and psychological) (Hedden & Gabrieli, 2004).

While, there is no reliable measure of decline in cognitive ability before the age of 60, longitudinal studies show that life-long age-related changes from age 20 to 60 tend to be small or non-existent (Hedden & Gabrieli, 2004). By 74, a significant and reliable average decline in all cognitive abilities emerges and, by 81, the average decrement in all cognitive abilities reaches approximately one standard deviation in healthy older adults (Schaie, 2005). Overall, as a person ages, the function of the neurons, or nerve cells in the brain, diminishes resulting in brief and

benign memory lapses. Thus, normal cognitive aging can be conceptualized as the benign changes and or benign memory losses that occur as a person ages (Area Agency on Aging, 2010).

Current research supports the theory that memory is not a single function or entity that either works well or does not. Rather memory is thought to be made up of various memory systems that are uniquely impacted by the process of aging or by other conditions (Luo & Fergus, 2008). Some types of memory decline with age, while others show little or no change, and some show improvement or appear to be repaired through training and practice (Luo & Fergus, 2008; Sattler & Ryan, 2009, pp.189). There is substantial evidence to support that not all cognitive abilities decline during adult development and normal-aging older adults display cognitive plasticity or the ability to regain some memory functioning through re-training and utilization of strategies (Hedden & Gabrieli, 2004; Sattler & Ryan, pp.189). This means that normal aging adults have the possibility of improving on cognitive and memory performance, if provided with effective training, tools, and support because “cognitive decline in old age is, for many older persons, likely to be a function of disuse rather than of the deterioration of the physiological or neural substrates of cognitive behavior (Luo & Fergus, 2008; Schaie, 2005, Dixon, 2003).”

It is important to note that normal aging does not affect a person’s procedural or semantic memories, which are responsible for remembering how to carry out processes such as tying a shoe or eating and

remembering the meaning of words in order to create speech, respectively. Procedural and semantic memories are the two areas that are most resilient to the aging process (Hedden & Gabrieli, 2004). Thus, cognitive decline remains normative as long as it does not impact a person's ability to carry out major daily activities or impair major functioning (Sattler & Ryan, 2009; Siegler, 2009, pp. 139).

In contrast to the differential decline seen throughout the various memory domains of a normal aging adult, an adult with Alzheimer's disease and Related Disorders (ADRD) shows a general decline in all domains. As a result, adults with ADRD do not perform relatively better in some areas than others, are not responsive to training, support, or tools that are aimed at improving memory abilities, and the disease severely impacts major functioning domains (Luo & Fergus, 2008).

Alzheimer's Disease and Related Disorders

Normal aging involves some decline in both physiological and cognitive functioning. However, it is important to note that ADRD are not a part of normal aging due to the severe impact on major functioning (Centers for Disease Control and Prevention, 2010). Rather dementia is a progressive and neurodegenerative disorder, which can be conceptualized as an overarching category that encompasses various types of dementia, including Alzheimer's disease. Furthermore, dementia is a syndrome, or a cluster of symptoms that can be caused by several underlying diseases (Sattler & Ryan, 2009). The following description of ADRD is not only

helpful in understanding the changes directly experienced by the patient, but also serves to elucidate the mental and physical deterioration witnessed by the ADRD caregiver through the progression of the disease, which may assist in better understanding the caregiving experience.

Alzheimer's disease (AD) is the most common type of dementia and accounts for an estimated 60-80 percent of the cases. AD is currently the seventh leading cause of death among all age groups and the fifth among those 65 and over. Approximately 5.3 million people have AD in the United States. Of these, 5.1 million people are aged 65 and over and 200,000 have early-onset AD (diagnosed before the age of 65). This translates to one in every eight people aged 65 and over, or 13 percent of the older adult population, having AD (Alzheimer's Association, 2010; CDC, 2009).

Although AD is the most common type of dementia, other types of dementia include: Vascular dementia, dementia with Lewy bodies, Frontotemporal dementias, Parkinson's dementia and mixed dementia. Vascular dementia, the second most common type of dementia, is often the result of brain damage from cerebrovascular or cardiovascular problems. It is also known as post-stroke dementia because it sometimes develops after a series of minor strokes. Dementia with Lewy bodies is another form of dementia that shares a similar pattern of decline with Alzheimer's disease, except it also presents with hallucinations and tremors, and is due to the presence of Lewy bodies in the brain's nerve

cells. Yet another form of dementia is Frontotemporal dementia, which refers to a group of dementias characterized by degeneration of nerve cells in the frontal and temporal lobes of the brain. Parkinson's dementia is a type of dementia often stemming from advanced Parkinson's disease. Lastly, mixed dementia shares a similar decline pattern in cognitive functioning to that of Alzheimer's disease, but is characterized by the co-occurrence of two or more types of dementia (Sattler & Ryan, 2009; Peskind & Raskind, 1996).

The onset of Alzheimer's disease (AD) is insidious and the progression is gradual and unremitting. AD typically develops after the age of 60 (late-onset), but on rare occasions it may manifest itself before the age of 60 (early-onset). Early-onset AD occurs in probably less than 1 percent of cases (Alzheimer's Association, 2010). When this occurs, AD may present itself as early as 30 years of age (Allen, 2007). Although the life expectancy of a person with AD varies, depending on the person's age at the time of diagnosis, research suggests that the median life expectancy is approximately 7 years and ranges approximately between 3-10 years. More specifically, people diagnosed in their 60s or early 70s are expected to live approximately 10 years, while people diagnosed in their 90s are expected to live 3 years (Zanetti, Solerte, & Cantoni, 2009). Since the prevalence of AD doubles every five years after the age of 60, it is estimated to affect 30 to 40 percent of the oldest-old population (85-99 years) (Steadman, Tremont, & Davis, 2007). Furthermore, research shows

there is an increase in short-term and intermediate-term memory risks at age 65, these risks particularly peaked at ages 75 and 85 years for both men and women. This means that the old-old (75-85 years) and the oldest-old (85-99 years) populations are predominantly at-risk for developing Alzheimer's Disease and related disorders (ADRD) (Alzheimer's Association, 2010).

While little is known about the etiology of this neurodegenerative disease, the pathophysiology of AD reveals severe and abnormal atrophy in various structures of the brain, particularly in the hippocampus which primary function is memory, when compared to a normal aging brain. In addition, AD is pathologically defined by an accumulation of amyloid beta proteins (neuritic plaques) and tau pathology (neurofibrillary tangles) in the neurons in the cerebral cortex (Buckner et al., 2005, Parks, Zec, & Wilson, 1993). Current studies theorize that the neuritic plaques and neurofibrillary tangles are the main cause of cell and neuron death in the brain (Parks, Zec, & Wilson, 1993, Waragai et al. 2009).

The primary risk factors of AD are age and family history. Studies suggest that almost 50 percent of people who have a first-degree relative with AD will not only develop the disease themselves by the time they turn 90 years old, but they are also likely to develop AD earlier in life. This may be explained by the presence of the apolipoprotein E-4 (APOE-4) allele, on chromosome 19, which current research has found to be related to an increase in risk for the common late-onset AD (Blazer, 1996; Reiman et al.

2009; Waragai et al., 2009). The augmented probabilities of developing AD when it is present in the family history and the accelerated onset associated with the APOE-4 allele make a strong argument for the hereditary and genetic characteristics of AD (Bowlby, 2004). Other factors that may increase the risk of developing AD are having Down syndrome, lifestyle and environment (e.g. smoking, diet, exercise), history of head trauma, gender, and lower educational or occupational status (Bowlby, 2004; Reiman et al., 2009).

The primary hallmark of dementia and dementia of the Alzheimer's type (AD) is acquired impairment of memory, but other syndromes include at least one of the following: aphasia (language impairment), apraxia (failure to perform complex motor tasks), agnosia (inability to identify objects despite intact sensory function), disorientation, impaired judgment, and difficulty in carrying out executive functions such as planning and organizing (Laczó, Vlček, Vyhnálek, et al., 2009; Mace & Rabins, 2006; Peskind & Raskind, 1996). Moreover, studies have found that AD not only directly impacts cognitive functioning, negatively affecting the person's ability to perform daily life activities, but it also may have a detrimental impact on the individual's mood and interpersonal relationships (Alzheimer's Association, 2010; Bowlby, 2004).

As a result of the various cognitive changes induced by AD, it is common for family members of individuals with AD to report that their loved one is manifesting personality changes, dysphoric mood (e.g.

irritability, anxiety, restlessness), depression, withdrawal, and apathy through the progression of the disease(Laczó et al., 2009; Ruby et al., 2009). Some of the most common psychiatric symptoms experienced by people with dementia are apathy, depression, agitation, and irritability (Meiland, 2005). Perhaps one of the most challenging aspects of AD, that may distress interpersonal relationships, is that the disease triggers behaviors or responses that are uncharacteristic of the person, for instance, a father may make inappropriate sexual advances on his daughter, an individual may display paranoia towards a spouse and complain of their treatment towards them and insult them, or an individual may be demanding and order a loved one to do something for them (Mace & Rabins, 2006; Meiland, Kat, Tilburg et al., 2005). Research has also revealed that although some individuals with AD may be unaware of their problems, others may show depressive or aggressive behavior and complain of wanting to die or threat to harm themselves or others (Bowlby, 2004).

It is not only important to communicate any concerns to a physician, as medication may alleviate mood problems and a plan can be established to ensure the safety of the individual and their family members, but also to understand that this neurodegenerative disease is responsible for the behaviors and not the individual (Parks et al., 1993). Additionally, as the disease progresses and the individual's mobility and ability to communicate verbally decreases, he/she may experience a

range of symptoms, such as pain and discomfort, which may not be perceived by family members. Therefore, it becomes important for the family to be attentive to visible signs of discomfort, such as bruises and sores, and seek a physician's assistance in determining other less visible signs of discomfort, such as arthritis and fractures, as these may also be factors contributing to the individual's mood changes (Mace & Rabins, 2006).

The Stages of ADRD

Since Alzheimer's Disease and Related Disorders (ADRD) can affect people differently and vary in progression, there is much debate about how to categorize the disease into stages. Nevertheless, stages of the disease have been described and may be used as guidelines in understanding both the progression of the disease and the role of the ADRD caregiver. The primary hallmark of ADRD appears during the Early Stage (mild impairment). Slight and subtle difficulties in remembering recent events may be observed, but the difficulties may be so subtle that neither the individual nor those around him/her may notice any changes. Given that the memory loss is periodic and inconsistent, mostly occurring around novel tasks or an unfamiliar environment, many may attribute these changes in memory to normal aging, stress, or fatigue thereby disregarding them and relying on long-term memory to function (Bowlby, 2004).

As the disease progresses towards the Middle Stage (moderate impairment), the individual begins to experience regular and noticeable difficulties in remembering things, such as how to write a check and how to get home, and especially struggle with complex tasks or activities that require problem solving and high levels of judgment, such as preparing a meal and managing finances (Mausbach, Coon, Depp, et al., 2004). During the Middle Stage, cognitive impairment continues to affect the individual's ability to carry out instrumental activities of daily living. The individual is no longer able to live independently and although he/she continues to rely on long-term memory and over learned skills to function and carry out activities of daily living (e.g. eat and dress), learning and retaining newly acquired information becomes increasingly difficult (Buckner, Snyder, Shannon, et al. 2005). Furthermore, the caregiver becomes particularly important at this stage as the individual starts to rely more on nonverbal methods of communication, begins to need prompting to care for personal hygiene and remember to take medications, becomes increasingly disoriented to time and place, and struggles with complex tasks such as using a telephone, shopping, and managing finances. One challenging aspect of this stage, for the caregiver, is the unpredictability and vacillation of the memory impairment. It may seem that some progress has been made one day, but functioning could be the same as it was before or worse the very next day, sometimes resulting in others

thinking that the individual is making things up or doing things on purpose (Gallagher-Thompson, Coon, Solano, et al. 2003; Mace & Rabins, 2006;).

As the disease progresses to the Advanced Stage (severely impaired), the individual's knowledge of personal history fades. It is also common for the individual to experience significant personality and behavioral changes (e.g. paranoia, increase in anxiety, repetitive behaviors, sundowning, urinary incontinence, asking questions repetitively), and tend to wander and become lost (Bowlby, 2004; Mace & Rabins, 2006). In the Advanced Stage, the individual is frequently disoriented and verbal cues are no longer sufficient. The individual may lose a great deal of mobility, thus requiring assistance, may experience fecal and urinary incontinence, and need constant supervision and physical assistance to carry out both activities of daily living and instrumental activities of daily living. Lastly, in the Terminal Stage, the individual is totally dependent on the caregiver and others. Physically, the body begins to shut down and the individual may have difficulty swallowing, speaking, moving, and breathing (Parks et al., 1993; Peskind & Raskind, 1996).

ADRD patients are greatly dependent on caregivers, especially in the Middle to Terminal stages of the disease. Caregivers play a critical role in the quality of life of the care recipient. Yet, caregiving for a person with Alzheimer's disease and other related disorders (ADRD) is a difficult undertaking that poses unique challenges in comparison to caregiving for

other chronic illnesses. ADRD caregivers provide more daily hours of care compared to their non-caregiver counterparts, and the hours of unpaid care increase as the disease progresses as well as when there are coexisting conditions in addition to ADRD (Alzheimer's Association, 2010). Consequently, the caregiver's role is demanding both physiologically and psychologically.

Impact of Caregiving

As a result of dedicating innumerable hours to assisting a loved one with ADRD, many caregivers may become so occupied in their caregiving responsibilities that many may fail to engage in activities that provide meaning and satisfaction or fail to set aside time to see a doctor or mental health professional, thereby neglecting their health (Stevens et al., 2004). A survey by the National Alliance for Caregiving/AARP reported that sixty-seven percent of caregivers said that one major reason they do not go to the doctor is because they put their family's needs first, or they put the care recipient's needs over their own (57%). More than half of caregivers (51%) said they do not have time to take care of themselves and almost half (49%) said they are too tired to do so (NAC, 2004).

A meta-analysis of recent studies that have focused on the impact of caregiving, found that caregiving has an overall negative impact on health (physical and psychological), employment, and financial stability (Vitaliano, Zhang, & Scanlan, 2003). More specifically, caregivers commonly suffer from aggravation of previous physical conditions , and

sustain muscular and skeletal injuries, among various other physical problems, as a result of assisting care recipients with daily activities such as bathing and changing (Shaw, 1997). Caregivers are also more likely than non-caregivers to have high levels of stress hormones, hypertension, coronary heart disease, slow wound healing, and reduced immune function (Lutgendorf, Garand, Buckwalter, Reimer, Hong, & Lubaroff, 1999; Shaw, Patterson, Zeigler, Dimsdale, Semple & Grant, 1999; Vitaliano, Scanlan, Zhang, Savage, Hirsch, & Siegler, 2002). Coon et al. (2004), highlight that caregiving for a loved one with a cognitive or physical impairment is also associated with poorer self-reported health and less implementation of preventive health behaviors by caregivers.

Caregivers are susceptible to depression, anxiety, anger, and other negative mental health concerns at higher rates than non-caregivers and caregivers of other illnesses, as well as are more likely to experience a lower overall quality of life (Mausbach, Coon, & Depp, 2004; Vitaliano, Zhang, & Scanlan, 2003). Research suggests that one-third of caregivers of people with ADRD have reported symptoms of depression and older-adult spousal caregivers (aged 66-96) who experienced caregiving-related stress are reported to have a 63% higher mortality rate than non-caregivers of the same age (Schulz & Beach, 1999; Taylor, Ezell, Kuchibhatla, Ostbye, Clipp, 2008). Lastly, due to the physical, psychological, and time demanding nature of ADRD caregiving, various caregivers face challenges in sustaining a job and maintaining social

connections. As a result, they are likely to experience financial difficulties and social isolation which may negatively impact their overall health. Caregivers are thus at an increased risk for psychiatric and medical morbidity as well as a higher mortality rate (Schulz & Beach, 1999; Schulz & Martire, 2004).

A System's Perspective

ADRD caregivers are at an increased risk for physical and psychological distress. A system's perspective suggests that caregiver and care recipient outcomes will be intricately connected (Beach et al., 2005; Lewis, Daniels, & D'Andrea, 2003, pp.20). Recent research on abuse by family caregivers found that depression in the caregiver was among the risk factors for providing a lower-quality of care (Adams, McClendon, & Smyth, 2008). In addition, Zarit and Edwards (2008) found that the kind of relationship between the caregiver and care recipient previous to the onset of the disease may also have an impact on the care recipient's stress and appraisal of the caregiving situation. Furthermore, a caregiver's report of a pre-morbid emotionally distant relationship with the care recipient is associated with greater caregiver burden and less favorable care recipient treatment or outcome. A caregiver's negative appraisal of the relationship with the care recipient is a predictor of depression and potentially abusive behavior (Steadman, Tremont, & Davis, 2007). Caregivers with means of coping have been associated with an increased survival of the person with dementia, possibly through a link

with quality of care (Adams, 2008). Consequently, the development or strengthening of existing culturally relevant interventions for diverse groups of family caregivers that address their particular needs and decrease caregiving-related distress is warranted.

Stress Process Model

The Stress Process Model (SPM) provides a theoretical framework for further understanding the factors that contribute to the mental and physical health consequences of caring for a loved one with ADRD. The model is important as it explains how stressors can accumulate to erode the caregiver's health and well-being, but also proposes how they can be contained in order to protect the caregiver from these effects. Thus, the SPM not only provides a basis for understanding the caregiving experience, but also provides a framework for informing the development of interventions that reduce caregiver distress by decreasing negative stressors and enhancing positive aspects of caregiving for someone with AD.

The model proposes that the cognitive impairments, functional decline, and behavioral problems of the care recipient comprise the primary objective stressors for the caregiver. As previously mentioned, ADRD not only impacts personality, judgment, orientation, and the ability to communicate, but the disease ultimately causes memory loss. Therefore, caregivers have not only reported physical health changes, stress, burden, and depression as the care recipient's memory diminishes,

but they also report increasing levels of distress and grief specifically associated with relational deprivation and loss of relationship reciprocity (Adams, Mckee, McClendon, & Smyth, 2008; Sanders, Ott, Kelber, & Noonan, 2008).

ADRD caregiving impacts the relationship by markedly altering the roles of the caregiver and care recipient (e.g. child caregiver playing a parental role and care recipient parent playing a child role) and disrupting the balance between help given and help received by the two parties. Eventually, the caregiver is providing more help than he or she is receiving and the care recipient is not able to reciprocate the relationship. Many caregivers report feeling that their loved one with dementia no longer seems to have any affection for them or that their loved one no longer seems to be “in there.” Due to the neurologically degenerative progression of the disease, it is common for caregivers to report that they feel they are mourning their loved one even though the care recipient has not passed away (Mace & Rabins, 2006). ADRD caregivers experience prolonged grief, as the course of the disease can last for various years, and has been described as “the constant yet hidden companion of Alzheimer’s disease and other related dementias (Doka, 2004).” ADRD caregiver grief shares more commonalities with true grief [post-death grief] than the anticipatory grief experienced by caregivers of other illnesses due to the cognitive decline which prevents the care recipient from being involved in the disease process and closure. The nature of the disease poses a

unique situation in which caregivers experience a phenomenon known as “dual dying” in which the caregivers grieve the loss of the care recipient prior to the actual death and grieve a second time at the time of their death. Research shows that caregivers experiencing intense prolonged grief may present symptoms such as yearning, bitterness, emotional numbness, shock, diminished sense of self, mistrust of others, trouble accepting the loss, avoidance of the reality of the loss, and are at risk for physical and mental health repercussions. It is important to keep in mind that caregiver’s grief is often unrecognized by informal supports and professionals, thereby leaving caregivers to face various challenges on their own (Sanders et al., 2008).

Furthermore, the SPM suggests that depression among caregivers is likely to be induced by a complex illness and caregiving situation, as opposed to a more organic, biologically based depression or a more chronic, dysthymic or neurotic depression (Adams, 2008). Thus, depression experienced by caregivers is situational and may actually manifest with different symptoms than other types of depression (Pinquart & Sorenson, 2003). For instance, depressive symptoms may be more a consequence of grief about the ongoing disease, fatigue from sleep deprivation or interruption, and or lack of self-efficacy or skills with regards to managing the caregiving situation.

Lastly, the SPM suggests that the demographic characteristics and psychosocial resources (e.g. sense of self-mastery, coping skills, and

social support) may moderate or mediate the effects of those primary stressors (e.g., care recipient's functional and behavioral problems) on what are termed primary subjective stressors (e.g. role overload and loss of intimate exchange). The primary subjective stressors are then followed by secondary stressors, which can be defined as role (e.g. work and family conflicts) and intrapsychic strains (e.g., lack of feelings of competence, loss of self) (Adams, 2008).

The model summarizes the development of the caregiving experience process into four domains: the context of the stress, caregiving stressors, resources/mediators, and caregiving outcomes. Thus, the impact of caregiving varies depending on various factors such as care recipient's health deterioration trajectory and behavioral problems, as well as the caregiver's coping style (Te Boekhorst et al., 2008).

A Diathesis-Stress Model

Diathesis-Stress models of psychopathology may also provide an additional way of conceptualizing the etiology of psychiatric disorders and understanding the impact of chronic stress on caregivers of AD. Thus, a diathesis-stress model helps to better understand the co-morbidity of disease experienced by caregivers and the high mortality rate.

A diathesis-stress model posits that psychopathology or psychiatric disorders are the result of multiple additive effects of diathesis, vulnerability, or predisposition. In other words, psychiatric disorders or emotional disturbance are the outcome of the interaction between "stress

and organic causes” and “esteem and social support systems.” Emotional disturbance includes both psychological and physical distress. Organic causes include both psychological and physical vulnerability, and esteem includes psychological resources and coping (Vitaliano, Russo, Young, Teri, & Maiuro, 1991).

$$\text{Emotional Disturbance} = \frac{\text{Stress and Organic Causes}}{\text{Esteem and Social Support Systems}}$$

Various studies provide support for a Diathesis-Stress model. A body of studies cited in Russo, Vitaliano, Brewer, Katon, & Becker (1995), found an association between psychological distress and psychiatric disorders in caregivers of ADRD. Studies revealed that the rates of major depressive disorder (MDD) vary from 41% (Coppel, Burton, Becker, & Fiore, 1985), to 21% (Gallagher, Rose, Rivera, Lovett, & Thompson, 1989), to 10%-55% (Pruchno & Potashnik, 1989). Moreover, a psychiatric history prior to the onset of a family member’s onset of dementia serves as the strongest predictor of psychiatric disorder in caregivers. Caregivers of ADRD are not only at risk for experiencing a psychiatric disorder due to the chronic stress they endure, but are incrementally at risk depending on previous mental health history.

The Diathesis-Stress model hypothesizes that psychiatric disorder may be improved by intervening in a way that decreases or eliminates undesirable factors, such as stressors, or by increasing and strengthening desirable factors such as esteem or coping strategies and social supports (Vitaliano, Russo, Young, Teri, & Maiuro, 1991). Thus, the implication of

interest to the current study is that the diathesis-stress model supports the improvement of emotional disturbance, both physical and psychological, of ADRD caregivers by the increase or strengthening of coping strategies.

Intervening to slow down the deterioration trajectory of AD and thoroughly targeting behavioral problems may require medical intervention and continuing research. Therefore, there is a need to provide caregivers with assistance in order to reduce distress associated with caregiving. Findings suggest that coping strategies are amenable to intervention and effectively reduce distress such as depression (Belle et al., 2006; Gallagher-Thompson et al., 2003). In addition, dysfunctional coping strategies are associated with the likelihood of developing anxiety and depression (Vedhara et al., 2001). Thus, strengthening positive coping strategies can serve as preventive measures for anxiety and depression in ADRD family caregivers.

Sociocultural Stress Model

Finally, Knight, Silverstein, McCallum, and Fox (2000) suggest in their sociocultural stress model that ethnicity and culture play a role in the stress and coping processes of caregivers. As both the older adult and Latino population continue to grow, it is increasingly important to consider differences in utilization of coping strategies utilized by Latinos and non-Hispanic Whites to achieve a better understanding of what coping strategies may be especially helpful and unhelpful in ADRD caregiving and determine whether the development or strengthening of available

interventions is warranted to increase positive coping strategies and thereby decrease caregiver distress.

Ethnicity and Culture in caregiving

In general ADRD caregivers tend to be family members, however, the literature suggests there are some ethnic differences between non-Hispanic White and Latino caregivers (Schulz, 2000). Latino caregivers are more likely to be daughters versus non-Hispanic White caregivers who are more likely to be spouses. Consequently, Latino caregivers tend to be younger than non-Hispanic Whites and a higher percentage of minority caregivers tend to be employed thus experiencing an additional level of stress due to the negative repercussions of caregiving on employment. Furthermore, there are a larger proportion of Latinos with lower income and lower education in the general population, therefore Latino caregivers are likely to reflect the demographics of the general population and have a lower income and lower education when compared to non-Hispanic White caregivers (Pinquart & Sorensen, 2005). Lower monetary influx and lower educational level in this population may also add to the stress associated with providing ADRD care.

Dilworth-Anderson and Anderson (1994) support the differences found in the literature and suggest that “ethnicity provides a context for caregiving.” Dilworth-Anderson and Anderson propose that ethnic groups may differ on various contextual levels such as: a) sociocultural (e.g., employment status, education), b) interpersonal (e.g., reciprocity, family

responsibility), c) situational (e.g., severity of patient impairment), d) temporal (e.g., timing of caregiver in the life cycle), and e) personal (e.g., coping styles, physical health). Aranda and Knight (1997) also propose that “ethnicity, culture, and minority group status play significant roles in the stress and coping process of caregivers as a result of a) a differential risk for exposure to stressors, b) variation in the appraisal of potential stressors, c) the effect on stress-mediating variables such as social support, coping, and other personal resources, and d) differential utilization of formal and informal service use.”

Hence, ethnicity and culture may play a role in caregiver stress and coping processes by serving as mediators. For example, *familismo* in collectivistic cultures may serve as a mediator for stress and perceived burden. A strong sense of *familismo* in collectivistic cultures may account for higher reported levels of positive appraisal of caregiving and lower levels of caregiver burden. A meta-analysis by Pinquart & Sorensen (2005) found that Latino caregivers report slightly lower levels of burden than non-Hispanic White caregivers. Furthermore, minority women reported less caregiving burden than non-Hispanic White female caregivers. Less reported burden may be mediated by ethnicity and culture as minority women may report less burden related to caregiving as they may be socialized into caregiver roles (e.g., *marianismo*), as opposed to non-Hispanic White women (Santiago-Rivera, Arredondo, Gallardo-Cooper, 2002, 2002, pp. 50).

For example, *marianismo* in Latinas is the cultural value that emphasizes women must be virtuous and self-sacrificing for the common good. The Maria Paradox exemplifies this value through the 10 commandments for women who subscribe to the paradigm of *marianismo*. The commandments most relevant to caregiving include: “Do not forget a woman’s place; Do not forsake tradition; Do not ask for help; Do not discuss personal problems outside the home; and Do not change. It is important to understand that Latinas may subscribe to these commandments to varying degrees depending on factors such as family culture, involvement in relationships that do not reinforce the commandments, education, and acculturation (Santiago-Rivera, Arredondo, Gallardo-Cooper, 2002, pp. 50).

The *marianismo* value of “not forsaking tradition” may explain the choice of Latino children or younger adults to provide care to older adults until the parent or older relative passes away. It is viewed negatively to place older adults in nursing homes, as this is often seen as abandonment and not fulfilling filial duties. Adult children and the family are therefore expected to take on responsibilities of rehabilitation, recovery, and daily care. Consequently, Latinos delay their access of medical care resources as well as institutionalization (Santiago-Rivera, 2002, pp. 78).

Another possibility for reporting less burden is that Latina females may share caregiving burden with other family members as a result of being part of a collectivistic society (Coon, Rubert, Solano, Mausbach,

Kraemer, Arguelles, Haley, Thompson, Gallagher-Thompson, 2004; Adams et al., 2002; Gallagher-Thompson & DeVries, 1994). Nonetheless, Latinos report and endorse significantly more depressed symptomatology, on average, than their non-Hispanic white counterparts and they also may experience more of other types of psychological distress (i.e. anxiety, anger) and strain (Coon, Rubert, Solano, Mausbach, Kraemer, Arguelles, Haley, Thompson, Gallagher-Thompson, 2004; Dolores-Gallagher & DeVries, 1994). These findings point out a contradiction for the Latino population as they report less caregiving burden yet endorse more distress symptoms. Attention should be given to the differences between perceived burden or stress (i.e. self-report) and assessed burden or stress (i.e. assessed by a mental health professional) among Latino caregivers. This contradiction also highlights alternative explanations for differences in psychological well-being that constitute two components on the stress model: appraisal and coping.

Research suggests that Latino caregivers often interpret dementia symptoms as a sign of normal aging, which may also contribute to a delay in seeking services and service utilization (Levkoff, Levy, and Weitzman, 1999). Other factors that may contribute to lack of or delayed service utilization for this population are financial limitations, language difficulties, lack of knowledge about service availability, fear of discrimination, and collectivistic values as previously mentioned (Gaugler, Kane, Kane, & Newcomer, 2007). Latinos endorsement of collectivistic and *familismo*

values contribute to a sense of pride in caregiving for older adults, as well as emphasize filial responsibility and the idea of reciprocity in family caregiving (Pinqart & Sorensen, 2005). The sense of pride in caregiving for older adults ties into self-worth. Self worth is generated by giving, respecting, and helping the family as well as others in the community. Loyalty and social connectedness are collectivistic values that are engrained in an individual's identity. In addition, the sense of obligation to the family and duty to be supportive is heightened during critical times, such as a chronic illness. Thus, even though those with a higher degree of acculturation tend to utilize medical and social services more than their counterparts with a lower degree of acculturation, more positive perceptions of caregiving and stronger familial support among this population tends to delay formal service utilization and institutionalization. As a result, Latinos report providing care for a longer period of time, on average, than non-Hispanic White caregivers (Coon et al., 2004). Moreover, although co-morbidity or co-occurring illnesses among the general ADRD caregiver and care recipient population is common, the double-jeopardy hypothesis proposes that minority caregivers and care recipients are at greater risk for poor health due to various compounding factors such as economic disadvantage and discrimination which make them more vulnerable to co-morbidity (Wykle & Kaskel, 1995).

In summary, the various ethnic and cultural differences in sociocultural, interpersonal, situational, and personal aspects may provide

greater understanding of the individual caregiving experiences of non-Hispanic Whites and Latinos. Since little is known about the coping strategies utilized by ADRD caregivers, especially those utilized by Latino ADRD caregivers, the purpose of this study is to explore the coping strategies utilized by both Latino and non-Hispanic White caregivers in an effort to learn more about the personal aspects that contribute to the caregiving experience of these populations.

Acculturation

Acculturation is a complex phenomenon that provides a framework for understanding the various ways in which someone from a culture is impacted when he/she comes into contact with a different culture. Acculturation has been conceptualized using both unidimensional and bidimensional models. The unidimensional model proposed that acculturation occurs on a linear continuum ranging from not acculturated (only having contact with the culture of origin) to completely acculturated (fully immersed into the dominant culture) (Lara, Gamboa, Kahramanian, Morales, and Hayes Bautista, 2005; Miranda, Bilot, Peluso, Berman, and Van Meek, 2006). Moreover, the unidimensional model posits that the more acculturated an individual becomes, the less that he/she identifies with their culture of origin. Similarly, the less acculturated an individual is, the less he or she identifies with the dominant culture. However, the unidimensional model does not appear to fully capture the complexity of acculturation (Berry, 2003).

The bidimensional model theorizes that acculturation can be more holistically captured by the concepts of integration, assimilation, marginalization, and segregation. Integration refers to an individual's incorporation or adoption of practices of the dominant culture into their culture of origin. Assimilation refers to an individual's abandonment of their original culture and complete adoption of the dominant culture. Marginalization refers to individuals who neither wish to maintain or participate in their own culture nor seek to partake in the dominant culture. Finally, segregation refers to an individual who focuses on solely embracing their culture of origin and rejects other cultures he/she comes in contact with (Blomstedt, Hylander, and Sundquist, 2006; Lara et al., 2005). Although the bidimensional model encompasses a more holistic understanding of acculturation, acculturation is nevertheless a more complex process that is experienced uniquely depending on various other factors.

Potential factors that may interact to produce various levels of acculturation for each individual include: language use or preference, educational level, generational status, family culture/values, social affiliation and daily living habits, and perceived prejudice/discrimination, as well as other more recently explored factors such as immigration status and language fluency (Cuellar, Arnold, and Maldonado, 1995; Zane and Mak, 2003). Different levels of acculturation have various psychological implications. Researchers have found that different levels of acculturation

may cause psychological distress to individuals as they adjust and negotiate their adaptation to the new or dominant culture. Various traditional values may be specifically impacted by the acculturation process. For example, *familismo*, or the preference for prioritizing and maintaining a close relationship with family, is a value that may become less salient through generations as a result of the acculturation process. Thus, there is evidence to suggest that increased acculturation may be correlated with lower levels of *familismo* or decreased filial obligation and responsibility to the family, which may result in less social, emotional and financial support to loved ones (Berry, 2003; Schulz, 1997).

Coon, Rubert, Solano, et al. (2004) also found that there are several differences between Latina women at various acculturation levels. For example, more acculturated Latinas tended to resemble their non-Hispanic White counterparts and tended to be more employed, have higher incomes, more years of formal education, and higher overall self-rated health than their less acculturated counterparts. More acculturated Latinas also tended to seek support from extended family members and formal service agencies more than their less acculturated counterparts (Chun, Organista, and Marini, 2003). Nevertheless, Latino caregivers, both more and less acculturated, appear to be particularly at risk for psychological distress related to caregiving responsibilities. These implications suggest the urgency for the development and strengthening

of interventions designed to meet the broad array of multicultural needs in order to address the needs of the emerging older adult population.

Coping Strategies

One potential way of developing or strengthening culturally relevant interventions is through an exploration of coping strategies used by non-Hispanic White and Latino caregivers, as positive and negative coping strategies have been associated with caregiver distress and have also been found to be effectively impacted by intervention (Coon et al., 2003).

According to Lazarus and Folkman (1984) coping is a “person’s efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the person’s resources.” There are various styles of coping and some are associated with positive outcomes, while others are associated with negative outcomes. Coping strategies associated with positive outcomes (i.e. information seeking, problem-solving, and social support seeking) can be labeled as positive coping strategies. “Approach” styles of coping such as “positive reappraisal (i.e. trying to see positive aspects of the situation), “seeking guidance and support (i.e. relying on or seeking others for advice and support), and “take problem-solving action (i.e. problem solving) appear to be protective against health problems as greater initial amounts of approach coping styles are associated with less changes in physical health. Approach coping has been associated with higher life satisfaction and lower depression, while the opposite is true for avoidant coping (Haley et al.,

1996). In particular, confidence in problem-solving, counting one's blessings, and seeking family support have been found to be beneficial for psychological health (Emmons & McCullough, 2003). In summary, positive caregiver outcomes have been mostly associated with problem-solving and acceptance coping strategies, while negative caregiver outcomes have been mostly associated with avoidance and wishful thinking.

“Avoidant” styles of coping can be labeled as negative coping strategies. “Avoidant” strategies such as “escape and avoidance (i.e. wishing the situation would go away),” “confrontive coping (i.e. angry confrontation of the patient or the situation, letting one's feelings out), and “accepting responsibility (i.e. blaming and criticizing self or others for problems) appear to have a negative impact on both physical and psychological health (Pruchno & Resch, 1989b). Evidence suggests that avoidant strategies were positively correlated with systolic and diastolic blood pressure, hypertension, and depression (Haley, Roth, Coleton, Ford, West, Collins, & Isobe, 1996; Vitaliano, Russo, Bailey, Young, & McCann, 1993; Vitaliano, Russo, Paulsen, & Bailey, 1995). However, Hinrichsen & Niederehe (1994), concluded that blaming strategies may be more of a reaction to stress than a precursor of psychological or physical distress. Therefore, it is important to be mindful of the design of the study when deriving interpretations regarding the relationship between coping strategies and caregiver outcomes.

Variation of Coping Strategies by Race and Culture

Few research studies focus on the relationship between coping strategies and both physical and psychological well-being for a diverse group of ethnicities. A study by Haley et al. (1996), found that coping responses utilized by non-Hispanic White and African-American caregivers were significantly related to race, with non-Hispanic Whites utilizing more approach coping and avoidance coping than African-American caregivers. Currently, there is a lack of literature addressing the differences in coping strategies between non-Hispanic White and Latino caregivers, as well as few studies address the effect of avoidance and approach coping on Latino caregivers. However, based on the previous findings for non-Hispanic White and African-American caregivers, it is likely that differences in coping strategies may also exist between Latino caregivers and other ethnic groups or cultures.

A review of the literature on ethnic minority caregivers by Aranda and Knight (1997), provided evidence to support higher levels of social support seeking for Latinos than for non-Hispanic Whites. However, one of the few studies that looked into differences in coping strategies for Latinos, non-Hispanic Whites, African-Americans, and Japanese American found that contrary to the majority of the literature, Mexican-Americans did not report higher levels of social support seeking or utilization than their non-Hispanic White counterparts (Adams et al., 2002). Yet, the sample pool may contribute confounding evidence as participants

were recruited from a human service agency rather than the general population, therefore those that seek assistance from a human service agency may only do so after their social supports have been depleted or other factors may be at hand. Another flaw of the study is that the sample may not be representative of the general Latino caregiver population, who tend to be primarily children, as it was composed of only spousal caregivers. Nevertheless, the contradicting literature on the utilization of social support seeking by the Latino population merits further exploration and replication.

Avoidance coping among Latino caregivers has not been addressed to date. However, cultural endorsement of *familismo*, reciprocity and filial responsibility, may contribute to a sense of guilt or shame on the part of Latino caregivers in acknowledging burden, distress, or lack of desire to care for a family member as this may be negatively perceived by the culture. Thus, Latino caregivers may exhibit more avoidant coping strategies as a way of managing conflict between values and feelings related to caregiving. The current literature has not yet explored the potential differences among non-Hispanic White and Latino caregivers in their use of other coping strategies explored in this study, such as count your blessings, problem focus, and blaming.

The previously mentioned study by Adams et al. (2002) noted that the Latinos in the sample were predominantly of low socioeconomic status. In light of the literature on acculturation, it is also important to be

mindful of SES and acculturation as potential confounds, as more acculturated Latinos tend to have higher income, more education, higher overall-self rated health, and exhibit more information and service seeking behaviors than their less acculturated counterparts. In addition, more acculturated Latinos may be more similar to their non-Hispanic White counterparts than their less acculturated counterparts. Hence it is important to take acculturation into consideration when exploring differences in coping strategies between non-Hispanic White and Latino ADRD caregivers (Coon et al., 2004). This study explores the differences in coping strategies among non-Hispanic White and Latino ADRD caregivers, while considering acculturation.

Based on a review of the literature, there is compelling evidence to support the need for further investigation into the interplay of ethnicity and utilization of coping strategies, with the goal of tailoring and strengthening interventions that may serve to positively impact the psychological and physical health of ADRD caregivers. Thus, the purpose of this study is to further investigate potential differences in coping strategies between non-Hispanic White, more acculturated Latino and less acculturated Latino ADRD caregivers.

Religious Coping

Several studies, including studies that have utilized the Resources for Enhancing Caregiver Health (REACH) data to be analyzed in the current study, have not only provided a more in-depth understanding of

religion as a coping strategy, but also addressed the use of religious coping by non-Hispanic White and minority caregivers. In general, there is evidence to suggest that religion is a common resource for dealing with stressful situations. Existing research supports the various outcomes of religious coping on caregiving, such as improved physical and psychological health by providing opportunities for social integration, social support, a relationship with a higher power, and a system of meaning and existential coherence (Ellis, 1991). Although there are limited studies looking at the use of religious coping by male caregivers, a substantial amount of female family caregivers report using religiosity as a coping strategy. In addition, studies suggest that female dementia caregivers tend to increase their use of religious coping as a primary coping strategy as care-recipients mental and physical deterioration increases through the progression of the disease (Salts, Denham, & Smith, 1991).

Religious coping by ethnicity has yielded important findings. Latinos in particular have been found to be less likely to seek professional assistance or talk about their situations or feelings, than non-Hispanic Whites, but instead rely more on faith or prayer (Valle, Cook-Gait, & Tabaz, 1993). A study by Mausbach et al. (2003), which utilized the REACH data being analyzed in this study, substantiates the previous findings. Mausbach et al. (2003), found that Latina ADRD caregivers reported both attending religious services and praying more than their non-Hispanic

White counterparts, as well as rated religion as more important.

Furthermore, Latinas reported greater use of positive religious coping strategies, in comparison to non-Hispanic White female caregivers, but there were no significant differences between ethnicities in negative religious coping strategies (i.e. wondering whether God had abandoned them or feeling that their relative's dementia was God's way of punishing them for their sins and lack of spirituality). The denomination was not predictive of positive religious coping strategies for either ethnicity.

Thompson, Solano, Kinoshita, Coon, Mausbach, and Gallagher Thompson (2002), which also utilized the data from the REACH sample, was among the first to look at the relationship between pleasant events and depression for Latinas. Since the literature has pointed out a link between depression and a decrease in pleasant activities, the aforementioned study aimed to observe the role of pleasurable events on mood and perceived burden. Thompson et al. (2002), found that religion could serve as a pleasant event and that there were differences in pleasant event preferences between Latinas and non-Hispanic Whites. non-Hispanic Whites were more likely to engage in pleasant activities that involved social functioning and nature, while Latinas more frequently to engage in pleasant activities that involved spiritual activities.

A number of studies have provided evidence for the beneficial effect of the utilization of religious coping by female caregivers of Mexican background as it is associated with reduced depression and decreased

suicidal ideation, but no comparisons were made to other ethnic groups (Hovey, 2000; Levin, Markides, & Ray, 1996). In a study by Levin et al. (1996), findings suggested that Mexican-Americans resembled African-Americans with regards to their high spiritual appraisals, however Mexican-Americans represented the most psychologically distressed group while African-Americans represented the least psychologically distressed group in comparison to each other and non-Hispanic White groups. Thus, in a discussion of the Levin et al. (1996) study, Aranda (2001) suggests that spiritual outlook on life may have more of a mitigating role in the stress of caregiving, but other mechanisms may still account for differences in psychological distress between the two groups.

Since the religious coping among Latino and non-Hispanic White female caregivers in this sample has already been addressed, the present study will only look at general coping strategies in an effort to address other mechanisms that may account for differences in psychological distress outcomes between ethnicities. Nevertheless, it is important to highlight that there is a need for studies to address the potential differences between religious coping among male and female caregivers of not only dementia patients, but of people with other health conditions, especially in light of the growing number of male caregivers.

Summary

The older adult and minority populations are projected to continue to increase rapidly. Furthermore, the older adult population is at-risk for

developing Alzheimer's Disease and Related Disorders, as the probability of developing dementia increases in incidence with age. ADRD significantly impacts both cognitive and physical functioning. More specifically, ADRD affects personality, mood, and behaviors as well as activities of daily living (ADLs) and instrumental activities of daily living (IADLs) (Alzheimer's Association, 2010). As a result of the gradual deterioration and length of the progression of the disease, as well as the interaction of various cultural attitudes related to caring for older adult family members, ADRD patients are mostly cared for at home by family caregivers.

Caregivers for people with dementia are known as the hidden patient because they experience higher stress levels and are at higher risk for poor psychological and physical health when compared to the overall population as well as caregivers of other illnesses (Sorensen & Pinquart, 2003). ADRD caregivers are thus at a higher risk for mortality and co-morbidity of illnesses. Furthermore, Minority ADRD caregivers are in a situation known as double jeopardy as many may have limited access to services and little may be known about relevant information and interventions that may be helpful to them. Thus, Latino caregivers not only report more depressed symptomatology and higher levels of distress than non-Hispanic White caregivers, but they are also susceptible to additional stress and underutilization of services (Sorensen et al., 2005).

Positive coping strategies have been associated with being protective against health problems, as well as other positive outcomes such as higher life satisfaction and lower depression (Haley et al., 1996; McCullough, 2003). Negative coping strategies have been associated with negative outcomes such as high blood pressure, depression and other forms of psychological distress (Pruchno & Resch, 1989b; Vitaliano et al., 1995; Vitaliano et al., 1993). Finally, a systems perspective suggests there is a link between caregiver health and quality of care provided (Lewis et al., 2003). Hence it is crucial to better understand the differences in utilization of coping strategies between Latino caregivers and non-Hispanic White caregivers, in order to more effectively address their unique caregiving experiences, thus decreasing caregiver distress and potentially enhancing the quality of care provided to ADRD patients.

Purpose of Study

The purpose of the present study was to explore the differences in coping strategies of non-Hispanic White, less acculturated Latina, and more acculturated Latina caregivers to better understand the implications of these differences for developing or strengthening culturally relevant interventions. Based on the review of the literature, the following hypotheses were posed:

Hypotheses

- 1) There would be differences among the three ethnicity/acclturation groups in their use of social support seeking as a positive coping strategy.
 - a. Less acculturated Latina caregivers would report more social support seeking than would more acculturated Latina and non-Hispanic White female caregivers.
 - b. There would be no differences between more acculturated Latina and non-Hispanic White female caregivers in social support seeking.
- 2) There would be differences among the three ethnicity/acclturation groups in their use of avoidance coping as a negative coping strategy.
 - a. Less acculturated Latina caregivers would report more use of avoidance coping than would more acculturated Latina and non-Hispanic White caregivers.
 - b. There would be no differences between more acculturated Latina and non-Hispanic White female caregivers in their use of avoidance coping.
- 3) There would be no differences among the three ethnicity/acclturation groups in their use of the blaming others as a negative coping strategy.

- 4) There would be no differences among the three ethnicity/acclulturation groups in their use of problem focused coping and count your blessings as positive coping strategies.

Chapter 3

METHODOLOGY

Recruitment and Participants

Data were collected at the California site of the Resources for Enhancing Alzheimer's Caregiver Health (REACH) Project sponsored by the National Institute on Aging and National Institute for Nursing Research.

The REACH project recruited a diverse sample of female family caregivers of individuals with Alzheimer's Disease and Related Disorders (ADRD) from memory disorder clinics, primary care clinics, social service agencies, and doctor's offices. Outreach efforts also included radio and television broadcasts, public service announcements, targeted newsletters, and community presentations. The current sample was comprised of 264 female caregivers who lived with their family members or other loved ones with ADRD and self-identified as non- Hispanic White or Latina.

Female family caregivers agreed to participate in a randomized clinical trial offering interventions for family caregivers of ADRD. Potential participants were initially screened over the telephone for eligibility to participate in the study. Informed consent, availability for workshop (i.e. day, time, location), and language preference (i.e. English or Spanish) was obtained from all eligible participants.

REACH investigators utilized a standardized screening, which consisted of inclusion and exclusion criteria, in order to determine participant eligibility. Inclusion criteria required the following: 1) The caregiver must have reported living with the care recipient. Living with a care recipient or family member was defined as sharing a cooking facility and/or washing appliances. 2) Family members were defined as a person having a close relationship with the care recipient, such as a friend or neighbor, and being referred to by a familial noun (e.g. aunt, uncle, etc...) regardless of biological relation. 3) Caregivers were required to be at least 21 years or older, have been caring for a family member for an average of at least four hours a day, and have provided care for at least six months. 4) The care recipient must have either been given a diagnosis of Alzheimer's disease or dementia (ADRD) by a physician or presented with characteristics consistent with a diagnosis of dementia as measured by a MMSE score of 23 or less (look in criteria of change of indices paper). 5) Finally, the care recipient must have presented with characteristics consistent with a Mini-Mental State Examination (MMSE) score of 23 or less, as well as demonstrated difficulties on two or more Instrumental Activities of Daily Living (IADLs) or one or more Activities of Daily Living (ADLs).

The inclusion criteria previously listed were chosen to ensure that family caregiver participants were involved in the various daily activities and responsibilities that are associated with increased caregiver distress.

Other logistical requirements included having access to a telephone, planning to remain in the geographic area for at least 6 months, and proficiency in the language specified by each study site (i.e., either English or Spanish).

Demographic variables were collected from participants who met eligibility requirements at baseline only. Then, participants were administered a battery of measurements that was carefully compiled to make up a standard measurement protocol. The measurement protocol was administered to eligible participants at baseline, 6, 12, and 18 months post-baseline. The current study limits its analysis to data collected at baseline.

Measures

Resources for Enhancing Alzheimer's Caregiver Health (REACH) baseline data were used in this study.

Social Demographics

The standard measurement protocol used at baseline gathered demographic information, about both the caregiver and care recipient, as well as other variables that may be relevant to potential differences and similarities in coping strategies utilized by non-Hispanic White and Latina family caregivers. Information collected included ethnicity, age, years of formal education, marital status, caregiver's relationship to the care recipient, amount of time caregiving, and caregiver's employment status (The Social Demographics measure can be found in Appendix A).

Acculturation Rating Scale for Mexican Americans-II- Brief (ARSMA-II; Cueller, 1995).

Latina participants completed the revised Acculturation Rating Scale for Mexican Americans. This instrument assessed the respondent's acculturation process through an orthogonal, multidimensional approach that measured cultural orientation toward the Mexican culture and the Anglo culture independently through the use of two subscales: 1) Anglo Orientation Subscale (AOS), consisting of 13 items, and 2) Mexican Orientation Subscale (MOS), consisting of 17 items. The MOS has a coefficient alpha of .88 and the AOS has a coefficient alpha of .83 (Cueller, 1995).

The ARSMA-II items inquired about the respondent's familial generational status and the respondent's degree of engagement in various activities related to the Anglo and Mexican culture. Familial generational status was established by the respondent's identification with one of the five generational status (1st generation= You were born in Mexico or other country; 2nd generation= You were born in the USA; either parent born in Mexico or other country; 3rd generation= You were born in the USA; both parents born in the USA and all grandparents born in Mexico or other country; 4th generation= You and your parents born in the USA and at least one grandparent born in Mexico or other country; 5th generation= You and your parents were born in the USA and all grandparents were born in the USA). The degree of engagement in each activity was

measured on a 5-point Likert scale ranging from 1 to 5 (1= Not at all; 2= Very little or not very often; 3= Moderately; 4= Much or very often; 5= Extremely often or Almost always). The participant's acculturation level was calculated by first obtaining the mean of both the AOS score, by summing the 13 items of the AOS scale and dividing the sum total by 13, and the mean of the MOS score, by summing the 17 items of the MOS score and dividing the sum total by 17. Secondly, the MOS mean was subtracted from the AOS mean to obtain a linear acculturation score that represented the individual's score along a continuum ranging from very Mexican oriented to Very Anglo oriented.

Unlike Cuellar's Acculturation Scale, the researchers in the REACH project created two groups: less acculturated and more acculturated. Participants were placed in the appropriate category according to their acculturation score. Those who were considered Very Hispanic and Slightly Hispanic were placed into the less acculturated category, while those who were considered Strongly Anglo and Very Anglicized were placed into the more acculturated category (The Acculturation Rating Scale for Mexican-Americans-II can be found in Appendix B).

Revised Ways of Coping Check List

The Ways of Coping Check List (WCCL; Aldwin, Folkman, Shaefer, Coyne & Lazarus, 1980) original measure was derived from Lazarus' transactional model of stress and consists of 68 items which are part of seven scales that assess coping strategies: Problem-focused, wishful

thinking, growth, minimize threat, seeks social support, blamed self, mixed scale (contains both avoidant strategies and help-seeking strategies). The Revised Ways of Coping Check List (RWCCCL; Vitaliano, 1985) is a revised 43 item measure that assesses the degree to which caregivers use the various types of coping strategies (both negative and positive) to cope with their caregiving situations. Through consultation between the REACH researchers and the author of the RWCCCL, representative negative and positive coping strategies were chosen for the purpose of simplifying the number of questions administered to assess the coping strategies utilized by participants. The coping strategies included in the present study are: blaming others and avoidance (negative coping strategies); and problem focused coping, social support seeking, and counting blessings (positive coping strategies). Caregivers were asked to express the degree to which they used a specific thought or behavior to deal with their caregiving situations. Response options ranged from 0 to 3 for each item (0= Never Used; 1= Rarely Used; 2= Sometimes Used; 3= Regularly Used). For example, caregivers were asked to rate the degree to which they “figured out who to blame,” “slept more than usual,” “came up with a couple of different solutions to my problem,” or “thought how much better off I am than others,” in dealing with caregiving situations. The Problem-Focused scale has a coefficient alpha of .88, the Social Support Seeking scale has a coefficient alpha of .81, and the Avoidance

scale has a coefficient alpha of .81 (Vitaliano et al., 1985) (*The Revised Ways of Coping Check List* can be found in Appendix C).

Data Analyses

Data was screened, prior to conducting analyses, through the use of box plots and appropriate tests, in order to identify outliers and assess violation of assumptions; as a result eleven outliers were removed from the sample. Descriptive statistics were determined to characterize the sample. Inferential statistics were conducted to examine differences in sociodemographic variables among the three ethnic/acclturation groups: non-Hispanic White, more acculturated, and less acculturated (Chi squares on categorical variables and ANOVAs on continuous variables). Based on identified differences between the three ethnic/acclturation groups, a correlation analysis was used to examine potential covariates with the dependent variable. A correlation analysis was also conducted to examine intercorrelation among the five dependent variables.

Based on the results of the correlation analyses, a one-way univariate analysis of variance (ANOVA) was conducted to determine differences among the three ethnicity/acclturation groups (non-Hispanic White, less acculturated Latina, more acculturated Latina caregivers) in their use of social support seeking as a positive coping strategy (H1). A multivariate analysis of variance (MANOVA) was conducted to determine ethnicity/acclturation differences in avoidance coping and blaming others coping (H2, H3). A multivariate analysis of variance (MANOVA) was also

conducted to determine ethnicity/acclulturation differences in problem focused coping and count your blessings coping (H4). Subsequent analysis of variance (ANOVAs) and post hoc tests were conducted when appropriate.

Chapter 4

RESULTS

Descriptive Statistics

Preliminary descriptive statistics were analyzed prior to testing the study hypotheses in order to determine differences in caregiver demographic characteristics at baseline. Table 1 presents the results of the analyses for the three ethnicity/acclturation groups (Ethnicity/Acculturation: non-Hispanic White, less acculturated Latina, more acculturated Latina).

The age for eligible less acculturated Latina caregivers ranged from 28 to 78, with a mean of 51.84 ($SD = 11.75$). The age for eligible more acculturated Latina caregivers also ranged from 25 to 78, with a mean of 51.02 ($SD = 13.61$). The age for eligible non-Hispanic White caregivers ranged from 23 to 89, with a mean of 61.18 ($SD = 12.99$). Less acculturated and more acculturated Latina caregivers were significantly more likely to be younger than non-Hispanic White caregivers, $F(2, 245) = 17.40, p < .001$.

Less acculturated ($M = 9.29, SD = 4.16$) and more acculturated Latina ($M = 11.41, SD = 3.59$) were significantly more likely to report fewer years of education, than non-Hispanic White caregivers ($M = 13.86, SD = 1.74$), $F(2, 245) = 49.45, p < .001$; Less acculturated ($M = 6.49, SD = 6.12$) and more acculturated Latina ($M = 6.56, SD = 7.61$) were significantly more likely to have provided more years of caregiving, than

non-Hispanic White caregivers ($M = 4.32$, $SD = 5.29$), $F(2, 245) = 3.97$, $p < .05$; less acculturated ($M = 17.02$, $SD = 17.01$) and more acculturated Latina ($M = 16.97$; $SD = 18.67$) were more likely to have less years living with care recipient than non-Hispanic White caregivers ($M = 24.00$; $SD = 21.66$), $F(2, 245) = 3.64$, $p < .05$.

Overall, less acculturated Latina and more acculturated Latina caregivers were more likely to be non-spousal caregivers (69% and 85%, respectively) than non-Hispanic White caregivers (49%), $\chi^2(2, 246) = 25.42$, $p < .001$. Non-Hispanic White and more acculturated Latina caregivers were more likely to earn more than or equal to 30,000 dollars a year (59% and 54% respectively) than less acculturated Latina caregivers (24%), $\chi^2(2, 246) = 22.13$, $p < .001$.

Table 1

Caregiver Social Demographics by Ethnicity/Acculturation

	NHW		LAL		MAL			
	(n = 140)		(n = 45)		(n = 61)			
Variable	n	(%)	n	(%)	n	(%)	χ^2	p
Income								
< \$30,000	57	(41)	34	(76)	28	(46)	22.13	< .001
≥ \$30,000	83	(59)	11	(24)	33	(54)		
Relationship to CR								
Spouse	72	(51)	14	(31)	9	(15)	25.42	< .001
Non-Spouse	68	(49)	31	(69)	52	(85)		
	Mean (SD)		Mean (SD)		Mean (SD)		F	p
Age	61.2 (13)		51.8 (11.8)		51.0 (13.6)		17.4	< .001
Years of Education	13.9 (1.7)		9.3 (4.2)		11.4 (3.6)		49.4	< .001
Years of Caregiving	4.3 (5.2)		6.5 (6.1)		6.6 (7.6)		4.0	< .05
Years living with CR	24.0 (21.7)		17.0 (17.0)		17.0 (18.7)		3.6	< .05

Note: NHW= Non-Hispanic White; LAL= less acculturated Latina; MAL= more acculturated Latina; CR= Care Recipient

Analysis of Hypotheses

Based on identified differences between the three ethnic/acclturation groups, a correlation analysis was used to examine potential covariates, such as age and education, with the five dependent variables. All correlations were considered small and less than $r = .15$, $p < .01$. Therefore, analysis of covariance (ANCOVA) or multivariate analysis of covariance (MANCOVA) to eliminate potential confounding variables were not warranted.

A correlation analysis was also conducted to examine intercorrelation among the five dependent variables. Social support seeking as a coping strategy was not significantly correlated with avoidance coping or blaming others coping. A small correlation was found between social support seeking and count your blessings coping, ($r = .29$, $p < .01$), and social support seeking and problem focused coping, ($r = .32$, $p < .01$). However, due to the strength of the correlations, a univariate analysis of variance (ANOVA) was conducted to determine differences among the three ethnicity/acclturation groups (Ethnicity/Acculturation: non-Hispanic White, less acculturated Latina, more acculturated Latina caregivers) in their use of social support seeking as a positive coping strategy (H1).

The means and standard deviations for the social support seeking coping strategy as a function of the three ethnicity/acclturation factors are presented in Table 2. The results for the ANOVA indicated no significant

differences among the three ethnicity/acculturation groups in their use of social support seeking as a positive coping strategy, ($F(2, 243) = 2.05$, $p = .13$). Thus, the results did not support the first hypothesis (H1) stating that there would be differences among the three ethnicity/acculturation groups in their use of social support seeking as a positive coping strategy. More specifically, the first hypothesis stated that less acculturated Latina caregivers would report more social support seeking than the more acculturated Latina and non-Hispanic White female caregivers. Yet, post hoc tests were explored to investigate whether there were any trends. The LSD post hoc test suggests there may be a trend towards less acculturated Latina caregivers to report more use of social support seeking than non-Hispanic White female caregivers.

Avoidance coping and blaming others coping were not significantly correlated with social support seeking, problem focused, or count your blessing coping. However, avoidance coping and blaming others coping were moderately correlated, ($r = .44$, $p < .01$). Therefore, to test hypotheses two and three, a multivariate analysis of variance (MANOVA) was conducted to determine ethnicity/acculturation differences in avoidance coping and blaming others coping (H2, H3). The means and standard deviations for avoidance and blaming others coping strategies of the three ethnicity/acculturation factors are presented in Table 2. The results for the negative coping strategies MANOVA revealed significant differences among the three ethnicity/acculturation groups on their use of

negative coping strategies, (Wilk's Lambda = .943, $F(2, 243) = 3.56$, $p = .007$, $\eta^2 = .029$). Univariate ANOVA and Bonferroni post hoc tests were conducted as follow-up tests. ANOVA results indicated differences between the three groups in their use of avoidance coping, ($F(2, 243) = 4.02$, $p = .012$, $\eta^2 = .032$). An analysis of the means revealed less acculturated Latina caregivers reported more use of avoidant coping strategies than non-Hispanic White caregivers; and, Bonferroni post hoc analysis revealed that less acculturated Latina caregivers significantly differed from non-Hispanic White caregivers in their use of avoidant coping strategies, but did not significantly differ from more acculturated Latinas. However, the Bonferroni post hoc analysis did reveal a trend for differences between less acculturated and more acculturated Latina caregivers; and, the less conservative LSD post hoc analysis revealed that less acculturated Latina caregivers significantly differed from both non-Hispanic White and more acculturated Latina caregivers. Both the Bonferroni and LSD post hoc analyses confirmed there are no differences in use of avoidant coping strategies by non-Hispanic White caregivers and more acculturated Latina caregivers. Therefore, the second hypothesis examining the differences among the three ethnicity/acclturation groups in their use of avoidance coping strategy was partially confirmed using the more conservative Bonferroni post hoc analysis.

A univariate (ANOVA) analysis for blaming others as a negative coping strategy revealed no significant differences among the three

ethnicity/acculturation groups on their use of blaming others coping, ($F(2, 243) = 1.35, p = .261, \eta^2 = .011$). The third hypothesis examining the differences among the three ethnicity/acculturation groups in their use of blaming others coping strategy was supported.

Problem focused coping and count your blessings coping were also moderately correlated, $r = .59, p = .01$. Therefore, a multivariate analysis of variance (MANOVA) was conducted to determine ethnicity/acculturation differences in problem focused coping and count your blessings coping (H4). The means and standard deviations for problem focused coping strategy as a function of the three ethnicity/acculturation factors are presented in Table 2. The results for the positive coping strategies MANOVA was not significant Wilk's Lambda = .975, $F(2, 243) = 1.51, p = .198$. Thus, the fourth hypothesis examining the differences among the three ethnicity/acculturation groups in their use of problem focused coping and count your blessings coping was supported.

Table 2

Means and Standard Deviation of Dependent Variables by

Ethnicity/Acculturation

	Non- Hispanic White	Less acculturated Latina	More acculturated Latina
Dependent Variable	Mean (SD)	Mean (SD)	Mean (SD)
social support seeking	12.3 (3.2)	11.2 (3.6)	11.7 (3.5)
problem focused	31.7 (6.0)	32.9 (5.9)	31.3 (6.6)
count your blessings	13.0 (3.1)	12.7 (2.9)	13.3 (3.1)
avoidance	13.8 (4.9)	16.1 (4.7)	13.9 (5.0)
blaming others	6.2 (3.8)	5.8 (3.8)	5.2 (3.8)

Chapter 5

DISCUSSION

In this section, the results of the study will be discussed by first addressing the findings for the three positive coping strategies (social support seeking, problem focused, count your blessing), and will be followed by a discussion of the findings for the two negative coping strategies (blaming others and avoidance). The chapter ends with the limitations, implications for future research, and conclusion.

The purpose of this study was to explore the differences in selected positive and negative coping strategies among non-Hispanic White, less acculturated Latina, and more acculturated Latina caregivers of family members with ADRD. Positive coping strategies, such as social support seeking, have been previously associated with positive outcomes such as higher life satisfaction and lower depression symptomatology (Haley et al., 1996). Negative coping strategies, such as avoidance, are reportedly positively correlated with negative outcomes such as hypertension and higher depression symptomatology (Vitaliano, et al., 1993). In general, ADRD caregivers appear to be especially vulnerable to the deterioration of their physical and psychological health. Moreover, Latino caregivers appear to report more distressed symptomatology than non-Hispanic White caregivers. Less acculturated Latino caregivers may be even more at-risk for negative physical and psychological repercussions as a result of acculturative stressors (Sorensen et al., 2005). Therefore, learning more

about the particular coping strategies being used by non-Hispanic Whites, less acculturated, and more acculturated Latina caregivers is important in order to develop or strengthen culturally relevant interventions in order to increase positive coping strategies, decrease negative coping strategies, and impact ADRD caregiver distress.

The first hypothesis stated that less acculturated Latina caregivers would report more social support seeking as a positive coping strategy than either non-Hispanic White or more acculturated Latina caregivers. However, the findings did not support any significant differences among the three groups. These findings are incongruent with the majority of the literature on ethnic minority caregivers suggesting Latino caregivers would actually report more use of social support seeking coping (Aranda & Knight, 1997). However, these findings are consistent with a study by Adams et al. (2002), which examined differences among Non-Hispanic White, African American, Japanese American and Mexican American dementia caregivers in their use of social support seeking. Moreover, there is also evidence to suggest non-Hispanic White dementia caregivers may report more social support seeking coping than Latino dementia caregivers (Valle, Yamada, & Barrio, 2004). Thus, there seems to be conflicting evidence regarding the use of social support seeking coping by Latino and non-Hispanic White caregivers.

A focus of the current study and one potential explanation for the conflicting evidence regarding the use of social support seeking coping

between Latino caregivers and non-Hispanic White caregivers is that studies tend to group less acculturated and more acculturated Latinos into one category. Overall, the literature suggests there may not only be significant differences between less acculturated and more acculturated Latinos, but more acculturated Latinos may actually be more similar to non-Hispanic Whites (Coon et al., 2004). Also, despite of the heterogeneity among the Latino population, studies typically group Latinos of various ethnic origins into one category. Therefore, it is important to take acculturation and the heterogeneity of the Latino population into consideration when designing studies to examine the differences in social support seeking coping and other coping strategies, as erroneous conclusions can result with regards to the similarities or differences in coping styles.

Another potential explanation is that the social support seeking items in the subscale used in the majority of studies, the revised Ways of Coping Check List, inquire about both formal and informal supports (i.e. “accepted sympathy and understanding from someone,” “got professional help and did what they recommended”). Researchers have found that Latino caregivers may prefer familial support to formal support (Salman, Diamond, Jusino, Sanchez, & Lebowitz, 1997). Furthermore, various studies report that Latino family caregivers receive more support from family members than non-Hispanic White caregivers (Rubert & Herman, 1994; Wood & Parham, 1990). It can be argued that Latino caregivers

may use more informal social support seeking coping, while non-Hispanic Whites maybe use more formal social support seeking coping. Therefore, studies exploring social support seeking may be measuring two types of social support seeking attitudes.

Due to the incongruence of the findings related to social support seeking between Latino and non-Hispanic White caregivers, post hoc analyses were used to explore the differences among the three groups. The results indicated there may be a trend suggesting less acculturated Latina caregivers reported more use of social support seeking than non-Hispanic White caregivers. Hence, there is a need for further exploration of social support seeking coping to better understand the similarities or differences among non-Hispanic White, less acculturated, and more acculturated Latina caregivers.

Ethnic differences in other positive coping strategies such as problem focused coping and count your blessings coping have been less explored in the literature. No differences emerged among the three groups in their use of either problem focused coping or count your blessings coping, which was consistent with the fourth hypothesis. Although studies examining differences in count your blessings coping between Latina and non-Hispanic White caregivers were not found, there is one study to date examining potential differences in problem focused coping. The current findings are consistent with the findings by Adams et al. (2002), which suggest there are no differences among Latino and non-

Hispanic White ADRD caregivers in problem focused coping. However, that study did not explore differences by acculturation level. Since count your blessings coping and problem focused coping have been found to be positively correlated with better psychological and physical health, it is important to continue to explore factors that may lead to utilization of these positive coping strategies in at-risk populations (Haley et al., 1996).

There are also few studies examining ethnic differences in the use of negative coping strategies such as avoidance and blaming others. To date, the literature has not investigated potential ethnic differences in the use of blaming others. Yet, a study by Hinrichsen & Niederehe (1994), suggests that blaming others may be a response to a stressor rather than a coping mechanism. Thus, a better understanding of blaming others is needed. Since no ethnic differences have been investigated, this study assumed there would be no differences among the three groups. The results were consistent with the third hypothesis.

However, the study by Adams et al. (2002), included Mexican American, African American, and non-Hispanic White dementia caregivers and examined their use of avoidance/ escape coping. Yet, no studies to date have examined differences among non-Hispanic White, less acculturated, and more acculturated Latina caregivers. The second hypothesis stated that less acculturated Latina would report more use of avoidance as a coping strategy than non-Hispanic White and more acculturated Latina caregivers. Post hoc analyses confirmed less

acculturated Latinas reported using avoidance coping more than non-Hispanic White caregivers and are consistent with the Adams et al. (2002) findings with Latino and non-Hispanic White caregivers. Post hoc analyses also identified a trend suggesting less acculturated Latina caregivers may use avoidant coping strategies more than more acculturated Latina caregivers. Taken together, these findings provide a more in-depth understanding for the various factors that may contribute to higher levels of reported distress among the Latino population, as avoidant coping strategies appear to have a negative impact on both physical and psychological health (Pruchno & Resch, 1989b ; Vitaliano et al., 1995; Haley et al.,1996).

Overall, the results of the study suggest the need to further explore the use of both types of coping strategies by diverse populations and levels of acculturation. It is also important to note the need for an improvement in the design of the study to gain a better understanding of the potential similarities and differences among the various populations.

Intervention Implications

Coping strategies have been found to be amenable to intervention and structured interventions, such as psychoeducational groups, have been found to be beneficial for both non-Hispanic White and Latino ADRD caregivers in reducing caregiver distress (Coon et al., 2004; Gallagher-Thompson & Coon, 2007; Gallagher-Thompson et al., 2003; Gallagher-Thompson et al., 2008). Therefore, the following suggestions are

proposed based on the current study. A psychoeducational format is recommended as this format provides various benefits. First, a psychoeducational approach would provide the structure needed to effectively modify coping strategies. It would also offer a supportive environment where participants can normalize their experiences, increase their social supports and resources, and provide an empowering experience by being able to offer suggestions and learn from people who have successfully managed a difficult situation similar to their own.

It is recommended that appropriate modifications are made to take into account language preferences and other cultural influences (Gallagher-Thompson et al., 2008). The literature suggests Latino caregivers may use more avoidant coping strategies than non-Hispanic White caregivers. Thus, it is recommended that interventionists consider providing the option of a group solely for Latinos in an effort to offer a venue to discuss specific cultural barriers that may be relevant to the coping strategies being employed. Furthermore, spending additional time addressing avoidant coping strategies may be beneficial for Latino caregivers, but may not be necessary for non-Hispanic White caregivers.

Moreover, Latinos, especially less acculturated Latinos, are hesitant to seek mental health services (Dingfelder, 2005). Less acculturated individuals are more likely to prefer ethnic and language match with a mental health professional (O'Sullivan, 1992; Smart & Smart, 1995). Thus, providing the option for caregivers to participate in a

psychoeducational group specific to their ethnicity or in Spanish may increase retention rate, particularly for less acculturated Latinos (Kanel, 2002; O'Sullivan, 1992). In addition, there is a “cultural-emotional message” that one must not tell their problems to strangers as doing so would be a negative reflection of themselves, their family, and their family's name (Santiago-Rivera, 2002). The group composition may also allow for the incorporation of culturally relevant idioms or “*dichos*” which can help create a therapeutic and cultural ambiance that reduces stress, threat, and resistance (Aviera, 1996). Lastly, the taboo around talking to others about personal problems may be reduced in a group of caregivers who ascribe to the same belief system.

The recommendations based on the findings of the current study provide support for the design of the REACH I and REACH II projects, which investigated promising interventions for a diverse population of ADRD caregivers and incorporated culturally sensitive practices to ensure culturally relevant interventions for a diverse population. The REACH investigators tailored recruitment, study materials, and study procedures to the specific racial or ethnic group being served (i.e., Black/African Americans, Hispanic/Latinos). Thus, all interventions were modified to be sensitive to the caregiver's cultural belief system, ethnic background, socioeconomic status, and education level. In addition, the REACH researchers ensured all involved staff members received cultural sensitivity training and used bilingual staff when serving the

Hispanic/Latino population. An effort was also made to match the race and/or ethnicity of the interventionist to that of the caregiver (Belle et al., 2003; Coon et al., 2004; Gallagher-Thompson et al, 2003). The current study only utilized baseline data from the REACH I at the California site (Palo Alto). However, the REACH I project provided empirical support for the effectiveness of skill-building approaches to manage distress in comparison to support groups alone. The skill-building intervention significantly reduced depressive symptoms, increased the use of adaptive coping strategies, and indicated a trend toward decreased use of negative coping strategies for both Latina and non-Hispanic White caregivers. Thus, the culturally sensitive study design was effective in impacting caregiver distress for Latina caregivers (Gallagher-Thompson, 2003).

Limitations

While this study found there are significant differences among non-Hispanic White, less acculturated, and more acculturated Latina caregivers in their use of avoidance coping, but no other negative or positive coping strategies, care must be taken in interpreting these findings due to the following limitations.

As previously mentioned, this study used secondary data from the REACH I project, at the California site, in which caregivers self-selected themselves to participate in a large, advertised randomized clinical trial aiming to decrease caregiver distress among dementia caregivers. Thus, the sample may not be representative of the general caregiver population

as it consists of participants who actively sought out services. In addition, the sample consisted solely of female caregivers who identified as either non-Hispanic White or Latina, which also limits generalizability of findings for male caregivers and caregivers of other ethnic/racial backgrounds. It is important to note there may be significant gender differences in coping styles (DeVries et al., 1997). Moreover, the study used “Latina” as a general term, however participants represented various Latin countries. It is important to note the heterogeneity and within-group differences of the Latino population. Due to the relatively small sample sizes of the less and more acculturated Latina groups, it was impossible to examine demographic differences of caregivers of different origins.

The acculturation index developed for this study also poses some limitations. Participants were dichotomized into two categories: Less acculturated and more acculturated, by grouping the Very/Slightly Hispanic levels into the less acculturated category and the Slightly/Strongly/Very Anglo levels into the more acculturated category. While dichotomizing acculturation into two categories is a step in the right direction this may have resulted in inaccurate placement of participants into these two categories. Furthermore, the study aimed to include a diverse pool of participants from various age groups and Latino backgrounds. However, the majority of participants were of Mexican-American descent. A detailed and more inclusive understanding of the participant characteristics and attitudes specific to the participant’s

generational status or particular country of origin was beyond the scope of this study.

Finally, the Revised Ways of Coping Check List is a self-report measure; therefore, the responses may not necessarily reflect actual behaviors. It is important to consider cultural factors such as “saving face” and *marianismo* as these may contribute to an under-reporting of behaviors which may seem negative or shameful. Future studies may also consider expanding and improving on this study by exploring differences in coping strategies among male and female caregivers, as well as spousal and non-spousal caregivers of multiple racial/ethnic and acculturation backgrounds.

Future Research

This study adds to the literature by highlighting the differences, and potential differences, in coping strategies used by non-Hispanic White, less acculturated, and more acculturated Latina caregivers of patients with ADRD. Consequently, these results suggest there are various directions in which future research could advance, including continuing to explore differences in coping strategies among the aforementioned groups and other ethnic/racial groups, while not only taking into consideration ethnic/racial and acculturation differences, but also other variables such as age, caregiver relationship (i.e., spousal, non-spousal), gender, cultural values (i.e., *marianismo*, “saving face”), education level, and income.

Future research may also benefit from implementing qualitative research methods to further develop an understanding of various coping strategies utilized by non-Hispanic White and Latino caregivers, as current available coping measures may be limited. For example, avoidant coping items may assess maladaptive coping, such as alcohol consumption to feel better, but may be overlooking or erroneously classifying adaptive “avoidant” coping strategies such as initially avoiding the problem (e.g. taking a walk, going to the mall) followed by problem solving. Furthermore, an analysis of item validity on various frequently used coping measures may also be helpful in order to better understand what type of coping strategies are being measured (e.g., informal social supports vs. formal social supports). Thus, coping measures may not holistically assess some coping strategies, such as avoidant coping, and may be assessing two different types of social support seeking coping for non-Hispanic White and Latino caregivers.

Qualitative research may also be useful in further understanding how non-Hispanic White and Latino caregivers interpret the language utilized in the measures. Anecdotal experience has highlighted that Latino caregivers frequently interpret the word “others” in coping measures such as the RWCCCL, as referring to people outside of their family. Language and culture may play a role in how caregivers respond to items.

Additional research in this area could facilitate the development and strengthening of culturally competent and efficient approaches for

providing services and interventions intended to decrease distress in ADRD caregivers.

Conclusion

By the year 2030, adults aged 65 and older will account for approximately 20% of the general population. In addition, Latinos are among the fastest growing minority groups and older adults in this population are expected to increase by 322% compared to 81% for older non-Hispanic Whites. As the older adult population continues to grow and experience increased longevity, they will also be at-risk not only for developing Alzheimer's Disease and Related Disorders (ADRD), which increase in incidence with age, but they will also be at risk for developing other leading causes of death among older adults.

As a result of the negative, and sometimes gradual, physical and cognitive repercussions of many of these diseases, individuals may require assistance from a caregiver, who will often be a family member(s). Family caregivers frequently provide constant care for their loved one and may do so for various years throughout the progression of the disease. Caregivers typically assist their loved one with their daily basic needs and oftentimes the care recipient may be completely reliant on the caregiver. As a result of the demanding nature of caregiving, family caregivers often suffer from deterioration of their physical and psychological health as they struggle to meet their own responsibilities while also caregiving for their loved one. Moreover, caregivers of ADRD experience a unique caregiving

situation as dementia is accompanied by a severe cognitive decline which affects the care recipients personality, mood, and behaviors, and ultimately creates a phenomenon known as “dual dying.” As a result, ADRD caregivers report more distress and depressed symptomatology than caregivers of other illnesses.

Coping strategies have been significantly linked with distress. Positive coping strategies such as count your blessings and social support seeking have been associated with positive outcomes, while negative coping strategies such as avoidance have been linked with negative outcomes. Therefore, the purpose of this study was to investigate the potential differences in coping strategies among non-Hispanic White, less acculturated, and more acculturated Latina caregivers in an effort to identify individual needs and facilitate the development or strengthening of culturally relevant and efficient interventions aimed at reducing ADRD caregiver distress.

There are several contributions of the current study to the ADRD caregiving literature. First, the study expanded on previous studies suggesting there are differences in social support seeking as a coping strategy between non-Hispanic and Latina caregivers. Although, the results were not significant, a trend was revealed which emphasizes the need for further investigation. Secondly, the study found less acculturated Latina caregivers report using more avoidance coping than non-Hispanic White caregivers, which may provide a more in-depth understanding of

potential factors that may contribute to a higher endorsement of distress symptomatology by Latina caregivers. In addition, this finding proposes the possible benefits of particularly addressing avoidance coping in interventions or services geared towards the Latina population. Finally, as a result of the differences found among the three groups investigated in this study, this study proposes further investigation of coping differences among other variables (i.e., racial/ethnic, gender, caregiver relationship) in an effort to better understand ADRD caregiver's needs and improve on currently available interventions aimed towards decreasing caregiver distress.

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APPENDIX A
SOCIAL DEMOGRAPHIC ITEMS FOR CAREGIVER

- 1) What is your marital status?
- 2) How many years of formal education did you complete?
- 3) What country did you reside in during the last year of formal education?
- 4) How would you describe your primary racial group?
- 5) In which country were you born?
- 6) How many years have you lived in the United States?
- 7) What is the primary occupation you have had most of your working life?
- 8) What is your current employment status?
- 9) Which category on this card best describes your yearly household income before taxes?
- 10) How many people are living with you in your home excluding yourself?
- 11) How long have you lived with (CR)?
- 12) Did you and (CR) start living together so that you could take care of him/her?

APPENDIX B

ACCULTURATION RATING SCALE FOR MEXICAN-AMERICANS-II

- 1) In what country did you complete your last year of school?
- 2) Which generation best applies to you?
 - a. 1st generation = You were born in Mexico or other country
 - b. 2nd generation = You were born in the USA; either parent born in Mexico or other country
 - c. 3rd generation = You were born in USA; both parents born in USA and all grandparents born in Mexico or other country
 - d. 4th generation = You and your parents born in USA and at least one grandparent born in Mexico or other country
 - e. 5th generation = You and your parents were born in the USA and all grandparents were born in USA
- 3) I speak Spanish.
- 4) I speak English.
- 5) I enjoy speaking Spanish.
- 6) I associate with Anglos.
- 7) I enjoy Spanish language television.
- 8) I enjoy listening to English language music.
- 9) I enjoy reading books in Spanish language.
- 10) I write in English (e.g. letters).
- 11) My thinking is done in the English language.
- 12) My thinking is done in Spanish.
- 13) My friends are of Anglo origin.

APPENDIX C
REVISED WAYS OF COPING CHECK LIST

- 1) Bargained or compromised to get something positive from the situation.
- 2) Counted my blessings.
- 3) Concentrated on something good that could come out of the whole thing.
- 4) Kept my feelings to myself.
- 5) Figured who to blame.
- 6) Asked someone I respected for advice and followed it.
- 7) Talked to someone about how I was feeling.
- 8) Stood my ground and fought for what I wanted.
- 9) Refused to believe that it had happened.
- 10) Took it out on others.
- 11) Came up with a couple of different solutions to my problem.
- 12) Accepted my strong feelings, but didn't let them interfere with other things too much.
- 13) Focused on the good things in my life.
- 14) Changed something about myself so that I could deal with the situation better.
- 15) Accepted sympathy and understanding from someone.
- 16) Got mad at the people or things that caused the problem.
- 17) Slept more than usual.
- 18) Felt bad that I couldn't avoid the problem.
- 19) I knew what had to be done, so I doubled my efforts and tried harder to make things work.
- 20) Thought that others were unfair to me.
- 21) Tried to forget the whole thing.

- 22) Got professional help and did what they recommended.
- 23) Changed or grew as a person in a good way.
- 24) Blamed others.
- 25) Went on as if nothing had happened.
- 26) Accepted the next best thing to what I wanted.
- 27) Told myself things could be worse.
- 28) Talked to someone who could do something concrete about the problem.
- 29) Tried to make myself feel better by eating, drinking, smoking, taking medications, etc.
- 30) Tried not to act too hastily or follow my own hunch.
- 31) Changed something so things would turn out right.
- 32) Avoided being with people in general.
- 33) Thought how much better off I am than others.
- 34) Just took things one step at a time.
- 35) Kept others from knowing how bad things were.
- 36) Found out what other person was responsible.
- 37) Came out of the experience better than when I went in .
- 38) Told myself how much I have already accomplished.
- 39) Made a plan of action and followed it.
- 40) Talked to someone to find out about the situation.
- 41) Avoided my problem.
- 42) Compared myself to others who are less fortunate.
- 43) Tried not to burn my bridges behind me, but left things open somewhat.

APPENDIX D

REVISED WAYS OF COPING CHECK LIST ITEM SUBSCALES

Social Support Seeking (SS- 6 items)

- 6) Asked someone I respected for advice and followed it.
- 7) Talked to someone about how I was feeling.
- 15) Accepted sympathy and understanding from someone.
- 22) Got professional help and did what they recommended.
- 28) Talked to someone who could do something concrete about the problem.
- 40) Talked to someone to find out about the situation.

Problem-Focused (PF- 15 items)

- 1) Bargained or compromised to get something positive from the situation.
- 3) Concentrated on something good that could come out of the whole thing.
- 8) Stood my ground and fought for what I wanted.
- 11) Came up with a couple of different solutions to the problem.
- 12) Accepted my strong feelings but didn't let them interfere with other things too much.
- 14) Changed something about myself so I could deal with the situation better.
- 19) I knew what had to be done, so I doubled my efforts and tried harder to make things work.
- 23) Changed or grew as a person in a good way.
- 26) Accepted the next best thing to what I wanted.
- 30) Tried not to act too hastily or follow my own hunch.
- 31) Changed something so things would turn out right.
- 34) Just took things one step at a time.

- 37) Came out of the experience better than when I went in.
- 39) Made a plan of action and followed it.
- 43) Tried not to burn my bridges behind me, but left things open somewhat.

Count Your Blessings (CYB- 6 items)

- 2) Counted my blessings.
- 13) Focused on the good things in my life.
- 27) Told myself things could be worse.
- 33) Thought how much better off I am than others.
- 38) Told myself how much I have already accomplished.
- 42) Compared myself to others who are less fortunate.

Avoidance (AV- 10 items)

- 4) Kept my feelings to myself.
- 9) Refused to believe it had happened.
- 17) Slept more than usual.
- 18) Felt bad that I couldn't avoid the problem.
- 21) Tried to forget the whole thing.
- 25) Went on as if nothing had happened.
- 29) Tried to make myself feel better by eating, drinking, smoking, taking medications.
- 32) Avoided being with people in general.
- 35) Kept others from knowing how bad things are.
- 41) Avoided my problem.

Blamed Others (BO- 6 items)

- 5) Figured out who to blame.
- 10) Took it out on others.
- 16) Got mad at people or things that caused the problem.
- 20) Thought that others were unfair to me.
- 24) Blamed others.
- 36) Found out what other person was responsible.

APPENDIX E

INSTITUTIONAL REVIEW BOARD APPROVAL LETTER

To: David Coon
USB

From: Mark Roosa, Chair
Soc Beh IRB

Date: 03/03/2010

Committee Action: **Exemption Granted**

IRB Action Date: 03/03/2010

IRB Protocol #: 1002004851

Study Title: Analysis of Caregiving Interactions

The above-referenced protocol is considered exempt after review by the Institutional Review Board pursuant to Federal regulations, 45 CFR Part 46.101(b)(4) .

This part of the federal regulations requires that the information be recorded by investigators in such a manner that subjects cannot be identified, directly or through identifiers linked to the subjects. It is necessary that the information obtained not be such that if disclosed outside the research, it could reasonably place the subjects at risk of criminal or civil liability, or be damaging to the subjects' financial standing, employability, or reputation.

You should retain a copy of this letter for your records.