THE EFFECTS OF CAREGIVER SUPPORT SERVICES ON RELIEVING CAREGIVING STRAIN IN OLDER ADULTS

by

YEN-LIN LEE

(Under the Direction of Denise C. Lewis)

ABSTRACT

The purpose of this thesis is to examine the effectiveness of the National Family Caregiver Support Program (NFCSP) on caregivers' well-being. Data from the 2004 National Long Term Care Survey (N =1600) were linked to data from the government expenditures on NFCSP in 2004. Hierarchical linear modeling was used to analyze the impact of expenditures on the three NFCSP services on caregiving strain. Findings indicate that expenditures on access assistance and respite care moderate the caregiving burden-caregiving strain relationships. Moreover, the interaction between hours of caregiving spent and access assistance indicates that caregivers who report more caregiving hours show higher caregiving strain, but also that the caregivers' strain is even higher for those who report more caregiving hours and live in states with higher expenditure of access assistance services. Findings suggest that NFCSP may represent an important factor that influences the caregiving burden-caregiving strain relationships of informal caregivers.

INDEX WORDS: Family caregiver, Caregiving strain, Caregiving burden, National family caregiver support program (NFCSP)

THE EFFECTS OF CAREGIVER SUPPORT SERVICES ON RELIEVING CAREGIVING STRAIN IN OLDER ADULTS

by

YEN-LIN LEE

B.A, National Taiwan Normal University, Taiwan, 2005

M.Ed., National Taiwan Normal University, Taiwan, 2007

A Thesis Submitted to the Graduate Faculty of the University of Georgia in Partial Fulfillment of the Requirements for the Degree

MASTER OF SCIENCE

ATHENS, GEORGIA

2013

THE EFFECTS OF CAREGIVER SUPPORT SERVICES ON RELIEVING CAREGIVING STRAIN IN OLDER ADULTS

by

YEN-LIN LEE

Major Professor:	Denise C. Lewis
Committee:	Kandauda As Wickrama Kerstin Gerst Emerson

Electronic Version Approved:

Maureen Grasso
Dean of the Graduate School
The University of Georgia
December 2013

ACKNOWLEDGEMENTS

I would like to dedicate this thesis to my dear major professor, Dr. Lewis, committee members, Dr. Wickrama and Dr. Emerson, and my families and friends. Without your kindness and support, I can never finish this study.

TABLE OF CONTENTS

CHAPTER THREE

LIST OF TABLES

Page

LIST OF FIGURES

CHAPTER ONE

INTRODUCTION AND LITERATURE REVIEW

The aging of the population is one of the most profound and far-reaching changes affecting contemporary society in most developed and developing countries. According to the Administration on Aging (2013), people who are 65 years old or older represented 13.1% of the population, which numbered 40.4 million in the United States in 2010. In addition, the graying of the baby boom generation, whose members began to turn 65 years old in 2011, will drive future caregiver needs and caregiving solutions accordingly. Baby boomers are projected to live longer than any previous generation, and the number of people aged 65 years or older is expected to double between 2000 and 2030 (Knickman & Snell, 2002).

The American public's attention has been focused on helping aged, disabled, and chronically ill individuals for decades and thereby numerous policies and programs have been implemented throughout the history of the United States, such as Medicare and Medicaid. Although one fourth of aged, infirm, and disabled individuals receive services from paid providers, almost two-thirds of them receive care solely from friends and family members (Lui, Manton, & Aragon, 2000; Whittier, Scharlach, & Dal Santo, 2005). According to *Caregiving in the U.S.* (National Alliance for Caregiving, 2009), an estimated 65.7 million people in the U.S. have served as unpaid family caregivers to provide care for their clinically ill, disabled, or aged family members or friends each year. Among these caregivers, seven in ten take care of someone 50 years of age or older. In other words, more than 46 million people have served as informal caregivers for their elder family members or friends.

Caregiving has only recently been acknowledged by the nation as an important topic for millions of Americans. Several factors have led to this reframing of its importance. First, since the care recipients and caregivers are usually closely related and mutually influenced, if the caregiver is healthy, the life quality of the care recipient will be improved. In return, the improvement of the well-being of care recipients will generally lead to a lower level of burden and strain for the caregivers. Second, caregivers with better health are more likely to sustain their caregiving roles and thereby the recipients are more likely to feel comfortable because they or their families will not be troubled by the need to find a substitute caregiver (Talley & Crews, 2007). On the other hand, caregivers who have an overwhelming burden of caregiving responsibilities may feel depressed and stressed, and therefore, lead to worse health for the care recipients as well.

The relationship between caregiving burden and caregiving strain is not an uncharted territory. A general perception of these two factors is that they are positively correlated. In general, a person with a higher level of caregiving burden is more likely to experience a higher level of depression, greater financial strain, or greater physical strain. Although few researchers argued that caregiving burden does not affect caregiving strain (Bass, Bowman, & Noelker, 1991; Kim & Schulz, 2008), most researchers claimed otherwise (Brouwer et al., 2004; Sugisawa, Nakatani, & Shibata, 1998; Zarit & Femia, 2008). That is, a majority of studies found that a higher level of caregiving burden is a key factor of a higher level of caregiving strain. Therefore, reducing caregiving burden is believed to be an effective approach to lower caregiving strain.

Unlike many existing public programs focusing on the care recipients, the National Family Caregiver Support Program (NFCSP) was established by Congress in 2000 amends the Older Americans Act in order to improve the physical and mental health of the “caregivers.” This program is one of the few federal policy initiatives aimed at supporting family caregivers. This NFCSP provides Federal grants to states, based on their percentage of the over 70 population, to offer a range of services to support family caregivers. In 2010, over 700,000 caregivers received services through the NFCSP (Administration on Aging, 2013). Under this program, states shall provide five different types of services, including information, access assistance, supplemental assistance, caregiver counseling/support groups/training services, and respite care (Administration on Aging, 2013). Among all the services, access assistance services, counseling and training services, and respite care services are the three main services (Administration on Aging, 2013). Accordingly, this study uses these three services as the main research factors in relieving caregiving strain.

A wealth of information regarding these caregiver support services can be found on government and community reports; however, this information consists mainly of descriptive statistics on how many people or how many units have been served. Few empirical articles have examined the effects of these services on relieving caregivers' strain. Because the aforementioned services are mainly funded by the government, this study will use the 2004 government expenditure on these three services as the major factor to measure the impacts on relieving caregiving strain.

Statements of Purpose

The present study seeks to examine both individually experienced caregiving burden as well as objectively measured environmental characteristics such as the expenditure of access assistance, counseling and training, and respite care services in NFCSP on caregiving strain. The purpose of this study is to understand (1) the impact on caregiving strain of government expenditure on access assistance, counseling and training, and respite care services; and (2) the impact on caregiving strain of caregiving burdens (duration, time spent, and types of caregiving); and (3) the impact on caregiving strain by the interaction of government expenditure on access assistance, counseling and training, and respite care services, and individual caregiving burden (duration, time spend, and types of caregiving).

Literature Review

The following section is a review of the literature relevant to this thesis, and it is divided into five parts. The first part presents an overview of the political economy perspective on aging grounded in Marx's theory of class structure and Weber's conception of stratification. This theory helps explain how family caregivers' backgrounds affect their knowledge and access to public policies and their experience on taking care of their family members. The second part reviews research that addresses the content and current situations of caregiving strain. The third part examines previous literature on objective caregiving burden and its impact on caregiving strain. The fourth part presents an overview of family caregiver support services, and the fifth part identifies other demographic variables that may affect caregivers' strain.

Theoretical Framework

The life-course perspective. The life-course perspective views a phenomenon, such as elder care, as a phase of the entire course of life. It emphasizes how experiences early in life affect subsequent outcomes and how historical events, social policies, personal decisions, and individual opportunities interact with one another (Elder, 1994; Zhan, 2002). Three life-course themes are relevant: timing, process, and context (Elder, 1985).

Timing relates to the incidence, duration, and sequence of roles throughout the life-course. The timing and duration of caregiving may be important to assess its emotional impacts (Moen, Robison, & Dempster-McClain, 1995). Process focuses on caregiving as a series of role transitions rather than as a single event. Some roles are left behind, such as in resignation from employment. Context, in terms of the personal circumstances of family caregivers' lives—their gender, race, and education, as well as their relationships with care recipients—may have important repercussions for their social integration and well-being in the later life (Moen, Dempster-McClain, & Williams, 1992).

In using the life-course perspective in the study of caregiving, researchers have argued that the transition of caregiving is socially constructed and that the state plays a significant policy role in that social construction (Zhan, 2002). In other words, caregiving cannot be understood without knowledge of the prior life-course. Not only the timing and duration of caregiving, but also caregivers' pervious circumstances, roles and resources, may well shape the impacts of caregiving on their well-being in their later lives.

The Political Economy perspective. The Political Economy perspective on aging issues is a macroanalysis of structural characteristics of capitalism that determines how scarce social resources are allocated in old age and those allocations serve to marginalize older people (Hooyman & Kiyak, 2011). The political economy perspective is concerned with the effect of early life opportunities, constraints and choices on income security, health, and well-being in later life. It is also concerned with the social construction of particular modes of distribution and how they perpetuate inequality (Kail, Quadagno, & Keene, 2009). Thus, socioeconomic and political constraints, not just individual factors, shape the experience and are patterned not only by age and class but also by gender, sexual orientation, functional ability, and race. These structural factors—often institutionalized and reinforced by public policy—limit the opportunities and choices, resulting in cumulative disadvantages in later life.

Cumulative disadvantage refers to the linkages of the accumulated effect of disadvantage to mechanisms of social stratification (Ferraro & Kelley-Moore, 2003). To complete the life-course perspective, the political economy perspective emphasizes a large and meaningful impact of aggregated disadvantages, especially in socioeconomic and political aspects, in later life. That is, family caregivers who are female, belong to a racial minority and who have lower education level, lower family income, and worse health status may not be able to fully access social resources, such as NFCSP, and thereby may suffer a higher level of caregiving burden and strain.

Caregiving strain

Caring for an aged or ill family member can be a very challenging task. Several scholars have argued that such a task could have huge impacts on caregivers' physical health, mental health, and quality of life because providing care exacts a heavy physical, emotional and financial toll (Amirkhanyan & Wolf, 2006; Roth, Perkins, Wadley, Temple, & Haley, 2009). One national survey investigated how much family caregivers spend and sacrifice for the care recipients (Evercare, 2007). The findings suggested that the amount of expenses on family caregiving was closely associated with reported stress, health and overall well-being of the caregiver. Survey respondents reported an estimated annual expense of $5,531 on family caregiving, which is more than 10% of the median income of the group ($43,026).

In terms of physical strain, people who provide informal caregiving are more likely to experience health deterioration. According to a national report, the Evercare Study of Caregivers in Decline (National Alliance for Caregiving, 2006), more than half (53%) of caregivers indicated that their health had become worse due to caregiving. However, these respondents did not go to the doctor because they either put their family's needs first (67%) or they put the care recipient's needs over their own (57%). Also, more than half (51%) said that they did not have time to take care of themselves and almost half (49%) said that they were too tired to do so (National Alliance for Caregiving, 2004). In regards to emotional stress, depressive symptoms are the most common outcomes accompanying informal caregiving (Butler, Turner, Kaye, Ruffin, & Downey, 2005). Recent studies have found that 32%–50% of caregivers had depressive symptoms at a level suggesting clinical depression (Rivera, 2009). These attributes of caregiving strain are usually related to each other (Pinquart and Sorensen, 2007; Vitaliano et al., 2003).

Caregiving burden

Caregiving burden is a recognized concomitant feature of caring for older family members (Freyne, Kidd, Coen, & Lawlor, 1999). Recent studies have operationalized caregiving burden in several ways, including the duration of caregiving, the number of hours of caregiving, and the types of caregiving (Keene, & Prokos, 2008). These attributes of caregiving burden are usually related to each other. In 2009, the National Alliance for Caregiving in collaboration with the American Association of Retired Persons (AARP) conducted a national survey to investigate the prevalence of caregivers in the U.S. According to their reports, caregivers averaged 20.4 hours per week providing care. Caregiving is particularly time-intensive for those who live with their care recipient (39.3 hours/week). Duration of care averaged 4.3 years. In terms of types of care caregivers provide, previous studies have classified into two types – activities of daily living (ADLs) and instrumental activities of daily living (IADLs). ADLs refers to the most basic tasks, such as eating, bathing, dressing, and toileting, while IADL refers to keeping track of money, errands, housework, and taking medicine (Freedman, 2004). A majority of caregivers help their loved one with at least one ADL (56%). The most common of these is helping the care recipient get in and out of beds and chairs (40%). Personal care tasks are also fairly common—32% help their care recipient get dressed, 26% assist with bathing or showering, 24% help with getting to and from the toilet, and 18% help deal with incontinence. One in five help feed their loved one (19%). Caregivers of adults also help on average with 4.4 out of seven IADLs, including transportation (83%), housework (75%), grocery shopping (75%), meal preparation (65%), managing finances (64%), and arranging or supervising outside services (34%). With respect to caregiving burden, the Level of Care Index, based on the number of hours of care given, as well as the number of ADLs and IADLs performed, was used to measure the level of burden experienced by the caregiver. Three in ten caregivers are in high burden situations (32%), 19% have a medium burden, and 46% have a low burden.

Generally, people who have more caregiving burden tend to experience more symptoms of depression, greater financial and physical strain, and lower levels of psychological well-being (Lin, Chen, & Li, 2013; Pinquart & Sörensen, 2011). On the basis of different durations of caregiving, the findings are mixed. Sugihara, Sugisawa, Nakatani, and Shibata (1998) found that duration shows a direct effect, as those who had been providing care for a longer duration of time reported higher subjective caregiving burden. That is, greater burden from longer durations of caregiving leads to more emotional strain. In addition, hours spent on providing care also influence caregiving strain. The more hours of care provided, the more the caregivers feel stress. Brouwer and his colleagues (2004) studied how objective burden, subjective burden, and quality of life impact informal caregivers of patients with rheumatoid arthritis. The result indicated that more time spent on caregiving led to higher subjective caregiving burden and worse quality of life. However, other studies indicated that duration of caregiving was not associated with caregiving strain (e.g., Kim & Schulz, 2008). The effects of caregiving duration on caregiving strain became insignificant when other factors were considered.

As far as detailed sources of caregiving strain, previous studies have found relationships between the types of caregiving and caregiving strain. Researchers usually use ADL as an indicator of individuals’ basic functioning. Lower levels of care refer to less ADL tasks, while higher levels of care refer to more ADL tasks. Gaugler and his colleagues (2000) utilized growth curve modeling to investigate the importance of elderly care recipients’ behavior problems when predicting changes in caregivers’ emotional reactions to behavior problems, activities of daily living dependencies, and cognitive impairment, and negative mental health status. Results showed that increases in ADL dependencies and behavior problems predicted increases in role overload. That is, the more ADL assistance, the more feelings of exhaustion. Similarly, Leggett, Zarit, Taylor, and Galvin (2011) explored stress and burden among caregivers of patients with Lewy body dementia. According to their findings, assistance with ADLs was a significant predictor of role strain. Patients with Lewy body dementia had many unique ADL and mobility challenges, and so assisting these patients may require considerable time and physical effort, leading to increased levels of subjective burden. Although a few studies suggest that caregiving type is not related to depression and leads to negative outcomes (Bass, Bowman, & Noelker, 1991), greater attention must be paid to the way in which the level of ADL significantly affects caregivers’ physical and emotional strain.

National Family Caregiver Support Program

Although family caregivers suggest providing care to their loved ones is greatly rewarding, balancing careers, needs of other family members, and personal needs with the complexities of caring for frail and cognitively impaired older persons can be extremely challenging. Recognizing such a dilemma, Congress created the National Family Caregiver Support Program (NFCSP, Title III-E of the Older Americans Act 2000 Reauthorization). Unlike many existing public programs focusing on the “care recipients,” The NFCSP, administered by the U.S. Administration on Aging provides an important opportunity to support and strengthen the role of informal caregivers and to bring together community agencies to meet the diverse needs of caregivers. The NFCSP is one of the primary welfare programs of the Administration on Aging (AoA) whose missions include providing home-based and community-based care for the elders and their caregivers. The AoA is part of the U.S Department of Health and Human Services and was created in 1965 based on the Older Americans Act.

The NFCSP is one of the few federal policy initiatives aimed at supporting family caregivers as the target group. This program provides Federal grants to states based on their percentage of the over-70 population to offer a range of services to support family caregivers. The caregiver services work in conjunction with other state and community-based services to provide a coordinated set of supports. In 2009, the government provided, on average, service expenditures of $1,058.54 to each family caregiver. However, individual expenditures varied across states due to different state-wide policies (Figure 1.1). This program supported caregivers with multiple programs and services. The three highlighted support service areas identified include: (1) assistance to caregivers in obtaining access to these services; (2) individual counseling, organization of support groups, and caregiver training to assist caregivers in making decisions and solving problems relating to their caregiving roles; and (3) respite care to enable caregivers to be temporarily relieved from their caregiving responsibilities (Table 1.1).

Access assistance services. Access assistance services provide contacts to caregivers, assisting them in locating services from a variety of private and voluntary agencies. One goal of NFCSP is to provide information to caregivers about available services and assistance to caregivers in gaining access to these services (Link, 2003). Accessibility to the family caregiving

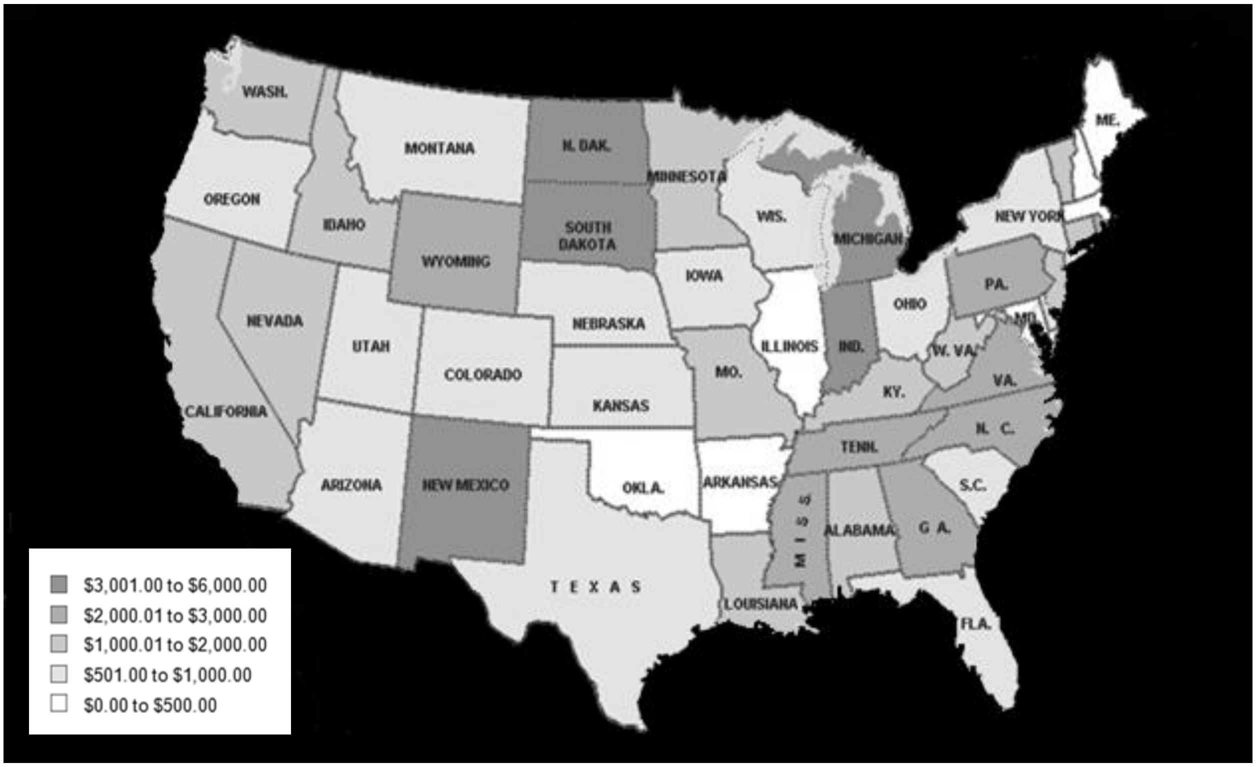

Figure 1.1 Government Expenditure on Caregiver Support Services for Each Caregiver Resource: Data from 2009 Reports (Administration on Aging, 2013).

Table 1.1 Title III-E Caregiver Service Type and Content

Access Assistance Service	Transportation Multilingual / culturally appropriate access Financial assistance In-home workers in rural areas Rural community services
Counseling and Training Service	Multilingual / culturally appropriate services Peer counseling Retreat Community education classes
Respite Care Service	Multilingual / culturally appropriate services Emergency respite Overnight respite In-home respite Adult day care In-home worker registry

Resource: Whittier, & Scharlach (2005)

service program in each state is a primary focus in the program's mission because, if caregivers are not aware of services, they cannot use any of those supportive services. Several states are actively addressing accessibility. For example, Alabama, California, Delaware, and Massachusetts have all utilized the concept of a "mobile van tour" to reach remote, hard-to-access areas of their states where caregivers have little opportunity to receive information, or because of the remote location, have difficulty getting to a central point such as a service center to obtain information and service (Link, 2003). For example, in 2002, states, tribes and communities across the country provided assistance in accessing services to approximately 440,000 caregivers (Administration on Aging, 2004).

Whittier, Scharlach and Dal Santo (2005) examined the scope and range of existing resources for family caregivers from the perspective of the Area Agencies on Aging (AAAs), which are charged with implementing Title III-E of the reauthorized Older Americans Act. Their findings showed that major barriers of service accessibility are transportation, financial assistance, in-home workers and other community services in rural areas, and translation services. In addition, the number of these service gaps was not significantly associated with the proportion of the population age 65 or older or the proportion with incomes below the poverty level.

Counseling and training services. Advice and guidance made available to caregivers through the NFCSP can minimize the negative financial, physical and emotional consequences of caregiving. When caregivers are provided opportunities to talk about these challenges, with counselors and peers in similar situations, they will be able to make better care-related decisions and better cope with problems or unique situations that may arise. The Resources for Enhancing Alzheimer's Caregiver Health studies developed and evaluated a variety of multicomponent interventions for family caregivers of persons with Alzheimer's disease at the mild or moderate level of impairment in Boston, Birmingham, Memphis, Miami, Palo Alto, and Philadelphia. They determined that interventions for caregivers should be multifaceted because only one type of intervention does not lead to maximum caregiver benefits (Schulz et al., 2003). Similarly, a systematic review performed by Lopez-Hartmann, Wens, Verhoeven, and Remmen (2012) studied the effectiveness of respite, psychosocial support, and information and communication technology support services targeting informal caregivers of community-dwelling frail elderly. They reviewed seven studies from 1996 to 2008 and concluded that group support has a positive effect on caregivers' coping ability, knowledge, social support and reducing depression.

In addition, training and instruction made available to caregivers through the NFCSP can diminish the negative consequences associated with caregiving as well. Proper caregiver training, such as appropriate lifting techniques to transfer an elder person from a chair to a bed, protects the care recipient and the caregiver from injury. Gallagher-Thompson (2007), in a review of 19 studies, identified evidence-based psychological treatments for reducing distress, and improving well-being, of family members caring for an older relative with significant cognitive and/or physical impairment. The results from these studies showed that the psychoeducational programs, psychotherapy, and multicomponent interventions should be all effective. However, individualized cognitive behavior counseling and skills training are considered the most effective approaches to reduce strain and improve caregivers' well-being. Moreover, Smith, Doty, and O'Keefe (2000) also indicated that well-trained informal caregivers are less likely to rely on more costly and formal supports.

Respite care services. Family caregivers play an important role in health care, but they need regular breaks to maintain their own health and well-being. In the context of family caregiving, respite care is an arrangement to give caregivers time for personal activities and space for temporarily relief from the stress they may experience while providing care for family members (Whittier, et al., 2005). Respite care can be either a planned service or short-term emergency relief for caregivers from the demands of ongoing care.

Most studies suggest that respite care services are beneficial and highly needed (AoA, 2013). The practical benefits for caregivers are commonly acknowledged, such as allowing time to rest and relax, freedom to pursue other activities, improve self-esteem, feeling secure about possible breakdown of care arrangements, improvement in family relationships and sleep patterns (Mohide, 2002; Perry & Bontinen, 2001). However, outcomes for caregivers' levels of stress, depression, subjective or objective burden, life satisfaction, physical and emotional well-being are inconsistent and less clear (Gottlieb & Johnson 2000; Mason et al, 2007; Shaw et al.,2009).

McNally, Ben-Shlomo, and Newman (1999) identified 29 studies examining the effect of respite provision on caregivers. However, they did not find consistent or conclusive evidence on the effects of respite intervention on caregivers' well-being. In those articles that tested the relationship between respite interventions and caregivers' depression, anxiety, or mood, ten studies reported improvements in psychological well-being, while six reported no effect. Also, in terms of the impact of respite on physical health, two studies reported no effects of respite care, and the other 27 studies reported improvements.

In the research that reported effectiveness, findings are also mixed. For example, Zarit, Stephens, Townsend and Greene (1998) indicated that caregiver depression, role overload, and anger are reduced when respite care is used at least twice a week and at least for three months. Lopez-Hartmann and her colleagues (2012) also demonstrated that respite care can be helpful in reducing depression, burden and anger. In addition, another factor affecting perceived caregiving burden may be the "type" of respite care. For example, emergency, unplanned, overnight, and weekend respite, especially in the care recipient’s home, were less available than reserved and day respite care (Whittier, et al., 2005). Therefore, the effects may not be identical for different respite care types. On the other hand, respite services may not generate anticipated effects. Jeon, Brodaty, and O'Neill (2006) interviewed several mental health professionals, elder caregivers, and respite service providers in order to explore older family caregivers’ needs for respite care and their use of respite services when caring for people with a mental illness. Unfortunately, the authors found that not all of the respite services were adequate to meet the primary needs of mentally ill patients and some older carers. As a result, the impacts of respite care and services need further investigation.

Other Individual Demographic Factors

The idea of gender difference in terms of subjective burden is well-studied – women generally tend to report higher levels of caregiving distress (Del-Pino-Casado, Frías-Osuna, Palomino-Moral, & Ramón Martínez-Riera, 2012; Silverstein, Gans, & Yang, 2006). Such differences mainly come from gender-linked vulnerabilities, socialization processes, and role-related inequality (Pinquart & Sorensen, 2003). For instance, Del-Pino-Casado and his colleagues (2012) found that female adult children caregivers showed slightly greater subjective burden than male adult children caregivers after controlling for the intensity of care and duration of caregiving.

The effect of socioeconomic status (SES), such as education and income, may also affect caregiving strain. Most studies indicated that people with higher SES, including higher income and more years of education, are less likely to suffer greater burden when providing care to families or friends (Pinquart & Sörensen, 2007). However, some scholars found that higher SES is associated with higher perceived burden, whereas others did not find such an association (e.g., Beach, Schulz, Yee, & Jackson, 2000). One study examined associations of SES (education and income) with general and domain-specific chronic stressors (e.g., work, relationships, and caregiving) in Mexican-American women. Their domain-specific analyses showed that women with higher income and educational attainment predicted a greater likelihood of chronic caregiving stress (Gallo et al., 2013). Other research also suggests that age, race, objective health, marital status, and the relationship with care recipients are associated with caregiving strain (Pinquart & Sörensen, 2011; Sörensen & Pinquart, 2005). Therefore, these factors will all be considered in this study.

Gaps in the Existing Literature

Given the aforementioned discussion, the effects of government programs on helping caregivers have not yet been comprehensively examined. The gaps in the existing literature are as followed. First, although the access assistance, counseling and training, and respite care services are the main focuses of the NFCSP, and the government reports have shown success in these services and their implementations, most of the reports are limited by their descriptive statistics in nature. Even for those who tried to examine the effects of the programs, many scholars suggested only modest impacts exist on helping caregivers because of insufficient funding, unawareness of services, or lack of time and other resources (Hooyman & Kiyak, 2011).

Second, although government has spent a great amount of money on providing these services, outcomes from previous research were not consistent. That is, although we have a broad picture of the relationship between caregiving burden and strain, we still do not know conclusively what type of burden will lead to a higher level of strain. However, if the government wants to make the best allocation of financial and human resources on its policies, further investigation on this issue is necessary.

Third, although a considerable number of studies have focused on the impacts of services on strain as well as that of burden on strain, few studies have discussed the interaction of both service and burden. Similarly, few studies have examined the effects from both individual and environmental levels. As a result, this study aims at bridging these gaps and providing a different perspective for researchers to examine this issue.

Hypotheses

This study evaluates the effects of caregiver support services on relieving family caregiver's strain in elder adults. The study examines the following hypotheses:

Hypothesis 1: Family caregivers who receive caregiver support services experience less caregiving strain than those who do not use caregiver support services.

1-1. Family caregivers whose state provides more funds on access assistance service in NFCSP will experience less caregiving strain.

1-2. Family caregivers whose state provides more funds on counseling and training service in NFCSP will experience less caregiving strain.

1-3. Family caregivers whose state provides more funds on respite care services in NFCSP will experience less caregiving strain.

Hypothesis 2: Family caregivers who report more caregiving burden experience more caregiving strain

2-1. Family caregivers who spend longer time on caregiving will experience more caregiving strain.

2-2. Family caregivers who spend more hours every week on caregiving will experience more caregiving strain.

2-3. Family caregivers who provide more ADL assistance will experience more caregiving strain.

Hypothesis3: Family caregivers reporting more caregiving burden (longer duration, more hours spent, and more ADL assistance) have more caregiving strain, but further, caregivers who live in states with less expenditure for family caregiver support services (access assistance services, counseling and training services, and respite care services) and who report more caregiving burden have the most caregiving strain.

CHAPTER TWO

THE EFFECTS OF CAREGIVER SUPPORT SERVICES ON RELIEVING CAREGIVING STRAIN IN OLDER ADULTS[1]

---

[1] Lee, Y. and Lewis, D. To be submitted to The Gerontologist.

Abstract

The National Family Caregiver Support Program (NFCSP) is one of the few federal policy initiatives aimed at supporting caregivers. NFCSP was established in 2000 to improve caregivers' physical and mental health through the provision of three major services –caregiver counseling/support groups/training, respite care, and access assistance. The purpose of this study is to examine the effectiveness of this program on caregivers' well-being. Data from the 2004 National Long Term Care Survey (N =1600) were linked to data from the government expenditures on NFCSP in 2004. Hierarchical linear modeling was used to analyze the main effects and the moderating effects of government expenditures on the three NFCSP services on caregiving strain. Findings from the study indicate that expenditures on access assistance and respite care moderate the caregiving burden-caregiving strain relationships. Caregivers reporting higher caregiving burdens have more caregiving strain. Additionally, caregivers who live in states with less expenditure of access assistance and respite care and who report more problems with ADLs, have the most caregiving strain. Interestingly, the interaction between hours of caregiving spent and access assistance indicates that caregivers who report more caregiving hours show higher caregiving strain, but also that the caregivers' strain is even higher for those who report more caregiving hours and live in states with higher expenditure of access assistance services. Findings suggest that NFCSP may represent an important factor that influences the well-being of informal caregivers, and that studies which examine factors at only one level may underestimate the effect of the social environment.

INDEX WORDS: Caregiving strain, Caregiving burden, National family caregiver support services (NFCSP)

Introduction

The American public's attention has been focused on helping aged, disabled, and chronically ill individuals for decades and thereby numerous policies and programs have been implemented throughout the history of the United States, such as Medicare and Medicaid. Although one fourth of aged, infirm, and disabled individuals receive services from paid providers, almost two-thirds of them receive care solely from friends and family members (Lui, Manton, & Aragon, 2000; Whittier, Scharlach, & Dal Santo, 2005). According to Caregiving in the U.S. (National Alliance for Caregiving, 2009), an estimated 65.7 million people in the U.S. have served as unpaid family caregivers to provide care for their clinically ill, disabled, or aged family members or friends each year. Among these caregivers, more than 46 million people have served as informal caregivers for their elder family members or friends.

Caregiving has only recently been acknowledged by the nation as an important topic for millions of Americans. Several factors have led to this reframing of its importance. First, since the care recipients and caregivers are usually closely related and mutually influenced, if the caregiver is healthy, the life quality of the care recipient will be improved. In return, the improvement of the well-being of care recipients will generally lead to a lower level of burden and strain for the caregivers. Second, caregivers with better health are more likely to sustain their caregiving roles and thereby the recipients are more likely to feel comfortable because they or their families will not be troubled by the need to find a substitute caregiver (Talley & Crews, 2007). On the other hand, caregivers who have an overwhelming burden of caregiving responsibilities may feel depressed and stressed, and therefore, lead to worse health for the care recipients as well.

The relationship between caregiving burden and caregiving strain is not an uncharted territory. A general perception of these two factors is that they are positively associated. In general, a person with a higher level of caregiving burden is more likely to experience a higher level of depression, greater financial strain, or greater physical strain. Although few researchers argued that caregiving burden does not affect caregiving strain (Bass, Bowman, & Noelker, 1991; Kim & Schulz, 2008), most researchers claimed otherwise (Brouwer et al., 2004; Sugisawa, Nakatani, & Shibata, 1998; Zarit & Femia, 2008). That is, a majority of studies found that a higher level of caregiving burden is a key factor of a higher level of caregiving strain. Therefore, reducing caregiving burden is believed to be an effective approach to lower caregiving strain.

Unlike many existing public programs focusing on the care recipients, the National Family Caregiver Support Program (NFCSP) was established by Congress in 2000 to improve the physical and mental health of the caregivers. Under this program, states provide five different types of services, including information, access assistance, supplemental assistance, caregiver counseling/support groups/training services, and respite car. Among all the services, access assistance services, counseling and training services, and respite care services are the three main services (Administration on Aging, 2013). Accordingly, this study uses these three services as the main research factors in relieving caregiving strain.

A wealth of information regarding these caregiver support services can be found on government and community reports; however, this information consists mainly of descriptive statistics on how many people or how many units have been served. Few empirical articles have examined the effects of these services on relieving caregivers' strain. Because the aforementioned services are mainly funded by the government, this study will use the 2004 government expenditure on these three services as the major factor to measure the impacts on relieving caregiving strain.

Therefore, the present study aims to examine both individually experienced caregiving burden as well as objectively measured environmental characteristics such as the expenditure of access assistance, counseling and training, and respite care services in NFCSP on caregiving strain. The purpose of this study is to understand (1) the impact on caregiving strain of government expenditure on access assistance, counseling and training, and respite care services; and (2) the impact on caregiving strain of caregiving burdens; and (3) the impact on caregiving strain by the interaction of government expenditure on access assistance, counseling and training, and respite care services, and individual caregiving burden.

Theoretical Framework

Both life-course perspective and political economy perspective provide useful lens with which to view family caregiving. The life-course perspective views a phenomenon, such as elder care, as a phase of the entire course of life. It emphasizes how experiences in early life affect subsequent outcomes and how historical events, social policies, personal decisions, and individual opportunities interact with one another (Elder, 1994; Zhan, 2002). In using the life course perspective in the study of caregiving, researchers have argued that the transition of caregiving is socially constructed and that the state plays a significant policy role in that social construction (Zhan, 2002). In other words, caregiving cannot be understood without knowledge of the prior life-course. Not only the timing and duration of caregiving, but also caregivers' pervious circumstances, roles and resources, may well shape the impacts of caregiving on their well-being in their later lives.

The political economy perspective on aging issue is a macroanalysis of structural characteristics of capitalism that determines how scarce social resources are allocated in old age and those allocations serve to marginalize older people (Hooyman & Kiyak, 2011). The political economy perspective is concerned with the effect of early life opportunities, constraints and choices on income security, health, and well-being in later life (Kail, Quadagno, & Keene, 2009). Thus, socioeconomic and political constraints shape the experience and are patterned not only by age and class but also by gender, sexual orientation, functional ability, and race. These structural factors—often institutionalized and reinforced by public policy—limit the opportunities and choices, resulting in cumulative disadvantages in later life. To complete the life-course perspective, the political economy perspective emphasizes a large and meaningful impact of aggregated disadvantages, especially in socioeconomic and political aspects, in later life. That is, family caregivers who are female, belong to a racial minority and who have lower education level, lower family income, and worse health may not be able to fully access social resources, such as NFCSP, and thereby may suffer a higher level of caregiving burden and strain.

Caregiving Strain

Research examining the effects of caregiving on well-being has focused on caregiving strain, which is the stress felt by the caregivers as they provide care (Prokos & Keene, 2005). A significant number of studies discussed caregiving strain from three perspectives – physical strain, emotional stress and financial hardship (Amirkhanyan & Wolf, 2006; Roth, Perkins, Wadley, Temple, & Haley, 2009). One national survey investigated how much family caregivers spend for the care recipients, and found that the amount of expenses on family caregiving was closely associated with reported stress, health and overall well-being of the caregiver. Survey respondents reported an estimated annual expense of $5,531 on family caregiving, which is more than 10% of the median income of the group ($43,026) (Evercare, 2007).

In terms of physical strain, people who provide informal caregiving are more likely to experience health deterioration. According to a national report, the Evercare Study of Caregivers in Decline (National Alliance for Caregiving, 2006), more than half of caregivers indicated that their health became worse but did not go the doctor. The most three reasons they did so included they put their family's needs first, they put the care recipient's needs over their own, and they did not have time to take care of themselves. In regards to emotional stress, depressive symptoms are the most common outcomes accompanying informal caregiving (Butler, Turner, Kaye, Ruffin, & Downey, 2005). Recent studies have found that 32%–50% of caregivers had depressive symptoms at a level suggesting clinical depression (Rivera, 2009). These attributes of caregiving strain are usually related to each other (Pinquart and Sorensen, 2007; Vitaliano et al., 2003).

Caregiving Burden

Caregiving burden is a recognized concomitant feature of caring for older family members (Freyne, Kidd, Coen, & Lawlor, 1999). Recent studies have operationalized caregiving burden in several ways, including the duration of caregiving, the number of hours of caregiving, and the types of caregiving (Keene, & Prokos, 2008). In 2009, the National Alliance for Caregiving in collaboration with the American Association of Retired Persons (AARP) reported that caregivers averaged 20.4 hours per week providing care. Caregiving is particularly time-intensive for those who live with their care recipient (39.3 hours/week). Duration of care averaged 4.3 years. In terms of types of care caregivers provide, a majority of caregivers help their loved one with at least one Activity of Daily Living (ADL). ADLs refers to the most basic tasks, such as eating, bathing, dressing, and toileting, while IADL refers to keeping track of money, errands, housework, and taking medicine (Freedman, 2004). Although ADL assistance and IADL assistance are two types of caregiving, researchers usually use ADL as an indicator of individuals' basic functioning. Lower levels of care refer to less ADL tasks assistance, while higher levels of care refer to more ADL tasks assistance.

Generally, caregiving burden and caregiving strain are positively correlated. In other words, people who provide longer duration (e.g. Sugihara, Sugisawa, Nakatani, and Shibata, 1998), more hours (e.g. Brouwer and his colleagues, 2004), and assist more ADLs (e.g. Gaugler et al., 2000) of caregiving tend to experience more symptoms of depression, greater financial and physical strain, and lower levels of psychological well-being (Leggett, Zarit, Taylor, & Galvin, 2011); Lin, Chen, & Li, 2013; Pinquart & Sörensen, 2011). Although a few studies showed insignificant relationships between caregiving burden and caregiving strain (Bass, Bowman, & Noelker, 1991; Kim & Schulz, 2008), greater attention must be paid to the way in which the level of caregiving burden significantly affects caregivers' financial, physical and emotional stress.

National Family Caregiver Support Program

Although family caregivers suggest providing care to their loved ones is greatly rewarding, balancing careers, needs of other family members, and personal needs with the complexities of caring for frail and cognitively impaired older persons can be extremely challenging. Recognizing such a dilemma, Congress created the National Family Caregiver Support Program (NFCSP, Title III-E of the Older Americans Act 2000 Reauthorization). This program is one of the few federal policy initiatives aimed at supporting family caregivers as the target group. In 2009, the government provided, on average, services expenditures of $1,058.54 to each family caregiver. However, individual expenditures varied across states due to different state-wide policies.

The NFCSP provides Federal grants to states based on their percentage of the over 70 population to offer a range of services to support family caregivers. The caregiver services work in conjunction with other state and community-based services to provide a coordinated set of supports. This program supported caregivers with multiple programs and services. The three highlighted support service areas identified include: (1) assistance to caregivers in obtaining access to these services; (2) individual counseling, organization of support groups, and caregiver training to assist caregivers in making decisions and solving problems relating to their caregiving roles; and (3) respite care to enable caregivers to be temporarily relieved from their caregiving responsibilities.

Access assistance services. Access assistance services provide contacts to caregivers, assisting them in locating services from a variety of private and voluntary agencies. One goal of NFCSP is to provide information to caregivers about available services and assistance to caregivers in gaining access to these services (Link, 2003). Accessibility to the family caregiving service program in each state is a primary focus in the program's mission because, if caregivers are not aware of services, they cannot use any of those supportive services. Several states are actively addressing accessibility. For example, Alabama, California, Delaware, and Massachusetts have all utilized the concept of a "mobile van tour" to reach remote, hard-to-access areas of their states where caregivers have little opportunity to receive information, or because of the remote location, have difficulty getting to a central point such as a service center to obtain information and service (Link, 2003). For example, in 2002, states, tribes and communities across the country provided assistance in accessing services to approximately 440,000 caregivers (Administration on Aging, 2004).

Whittier, Scharlach and Dal Santo (2005) examined the scope and range of existing resources for family caregivers from the perspective of the Area Agencies on Aging (AAAs), which are charged with implementing Title III-E of the reauthorized Older Americans Act. Their findings showed that major barriers of service accessibility are transportation, financial assistance, in-home workers and other community services in rural areas, and translation services. In addition, the number of these service gaps was not significantly associated with the proportion of the population age 65 or older or the proportion with incomes below the poverty level.

Counseling and training services. Advice and guidance made available to caregivers through the NFCSP can minimize the negative financial, physical and emotional consequences of caregiving. When caregivers are provided opportunities to talk about these challenges, with counselors and peers in similar situations, they will be able to make better care-related decisions and better cope with problems or unique situations that may arise. The Resources for Enhancing Alzheimer's Caregiver Health studies evaluated a variety of multicomponent interventions for family caregivers of persons with Alzheimer's disease and determined that interventions for caregivers should be multifaceted because only one type of intervention does not lead to maximum caregiver benefits (Schulz et al., 2003). Similarly, a systematic review performed by Lopez-Hartmann, Wens, Verhoeven, and Remmen (2012) concluded that group support has a positive effect on caregivers' coping ability, knowledge, social support and reducing depression.

In addition, training and instruction made available to caregivers through the NFCSP can diminish the negative consequences associated with caregiving as well. Proper caregiver training, such as appropriate lifting techniques to transfer an elder person from a chair to a bed, protects the care recipient and the caregiver from injury. Gallagher-Thompson (2007) , in a review of 19 studies, identified evidence-based psychological treatments for reducing distress, and improving well-being, of family members caring for an older relative with significant cognitive and/or physical impairment. The results from these studies showed that the psychoeducational programs, psychotherapy, and multicomponent interventions were all effective. However, individualized cognitive behavior counseling and skills training are considered the most effective approaches to reduce strain and improve caregivers' well-being. Moreover, Smith, Doty, and O'Keefe (2000) also indicated that well-trained informal caregivers are less likely to rely on more costly and formal supports.

Respite care services. Family caregivers play an important role in health care, but they need regular breaks to maintain their own health and well-being. In the context of family caregiving, respite care is an arrangement to give caregivers time for personal activities and space for temporarily relief from the stress they may experience while providing care for family members (Whittier, et al., 2005). Respite care can be either a planned service or short-term emergency relief for caregivers from the demands of ongoing care.

Most studies suggest that respite care services are beneficial and highly needed (AoA, 2003). The practical benefits for caregivers are commonly acknowledged, such as allowing time to rest and relax, freedom to pursue other activities, improve self-esteem, feeling secure about possible breakdown of care arrangements, improvement in family relationships and sleep patterns (Mohide, 2002; Perry & Bontinen, 2001). However, outcomes for caregivers' levels of stress, depression, subjective or objective burden, life satisfaction, physical and emotional well-being are inconsistent and less clear (Gottlieb & Johnson 2000; McNally, Ben-Shlomo, & Newman, 1999; Mason et al, 2007; Shaw et al., 2009).

In the research that reported effectiveness, findings are also mixed. For example, Zarit, Stephens, Townsend and Greene (1998) indicated that caregiver depression, role overload, and anger are reduced when respite care is used at least twice a week and at least for three months. Lopez-Hartmann and her colleagues (2012) also demonstrated that respite care can be helpful in reducing depression, burden and anger. On the contrary, Jeon, Brodaty, and O'Neill (2006) interviewed several mental health professionals, elder caregivers, and respite service providers in order to explore older family caregivers' needs for respite care and their use of respite services when caring for people with a mental illness. Unfortunately, the authors found that not all of the respite services were adequate to meet the primary needs of mentally ill patients and some older carers. As a result, the impacts of respite care and services need further investigation.

Other Individual Demographic Factors

Based on the political economy perspective on aging, family caregivers' background, such as gender, race, socioeconomic status (SES), and functional ability, may shape their experience, and then lead to different levels of caregiving strain in later life. Indeed, women generally tend to report higher levels of caregiving distress (Del-Pino-Casado, Frías-Osuna, Palomino-Moral, & Ramón Martínez-Riera, 2012; Silverstein, Gans, & Yang, 2006). Such differences mainly come from gender-linked vulnerabilities, socialization processes, and role-related inequality (Pinquart & Sorensen, 2003).

The effect of socioeconomic status (SES), such as education and income, may also affect caregiving strain. Most studies indicated that people with higher SES, including higher income and more years of education, are less likely to suffer greater burden when providing care to families or friends (Gallo et al., 2013; Pinquart & Sörensen, 2007). Other research also suggests that age, race, objective health, and the relationship with care recipients are associated with caregiving strain (Pinquart & Sörensen, 2011; Sörensen & Pinquart, 2005). Therefore, these factors were all considered in this study.

Design and Methods

The data used in this research was drawn from the 2004 National Long Term Care Survey (NLTCS),[2] which was sponsored by the U.S. Department of Health and Human Services and was conducted by the Bureau of the Census. The 2004 NLTCS is a survey designed to study the health and functional status of the older population (aged 65 or over) in the United States. Information about caregivers was collected in the caregiver complementary module. Family caregivers who completed the survey were used in the present study (N=1,600).

Dependent Variable

The dependent variable in this study comes from three survey questions in the 2004 NLTCS: "How much of a physical strain would you say that caring for the person is for you?", "How emotionally stressful would you say that caring for the person is for you?", and "How much of a financial hardship would you say that caring for the person is?". Answers were measured in a 5-point Likert Scale: 5 indicating that the caregivers feel a very high level of strain; 1 indicating that the caregivers do not feel strain at all. These three questions were added to create an index for the integrated level of caregiver strain, ranging from 3 (the lowest level of strain) to 15 (the highest level of strain). The reliability of this scale is good (Cronbach's alpha=0.78).

Independent Variable

In order to examine whether the NFCSP has effectively relieved the strains of caregivers, this study collected information about numbers of caregivers from Family Caregiver Alliance

---

[2] "The NLTCS (National Long Term Care Study) is sponsored by the National Institute of Aging and was conducted by the Duke University Center for Demographic Studies under Grant No. U01-AG007198."

(2004) and government expenditures on the NFCSP from the Administration on Aging (2013). The main independent variable of this study is the per capita expenditure on three different categories of the NFCSP services – access assistance, counseling and training, and respite care services. These variables were used to examine whether specific services are effective in relieving caregivers' strain. The per capita expenditure was calculated from dividing the states' expenditures on each service by the total number of caregivers in that state. In order to get reasonable information on government expenditure, states that had fewer than five caregivers on record were excluded. These states were: Alabama, Delaware, District of Columbia, Nevada, New York, North Carolina, Oklahoma, South Dakota, and Virginia. A total of 42 states were used for final analyses. The expenditures were merged with the 2004 NLTCS caregiver module.

The caregiver burden variables include ADL assistance, hours spent, and duration. Hours spent on helping the care recipients was measured by the question, "On average, about how many hours do you spend helping [SAMPNAME] in a typical week?" Duration was measured by the question, "How long ago did you start taking care of [SAMPNAME] because of (his/her) disability?" The ADL assistance was calculated from caregivers' response to six questions, such as "On the days that you helped, how many times per day, on the average, did you help [SAMPNAME] get in or out of bed?" Responses were added into an index where a higher number represents more ADLs that caregivers provided. Other control variables included: a) Gender of the caregivers, b) Race of the caregivers, c) Education level, d) Employment, e) Relationship with the care recipients, f) Health Condition, and g) Having a helper.

Analysis

I tested multilevel regression models in order to examine the influence of individual and community-level predictors on the individual-level outcome variable—caregiving strain. The

Hierarchical Linear Model (HLM) is a multivariate technique suited for this type of design, not only because it accounts for autocorrelation due to clustering, but also because HLM was built from a theoretical base designed to examine multilevel factors (Raudenbush & Bryk, 2002). The analytic plan was to perform a series of HLM models, with initial models including previously identified individual level predictors of caregiving strain, then building to final multilevel models. In order to examine the hypothesis that the association between caregiving strain and caregiving burden is influenced by state-level factors related to the caregiver support services, the final model included state expenditure of access assistance, counseling and train, and respite care services as possible predictors of the slope of caregiving strain. In notation:

$\text{(Caregiving strain)}_{ij} = \beta_{0j} + \beta_{1j}(X_{1ij}) + \beta_{2j}(X_{2ij}) + \ldots + \beta_{14j}(Duration_{ij}) + \beta_{15j}(Hours_{ij}) + \beta_{16j}(ADL_{ij}) + r_{ij}$

Where $r_{ij} \sim N(0, \sigma^2)$

and

$\beta_{0j} = \gamma_{00} + \gamma_{01}\text{(access assistance)} + \gamma_{02}\text{(counseling and train)} + \gamma_{03}\text{(respite care)} + u_{0j}$

$\beta_{1j} = \gamma_{10}$

$\vdots$

$\beta_{13j} = \gamma_{130}$

$\beta_{14j} = \gamma_{140} + \gamma_{141}\text{(access assistance)} + \gamma_{142}\text{(counseling and train)} + \gamma_{143}\text{(respite care)}$

$\beta_{15j} = \gamma_{150} + \gamma_{151}\text{(access assistance)} + \gamma_{152}\text{(counseling and train)} + \gamma_{153}\text{(respite care)}$

$\beta_{16j} = \gamma_{160} + \gamma_{161}\text{(access assistance)} + \gamma_{162}\text{(counseling and train)} + \gamma_{163}\text{(respite care)}$

The most important thing to note is that while caregiving burden were hypothesized to predict caregiving strain, the slopes of caregiving burden are themselves functions of the state-level variables, expenditure of access assistance service (γ_{Q1}), counseling and training service (γ_{Q2}) and respite care service (γ_{Q3}). This allows for an examination of the hypothesis that individual factors may be influenced by objective state conditions. In regards to centering, individual-level variables use grand mean centering in order to avoid nonsensical results because the minimum scores of some variables are more than zero (Raudenbush & Bryk, 2002). Analyses were conducted with HLM 7.0 and PASW18.0.

Results

Table 2 describes the characteristics of the 1600 caregivers and 42 states. Caregivers are moderately healthy and educated. Most of caregivers are white (87.2%), female (65.9%), and taking care of their parents or spouses (84.7%). One third of caregivers still work (34.8%). Two thirds of caregivers have other helpers when they are unavailable (66.6%). On average, caregivers provide median levels of ADL (M=3.447, *SD*=6.686), spend nearly 26 hours per week caring for family members (M=25.089, *SD*=34.457), and take care of those care recipients over two years (M=5.356, *SD*=1.357). In addition, caregivers report a moderately low level of caregiving strain due to caregiving burden or state conditions (M=5.571, *SD*=2.972).

Table 3 represents the hierarchical linear models for caregiving strain. Model 1 examines the associations between individual-level variables excluding caregiving burden and caregiving strain. Results show that gender, race, relationship to caregiver (spouse and child), education level, having other helper, and objective health have significant effects on caregiving strain (β=-0.464, p=0.002; β=2.255, p<0.001; β=0.616, p=0.012; β=0.731, p<0.001; β=0.653, p<0.001; β=-1.533, p<0.001; β=-0.457, p<0.001, respectively). In other words, female, Asian, less healthy individuals, people with some college education, people who take care of their parents or spouses, and people who don't have helpers tend to experience more caregiving strain. Model 2 adds all

Table 2.1

Characteristics of caregivers (n=1600) and states (n=42)

	n	%	
Gender			
Male	546	34.1	
Female	1054	65.9	
Race			
White	1378	86.1	
African American	157	9.8	
Hispanic	18	1.1	
Asian	30	1.9	
Others	17	1.1	
Relationship			
Adult child	833	52.1	
Spouse	521	32.6	
Others	246	15.4	
Education			
High school or less	825	51.6	
Some college	282	17.6	
Bachelors degree	327	22.9	
Master's degree or more	126	7.9	
Employment			
Yes	557	34.8	
No	1043	65.2	
Other helper			
Yes	1065	66.6	
No	535	33.4	
	M	SD	Range
Health	6.701	0.736	1-7
Caregiving Burden			
ADL assistance	3.447	6.686	0-52
Hours spent	25.089	34.157	0-168
Duration	5.356	1.839	1-8
Caregiving Strain	5.571	2.972	3-15
Expenditure of NFCSP (dollar/enrollee)			
Access Assistance	1.306	1.609	0.00-10.93
Expenditure of Counseling & Traini	0.661	0.561	0.00-2.91
Expenditure of Respite	2.444	2.125	0.35-11.07

Table 2.2

Multilevel models for effects of individual and state characteristics on caregiving strain (n=1600)

	Model 1		Model 2		Model 3		Model 4	
	Coefficient	SE	Coefficient	SE	Coefficient	SE	Coefficient	SE
Intercept	5.571	(0.066)***	5.572	(0.060)***	5.570	(0.056)***	5.571	(0.056)***
Male (vs. Female)	-0.464	(0.147)**	-0.289	(0.126)*	0.289	(0.127)*	0.294	(0.127)*
Race (vs. White)								
African American	0.365	(0.340)	0.110	(0.279)	0.089	(0.274)	0.088	(0.271)
Hispanic	0.998	(0.732)	0.693	(0.820)	0.671	(0.796)	0.818	(0.777)
Asian	2.255	(0.456)***	1.510	(0.455)***	1.197	(0.460)***	1.452	(0.494)**
Others	-0.162	(0.594)	-0.184	(0.567)	-0.156	(0.556)	-0.297	(0.526)
Relationship (vs. Others)								
Spouse	0.616	(0.245)*	0.324	(0.222)	0.330	(0.225)	0.327	(0.218)
Child	0.731	(0.190)***	0.581	(0.196)**	0.589	(0.197)**	0.558	(0.192)**
Education (vs. High school								
Some college	0.653	(0.171)***	0.478	(0.170)**	0.477	(0.171)**	0.491	(0.166)**
Bachelors degree	0.250	(0.163)	0.050	(0.158)	0.053	(0.157)	0.070	(0.161)
Master’s degree or more	0.240	(0.199)	0.296	(0.185)	0.279	(0.186)	0.264	(0.186)
Employment (no=0)	-0.087	(0.170)	-0.259	(0.157)	-0.253	(0.157)	-0.269	(0.161)
Other helper (no=0)	-1.533	(0.189)***	-1.079	(0.182)***	-1.086	(0.181)***	-1.075	(0.179)***
Health	-0.457	(0.101)***	-0.473	(0.094)***	-0.469	(0.095)***	-0.460	(0.095)***

Caregiving Burden				
ADL assistance		0.107 (0.012)***	0.107 (0.012)***	0.109 (0.012)***
Hours spent		0.018 (0.003)***	0.018 (0.003)***	0.018 (0.003)***
Duration		0.173 (0.041)***	0.173 (0.042)***	0.169 (0.041)***
Effect on slope of intercept				
Access Assistance ($)			0.013 (0.020)	0.032 (0.022)
Counseling & Training ($)			-0.156 (0.087)	-0.173 (0.088)
Respite Care ($)			0.015 (0.022)	0.016 (0.023)
Effect on slope of ADL assistance				
Access Assistance($)				-0.008 (0.007)**
Counseling & Training ($)				0.040 (0.013)
Respite Care($)				-0.007 (0.003)*
Effect on slope of hours spe				
Access Assistance ($)				0.005 (0.001)***
Counseling & Training ($)				-0.003 (0.003)
Respite Care ($)				0.001 (0.001)
Effect on slope of duration				
Access Assistance ($)				0.009 (0.012)
CSGT($)				-0.062 (0.039)
Respite Care ($)				0.012 (0.012)
Deviance	7879.180347	7617.784436	7630.219566	7638.658549

**p*<0.05; ***p*<0.01; ****p*<0.001

individual-level factors, including three caregiving burdens simultaneously. ADL assistance (β=0.107, p<.001), hours spent(β=0.018, p<.001), and duration (β=0.173, p<.001) are all significantly associated with caregiving strain in the expected direction, supporting prior research that higher level, more hours and longer duration of caregiving lead to more negative psychological outcomes (Pinquart & Sörensen, 2011).

Model 3 includes state-level variables, average per capita expenditure of access assistance, counseling and training, and respite care services, to predict estimated group outcome scores (β_{0j}). Findings show that expenditures of access assistance, counseling and training, and respite care services are not significantly associated with the slope of the intercept. That is, there are no directed effects of average expenditures of caregiver support services on individual's caregiving strain.

Finally, Model 4 adds the state-level variables of expenditure of access assistance, counseling and training, and respite care services to the slopes of the intercept, ADL assistance, hours spent per week, and duration of caregiving. Findings show three significant cross-level interactions between caregiving burden and expenditure of NFCSP. The significant interaction between ADL assistance and counseling and training (β=-0.008, p=.002) indicates 0.08 decrease in the influence of ADL assistance on caregiving strain between two individuals who differ in state expenditure of access assistance services by increasing one dollar when other variables are controlled. Figure 2.1 graphs the interaction between ADL assistance and access assistance, illustrating that caregivers reporting higher level of caregiving have more caregiving strain, but further, that caregivers who live in states with less expenditure of access assistance services and who provide more ADL assistance, experience the most caregiving strain.

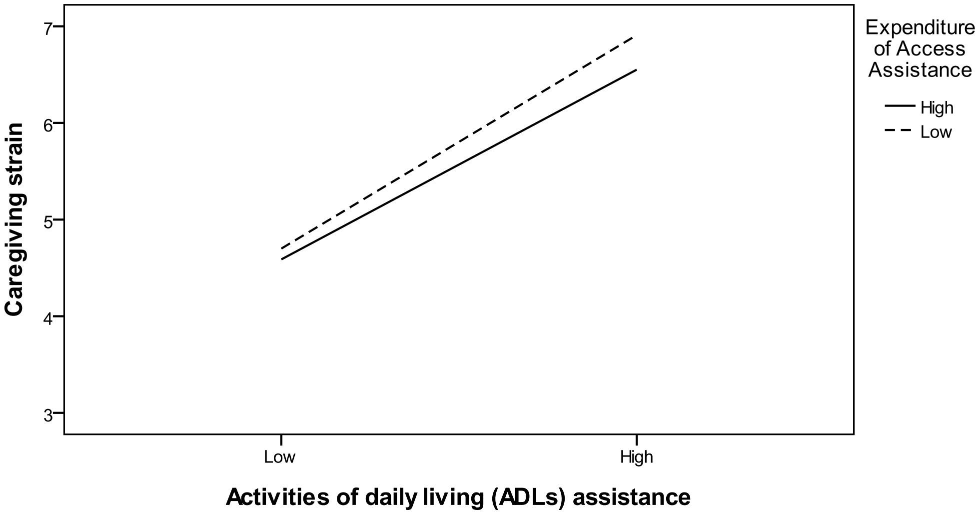

Figure 2.1 Interaction between ADL assistance and access assistance on caregiving strain

Similarly, the significant interaction between ADL assistance and respite care (*β*=-0.007, *p*=.015) indicates a 0.007 decrease in the influence of ADL assistance on caregiving strain between two individuals who differ in state expenditure of respite care services by increasing one dollar when other variables are controlled. Figure 2.2 shows the interaction between ADL assistance and respite care services, demonstrating that caregivers who provide more activities of

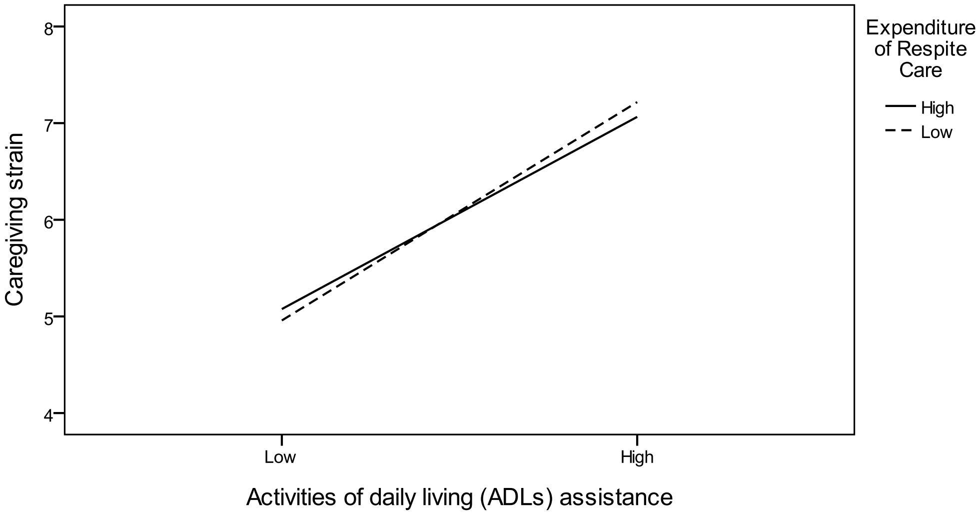

Figure 2.2 Interaction between ADL assistance and respite care on caregiving strain

daily living show higher caregiving strain, but also that the caregivers' strain is even higher for those who report more ADL assistance and live in states with low expenditure of respite care services. The significant interaction between hours spent and access assistance (*β*=0.005, *p*=.001) indicates a 0.005 increase in the influence of hours spent on caregiving strain between two individuals who differ in state expenditure of access assistance services by increasing one dollar when other variables are controlled. Figure 2.3 illustrates the interaction between hours spent and access assistance services. It indicates that caregivers who report more caregiving hours every week show higher caregiving strain, but also that the caregivers' strain is even higher for those who report more caregiving hours and live in states with higher expenditure of access assistance services.

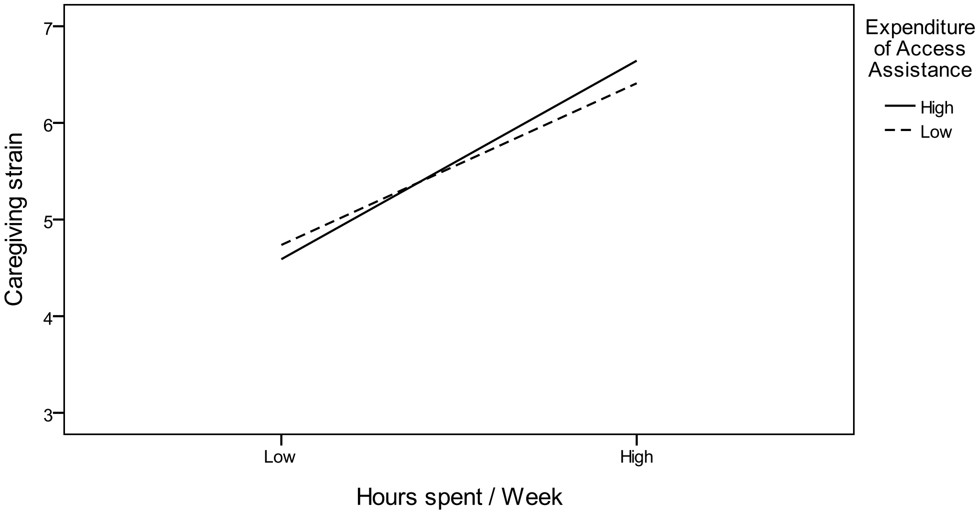

Figure 2.3 Interaction between hours spent and access assistance on caregiving strain

Discussion

This study contributes to the existing literature by providing empirical evidence on the effectiveness of public programs and other important factors that are associated with caregiver's well-being. Based on the aforementioned arguments and evidence from the literature, we proposed a model of how public spending and individual factors could affect caregiver’s strain. Major findings from the study indicate that there exists substantial variation in different types of expenditures. More specifically, expenditures on access assistance and respite care services are found to be influential in caregiving burden-caregiving strain relationships.

The interaction between ADL assistance and access assistance indicate that caregivers who reported ADL assistance and who live in states with high expenditures of access assistance services have significantly lower caregiving strain than those living in areas with low expenditures. That is, the effect of ADL assistance on caregiving strain is worse for caregivers living in environments with less public resources, compared to those living in areas with more public resources. The access services provide community service and send in-home workers to help the caregivers. Therefore, in areas where more funds are allocated to such services, the impact of caregiving tasks on caregivers’ strain would be attenuated by the availability of this assistance. Similarly, the interaction is also found between ADL assistance and respite care services, demonstrating that caregivers who help care recipients with ADLs show higher caregiving strain, but further, the caregivers’ strain is even higher for those who report more ADL assistance and live in states with low expenditures of respite care services. It is not surprising that many in-home respite services provide companionship, supervision and/or assistance with activities of daily living for mental or physically disabled and frail elderly persons in the absence of the primary caregiver (Michigan Office of Services to the Aging, 2007).

Interestingly, the interaction between hours of caregiving spent in a week and access assistance services indicates that caregivers who report more caregiving hours show higher caregiving strain, but also that the caregivers’ strain is even higher for those who report more caregiving hours and live in states with higher expenditure of access assistance services. In states where more money was spent on access service, caregivers generally should have received more help from the program, which may eventually relieve their strain. However, such a relief may create negative impact on caregivers who are aware of but cannot utilize the service. In other words, caregivers who are aware of but unable to use caregiving-related assistance may be more depressed than others who spend the same amount of time for caregiving but are not aware of these services. In terms of duration of caregiving, however, we did not find any significant interaction with those services. It may be because the duration of caregiving mainly depends on care recipients' illnesses (Freyne, Kidd, Coen, & Lawlor, 1999).

In addition to the expenditure of the three main services in NFCSP, findings indicate that more caregiving burdens lead to higher caregivers' strain. Consistent with prior literature, people who provide higher levels, more hours and longer duration of caregiving tend to show more depressive symptoms or physical strain, since taking care of older family members is such a highly stressful task (Keene & Prokos, 2008). Other individual-level variables including the caregiver's gender, race, educational level, physical health status, and relationship to care recipients influence caregiving strain as well. The outcome reflects the political economy perspective on aging that minority is less likely to access social resources, and then suffer a higher level of caregiving strain.

Consistent with previous studies, women tend to experience more caregiving strain because they are more likely to sense stress and be emotional (Silverstein, Gans & Yang, 2006). Also, people with worse physical health may have more caregiving strain since they are less able to handle such a heavy workload (Roth, et al., 2009). In terms of relationship to care recipients, people who take care of their parents or parents-in-law tend to have psychological stress and feelings of guilt (Conde-Sala, Garre-Olmo, Turró-Garriga, Vilalta-Franch & López-Pousa, 2010).

This finding may also explains why Asian exhibits higher level of caregiving strain. Asian-American caregivers are often daughters-in-law who are expected to take on the caregiver role regardless of the quality of their relationship to their in-laws (Pinquart & Sörensen, 2005).

Admittedly, there are some limitations that need to be addressed. First, although the expenditure information used in this study is the actual spending on each of the NFCSP services, such information does not represent the quantity and quality of services provided. It is challenging to determine the quantity and quality of each NFCSP service caregivers receive from the existing data. The relationship between the government expenditure and services caregivers receive is beyond the scope of this study.

Second, although we include most of the major factors that could affect caregiver's strain, we cannot rule out the possibility that omitted variables exist. For example, one commonly mentioned characteristic that could drive people to seek public employment is caregivers' age (Kim & Schulz, 2008). People with younger age generally suffer less caregiving strain than people with older age. If so, then neglecting caregivers' age may cause omitted variable bias to this study. However, missing this variable may not lead to serious omitted variable bias. Not only because caregivers' age is not highly correlated with government expenditure, but also other factors related to caregivers' age, such as relationship and health conditions, are controlled in the model. Therefore, missing it should not lead to serious bias since the impacts were captured in the error term.

Finally, although expenditures on helping caregivers vary from state to state, information at the state level may not capture detailed variations in terms of local differences. For example, every county has its own Area Agencies on Aging (AAAs), and sometimes the AAAs may provide caregiver support services by integrating with other programs. However, such limitation may suggest avenues for further research. With sufficient resources and access to more detailed information at the county level, researchers may be able to further investigate the impacts of local government expenditure.

Reference

Administration on Aging (2013). *National Family Caregiver Support Program (OAA Title IIIE)*. Retrieved from: http://www.aoa.gov/AoARoot/AoA_Programs/HCLTC/Caregiver/index.aspx

Administration on Aging (2013). *FY 2004 Title III-E - National Family Caregiver Support Program*. Retrieved from: www.aoa.gov/aoaroot/program_results/SPR/docs/III-E%202004.xls

Administration on Aging (2004). *The older Americans act-National family caregiver support program: Compassion in Action.* Retrieved from: http://www.aoa.gov/aoaroot/program_results/docs/Program_Eval/FINAL%20NFCSP%20Report%20July22,%202004.pdf

Amirkhanyan, A. A., & Wolf, D. A. (2006). Parent care and the stress process: Findings from panel data. *Journals of Gerontology Series B-Psychological Sciences and Social Sciences, 61*(5), S248–S255.

Bass, D. M., Bowman, K., & Noelker, L. S. (1991). The influence of caregiving and bereavement support on adjusting to an older relative's death. *The Gerontologist, 31*(1), 32-42.

Brouwer, W. B. F., van Exel, N. J. A., van de Berg, B., Dinant, H. J., Koopmanschap, M. A., & van den Bos, G. A. M. (2004). Burden of caregiving: Evidence of objective burden, subjective burden, and quality of life impacts on informal caregivers of patients with rheumatoid arthritis. *Arthritis & Rheumatism, 51*(4), 570-577.

Butler, S. S., Turner, W., Kaye, L. W., Ruffin, L., & Downey, R. (2005). Depression and caregiver burden among rural elder caregivers. *Journal of Gerontological Social Work, 46*(1), 47-63.

Conde-Sala, J. L., Garre-Olmo, J., Turró-Garriga, O., Vilalta-Franch, J., & López-Pousa, S. (2010). Quality of life of patients with Alzheimer's disease: differential perceptions between spouse and adult child caregivers. *Dementia and geriatric cognitive disorders*, *29*(2), 97-108.

Del-Pino-Casado, R., Frías-Osuna, A., Palomino-Moral, P. A., & Ramón Martínez-Riera, J. (2012). Gender Differences Regarding Informal Caregivers of Older People. *Journal Of Nursing Scholarship*, *44*(4), 349-357. doi:10.1111/j.1547-5069.2012.01477.x

Elder, G. H. (1994). *Families in troubled times: Adapting to change in rural America*. Transaction Publishers.

Evercare in collaboration with National Alliance for Caregiving (2007). *Family caregivers – What they spend, what they sacrifice: Findings from a national survey.* Retrieved from: http://www.caregiving.org/data/Evercare_NAC_CaregiverCostStudyFINAL20111907.pdf

Family Caregiver Alliance 2004. *The state of the states in family caregiver support: A 50-state study*. Retrieved from: http://www.caregiver.org/caregiver/jsp/content/pdfs/50_state_report_complete.pdf

Freedman, V. A., Crimmins, E., Schoeni, R. F., Spillman, B. C., Aykan, H., Kramarow, E., ... & Waidmann, T. (2004). Resolving inconsistencies in trends in old-age disability: report from a technical working group. *Demography, 41*(3), 417-441.

Freyne, A., Kidd, N., Coen, R., & Lawlor, B. A. (1999). Burden in carers of dementia patients: higher levels in carers of younger sufferers. *International Journal of Geriatric Psychiatry, 14*(9), 784-788.

Gallagher-Thompson, D. (2007). Exciting advances in family caregiver research. *Aging & Mental Health, 11*(6), 613-615.

Gallo, L., Shivpuri, S., Gonzalez, P., Fortmann, A., los Monteros, K., Roesch, S., & ... Matthews, K. (2013). Socioeconomic status and stress in Mexican-American women: a multi-method perspective.*Journal Of Behavioral Medicine*, *36*(4), 379-388. doi:10.1007/s10865-012-9432-2

Gaugler, J. E., Edwards, A. B., Femia, E. E., Zarit, S. H., Stephens, M. A. P., Townsend, A., & Greene, R. (2000). Predictors of Institutionalization of Cognitively Impaired Elders Family Help and the Timing of Placement. *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences*, *55*(4), 247-255.

Gottlieb, B. H., & Johnson, J. (2000). Respite programs for caregivers of persons with dementia: a review with practice implications. *Aging & Mental Health*, *4*(2), 119-129.

Hooyman, N., & Kiyak H. A. (2009). *Social gerontology: A multidisciplinary perspective* (9th Edition). MA: Pearson Education Inc.

Jeon, Y. H., Brodaty, H., O'Neill, C., & Chesterson, J. (2006). ‘Give me a break’–respite care for older carers of mentally ill persons. *Scandinavian journal of caring sciences*, *20*(4), 417-426.

Kail, B. L., Quadagno, J., & Keene, J. R. (2009). The political economy perspective of aging. *Handbook of theories of aging*, 555-72.

Keene, J. R., & Prokos, A. H. (2008). Widowhood and the end of spousal care-giving: Relief or wear and tear? *Ageing & Society, 28*(4), 551-570.

Kim, Y., & Schulz, R. (2008). Family caregivers' strains: Comparative analysis of cancer caregiving with dementia, diabetes, and frail elderly caregiving. *Journal of Aging and Health, 20*(5), 483-503.

Leggett, A. N., Zarit, S., Taylor, A., & Galvin, J. E. (2011). Stress and burden among caregivers of patients with Lewy body dementia. *The Gerontologist,51*(1), 76-85.

Lin, W., Chen, L., & Li, T. (2013). Adult Children's Caregiver Burden and Depression: The Moderating Roles of Parent-Child Relationship Satisfaction and Feedback from Others. *Journal Of Happiness Studies,14*(2), 673-687. doi:10.1007/s10902-012-9348-0

Link, G. (2003). The Aging Network Implements The National Family Caregiver Support Program. Washington, D.C.: Department of Health and Human Services.

Liu, K., Manton, K. G., & Aragon, C. (2000). Changes in home care use by disabled elderly persons: 1982-1994. J*ournals of Gerontology: Series B: Psychological Sciences and Social Sciences*, *55B*(4), 245-S253.

Lopez-Hartmann, M., Wens, J., Verhoeven, V., & Remmen, R. (2012). The effect of caregiver support interventions for informal caregivers of community-dwelling frail elderly: a systematic review. *International Journal of Integrated Care (IJIC)*, 121-16.

Mason, A., Weatherly, H., Spilsbury, K., Arksey, H., Golder, S., Adamson, J., ... & Glendinning, C. (2007). A systematic review of the effectiveness and cost-effectiveness of different models of community-based respite care for frail older people and their carers.

McNally, S., Ben-Shlomo, Y., & Newman, S. (1999). The effects of respite care on informal carers' well-being: a systematic review. *Disability & Rehabilitation*, *21*(1), 1-14.

Michigan Office of Services to the Aging (2007). *State plan for services to Michigan's older adults fiscal years 2008-2010.* Retrieved from: http://www.michigan.gov/documents/miseniors/StatePlan08-10-final_216462_7.pdf

Mohide, E. A. (2002). Caregivers described how an Alzheimer's disease respite programme gave them time to attend to their own needs. *Evidence Based Mental Health*, *5*(1), 32-32.

National Alliance for Caregiving (2006). *Evercare Study of Caregivers in Decline.* Retrieved from: www.caregiving.org/data/Caregivers%20in%20Decline%20Study-FINAL-lowres.pdf

National Alliance for Caregiving in collaboration with AARP (2009). Caregiving in the U.S. 2009: Executive summary. Retrieved from: http://assets.aarp.org/rgcenter/il/caregiving_09_es.pdf

National Long Term Care Study, Beta2 public use dataset 2006. Produced by the Duke University Center for Demographic Studies with funding from the National Institute on Aging under Grant No. U01-AG007198." 2006. Ann Arbor, MI: Inter-university Consortium for Political and Social Research [distributor].

Perry, J., & Bontinen, K. (2001). Evaluation of a weekend respite program for persons with Alzheimer disease. *The Canadian journal of nursing research= Revue canadienne de recherche en sciences infirmieres*, *33*(1), 81-95.

Pinquart, M., & Sorensen, S. (2003). Differences between caregivers and noncaregivers in psychological health and physical health: A meta-analysis. *Psychology and Aging, 18,* 250–267.

Pinquart, M., & Sörensen, S. (2005). Ethnic differences in stressors, resources, and psychological outcomes of family caregiving: A meta-analysis. *The Gerontologist*, *45*(1), 90-106.

Pinquart, M., & Sörensen, S. (2007). Correlates of physical health of informal caregivers: a meta-analysis. *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences*, *62*(2), 126-137.

Pinquart, M., & Sörensen, S. (2011). Spouses, adult children, and children-in-law as caregivers of older adults: A meta-analytic comparison. *Psychology and Aging, 26*(1), 1-14.

Prokos, A. H., & Keene, J. R. (2005). The Long‐Term Effects of Spousal Care Giving on Survivors' Well‐Being in Widowhood*. *Social science quarterly*, *86*(3), 664-682.

Rivera, H. R. (2009). Depression symptoms in cancer caregivers. *Clinical Journal Of Oncology Nursing, 13*(2), 195-202.

Roth, D. L., Perkins, M., Wadley, V. G., Temple, E. M., & Haley, W. E. (2009). Family caregiving and emotional strain: associations with quality of life in a large national sample of middle-aged and older adults. *Quality Of Life Research: An International Journal of Quality Of Life Aspects of Treatment, Care and Rehabilitation, 18*(6), 679-688.

Schulz, R., Mendelsohn, A. B., Haley, W. E., Mahoney, D., Allen, R. S., Zhang, S., & Belle, S. H. (2003). End-of-life care and the effects of bereavement on family caregivers of persons with dementia. *The New England Journal of Medicine, 349*(20), 1936-1942.

Shaw, C., McNamara, R., Abrams, K., Cannings-John, R., Hood, K., Longo, M., ... & Williams, K. (2009). Systematic review of respite care in the frail elderly. *Health Technology Assessment: Executive summaries, 13*(20). doi: 10.3310/hta13200

Silverstein, M., Gans, D., & Yang, F. M. (2006). Intergenerational support to aging parents. Journal of Family Issues, 27(8), 1068–1084.

Smith, G., Doty, P., & O'Keefe, J. (2000). Supporting informal caregiving.*Understanding Medicaid Home and Community Services: A Primer. US Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation, Washington, DC*.

Sörensen, S., & Pinquart, M. (2005). Racial and ethnic differences in the relationship of caregiving stressors, resources, and sociodemographic variables to caregiver depression and perceived physical health. *Aging & Mental Health*, *9*(5), 482-495.

Sugihara, Y., Sugisawa, H., Nakatani, Y., & Shibata, H. (1998). Impact of duration of caregiving of stress among primary caregivers of elderly. *Japanese Journal of Public Health, 45,* 320-335.

Talley, R. C., & Crews, J. E. (2007). Framing the public health of caregiving.*American Journal of Public Health*, *97*(2), 224-228.

Vitaliano, P. P., Scanlan, J. M., Zhang, J., Savage, M. V., Hirsch, I. B., & Siegler, I. C. (2002). A path model of chronic stress, the metabolic syndrome, and coronary heart disease. *Psychosomatic medicine*, *64*(3), 418-435.

Whittier, S., Scharlach, A., & Dal Santo, T. S. (2005). Availability of caregiver support services: Implications for implementation of the National Family Caregiver Support Program. *Journal of Aging & Social Policy*, *17*(1), 45-62.

Zarit, S. H., Stephens, M. A. P., Townsend, A., & Greene, R. (1998). Stress reduction for family caregivers: Effects of adult day care use. *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences*, *53*(5), S267-S277.

Zarit, S., & Femia, E. (2008). Behavioral and psychosocial interventions for family caregivers. *American Journal of Nursing, 108*(Supplement), 47-53.

Zhan, H. J. (2002). Chinese caregiving burden and the future burden of elder care in life-course perspective. *The International Journal of Aging and Human Development*, *54*(4), 267-290.

CHAPTER THREE

CONCLUSION

This study contributes to the existing literature by providing evidence for the impacts of caregiving burden and caregiver support services on family caregivers' strain. Findings from the 2004 NLTCS data suggest significant association between caregiving burden and caregiving strain. Consistent with prior literature, people who provide higher levels, more hours and longer duration of caregiving tend to show more strain because taking care of older family members is considered a highly stressful task (Keene & Prokos, 2008).

Findings further suggest that the association between caregiving strain and caregiving burden is influenced by the state-level factors related to the caregiver support services. Although caregiving burden is associated with decreased well-being for all respondents, persons who provided more ADL assistance and who lived in states with high expenditures of access assistance and respite care services have significantly lower well-being than those living in areas with low expenditures of access assistance and respite care services. The access assistance provides services such as multilingual and culturally appropriate access, transportation, and in-home workers in rural areas to help the caregivers (Whittier, & Scharlach, 2005). Thus, in areas where more funds are allocated to such services, the impact of caregiving tasks on caregivers' strain would be attenuated by the availability of this assistance. In addition, in the absence of the primary caregiver, respite care services would provide companionship, supervision, and assistance with ADLs for mental or physically disabled and frail elderly persons. Therefore, caregivers may be able to take a break and maintain their own health and well-being.

An unexpected outcome is found from the interaction between hours of caregiving spent in a week and access assistance services. That is, caregivers who report more caregiving hours show higher caregiving strain, but that the caregivers' strain is even higher for those who report more caregiving hours and live in states with higher expenditure of access assistance services. Since expenditure information does not represent the quantity and quality of services received, caregivers who are aware of but unable to use caregiving-related assistance may be more depressed than others who spend the same amount of time for caregiving but are not aware of these services.

Another contribution of this study is that caregiver's personal circumstances are related to their caregiving strain. These results are consonant with the political economy perspective and life-course perspective that individual's experience in early life may affect subsequent outcomes on income security, health, and well-being in later life. Findings suggest that female, Asian, individual with some college education, and unhealthy person tend to experience more caregiving strain and lower levels on their well-being. The outcome reflects theoretical perspective that minorities are less likely to have access to social resources and thereby resulting in higher levels of caregiving strain.

Implications and future research

Several important implications can be drawn from the aforementioned findings. First, according to the expenditure information in this study, the total expenditure for NFCSP funding, including the funding for Native American Caregiver Support, is $171 million for fiscal year 2004. Since the estimated economic value of caregivers' unpaid contributions was approximately $375 billion, this represents less than one-twentieth of one percent of the economic value of caregivers' contributions. In order to keep government expenditure for family caregivers as low as possible and promote caregivers' well-being to avoid the need for costly formal care, federal and state governments should allocate more money and advance the existing caregiver support services infrastructure, especially access and respite care services.

Second, since only indirect and moderate effects of caregiver support services are found, governments and communities should further evaluate each service provided. Policymakers and program managers should evaluate services that did not effectively help relieving family caregiver's strain in order to provide more appropriate services. Specifically, these services should target minorities because their current positions are relatively disadvantaged and they generally have more difficulties access social resources. Therefore, it is the government's responsibility to leverage policy tools such as these welfare programs to maximize the welfare of the least well-off. Third, since caregiving strain and caregiving burden are positively correlated, caregivers may increase their overall well-being if they have more knowledge on how to reduce their caregiving burden. In order to achieve this goal, however, caregivers should actively seek helps, which includes asking friends for help or take advantage of all kinds of services provided by the government programs. For example, the family support service teaches caregivers the skills they need to better taking care of their families. With adequate knowledge and skills, caregivers may feel more comfortable doing their jobs and thereby sense less stress at the same time. Also, caregivers could seek more helps from the respite care service so that they could get more free time and personal spaces when they feel their levels of stain have reached the boiling point.

Some of the research findings and limitations suggest avenues for further research. First, since every county has its own AAA, and sometimes the AAAs may provide caregiver support services by integrating with other programs, using information at the state level may not capture all these variations. Therefore, with sufficient resources and access to more detailed information at the county level, researchers may be able to further investigate the impacts of local government expenditure.

Second, although three family support services discussed in this study were the highlighted services from AoA, each main service includes several contents. Different contents may show different impacts on caregivers' well-being. For example, the counseling and training services include peer counseling, retreat, and community education classes. Researcher may explore the influence of each content on relieving caregivers' strain.

REFERENCE

Administration on Aging (2013). *National Family Caregiver Support Program (OAA Title IIIE)*. Retrieved from: http://www.aoa.gov/AoARoot/AoA_Programs/HCLTC/Caregiver/index.aspx

Administration on Aging (2004). *The older Americans act-National family caregiver support program: Compassion in Action.* Retrieved from: http://www.aoa.gov/aoaroot/program_results/docs/Program_Eval/FINAL%20NFCSP%20Report%20July22,%202004.pdf

Amirkhanyan, A. A., & Wolf, D. A. (2006). Parent care and the stress process: Findings from panel data. *Journals of Gerontology Series B-Psychological Sciences and Social Sciences, 61*(5), S248–S255.

Barnett, R. & Baruch, G. (1987). Social roles, gender, and psychological distress. In Barnett, R., Biener, L., & Baruch, G. (eds.), *Gender and Stress*. New York: Free Press.

Bass, D. M., Bowman, K., & Noelker, L. S. (1991). The influence of caregiving and bereavement support on adjusting to an older relative's death. *The Gerontologist, 31*(1), 32-42.

Beach, S. R., Schulz, R., Yee, J. L., & Jackson, S. (2000). Negative and positive health effects of caring for a disabled spouse: Longitudinal findings from the Caregiver Health Effects Study. *Psychology and Aging, 15*, 259–342.

Brouwer, W. B. F., van Exel, N. J. A., van de Berg, B., Dinant, H. J., Koopmanschap, M. A., & van den Bos, G. A. M. (2004). Burden of caregiving: Evidence of objective burden, subjective burden, and quality of life impacts on informal caregivers of patients with rheumatoid arthritis. *Arthritis & Rheumatism, 51*(4), 570-577.

Butler, S. S., Turner, W., Kaye, L. W., Ruffin, L., & Downey, R. (2005). Depression and caregiver burden among rural elder caregivers. *Journal of Gerontological Social Work, 46*(1), 47-63.

Choi, H. (1993). Cultural and non-cultural factors as determinants of caregiver burden for the impaired elderly in South Korea. *The Gerontologist, 33*(1), 8-15.

Del-Pino-Casado, R., Frías-Osuna, A., Palomino-Moral, P. A., & Ramón Martínez-Riera, J. (2012). Gender Differences Regarding Informal Caregivers of Older People. *Journal Of Nursing Scholarship*, *44*(4), 349-357. doi:10.1111/j.1547-5069.2012.01477.x

Elder, G. H. (1994). *Families in troubled times: Adapting to change in rural America*. Transaction Publishers.

Elder, G. H. (Ed.). (1985). *Life course dynamics: Trajectories and transitions, 1968-1980* (p. 23). Ithaca, NY: Cornell University Press.

Evercare in collaboration with National Alliance for Caregiving (2007). *Family caregivers – What they spend, what they sacrifice: Findings from a national survey.* Retrieved from: http://www.caregiving.org/data/Evercare_NAC_CaregiverCostStudyFINAL20111907.pdf

Ferraro, K. F., & Kelley-Moore, J. A. (2003). Cumulative disadvantage and health: long-term consequences of obesity. *American Sociological Review,68*(5), 707.

Freedman, V. A., Crimmins, E., Schoeni, R. F., Spillman, B. C., Aykan, H., Kramarow, E., ... & Waidmann, T. (2004). Resolving inconsistencies in trends in old-age disability: report from a technical working group. *Demography, 41*(3), 417-441.

Freyne, A., Kidd, N., Coen, R., & Lawlor, B. A. (1999). Burden in carers of dementia patients: higher levels in carers of younger sufferers. *International Journal of Geriatric Psychiatry, 14*(9), 784-788.

Gallagher-Thompson, D. (2007). Exciting advances in family caregiver research. *Aging & Mental Health, 11*(6), 613-615.

Gallo, L., Shivpuri, S., Gonzalez, P., Fortmann, A., los Monteros, K., Roesch, S., & ... Matthews, K. (2013). Socioeconomic status and stress in Mexican-American women: a multi-method perspective.*Journal Of Behavioral Medicine*, *36*(4), 379-388. doi:10.1007/s10865-012-9432-2

Gaugler, J. E., Edwards, A. B., Femia, E. E., Zarit, S. H., Stephens, M. A. P., Townsend, A., & Greene, R. (2000). Predictors of Institutionalization of Cognitively Impaired Elders Family Help and the Timing of Placement. *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences*, *55*(4), 247-255.

Gottlieb, B. H., & Johnson, J. (2000). Respite programs for caregivers of persons with dementia: a review with practice implications. *Aging & Mental Health*, *4*(2), 119-129.

Hooyman, N., & Kiyak H. A. (2009). *Social gerontology: A multidisciplinary perspective* (9th Edition). MA: Pearson Education Inc.

Jeon, Y. H., Brodaty, H., O'Neill, C., & Chesterson, J. (2006). ‘Give me a break’–respite care for older carers of mentally ill persons. *Scandinavian journal of caring sciences*, *20*(4), 417-426.

Kail, B. L., Quadagno, J., & Keene, J. R. (2009). The political economy perspective of aging. *Handbook of theories of aging*, 555-72.

Keene, J. R., & Prokos, A. H. (2008). Widowhood and the end of spousal care-giving: Relief or wear and tear? *Ageing & Society, 28*(4), 551-570.

Kim, Y., & Schulz, R. (2008). Family caregivers' strains: Comparative analysis of cancer caregiving with dementia, diabetes, and frail elderly caregiving. *Journal of Aging and Health, 20*(5), 483-503.

Leggett, A. N., Zarit, S., Taylor, A., & Galvin, J. E. (2011). Stress and burden among caregivers of patients with Lewy body dementia. *The Gerontologist,51*(1), 76-85.

Lin, W., Chen, L., & Li, T. (2013). Adult Children's Caregiver Burden and Depression: The Moderating Roles of Parent-Child Relationship Satisfaction and Feedback from Others. *Journal Of Happiness Studies,14*(2), 673-687. doi:10.1007/s10902-012-9348-0

Link, G. (2003). The Aging Network Implements The National Family Caregiver Support Program. Washington, D.C.: Department of Health and Human Services.

Liu, K., Manton, K. G., & Aragon, C. (2000). Changes in home care use by disabled elderly persons: 1982-1994. J*ournals of Gerontology: Series B: Psychological Sciences and Social Sciences*, *55B*(4), 245-S253.

Lopez-Hartmann, M., Wens, J., Verhoeven, V., & Remmen, R. (2012). The effect of caregiver support interventions for informal caregivers of community-dwelling frail elderly: a systematic review. *International Journal of Integrated Care (IJIC)*, 121-16.

Mason, A., Weatherly, H., Spilsbury, K., Arksey, H., Golder, S., Adamson, J., ... & Glendinning, C. (2007). A systematic review of the effectiveness and cost-effectiveness of different models of community-based respite care for frail older people and their carers.

McNally, S., Ben-Shlomo, Y., & Newman, S. (1999). The effects of respite care on informal carers' well-being: a systematic review. *Disability & Rehabilitation*, *21*(1), 1-14.

Moen, P., Dempster-McClain, D., & Williams Jr, R. M. (1992). Successful aging: A life-course perspective on women's multiple roles and health. *American Journal of Sociology*, 1612-1638.

Moen, P., Robison, J., & Dempster-McClain, D. (1995). Caregiving and women's well-being: A life course approach. *Journal of Health and Social Behavior*, *36* (3), 259-273.

Mohide, E. A. (2002). Caregivers described how an Alzheimer's disease respite programme gave them time to attend to their own needs. *Evidence Based Mental Health*, *5*(1), 32-32.

National Alliance for Caregiving (2006). *Evercare Study of Caregivers in Decline.* Retrieved from: www.caregiving.org/data/Caregivers%20in%20Decline%20Study-FINAL-lowres.pdf

National Alliance for Caregiving and AARP (2004). *Caregiving in the U.S.* Retrieved from: http://www.caregiving.org/data/04finalreport.pdf

National Alliance for Caregiving in collaboration with AARP (2009). Caregiving in the U.S. 2009: Executive summary. Retrieved from: http://assets.aarp.org/rgcenter/il/caregiving_09_es.pdf

Perry, J., & Bontinen, K. (2001). Evaluation of a weekend respite program for persons with Alzheimer disease. *The Canadian journal of nursing research= Revue canadienne de recherche en sciences infirmieres*, *33*(1), 81-95.

Pinquart, M., & Sorensen, S. (2003). Differences between caregivers and noncaregivers in psychological health and physical health: A meta-analysis. *Psychology and Aging, 18,* 250–267.

Pinquart, M., & Sörensen, S. (2005). Ethnic differences in stressors, resources, and psychological outcomes of family caregiving: A meta-analysis. *The Gerontologist*, *45*(1), 90-106.

Pinquart, M., & Sörensen, S. (2007). Correlates of physical health of informal caregivers: a meta-analysis. *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences*, *62*(2), 126-137.

Pinquart, M., & Sörensen, S. (2011). Spouses, adult children, and children-in-law as caregivers of older adults: A meta-analytic comparison. *Psychology and Aging*, *26*(1), 1-14.

Rivera, H. R. (2009). Depression symptoms in cancer caregivers. *Clinical Journal Of Oncology Nursing*, *13*(2), 195-202.

Roth, D. L., Perkins, M., Wadley, V. G., Temple, E. M., & Haley, W. E. (2009). Family caregiving and emotional strain: associations with quality of life in a large national sample of middle-aged and older adults. *Quality Of Life Research: An International Journal of Quality Of Life Aspects of Treatment, Care and Rehabilitation*, *18*(6), 679-688.

Schulz, R., Mendelsohn, A. B., Haley, W. E., Mahoney, D., Allen, R. S., Zhang, S., & Belle, S. H. (2003). End-of-life care and the effects of bereavement on family caregivers of persons with dementia. *The New England Journal of Medicine*, *349*(20), 1936-1942.

Shaw, C., McNamara, R., Abrams, K., Cannings-John, R., Hood, K., Longo, M., ... & Williams, K. (2009). Systematic review of respite care in the frail elderly. *Health Technology Assessment: Executive summaries, 13*(20). doi: 10.3310/hta13200

Silverstein, M., Gans, D., & Yang, F. M. (2006). Intergenerational support to aging parents. Journal of Family Issues, 27(8), 1068–1084.

Smith, G., Doty, P., & O’Keefe, J. (2000). Supporting informal caregiving.*Understanding Medicaid Home and Community Services: A Primer. US Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation, Washington, DC.*

Sörensen, S., & Pinquart, M. (2005). Racial and ethnic differences in the relationship of caregiving stressors, resources, and sociodemographic variables to caregiver depression and perceived physical health. *Aging & Mental Health*, *9*(5), 482-495.

Sugihara, Y., Sugisawa, H., Nakatani, Y., & Shibata, H. (1998). Impact of duration of caregiving of stress among primary caregivers of elderly. *Japanese Journal of Public Health, 45,* 320-335.

Talley, R. C., & Crews, J. E. (2007). Framing the Public Health of Caregiving. American Journal of Public Health, 97(2), 224-228.

Talley, R. C., & Crews, J. E. (2007). Framing the public health of caregiving.*American Journal of Public Health*, *97*(2), 224-228.

Vitaliano, P. P., Scanlan, J. M., Zhang, J., Savage, M. V., Hirsch, I. B., & Siegler, I. C. (2002). A path model of chronic stress, the metabolic syndrome, and coronary heart disease. *Psychosomatic medicine*, *64*(3), 418-435.

Whittier, S., Scharlach, A., & Dal Santo, T. S. (2005). Availability of caregiver support services: Implications for implementation of the National Family Caregiver Support Program. *Journal of Aging & Social Policy*, *17*(1), 45-62.

Zarit, S. H., Stephens, M. A. P., Townsend, A., & Greene, R. (1998). Stress reduction for family caregivers: Effects of adult day care use. *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences*, *53*(5), S267-S277.

Zarit, S., & Femia, E. (2008). Behavioral and psychosocial interventions for family caregivers. *American Journal of Nursing, 108*(Supplement), 47-53.

Zhan, H. J. (2002). Chinese caregiving burden and the future burden of elder care in life-course perspective. *The International Journal of Aging and Human Development*, *54*(4), 267-290.