2005

The role of religious beliefs and practices in the lives of African American family caregivers

Lisa Renee Hebert

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THE ROLE OF RELIGIOUS BELIEFS AND PRACTICES
IN THE LIVES OF AFRICAN AMERICAN FAMILY CAREGIVERS

A Thesis
Presented to the
Faculty of
California State University,
San Bernardino

In Partial Fulfillment
of the Requirements for the Degree
Master of Arts
in
Education:
Health Education

by
Lisa Renee Hebert
December 2005
THE ROLE OF RELIGIOUS BELIEFS AND PRACTICES
IN THE LIVES OF AFRICAN AMERICAN FAMILY CAREGIVERS

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Approved by:

Kim Clark, First Reader

Enrique Munillo, Second Reader
ABSTRACT

Family caregivers of persons with adult onset brain disorder provide an inordinate and escalating level of care. It has been postulated that: (1) religious beliefs and/or spirituality may assist individuals in their caregiving efforts; and (2) coping strategies may vary depending on ethnicity. The intent of this study was to examine these theories by interviewing three African-American females who were currently caregivers for the spouses diagnosed with an adult onset brain disorder using qualitative methods that addressed their spirituality, religious practices, and ethnicity.

Results revealed that all caregivers felt their spirituality and/or religious practices shaped how they approached providing care and all reported that they were influenced by their ethnic background. They stated that religious practices and spirituality affected how they felt about providing care for their spouses and that religion and spirituality helped them deal with difficult challenges. Through a better understanding of the importance of different coping mechanisms among caregivers,
professionals are able to provide more sensitive care to persons of diverse groups.
ACKNOWLEDGMENTS

I would like to extend acknowledgments my family. My husband Michael, thanks for your support, prayers, words of encouragement and late night Del Taco runs. My children, O.B., Micah, Tyler and Blake, thanks for all of your prayers and for being you! My mother, thanks for your prayers, concern and constant support. To my faculty advisors, thank you for all of the support, without you it would have been very difficult to keep my sanity and complete this project.
DEDICATION

I would like to dedicate this thesis project to my father Mr. Richard W. Brown. Although he passed away prior to the completion of this project, he was my true inspiration.
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CHAPTER ONE
CAREGIVING

Introduction

Caring for a loved one with a chronic or disabling condition is one of the most prominent issues challenging American families. It is currently estimated that one in four U.S. households (22.4 million households) provides some assistance to a loved one who is disabled or chronically ill. This number is projected to increase to 39 million by the year 2007 (National Alliance for Caregiving & AARP, 1997).

According to the Department of Human and Health Services (1998), throughout the United States, women are the primary source of informal care. They provide the majority of informal care to their spouses, parents, parents-in-law, friends and neighbors, and they play many roles while caregiving, such as hands-on health provider, care manager, friend, companion, surrogate decision-maker and advocate (Navaie-Waliser, Feldman, Gould, Levine, Kuerbis, & Donelan, 2002). In fact, it is estimated that women make up 75% of all family or informal caregivers in the U.S. (Arno, 2002). Researchers indicate that if the services
provided by these women were replaced by paid services it would cost an estimated $196 billion annually (Arno, Levine, and Memmott, 1999).

An emerging concern is the providing of care for a loved one who has been diagnosed with an adult onset brain impairment. Since many of the diseases and disorders that affect the brain are progressive and their incidence and prevalence increase with age, the occurrence of the major causes of brain impairments in adulthood is often underestimated. Although most are more common in later life, brain impairments can and do occur in individuals under 60 years of age.

The following tables illustrate an estimate of the incidence and prevalence of the major causes of brain impairment in adulthood in the United States in general and in California in particular.

According to the data presented in Table 1 (National Family Caregivers Association, 2004), more than one million adults in the U.S. are diagnosed annually with a chronic brain disease or disorder. Clearly, the need for both long-term care and support for family caregivers is dramatic. Many of these conditions, for example Alzheimer’s, Stroke and Parkinson’s, are associated with increasing age and
given the aging of the United States population these figures will most likely increase proportionately in the coming decades.

Table 1. Incidence of Adult Onset Brain Disorders.

<table>
<thead>
<tr>
<th>Diagnosis/Cause</th>
<th>People Diagnosed Annually</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alzheimer’s Disease</td>
<td>250,000</td>
</tr>
<tr>
<td>Amyotrophic Lateral Sclerosis</td>
<td>5,000</td>
</tr>
<tr>
<td>Brain Tumor</td>
<td>33,039</td>
</tr>
<tr>
<td>Epilepsy</td>
<td>135,500</td>
</tr>
<tr>
<td>HIV (AIDS) Dementia</td>
<td>1,196</td>
</tr>
<tr>
<td>Huntington’s Disease</td>
<td>N/A</td>
</tr>
<tr>
<td>Multiple Sclerosis</td>
<td>10,400</td>
</tr>
<tr>
<td>Parkinson’s Disease</td>
<td>54,927</td>
</tr>
<tr>
<td>Stroke</td>
<td>600,000</td>
</tr>
<tr>
<td>Traumatic Brain Injury</td>
<td>80,000</td>
</tr>
<tr>
<td>TOTAL ESTIMATED INCIDENCE</td>
<td>170,312</td>
</tr>
</tbody>
</table>

(Source: National Family Caregivers Association, 2004)

Table 2, illustrates that there are between an estimated 13.3 and 16.1 million individuals age 18 and over who are currently afflicted with common brain disorders and diseases.

Table 3, presents a comparison of data between the overall population of the United States and California. According to the data, an estimated 13% - 16% of the United States and California households be may dealing with the
burden of caring for a loved one with an adult-onset brain disease/disorder.

Table 2. Prevalence of the Major Causes of Adult Onset Brain Disorders.

<table>
<thead>
<tr>
<th>DIAGNOSIS/CAUSE</th>
<th>People Currently Living with Disorder:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Low Estimate</td>
</tr>
<tr>
<td>Alzheimer’s Disease</td>
<td>4,000,000</td>
</tr>
<tr>
<td>Amyotrophic lateral Sclerosis</td>
<td>20,000</td>
</tr>
<tr>
<td>Brain Tumor</td>
<td>N/A</td>
</tr>
<tr>
<td>Epilepsy</td>
<td>1,984,000</td>
</tr>
<tr>
<td>HIV (AIDS) Dementia</td>
<td>14,537</td>
</tr>
<tr>
<td>Huntington’s Disease</td>
<td>30,000</td>
</tr>
<tr>
<td>Multiple Sclerosis</td>
<td>250,000</td>
</tr>
<tr>
<td>Parkinson’s Disease</td>
<td>500,000</td>
</tr>
<tr>
<td>Stroke</td>
<td>4,000,000</td>
</tr>
<tr>
<td>Traumatic Brain Injury</td>
<td>2,500,000</td>
</tr>
<tr>
<td>TOTAL ESTIMATED INCIDENCE</td>
<td>13,298,537</td>
</tr>
</tbody>
</table>

(Source: National Family Caregivers Association, 2004)

With taxing demands that include performing fundamental activities of daily living such as dressing, eating, bathing, and toileting, as well as the efforts needed to manage the behavioral and cognitive problems that are symptomatic of the disease, caregiving for these
individuals is quite often a 24-hour, 7 day a week responsibility.

Table 3. Selected Population Characteristics: U.S. and California.

<table>
<thead>
<tr>
<th></th>
<th>United States</th>
<th>California</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total Population</td>
<td>274,634,000(^1)</td>
<td>34,336,091</td>
</tr>
<tr>
<td>Total Population 18+</td>
<td>203,852,000(^3)</td>
<td>30,000(^4)</td>
</tr>
<tr>
<td>Total Households</td>
<td>101,041,000(^5)</td>
<td>12,242,576</td>
</tr>
<tr>
<td>Total Estimated Adults with</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Brain Impairment</td>
<td></td>
<td></td>
</tr>
<tr>
<td>a. Low Estimate</td>
<td>13,298,537</td>
<td>1,622,422(^7)</td>
</tr>
<tr>
<td>a. High Estimate</td>
<td>16,068,150</td>
<td>1,960,314(^8)</td>
</tr>
<tr>
<td>Percentage of Adult</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Population</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Affected by Brain Impairment</td>
<td></td>
<td></td>
</tr>
<tr>
<td>a. Low Estimate</td>
<td>6.5%</td>
<td>6.5%</td>
</tr>
<tr>
<td>a. High Estimate</td>
<td>7.9%</td>
<td>7.9%</td>
</tr>
<tr>
<td>Percentage of Households</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Affected by Brain Impairment</td>
<td></td>
<td></td>
</tr>
<tr>
<td>a. Low Estimate</td>
<td>13.2%</td>
<td>13.3%</td>
</tr>
<tr>
<td>a. High Estimate</td>
<td>15.9%</td>
<td>16.0%</td>
</tr>
</tbody>
</table>

(Source: National Family Caregiver Association, 2004).

Cultural Influences

Aranda and Knight (1997), argued that ethnicity implies specific cultural differences that directly affect the appraisal of caregiving as stressful, and changes mediating variables such as coping skills. The socio-cultural stress...
and coping model adds to the typical interpretation of ethnicity as a structural status variable (i.e., ethnicity as mainly reflecting disadvantaged minority group status, which in turn is confounded with socioeconomic status, (Markides, Liang, & Jackson, 1991), and reinterprets the influence of ethnicity on stress and coping as affecting: (a) other status variables because of differences between ethnic groups in the gender, relationship, and other characteristics of who provides care; (b) the demands of caregiving which may differ by group; (c) the appraisal of caregiving via cultural values which are related to the appraisal of caregiving as stressful; (d) coping styles which are affected by cultural differences; and (e) the mental health outcomes of the stress and coping process.

These influences of ethnicity can affect each stage of the stress and coping model simultaneously, and in differing directions. That is, appraisal might ameliorate emotional distress outcomes at the same time that greater frailty in the care recipient and the use of nonproductive coping styles may exacerbate distress.

**Latino Caregivers**

Aranda and Knight (1997), indicated that several factors inherent in the ethnicity and culture of Latino caregivers,
such as higher care recipient frailty, emphasis on family and distinctive social support networks, may play a significant role in the stress and coping process of Latino caregivers. Moreover, Latino elders report higher levels of impairment and a greater need for community-based services than the general population, suggesting that their caregivers will experience higher burden and psychological distress. However, since Latinos hold strong family values, caregivers who place higher value on the family will be more willing to provide for the family, and consequently, will experience less burden and depression. Finally, Latino social networks are likely to be larger, composed of multigenerational households, extended family, and non-kin family, thereby mediating caregiver distress. Thus, several socio-cultural factors pertaining to Latinos may influence the stress and coping process of Latino caregivers.

A key issue in understanding cultural influences on Latino caregivers is acculturation. Acculturation is perceived as multi-dimensional; individuals can be independently involved in both Latino and Anglo cultures.

According to Robinson and Knight (2002) culture, as measured by acculturation, does not directly affect the
appraisal of caregiving as burdensome or outcomes such as depressive symptoms in the stress and coping model for Latino caregivers, but rather, it has small to negligible indirect effects on caregiving outcomes, thereby indicating limitations to the influence of culture on the caregiving outcomes of Latino caregivers. Thus, researchers Robinson and Knight (2002) concluded that culture does in fact play a significant role in the process of caregiving, but not in the emotional distress outcomes of Latino caregivers.

Korean Caregivers

East Asian cultures are widely considered to have the strongest family ties and values primarily because of their cultural emphasis on Confucian values of filial piety and respect for elders. Researchers Youn, Knight, Jeong & Benton, (1999) discovered that Korean and Korean American caregivers reported higher levels of anxiety, depression, and burden than white caregivers, even though they had stronger family ties than White, U.S. caregivers.

It is believed that higher levels of emotional stress among Korean caregivers is associated with the gap that exists between real family dynamics and traditional Korean values, which are still perceived as the norm among
Koreans, but may not be strong enough to influence family caregiving behavior due to the Westernization and industrialization of Korea. Shin (1999) explained that the traditional Korean family ideology still exists, therefore, family caregiving behaviors are assessed based on this ideology. However, the changes in living arrangements and life styles that accompany social change may make it difficult to follow traditional family values, so that family stress results from the discrepancy between ideal attitudes and actual caregiving behavior.

A lack of social support may also explain the higher emotional distress of Korean caregivers. In a study conducted by Youn, et al (1999), Korean caregivers reported the lowest levels of emotional and instrumental support. The level of social support for Korean American caregivers was also low, although higher than Koreans. Korean American caregivers have been reported to receive more social support from the church and other informal resources, than Korean caregivers (Koh & Bell, 1987; Moon, 1996).

Different family relationships between primary caregivers and care-receivers may also be associated with high levels of emotional distress among Korean caregivers. For Koreans, the eldest son's wife is primarily responsible
for caring for the elderly because the eldest son is physically and financially responsible for his parents (Choi, 1993; Youn & Song, 1992). This means that the eldest son’s wife takes care of her parents-in-law due to obligation, rather than affection. Consequently, Korean caregivers may feel higher emotional stress than white caregivers, most of whom are spouses or daughters caring for their family members with affection.

**Japanese American Caregivers**

In discussing caregiving and Japanese Americans, it is necessary to identify three culturally specific elements that may affect the stress and coping styles of this particular population. Traditional cultural values such as omae (the importance of interpersonal harmony and relationships), oykoko (filial piety) and giri (obligation to one's family) encourage caregivers to provide home based care for their elder, terminally ill and disabled family members.

In addition, traditional Japanese culture discourages burdening others. “Gaman” or “perseverance” is a specific cultural value often considered a strength, so as not to cause trouble or impose a burden to others. For example, when issues and problems arise such as emotional distress,
a caregiver from Japanese culture may try to hold it within them self, or within the family. The phrase “Shikata ganai” or “it cannot be helped” is a phrase and conceptual approach that is frequently used to redress emotional strain caused by difficulties and injustices that an individual might face. The concept of “filial piety” refers to Asian specific values that describe parent care and parent-child relationship, which characterizes children's paramount concern for their parents' well-being and manifests in respect, conformity to parents' desires, and a caring attitude and behavior toward parents (Young, McCormick and Vitaliano, 2002).

According to literature, in regards to culture and U.S. immigration history, Japanese Americans are among the most acculturated subgroups of Asian Pacific Islanders (Lin-Fu, 1994; Nickens, 1991), with an incremental acculturation from the first generation immigrants to later born generations. Later born generations are more likely to assimilate into the dominant culture and depart from Japanese traditions (Wooden, Leon, & Toshima, 1988). Moreover, compared to the later born siblings, firstborn are more likely to hold strong Japanese family values (Manaster, Rhodes, Marcus, & Chan, 1998). This multifaceted
concept of acculturation raises a question regarding the effects of dementia caregiving on psychological well-being of Japanese American caregivers, who are caught between the mainstream and traditional Japanese cultures.

African American Caregivers

What is currently known about African American caregivers has come from ethnographic studies of black elders. Findings from these studies indicate that filial responsibility of caregivers ensures that more black elders than whites will be cared for at home by their families (Martin and Martin, 1985; Mutran, 1985 and Watson, 1982).

Regardless of the disability level of the care recipients, African-American caregivers provide care with limited use of formal services such as home health, assisted living or nursing home facilities (Logan & Spitze, 1994; Sudha & Mutran, 1999). This raises concerns that African-American care-givers have potentially high levels of burden and strain (Miller et al., 1999). Paradoxically, they are documented as experiencing less role strain than White caregivers (Farran et al., 1997; Mui, 1992) and also Hispanic caregivers (Cox & Monk, 1990).
It has been suggested that African-American caregivers possess some 'unique emotional strength that buffers the experience of providing care to older family members (Wood & Parham, 1990). Positive appraisals of caregiving within a cultural context that views caregiving as an important part of family life have also been offered as a reason for lower role strain and/or burden in African-American caregivers (Haley et al, 1996; Knight & McCallum, 1998).

Previous research has also documented the presence of a large informal support system in African-American families (Barer & Johnson, 1990; Wood & Parham, 1990), which is thought to increase the availability of a network to provide care to elderly, disabled and terminally ill African-Americans and their caregivers. It was suggested that informal caregiving was promoted within the African American extended family system because it is often highly integrated and is an important resource for survival and social mobility for its members. These studies have also indicated that African American family ties as indicated by joint residency, visiting and the exchange of mutual aid among family members are stronger than they are for whites (Hays & Mindle, 1973).
Recent findings, however, have shown that the strength and size of the network in African-American families may be changing. These findings show that the size and strength of the kin network is being challenged by the needs of multiple generations in the family coupled with declining resources in the network to address the needs of family members (McDonald & Armstrong, 2001; Jarret & Burton, 1999; Roschelle, 1997). In light of such changes, it is believed that African-American women, the typical caregivers to elder, disabled or terminally ill persons in the family, are at risk for experiencing role strain and other negative emotional outcomes as they attempt to manage the multiple roles they occupy.

In examining the relationship between ethnicity and emotional distress, researchers Knight and McCallum (1998), found that ethnicity was not directly related to emotional distress. The effects of ethnicity on caregiver distress were mediated through appraisal and coping, with the effects operating in opposite directions. On one hand, being of African American decent was associated with decreased burden, which led to lower levels of distress. On the other hand, African American ethnicity was also related to an increase in the use of emotion focused
coping, which was related to higher levels of distress. There was no relationship between ethnicity and active coping. It appears that for African American caregivers, the benefit of appraising the demands of caregiving as less stressful is cancelled out by coping that is not helpful, so that depression levels equal those of the non-African American caregivers who appraise the caregiving events as more burdensome, but who use other coping strategies.

Caregiver Role and Support

The multi-faceted role of the family and informal caregiver requires a range of support services to remain healthy, improve their caregiving skills and to remain in their caregiving role. Over the years, researchers have paid close attention to the tribulations, burdens and psychological costs of family and informal caregiving. Literature suggests that family caregiving involves multiple stressors and demands that compromise the common core of the stressful context of family caregiving. In addition, the repercussions of these stressors and demands involve tensions in the relationship with the care recipient, perturbations in the caregivers' commerce with other family members, and a variety of other dislocations
in life such as employment and socialization (Gottlieb, 1989).

The scope and subjective appraisal of these demands vary among caregivers. A growing body of literature suggests that a caregivers religious beliefs and practices may ameliorate their ability to cope with the stressors and demands that are associated with the providing of care to a family member with a chronic brain impairment.

A number of studies have shown significant links between the use of religious methods (beliefs and practices) of coping with major life stressors and a variety of criteria of health and well-being. In fact, many have found that religious coping measures predict health and well-being about and beyond the effects of other explanatory variables. For example, in a study of hospice caregivers, researchers Mickley, Paragment, Brant and Hipp (1998) distinguished religious appraisals (e.g., redefining the dying process a potentially benevolent act from God, feeling the dying process was God’s punishment) from general non-religious appraisals (e.g., redefining the dying process as an opportunity for growth; blaming the doctors or loved ones for the situation). Even after controlling for the effects of general non-religious
appraisals, religious appraisals were significant predictors of meaning in life, anxiety and depression, spiritual well-being and coping efficacy.

Statement of the Problem

Limited attention has been given to the impact of religious beliefs and practices on the caregiver role and on those resources needed to cope with and reduce the stress and adverse emotional and physical outcomes associated with caregiving.

Caregiving can be an emotional roller coaster. On one hand, caring for a loved one demonstrates love and commitment. On the other hand, exhaustion, inadequate resources, and continuous caring can lead to burn out, stress and depression. It is estimated report that between 46%-59% of all caregivers are clinically depressed and approximately 49% of female caregivers and 31% of male caregivers experience depression as a result of caregiving (Gallagher, Rivera, Lovett and Thompson, 1989). Among spouse caregivers, 21-25% of husbands and 50-52% of wives are depressed (Cohen, Luchins, Eisdorfer, Paveza, Ashford, Gorelick, Hirschman, Freels, Semia, and Shaw, 1990). Researchers George and Gwyther (1986), report that caregivers use prescription drugs for depression, anxiety
and insomnia two to three times as often as the rest of the population.

Compounding this picture, are the physical ailments associated with caregiving. According to researchers Lee, Colditz, Berkman, & Kawachi, (2003) women who spend nine or more hours a week caring for an ill or disabled spouse or loved one increase their risk of coronary heart disease twofold. Other health effects include elevated blood pressure and increased risk of developing hypertension; lower perceived health status; poorer immune function; slower wound healing; and an increased risk of mortality (Lee et al, 2003). In a study conducted with elderly spousal caregivers aged 66-96 years, researchers Schulz and Beach (1999) found that caregivers who experience mental or emotional strain have a 63% higher risk of dying than non-caregivers (Schulz, and Beach, 1999). Prior research has demonstrated the mediating influence of religious beliefs and practices on individual health; however, no little research has been conducted on the mediating influence of religious belief or practice on the coping ability of caregivers.
Purpose of the Study

The purpose of this study is to investigate whether religious beliefs or practices has a positive or negative influence on the perceived level of stress and coping ability of family care providers. Based on an extensive review of literature on African Americans, stress, coping, care giving and religion (practices and beliefs), the aim of this study is to determine if religious beliefs and practices regulate the emotions, improve practical problems and maintain the psychological resistance and fortitude needed to remain productively engaged in family care giving for an extended period of time.

Limitations of the Study

The one strength and a limitation of the study sample is its homogeneity. Homogeneity was favorable to the operation of the focus group discussions because it provided for easier communication among the participants. Other limitations to this study include, the small sample size which limits the power of the quantitative analyses. Hence, cross validation of the study with larger samples is needed to verify the role that religious coping appears to play in the lives of these
caregivers of loved ones with adult onset brain impairments. Furthermore, the sample consists of wives of African American ethnicity. Hence, the results may not be representative of wives from other cultures (e.g., Caucasian, Hispanics, and Asian Americans). In addition, the respondents to the survey are the wives of men diagnosed with adult onset brain impairment. Studies involving husbands of women diagnosed with this type of impairment would help us understand whether these findings can be generalized to males as well. Another limitation lies in the results of the study which might be biased by its reliance on self-report measures. Research involving external reports and behavioral measures about the respondent's functioning is recommended. Finally, because of the potential impact of social desirability in studies of religion and spirituality, participants may focus heightened attention on the importance of religiosity in their coping experience and may be reluctant to discuss the negative impact of religion in their lives.

The methodology limitation focuses on the researchers use single of a single coder's application of the coding scheme to the narratives for the analysis of data which leaves room for bias.
Theoretical Bases

The theoretical bases of this study stems from the Theory of Reasoned Action, the Theory of Religious Coping (Paragament, 1997) and the Transactional Theory of Stress and Coping (Lazarus & Folkman, 1991). The Theory of Reasoned Action assumes that behavioral outcomes are determined by an individual's beliefs regarding the target behavior, in addition to the affects and values plus their perception of social norms and expectations. In other words, when an individual is faced with a decision, they will generate a set of beliefs (anticipated outcomes), experience affect related to the anticipated outcomes, and assign values to those outcomes. This theory also assumes that perceived social norms and significant interpersonal relationships play an important mediating role in an individual's decision making processes. The perceptions of other's beliefs, feelings, and values are therefore expected to influence an individual's appraisal of and behavioral intentions in a stressful situation.

The Theory Religious Coping emphasizes that all humans encounter trials and transitions that push them beyond their own capabilities, triggering a dynamic process of coping, which is distinguishable both from the triggering
event and from the outcome of coping. It also assumes that, in coping, the individual is a proactive agent, engaging multiple possibilities and choices, and an a priori orienting system (Paragament, 1997).

According to the Transactional Theory of Stress and Coping (Lazarus & Folkman, 1991), stress is the result of transaction between a person's objective situation (i.e. environment), which is appraised as exceeding that person's resources and as endangering their well-being and their coping strategies.

It is not the objective presence of stressful demands that relate to well-being, rather the person's appraisal of these demands and resources as well as their repertoire of coping strategies to face these demands.

Definition of Terms
For the purpose of this study the following definition of terms should be applied:
Caregiver: Anyone who provides assistance to someone else that is in some degree incapacitated and needs help.
Informal caregiver and family caregiver: Any unpaid individual who provides care for a loved one with adult onset brain impairment.
Coping: The process through which individuals try to understand and deal with significant demands in their lives.

Religion: A process, a search for significance in ways related to the sacred. Religion has to do with building, changing and holding on to the things people care about in ways that are tied to the sacred.

Stress: A symptom or reaction to unacknowledged feelings and unmet needs.

Adult onset brain impairment: A disease or condition which affects the brain and consequently memory, personality and behavior (i.e., dementia, Alzheimer's, brain tumors)

Acculturation: Choosing a mode of adaptation when dealing with issues of whether one's cultural identity is of value and should be retained, and whether positive relations with the larger society should be sought (Berry, 1980).

Prayer: A private, religious activity that implies communication with God, a religious and/or spiritual activity that serves as a means of adapting to the uncertainty of life events (Stolley, 1999)

Private religious practice: prayer, meditation and worship that take place outside of a religious institution.
Public religious practice and formal religious activity:
Any type of church attendance (i.e., Church services, bible study, prayer meetings).
Religious practices: Both private and public religious activities.
A religious institution: A church, or place of worship.

Significance of the Proposed Study

The significance of this study lies in the examination of the effects of religious beliefs and affiliation on an individual's mental and physical health outcomes. The information in this study should also provide a better understanding of how religion is utilized by African American caregivers as a coping mechanism and assist policy makers, program developers and formal service providers in enhancing and strengthening the family as an effective caregiving unit.
CHAPTER TWO
REVIEW OF LITERATURE

Introduction

The focus of this review is on religion, its significance in the lives of African Americans and its role in stress and coping, caregiving and positive well-being. The topic religion has been of interest since the early writings of Durkheim. Durkheim (1951), argued that religion served both a social and mental health function. Not only was it an important social activity, but also those who adhered to religions with clear lines of unquestioned religious authority were less likely to commit suicide than those who followed religions that offered a less defined authority structure. James (1958), explained the different aspects of religion noting that it may have beneficial or deleterious effects on individuals. The healthy soul is one that has completely integrated religious beliefs into their lifestyle, and has a positive view of religious beliefs. The sick soul has an undue focus on the guilt associated with failing to measure up to certain standards of a particular religion.
Religion and African Americans

Explanations of the significance of religion in the lives of African Americans can be found in their history. Without any regard for family or tribal affiliations, Africans were stripped of their social heritage by being captured, shipped, and sold as slaves. Any attempt to preserve their religious traditions was prohibited (Frazier & Lincoln, 1974). Christianity was forced on the slaves and used to justify slavery. This new Christian religion, its beliefs, practices and traditions formed a new basis of social cohesion, created solidarity and a sense of union among these individuals who were from a variety of African nationalities. Despite prohibition of any assembly of slaves without the presence of European Americans, the invisible institution of the African American church took root through secret meetings in secluded places (Raboteau, 1978). The church became the most important social institution in African American culture and has remained a source of social stability and a place of refuge during times of adversity.

When evaluating the race differences in religion by utilizing data from four nationwide surveys researchers Levin, Taylor, and Chatters (1994), found that in 19 of the
test that were performed, African Americans were more religious than their Caucasians counterparts. Consistent with a number of previous studies, Levin et al. (1994), reported that African Americans pray more often than Caucasians. Furthermore, African American adults demonstrated higher levels of both public (e.g., religious attendance) and private (e.g., reading religious materials) religious behaviors. These differences persisted despite controls for demographic (e.g., socio-economic status, region) and religious factors (e.g., religious affiliation) that are differentially distributed within African American and Caucasian populations and are known to be of consequence for religious involvement.

Religion and the African American Woman

A body of research suggests that in their efforts to cope with life’s challenges African American women employ myriad strategies including humor, revenge (Aptheker, 1982) and the advice of other African American women within their social networks (Smyth & Williams, 1991). However, the most consistent finding regarding the coping experiences of African American women is that religion and spirituality hold central places in these women’s coping repertoires.
African American women use formal religious involvement and private devotional practices to negotiate a range of adversities including race, class and gender oppression, family and parenting stress, financial stress, illness, psychological distress, and a vast array of daily hassles (Mattis, 2002). Moreover, African American women tend to use prayer as the primary means of coping with hardship regardless of their level of church participation.

Private and Public Religious Practice
A specific coping behavior associated with religion is prayer. William James described prayer as "the very soul and essence of religion (1997:486). Data on the frequency of prayer is consistent with this assertion because it indicates that that prayer is perhaps the most common form of religious practice. In a study conducted by Gallup and Lindsay (1999), it was reported that 95 percent of American adults pray, and 74 percent pray at least once a day. Given the central role of prayer in religious life, several studies have been conducted examining the many aspects of prayer. Some of the most intriguing studies, however, have focused on the potential physical and psychological health related benefits of prayer.
McCollough and Larson (1999), observed that people frequently turn to prayer in an effort to cope with the stressors in which they encounter. However, Matlin, Wethington, and Kessler (1990), indicate that it has become increasingly evident that the nature of the stressor may determine the specific coping strategy that is used to deal with it. Since prayer is a coping resource, this insight suggests that prayer may be used in different ways to cope with the effects of different kinds of stress.

Although prayer is commonly used as a form of religious coping among many ethnic populations various studies over the years have reported that religious coping—particularly the use of prayer and related mechanisms is especially common among African Americans. Researchers Levin, Taylor and Chatters (1995), examined the patterns of religiosity of African Americans and found that those who exhibit high levels of church participation, devotional activity and strong religious identity were more likely than others to turn to prayer when coping with a particularly trying event or condition.

Ellison and Taylor (1996), contend that African Americans tend to use prayer and asking others to pray on their behalf as forms of religious coping when confronted
with serious personal problems. They also found that persons coping with bereavement and health related problems are considerably more likely to report praying, or having others pray for them, than are persons confronting other types of problems (Ellison and Taylor, 1996). Other studies suggests, however, that although the use of prayer in coping efforts is quite common among African Americans, such coping behaviors are not always associated with positive mental health outcomes (Ellison, 1995).

Therefore, it is conceivable that religious coping is beneficial only under certain circumstances. For instance, Mattlin and colleagues (1990), report that religious coping reduces symptoms of depression and anxiety among persons dealing with bereavement, but that it appears relatively ineffective as a response to other types of problems and crises.

Empirical evidence suggests that participation in public religious practices enhances an individual’s social support (Ellison, 1994). Idler (1987), reported that church participation offered individuals emotional, cognitive and material support which fosters an individual’s perception that they are cared for and loved (p. 228). Such support may be formally provided by fellow church members, obtained
through church programs offering financial and food assistance or through pastoral counseling.

In a study of elderly African Americans, Taylor and Chatters (1988), found that informal support from fellow church members was second only to family support as a primary source of assistance during illness. Moreover, clergy has been identified as the most frequently sought source of help for general psychological distress (Chalfant, 1990).

Participation in religious institutions facilitates the formation of friendships by providing an opportunity for sustained contact among individuals with shared values, beliefs and typically social status (Ellison & Levin, 1998). In addition, it has been noted that because individuals often belong to the same congregation for an extended period of time, and church members often reside in close proximity of one another, social ties developed through religious institutions may extend into relationships outside of church, resulting in denser social networks (Taylor & Chatters, 1986).
Religion and Psychological Health

A growing research literature suggest that religion and its related practices may assist in the regulation of negative emotions associated with specific events or conditions, by helping the faithful to redefine the potential stressors in ways that seem less threatening and by diverting attention from these problems (Koenig, 1994). The weight of evidence seems to indicate that religion and various dimensions of religious involvement promote subjective states of well-being (Schoenbach, Kaplan, Fredman, and Kleinbaum, 1986), reduce levels of depression and anxiety (Williams, Larson, Buckler, Heckman, and Pyle, 1991) and lower the risk of certain health problems (Levin and Vanderpool, 1987).

Most of the work examining the relationship between religious practice and psychological well being has focused on the effects of religion and its practices on psychological distress and depression. Thus far, these studies have yielded inconsistent results. For example, Harrison et al. (2001) report that the lowest rates of depressive symptoms have been associated with religious practices such as seeking spiritual support, expressing spiritual contentedness, receiving congregational support,
benevolent reframing of the stressful event, and collaborative partnerships with God. On the other hand, Ellison (1995), reports that the frequency of church or religious attendance is inversely associated with depressive symptoms among whites but not among African Americans, while the frequency of private devotional activity is positively associated with depressive symptoms among both black and white respondents. Interestingly, those African Americans with no religious affiliation report considerably higher levels of depression than their affiliated counterparts, this is a pattern which also surfaced among African American males in the urban South (Brown & Gary, 1994).

Other studies have examined the hypothesis that religious practice buffers the deleterious impact of negative events and conditions on distress or depression among African Americans. Here again, findings have been discrepant. At least two studies of African Americans residing in the South independently concluded that religious practices mitigate the otherwise negative effects of stressors on mental health (Neff & Husaini, 1982; Brown & Gary, 1988). However, in a cross sectional study of blacks in a southern city, Brown and colleagues (1992)
found that high levels of religious practice actually seem to exacerbate the destructive psychological consequences of chronic economic strain. According to Dressler (1991), the effects of religious practice among younger blacks of low socioeconomic status and among older blacks of higher socioeconomic status, bear a direct inverse association with depressive symptoms and decrease the impact of stressors on mental health. However, among younger blacks of high socioeconomic status, involvement in religious practices exhibits a direct positive relationship to depressive symptoms.

Religion and Physical Health

Evidence of the relationship between religious beliefs and practices and physical well being is vague. For example, studies done on the impact of prayer and spirituality generally focus on the effect of religious beliefs and behavior on health, survival, and quality of life and the effects of intercessory prayer. The results of many of these studies have been inconsistent. Although some research has found that religious groups with orthodox beliefs and behavior have lower cancer death rates, other
studies have not found any health benefits related to religion and health.

The U.S. Office of Technology Assessment (OTA, 1990), reported that a survey spanning 10 years of issues of the Journal of Family Practice found that 83% of the studies on religiosity found a positive effect on physical health. Another study on 12 years of issues of two major psychiatric journals found that for the studies that measured religiosity, 92% showed a benefit for mental health, 4% were neutral, and 4% showed harm. Religiosity was measured by participation in religious ceremony, social support, prayer, and belief in a higher being.

Research has also been conducted investigating the effects of intercessory prayer (praying for others) in coronary care patients. A randomized clinical trial conducted in 1988 at a San Francisco hospital coronary care (heart attack) unit found that those seriously ill patients who were prayed for were less likely to need antibiotics and had fewer complications, although length of hospital stay and death rates did not differ between groups (www.americancancersociety.com, 2004). A larger randomized clinical trial conducted at a Kansas City hospital coronary care unit found similar findings. Overall length of
hospital stay and time in critical care unit did not differ between groups. However, the group that had been prayed for had 11% fewer complications. The researchers concluded that these results suggest that prayer may be an effective complementary therapy to conventional medical treatment.

Religious Coping

The Coping Process: The coping process is a process that is influenced by contextual, environmental, and personal factors (Folkman and Lazarus, 1985). It is an ongoing transactional process in which an individual assesses the person-environment relationship and appraises the relevance of the experience and the perceived threat, loss, challenge or benefit of the situation. Coping behaviors are then selected by the individual in an attempt to manage, alter, and master the situation or to regulate an emotional response (Bjorck, 1997).

According to Pargament, (1997), when religious beliefs and practice is incorporated into this process, it enables us to address those situations in which we are pushed beyond our own immediate resources and confront our vulnerability to others, ourselves and the world.
Research has pointed to a variety of religious coping methods that serve various ends. For example, Pargament et al. (1988) have distinguished three different approaches to coping in a stressful situation: (1) The self-directing approach, in which the individual relies on self rather than on God; (2) The deferring approach, where the individual places the responsibility for coping on God, and (3) The collaborative coping approach, where the individual and God are both active partners in coping. Wong-McDonald (1997) proposed a fourth religious coping style, Surrender, in which the individual works with God while valuing God’s direction above his or her own.

Maynard et al (2001), hypothesized that the use of Paragament’s religious coping styles would be positively correlated with an individuals perceptions of others values. In other words, the perceived beliefs of others would positively predict an individual’s utilization of a coping response. In addition, it was also hypothesized that the use of religious coping styles would be significantly correlated with the individual’s concept of God and their report of religious and spiritual importance as well as religious participation. The results of the study strongly supported the assertion that the perception of others'
beliefs and values influenced the individual's own use of a coping style. Researchers also found that individuals who used the Surrender coping style felt most comfortable giving over the ultimate outcome of their situation to a God who they believe cares for them and has the power to know, act on behalf of, and guide the individual in times of distress. Participants also felt comfortable endorsing the "Deferring Style", leaving their outcomes solely in God's hands, when they perceived God to be a stable and guiding force. Those participants who utilized the "Self Directing" coping style preferred not to try to solve problems on their own in the presence of a deity who they perceived to possess the qualities necessary to assist in times of distress. In addition, these same participants (those utilizing the "Self Directing" coping style) preferred to take matters into their own hands when God was perceived to be false, distant or removed from human affairs.

Pargament (1997), identified other forms of religious coping, such as benevolent religious appraisals, seeking support from clergy or church members, seeking spiritual support, discontent with congregation and God, negative religious refraining, and expressing interpersonal
religious discontent. Some forms of religious coping, such as perceiving illness as the will of God or as an opportunity for spiritual growth (Jenkins & Pargament, 1988), use of collaborative religious coping (Pargament et al, 1990), and seeking spiritual support (Wright, Pratt, & Schmall, 1985), are tied to better outcomes (e.g., higher self-reported self-esteem, better psychological adjustment) for the individual. On the other hand, certain forms of religious coping, such as expressions of religious discontent with congregation and God, are associated with poorer outcomes (e.g., poor mental health status, poor resolution of the negative event) (Pargament, 1997).

Religion and Stress

The majority of research investigating the stress buffering effects of religion has focused primarily on public religious activities such as church attendance. Williams, Larson, Buckler, Heckman, Pyle (1991) found that in a community sample of adults, church attendance buffered the effects of stressful life events and health problems. Ellison, (1993) however, reports that these public religious activities do not appear to protect individuals from all forms of stress. This researcher examined whether
public or private religious activity buffered the impact of three types of stressors: physical unattractiveness, recent negative life events and chronic illness on self esteem among a national sample of African Americans. He found that public religious participation moderated the negative impact of physical unattractiveness on self esteem and private devotional activities buffered the negative impact of chronic illness on self esteem. However, neither public religious or private devotional practices moderated the negative impact of recent stressful life events on self esteem.

In another study conducted by Ellison (1991), examining the stress buffering effects of other forms of religiosity, it was concluded that stability of religious faith buffered the impact of traumatic life events, including health related crises. However, as with other studies (Ellison and Gay, 1990; Idler, 1987; Krause and Van Tran, 1989 and Pollner, 1989), researchers found no evidence of the stress buffering effects of divine interaction.
Religion and Caregiving

Few studies have been conducted examining the specific role of religion practice in the caregiving experience. Of the work that has been done four different themes have developed: (1) church as a support network; (2) use of religion or spirituality as coping resources; (3) personal accounts of spiritual growth; and (4) transcending loss to find meaning.

The first theme emphasizes the supportive role that churches play in the caregiving experience. Burgener (1994), reported that churches not only attend to an individuals spiritual needs and increased well being, but also when linked with health care providers helped to bridge the mistrust of the social service industry inherent in certain age and religious groups. In addition, churches legitimized the importance of seeking help in the caregiving situation and facilitated initial and follow up interactions with service providers.

According to Taylor and Chatters (1986), the informal support and assistance offered to African American caregivers by African American churches is often second only to the support provided by the actual family. The most prevalent type of assistance is help during illness,
followed by spiritual support, advice and encouragement, and lastly instrumental aid.

Second, relying on religious beliefs and practices has consistently been shown to be an important coping strategy in the caregiving situation. Whitlatch, Meddaugh, and Langout (1992) reported that religiosity emerged as a significant coping resource across multiple aspects of caregiving. Stolley, Buckwalter, and Koenig (1999), identified prayer as an important way that caregivers cope with their situations. Picot et al. (1997), emphasized the need for practitioners to attend to the spiritual and religious coping needs of caregivers, particularly among African Americans.

The third theme encompasses the work of Fish (1996), and Sisk (1992). Fish a caregiver for her mother and Sisk for her parents-in-laws, both spoke of spiritual growth during their respective caregiving experiences. Fish adhered to the promise that God would never abandon her and describes how she gained strength from this promise. Sisk wrote of how her faith in God sustained her during the challenges of caregiving.

Finally, there is evidence that supports the fact that caregivers use their religious beliefs to bring meaning and
purpose to their circumstances (Farran, Keane-Hagerty, Salloway, Kupferer & Wilken, 1991; Kay & Robinson, 1994; Wright, Pratt & Schmall, 1985). Rather than focusing on the sadness of the disease, they relied on their faith to transcend the losses associated with the disease and looked for positive outcomes that had emerged despite the loss.

Research by Williams (1991), indicates that religiosity among adults is associated with positive well-being as measured by decreased anxiety, fewer health problems, and fewer deleterious consequences as a result of stress. There is little empirical research that explains the specific ways in which these positive ramifications of religion are achieved. Some assert that many of the effects of religion are derived from cognitive strategies that are made by religious adherents (Pargament and Hahn, 1986). Few of these studies, however, attend specifically to the experiences of African Americans.

Negative Aspects of Religion

Many researchers have argued that religious beliefs and practices may have an adverse effect on one's adjustment to illness (Baider and Surwell, 1983). Studies on religious coping have identified a number of religious coping
strategies that are predictive of poorer adjustment to illness. In a study conducted by Paragament et al (1998), among a sample of students from a large Midwestern University and roman catholic church, members who had experienced a significant life event (including illness) during the past two years, researchers identified several ineffective religious coping that were related to poorer mental health and event related outcomes. These included religious based apathy and inappropriate self condemnation, doubts about ones religious beliefs and feeling at odds with ones religious practices. In another study, Koenig, Paragament and Nielson (1998), found that those patients who adopted negative religious strategies such as reappraising God for punishing them, feeling religious discontent, and attempting to cope without God’s help had higher levels of depression. Other studies have found that when individuals attribute negative life events to a punishing God, generally results in poorer outcomes (Greengoed, Pargament 1987 & Pargament et al, 1990).

It has also been suggested that religious beliefs may hinder the utilization of certain kinds of medical procedures and treatments (Chatters, 2000). In addition, researchers have proposed that an individual’s religious
beliefs and practices may lead to noncompliance when they completely surrender their illness to God (Dull and Skokan, 1995).

Existing literature has demonstrated the importance of religion in mediating the relationship between stress and one’s physical and psychological health. However, what is yet undefined is the role in which religious beliefs and practices play in coping with the physical, emotional and cognitive burdens of family caregiving within the African American family unit.
CHAPTER THREE

METHODOLOGY

Design: This study was designed to utilize both a qualitative and a quantitative approach to examine the ways in which religion acts as a protective factor against the stressors and demands of family caregiving for persons with adult onset brain impairments.

Population: Participants in this study were selected from a convenience sample of African American women who are members of a large Christian church located in a metropolitan area of Southern California. All of the participants were currently caring for their spouses who had been diagnosed with an adult onset brain impairment. The mean age of the participants was 59.3 and all have earned a high school diploma. Only one of the participants had some post high school education. The participants have all been married to their spouses for more than 27.5 years and their annual income ranged from 30,000 to 47,000. See Table 4 for additional caregiver characteristics.
Table 4. Caregiver Characteristics.

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<tr>
<th>Caregiver 1: H.S. Age: 61 years</th>
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<tbody>
<tr>
<td>Married: 27 1/2 years</td>
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<tr>
<td>Spouses Diagnosis: Early Onset Dementia (diagnosed in 1999)</td>
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<tr>
<td>Number of Children: 4 (2 male; 2 female)</td>
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</tr>
<tr>
<td>Husband is completely dependent upon caregiver to complete all daily living skills (eating, bathing, dressing and toileting). He is ambulatory and severely cognitively impaired.</td>
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<tr>
<th>Caregiver 2: L.B. Age: 60 yrs.</th>
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<tr>
<td>Married: 35 years</td>
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<tr>
<td>Spouses Diagnosis: Glioblastoma Multiforme Brain tumor (diagnosed Aug. 2003)</td>
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<tr>
<td>Number of Children: 1</td>
<td></td>
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<tr>
<td>Husband is dependent upon caregiver to complete daily living skills such as bathing, dressing and grooming. He is limited in his cognitive abilities and ambulatory status.</td>
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<tr>
<th>Caregiver 3: J.C.W. Age: 59 years</th>
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<tbody>
<tr>
<td>Married: 32 years</td>
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<tr>
<td>Spouses Diagnosis: Severe brain trauma caused by automobile accident during the late 80's.</td>
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<tr>
<td>Number of Children: 6 (3 male; 3 female)</td>
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<tr>
<td>Husband can complete all of his daily living skills independently with supervision. He has limited cognitive abilities and is ambulatory with the use of adaptive equipment.</td>
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Qualitative Design

The purpose for the qualitative portion of the study is to explore the unexpected reasons for the participant's ability to cope with the stressors that are a result of
family caregiving and to elicit personal views on the effects in which religious beliefs and affiliation have on those providing care.

The qualitative data collection consisted of personal interviews and focus group discussions. Interviews were conducted by the research investigator and were took place in the setting of the participants choice. Participants were asked questions from a semi-structured interview tool developed from the literature and previous work on religion and caregiving (Appendix A). In order to preserve the natural flow of the dialogue between the research investigator and the participants, the questions were introduced once the participants mention God or religion as coping resources. If no spontaneous reference to God or religion was made, then the question was asked after the participant had responded to all questions about the ways in which she has coped with the adverse events of caregiving. The interviews ranged in length from 60 to 90 minutes (M= 70). All of the interviews were audio taped and later transcribed verbatim. The verbatim transcripts were used as the source for content analyses. No monetary compensation was provided to study participants.
Focus group discussions were conducted with the participants to discuss how the church could better support caregivers and to identify the strategies needed to ensure that this support is provided. In addition, the focus group discussions also helped the investigator obtain the caregivers perceptions on why African American family caregivers tend to rely on informal support such as their religion, rather than formal services to assist with family caregiving.

All interviews and focus group discussions were audio taped and transcribed verbatim. The transcripts were continuous checked for accuracy. Independent content analysis by the research investigator was conducted to develop major themes. The data was continuously analyzed as collected and a comparison between the newly and previously gathered data to examine the similarities and differences between participants.

Quantitative Design

The data for the quantitative portion of this study was gathered through the use of two self report measures: “The Caregivers Stress Scale” (Appendix B) and “The Ways of Religious Coping Scale” (Appendix C). The Caregivers Stress
Scale was developed by Dale Lund, PhD and Scott Wright, PhD of the University of Utah Gerontology Center. The scale is designed to assess the physical and emotional effects of caregiving. The scale lists statements that describe the participants' feelings about their time, physical and emotional health and social relationships.

The Ways of Religious Coping Scale (WORCS), developed by Edwin Boudreaux, Sheryl Catz, Laurie Ryan, Marta Amaral-Melendez, and Phillip J. Brantley is a 40-item scale that is used to assess the degree to which subjects engage in religious behaviors to cope with stressful situations (Boudreaux et al., 1995). A stressful situation is any situation that is difficult or troubling, either because the individual feels distressed about what is happening or because they have to use a considerable amount of effort to dealt with the situation. The behaviors included in the scale range from internally-focused processes such as prayer to externally-focused processes such as participating in a church support group, with higher scores reflecting greater use of religious coping strategies. The scale was validated on a sample that consisted primarily of Caucasians (80%, N=131) and a small percentage of African
Americans (9% N=15). The overall scale has an internal consistency of .95.

The findings derived from this study will further clarify the role of religion in the coping efforts of caregivers and enhance our professional understanding of the multifaceted relationships between religious involvement and personal well being.
CHAPTER FOUR

FINDINGS AND RESULTS

Qualitative Results

There were several common themes that emerged from the interviews conducted with the caregivers in the study. However, there were four in particular that merit discussion. The four themes of commonality are:

1. Coping;
2. The importance of "the church"
3. Optimism and making the most of the situation.
4. Challenges to caregiving

In depth Caregiver Interview

Coping. The first pervasive theme that emerged from the in depth caregiver interviews was their unusual ability to cope with their caregiving responsibilities. Faith and their belief in God was a significant coping resource for them in their daily lives. Transcripts from the interviews revealed that not only did their faith help them to construct a framework that brought purpose and meaning to their lives, it also consistently provided them with a resource for coping with caregiving and other adverse life events.

One caregiver stated, "You are never going to go through life with having everything the way you want it."
There are times when you are going to have problems . . . and you just have to have faith and believe that God is going to see you through." Another exclaimed, "Faith helps me to cope with life and all of my problems . . . it gives me strength and inner peace during times of trouble."

Closely linked with the importance of faith was the connection of faith to hope. One caregiver explained that the Bible says that "faith is the substance of things hoped for and the evidence of things not seen. "They have a song that they used to sing about: If God is dead who makes the wind to blow in the trees? Who makes the sun shine? So this 'power' still has to be living and active and working through all of us. And we just have to go with the flow and have faith that it's alright", one caregiver stated. Another exclaimed, "I don't know how I could cope without my faith . . . it really means so much to me. It gives me so much hope and strength".

Spiritual practices such as prayer and reading the Bible or other religious materials played a prominent role in the study participants' ability to cope with their caregiving responsibilities. The most frequently noted coping strategy utilized by each of the caregivers was prayer. It is important to point out that the significance
of prayer emerged spontaneously during the interviews, rather than after a prompt or probe by the interviewer. Prayer was described as "a conversation with God ...a way of communicating with Him about a situation." The caregivers all reported that they incorporated prayer in their daily lives no less than three times a day. It was not only used as the vehicle to ask for strength, wisdom and guidance to get through the day, but also to ask for miraculous healings for their spouses from God.

Reading the Bible and other religious materials was also significant in the caregivers coping repertoire because it was said to provide them with a clear understanding of God’s will and His power. One caregiver reported, reading the bible the Bible drew her closer to God and helped her grow in her relationship with Him and her care receiving spouse.

The importance of the church. The second theme, the importance of the church revealed how the caregivers relationship with God and their church congregation provided the basis for a more personal spiritual philosophy that included their views about life and family caregiving. Views held by the caregivers included the belief that life has both trials and blessings. One caregiver called herself
'God's super woman' because of all that she has experienced while caring for her spouse. Despite such experiences, she said, "I'm too blessed to be stressed" and that "God has preplanned my life." Another's philosophy was simply, "This too, shall pass."

The three caregivers reported that they participate in weekly or more frequent church attendance. They described their church/congregation not only as an organization and an integral part of their culture, but also as a place where they received comfort, encouragement, admonishment and a sense of extended family. One caregiver stated, "Church is like any other family... you don't always agree, but they're always there... You can depend on them (the church). Another referred to the church as a 'resource place'. She explained that the church 'nurture' her and that going to church is 'like getting a refill at a gas station, when you're feeling empty and down they (the church) provide you with the comfort and strength that you need to fill you up so that you can make it'.

Optimism. It is inherent in the human experience to desire to make the most of a difficult situation. Barriers such as caregiving for a terminally ill or brain impaired spouse, depression and social isolation can prevent a
person from seeing the positive side of stressful life events. However, all three of the study participants exhibited an ‘if you can’t change it, make the most of it’ attitude. “When, you look around the world you’ll find that there are people in worse shape than my husband is. So instead of concentrating on what we don’t have, I try to concentrate on what we do have . . . I try to concentrate on the positive things and not be bitter about what he can’t do . . . I’ve always believed – and my father taught us this, too – if you spend your time being bitter and hating, you’re not hurting anyone but yourself” one caregiver explained. Another stated “If you cannot change something, you should just stop struggling for a moment and be still and let it evolve, it might evolve into something really good for you. And I think caregiving is the same thing . . . I can’t see anything good coming out of this, but the simple fact of the matter is that I can’t change it. If I do my best within the context of it and stop struggling and really try to enjoy the time with him (her spouse) that I have, to the best of our abilities to enjoy it, then that’s enough. And I’ll see what happens as it happens down the line . . . things have always been okay. I’m kind of a survivor.”
Challenges. The final theme revealed in detail the challenges that are faced by the caregivers on a daily basis. First, the caregiving role was reported to be challenging and stressful because of the changes in their spouses' behavior and personality due to their brain impairment, and the caregivers' own emotional responses to the experience of providing in home care. One caregiver expressed having difficulty with her own emotional responses to caregiving and said that these emotional responses affected her feelings about herself as a spiritual being. Emotional responses experienced by caregivers included anger, sadness, and turmoil. When talking about herself one caregiver said, 'There is some anger there. The Lord has brought me to a new level in Him... but I sure could use some help. Another caregiver expressed feelings of sadness and turmoil.

The second challenge was described as having mistrust in and frustration with the health care system. The caregivers expressed varying levels of negative emotions which reportedly stemmed from feelings of humiliation, disrespect and the belief that their husbands were receiving sub-standard care (interestingly, the three dyads are members of the same HMO). Each gave a detailed example
of a recent disrespectful encounter that had taken place with a health care professional. One caregiver summed this problem up by saying, "Some of the doctors, nurses and others speak to you like you are less than human, they do not speak to us in a respectful manner. So how can I trust that (spouse’s name) is going to receive the best of care." Another caregiver bluntly equated disrespectful communication by health care professionals with prejudicial care toward African Americans, she explained, "there is definitely a multi-tier system of health care at (names the HMO) and African Americans are at the bottom when it comes to respect."

Focus Group

Responses generated during the focus group discussions revealed that the caregivers in this study expected and desired a variety of social supports from their church organization. Although they relied heavily on their church to provide them with emotional, spiritual and financial supports as well as meal preparation and hospital and home visitation, they identified many additional services in which they felt that the church could better support the members of the congregation who are providing in home care for their loved ones. Suggested services included caregiver
and family support groups, respite, transportation to church and medical appointments, help with housing repairs, bereavement support, and educational programs (programs that provide the caregivers with education about their loved ones illness).

Also emerging from the focus group discussions were several suggestions for strategies needed to fill the previously discussed gaps in services provided by the church. One strategy involved a church, public agency and community provider collaboration that would address the issues unique to caregivers, care receivers and their families.

Another addressed the churches willingness to relinquishing the notion of their role as solely to meet the spiritual needs of the congregants and move toward the idea of addressing other needs that might exists amongst its members. An example of this was provided by one caregiver who suggested that the church establish a health ministry. According to the caregiver, a ministry as such would generally address health care needs and identify resources to nurture the well-being of individuals and families within the church. She added that the ministry would focus on encouraging each individual's physical,
emotional, spiritual, and social well-being as well as to provide health counseling, assessment of problems, health promotion and referrals to community-based resources.

Other suggestions included an increase in the churches' involvement in legislation, policy making and advocacy. It was believed that involvement in such arenas could provide pastors with the opportunity to influence community leaders by advising them of the needs of their congregation.

Corresponding with the individual caregiver interviews, the topic of health care provider disrespect toward family caregivers during medical office visits emerged from the focus group discussion as a major theme of difficulty. This constituted a troubling and serious barrier perceived by family caregivers in their quest for services and care for their brain impaired spouses. These negative family caregiver-health care provider interactions caused the caregivers to experience deep feelings of disrespect. Stress was usually generated from experiencing the duality of tension between respect and disrespect during these encounters. While the caregivers respected the dignity and independence of their spouses, they experienced frank disrespect from health care providers when expressing their concerns about the cognitive and behavioral changes
in which they were observing in their husbands. The feeling generated by this duality of respect versus disrespect constituted a type of caregiver stress that has not previously been identified in the literature. Whether this duality is experienced because of cultural and ethnic issues or structural problems is not yet clear and should be considered in future research.

Quantitative Results

Results from the Ways of Religious Coping Survey revealed that the caregivers in this study use a range of coping mechanisms to deal with the demands of caregiving. Praying was the most commonly reported method of coping followed by fellowship with friends and reading the bible. Seeking help from a pastor or church leader were less commonly used techniques.

An analysis of the Caregiver Stress survey results revealed two specific areas that together were the strongest factors contributing to the caregivers increase in their perceived levels of stress. According to the data, the caregivers were more likely to experience a perceived high level of stress when: 1) their spouse was completely dependent upon them and they were performing a
great number of caregiving tasks and (2) they felt that their caregiving responsibilities were significantly affecting their social relationships. On the contrary, their physical health and psychological well being were not significant factors in their perceived increased levels of stress.

Discussion

Consistent with prior research, the results of this study suggest that the religious beliefs and practices of family caregivers play a pivotal role in the caregiver’s ability to better cope with their family caregiving responsibilities.

This study examined the role of religious beliefs and practices in the coping strategies used by caregivers and how these beliefs and practices impact the outcome of caregiver burden for family caregivers of spouses with adult onset brain impairments. Previous research with family caregivers of brain impaired victims has shown religion to be a widely used and generally effective coping strategy in dealing with the stresses of caregiving. Findings from this study confirmed the importance of religious factors in the coping scheme of family
caregivers. In fact, the caregivers in this sample reported that not only did they find happiness, strength, and positive changes in their lives as a result of their religious beliefs (faith) and practices (prayer), their religious beliefs and practices helped them to deal with the stressful aspects of caregiving as well as to place their life experiences in a broader perspective.

The caregivers expressed strong beliefs about God and the important role that God played in all areas of their lives. Their beliefs and expressions about God closely resembled their expressions about belonging to a church community and the role that the church played in their lives. Their relationships with God and fellow congregations also provided the basis for supporting their underlying personal religious beliefs. Rich imagery and commonly held biblical and other expressions were continuously used by the caregivers to describe how their religious beliefs helped them to make sense of their caregiving experience.

The importance of religion was established before they became family caregivers and appeared to play a key role in how they experienced and expressed their feelings about their family caregiving responsibilities. Their religious
beliefs and practices affected their relationship with their spouse, the challenges accompanying the caregiver role, and how they survived and grew through the experience of caring for their loved one. Other authors and researchers have supported these findings, especially for African-Americans (Lincoln & Mamiya, 1990; Proctor, 1995). For example, while Hispanic American caregivers of Cuban and Puerto Rican descent were found to rely more on their families than on the Catholic Church (Henderson, 1996), African-Americans were consistently found to rely equally on family and church for support in meeting caregiving demands and coping with the associated strains (Lewis & Ausberry, 1996). As Dilworth-Anderson and Rhoden suggest, the strict discipline used by female family members in teaching the faith may be attributed to the fact that black women are teaching 'respect for order in a world where life is threatened on a regular basis' (Dilworth-Anderson & Rhoden, 2000, p. 90). The importance of organized religion, usually a mainline denomination, in African-Americans has also been documented (Lincoln & Mamiya, 1990).

The comments made throughout the interviews and focus group discussions reflected perceptions found in the literature of a historical mistrust and suspicion of formal
systems and fear of institutional racism held by many African Americans when they interface with the health care system (Edwards, Baum, Meisel, Depke, Williams, Bradford, et al., 1999; Gamble, 1993, 1997; Johnson & Barer, 1990; Green et al., 1997; LaViest, Nickerson, & Bowie, 2000; Lillie-Blanton, Brodie, Rowland, Altman, & McIntosh, 2000). The caregivers in this study perceived experiences of racism and feelings of powerlessness and alienation in the system. They viewed accessing and receiving health care for their spouses as a degrading, demeaning and humiliating experience. That these perceptions continue to exist represents another factor that increases caregiver stress and causes African American caregivers to delay seeking assistance from formal service providers.
Overall, although the findings cannot be generalized to all caregivers of loved ones with adult onset brain impairments, the diversity among informal caregivers and the complexity of the issues they face were readily apparent. Each caregiver had unique situations and circumstances related to their family caregiving experience. Their religious beliefs and practices, family dynamics, history, values and beliefs regarding the role of family and the formal care system in providing assistance, financial circumstances, personalities of both the caregiver and the care receiver, and the nature of the caregiving network all had an influence on their family caregiving experience.

The caregivers in this study reported that their religious beliefs and practices, impacted their lives and family caregiving efforts. Their beliefs and practices helped them deal with the stress of the ongoing, escalating level of care that they must provide. The quality of life for the brain impaired individual can be greatly increased
when a caregiver is able to effectively cope with their care responsibilities.

It has only been in recent years that religion has been seriously considered within the scope of scientific inquiry regarding terminally ill (i.e. brain impaired) individuals and their caregivers. This small qualitative/quantitative study made it is possible to hear the caregivers' voices with respect to their beliefs and cultural values. This study allowed the individual caregivers to explain their understanding of how they obtained their religious beliefs and practices, how their own ethnicity impacted their beliefs, and how both have affected their lives as caregivers.

Recommendations

This study adds to a growing body of literature that calls for the development of policy that better recognizes the critical role of the informal caregiver. It is important to embrace an expanded understanding of what role religious beliefs and spiritual practices play within the life of the individual and the life of the community. These efforts might include contacts with family caregiving ministries, faith and action groups, or health and wellness
ministries that already exist within a particular congregation. Other examples might include working with various denominational or already-existing clergy groups to provide specific educational efforts for clergy and congregational members, and/or specific services provided by members to persons with dementia and their family members (Gwyther, 1995; Stuckey, 1998)

Health policy and programming should include a deliberate plan for increasing community awareness about the needs and resources for informal caregivers. Informal caregivers should be considered as team members and collaborators in the assessment and planning process with brain impaired individuals and community service providers. Community resources for informal caregivers are made more available, accessible, flexible, and responsive to caregivers' needs. Greater collaboration across systems is recommended to enhance the understanding of family caregiving issues and to initiate innovative strategies to deal with these issues in an effective manner.

Recommendations for future research efforts include both qualitative and quantitative studies specifically focused on minority populations. Qualitative analyses that include in-depth, individual interviews are needed to
further expand the issues of religion and family caregiving. Quantitative studies that appropriately measure religious coping strategies as a variable are also needed, as are multivariate approaches to understanding the relationship of religion to the family caregiving experience and to caregivers mental and physical health outcomes.

In order to provide adequate health interventions to assist diverse caregivers and care recipients, health care professionals must understand their particular beliefs and cultural values. By acknowledging these belief systems, health care professionals may be better able to help the caregiver provide the best care possible for the brain impaired loved one. For outreach efforts to succeed, the underlying beliefs of the individuals being served must be understood so that they can be incorporated into the planning of service delivery.

The religious beliefs and practices a person adheres to, how someone has made sense of this world, including losses and positive experiences, are some of the most personal beliefs and practices inherent in the human experience. Often these beliefs and practices stem from one's cultural or ethnic heritage. Consequently, it is
paramount to be sensitive to the personal religious beliefs, practices and traditions of caregivers and receivers when trying to offer medical care and support. Through a better understanding of the religious beliefs and perspectives of persons with terminal illness such (i.e. brain impairments) and their caregivers, health care professionals will be better able to provide more sensitive care and help bring hope and meaning to what might otherwise be abject sadness and despair.
APPENDIX A

INFORMED CONSENT FORM
INFORMED CONSENT FORM

Lisa R. Hebert
Graduate Department of Education: Health Option
California State University, San Bernardino
(909) 537-5000

My name is Lisa Hebert and I am currently a graduate student under the supervision of Dr. Kim Clark in the Health Sciences and Human Ecology Department at California State University in San Bernardino. I am conducting research for my Master's thesis project which is designed to investigate the possible effects that religious beliefs and practices might have on the female caregivers' ability to cope with the demands of caregiving situation. This study has been approved by the Institutional Review Board, California State University, San Bernardino.

My research will consist of the completion of two surveys (The Caregiver Stress Survey and The Ways of Religious Coping Survey) which should take about a total of 20 minutes to complete. You will also be asked to participate in a 1 to 2 hour focus group interview. The focus group sessions will be audio-taped and transcribed by the researcher. Tape recordings, transcriptions will be stored safely at my home. However, the university committees that govern the rules and policy about how research is to be conducted have the right to review these records. As do the faculty members on my thesis committee.

Your participation is totally voluntary. You are free not to answer any questions and withdraw at any time during this study without penalty. When you have completed the surveys, you will receive a debriefing statement describing the study in more detail. In order to ensure the validity of the study, please do not discuss this study with the other participants.

There are no direct benefits for those who participate in this project.

There are no foreseeable risks or discomforts that will result from this research. Because the participants are
members of the same church congregation and focus group sessions are a part of the project, the confidentiality of your identity cannot be guaranteed. Your name will not appear, however, in the results of the study.

If you have any questions regarding this study or your rights as a participant in this research, please feel free to contact me or my faculty advisor Dr. Kim Clark at California State University San Bernardino at (909) 880-5323.

By placing a check mark on the line below, I acknowledge that I have been informed of, and that I understand the nature and purpose of this study and I freely consent to participate. I also acknowledge that I am at least 18 years of age.

Place a check mark here _____
Today's date ________________
APPENDIX B

INTERVIEW QUESTIONS
INTERVIEW QUESTIONS

1. Please tell me about a time in the past six months when you had to deal with a difficult situation related to your spouse and his illness.

2. In what ways have you tried to cope with this difficulty?

3. Which ways of coping have been helpful to you in dealing with the problem?
   a) How have they been helpful?

4. Which ways of coping have not helped or have hurt you in dealing with the problem?
   a) How have they hurt you?

If the caregiver did not mention religion as a way of coping, she will be asked the following question:

Has your religion or spirituality been involved in coping during your role as a caregiver? If so, how? If not, why not?
APPENDIX C

CAREGIVER STRESS TEST
CAREGIVER STRESS TEST

This checklist was developed by Dale Lund, Ph.D. and Scott Wright, Ph.D. of the University of Utah Gerontology Center. It is designed to assess the physical and emotional effects of caregiving.

After each question, rate your response according to the scale below. Then, add them up for a total score.

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

Time Dependency Items

☐ 1. S/he needs my help to perform many daily tasks.

☐ 2. S/he is dependent on me.

☐ 3. I have to watch him/her constantly.

☐ 4. I have to help him/her with many basic functions.

☐ 5. I don't have a minute's break from his/her chores.

Development Items

☐ 1. I feel that I am missing out on life.

☐ 2. I wish I could escape from this situation.

☐ 3. My social life has suffered.

☐ 4. I feel emotionally drained due to caring for him/her.

☐ 5. I expected that things would be different at this point in my life.
Physical Health Items

☐ 1. I'm not getting enough sleep.

☐ 2. My health has suffered.

☐ 3. Caregiving has made me physically sick.

☐ 4. I'm physically tired.

Social Relationships Items

☐ 1. I don't get along with other family members as well as I used to.

☐ 2. My caregiving efforts aren't appreciated by others in my family.

☐ 3. I've had problems with my marriage or other significant relationship.

☐ 4. I don't get along as well as I used to with others.

☐ 5. I feel resentful of other relatives who could, but do not, help.

Emotional Health Items

☐ 1. I feel embarrassed over his/her behavior.

☐ 2. I feel ashamed of him/her.

☐ 3. I resent him/her.

☐ 4. I feel uncomfortable when I have friends over.
5. I feel angry about my interactions with him/her.

Lund and Wright, authors of the Caregiver Stress Scale, strongly suggest that:

- You use respite and other services if your score is near or above 36.
- You check and see if you answered any question with a 3 or 4. Think about why you scored so high on the question and how you might reduce the stress you are experiencing.
APPENDIX D

WAYS OF RELIGIOUS COPING SCALE
WAYS OF RELIGIOUS COPING SCALE (WORCS)

Scale items:
The following questions relate to how you handle stressful situations in your life. A "stressful" situation is any situation that is difficult or troubling for you, either because you feel distressed about what is happening or because you have to use considerable effort to deal with the situation. The situation may involve your family, your job, your friends, or something else important to you.

Read each statement carefully and indicate how often you engage in the following behaviors when you experience a stressful situation. Indicate your answer by circling the appropriate answer. Please respond to every item.

USE THE FOLLOWING RESPONSE CATEGORIES:
0. not used at all/does not apply
1. used sometimes
2. used often
3. used very often
4. used always
Items followed by an R should be reversed when scoring.

1. I say prayers.
2. I read scriptures.
3. I attend a religious support group.
4. I allow the Holy Spirit to direct my actions.
5. I confess to God.
6. I do not pray. R
7. I get support from church/mosque/temple members.
8. I talk to church/mosque/temple leaders.
9. I look for a lesson from God in the situation.
10. I try to be a less sinful person.
11. I pray to God for inspiration.
12. I try to make up for my mistakes.
13. I put my problems in God's hands.
15. I talk to church/mosque/temple members.
17. I talk to my minister/preacher/rabbi/priest.
18. I recall a Bible passage.
19. I stop going to religious services. R
20. I get help from clergy.
21. I use a Bible story to help solve a problem.
22. I pray for the help of a religious figure.
23. I solve problems without God's help. R
24. I ask for God's forgiveness.
25. I donate time to a religious cause or activity.
26. I ask my religious leader for advice.
27. I share my religious beliefs with others.
28. I think about Jesus as my friend.
29. I get involved with church/mosque/temple activities.
30. I give money to a religious organization.
31. I base life decisions on my religious beliefs.
32. I find peace by going to a religious place.
33. I ask someone to pray for me.
34. I ask for a blessing.
35. I pray for help.
36. I go to a religious counselor.
37. I work with God to solve problems.
38. I find peace by sharing my problems with God.
39. I stop reading scriptures. R
40. I recite a psalm.
APPENDIX E

WAYS OF RELIGIOUS COPING SCALE
DATA SUMMARY
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<th>Activity</th>
<th>N</th>
<th>Minimum</th>
<th>Maximum</th>
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