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The New Face of Caregiving: Multidimensional Factors of Caregiver Burden Among Young Adult Caregivers

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The New Face of Caregiving:
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in Social Welfare

by

Courtney Marie Demko

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ABSTRACT OF THE DISSERTATION

The New Face of Caregiving:
Multidimensional Factors of Caregiver Burden
Among Young Adult Caregivers

by

Courtney Marie Demko
Doctor of Philosophy in Social Welfare
University of California, Los Angeles, 2021
Professor Fernando M. Torres-Gil, Chair

As the older adult population increases in the United States, more young adults will become family caregivers. This study examines the multidimensional factors associated with caregiver burden among young adult caregivers aged 18-34 years old caring for a loved one aged 50 and over. The theory of Emerging Adulthood reinforces the importance of studying young adult caregivers. The theory illustrates how young adults are at a "critical developmental stage" of identity exploration in "love, work and worldviews" and adding on the role of caregiving could be particularly challenging compared to older generations of caregivers (Arnett, 2000 p. 469). The Stress Process Model explores the socio-demographic factors, primary stressors and secondary stressors of young adult caregivers aged 18-34 years old compared to caregivers over the age of 35 years old using the National Alliance for Caregiving and AARP's 2015 *Caregiving* *in the U.S.* nationally representative survey data (*n* = 1,228). The data were collected through randomly selected online interviews among adults aged 18 and older.

Hierarchical multiple linear regression analysis revealed that increasing instrumental activities of daily living and younger age of the caregiver was associated with an increase in young adult's caregiver burden. Findings also revealed that instrumental younger caregivers, race, activities of daily living caregivers, activities of daily living of the caregivers, caregiving hours per week, being unemployed, workplace impacts and care recipient’s with Alzheimer’s disease were related to higher caregiver burden among caregivers over the age of 35 years old. Interactions effects also showed a statistically significant difference between caregivers 18-34 years old and caregivers 35 and over in ADLs with caregiver burden. This shows that the average effect of ADLs on caregiver burden depends on the age of the caregiver. For caregivers 35 and over, the higher the number of ADLs the higher the level of caregiver burden, whereas caregivers 18-34 years old with the same number of ADLs as caregivers 35 and over had lower caregiver burden. No other significant interactions were found with caregiver age and caregiver burden.

The findings show that young adult caregivers need tailored policies, programs and practices to assist with instrumental activities of daily living. In addition, younger age contributed to caregiver burden among caregivers aged 18-34 years old and therefore more programs and policies should be aimed towards younger caregivers within the millennial cohort.

The dissertation of Courtney Marie Demko is approved.

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University of California, Los Angeles

2021

To my daughters Samantha and Olivia

and in memory of Professor Steven Wallace

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CHAPTER 1

INTRODUCTION

Young adults will become the new face of caregiving as the older adult population increases in the United States (Ortman et al., 2014). The U.S. Census Bureau projects the number of older adults aged 65 and older will double from 43 million in 2016 to nearly 84 million in 2050 (Ortman et al., 2014). This trend indicates an unprecedented longevity challenge and as a result more young adults may be stepping into the caregiving role.

The millennial generation, born between 1980 and 1998, surpassed the baby boomer generation in 2019 and became the largest cohort in the United States with 73 million people (U.S. Census Bureau, 2017). Millennials constitute 16% of caregivers in the United States and that number will continue to rise as the number of older adults increase (NAC/AARP, 2015). More young adults from the millennial cohort may become caregivers, but little is known about the particular challenges they face caring for an older adult.

Young adults, aged 18-34 years old, are at a “critical developmental stage” that could make caregiving particularly challenging compared to older caregivers (Arnett et al. 2000; Levine et al., 2005, p. 2071). The theory of Emerging Adulthood highlights the importance of studying young adult caregivers. The theory illustrates how young adults are exploring life in “work, love and worldviews” and; therefore, adding on the role of caregiving could be particularly challenging for them compared to older generations of caregivers (Arnett, 2000 p. 469).

Few studies focus on challenges facing young adult caregivers and this dissertation examines the multidimensional factors associated with caregiver burden among young adult caregivers using the Stress Process Model (SPM) as the conceptual framework. The SPM emphasizes the interplay of multidimensional factors that are associated with caregiver burden (Kim et al., 2012; Pearlin, 1990). The key factors examined include 1) the caregiver background and context including gender, age, race and marital status, 2) primary stressors including activities of daily living (ADLs), instrumental activities of daily living (IADLs), caregiving hours per week and Alzheimer's care recipient and 3) secondary stressors including the employment status of the caregiver and work-related impacts of caregiving.

The dissertation compares the sociodemographic and stress-related factors associated with caregiver burden among young adult caregivers aged 18-34 years old in the millennial cohort in relation to caregivers 35 years old and over caring for an adult aged 50 and older. This work examines evidence for age differences in characteristics and responsibilities to better inform tailored practices and policies for a growing young adult population of caregivers.

The dissertation uses cross-sectional survey data from the National Alliance for Caregiving and AARP's *Caregiving in the U.S. 2015* public use dataset. Multivariable analysis explores factors associated with caregiver burden among young adult caregivers.

The research questions are:

What multidimensional factors are associated with caregiver burden among young adult caregivers caring for an adult aged 50 and over?

1) What is the relationship between socio-demographic factors (caregiver age, caregiver gender, caregiver marital status and caregiver race) and caregiver burden among young adult caregivers caring for an adult aged 50 and over?

2) What is the relationship between primary stressors (activities of daily living, instrumental activities of daily living, caregiving hours per week and Alzheimer's care recipient) and caregiver burden among young adult caregivers?

3) What is the relationship between the secondary stressors of employment status and work-related impacts and caregiver burden among young adult caregivers?

4) To what extent are multidimensional factors differentially associated with caregiver burden in young adult caregivers aged 18-34 years old compared to caregivers aged 35 and older caring for an adult aged 50 and over?

Background

Caregiver burden affects millions of Americans and that number will continue to increase as the population ages. About 34 million caregivers or 14.3% of the U.S. population provide care to an adult aged 50 and over (NAC/AARP, 2015). Caregiving can be defined as "any relative, partner, friend or neighbor who has a significant personal relationship with, and provides a broad range of assistance for, an older person or an adult with a chronic or disabling condition" (Family Caregiver Alliance, 2014, np). This study focuses on informal and unpaid caregivers.

Studies show that many caregivers experience caregiver burden, which can adversely affect the physical, emotional and financial health of caregivers (Brodaty et al., 2009; Schulz et al., 2004; Zarit et al., 1980). This dissertation defines caregiver burden as physical, emotional and financial strain due to caring for a family member or friend with a chronic or disabling condition (NAC/AARP, 2015, p. 24).

Alzheimer's Disease

According to the Centers for Disease Control and Prevention (CDC), the number of Americans with Alzheimer's disease and other types of dementia will nearly triple from 5.4 million in 2017 to 13.8 million in 2050 (CDC, 2017). The CDC considers the projected increase in Alzheimer's disease as a public health problem for the nation and for the health and well-being of millions of family and unpaid caregivers (CDC, 2017). Over 16 million caregivers provide care for someone with Alzheimer's disease or other types of dementia in the United States (Alzheimer's Association, 2018). Alzheimer’s disease (AD) is the most common type of dementia and poses particular challenges for caregivers due to the older adult’s loss of memory, behavioral changes and ability to function over time (Brodaty et al., 2009; Schultz et al., 2009). AD is considered to be one of the most “burdensome diseases” on caregivers due to the long duration of the disease spent in a state of “disability and dependence” (Alzheimer’s Association, 2018, p. 29). The average life expectancy of someone with dementia from is 8 to 10 years, and the longest period of the disease is spent in the moderate stages in which people may wander, experience behavior and personality changes and forget how to do simple everyday tasks such as eating or going to the bathroom. Studies show how this often results in high levels of burden including physical, mental and emotional stress on the caregiver. As a result, AD caregivers are often called the “invisible second patients,” because caregiver burden can cause a deterioration in their own health and well-being; however, caregivers rarely receive the treatment and support necessary to navigate this complicated relationship (Alzheimer’s Association, 2018; Brodaty et al. 2009, p. 217).

Much of the caregiving literature focuses on caring for someone with Alzheimer’s disease and/or other type of dementia because studies show they experience more caregiver burden than non-dementia caregivers (Alzheimer’s Association, 2018; Ory et al., 1999; Schulz et al., 2004). The NAC/AARP *Caregiving in the U.S. 2015* survey used in this dissertation includes caregivers caring for older adults with differing conditions, including cancer, mobility issues, heart disease, stroke and Alzheimer’s disease (NAC/AARP, 2015, p. 29). This dissertation looks at both AD and non-AD caregivers to determine whether the care recipient’s condition relates to caregiver burden as shown in previous studies (Riffin et al., 2017; Wolf et al., 2016).

Alzheimer’s is one of the “Costliest Conditions” in the U.S.

Not only can Alzheimer’s affect the caregiver’s mental, emotional and physical health, but it is also considered one of the “costliest conditions” in the U.S. and creates a great financial burden on caregivers and the nation’s health care costs (Alzheimer’s Association Facts and Figures, 2018, p. 43). In 2017, caregivers provided an estimated 18.6 billion hours of unpaid care to someone with AD, which equals a value of $232 billion Caregivers provide 70% of the costs to care for someone with AD, including out-of-pocket health and long-term care expenses as well as the value of the unpaid care they provide The U.S. relies on caregivers to provide the majority of long-term care to their loved ones with AD which reduces the nation’s health care costs.

Based on projected increase in the number of older adults with AD the costs to the nation will rise. The CDC reports that in 2017 total payments in AD health care, hospice and long-term care were estimated at $259 billion with Medicare paying almost half of these costs (CDC, 2018). Without a cure or treatment for AD, the costs will increase to $1.1 trillion in 2050 (Alzheimer’s Association, 2018). Since the need for caregivers caring for people with AD will increase without a cure or treatment, understanding millennial’s experiences as they step into the caregiving role is needed.

Non-Dementia Caregivers

While Alzheimer’s disease and other types of dementia pose particular challenges for caregivers, non-dementia caregivers also experience caregiver burden. While many previous studies focus on dementia caregivers, other studies suggest that more research should include all types of caregivers because as the older adult population continues to rise, more caregivers will be needed for all types of diseases (Riffin et al., 2017).

About six in ten adults have at least one chronic condition in the U.S. (CDC, 2018). In addition to Alzheimer's disease, other leading causes of death and disability include heart disease, cancer, stroke, chronic lung disease, diabetes and chronic kidney disease (CDC, 2018). Caregivers who care for an older adult without dementia can also suffer from high caregiver burden levels, poor health and lack of formal and informal support, and, therefore, should not be overlooked in research (Riffin et al., 2017).

Young Adults: The New Face of Caregiving

A caregiver faces physical, emotional and financial strain and more research is needed on young adult caregivers to inform practice and policies now and in the future. The overall aim of this dissertation focuses on the multidimensional factors associated with caregiver burden of young adult caregivers aged 18-34 years old compared to caregivers 35 and over. Most caregiver burden studies focus on the health and well-being of older adult caregivers, but a gap in the literature exists related to young adult caregivers. More young adults, aged 18-34 years old, are becoming caregivers; however, few studies focus on this growing population of caregivers (AP-NORC, 2017; Levine et al., 2005; NAC/AARP, 2015).

Young adult caregivers may be stepping into the caregiving role more than previous generations due to demographic trends and a shift in the American family structure. The U.S. faces an unprecedented longevity challenge because the older adult population will double in the next 30 years as the baby boomer population ages (Ortman et al., 2014). The fastest growing age group in the U.S. are those 85 and older (Ortman et al., 2014). Older adults are living longer lives but with more chronic diseases, and therefore the demand for caregivers will increase (CDC, 2017).

In addition, a shift in the “traditional” American family structure of a married, two-parent household may cause older adults to turn to young adult caregivers (Pew, 2015). Divorce rates for adults aged 50 and over have doubled in the last 25 years, making them more likely to live alone than previous generations (Pew, 2017). Eight-seven percent of older adults aged 65 and older report that they want to live at home, and therefore they are turning more to young adult family members and friends for unpaid caregiving help (AARP, 2014). More women are also entering the workforce at higher rates than previous generations (Pew, 2015). As a result, more young adult men are becoming caregivers than previous generations (AP-NORC, 2017; NAC/AARP, 2015). Little is known about gender differences in young adult caregivers and this study explores potential differences between caregiver burden in men and women.

More young adults are being called on for caregiving assistance at a time when they may just be entering college, starting their careers and building lifelong relationships. These points are explored further turning to insights from empirical studies and theoretical perspectives.

Generational Caregiving: More Millennials Step into the Caregiving Role

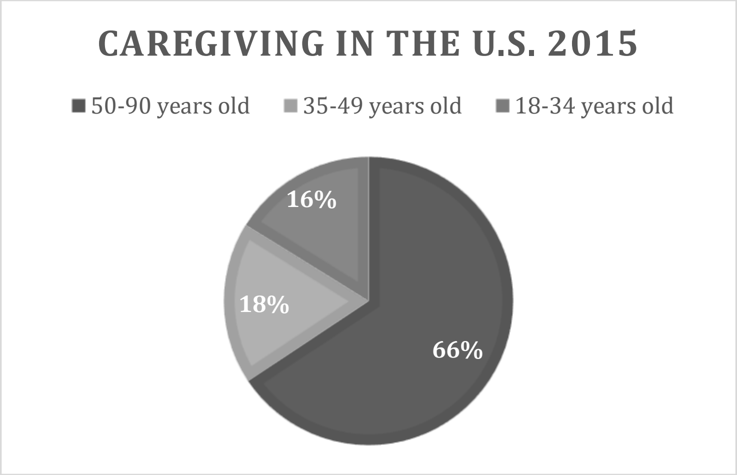
The millennial generation, born between 1980 and 1998, make up the largest living cohort in the United States with over 83 million people (U.S. Census Bureau, 2017). Approximately 16% of caregivers caring for an adult aged 50 and over are in the millennial generation (NAC/AARP, 2015, p. 18). Millennials also comprise an increasing portion of dementia caregivers with an estimated 15% or one in six dementia caregivers in the United States (NAC/AARP, 2015).

Figure 1 shows that caregivers from all generations are represented in the United States with 16% of all caregivers being Millennials, 18% of Generation X and 66% of Baby Boomers and Silent generation. Much of the literature focuses on older generations of caregivers from the

Generation X, Silent, and Baby Boomer Generations (Del-Pino-Casado et al., 2012; Kim et al., 2012; Pinquart & Sorensen, 2006; Sharma et al., 2016.).

Figure 1

The percentage of caregivers in the United States in 2015 by age.



Source: NAC/AARP (2015)

Studies reveal similarities and differences between each generation of caregivers. Young adults from the millennial cohort deserve further study, because 1) More men are stepping into the caregiving role, but little is known about young adult male caregivers and their caregiving responsibilities, burden levels and impacts on work (AP-NORC, 2017); 2) Young adult caregivers from the millennial cohort are more likely to be employed than older generations and are more likely to experience "adverse action" taken by employers such as losing their job as result of their caregiving (Transamerica Institute, 2017, p. 11); 3) Few studies focus on young adult caregivers but recent reports find they experience high emotional distress due to balancing work at a young age, school and their social life with caregiving (Vega et al., 2017). More research on the multifaceted issues facing young adult caregivers is needed for more tailored practices and policies.

Workplace Impacts

Studies find that young adult caregivers experienced more negative impacts of work compared to other generations such as losing their jobs, being given less tasks, not receiving promotions and having to reduce hours and duties against their will (Transamerica Institute, 2017). A national online survey by the Transamerica Institute (2017) compared the duties, health and work-related impacts among different generations of non-professional caregivers in the United States. The study found that the majority of millennial (68%) and Generation X (62%) caregivers are employed, but millennial caregivers tend to suffer from more work-related impacts than any other generation (Transamerica Institute, 2017).

Similarly, Vega et al. (2017) found millennial dementia caregivers also experience disruptions in their work as a result of caregiving. They found that one out of two millennial dementia caregivers reported interference with work as a result of caregiving and 33% reported “severe interference with work” including cutting back hours, losing job benefits and being fired (Vega et al., 2017, p. 2). Vega et al. (2017) did not compare generations like the Transamerica Institute survey, but instead compared caregivers and non-caregivers. Vega et al. (2017) used cross-sectional survey data from NAC/AARP 2015 dataset, the same dataset used in this dissertation. This present study looks at work-related impacts among young adult caregivers and caregivers over the age of 35 years old. It compares young adult caregivers with older caregivers focusing on differences in caregiving stressors of dementia and non-dementia caregivers, as well as gender differences in caregiving responsibilities, hours and impacts on work.

Health and Managing Stress

Reports found young adults from the millennial cohort experience high levels of emotional stress and caregiver burden. The Transamerica (2017) report revealed generational caregiving differences related to health and managing stress. Findings showed that Millennials and Generation X caregivers are more likely than Baby Boomer and Silent generation caregivers to put their loved one's health needs ahead of their own (Transamerica Institute, 2017). Further, compared to older generations, millennial caregivers wanted more information on how to manage the stress of caregiving (Transamerica Institute, 2017). Thus, information may help millennial caregivers cope with the stress and burden of caregiving.

Two cross-sectional surveys also found high burden levels in young adult caregivers. Vega et al. (2017) reported that 79% of millennial dementia caregivers experienced emotional distress and 18% said caregiving worsened their overall health (Vega et al., 2017). The Associated Press-NORC (AP-NORC) Center for Public Affairs Research (2018) focused on young adult caregivers aged 18-39 years old. AP-NORC found that 80% of young adult caregivers reported feeling at least moderately stressed (AP-NORC, 2018). Also, one-third of young adult caregivers expected to provide care in the next five years, but most felt unprepared to do so (AP-NORC, 2018).

This dissertation explores these issues further by focusing on what factors such as age, gender and work-related impacts contribute to caregiver burden among young adult caregivers. Instead of only focusing on millennial dementia caregivers, like Vega et al.'s (2017) report, this dissertation adds to the literature by comparing young adult dementia and non-dementia caregivers with older dementia and non-dementia caregivers to glean insights on any key differences about the stress-related factors associated with caregiver burden.

The Theory of Emerging Adulthood: A "Critical Developmental Stage"

As the young adult caregiving research shows, this population of caregivers also needs further study to better understand their unique needs as they navigate their careers, education and building families all while taking on the caregiving role. Young adults at the time of data collection were aged 18-34 years old (NAC/AARP, 2015). This means they may be in college, starting their careers or building their families. Because of these social role transitions, taking on the additional role of caregiving may pose unique challenges for them compared to older generations of caregivers; they may need to put off critical life course stage events to be available as caregivers.

Erik Erickson's theory on psychosocial developmental stages provides insight into the population of young caregivers. Erikson's theory posits eight developmental stages throughout the life course and the particular social crisis one must overcome in order to move to the next developmental stage. The millennial population falls into Erikson's stage of young adulthood, which spans ages 18-40 years old, and for which the primary social conflict is of intimacy versus isolation (Erikson, 1994). Erikson characterizes the stage of intimacy versus isolation as a stage of entering meaningful lifelong relationships; if one does not successfully navigate this life stage, it could result in loneliness and depression (Erickson, 1994).

Arnett (2000) expanded on Erikson's psychosocial developmental theory and highlighted the theory of emerging adulthood that includes ages 18 to 25 years old. As opposed to Erickson's young adulthood of 18 to 40 years old, Arnett believed emerging adulthood between the ages of 18 to 25 years old required its own stage. He describes this as a stage of "frequent change as various possibilities of love, work and worldviews are explored" (Arnett, 2000, p. 469). He also discusses how emerging adults are heterogenous and discusses the potential positive and negative aspects of this stage (Arnett, 2007) while arguing that most emerging adults enjoy the "self-focused freedom from role obligations and restraints." However, Arnett also notes some emerging adults may be more susceptible to serious mental health problems due to the stress in finding intimate relationships and a career coupled with lack of structure from educational settings (Arnett, 2007). Young adult caregivers may not be able to enjoy the self-focused freedom he describes if they are caring for a loved one.

The few young adult caregiving studies that do exist, point to this period of time as a “critical developmental stage” as young adults try to navigate their education, starting a career and building a family and while also juggling the strain of caring for an older adult (Levine et al., 2005, p. 2071). The identity exploration of emerging adults may be disrupted by the obligations of caregiving (Arnett, 2007 p. 71). Erikson’s and Arnett’s theories help provide insight into why young adults may face unique caregiving challenges compared to older caregivers.

More Young Adult Men Become Caregivers: Theoretical Developments in Gender Differences

Studies show that the Millennial generation differs from previous older generations of caregivers in that men are just as likely as women to become caregivers with 48% female and 52% male taking on caregiving roles (AP/NORC, 2018; Brodaty et al., 2009, Gallicchio, 2002; Vega et al. 2017). Most older generations of caregivers, aged 40 and older, are female with 59% and 41% male (AP/NORC, 2018). More men are stepping into the caregiving role as a shift in the “traditional” family structure occurs and more women enter the workforce (Pew, 2015). In understanding gender differences, the literature has posited various theories and concepts about the role of older men and women caregivers. This dissertation addresses a gap in the literature by looking at gender and caregiver burden among young adult caregivers and older caregivers from previous generations.

Previous caregiver burden studies acknowledge that a better understanding of potential gender differences will help provide more effective interventions, programs and policies now and in the future. Several previous studies look at gender differences and their impacts on caregiver burden among older caregivers, but the findings are inconsistent as to whether gender differences exist (Pinquart & Sorensen, 2006). Pinquart and Sorensen (2006) discuss potential theoretical explanations for gender differences in dementia caregiving. The gender-role socialization framework (Gilligan, 1982), the gender-role expectation framework (Barusch & Spaid, 1989) and theories associated with labor market segregation and household labor (Barusch & Spaid, 1989; Ross 1987) suggest that because of social roles and expectations women put in more hours of caregiving, take on more caregiving tasks and thus are more susceptible to a decline in their own health and well-being compared to men (Pinquart & Sorensen, 2006). This dissertation specifically examines the effects of caregiver burden among young adult caregivers and older caregivers by gender.

The theory Gender as a Social Structure provides additional insights into gender differences in caregiving. Barbara Risman's book *Gender Vertigo* (1989) posits that gender is a social structure that organizes the world on an individual, interactional and institutional level. The multilevel framework consists of: 1) The individual level - the emergence of a gendered self through personality or socialization, 2) the interactional level - how people "do gender" or "do family" in their everyday interactions with other people to follow rules and expectations, and 3) the institutional level – consisting, in part, of segregated work or wage gaps (Risman, 1989). The interactional level bares "heavy responsibility for continuing gender inequality in the United States," and it is also at this level where many decisions about family caregiving are made (Risman, 1989, p. 6). The theory suggests that gender roles change slowly, because everyday interactions perpetuate these engrained gender roles.

Similarly, Stress and Coping Theory also suggests men and women differ in their caregiving tasks and levels of caregiver burden. Much of the literature uses Stress and Coping Theory to provide context and insight into gender differences in caregiver burden (Del-Pino-Casado et al., 2012; Kim et al., 2012; Pinquart & Sorensen, 2006; Sharma et al., 2016). Stress and Coping Theory suggests that women are more prone to stressors that contribute to caregiver burden, in large part because they "perceive, report and cope" with caregiving stressors differently than men (Sharma et al., 2016, p. 7). Many studies that look at gender differences from this lens report that women are more emotionally-focused, and men are more task-oriented in their caregiving responsibilities (Pillemer, 2018). This makes women more susceptible to emotional and physical strain and higher caregiver burden levels, because they spend more time doing caregiving tasks and take on more of the assistance with daily living personal care tasks than men (Sharma et al., 2016).

The literature, however, reveals conflicting findings when looking at gender differences in caregiver burden (del-Pino Casado et al., 2012). Pinquart and Sorensen's (2006) study uses the Stress and Coping Theory to better understand gender differences in caregiving burden. They conducted a meta-analysis that examined 229 studies on gender differences in caregiver stressors, social resources and health and ultimately found that there are "small to very small" gender differences in burden, depression and the number of caregiving among men and women (Pinquart & Sorenesen, 2006, p. 33). They also found that younger men and women caregivers report even fewer differences in their caregiving experiences, suggesting that future studies look at whether caregiving stressors and resources affect women differently than men. Because of the ambiguous findings related to gender differences in the caregiving literature, this dissertation fills an important empirical gap by looking at gender differences related to caregiver burden among young adult caregivers and then compared with older caregivers. Based on these theoretical perspectives, the dissertation hypothesizes that gender differences will be associated with caregiver burden, with young and older women having more caregiver burden compared to young and older men caregivers.

Summary

This chapter described the significance in studying a new and growing population of young adult caregivers. A caregiver faces physical, emotional and financial strain and more research is needed on young adult caregivers to inform practice and policies now and in the future. The overall aim of this dissertation focuses on the multidimensional factors associated with caregiver burden of young adult caregivers aged 18-34 years old compared to caregivers 35 and over. Most caregiver burden studies focus on the health and well-being of older adult caregivers, but a gap in the literature exists related to young adult caregivers. More young adults, aged 18-34 years old, are becoming caregivers; however, few studies focus on this growing population of caregivers (AP-NORC, 2017; Levine et al., 2005; NAC/AARP, 2015). This dissertation fills a gap in the young adult caregiver literature by looking specifically at the multidimensional factors that contribute to caregiver burden.

CHAPTER 2

LITERATURE REVIEW

This chapter presents a literature review of empirical studies on factors that contribute to caregiver burden among dementia and non-dementia caregivers, synthesizes studies on stress-related gender differences among caregivers and then explores the literature on young adult caregivers. The chapter then introduces the Stress Process Model – the conceptual framework used to guide this dissertation. Finally, the chapter concludes with the research questions and hypotheses.

Empirical Studies on Dementia and Non-Dementia Caregivers

This dissertation compares dementia and non-dementia young adult caregivers with older caregivers to highlight any differences and similarities in the socio-demographic and stress-related factors associated with caregiver burden. Several studies compare the differences in caregiver burden among dementia and non-dementia caregivers. Much of the literature finds that dementia caregiving requires more complex caregiving tasks and more caregiving hours than caregivers caring for someone with other chronic conditions, disabilities or diseases (Alzheimer’s Association, 2017; Kasper et al., 2015; Ory et al., 1999; Schulz et al., 2004). Compared to non-dementia caregivers, dementia caregivers perform more stressful caregiving tasks that involve more ADLs (activities of daily living) such as assistance with bathing, eating, toileting and dressing, provide more hours of care and manage behavioral changes such as agitation and lack of sleep (Alzheimer’s Association, 2018; Kasper et al., 2015, Ory et al., 1999). Dementia caregivers also spend more continuous time caring for their loved one compared to non-dementia caregivers. As a result, much of the caregiver literature focuses on dementia caregivers’ experiences, because dementia caregivers experience more burden than non-dementia caregivers (Alzheimer's Association, 2017; Ory et al., 1999; Schulz et al., 2004). This dissertation adds to the literature by comparing the caregiver burden of young adult dementia and non-dementia caregivers with older dementia and non-dementia caregivers.

Most studies focus on older dementia and non-dementia older caregivers. Two recent studies compared dementia and non-dementia caregivers and found dementia caregivers experience more burden than non-dementia caregivers. Kasper et al. (2015) used nationally representative survey data to look at caregiving tasks and the types of care needed by older adults with dementia and without dementia. They found "striking differences" between the amount and type of care provided by dementia and non-dementia caregivers (Kasper et al., 2015, np). Dementia caregivers provided more help with self-care activities than non-dementia caregivers and also spent more hours providing care than non-dementia caregivers. The researchers attribute these differences in large part to the nature of the disease and the inability of a person with dementia to physically and mentally function overtime (Kasper et al., 2015). Similarly, Wolf et al. (2016) found that dementia caregivers face "special challenges" and nearly half of all caregivers provide "substantial help" with health-care activities are dementia caregivers (Wolf et al., 2016, p. 372). They found that caregivers who provide a substantial amount of help or more caregiving hours per week suffered from more emotional, physical, financial difficulties (Wolf et al., 2016, p. 372).

Some studies also draw insights into how dementia caregiving impacts work. Wolf et al. (2016) found that caregivers who provided a substantial amount of help were more than three times as likely to experience a loss of productivity at work compared to caregivers who provided no help (Wolf et al., 2016, p. 372). This dissertation builds on this research to glean new insights into how caregiving may impact the work of young adult caregivers and also compare work-related impacts among young and older dementia and non-dementia caregivers.

Studies suggest that more research should include caregivers of all types of diseases, because as the older adult population continues to rise, more caregivers will be needed for all types of diseases. Studies show that non-dementia caregivers should not be overlooked in research because they can also suffer from high caregiver burden, poor health and lack of formal and informal support. Riffin et al. (2017) used a nationally representative survey to examine the caregiving tasks and differences in caregiver burden levels among dementia and non-dementia caregivers. They defined non-dementia caregivers as those caring for a loved one with a disability or those that provided help with two or more "self-care or mobility activities in the last month" (Riffin, 2017, p. 1822). They found that more caregiving tasks were associated with greater burden and caregiving difficulty. The researchers noted that even though the dementia caregivers had higher burden levels and poorer health; the non-dementia caregivers also suffered from high levels of burden and caregiving difficulty and, therefore, more research should take into account the stressors all caregivers experience caring for an older adult.

Empirical Findings in Gender Differences Among Caregivers

This dissertation also looks at gender differences in caregiver burden among young adult caregivers as more men step into the caregiving role compared to earlier generations of caregivers (AP-NORC, 2018; Vega et al., 2017). Several empirical studies reveal contradictory findings on whether gender differences exist in levels of caregiver burden, depression, physical health, subjective well-being and use of formal and informal support networks (Etters et al., 2008; Vitaliano et al., 2003; Yee & Schulz, 2000). For example, many studies support Stress and Coping Theory and Gender as a Social Structure Theory and show that women tend to report higher levels of caregiver burden, physical health issues and higher levels of depression compared to men (Almberg et al., 1998; Gallicchio et al., 2002; Pillemer et al., 2018).

Recent studies acknowledged the need for more gender differential studies in caregiver burden, since more men are becoming caregivers (Pillemer et al., 2018). Pillemer et al. (2018) used a longitudinal intervention survey to examine the gender differences in caregiver burden and depression of 211 dementia caregivers. They showed how previous literature revealed conflicting findings on whether gender differences existed in caregiver burden and depression among dementia caregivers and acknowledge the need to fill the gap in the literature by conducting further research on the multidimensional factors that may contribute to caregiver burden among men and women. This dissertation looks at gender differences in caregiver burden among young adult caregivers compared to older caregivers.

Several studies find that women experience higher levels of caregiver burden than men (Chappell et al., 2015; Kahn, 2016; Pillemer et al., 2018). Pillemer et al. (2018) found that overall women experienced both higher levels of burden and depression than men when caring for a loved one with dementia. Women tend to be more emotionally focused in their caregiving styles than men and men experience the negative strains of caregiving in different ways, such as poor health and poor sleep. This research supports Stress and Coping Theory in that women’s caregiving tasks tend to be more emotionally focused, while men tend to be more task-oriented in their caregiving styles. The researchers note, however, that their sample consisted of predominately white females and suggested that future studies should look at more diverse populations to increase generalizability.

The Gender as a Social Structure theory suggests that gender roles are slow to change due to engrained social interactions. Therefore, this dissertation hypothesizes that young adult female caregivers will experience more burden than young adult male caregivers.

Studies have also found that women have higher caregiver burden levels than men, but also looked at the caregiver's relationship to the care recipient as an important factor. Chappell et al. (2015) and Kahn et al. (2016) studied gender differences in caregiver burden and focused on spousal and adult children dementia caregivers. Chappell et al.'s (2015) study found that daughters experienced the highest levels of burden, but also the highest self-esteem; whereas wives were the most susceptible overall to both burden and low self-esteem. Kahn et al. (2016) also found that women and adult child dementia caregivers experience the highest burden levels. Kahn's study was limited by a small sample size (*n* = 82).

Other studies similarly note that men are less likely to report caregiver burden than women (Akpinar et al., 2011; Papastavrou et al. 2009). Papastavrou et al. (2009) uses a cross-sectional quantitative study with a sample of 172 family caregivers. The study's main objective was to explore gender differences in caregiver burden. They found higher levels of caregiver burden among women but speculated that men may experience similar levels of depression and burden but be less likely to report it. They also supported the Stress and Coping Theory finding that women tended to use more emotionally-focused coping styles than men who were more task oriented and problem-focused (Papastavrou et al., 2009).

Overall, most studies support the Stress and Coping Theory and Gender as a Social Structure Theory on gender differences and find that women report higher caregiver burden levels than men, but it is important to note that some of the literature find little to no gender differences (Annerstedt et al., 2000; Chumbler et al., 2003; del-Pino-Casado, 2012; Sharma et al., 2016). Pinquart and Sorensen (2006) conducted a meta-analysis on gender differences in caregiving stressors and found that conflicting findings on gender differences in caregiving may be attributed to differing methodologies and small homogenous samples. This dissertation examines gender differences in caregiving but fill a gap in the literature by studying young adult caregivers and then comparing it with older caregivers using a nationally representative sample.

Empirical Studies on Young Adult Caregivers

As the older adult population continues to increase, more young adult caregivers will be caring for aging parents and grandparents. Few studies focus on young adult caregivers, but some point to the need for more research on this growing population of caregivers (Dellman-Jenkins, 2003; Dellman-Jenkins, 2000; Pinquart & Sorensen, 2006; Kim et al., 2012; Levine et al., 2005). Studies focused on young adult caregivers aged 18-40 years old but did not look specifically at dementia caregivers or gender differences in caregiver burden. Most studies also utilized small sample sizes and were conducted more than 15 years ago.

The extant literature demonstrates that that many young adult caregivers spent several hours a week devoted to caregiving and as a result it interfered with other aspects of their lives such as work and personal relationships (Dellman-Jenkins et al., 2003; Levine et al., 2005). Levine et al. (2005) found that between 20-25% of young adult caregivers provided 21 or more hours of caregiving to an older adult which is “more than a part-time job” (Levine et al., 2005, p. 2072). In addition, Dellman-Jenkins (2003) found that 70% of caregivers noted that there was “too little time for themselves” and caregiving interfered with their work as well as increased financial pressure and strained personal relationships (Dellman-Jenkins et al., 2003, p. 223). Thus, they concluded that future studies should look at workplace impacts of caregiving among young adult caregivers. Both studies contained relatively small sample sizes and were conducted between 10-15 years ago so the findings may not be trustworthy or applicable to current young adult caregivers. Dellman-Jenkins et al. (2003) used both qualitative and quantitative methods and compared young adult caregivers caring for an older family member with a group of young adults aged 18-40 years old who were not caregivers.

One study conducted more than 15 years ago found that the face of caregiving was changing, and more studies should focus on the younger population of caregivers. Levine et al. (2005) used two nationally representative surveys (Harvard School of Public Health and the National Alliance for Caregiving/AARP 2004 study) and focused on young adult caregivers aged 18-25 years old caring for a family member or friend who is either an older adult, disabled or ill. This dissertation uses the more recent data from NAC/AARP *Caregiving in the U.S. 2015* and focus more on the relationship between workplace impacts and caregiver burden among young adult caregivers using bivariate and multivariate analyses. This study compares young adults with older caregivers in order to better understand any key differences in caregiving responsibilities, hours, gender differences and work-related impacts.

Studies also found that more formal support services tailored for young adult caregivers are needed because they experience unique challenges as they juggle the demands of their careers, education, personal relationships and their role as a caregiver (Dellman-Jenkins et al., 2003 and Dellman-Jenkins et al., 2000; Levine et al., 2005). Levine et al. (2005) found that young adults needed help with end-of life decision-making and how to obtain medical help. They also recognized that due to the high proportion of men becoming caregivers, more support services should be geared towards younger male caregivers.

The young adult caregiving literature also focused on the motivations and rewards for caregiving. Dellman-Jenkins et al (2000) found that young adult caregiving children had more of a sense of obligation to care for their parents while grandchildren caregivers were more motivated by feelings of attachment. The young adult children also found greater instrumental rewards from caregiving such as avoiding nursing home placement and grandchildren had more personal rewards such as greater closeness and memories (Dellman-Jenkins et al., 2003)

While the literature is small on young adult caregivers, the research is growing. Two dissertations focused on the millennial generation of caregivers. Koltz (2015) used semi-structured qualitative interviews to explore the lived experiences of millennial caregivers and found millennial caregivers perceive caregiving as a responsibility or obligation to care for a loved one. Dehn (2017) found that millennial caregivers living with an aging baby boomer parent experienced several challenges such as a decline in their own physical and mental health as well as delays in traveling, attending college and entering personal relationships.

While the young adult caregiver studies provide some insight into what it is like to be a young caregiver, this dissertation examines the multidimensional factors that are associated with caregiver burden among young adult caregivers using the Stress Process Model (SPM). It also uses nationally representative cross-sectional survey data from NAC/AARP 2015 on young adult caregivers to capture what current challenges they face with caregiving responsibilities, tasks and work-related impacts and compares it to older caregivers.

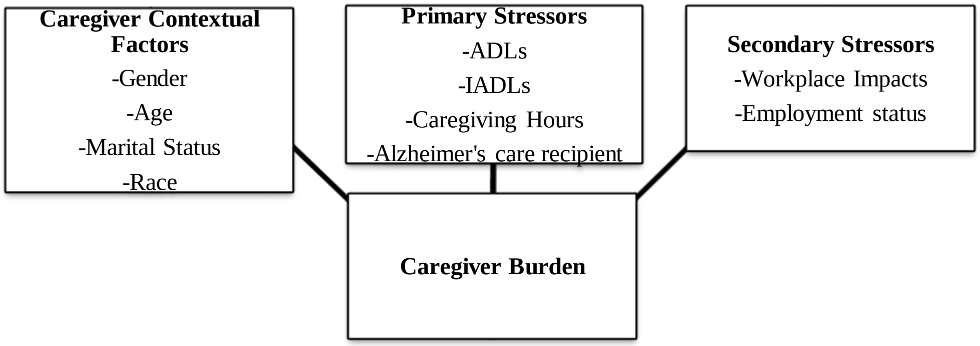
Conceptual Framework: The Stress Process Model

This dissertation examines the multidimensional factors associated with caregiver burden of young adult caregivers using the Stress Process Model (SPM) (Kim et al., 2012; Pearlin et al., 1990; Schulz & Matire 2004). The SPM is the “predominant organizing framework” to help explain the multidimensional predictors of caregiver burden among caregivers (Kim et al., 2012).

The SPM conceptualizes caregiver stress as four related factors: 1) the caregiving context, including socio-demographics of care recipients and of caregivers; 2) primary stressors which involve patient symptomology such as their level of disease progression, problem behaviors, and their ADLs (activities of daily living) and IADLs (instrumental activities of daily living and caregiving hours 3) Secondary stressors such as difficulties at work and financial issues; and 4) potential mediators such as social support, treatment and interventions, and use of social resources (Kim et al., 2012; Pearlin et al., 1990). Figure 2 shows the SPM used as the conceptual framework in this dissertation.

Figure 2

Stress Process Model, Conceptual framework



Several caregiver burden studies use the SPM as their conceptual framework (del-Pino-Casado et al., 2012; Kim et al., 2012; Pinquart & Sorensen, 2006). Del-Pino-Casado et al. (2012) use the SPM to examine gender differences among primary and secondary stressors of caregivers. They used cross-sectional survey data looking at potential gender differences among 1,272 caregivers (aged 65 and older) caring for a disabled older adult. They found no statistically significant gender differences in primary stressors such as intensity of care and duration of care but did find differences on subjective burden or defined as caregiver burden related to the overall physical, mental, and financial health of caregivers (Del-Pino Casado, 2012). They concluded that a caregiver's context and characteristics were more closely linked to sources of caregiving satisfaction than gender differences. The study was limited in that did not mention the disease of the older adult care recipient and did not define what criteria they used for an older disabled adult which could have potentially affected the outcomes (Del-Pino Casado, 2012).

Kim et al. (2012) examined the multidimensional predictors of caregiver burden in dementia family caregivers. The study analyzed the National Alliance for Caregiving/AARP 2004 survey and used the SPM as the conceptual framework to look at the socio-demographic and primary stressors that may predict caregiver burden. Primary stressors (ADLs and IADLs) were the most significant predictors of caregiver burden followed by socio-demographical (gender, spousal status, co-residence) and caregiving related factors (coping strategies). They found that women experience more caregiver burden than men, and the age of the caregiver did not predict caregiver burden. These findings do not support Pinquart and Sorensen's (2006) study and several other studies that find age is related to caregiver burden (Papastavrou et al., 2007; Rinaldi et al., 2005). Kim et al. (2012) suggest that because of the conflicting findings, future studies should look at predictors of caregiver burden in younger generations.

Significance of Research

The dissertation adds to the literature and builds on Kim et al.'s (2012) study using the NAC/AARP most recent survey *Caregiving in the U.S. 2015* and also explores predictors of caregiver burden including socio-demographic factors, primary stressors and secondary stressors among young adult caregivers using the Stress Process Model. It incorporates work-related impacts, employment status and compares the caregiver burden of young and older caregivers.

Research Questions

As the literature shows, young adult caregivers experience a multitude of challenges including high caregiver burden levels, a lack of formal and informal support and work-related conflicts (Levine et al., 2005; Vega at al., 2017). As more men step into the caregiving role, this dissertation tested the associations between gender and caregiver burden.

This dissertation proposes to address a gap in the literature by focusing on young adult caregivers, which will add to our theoretical understanding of the SPM and Stress and Coping Theory on what multidimensional factors contribute to caregiver burden. This provides directions for future research on this expanding population of caregivers.

The aim of this study is to examine the multidimensional factors associated with caregiver burden among young adult caregivers using the SPM. The dissertation poses the following research questions:

What multidimensional factors are associated with caregiver burden among young adult caregivers caring for an adult aged 50 and over?

1) What is the relationship between socio-demographic factors (caregiver age, caregiver gender, caregiver marital status and caregiver race) and caregiver burden among young adult caregivers caring for an adult aged 50 and over?

2) What is the relationship between primary stressors (activities of daily living, instrumental activities of daily living, caregiving hours per week and caring for an adult with Alzheimer's) and caregiver burden among young adult caregivers?

3) What is the relationship between the secondary stressors of employment status and work-related impacts and caregiver burden among young adult caregivers?

4) To what extent are multidimensional factors differentially associated with caregiver burden in young adult caregivers aged 18-34 years old compared to caregivers aged 35 and older caring for an adult aged 50 and over?

Hypothesis #1:

I hypothesize that socio-demographic factors such as gender, age and care recipient condition will be associated with caregiver burden among young adult caregivers.

- Based on previous gender differential studies on caregiving (Pinquart & Sorensen, 2006), the Stress Process Model (Pearlin et al., 1990), Gender as a Social Structure theory (Risman, 1989) and Stress and Coping Theory, I hypothesize that women caregivers will experience higher caregiver burden levels than men caregivers.
- I hypothesize that the age of the caregiver will be associated with caregiver burden. Based on Arnett's theory of Emerging Adulthood, I hypothesize that younger caregivers experience more burden than older caregivers (Arnett, 2000).
- I hypothesize that Alzheimer's care recipients will be associated with higher caregiver burden. Based on previous studies, I hypothesize that dementia young adult caregivers will experience more caregiver burden than non-dementia caregivers (Alzheimer's Association, 2017; Kasper et al., 2015; Ory et al., 1999; Schulz et al., 2004; Wolff et al., 2016).

Hypothesis #2: Based on previous literature that uses the SPM to investigate what factors contribute to caregiver burden, I hypothesize that IADLs will be positively associated with more caregiver burden among young adult caregivers compared to older caregivers (Kim et al., 2012).

Hypothesis #3: Based on previous literature that reviews workplace impacts among caregivers and based on the SPM, I hypothesize that more workplace impacts will be positively associated with more caregiver burden in young adult caregivers (Pearlin et al., 1990, Transamerica Institute, 2017, Vega et al., 2017).

Hypothesis #4: When comparing the multidimensional factors associated with caregiver burden among young adult caregivers aged 18-34 years old to caregivers aged 35 and over, I hypothesize that there will be significant age-related differences in IADLs and ADLs with caregiver burden. Older caregivers will have increased levels of ADLs and caregiver burden compared to young adult caregivers, but younger caregivers will have increased levels of IADLs and caregiver burden.

Summary

The literature review suggests that several factors are associated with caregiver burden of caregivers. Using the SPM, this dissertation explores the multidimensional factors that may be associated with caregiver burden in young adult caregivers including 1) The caregiver's background and contextual factors such as age, race, marital status and gender 2) the primary stressors such as the influence of ADLs, IADLs, Alzheimer's care recipient and caregiving hours on caregiver burden and 3) the employment status and work-related impacts as a result of caregiving. The study also builds on previous caregiver burden studies that look at gender differences using the SPM but address an important gap in the literature by focusing on gender differences among young adult caregivers. The study also adds to our theoretical understanding of Stress and Coping Theory, Gender as a Social Structure Theory as well as the SPM and helps explain how multidimensional factors among young adult caregivers may contribute to caregiver burden. The dissertation suggests future directions for tailoring interventions, community support programs and policies for young adult caregivers.

CHAPTER 3

METHODS

This chapter discusses the methods used to determine the multidimensional factors associated with caregiver burden among young adult caregivers aged 18-34 years old compared to caregivers aged 35 and over caring for an adult aged 50 and over. First, the research design will be explained. Second, the data source, data collection, sample, and variables measured will be discussed. Finally, the analysis plan will be outlined.

Data Source

This study uses a quantitative research design using cross-sectional survey data from the National Alliance for Caregiving and AARP's *Caregiving in the U.S. 2015* public use data set. The UCLA institutional review board confirmed that use of this public data did not require formal review.

The NAC/AARP 2015 survey conducted 7,660 online interviews among adults aged 18 and older using GfK's national probability based online system Knowledge Panel. The first main goal of the study was to garner caregiver prevalence regardless of age within the U.S. population. A screener was given to all respondents regardless of caregiver and care recipient age. The second main goal was to "describe the characteristics, roles and needs" of caregivers caring for an adult over the age of 18 (NAC/AARP, 2015, p. 1). The base study resulted in 1,248 full online interviews with caregivers aged 18 and over caring for an adult aged 50 and over. The sample included 698 non-Hispanic whites, 206 non-Hispanic African-Americans, 208 Hispanics, 95 Asian Americans and 41 caregivers of another race. The study consisted of four samples – a general population sample as well as targeted oversampling of African-Americans, Hispanics and Asian Americans. The remaining 6,412 online interviews consisted of those who were not caregivers, who did not complete the full online interview and caregivers caring only for a child under the age of 18.

Data Collection

The study utilized a national, probability-based online panel called Knowledge Panel instead of a random digit dial (RDD) sample like what was used in past NAC/AARP Caregiving survey waves (1997, 2004 and 2009). The researchers noted that this change was necessitated due to the change in technology from use of landline phones to cell phone use. The researchers state that the 2015 study should not be compared to prior waves that only used landline telephones. Panelists were selected by random selection of telephone number and residential addresses and then notified by telephone or mail and invited to participate in the online interview survey.

Data collection procedures entailed conducting 7,660 online interviews among adults aged 18 and older. The online interview started with the screener and respondents only continued onto the core part of the caregiving interview if the initial respondent identified as a caregiver of an adult. The base study of 1,248 was comprised of only the randomly-selected initial respondents who were caregivers caring for an adult and only one caregiver per household was interviewed. In order to complete the full online interview, caregivers needed to self-identify as caregivers and needed to report helping an adult with at least one Activity of Daily Living (ADL), Instrumental Activity of Daily Living (IADL), or medical/nursing task. The screening question used to determine the caregiver of an adult was:

> At any time in the last 12 months, has anyone in your household provided unpaid care to a relative or friend 18 years or older to help them take care of themselves? This may include helping with personal needs or household chores. It might be managing a person's finances, arranging for outside services, or visiting regularly to see how they are doing. This adult need not live with you (NAC/AARP, 2015, p. 5).

The online questionnaire used a computer-aided web interviewing system (CAWI). CAWI was also translated into Spanish and 45% of Hispanic respondents took the survey in Spanish. The completed online interviews averaged about 24 minutes in length. The NAC, AARP Public Policy and Greenwald and Associates designed the questionnaire. Many questions were repurposed from the prior 2004 and 2009 waves, but the 2015 study included additional questions. The 2015 study focused on recent issues facing caregivers in the U.S. such as medical/nursing tasks, hospitalizations, workplace conflicts and the experience of caregivers providing care to someone more than 21 hours per week (NAC/AARP, 2015).

Study Sample

The subpopulation study sample included young adult caregivers aged 18-34 years at the time of the study in 2015, born between 1980-1998. The caregiver comparison group consisted of caregivers aged 35 and older born 1979 and before. Eligibility criteria included participants that provided unpaid care within the last 12 months to an adult 50 years old or older. To determine the care recipient's condition, participants needed to answer yes or other to the question – "Does/did your [relation] suffer from Alzheimer's or other mental confusion?" The caregiver did not need to be living with the care recipient but needed to have provided at least one ADL, IADL or medical/nursing task to be eligible for the study. The total sample for young adult caregivers aged 18-34 years old is 222 participants. The sample size for caregivers aged 35 and older is 1,006.

Variables and Measures

Outcome: Caregiver Burden (Physical, Emotional and Financial Strain)

Caregiver burden served as the dependent variable for all the research questions. It was measured using a composite score by computing a mean for the three self-report responses from the NAC/AARP, 1) "How much of a physical strain caring for a recipient is/was?' 2) "How emotionally stressful caring for recipient is/was?" and 3) How much of a financial strain caring for recipient is/was?" Responses for each item were on a 5-point Likert scale (1= *Not a strain at all* and 5 = *Very much a strain/very stressful).* Two previous studies that both use the NAC/AARP *Caregiving in the U.S. 2004* data and examine the multidimensional factors associated with caregiver burden used this method of calculating the caregiver burden outcome variable (Kim et al., 2012; Kim & Schulz, 2008). Internal consistency was calculated and found (Cronbach's alpha = 0.74).

Socio-demographic variables (Age, Race, Marital Status and Gender)

Several demographic variables described the caregivers and care recipients. The questionnaire asked standard demographic questions including age, race, marital status and gender. For the age variable, the caregiver was asked what age they were on their last Birthday and self-reported their age. Sixteen caregivers reported "don't know" and "refused" options and those responses were not used in the analysis. The caregiver's race was self-reported as White, Black, Asian, Other or Hispanic. The category of White served as the reference group with four levels where (Black =1, White = 0; Asian = 1, White = 0; Other = 1, White = 0 and Hispanic = 1, White = 0). The gender of the caregiver was coded as female with a reference group of male. The marital status variable was determined by the question "Are you currently/When you were last caregiving were you…" and given seven response options including married, living with partner, widowed, separated, divorced, single/never married and decline to respond. Twenty-three caregivers responded to the decline to respond option and they were not used in this analysis. The marital status variable was coded as "yes" for married or "no" for not married with living with partner, widowed, separated, divorced, single/never married put into the reference group category.

Primary Stressors: Alzheimer's Care Recipient, Activities of Daily Living (ADLs), Instrumental Activities of Daily Living (IADLs), Caregiving Hours per week

The independent variables used to account for primary stressors included Alzheimer's care recipient, Activities of Daily Living (ADLs), Instrumental Activities of Daily Living (IADLs) and caregiving hours per week. ADLs included help with getting in and out of bed, getting dressed, getting to and from the toilet, bathing or showering, dealing with incontinence or diapers and feeding. A variable that counted the number of ADLs was used to determine the number of ADLs with which the care recipient needed help. The IADLs included giving medicine, managing finances, grocery or other shopping, housework, preparing meals, transportations and arranging outside services. The count of IADLs performed was used to determine the number of IADLs with which the caregiver helped.

The number of caregiving hours provided per week also served as an independent variable. The question asked in the survey to determine the number of caregiving hours per week was, "Thinking now of all the kinds of help you {provide/provided} for your [loved one], about how many hours {do/did} you spend in an average week, helping him/her?" (NAC/AARP, 2015, p. 9). The respondents self-reported the exact number of hours of care they provided.

The condition of the care recipient served as one of the independent variables to determine if the care recipient has/had Alzheimer's or mental confusion compared to a care recipient with another type of disability but with no Alzheimer's or mental confusion. The question asked was, "{Does/Did} your [loved one] suffer from Alzheimer's or other mental confusion?" with a yes, yes other, no, not sure and refused response option (NAC/AARP, 2015,

p. 7). The question was coded as a categorical variable for “yes” for Alzheimer’s disease or mental confusion and “no” for no Alzheimer’s disease or mental confusion.

Secondary Stressors: Count of workplace impacts as worker/caregiver and employment status

The count of caregiving workplace impacts as a worker/caregiver was also used as an independent variable. The count of workplace impacts variable included the question, “As a result of caregiving, did you ever experience any of these things at work?” and the options were: went in late, left early, took time off to provide care as a worker/caregiver; took leave of absence as a worker/caregiver; went from working full time to part time or cut back hours as a worker/caregiver; turned down promotion; lost any job benefits; gave up working entirely as a worker/caregiver; retired early; and received warning about performance or attendance as a worker/caregiver (NAC/AARP, 2015, p. 28). This variable was treated as a count variable and summed across all types of workplace impacts.

The employment status of the caregiver was also used as an independent categorical variable. The question asked was, “Are you currently employed?” and the responses included “yes,” “no,” “not sure,” and “refused.” The “not sure” and “refused” responses were treated as missing and this accounted for 3 responses. The variable was coded yes for employed and no was coded for unemployed and served as the reference group.

Interaction Effects: Age differences with predictor variables and caregiver burden

Interaction effects were also tested to see if there were primary and secondary stressor predictor variables that related to higher caregiver burden that depended on age. An age dichotomous variable was created to compare caregivers 18-34 years old with caregivers 35 and older as the reference group with the predictor variables of ADLs, IADLs, Hours and work-related impacts.

Analysis Plan

All of the analyses in this study used SAS statistical software, 9.4 edition (SAS Institute Inc., 2021). The analysis used descriptive statistics for caregivers aged 18-34 years old and 35 years old and over and their care recipients aged 50 and over. The means, frequencies and percentages were calculated to give an accurate description of the study sample and the statistical difference in significance between the two age groups was tested using t-tests and chi-square tests.

Bivariate Analysis

The aim of the bivariate analysis was to examine the multidimensional factors by isolating variables that are associated with caregiver burden among caregivers aged 18-34 years old and 35 years old and over.

Bivariate analysis was used to examine the relationship of each independent variable with the dependent variable of caregiver burden. Pearson's correlations were used with one continuous independent variable each time in the bivariate analysis. This method allows for the independent variables to be evaluated since both dependent and independent variables are continuous. The categorical variables of Alzheimer's care recipient, gender, marital status and employment status used t-tests and race with four levels used ANOVA.

Multivariable Analysis

Three hierarchical multiple linear regression models were used in the multivariable analysis. One hierarchical regression model consisted of all caregivers aged 18 and over in order to test age differences in caregiver burden among caregiver age groups 18-34 years old compared to caregivers aged 35 and older. A dichotomous variable was created with the caregivers aged 18-34 years old with a reference group of caregivers aged 35 years old and older. Interaction effects were tested with the predictor variables and age to determine whether independent variables differentially predicted caregiver burden for young adult caregivers compared to caregivers 35 and over. Interactions were dropped from the model if found to be non-significant. ADLs were centered at the mean in order for the main effects to have a meaningful reference point.

The second hierarchical regression model consisted of only young adult caregivers aged 18-34 years old to highlight the particular correlates related to caregiver burden among young adult caregivers. This helps to better understand what policies, practices and programs can be geared towards this particular age group. The third model consisted of only caregivers aged 35 and older which was used to highlight findings among this caregiver age group. The hierarchical multiple linear regression models was used to assess the relationships between socio-demographic and caregiver contextual factors, primary stressors and secondary stressors and the dependent variable of caregiver burden.

The rationale for using a hierarchical approach is based on previous studies that use the same but less recent 2004 NAC/AARP data set as this study and use a hierarchical regression analytic procedure to examine the socio-demographic variables in the first step, primary stressors in the second step and secondary stressors in the third step (Kim et al., 2012, Kim & Schulz, 2008). These studies also use the SPM to help guide the block organization. In addition, the hierarchical approach was used in this study based on the criteria in previous hierarchical regression research which states the hierarchical approach should be used when research questions are theoretically based and when predictor variables entered in later blocks can explain the variance over and above variables entered in earlier steps (Petrocelli, 2003). Since the SPM used in this study examines multidimensional factors and how they might contribute to caregiver burden, the hierarchical approach is useful to see how each category of variables in the SPM (socio-demographic, primary and secondary stressors) explains the variance in caregiver burden over and above earlier steps.

Predictor variables were entered into the model in three blocks based on the SPM (Pearlin et al., 1990). The SPM categorizes multidimensional factors that could contribute to caregiver burden into 1) socio-demographic and caregiving contextual variables, 2) primary stressors and 3) secondary stressors. In all three hierarchical models, the first block consisted of the socio-demographic and caregiving contextual variables including the caregiver's age, the caregiver's gender, marital status and race. The second block consisted of primary stressor independent variables including ADLs, IADLs, caregiving hours per week and Alzheimer's care recipient. The third block consisted of the secondary stressors of employment status and workplace impacts and the fourth block consisted of interaction effects of age and ADLs. In addition, research on hierarchical regression methodology and rationale states that predictor entry should be based on causal priority. It is further noted that researchers typically enter more static variables such as gender, age or race into the model first before entering more dynamic variables in subsequent steps. For example, by entering socio-demographic variables into block 1, the researcher can better understand how the primary stressors entered in block 2 and the secondary stressors entered in block 3 explain variance in caregiver burden over and above the previous steps. One main advantage of using a hierarchical linear regression approach is to see the significance in the incremental increases in R^2 when predictor variables are entered at each step (Petrocelli, 2003).

CHAPTER 4

RESULTS

This chapter reports what multidimensional factors were associated with caregiver burden among young adult caregivers aged 18-34 years old, caregivers aged 35 and all caregivers aged 18 over caring for an adult aged 50 and over. First, univariate results will be presented to describe the characteristics of caregivers aged 18-34 years old and caregivers 35 and over and their care recipients aged 50 and over. Second, the bivariate results will be presented to show the relationships between isolated independent variables and the dependent variable of caregiver burden among caregivers 18-34 years old, caregivers 35 and older and all caregivers aged 18 and over using t-tests, ANOVA and Pearson's correlations. Lastly, the chapter reports the results of three hierarchical linear regression models used to analyze the ten independent variables with the dependent variable of caregiver burden. The first hierarchical regression model sample consists of all caregivers aged 18 and over, the second hierarchical regression model consists of young adult caregivers aged 18-34 years old and the third model is comprised of caregivers aged 35 and over.

Sample Description

In Table 1, the means, percentages and standard deviations were calculated for caregivers aged 18-34 years old and caregivers aged 35 years old and over and their care recipients (aged 50 and over). T-tests and chi-squared tests were conducted to test statistically significant differences between the two caregiver age groups.

The study consisted of 1,228 caregivers over the age of 18 years old, with 222 caregivers aged 18-34 years old and 1,006 caregivers over the age of 35 years old. The care recipient age was statistically significant between the two caregiver age groups with a mean age of 67 years old among caregivers 18-34 years old ($t = 13.05$, $p < .001$) and a mean age of 78 years old among caregivers 35 and over. There was also a statistically significant difference in the caregiver's gender ($t = 6.90$, $p < .02$) with 51% female among 18-34 year old caregivers and 60% female among caregivers 35 and over. Sixteen percent of caregivers aged 18-34 cared for someone with Alzheimer's disease; whereas, 14% of caregivers aged 35 and over cared for someone with Alzheimer's disease. This did not reveal a significant difference between the two caregiver age groups ($t = 0.78$, $p = .45$).

Caregivers 18-34 years old were significantly more diverse than caregivers 35 and over with 44% white caregivers among 18-34 years compared to 72% white caregivers among caregivers 35 and over ($X^2 = 65.9$, $p < .001$). There was also a statistically significant difference in education among the two caregiver age groups ($X^2 = 21.0$, $p < .01$) with 9% of young adult caregivers completing graduate school compared to 18% among caregivers 35 and over.

Caregivers 18-34 years old more likely to be single (49%) compared to caregivers 35 and older ($t = 207.3$, $p < .001$). Caregivers 18-34 years old were also more likely to be employed at 69% compared to 35% of caregivers 35 and over ($t = 55.0$, $p < .001$). There was also a statistically significant difference in income among the two caregiver age groups ($X^2 = 31.7$, $p < .001$), with 37% of caregivers 18-34 years old making less than $30,000 per year compared to 24% of caregivers 35 and over. In addition, caregivers 18-34 years were less likely to be a primary caregivers with 56% compared to 65% of caregivers 35 and over ($t = 7.9$, $p < .036$).

The two caregiver age groups did not differ on reported caregiver burden. Caregivers aged 18-34 years old reported that they experienced caregiver burden an average of 2.5 out of a 5 point scale and caregivers 35+ experienced caregiver burden an average of 2.6 out of 5. The caregiver burden scale was a 5-point scale 1=*low burden* and 5=*highest level* of burden. This did not reveal a statistically significant difference (t=1.10, p = .28). Caregivers 18-34 years old spent fewer hours per week on caregiving (M = 20) compared to caregivers 35 and older (t = 2.9, p < .01). The two age groups of caregivers did not differ on reported ADLs ($M_{18\text{-}34}$ = 1.6; M_{35+} = 1.7; t = .44, p = .66). Caregivers 18-34 years old assisted with less IADLs (M = 3.9) compared to caregivers 35 and over (t = 2.84, p < .005). The two age groups did not differ on reported workplace impacts ($M_{18\text{-}34}$ = .63; M_{35+} = .49; t = -1.60, p = 0.11).

Table 1

Demographic description of caregivers (all ages) and their care recipients (ages 50+), weighted distributions and means, U.S. 2015

Variables	Caregivers 18-34 *N* = 222 (SD)	Caregivers 35+ *N* = 1,006 (SD)	Statistic, Level of Significance *t*, X^2
Mean Age of Caregiver	27 (4.9)	61 (13.4)	35.8***
Mean Age of Care Recipient	67 (12.6)	78 (10.9)	11.9***
Caregiver Burden (1-5)	2.50 (1.0)	2.60 (.98)	1.10
Caregiver Gender			6.90*
Female	51% (3.9)	60% (1.5)	
Male	49% (3.9)	40% (1.5)	
Care Recipients with Alzheimer's (Yes%)	16% (2.9)	14% (1.1)	0.78
Mean Count of ADLs (0-6)	1.60 (2.0)	1.70 (1.8)	0.48
Mean Count of IADLs (0-7)	3.90 (2.0)	4.30 (1.8)	2.60**
Caregiving Hours per week (.5 – 98)	20 (30)	27 (29)	2.80**
Caregiving Workplace Impacts (0-7)	0.63 (1.2)	0.49 (.93)	-1.90
Caregiver Race/Ethnicity			65.9***
White	44%	72%	
Black	20%	9%	
Asian	9%	5%	
Hispanic	23%	12%	
Other	4%	2%	
Caregiver Education			21.0**
High School or less	34%	33%	
Some college	30%	20%	
Technical School	6%	8%	
College Graduate	21%	21%	

Graduate School	9%	18%	
Marital Status			207.3***
Single, Never Married	49%	10%	
Widowed/Divorced	3%	20%	
Currently Employed %	69%	42%	55.0***
Income Level			31.7***
Less than \$30,000	37%	24%	
\$30,000-49,000	21%	20%	
\$50,000-100,000	28%	33%	
\$100,000 or greater	14%	23%	
Primary Caregiver Status	56%	65%	7.90*
Caregiver Lives with Care Recipient	4%	31%	0.24
Parent/Parent-in-Law	50%	48%	
Grandparent	29%	2%	
Other Family	11%	12%	
Friend/other non-relative	10%	15%	
Spouse/Partner	0%	21%	
Sibling/Sibling-in-law	0%	1%	

**p* < .05. ***p* < .01. ****p* < .001.
Note. SD = standard deviation; ADLS = Activities of Daily Living; IADLS = Instrumental Activities of Daily Living.

Bivariate Correlations

Bivariate analyses were conducted on the entire sample of caregivers aged 18 and over caring for an adult aged 50 and over and then separate bivariate analyses were conducted on caregivers 18-34 years old and caregivers aged 35 and over.

Caregivers 18+. Results of the correlation analysis for all caregivers appear in Table 2. For the entire sample of caregivers aged 18 and over, correlation analyses revealed that age (M = 55); r=-.02, p = .50 was not associated with caregiver burden, but all other variables were positively correlated with caregiver burden including the primary stressors of ADLs, IADLs and caregiving hours per week as well as the secondary stressor of workplace impacts. Caregivers who cared for someone with more impairments of activities of daily living (M = 1.7); r = .32, p < .001) and instrumental activities of daily living (M =4.3); r = .33, p < .001 experienced higher caregiver burden. In addition, a higher number of caregiving hours was associated with higher caregiver burden (*M* = 26); $r = .26$, $p < .001$. Additionally, the more workplace impacts a caregiver experienced, the higher the caregiver burden (*M* = .5); $r = .19$, $p <.001$.

Caregivers 18-34 years old. For young adult caregivers aged 18-34 years old, correlation analyses revealed that age (*M* = 27); $r= -.10$, $p =.15$ was not associated with caregiver burden, but all other variables were significantly associated with caregiver burden including the primary stressors of ADLs, IADLs and caregiving hours per week as well as the secondary stressor of workplace impacts. Caregivers who cared for someone with more impairments of activities of daily living (*M* = 1.6); $r = .21$, $p < .01$ and instrumental activities of daily living (*M* = 3.9); $r = .30$, $p < .001$ experienced higher caregiver burden. The higher number of caregiving hours was also positively associated with higher caregiver burden (*M* = 20); $r = .15$, $p < .05$. Additionally, increased workplace impacts (*M* = .63) were also positively associated with higher caregiver burden ($r = .17$, $p <.05$).

Caregivers 35 and over. For caregivers aged 35 and over, correlation analyses revealed that age (*M* = 61); $r= -.06$, p = .06 was not associated with caregiver burden, but all other variables were positively associated with caregiver burden including the primary stressors of ADLs (*M* = 1.7); $r = .21$, $p < .01$, IADLs (*M* =4.3); $r = .34$, $p < .001$and caregiving hours per week (*M* = 26); $r = .28$, $p < .001$ as well as the secondary stressor of workplace impacts (*M* = .5); $r = .20$, $p < .001$.

Table 2

Pearson's Correlations of Caregiver Burden with Age, Disease Status, and Workplace Factors (Caregivers 18 years old and over, 18-34 years old and 35 and over)

Predictor Variables	Caregivers 18+ years old (*N* = 1,228)	Caregivers 18-34 (*N = 222)*	Caregivers 35+ (*N = 1,006)*
	r	*r*	*r*
Caregiver Age	-.02	-.11	-.06
ADL	.32***	.21**	.34***
IADL	.33***	.30***	.34***
Caregiving Hours	.26***	.15*	.28***
Workplace Impacts	.19***	.17*	.20***

*$p < .05$. ** $p < .01$. ***$p < .001$.

ADL = Activities of Daily Living; IADL = Instrumental Activities of Daily Living

For the categorical variables of caregiver gender, caregiver marital status, care recipient's with Alzheimer's disease, caregiver race and caregiver employment status t-tests and ANOVA tests were conducted to compare the differences in caregiver burden.

Gender

Mean differences in caregiver burden between men and women were examined among all caregivers aged 18 and over. No statistically significant differences emerged in caregiver burden between men (M = 2.54, SD = .97); and women (M = 2.60, SD = 1.00); t = -.25, p = .80. Mean differences were also examined among caregivers aged 18-34 years old and caregivers 35 and over. No statistically significant differences in caregiver burden were found between men and women in both young adult caregivers and caregiver 35 and over. For young adult caregivers, there was not a statistically significant difference in caregiver burden between men (M = 2.50, SD = 1.15) and women (M = 2.50, SD = .90); t = .13, p = .90. In addition, there was not a statistically significant difference in caregiver burden between men (M = 2.60, SD = .94) and women (*M* = 2.60, *SD* = 1.02); *t* = -.25, *p* = .80 among caregivers 35 and over. The results show that gender in all age groups did not statistically significantly related to higher caregiver burden.

Marital Status

Mean differences in caregiver burden between caregivers who were married or not married were examined among all caregivers aged 18 and over. There were no statistically significant differences in caregiver burden between caregivers 18+ who were married (*M* = 2.59, *SD* = 1.01); and not married (*M* = 2.48, *SD* = 1.01); *t* = -1.82, *p* = .07. For young adult caregivers, no statistically significant differences occurred in caregiver burden between caregiver's who were married (*M* = 2.51, *SD* = .88) and not married (*M* = 2.40, *SD* = .92); *t* = .76, *p* = .45. No statistically significant difference occurred in caregiver burden between married (*M* = 2.60, *SD* = .04) and not married (*M* = 2.50, *SD* = 1.04); *t* = -1.48, *p* = .14 among caregivers 35 and over. The results show that marital status in all age groups were not statistically significantly associated with caregiver burden.

Race

An ANOVA test with four levels of race/ethnicity compared caregiver burden among the different racial/ethnic groups of White, Black, Asian, Other and Latino. Mean differences in race/ethnicity with caregiver burden were tested among all caregivers aged 18 years old and over. There were no statistically significant differences in caregiver burden among caregivers of different races where White *(M* = 2.56, *SE* = .04); Black (*M* = 2.52, *SE* = .09); Asian (*M* = 2.59, *SE* = .11); Other *(M* = 2.64, *SE* = .18); and Latino *(M* = 2.54, *SE* = .08); *F*(4) = .12, *p* = .97. Mean differences in race with caregiver burden were also tested among young adult caregivers aged 18-34 years old. Findings showed that no statistically significant differences occurred in race with caregiver burden where White *(M* = 2.40, *SE* = .10); Black (*M* = 2.73, *SE* = .20); Asian

(*M* = 2.76, *SE* = .21); Other (*M* = 2.80, *SE* = .30); and Latino (*M* = 2.30, *SE* = .14); *F (4)* = 1.92, *p* = .11. Mean differences in race with caregiver burden were also tested among caregivers aged 35 years old and older. No statistically significant differences occurred in race with caregiver burden where White (*M* = 2.60, *SE* = .04); Black (*M* = 2.42, *SE* = .09); Asian (*M* = 2.51, *SE* = .12); Other (*M* = 2.57, *SE* = .23); and Latino (*M* = 2.65, *SE* = .09); *F(4)* = .77, *p* = .54. Thus, race was not statistically significantly associated with caregiver burden among any of the age groups.

Alzheimer's Care Recipient

T-tests were conducted to compare caregiver burden among care recipient's with and without Alzheimer's disease (AD). All caregivers over the age of 18 years old caring for a loved one with Alzheimer's disease (*M* = 2.84, *SD* = .92) experienced statistically significantly higher caregiver burden compared to care recipients without AD (*M* = 2.50, *SD* = 1.00); *t* = -4.18, *p* <.0001. Among caregivers 18-34 years old, there was not a statistically significant difference in care recipient with AD (*M* = 2.70, *SD* = .77) and care recipient without AD (*M* = 2.45, *SD* = 1.04); *t* = -1.22, *p* = .23. The results suggest that no statistically significant differences occurred in caregiver burden among care recipients with and without Alzheimer's disease among young adult caregivers. Among caregivers over the age of 35 years old, a statistically significant difference occurred among care recipients without AD (*M* = 2.50, *SD* = .98) and care recipients with AD (*M* = 2.90, *SD* = .94), *t* = -4.10, *p* <.0001. In all, caregivers 35 and over caring for a loved one with Alzheimer's disease experienced higher caregiver burden than care recipients without Alzheimer's disease.

Employment

T-tests were also conducted to compare caregiver burden among caregivers who were currently employed. All caregivers over the age of 18 years old who were not currently employed (*M* = 2.60, *SD* = 1.04) experienced higher caregiver burden compared to caregivers who were employed (*M* = 2.47, *SD* = .97), *t* = 2.54, *p* =.01. For young adult caregivers, there was not a statistically significant difference in caregiver burden between caregivers who were employed (*M* = 2.40, *SD* = .87) and not employed (*M* = 2.56, *SD* = .95), *t* = 1.14, *p* = .26. However, a statistically significant difference occurred in caregiver burden between employed (*M* = 2.49, *SD* = .99) and not employed (*M* = 2.62, *SD* = 1.05); *t* = 2.05, *p* = .04 among caregivers 35 and over. Thus, caregivers 35 and over who were unemployed experienced higher caregiver burden than those who were employed.

Multivariable Analysis: Hierarchical Linear Regression

Three hierarchical linear regression models were used to determine the multidimensional factors associated with caregiver burden. The first hierarchical model consisted of caregivers aged 18 and over to test differences among the caregiver age groups of 18-34 years old and 35 and over. The second model consisted of young adult caregivers 18-34 years old and the third model consisted of caregivers 35 and older to highlight any key findings in each age group.

Hierarchical Multiple Linear Regression Model I: Caregivers aged 18 and over

The first hierarchical regression model used the sample of all caregivers aged 18 and over caring for an adult aged 50 and over. The model included ten predictor variables and the outcome variable of caregiver burden. It also tested interaction effects with age, caregivers 18-34 years old with reference group of caregivers 35 and over, with the primary and secondary stressor predictor variables of ADLs, IADLs, hours and work-related impacts (see Table 3). The statistically significant interaction of age and ADLs was reported. Other non- statistically significant interactions were not reported.

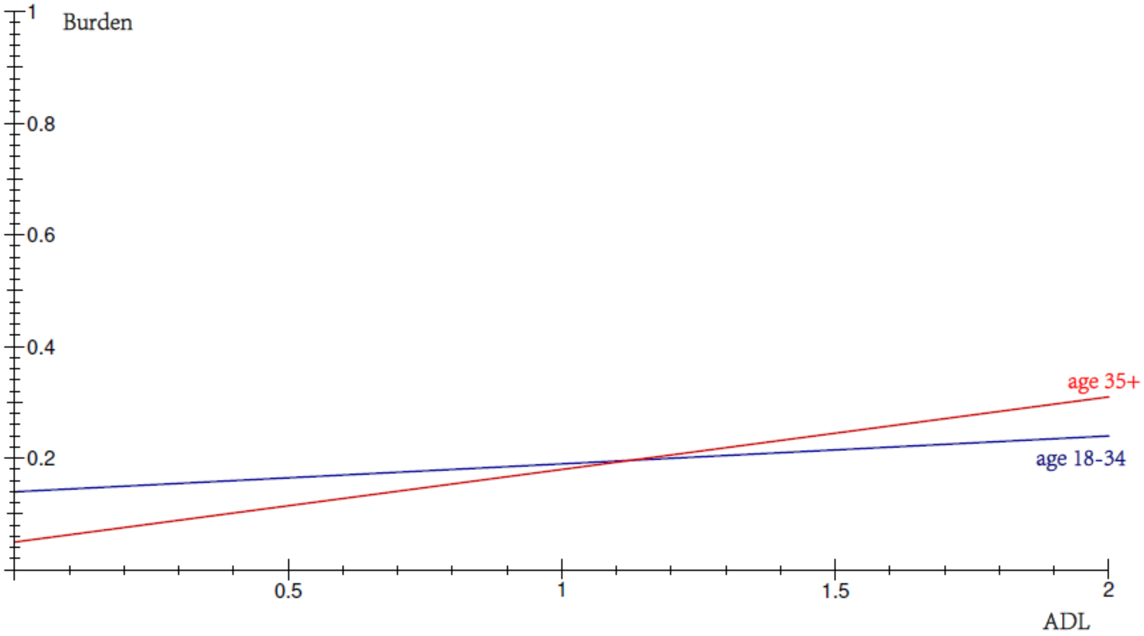
The first block consisted of socio-demographic and caregiving contextual variables including the caregiver's age dichotomous variable, caregiver gender, caregiver race and marital status of the caregivers. Results in block 1 showed that the caregiver's age, caregiver gender, race and marital status did not relate to caregiver burden and accounted for about 2% of the variation in caregiver burden.

The block 2 predictors consisted of the primary stressor variables including activities of daily living, instrumental activities of daily living, the number of caregiving hours per/week and Alzheimer's care recipient. With the addition of block 2 predictor variables, the variation in caregiver burden explained by the predictors increased from 2% to 16%. All of the primary stressor variables contributed to higher caregiver burden including, ADLs (B =.110, $p < .001$), IADLs (B =.110, $p < .001$), caregiving hours per week (B =.003, $p < .01$) and Alzheimer's care recipient (B=.17, p <.05). The third block consisted of the secondary stressor predictor variables of workplace impacts which was associated with higher caregiver burden (B = .17, $p < .001$) and employment status where being employed was associated with lower caregiver burden (B = -.18, p <.01). The variation of caregiver burden increased to 18%.

The interaction effects of caregivers aged 18-34 years old with reference group of 35 and older were tested in block 4. The interaction of ADLs with caregiver age statistically significantly relates to caregiver burden (B = -.08, $p < .05$). The average effect of ADLs on caregiver burden depends on the age of the caregiver. In Figure 3, the effect of ADLs (B= .11) on caregiver burden is moderated by age (B = .007). As the number of ADLs increase, burden increases more significantly among caregivers 35 and over compared to caregivers 18-34 years old. The addition of the interaction changed the variation in the overall model slightly from 18% to 19%. No other significant interactions were found with caregiver age and caregiver burden.

Figure 3

The Effect of ADLs on Caregiver Burden Moderated by Age (18-34 year old caregivers with reference group 35 and over caregivers)



In summary, the primary stressors of ADLs, IADLs, caregiving hours, the secondary stressors of employment status and workplace impacts and the interaction of age with ADLs contributed significantly to caregiver burden among all caregivers aged 18 and over. The caregiver's gender, race, marital status and the care recipient's condition were not statistically significantly associated with caregiver burden.

Table 3

Hierarchical Multiple Linear Regression of Caregiver Burden on Age, Gender, Disease Status, ADLs/IADLs and Work-related Factors (Caregivers ages 18+ and care recipients 50+)

N = 1,228	Block 1	Block 2	Block 3	Block 4
	ß	ß	ß	ß
Intercept	2.50	1.83	1.89	2.06
Caregiver Age (18-34) (Reference: 35+)	0.06	0.10	0.08	.007
Caregiver Gender (female=1, male=0)	-.003	.004	.006	-.0002
Married (yes =1, no =0)	0.08	-.004	0.02	.017
Race (ref. White)				
Black	-0.02	-0.09	-0.10	-0.09
Asian	0.02	0.02	0.02	0.04
Other	0.09	0.08	0.05	0.03
Latino	-0.04	-0.13	-0.15*	-0.14
Alzheimer's Care Recipient (yes=1, no=0)		0.17*	0.15	0.14
ADLs (0-6)		0.11***	0.09***	0.11***
IADLs (0-7)		0.11***	0.10***	0.10***
Caregiving hours/week (0-96)		.003**	.003**	.003**
Caregiver Employed (yes=1, no=0)			-0.18**	-0.18**
Caregiver work impacts (0-7)			0.17***	0.17***
Age (18-34, ref group 35+) x ADL				-0.08*

R^2	.002	0.16	0.18	0.19

*p < .05. **p < .01. ***p < .001.

Note: ADLs centered at its mean. ADLs = activities of daily living; IADLs = instrumental activities of daily living; Alzheimer's CR = Alzheimer's care recipient.

Hierarchical Multiple Linear Regression Model II: Caregivers aged 18-34 years old

The second hierarchical linear regression model used the sample of young adult caregivers aged 18-34 years old caring for an adult aged 50 and over. It used the independent variables and the dependent variable of caregiver burden in three blocks. Results of this analysis are reported in Table 4. It used the same block organization as the first hierarchical regression model but did not use the age dichotomous variable and instead used age as a continuous variable to test differences in age among 18-34 years old with caregiver burden.

In block 1, results revealed that the caregiver's age (*B* = -.024, *p* = .11), caregiver gender (*B* = -.112, *p* = .69*)* and marital status (*B* = .082, *p* = .58) were not associated with caregiver burden. The race of the caregiver (with a reference group of white) showed that Black (*B* = .33, *p* = .07), Asian (*B* = .37, *p* = .13), Other (*B* = .44, *p* = .23), Latino (*B* = -.13, *p* = .44) caregivers did not have higher caregiver burden compared to white caregivers. The socio-demographic variables in block 1, explained 6% of the variation in caregiver burden.

In block 2, the variables of ADLs, IADLs, caregiving hours and Alzheimer's care recipient were added to the model. ADLs (*B*= .077, *p* =. 047) and IADLs (*B*= .114, *p* =. 003) were associated with higher caregiver burden, but caregiving hours and Alzheimer's care recipient were not related to caregiver burden. The caregiver's younger age (*B* = -.032, *p* =.03) became statistically significant with the addition of block two variables. In block 3, the variable of Latino became statistically significant, where White caregivers experienced statistically more burden than Latino caregivers. In addition, the employment status and work-related impacts did not relate to caregiver burden and the overall model explained 18% of the variation in caregiver burden. ADLs became no longer statistically significant with the addition of block 3 variables. In sum, the caregiver's younger age and IADLs were associated with higher caregiver burden in caregivers aged 18-34 years old.

Table 4

Hierarchical Multiple Linear Regression of Caregiver Burden on Age, Gender, Disease Status, ADLs/IADLs and Work-related Factors (Caregivers 18-34 years old, Care Recipient's 50+)

N = 222	Block 1	Block 2	Block 3
	ß	ß	ß
Caregiver Age 18-34	-.024	-.032*	-.032*
Caregiver Gender (female =1, male = 0)	-.112	-.169	-.167
Married (yes=1, no=0)	.082	.086	.080
Race (ref. white)			
Black	.334	.229	.192
Asian	.368	.172	.164
Other	.436	.475	.468
Latino	-.135	-.325	-.337*
Alzheimer's care recipient (yes=1, no=0)		.151	.116
ADLs (0-6)		.077*	.068
IADLs (0-7)		.114**	.111*

Caregiver Employed (yes=1, no=0)			-.101
Caregiver work impacts (0-7)			.082
R^2	.063	.177	.186

*p < .05. **p < .01. ***p < .001.
Note. ADLs = activities of daily living; IADLs = instrumental activities of daily living

Hierarchical Multiple Linear Regression Model III: Caregivers aged 35+ years old

The third hierarchical linear regression model used the sample of caregivers aged 35 years old and older caring for an adult aged 50 and over. It used the same three block structure used in the previous hierarchical models. Results of the analysis are reported in Table 5. In block 1, results revealed that the caregiver's age ($B = -.004$, $p=.05$), the caregiver's gender ($B = .012$, $p = .84$), marital status ($B=.08$, $p=.22$) and race with Black ($B = -.17$, $p=.12$), Asian ($B = -.10$, $p=.51$), Other ($B = -.01$, $p=.96$), Latino ($B = .10$, $p=.84$) did not contribute significantly to caregiver burden. This explained 7% of the variation in caregiver burden. In block 2, ADLs, ($B= .115$, $p < .001$), IADLs ($B= .106$, $p < .001$), caregiving hours ($B= .004$, $p< .01$) and Alzheimer's care recipient ($B = .18$, $p = .03$) was associated with higher caregiver burden. In addition, the caregiver's younger age ($B= -.007$, $p=.0006$) became significant with higher caregiver burden with the addition of block two variables. In block 3, employment status was related to caregiver burden, with employed caregivers being associated with lower caregiver burden ($B = -.32$, $p < .001$). In addition, for caregivers who were employed, the greater the number of workplace impacts the higher the caregiver burden ($B= .19$, $p < .0001$). Race became statistically significant with burden, where white caregivers experienced statistically significantly more caregiver burden than Black caregivers. The overall model explained 21% of the variation in caregiver burden. In sum, younger age, the Alzheimer's care recipient, race, ADLs, IADLs, hours, being unemployed and workplace impacts was associated significantly with higher caregiver burden among caregivers aged 35 and over. The caregiver's marital status and gender did not contribute significantly to caregiver burden.

Table 5

Hierarchical Multiple Linear Regression of Caregiver Burden on Age, Gender, Disease Status, ADLs/IADLs and Work-related Factors (Caregivers 35+ years old, care recipients 50+)

N = 1,006	Block 1	Block 2	Block 3
	ß	ß	ß
Caregiver Age	-.004	-.007***	-.009***
Caregiver Gender (female = 1, male=0)	.013	.022	.019
Married (yes=1, no=0)	.085	-.002	.037
Race (ref. White)			
Black	-.171	-.275**	-.271**
Asian	-.099	-.041	-.023
Other	-.012	-.099	-.137
Latino	.020	-.076	-.115
Alzheimer's care recipient (yes = 1), no =0)		.180*	.176*
ADLs (0-6)		.116***	.102***
IADLs (0-7)		.106***	.097***
Caregiving hours week (0-96)		.004**	.003**
Caregiver currently employed			-.317***

(yes=1, no=0)			
Caregiver work impacts (0-7)			.187***
R^2	.007	.18	.21

*p < .05. **p < .01. ***p < .001.

Note. ADLs = activities of daily living; IADLs = instrumental activities of daily living

Summary of Multivariable Findings

The entire sample of caregivers over the age of 18 years old found that ADLs, IADLs, hours, employment status and work-related impacts all contributed significantly to caregiver burden, but caregiver’s age 18-34 years old with reference group of 35+ caregivers and caregiver’s gender did not contribute significantly caregiver burden. The interaction of caregiver age and ADLs was statistically significant associated with caregiver burden. IADLs was the only variable that contributed statistically significantly to caregiver burden among all three models. In the young adult aged 18-34 year old caregiver model, the findings showed that the caregiver’s younger age, race and assistance with IADLs were statistically significantly associated with higher caregiver burden. The 35-year-old and older caregiver model revealed that caregiver age, race, Alzheimer’s care recipient, assistance with ADLs, assistance with IADLs, hours, being unemployed and workplace impacts were associated with higher caregiver burden.

CHAPTER 5

DISCUSSION

The dissertation examined the multidimensional factors associated with caregiver burden among young adult caregivers aged 18-34 years, caregivers over the age of 35 years old and all caregivers 18 and over using the Stress Process Model (SPM) as the conceptual framework (Pearlin et al., 1990). Three hierarchical multiple linear regression models were used to better understand what socio-demographic factors, primary stressors and secondary stressors related to higher caregiver burden among caregivers 18 years old and older, 18-34 year old and 35 and over caregivers. This study showed that young adult caregivers between the ages of 18-34 years old caring for an older adult loved one experience caregiver burden and need more support particularly with IADL tasks. In addition, older caregivers over the age of 35 years old experience additional issues that contribute to caregiver burden including younger age, Alzheimer's care recipient, race, ADLs, caregiving hours per week, being unemployed and workplace impacts. The relevance, importance and implications of the findings are discussed in this chapter.

Socio-demographic and Caregiving Context: Age, Gender, Race and Marital Status

Caregiver Age

Findings demonstrate that caregiver age is associated with caregiver burden among caregivers 18-34 years old and caregivers 35 and over. In both caregiver age groups, younger caregivers experienced more burden than the older caregivers within the respective age cohort. Younger caregivers experienced higher caregiver burden than older caregivers within the young adult caregiver population. This supports the theory of Emerging Adulthood, showing that emerging adults between the ages of 18-25 years old are at an age of exploration in "love, work and worldviews" and adding the role of caregiving may disrupt this stage of exploration and possibly relate to higher caregiver burden at younger ages (Arnett, 2000, p. 469). The finding also supports previous young caregiver studies that find emerging adults to be at a "critical developmental stage" as they try to navigate their education, starting a career and building a family and juggle the strain of caring for an older adult (Levine et al., 2005, p. 2071). For example, an 18-year-old in college providing care to a grandparent or parent may struggle academically, emotionally and socially if they also need to be caring for a sick loved one who might need help grocery shopping, being taken to doctor appointments or help dressing, eating or bathing. This could impose higher caregiver burden on the young caregiver whereas an older caregiver who is 34 years old may be more likely to already be established in their careers, have the support of a spouse, financially comfortable or have the developmental maturity to better manage caregiving tasks.

This finding adds to the caregiving research by showing that younger caregivers within the millennial cohort are particularly susceptible to higher caregiver burden. Since younger caregivers are stepping into the role of caregiving as the older adult population increases, more interventions are needed to support young caregivers, so they do not have long-term consequences (NAC/AARP, 2015). Erik Erickson's theory of psychosocial development suggests that if a young adult does not progress through the developmental stage of intimacy vs. isolation they may not have close personal relationships throughout their life and be more susceptible to depression, anxiety and stress (Erikson, 1994). If a young caregiver is caring for a sick loved one and susceptible to high caregiver burden, they may not have the time or may be too emotionally drained to form sustaining personal relationships. This hold implications for programs and practices to be geared towards young adult caregivers. Future research should consider a qualitative research study conducting in-depth interviews with young adult caregivers to gain a richer and more detailed understanding of what types of programs and practices could support them physically, emotionally and financially. More support groups should be tailored and marketed to young adult caregivers.

Interaction of Age and ADLs

Among caregivers 18 and over, caregiver burden differs by age and ADLs. The findings showed that ADLs relate to burden differently depending on the age group. As the number of ADLs increased, caregiver burden increased among caregivers 35 and over significantly more than caregivers 18-34 years old. The significant interaction could be explained by the relationship to the care recipient and whether they are living with the care recipient or not. The findings showed that caregivers 35 and over are more likely to be the care recipient's spouse compared to younger caregivers. As a spousal caregiver, different types of ADL tasks may be performed compared to a young adult caregiver caring for a parent or grandparent. For example, older caregivers aged 35 and over may be more likely to be feeding, toileting, showering and dressing the care recipient if they are a spouse and residing with the care recipient compared to younger caregivers who are more likely to be caring for a grandparent or parent and not living with the care recipient (Kim et al., 2012).

In addition, since caregivers 35 and over are more likely to be caring for a spouse, they may also be more likely to have not had a choice in providing certain ADL tasks to the care recipient compared to younger caregivers. Lack of choice in becoming a caregiver has been shown in previous studies to be associated with higher caregiver burden (Schulz et al., 2012). If a caregiver feels obligated to care for someone rather than volunteers to care for someone, they may be more prone to caregiver burden (Schulz et al., 2012, Longacre et al., 2013). Younger caregivers may be more likely to choose to become a caregiver. As explained in the theory of Emerging Adulthood, this stage of life is characterized by role exploration and possibly feeling less settled in their careers (Arnett, 2000). Because of this, young adults may be more inclined to choose to help with caring for an older adult.

The finding could also be explained by older caregivers potentially being physically burdened performing ADL tasks (Jones et al., 2011). It could be physically straining for an older caregiver in their 60s and 70s helping a loved one dress or lifting them in and out of bed, while doing these type of tasks might not be as physically taxing on an 18-34 year old caregiver.

More research is needed to better understand the different predictors of caregiver burden for different age groups. Previous studies examine ADLs as a predictor to caregiver burden, but do not compare differences in caregiver age groups by ADLs (Kim et al., 2017; Wolff et al., 2016). Future studies should look at the different components of caregiver burden separately to better understand the differences in age and ADLs with physical, emotional, and financial strain. This finding also underscores the importance of respite care programs and the need for better financial support for caregivers so that they can afford in-home care services to help assist with ADLs.

Gender

The caregiver’s gender did not relate to caregiver burden in caregivers 18 and over. This finding is inconsistent with several previous findings that show women exhibit more caregiver burden than men (Almberg et al., 1998; Gallicchio et al., 2002; Gibbons et al., 2014; Kim et al., 2012; Pillemer et al., 2018). The dissertation’s findings do support some studies that report little to no differences in the caregiver’s gender with caregiver burden (Akpinar et al., 2011; del-Pino Casado et al., 2012; Pinquart & Sorensen, 2006). Pinquart and Sorensen (2006) found few caregiving gender differences existed in burden, depression and the number of caregiving among men and women (Pinquart & Sorenesen, 2006, p. 33). They also found that younger men and women caregivers report even fewer differences in their caregiving experiences.

The findings also do not support Stress and Coping Theory. Several studies use Stress and Coping Theory to better understand gender differences in caregiving (Del-Pino Casado, 2012; Sharma et al., 2016,). Stress and Coping Theory suggests that women tend to exhibit more caregiver burden than men because they are more emotionally-focused and men are more task-oriented and therefore they tend to experience caregiving stressors differently than men (Sharma et al., 2016). The findings in the dissertation showed that gender did not relate to caregiver burden and this could be explained by the dependent variable of caregiver burden not fully capturing the emotional and psychological aspects that other studies do. It could also be explained by more men being included in the sample of caregivers than past studies and they are also taking on caregiving roles in higher frequency (Vega et al., 2017). Future studies should continue to include more men in the sample to better generalize to the population and understand potential gender differences in caregiving.

Race and marital status were also used as control variables in this analysis. Marital status did not contribute to caregiver burden among any of the caregiver age groups. Race was found to be a significant predictor among caregivers 18-34 years old and caregiver 35 and over. Among caregivers 18-34 years old, the findings revealed that White caregivers experienced higher caregiver burden than Latino caregivers. Among caregivers 35 and over, findings showed that White caregivers experienced higher caregiver burden than Black caregivers. Race and marital status were beyond the scope of this study, but future studies should incorporate these variables to better understand what factors contribute to caregiver burden among different age groups.

Primary Stressors: Activities of Daily Living (ADLs), Instrumental Activities of Daily Living (IADLs), Caregiving Hours and Alzheimer's disease

The primary stressors of ADLs, IADLs and caregiving hours per week all contributed significantly to caregiver burden among caregivers over the age of 18 years old and caregivers aged 35 and over. ADLs and caregiving hours were not associated with caregiver burden among caregivers 18-34 years old, but IADLs was associated with higher caregiver burden. This could be because younger caregivers are more likely to be caring for a grandparent or parent and are less likely to be a primary caregiver compared to caregivers 35 and over. The findings show that they are less likely to provide help with ADLs and this could be because of the sensitive and difficult nature that might come with ADL assistance such as bathing and going to the bathroom. Young adult caregivers are also at a time in their life where they are most likely to be in school, working or caring for young children, so they have less time to care for an older adult due to other obligations compared to older caregivers. Since the majority of young adult caregivers are working, they can better manage IADL tasks such as making phone calls, scheduling doctor's appointments and grocery shopping in conjunction with their own lives.

The results confirm previous findings that primary stressors, particularly the amount and type of care provided to a loved one, significantly impacts caregiver burden (Kim et al., 2012; Riffin, 2017). This also supports Stress and Coping Theory showing that it is the interplay of multiple factors that contribute to higher levels of caregiver burden.

Alzheimer's Disease

Much of the literature shows that caregivers caring for a loved one with Alzheimer's disease experience increased caregiving demands due to the nature of the disease and, therefore, experience higher caregiver burden levels than caregivers who are caring for someone with another type of condition (Kasper et al., 2016; Ory et al., 1999; Schulz et al., 2004; Wolff et al., 2016). Findings from this research showed that being an Alzheimer's care recipient is related to higher caregiver burden among caregivers over the age of 35 years old, but not among young adult caregivers aged 18-34 years old. In addition, the Alzheimer's care recipient measure did not capture the level of cognitive impairment which would be important factor to consider with caregiver burden.

The results also showed that caregivers of recipients with Alzheimer's disease did not have higher caregiver burden among young adult caregivers aged 18-34 years old. This might be explained by young adult caregivers providing mostly IADLs for their loved one and are less likely to be helping with ADL care that many Alzheimer's patients need as their disease progresses (Alzheimer's Association, 2017). Much of the current literature looks at older caregivers and the studies reveal that caregivers who care for someone with Alzheimer's disease often experience more caregiver burden than caregivers caring for someone with other diseases (Kasper et al., 2015; Wolf et al., 2016).

Secondary Stressor: Workplace Impacts and Employment Status

The findings showed that workplace impacts was associated with higher caregiver burden among the entire sample of caregivers over the age of 18 years old and caregivers 35 and older. This confirms previous findings that interference with work contributes to caregiver burden among caregivers (TransAmerica Institute, 2017; Wolff et al., 2017). However, workplace impacts was not associated with higher caregiver burden among young adult caregivers. The finding does not support studies that show workplace impacts contribute to caregiver burden among young adult caregivers who may suffer from severe work-related impacts such as losing their jobs (Transamerica Institute, 2017). This could be due to a small young adult caregiver sample and could also be due to the younger cohort aged 18-22 years old being in college or school and not experiencing workplace impacts. Future studies should examine how caregiving impacts caregivers in school performance. In addition, findings showed that being employed was associated with lower caregiver burden among caregivers 35 and over and all caregivers 18 and over. Future studies should include this variable to better understand how being employed contributes to lower caregiver burden among different age groups.

Implications for policy and practice

First, it will be discussed how existing federal policies such as the Family Medical Leave Act can better support family caregivers in the workplace. Then other policies will be discussed to examine what is being done on both a federal and state level to support family caregivers in other aspects of their lives such as assistance with primary stressors such as ADLs and IADLs. Lastly, the types of programs and practices will be examined that could better serve young adult caregivers.

Policy Implications

Family Medical Leave Act. The findings showed that an increased number of workplace impacts such as taking a leave of absence or needing to cut back work hours was related to higher caregiver burden among all caregivers over the age of 18 years old. While states are beginning to make steps to supporting family caregivers in the workplace, the Family Medical Leave Act (FMLA) should be expanded to include more caregivers. Since workplace impacts contributed significantly to caregiver burden among all caregivers aged 18 and over, it is important to better understand what policies are in place to help working caregivers. The findings from the study can also support young adult caregivers aged 18-34 years old as they look towards the future of juggling work with caregiving.

More policies are needed to better support family caregivers particularly in the workplace as the older adult population increases. The FMLA is a federal policy that aims to support workers who need to take a leave of absence due to a serious health condition or to those who are providing care to someone with a serious health condition. The FMLA provides 12 weeks of unpaid, job protected leave, and, while it may help some workers it contains several limitations. In order to be eligible for the FMLA, a person must work for a company that has 50 or more employees or works for a public agency, elementary or secondary school for at least 12 months. Additionally, the employee must have worked at least 1,250 hours in the last 12 months and be 75 miles from their workplace (U.S. Department of Labor, n.d.).

Young adult caregivers may be particularly disadvantaged by the FMLA due to its restrictions. Many young adults, aged 18-34 years old, may not be able to afford to take time off of work to care for a loved one because they are early in their careers and may not have the savings and support of older caregivers who have accumulated more wealth over the years. Therefore, young adults may have to use sick and vacation time to care for a loved one. The 2012 FMLA employee survey found that 46% of employees did not take leave from work because they could not afford to (Family Medical Leave Act, 2012). Policies such as the FMLA should be expanded to include more workers from smaller companies with less than 50 employees and provide paid leave so that working caregivers are not forced into financial turmoil to provide care to a loved one and should not need to be 75 miles from their workplace.

State workplace policies are making efforts to better support family caregivers. Some states offer paid family leave to employee caregivers and provide cash benefits to eligible workers (Congressional Research Service, 2019). States like California, Rhode Island and New Jersey provide paid family leave insurance (FLI) for family caregivers and offer 4 to 10 weeks of benefits to eligible workers (Congressional Research Service, 2019). New York, Washington DC and Massachusetts have also enacted FLI. More states should offer FLI so that employees are not left to make a decision between their jobs and caring for a loved one.

The findings showed that workplace impacts such as needing to take a leave of absence due to caregiving increased caregiver burden. Because of this, the FMLA should also include paid job protected leave for caregivers caring for someone with a serious condition. If working caregivers are unable to receive paid job-protected leave from work, then their loved one may need to be placed in a long-term care facility or require additional costly paid care. This might cause financial, physical and emotional consequences for the caregiver and the older adult (Brodaty et al., 2009). States like California provide partial paid leave to eligible workers who provide care to a sick loved one, but it does not protect them from losing their job (Employment Development Department State of California, n.d.). Therefore, if a caregiver works and lives in California, only some may be protected by the FMLA and receive job protection.

The findings also showed that young adult caregivers are more likely to be caring for a grandparent, so the definition of "family" should also be broadened under the FMLA to accommodate more caregivers as the older adult population increases. The FMLA defines a family member as a spouse, son, daughter or parent with a serious condition (U.S. Department of Labor, n.d.). The FMLA should expand the definition to include domestic partners, parents-in-law, grandparents and siblings. More state workplace policies should also broaden the definition of family. For example, California recognizes a "seriously ill family member" as a registered domestic partner, parent, child, parent-in-law, sibling and grandparent (Employment Development Department State of California, n.d.).

The findings showed that work-related impacts relates to higher levels of caregiver burden in caregivers 18 and over, therefore particular attention should be paid to expanding the definition of family in workplace policies and providing paid job protected leave to employees who work in smaller companies so that more caregivers are included under this policy. While efforts are being made on both the federal and state level to help working caregivers, more needs to be done so that no caregiver is excluded from receiving assistance and protection from losing their job for caring for a loved one.

Federal and State Policies for Caregivers. The findings showed that IADLs contribute to higher caregiver burden among young adult caregivers and some federal and state policies are currently in place to support family caregivers and address their physical, emotional and financial needs. Policymakers recognize that family caregivers are the "backbone" of the long-term care system and are making efforts to provide services and support to family caregivers (Department of Health and Human Services, 2019). Under the Older American Act (2000), the National Family Caregiver Support Program aims to keep older adults in their homes as long as possible by providing funding to states for caregiving support programs (Department of Health and Human Services, 2019). This policy provides information and accessibility to services such as respite programs, support groups, caregiver training and counseling for caregivers (Department of Health and Human Services, 2019). The 2016 reauthorization of Older American Act also expanded eligibility of caregivers and care recipients to benefit from the program including caregivers aged 18 and over caring for an older adult aged 60 and over (Department of Health and Human Services, 2019).

In addition, the findings also showed that increased ADLs, IADLs and workplace impacts related to higher caregiver burden among caregivers. Policies and programs are currently in place to help address these needs. RAISE (Recognize, Assist, Include, Support and Engage) Family Caregivers Act was enacted in 2018 and serves as a federal advisory council that advises the Secretary of Health and Human Services to develop a national strategy to support family caregivers in a variety of ways including workplace issues, respite care, person-centered care and other services that provide information, training and referrals (Department of Health and Human Services, 2019). While RAISE is a relatively new effort aimed to support family caregivers, future studies should provide an analysis on how the legislation is impacting all caregivers particularly young adult caregivers. Young adult caregivers feel unprepared and need more information on how to manage stress and obtain medical help (AP-NORC, 2018; Levine et al., 2005; TransAmerica, 2017).

Some states are also making initiatives to support an aging population. For example, California Governor Gavin Newsom created a California Master Plan for Aging (MPA) in 2019 in which a cabinet work group, and two subcommittees on research and long-term care services will create a state and local plan in how to support an aging population in California. The plan states that it will include recommendations for how to better support caregivers, older adults and families (Master Plan for Aging Progress Report, 2019). The goals of the plan include addressing 1) Services and Supports 2) Livable Communities 3) Health and Well-Being and 4) Economic Security and Safety (Master Plan for Aging Progress Report, 2019). The Long-Term Services and Support subcommittee met in October, November and December 2019 and discussed information and assistance networks, a public long-term care benefit and in-home supportive services. The MPA shows that California is making a statewide effort to better address the needs of an aging population.

Practice and Program Implications

In addition to policy reform, more tailored programs and practices should be geared towards young adult caregivers, paying particular attention to support with IADLs and the needs of younger caregivers. Of the few studies that focused on young adult caregivers, all pointed to the need for more tailored programs and practices for young caregivers (Dellman-Jenkins, 2003; Levine et al., 2005). For example, programs and practices should be more easily accessible to young working caregivers such as phone-based and online services and support. Practitioners that support family caregivers could provide care consultations over the phone or online as to not interfere with the caregiver taking time off of school or work. Telephone consultations could also help assess young adult caregivers' needs and connect them to resources that can assist them with IADLs and help improve their burden. Studies show that telephone interventions for caregivers that include support groups, skills training, problem solving and stress management reduced caregivers' depression and burden levels (Belle et al., 2006). Telephone interventions can be helpful in improving caregiver burden in older caregivers, and interventions should be marketed to young adult caregivers in the workplace and in colleges to make young caregivers more aware of caregiving support programs (Belle et al., 2006). In addition, future studies should focus on how these interventions impact young adult caregivers.

Respite care services could also benefit young adult caregivers and ease their caregiver burden. Respite services could provide caregivers in school and work with more time to focus and spend time at work knowing their loved one is being cared for. It could also give the caregivers more time to assist with IADLs such as making phone calls and grocery shopping while their loved one is being cared for in a respite program. Respite care services such as daytime assisted care and in-home care improved caregiver burden among informal caregivers

(Vandepitte et al., 2016). Future studies should include young adult caregivers to better understand the potential benefits of respite care.

While several practices, programs and interventions exist to alleviate caregiver burden, more tailored programs for young caregivers are needed. Future research should focus on young adult caregivers and what types of tailored program and policies could best support them particularly with IADL assistance. More practices and programs should also be marketed to young caregivers particularly, in workplaces, colleges and doctor's offices.

Limitations and Future Directions

Sample

This study contains several limitations. First, it relies on a small subpopulation sample size among young adult caregivers aged 18-34 years old (n = 222). However, this study provides initial insights into young adult caregiver burden, and future studies can use larger samples of young adult caregivers. The sample size was also small for calculating effects among (n =31) young adult dementia caregivers. Future studies should include a larger sample of young adult dementia caregivers to better understand their specific needs. In addition, this study was limited by a smaller sample of men than women. Because more men are becoming caregivers than previous generations of caregivers, it was important for this study to factor in potential gender differences. Future studies should focus on recruiting more male participants in order to glean insights into their particular caregiving styles, challenges and coping methods to better inform future practices and policies.

Data

The study was also limited by the data source. The SPM factors in mediating variables such as coping, social support, personality characteristics and spirituality. The survey did not contain questions on mediator variables such as coping methods, spirituality and social support; thus, the findings may not fully illustrate what factors lead to caregiver burden. This study also used a composite of three survey questions to create the caregiver burden dependent variable. Future studies should look at each component of the caregiver burden variable separately to better understand what factors contribute to the physical, emotional and financial stress of caregivers. This will help give more specific policy and practice recommendations and identify specific needs among caregivers.

The survey data was also cross-sectional and future studies should use longitudinal data in order to understand caregiver burden overtime among young adult caregivers. In addition, the survey data relied on self-report data; therefore, the responses to the survey questions may not accurately capture the caregiving experience.

Future studies could also consider conducting a qualitative study to gather more in-depth understanding of the young adult caregiving experience, specifically the types of practices, programs and policies needed to support them with IADLs and with younger caregivers.

Future studies could also focus on what specific types of workplace impacts are contributing most significantly to caregiver burden to better understand how federal, state and workplace policies can better support caregivers as more step into the caregiving role and are also juggling careers. More studies are also needed to better understand the impact of paid family leave on both caregivers and employers.

Conclusion

While practices, programs and policies on both the federal, state and local level recognize the need to support family caregivers as the older adult population increases in the United States, more must be done to alleviate caregiver burden among family caregivers. This dissertation shows that young adult caregivers between the ages of 18-34 years old caring for an older adult loved one experience caregiver burden and need more support particularly with IADL tasks. In addition, older caregivers over the age of 35 years old experience additional issues that contribute to caregiver burden including younger age, Alzheimer's care recipient, race, ADLs, caregiving hours per week, being unemployed and workplace impacts. This shows that caregivers are impacted by caregiving tasks on a physical, emotional and financial level and therefore more research is needed to focus particularly on current federal, state and local programs and policies to better understand what needs to be done to make sure caregivers are given the support they need.

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