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## GENDER DIFFERENCES IN CAREGIVER BURDEN AMONG ALZHEIMER'S PATIENTS

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GENDER DIFFERENCES IN CAREGIVER BURDEN  
OF ALZHEIMER'S PATIENTS

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

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In Partial Fulfillment  
of the Requirements for the Degree  
Master of Social Work

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by  
Janet Shin Yi Torres

June 2018

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## ABSTRACT

The purpose of this research was to explore the gender differences in caregiver burden in Alzheimer's patients in the Inland Empire. Due to an increase in the older population and the rise of informal caregivers, the study provided insight as to how males and females perceive caregiver burden and how each gender responds to caregiver burden. This exploratory study utilized a quantitative research design through the use of questionnaires which measured caregiver burden through the use of the Zarit Burden Interview. A total of 38 participants were recruited through support groups at the Inland Caregiver Resource Center. Though findings did not suggest a gender difference in caregiver burden, they did indicate that there was a relationship between ethnicity and gender in relation to the caregiver and care receiver relationship. Implications for social work practice include assessment for and aid in the development of gender appropriate resources for informal caregivers of Alzheimer's patients.

## ACKNOWLEDGEMENTS

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## DEDICATION

This research project is dedicated to my Aunt Joann who was an informal caregiver for her spouse who had early onset Alzheimer's disease prior to his passing. Thank you for allowing me to walk alongside you in your experience so that I can, in turn, help those who are in need.

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## CHAPTER ONE

### INTRODUCTION

#### Problem Formulation

A study completed in 2015 estimated there are 15.7 million informal caregivers for a loved one who had Alzheimer's disease (Alzheimer's Association, 2015). That number is even higher now in the informal caregiving population due to the rising population of the elderly. Informal caregivers, as opposed to formal caregivers, are typically unpaid family members of an individual who requires daily assistance (Family Caregiver Alliance, 2016). Informal caregivers may experience caregiver burden due to assuming added responsibility of caring for an individual in addition to everyday responsibilities.

Caregiver burden is characterized as a negative response to the stressors of caregiving on caregivers' physical, emotional, social, and psychological health (Given, Kozachic, Collins, Devoss, & Given, 2001; Kim, Chang, Rose, & Kim, 2011). Often times caregivers become overshadowed by the needs of the patient which can result in an increase of psychological illness, a decrease in emotional welfare, an increase of physical risks, and resentment towards the patient (Razani et al., 2007). Caregiver burden is more prevalent in caregivers of Alzheimer's disease (AD) patients compared to other diseases due to the patients' loss of mental functioning and memorization skills (D'Onofrio et al., 2014). Caregiver burden affects approximately 50% of caregivers of dementia

patients, of which a percentage is for caregivers of AD patients (Brodaty, Woodward, Boundy, Ames, & Balshaw, 2014).

Caregiver burden directly impacts the caregiver's roles which include their personal life, social life, and work life (Given et al., 2001). Although adult children take on the role of caregiver, spouses comprise most of the caregivers of AD patients due to physical proximity and emotional attachment (Mills et al., 2009). Of these spousal caregivers, approximately two-thirds of informal caregivers are females, although male caregivers are expected to rise over the next few years (Brodaty & Donkin, 2009).

Female caregivers may experience caregiver burden as a result of added responsibility in caring for the care receiver and attempting to maintain the demands of homemaking. This can lead to a decrease in supportive social relationships (Adams, 2006). In contrast, male caregivers may be unwilling to seek help which can lead to caregiver burden. Males may also lack the knowledge of how to physically and emotionally provide care (Fjellstrom, Starckenberg, Wesslen, Licentiate, Backstrom, & Faxen-Irving, 2010; Brown, Chen, Mitchell, & Province, 2007).

It is important to recognize that females typically utilize emotion-based coping strategies, whereas males utilize problem-based coping strategies (Papastavrou, Kalokerinou, Papacostas, Tsangari, & Sourtzi, 2007). Cultural factors also affect the possibility of experiencing caregiver burden among each gender. For example, Asian-American and Latin-American families typically have

strong familial support and uphold the idea that the females provide care for the family, whereas males do not typically identify as the caregiver (Hong & Kim, 2007; Friedemann & Buckwalter, 2014). Cultural implications of caregiver burden are important for macro level practice because social workers have the duty to be culturally competent, and appropriately assess for risk factors amongst AD patient caregivers.

Furthermore, implications of mental health problems due to caregiver burden is important for micro and macro level practice. The National Association of Social Workers (2010) states that not only is the mental well-being of the caregiver crucial for the individual, but for the family as an entire system. The mental well-being of informal caregivers is important to their physical, psychological, and social health in addition to the overall health of the care recipients and other family members. In regards to macro level practice, a high level of caregiver burden can influence the institutionalization of AD patients (Robison, Fortinsk, Kleppinger, Shugrue, & Porter, 2009). Institutionalization can increase costs for the caregiver which may lead to higher levels of caregiver burden. Unfortunately, informal caregiving can cost upwards of \$20,000 annually in the U.S. (Thompson, Spilsbury, Hall, Birks, Barnes, & Adamson, 2007).

### Purpose of the Study

The purpose of the research study is to assess gender differences in caregiver burden of AD patients in the Inland Empire, so that the social work field can gain knowledge in how to effectively advocate for gender appropriate

resources to help with this population. Informal caregiving is becoming more and more favorable over institutionalization of the patient due to a lack of adequate insurance, geographical proximity, and cultural preference (Kemper, 1992). However, many first-time caregivers may not be able to foresee the potential consequences of caring for a patient that has a terminal illness. In order to help prevent the negative effects of informal caregiving, research should possess a multi-faceted approach to addressing differential factors that may contribute to caregiver burden. This knowledge may help the social work field develop specific resources that can be able to assist caregivers of any background, and may also help to bring global awareness of this issue. Additionally, these resources may help caregivers recognize symptoms of caregiver burden. Once symptoms are identified, specific resources will be readily available at social service organizations to assist caregivers of AD patients.

To examine the question of gender differences in caregiver burden of AD patients in the Inland Empire, the study utilized a self-administered questionnaire design. This research design effectively addressed the issue because it was able to collect data from a large number of individuals at once, while also examining why there are differences in the experience of caregiver burden between males and females.

#### Significance of the Project for Social Work Practice

The study is needed to first and foremost bring awareness to the caregiving population and its implications on caregiver and care receiver's overall

health. Roth, Haley, Hovater, Perkins, Wadley, and Judd (2013) claim that research should focus on caregiver subgroups and the risk of mortality among those groups. Secondly, the study is needed to develop gender, cultural, and personality specific resources to combat caregiver burden.

The findings of this study will impact social work practice because it will increase awareness of AD patient caregiver burden, promote understanding of the associated gender and other differences in levels of caregiver burden, and advocate for the availability of necessary resources that will assist both male and female caregivers' overall needs. Even though Schulz and Sherwood (2008) claim that the effects of caregiving have alerted policymakers, no clear policies exist in place for informal caregivers as is evidenced by the lack of information found in journal articles. An increase in awareness of caregiver burden will hopefully encourage the development of policies to equip social workers on how to provide assistance to this population. Furthermore, social workers have the responsibility of providing services by upholding the NASW Code of Ethics such as dignity and worth of a person and importance of human relationships (National Association of Social Workers, 1999). The phase of the generalist intervention process that was informed by this study is assessing for needs.

Both male and female AD caregivers experience caregiver burden due to differences in coping strategies against caregiving stressors. In saying that, the research question for this project is as follows: Do female caregivers or male

caregivers of AD patients experience a higher level of caregiver burden in the Inland Empire?



## CHAPTER TWO

### LITERATURE REVIEW

#### Introduction

The purpose of this chapter is to review literature by identifying themes that contribute to caregiver burden and recognizing gaps in the studies. Such themes include coping mechanisms of the caregivers, the behavioral and psychiatric characteristics of the care receiver, and caregiver type and culture. Theories guiding conceptualization will also be discussed, followed by a summary of the chapter.

Almost all of Alzheimer's disease (AD) patients are cared for by a family member (Vellone, Piras, Talucci, & Cohen, 2007). Informal caregiving has a direct effect on quality of life, and simply adopting the primary role of caregiving increased caregiver's mortality rate by 63% in as little as four years (Schulz & Beach, 1999). Fox and Brenner (2012) found that about a third of the state's population associated themselves as the sole caregiver for a family member. Although the care receiver's health and well-being are of utmost concern, it is also crucial for the caregiver to attend to their own well-being. However, the caregiver's well-being is not solely determined by themselves, but is influenced by external forces as well. These external influences include patient characteristics, caregiving demands, and culture. Internal influences include gender, coping mechanisms, and caregiver types.

### Coping Mechanisms

According to Cooper, Katona, Orrell, and Livingston (2008), the impact of stressors is mediated through the use of coping strategies. Most informal caregivers willingly oblige to caring for their family members, and individual characteristics such as coping techniques influence how easy or difficult it is to manage the demands of caregiving. In a general sense, males and females utilize different coping techniques. Papastavrou et al. (2007) sought to learn how males and females use coping strategies when experiencing caregiver burden. Results indicated that women experienced higher levels of depression due to using emotional coping strategies such as wishful thinking, prayer, and meditation; than men who used problem-focused strategies such as time management and problem solving (Papastavrou et al., 2007). However, Cooper and colleagues' (2008) findings show that depression was not predicted by coping strategies, but did predict higher anxiety levels in caregivers who used problem-focused strategies. Though these findings do not agree, gender differences among coping mechanisms is important because it can determine the likelihood of experiencing caregiver burden.

### Behavioral and Psychiatric Characteristics

The characteristics of a care receiver influence the caregiving atmosphere, which inevitably affects the caregiver and their likeliness of experiencing caregiver burden. Mohamed, Rosenheck, Lyketsos, and Schneider (2014) found that severe behavioral characteristics such as behavioral

disturbances and psychiatric characteristics such as cognitive impairment of the care receiver were significantly correlated with increased levels of caregiver burden. Similar findings suggest that the acuity of behavioral disorders and the length of the disorder were associated with an increase of burden (Ferrara, Langiano, Di Brango, Di Cioccio, Bauco, & De Vito, 2008). However, male caregivers whose spouse was at a more severe stage of an illness experienced lower burden than female caregivers whose spouse was at a less severe stage of an illness (Poysti, Laakkonen, Strandberg, Savikko, Tilvis, Eloniemi-Sulkava, & Pitkala, 2012). The authors caution that this finding should be further explored to be confirmed (Poysti et al., 2012).

#### Caregiver Type and Culture

Depending on culture, caregivers may vary in types. Hong and Kim (2007) set out to compare caregiver burden and who gives the care. Findings illustrate that in Asian households, 33.8% of caregivers were daughters-in-law, 26.8% were spousal caregivers, 26.1% of caregivers were daughters, and 13.4% of caregivers were sons. Of these caregivers, the highest level of burden appeared in spousal caregivers even though daughters-in-law cared for family members with severe illness (Hong & Kim, 2007). Conde-Sala, Garre-Olmo, Turro-Garriga, Vilalta-Franch, and Lopez-Pousa (2010) had different findings which indicated that 44.5% of caregivers were spouses and 55.5% of caregivers were adult children in this Spanish study. Spousal caregivers reportedly experienced higher levels of burden than did adult-child caregivers (Conde-Sala et al., 2010). These

results may or may not have been influenced by the duration of care time, the quality of relationship, and living situation.

### Studies Focusing on Caregivers of Alzheimer's Disease Patients

Though much research is found on caregiver burden among dementia patients' caregivers, there is minimal research targeting caregiver burden among AD patients' caregivers in the Inland Empire. Therefore, this study reviewed recent research conducted on caregiver burden of those caring for AD patients in the U.S. Gender differences and factors of experiencing caregiver burden were also reviewed.

In a study of 700 participants (19% male), Geiger, Wilks, Lovelace, Chen, and Spivey (2015) set out to examine the relation between different coping strategies and burden among male caregivers of AD patients. They accomplished this by utilizing secondary data from a previous study and distributing questionnaires to various agencies in southern United States. African Americans made up about 35% of the sample, while about 60% of the sample was Caucasian.

The study found that males did indeed lean more towards using task-focused strategies than avoidance-focused or emotion-focused strategies. However, this did not indicate a lower level of burden because the usefulness of this strategy is the ability to set reachable goals, not the coping skill itself (Geiger et al., 2015).

The gaps that this study presents are the lack of an ethnically well-rounded sample of caregivers, severity of the AD, and social support. This leads to several limitations of the study which include only measuring the variables at a single point in time, utilizing convenience sampling instead of random sampling, and not controlling other factors that may contribute to burden (Geiger et al., 2015).

Siegler, Brummett, Williams, Haney, & Dilworth-Anderson (2010) conducted a similar cultural review of AD caregiver burden which suggested that black caregivers reported higher levels of overall well-being than white caregivers. The authors found that the higher level of overall well-being may be attributed to the higher levels of religiosity which promotes self-efficacy. These findings were measured by self-reports which can affect the quality of the results via responder bias. Another limitation would be that the sample only included adult-child caregiver and not spousal caregivers (Siegler et al., 2010). A gap that this study failed to address was the difference between male and female adult-child caregivers.

These identified gaps in caregiver burden in relation to mental health can also be identifiable gaps in caregiver burden in relation to physical and social health as well. The following research provided findings on caregiver burden and physical health, which is also an area of importance in terms of caregiver well-being. In a study of Caucasian participants, 66% of which were AD caregivers (male and female), researchers set out to examine the association between

caregiver gender and AD severity on overall biological functioning (Mills et al., 2009). The authors accomplished this study by monitoring participants' sleep. It was found that males who cared for a spouse with mild memory loss had better sleep than males who cared for a spouse with severe memory loss (Mills et al., 2009). It is important to note that this study takes into account the caregiver's age which is found to be at a higher risk of experiencing cardiovascular diseases (Mills et al., 2009).

Although sleep, inflammation, and coagulation do not directly indicate physical illness, if left untreated, can turn into a worsening condition. The study did not address the gap of socioeconomic status, nor did it address an ethnicity besides Caucasian. A limitation of the study is that male caregivers did not sufficiently reflect the sample size (Mills et al., 2009).

Mohamed et al. (2014) conducted a similar study in which spousal caregivers comprised half of the sample size, while 33% were adult-child caregivers or children-in-law. Additionally, more than half of the sample size were females and 78.8% of the sample size were Caucasian. The authors had similar findings to the previous study in that the severity of AD was associated higher levels of overall caregiver burden. Spousal caregivers also reported an elevated sense of burden (Mohamed et al., 2014). Difficulties with activities of daily living positively correlated with caregiver burden because the more assistance the care receiver needed, the higher the adverse impact on caregivers' psychological and physical health. Also, care receiver behavioral problems such as agitation and

social problems such as isolation may be a stronger indicator of burden than cognitive disturbances (Mohamed et al., 2014). A gap that the study did not address is the social health of the caregiver as social support is important to overall well-being. A few limitations exist in this study which includes inconclusive findings due to not using an experimental design as well as responder bias (Mohamed et al., 2014).

Although there were findings of caregiver burden among AD patients, the lack of adequate research indicates a need to further develop knowledge of cultural, gender, and external outliers on caregiver burden.

### Theories Guiding Conceptualization

Two theories used to conceptualize the ideas in this study are the Ecosystems Theory and the Strengths Perspective.

Zastrow & Kirst-Ashman (2015) integrate both the systems theory as well as the ecological perspective as a way to explain the importance of the person-in-environment. This allows the helping process to develop from the view of how the individual interacts with the environment and how the environment interacts with the individual. It is important to focus on the transaction between the individual as well as the systems that the individual engages in which may include the family system (mezzo system), the religious system (macro system), and the employment system (mezzo system), amongst other systems (Zastrow & Kirst-Ashman, 2015). The macro, mezzo, and micro systems differ on the level of

focus. The macro system focuses on political forces and how they shape mezzo systems, which focus on relationships with others. This is then influenced by the micro systems' focus on the individual's personality and characteristics (Zastrow & Kirst-Ashman, 2015).

This theory helps to frame how individual characteristics of the caregiver influences how they respond to the stressors of caregiving. These micro level characteristics include coping mechanisms, gender, and age. Mezzo systems include the interaction between the caregiver and the care receiver, the caregiver type, the living situation, as well as any support groups outside of the dyad affect caregiver burden. Macro systems include the social service system as well as the political system which may affect the resources that are applicable to caregivers who experience burden.

Due to the effect of caregiver burden on the caregiver's personal, social, and work life, the Strengths Perspective is a valuable asset in empowering caregivers. Zastrow and Kirst-Ashman (2015) put forth that this perspective focuses on the individual's positive qualities and relates it to how that individual is able to overcome challenges and solve problems. An important factor of the strengths perspective is that every individual and relationships thereafter have strengths that are capable of empowering individuals to achieve their goals (Zastrow & Kirst-Ashman, 2015).

Previous research utilized the stress-process model which focuses on the different stressors that an individual experiences from a macro level to a micro



level. This model is a good model to base caregiver burden research on because stress is a major aspect of caregivers experiencing caregiver burden. However, a stress-process model may not adequately address personality, cultural, or gender differences among caregivers. This may result in research that lacks insight into the multiple factors of why a caregiver is experiencing caregiver burden, which may result in insufficient knowledge for developing resources for this population.

### Summary

Although caregiver burden research is readily available, research on caregiver burden among AD patients in the Inland Empire is much needed. Not only are caregivers negatively affected, but the care receivers, as well as the families, are negatively affected by caregiver burden as well. Furthermore, individuals experience stress differently and that is congruent with how caregivers experience caregiver burden based on gender, culture, and personality traits. Ultimately, caregivers require resources that are specific and address the issue from the viewpoint of the systems theory and the strengths perspective.

## CHAPTER THREE

### METHODS

#### Introduction

This research study sought to explore the gender differences in caregiver burden of Alzheimer's disease (AD) patients and help the social work field in identifying gender appropriate resources for this population. This chapter will cover how the research study was completed. Details such as the study design, sampling, data collection and instruments, procedures, protection of human participants, and data analysis will be discussed.

#### Study Design

The purpose of this study was to explore and describe gender differences in caregiver burden of AD patient in the Inland Empire, and to help the social work field in identifying gender appropriate resources. As a result of limited research regarding the gender differences of the informal caregiving population of AD patients, the research design in this study was exploratory. A quantitative method was appropriate to use in assessing gender differences. Data was collected through a questionnaire that was self-administered and from secondary sources.

A strength in using exploratory, quantitative research with self-administered questionnaires is that respondents are completely anonymous and are less likely to be biased in their responses as the researcher was not present

in the study room during this time. This ensured that the respondents were free of pressure, thus it encouraged them to answer truthfully. Additionally, distributing questionnaires was beneficial to the caregiving population as it is time-effective and practical. It was also beneficial to the researcher as large amounts of data were collected over a short period of time from a large number of participants. This ensured that the results from the gathered data were generalizable.

A limitation of utilizing self-administered questionnaires was that there may have been subjectivity on the respondents' behalf that may have lead them to respond to questions based on their own interpretations of what the question was asking. Additionally, due to the number of questionnaires that was provided, there may have been chances of acquiescence bias (providing all positive or agreeable answers) which can also negatively affect internal validity. Furthermore, questionnaires leave little to no room for the respondent to write down their feelings and attitudes because of close-ended questions. Such a research method may not accurately reflect how an individual perceives or feels about the questions. Lastly, the findings of this study did not intend to determine cause and effect due to the essence of the exploratory research design.

This study sought to answer this question regarding gender differences of caregiver burden of AD patients: 1) Do female caregivers or male caregivers of AD patients experience a higher level of caregiver burden in the Inland Empire?

## Sampling

This study utilized a non-random quota sample of AD patient caregivers in the Inland Empire. A non-random quota sample was used in this research project because the study is focused strictly on the caregivers of AD patients only. The respondents were selected from a local caregiver support agency that serves all types of informal caregivers ranging from cancer to dementia. Though this is the case, it is imperative to the study that only AD patient caregivers were recruited and that there was an appropriate balance of male and female caregivers. The study aimed to collect data from 30 respondents.

## Data Collection and Instruments

Quantitative data was collected through use of self-administered questionnaires applied to individuals and to secondary data. The independent variable of the study was gender and the level of measurement was nominal, dichotomous. Gender was measured via socio-demographic data collection (Appendix A). The dependent variable of the study was caregiver burden and the level of measurement was interval. Caregiver burden was measured via the revised Zarit Burden Interview created by Zarit, Orr, and Zarit (1985) (Appendix A).

The Zarit Burden Interview (ZBI) is an existing interview that is widely used to assess for caregiver burden (Hebert, Bravo, & Preville, 2000). The interpretation of the ZBI is as follows: “1= little to no burden”, “2= mild to moderate burden”, and “3= moderate to severe burden” (Hebert et al., 2000).

Hebert and colleagues (2000) also found that the measure had good internal reliability as is evidenced by a .92 on Cronbach's alpha. The validity of the measure was not supported for all the translations of the ZBI because it failed to incorporate all aspects of caregiver burden. However, scores on the measure are unrelated to language and locale which may suggest that the interview is culturally sensitive (Hebert et al., 2000). A strength of the ZBI is that it has many translations available for those whose primary language is not English; however, a limitation of the ZBI may include not encompassing all factors of caregiver burden.

### Procedures

A flier consisting of the purpose the study, what will be asked of participants during the study, and investigator information was created. The time and date of the study was subject to the discretion of the executive director and the times and dates in which the support groups were held, as the study was conducted as an additional activity for respondents that were already in a support group. The support group facilitators aided the researcher in explaining the research study to their support group members and inquired if anyone was interested and willing to be a participant.

After the four participants volunteered to participate in the study, they were first and foremost asked not to give any identifiable information. Participants were then provided a packet containing consent forms (Appendix B) to be turned in prior to being provided the questionnaire. Only the English language version of

the questionnaire was distributed to participants who wanted to participate. After a brief introduction from the support group facilitator was given, confidentiality and protection of information was discussed. The study took a total of 30 minutes. Participants were asked to turn in their completed questionnaires to the group facilitator. After turning in their completed questionnaires, the group facilitators thanked them for their time. Due to the low number of “live” participants recruited for the study, the research communicated with the point person at the local caregiver support agency if there are any other avenues to conduct the study. The point person at the agency informed the researcher that she was able to utilize secondary data from their chart records. Therefore, the agency’s operation manager was able to obtain the secondary data based on the variables listed on the questionnaire and emailed it to the researcher in an excel sheet.

#### Protection of Human Subjects

The identity of the “live” participants will remain unknown and they were asked to place an “X” in any questionnaires that asks for a name. Additionally, no identifying information was collected from the secondary data information. The study was conducted inside a room that the agency normally holds support groups in. As stated in the last section, confidentiality and protection of information were discussed with participants. Participants were asked to sign an informed consent (Appendix B) before questionnaires were handed out. The

questionnaires will be kept in a locked clipboard in a locked desk for a year, after which they shall be destroyed.

### Data Analysis

This study used a quantitative method to explore gender differences in caregiver burden in AD patients. The independent variable of the study was gender, while the dependent variable of the study was caregiver burden. All data to be gathered by the self-administered questionnaire was entered and analyzed via IBM's SPSS program. Descriptive statistics analyses were run in order to establish the demographic description of the sample based on variables such as age, ethnicity, household income, education status, and religious affiliation. A t-test was used to examine the effect of gender on caregiver burden. Chi-square tests were conducted to determine if the males and females of the sample were similar or not in demographic characteristics. Correlational analyses were conducted in order to determine if there was a relationship between major study variables and caregiver burden.

### Summary

A quantitative design was chosen for assessing gender differences in caregiver burden of AD patients. Non-random quota sampling was used to ensure recruitment of caregivers of AD care receivers. Recruitment of participants was completed at a local caregiver support agency and through use

of secondary data. Participants were given a questionnaire that included demographic questions and the ZBI. These variables were then analyzed in IBM's SPSS program through use of t-tests, Chi-square tests, and correlation analyses.



## CHAPTER FOUR

### RESULTS

#### Introduction

This chapter will present the findings of the statistical analyses conducted in this study. A description of the study sample is illustrated in order to focus attention on important demographic variables. The mean and standard deviations of the scale variable are presented to discuss the descriptive statistics. Following the univariate statistical analysis; bivariate t-test, Chi-square, and correlational analyses will be presented to test the associations between the study variables, including between gender and caregiver burden.

#### Presentation of Findings

##### Description of the Study Sample

As seen in Table 1, the study sample consisted of 38 participants, 32 of which were female (84.2%) and 6 of which were male (15.8%). The mean age of the study sample was 61 years. The study sample consisted of primarily White-Caucasian (44.7%) and Hispanic-Latino (42.1%), followed by Black-African American (5.3%) and American Indian- Alaska Native (5.3%), and Native Hawaiian or Other Pacific Islander (2.6%).

The majority of the participants were married (57.9%) followed by single/never married (21.1%), divorced (10.5%), (the remaining participants were either separated, widowed, or in a domestic partnership). Most of the participants

were retired (42.1%), 23.7% worked part-time, 21.1% worked full-time, and 13.2% were unemployed. The mode income of the sample was \$4,000+, while the range of the income was from \$0-\$4,000+. Lastly, daughters (47.4%) made up most of the study sample followed by wives (15.8%), husbands (13.2%), adult child (5.3%), son-in-law (5.3%), non-relative (5.3%), sister (2.6%), mother (2.6%), and granddaughter-in-law (2.6%). Table 1 presents the demographic characteristics of the study sample.

Table 1. Demographic Characteristics of Study Sample

	<i>N</i> = 38	%	<i>M</i>	<i>SD</i>
<i>Gender</i>				
Female	32	84.20%		
Male	6	15.80%		
<i>Age</i>	38	N/A	61.13	14.61
<i>Ethnicity</i>				
White-Caucasian	17	44.70%		
Hispanic-Latino	16	42.10%		
Black-African American	2	5.30%		
American Indian- Alaska Native	2	5.30%		
Native Hawaiian or Other Pacific Islander	1	2.60%		
<i>Marital Status</i>				
Married	22	57.90%		
Single	8	21.10%		
Divorced	4	10.50%		
Separated	2	5.30%		

Domestic Partner	1	2.60%
Widowed	1	2.60%
<i>Employment Status</i>		
Retired	16	42.10%
Part-Time	9	23.70%
Full-Time	8	21.10%
Unemployed	5	13.20%
<i>Income</i>		
\$4,000+	13	34.20%
\$2,500-\$3,999	10	26.30%
\$1,000-\$2,499	10	26.30%
\$500 and under	2	5.30%
<i>Relation to Care Receiver</i>		
Daughter	18	47.70%
Wife	6	15.80%
Husband	5	13.20%
Child	2	5.30%
Son-in-law	2	5.30%
Non-Relative	2	5.30%
Sister	1	2.60%
Granddaughter-in-law	1	2.60%
Mother	1	2.60%

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### Zarit Burden Interview Score

The ZBI had a Cronbach's alpha of .87 in relation to the study. This finding indicates good internal reliability. The mode of the ZBI score was 2, which

translates to mild to moderate burden. The range of the ZBI score is from 0 (little or no burden) to 3 (moderate to severe burden). The mean participant score on the ZBI was 1.78 (SD= .64) which equates to little or no burden. Of the participants, 31.6% scored a 1, 52.6% scored a 2, and 10.5% scored a 3. The mean of 1 (little or no burden) is .33, the mean of 2 (mild to moderate burden) is .52, and the mean of 3 (moderate to severe burden) is .10.

#### Bivariate T-test Analysis of Demographic Variables by Gender

An independent samples t-test was conducted in order to compare the means between two different groups (males and females) and demographic variables to determine if they were different prior to testing the main research question.

Although the age mean appears different, no statistically significant differences were found between gender and age, males (M= 71.00, SD= 17.40) and females (M= 59.28, SD= 13.55;  $t(36) = 1.86, p = .07$ , two-tailed); or gender and income, males (M= 5.00, SD= 2.53) and females (M= 4.72, SD= 2.98;  $t(33) = .21, p = .84$ , two-tailed); nor gender and ZBI scores, males (M=1.83, SD= .41) and females (M= 1.77, SD= .68;  $t(34) = .23, p = .82$ , two-tailed).

#### Bivariate Chi-square Analysis of Variables

While not a main research question, a Chi-square test for independence was conducted to determine if there were any associations between demographic variables and the burden scale.

Five Chi-square tests for independence between categorical demographic variables such as gender, employment, relation to care receiver, ethnicity and the burden scale. Only two tests were found to be statistically significant. A significant association was found between gender and relation to care receiver,  $X^2(8, n=38) = 31.98, p = .00$ . This means that females were more likely to be daughters to the care receivers, and males were more likely to be husbands to the care receivers. A significant association was also found between ethnicity and relation to care receiver,  $X^2(32, n=38) = 88.17, p = .00$ . This means that both Hispanic-Latino caregivers were more likely to care for a parent, while Caucasian caregivers were more likely to care for a spouse. No significant associations were found between gender and employment,  $X^2(3, n=38) = 4.16, p = .25$ ; between gender and ZBI scores,  $X^2(2, n=38) = 2.40, p = .30$ ; nor between ethnicity and employment,  $X^2(12, n=38) = 14.63, p = .26$ .

Table 2. Gender \* Zarit Burden Interview Chi-square Test

	Zarit Burden Interview		
	1 little or no burden	2 mild to moderate burden	3 moderate to severe burden
<u>Sex</u>			
<i>Female</i>			
Count	11	15	4
% within sex	36.70%	50%	13.30%
<i>Male</i>			
Count	1	5	0
% within sex	16.70%	83.30%	0%

### Bivariate Correlation Analysis of Variables

A correlation analysis was conducted in order to indicate if there was a relationship between continuous demographic variables and the burden scale.

Table 3 presents the result of the correlation analysis of this study.

There was no statistically significant relationship noticed between income and ZBI scores ( $r = -.09$ ,  $p = .63$ ). However, with what little amount of association there was, income was noticed to be negatively correlated with ZBI scores. There was also no statistically significant relationship noticed between age and ZBI scores ( $r = .01$ ,  $p = .95$ ). However, with what little amount of association there was, age was noticed to be positively correlated with ZBI scores.

Table 3. Bivariate Correlation Analysis of Demographic Variables and Zarit Burden Interview

	Zarit Burden Interview
<i>Income</i>	
Pearson Correlation	-0.09
Sig. (2-tailed)	0.63
N	33
<i>Age</i>	
Pearson Correlation	0.01
Sig. (2-tailed)	0.95
N	36

## Summary

This chapter reported the significant findings of this study. Descriptive statistics were used to discuss the study sample and offer a description of the population. The ZBI mean score indicated little or no burden. A bivariate Chi-square test for independence analysis was used to identify an association between demographic variables and the study scale. The findings of this test indicated that a relationship was found between gender and ethnicity to relation to care receiver. A bivariate correlation analysis was used to identify the relationship between study variables. The findings of this test indicated that there was no statistical significance noticed between age or income and ZBI scores. Lastly, a bivariate independent samples t-test was used to compare means between gender and major study variables. There was no indication of a statistically significant difference between gender and ZBI scores.

## CHAPTER FIVE

### DISCUSSION

#### Introduction

The purpose of this chapter is to review and discuss the significant findings of the study. Any unanticipated results will be identified and explained. The limitations of the study and recommendations for future research studies will be discussed. This chapter will conclude with recommendations for micro and macro social work practice, policy, and future research.

#### Findings

The study results did not indicate that either female or male AD caregivers experience a higher level of burden. The findings indicated that, on average, both males and females scored “little or no burden” on the ZBI questionnaire (Hebert et al., 2000). However, over half of the participants scored mild to moderate burden on the ZBI questionnaire. While not statistically significant, of the male participants, 83% scored a mild to moderate burden; while 50% of female participants scored a mild to moderate burden. Additionally, on average, male participants scored a .06% higher in caregiver burden than females. This suggests that males and female experience caregiver burden to some extent; however, not one gender overtly experienced caregiver burden more than the other. It was anticipated that ZBI scores would be correlated with income due to resources that individuals with a higher income could receive; however, there



was no statistically significant finding that ZBI scores were correlated with income.

The study results indicate that there is a relationship between gender and caregiver relationship to care receiver. Within the male gender, four of the participants were of spousal relation to the care receiver, while two of the participants were of child relation to the care receiver. Within the female gender, six of the participants were of spousal relation to the care receiver, while twenty of the participants were of child relation to the care receiver. This finding is congruent with the Conde-Sala et al. (2010) study which found that AD caregivers were comprised mostly of female adult children rather than spouses. This finding may be due to culturally accepted traditions such as the female adult child taking the responsibility of caring for the elderly in the family. Another explanation may be due to the usual onset of AD at a later age and the events that may occur around that time, such as a death of a spouse; which results in the adult child assuming responsibility of caring for the care receiver.

The other significant finding of the study indicates that there is a relationship between ethnicity and caregiver relationship to care receiver. Within the White-Caucasian ethnicity, six of the participants consisted of daughters, while eight of the participants consisted of spouses (four of the eight participants were wives, and the other four were husbands). However, within the Hispanic-Latino ethnicity, eleven of the participants consisted of daughters, while two of the participants consisted of son-in-law's.

## Limitations

The main limitation of this research study is its quantitative design. Due to the descriptive nature of quantitative designs, the study did not allow for participant subjectivity; rather, the study focused more on the comparison between variables. Though the research design was an appropriate approach in answering the research question, there were many factors such as religious affiliation, coping strategies, and mental health that were identified during data analysis that could have influenced the experience of caregiver burden. Unfortunately, these factors were unable to be addressed in this study due to time and resource restraints. Therefore, for future research, this researcher would suggest utilizing a qualitative design so that researchers are able to interview participants to receive subjective data that may provide additional insight as to how and why participants are experiencing, or not experiencing, caregiver burden.

In relation to the quantitative design of this study, another limitation is the small and unbalanced sample size. A total of 38 participants (4 of which were “live” participants) were recruited for this study with nearly 85% of the participants being female. Ideally, researchers would recruit more than 50 participants for a quantitative design in order to attain generalizability. Furthermore, because the research question focused on the gender differences of caregiver burden, the sample would ideally have been comprised of a more balanced ratio of male and female caregivers. Therefore, this researcher would suggest recruiting a larger

sample size and obtaining a more equal ratio of male and female participants for future research. This imbalance may have affected statistical tests.

The study's use of non-random quota sampling hindered the researcher in recruiting an appropriate size and gender ratio of participants due to time restraints and the lack of geographically available caregiver agencies. Though this sampling type was appropriate for the research, this researcher suggests that future researchers utilize purposive sampling and a qualitative design to explore gender differences in caregiver burden. Additionally, this researcher suggests that a similar type of study be conducted in areas in which caregiver resources are not readily available to the population in order to ensure that data is not skewed by such resources.

Lastly, the research study excluded monolingual Spanish-speaking participants. However, the agency in which this study recruited participants from consisted of many monolingual Spanish-speaking clients unbeknownst to the researcher. Monolingual Spanish-speaking participants would have benefitted the sample because it would have increased the sample size and potentially have evened the ratio of male and female caregivers, and included more cultural variability. Therefore, this researcher suggests that future researchers identify participants who speak languages aside from English and provide questionnaires in their respective languages if a quantitative study is to be conducted.

## Implications for Social Work Practice, Policy, and Future Research

The implications of the study are speculative because there was no statistically significant difference between gender and caregiver burden in this study. Overall, the participants of the sample size scored low on caregiver burden as evidenced by the mean average of participants scoring little or no burden. However, this may be due to the fact that the participants that were recruited were already receiving services to help reduce caregiver burden. Therefore, a change in policy and program development is essential in reducing the risks that are associated with caregiver burden.

The effects of caregiver burden are detrimental to the overall well-being of the caregiver, care receiver, and family. Such effects include a surge of physical risks, psychological risks, emotional risks, and resentment towards the patient (Razani et al., 2007). These consequences may produce short-term or long-term effects in the individuals involved. Not much research has been conducted on caregiver burden among Alzheimer's patients; however, it would be of service to the social work field, AD caregiver population, and care receivers themselves (Brodaty, et al., 2014).

### Policy Change and Program Development

The exposure of the informal caregiver population is important because as the findings suggest, there is a relationship between gender and ethnicity and relation to care receiver. Policy change should be enacted in order for both males and females of any ethnicity have easily accessible resources to decrease the

impact of caregiver burden. Schulz and Sherwood (2008) argue that no clear policies exist for caregivers who are experiencing caregiver burden, though they have been alerted. Additionally, the Family Caregiver Alliance (2018) have made suggestions to develop national level policies for informal caregivers such as resource funding, insurance benefits, and the promotion of the geriatric labor force. Resource funding is virtually the single-most important policy to develop for informal caregivers because informal caregiving can cost nearly \$20,000 annually in the U.S. (Thompson et al., 2007). This does not mention how much informal caregiving costs businesses due to lost productivity (Family Caregiver Alliance, 2018). An expansion of insurance benefits can allow informal caregivers to receive services such as care coordination and sufficient education and training. However, with the lack of interest in the elderly population; many policies are not placed to help these informal caregivers. Therefore, monies should be spent on attracting individuals to work with this population so that burden is lessened in informal caregivers (Family Caregiver Alliance, 2018).

Programs such as the ones found at the Inland Caregiver Resource Center- supportive counseling, respite care, and support groups- are linked to lower levels of caregiver burden. Therefore, such programs should be made geographically and financially accessible to caregivers regardless of demographics. Additionally, educational classes and trainings can help both informal caregivers and those that work with informal caregivers (social workers,

case managers, and healthcare professionals) strengthen their skills in working with this population and with one another.

### Implications for Micro Practice

Though this study did not demonstrate a gender difference in caregiver burden, it did allude to the benefit of having programs and services available to the informal caregiving population. As previously discussed, caregiver burden not only affects the caregiver, but also the care receiver and the family unit as well. Caregiver burden may even result in the institutionalization of the care receiver, which can initially produce positive short-term effects; however, the cost of institutionalizing an individual can perpetuate negative long-term effects as well (Robison et al., 2009). The availability of programs to alleviate burden from these caregivers are essential to the social work field of gerontology.

Due to the indication of the relationships between gender and relation to care receiver and ethnicity to care receiver, social workers have the to uphold the ethical responsibility of social and political action by exploring the needs of this marginalized population (National Association of Social Workers, 2018). Perhaps, some ways in which social workers can achieve this is to develop gender-specific or ethnicity-specific resources for the informal caregiving population. Moreover, because the findings indicated Latino daughters and Caucasian spouses were the bulk of the sample size, support targeting these sub-populations would be advantageous.

Not enough information is known on this population because much of the focus in the geriatric field is on the care receiver and not on the caregiver. However, research has recently increased in exploring this population and as stated above, policies have been suggested to help informal caregivers. Additionally, micro practice social workers should uphold the ethical principle of service by exercising the responsibility of assessing the informal caregiving population for barriers that hinder their ability to appropriately care for their loved ones (National Association of Social Workers, 2018). Barriers for this population may look a lot different from barriers of any other population because consequences of caregiver burden directly affect the care receiver's well-being which may perpetuate further negative consequences.

Lastly, micro practice social workers should build and maintain relationships with other agencies and organizations that can alleviate caregiver burden such as the local caregiver support agency. By doing so, resources can be made accessible and be plentiful to share with informal caregivers.

#### Recommendations for Future Research

Future research of caregiver burden would benefit from additional exploration of informal caregivers in geographical areas without easily obtainable services. These findings may indicate that there is a difference in caregiver burden due to the lack of programs to help reduce caregiver burden. Additionally, a larger sample size consisting of an equal ratio of males and females is recommended for future research in order to find a statistically significant

difference. Furthermore, future research should aim to interview informal caregivers' perceptions of social workers and how they believe caregiver burden can be reduced.

### Conclusion

The purpose of this study was to explore the gender differences of in caregiver burden among AD patients. Study findings did not indicate a statistically significant difference between male caregivers and female caregivers. Recommendations for future research included conducting research in areas with a lack of caregiver services, conducting a similar study with a larger sample size, and interviewing caregivers to gain insight as to how caregivers perceive social workers and how social workers can play a role in reducing caregiver burden.



APPENDIX A  
QUESTIONNAIRE

### Demographic Survey

1	Age	
2	Sex	
3	What race do you identify with?	<input type="radio"/> American Indian or Alaskan Native <input type="radio"/> Asian <input type="radio"/> Black or African American <input type="radio"/> Hispanic or Latino <input type="radio"/> Native Hawaiian or <u>Other</u> Pacific Islander <input type="radio"/> White <input type="radio"/> Other
4	What is your marital status?	<input type="radio"/> Single/Never Married <input type="radio"/> Married <input type="radio"/> Widowed <input type="radio"/> Divorced <input type="radio"/> Separated
5	What is the highest degree of level of school you have completed?	<input type="radio"/> Less than a high school diploma <input type="radio"/> High school degree of equivalent <input type="radio"/> Some college, no degree <input type="radio"/> Associate degree <input type="radio"/> Bachelor's degree <input type="radio"/> Master's degree <input type="radio"/> Professional degree <input type="radio"/> Doctorate
6	What is your current employment status?	<input type="radio"/> Employed full-time <input type="radio"/> Employed part-time <input type="radio"/> Unemployed <input type="radio"/> Student <input type="radio"/> Retired <input type="radio"/> Self-employed <input type="radio"/> Unable to work/Disabled
7	What is your household income?	<input type="radio"/> Less than \$20,000 <input type="radio"/> \$20,000 to \$34,999 <input type="radio"/> \$35,000 to \$49,999 <input type="radio"/> \$50,000 to \$74,999 <input type="radio"/> \$75,000 to \$99,999 <input type="radio"/> Over \$100,000
8	What is your religious affiliation?	<input type="radio"/> Baptist <input type="radio"/> Buddhist <input type="radio"/> Hindu <input type="radio"/> Jewish <input type="radio"/> Mormon <input type="radio"/> Lutheran <input type="radio"/> Muslim <input type="radio"/> Roman Catholic <input type="radio"/> Other

Zarit Burden Interview

**Please circle the response that best describes how you feel.**

	Never	Rarely	Sometimes	Quite Frequently	Nearly Always	Score
1. Do you feel that your relative asks for more help than he/she needs?	0	1	2	3	4	
2. Do you feel that because of the time you spend with your relative that you don't have enough time for yourself?	0	1	2	3	4	
3. Do you feel stressed between caring for your relative and trying to meet other responsibilities for your family or work?	0	1	2	3	4	
4. Do you feel embarrassed over your relative's behavior?	0	1	2	3	4	
5. Do you feel angry when you are around your relative?	0	1	2	3	4	
6. Do you feel that your relative currently affects your relationships with other family members or friends in a negative way?	0	1	2	3	4	

7. Are you afraid of what the future holds for your relative?	0	1	2	3	4	
8. Do you feel your relative is dependent on you?	0	1	2	3	4	
9. Do you feel strained when you are around your relative?	0	1	2	3	4	
10. Do you feel your health has suffered because of your involvement with your relative?	0	1	2	3	4	
11. Do you feel that you don't have as much privacy as you would like because of your relative?	0	1	2	3	4	
12. Do you feel that your social life has suffered because you are caring for your relative?	0	1	2	3	4	
13. Do you feel uncomfortable about having friends over because of your relative?	0	1	2	3	4	
14. Do you feel that your relative seems to expect you to take care of him/her as if you were the	0	1	2	3	4	

only one he/she could depend on?						
15. Do you feel that you don't have enough money to take care of your relative in addition to the rest of your expenses?	0	1	2	3	4	
16. Do you feel that you will be unable to take care of your relative much longer?	0	1	2	3	4	
17. Do you feel you have lost control of your life since your relative's illness?	0	1	2	3	4	
18. Do you wish you could leave the care of your relative to someone else?	0	1	2	3	4	
19. Do you feel uncertain about what to do about your relative?	0	1	2	3	4	
20. Do you feel you should be doing more for your relative?	0	1	2	3	4	
21. Do you feel you could do a better job in caring for your relative?	0	1	2	3	4	
22. Overall, how burdened do	0	1	2	3	4	

<b>Total Score (out of 88)</b>	
--------------------------------	--

© 1985 Steven Zarit

Interpretation of Score:	
0-21	little or no burden
21-40	mild to moderate burden
41-60	moderate to severe burden
61-88	severe burden

Score values and interpretation are guidelines only, as discussed in:

Hebert R, Bravo G, and Preville M (2000). *Canadian J Aging* 19: 494-507.

APPENDIX B  
INFORMED CONSENT



California State University, San Bernardino  
Social Work Institutional Review Board Sub-Committee  
APPROVED 1/16/2018 VOID AFTER 1/15/2019  
IRB# SW 1836 CHAIR [Signature]

College of Social and Behavioral Sciences  
School of Social Work

**INFORMED CONSENT**

The study in which you are asked to participate in is designed to explore the gender differences of caregiver burden among Alzheimer's patients in the Inland Empire. The study is being conducted by Janet Torres, a graduate student, under the supervision of Dr. Herb Shon, Assistant Professor in the School of Social Work at California State University, San Bernardino (CSUSB). The study has been approved by the Institutional Review Board Social Work Sub-committee at CSUSB.

**PURPOSE:** The purpose of the study is to explore the gender differences of caregiver burden among Alzheimer's patient in the Inland Empire.

**DESCRIPTION:** Participants will complete a demographic survey and a questionnaire without interruption from the researcher.

**PARTICIPATION:** Your participation in the study is totally voluntary. You can refuse to participate in the study or discontinue your participation at any time without any consequences.

**CONFIDENTIALITY OR ANONYMITY:** Your responses will remain anonymous and data will only be reported to the researcher.

**DURATION:** It will take about 30 minutes to complete the survey.

**RISKS:** There may be minor risks associated with the study in the form of the participant experiencing some discomfort regarding questions asked on the survey.

**BENEFITS:** There will not be any direct benefits to the participants; however, results from this study may help researchers gain more insight into informal caregiving and caregiver burden.

**CONTACT:** If you have any questions about this study, please feel free to contact Dr. Shon at hshon@csusb.edu

**RESULTS:** Results of the study can be obtained from the Pfau Library ScholarWorks database (<http://scholarworks.lib.csusb.edu/>) at California State University, San Bernardino after July 2018.

.....  
This is to certify that I read the above and I am 18 years or older.

\_\_\_\_\_ Place an X mark here

\_\_\_\_\_ Date

909.537.5501

5500 UNIVERSITY PARKWAY, SAN BERNARDINO, CA 92407-2393

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Maritime Academy • Monterey Bay • Northridge • Pomona • Sacramento • San Bernardino • San Diego • San Francisco • San Jose • San Luis Obispo • San Marcos • Sonoma • Stanislaus



APPENDIX C  
IRB APPROVAL LETTER

**CALIFORNIA STATE UNIVERSITY, SAN BERNARDINO**  
**SCHOOL OF SOCIAL WORK**  
*Institutional Review Board Sub-Committee*

Researcher(s) Janet Torres  
Proposal Title Gender Differences Among Caregiver Burden  
of Alzheimer's Patients  
# SIJ 1836

Your proposal has been reviewed by the School of Social Work Sub-Committee of the Institutional Review Board. The decisions and advice of those faculty are given below.

-----

Proposal is:

- approved  
 to be resubmitted with revisions listed below  
 to be forwarded to the campus IRB for review

Revisions that must be made before proposal can be approved:

- faculty signature missing  
 missing informed consent  debriefing statement  
 revisions needed in informed consent  debriefing  
 data collection instruments missing  
 agency approval letter missing  
 CITI missing  
 revisions in design needed (specified below)
- \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

Janet Torres  
Committee Chair Signature

1/16/2018  
Date

Distribution: White-Coordinator; Yellow-Supervisor; Pink-Student

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