

ADULT CHILDREN CAREGIVERS OF PARENTS WITH ALZHEIMER'S DEMENTIA

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ABSTRACT

Dementia is a neurological disease that affects cognitive functioning. Those who suffer from dementia lose their cognitive abilities and the ability to care for themselves, and as the disease progresses, they often require assistance with daily living. The purpose of this study was to examine familial caregivers – specifically adult children -- of Alzheimer patients. This study investigated (1) sociocultural factors that may contribute to the decision to take on the caregiver role (i.e., gender roles and cultural beliefs); (2) family-level factors that may contribute to burden (i.e., family decision making process, family coping), and (3) health habits associated with caregiver burden (i.e., alcohol and drug use). A total of 391 family caregivers of Alzheimer's patients were recruited from Amazon's Mechanical Turk website. This study showed that sociocultural factors contribute to the decision to care for a parent, family-level factors contribute to burden, and health habits are associated with that burden.

DEDICATION

This thesis is dedicated to anyone taking care of a person with Alzheimer's Dementia. Your dedication and selflessness in aiding people with this disease is inspiring. I would also like to dedicate this thesis to my family. The strength and bond that we have held through the past few years is beautiful and I am so lucky to have you for support and love.

LIST OF ABBREVIATIONS AND SYMBOLS

α	Cronbach's Alpha
df	Degree's of Freedom
$<$	Less Than
$=$	Equal To
r	Correlation Coefficient
t	T-value
p	P-value
χ^2	Chi Squared

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Chapter One

INTRODUCTION

Dementia is a neurological disease that affects cognitive functioning. Those who suffer from dementia lose their cognitive abilities and the ability to care for themselves, and as the disease progresses, they often require assistance with daily living. In the year 2030, it is expected that dementia will impact 66 million individuals in the world, which will subsequently increase the number of caregivers (Lou, Liu, Huo, Megnyuan, Shuai, & Yong, 2015). In 2015, 15 million family members were caring for a person with Alzheimer's or other forms of dementia. Of those 15 million family members, 38% were caring for someone for six months and 86% were caring for someone for a year (Alzheimer Association, 2016). The caregiving role brings both positive and negative consequences. Positive outcomes include a sense of purpose, a sense of mastery, feelings of gratification and gratitude, increased patience and tolerance, learning to let go, a closer bond with the patient, and the ability to keep a positive mindset (Cheng, Mak, Lau, Ng, & Lam, 2016). Negative outcomes associated with caregiving include depression, anxiety, poor health habits, poor sleep patterns, and burden (Abdollahpour, Nedjat, Noroozian, Salimi, & Majdzadeh, 2014). The purpose of this study is to look at familial caregivers – specifically adult children -- of Alzheimer patients. This study will examine (1) sociocultural factors that contribute to the decision to take on the caregiver role for a parent (i.e., gender roles, cultural values); (2) family-level factors that may contribute to burden (i.e., family

decision making, family coping styles), and (3) health habits associated with caregiver burden (i.e., alcohol and drug use).

Chapter Two

LITERATURE REVIEW

Dementia

Dementia is a growing disease that affects more and more people every year. It is predicted that by the year 2040, over 80 million individuals will be affected with dementia (Oliveira, Vass, & Aubeeluck, 2015). Dementia is the decline in memory function that is severe enough to impact your day-to-day life. The two most common forms of dementia are Alzheimer's disease and vascular dementia. Major symptoms are memory loss, communication and language, ability to focus and pay attention, reasoning, judgment, and visual perception (APA, 2013). Dementia symptoms start out slow and progress over time. Patients typically lose track of objects, misplace items, and struggle over thinking skills. Further symptoms of Alzheimer's include disorientation, mood and behavior changes; confusion about time, events, and places; unfounded suspicions. As the disease reaches the end, some patients suffer from the inability to swallow, speak, or walk (Alzheimer Association, 2016).

Dementia is caused by damage to brain cells, which then affects communication between cells. In terms of Alzheimer's disease, high levels of proteins make it difficult for brain cells to remain healthy and communicate with each other. More specifically, these proteins cause plaques and tangles that make cellular communication impossible, first affecting memory and then spreading to other regions. The hippocampus is the source memory and learning and this region of the brain is the first region to be damaged. This is an explanation as to why in Alzheimer's disease, memory is the first function to be affected (Alzheimer Association, 2016).

Alzheimer Caregiver Burden

As the disease progresses into the stages that require others for support, the stress and burden of that task increases on the family member caregiver. Caregiver burden is a term used when the caregiver perceives stress in the care environment. The most common forms of burden come from psychological, financial, social, or physical demands from caring for an individual and is seen as a multidimensional response (Park, Sung, Kim, Kim, Lee, 2015; Werner, Mittelman, Goldstein, & Heinik, 2012). Since Alzheimer's is a disease that affects memory function, the demands of caring for that person can cause frustration, which can lead to burden. Patients with Alzheimer's may need more hands-on care and attention compared to patients with other illnesses (Park et. al., 2015).

As the Alzheimer's patient's neuropsychological symptoms grow, so does the burden for the caregiver and the cost of care for the patient. The amount of time before long-term institutionalization decreases at this point (Garcia-Alberca, Lara, Garrido, Gris, Gonzalez-Herero, & Lara, 2014). According to some studies, there is a positive correlation between caregiver distress and the patient's cognitive level of functioning (Raggi, Tasca, Panerai, Neri, & Ferri, 2015).

Studies show that women are more likely to be expected to take on a role as caregiver than men. Iavarone, Ziello, Pastore, Fasanaro, & Poderico (2014) found that caregivers are primarily female, wives or adult daughters. In a national sample, according to Ford et al. (1997), 71% of caregivers for Alzheimer's patients are women. Also, this study showed that women face more psychological and emotional stress due to caregiving. According to research, higher levels

of stress are found in older, female spouse caregivers (Raggi et. al., 2015). Men tend to take emotions out of caregiving and look at their new role as a job and their daily caregiving duties as tasks that need to be complete (Wennberg, Dye, Streetman-Loy, & Pham, 2015). Research also shows that adult-children feel more burden than spousal caregivers. This may due to the fact that spouses feel that being a caregiver is part of their marital duties and adult-children have to change their lifestyles to fit the caregiver role (Wennberg, Dye, Streetman-Loy, & Pham, 2015).

Little is known about the decision-making process surrounding the choice to adopt a caregiving role for a parent with Alzheimer's dementia. Gender, and possibly gender roles that promote caregiving behaviors, may influence decisions about caring for a parent. Other sociocultural variables may play a role as well, such as cultural beliefs and traditions. Powers and Whitlatch (2016) conducted a study measuring cultural justification between African American and White caregivers. They focused on duty and reciprocity in terms of cultural values regarding caregiving. They defined duty as a level of obligation to take on responsibility as caregiver for their loved one and reciprocity as expectations to care for parents through cultural beliefs. The decision making-process may in turn impact caregiver burden. For example, if a family member feels forced into the role, he/she may experience increased levels of burden. Alternatively, if a family member actively chooses this position, he/she may experience lower levels of burden. This study will aim to measure how the individual decides to become the primary caregiver and whether or not their feminine characteristics or cultural beliefs are associated with that decision.

Family Dynamics and Coping

When taking on the role of primary caregiver, burden, stress, anxiety, and depressive levels may increase (Lou et. al., 2015). Coping strategies have become a way for caregivers to handle the stressful situations they are in. Certain coping strategies can help with wishful thinking, emotional expression, social withdrawal, and problem avoidance (Garcia-Alberca et. al., 2014). Certain studies have aimed to connect caregiver burden and distress with coping strategies caregivers use to deal with their day-to-day lives. Garity (1997) found that with resilience, time spent with extended family, and conflict reframing, stress levels decreased. Iavarone et. al. (2014) showed emotion-focused tasks (expressed emotions, day dreaming, or thought reflection) were mainly performed by women and emotion-focused tasks were strongly related to burden. Men do not typically focus on emotions because they receive support from outsiders; women are typically the designated caregiver and therefore feel more burdened (Iavarone et. al., 2014).

In a recent research study with 102 family caregiver participants (both male and female), caregivers who report having healthy family dynamics have better relationships with their patient and are more willing to listen to their needs and provide better care for their loved one. They also have more social support from their family and provide higher quality care for their parent (Panyavin, Trujillo, Peralta, Stolfi, Morelli, Perrin, Lasa, & Arango-Lasprilla, 2015).

Families play a very important role in coping with crises in general and in coping with a parent with Alzheimer's. When families display positive copying strategies, caregivers may be better equip to handle the stress of caregiving. When there is support and caregivers report

having a healthy relationship with their family, the levels of burden may decrease and the quality of care may increase. What is missing from the literature is how family-level coping (social support, spiritual support, and reframing) impacts the level of burden. This study will aim to measure how families cope as a group and how the support of the family will relate to the levels of burden the individual feels.

Caregiver Health Habits

Caregiving interferes with preventative health behaviors and contributes to high risk behaviors (overeating, alcohol and substance abuse). In a sample of 60,000 Japanese participants, Goren and colleagues (2016) found a host of negative outcomes among caregivers compared to non-caregivers, with caregivers drinking more than 2 to 3 times per week and smoking cigarettes more often than non-caregivers (Goren, Montgomery, Kahle-Wroblewski, Nakamura, & Ueda, 2016). Similarly, Connell (1994) in a sample of 44 spouses, alcohol and smoking were used as a way to cope with caring for their spouse.

Other studies, though, have found contradictory results. In a survey of spousal caregiving, 54% of the caregivers reported drinking alcohol, but all 54% were previous alcohol users. One fourth of that sample decreased their alcohol consumption when in the caregiver role, and only one caregiver reported an increase in their alcohol intake (Connell, 1994). A decrease in drinking was attributed to decreased socialization; caregivers may not have time to go out with friends to drink. Connell (1994) found that of the 25 participants who drank, 7 decreased their consumption, 17 remained the same and 1 increased their alcohol consumption. Those who drank, drank socially and those who do not drink do not find the time to drink based on their

caregiver obligations. In the same caregiver samples, only one-third reported taking any form of antidepressants or sedatives (Connell, 1994).

In a sample of 233 spouses, Gallant and Connell (1997) also found decreased rates of alcohol consumption, but they measured binge drinking only (having four or more drinks in a row) and the respondents were spouses and not adult children. Also, Gallant and Connell (1997) found that few caregivers reported an increase in their binge drinking and half of the sample of drinkers reported that they have decreased their drinking.

Previous research has shown that caregivers who drink alcohol have decreased their usage, likely because they drink for social reasons, which is a common drinking motive (Cooper, 1994). Previous research has also reviewed the impacts on spousal caregiving. What is missing from the literature is information on adult children caregivers' drinking motives and substance use behaviors. One aim of this study was to examine whether caregivers who feel burdened in their role drink to cope with stress and whether they engage in a variety substance use behaviors (and not just binge drinking) including self-medication behaviors, such as the use and abuse of illicit drugs or prescription medication.

Theoretical Considerations

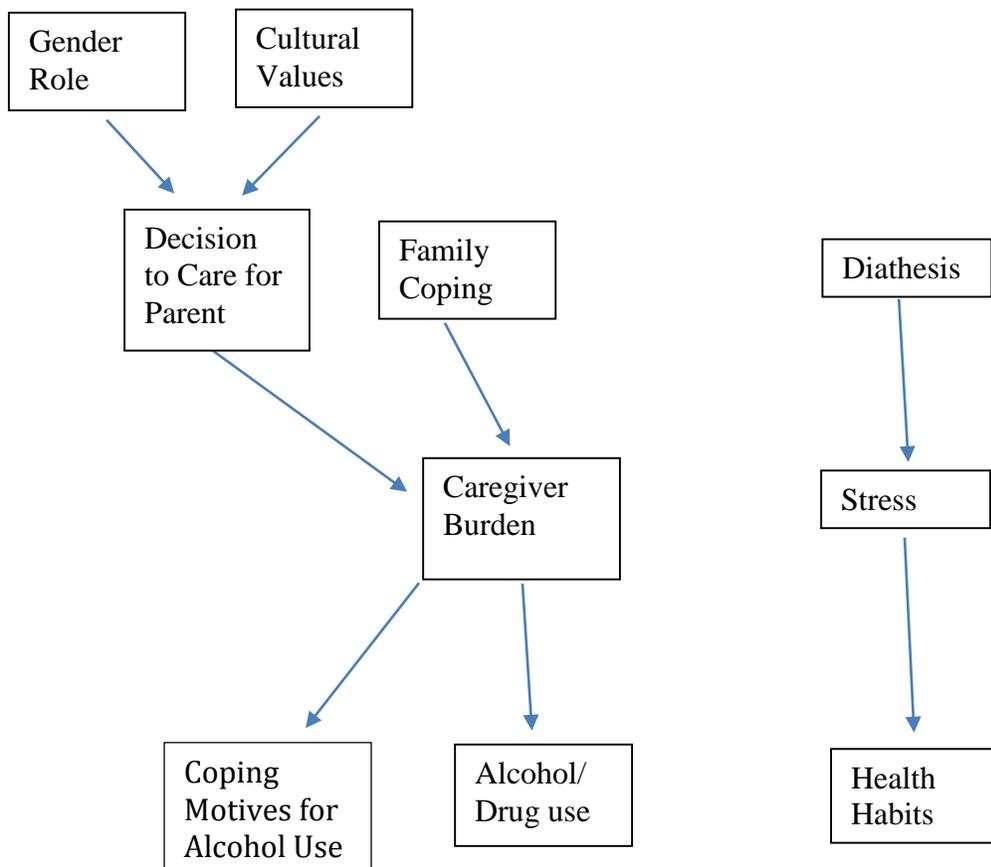
Based on a large meta-analysis, 45 studies have shown that caregiver burden leads to poor health outcomes for the caregiver. Vitaliano, Zhang and Scanlan (2003) introduced a stress-diathesis model to help connect stress to caregiver burden and to subsequent health outcomes. Stress-diathesis model is a psychological based theory that connects predispositional vulnerabilities (any quality/situation that makes the person vulnerable to poor stress outcomes)

with stress from life experiences. In this case, being in stressful situations (e.g., caring for a loved one with Alzheimer's) can be a life experience that can impact stress levels. There are two different paths that can explain how stress can impact the individual caring for their loved one. The first path refers to chronic stress, turning into psychological stress, which turns into hormonal stress. For example, the caregiver is constantly nervous about picking up after their patient or is afraid of having a negative interaction with their loved one. That fear turns into a constant reminder that at any time there could be a negative interaction. This reminder would then make the caregiver nervous, anxious, or constantly on edge. This could lead to an allostatic load and the caregiver can start to lose control over their emotions. The second pathway looks at how stress impacts the caregiver's personal health behaviors. The caregiver may start to take on a poor diet, reduce their rate of exercising, or begin drinking alcohol or using other substances to cope. Both of these pathways may lead to illness of the caregiver, which will impact the level of care for the Alzheimer patient (Vitaliano, Zhang & Scanlan, 2003).

Gallant & Connell (1997) propose that stress can directly affect a person based on their relationship with the environment. If the person does have resources to process the demands of his/her environment, that person may suffer direct consequences (poor health outcomes, poor behavioral and psychological responses). This theory states that there are a number of factors that contribute to how the individual copes with their role as caregiver. For example, caregivers who feel forced in the caregiving role, feel as if their family members (e.g., siblings) are not helping, and feel alone in their efforts in caring for their parent may feel burdened, which in turn may lead to poor health habits and the use of unhealthy coping mechanisms (drinking, taking

their parents medication, or using illicit drugs). (See Figure 1.) Once their health suffers, so will the quality of care they provide for their parent.

Figure 1. Theoretical Model of Caregiver Burden, Family-level Coping, Health Habits, and Poor Outcomes



Present Study

The purpose of this study was to examine familial caregivers – specifically adult children -- of Alzheimer patients. This study investigated (1) sociocultural factors that may contribute to the decision to take on the caregiver role (i.e., gender roles and cultural beliefs); (2) family-level factors that may contribute to burden (i.e., family decision making process, family coping), and (3) health habits associated with caregiver burden (i.e., alcohol and drug use). See Figure 1.

RQ1: Are feminine gender role adherence and cultural values regarding caregiving associated with volunteering for the role of family caregiver? It was hypothesized that feminine gender role adherence and cultural values regarding caregiving would be positively correlated with the degree to which the family member volunteered for the role of caregiver.

RQ2: Is caregiver burden related to (1) the degree to which the family member volunteered for the role of caregiver and to (2) family-level adaptive coping? It was hypothesized that caregiver burden would be negatively related to the degree to which the family member volunteered for the role of caregiver and to adaptive family-level coping.

RQ3: Is caregiver burden related to drinking/drug/medication use and with coping motives for drinking/substance use? It was hypothesized that caregiver burden would be positively associated with drinking/drug/medication use and with coping motives for drinking/substance use.

Chapter Three

METHODS

Participants

A total of 455 family caregivers of Alzheimer's patients were recruited from Amazon's Mechanical Turk website. MTURK is an online crowdsourcing platform that offers opportunities for individuals to take part in a variety of surveys and experiments facilitated by private and public institutions. The data set was cleaned by removing 37 participants who completed the survey in less than 2 minutes and removing 27 participants who reported spending 0 hours with their parent, leaving the final total to be 391 participants. When the participants that were removed from this study were compared to the participants that were kept, there was no difference in their education ($\chi^2(6) = 4.56, p = .602$), ethnicity ($\chi^2(1) = 2.33, p = .127$), marital status ($\chi^2(4) = 4.46, p = .347$), employment status ($\chi^2(3) = 1.39, p = .709$), and age ($t(410) = .634, p = .526$). However, there was a difference in race ($\chi^2(5) = 17.21, p = .004$) in that there were more Asian participants removed than there were that remained in this study.

Participant ages ranged from 19 years to 69 years old, with an average age of 34.29. The majority of the participants were Caucasian (79.5%), non-Hispanic or Latino (85.2%). Most of the participants had a Bachelor's degree (35%) or had some college experience (26.1%). There was a split in terms of marital status: 46% were single and 44% were married. A majority of participants had 0 to 2 children (84.1%) and a majority of the participants were employed full time (59.8%). All participants reported having a mother- and/or father-figure with Alzheimer's Dementia. Of the 391 participants, 62.7% said their mother was diagnosed with Alzheimer's

Dementia (with an additional 4.6% reporting “maybe”) and 33% said their father had Alzheimer’s Dementia (with an additional 4.1% reporting “maybe”). In addition, 9.5% reported that both their parents had Alzheimer’s Dementia. A majority of participants (61.1%) indicated that they lived with their mother- or father-figure with Alzheimer’s Dementia and were getting help from other people in their family (74.9%). On a scale of 1 to 5, 1 being 0 hours and 5 being 12+ hours spent with their parent, the average score was a 3.12, which equates to 4-6 hours spent with their parent. See Table 1.

Table 1. Sample demographic characteristics.

Age (M, SD)	34.26 (11.69)
Race (%)	
White	79.5
African American	9.5
Asian	5.1
American Indian/Alaska Native	1.3
Native Hawaiian/Pacific Islander	.5
Other	3.8
Ethnicity (%)	
Hispanic, Latino, Spanish	10.7
Not Hispanic, Latino, Spanish	85.2
Education Background (%)	
High School/GED	10.0

Some College	26.1
Associate Degree	16.2
Bachelor Degree	35.2
Masters Degree	10.5
Ph.D.	1.5
Certificate	.3
Marital Status (%)	
Single	46.0
Divorced	6.4
Separated	1.5
Married	44.3
Widowed	1.3
Number of Children (%)	
0-2	84.1
3-5	14.1
6-9	.8
10+	.5
Current Employment (%)	
Full Time	59.8
Part Time	21.5

Unemployed	12.8
Retired	
Region of US (%)	4.6
West	17.1
Midwest	17.9
South	42.5
Northeast	22.0
Mother Alzheimer's (%)	
Yes	62.7
No	32.5
Maybe	4.6
Father Alzheimer's (%)	
Yes	33.0
No	65.4
Maybe	4.1
Time Spent with Mother/Father (%)	
1-3 Hours	33.5
4-6 Hours	37.1
7-11 Hours	13.3
12+ Hours	16.1

Other People Helping (%)

Yes	74.9
No	24.8

Materials

Demographic Survey. A brief demographic survey was used to measure the following things: age, race, education, marital status, employment status, number of children, presence of Dementia (both mother and father), amount of time spent in the caregiving role, and the amount of help received by family members.

BEM Sex Role Inventory. This 60-question inventory measures levels of masculinity, femininity, and androgyny. The inventory uses a 7-point likert scale from “never” to “always.” Example items on the BEM Sex Role Inventory include the following qualities: warm, jealous, moody, helpful, analytical, and aggressive. In a recent study, conducted by Ahmed, Vafaei, Belanger, Phillips, and Sunzunegui (2016), they tested the validity of the BEM Sex Role Inventory and confirmed that the inventory shows significant differences between men and women. The test-retest for this inventory is a .90 for both masculinity and femininity and a .93 for androgyny (Monto, 1993). Femininity was the only subscale used for this study. Cronbach’s Alpha for internal consistency for this subscale in this study was .85.

Decision to Care for Parent Scale - This scale was developed for the purpose of this study. Participants rated several statements that described possible reasons for stepping into the

caregiving role using a 5-point likert scale from “strongly agree” to “strongly disagree.” Sample statements for the Decision to Care for Parent Scale include: My siblings told me I had to, I volunteered for the position, I felt that I was the most qualified person for the caregiver role, My parent made me feel obligated to be their primary caregiver, and I didn’t want anyone else to be their caregiver. Cronbach’s Alpha for internal consistency for this subscale was .81.

Family Crisis Oriented Personal Evaluation Scale (F-COPES) – This scale measures problem solving attitudes and behaviors that families adopt while responding to difficulties that arise. It is a 30-question likert scale that the participant responds from “strongly disagree” to “strongly agree.” This scale measures family styles of coping such as acquiring social support, reframing, seeking spiritual support, mobilizing family to acquire and seek help, and passive appraisal. Higher scores indicate more positive coping and problem solving strategies for the family during times of crisis. Example items on the F-COPES scale regarding how the family deals with crises are: sharing our difficulties with relatives, seeking encouragement and support from friends, knowing we have the power to solve major problems, seeking advice from relatives (McCubbin, Larson, & Olson, 1987). Previous research shows strong psychometric properties for this scale: Cronbach’s Alpha ranges from .77-.86, and test-retest reliability is .81 (McCubbin, Olson, Larsen, Corcoran, & Fisher, 2000). Cronbach’s Alpha for internal consistency for this scale in this study was .87.

The Daily Drinking Questionnaire (DDQ) – This widely-used brief scale asks participants to record alcohol use during a typical week in the past month and the heaviest drinking week within the last 3 months (Collins, Parks, & Marlatt, 1985). Additional questions

were added to the DDQ to assess additional drinking, drug, and medication-using habits specific to this population, such as the use of their parent's medication.

Drinking Motives Scale - This is a widely-used scale that measures various reasons and motivations behind drinking. This 20-item scale measures the frequency with which individuals consume alcohol for four reasons: Coping, Enhancement, Conformity, and Social. Example items include a variety of possible reasons to drink: to be sociable, to get high, because it gives me a pleasant feeling, because I feel more self-confident and sure of myself, and to fit in with a group I like. Response options range from 1 "almost never/never" to 5 "almost always/always" (Cooper, 1994). The Coping subscale was the only subscale used in this study. Cooper (1994) confirmed a 4-factor model for the Drinking Motives Scale and found strong internal consistency for each factor. In addition, each factor reliably assessed drinking motives with a variety of demographic groups (gender, races & age subgroups). Cronbach's Alpha for internal consistency for this subscale in this study was .93.

Caregiver Burden Inventory – This a 29-item scale that asks about caregivers' health, psychology, finances, social life, and the relationship between the caregiver and the individual being cared for (Zarit, Reever, & Bach-Peterson, 1980). Example variables from the Caregiver Burden Inventory include: I feel guilty about my interactions with my [mother/father], I am afraid of what the future holds for my [mother/father], I feel that my health has suffered because of my involvement with my [mother/father], and I feel resentful of other relatives who could but who do not do things for my [mother/father]. Using a 5-point Likert scale, participants can respond from 1 "never" to 5 "nearly always." In a previous study, Zarit, Reever, & Bach-

Peterson (1980) studied burden in relation to family visits and behavior and found a negative correlation that showed those caregivers who had visits from grandchildren and their children (those who were not the primary caregiver) had lower levels of burden. There was no significant difference in burden depending on whether the husband or wife needed the care. Cronbach's Alpha for internal consistency for this scale in this study was .93.

Cultural Justification for Caregiving Scale – This brief scale consists of 10 statements discussing possible cultural reasons for why the individual cares for their parent. Example statements include: I give care because it is my duty to provide care to elderly dependent family members, it is what my people have always done, and my family expects me to provide care. Questions are answered based on a 4-point scale, where 1 is “strongly disagree” and 4 is “strongly agree” (Dilworth-Anderson, Goodwin, & Williams, 2004). There are two subscales for this survey, Reciprocity and Duty. In a previous article, Powers and Whitlatch (2016) found Cronbach's Alpha coefficients ranging from .86 to a .79 in their sample. For this study, Cronbach's Alpha for internal consistency for the Reciprocity subscale was .78 and the Cronbach's Alpha for internal consistency for the Duty subscale was .68.

Procedure

Internal Review Board approval was gained before the start of this study. Eligible participants completed an anonymous, online survey administered through Qualtrics on Amazon's MTURK. Participants read a brief description of the current study: “Are you caring for a family member with Alzheimer's Dementia?” When participants clicked on the survey, they were able to read a more detailed description of the study: “We are looking for adult

children who are serving as the primary caregiver for a parent with Alzheimer's Dementia to participate in this survey. We are investigating the ways in which children come into the role of caregiver for their parent and the ways in which they cope with this role." The survey took approximately 24 minutes and participants were paid .30 cents for their time.

Data Analysis

RQ1 – Correlations and multiple regression were used to measure the association between the degree to which the family member volunteered for the caregiving role and (1) feminine gender role adherence and (2) cultural justification for caregiving. Using the Femininity subscale of the BEM Sex Role Inventory and the Decision to Care for Parent Scale, it was hypothesized that there would be a positive correlation between these two variables. Using the Reciprocity and Duty subscales of the Cultural Justification for Caregiving Scale and the Decision to Care for Parent Scale, it was hypothesized that there would be positive correlations among these variables.

RQ2 – Correlations and multiple regression were used to measure the associations between caregiver burden and (1) the degree to which the family member volunteered for the caregiving role and (2) adaptive family coping skills. Using the Decision to Care for Parent Scale, the F-COPES scale, and the Caregiver Burden Inventory, it was hypothesized that there would be negative correlations between the Caregiver Burden Inventor and the Decision to Care for Parent Scale as well as the F-COPES scale.

RQ3 - Correlations were used to measure the association between caregiver burden and maladaptive health habits. Using the Caregiver Burden Inventory and the Daily Drinking

Questionnaire and the Drinking Motives Questionnaire, it was anticipated that there would be positive correlations between feelings of burden, drug/medication use or drinking, and coping motives for substance use.

Chapter Four

RESULTS

Prior to testing the hypotheses, each variable was examined to determine if it was normally distributed. Descriptive statistics are presented on Table 2. Skewness and Kurtosis levels were below 3 and 10 respectively, thus were considered normal (Kline, 2011).

Scales	Range	Mean	SD	Skew	Kurtosis
Caregiver Burden Inventory	1-145	82.6	19.9	0.08	.284
BEM Sex Role Inventory	1-20	4.9	0.75	-0.43	0.36
Decision to Care for Parent Scale	1-84	35.85	9.58	0.14	0.04
F-COPES	1-150	101.0	16.43	-0.31	0.04
Cultural Justification					
Reciprocity	6-24	10.73	3.80	0.77	0.11
Duty	6-16	6.78	2.44	0.72	-0.45
Daily Drinking Questionnaire					
Number of Drinks in a Typical Week		15.05	14.04	2.50	6.45
Number of Drinks in the Heaviest Week		19.14	17.76	2.10	3.89
Drinking Motives Scale: Coping	5-25	20.66	5.16	-1.07	.23
Alcohol/Drug Use Frequency					
Drink Alcohol	1-5	4.33	0.90	-1.56	2.53
Take Prescription Medication	1-5	3.73	1.53	-0.82	-0.89

Take Parent's Prescription Medication	1-5	4.64	.92	-2.68	6.45
Smoke Marijuana	1-5	4.44	1.14	-1.96	2.58
Take Illicit Drugs	1-5	4.72	0.81	-3.09	9.06

Consistent with H1, results showed a significant positive correlation between the Femininity subscale of the BEM and the Decision to Care for Parent Scale, $r(281) = .24$, $p < .001$. Participants with higher levels of femininity scored higher in the degree to which they volunteered for the role of caregiver. In terms of the Cultural Justification Scale, results show a significant positive correlation between Decision to Care for Parent Scale and both subscales, Reciprocity, $r(285) = .37$, $p < .001$ and Duty, $r(292) = .23$, $p < .001$. Participants with higher levels of Duty and Reciprocity scored higher in the degree to which they volunteered for the caregiving role.

Multiple regression analysis was then used to test if the sociocultural factors predicted the degree to which the participant volunteered for the caregiving role. The results of the regression indicated that the three predictors (Femininity, Duty, and Reciprocity) explained 13.8% of the variance ($R^2 = .37$, $F(3,269) = 14.19$, $p < .001$) in Decision to Care. It was found that Reciprocity was a significant independent predictor of Decision to Care ($\beta = .37$, $p < .001$), but Duty ($\beta = -.08$, $p = .31$) and Femininity ($\beta = -.09$, $p = .13$) were not.

Consistent with H2, results showed a significant negative correlation between the Caregiver Burden Inventory and the Decision to Care for Parent Scale, $r(268) = -.40$, $p < .001$.

Participants who scored low on the degree to which they volunteered for the role of caregiver showed higher levels of burden. Consistent with the second part of H2, results show a significant negative correlation between the Caregiver Burden Scale and the F-COPES Scale, $r(337) = -.17$, $p = .004$. Participants with maladaptive family coping styles showed higher levels of burden.

Multiple regression analysis was then used to test if family-level coping styles (FCOPES) and the Decision to Care for Parent jointly predicted Caregiver Burden. The results of the regression indicated that the two predictors explained 17.9% of the variance ($R^2 = .42$, $F(2,268) = 26.54$, $p < .001$). It was found that Decision to Care was a significant independent predictor of burden ($\beta = .42$, $p < .001$), but FCOPES was not ($\beta = .08$, $p = .933$).

Consistent with H3, results showed significant positive correlations between the Caregiver Burden Scale and the amount of drinks the caregiver had in a typical week in the last 30 days, $r(327) = .23$, $p < .001$, and the amount of drinks the caregiver had in the heaviest week of drinking within the last 90 days, $r(328) = .19$, $p = .001$. In addition, there were significant positive correlations between burden and how often they drank alcohol, $r(334) = .15$, $p = .007$, took medication that was prescribed to their parents, $r(334) = .13$, $p = .022$, and took illicit drugs, $r(334) = .16$, $p = .003$. However, results did not show any significant correlations between burden and the frequency with which participants took their own prescription medication, $r(334) = .09$, $p = .093$, or used marijuana, $r(335) = .13$, $p = .114$. Also consistent with H3, there was a significant positive correlation between burden and the Coping subscale of the Coping Motives Scale, $r(330) = .25$, $p < .001$, suggesting that participants with high levels of burden use alcohol to cope with life stressors.

Chapter Five

DISCUSSION

The purpose of this study was to examine sons and daughters who are providing care for their mother- or father-figure with Alzheimer's Dementia. It was important to first look at caregiver characteristics (sociocultural factors) and how these factors led to the decision to care for their parents. Second, caregiver burden was examined in relation to the decision to care for their parent and family-level styles of coping. Finally, the association between burden and certain poor health habits (i.e., alcohol and drug use) was examined.

The first hypothesis aimed to examine how two specific sociocultural factors -- femininity and cultural beliefs -- would correlate with an individual's decision to care for their parent. Since research has shown that most caregivers are women (wives and adult daughters) it was important to examine feminine characteristics as they correlated with caregivers' decision to care. Also, it was important to look at cultural beliefs and values in terms of this decision making process. Research has shown that, in some cultures, it is the child's duty to care for their parent (Powers & Whitlatch, 2016). Consistent with the hypotheses, femininity was positively correlated with the decision to care for the family member. It is possible that traditional feminine traits such as being compassionate, warm, tender, and sincere makes caregiving a natural fit. Furthermore, also consistent with the hypotheses, cultural beliefs associated with reciprocity and duty (e.g., it is what their culture dictates, it is consistent with their spiritual or religious belief, they were raised to believe care should be provided by the family, or they were taught to take care of their elderly dependent family members) were positively correlated with

the decision to take on the caregiving role. Since they were raised to respect their elderly parent and were shown that that is what is expected, these participants may have made a natural decision to care for their parent. Based on a multiple regression analysis, feminine traits and cultural beliefs regarding duty and reciprocity were important factors that, together, predicted the participants' decision to care for their parent. However, when each variable was examined individually, cultural beliefs regarding reciprocity was the only independent contributor that influenced the decision to which an individual cared for their parent. It seems that out of those three variables, reciprocity was a critical factor that uniquely predicted the decision to care for one's parent.

The second hypothesis focused how caregiver burden – feeling stressed in the caregiving role -- was related to the individual's decision to care for their parent. In addition, the second hypothesis examined how individuals and their families work through their problems and cope as a unit. Research has shown that those who spend a healthy amount of time with their family and have a positive relationship with their family have lower levels of burden and a more positive relationship with the parent they are caring for (Panyavin et. al., 2015). The results from this study showed that participants who did not volunteer for the caregiver role were more likely to feel burdened by being a caregiver. Results also showed that participants who reported having a family that used poor coping skill were more likely to feel burdened by being a caregiver. Based on a multiple regression analysis, family-level coping and the degree to which the participant volunteered for the position of caregiver were important factors that, together, predicted the participants' levels of burden. However, when each variable was examined individually, the

degree to which the participant volunteered for the position was the only independent contributor that influenced the participants' level of burden. Thus, the way one comes into the role of caregiver is a vital factor in predicting burden levels.

The third hypothesis focused on unhealthy coping mechanisms for the caregiver. This topic is not widely researched and the information that is available on drinking as a coping mechanism is based off binge drinking patterns and spouses as the primary caregiver (Connell, 1994). This study examined a variety of substance use behaviors: the number of drinks in a "typical week" in the past month, the number of drinks in the "heaviest drinking week" within the past 90 days, prescription pill usage, marijuana usage, and illicit drug usage. In addition, this study examined how caregiver burden correlated with drinking as a means to cope. Results showed strong associations between burden and drinking alcohol to cope, typical week drinking levels, and heaviest week drinking levels. Most interesting, participants experiencing high levels of burden were not taking their own prescribed medication but they were taking their parents medication and using illicit drugs. Marijuana usage was not significantly related to burden levels. These findings provide important information that fills in gaps in the existing literature.

Overall, these findings are consistent with the stress-diathesis model, which connects an individuals' predispositional vulnerabilities (diathesis) and with stress that evolves from life experience and how those life experiences can impact the individuals health. For this study, caring for your mother or father with Alzheimer's disease can add to an individuals' stress level. This study examined how the individual's decision to care for their parent and their families coping strategies (diatheses) impacted their levels of burden (stress). From feeling burdened, the

caregiver then turned to negative coping skills such as drinking and the use of prescription medication and illicit drugs (health habits).

Overall, this study showed that certain traits and cultural beliefs led to the decision to care for a parent with Alzheimer's Dementia. In addition, family-level variables such as feeling forced in the role and poor family-level coping mechanisms led to feelings of caregiver burden. Previous studies have shown how stress and burden are common among caregivers, and how burden can lead to negative physical and mental outcomes due to an increasing allostatic load, but this study shined a light on certain maladaptive coping mechanisms that caregivers use to get through this process, which may be related to these poor outcomes. The overuse of alcohol, drugs, and taking their parents' medications are unhealthy ways to cope with this role and were each related to elevated levels of burden. The use of unhealthy coping mechanisms may be due to the fact that these caregivers feel alone in their role. It is important for caregivers to feel that there are healthier outlets to cope. The Alzheimer's Association provides links and resources for caregivers. This outlet could help caregivers by possibly taking the burden off their shoulders by showing them positive and healthy coping strategies. It would also be helpful for national websites to include information about screening, assessment, and treatment for individuals who have a drug/alcohol problem in this population.

It is important to note some limitations in this study. The majority of the participants were White, non-Hispanic so findings cannot be generalized to all races and cultures. Another limitation for this study was the use of a self-report survey rather than an interview. Self-report surveys only provide a small amount of information while interview formats can provide a more

in-depth look at complex issues such as caregiving. In addition, although a main focus of this study was on gender roles, gender identity would have been important to measure, as well, to determine whether there are any differences in decision making, burden, and substance use between men and women. Finally, the Decision to Care for Parent Scale was also a limitation because it was created specifically for this survey and has not yet been validated.

Future research should examine other individual and family-level coping mechanisms, whether healthy or unhealthy (binge eating, exercise, therapy, etc.). Now that there is information surrounding how caregivers cope, there should be a support program for someone takes on this role, and research to evaluate such programs. As previously stated, there are websites that provide information and resources for caregivers, on those website, there could be resources for support groups, family therapists, or important information for the caregiver, even before they start this role.

Chapter Six

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Appendix A: Demographics

How old are you?

What is your race?

- Caucasian/White (1)
- African American/Black (2)
- Asian (3)
- American Indian or Alaska Native (4)
- Native Hawaiian or Other Pacific Islander (5)
- Other (6)

What is your ethnicity?

- Hispanic, Latino, Spanish (1)
- Not Hispanic, Latino, Spanish (2)

Please describe your educational background.

- High School/GED (1)
- Some College (2)
- Associate Degree (3)
- Bachelor Degree (4)
- Master Degree (5)
- Ph. D (6)
- Certificate (7)

What is your marital status?

- Single (1)
- Married (2)
- Separated (3)
- Divorced (4)
- Widowed (5)

How many children do you have?

- 0-2 (1)
- 3-5 (2)
- 6-9 (3)
- 10+ (4)

What is your current employment status?

- Full time employment (1)
- Part time employment (2)
- Unemployed (3)
- Retired (4)

In which country were you born?

If you were born outside of the United States, which year did you first come to live in the United States?

Where do you live?

- Region 1: West (Alaska, Arizona, California, Colorado, Hawaii, Idaho, Montana, New Mexico, Oregon, Nevada, Utah, Washington, Wyoming) (1)
- Region 2: Midwest (Illinois, Indiana, Iowa, Kansas, Michigan, Minnesota, Missouri, Nebraska, North Dakota, Ohio, South Dakota, Wisconsin) (2)
- Region 3: South (Alabama, Arkansas, Delaware, District of Columbia, Florida, Georgia, Kentucky, Louisiana, Maryland, Mississippi, North Carolina, Oklahoma, South Carolina, Tennessee, Texas, Virginia, West Virginia) (3)
- Region 4: Northeast (Connecticut, Maine, Massachusetts, New Hampshire, New Jersey, New York, Pennsylvania, Rhode Island, Vermont) (4)

Does your mother, step-mom, mother-in-law, or mother figure have Alzheimer's Dementia?

- Yes (1)
- No (2)
- Maybe (3)

Does your father, step-dad, father-in-law, or father figure have Alzheimer's Dementia?

- Yes (1)
- No (2)
- Maybe (3)

Do you live with the mother figure or father figure that has Alzheimer's Dementia?

- Yes (1)
- No (2)

How much time per day do you spend with the mother figure or father figure that has Alzheimer's Dementia? (If more than one mother figure and/or father figure has Alzheimer's Dementia, focus on the one you spend the most time with.)

- 0 hours (1)
- 1-3 hours (2)
- 4-6 hours (3)
- 7-11 hours (4)
- 12+ hours (5)

Are there other people (family members, nurse, aid, etc.) caring for your mother or father figure with Alzheimer's Dementia? (If more than one mother figure and/or father figure has Alzheimer's Dementia, focus on the one you spend the most time with.)

- Yes (1)
- No (2)

How far were you living from your parent with Alzheimer's right before the diagnosis? (If more than one mother figure and/or father figure has Alzheimer's Dementia, focus on the one you spend the most time with.)

Appendix B: BEM Sex Role Inventory

Rate yourself on a scale of never true to always true

	Never True (1)	Often Never True (2)	Somewhat Never True (3)	Neutral (4)	Somewhat Always true (5)	Often True (6)	Always True (7)
self reliant (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
yielding (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
helpful (3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
defends own beliefs (4)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
cheerful (5)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
moody (6)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
independent (7)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
shy (8)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
conscientious (9)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
affectionate (10)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
theatrical (11)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
reliable (12)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
analytical (13)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
sympathetic (14)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
jealous (15)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
leadership ability (16)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
sensitive to others needs (17)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
truthful (18)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
willing to take risks (19)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
understanding (20)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
secretive (21)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
makes decisions easily (22)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
compassionate (23)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

warm (24)	<input type="radio"/>						
solemn (25)	<input type="radio"/>						
willing to take a stand (26)	<input type="radio"/>						
tender (27)	<input type="radio"/>						
friendly (28)	<input type="radio"/>						
aggressive (29)	<input type="radio"/>						
gullible (30)	<input type="radio"/>						
inefficient (31)	<input type="radio"/>						
acts as a leader (32)	<input type="radio"/>						
childlike (33)	<input type="radio"/>						
adaptable (34)	<input type="radio"/>						
individualistic (35)	<input type="radio"/>						
assertive (36)	<input type="radio"/>						
flatterable (37)	<input type="radio"/>						
happy (38)	<input type="radio"/>						
strong personality (39)	<input type="radio"/>						
loyal (40)	<input type="radio"/>						
unpredictable (41)	<input type="radio"/>						
forceful (42)	<input type="radio"/>						
feminine (43)	<input type="radio"/>						
sincere (44)	<input type="radio"/>						
self-sufficient (45)	<input type="radio"/>						
eager to soothe hurt feelings (46)	<input type="radio"/>						
conceited (47)	<input type="radio"/>						
dominant (48)	<input type="radio"/>						
soft spoken (49)	<input type="radio"/>						
likable (50)	<input type="radio"/>						
masculine (51)	<input type="radio"/>						
does not use harsh language (52)	<input type="radio"/>						
unsystematic (53)	<input type="radio"/>						

competitive (54)	<input type="radio"/>						
loves children (55)	<input type="radio"/>						
tactful (56)	<input type="radio"/>						
ambitious (57)	<input type="radio"/>						
gentle (58)	<input type="radio"/>						
conventional (59)	<input type="radio"/>						

Appendix C: Decision to Care for Parent Scale

Rate the following statements regarding your feelings about being in the caregiving role.

	Strongly Agree (1)	Agree (2)	Somewhat Agree (3)	Strongly Disagree (4)	Disagree (5)	NA (6)
I volunteered to be in the caregiving role (1)	<input type="radio"/>					
It was not my choice to be in the caregiver role (2)	<input type="radio"/>					
My family members (e.g., siblings) knew that I wanted to take on this role (3)	<input type="radio"/>					
I didnt feel forced by my family (e.g., siblings) to be in the caregiving role. (4)	<input type="radio"/>					
I felt obligated to be in the caregiving role. (5)	<input type="radio"/>					
I wanted to be in the caregiving role. (6)	<input type="radio"/>					
I felt like it was natural progression of our relationship to become a	<input type="radio"/>					

caregiver of my parent. (7)						
My family (e.g., siblings) volunteered me to be the primary caregiver. (8)	<input type="radio"/>					
Nobody in my family (e.g., siblings) pressured me to take on the role of caregiver. (9)	<input type="radio"/>					
My parents volunteered me to be their primary caregiver (10)	<input type="radio"/>					
My parents made me feel obligated to be their primary caregiver. (11)	<input type="radio"/>					
I felt that I was the most qualified person for the caregiver role. (12)	<input type="radio"/>					
Being my parent's caregiver was my own choice (13)	<input type="radio"/>					
I felt that I was the best candidate for the caregiver role. (14)	<input type="radio"/>					

Appendix D: Family Crisis Oriented Personal Evaluation Scale (F-COPES)

When we face problems or crises in our family of origin (e.g., siblings, parents, etc.), we respond by:

	Strongly Disagree (1)	Moderately Disagree (2)	Neither Agree nor Disagree (3)	Moderately Agree (4)	Strongly Agree (5)
Sharing our difficulties with relatives (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Seeking encouragement and support from friends (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Knowing we have the power to solve major problems (3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Seeking information and advice from persons in our families who have faced the same or similar problems (4)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Seeking advice from relatives (grandparents, etc.) (5)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Seeking assistance from community agencies and programs designed to help families in our situation (6)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Knowing that we have the strength within our own	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

family to solve our problems (7)					
Receiving gifts and favors from neighbors (e.g., food, taking in mail, etc.) (8)	<input type="radio"/>				
Seeking information and advice from the family doctor (9)	<input type="radio"/>				
Asking neighbors for favors and assistance (10)	<input type="radio"/>				
Facing the problems "head-on" and trying to get solutions right away (11)	<input type="radio"/>				
Watching television (12)	<input type="radio"/>				
Showing that we are strong (13)	<input type="radio"/>				
Attending church services (14)	<input type="radio"/>				
Accepting stressful events as a fact of life (15)	<input type="radio"/>				
Sharing concerns with close friends (16)	<input type="radio"/>				
Knowing luck plays a big part in how well we are able to solve family problems (17)	<input type="radio"/>				
Exercising with friends to stay fit and reduce tension (18)	<input type="radio"/>				

Accepting that difficulties occur unexpectedly (19)	<input type="radio"/>				
Doing things with relatives (get-togethers, dinners, etc.) (20)	<input type="radio"/>				
Seeking professional counseling and help for family difficulties (21)	<input type="radio"/>				
Believing we can handle our own problems (22)	<input type="radio"/>				
Participating in church activities (23)	<input type="radio"/>				
Defining the family problems in a more positive way so that we do not become too discouraged (24)	<input type="radio"/>				
Asking relatives how they feel about problems we face (25)	<input type="radio"/>				
Feeling that no matter what we do to prepare, we will have difficulty handling problems (26)	<input type="radio"/>				
Seeking advice from a minister (27)	<input type="radio"/>				
Believing if we wait long enough, the problem will go away (28)	<input type="radio"/>				

Sharing problems with neighbors (29)	<input type="radio"/>				
Having faith in God (30)	<input type="radio"/>				

Appendix E: Daily Drinking Questionnaire (DDQ)

Think about the last month (30 days). How many alcoholic beverages did you have on a TYPICAL WEEK in the last month? Fill in the chart below

	0 (1)	1 (2)	2 (3)	3 (4)	4 (5)	5 (6)	6 (7)	7 (8)	9 (9)	10 (10)	10 (11)	11 (12)	12+ (13)
Sunday (1)	<input type="radio"/>												
Monday (2)	<input type="radio"/>												
Tuesday (3)	<input type="radio"/>												
Wednesday (4)	<input type="radio"/>												
Thursday (5)	<input type="radio"/>												
Friday (6)	<input type="radio"/>												
Saturday (7)	<input type="radio"/>												

Think about the last 3 months (90 days). How many alcoholic beverages did you have on the HEAVIEST DRINKING WEEK in the last 3 months?

	0 (1)	1 (2)	2 (3)	3 (4)	4 (5)	5 (6)	6 (7)	7 (8)	8 (9)	9 (10)	10 (11)	11 (12)	12+ (13)
Sunday (1)	<input type="radio"/>												
Monday (2)	<input type="radio"/>												
Tuesday (3)	<input type="radio"/>												
Wednesday (4)	<input type="radio"/>												
Thursday (5)	<input type="radio"/>												
Friday (6)	<input type="radio"/>												
Saturday (7)	<input type="radio"/>												

During your time in the caregiving role, how often have you done the following:

	Always (1)	Most of the time (2)	About half the time (3)	Sometimes (4)	Never (5)
Drink alcohol (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Take medication that was prescribed to me by a physician/psychiatrist (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Take my mother/father's medication (the parent im caring for) (3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Take medication prescribed to a friend or other family member (4)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Smoke/ingest marijuana (5)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Use illegal drugs (e.g., cocaine, heroin) (6)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

When do you use alcohol/medication/drugs:

	Always (1)	Most of the time (2)	About half the time (3)	Sometimes (4)	Never (5)
When I get anxious about the day (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
To cope with stress (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
When my mother/father becomes aggressive (3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
When I have a bad day (4)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other (5)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Appendix F: Drinking Motives Scale

Below is a list of reasons people sometimes have for drinking alcohol or using drugs. In general (in the past and present) how often would you say that you drink alcohol or use drugs for each of the following reasons?

	Always (1)	Most of the time (2)	About half the time (3)	Sometimes (4)	Never (5)
To forget my worries (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Because my friends pressure me to drink (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Because it helps me enjoy a party (3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Because it helps when I feel depressed or nervous (4)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
To be sociable (5)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
To cheer up when I am in a bad mood (6)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Because I like the feeling (7)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
So others wont kid me about not drinking (8)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Because its exciting (9)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
To get high (10)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Because it makes social gatherings more fun (11)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
To fit in with a group I like (12)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Because it gives me a pleasant feeling (13)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Because it improves parties and celebrations (14)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Because I feel more self confident and sure of myself (15)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

To celebrate special occasions with friends (16)	<input type="radio"/>				
To forget about my problems (17)	<input type="radio"/>				
Because its fun (18)	<input type="radio"/>				
To be liked (19)	<input type="radio"/>				
So I won't feel left out (20)	<input type="radio"/>				

Appendix G: Caregiver Burden Inventory

Rate the following statements regarding your feelings about being in the caregiving role.

	Never (1)	Rarely (2)	Sometimes (3)	Quite Frequently (4)	Nearly Always (5)
I feel resentful of other relatives who could but who do not do things for my parent (with Alzheimer's) (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel that my parent (with Alzheimer's) makes requests which I perceive to be over and above what s/he needs (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Because of my involvement with my parent, I do not have enough time for myself (3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel stressed between trying to give to my parent as well as to other family responsibilities, jobs, etc (4)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel embarrassed over my parent's behavior (5)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel guilty about my interactions with my parent (6)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel that I don't do as much for my parent as I could or should (7)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel angry about my interactions with my parent (8)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

I feel that in the past, I haven't done as much for my parent as i could have or should have (9)	<input type="radio"/>				
I feel nervous or depressed about my interactions with my parent (10)	<input type="radio"/>				
I feel that my parent currently affects my relationships with other family members and friends in a negative way (11)	<input type="radio"/>				
I feel resentful about my interactions with my parent (12)	<input type="radio"/>				
I am afraid of what the future holds for my parent (13)	<input type="radio"/>				
I feel pleased about my interactions with my parent (14)	<input type="radio"/>				
It's painful to watch my parent age (15)	<input type="radio"/>				
I feel useful in my intetactions with my parent (16)	<input type="radio"/>				
I feel my parent is dependent (17)	<input type="radio"/>				
I feel strained in my interactions with my parent (18)	<input type="radio"/>				
I feel that my health has suffered because of my involvement with my parent (19)	<input type="radio"/>				
I feel that I am contributing to the well-being of my parent (20)	<input type="radio"/>				

I feel that the present situation with my parent doesn't allow me as much privacy as I'd like (21)	<input type="radio"/>				
I feel that my social life has suffered because my involvement with my parent (22)	<input type="radio"/>				
I wish that my parent and I had a better relationship (23)	<input type="radio"/>				
I feel that my parent doesn't appreciate what I do for him/her as much as I would like (24)	<input type="radio"/>				
I feel uncomfortable when I have friends over (25)	<input type="radio"/>				
I feel that my parent tries to manipulate me (26)	<input type="radio"/>				
I feel that my parent seems to expect me to take care of him/her as if I were the only one s/he could depend on (27)	<input type="radio"/>				
I feel that I don't have enough money to support my parent in addition to the rest of the expenses (28)	<input type="radio"/>				
I feel that I would like to be able to provide more money to support my parent than I am able to now (29)	<input type="radio"/>				

Appendix H: Cultural Justification for Caregiving Scale

I am caring for my parent with Alzheimer's Dementia because:

	Strongly Agree (1)	Somewhat Agree (2)	Somewhat Disagree (3)	Disagree (4)
It is my duty to provide for elderly dependent family members (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
It is important to set an example for the children of the family. (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I was taught by my parents to take care of elderly dependent family members. (3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Of my religious and spiritual beliefs. (4)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
By giving care to elderly dependent family members, I am giving back what has been given to me. (5)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
It strengthens the bonds between me and them. (6)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I was raised to believe care should be provided in the family. (7)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
It is what my people have always done. (8)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel as though I am being useful and making a family contribution. (9)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My family expects me to provide care. (10)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Appendix I: IRB Certification



December 15, 2016

Grace Meyer
Dept of Human Development & Family Studies
College of Human Environmental Sciences
Box 870160

Re: IRB # 16-OR-437-ME, "Adult Children Caregivers of Parents with Alzheimer's Dementia"

Dear Ms. Meyer:

The University of Alabama Institutional Review Board has granted approval for your proposed research.

Your application has been given expedited approval according to 45 CFR part 46. You have also been granted the requested waiver of written documentation of informed consent. Approval has been given under expedited review category 7 as outlined below:

(7) Research on individual or group characteristics or behavior (including, but not limited to, research on perception, cognition, motivation, identity, language, communication, cultural beliefs or practices, and social behavior) or research employing survey, interview, oral history, focus group, program evaluation, human factors evaluation, or quality assurance methodologies.

Your application will expire on December 14, 2017. If your research will continue beyond this date, please complete the relevant portions of the IRB Renewal Application. If you wish to modify the application, please complete the Modification of an Approved Protocol form. Changes in this study cannot be initiated without IRB approval, except when necessary to eliminate apparent immediate hazards to participants. When the study closes, please complete the Request for Study Closure form.

Should you need to submit any further correspondence regarding this proposal, please include the above application number.

Good luck with your research.

Sincerely,



Carpunzio T. Myles, MSW, CMI-CIP
Director & Research Compliance Officer
Office for Research Compliance
The University of Alabama

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