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The Role of Social Location in Coping with Caregiving

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THE ROLE OF SOCIAL LOCATION IN COPING WITH CAREGIVING

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ABSTRACT

A salient concern stemming from population aging is the expected rise in demand for informal family caregivers for diseases impacting the elderly, including dementia (MMMI 2010; NIA and WHO 2011). Studies of caregiver well-being often problematize the sociodemographic caregivers (e.g. gender, marital status) while caregiver intervention studies typically focus on the program itself (Gallagher-Thompson et al., 2008; Rabinowitz et al., 2006; Shulz et al., 2003). In this dissertation I unite these two bodies of caregiver research and examine how the sociodemographic characteristics of participants in a caregiver intervention program relate to the program's effectiveness. I use secondary data from the Stress Management Project Dataset (Spiegel, 2001) and evaluate how participants' social location (specifically, race and education) impacts the effectiveness of each program on caregivers' depressive symptoms and stress. This study employed a sociological perspective to examine how social location (specifically race and education) impacts the benefits of a dementia caregiver intervention program. Using secondary data, I performed OLS regression analyses and found support for the initial hypothesis that suggested that the Coping with Caregiving (CWC) intervention would be more effective than the Telephone Support Control (TSC). There was no support for the remaining hypotheses that proposed that White caregivers with more education would benefit more from the program, or that the effects of race and education on caregiver outcomes would be contingent upon each other.

Key words/phrases: Coping with Caregiving, dementia caregivers, intervention programs, social location

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DEDICATION

I dedicate this dissertation to the following men in my life: my dear husband, David Ragin, who has been and will always be my rock; my loving brothers, Cassie, Charlee and Brendan Thornicroft; my doting father, Jack Thornicroft, 'aka' Pops; my inspiring father-in-law, James Ragin; my supportive uncle, Herman Ragin; and lastly, my precious son, Marcus Ragin. You have all inspired me in your own way.

TABLE OF CONTENTS

ABSTRACT.....	iii
ACKNOWLEDGMENTS	iv
DEDICATION.....	v
LIST OF TABLES	ix
LIST OF FIGURES	x
LIST OF ABBREVIATIONS.....	xi
CHAPTER 1: INTRODUCTION.....	1
Statement of the Problem	3
Statement of Purpose, Research Questions and Hypotheses.....	4
Nature of the Study and Design Rationale	6
Description of the Dataset and Nature of the Study.....	6
Brief Background of the Stress, the HPA and Health in Aging Project.....	7
Significance of the Study	8
Scope, Limitations, and Delimitations	9
Definitions of Key Terms/Words.....	10
Summary and Chapter Outline.....	13
CHAPTER 2: LITERATURE REVIEW	15
Part 1: Background - Overview of an Aging World	15
What is old age?	16
Why is the population aging?	17
Differences in global and national aging.....	19
Why the concern over population aging?	21
Summary of the challenges of global aging	25
Part 2: Informal Caregiving and the Caregiver	25
What is an Informal Caregiver?	26
Caregiving Role.....	26
Caregiving Intensity: Burden, Stress, and Depression (Depressive Symptoms).....	28
The Cost of Caregiving.....	34

Caregiving and Dementia Patients	38
Caregiving Interventions	42
REACH.....	44
Coping with Caregiving (CWC).....	47
Coping with Caregiving (CWC) Vs. Automated Telephone Support (TSC)	47
Caregiving, Social Location, and CWC	48
Race	49
Education	54
Summary of Caregiving and the Caregiver.....	56
Part 3: Theoretical Framework.....	57
The Stress Process Model.....	58
Life Course Perspective (LCP).....	60
Conceptual Model for the Dissertation.....	63
Summary of Theoretical Framework.....	64
CHAPTER 3: METHODS	65
Review of Statement of Purpose	65
Research Questions and Hypotheses.....	66
Research Design and Rationale.....	68
Dataset Description.....	69
Recruitment and Data Collection	69
Concepts and Measures	70
Dependent Variables.....	70
Independent Variables	72
Covariates	73
Analytic Strategies	74
CHAPTER 4: RESULTS	78
Research Questions	78
Pre/Post-Tests and Descriptive Results for the Study Sample.....	79
Sample Description.....	80
Results of Dependent and Independent <i>t</i> -tests	83
Check of Regression Assumptions and Sensitivity Analysis	85

Section 1 – Depressive Symptoms	87
Model 1 Summary	87
Section 2 – Stress	88
Model 2 Summary	89
Summary	91
CHAPTER 5: DISCUSSION & CONCLUSION.....	92
Discussion of Findings	92
Section 1 – Depressive Symptoms	96
Section 2 – Stress	97
Limitations	99
Interventions/Treatment.....	99
DataSet.....	100
Summary and Conclusion	100
Implications for Practice	102
Recommendations for Future Research	103
APPENDIX A: CENTER FOR EPIDEMIOLOGIC STUDIES DEPRESSION SCALE (CES-D)	
.....	106
APPENDIX B: PERCIEVED STRESS SCALE (PSS).....	107
APPENDIX C: CODE SHEET.....	108
REFERENCES	110
CURRICUMLUM VITAE	123

LIST OF TABLES

Table 1: Overview of Study Hypotheses	68
Table 2: Coding of Independent Variable and Covariates	74
Table 3: Study sample outcome measures (n=156)	79
Table 4: Power Analysis Results	80
Table 5: Study sample characteristics at pre-test by group.....	81
Table 6: Study sample demographics at pre-test (n=156)	82
Table 7: Dependent <i>t</i> -test results for CES-D and PSS	84
Table 8: Independent t-test and Chi-Square results for dependent variables and covariates.....	85
Table 9: Overview of Regression Assumption Checks	86
Table 10: Regression model predicting CES-D scores.....	88
Table 11: Hypothesis Results for the Dependent Variable Depressive Symptoms	88
Table 12: Regression model predicting PSS scores.....	90
Table 13: Hypothesis Results for the Dependent Variable Stress	91

LIST OF FIGURES

Figure 1. Shah et al. (2010) stress-process model of stress (adapted from Pearlin et al. 1990) ...	60
Figure 2. Dissertation Theoretical Conceptual Model.....	63

LIST OF ABBREVIATIONS

ACA	Affordable Care Act
AD	Alzheimer's disease
ADC	Adult Day Care Centers
ADL	Activity of Daily Living
CES-D	Center for Epidemiologic Studies Depression Scale
CG	Caregiver
CR	Care Receiver
CWC	Coping with Caregiving
ESG	Enhanced Support Group
HPA	Hypothalamic Pituitary Adrenal Axis
HRS	Health and Retirement Study
FCA	Family Caregiver Alliance
FIFARS	Federal Interagency Forum on Aging-Related Statistics
IADL	Instrumental Activities of Daily Living
LBD	Lewy Body Dementia
LCP	Life Course Perspective
MEPS	Medical Expenditure Panel Study
MMMI	MetLife Mature Market Institute
MMSE	Mini-Mental Status Examination
NIA	National Institute on Aging
NIH	National Institute on Health
NINR	National Institute on Nursing Research
OAA	Older Americans Act
OLS	Ordinary Least Squares
OMB	Office of Management and Budget
PRB	Population Reference Bureau
PSS	Perceived Stress Scale
RCI	Rosalyn Carter Institute
RCT	Randomized Controlled Trials
REACH	Resources for Enhancing Alzheimer's Caregiver Health
SES	Socioeconomic Status
TSC	Telephone Support Control
WHO	World Health Organization
WMH	World Mental Health
UN	United Nations
UNFPA	United Nations Fund for Population Activities
USCB	United States Census Bureau
USDHHS	United States Department of Health and Human Services
VA	Veterans Affairs

CHAPTER 1: INTRODUCTION

“There are only four kinds of people in the world – those who have been caregivers, those who are currently caregivers, those who will be caregivers and those who will need caregivers.” -

Rosalynn Carter

The world is experiencing a new and demographic phenomenon: a dramatically aging population (United Nations Fund for Population Activities [UNFPA] & HelpAge International, 2012). With the advent of modern medicine has come significant advances in overall healthcare that have not only led to decreased infectious diseases and decreased mortality, but also rapidly declining fertility rates and increasing life expectancy (National Institute on Aging [NIA] & World Health Organization [WHO], 2011; National Institutes of Health [NIH], 2011; United Nations [UN], 2002; United States Census Bureau [USCB], 2009; Werner, 2011). As a result of these trends, the experience of aging has changed so significantly that the world’s population age structure has completely shifted to one where the majority of the global population is increasingly old (NIA and WHO, 2011; UNFPA & HelpAge International, 2012). Such demographic momentum is truly a first in history, and though it might be considered an astounding success that humans are living much longer than ever thought possible, it has also brought unforeseen challenges of a magnitude yet to be fully comprehended.

One of the greatest challenges of our aging population is the increased risk and occurrence of age-related illness and physical disability that will impact our social and economic infrastructures, and the overall sustainability and viability of a healthy and productive world (UNFPA & HelpAge International, 2012; USCB, 2010; Werner, 2011). Diseases such as dementia, particularly Alzheimer’s disease (AD), are rising sharply, also impacting those who are entrusted with caring for elderly people with such ailments (De Fazio, 2015; Werner, 2011;

WHO 2013; USCB, 2010). In the context of the intense long-term care needs of the current cohorts of older adults and the projected needs of future cohorts, caregiver burden is an increasingly critical issue to investigate and anticipate. The emotional and financial costs of caregiver burden (on families and in workplaces) are potentially profound. It is also important to consider how the experience of caregiver burden shifts in response to the care recipient's and the caregiver's health. With these issues at the forefront of contemporary discussions about population aging, there is increasing global recognition that the course of healthcare and public policies need to address the entire spectrum of the effects of aging, with particular attention to the impact on informal family caregivers (MMMI, 2010; NIA & WHO, 2011; UN, 2002; UNFPA & HelpAge International, 2012).

Researchers have produced a significant body of literature on informal caregiving, however there is limited publically available data on intervention programs designed to alleviate the burden of informal caregiving. In particular, little sociological research examines the efficacy of various types of caregiver interventions. Instead, those kinds of program evaluations have largely been left to other disciplines. The benefit of examining caregiver intervention programs sociologically is the ability to focus on the social factors (rather than only psychological factors) that matter for the programs' ability to reduce caregiver burden. One program intervention in particular would benefit from a sociological evaluation: Coping with Caregiving (CWC). CWC is an intervention program aimed at reducing the burden of stress and depressive symptoms among informal family caregivers (Brodaty & Donkin, 2009; De Fazio et al., 2015; Gallagher-Thompson & Coon, 2007; Kosberg et al., 2007). My goal in this dissertation is to assess CWC with attention to the role of social location factors (such as race and education) on the benefits of the CWC program. This study addresses a void in the literature and may inform research and

practice by addressing for whom the CWC program works best. It may, therefore, aid in the evaluations and future designs of such intervention programs to ensure that all participants benefit equally (Coon et al., 2004; De Fazio et al., 2015; Gallagher-Thompson & Coon, 2007; Kosberg et al., 2007).

In this dissertation, I used a sociological approach to take a fresh look at the Stress Management Project Dataset (Spiegel, 2001) that was originally designed to systematically examine the effects of stress, endocrine function, and social support on health and aging. The original researchers used part of the dataset (Gallagher-Thompson et al., 2008) to evaluate the effects of stress-management treatments for caregivers of elders with dementia on hypothalamic-pituitary-adrenal axis (HPA) function and distress. My sociological contribution is to examine the role of participants' social location in enhancing or diminishing the benefits of the caregiving intervention program, CWC. This study examined the influence of race and education (sociological factors) on the effectiveness of the CWC program intended to reduce informal dementia caregivers' stress and depressive symptoms.

Statement of the Problem

We are facing an urgent and critical need to address population aging and the resulting challenges. From the immediate family to all aspects of social, economic, and political spectrum, the rise in global aging is having an astounding, unforeseen effect across the world. The U.S. is no exception. Among the resulting challenges being witnessed in the U.S. is the acute increase in those who need care and the related costs—both financial and emotional—to those providing the care (MMMI, 2010; NIA & WHO 2011). Specific attention needs to be paid to this latter group as more often, caregivers are unpaid, family members, and the burden and stress of caregiving

ultimately affects their own health. Attention to caregiving and relieving caregiver's burden is therefore also vital, along with the needs of the care recipient.

Existing research indicates that informal caregiving is stressful and can negatively impact the caregiver in a number of ways (Jarrot et al., 2005; Reinhard, Levine, & Samis, 2012). In response to this dilemma, some interventions have been developed and successfully implemented that provide a way to alleviate caregivers' stress (Gallagher-Thompson & Coon, 2007; Rabinowitz et al., 2006). Prior studies have shown that caregiver interventions such as CWC have reduced caregiver stress and depressive symptoms overall (Gallagher-Thompson et al., 2008; Rabinowitz et al., 2006; Shulz et al., 2003) however, few studies have explored at the granular level which groups of dementia caregivers benefit the most from these interventions (Gallagher-Thompson & Coon, 2007). In particular, limited studies directly address the role of social location on coping with caregiving. Therefore, this study examined how the role of social location, and operationalized as race and education, impacts the benefits of CWC intervention program.

Statement of Purpose, Research Questions and Hypotheses

The purpose of this study was to examine how social location and operationalized by race and education, impacts the effectiveness of caregiving intervention programs for dementia caregivers. Although the goal of each caregiver intervention is to reduce dementia caregivers' stress and depressive symptoms, the question of exactly who benefits the most when participating in a dementia caregiver intervention program is rarely quantified under the sociological premise of social location. In this dissertation, I problematized caregivers' social location in terms of their race and education, and asked how these characteristics influence the effectiveness of the intervention on reducing stress and depressive symptoms.

Thus, the primary research question for this study was “*how do race and education impact (or influence) benefits of dementia caregiver intervention programs, specifically CWC?*” Given that previous studies demonstrate that CWC is generally a better intervention for dementia caregivers than Telephone Support Control (TSC), my goal was to understand whether the socioeconomic factors of race and education predict even greater benefits for caregivers. Gallagher-Thompson’s study (2008) also showed that CWC was a more effective intervention for reducing caregiver stress and depressive symptoms than TSC. Therefore, in this study, I first attempted to replicate this previous finding before addressing the impact of race and education on the effectiveness of CWC.

In support of the primary research question, I addressed the following secondary research questions and subsequent hypotheses that guided the research methods and data analyses of the study and helped understand the role of social location on intervention programs.

R₁: Are there differences among dementia caregivers’ depressive symptoms and stress between CWC and TSC participants?

H₁: CWC has a greater (positive) effect on participants’ stress and depression outcomes than TSC.

R₂: Are the effects of CWC on caregivers’ depressive symptoms and stress different by race?

H₂: Non-Hispanic White caregivers will experience a greater reduction in stress and depressive symptoms than Hispanic caregivers.

R₃: Are the effects of CWC on caregivers’ depressive symptoms and stress different by educational attainment?

H₃: Caregivers with higher education will experience a greater reduction in depressive symptoms and caregiver stress than those with lower education

R₄: Are the effects of CWC on caregivers' depressive symptoms and stress contingent upon the relationship between race and educational attainment?

H₄: Non-Hispanic White caregivers with higher education will experience a greater reduction in stress and depressive symptoms than Hispanic caregivers with higher education.

In the following sections I review the background literature on informal caregiving, race and education differences among caregivers, and caregivers' depressive symptoms and stress. In doing so, I lay the underlying rationale for the above research questions and hypotheses and explain and justify they further.

Nature of the Study and Design Rationale

Description of the Dataset and Nature of the Study

The study was quantitative in nature, and used the Stress Management Project Dataset (Spiegel, 2001), a secondary dataset that was de-identified and made available by the original research team to me. The Stress Management Project Dataset (Spiegel, 2001) is ideal for this dissertation for five reasons. First, it is a comprehensive dataset that collected health and aging information at two time points for the same participants. Second, the data was not publicly released, thus being granted permission to use the dataset is an opportunity to explore sociological factors not previously examined by the original research team. The third advantage is that the data contained a very diverse group of individuals, which allowed the researcher to take a close look at the participants and address the overall research question of *who benefits the most and least from this intervention?* Fourth, the data has several connections to the original REACH project. Dr. Dolores Gallagher-Thompson, a principal investigator, was also a part of the original REACH project at one site. Additionally the pre and post data used a questionnaire adapted from the REACH program (Gallagher-Thompson et al., 2003). Finally, the CWC

intervention was tested in the original REACH study although slightly modified for this research; however, CWC is considered an evidence-based practice.

It should also be noted that using a secondary dataset was necessary for this dissertation study because conducting a first-hand data collection study on this subject matter was beyond the logistical and financial scope available to me. However, using secondary data is, in fact, a valid method of study. According to Church (2001), “secondary analysis of original data ... has been used primarily in fields in which there is a large amount of data and the cost of the data collection is particularly high” (p. 43). Indeed, “the close examination of the quantitative results of published studies has often facilitated the development and testing of new quantitative theory” (Church, 2001, p. 40). Thus, using this secondary dataset released was the most appropriate and is the best possible data available to address my research questions. Below is a brief description of the dataset. Additional details on the dataset are provided in chapter 3.

Brief Background of the Stress, the HPA and Health in Aging Project

This dissertation employed the Stress Management Project Dataset (Spiegel, 2001) that was used in the 2008 intervention study “*Reducing Stress in Hispanic and Anglo Dementia Family Caregivers*” by D. Gallagher-Thompson, Ph.D., Principal Investigator. The study was a sub-project, part of a four-project research program on health and aging originally funded by the National Institutes of Health (NIH); through the National Institute on Aging (NIA), project number 3P01AG018784, supported by grant number AG 18784 entitled, “Stress, the HPA, and Health in Aging” which was a program project awarded to David Spiegel, M.D., Principal Investigator. The four specific projects were carried out by collaborating investigators from the Department of Psychiatry and Behavioral Sciences at Stanford University. The overall purpose of the multi-research project was to assess the effects of psychosocial support on physiological

stress by examining measurements of the hypothalamic-pituitary-adrenal axis (HPA) in aging adults with different diseases and health programs.

Since the focus of this dissertation was on CWC, the dataset from the fourth study that evaluated effects of stress-management treatments for caregivers of elders with dementia on HPA function and distress was the most appropriate. The data was collected between 2002 and 2006, with the first publication of results released in 2008 (Dr. Jason Holland, personal communication, October 5, 2015). The data is not publicly available. The dataset was provided for use in this dissertation by Dr. Jason Holland, who was granted permission by Dr. Dolores Gallagher-Thompson, one of the principal investigators.

Significance of the Study

Throughout the process of reviewing the research in this area, one of the most consistent themes in the caregiving literature (see next chapter for literature review) is that caregiving scholars routinely call for the review and implementation of evidence-based practices (UWM, 2010). Research consistently calls for using evidenced-based practices as this approach utilizes best practices and recognizes that care is individualized. Additionally, more research that is conducted on evidence-based practices will allow the body of work to accumulate and strengthen this position. This study addresses that call and analyzed the effectiveness of two caregiver interventions using a sociological lens.

Although research has established that CWC is an effective intervention that reduces caregiver stress and depressive symptoms, it has not addressed for whom the benefits of CWC are greatest (Gallagher-Thompson & Coon, 2007). Is CWC effective *equally* for all participants, or is there a difference in actual benefit (as measured by caregiver stress and depressive symptoms) across different groups of participants? This is a critical point to address in order to

accurately examine the CWC intervention program. Prior analysis of the data was conducted by psychiatrists and psychologists, whereas this analysis was undertaken from a sociological perspective. The difference between the two perspectives is that the psychological perspective does not primarily address socio-demographic factors. This study might benefit the broad spectrum of the caregiver community, especially those professionals who want to implement evidence-based practices that address the issue of caregiver depressive symptoms and stress. It was the expectation that the results would show how social location, operationalized by race and education, impacts the effectiveness of CWC, thereby improving how the caregiving community implements the program. The informal or family caregiver plays such a pivotal role in this delicate system that it is without question that research should focus on ways to ensure that caregivers' health and well-being are preserved at all costs. "It is ...vital from a societal perspective to maintain the functional integrity of the informal family caregiving system" (Viana et al. 2013, p. 124).

Scope, Limitations, and Delimitations

The scope of a study addresses its timeframe, the amount and quality of relevant information that will be available, and the geographic location for the study (Cooper & Schindler, 2003). The limitations, or weaknesses, refer to factors that may affect the internal validity of the study, such as measures of variables that are not clearly conceptualized, or a small sample size (Cooper & Schindler, 2003). The delimitations refer to the factors that may threaten the external validity of the study, such as an inability to generalize to other settings (Cooper & Schindler, 2003).

The scope of this study was limited to the Stress Management Project Dataset (details of which are described in chapter 3). The study focused on only two racial groups, Non-Hispanic

Whites and Hispanics, and had a relatively small sample size of 156 participants for a quantitative study. According to Hackshaw (2008), a limited site or sample population makes it more difficult to determine whether an observed effect is real or just a random variation. Furthermore, restricting the study to a single dataset and limited sample size also may potentially pose a threat to the interval validity in the form of possible subject bias. This study, therefore, did not contend that the research participants would absolutely represent the caregiver population as a whole; rather, through this research, I attempted to identify who benefits the most and least from this intervention, which may then facilitate future research and improvement on this program.

Definitions of Key Terms/Words

The following definitions of key words and terms will aid in the understanding of the literature review and study:

1. *Activities of Daily Living (ADL)*: "...refers to basic tasks of everyday life, such as eating, bathing, dressing, toileting, and transferring" used to measure disability. (Weiner et al.,1990, p.1)
2. *Alzheimer's disease (AD)*: The most common form of dementia, with symptoms including apathy and depression, impaired judgment, disorientation, confusion, difficulty speaking, swallowing, walking, eating, performing personal hygiene, and mood, personality and behavior changes. It is a progressive neuro-degeneration of the brain that eventually leads to death (Alzheimer's Association, 2013).
3. *Caregiver Burden*: "...the caregiver's appraisal of the balance between level of care demands, level of resources available, and quality of caregiver-care recipient relationship...two dimensions of burden: personal burden affecting the caregiver's choice

of personal actions and activities, and interpersonal burden affecting the interpersonal relationship between the caregiver and the care-receiver.” (Miller & McFall, 1989, p. vii)

4. *Caregiver*: “... an unpaid individual (a spouse, partner, family member, friend, or neighbor) involved in assisting others with activities of daily living and/or medical tasks” (Family Caregiver Alliance, 2010, p.1).
5. *Dementia*: A general term for a decline in memory and other cognitive functioning/mental ability that is severe enough to interfere with, and often leads to loss, of independent function which impacts the ability to perform basic ADLs. It is progressive and caused by damage to brain cells (Alzheimer’s Association, 2013).
6. *Depression*: Is a common but serious mood disorder. It causes severe symptoms that affect how you feel, think, and handle daily activities, such as sleeping, eating, or working (National Institute of Mental Health [NIMH], 2016).
7. *Depressive Symptoms*: Most of these symptoms of depression occur on a daily basis: feelings of hopelessness, or pessimism; irritability; feelings of guilt, worthlessness, or helplessness; loss of interest or pleasure in hobbies and activities; decreased energy or fatigue; moving or talking more slowly; feeling restless or having trouble sitting still; difficulty concentrating, remembering, or making decisions; difficulty sleeping, early-morning awakening, or oversleeping; appetite and/or weight changes; thoughts of death or suicide, or suicide attempts; aches or pains, headaches, cramps, or digestive problems without a clear physical cause and/or that do not ease even with treatment” (NIMH, 2016).

8. *Disability*: A physical or mental impairment or condition that substantially limits a person's ability to perform one or more major life activity, that is considered as substantial gainful activity (Americans with Disabilities Act [ADA], n.d.).
9. *Intervention (Program)*: Strategies or tools designed to mitigate caregiver burden and stress by facilitating improvement in behavior and health status through skills education, counseling and support (Rabinowitz et al., 2006). They are "designed to alleviate caregivers' distress and enhance their coping skills and sense of self-efficacy" in order to improve the quality of informal care (Gallagher-Thompson & Coon 2007, p. 37).
10. *Instrumental Activities of Daily Living (IADL)*: "...full range of activities necessary for independent living in the community... that are more complex than ...ADLs, including handling personal finances, meal preparation, shopping, traveling, doing housework, using the telephone, and taking medications," also used to measure disability. (Weiner et al., 199, p. 3)
11. *Race*: Is generally defined as a group of people classified as one (distinct from another group), on the basis of shared biological, sociological and/or political factors such as physical traits, nationality, or geographic distribution. In the U.S., "Racial categories represent a social-political construct for the race or races that respondents consider themselves to be" or "self-identify with" (Office of Management and Budget (OMB) and the United States Census Bureau, n.d.). The term Caucasian has been used interchangeably with Non-Hispanic White in this dissertation as it was frequently noted as such in the literature as well.
12. *Social Location*: "The group membership that people have because of their location in history and society" (Henslin 2013, p. x).

13. *Strain*: The (perceived negative) emotional response, in terms of degree of mental strain/worry, when faced with certain challenges such as caregiving; can lead to health issues (Miller & McFall, 1989; National Institute of Mental Health, 2016).
14. *Stress*: Feeling of being overwhelmed or experiencing mental tension due to external stresses (from the environment, psychological, or social situations) or internal stresses (from illness or a medical procedure). An extreme amount of stress can trigger the “fight or flight” response and can adversely affect the immune, cardiovascular, neuroendocrine and central nervous systems, and result in serious health consequences. (Family Caregiver Alliance, 2010; Miller & McFall, 1989; National Institute of Mental Health, 2016).

Summary and Chapter Outline

Population aging and the consequent challenges are unprecedented in global history. One of the profound issues emanating from this event is the sharp rise in demand for caregivers for diseases impacting the elderly, such as Dementia (MMMI, 2010; NIA & WHO, 2011). Addressing the subsequent financial cost and emotional burden on these caregivers is critical as the burden and stress of caregiving can be detrimental to the caregiver’s own personal health (Jarrot et al., 2005; Reinhard, Levine, & Samis, 2012).

Although some studies have shown that caregiver interventions such as Coping with Caregiving (CWC) have reduced stress and depressive symptoms in dementia caregivers, very few have explored if there are differences in these benefits. In this study, I take a sociological perspective to directly address the role of social location on CWC. Thus, the purpose of this study is to examine how social location (such as race and education) impacts the benefits of CWC intervention programs.

This dissertation is divided into five chapters. Chapter 1 (above) provides a brief introduction to the problem at large; a statement of the problem; a statement of purpose, research questions, and hypotheses under investigation; the nature of the study and design rationale, with a brief background of the dataset to be used for the study; the significance of the study; scope, limitation and delimitation; definition of key terms; and brief chapter outlines of this dissertation.

The second chapter presents a comprehensive review of the literature, including detailed background research on the problem and a theoretical framework for the study. The third chapter provides a review of the statement of purpose; research questions and hypotheses; concepts; measures; research design; data source and, the analytic plan for the study. The fourth chapter presents the results of the data analysis, followed by the fifth chapter, which presents the discussion and conclusion, with implications for future studies and an autobiographical reflection.

In addition, an appendix section is provided at the end of the dissertation, beginning with copies of the two instruments used in the study in Appendix A and B, the Center for Epidemiologic Studies Depression Scale (CES-D) and Perceived Stress Scale (PSS), and lastly the codebook (Appendix C) that was created during the data analysis.

CHAPTER 2: LITERATURE REVIEW

Understanding informal caregiving for people with dementia requires a multidisciplinary approach. Although this study focused on Coping with Caregiving (CWC) and the role of social location on CWC benefits (the reduction of depressive symptoms and stress), this literature review expands beyond this realm in order to anchor the issue within an aging context that accounts for the multi-dimensional aspects of caregiving. This chapter begins with a review of the literature on population aging and its associated challenges in order to provide the necessary background before addressing the literature on caregiving. The chapter ends by identifying the sociological theories that provided the theoretical framework for this study.

This literature review is divided into three main parts: an overview of an aging world; informal family caregiving and the caregiver; and salient theoretical frameworks that informed this study. The first part provides a general background on global and national aging trends. It is important to review this literature because it provides the basis for understanding the aging context, from how aging is defined to the demographic trends that led to the current situation. The second part focuses on caregiving and the caregiver, with attention to the burden, cost, interventions, and finally, sociological factors that may impact caregiving such as education and race, factors that also indicate social location. The third part reviews the relevant social gerontological theories that help frame how the role of caregivers of patients with dementia are affected and impacted over time; this includes the stress process model and life course perspective (LCP). A summary is provided at the end where I identify gaps in the literature.

Part 1: Background - Overview of an Aging World

According to a joint NIA and WHO report (2011) on global health and aging, it is projected that in approximately five years' time the number of people aged 65 or older will

outnumber children under age five. This new age structure represents global aging at an unprecedented rate: “In 2006, almost 500 million people worldwide were 65 and older. By 2030, that total is projected to increase to 1 billion—1 in every 8 of the earth’s inhabitants” (NIA, U.S. Department of Health & Human Services [USDHHS], & U.S. Department of State 2007, p. 2). Moreover, there will be more people surviving into extreme old age (NIA& WHO, 2011).

What is old age?

At one point in history, the first gray hair signaled onset of old age. Today, the definition and perception of old age varies across the world, starting as low as age 50 in some regions (most commonly in poorer, less developed countries) and at age 65 in other more developed parts of the world like the U.S. and Japan (WHO, 2013; UNFPA & HelpAge International, 2012; USCB, 2009). The United Nations uses 60 years as a reference point for older people. According to UNFPA and HelpAge International (2012) the term ‘old’ has different meanings in different societies, so there is no exact definition. For the purposes of this study, it is important to note that population aging is primarily used in the context of a demographic transition, which is “the process whereby older individuals become a proportionately larger share of the total population” (UNFPA & HelpAge International, 2012, p. 20). Specifically, the age group of 65 and older was used in this study to refer to older people, although trends in population aging suggest that people will eventually be living easily into their 100s (henceforth, this age group was interchangeably referred to as the ‘elderly’ and the ‘older population’). The reasons for the shift towards rapidly aging population are best explained by the Demographic Transition Theory (Caldwell, 2010; Dyson, 2010), which was outside the scope of this study. However, as part of the theoretical framework for this study, old age is later also discussed in terms of a life course perspective because it is a process that begins from the moment one is born (Bartley & Blane,

2009). Indeed, aging is not uniformly experienced as a direct consequence of chronological aging due to variations in physical and cognitive functioning over the life course (Lazarus & Harridge, 2010).

Why is the population aging?

The probability of increasing the life span was once seen as very remotely possible. In recent decades, however, life expectancy at birth has gained momentum, and reports indicate current estimates of the average length of life reaching 90 years for women and 85 years for men, and that there is an increase in the number of people surviving up to age 100 (Crimmins & Solé-Auró, 2013; Sadana, Foebel, Williams, & Beard, 2013; WHO, 2013; UNFPA & HelpAge International, 2012; Horiari, 2009; USCB, 2009). This phenomenon is primarily due to advances in medicine and healthcare technology that were initially developed to reduce infectious diseases and infant death rates (Crimmins & Solé-Auró, 2013; Sadana et al., 2013; WHO, 2013). Moreover, two factors post-World War II initiated population trends that raised concern at that time: a baby boom in many developed countries, and increased disparity in socio-economic climates between the developed and developing nations. The gap between rich and poor nations is often attributed to poor education and increases in poverty in most third world countries that continued to fuel high infant mortality rates, and lack birth control due to regional cultural beliefs (Chen, Kleinman, & Ware, 1992; UNFPA, 1985; Ware, 1981). As advances in health and technology continued and mortality rates began to decline significantly, a new concern for a rapid population explosion arose (UN, 2002; UNFPA, 1985). Countries like China began instituting birth control by law, enforcing a one-child-only policy (UN, 2002). As life expectancy began to rise along with the cost of living in many third world countries, the need to have many children as insurance for care and support also became increasingly unaffordable (Sen, Germain,

& Chen, 1994; Ware, 1981; UN, 2002). Further, as women increasingly gained access to education and joined the work force, the traditional perception that large families were desirable rapidly altered, particularly in the developed countries in Europe which began to see significant declines in fertility rates by the 1980s (Horiari, 2009; Sen, Germain, & Chen, 1994; Ware, 1981).

Today's population aging is a consequence of continued declining fertility rates, lower mortality rates, and subsequent increases in life expectancy (Crimmins & Solé-Auró, 2013; Sadana et al., 2013; WHO, 2013). Fertility rates have dropped globally, from five children per woman in the mid-1950s to 2.5 children in 2010 (and expected to continue declining further), in fact, fertility rates in many developed countries have reached below replacement level (WHO, 2013; UNFPA & HelpAge International, 2012; USCB, 2009). General mortality rates, and in particular infant mortality rates, have also dropped and remained at low levels in many parts of the world due to continued advances in medicine and technology. In addition, the latter has led to a shift in the leading causes of diseases and death, from infectious diseases inflicting primarily infants and children to a rise in non-communicable diseases that affect mostly adults (WHO, 2013).

Consequently, the rise in life expectancy is a global event, not specific to developed nations (Horiari, 2009; WHO, 2013). For the 2010-2015 timeline, the average life expectancy is estimated at 78 years in developed countries and 68 years in developing nations (Crimmins & Solé-Auró, 2013; Sadana et al., 2013; WHO, 2013). By 2045-2050, this is projected to rise to 83 years in developed regions and 74 years in developing regions (Sadana et al., 2013; WHO, 2013; USCB, 2009).

Differences in global and national aging

It is important to note that, despite the common factors leading to population aging mentioned above there are significant differences at the rate at which it is occurring. For instance, Japan is the first country to have already “aged” with its population of 65 and older doubling just within 25 years (a process that took 85 years in Sweden); it has already achieved the status of the country with the highest life expectancy (average rate of 82.25) in the developed world, and has the highest proportion (23 percent of total population) of people aged 65 and above (Horiari, 2009). Moreover, Japan is showing evidence of the highest percentage of potential for overall population decline by 2050 (Population Reference Bureau [PRB], 2010). Many industrialized countries, especially in Europe, (for example Sweden) are forecasted to follow suit (PRB, 2010; WHO, 2013).

The U.S. is on a similar path of rapid aging. According to a congressional report, not only has the U.S. population doubled in size since 1950, but it has also “become qualitatively different...getting bigger, older, and more diverse” (Shrestha & Heisler, 2011, p. 1). The U.S. Census Bureau revealed two significant differences between 2000 and 2010: there was an increase in both the number of people (5.3 million) aged 65 years and older as well as the percentage of population (13 percent of total population) in that age group (Werner, 2011). This profound increase in the number of older people compared to just a decade ago confirms that within a decade “... the population 65 years and over increased at a faster rate (15.1 percent) than the total U.S. population (9.7 percent)” (Werner, 2011, p. 1). Shrestha and Heisler (2011) stated that this inexorable demographic momentum will produce an increasingly older population in the United States. The only difference for the U.S. is that fertility rates (2.08 in 2008) are not quite as below replacement levels as in other developed countries primarily due to immigration trends,

whereby differential fertility rates are observed by racial and ethnic groups, mitigating the speed of aging (USCB, 2009; Shrestha & Heisler, 2011).

Surprisingly, the fastest rate of population aging is being experienced by developing countries (NIA & WHO, 2011). “Significantly, the most rapid increases in the 65-and-older population are occurring in developing countries, which will see a jump of 140 percent by 2030” (NIA, USDHHS, & U.S. Department of State, 2007, p. 2). According to UNFPA and HelpAge International (2012) and WHO (2013), by 2050 developing countries will have about four in five people aged 60 and above. In addition, the PRB reports that the world will also continue to be demographically divided, with the population growth rate at just 0.2 for the “global north” (comprising the developed/industrialized regions) and the “global south” (referencing the regions still struggling to reach the industrialized stage of development) growing at 1.4 percent (PRB, 2010).

Aside from the regional differences, gender and age cohort variations also exist. Globally, women outnumber men in the cohort over 60 by 66 million (PRB, 2010), although gender differences are also evident regionally. The U.S., for example, is seeing a decrease in the gap between males and females in the older age groups (Crimmins & Solé-Auró, 2013; Sadana et al., 2013). “The United States has the longest life expectancy for men...” (Crimmins & Solé-Auró, 2013, p. 4). Interestingly, the fastest growing age group is for the cohort of 80 and older, a significant shift in the demographics within the “old age” groups. According to Sadana et al. (2013, p. 8), “...longevity in those over 85 may reflect improvements in socioeconomic conditions across life, increased coverage of health services, and advances in medical treatment.”

Why the concern over population aging?

According to the United Nations Population Division, “population aging is enduring: we will not return to the young populations that our ancestors knew” (UN, 2010, p.1). Not only is global aging unprecedented in history, but it is also expected to occur even more rapidly in the near future, affecting every single individual on earth, regardless of the rate of change per region, resulting in “profound implications for many facets of human life” (UN, 2010, p.1). In the U.S., “the 85 to 94 year old group experienced the fastest growth between 2000 and 2010. This group grew by 29.9 percent, increasing from 3.9 million to 5.1 million” (Werner 2011, p.4). The implications of this are astounding.

As seen in the case of Japan (Horiari, 2009), there are significant socio-economic consequences of an aging population. Foremost is the shift in the young-old balance across the globe. This means an increase in the old-age dependency ratio, resulting in steeper demands on the working-age population as more elderly people access pension funds and health care benefits that are primarily supported by taxes and other contributions by the young working age group (Horiari, 2009; UN, 2010). The cost of supporting the old is estimated to be much higher than the cost of supporting the young, especially in terms of health care needs (NIA and WHO 2007; UNFPA & HelpAge International, 2012; USCB, 2010; Werner, 2011). In fact, there are six main categories that affect the health and social well-being of the elderly: disability, elder abuse, caregiving, long-term care, cognitive impairment, and civic engagement (Federal Interagency Forum on Aging-Related Statistics [FIFARS], 2012; PRB, 2013). Further, even though there is an increase in life expectancy, it is not without an increase in morbidity. The demand and cost for health care needs for the elderly, especially regarding caregiving, is rising as many countries are also seeing an increase in disability and non-communicable diseases like cancer,

Alzheimer's, and dementia (MMMI, 2010; NIA & WHO, 2011). With the rise of chronic non-communicable diseases such as heart disease and diabetes, which reflect changes in lifestyle and diet, as well as aging, older people impose the greatest burden on global health. The potential economic and societal costs of these types of diseases increase sharply with age, impacting economic growth (NIA and WHO 2011).

Therefore concerns arise over the future of the labor force participation due to the aforementioned young-old balance shift. This is visually evident by the change in the population pyramid; with a shrinking base as the number of young decline, questions are raised about how to sustain the global economic environment without enough workforce to support it (Crimmins & Solé-Auró, 2013; Sadana et al., 2013; UN, 2010). Factor in that many in this workforce have to double-duty as caregivers, the potential for a significantly weakened workforce is even greater. For instance, Europe is projected to have only two workers per older person by 2050 as the baby boomers retire yet have increased life expectancy (NIA, USDHHS, & U.S. Department of State, 2007). This has the potential to be an economic disaster as many countries will have to expand on social insurance, pension plans, and public sector support for the elderly with part of gross domestic product, which is already strained in many European countries since the 2008 global economic meltdown (NIA, USDHHS, & U.S. Department of State, 2007; UN, 2010).

Many Asian countries began this demographic transition later than industrialized countries, yet as noted earlier, most of these developing countries are experiencing aging at a much faster rate. Following Japan's trend, the three most populous countries in the world India, China, and Indonesia are projected to also double their older population in about 25 years, compared to the U.S. which is estimated to double in about 70 years (PRB, 2010; Shanghai Municipal Center for Disease Control and Prevention, (2012); UN, 2010; UNFPA & HelpAge

International, 2012). By 2050, approximately 80 percent of the world's population aged 65 and above is estimated to live in developing countries (Wan, Muenchrath, & Kowal, 2012), and the majority of this will be residing in Asia, causing concerns for a region still challenged by the conundrum of social, cultural, and political differences.

Africa is showing a similar trend, although slowly and varied across the continent. The life expectancy has remained at lower levels compared to the rest of the world mostly due to prevailing poverty and infectious diseases—primarily attributed to lack of access to education and advanced medical technology (UN, 2010; UNFPA & HelpAge International, 2012; Wan et al., 2012). However, due to limited systems of data collection across the continent, a true picture of the shifts in demographic transitions cannot be accurately derived (Wan et al., 2012). Nevertheless, from where data is being collected, it is evident that here, too, the number of older people is growing, especially in countries like South Africa, Nigeria, and Ethiopia (Wan et al., 2012). There are still countries in Africa, such as Zambia and Lesotho, which are not experiencing significant population aging or not projected to witness any increase primarily due to the severe HIV/AIDS epidemic (UNFPA & HelpAge International, 2012; Wan et al., 2012). Overall, there are still so many other significant factors affecting the economic growth of Africa such as prevailing political instability in many countries, unemployment for the many youth, poor literacy levels, and epidemics like HIV/AIDS. Yet most of these countries have no established healthcare, social security, or pension funds for the elderly, and consequently the scope of challenges facing Africa are daunting should this demographic trend gain momentum here.

Further aggravating economic growth for many countries is the fact that older women outnumber older men in many regions, and the potential shortage of job opportunities might be

related to the continued disparity in education levels between males and females in many parts of the world, thereby contributing to the lack of skills and knowledge needed to work well into old age (Sadana et al., 2013; UNFPA & HelpAge International, 2012). Education, as noted here and earlier, plays a key role in socio-economic well-being, and as such, was considered in this study as one of the factors denoting social location.

Another concern is changing family demographics, a significant factor underlying caregiving. More families will experience the need for parental support, whereby the burden of care and cost for their elderly parent will increase (MMMI 2010; NIA & WHO 2011; UN 2010). On the other hand, as people have fewer or no children, they will have limited or no options for care from family members as they get older, shifting the burden to communities and states (MMMI, 2010; NIA, USDHHS, & U.S. Department of State, 2007). Moreover, shrinking families have a latent capacity to eventually lead to lack of familial successors, resulting in the old as a majority with no potential for population replacement. And just as Japan is projected to experience a population decline within a few decades, so is the rest of the world (PRB, 2010). A shrinking global population, with no potential replacement capacity, is cause for grave concern because even though the world population is rapidly aging, the total population in some countries is already declining simultaneously (NIA, USDHHS, & U.S. Department of State, 2007). This is indeed a profound implication for the world's future should these trends continue, and they are expected to in the next few decades (UN, 2010). As Horiari (2009) so accurately noted, the world's demographic transition concerns have shifted from a population "explosion" to a population "implosion" in less than three decades.

Summary of the challenges of global aging

The concerns noted above provide but a snapshot of the major challenges of an aging world. There are gender, regional, and cohort differences at the speed with which aging is occurring, but it is happening globally and the world needs to understand and prepare as much as possible. As populations age, they threaten the existing models of socio-economic support systems. Although these systems already vary across the globe, each system is challenged. From the strains on social security, social insurance, health and pension systems in more advanced countries, to the basic family structure and social support systems in less developed countries. From the young-old dependency ratio that ultimately affects economic stability and prosperity through labor, supply and trade, to human rights for the elderly, migration, disease patterns, and ultimately human replacement capacity. Every fundamental way of life as the world has known in the past is being challenged in some form.

Part 2: Informal Caregiving and the Caregiver

There is a saying in many Eastern cultures that “old people are like children—they must be handled with the same love, attention, and care” (A. H. Khan, personal communication, November 25, 2013). A common theme emerging from the literature is that frail, old people need to be cared for. “Despite an increasing reliance on paid long-term care for elders, informal care persists as the most common form of long-term care provided in the U.S.” and worldwide (Van Houtven, Voils, & Weinberger, 2011, p.1) With an increasingly aging global population, the role of caregivers is gaining recognition for their contributions to functional, economical, and even emotional well-being (House et al., 1994; Keene & Prokos, 2007; Reinhard, Levine, & Samis, 2012).

What is an Informal Caregiver?

A caregiver is someone who is responsible for the care of another (in this context, an elder) person, and their responsibilities often extend beyond the traditional assistance with some form of activities of daily living (ADLs) and instrumental activities of daily living (IADLs) [National Alliance for Caregiving and the AARP Public Policy Institute, 2015]. The need arises because that person has developed some cognitive or physical disability or his/her health is impaired due to an accident, illness, or simply old age. Informal caregivers are usually unpaid friends or family (also known as informal caregivers), but there are also paid or formal caregivers, in the form of either private personal care assistants or a group of professionals working in established facilities.

Caregiving Role

Traditional roles of family caregivers were mainly to provide assistance with basic ADLs such as bathing, toilet, dressing and grooming, eating, and even some IADLs such as household tasks like cleaning, cooking, shopping, and managing finances. Such home-based supervised care, or caregiving, plays a critical role in enabling the care recipient to avoid or delay being institutionalized. The majority of care recipients prefer to remain in their own home, and caregivers can provide all or some of the essential long-term care and support to facilitate this. However, the range of responsibilities for supervised caregiving "...has dramatically expanded to include performing medical/nursing tasks of the kind and complexity once provided only in hospitals" (Reinhard et al., 2012, p. 1). For example, caregivers are often responsible for managing medications and/or taking care of someone who has a chronic disease. Thus, "caregiving activities encompass: (1) clinical skills and knowledge; (2) psychological skills and resources; (3) support seeking skills; and (4) quantity of caregiving." (Van Houtven et al., 2011,

p. 5). As the role of a caregiver becomes more complex, so does the stress and burden associated with it. In particular, caregivers who provide care at home for older adults with some form of cognitive impairment consequently suffer from poor health themselves (Springate & Tremont, 2013).

According to the National Alliance for Caregiving and the AARP Public Policy Institute research report (2015), there are about 44 million caregivers in the U.S., two-thirds of whom are female, and estimated 34 million unpaid caregivers provided care for a relative or friend aged 50 or over. In addition, these caregivers provide long-term support, averaging 4 years, with at least an average of 24 hours per week (National Alliance for Caregiving and the AARP Public Policy Institute, 2015). The Rosalynn Carter Institute of Caregiving (RCI, 2010) estimates that in a year, approximately 9.8 million caregivers provide 8.4 billion hours of care. In fact, about 14 percent of all U.S. healthcare consumers report that they have at least one family member who requires constant care (Keckley, Coughlin, & Stanley, 2012). Most caregivers are working, therefore performing at least dual roles, if not more (such as also being a parent and/or spouse in addition to working for pay and caring for an elder). Other life course studies confirm that the responsibility of caregiving remains primarily women's (Allen & Barber, 1994; O'Connor, 1996; Keene & Prokos, 2007). This is in spite of increased number of women joining the workforce. One explanation is derived from social role theory, which fundamentally states that people tend to conform to expectations ingrained from childhood (observations), and as such, will assume roles they are expected to. Similarly, according to the life course perspective, a number of factors can shape the decisions one eventually makes, such as the timing of when help is needed, past experiences of observing who provides the primary care and the connection with the person

needing help. I elaborate on the theories I used as the framework for this study later in the chapter.

Caregiving Intensity: Burden, Stress, and Depression (Depressive Symptoms)

According to Thornton and Travis (2003), the terms burden, stress and strain are often used interchangeably in the literature (these terms are defined in chapter 1). These concepts are some of the most extensively researched within the caregiving literature (Bedard et al, 2001; Dumont et al., 2008; Gupta, 2004; Pearlin et al. 1990). In two separate 20-year reviews of caregiving research, depression and burden were noted as “the two main areas of focus in studying the negative effects of caregiving” (Dilworth-Anderson, Williams & Gibson, 2002, p.258; Gallagher-Thompson & Coon, 2007). Since measures of depressive symptoms and caregiver burden are the most commonly studied (Gallagher-Thompson & Coon, 2007), it should be also noted that, to date, a number of instruments continue to be used to measure caregiver burden, such as the Zarit Burden Inventory, Caregiver Burden Inventory, Caregiver Burden Scale, Montgomery Burden Interview, Perceived Caregiver Burden Scale and Screen for Caregiver Burden. In addition, for most caregiver studies involving stress and depression, caregiver depression is usually measured using the Center for Epidemiologic Studies Depression Scale (CES-D). The original screening 20-item tool that is widely used was developed by Lenore Radloff (1977). The scale asks participants how often they experienced depressive symptoms in the past week, with a possible range of scores from 0-60; with a score of 16 points or more indicating depression.

Caregiver stress is often measured using the Perceived Stress Scale (PSS) (Cohen et al., 1983). PSS measures general appraisal of stress in the past month. The PSS10 (Cohen & Williamson, 1988) was developed from the 14-item scale by Cohen et al. (1983). In a ten item

scale, the PSS has a possible range of scores from 0-40, with a score of 20 points or more indicating high stress (Cohen, Kamarck & Mermelstein, 1983). These instruments are widely used by psychologists and psychiatrists to study mental health, and provide valuable psychometric properties for sociologists too (Dilworth-Anderson et al., 2002; Gallagher-Thompson & Coon, 2007).

Schulz and Martire (2004) state that caregiving typically involves a significant expenditure of time, energy, and money over potentially long periods of time. Additionally, caregiving involves tasks that may be unpleasant and uncomfortable and are psychologically stressful and physically exhausting. As noted in the section above, a wide range of responsibilities are associated with caregiving. Keckley et al. (2012) have grouped caregiving into two broad levels of caregiving intensity. The first lower level entails less intense tasks, requiring an average of less than 10 hours of care per week. Examples of tasks include taking someone grocery shopping or to the doctor, or performing housework. The higher levels consist of more intense tasks, resulting in an average of 12 to 87 hours of care per week, such as providing assistance with bathing or grooming, eating, and cooking. The level of intensity varies from person to person, and can also vary for the same individual on a daily or weekly basis due to factors such as co-residency, age of both the caregiver and care recipient, and also the care recipient's level of functional ability (Keckley et al., 2012; Iecovich, 2008). If the care recipient does not live with the caregiver, then the time and cost to drive also needs to be accounted for as well as the scheduling conflicts of when to go help. The age of the caregiver can influence time and effort to perform the caregiving tasks, for instance, someone aged 25 years may be more energetic than someone aged 45 years, thereby able to perform tasks like housework in less time. The functional ability of the care recipient is critical at all levels because most tasks (especially

more personal care) require some level of reciprocal effort from the patient. This latter aspect can be stressful to the caregiver in terms of time (have to get back to their family or job) or concern over care recipient's discomfort or reluctance to complete the task once started.

An AARP study in 2012 confirms that the levels of caregiving are intensifying (Reinhard et al., 2012). The study found that about 46 percent (almost half) of family caregivers provided tasks that were all once medical/nursing tasks, such as managing medications, including injections, help with mobility assisting devices, operating specialized medical equipment, and even caring for wounds. Managing medication was reported as one of the most stressful tasks because of anxiety of making a mistake in dosage or timing, or even getting the care recipient to accept the medicine (Reinhard et al., 2012). Very rarely does a caregiver receive assistance or training from the doctor or health care professional during an office visit and so family caregivers cope by learning how to manage medications or treat a wound by themselves, yet again inducing stress. The study also revealed that family caregivers providing medical/nursing tasks were twice as likely as those who only provided personal care to inevitably take on the role of care coordinator as well (Reinhard et al., 2012). These results confirm that within the spectrum of caregiving, the levels of stress vary according to the intensity of the task: the more complex the task, the higher the stress. Obviously, complexity of task is related to the care recipient's medical condition. Many chronic conditions lead to some functional disability that hinders at least one ADL, such as rheumatoid arthritis or lupus (CDC, 2011), and many older people in the U.S. suffer from at least one chronic condition.

The rise in cognitive disability from dementia related disorders such as Alzheimer's triggers more concern for the caregiver as the emotional stress also rises when one has to watch another family member suffer from such diseases. Furthermore, some studies have shown that

there is a difference in the level of caregiver's burden when caring for an elderly with physical disability versus caring for an elderly with cognitive disability (MMMI, 2010; Iecovich, 2008). The greatest burden arises from caregiving to one with cognitive disability as a result of dementia by impacting the caregiver's psychological well-being (Iecovich, 2008; Zarit et al., 2011). Most notably, memory loss issues and behavioral problems resulting from dementia have a significant impact on the emotional well-being of the family caregiver. Caregivers support groups have been recommended to aid reduction in psychological burden of the caregiver, such as those provided in more formal settings like Adult Day Care Centers (ADCs) or through intervention programs such as CWC (Iecovich, 2008; Zarit et al., 2011; Gallagher-Thompson & Coon, 2007). In a two-month study by Zarit et al. (2011), the authors found that when care recipients used ADCs for all or part of the day, the stress levels were reduced significantly for the caregiver, suggesting that ADC usage alleviates some caregiver burden. Furthermore, the study revealed that care recipients who suffered from cognitive disability as a result of dementia and Alzheimer's also benefited most in terms of lowering behavioral problems (Zarit et al., 2011). Lack of activity has been identified as a cause of some behavioral and emotional problems resulting from these cognitive diseases, and these results corroborate findings from CDC (2011) and MMMI (2010) that some form of civic engagement can help mitigate or delay the impact of dementia and Alzheimer's.

The stress of performing some of these caregiving tasks impacts the quality of life of the caregiver. Most family caregivers take on the responsibility because they feel they have no choice, or that they are helping to keep the care recipient home, avoiding (costly) institutionalization (Reinhard et al., 2012). Most people already struggle with work-life balance (Justice, 2010), trying to cope with demands of work and their own children or personal life,

adding a third dimension to this struggle elevates already existing stress, thereby paving the way for serious health problems of their own. Studies have shown that the negative impact of caregiving on the caregiver's health has remained consistent over time, triggering such health issues as stress-related depression, anxiety, family conflict, and even physical health (Jarrot et al., 2005; Strawbridge et al., 1997). According to Keckley et al. (2012), caregiving may be a positive experience, but not for those who encounter economic, social, interpersonal, and health-related difficulties that make it difficult to sustain services. This potential strain to caregivers might be overwhelming and detrimental to their well-being. Results from World Mental Health (WMH) surveys conducted by the World Health Organization (WHO) indicate that, globally, the "caregiving burdens associated with serious family mental and physical conditions are substantial" (Viana et al., 2013, p.123).

Research by Jarrot et al. (2005) also showed that when caregivers received some form of formal or informal help, their physical and mental strain was reduced. Additional studies have confirmed this, such as the study by Judge et al. (2013) on the use of intervention, which revealed that caregivers had fewer symptoms of depression and anxiety, and improved well-being. These studies reveal that as the burden of care shifts from the unpaid, family caregiver to the (usually paid) support provider, the levels of stress reduce, and the quality of life of the caregiver can improve again. The use of intervention programs was noted as helping to decrease the caregiver's burden, which also leads to lowered depressive symptoms, stress, family conflict, and anger (Jarrot et al., 2005).

Some studies specifically integrate existing theories to relate to the current caregiver conundrum. One classic example is the study by Moen, Robinson, & Dempster-McClain, (1995), which showed the utility of incorporating role theory and the life course into investigations of the

connections between women's caregiving and their psychological well-being. The research used panel data from the Women's Roles and Wellbeing Project to examine role occupancy and the duration of caregiving as well as factors that may moderate the effects of caregiving on well-being. The life course themes in this study emphasized social interdependence, early experiences shaping later experiences, and the significance of time. Results revealed that women's life pathways tend to be embedded in, and structured by, the experiences and expectations of husbands, children, and aging parents. Caregiving epitomizes the notion of linked lives. Early experience shaping late experience is examined by knowing the women's previous roles and resources as the life course suggests that this will shape the impact of caregiving on well-being. The element of time is reflected by the on-set and duration of caregiving. Using principles embodied in the life course, the authors derived testable hypotheses related to the timing of caregiving, caregiver's resources, and their level of social integration. Results showed no significant relationship between direct effects of currently, or ever caregiving, or duration of time spent in this role, on any well-being measures. However, when considering moderators, there were some differences. These findings shed light on the complex caregiving picture and the life course notion of cumulativeness of advantage or disadvantage.

A second example is a more recent study by Matzek (2011). In order to investigate the impact of family and non-family roles on caregiver health overtime, Matzek used both the life course and stress process theories. The research focused on investigating the pathways of adult child caregivers' family (caregiving, marital, parenting) and non-family (employment) roles and their relation to caregiver's psychological and physical health over time. Using data from the Health and Retirement Study (HRS), and specifically eight waves from 1992 to 2006, Matzek's findings were that (a) adult child caregivers have distinct family and non-family role pathways;

(b) caregivers' gender, race/ethnicity, and age predict pathway membership; and (c) caregivers' role pathways are connected to psychological and physical health over time. The life course suggests that roles will influence a caregiver's experience of stressors, as well as the personal and social resources available to handle these stressors over time. In Maztek's study, the life course provided a theoretical basis for conceptualizing caregiving, marital, parenting, and employment roles as roles that individuals are likely to enter and exit throughout the life course. Matzek concluded that, through LCP, pathways resulting from the various timing and ordering of transitions into and out of the family and non-family roles have diverse associations with caregiver outcomes.

The Stress Process Model has also been most commonly used in several caregiver studies to help explain the role of stressors and coping for caregivers, such as the Dilworth-Anderson et al. (2002) and Judge et al. (2013) referenced earlier. All these studies reveal that the caregiver's experience is anchored not only in a particular socio-cultural context, and geographical region, but also in a particular time. People can have different experiences, not only as individuals, but also as groups, and all these different experiences depend heavily upon their positions in the social structure. In fact, individual family structures can also cause variances in feelings of burden. According to Conde-Sala et al. (2010, p. 3), "The differences in burden between spouse and adult-child caregivers were not associated with age, physical health or clinical factors of the patients." Rather, "...spouses regard caregiving as part of their marital duties, whereas for adult children such tasks imply an important change in their lifestyle" (Conde-Sala et al., 2010, p.3).

The Cost of Caregiving

The cost of caregiving refers to the emotional, social and financial burden experienced by the majority of family caregivers. These issues arise from the complexity and strain of caring for

relatives, “especially when the care is for a person with dementia” (Family Caregiver Alliance, 2006). Problems can range from lost career opportunities to strained or lost personal relationships and poorer personal physical and emotional health due to stress (Jarrot et al., 2005; Reinhard et al., 2012). Foremost is the dual impact on other relationships as well as on personal health. According to a 2010 survey by Caring.com, 69 percent of caregivers say caring for a loved one is the number one source of stress in their lives; and one in four caregivers say family relationships have suffered because of caregiving responsibilities. As a parent, there is a struggle to balance parenting demands and caregiver demands. Those who have younger children age eight and below feel more frustration at losing out on sharing growing moments. Twenty-seven percent of caregivers reported being in the Sandwich Generation, caring for children as well as aging parents (Caring.com, 2010). There are also spousal/partner issues that arise as well as conflicts between other family members such as siblings who are not the caregiver (Conde-Sala et al., 2010). In a November 2014 survey of 973 family caregivers, 97 percent said that their personal (marriage and friendship) relationships have suffered or even ended as a result of caring for a loved one with Alzheimer’s or dementia (Caring.com, 2010).

Resentment, anger, frustration, stress, anxiety, can all lead to an emotional toll that becomes detrimental to the caregiver’s own health and happiness (Jarrot et al., 2005; Reinhard et al., 2012). Caregivers experience physical and mental health problems directly and indirectly related to caregiving. Between 40 to 70 percent of family caregivers have clinically significant symptoms of depression (Family Caregiver Alliance, 2012).

The financial cost of family caregiving by people who are also employed is two-fold: costs to the employer perspective and to the employee. A 2006 study by MetLife Mature Market Institute (MMMI) on caregiver cost estimated that employers lose as much as \$33.6 billion in

lost productivity annually from their full-time employed caregivers. For an employee with intense caregiving responsibilities, the average cost is \$2,441 (MMMI 2006). Furthermore, the study revealed that 60 percent of employed caregivers had to make work-related adjustments, 10 percent reduced their hours from full-time to part-time, 3 percent took early retirement, and 6 percent resigned from work. Feinberg and Houser (2012) note that in 2009, “family caregivers of adults with chronic or disabling conditions provided an estimated 40 billion hours of unpaid care with an estimated economic value of \$450 billion” (p.1). The financial burdens are most felt in low income households, worldwide. According to the WHO/WMH survey results, up to 44 percent of median household income can be devoted to activities related to caregiving of an ill relative in low income countries and as much as 32 percent in upper-middle income countries (Viana et al., 2013).

Findings from a study by Keene and Prokos (2007) had similar results, whereby caregivers had to quit their job, cut back hours, or make significant changes at home in order to accommodate the demands of caregiving. Considering that the WHO/WMH survey results reveal that, across all countries, the mean caregiving hours per week among those devoting any caregiving time are 13.9 hours per week, there is always the potential of lost income once someone becomes a caregiver in any part of the world (Viana et al., 2013). Furthermore, the potential to advance in the work place is also diminished. A study by Gottlieb, Kelloway, & Fraboni (1994), in Keene & Prokos (2007) found that assistance with ADL, care and activity coordinating, and the number of crisis responses significantly contributed to reduction in job performance, resulting in less opportunity to advance at work. Another study in 2009 funded by Deloitte on “The hidden costs of U.S. health care for consumers” concurs with this analysis. The study found that caregiving had a significant impact on employees’ earnings ability especially

for households with less than \$25,000 annual income, or where someone had to be a caregiver for more than two years (Keckley et al., 2012).

The cost of formal or institutionalization varies due to lack of systematic data collection that includes hidden costs (Keckley et al., 2012). At the national level, the Deloitte study estimated costs associated with formal care at \$199 billion, which was higher than spending on home- and community-based care (\$191 billion) and nursing home care (\$137 billion), (Keckley et al., 2012). The Health and Retirement Study (HRS) and the Medical Expenditure Panel Survey (MEPS) provided data for this study, which also revealed that approximately 9 million at-home care recipients over the age of 50 received 28 hours of care per week (Keckley et al., 2012). At the state level, in 2011 in the state of Nevada, the annual cost of care from a skilled nursing home facility was \$76, 650; cost for home health services was \$48, 8846; and cost for assisted living facility was \$33, 000 (Fact sheet, Bureau of Health Care Quality and Compliance, n.d.). The AARP projects about a 25 percent increase in healthcare costs by 2030, indicating strong shift in the cost burden from private to public sectors, particularly an increase in Medicaid and Medicare (Reinhard et al., 2012).

According to Keckley et al. (2012), the Affordable Care Act (ACA) of 2010 provides limited options for in-home and community care, and none that directly support caregiving; although legislation has been proposed to improve programs for seniors and caregivers, such as the Strengthening Services for America's Seniors Act legislation. Introduced in November 2011, this legislation aims to improve existing Older Americans Act (OAA) programs by targeting attention to caregiving and thereby ensuring that caregivers receive much needed support and services (Keckley et al., 2012). However, it should be noted that there is growing concern about the future of social security and health care, particularly for low-income individuals and seniors.

Although the new administration as of 2017 recently failed to repeal and replace Obamacare, the uncertainty of healthcare in America will continue to be an issue in the coming years.

The data available on caregivers indicates that the scope of caregiving is broadening for many people. Addressing how these burdens shift, both positively and negatively, is crucial to implementing sound policies regarding the future of caregivers. Reinhard et al. (2012) state that current federal and state health policy is driving changes to reduce hospitalizations and nursing home admissions and therefore it is critical to consider who will care for people, as the default caregiver is the family, despite their readiness or ability to do so.

Caregiving and Dementia Patients

As life expectancy increases, so does the risk of age-related illness and physical and cognitive disability. The most prevalent in the manifestation of cognitive disability is dementia and related diseases such as Alzheimer's disease (AD) (Alzheimer's Association, 2013). According to Wisniewski et al. (2003), AD and related dementia disorders constitute a major public health problem.

Dementia is a general term for a decline in mental ability that is severe enough to interfere with activities of daily life (Alzheimer's Association, 2013). Since Dementia and AD are actually progressive neuro-degeneration of the brain, they cover a wide range of symptoms, such as decline in memory and other cognitive functioning, that often leads to loss of independent function which impact the ability to perform basic activities of daily living (ADL) such as eating, bathing, walking, etc., as well as instrumental activities of daily living (IADL) such as cooking, money management, grocery shopping, etc.; this in turn, leads to a number of serious implications for individuals and families. Alzheimer's is the most common form of dementia, accounting for an estimated 60 to 80 percent of cases (Alzheimer's Association, 2013).

The most typical symptoms begin with difficulty remembering names and recent events. Subsequent other symptoms develop, including apathy and depression, impaired judgment, disorientation, confusion, difficulty speaking, swallowing, walking, eating, performing personal hygiene, and mood, personality and behavior changes (Alzheimer's Association, 2013). Other types of dementia include, but are not limited to, Lewy Body Dementia (LBD), Parkinson's disease, and Creutzfeldt-Jakob disease. All these diseases ultimately impact both cognitive and physical normal functioning, thereby requiring patients to have a caregiver.

The 2015 Alzheimer's Disease Facts and Figures report estimated that in 2015, 5.3 million Americans had AD (Alzheimer's Association, 2015). Of this number 5.1 million or one in nine people were age 65 and older. As disability and cognitive impairments increase with age, the need for long-term care is also expected to increase because of the sheer increase in the 85 plus group (which experienced the fastest growth from 3.9 million to 5.1 million between 2000 and 2010) (Alzheimer's Association, 2015). Thus, as the older population increases, the projected number of people diagnosed with dementia, in particular Alzheimer's will increase. For example, according to the 2015 Alzheimer's Facts and Figures, in the state of Nevada alone, the projected change in the total number of Americans age 65 and older with Alzheimer's will go from 39,000 in 2015 to 64,000 in 2025 (64.1 percentage change from 2015 to 2025).

In addition, dementia is noted to affect women disproportionately because more women survive into old age than men, so they are more likely to be diagnosed with the disease; and often more women than men tend to be the caregivers, usually as daughters (Ludwin & Parker, 2015). According to Ludwin and Parker (2015), this positions dementia impact more commonly stratified in social location. For example, Ludwin and Parker posit that "women with dementia may have better coping strategies for dealing with a dementia diagnosis based on having

developed strategies to manage prior experiences of inequality” (p.20). On the other hand, women tend to have higher levels of dementia because of this inequality, which is often in terms of poor socio-economic conditions (Ludwin & Parker, 2015).

In 2013, according to the Alzheimer’s Association (2013), Americans provided 17.7 billion hours of unpaid care to people with Alzheimer’s disease and other dementia. Caregivers of people with AD and other dementias provide care for a longer period, overall, than do caregivers of older adults with other health conditions (Alzheimer’s Association 2013). Therefore, it is not surprising that dementia caregiving is the most frequently studied type of caregiving represented in the literature (Schultz & Martire, 2004).

Health effects are especially pronounced for family caregivers of persons with Alzheimer’s disease. The Alzheimer’s Association (2013), estimates about 2.3 million people in the U.S. are currently caregivers for a person with Alzheimer’s disease or other dementia who lives at least one hour away. Both the nature of care provided and the cost in terms of distance and time lost often increase the toll of strain on the caregiver (Alzheimer’s Association 2013). In a study commissioned by the National Alliance for Caregiving (2011) using data from REACH I, researchers found that the strain of caring for someone with AD may cause family caregivers to use health care services at higher rates than non-caregivers of the same age. This was especially true for caregivers who initially rated their health as fair or poor and for those whose care recipient became more disabled over time.

Kim et al. (2011) studied multidimensional predictors of caregiver burden in caregivers of individuals with dementia, using nationally representative secondary data collected via a telephone survey of randomly selected adults in seven states. They found that impaired function (either with ADLs or IADLs) in care-recipients predicted (greater) caregiver burden, and 16

percent of caregiving burden was explained by disease-related factors (Kim et al., 2011). This study was also based on the Stress Process model.

Leggett, Zarit, Taylor and Galvin (2011) looked at stress and burden among caregivers of patients with LBD—the second most prevalent type of dementia in the U.S., displaying unique symptoms. Findings were based from the researcher’s web-based survey, showing moderate to high levels of burden measured by the Zarit Burden Interview. Additionally, the study found support for the Stress Process Model of Caregiving, which underscores the point that caregiver burden is largely context driven and not a straight pathway from a specific stressor to burden.

“Caring for a family member with dementia is often associated with reduced psychological well-being in the family caregiver. Many studies revealed that providing care to an older family member with dementia is associated with depressive symptoms and increased sense of ‘burden’ because the strains of witnessing and adapting to the family member’s cognitive, behavioural and personality changes are typically quite challenging to the family caregiver and may over-tax his or her resources...” (Au et al., 2009, p. 761)

Schulz and Martire (2004) acknowledge that there has been an accumulation of evidence on the impact of caregiving. This has prompted intervention studies, such as REACH, aimed at decreasing the burden and stress of caregiving (Rabinowitz et al., 2006). Findings show that interventions combining different strategies and providing caregivers with diverse services and supports tend to have larger effects than narrowly focused interventions (Gallagher-Thompson, 2007). Additionally the frequency and intensity of interventions make a difference to the outcome, a greater impact is seen the higher the frequency and intensity.

Caregiving Interventions

The aforementioned studies reveal that the significant depressive symptoms and stress often experienced by informal caregivers (resulting from the caregiver burden), may be mitigated by caregiving intervention programs. Caregiving interventions are necessary tools that provide support to caregivers to help reduce burdens and potential personal health risks that can hinder or even cripple a caregiver's ability to provide care (Feinsberg & Houser, 2012; Gallagher-Thompson & Coon, 2007). "Providing quality care for the care recipient often requires an understanding of the family caregiver's situation and needs. However, these needs are frequently not identified or addressed in the recipient's care plan." (Feinberg and Houser, 2012, p.1). Caregiving interventions should ideally include assessing the needs of a caregiver and then providing the appropriate tools to support the caregiver (Feinsberg & Houser, 2012; Gallagher-Thompson & Coon, 2007). Indeed, the purpose of most intervention programs is "to alleviate caregivers' distress and enhance their coping skills and sense of self-efficacy" (Gallagher-Thompson & Coon, 2007, p. 37).

Research by Judge et al. (2013) highlights the various intervention programs designed to alleviate caregiver burden in some form. These interventions ranged from providing social support to education, with most of the interventions targeting specific areas separately—for example, counseling-based only programs or skills-building training only (Judge et al., 2013). Such interventions neglect to encompass the complex individual needs of caregivers that may require a combination of these. While to some people this finding reveals that there has been limited progress in developing sustainable, viable, multi-component interventions that are applicable to all populations of caregivers, others might conclude that caregiving issues are too multi-faceted to restrict to one type of intervention.

Indeed, an earlier analysis by Gallagher-Thompson and Coon (2007) reviewed studies from 1980 through 2005, and addressed the complex nature of caregiving that makes it difficult to have only one specific intervention program. They identified “three categories of interventions that can be considered evidence-based, using currently accepted criteria: psychoeducational–skill building programs, psychotherapy– counseling, and multicomponent interventions” (p. 47).

Gallagher-Thompson & Coon (2007) observed that intervention programs under the psychoeducational-skill building category were most commonly used in a majority of the studies that revealed reduction in caregiver distress and improvement in caregiver coping skills.

Interventions in the psychotherapy category, however, showed the largest average effect in reducing depressive symptoms. It appears that cognitive-behavioral treatments can particularly benefit caregivers in greater distress. Gallagher-Thompson & Coon’s findings concurred with previous studies that concluded:

“...programs that target specific components of caregivers’ quality of life (such as perceived burden, mood, and perceived stress, as well as coping and self-efficacy) and that include some combination of skill building, education, and support are currently the most effective interventions” (2007, p. 47).

Furthermore, the theoretical frameworks for most of these studies reviewed follow the stress and coping theoretical models (Gallagher-Thompson & Coon, 2007). In a study conducted in Iran, Navidian, Kermansaravi & Rigi (2012) assessed the effectiveness of a group psycho-educational program on 100 family caregivers for patients with mental disorders, specifically schizophrenia and mood disorders. They found that the group intervention program was effective to reduce the caregiver burden equally for each disorder. Andren & Elmstahl (2008) document a

six to 12 month pre and post intervention study that reveals the benefits of a psychosocial intervention for family caregivers of people with dementia by reducing caregiver burden.

Additional evidence in support of interventions came from a special study, described in a white paper by Katie Maslow (2012). This paper reviewed 44 non-pharmacological treatments and care practices that have shown positive effects for some people with Alzheimer's or other dementias who live in the community and some family caregivers. According to Maslow (2012), all of these treatments and care practices have been tested in randomized controlled trials (RCTs), dating as far back as 1993. It was noted that despite there being a significant number of non-pharmacological treatments and care practices that have been tested in RCTs, they were not widely known or available in communities across the country. At the time of writing the paper, the author noted that a number of translation studies were underway or had only recently been completed. Findings from such studies provide valuable information on which treatments or care practices work in the real world.

Of the 44 interventions discussed in the paper, 30 primarily targeted the family caregiver, 23 had the treatment or care practices delivered at home, and 25 had the treatment or care practices delivered individually and not in a group (Maslow, 2012). Coping with Caregiving and automated telephone support were both in the list of interventions. Both of these interventions came about as a result of the Resources for Enhancing Alzheimer's Caregiver Health (REACH) study.

REACH

Resources for Enhancing Alzheimer's Caregiver Health (REACH) was a study that occurred due to the overwhelming concern for caregivers, and sponsored by the National Institute on Aging (NIA) and the National Institute on Nursing Research (NINR) (Shultz et al.,

2003). The REACH study was a unique five-year, multi-site study investigating the effectiveness of innovative interventions to support family caregivers. Its goals were “(a) to test diverse theory-driven caregiving interventions, (b) to develop a standardized outcome protocol, to assess the impact of different strategies on caregivers and their care recipients, and (c) to create a common database that would enable the pooling of data across sites” (Wisniewski et al., 2003, p. 2). More than anything, REACH was made to probe the feasibility and outcomes of multiple different intervention approaches that would prove effective caregiver intervention and was performed in two phases. Specifically, REACH implemented the following interventions: individual information and support strategies; group support and family systems therapy; psycho-educational and skill-based training; home-based environmental interventions; and enhanced technology support systems (Schulz et al., 2003). These interventions were all consistent with basic health-stress models in which the goal is to change the nature specific stressors, their appraisal, and/or response (Schulz et al., 2003). The results revealed distinct changes in the overall well-being of the caregivers, with reductions in feelings of stress and depressive symptoms (Belle et al., 2006).

In fact, the original REACH study revealed several significant findings that added to the evidence-based literature on caregiving, and one of the reasons for the success of this study was its design and methodology (Schultz et al., 2003; Belle et al., 2006; APA, 2014). It was a multisite design that tested a variety of caregiver interventions under scientifically controlled conditions in a large and ethnically diverse sample population, thereby ensuring strong validity and generalizability (Schultz et al., 2003; APA, 2014). REACH was thoroughly documented and monitored, which facilitated translational versions, such as REACH II and REACH VA.

REACH II (2002) was sponsored by the National Institute on Aging and the National Institute on Nursing. The primary change in REACH II was the use of a combination of the interventions that worked in REACH I, allowing for a more structured multicomponent intervention that adapted to the individual risk profiles. One significant finding of REACH I was that a single intervention was not enough to deal with the myriad of challenges caregivers faced—challenges that were not necessarily uniform across populations. The findings also indicated that active training such as role play was more successful in reducing caregiver burden when compared to passive methods such as providing educational information (Schultz et al. 2003). Thus it was vital to have an intervention program that considered each individual's risk profile. The intervention strategies included techniques such as problem solving and skills training. These techniques were introduced to reduce the risk in five target areas: depression, burden, self-care/healthy behaviors, social support, and problem behaviors (Lykens et al., 2014). This strategy proved successful, and paved the way for translational research of REACH II in various other sites.

REACH VA was the first national clinical translation of REACH II. The intervention was delivered by clinical staff members from 24 facilities in 15 states in 2009 (Nichols et al., 2011). Nichols et al. (2011) found that caregivers reported significant decreased burden, depressive symptoms, lessened impact of depression on daily life, caregiving frustrations, and a number of troubling dementia-related behaviors. These outcomes were similar to the REACH II findings. The success of REACH II and REACH VA kept the ball rolling, with further translational studies being funded.

Coping with Caregiving (CWC)

Coping with caregiving (CWC) stemmed from the results of one site, Palo Alto, in the original REACH multi-site study. “The primary outcomes for the Palo Alto REACH site indicated that a cognitive behavioral, psychoeducational intervention, called coping with caregiving (CWC), was more effective than a community-based enhanced support group (ESG) on a number of psychosocial variables...” (Rabinowitz et al., 2006, p. 643). Rabinowitz et al. (2006) expanded on this finding to determine effective pre-intervention screening mechanisms by developing a profile of caregiver characteristics that predict positive response to these treatments. “The findings suggest that skills-based interventions are not only appropriate, but needed most by caregivers with a reduced sense of agency in managing the stress and negative cognitions often associated with caregiving” (Rabinowitz et al. 2006, p. 648).

Coping with Caregiving (CWC) Vs. Automated Telephone Support (TSC)

CWC is an intervention that is based on cognitive behavioral principles and uses a skills-based approach conducted in small groups of four to eight participants (Gallagher-Thompson et al., 2008). The program follows a detailed treatment manual similar to REACH, where participants enroll in a total of 13 classes, and groups meet weekly for two-hour sessions. Comparatively the TSC intervention or control is based on education and counseling principles to provide empathic support over the phone to participants for 15-20 minutes every two weeks, for a four-month period as well as mailing some education material to the participant’s home (Gallagher-Thompson et al., 2008).

The following section reviews additional literature on CWC in the context of social location as it aligns with the purpose of this study.

Caregiving, Social Location, and CWC

Table 6 in chapter 4 provides the socio-demographic characteristics of the dataset that I used for this study. Collecting basic socio-demographic information for most research studies, especially those pertaining to socio-economics or healthcare, has become the norm because of the nature of increasing diverse populations and the resulting variety of needs and demands. This is no different in the case of caregiving research. In fact, several of the studies cited earlier, considered such socio-demographic variables as race, income, age, education, gender, marital status, living arrangements, etc. (Gallagher-Thompson et al., 2008; Judge et al., 2013; Rabinowitz et al., 2006; Nichols et al., 2011; Schultz et al., 2003; Belle et al., 2006; Viana et al., 2013). There is a plethora of information that can be gained by considering every aspect of the impact or role of these factors under the caregiving research. As such, some of these factors are particularly relevant for providing sociological perspectives on caregiving in terms of social location.

A major aspect of sociological studies falls under the tenet of social location.

“Social location is defined as the social position an individual holds within their society and is based upon social characteristics deemed to be important by any given society. Some of the social characteristics deemed to be important by U.S. society include social class position, gender, sexual orientation, ethnicity, race, religion and so on. Sociologists argue that the social location of an individual profoundly influences who they are and who they become, interactions with others, self-perception, opportunities and outcomes”. (Wordpress, n.d.)

Race and education are two such factors that most commonly delineate social location. Ludwin and Parker (2015) posit that the intersection of “...social location and identities converge to create conditions of inequality and privilege” such that individuals occupy

“...multiple social locations that intersect to give more or less social capital and privilege” (p. 5).

An attempt to understand the association between race, socioeconomic status, and health was done in a paper by Williams, Priest and Anderson (2016). At the start, Williams et al. (2016) note that, compared to the average person in their society, racially stigmatized people exhibit poorer quality of care received and higher rates of illness, impairment, and death—and this is observed across multiple health outcomes. Further, Williams et al. (2016) reinforce the notion that “socioeconomic status (SES), whether measured by income, education or occupational status, is among the most robust determinants of variations in health outcomes in virtually every society throughout the world (WHO Health Commission, 2008, p.1.)”.

Several of the studies referenced in the literature review thus far had both significant and salient findings that indicated potential roles of race and education. Few studies, however, specifically target these social location factors in the context of coping with caregiving.

Race

Many studies on caregiving originally addressed White populations as initially the aging demographic momentum entailed populations in advanced countries, which are predominantly Non-Hispanic White. However, as seen in the earlier section on aging, current demographic trends have shifted to encompass aging across global populations, an increasing number of empirical studies have been done to assess racial differences in caregiving burden and coping, also with focus on CWC impact.

The literature on the relationship between racial/ethnic differences in caregiving burden is often mixed. While some studies provide evidence that minority groups like African Americans and Hispanics experience more caregiver burden and stress than Whites, others indicate that White caregivers feel more stress and experience greater depressive symptoms than

other races (Dilworth-Anderson et al., 2002; Knight et al., 2000). However, there is increasing empirical evidence that shows that Black caregivers are less distressed than White caregivers. Siegler et al. (2010) evaluated the psychological responses to caregiving between 37 Black and 50 White dementia caregivers measured by self-reports of depressive symptoms with the CES-D scale, and residence. The results inexplicably revealed a significant race by residence interaction: when the caregiver lived apart from the care recipient, Whites reported more depressive symptoms than Blacks. On the other hand, Blacks reported higher depressive symptoms than Whites when the caregiver and care recipient lived in the same home. This clearly indicates that other social location factors, such as co-residence, have an interactive effect on self-reports of depressive symptoms.

Several studies indicate that Hispanic/Latino caregivers experience greater caregiver burden and report more depressive symptoms than other ethnic groups, including American Asians and African-American. A study that used the REACH study dataset looked at differences between Latino and Caucasian caregivers (Coon et al., 2004). Results from this study concurred with previous studies that there are several caregiver characteristics that differentiate Latino caregivers from Caucasian ones. Latino caregivers tend to be younger in age, attain less education, have lower income, and more likely to be unemployed than Caucasian caregivers (Coon et al. 2004). This also helps explain why Caucasian caregivers tend to be spouses while Latino caregivers usually are daughters and provide more average hours of care (Coon et al., 2004). Coon et al. (2004) also report results from Cox and Monk (1990), in Coon et al. (2004) which reveals that Hispanic caregivers perceive a greater negative change in their health over a six-month period compared to African-American caregivers. This is largely attributed to differences in cultural values and filial expectations (Coon et al., 2004; Gallagher-Thompson,

2008; Judge et al., 2013; Rabinowitz et al., 2006; Nichols et al., 2011; Schultz et al., 2003; Viana et al., 2013).

Coon et al. (2004) also found that Latino caregivers expressed greater caregiving satisfaction than Caucasian caregivers, despite the disparities in financial burden, with Non-Hispanic Whites having more income, education, and employment. Miyawaki (2015) and Wattai (2013) study results concurred about cultural, familial sense of responsibility that mitigates feelings of emotional burden in minority ethnic groups.

Studies on caregiving for elder relatives with dementia among the Asian ethnic groups has shown that cultural beliefs again have a great impact on the caregiving process, including caregivers' appraisal of stress, coping strategies, and seeking informal and formal support (Sun, Ong & Burnette, 2012). Often familial expectations and obligations are linked to lower depressive symptoms as not only is dementia considered as a normal part of aging in these cultures, but providing care for the elderly is also considered normal (Sun et al., 2012).

Miyawaki (2015) attempted to address caregiving issues within Asian ethnic groups. A meta-analysis of 46 peer-reviewed articles on Chinese, Filipino, Japanese, Korean, and Vietnamese American and Canadian family caregivers of older adults from 2000 to 2012, were compared and analyzed to determine caregivers' experiences, cultural values, and acculturation. This review revealed an interesting finding: that despite all ethnic subgroups expressing deep commitment and filial responsibility to caregiving for a loved elderly, "...depending on the immigrant generations of caregivers, their needs and approaches to caregiving differed, which may be a reflection of acculturation to the Western way of caregiving" (Miyawaki, 2015, p. 14). A study by Coon et al. (2004) concurs with Miyawaki's (2015) findings that original ethnic and cultural influences in caregiving may be diluted by acculturation to Western culture that many

immigrant generations experience. One possible reason for this was the influence of higher education on Asian's greater financial resources (especially among the Japanese) in facilitating changes in language and cultural values regardless of race/ethnicity (Miyawaki, 2015).

On the other hand, some research indicates that there are differences between emotional burden and financial burden among the racial/ethnic groups. A thesis by Wattai (2013) examined how the social locations of 768 caregivers affected overall stress/burden using secondary data from the 2003 "Caregivers in the U.S." data set distributed by the Roper Center. The results indicated that White women were the most emotionally stressed caregivers, while minority (African American, Hispanic, and Asian) men and women were most financially stressed. Minority women also appeared more burdened than other caregivers in one test. The surprise finding was that children in the caregivers' households alleviated stress/burden for elder caregivers, suggesting that caregivers with multiple care responsibilities may not be more stressed/burdened than caregivers who care only for elders.

Another study by Kosberg et al. (2007) indicated similar results whereby White caregivers experienced less financial burden due to higher income and more emotional burden as they were older and/or married. African American caregivers felt less emotional burden because of religion or denial as coping styles even though they had more financial burden. This supports previous research findings that indicate that in general African American caregivers experience lower levels of stress and burden compared to White caregivers (Toth-Cohen, 2004).

Overall, the empirical evidence suggests that to a large extent, there are definite differences in caregiving experiences among racial/ethnic groups, with minority groups (and usually low income, younger, less educated) more often feeling greater caregiving satisfaction despite greater financial burden. A common reason explaining this is that "less privileged

respondents have had to acquire resilience through their lives” (Ludwin & Parker, 2015, p. 16), and so they take on caregiving as yet another task. Racial/ethnic differences in cultural values also affect how caregivers take on their roles because they are obligated to do so as a family and feel good about contributing in that manner (Coon et al., 2004).

While much research indicates that there are racial differences in caregiving burden and stress, the impact of coping interventions such as CWC appears universal, with no evident ethnic differences in the benefits of CWC.

There is some empirical evidence that shows that CWC intervention not only works better at reducing stress and depressive symptoms in dementia caregivers than other interventions, but it is so regardless of differences in ethnic groups. Gallagher-Thompson et al. (2003) presented site-specific (from Palo Alto) results from the REACH national collaborative study on differences in impact of interventions on distress between Latino and Anglo female caregivers of dementia relatives. For a ten week program, seen once-a-week, a sample of 122 Anglo and 91 Latino female caregivers were given two types of interventions to determine change from baseline/pre-assessment to three months/post-assessment. The CWC group used psycho-educational programs, which included instruction and practice in small groups to learn specific cognitive and behavioral skills, while the Enhanced Support Group (ESG) used guided discussion and empathic listening to develop support. Respective language and cultural concerns of caregivers were taken into consideration. The findings revealed that overall, the CWC intervention worked better in reducing depressive symptoms than the ESG intervention, regardless of ethnicity. These findings were so significant that they were also presented separately by Rabinowitz et al. (2006) and serve as the baseline comparative study for CWC effectiveness (Rabinowitz et al., 2006).

Similar results were obtained in another study by Gallagher-Thompson et al. (2008) that randomly compared CWC intervention to TSC intervention in 95 Non-Hispanic White and 89 Hispanic/Latino women caregivers of dementia or AD relatives. The intervention lasted about four months, with a single post-treatment assessment at six months after baseline by interviewers blind to the intervention condition. Interviews and interventions were conducted in English or Spanish by trained staff. Results indicated that, regardless of ethnicity, the CWC group showed greater improvement from pre to post intervention than those in the TSC on measures of depressive symptoms, overall life stress, and caregiving specific stress.

Other studies have consistently shown that when language and cultural influences are taken into consideration and modifications made accordingly, Anglo and Hispanic/Latino ethnic groups respond and experience equal benefits from interventions such as CWC (Llanque & Enriquez, 2012). It should be noted, however, that these studies were conducted on female caregivers only, so whether men show equal response across ethnic groups remains in question.

Education

The racial differences in caregiving experiences of burden and stress, and coping strategies have, in large part, been attributed to differences in socio-economic status; the latter, in turn, has been more often characterized by privilege. Education has consistently been identified as a key variable in the social location context of determining socio-economic status of people (Pinquart & Sorenson, 2005; Williams et al., 2016).

In an Italian study by De Fazio et al. (2015), it was observed that among other social location factors, lower socio-economic status was a good predictor of more severe depressive symptoms in caregivers of an elder dementia relative. In fact, the authors concluded that “low socioeconomic status is a risk factor for depressive symptoms among caregivers”...and

caregivers in southern Italy have “threefold increased risk for experiencing high burden.” (De Fazio et al., 2015, p. 1089). Education and income level were part of the variables used to assess socio-economic status (De Fazio et al., 2015).

Pinquart and Sorenson (2005) conducted a meta-analysis examining ethnic differences in sociodemographic variables and the impact on caregiving experiences. Among the findings was that despite ethnic minorities consistently having less educational attainment, they sought informal support and had better psychological coping strategies than White caregivers (Pinquart & Sorenson, 2005). Cultural and religious beliefs played a big role in these differences. Many studies have documented the effect of low education and income on gender differences in caregiving experiences, with women being more likely to take on the role of a caregiver and feeling greater burden, especially financially (Dilworth-Anderson et al. 2002; Keene & Prokos, 2007; Knight et al., 2000; Gallagher-Thompson et al., 2003; Ludwin & Parker, 2015; Moen et al., 1995; Van Houtven et al., 2011; Viana et al., 2013). Studies such as REACH and RCI have indicated that cognitive behavioral and educational interventions such as CWC are more effective equally if the programs take into account the language and cultural differences (Gallagher-Thompson et al., 2003; Rabinowitz et al., 2006; RCI, 2010). However, as Miyawaki (2015) noted, education plays a big role in acculturation, which can facilitate desire to seek intervention.

The intersection of race and education has not been widely studied in the context of coping with caregiving. In fact, there is no consensus as yet as to the best approach regarding these social location factors in terms of CWC. On one hand, some recent studies strongly recommend understanding further the concept of “intersectionality” when considering caregiving (Ludwin & Parker, 2015; Wattai, 2013). On the other hand, some older studies consistently

highlight the need to first evaluate individual factors impacting caregivers. For example, Coon et al. (2004) urges researchers to study education as an individual factor when designing and implementing caregiving interventions.

Summary of Caregiving and the Caregiver

Caregiving is the informal care provided by family members (the caregivers) to an elderly ailing relative (the care recipient) who has lost the ability to care for himself/herself due to some chronic illness, disability, or accident. The cost and burden of caregiving is intense, both emotionally and financially, impacting caregivers in the lower socio-economic category the greatest. Caregiving for dementia patients is the biggest dilemma: it can be a burden and stressful on the caregiver, and in turn, also cause decreased quality of life for the caregiver, who ends up needing support as well. Studies are showing that caregiving interventions such as CWC help reduce the cost of long-term care and reduce caregiver's burden of stress and depressive symptoms to some degree (Baumgarten et al., 2002; Iecovich & Biderman, 2012; Gallagher-Thompson, 2007).

Racial/ethnic differences in caregiving burden and stress also exist, with the minority groups of caregivers (Blacks and Hispanics) feeling more financial burden, and White caregivers feeling more distress. Most studies reveal no race or ethnic differences in the effect of CWC intervention in that it works for all participants equally.

More research is needed to add to our understanding of how caregiving burden can shift the impact on both the caregiver and the care recipient, and also on the hidden costs of caregiving, with respect to social location. Further research on these issues is highly recommended to help not just the caregivers, but also policy makers and other health care professional so that they may make better, informed decisions on the future of support for

caregivers and care recipients in the U.S. for this (caregiving) is an inevitable consequential need with an aging population that is increasingly becoming so diverse.

Part 3: Theoretical Framework

Two social gerontological theories provide the framework for this study; the Stress Process Model and the Life Course Perspective. This study does not examine all elements of each theory; however, it looks at several components.

First, the Stress Process Model developed by Pearlin (1981) helps to frame the relationship between stress, social support and health, as it pertains to caregivers' burden and experience of stress (Gallagher-Thompson & Coon, 2007; Judge et al., 2013). Pearlin's Stress Process Model addresses the impact of stress and support on mental health. This theory is particularly relevant, as it has been recognized as a useful tool for both research and practice by the Family Caregiver Alliance [FCA], (2006). Second, the life course perspective provides a multidisciplinary paradigm to explain the contexts and processes of change and development in the human life, in this case, to understand the phenomenon of the consequences of aging and how to approach solutions (such as to caregiving, caregiver's burden, and how they cope). Currently, the life course perspective is the dominant theoretical perspective among social gerontologists and is the guiding force behind the most cutting edge research in the field. These two theories provide a bifocal perspective that is needed in order to fully comprehend the myriad of factors that are involved in the subject matter of caregiving of an elderly.

The next section discusses the theories in more detail and applies them to the present study. I then present the conceptual model for my study and identify which components I tested.

The Stress Process Model

Pearlin, Menagan, Lieberman & Mullan (1990) conceptualized social stress as a process combining three major conceptual domains: the sources of stress (eventful experience, life strains and self-concepts), the mediators of stress (social supports, and coping), and the manifestations of stress. Using longitudinal data, the authors aimed to identify the manner in which the various components of stress are interconnected.

According to Pearlin (2010), the stress process framework is comprised of a number of conceptual components, “each of them potentially related to the status placement of people in the hierarchical arrangement of the society” (p. 208). Stressors are problematic conditions and experiences that can challenge the adaptive capacities of people. The stressors that sociologists are interested in are those related to individuals’ social and economic status and to indicators of their health. Exposure to stress can lead to stress proliferation, which is exposure to secondary stressors. Pearlin (2010) emphasizes those protective barriers, such as social support, social integration, various belief systems, coping repertoires, self-mastery and self-esteem, that may explain why people exposed to similar stressors may not suffer the same consequences.

In the case of caregiving, primary stressors include duration and type of care provided and the functional and cognitive disabilities of the care recipient. Examples of primary stressors maybe supervising the care recipient, restraining them, performing bodily maintenance tasks, such as activities of daily living (ADLS’s) and instrumental activities of daily living (IADL’s), doing such tasks daily (Aneshensel, Pearlin & Schuler, 1993). Examples of secondary stressors are finances, family conflict, constriction of social ties and leisure activities, and conflict with work responsibilities. These secondary stressors, according to Aneshensel et al. (1993), develop or intensify as caregiving continues through time. These stressors emerge as problems in other

social roles, network relations, and feelings about self. A person's health and well-being is influenced by the stress they experience and the resources they are able to mobilize to deal with those experiences (Turner et al., 2008).

According to Schultz and Sherwood (2008) caregiving can be studied from the stress coping model. Within the stress coping model objective stressors include the patient's physical disabilities, cognitive impairment, and problem behaviors as well as the type and intensity of care provided. These objective stressors lead to effects such as psychological stress and impaired health behaviors, although the effects are moderated by individual differences in resources and vulnerabilities like prior health status, socioeconomic status and level of social support.

Figure 1 below provides an overview of the mechanism of the Stress Process Model as depicted in Shah, Wadoo & Latoo (2010, p. 2). The model clearly shows how the caregiving context variables affect each part of the stress process and what the potential implications for the types of stressors facing the caregivers. Following the 2006 National Consensus Development Conference, the Family Caregiver Alliance (FCA) published a report suggesting that the Pearlin Stress Process Model was a particularly useful tool for both research and practice. The FCA report highlights the measures that can be used under various constructs, thereby making Pearlin's original Stress Process Model accessible to professionals who work with family caregivers (FCA, 2006).

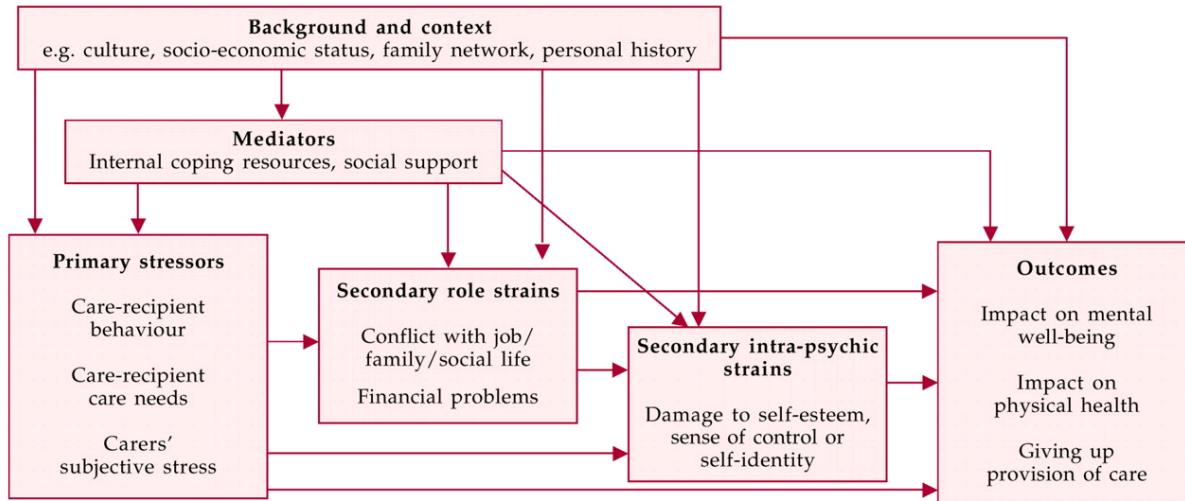


Figure 1. Shah et al. (2010) stress-process model of stress (adapted from Pearlin et al. 1990)

Shah et al. (2010) provide additional support for why Pearlin’s Stress Process Model helps explain the complexity of assessing caregiver burden. The nature and level or intensity of burden experienced by a caregiver is linked to gender, age, health status, cultural background, level of social support available, coping style, and type of ailment of the care recipient. This evidently complex process is categorized in the Stress Process Model, thereby permitting a practical application to seeking effective solutions for understanding and allaying caregivers stress and burden.

All of the aforementioned interlinked factors give credence to the need to also highlight the next theory.

Life Course Perspective (LCP)

The life course perspective (LCP) is a third generation theory that examines differences in aging across cohorts by emphasizing how individual biography is situated within the context of social structures and historical circumstances. According to Clausen (1986), the LCP is the biological, psychological and cultural study of human development that is approached from a multi-disciplinary perspective. Whether the life course perspective should be considered a

theory, a model, or a paradigm is debatable (Bengtson et al., 1997); however, with its intellectual roots in structural functionalism, it represents a convergence of thinking in sociology and psychology to highlights aspects of social interaction and social structure in order to understand and explain research findings related to aging.

According to the pioneer of LCP, Glen Elder (1994), the theory is an approach that involves the interaction of historical events, individual decisions and opportunities, and the effect of early life experiences in determining later life outcomes. Elder's five principles have become the foundation for LCP: (1) Development and aging are lifelong processes; (2) People are actors with choices that construct their lives; (3) The timings of life, events, and roles have a significant impact, forming a trajectory and/or a transition; (4) Linked lives—people are embedded in relationships with others and influenced by them; and (5) Changing historical times and places profoundly influence people's experiences.

Although LCP is a dominant approach in the sociology of aging, critics often cite that it is too broad, lacks “theoretical rigor” and tends to be more descriptive—perhaps due to research being problem-driven rather than theory-driven (Bengtson et al., 2009). However, accurate sociological perspectives rely on the description and explanation of changes of roles and relationships among family members, and in societies, over time to go beyond the individual life span.

The collective concepts of LCP, according to Pearlin (2010), aid in understanding how the life course trajectories of individuals and groups come to differ. The life course framework attempts to document long-term patterns of development (Tuner et al., 2003). Elder (1994) states that unexpected transitions such as caregiving are more stressful than expected ones such as employment or marriage. Adult children are often not prepared for the role of caregiver, yet may

gradually or immediately assist with caregiving tasks like paying bills, assisting with ADL's, transportation, medication, house maintenance, when the care recipient is no longer able to safely carry out these tasks. According to several researchers, this gradual accumulation of caregiving tasks has been related to increased caregiver stress (Kahn & Pearlin, 2006; Moen, Dempster-McClain, & Williams, 1992; O'Rand, 2009).

The LCP perspective applies to the success of CWC as a caregiver intervention in three ways. First, when stress levels increase for a caregiver to such an extent that it impacts the caregiver's own personal life and well-being then the caregiver often resorts to seeking affordable assistance in some form. This literature review indicates that caregivers need intervention programs, which provide a range of tools that can aid in alleviating the burden of stress and depressive symptoms. Second, this is directly related to the LCP perspective regarding differences in life trajectories, especially those that are of the unexpected kind –which is often the experience of caregivers. The design of CWC interventions take into consideration that people can come across a situation in their lives when they become caregivers of someone, but are unable to cope with the transition of becoming a caregiver for someone with a disease like dementia. Third, In addition, the LCP perspective on the socio-historical time reference also helps explain how life trajectories are linked to social location. The example of increased education may be best referenced here to show how such life trajectories impact rise in social locations, which in turn, impact the burden of a caregiver differently. For instance, women with increased educational attainment contribute significantly to the labor force (Rosener, 2003). Their position in the family and in the workforce changes with education, (often) to one now set with dual responsibilities. Thus, CWC intervention programs provide a range of tools that would

help both the patient and the caregiver, thereby, aid coping with the transitional and ultimate new life trajectory of now being a caregiver.

Conceptual Model for the Dissertation

Based on Pearlin’s Stress Model Process, and drawing on elements of the LCP, Figure 2 provides a conceptual model for this study. The model depicts the relationship of the study variables (blue font showing primary variables). The box at the start of the timeline indicates the point in time where the caregiver took on the unexpected role or transition of caregiving to their loved one (care recipient). This role is believed to be the primary stressor for the caregiver that leads to the poor outcomes of increased depressive symptoms and high stress as measured by CES-D and PSS. During the caregiver’s lifetime individuals were introduced to one of two interventions (mediators), CWC or TSC. The outcome measures CES-D and PSS were taken at time one and time two. In this study, the change in scores from time one to time two provide evidence to examine if race or education have any effect on these outcomes (see research questions and hypotheses stated in chapter 1).

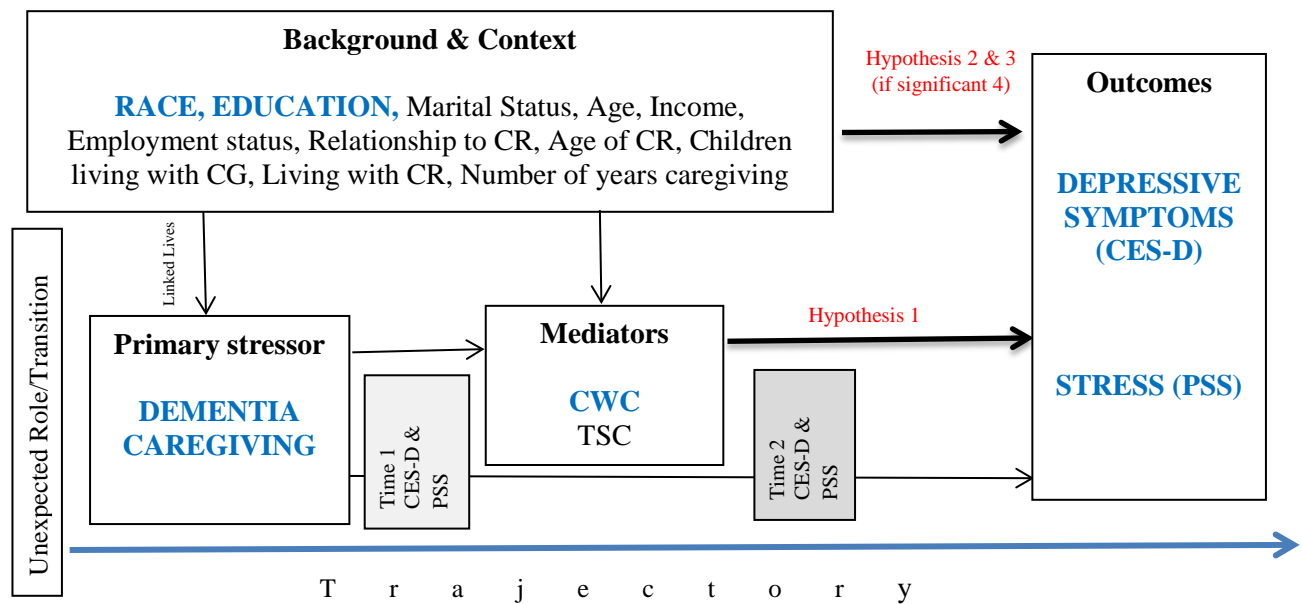


Figure 2. Dissertation Theoretical Conceptual Model

Summary of Theoretical Framework

The theoretical framework presented here provides a model that accounts for the nature of both the caregiver and the patient, and the potential reasons why a person would seek assistance from an intervention program to cope with informal caregiving.

Two main concepts underlie this theoretical framework. First, the Stress Process Model and LCP provide some of the foundational factors to the nature of a caregiver and the role of social location. Since caregivers are usually thrown into their role unexpectedly, these theories help us understand that when random and sudden changes in life occur, the choices people make may be affected by their own upbringing and life experiences, as well as what is expected of them, both by their own families and their societies, and depending on their social location. It is noted in the literature that more often, it is a female relative entrusted with the role of a caregiver, a female who most likely already has several other roles in her life, such as a mother, wife, office worker, etc. (Eagly, 1987; Maztek, 2011). Second, and most relevant, the stress process model establishes how these changes in life can impact one's own health and well-being should there not be a system of support to buffer the responsibilities.

CHAPTER 3: METHODS

The literature review revealed that programs such as Coping with Caregiving (CWC) can reduce dementia caregiver depressive symptoms and stress. However, few studies have taken a more in depth look at which participants benefit the most from CWC. This dissertation aimed to contribute to the research by examining how participants' social location (operationalized as race and education) matter for the effectiveness of CWC in reducing caregivers' depressive symptoms and stress. In keeping with previous studies, this dissertation employed data about a treatment program (intervention): CWC and the control, Telephone Support Control (TSC), and first compared their effectiveness in helping relieve depressive symptoms and caregiver stress. Next the dissertation probed further to examine which participants benefitted the most from the more effective program.

This chapter begins with a review of the purpose of the study, research questions and hypotheses. Presented next are the concepts and measures, research design and rationale, data source, and finally, analytic strategies I used in this study. The final analytic models used Ordinary Least Squares (OLS) regression in SPSS version 20.0 (IBM, 2011).

Review of Statement of Purpose

The purpose of the study was to examine how social location (operationalized as race and education) relates to the effectiveness of caregiving intervention programs targeted at reducing stress and depressive symptoms for dementia caregivers. Much of the research on these types of caregiver interventions focus on the outcomes for caregivers, but rarely problematize participants' social location or demographic characteristics. From a sociological perspective, we would expect that caregiver interventions may be effective for reducing caregiver stress, but that not all participants may benefit equally due to their socioeconomic status or race and ethnic

background. For example, it may be the case that caregivers with more education will be better able to use the techniques offered by the program or may have more economic resources to do so. Similarly, it is possible that the race or ethnic background and culture of some caregivers' influence the ways in which they receive the intervention and also the degree to which they employ the strategies offered by the intervention. Given that most caregiver intervention programs are not specifically designed to be culturally or economically sensitive (Gallagher-Thompson et al. 2004), this line of inquiry may be helpful for identifying ways of adapting programs to benefit various groups of caregivers more effectively. My goal was to understand whether the socioeconomic factors of race and education predict an even greater benefit for Non-Hispanic White, highly educated caregivers.

Research Questions and Hypotheses

The overarching research question for this dissertation was how does social location (operationalized as race and education) impact or influence benefits of dementia caregiver intervention programs, specifically CWC. To address the overarching research question, I designed a series of secondary research questions that guided my analyses. The first research question is a baseline question intended to address the comparative effectiveness between CWC and TSC. The remaining research questions address the larger issue of the relationship between social location and caregiver outcomes.

R₁: Are there differences among caregivers' depressive symptoms and stress between CWC and TSC participants? This question was asked to determine (and confirm) whether CWC provides greater benefits (lowers depressive symptoms and stress) to participants than TSC, which serves as the reference group. Based on previous findings by Gallagher-Thompson et al. (2008), CWC was shown to be more effective than TSC in reducing caregiver stress and depressive symptoms.

H₁: CWC has a greater (positive) effect on participants' stress and depressive symptoms outcomes than TSC.

If the results of this part of the analysis would demonstrate the baseline that CWC is more effective than TSC in reducing caregiver stress and depressive symptoms, then the remainder of the analyses focus on CWC only, and investigate the relationships between the social location indicators and caregiver outcomes.

R₂: Are the effects of CWC on caregivers' depressive symptoms and stress different by race? I expected that Non-Hispanic White caregivers would experience a greater reduction in stress and depressive symptoms than Hispanic caregivers because previous studies suggest that Non-Hispanic White women feel most stressed as caregivers in comparison to other races (Wattai, 2013; Kosberg et al., 2007; Toth-Cohen, 2004). Non-Hispanic White caregivers therefore may stand to gain the most benefit from the CWC intervention.

H₂: Non-Hispanic White caregivers will experience a greater reduction in stress and depressive symptoms than Hispanic caregivers.

R₃: Are the effects of CWC on caregivers' depressive symptoms and stress different by educational attainment? Based on findings from previous research (De Fazio et al., 2015; Pinquart & Sorenson, 2005; Williams et al., 2016) I expected that caregivers with higher levels of education would benefit more from the CWC intervention.

H₃: Caregivers with higher education will experience a greater reduction in depressive symptoms and caregiver stress compared to those with lower education.

R₄: Are the effects of CWC on caregivers' depressive symptoms and stress contingent upon the relationship between race and educational attainment? This question examined the possible interaction effects of race and education. I expected that highly educated Non-Hispanic White

Caregivers would have significantly lower stress and depressive symptoms after participating in CWC than Hispanic caregivers with higher education. I based this expectation on the predictions for research question two. If Non-Hispanic White caregivers benefited more from CWC, and highly educated caregivers also benefited more, then the logical deduction is that those who are both Non-Hispanic White and highly educated would experience an even greater benefit from CWC.

H₄: Non-Hispanic White caregivers with higher education will experience a greater reduction in stress and depressive symptoms than Hispanic caregivers with higher education.

The following table provides a quick review of the aforementioned hypotheses for this study.

Table 1

Overview of Study Hypotheses

<i>Hypotheses</i>	
H ₁	CWC has a greater (positive) effect on participants' stress and depressive symptoms outcomes than TSC.
H ₂	Non-Hispanic White caregivers will experience a greater reduction in stress and depressive symptoms than Hispanic caregivers.
H ₃	Caregivers with higher education will experience a greater reduction in depressive symptoms and caregiver stress compared to those with lower education.
H ₄	Non-Hispanic White caregivers with higher education will experience a greater reduction in stress and depressive symptoms than Hispanic caregivers with higher education.

Research Design and Rationale

This was a quantitative study that used secondary data collected by Gallagher-Thompson et al. (2008) for the purpose of evaluating the effects of stress-management treatments for caregivers of elders with dementia on hypothalamic-pituitary-adrenal axis function and distress. This dataset was suitable to address the research questions as it contained relevant information

from a socio-demographically diverse group of caregivers, as well as the type of intervention and outcomes (i.e., CES-D, PSS)

Dataset Description

This dissertation employed the secondary data that was used in the intervention study “*Reducing Stress in Hispanic and Anglo Dementia Family Caregivers*” (Gallagher-Thompson et al., 2008). Gallagher-Thompson et al. (2008) initially recruited 231 participants for their study through community-based recruitment efforts employing a number of strategies such as target calls and mailings.

Recruitment and Data Collection

The underrepresentation of Latinos in clinical research was identified as a significant issue and considered as a target sub-population for the caregiver study by Gallagher-Thompson et al. (2004). According to Gallagher-Thompson et al. (2004), three recruitment strategies including media advertisements (flyers and announcements), non-professional referrals (friends, neighbors and word-of-mouth), and professional referrals were used. All recruitment strategies were implemented both in English and Spanish to reach out to the target populations and provided a toll-free phone number for potential participants to call for any questions. Through the recruitment efforts, 195 Latinos and 115 Non-Hispanic White people were contacted. Participants were then screened for eligibility (listed in the next section) to participate in one of two clinical trials.

Eligibility requirements for the Gallagher-Thompson et al. (2008) study included: at least 21 years of age; a Non-Hispanic White or Hispanic/Latina female; at least eight hours or more of care per week (for at least six months) to a family member that needed assistance with at least two instrumental activities of daily living (IADL) or one activity of daily living (ADL); either a

physician's diagnosis of dementia or a recent mini-mental state examination (MMSE) with a score less than or equal to 23 (Gallagher-Thompson et al., 2008; Cucciare et al., 2010; Holland et al., 2011). Participants also needed to have a phone, planned to remain in the area for the duration of the study, and be willing to be randomly assigned to one of two caregiver interventions (Gallagher-Thompson et al., 2008).

Data was collected from participants between 2002 and 2006. Of the 231 recruited participants, 184 completed the initial baseline assessment, including the CES-D and PSS pre-tests. Participants were then stratified by ethnicity and randomly assigned to either CWC or TSC. During the study, 28 participants withdrew, leaving 156 caregivers who completed the post assessment. Of the 28 participants who withdrew, the reasons cited were: the death of the care recipient, relocation, dissatisfaction, loss of interest, too time consuming, and pregnancy. Post assessment was conducted approximately two months after the intervention ended. The type of intervention was not disclosed to the researchers who conducted the post assessment in order to reduce potential bias. According to Gallagher-Thompson and colleagues (2008), there was no association between treatment modality and completion. Therefore, the final sample in the current study was 156 individuals (83 participants are from the CWC intervention and 73 participants are from TSC).

Concepts and Measures

Dependent Variables

The two dependent variables examined in this study were depressive symptoms and caregiver stress.

Depressive Symptoms. In the 2008 Gallagher-Thompson et al. study, caregiver depressive symptoms were measured using the Center for Epidemiologic Studies Depression Scale (CES-D)

(Radloff, 1977). Gallagher-Thompson et al. (2008) reported a high internal consistency of CES-D in their study (Cronbach's alpha = .92). This study used the dataset that was collected in the Gallagher-Thompson et al. (2008) research. However, in this dataset, only total overall CES-D scores were available, therefore I was unable to examine the internal consistency of the scale. The 20-item scale had a possible range of scores from 0-60 (Radloff, 1977), with a score of 16 or higher being used as the cut-off point for possible depressive symptoms (Radloff, 1977). Participants were asked to indicate how often they had felt a certain way (e.g., "I felt depressed") during the past week. The response was recorded in the 4-point Likert Scale: rarely or none of the time (less than 1 day); some or a little of the time (1-2 days); occasionally or a moderate amount of time (3-4 days); and all of the time (5-7 days). A list of the 10 CES-D items is included in the Appendix A.

Stress. Caregiver stress was measured using the ten-item Perceived Stress Scale 10 (PSS) (Cohen & Williamson, 1988), which is a shortened version of the original 14 item scale. Cohen & Williamson (1988) stated that the PSS had a slightly better internal consistency than the original scale, and therefore, recommended the use of PSS in future research. Gallagher-Thompson et al. (2008) reported an acceptable internal consistency with the PSS (Cronbach's alpha = .57). Again, I was unable to examine the consistency of the scale due to lack of individual item scores for each participant. The scale had a score range from 0 to 40 with a higher score indicating more stress (Cohen, Kamarck & Mermelstein, 1983). Respondents for the PSS were asked about their feelings and thoughts during the past month. Each question asked how often they felt or thought a certain way (e.g., "in the past month, how often have you felt that difficulties were piling up so high that you could not overcome them?"). The response was recorded in the 5-point Likert Scale: never; almost never; sometimes; fairly often; and very

often. The total score is calculated by finding the sum of the ten items: questions 1,2,3,6,9,10 are coded 0-4 from never to very often; and questions 4,5,7,8 are coded from 0-4 from very often to never (Cohen et al., 1983). A copy of the scale is contained in the Appendix B.

Independent Variables

The independent variable for this study was the participation in the specific type of treatment (1 = CWC; 0 = TSC). In order to evaluate the differences in the outcomes between these two programs, treatment is coded 1 for CWC and 0 for TSC. The interventions differ by approach and intensity. CWC is considered skills-based whereas TSC is a support based approach and individuals only received a 15-20 minute phone call very two weeks (Gallagher-Thompson et al. 2008). CWC's intervention is conducted in small groups, consisting of between four to eight caregivers. The updated version was used in this study (Gallagher-Thompson et al., 2008), which according to the researchers included two additional content areas and more time spent in active participation in each session. Groups met weekly for sessions lasting two hours. The program follows a detailed treatment manual similar to REACH, where caregivers participate in a total of 13 classes. The TSC treatment provided empathic support over the phone to participants for 15-20 minutes every two weeks (Gallagher-Thompson et al., 2008). Participants received seven phone calls over four months and some educational materials that were mailed to the home.

Participants were randomly assigned to one of the two intervention groups: either CWC or TSC. To maintain a balanced distribution by ethnicity across groups the "biased coin" (Efron, 1971) strategy was used (Gallagher-Thompson et al. 2008). The biased coin strategy is a restricted randomization procedure that is designed to promote balance between two treatment groups (Markyaryan & Rosenberger, 2010). According to Gallagher-Thompson et al. (2008), of

the 231 recruited participants, 184 caregivers completed the baseline assessments, which included the pre-tests of CES-D and PSS.

Race is defined by the Office of Management and Budget & the U.S. Census Bureau (n.d.) as a group of people classified as one (distinct from another group), on the basis of shared biological, sociological and/or political factors such as physical traits, nationality, or geographic distribution. Participants enrolled in the study identified with one of two races, either Non-Hispanic White or Hispanic/Latina. I coded Non-Hispanic White as 1 and Hispanic/Latina as 0. The dataset being used in this study was oversampled for Hispanics. Therefore the sample is not a probability sample, which is a threat to the external validity of the study and an issue that previous studies have addressed (Holland et al., 2011) and that I address in the next chapter.

Education was recorded as the number of years of formal education (e.g., Gallagher-Thompson et al., 2008) and was measured from zero years, representing no formal education, to 20 years, which reflected the attainment of an advanced degree(s). Formal education is, “The knowledge, skill, and understanding that you get from attending a school, college, or university” (Merriam-Webster.com, n.d.).

Covariates

The following covariates were included in analysis in order to adjust for potential confounding and bias in this study: number of years caregiving, age of the caregiver (i.e., respondent), age of the care recipient, relationship to care recipient, marital status, employment status, and income. The covariates for the study were measured through a brief telephone screening that was conducted prior to enrollment into the program and via the first in-home interview questionnaire, that was adapted by the REACH program (Gallagher-Thompson et al. 2003).

The number of years caregiving is a continuous variable and was obtained from the screening form and represents the total number of years the caregiver had been caring for the care recipient prior to enrolling into the project. The age of the caregiver and the age of the care recipient were both measured during the in-home interview with question that asked the date of birth for both the caregiver and care recipient.

The table below describes how the independent and covariates were coded.

Table 2

<i>Coding of Independent Variable and Covariates</i>	
Covariate	Coding
Race	0= Hispanic/Latina; 1= White Non-Hispanic
Caregiver education	0-20
Number of years caregiving	0-20
Age of the caregiver	24-85
Age of the care recipient	46-98
Relationship to Care Recipient	0=Non spouse; 1=Spouse
Marital Status	0= Not Married; 1=Married/living as married
Employment Status	0=Not employed; 1=Employed (full or part-time) paid
Income	0=Less than 30K; 1=More than 30K

Two covariates had missing data. Income had six missing data points but was included in the final regression model. Having children under the age of eighteen living at home had twenty-four missing data points, which represented 15 percent of the sample size and was excluded from the analysis.

Analytic Strategies

I addressed the research questions and evaluated the hypotheses using regression analysis. Regression analysis is considered most appropriate to use when trying to examine the complex relationships with the secondary data (Moonie, 2013; Penn State University, 2016). Specifically, I used ordinary least squares (OLS) method (Weisberg, 2005) given the continuous outcome measures (i.e., CES-D, PSS) in this study.

Statistical analysis was performed using SPSS version 20.0 (IBM, 2011). I analyzed the data at two time periods: baseline pre-program (pre-test) and approximately after two months after program completion (post-test). To evaluate treatment effectiveness I used the change scores from the pre-test to the post-test in depressive symptoms (CES-D) and caregiver stress (PSS). I used the following steps to analyze the data and address my research questions and hypotheses:

1. Based on the preliminary descriptive statistics, I assigned the missing value of 999 to all invalid responses and/or cases (e.g., income categories; children under the age of 18 living with caregiver). I corrected two abnormal PSS scores whose values were 14.22 (Case ID 400052) and 10.22 (Case ID 400067). The values were corrected to 14 and 10 respectively. These values appeared to be a mistake so the correction was made to the nearest whole number since each item on the PSS is scored in whole numbers. Only the values of zero, one, two, three or four can be assigned to PSS responses (Cohen et al. 1983).
2. I then coded the variables of interest (described in the earlier section, and also see the Appendix C for the codebook) and checked the coding outcomes by comparing them to the preliminary descriptive statistics. I also created two new variables in order to test some of my hypotheses. The new variables were the products of treatment and race and of treatment and education.
3. I computed descriptive summary statistics and frequencies to develop histograms, Q-Q plots and box plots to examine the distribution of data further and check the normality assumption of dependent variables.

4. I ran the dependent *t*-test to assess the mean difference in CES-D and PSS scores by the two intervention groups (CWC vs. TSC). I ran the independent *t*-tests to see if there was any significant association between the treatment groups for the continuous variables. I also ran the *chi*-square test for independence to see if there was any significant association between the treatment groups for the categorical variables. Statistical significance was evaluated based on the *p*-value of less than 0.05.
5. I ran linear regression analyses using the ordinary least squares (OLS) method to examine the research hypotheses for the Depressive Symptoms Model (Model 1a, 1b and 1c) with the change score of CES-D and the Stress Model (Model 2a, 2b and 2c) with the change score of PSS.
 - Model 1a_{Depressive Symptoms} examined the effect of treatment with no control variable.
 - Model 1b_{Depressive Symptoms} examined the effect of treatment controlling for covariates.
 - Model 1c_{Depressive Symptoms} examined the effect of treatment controlling for covariates and the interaction of race and education.
 - Model 2a_{Stress} examined the effect of treatment with no control variable.
 - Model 2b_{Stress} examined the effect of treatment controlling for covariates.
 - Model 2c_{Stress} examined the effect of treatment controlling for covariates and the interaction of race and education.
6. I next performed the following regression assumption checks on data to ensure that none of the assumptions were violated.
 - a. The normality assumption was checked through visual inspection of histograms and Q-Q Plots and found to be acceptable.

- b. I checked for outliers using Cook's distance statistic. Outliers are known to substantially influence the estimation of the coefficient in OLS regression model (Jacoby n.d.). Generally a Cook's D value of more than 1 is cause for concern.
- c. The multicollinearity was not observed in the regression models (Moonie 2013). Multicollinearity occurs when two or more of the predictors in a regression model are highly correlated (Penn State University 2016). Multicollinearity was checked using the Variance Inflation Factor (VIF). VIF greater than 4 indicates possible multicollinearity and warrants further data screening (Penn State University 2016).
- d. The residuals have constant variance (Moonie 2013). I checked for homoscedasticity using a scatter plot of the standardized residuals and the predicted dependent values. Once the scatter plot was created, I visually inspected its shape to ensure no pattern was detected. A rectangular shape is indicative of homoscedasticity, where as a funnel shape is a sign of heteroscedasticity (Pryce 2002).
- e. The errors are normally distributed (Moonie 2013). The distribution was reviewed by checking the residuals (errors) using a histogram (with a superimposed normal curve).

CHAPTER 4: RESULTS

The purpose of the study was to examine how participants' social location (operationalized as race and education) matters for the effectiveness of CWC in reducing caregivers' depressive symptoms and stress. This chapter presents the results of the statistical analyses that were performed using SPSS version 20.0 (IBM 2011), and per the analytic strategies described in chapter 3. The chapter provides an overview of the research questions, presents the results for the pre- and post-tests and descriptive statistics, the dependent *t*-test, the independent *t*-test, the review of regression assumptions and sensitivity analysis. The regression models and results of the hypotheses are presented in two sections representing the dependent variables, depressive Symptoms and stress.

Research Questions

The overall premise of the study was to determine who benefits the most when participating in a dementia caregiver intervention program. Thus, the primary research question was "how do race and education impact (or influence) benefits of dementia caregiver intervention programs?" The hypotheses tested were based on the following supporting research questions:

R₁: Are there differences among caregivers' depressive symptoms and stress between CWC and TSC participants?

R₂: Are the effects of CWC on caregivers' depressive symptoms and stress different by race?

R₃: Are the effects of CWC on caregivers' depressive symptoms and stress different by educational attainment?

R₄: Are the effects of CWC on caregivers' depressive symptoms and stress contingent upon the relationship between race and educational attainment?

The purpose of the first research question was to provide a baseline confirmation of previous studies (Gallagher-Thompson & Coon 2007; Gallagher-Thompson et al. 2008) that have shown that CWC is a more effective intervention program than TSC. This was an important step to validate as the underlying premise of the study focused on CWC, as reflected by the other three research questions.

Pre/Post-Tests and Descriptive Results for the Study Sample

As described in chapter 3, this study used a secondary dataset. The first analytical task was to describe characteristics of the study sample. I began with an overview of the measures of central tendency of the CES-D and PSS scores for this study’s sample. Table 3 provides the mean and standard deviation for the pre- and post-tests, as well as the minimum and maximum values for each.

Table 3

Study sample outcome measures (n=156)

Variable	M (SD)	Min-Max
CES-D		
CES-D Pre-test	14.60 (11.71)	0, 48
CES-D Post-test	11.25 (9.73)	0, 42
PSS		
PSS Pre-test	18.06 (7.38)	1, 37
PSS Post-test	15.66 (6.49)	0, 30

M=Mean, SD=Standard deviation, CES-D = Center for Epidemiological Studies Depression Scale (Radloff 1977), PSS = Perceived Stress Scale (Cohen & Williamson 1988).

Next, using the pwr package of R (Champely, 2012), a power analysis (Weisberg, 2005) was run to estimate the power of the regression model for the study. Table 4 shows the sample size, degrees of freedom and effects sizes in the power analysis. I adapted the power of 0.8, which is conventionally accepted in the social sciences. The result of the multiple regression power calculation was 0.81, and for the *t*-test power calculation it was 0.87. Based on previous studies, the high-medium effect size was assumed.

Table 4

Power Analysis Results

Multiple regression power calculation	<i>t</i> -test power calculation
Degrees of freedom for nominator (u) = 155	Sample size (n1) = 83, (n2) =73
Degrees of freedom for denominator (v) = 140	Effect size (d) = 0.5
Effect size (f2) = 0.27	Significance level = 0.05
Significance level = 0.05	power = 0.872
power = 0.815	alternative = two sided

Sample Description

Participants provided caregiver and care recipient demographic information through an interview during the first in-home visit. Interviewees used a questionnaire adapted from the REACH program (Gallagher-Thompson et al., 2008). Some information such as the number of years caregiving was obtained during the initial screening. Table 5 provides the mean, standard deviation and minimum and maximum values by the overall group and by the treatment group (CWC or TSC) for the continuous variables of age, number of years caregiving and education.

Overall, the average age of the caregiver was 57.5 years old, while the average age for the care recipient was 79 years. The length of time caregiving ranged from less than a year up to 20 years, with the average being close to four years at 3.98. Although the number of years a caregiver was educated ranged from less than one to twenty, on average, the caregivers had 13.03 years of education.

Comparing the characteristics by treatment group revealed that the caregivers from the CWC group were, on average, slightly younger than those of the TSC group. However, on average the CWC group had spent four years caregiving compared to 3.77 by the TSC group. In terms of level of education, it was interesting to find that the TSC group was slightly more educated than the CWC group, with an average of 13.19 years of education compared to 12.88. The possible implications of this finding are further discussed in the next chapter.

Table 5

Study sample characteristics at pre-test by group

Variable	M (SD)	Min-Max
All (n=156)		
Caregiver age (years)	57.58 (13.99)	24, 85
Care recipient age (years)	79.18 (8.61)	46, 98
Number of years caregiving	3.89 (3.71)	0, 20
Education	13.03 (4.197)	0, 20
CWC (n=83)		
Caregiver age (years)	56.48 (13.53)	27, 84
Care recipient age (years)	79.18 (8.88)	58, 98
Number of years caregiving	4.00 (3.93)	0, 17
Education	12.88 (4.80)	0, 20
TSC (n=73)		
Caregiver age (years)	58.82 (14.48)	24, 85
Care recipient age (years)	79.18 (8.36)	46, 97
Number of years caregiving	3.77 (3.46)	0, 20
Education	13.19 (3.41)	5, 18

M=Mean and SD=Standard Deviation

Table 6 reports the frequencies of the categorical variables for the group overall and by treatment (CWC or TSC). The table confirms that the sample was almost evenly split by race (see recruitment section under dataset description). Daughters represented the largest group providing care at 51 percent. Overall, 70 percent of the participants were married. As a whole, 28 percent of the participants described their employment status as full-time paid/30 hours per week, while 25 percent were retired. Yearly incomes were spread very broadly from one percent of individuals earning less than five thousand to 15.5 percent of individuals earning over one hundred thousand per year. Over three quarters (76.3%) of the caregivers were living with the care recipient and nearly 40 percent had children under the age of 18 living in the home.

Table 6

Study sample demographics at pre-test (n=156)

Variable	n (%)		
	All (n=156)	CWC (n=83)	TSC (n=73)
Race			
Non-Hispanic White	80 (51.3%)	42 (50.6%)	38 (52.1%)
Hispanic/Latina	76 (48.7%)	41 (49.4%)	35 (47.9%)
Relationship to care receiver			
Spouse, Past spouse, Significant Other, Domestic Partner	76 (39.1%)	29 (34.9%)	32 (43.8%)
Daughter, Daughter-in-law/Sister/Granddaughter	95 (60.9%)	54 (56%)	41 (56.1%)
Caregiver Marital Status			
Married/Living as Married	109 (69.9%)	61 (73.5%)	48 (65.8%)
Divorced, Separated, Widowed	25 (16%)	13 (15.6%)	12 (16.5%)
Single	22 (14.1%)	9 (10.8%)	13 (17.8%)
Employment Status			
Full-time paid/30hrs per week	44 (28.2%)	21 (25.3%)	23 (31.5%)
Part-time paid/<30hrs per week	27 (17.3%)	16 (19.3%)	11 (15.1%)
Not Employed/ Homemaker/Retired	85 (54.5%)	46 (55.5%)	39 (53.4%)
Income			
Less than 29,999K	65 (41.7%)	36 (43.3%)	29 (39.7%)
30K-59,999K	44 (28.3%)	20 (24%)	24 (32.9%)
60K-99,999K	20 (12.9%)	10 (10.8%)	11 (15%)
100K or more	21 (13.5%)	14 (16.9%)	7 (9.6%)
Residence			
Living with care recipient	119 (76.3%)	63 (75.9%)	56 (76.7%)
Does not live with caregiver	37 (23.7%)	20 (24.1%)	17 (23.3%)
Children <18 living with caregiver			
Yes	62 (39.7%)	35 (42.2%)	27 (37.0%)
No	70 (44.9%)	35 (42.2%)	35 (47.9%)

Note. Only valid cases were used.

Comparing the frequencies by group showed that race was still evenly split for both groups. Daughters predominantly provided the overall care for the CWC group, but this was not the case for the TSC group. Individuals who identified as taking care of a spouse, past spouse, significant other, or domestic partner provided as much care as daughters. Looking at caregiver marital status revealed that the TSC group had comparably more caregivers who identified as single, 17.8 percent compared to 10.8 percent. The TSC group also had slightly more people who stated that they were in full time/30 hours per week employment, but less in part time

employment. Income was fairly evenly distributed for most of the twelve categories, but the CWC group had almost double the number of caregivers classified in the 20K-29,999K and 100K or more categories. Both the TSC and CWC groups had at least three quarters of care recipients living with them. Overall the CWC group had slightly more children under the age of 18 living in the home with them. However, both groups had a substantial amount of cases missing for this variable, 11 for TSC and 13 for CWC. This variable was only used for descriptive purposes and was not included in any analysis.

Results of Dependent and Independent *t*-tests

The dataset included 231 participants, however only 156 participants with complete information on the pre- and post-test results for the CES-D and PSS were used for analysis. Participants were randomly assigned to a treatment group. Eighty-three (83) participants received CWC and seventy-three (73) received TSC. Dependent and independent *t*-tests were conducted in order to address the first research question.

The dependent *t*-test or paired samples *t*-test was conducted to compare the mean changes in CES-D scores and PSS scores before and after the intervention (i.e., pre-test vs. post-test). Table 7 provides the results of the dependent *t*-tests both for the CWC and TSC. There was no significant difference in the change in pre- and post-test scores of the CES-D or PSS for the TSC treatment group at an alpha of .05. This was determined as results show the *p* value for CES-D to be .073 and .071 for the PSS. A result is considered significant if the *p* value is less than or equal to .05.

There was a significant difference in the scores for the CWC group CES-D pre score ($M=14.70$, $SD=11.537$) and CES-D post score ($M = 10.13$, $SD = 9.479$); $t(82) = 4.467$, $p < .001$. Additionally, there was a significant difference in the scores for the CWC group PSS pre score

(M=18.47, SD=7.394) and PSS post score (M = 14.99, SD = 6.389); $t(82) = 4.621, p < .001$.

However, no statistically significant changes between the pre- and post-scores were observed among the TSC group.

Table 7

Dependent t-test results for CES-D and PSS

	CWC (n=83)			TSC (n=73)		
	Pre M (SD)	Post M (SD)	p-value	Pre M (SD)	Post M (SD)	p-value
CES-D	14.70 (11.537)	10.13 (9.479)	.000	14.49 (11.983)	12.52 (9.930)	.073
PSS	18.47 (7.394)	14.99 (6.389)	.000	17.59 (7.384)	16.41 (6.576)	.071

Note. M=Mean, SD=Standard deviation, PSS = Perceived Stress Scale (Cohen & Williamson 1988); CES-D = Center for Epidemiological Studies Depression Scale (Radloff 1977)

An independent *t*-test or two sample independent *t*-test was conducted to determine if there was a statistically significant difference in the mean change scores between the treatment condition groups (i.e., CWC vs. TSC). The results showed that there was no significant difference between the CES-D change scores of the CWC and TSC groups (see Table 8). However, there was a statistically significant difference in the PSS change scores between the CWC and TSC groups. Specifically, the change score (i.e., improvement in the perceived stress) was greater among the CWC group than the TSC group. On a related note, the *Chi*-Square test results also revealed that there were no significant differences between the means of the CWC and TSC groups for the categorical covariates. That is, the CWC and TSC groups are comparable in terms of the key characteristics (shown in Table 8). As such, the differential outcomes on the PSS change scores between these groups are least likely due to the baseline characteristics. All *p* values were greater than .05, which indicates that there is no statistically significant bivariate relationship between the variables tested.

However, there was a significant difference in the scores for the PSS test between CWC group (M = - 4.57, SD = 9.312) and TSC group (M = -1.97, SD = 9.227); $t(154) = 2.292, p =$

.023. The table below provides a summary of results for the independent *t*-tests and the *Chi*-Square tests. According to these results, there was a significant affect for only one variable: stress. This finding is discussed further in the next chapter.

Table 8

Independent t-test and Chi-Square results for dependent variables and covariates

	TSC (<i>n</i> = 73)	CWC (<i>n</i> = 83)	<i>t</i>	<i>p</i>
	M(SD)	M(SD)		
CES-D	-1.97 (9.227)	-4.57 (9.312)	1.747	.083
PSS	-1.18 (5.501)	-3.48 (6.865)	2.292	.023*
Caregiver years of caregiving	3.77 (3.461)	4.00 (3.930)	-.386	.700
Caregiver age	58.82 (14.484)	56.48 (13.525)	1.043	.299
Caregiver years of education	13.19 (3.406)	12.88 (4.802)	.463	.644
Care recipient (CR) Age	79.18 (8.359)	79.18 (8.882)	-.002	.998
	n (%)	n (%)	X ²	<i>p</i>
Caregiver Relationship				
Spouse	32 (43.8%)	29 (34.9%)	1.291	.256
Non-spouse	41 (56.2%)	54 (65.1%)		
Caregiver marital status				
No	48 (65.8%)	61 (73.5%)	1.105	.293
Yes	25 (34.2%)	22 (26.5%)		
Caregiver Ethnicity				
Non-Hispanic White	38 (52.1%)	42 (50.6%)	.033	.856
Hispanic/Latina	35 (47.9%)	41 (49.4%)		
Caregiver employed				
No	39 (53.4%)	42 (55.4%)	.062	.803
Yes	34 (46.6%)	37 (44.6%)		
Caregiver income				
Less than 30K	29 (40.8%)	34 (43.0%)	.074	.786
More than 30K	42 (59.2%)	45 (57.0%)		
Care receiver lives with caregiver				
No	17 (23.3%)	20 (24.1%)	.014	.906
Yes	56 (76.7%)	63 (75.9%)		

Note. *M* Mean, *SD* Standard Deviation, *TSC* Automated Telephone Support, *CWC* Coping with Caregiving

*significant value

Check of Regression Assumptions and Sensitivity Analysis

Performing a regression assumptions checks ensures that the results obtained through the regression analysis are trustworthy. Without ensuring the assumptions were not violated, the

regression models may result in over- or under-estimation of coefficients and their associated p -values (Moonie 2013). When constructing the regression analysis, I conducted several assumption tests in order to confirm the validity of the results. Detailed information about these assumptions was discussed in chapter 3. This chapter presents the findings and I concluded that no regression assumptions were violated during my analysis. Table 9 below provides an overview of each assumption check performed. A brief narrative of this process follows.

Table 9

Overview of Regression Assumption Checks

Assumption	Analytic strategy	Check
Normality	Histogram, Q-Q Plot, skewness, kurtosis	Normal distribution
Outliers	Cook's D, residual plot	No value >1, alignment
Multicollinearity	VIF, residual plot	No value >4
Homoscedasticity	Scatter plot of the standardized Residuals	Rectangle shape
Residuals (errors)	Histogram	Normal distribution

Normality: A visual inspection of the histograms and Q-Q Plots results confirmed normal a distribution. An additional visual inspection of model 2b's residual plot showed that the residuals appeared to be in alignment, concluding that it was normally distributed.

Outliers: The data was also checked for outliers using the stem and leaf plot. The Cook's D was generated for the final model and none of the output showed a value greater than 1, suggesting there were no cases exerting undue influence on model 2b. Additionally the residuals were observed to be in alignment.

Multicollinearity: The VIF values in all models indicated that they were not greater than four and therefore did not warrant further investigation. Multicollinearity was not considered an issue in this regression.

Homoscedasticity: A visual inspection of a plot of the standardized residuals (zresid) by the regression standardized predicted value (zpred) detected no pattern. Thus, homoscedasticity was assumed since the plot had a rectangular shape.

These test results provided evidence that none of the regression assumptions were violated and that the analysis results obtained would be trustworthy. The next step in the analysis employed OLS regression to address the research questions. Since regression analysis employs modeling predictor and control variables to determine outcomes, a set of models was created for each dependent variable (as stated in chapter 3). This step was also necessary since the data analysis for each research question required addressing two specific sets of hypotheses: one for depressive symptoms and the other for stress. The relevant regression model results, therefore, are presented below in terms of these two dependent variables.

Section 1 – Depressive Symptoms

The CES-D was used to measure depressive symptoms. The change in score was calculated by subtracting the pre-test score from the post-test. A negative difference revealed that the participant reported experiencing less depressive symptoms after the treatment.

Model 1 Summary

Ordinary least squares (OLS) regression analysis was performed for the depressive symptoms model. Model 1a was unconditional and only included the treatment group (CWC or TSC) as a predictor. CWC was coded as 1 and the reference group TSC as 0.

Results showed that this model was not significant (p -value of 0.83) and therefore the remaining models 1b (fully conditional, including covariates) and 1c (includes interaction terms) were not constructed to investigate the other depressive symptoms hypotheses. Table 10 provides the results of the regression model predicting CES-D scores.

Table 10

Regression model predicting CES-D scores

	CES-D			
	<i>B</i>	(SE)	t	Sig.
<i>Model 1</i>				
Treatment (TSC is reference)	-2.600	1.488	-1.747	0.83
R ²		.019		

Note. β =regression coefficient, R²=measure of model performance/fit

The overall results shown in Table 10 indicate that there is no statistical significance to support any of the hypotheses’ predictions for the depressive symptoms variable. Since the model was not significant, I accepted the null hypothesis that “the model has no predictive value” and that I have no evidence that CWC is more beneficial for participants’ depressive symptoms than TSC. Table 11 shows the summary results regarding each hypothesis testing.

Table 11

Hypothesis Results for the Dependent Variable Depressive Symptoms

	Hypotheses	Findings
1	CWC has a greater (positive) effect on depressive symptoms outcomes than TSC.	Not supported
2	Non-Hispanic White caregivers experience a greater reduction in depressive symptoms than Hispanic caregivers.	Not supported
3	Caregivers with higher education experience a greater reduction in depressive symptoms than those with lower education.	Not supported
4	Non-Hispanic White caregivers with higher education will experience a greater reduction in depressive symptoms than Hispanic caregivers with higher education.	Not supported

Section 2 – Stress

The PSS was used to measure stress. The change in score was calculated by subtracting the pre-test score from the post-test. A negative difference meant that the participant reported having less stress after the treatment.

Model 2 Summary

Ordinary least squares (OLS) regression analysis was performed for the stress model. Model 2a was unconditional and only included the treatment group (CWC or TSC) as a predictor. CWC was coded as one (1) and the reference group TSC as zero (0). Results showed that the treatment group was significantly associated with the stress outcome ($p < 0.05$). As the model was significant, I rejected the null hypothesis that “the model has no predictive value.” The R-squared in this model was .033, which means that participating in the CWC intervention can explain about 3.3% of the change in PSS score. The unstandardized coefficient of -2.304 indicates that participating in CWC facilitates an average decrease of 2.304 on the PSS.

Model 2b was a fully conditional model that included the treatment group and 10 additional variables: years of caregiving, caregiver age, care recipient age, caregiver education, relationship to care recipient, living with caregiver, marital status, employment and income. Table 12 provides the results of the regression model predicting PSS scores for both model 2a and 2b.

Both models 2a and 2b showed that only the treatment variable had statistical significance in predicting change in PSS scores. Model 2c was run to include the interaction variables (treatment * race and treatment * education). As the interaction effects were not significant, the results were excluded from the final model.

Table 12

Regression model predicting PSS scores

	PSS			
	<i>B</i>	(SE)	<i>t</i>	Sig.
<i>Model 2a</i>				
Treatment (TSC is reference)	-2.304	1.005	-2.292	.023*
R ²		.033		
<i>Model 2b</i>				
Treatment (CWC or TSC)	-2.348	1.050	-2.236	.027*
Years of caregiving	.074	.141	.527	.599
Caregiver Age	.075	.062	1.206	.230
Care recipient Age	-.029	.082	-.356	.723
Caregiver years of education	-.060	.164	-.366	.715
Spouse/Non-spouse	-2.115	2.005	-1.055	.293
Lives with caregiver	.130	1.277	.101	.919
Caregiver Married	-.446	1.446	-.309	.758
Caregiver Ethnicity	-.447	1.410	-.317	.751
Caregiver Employed	-1.169	1.279	-.914	.362
Caregiver Income	.076	.180	.425	.672
R ²		.057		

Note. β =regression coefficient, R²=measure of model performance/fit

The overall results shown in Table 12 above indicate that there is statistical significance to support only one of the hypotheses for the stress variable. As model 2b was significant, I rejected the null hypothesis that “the model has no predictive value.” The R-squared in this model was .057, which means that participating in the CWC treatment can explain about 5.7 percent of the change in PSS score. The unstandardized coefficient of -2.348 indicates that participants can experience an average decrease of 2.348 on the PSS by participating in the CWC program. Table 13 below shows the findings regarding each hypothesis for stress.

Table 13

Hypothesis Results for the Dependent Variable Stress

	Hypotheses	Findings
1	CWC has a greater (positive) effect on stress outcomes than TSC.	Supported
2	Non-Hispanic White caregivers experience a greater reduction in stress than Hispanic caregivers.	Not supported
3	Caregivers with higher education experience a greater reduction in stress than those with lower education.	Not supported
4	Non-Hispanic White caregivers with higher education will experience a greater reduction in stress than Hispanic caregivers with higher education.	Not supported

Summary

This chapter presented the results of the data analysis performed using SPSS. First, simple descriptive and pre/post-test statistical analyses were performed to provide an overview of the study sample characteristics. After the mean and standard deviation for both the pre- and post-tests were calculated, a power analysis was done to ascertain the validity of the secondary dataset used. Following steps outlined in chapter 3, *t*-tests and OLS regression analysis results revealed that there was no statistical significance to support any of the hypotheses predictions for the depressive symptoms variable. Further, only one hypothesis was supported by the findings for the stress variable: that CWC has a greater effect on stress outcomes than TSC. A detailed discussion about these results is presented next in chapter 5.

CHAPTER 5: DISCUSSION & CONCLUSION

The overall purpose of this study was to examine how social location and operationalized by race and education, influenced the effectiveness of caregiving intervention programs for dementia caregivers, more specifically, the Coping with Caregiving (CWC) treatment. The overarching question for this research was “how do race and education impact the benefits of dementia caregiver intervention programs, specifically CWC?” Benefits were determined by a reduction in depressive symptoms and stress as measured by the CES-D and PSS respectively. Thus this chapter presents the discussion of the study’s findings, beginning with an overview of the demographics, and then by the two dependent variables: depressive symptoms and stress. It then reviews the study’s limitations, provides a summary and conclusion, followed by the implications for practice and recommendations for future research. Finally, I provide my autobiographical reflection.

Discussion of Findings

Since previous studies (Gallagher-Thompson & Coon, 2007; Gallagher-Thompson, 2008) showed that CWC was a more effective intervention for reducing caregiver stress and depressive symptoms than TSC, my goal was two-fold: first, to confirm that CWC is indeed a better intervention program for dementia caregivers than TSC, and second, to understand whether the socioeconomic factors of race and education predict even greater benefits for dementia caregivers enrolled in a CWC intervention program. Figure 2 provided the theoretical conceptual model upon which this dissertation was based (see chapter 2).

The first research question addressed the first part of my goal, while the remaining three research questions addressed the second part. Given that there were two dependent variables in

this study, the data analysis for each research question was addressed in terms of two sets of hypotheses: one for depressive symptoms and the other for caregiver stress.

Specifically, the study compared pre- and post-test results for the CES-D (measure of depressive symptoms) and PSS (measure of stress) for two independent groups. The groups comprised dementia caregivers who received the CWC treatment and the reference group who received TSC treatment. The initial analysis pertained to the first research question, whereby both dependent and independent *t*-tests were conducted, as well as a *chi*-square test, in order to determine whether or not there was any significant association between the treatment groups and outcomes. The results of the dependent *t*-test indicated that, overall, there were differences among caregivers' depressive symptoms and stress between the two treatment groups as a whole. Specifically, there was a significant difference in the change in pre- and post-test scores of the CES-D or PSS for the CWC group compared to none for the TSC group. This means that compared to no evident change in depressive symptoms and stress for the TSC group, the CWC group in this study sample showed some improvement in decreasing depressive symptoms and stress. This result does confirm my first goal and supports earlier findings that CWC is a more effective intervention program than TSC (Gallagher-Thompson et al., 2008). The finding supports the conceptual model in relation to hypothesis one, in that the stress process is interrupted by the mediator (CWC), thereby reducing the outcome manifestations (depressive symptoms and stress) of the primary stressor (dementia caregiving).

Once it was ascertained that the CWC intervention program was more effective overall, I then addressed the remaining three research questions by performing additional analyses. First, I conducted independent *t*-test and *chi*-square test to take into account the specific variables and all covariates. These results showed that there was no significant association between the CWC and

TSC groups when comparing caregiver race, caregiver education, number of years caregiving, age of the caregiver, age of the care recipient, relationship to care recipient, marital status, employment status, and income (background and context). In this study, the predictor variables of race and education played no role in the outcomes. Although the conceptual model relating to hypotheses two, three, and four was not validated, it does explain the study findings in the context of a dementia caregiver. That is, despite the multidimensional background and content from which the caregivers come from, collectively the identified primary stressor in this situation is being a dementia caregiver. The source of stress is caregiving and the intervention program CWC mediates this stress as supported by hypothesis one. However the null findings of the remaining hypotheses indicate that race and education had no apparent effect on the intervention. A summary of the sample demographics is reviewed next in order to determine if the comparison of pre- and post-test scores was actually done between demographically similar groups, a possible reason for the results.

Summary Discussion of Sample Demographic Characteristics. All participants in the study sample were females from only two racial categories: Non-Hispanic Whites and Hispanics. The average age of the caregiver was 57.5 years old, while the average age for the care recipient was 79 years. With a range from less than a year to 20 years, the average length of time spent caregiving was almost four years and, similarly, the average years of education a caregiver had attained was 13 years. Overall, 70 percent of the participants were married, with daughters representing the largest group providing care (51 %). These results are fairly consistent with the characteristics of caregivers from previous studies, particularly regarding that daughters tend to be the family caregiver (Holland et al., 2011; Gallagher-Thompson & Coon, 2007; Rabinowitz et al., 2006). These results are also in alignment with the LCP theory that, due to certain life course

trajectories and expectations, females—and especially daughters—are more likely to take on the role of a caregiver (Pearlin, 2010; Tuner et al., 2003; Elder, 1994).

When comparing the characteristics by treatment group, both the TSC and CWC groups had at least three quarters of care recipients living with them. In addition, the data showed that the sample was almost evenly split by race. This indicates that there was no over sampling for any one racial category; however, it should be noted that since only two race categories were considered in this study, generalizability of these results across all racial categories may not be valid due to biased sampling.

There were some slight differences between the two groups worth noting here. First, caregivers from the CWC group were observed, compared to the TSC group on average, to have the following characteristics: (1) slightly younger; (2) spent slightly more time caregiving; (3) slightly less educated; (4) predominantly daughters; (5) had slightly more children under the age of 18 living in the home with them; and (6) twice as likely to be classified in the 20K - 29,999K and 100K or more income categories. Second, caregivers in the TSC group were observed, compared to the CWC group on average, to have comparably more caregivers who identified as being single and stated that they were in full time employment (at least 30 hours per week).

Given that many of the differences were very slight, the main differences worth reiterating here are that the caregivers in the CWC group were predominantly daughters and in the income categories of 20K - 29,999K and 100K or more. Caregivers in the TSC group, on the other hand, were mostly single status individuals and working fulltime. This latter finding suggests that these might be reasons why participants enroll in a TSC program. If participants are working fulltime, and are mostly single (not necessarily daughters), then they may not have the

time or the motivation to seek a more in-depth program such as the CWC. The implication for this is discussed in the latter section of this chapter.

Overall, the data indicated that the two groups' characteristics were demographically similar enough that no significant associations were evident from the independent *t*-test and *chi*-square test. This lack of demographic diversity may have added to the limitation of the dataset and affected the potential outcome of the study.

When conducting quantitative studies, performing *t*-tests and *chi*-square are not always sufficient to determine the accuracy of the results. Regression analysis provides a more viable analytical strategy to test hypotheses. The results of the two sets of models created to test the hypotheses for the two dependent variables are discussed next.

Section 1 – Depressive Symptoms

Results of the dependent *t*-test revealed that there was a significant difference for the CWC group between the means of the pre- and post-test score for the CES-D. These results suggest that participating in the CWC intervention does positively impact CES-D scores. Specifically, my results suggest that when a caregiver participates and completes the CWC treatment, their depressive symptoms, as measured by the CES-D, reduce. This supports earlier findings that CWC is an effective intervention in reducing caregiver depressive symptoms (Gallagher-Thompson et al., 2008).

However, findings for the regression model (1a) for depression show that the model was not predictive. As this model did not support the first hypothesis, no other models were run for depression. Thus, none of the hypotheses for the depressive symptoms were confirmed through the regression analysis models. There may be two possible reasons for this finding. First, depression is a complex mood disorder (NIMH, 2016) that is difficult to treat. The treatment of

depression is a debatable topic too broad for the scope of this dissertation. However, it is well known that treatments for depression are comprised of non-pharmacological and pharmacological interventions. Second, although the intervention was only administered for 13 weekly sessions, there was an estimated two month period between the pre- and post-test period to determine any change in scores. This timeframe was likely too short to establish any significant changes in depressive symptoms. Given that the treatment for this study was non-pharmacological, and administered in a short timeframe, it is not surprising that the model could not be predictive. Concepts like depression are multilayered and have many facets in defining them, which makes it difficult to strategically target effect treatments. Although it was promising that the pre and post CES-D scores were significantly reduced after participating in CWC.

Section 2 – Stress

Results of the dependent *t*-test for the PSS revealed that there was a significant difference for the CWC group between the means of the pre- and post-test scores. These results suggest that participating in the CWC intervention does positively impact PSS scores (scores are reduced). Specifically, my results suggest that when a caregiver participates and completes the CWC treatment, their stress is reduced as measured by the PSS. This supports earlier findings that CWC is an effective intervention in reducing caregiver stress (Gallagher-Thompson et al., 2008; Rabinowitz et al., 2006).

The first stress model (2a) was predictive and so the conditional model (2b) was run. This too was predictive by treatment only. However, the third model (2c) that included the interactions (race and treatment) and (education and treatment) were not predictive so the model was not included in the results section. This discussion focuses on the final model (2b).

How well did the final model work? Participating in the treatment group was the only predictor that contributed to the model. It accounted for 5.7 percent of the variation. Although the coefficient of determination was small, it can still be considered reliable. The model predicted that, on average, PSS scores would be reduced by -2.348 points after participating in the CWC program. The PSS scores range from 0 to 40, with an average score being considered 13, while groups with high stress have a score of 20 or more (Cohen et al., 1983). Reducing a PSS score by a little more than two points appears to be a significant accomplishment considering the important role that dementia caregivers play. Therefore, these results did confirm one of the hypotheses of this study: that CWC has a greater (positive) effect on stress outcomes than TSC.

Given that informal caregivers play a significant role in the care of a person diagnosed with dementia, one of the research questions was, “Are the effects of CWC on caregivers’ depressive symptoms and stress contingent upon the relationship between race and educational attainment?” This was hypothesized as “Non-Hispanic White educated caregivers would see a greater reduction in depressive symptoms and stress than Hispanic educated caregivers”. This hypothesis was aligned with other researcher’s findings that suggested that Non-Hispanic White women feel most stressed as caregivers in comparison to other races (Wattai, 2013; Kosberg et al., 2007; and Toth-Cohen, 2004).

In addition, race and education were two parameters selected to represent social location in this study because they are the two most predominant indicators in research for measuring socioeconomic status or SES (Sadana et al., 2013; UNFPA & HelpAge International, 2012; Williams et al., 2016). According to Williams et al., race plays a key role in the health disparities evident across populations and education plays a key role in the “...non-equivalence of SES

indicators across racial groups” (2016, p. 3). In fact, Williams et al. (2016, p. 3) posit that “...compared to Whites, Blacks and Hispanics receive less income at the same education levels.” It is evident therefore that these social location indicators matter greatly when trying to understand any healthcare issue. Yet, there is no consensus as to the best approach regarding these social location factors in terms of CWC. Furthermore, there is also no consensus as to whether an intersection of race and education should be studied in the context of CWC alone. While some studies strongly recommend understanding the concept of “intersectionality” when considering caregiving (Ludwin & Parker, 2015; Wattai, 2013), others consistently position the need to first evaluate individual factors impacting caregivers (Coon et al., 2004). In either case, there is no doubt that these variables are very important when studying caregiving as they may greatly affect how caregivers respond to intervention programs.

However, the results of this study overall did not support the majority of hypotheses put forward. One reason for such results may be due to the limitations of the study.

Limitations

Both the internal and external validity of this study were potentially affected by the limitations of the study parameters.

Interventions/Treatment

This research was limited in that it primarily focused on the CWC intervention program. As the literature revealed, dementia caregivers have received a fair amount of attention with regards to their health and wellbeing. Given this attention, there are a number of interventions available that specifically target this population with respect to improving the caregiver’s physical and mental health. Maslow (2012) cites 30 evidenced-based non-pharmacological treatments and care practices that specifically targeted the family caregiver. Therefore, the

generalizability of this study is limited to only CWC intervention programs: thus potentially posing a threat to the internal validity in the form of possible subject bias.

DataSet

I identified two limitations concerning the dataset. The sample size was small and lacked demographic diversity. Specifically, it comprised only female caregivers who came from one geographical location and only two racial groups, Non-Hispanic Whites and Hispanics. Therefore the sample was most likely not a probability sample and this is a threat to the external validity of the study. Such a limitation makes it difficult to determine whether the observed effect was real or just a random variation (Hackshaw, 2008). Additionally there were several income data points missing from the dataset, although the income variable was still considered in this analysis it should still be noted that this was a limitation.

Summary and Conclusion

With the sharp rise of an aging population, there is growing realization that caregiving of an elder with some form of chronic or disabling condition is increasingly inevitable. Caregivers, and the burden they face, are now recognized as an essential part of the spectrum of healthcare for the elderly. A key aspect of ensuring this support system does not become overwhelmed and neglectful, due to the burdens involved, is to determine effective and comprehensive tools and strategies (such as caregiving intervention programs) to provide support back to the caregivers so that they are better able to manage and sustain their caregiving role. CWC has been well documented in the literature as one of the more effective intervention programs that help alleviate the burden of caregiving. However, a gap was identified in the literature that addressed lack of a sociological approach to establish a link, if any, between social location and benefits of the CWC intervention program aimed at reducing the burden of stress and depressive symptoms.

Therefore, using secondary data, this study took a sociological perspective to examine how social location impacts the benefits of dementia caregiver intervention programs. Social location was operationalized by race and education for this study's scope. Benefits were determined by a reduction in depressive symptoms and stress. Quantitative analysis was performed using SPSS version 20.0 to analyze the data at two time periods: baseline (pre-test) and approximately two months after program completion (post-test). Treatment effectiveness was evaluated using the change in scores from the pre-test to the post-test in depressive symptoms (measured by CES-D) and caregiver stress (measured by PSS). While the study did conform to previous studies in that CWC was shown as more effective than TSC overall, in terms of this study's variables, the majority of the hypotheses were not confirmed. In fact, only one hypothesis was confirmed by the results of this study: that participating in a CWC treatment program has a greater (positive) effect on reducing stress than participating in a TSC program. One viable reason for no confirmatory results regarding the depressive symptoms might be that the complex nature of depression, its diagnoses, measurements and treatments were beyond the scope of this study.

Given the limitations of the study parameters, it is not without a doubt that future studies on the subject matter may yield different results. It must be noted here that this study did confirm one aspect of caregiving studies: they are complex in nature and require diligent research if one is to determine the best evidence-based practices and enhance the body of literature on the topic. In light of the results of this study, therefore, the following implications and future recommendations are proffered.

Implications for Practice

Studies have shown that caregiver depressive symptoms and stress are experienced in different degrees by different racial groups and socio-economic status (Holland et al., 2011; Cucciare et al., 2010). However, while many studies have also shown that CWC is an effective intervention program for those struggling to cope with caregiving, they have not directly addressed the role of social location when delineated by race and education. This study will benefit the broad spectrum of the caregiver community, especially those professionals who want to implement evidence-based practices that address the issue of caregiver depressive symptoms and stress. Gaining a better understanding of how these factors impact the effectiveness of CWC may facilitate improvements on how the caregiving community implements such programs.

One of the subtle findings from the demographics of this sample was that caregivers in the TSC group were mostly single status individuals and working fulltime, with at least 30 hours employment per week. Another was that caregivers in the CWC group were predominantly daughters and in the income category of 20-29K, 99K and 100K or more. The implications of these findings must not be overlooked. It is apparent that there is a notable difference between the TSC and the CWC group demographics. Understanding the various life trajectories and social expectations that lead to one's status as a caregiver would benefit many a design of an intervention program that aims to help reduce the caregiver's burden of stress and depressive symptoms.

In particular, as this study has shown that daughters are the predominant caregivers in the CWC program, it is imperative that changing family dynamics be addressed as a significant underlying factor in caregiving. Previous studies have indicated that the burden of care and cost of an elderly parent will increase (MMMI, 2010; NIA & WHO, 2011; UN, 2010). With a rapidly

aging population and continuing decline in fertility rates, the possibility of family caregivers diminishes and likelihood of a shifting burden to communities and state increases (MMMI, 2010; NIA, USDHHS & U.S. Department of State, 2007).

Given this study showed that education and race did not differ the effects of the CWC programs on the mental health outcomes of caregivers, a few insights can be drawn. It is widely known, that population aging along with the increasingly diverse populations in the U.S. inevitably place heavy demands on all forms of formal and informal, private and public, social and medical services (CDC, 2011; PRB, 2013). The continued reliance on the informal or family caregiver is a serious public concern. Consequently, alleviating caregiving-related stress in order to maintain caregivers' well-being should be an important policy goal. In this context, this study provided preliminary empirical evidence showing that the CWC intervention programs are equally effective for Non-Hispanic White and Hispanic caregivers, as well as those with any level of education, and therefore, practitioners may gain more confidence about the applicability of the CWC program in the racially and socioeconomically diverse caregivers. In other words, this study informs practitioners who work with caregivers of people with dementia, that not only does CWC work better than TSC, but the effectiveness of intervention does not seem to be influenced by social locations.

Recommendations for Future Research

Given the immense implications of caregiving needs and demands in the foreseeable future, it is imperative that there be continuous research that addresses caregiving from all perspectives. Based on this study, a number of recommendations can be made for future studies using a sociological lens.

First, future research should examine more closely the role of race and education in the actual effectiveness of caregiving intervention programs. Taking into account the limitations of this study, a similar study using a larger and more diverse sample may produce different more definitive results. Previous research has shown that CWC is more effective equally if the programs consider the language and cultural differences by race (Gallagher-Thompson et al. 2003; Rabinowitz et al., 2006; RCI, 2010). In addition, some research has also shown that education plays a big role in acculturation, which can facilitate an individual's choice and need to seek intervention (Miyawaki, 2015). Therefore, it is imperative that race and education be addressed in future studies of effectiveness of caregiving intervention programs. Researchers should also bear in mind that income and employment are closely tied to education (Williams et al., 2016), so when designing future studies these variables should be factored in separately, as it was in this study. Considering an intersection of the two indicators would provide additional knowledge that is currently lacking.

Second, future studies may also look into the assessment of tools used to measure depressive symptoms and stress in order to determine more accurately any changes post intervention. The CES-D tool used in this study to measure depressive symptoms has been a consistent for many years. However, as population demographics and dynamics are changing rapidly, it may be prudent to revise some of these tools. Alternatively, future research may also examine how the levels, timing and accumulation of depressive symptoms of caregivers over the life-course may combine with other caregiving stressors to influence the desire to seek intervention. It may be possible to refer to my conceptual model (Figure 2) as a foundational guide when addressing such links over longer durations.

Finally, future studies may also benefit by classifying stress further, such as emotional stress, physical stress, social stress, mental stress, etc., and determine how the level of intensity of caregiving impacts decision to seek (type of) intervention. Given that some studies have shown that there is a difference in the level of caregiver's burden depending on the ailment of the elderly, categorizing the type of stress and how to measure it may inform the design of intervention programs further (MMMI, 2010; Iecovich, 2008). If caregivers have more options that cater more closely to their specific needs, it is possible that participation in, and success of, these interventions may increase.

Integrating social location into all these recommended studies would provide the sociological scope that is much needed to fill the gap in the caregiving literature.

Caregiver interventions may help improve the quality of informal care. Yet the lack of a systematic framework specifying the targets and outcomes of caregiver interventions hampers our ability to understand what has been studied, to evaluate existing programs, and to inform the design of future programs (Van Houtven et al., 2011 p.1).

APPENDIX A: CENTER FOR EPIDEMIOLOGIC STUDIES DEPRESSION SCALE (CES-D)

Center for Epidemiological Studies Scale (CES-D)

Instructions: Below is a list of ways you might have felt or behaved. Please tell me how often you have felt this way during the past week.

	Rarely or none of the time (less than 1 day)	Some or a little of the time (1-2 days)	Occasionally or a moderate amount of time (3-4 days)	Most or all of the time (5-7 days)
1. I was bothered by things that usually don't bother me.				
2. I did not feel like eating; my appetite was poor.				
3. I felt I could not shake off the blues even with help from my family or friends.				
4. I felt I was just as good as other people.				
5. I had trouble keeping my mind on what I was doing.				
6. I felt depressed.				
7. I felt that everything I did was an effort.				
8. I felt hopeful about the future.				
9. I thought my life had been a failure.				
10. I felt fearful.				
11. My sleep was restless.				
12. I was happy.				
13. I talked less than usual.				
14. I felt lonely.				
15. People were unfriendly.				
16. I enjoyed life.				
17. I had crying spells.				
18. I felt sad.				
19. I felt that people disliked me.				
20. I could not "get going".				

Scoring:

	Rarely (less than 1 day)	Some (1-2 days)	Occasionally (3-4 days)	Most (5-7 days)
Questions 5 & 8	3	2	1	0
All other questions	0	1	2	3

The total score is calculated by finding the sum of 10 items. Do not score the form if more than 2 items are missing.

APPENDIX B: PERCIEVED STRESS SCALE (PSS)

Perceived Stress Scale (PSS)

The questions in this scale ask you about your feelings and thoughts during the last month. In each case, please indicate with a check how often you felt or thought a certain way.

	Never	Almost Never	Sometimes	Fairly Often	Very Often
1. In the last month, how often have you been upset because of something that happened unexpectedly?					
2. In the last month, how often have you felt that you were unable to control the important things in your life?					
3. In the last month, how often have you felt nervous and “stressed”?					
4. In the last month, how often have you felt confident about your ability to handle your personal problems?					
5. In the last month, how often have you felt that things were going your way?					
6. In the last month, how often have you found that you could not cope with all the things that you had to do?					
7. In the last month, how often have you been able to control irritations in your life?					
8. In the last month, how often have you felt that you were on top of things?					
9. In the last month how often have you been angered because of things that were outside of your control?					
10. In the last month, how often have you felt difficulties were piling up so high that you could not overcome them?					

Scoring:	Never	Almost Never	Sometimes	Fairly Often	Very Often
Questions 1, 2, 3, 6, 9, & 10	0	1	2	3	4
Questions 4, 5, 7, & 8	4	3	2	1	0

The total score is calculated by finding the sum of 10 items reverse coding questions 4, 5, 7, & 8 - as pictured above. The PSS has a range of scores between 0 and 40. A higher score indicates more stress.

APPENDIX C: CODE SHEET

#	Label	Name	Value
1	PARTICIPANT ID	ID	None
2	CAREGIVER TREATMENT	condition	TSC, CWC
3	CG WIFE OR DAUGHTER	cg_relcr	Daughter, Daughter-in-Law, Domestic Part, Granddaughter, Other, Sig. Other, Sister, Wife
4	CG SPOUSE/NON-SPOUSE TO CR	cg_spouse	Non Spouse, Spouse
5	CR RELATIONSHIP TO CG	crismy	Brother, Domestic Part, Mother, Mother-in-Law, Husband, Sig. other, grandmother, father, father-in-Law, sister, Other
6	MONTHS CAREGIVING	lengthcg	6-240
7	YEARS CAREGIVING	yrscg	0-20
8	HOURS PER DAY PROVIDING CARE	hrs_cg	1-24
9	CR LIVES WITH CG (RESIDENCE)	cr_place	Does not live with CG/Lives with CG
10	CR PLACE OF RESIDENCE	cr_res	Alone, Extended care, Other, With Another Relative, With CG
11	CG Children live with CG	dem2b_children	Yes, No
12	CG AGE IN YEARS	cg_age	24-85
13	CR AGE IN YEARS	cr_age	46-98
14	CG RELATIONSHIP STATUS	dem1	Divorced/Not currently married, Married/living as married, Separated, Single, Widowed/not currently married
15	CG ETHNICITY	dem5	Caucasian/Anglo, Hispanic/Latina
16	CG FORMAL EDUCATION	dem7	Grades 2,3,5,6,8,9,10,11,12/GED, BA, MA, No formal education, PHD, Some College/Associates Degree, Vocational/Trade School
17	CR YEARS OF EDUCATION	cr_eduys	0-20
18	CG PRIMARY OCCUPATION	dem9a	Accounting, Attorney...
19	CG EMPLOYMENT STATUS	dem10	Full-time paid/30hrs per week; Part-time/less than 30 hrs per week, Not currently/employed/not retired, Homemaker not paid, Retired
20	CG INCOME – CATEGORIES	dem11	<5K, 5K-9,999, 10K-14,999, 15K-19,999, 20K-29,999, 30K-39,999, 40K-49,999, 50K-59,999,60K-69,999,70K-79,999,80K-99,999,100K or more, refused/DNK

#	Label	Name	Value
21	CESD: TOTAL SCORE	totcesd	0-60
22	CESD POST: TOTAL SCORE	totcesd_post	0-42
23	DIFFCESD	N/A	POST – PRE = DIFF
24	PSS: TOTAL SCORE	psstot	0-40 (1-37)
25	PSS POST: TOTAL SCORE	psstot_post	0-30
26	DIFFPSS	N/A	POST – PRE = DIFF
27	NEWCAREGIVER	N/A	0=TSC, 1=CWC
28	NEWSPOUSE	N/A	0=Non-Spouse, 1=Spouse
29	NEWYRSCG	N/A	0= 3 or more years, 1=2 or less years
30	NEWRESIDENCE	N/A	0=Does not live with caregiver; 1=lives with caregiver
31	NEWDEM1MARITAL	N/A	0=Divorced/Not Currently Married, Single, Widowed/Not Currently Married, Separated; 1=Married/Living As Married
32	NEWDEM5RACE	N/A	0=Hispanic/Latina; 1-Non-Hispanic White
33	NEWCGEDUYRS	N/A	0=13 years or less, 1=14 or more years (Some college & above)
34	NEWDEM10EMLOY STATUS	N/A	0= Not employed, including retired, 1=Employed (full and part-time) paid
35	NEWDEM11INCOME	N/A	999=Missing, 1=Less than 5K, 2=5K-9,999K, 3=10K-14,999K, 4=15K-19,999, 5=20K-29,999, 6=30K-39,999, 7=40K-49,999, 8=50K-59,999, 9=60K-69,999, 10=70K-79,999, 11=80K-99,999, 12=100K or more
36	NEWDEM11INCOME 30	N/A	0=Less than 30K, 1=More than 30K
37	NEWRACECOM	N/A	NEWCAREGIVER * NEWDEM5RACE
38	NEWEDUCOM	N/A	NEWCAREGIVER * NEWCGEDUYRS

Computed variable

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CURRICULUM VITAE

Jacqueline Sue Ragin

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Education:

- PhD, Sociology, University of Nevada, Las Vegas, (*Expected Summer 2017*)
- MPH, Environmental Health, Fort Valley State University, 2006
- MS, Mental Health Counseling, Fort Valley State University, 2000
- BA, Psychology and Economics, University of Zambia, 1993

Experience:

Grant Evaluator, 2012-present, *Grants Development and Administration, Clark County School District*

Conduct project evaluation and analysis. Assist with needs assessment development.

Coordinate data collection. Write evaluation reports. Develop surveys. Identify potential funding opportunities.

Coordinator, 2007-2012, *Interdisciplinary Center for Aging Research and Education/Gerontology Program, University of Nevada, Las Vegas*

Assist with grant applications. Identify potential funding opportunities. Work on special projects and aging related committees. Coordinate and facilitate program events, conferences, meetings and workshops. Coordinate all related administrative functions and maintain office budgets.

Academic Advisor/Coordinator, 2000-2006, *Upward Bound Program, Fort Valley State University*

Assist with grant writing, research, compiling and production of performance reports.

Analyze project outcomes. Coordinate and supervise all academic, cultural and social activities.

Graduate Assistant, 1998-2000, *College of Education, Fort Valley State University*

Conduct research and administration.

Part Time Experience:

Mobile Assessor, 2006-present (Saturday evenings), *Spring Mountain Treatment Center*

Evaluate mental health emergency room and hospital patients. Conduct psychological evaluations, liaise dispositions and facilitate patient admissions. Coordinate insurance pre-certification for patient admissions.

Instructor, 2008-2011, *Counselor Education Department, University of Nevada, Las Vegas*

Course development and online instruction for Counseling the Older Adult (CED 408/608).

Focus Group Moderator, 2010-2011, *Cannon Survey Center, University of Nevada, Las Vegas*

Conduct focus groups for Ryan White Advisory Board.

Crisis Worker (Sundays), 2001-2006, *Medical Center of Central Georgia*

Conduct crisis evaluation and dispositions. Facilitate inpatient psychiatric admissions and provide emergency room mental health patient care.

Volunteer, Board Experience & Memberships:

Board Member, Clark County Representative, 2009 – present, *Nevada Coalition for Suicide Prevention*

Grant Reviewer, 2010 – present, *Nevada Aging and Disability Services Division*

General Member, Nevada Public Health Association, 2016 – present

Secretary and Board Member, 2007 – 2012, *Nevada Lifespan Respite Care Coalition*

Board Member, 2010-2012, *Senior Citizens Law Project*

Board Member, 2010-2011, *Nevada Geriatric Education Center*

Community Outreach Volunteer, 2007-2009, *Rape Crisis Center*

Presentations, Posters & Publications:

Keene, Jennifer Reid, Kathryn A. McClain, and Jacqueline Ragin, “Aging Trends and Challenges in Nevada.” 2012. In *The Social Health of Nevada: Leading Indicators and Quality of Life in the Silver State*, edited by Dmitri N. Shalin. Las Vegas, NV: UNLV Center for Democratic Culture, <http://cdclv.unlv.edu>

2011 ASA Annual Conference (San Diego, CA) – A Portrait of Nevada: A Study of the Diverse Bio-Psycho-Social Conditions of Men and Women

2010 GSA Annual Scientific Meeting (New Orleans, LO) – A Portrait of Nevada Seniors: A Collaborative Study on the Social, Economic, and Health Conditions Facing the Aging Population in the Silver State

2009 ASA/NCOA Annual Conference (Las Vegas, NV) – A Portrait of Nevada Seniors

2009 ASHA Annual School Health Conference (Denver, CO) – Assessing Environmental Attitudes at Fort Valley State University

2005 AAHE National Convention and Exposition (Chicago, IL) - Using Technology to Teach Environmental Law to Public Health Professionals

2005 AAHE National Convention and Exposition (Chicago, IL) - The History of Health Education: A CDROM