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# Subject Cognitive Decline in Informal Caregivers

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# SUBJECT COGNITIVE DECLINE IN INFORMAL CAREGIVERS

by

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# DEDICATION

I dedicate this dissertation to my mother, Joyce Simons Poulard, my late father, Blease E. Simons, Jr., my grandfathers, Blease Simons, Sr., and William H. Spears, and my grandmother, Emma Fuller Simons. My mother has been a source of encouragement and support since I began this journey, and I am thankful for all she has given me throughout my life and every other adventure along the way. My father passed away before the completion of the dissertation, but in the time before, he encouraged and supported me to finish this work. Both of my grandfathers encouraged me and told me from a very young age that I could do anything, and I would accomplish much. I believed them and have worked to ensure their predictions came true. I am so grateful for their love and guiding spirits through this process. And finally, to my grandmother Emma, our relationship defined and inspired my research—I became a caregiver, which changed my life forever.

I also dedicate this work to Shannon Joi Rogers, now one of God's Angels. Shannon departed this earthly realm before I completed my dissertation, but I know she is smiling down and is so very proud of me. I can hear her voice encouraging and cheering me on. Shannon, I finished!

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Lastly, if I did not name you individually, blame my head and not my heart and the limited space. I am eternally grateful for my support system and my extended family. I love you all.

# ABSTRACT

*Purpose.* The United States is experiencing unprecedented demographic shifts as the population continues to age. More than 53 million Americans are caregivers and that number is continuing to grow. Caregiving has become a significant societal and public health issue to be addressed. This study provided a population-based national perspective regarding informal caregivers to identify differences between caregivers reporting cognitive decline and those caregivers reporting no cognitive decline. The analysis explored the relationships between the type and characteristics of informal caregivers, the nature of the caregiving relationship, caregiver unmet needs, and the general, physical, and mental health-related outcomes of the caregivers.

*Methods.* The study used the Behavioral Risk Factor Surveillance System (BRFSS) years 2015-2018 pooled to gather information about caregivers and caregivers reporting subjective cognitive decline. Chi-square and logistic regression were used to analyze data from the BRFSS to examine the associations of caregivers and subjective cognitive decline to determine health outcomes, socio-demographic information, and the functional and social impacts of cognitive impairment.

*Results.* More than half of caregivers reported memory loss/confusion has interfered with daily activities: work, volunteer, or social activities, and their daily lives were affected by subjective cognitive decline. The study suggests significant differences in demographic characteristics, the nature of the caregiving, and caregiver unmet needs. The findings conclude there is an association between caregivers with subjective cognitive decline and reported poorer health outcomes. The strongest associations with subjective decline were sex—males, employment status—unemployed and unable to work, which may indicate the current status of the caregiver

*Conclusion.* These findings support the need for further exploration of informal caregivers and in this instance, subjective cognitive decline. The health care system must include caregiver health in the care plans of those care recipients, especially with chronic, long-term health concerns including Alzheimer’s and dementia. Those care recipients require more complex care over a longer period of time and more formal care options might not be available due to cost and geographical location.

# TABLE OF CONTENTS

# LIST OF TABLES

## LIST OF FIGURES

# CHAPTER 1

## INTRODUCTION

The United States is experiencing unprecedented shifts as the population continues to age. The aging of America has impacts on all facets of society, socially and economically, for example, in terms of care for older adults and related costs, the rising cost of living and health care (The National Institute on Aging (NIA), 2020). According to The National Institute on Aging (NIA) living arrangements, the availability of services, and caregiving are significant areas of concern deserving consideration and further research (The National Institute on Aging (NIA), 2020). In fact, caregiving has become a significant societal and public health issue to be addressed. Van Durme et al. (2012) reported that caregiving and the role of caregivers are important issues at the political, sociological, and economic levels. According to the Utah Coalition for Caregiving Support (2018), caregiving "refers to the provision of assistance to another person who is ill, disabled, or needs help with daily activities. It often requires attention to the physical, mental, social, and psychological needs and well-being of both the caregivers and the elderly person requiring care (Caregiving, para 1, Utah Coalition for Caregiving Support). The American Cancer Society (2018) defined a caregiver as a paid or unpaid person providing aid to an individual who is sick or disabled. Typically, informal caregivers are unpaid and usually spouses, children, siblings, or other family relations or friends not affiliated with any institution. The National Alliance for Caregiving (NAC) and the AARP Public Policy Institute in *Caregiving in the US 2020* reported about 53.0 million adults have provided unpaid care to an adult or a child in the prior 12 months in the US.

*Caregiving in the US 2020* also reported that 61% of caregivers are women and are between 49 through 51 years old. Most caregivers are caring for a family member or spouse. The average length of time the caregiver has spent providing care is four years, and for about 25 hours a week, given the care recipient's needs. Caregiving duties included assistance with Activities of Daily Living (ADLs) like bathing, toileting, transferring, feeding, dressing, and ambulating. Caregivers also provided assistance with Instrumental Activities of Daily Living (IADLs). Those tasks included managing finances and transportation, shopping and meal preparation, household maintenance, managing communication, and medications. The caregiver is usually employed and serves as the primary unpaid care provider.

Raggi et al. (2015) stated caregiving could cause stress, particularly when taking care of those individuals with dementia and others unable to care for themselves. Further, Raggi et al. (2015) indicated that caregivers who are advanced in age, are the female spouses, those caregivers with limited social support, and caregivers with health issues themselves have the highest rates of stress. Caregiving in the US in 2020 also reported about 7% of caregivers are 75 years or older. Van Durme et al. (2012) stated, "Caring for a dependent elderly may affect negatively the physical, psychological, psychosocial, social, and financial health of her/his informal caregiver" (p.491).

The AARP Public Policy Institute in *Valuing the Invaluable: 2020* reported the estimated economic value of $470 billion in 2017 for unpaid caregiving. The report also stated the value of unpaid caregiving exceeded the value of paid home care and total Medicaid spending in 2016 at $154 billion. In fact, the economic value of unpaid caregiving ($470 billion) was comparable to the value of sales, $524 billion, of Wal-Mart, the world's largest company, in 2020. Caregiving can impact families at any age, but the current demographic shifts bring more attention to the health of aging adults. For example, chronic illnesses, cancer, heart disease, dementia, and Alzheimer's disease are some of the conditions associated with aging. These conditions require specific care and can be quite costly over time. According to the Alzheimer's Association's *2020 Alzheimer's Disease Facts and Figures*, the value of care for individuals with dementia and/or Alzheimer's disease totals roughly $256.7 billion, which is upwards of 12 times the revenue of McDonald's in 2019 at $21.1 billion.

## Study Rationale

Raggi et al. (2015) found that caregivers' burden and stress increased with the severity of the care recipient's Alzheimer's disease. De Vugt et al. (2016) also found cognitive decline was present in caregivers and that decline is coupled with a decrease in caregiver's competence level and increasing levels of dysfunction. In addition, Oken et al. (2011) found increased stress levels in caregivers were present with caregivers with cognitive decline. Subjective cognitive decline among caregivers should be explored. It is critical to understand and explore what caregivers who report some subjective cognitive decline need to support and improve their ability to care for their care recipients.

Much of the current research examines the stress response of caregivers and the impact of caregiving on caregivers. There is also specific research focusing on the effects of caregiving for individuals with Alzheimer's and dementia. However, there is limited exploration of population-based information on caregivers and for those caregivers with cognitive decline. The National Alliance for Caregiving and AARP published the study *Caregiving in the U.S. 2020*, which provides a national snapshot of family caregiving in the United States. *Caregiving in the U.S. 2020* is used frequently for data and profiles on informal caregiving. The AARP study has a sample size of about 1400 caregiver interviews and includes in-depth information and data on the scope of caregiving. Moreover, the previous research has detailed the impact of the caregiver and their significance in caregiving. Still, research has yet to provide data on the population of caregivers, their available resources (health insurance, income, etc.), and how that data may differ if the caregivers themselves self-report some cognitive decline.

## Dataset

The study used the Behavioral Risk Factor Surveillance System (BRFSS) to explore caregiving and cognitive decline in caregivers. BRFSS uses telephone surveys to collect health-related state data on residents regarding their health-related risk behaviors, chronic health conditions, and the use of preventive services for US residents. The BFRSS collects data in all 50 states, the District of Columbia, and three US territories. More than 400,00 surveys are collected each year, "making it the largest continuously conducted health survey system in the world. (Behavioral Risk Factor Surveillance System, CDC)." Therefore, the BRFSS is infinitely valuable for providing health risk data across the US, at both the state and local levels, to impact public health research and activities. The BFRSS is sponsored by most divisions in the CDC National Center for Chronic Disease Prevention and Health Promotion; other CDC centers; and federal agencies, such as the Health Resources and Services Administration, Administration on Aging, Department of Veterans Affairs, and Substance Abuse and Mental Health Services Administration (Behavioral Risk Factor Surveillance System, CDC).

## Research Questions and Study Aims

The study explored the following study aims and research questions.

Aim 1**:** Described the type and demographic characteristics of caregivers, the nature of the caregiving relationship, and caregiver unmet needs, and compared these between caregivers reporting cognitive decline compared to those who did not report subjective cognitive decline.

Research Question: What were the demographic and other characteristics of caregivers, and how did those caregivers with subjective cognitive decline compare to other caregivers?

Aim 2: Described subjective cognitive decline deficits among caregivers.

Research Question: Among caregivers who reported subjective cognitive decline, what specific deficits are reported?

Aim 3: Assessed whether caregivers who reported subjective cognitive decline have worse health status than other caregivers.

Research Question: Compared to caregivers without subjective cognitive decline, did those caregivers who reported some subjective cognitive decline differ in their health status?

# CHAPTER 2

# LITERATURE REVIEW

## Caregiving in the United States

This study recognized the "invisible workforce" of caregivers across the United States and took notice of the burden that can lead to cognitive decline. Using the Behavioral Risk Factor Surveillance System (BRFSS) Caregiver and Cognitive Decline Modules, this study examined the percentage of adults that are caregiving, the health outcomes and behaviors of those caregivers, and the length and intensity of the work caregivers conducted. In short, this study focused on bringing light to the caregiver, defining who they are and what are their characteristics, and explored the consequences their day-to-day caregiving effort has on their own health and well-being.

According to the Centers for Disease Control (CDC), caregiving is a significant public health issue demanding attention from every facet of the community (2019). In fact, the CDC names caregiving as a public health priority, particularly with the current trend of the increasing number of aging adults (CDC, 2020). Caregiving impacts millions of individuals and families, both those providing care and those receiving care. Caregivers can be formal paid caregivers or unpaid friends or family, with higher numbers of middle-aged or older adults caring for their parents, spouses, children, friends, and other extended family members. The CDC (2019) continued by stating those informally providing care are "the backbone of long-term care provided in people's homes" (p.1). Caregivers provide a myriad of services to support and assist with health and social needs. Tasks may include activities of daily living such as feeding, dressing, bathing, financial assistance and support, shopping, transportation, etc. Caregiving can also involve chronic disease management and emotional support (CDC, 2019).

Caregiving and caregiver experiences are unique. Caregiving and its responsibilities are complex and fluctuating (Zauszniewski et al., 2020). As the care recipients' needs change, the intensity of caregiving can increase and change, as well. Those changes in conditions and the levels of caregiving tasks may contribute to caregiver burden or strain (CDC, 2019, Talley and Crews, 2007, Montogomery and Koloski, 2013, Zauszniewski et al., 2020). Taking on the responsibilities of caring for an individual can have significant impacts on the caregiver's life. Caregivers may experience a vast array of life changes, including changes in their own health, social relationships, and the ability to continue to work; the impacts can also be positive, bringing satisfaction and purpose, enhancing relationships with the care recipient, and in their quality of life (CDC, 2019).

Caregiving is influenced dramatically by the combination of longer lives, more chronic diseases, medical technology advances, shortages in the health care industry, and fewer available numbers of caregivers. From both a public health approach and the impact on the community, caregiving, and its effect on caregivers, further research is needed to fully understand the burden and strain placed on the informal caregivers. Caregivers may face physical and mental health issues exacerbated by the range and intensity of tasks caregivers may perform and the societal and economic impacts of long-term chronic diseases or disabilities (CDC, 2019). Although caregiving as a concept is familiar because it impacts so many families, it is clear while knowledge about the impacts of caregiving has increased, policy responses have not followed at the same rate (Talley & Crews, 2007; Schulz et al., 2018). For example, caregivers are not screened for health and functional challenges and may not be recognized as a part of the care recipients' care team (Schulz et al., 2018). Continued exploration and research of caregiving as a concept and the impacts of caregiving on those providing care is necessary to develop effective interventions to maintain the health of caregivers and care recipients.

## Caregiving Terms and Definitions

### *Caregiving*

Caregiving is generally defined as regularly providing care to an individual with a chronic or debilitating illness. Recipients can be adults or children, and the care can be acute or over several years. Caregiving has been recently recognized as a significant public health issue (Talley and Crews, 2007). Caregivers can be categorized as informal or formal. Caregiving can also be examined through the number of hours of care provided and assistance with activities of daily living

(ADLs) and instrumental activities of daily living (IADLs). Caregivers who provide at least 21 hours of care each week are "higher-hour" and assist with more ADLs and IADLs, while "lower-hour" caregivers are those who provide 20 or fewer hours of care weekly (AARP, 2020). The intensity of caregiving also contributes to caregiver burden.

### ***Informal Caregivers***

Informal caregivers are individuals—family members, spouses, siblings, children, parents, etc. that provide unpaid care (AARP, 2020).

### ***Formal Caregivers***

Formal caregivers are paid for their caregiving services, either in the home or in a care setting (assisted living facility, nursing home, adult day care, residential facility, etc.). Formal caregivers are staff or other care providers (AARP, 2020).

### ***Activities of Daily Living (ADLs)***

According to Cook and Cohen (2018), activities of daily living (ADLs) are related to personal care. ADLs include feeding, bathing, dressing, toileting (if assistance is needed and at what level), and transferring (does the care recipient need assistance moving from one place to another). ADLs are quantified and relate to the level of care a care recipient receives daily. The number and intensity of the ADLs also contribute to caregiver burden.

### ***Instrumental Activities of Daily Living (IADLs)***

Cook and Cohen (2018) also define instrumental activities of daily living. IADLs are not related to personal care but are needed to increase the occurrence of living independently and are necessary for the care and function of the care recipient. IADLs include medication management, scheduling and, if required, transportation to medical visits, shopping, housekeeping, money and household financial management, meal preparation, transportation, and communications.

### ***Health Management***

Riffin et al. (2017) defined health management as those tasks related to the actual physical care of the care recipient. The tasks may include dietary assistance, skin and foot care, wellness and exercise, and dental care. All of those tasks are provided by the caregiver to the care recipient.

### ***Long-Term Services and Supports (LTSS, also referred to as Long-term care)***

AARP (2019) defined long-term services and support as an overarching term to describe the assistance and care needed for individuals with long-term chronic conditions, disabilities, or other illnesses. The care can include ADLs, IADLS, and other services as needed. LTSS can be provided in formal settings, like nursing homes, assisted living, or other supportive settings. LTSS can also be provided in the home or some combination of integrated settings that provide healthcare and support services. In some cases, LTSS can also support informal caregivers.

### ***Cognitive Decline (also known as Cognitive Impairment), also referred to as Subjective Cognitive Decline***

CDC (2019) defined cognitive decline as a broad term encompassing impairment related to brain processes. Cognitive decline can be mild or as advanced as dementia and/or Alzheimer's disease. Cognitive decline is characterized by impairment in the "ability to learn, remember, and make judgments" (p.1).

*Subjective Cognitive Decline* refers to individuals self-reporting experiencing issues with memory or other cognitive processes (CDC, 2019). Jensen et al. (2020) state subjective decline has two criteria: (1) the individual reports their own experiences related to impairment with cognitive processes; and (2) the individual performs normally on standardized instruments used to classify cognitive decline.

## The Need for Caregiving: Characteristics of Care Recipients

Before the advent of medical technologies and medications, like antibiotics, for instance, life expectancy in the US was about 45-50 years old (Talley and Crews, 2007, Schulz et al., 2018). Talley and Crews (2007) note further the increase in life expectancy, which is currently nearly 80 years old. With longer life expectancies, there are large segments of the population moving into advanced age; thus, caregiving has become more frequent and requires a longer commitment. Advancements in medical technology and diseases being more chronic, as opposed to acute infections, have resulted in not only individuals living longer but also a reshaping of caregiving needs and requirements. Talley and Crews (2007), Choi and Seo (2019), Kasper et al. (2015), as well as other studies, state that the need for caregiving is not only a function of an aging population but also related to the costs and shortages in healthcare. One unintended consequence of attempts to control costs by discharging patients earlier is that responsibility of care shifts to informal caregivers (Schulz et al., 2018). Many times, those caregivers do not have the needed support or necessary care instructions, leading to overwhelmed and burdened families or other unpaid caregivers (AARP, 2019). When exploring health care industry shortages, specifically, nurses, physicians, and other direct-care workers, more rapid patient discharges associated with increasing costs related to hospitalizations, and more long-term care all contribute to the increasing number of and the need for caregivers (Schulz et al., 2018).

The Institute of Medicine's (IOM) report, *Retooling for an Aging America: Building the Health Care Workforce* discusses the impact of the current demographic shifts and the need for healthcare workers. In 2029, the vast majority of the Baby Boomers will be at least 65, estimating about 70 million people. According to the United States Census (2020), by 2030, 1 in 5 Americans will be 65 years and older. The US Census (2020) states by 2034, older adults will outnumber children, as all Baby Boomers will be over 65 in 2030. Given the combination of the aging of the Baby Boomer population, an increase in life expectancy, and a decrease in the relative number of younger persons, there will be a greater need for formal and informal care. These demographic shifts will have an unprecedented impact on the healthcare industry and the US as a whole.

Caregiving is not relegated to elderly adults or those with chronic and/or terminal illnesses. Medical technology can also provide life-saving care for infants born prematurely, with disabilities, health issues, or other chronic conditions. Many of those infants will require lifelong care than in previous years (Talley and Crews, 2007). Choi and Seo (2019) state current advancements in treatments and technology have extended the lives of individuals with terminal illnesses. So, caregivers are now caring for family members for more extended periods of time, increasing the demands and intensity of caregiving responsibilities (Choi and Seo, 2019). In *Valuing the Invaluable* (2019), the report states most people are or will be affected by caregiving. The report also characterizes caregivers as the "invisible workforce," and the contributions of caregivers go unnoticed. Yet the *Valuing the Invaluable Report* (2019) posits that informal caregiving keeps the "economic costs to the U.S. health and long-term services and supports" from skyrocketing. "The need to support family caregivers will grow as our population ages, more people of all ages live with disabilities, and the complexity of care tasks increases" (Valuing the Invaluable, 2019).

### ***Care Recipient Conditions***

As caregiver experiences are unique, so are the conditions and demographics of the care recipients. Most care recipients are females at about

61% compared to males at 39%, yet a larger proportion of caregivers are caring for a male care recipient (AARP, 2020). Current trends show increases in the number of caregivers providing care for more than one adult (AARP, 2020). Schulz et al. (2018) used data from the National Health and Aging Trends Survey (NHATS) and National Study of Caregiving (NSOC) to identify the types of care recipients requiring the most care and attention. Care recipient types include those with (1) functional limitations of ADLs and have three or more chronic conditions, (2) near the end of life, and (3) those with dementia or related condition (Schulz et al., 2018). Individuals in either or all of those groups demand the most care and are some of the highest-cost care recipients, even for informal caregivers (Schulz et al., 2018). Caregivers provide care in various locations and to individuals with different health statuses. Montgomery and Koloski (2013) introduced caregiver identity theory to conceptualize the common elements of the caregiving role and the delivery of support services. The authors contend the caregiving experience is unique among individuals, and therefore there is no generic caregiver identity (Montgomery and Koloski, 2013).

Zauszniewski et al. (2020) state caregiver identity is a function of the care and level of care provided and the health condition of the care recipient. Much of the existing research examines caregiving experiences in reference to one health condition, such as cancer, dementia, or other more well-known conditions. Chronic health conditions are therefore linked to caregiving experiences. The intensity of caregiving is related to the number of ADLs and IADLs the caregiver provides and the time spent caregiving, both in hours per month and in the length (years) of time the care recipient has required assistance (Cook & Cohen, 2018). The health condition of the care recipient impacts the caregiving tasks, time spent providing care, and subsequently caregiver burden. The CDC (2020) reports while individuals are living longer, older adults are at higher risk for chronic diseases and also chronic diseases in combination—comorbidities.

Chronic diseases, particularly those conditions related to cognitive decline, can lead to limitations in one's ability to function and complete day-to-day tasks (CDC, 2020). Many aging adults have multiple conditions which require additional care and more complex assistance from the caregivers. Kasper, Freedman, Spillman, and Wolff (2015) focus on caregiving related to dementia, not unlike most research in this area. Their study reports about one-third of caregivers for adults in non-institutionalized settings are caring for individuals with dementia or dementia-related illness (Kasper, Freedman, Spillman, & Wolff, 2015).

The tables (Table 2.1 and Table 2.2) below clearly illustrate the prevalence of chronic disease currently and identify the most common health conditions affecting care recipients. In *Caregiving in the US* (2020), AARP provides a snapshot of the problem or illness by care recipient age. The table (Table 2.1) below illustrates the variation in recipient conditions. The conditions below are the most common illnesses requiring care. The tables and those that follow indicate the complexity of health conditions caregivers may face.

The following table (Table 2.2) from the CDC indicates the ongoing chronic health challenges as the population continues to live longer. The tables also provide insight into the prevalence of comorbidities and the presence of cognitive decline. Having multiple chronic health conditions simultaneously are a greater risk for older adults and is challenging to manage. When those chronic health conditions occur with cognitive decline, many times, this is the onset of more intense and complex informal care. As stated previously, health conditions contribute to caregiver stress and burden (CDC, 2020).

Table 2.1 Selected Main Problem or Illness by Care Recipient Age

| | Recipient Age 18–49 (n = 188) A | Recipient Age 50–64 (n = 256) B | Recipient Age 65+ (n = 944) C |
|---|---|---|---|
| Alzheimer's, dementia | 2% | 2% | 15%$^{AB}$ |
| Back problems | 8%$^{C}$ | 10%$^{C}$ | 3% |
| Cancer | 6% | 7% | 6% |
| Developmental or intellectual disorder or delay | 13%$^{*BC}$ | 1% | 0% |
| Diabetes | 2% | 8%$^{AC}$ | 3% |
| Heart disease or attack | 1% | 4%$^{A}$ | 4%$^{A}$ |
| Mental/Emotional illness | 15%$^{BC}$ | 7%$^{C}$ | 2% |
| Mobility issues | 7% | 10% | 13%$^{A}$ |
| "Old Age," frailty | - | 4%$^{A}$ | 23%$^{AB}$ |
| Stroke | 1% | 6%$^{A}$ | 5%$^{A}$ |
| Substance Abuse | 5%$^{C}$ | 3%$^{C}$ | 0% |
| Surgery, wounds | 4% | 12%$^{AC}$ | 5% |

* Significantly higher than in 2015.

Note. Letters in superscript indicate a figure is significantly higher than the figure in the column indicated. Reprinted from AARP and National Alliance for Caregiving. "Caregiving in the United States 2020." Washington, DC: AARP. May 2020.

Cognitive decline can limit a person's ability to complete day-to-day activities, live independently, and increase their risk for harm. Cognitive decline or memory loss can make the management of other chronic diseases much more challenging, especially in individuals with comorbidities (CDC, 2020). The following two figures (Figure 2.1 and Figure 2.2) are age-related co-morbid chronic health conditions and the presence of subjective cognitive decline.

Table 2.2 Adults Aged 45 Years and Older with Chronic Disease by Subjective Cognitive Decline (SCD) Status

| | Age 45–64 years | | Age 65+ years | |
|---|---|---|---|---|
| Disease | Without SCD (%) | With SCD (%) | Without SCD (%) | With SCD (%) |
| Arthritis | 29.6 | 60.3 | 49.4 | 63.9 |
| Asthma | 8.5 | 18.5 | 7.8 | 11.8 |
| Cancer | 6.8 | 11.6 | 17.5 | 20.7 |
| COPD | 6.2 | 22.1 | 11.2 | 22.0 |
| Coronary Heart Disease | 5.7 | 17.5 | 16.3 | 27.6 |
| Diabetes | 13.4 | 24.0 | 22.3 | 30.2 |
| Kidney Disease | 2.6 | 7.4 | 5.5 | 10.5 |
| Stroke | 2.7 | 11.6 | 6.6 | 15.0 |

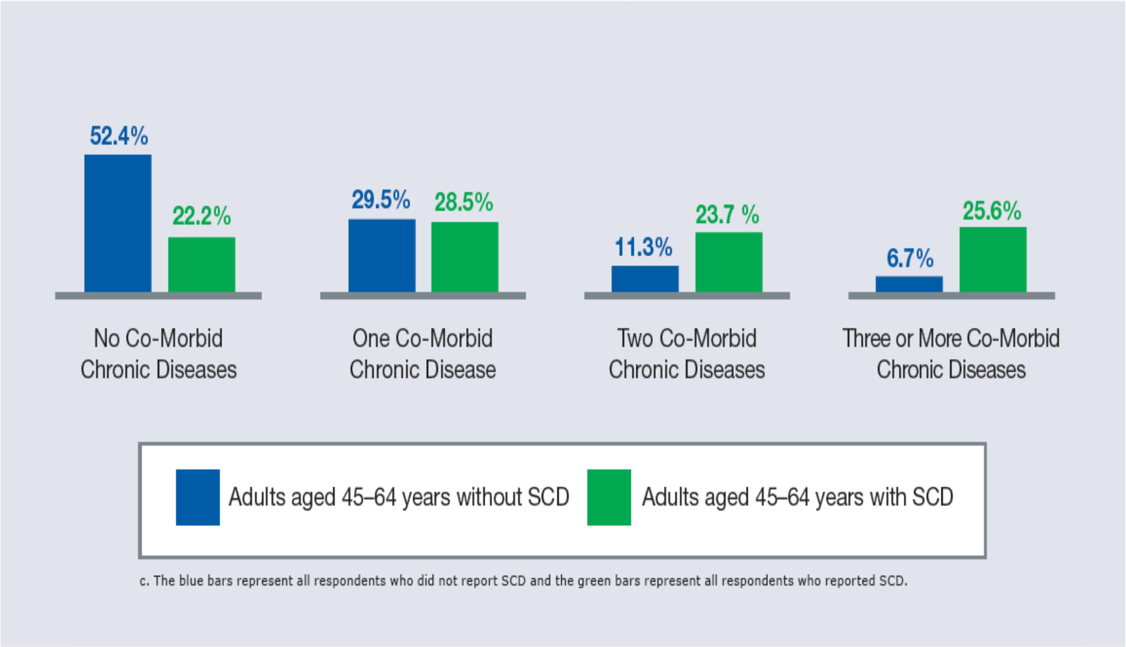
Note. Reprinted from Centers for Disease Control. "Chronic diseases and cognitive decline—A public health issue." Atlanta, GA: Division of Population Health, National Center for Chronic Disease Prevention and Health Promotion. September 2020.

The figures (Figure 2.1 and Figure 2.2) below from the *Chronic Diseases and Cognitive Decline—A Public Health Issue Brief* (CDC, 2020) provide detailed data regarding the occurrence of chronic diseases and when there is also cognitive decline. In the tables (Table 2.1 and Table 2.2) above, chronic disease was a previous diagnosis of one of the following eight chronic diseases: asthma, COPD, coronary heart disease, arthritis, stroke, kidney disease, cancer, and diabetes. The presence of a chronic disease, including comorbidities, was higher in those with subjective cognitive decline compared to those without cognitive decline for both age groups. The prevalence of subjective cognitive decline and chronic diseases increases with age. Chronic diseases are challenging to manage; if not managed properly, those conditions may lead to further cognitive impairment. This may lead to difficulties with an individual managing their own conditions, which can lead to an individual needing care, an impetus for the development of the caregiving relationship. When there are poorer health outcomes, more preventable hospitalizations, and an increase in cognitive impairment, the stress, and burden for caregivers are more likely to increase (CDC, 2020).

## Health Care Workforce Shortages

The current health care workforce overall is not substantial enough to

meet older patients' needs. The scarcity of workers specializing in the care of older adults – the eldercare workforce – is even more pronounced. It is estimated that by 2030, 3.5 million additional health care professionals and direct-care workers will be needed (AAMC, nd). In a report on workforce shortages, the Association of American Medical Colleges (AAMC) reported there



c. The blue bars represent all respondents who did not report SCD and the green bars represent all respondents who reported SCD.

Figure 2.1 *Adults Aged 45-64 Years by Number of Co-Morbid Chronic Diseases and Subjective Cognitive Decline Status*

Note. This figure was produced by Centers for Disease Control to illustrate co-morbid health conditions in individuals with impaired cognitive function between the ages of 45-64. Reprinted from Centers for Disease Control. "Chronic Diseases and Cognitive Decline—A Public Health Issue." Atlanta, GA: Division of Population Health, National Center for Chronic Disease Prevention and Health Promotion. September 2020.

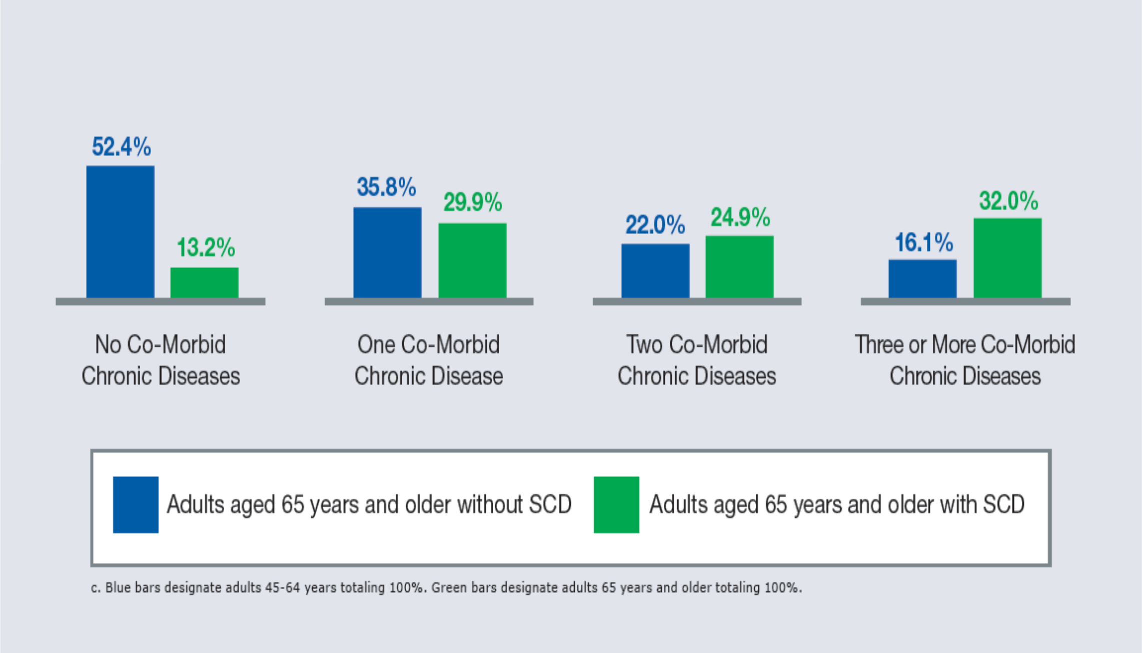


Figure 2.2 *Adults Aged 65 Years and Older by Number of Co-Morbid Chronic Diseases and Subjective Cognitive Decline Status*

Note. This figure was produced by the Centers for Disease Control to illustrate co-morbid health conditions in individuals with impaired cognitive function aged 65 and older. Reprinted from Centers for Disease Control. "Chronic Diseases and Cognitive Decline—A Public Health Issue." Atlanta, GA: Division of Population Health, National Center for Chronic Disease Prevention and Health Promotion. September 2020.

would be a shortage of up to 139,000 physicians by 2033, between 9,300 and 17,800 medical specialists; 17,100 and 28,700 surgical specialists; and 17,100 and 41,900 other specialists, including pathologists, neurologists, radiologists, and psychiatrists. Zhang et al. (2018) report the nursing shortage to be more than 510,000 nurses, with higher shortages in the Southern and Western regions of the US.

Further, the *Long-Term Services and Supports* reported by the US Department of Health and Human Services (2017) projected a shortage in direct care workers; there will need to be an estimated 3.5 million direct care workers to work in LTSS settings to maintain the current worker to older care recipient ratios (Spetz et al., 2015). According to Zallman et al. (2019), the current uncertainties in immigration policy are also a contributing factor to current and projected workforce shortages. Zallman et al. (2019) explained immigrants comprised 18.2% of health care workers and 23.5 % of the workers in LTSS in 2017. In fact, among staff at nursing homes in maintenance and housekeeping positions, about 30% are held by immigrants. Zallman et al. (2019) further stated, "policies curtailing immigration will likely compromise the availability of care for elderly and disabled Americans" (pg. 1).

Among the key factors contributing to the workforce shortage are the demographic shifts occurring in the US, both in the population growth and the healthcare workforce. Spetz et al. (2015) projected more than 70 million Americans will be 65 years or older by 2030. That will amount to 20% of the total US population. As a general rule, older adults require more complex care. Complicating the issue of the workforce shortage, according to IOM (n.d.), is the healthcare workforce is also aging and will retire as the older population continues to grow. The Keck School of Medicine (n.d.) identified the additional factors of increases in chronic diseases and the limited capacity of education programs for training. *The Atlantic* reported on the nursing shortage and stated a majority of current nurses entered the field before 1970, and about one million registered nurses (RNs) are currently over the age of 50. The resulting consequence is about a third of the nursing workforce will retire in the next 10 to 15 years (Keck School of Medicine, n.d.).

The healthcare workforce shortage is not limited to physicians and nurses. The Center for State and Local Government Excellence at ICMA-RC, in its report, *The Impending Shortage in the State and Local Public Health Workforce*, documented the public health workforce is also nearing retirement age. Moreover, approximately 45% to 50% of public health employees will become eligible to retire in the next five years. "This wave of retirements comes just as public health departments are assuming greater responsibility for threats such as pandemic influenza, bioterrorism, and drug-resistant strains of common diseases" (A Workforce in Crisis, n.d.). According to Warshaw and Brigg (2014), shortages exist for those in certain medical specialties. These include geriatricians, in 2012, there were 7,147 with a projected need of more than 36,000 by 2030; geriatric psychiatrists, in 2012, there were 1,554, and there is a current shortage. The demand is clearly outpacing the need. Other expected shortages include neurologists and social workers.

Shortages are also significant in the direct care workforce. According to the Paraprofessional Healthcare Institute (PHI) (2021), the direct care workforce includes certified nursing assistants, personal care aides, home health aides, and other titles where the assistance with ADLs and IADLs are the primary care tasks. Zallman et al. (2019) reported by 2030, 3.5 million additional health workers will be needed to meet the growing demographic and changing health-related needs. Spetz et al. (2019) also stated there are approximately 3 million direct care workers at present, and it will be one of the fastest-growing occupations, expecting to grow 40% by 2026. And despite the growing need, the direct care workforce experiences high turnover and inadequate compensation (Spetz et al., 2019). The direct care workforce has several factors contributing to the challenges in recruiting and retaining workers.

According to PHI (2021), most direct care workers are women with low incomes, people of color, and members of other communities that experience barriers with education and equity. This complicates the already challenged direct care workforce. Moreover, Spetz et al. (2019) report low wages, lack of value, low career mobility, and occupational safety concerns contribute to high turnover, which contributes to the existing and expected workforce shortages.

These shortages will have far-reaching impacts on LTSS. Spetz et al. (2015) projected the anticipated need for services for adults 65 and over will double, from roughly 8 million to 19 million by 2050. About 75% of older adults receive LTSS at home or in other community-based settings, and given the projected population growth, there will be a greater need for informal caregivers (Spetz et al., 2015). As the population of Americans over 65 continues to grow, there will be an increase in the need for complex care in both medical, institutional, home, and community-based settings.

## Costs of Care

The following table (Table 2.3) is a summary of the costs of formal care in multiple settings. Research states caregivers provide an average of 17-20 hours a week for basic assistance with ADLs (Home Alone Revisited, 2019). As the need for care increases and becomes more complex, families are faced with decisions on how to meet care needs and how to finance that care. The U.S. Census Bureau, Current Population Survey, 2019 and 2020 Annual Social and Economic Supplements reported the median income for older adults over 65 is $47,357. A review of the costs of care provided by Genworth Financial details those costs will consume all of an older adult's income for care without accounting for living expenses, medication, transportation, and other needed services.

According to *Home Alone Revisited* (2019), external market forces impact caregiving and caregivers' ability to care for their families. Rising healthcare costs have precipitated service delivery changes from more hospital-based services to more home and community-based services (AARP, 2019).

Hospitals discharge patients sooner as a method of controlling costs which ultimately shifts the care and responsibility for individuals to caregivers at a more challenging time during treatment (Van Houtven et al., 2020). Caregivers are thrust into caregiving roles in situations where patient care has limited support

Table 2.3 *Summary of Costs of Formal Care*

| Location | Type of Service | National Rates | Change Since 2019 | Five-Year Annual Growth |
|---|---|---|---|---|
| **Home** | **Homemaker Services**: Services providing helpful household possible for not being managed alone. Homemaker services include hands-off care such as cooking, cleaning, and running errands. | Median Hourly Rate<br>$23.50 | 4.44% | 3.80% |
|  | **Home Health Aide Services:** Home Health Aides offer services to people who need more extensive care. It is hands-on personal care, but not medical care. The rate listed here is the rate charged by non-Medicare certified, licensed agency. | Median Hourly Rate<br>$24.00 | 4.35% | 3.71% |
| **Community** | **Adult Day Health Care:** Provides social and support services in a community-based, protective setting. Various models are designed to offer socialization, supervision, and structured activities. Some programs may provide personal care, transportation, medical management, and meals. | Median Monthly Rate<br>$74.00 | -1.33% | 1.45% |

|  |  |  |  |  |
|---|---|---|---|---|
| **Facility** | **Assisted Living Facility:** residential arrangements providing personal care and health services, the level of care may not be as extensive as that of a nursing home. Assisted living is often an alternative to a nursing home, or an intermediate level of long-term care. | Median Monthly Rate<br>$4300 | 6.15% | 3.62% |
|  | **Nursing Home Care:** these facilities often provide a higher level of supervision and care than assisted living facilities. They offer residents personal care assistants, room and board, supervision, medication, therapies and rehabilitation, and on-site nursing care 24 hours a day. | **Semi-Private Room** |  |  |
|  |  | Median Daily Rate<br>$255 | 3.24% | 3.00% |
|  |  | **Private Room** |  |  |
|  |  | Median Daily Rate<br>$290 | 3.57% | 3.01% |

Note. Reprinted [adapted] Genworth Financial Inc., Genworth 2020 Cost of Care Survey Conducted by CareScout® (Richmond, VA: Genworth Financial Inc., June 2020), https://www.genworth.com/about-us/industry-expertise/cost-of-care.html; US Census Bureau, 2016.

and usually without the instruction and training to care for their loved ones (Schulz et al., 2018).

*Valuing the Invaluable* (2019) stated there are roughly about 41 million family caregivers, providing an estimated 34 billion hours of care to an adult. The report also notes the estimated economic value of services provided by informal caregivers as of 2017 is $470 billion, which is a steady increase from $450 billion in 2009 and $375 billion in 2007. Much of the research regarding caregiving is focused on health conditions related to caregiving like dementia or Alzheimer's. Those conditions are often associated with aging, so caregivers taking care of older adults also have more complex care responsibilities, both in direct care and management of the recipient's business affairs (AARP, 2019).

Examining the data just on Alzheimer's disease and other dementias, the Alzheimer's Association in the *2020 Alzheimer's Disease Facts and Figures* reported there are 16 million family caregivers for those conditions alone. As further stated by the Alzheimer's Association in the *2020 Alzheimer's Disease Facts and Figures*, those caregivers provided roughly 18.6 billion hours of care for an estimated economic value of $244 billion (Alzheimer's Association, 2020). To contextualize these figures, *Valuing the Invaluable* (2015, 2019) stated that of the $470 billion, the estimated value of caregiver services is:

- Nearly three times Medicaid LTSS spending in 2013 ($154 billion)
- More than total out-of-pocket spending on health care in 2017 ($366 billion)

- As much as sales of the world's largest company (Walmart: $476.6 billion in 2013–2014)
- More than the total combined value added to the US economy by the education and arts/ entertainment sectors ($460 billion in 2017)
- As much as sales of the four largest U.S. technology companies combined (Apple, IBM, Hewlett Packard, and Microsoft: $469 billion in 2013–2014)
- About $1,450 for every person in the United States (325 million people in 2017)

Rabarison et al. (2018) conducted a study examining the economic value of caregiving for individuals with dementia. The study reported demographic trends would continue to increase the need for informal caregivers. Also, Medicare payment to home health providers was reduced by 3.5% from 2014 to 2017 (Rabarison et al., 2018). This cost shift increases the need for unpaid caregivers, particularly for those in challenging economic situations. The authors quantify this care by conducting a cost-replacement model. Rabarison et al. (2018) report roughly 4.1 billion hours of care are provided yearly by about 3.2 billion caregivers caring for those with dementia. The cost of dementia caregiving is valued at about 41.5 billion dollars (Rabarison et al., 2018).

According to AARP (2019), in 2017, $235 billion was spent on paid LTSS, 57% was paid by Medicaid, but those funds were influenced by individuals eligible for Medicaid, which is income-based. Out-of-pocket or funds by care recipients and their caregivers comprised 23% of the $235 billion (AARP, 2019). These data underlie the essential and necessary work of informal caregivers and the resulting cost-savings to the formal health care system.

## The Burden of Caregiving on Caregivers

### *Caregiver Prevalence*

According to the National Alliance for Caregiving (NAC) and the AARP's Caregiving in the US (2020) report, about 53 million adults have provided unpaid care to an adult or a child in the prior 12 months in the US. 1 in 5 Americans, about 21.3% are caregivers, either to an adult or a child with special needs. Most caregivers (82%) care for adults 50 years or older (AARP, 2020). The CDC reports that 1 in 5 or about 20% of adults (18 or older) report being a caregiver; those caregivers provide care and/or assistance to an individual with a long-term illness or disability (CDC, 2020). Most caregivers provide care for one adult (76%), but 24% report providing care for two or more adults (AARP, 2020), and that number is increasing. In rural communities, caregivers more frequently care for multiple adults (34%), as opposed to more suburban/urban areas (23%) (AARP, 2020). Further complicating the issues is the increase in the number of care recipients because caregiving affects all generations, racial/ethnic groups, and all income and educational levels (CDC, 2020, AARP, 2020).

The CDC's data specifically focused on the prevalence of caregiving over a 30-day period. When examining age, the Caregiving for Family and Friends (2019) reported that 18.8% of caregivers are caring for 65 years and older, and

24.4% of caregivers are caring for adults 45-64 years old. More than 20% of adult caregivers have provided care to a friend or family member in the past 30-days. As in other data, most caregivers are women (25.4 %) as opposed to men (18.9%). More Blacks/African-Americans (24.3%) are caregivers when compared to Whites (23.1%), Hispanics (17.9%), or Asians/Pacific Islanders (10.2%.) (CDC, 2019).

AARP reports most informal caregivers are female, 61% (AARP, 2020), while the Institute on Aging (2016) notes nearly 75% of caregivers are female. Both reports are consistent in recognizing most caregivers are women. The younger the care recipient, the more likely the recipient is male (42% among ages 18-49), as opposed to middle-aged men (35% among ages 50-64). Thirty-six percent of female caregivers handle personal caregiving tasks, for example, bathing, toileting, and dressing, which are the more difficult caregiving tasks. Yet 24% of male caregivers help with finances, arrangement of care, and less personal needs tasks (AARP, 2009). The average age of caregivers is 49.4 years old, and 47% of caregivers are 18-49 years old. 35% of caregivers are 65 years old or older, 12 % are 65-74 years old, and 7% of caregivers are more than 75 years old (AARP, 2020). The average age of the care recipient is 68.9 years old, with a median age of 72 years old, with 14% of the care recipients between 18-49 years old; 47% of care recipients are 75 years old or older (AARP, 2020). 61% of care recipients are women, and 39% are men; more senior caregivers typically care for individuals near their own age, while younger caregivers care for older adults (AARP, 2020).

Primary caregivers are individuals providing all or most of the unpaid care to a family member, spouse, sibling, child, parent, etc. Most adult caregivers are caring for a relative (89%), comprising a parent or parent-in-law (50%), spouse or partner (12%), grandparent or grandparent-in-law (8%), or adult children (6%) (AARP, 2020). In the AARP *Home Alone Revisited* (2019), the study reports adult children comprise the largest group of caregivers, followed by spouses. Other caregivers, categorized as nonprimary caregivers, are three times more likely to provide care for extended family, such as a grandparent, parent-in-law, or aunt/uncle (28% vs. 11% for primary caregivers) (AARP, 2020). Yet, as caregivers age themselves, they are more likely to be caring for their spouse, about one in 10 caregivers are caring for their spouse/partner (AARP, 2020). For caregivers (70%) ages 50-64, caring for parents is the primary caregiving situation (Wagner & Takagi, 2010). Most spousal caregiving is for the male spouse (55%) (AARP, 2015).

Caregivers in the National Alliance for Caregiving and AARP (2020) report the following racial/ethnic identities as caregivers: 61% White; 14 % African-American; 17% Hispanic (non-White, non-African-American); and 5% Asian-American. On average, White caregivers are older than African American, Hispanic, and Asian American caregivers. The average age of caregivers by race is White caregivers at 51.7 years; Asian-American caregivers at 49.3 years old;

African-American caregivers at 47.7 years old, and Hispanic (non-White, non-African-American) caregivers at 43.3 years (AARP, 2020).

AARP (2020) also reports the prevalence of caregivers, particularly as the number of adults aging continues to increase; for example, in 2015, there were about 43.5 million reported caregivers. In 2020, AARP stated that the number of caregivers is estimated to be up to 53 million Americans. The increases are due to a confluence of factors: the aging baby boomer population needing more care, workforce shortages in healthcare and in LTSS formal care settings, medical technology prolonging life expectancy, national efforts to facilitate more home and community-based services, and the cost of care in traditional care settings (Schulz et al., 2018). Additionally, a shortage of potential caregivers is a genuine concern, as more women are working in the labor force, declines in family size, and the number of children couples are choosing to have (Schulz et al., 2018; Van Houtven et al., 2020). Particularly concerning rural communities, where there is typically lower population density, is the higher the geographic mobility of young adults (CDC, 2019).

Data from the Centers for Disease Control and Prevention's (CDC) Behavioral Risk Factor Surveillance System (BRFSS) stated by 2030, there will be about four potential family members available for caregiving; at present, there are seven potential family caregivers per older adult (CDC, 2020). The most common source of home care is provided by informal caregivers (Van Houtven et al., 2020). The US does not have a national system or approach to finance long-term care services for older adults with disabilities and/or chronic illnesses, so the responsibility for much of the care needs is managed and provided by informal caregivers (Van Houtven et al., 2020). Caregivers are responsible for multiple tasks, including providing information about care recipient health to providers, which, if noted by the physician, may also offer opportunities to assess caregiver needs as well (Hsu et al., 2017).

## Caregiver Burden

Caregiving can be emotionally, financially, and physically demanding. Informal caregiving provides opportunities for individuals who are aging and/or have a chronic illness to receive care at home. Caregivers are often responsible for providing physical care and maintenance, emotional support, and social interaction for those in their care, often at the expense of their own health and need for social activities (Bastarowos, 2013). If caregivers have significant social support within their families and the community, the impact of the stress and anxiety on caregiver burden is lessened, but without that support, the effects on the health, financial, and psychological well-being of caregivers can be severely compromised. How caregivers are able to manage their own experiences and health affects the care they are able to provide as well (Bastarowos, 2013).

Caregiving is not a new phenomenon. Families have been the primary caregivers, particularly of aging parents or spouses, since the beginning of time. In *Valuing the Invaluable* (2019), the challenges with caregiving now are "more complex, costly, stressful, and demanding than any other time in human history

(p. 6)," and the challenges are related to the constant and everchanging pace of social, health and financial issues. Informal caregiving is an unpaid role, and while many may find it emotionally fulfilling, it is also difficult. The systems engaged in caregiving, health care, social services, etc., are notoriously hard to navigate, leaving many caregivers trying to figure out where and how to get help and, at a minimum, what to do (Valuing the Invaluable, 2019). *Valuing the Invaluable* (2019) reports a study that found 9 in 10 individuals with middle-income in the midlife stage said that being a caregiver was significantly more challenging than anticipated and required more time, patience, and emotional stability than was initially thought. The *Valuing the Invaluable* report continues by describing "family caregivers as an 'invisible, isolated army' carrying out increasingly complicated tasks and experiencing challenges and frustrations without adequate recognition, support, or guidance, and at great personal cost (p.5)." One of the major challenges faced by informal caregivers is the isolation and their relative invisibility (Sullivan and Miller, 2005). Even though caregivers are intimately and extensively involved in the daily care of the care recipients, caregivers are not usually recognized by healthcare providers and/or payers (Schulz et al., 2018). The system is not actively assessing the needs, capabilities, and well-being nor acknowledging how intertwined and interdependent the lives of care recipients are with the caregivers (Valuing the Invaluable, 2015).

While the concept of caregiver burden is common in healthcare research, it is challenging to define clearly. Zarit et al. (1980) coined the first accepted definition, which was expanded by Given et al. (1992). Both of those well-known authors and gerontologists focused on caregiver discomfort, physical limitations, and role strain and are the most used in research (Choi & Seo, 2019). Many studies use a complex, multi-dimensional definition, but there is no definitive definition. As explained by Bastarowos (2013), the term/concept "caregiver burden" is commonly researched as an outcome of caregiving and is examined at many levels of research. Yet, the term is not always well-defined or conceptualized, nor do the studies frequently illustrate the qualitative, detailed experiences of caregivers (Bastarowos, 2013). Even without a definitive definition, caregiver burden is an authentic experience of informal caregivers. Choi and Seo (2019) provide a definition that captures the complexity of caregiver burden, and while not complete, it is comprehensive. Choi and Seo (2019) define caregiver burden as:

> a multi-dimensional concept that is attributed to the perception of physical symptoms, psychological distress, impaired social relationships, spiritual distress, and financial crisis that arise from caregiving tasks or care demands. The results of unresolved caregiver burden are the diagnosis of psychiatric illness, impaired physical health status, and poor quality of life (p.8).

There has been much research in order to more fully understand caregiver burden and its multiple dimensions. Choi and Seo (2019) and Leow and Chan (2011) conducted study reviews to further define caregiver burden. Both sets of authors sought to identify the factors contributing to caregiver burden, to include gender, age, employment status, education, race, length of the caregiving relationship, and caregiver's health status, which were the most common characteristics identified (Choi and Seo, 2019; Leow and Chan, 2011). Leow and Chan (2011) posited four main categories to examine caregiver burden:

1. Caregiver characteristics
2. Patient characteristics
3. Social support
4. Caregivers' personal protective resources (p.1895)

According to Leow and Chan (2011), caregiver characteristics correlated to caregiver burden include gender, employment status, financial status, race, age, health status, and the duration of caregiving. Patients' characteristics correlated to caregiver burden include the patient's diagnosis, the patient's quality of life, and the caregiving demands of patients; also, the presence or absence of social supports can also impact the severity of caregiver burden. Further, the authors, Leow and Chan (2011), then describe the term, caregivers' personal protective resources as "referred to the way they perceive the caregiving situation, and their ability to cope with the situation" (p. 1894).

Chiao et al. (2015) also examined the risk factors for caregiver burden. The authors categorized the risk factors into two groups: patient and caregiver characteristics. The characteristics associated with patients include the patient's socio-demographic factors, behavioral/psychological factors, and disease-related factors (Chiao et al., 2015). The attributes related to caregivers include three similar categorizations, psychological factors, the socio-demographic factors of the caregiver, and factors related to care provision (Chiao et al., 2015).

Choi and Seo (2019) further developed the attributes or characteristics of caregivers and expanded their study to include the antecedents, which are related to the causes of caregiver burden. Much of the research, including Choi and Seo (2019), identify caregiver burden as strongly related to the tasks (ADLs and IADLs) required of the caregiver and the level and intensity, and demands of that care (Choi and Seo, 2019, Chiao et al., 2015, Sullivan & Miller, 2015, Cook et al., 2018). Riffin et al. (2018) continued to explore indicators and contributing factors for caregiver burden. They found an association between higher levels of caregiver burden and a greater number of tasks (ADLs, IADLs, health management) and intensity. Hsu et al. (2017) also found caregiver burden was related to caregiver perceptions about the care recipient’s level of dependence, which other researchers have framed as demands.

Because caregiving experiences are not generic but complex and multi-dimensional, exploration of caregiver burden should be examined through the lens of both the caregiver characteristics and the impacts of caregiving leading to caregiver burden (Cook et al., 2018). This study attempted to extend the research to look at caregiver burden as a demographic variable with predictor variables, including those found in the BRFSS caregiving module.

## Factors Influencing Caregiver Burden

There are numerous factors that could influence caregiver burden, and this study will focus on those factors found in the BRFSS caregiving module. As described above, two of the most common factors are race and gender. In addition to race and gender, this study evaluated other variables that could influence the caregiver burden of the "invisible workforce."

### ***Race***

According to AARP (2020), 34% of caregivers are non-white. Also, in AARP (2019) comparing White and Black/African-Americans, 6 in 10 Whites perform medical/nursing tasks, as well as providing personal care, as opposed to 3 in 4 Black/African-Americans. There are differences across racial and cultural groups in caregiving responses. Bekhet et al. (2015) found that while Black/African-Americans were more likely to have poorer health and more negative health outcomes, they showed more positive emotional responses, such as less perceived burden, less psychological stress, and less depression when compared with their White counterparts. Cook and Cohen (2018) also report that among female, non-white, and low-income caregivers, there is a higher intensity of caregiving. AARP (2020) reports about half of African-Americans report caring for both an older adult and a child under 18 and providing care for more than 20 hours weekly. Also, African-American care recipients are more likely to live with their caregivers. Leow and Chan (2011) also found differences in caregiver responses affected by race. Whites experienced more strain than non-whites.

### *Gender*

Leow and Chan (2011) stated gender is a factor in caregiver burden. Riffin et al. (2018) found that caregivers were primarily women—adult children and spouses, which is consistent with other studies. Also reported is caregiver burden is highest in females (Chiao et al., 2015). Caregiver burden is associated with higher levels of stress (Riffin et al., 2018). In fact, females providing higher levels of IADLs were three times more likely to experience caregiver strain than females reporting lower levels of care related to IADLs (Cook et al., 2018). Leow and Chan (2011) found that perhaps the higher reports of burden were associated with a focus on female caregiving experiences. A current trend, however, is an increase in the number of male caregivers (AARP, 2020). As family structures continue to change, such as smaller nuclear families, more women working full-time in the labor force, and lower birth rates, there have been gradual increases in caregiving among males. The bulk of caregiving is still a female-oriented task (Leow and Chan, 2011).

### *Impact on Physical Health*

Caregiving has been shown to influence physical health negatively. Studies reported issues such as fatigue, back issues, low appetite, and insomnia. Often caregivers forgo their own self-care, health maintenance, and treatment for their own health conditions when caregiving (Sullivan & Miller, 2015; Choi and Seo, 2019). The CDC (2020) reports that 17.6% of those identified as caregivers experienced 14 or more physically unhealthy days within the last 30 days. Caregivers are frequently required to complete physically demanding tasks, such as transferring the care recipient to locations, bathing, dressing, or basic lifting. Most caregivers have not received any formal training in how to safely complete their necessary care tasks, which may increase the risk for injuries (Sullivan & Miller, 2015). If caregivers find it difficult to manage their own care, it is likely they are also not being proactive about their health in general, which can have negative impacts on the caregivers' quality of life (Choi and Seo, 2019; Sullivan & Miller, 2015).

### ***Psychological and Mental Health Impacts***

Positive responses to caregiving are related to caregivers feeling their role has given their lives meaning and purpose. Yet, in many caregivers, those positive perspectives co-occur with stress and strain (AARP, 2020). Caregiving can be rewarding, but over time the decline in the recipient's condition, financial strain and stress, and isolation can present significant challenges (Sullivan and Miller, 2015). Among current studies, caregivers are dealing with depression or anxiety (Choi and Seo, 2019; Riffin et al., 2018). A particular struggle unique to the caregiving experiences is anticipatory grief, which also contributes to depression and anxiety. Also, anticipatory grief can last the length of the caregiving duration, which can last years (Choi and Seo, 2019; Sullivan and Miller, 2015). Increased stress, depression, and anxiety can lead to other illnesses, such as cognitive impairment, particularly in spouses caring for a spouse with dementia, Alzheimer's disease, and related diseases (Vitaliano et al., 2009; Dassel et al. 2017).

### *Impact on Social Relationships*

Caregiving can be all-encompassing and time-consuming. Caregivers can experience loneliness, isolation, restrictions in their own social relationships/activities, and a loss of existing social networks (Choi and Seo, 2019). High levels of social strain are experienced across the caregiving continuum (Cook et al.,2018). A major source of distress among caregivers is the change in social activities and networks (Choi and Seo, 2019). Also, the relationship between caregiver and recipient can shift as the complexity of caregiving shifts from the existing relationship to a focus on the caregiving tasks and the accompanying challenges—decreases in time, money, and energy (Sullivan and Miller, 2015). Riffin et al. (2018) found that restrictions on social participation were strongly associated with higher levels and demands on caregivers. In spousal relationships, the resulting strain may be due to a cognitive impairment in the recipient not being invited to or choosing not to participate in their former "couple life" because of the severity of the spouse's disability. Caregivers may lose their employment. They also may not be able to participate in religious or other activities due to time and care restrictions (Sullivan and Miller, 2015). Given the importance of spirituality and religion in the lives of many individuals—the loss of that essential social network can negatively impact the emotional health of anyone providing care.

### ***Impact on Financial Status and Employment***

Caregivers and care recipients experience burdens related to income and financial status. Caregiver burden is associated with annual income levels (AARP, 2019). Caregiver care needs, such as incontinence supplies, assistive devices, medication management, etc., are more challenging for caregivers with incomes below $25K; but less challenging for those with incomes over $100K (AARP, 2019). Caregivers will sell assets, take out a loan, and take on additional employment to provide funds for care (Choi and Seo, 2019). Care is expensive. Johnson and Wang (2019) found adults over 65 years, if liquidating all their assets, 74% could fund moderate home care for about two years; 58% could provide two years of funding if the care needed was more intensive.

Caregivers typically find themselves supplementing the cost of care, particularly if the caregiver is the primary wage earner (Sullivan and Miller, 2015). AARP (2019) reported caregivers spent between $7,000-$12,000 in 2016 on caregiving expenses. The range in spending accounts for caregivers who live more than an hour away. Nearly one in five caregivers reported experiencing a high level of financial strain (AARP, 2020). Caregivers have eroded their savings and forgone their personal financial responsibilities in an attempt to provide financial support to their care recipient (AARP, 2020). Mudrazija (2019) found the cost of lost wages and forgone earnings is currently $67 billion, which may double by 2050. Caregivers have reported missing work, tardiness, or taking time off to accommodate care demands (AARP, 2020; Sullivan and Miller, 2015).

Caregivers have lost employment or have been forced to involuntary retire because of caregiving demands, which in many cases only exacerbates the financial strain (AARP, 2020; Mudrazija, 2019).

### *Role Strain*

While the oldest caregivers in the study are not experiencing significantly more emotional stress or physical or financial strain than younger caregivers, they are more likely to be caregiving without other unpaid help (Riffin et al., 2018). They are communicating with health care professionals and advocating for their recipient, making themselves an essential part of the care team, hopefully (Schulz et al., 2018). Caregivers are less likely to be employed, more likely to be caring for their own spouse (and living with them), and more likely to be managing finances for their recipient (AARP, 2020). This means that, at a time of life when income may be fixed, they are performing the difficult task of managing household finances for both themselves and their spouse (Caregiver.org). Caregivers also fear providing inadequate care or mistakenly forgetting a task while attempting to maintain their own identity and roles prior to caregiving (Choi and Seo, 2019).

## Previous Research on Cognitive Decline in Informal Caregivers

According to the CDC (2019),

> Subjective Cognitive Decline (SCD) is the self-reported experience of worsening or more frequent confusion or memory loss. It is a

> form of cognitive impairment and one of the earliest noticeable symptoms of Alzheimer's disease and related dementias. (pg.1)

Cognitive impairment is characterized by problems up to the inability to learn, remember, and make decisions or judgments. Impairment can greatly influence one's health and well-being (CDC, 2019)

Cognitive impairment can occur in individuals with chronic diseases, especially those not managed well (CDC, 2020). It is not uncommon for caregivers to forgo their own care, which can place them at higher risk for cognitive impairment and challenges with pre-existing conditions (Dassell, 2017). Also, the stress related to caregiving is linked to poor health outcomes, and cognitive impairment may result (AARP, 2019; Choi and Seo, 2019; Schulz et al., 2018). As stated previously, the physical and psychological health may be compromised when the caregiving needs are high intensity and long-lasting (Schulz et al., 2018).

While there is a great deal of research on caregiver burden and its consequences, there is limited research on this impairment in caregivers. Of the current studies specifically exploring cognitive decline in caregivers, five of those studies focus on either spousal relationships or caregivers caring for an individual with dementia or Alzheimer's disease. One study compared caregivers caring for an individual with dementia or Alzheimer's disease with caregivers caring for someone without a similar disease, but the study is about residents of Canada. Another study was focused on biological and hormonal markers and was based in Ireland. Three other studies also focused on the relationship to Alzheimer’s or dementia, and one was based in the Netherlands while the other two were based in Brazil. Recently there has been more interest in researching subjective cognitive decline and caregivers. Jeffers et al. (2021) examined the prevalence and characteristics of subjective cognitive decline and unpaid caregivers. They found that subjective cognitive decline was higher in caregivers compared to non-caregivers. Brown and Cohen (2020) found associations between subjective cognitive decline, poor mental health, and informal caregiving. Bouldin et al. (2021) found that individuals with subjective cognitive decline needed assistance with an unmet need, and having an unmet need increased mental distress. Their findings support this study’s efforts to expand further the research on the caregiver experience as related to subjective cognitive decline. The table (Table 3.4) below details the current research. The studies consistently indicated increased cognitive decline in spousal relationships with care recipients with dementia or Alzheimer’s disease. This study examined the caregiver burden within the United States.

Table 2.4 Empirical Research of Caregivers’ Cognitive Decline

| **Author, Year** | **Data Source** | **Setting (Country)** | **Specificity of condition** | **Key Findings of Cognitive Decline in Caregivers** |
|---|---|---|---|---|
| Allen, A et al., 2017 | Meta-analysis | Ireland | Biological markers— chronic stress | Increase in cortisol; caregiver performance on attention and functioning tests was poor; most of the focus was biological |
| Bouldin, E et al., 2021 | BRFSS | US | Subjective cognitive decline | Unmet needs associated with increased subjective cognitive decline and increased mental distress |
| Brown, M & Cohen, 2020 | BFRSS | US | Subjective Cognitive Decline | Subjective cognitive decline associated with poor mental health, and informal caregiving |
| Corrêa, M et al., 2015 | Salivary cortisol, DHEA level | Brazil | Biological markers— Alzheimer’s disease | Caregivers’ cognitive impairment related to alterations on cortisol/DHEA ratios; chronic stress can alter BDNF levels |

| | | | | |
|---|---|---|---|---|
| Corrêa, M et al., 2016 | Salivary cortisol, DHEA level | Brazil | Biological markers—Alzheimer’s disease | Younger caregivers—significant cognitive dysfunction; older caregivers—more compromised cognitive performance |
| Dassel, K et al., 2017 | Health and Retirement Study; Telephone Interview for Cognitive Status | US | Dementia; Spouses | Spousal caregivers of individuals with dementia more accelerated decline than in nondementia spousal caregivers |
| De Vugt, ME et al., 2005 | Spousal caregivers of dementia patients from Memory Clinic of the Academic Hospital Maastricht and the Regional Institute for Community Mental Health Care and non-caregiver controls | Netherlands | Dementia; Spouses | Caregivers performed significantly worse on several cognitive domains compared with control subjects |
| Jeffers, E et al., 2021 | BRFSS | US | Subjective cognitive decline | Subjective cognitive decline associated more with informal caregivers |
| Mallya, S & Fiocco, AJ, 2018 | Informal caregivers of a person with dementia or related disease and non-caregivers completed a series of neurological assessments | Canada | Cognitive function/well-being | Caregivers made more errors on cognitive flexibility measures; more stress and depression |

|  |  |  |  |  |
|---|---|---|---|---|
| Oken, B et al., 2011 | Spousal or close relative caregivers of a person with dementia and controls series of neurological assessments; salivary cortisol | US | Dementia or related disease | Cognitive differences between caregivers and non-caregivers on timed and attention tasks |
| Olivari, B et al., 2021 | BRFSS | US | Subjective cognitive decline | Subjective cognitive decline associated with dementia-related illnesses; policy implications |
| Vitaliano, P et al., 2009 | Spousal caregivers of a person with Alzheimer's disease and similar non-caregivers controls completed digital symbol test | US | Alzheimer's disease | Caregivers had lower scores than non-caregivers |

## Study Design and Purpose

Much of the current research examined the stress response or burden of caregivers and the impact of caregiving on caregivers. There was also specific research focusing on the effects of caregiving for individuals with Alzheimer's and dementia. However, there was limited exploration of a specific stress-related response—cognitive decline and its occurrence in caregivers. Cognitive decline in the caregiver affects not only the health of the caregiver but also the care of the care recipient. Data showed that caregivers may not be focused on their own health and therefore may miss regular check-ups and screenings. Unfortunately, when care recipients have medical visits or assessments, they are the sole focus of the visit. Physicians and other healthcare workers do not receive payment for the caregiver unless the caregiver is the actual patient nor for patient education and training. Caregiving is intense and demanding and made more so by the condition of the care recipient. The failure to identify the care conditions and needs of the caregivers places both the care recipient and the caregiver at risk. Even though there is no comprehensive system in place to support caregivers, it is vital to continue to explore their experiences and the consequences of caregiving. Effective interventions and policies can not be developed without a complete understanding of the caregivers themselves.

This study sought to fill one of the many gaps in research on the impacts of caregiving on caregivers. The purpose was to examine the socio-demographic characteristics, health status, and conditions of those caregivers who also reported themselves as experiencing cognitive decline or impairment. The study aims were to examine the following:

**Aim 1:** Described the demographic characteristics of caregivers, their caregiving tasks, and compared these between caregivers who report experiencing cognitive decline compared to those who do not report subjective cognitive decline.

**Aim 2:** Described subjective cognitive decline among caregivers.

**Aim 3**: Assessed whether caregivers who reported subjective cognitive decline have worse health status than other caregivers.

# CHAPTER 3

## METHODOLOGY

### Purpose

The purpose of this study was to provide a population-based national perspective regarding informal caregivers to identify differences between caregivers reporting cognitive decline and those caregivers reporting no cognitive decline. The analysis explored the relationships between the type and characteristics of informal caregivers, the nature of the caregiving relationship, caregiver unmet needs, and the general, physical, and mental health-related outcomes of the caregivers.

### Theoretical Framework

This research study was grounded in Cho's (2007) proposed framework for evaluating the effects of informal caregiving on health-related outcomes for elderly care recipients. Caregiving and receiving care are parallel processes affecting the individual providing care and the individual receiving care. Cho's (2007) model focused on the experiences and needs of those receiving care, the quality of that care, and how the care is impacted by social network theories, social support theories, and the existing literature on informal caregiving. The elements of the model developed by Cho are: (1) Type a of Informal Caregivers, (2) Nature of Caregiving Relationship, (3) Caregiving, (4) Internal Processes of a

Care Recipient, which ultimately impacts the (5) Health-Related Outcomes of a Care Recipient. Figure 3.1 illustrates Cho’s model without adaptation. This study focused on the experiences of caregivers and used an adapted version of Cho’s model.

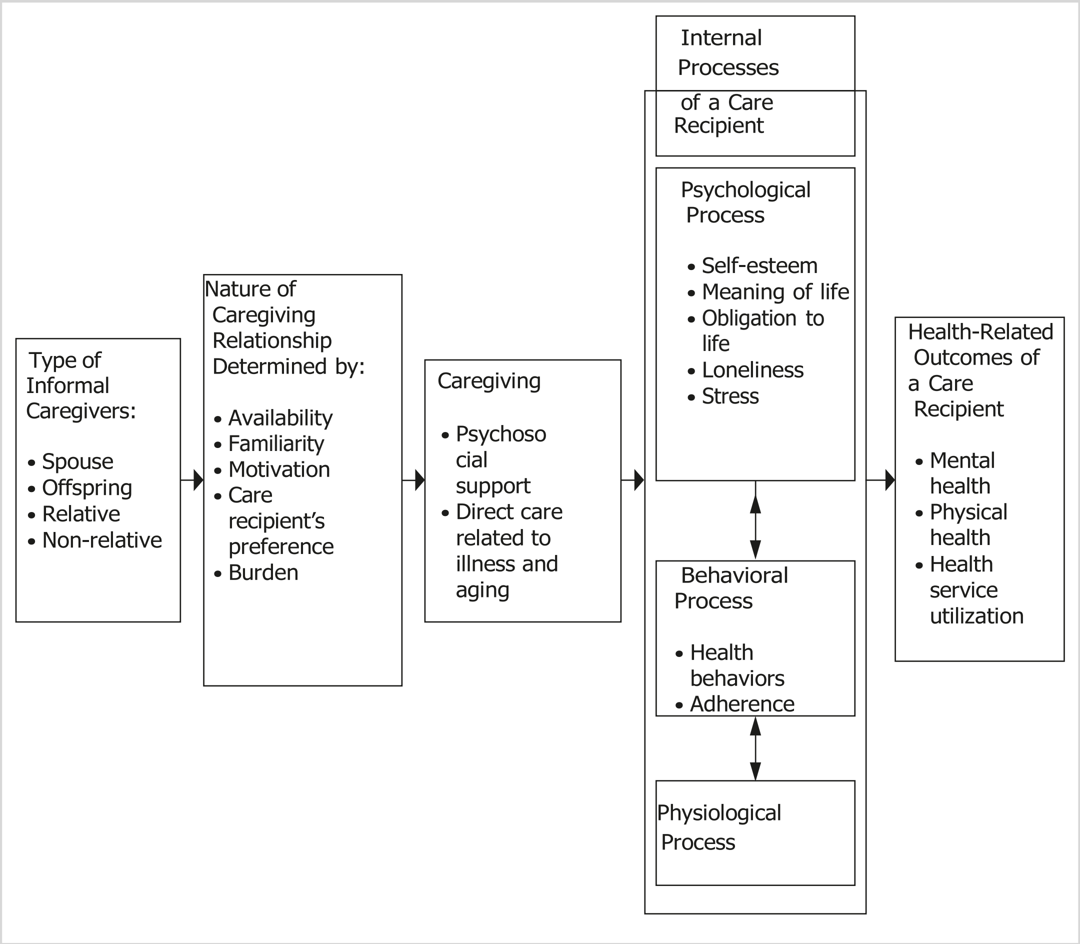


Figure 3.1: Cho's Framework Addressing the Effects of Informal Caregivers on Health-Related Outcomes of Elderly Recipients in Home Health Care.

*Cho, Eunhee. (2007). "A Proposed Theoretical Framework Addressing the Effects of Informal Caregivers on Health-Related Outcomes of Elderly Recipients in Home Health Care." Asian Nursing Research,1(1), 23–34. https://doi.org/10.1016/S1976-1317(08)60006-7.*

This study used an adapted model of Cho's (2007) framework to investigate and examine issues with caregiving. Both caregivers and care recipients are experiencing life changes simultaneously and experience significant changes in their health outcomes. The elements of Cho's model were adapted and redefined to examine the caregiver's perspective. The elements in the new model are (1) Type and Characteristics of Informal Caregivers, (2) Nature of the Caregiving Relationship, (3) Caregiver Unmet Needs, (4) Internal Processes of Caregiver (Caregiver Burden), which leads to the (5) Health-Related Outcomes of a Caregiver (Figure 2). The literature on caregiving informed the adapted definitions.

1. Type and Characteristics of Informal Caregivers were examined in the Behavioral Risk Factor Surveillance System (BRFSS) as the relationship to the caregiver (spouse, child, sibling, etc.) and the following demographic categories (age, sex, race, gender, living status, education, employment, income) (CDC, 2020).
2. Nature of Caregiving Relationship was defined in the literature as the health condition (s) of the care recipient, the length of time the caregiver has been providing care, hours of care monthly-the duration of care, and the type of care provided (ADLs and IADLs). These characteristics were central to the severity of caregiver burden (Talley and Crews, 2007, Montgomery and Koloski, 2013, Zauszniewski et al., 2020). The nature of the relationship was examined in the BRFSS using questions related to the

above-identified factors: how long the caregiver has been providing care, how many hours per month of care was provided, and the type of direct care related to illness and aging (caregiving tasks) given to the care recipient (CDC, 2019).

3. Caregiver unmet needs are a function of caregiving experiences related to the type of care the caregiver provides, which is based on the condition of the care recipient and the support the caregiver receives while undergoing caregiving tasks (Cook and Cohen, 2018, Bastarowoas, 2013, Choi and Seo, 2019, Leow and Chan, 2011). Caregiver unmet needs were examined in (BRFSS) using questions related to the psychosocial support the caregiver receives (support needed) (CDC, 2019).
4. Internal Processes of Caregiver (Caregiver Burden) was defined in the literature as Caregiver Burden, which was the physical, mental, and emotional responses a caregiver has related to caregiving. Caregiver burden is associated with caregiver distress, which includes financial challenges, health challenges (Cook and Cohen, 2018, Bastarowoas, 2013, Choi and Seo, 2019, Leow and Chan, 2011). Internal Processes of Caregiver (Caregiver Burden) can be explored in (BRFSS) using questions related to psychological processes (depression, perceived mental health, life purpose), behavioral processes (health behaviors), and physiological processes (health conditions and health activities) (CDC, 2019). While the Internal Processes of the caregiving are important to understanding the

caregiver experience, this study does not address this concept, as it needs additional focus beyond the scope of this study (Cook and Cohen, 2018, Bastarowoas, 2013, Choi and Seo, 2019, Leow and Chan, 2011).

5. Health-Related Outcomes of a Caregiver were defined in the literature as the potential health conditions caregivers have or develop as a result of the stresses of caregiver burden. This study examined the physical, mental, and general health of those reporting as caregivers with or without cognitive decline. (Choi and Seo, 2019, Leow and Chan, 2011, CDC, 2020) (See Figure 2). Health-Related Outcomes were examined in (BRFSS) using questions related to overall general health, the number of physically healthy days, and the number of mentally healthy days (CDC, 2019).

## Institutional Review Board (IRB)

Approval from the University of South Carolina Institutional Review Board was granted on March 21, 2022. The study was categorized as "exempt status," as de-identified secondary data was utilized for this study.

## Data Sources

The study used the Behavioral Risk Factor Surveillance System (BRFSS) years 2015-2018 pooled to gather information about caregivers and caregivers reporting subjective cognitive decline. BFRSS is collected via landlines, cellular, the mail and collects more than 400,00 interviews yearly (CDC, 2018).

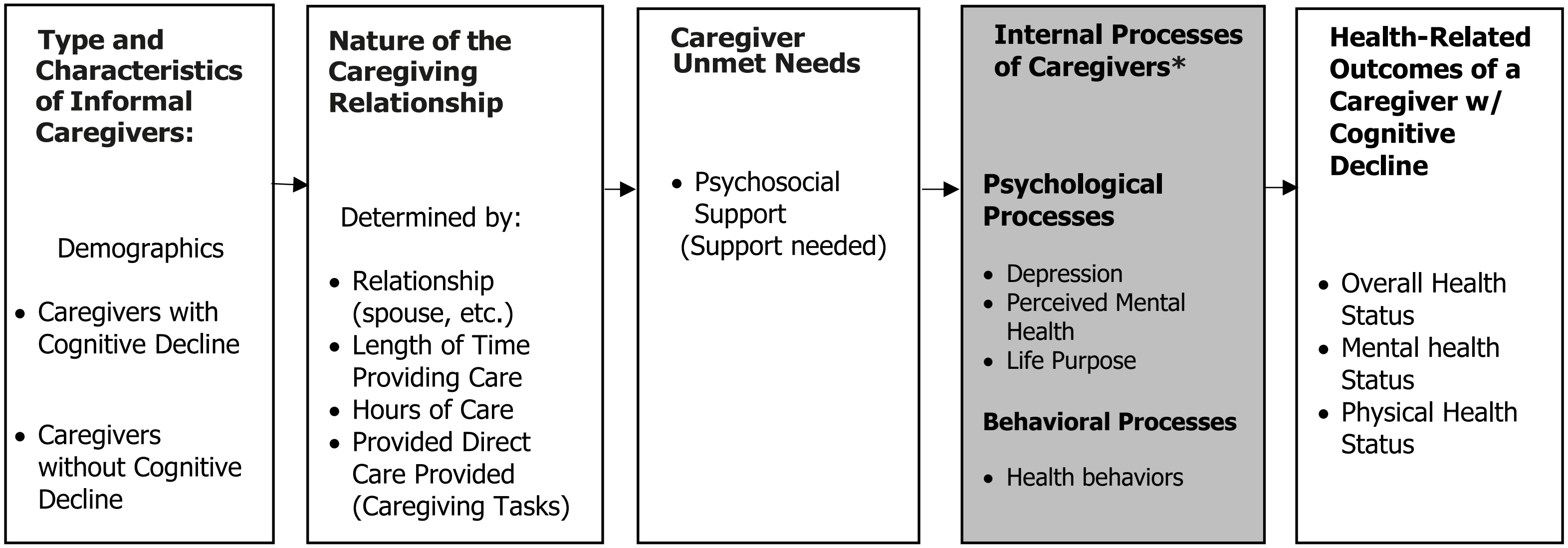


Figure 3.2 *Adapted Framework Addressing the Experiences of Informal Caregivers on Their Own Health-related Outcomes.*

Note. *Adapted from Cho, Eunhee. (2007). A Proposed Theoretical Framework Addressing the Effects of Informal Caregivers on Health-Related Outcomes of Elderly Recipients in Home Health Care." Asian Nursing Research,1(1), 23–34. https://doi.org/10.1016/S1976-1317(08)60006-7.*

Currently, all 50 states administer the survey through state health departments with guidance from the CDC.

The survey collected data on health status, health conditions, and preventive care. The yearly surveys are comprised of three components: the core sections (fixed core, rotating core, and emerging core), optional modules, and questions added at the state level. The fixed core is the questions required to be administered by all the states. The fixed core covers demographic questions and health behaviors. The rotating core questions are asked in alternating years, and the emerging core focuses on current trends. Optional modules are administered yearly by the state. State responses to state-added questions are available if requested. In this study, state-added questions and responses were not analyzed.

This study used BRFSS data from pooled 2015-1018 and questions from the following Core Sections: Demographics, Health Care Access, Health Status, and Healthy Days, and Optional Modules: the Caregiver Module: gathered information about caregivers' activities and experiences to assess caregiver status and health. The Cognitive Decline Module: collected data to ascertain how cognitive decline affects the lives of respondents aged 45 years and older, including people with difficulties performing activities or caring for themselves.

## Study Sample

The study sample was comprised of respondents answering two sets of questions, from the Caregiver Module and the Cognitive Decline Module in the years 2015-2018, who reported they were caregivers in the Caregiver Module (n=47227). Caregivers were defined as persons who "YES" to Question 1 in the Caregiver Module: "People may provide regular care or assistance to a friend or family member who has a health problem or disability. During the past 30 days, did you provide regular care or assistance to a friend or family member who has a health problem or disability?" (CDC, 2018). Within all caregivers, the study identified caregivers who reported experiencing some cognitive decline. These respondents responded "YES" to Question 1 in the Caregiver Module, and responded “YES” to Question 1 in the Cognitive Decline Optional Module: “During the past 12 months, have you experienced confusion or memory loss that is happening more often or is getting worse?” (CDC, 2018).

## Study Aims

**Aim 1:** Described the demographic characteristics of caregivers, the nature of the caregiving relationship, and caregiver unmet needs, and compared these between caregivers who reported experiencing subjective cognitive decline compared to those who did not report any subjective cognitive decline.

**Research Question:** What were the demographic *(age, sex, race, gender, marital status, education, employment, income)* characteristics of caregivers, the nature of the caregiving relationship, and caregiver unmet needs, and how did those caregivers who reported cognitive decline compare to other caregivers?

**Hypothesis:** There would be a difference in the demographic characteristics, the nature of the caregiving relationship, and caregiver unmet needs of caregivers who report cognitive decline compared to caregivers who did not report any cognitive decline.

**Study Variables:** In exploring differences between caregivers reporting subjective cognitive decline or not, using the adapted model from Cho, this study aim addressed the type and characteristics of informal caregivers, which included demographic responses and the caregiver's relationship to the care recipient. The model also addressed caregiving tasks, the time spent caregiving, and caregiver unmet needs-needed supports which are all factors that contributed to caregiver burden.

### *I. Independent Variables*

The independent variables for Aim 1 (Table 3.1) were the demographic characteristics of caregivers, the nature of the caregiving relationship, and the caregivers' unmet needs—needed supports. The demographic variables were defined as (1) sex, male/female, (2) age, 18-34, 35-44, 45-54, 55-64, 65 and over, (3) race, Non-Hispanic White, Non-Hispanic African-American, Non-Hispanic American Indian, Alaska Native, Non-Hispanic Asian, Native Hawaiian, or Pacific Islander, Hispanic, (4) marital/relationship status, living together/ not living together, (5) educational attainment, not completed high school, completed high school, some technical school/ college, college graduate, (6) employment status, employed, unemployed, homemaker, retired, unable to work, (7) income, less than $25K, $25K-$45K, $46K-$60K, $61K-$75K, more than $75K, (8) insurance coverage, have coverage/no coverage, (9) medical provider, only one, more than one, no provider. Additionally, the independent variable also included the relationship to the care recipient, defined as parent/grandparent, spouse/partner, mother/father-in-law, sibling or brother/sister-in-law, child/grandchild, other relative, or non-relative. Independent variables further explored were defined as the (1) length of time providing care, less than 30 days, one month to less than six months, six months to less than two years, two years to less than five years; more than five years; (2) hours per week providing care, up to 8 hours per week, 9 to 19 hours per week, 20 to 39 hours per week, 40 hours or more, (3) caregiving tasks (ADLs), yes/no, (4) caregiving tasks (IADLs), yes/no, (5) support needed for caregiver, classes about giving care, help in getting access to services, support groups, individual counseling to help cope with giving care, respite care, no help needed.

All independent variables were converted to categorical variables for the study.

### *II. Dependent Variable*s

The dependent variable in Aim 1 was the presence of subjective cognitive decline. BFRSS respondents were asked if they had experienced confusion or memory loss that is happening more often or is getting worse within the last 12 months. Respondents answering yes or no were included in the study.

Table 3.1 Independent Variables Defined for Examining Aim

| ***Demographics, relationship to care recipient, caregiving tasks, unmet needs*** | **Defined Responses for Study** |
|---|---|
| Sex | **Categorical:**<br>1: M<br>2: F |
| Age | **Categorical:**<br>1: 18-34<br>2: 35 to 44<br>3: 45 to 54<br>4: 55 to 64<br>5: 65 and Over |
| Race | **Categorical:**<br>1: NH White<br>2: NH African-American<br>3: NH American Indian or Alaskan Native<br>4. NH Asian, Native Hawaiian, or Pacific Islander<br>5: NH Multiracial/other |

| | |
|---|---|
| | 6: Hispanic |
| Marital Status | **Categorical:** |
| | 1: Living together |
| | 2: Not living together |
| Educational Attainment | **Categorical:** |
| | 1: Not completed high school |
| | 2: Completed high school |
| | 3: Some technical school/ college |
| | 4: College graduate |
| Employment Status | **Categorical:** |
| | 1: Employed |
| | 2: Unemployed |
| | 3: Homemaker |
| | 4: Retired |
| | 5: Unable to work |
| Income | **Categorial:** |
| | 1: Less than $25K |
| | 2: 25K-45K |
| | 3: 46K-60K |
| | 4: 61K-75K |
| | 5: more than 75K |
| Any kind of Insurance Coverage | **Categorical:** |
| | 1: Have coverage |

| | |
|---|---|
| | 2: No coverage |
| Medical Provider | **Categorical:**<br>1: One provider<br>2: More than one provider |
| Relationship to recipient | **Categorical:**<br>1: Parent/Grandparent<br>2: Spouse, partner, or mother/father-in-law<br>3: Sibling or brother/sister-in-law<br>4: Child/Grandchild<br>4: Other relative<br>5: Non-relative |
| Provide Care --How long | **Categorical:**<br>1: Less than 30 days<br>2: 1 month to less than 6 months<br>3: 6 months to less than 2 years<br>4: 2 years to less than 5 years<br>5: More than 5 years |
| Hours | **Categorical:**<br>1: Up to 8 hours per week<br>2: 9 to 19 hours per week<br>3: 20 to 39 hours per week<br>4: 40 hours or more |
| Tasks-Medication (ADLS) | **Categorical:**<br>1: Yes<br>2: No |

| | |
|---|---|
| Tasks-Cleaning (IADLS) | **Categorical:**<br>1: Yes<br>2: No |
| What supports are needed | **Categorical:**<br>1: Classes about giving care, such as giving medications<br>2: Help in getting access to services<br>3: Support groups<br>4: Individual counseling to help cope with giving care<br>5: Respite care<br>6: No support needed |

**Aim 2:** Described functional subjective cognitive decline among caregivers.

**Research Question:** Among caregivers who reported subjective cognitive decline, what specific deficits were reported?

**Study Variables:** The study aim was purely descriptive. BRFSS respondents answering yes to both the survey question identifying them as caregivers—providing regular care or assistance to someone with a health problem or disability in the last 30 days (BRFSS, CDC 2015, 2016, 2017, 2018) and as experiencing cognitive decline—experienced confusion or memory loss that is happening more often or is getting worse within the last 12 months were included in this research (BRFSS, CDC 2015, 2016, 2017, 2018). Variables (Table

3.2) were defined as (1) experiencing memory loss within the last 12 months, yes/never, (2) given up household tasks within the last 30 days because of memory loss, yes/never, (3) needing assistance with household tasks within the last 30 days because of memory loss, yes/never, (4) received assistance when needed within the last 30 days because of memory loss, yes/never, (5) memory loss interfering with social or out of home activities, yes/never.

This study aim explored the functional and daily effects (ADLs and IADLs) of subjective cognitive decline specifically for caregivers, including day-to-day household activities or chores you used to do, such as cooking, cleaning, taking medications, driving, or paying bills. When examining caregiver burden, subjective cognitive decline was one of the outcomes of caregiver burden. Because of the nature of the caregiving relationship, spousal dyads, aging caregivers, elevated stress, there are physical and mental impacts. This study examined one of those impacts, subjective cognitive decline. The study explored the functional impacts of cognitive decline for individuals reporting as caregivers. As subjective cognitive decline was a potential outcome with far-reaching effects of caregiver-related stress and burden, the study explored this particular facet of caregiver health. The Cognitive Decline module from BRFSS allowed an analysis of the individuals who identified as caregivers and how their self-reported cognitive decline impacted their activities and relationships. Exploring the adapted model from Cho, this study aim addressed the Type and Characteristics of Informal Caregivers reporting subjective cognitive decline. Typically, in most research, only care recipients were assessed for functional impacts.

Table 3.2 Functional Cognitive Decline Variables for Examining Aim 2

| ***Optional Module: Cognitive Decline*** | **Defined Responses for Study** |
|---|---|
| During the past 12 months, have you experienced confusion or memory loss that is happening more often or is getting worse? | **Categorical:**<br>1: Yes<br>2: Never |
| During the past 12 months, as a result of confusion or memory loss, how often have you given up day-to-day household activities or chores you used to do, such as cooking, cleaning, taking medications, driving, or paying bills? | **Categorical:**<br>1: Yes<br>2: Never |
| As a result of confusion or memory loss, how often do you need assistance with these day-to-day activities? | **Categorical:**<br>1: Yes<br>2: Never |
| When you need help with these day-to-day activities, how often are you able to get the help that you need? | **Categorical:**<br>1: Yes<br>2: Never |
| During the past 12 months, how often has confusion or memory loss interfered with your ability to work, volunteer, or engage in social activities outside the home? | **Categorical:**<br>1: Yes<br>2: Never |

**Aim 3**: Assessed whether caregivers who reported subjective cognitive decline have worse health status than other caregivers.

**Research Question:** Compared to caregivers without subjective cognitive decline, do those caregivers who reported subjective cognitive decline differ in their health status?

**Hypothesis:** Caregivers without subjective cognitive decline reported better health status than caregivers with subjective cognitive decline.

*I. Independent Variable*

In exploring differences between caregivers reporting cognitive decline or not, in the adapted model from Cho, this study aim addressed the Health-Related Outcomes and Cognitive Decline. The independent variable is the presence of cognitive decline (Table 3.3). BFRSS respondents were asked if they had experienced confusion or memory loss that is happening more often or is getting worse within the last 12 months. Respondents answering yes or no were included in the study.

*II. Dependent Variable*

The dependent variables for Aim 3 were the Health-Related Outcomes of Caregivers. The variables were the self-reported responses general health, Poor/Fair or Excellent/Very Good/Good, physical health within the last 30 days, yes, none, and mental health within the last 30 days, yes or no.

None of the study aims explored the health of the care recipient, the study examined caregiver experiences and when subjective cognitive decline was reported in those caregivers.

All independent and dependent variables were converted to categorical variables for the study.

Table 3.3 Dependent Variables Defined for Examining Aim 3

| ***Health-Related Outcomes*** | **Defined Responses for Study** |
|---|---|

| | |
|---|---|
| General Health: Would you say that in general, your health is— | **Categorical**:<br>1: Excellent/Very Good/Good<br>2: Fair/Poor |
| Physical Health: Now thinking about your physical health, which includes physical illness and injury, for how many days during the past 30 days was your physical health not good? | **Categorical**:<br>1: Yes (any number 1-30)<br>2: None |
| Mental Health: Now thinking about your mental health, which includes stress, depression, and problems with emotions, for how many days during the past 30 days was your mental health not good? | **Categorical**:<br>1: Yes (any number 1-30)<br>2: None |

## Analytic Approach

### *Aim 1*

Chi-square tests (α = 0.05) were conducted to assess whether demographic differences, the nature of the caregiving relationship, or caregiver needs differed if caregivers were reporting or not reporting subjective cognitive decline. Additionally, logistic regression models (α = 0.05) were conducted to measure associations in demographic differences, the nature of the caregiving relationship, or caregiver needs for caregivers reporting subjective cognitive decline.

### *Aim 2*

We conducted chi-square test for a descriptive analysis of the functional ability of the study sample to determine the impact of subjective cognitive decline on caregivers. Only individuals who reported as caregivers were analyzed.

### *Aim 3*

We conducted chi-square tests (α = 0.05) to measure differences in the health-related outcomes of caregivers reporting or not reporting subjective cognitive decline. Next, logistic regression models (α = 0.05) were used to measure associations of health-related outcomes with reported subjective cognitive decline among caregivers.

# CHAPTER 4

## MANUSCRIPT ONE

### INFORMAL CAREGIVERS: CHARACTERISTICS AND THE FUNCTIONAL IMPACT OF SUBJECTIVE COGNITIVE DECLINE

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To be submitted to *Alzheimer's and Dementia*

## ABSTRACT

*Purpose.* The United States is experiencing unprecedented demographic shifts as the population continues to age. More than 53 million Americans are caregivers and that number is continuing to grow. Caregiving has become a significant societal and public health issue to be addressed. The purpose of this research was to provide a population-based national perspective describing the demographic characteristics of caregivers, the nature of the caregiving relationship, and caregiver unmet needs, and compare these between caregivers who report experiencing cognitive decline compared to those who do not report any cognitive decline. The study also examined the functional impacts of cognitive decline among caregivers.

*Methods.* The study used the Behavioral Risk Factor Surveillance System (BRFSS) years 2015-2018 pooled to gather information about caregivers and subjective cognitive decline. Chi-square tests ($\alpha = 0.05$) were conducted to assess whether demographic differences, the nature of the caregiving relationship, or caregiver needs differed if caregivers are reporting or not reporting cognitive decline. We also used chi-square test for a descriptive analysis of the functional impacts of subjective cognitive decline on informal caregivers. Additionally, logistic regression models ($\alpha = 0.05$) were conducted to measure associations demographic differences, the nature of the caregiving relationship, or caregiver needs for caregivers reporting cognitive decline.

*Results.* More than half of caregivers reported memory loss/confusion has interfered with daily activities: work, volunteer, or social activities. The study also suggests significant differences in demographic characteristics, the nature of the caregiving, and caregiver unmet needs. The strongest associations with subjective decline were sex—males, employment status—unemployed and unable to work, which may indicate the current status of the caregiver. Additional strong associations were income and ADLs (activities of daily living).

*Conclusion.* As evidenced by this study, caregivers with cognitive decline are experiencing limitations in their own daily and social activities, which merits exploration of how those challenges might impact the care being provided. Moreover, these findings support the need for further exploration of informal caregivers and in this instance, subjective cognitive decline. The health care system must include caregiver health in the care plans of care recipients and policies need to be developed to support the work of the caregiver or the current model will continue at its current unsustainable pace.

## Introduction

The United States is experiencing unprecedented shifts as the population continues to age. The aging of America has impacts on all facets of society, socially and economically, for example, in terms of care for older adults and related costs, the rising cost of living and health care (The National Institute on Aging (NIA), 2020). According to The National Institute on Aging (NIA) living arrangements, the availability of services, and caregiving are significant areas of concern deserving consideration and further research (The National Institute on Aging (NIA), 2020). In fact, caregiving has become a significant societal and public health issue to be addressed. Van Durme et al. (2012) reported that caregiving and the role of caregivers are important issues at the political, sociological, and economic levels. According to the Utah Coalition for Caregiving Support (2018), caregiving "refers to the provision of assistance to another person who is ill, disabled, or needs help with daily activities. It often requires attention to the physical, mental, social, and psychological needs and well-being of both the caregivers and the elderly persons requiring care (Caregiving, para 1, Utah Coalition for Caregiving Support). Jeffers et al. (2021) report that upwards of 20% of adults are caregivers in the US.

Positive responses to caregiving are related to caregivers feeling their role has given their lives meaning and purpose. Yet, in many caregivers, those positive perspectives co-occur with stress and strain (AARP, 2020). Caregiving can be rewarding, but over time the decline in the recipient’s condition, financial strain and stress, and isolation can present significant challenges (Sullivan and Miller, 2015). Although caregiving as a concept is familiar because it impacts so many families, it is clear that while knowledge about caregiving impacts has increased, policy responses have not followed at the same rate (Talley & Crews, 2007; Schulz et al., 2018). For example, caregivers are not screened for health and functional challenges and may not be recognized as a part of the care recipients' care team (Schulz et al., 2018). Continued exploration and research of caregiving as a concept and the impacts of caregiving on those providing care is necessary to develop effective interventions to maintain the health of caregivers and care recipients.

### Subjective Cognitive Decline and Cognitive Impairment

The CDC (2019) defines cognitive decline as a broad term encompassing impairment related to brain processes. Cognitive decline can be mild or as advanced as dementia and/or Alzheimer's disease. Cognitive decline is characterized by impairment in the "ability to learn, remember, and make judgments" (p.1). *Subjective Cognitive Decline* refers to individuals self-reporting experiencing issues with memory or other cognitive processes (CDC, 2019).

Cognitive impairment is characterized by problems up to the inability to learn, remember, and make decisions or judgments. Impairment can significantly influence one's health and well-being (CDC, 2019). Cognitive impairment can occur in individuals with chronic diseases, especially those not managed well (CDC, 2020). It is not uncommon for caregivers to forgo their own care, which can place them at higher risk for cognitive impairment and challenges with pre-existing conditions (Dassell, 2017). Also, the stress related to caregiving is linked to poor health outcomes, and cognitive impairment may result (AARP, 2019; Choi and Seo, 2019; Schulz et al., 2018). Physical and psychological health may be compromised when the caregiving needs are high-intensity and long-lasting (Schulz et al., 2018). While there is a great deal of research on caregiver burden and its consequences, there is limited research on subjective cognitive impairment in caregivers.

## Caregiver Burden, Functional Impacts, and Subjective Cognitive Decline

Caregiving can be emotionally, financially, and physically demanding. Informal caregiving provides opportunities for individuals who are aging and/or have a chronic illness to receive care at home. Caregivers are often responsible for providing physical care and maintenance, emotional support, and social interaction for those in their care, often at the expense of their own health and need for social activities (Bastarowos, 2013). How caregivers are able to manage their own experiences and health affects the care they are able to provide as well (Bastarowos, 2013). Caregivers are responsible for for tasks related to personal care, called ADLs, activities of daily living. According to Cook and Cohen (2018), ADLs are related to personal care. ADLs include feeding, bathing, dressing, toileting (if assistance is needed and at what level), and transferring (does the care recipient need assistance moving from one place to another.

Caregivers may also be responsible for other caregiving tasks unrelated to personal care, called IADLs, instrumental activities of daily living. According to Cook and Cohen (2018), IADLs are needed to increase the occurrence of living independently and are necessary for the care and function of the care recipient. IADLs include medication management, scheduling and, if required, transportation to medical visits, shopping, housekeeping, money and household financial management, meal preparation, transportation, and communications.

Caregiving is not a new phenomenon. Families have been the primary caregivers, particularly of aging parents or spouses, since the beginning of time. In *Valuing the Invaluable* (2019), the challenges with caregiving now are "more complex, costly, stressful, and demanding than any other time in human history (p. 6)," and the challenges are related to the constant and everchanging pace of social, health and financial issues. *Valuing the Invaluable* (2019) reports a study that found 9 in 10 individuals with middle-income in the midlife stage said that being a caregiver was significantly more challenging than anticipated and required more time, patience, and emotional stability than was initially thought.

The *Valuing the Invaluable* report continues by describing "family caregivers as an 'invisible, isolated army' carrying out increasingly complicated tasks and experiencing challenges and frustrations without adequate recognition, support, or guidance, and at great personal cost (p.5)." One of the major challenges faced by informal caregivers is the isolation and their relative invisibility (Sullivan and Miller, 2005). Even though caregivers are intimately and extensively involved in the daily care of the care recipients, caregivers are not usually recognized by healthcare providers and/or payers (Schulz et al., 2018). The system is not actively assessing the needs, capabilities, and well-being nor acknowledging how intertwined and interdependent the lives of care recipients are with the caregivers (Valuing the Invaluable, 2015). Caregiving can lead to increased levels of stress, financial complications, and increased mental and physical demands on the part of the caregiver. Those challenges are associated with increased caregiver burden, which can impact the caregiver's ability to care for themselves, have social activities, and the management of their own affairs. This complex confluence of factors can contribute to subjective cognitive decline, affecting the health of the caregiver and the care recipient.

## Caregiver Prevalence

According to the National Alliance for Caregiving (NAC) and the AARP's Caregiving in the US (2020) report, about 53 million adults have provided unpaid care to an adult or a child in the prior 12 months in the US. 1 in 5 Americans, about 21.3% are caregivers, either to an adult or a child with special needs. Most caregivers (82%) care for an adult 50 years or older (AARP, 2020). The CDC reported 1 in 5 or about 20% of adults (18 or older) report being a caregiver; those caregivers are providing care and/or assistance to an individual with a long-term illness or disability (CDC, 2020). Most caregivers provide care for one adult (76%), but 24% report providing care for two or more adults (AARP, 2020), and that number is increasing. In rural communities, caregivers more frequently care for multiple adults (34%), as opposed to more suburban/urban areas (23%) (AARP, 2020). Despite increases in the number of care recipients, caregiving affects all generations, racial/ethnic groups, all incomes, and educational levels (CDC, 2020, AARP, 2020). When examining age, the Caregiving for Family and Friends (2019) reports 18.8% are caring for those aged 65 years and older, and 24.4% care for adults aged 45-64 years old.

AARP reports most informal caregivers are female, 61% (AARP, 2020), while the Institute on Aging (2016) reports nearly 75% of caregivers are female. Both reports are consistent in recognizing most caregivers are women. The younger the care recipient, the more likely the recipient is male (42% among ages 18-49), as opposed to middle-aged men (35% among ages 50-64). Primary caregivers are individuals providing all or most of the unpaid care to a family member, spouse, sibling, child, parent, etc. Most adult caregivers are caring for a relative (89%), comprising a parent or parent-in-law (50%), spouse or partner (12%), grandparent or grandparent-in-law (8%), or adult children (6%) (AARP, 2020). Caregivers in the National Alliance for Caregiving and AARP (2020) report the following racial/ethnic identities as caregivers: 61% White; 14 % African-American; 17% Hispanic (non-White, non-African-American); and 5% Asian-American. White caregivers are older than African American, Hispanic, and Asian American caregivers, on average. The average age of caregivers by race is White caregivers at 51.7 years; Asian-American caregivers at 49.3 years old; African-

American caregivers at 47.7 years old, and Hispanic (non-White, non-African-American) caregivers at 43.3 years (AARP, 2020).

AARP (2020) also reports the prevalence of caregivers, particularly as the number of adults aging continues to increase; for example, in 2015, there were about 43.5 million reported caregivers. In 2020, AARP reported the number of caregivers is estimated to be up to 53 million Americans. The increases are due to a confluence of factors: the aging baby boomer population needing more care, workforce shortages in healthcare and in long-term services and supports (LTSS) formal care settings, medical technology prolonging life expectancy, national efforts to facilitate more home and community-based services, and the cost of care informal care settings (Schulz et al., 2018). Additionally, a shortage of potential caregivers is a genuine concern, as more women are working in the labor force, declines in family size, and the number of children couples are choosing to have (Schulz et al., 2018; Van Houtven et al., 2020).

The purpose of this study was to illuminate the extent to which caregivers report experiencing subjective cognitive decline and to outline demographic factors associated with this self-reported decline for purposes of screening and interventions. The study also examined the functional impacts of subjective cognitive decline on those caregivers reporting subjective cognitive decline.

## Methodology

### *Theoretical Model*

The analysis was grounded in an adapted model of Cho's (2007) proposed framework for evaluating the effects of informal caregiving on health-related outcomes for elderly care recipients (Figure 4.1). Since caregiving and receiving care are parallel processes affecting the individual providing care and the individual receiving care, the adapted model shifts the focus from care recipients to caregivers. The elements of the model developed by Cho are (1) Type of Informal Caregivers, (2) Nature of Caregiving Relationship, (3) Caregiving, (4) Internal Processes of a Care Recipient, which ultimately impacted the (5) Health-Related Outcomes of a Care Recipient.

This study focused on caregivers' experiences and used an adapted version of Cho's model: an Adapted Framework Addressing the Experiences of Informal Caregivers on their own Health-Related Outcomes (Figure 4.2). Both caregivers and care recipients are experiencing life changes simultaneously and can experience significant changes in their health outcomes. The elements of Cho's model have been adapted and redefined to examine the caregiver's perspective. The elements in the new model are (1) Type and Characteristics of Informal Caregivers, (2) Nature of the Caregiving Relationship, (3) Caregiver Unmet Needs, (4) Internal Processes of Caregiver (Caregiver Burden), which leads to the (5) Health-Related Outcomes of a Caregiver (Figure 4.2). The literature on caregiving informed the adapted definition (CDC, 2019, 2020, Cook and Cohen, 2018, Bastarowas, 2013, Choi and Seo, 2019, Leow and Chan, 2011).

The purpose was to provide a population-based national perspective regarding informal caregivers to identify differences between caregivers' self-reporting cognitive decline and those caregivers' self-reporting no cognitive decline. Using the adapted framework, we examined the type and characteristics of informal caregivers, the nature of the caregiving relationship, and caregiver unmet needs. We then compared those elements with caregivers who reported experiencing subjective cognitive decline compared to those who did not report any subjective cognitive decline.

We hypothesized there would be a difference in the type and characteristics of informal caregivers, the nature of the caregiving relationship, and caregiver unmet needs of those caregivers who self-report cognitive decline compared to caregivers who do not report any subjective cognitive decline.

## Data Sources

The study used the Behavioral Risk Factor Surveillance System (BRFSS) years 2015-2018 pooled to gather information about caregivers and caregivers reporting subjective cognitive decline. BFRSS is collected via landlines, cellular, the mail and collects more than 400,00 interviews yearly (CDC, 2018). Currently, all 50 states administer the survey through state health departments with guidance from the CDC.

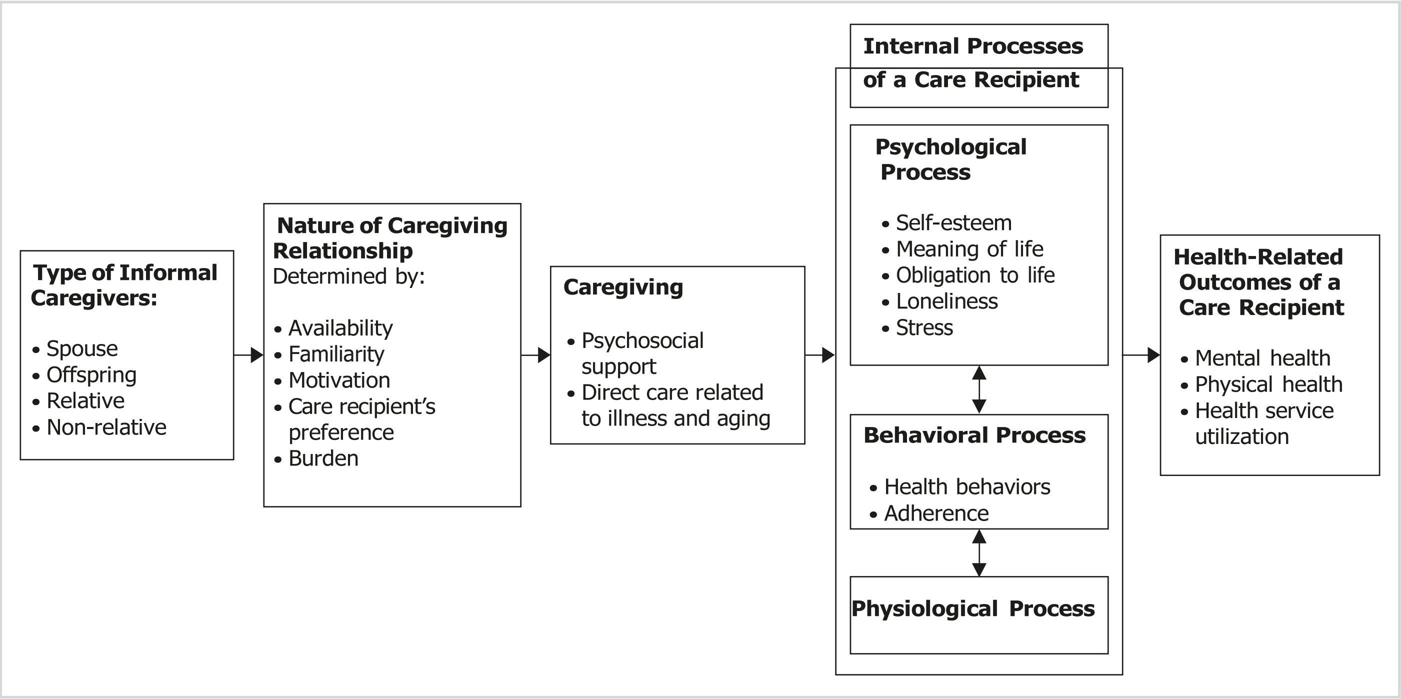

Figure 4.1 Cho's Framework oAddressing the Effects of Informal Caregivers on Health-Related Outcomes of Elderly Recipients in Home Health Care.

*Cho, Eunhee. (2007). "A Proposed Theoretical Framework Addressing the Effects of Informal Caregivers on Health-Related Outcomes of Elderly Recipients in Home Health Care." Asian Nursing Research,1(1), 23–34. https://doi.org/10.1016/S1976-1317(08)60006-7.*

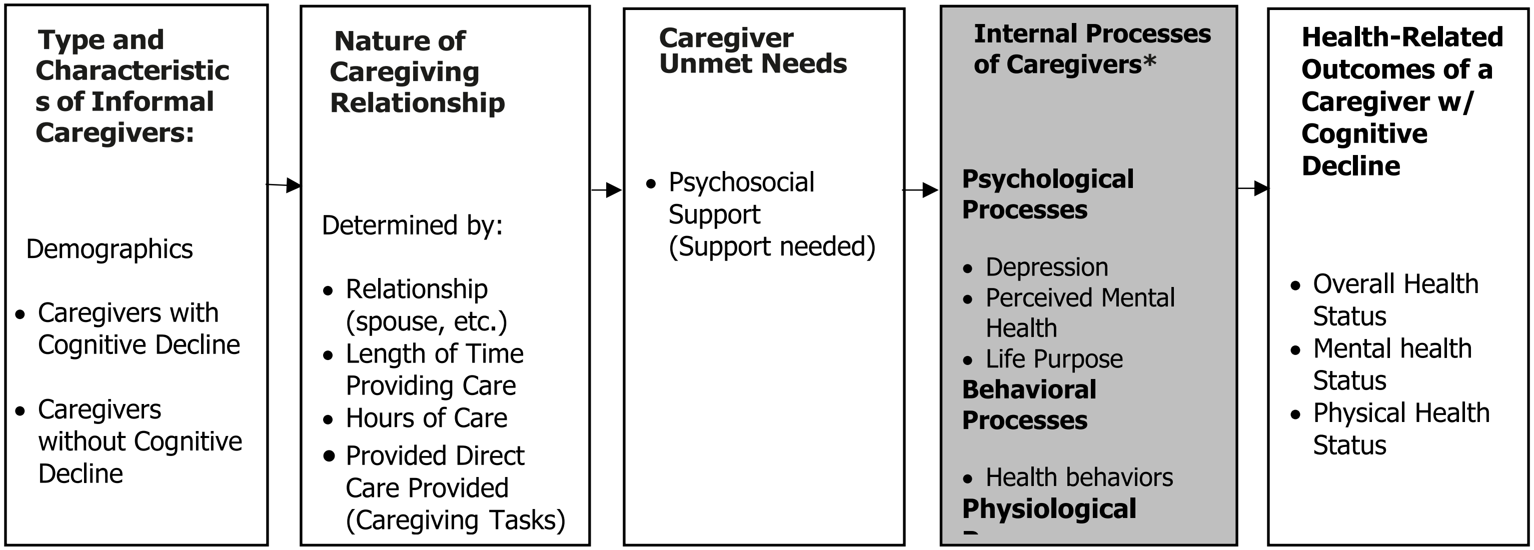

Figure 4.2 Adapted Framework Addressing the Experiences of informal Caregivers on Their Own Health-Related Outcomes

Note. *Adapted from Cho, Eunhee. (2007). A Proposed Theoretical Framework Addressing the Effects of Informal Caregivers on Health-Related Outcomes of Elderly Recipients in Home Health Care." Asian Nursing Research,1(1), 23–34. https://doi.org/10.1016/S1976-1317(08)60006-7.*

The survey collected data on health status, health conditions, and preventive care. The yearly surveys are comprised of three components: the core sections (fixed core, rotating core, and emerging core), optional modules, and questions added at the state level. The fixed core is the questions required to be administered by all the states. The fixed core covers demographic questions and health behaviors. The rotating core questions are asked in alternating years, and the emerging core focuses on current trends. Optional modules are administered yearly by the state. State responses to state-added questions are available if requested. In this study, state-added questions and responses were not analyzed.

This study used BRFSS data from pooled 2015-1018 and questions from the following Core Sections: Demographics, Health Care Access, Health Status, and Healthy Days, and Optional Modules: the Caregiver Module: gathered information about caregivers' activities and experiences to assess caregiver status and health. The Cognitive Decline Module: collected data to ascertain how cognitive decline affects the lives of respondents aged 45 years and older, including people with difficulties performing activities or caring for themselves.

### Study Sample

The study sample was comprised of respondents answering two sets of questions, from the Caregiver Module and the Cognitive Decline Module in the years 2015-2018, who reported they were caregivers in the Caregiver Module (n=47227). Caregivers were defined as persons who "YES" to Question 1 in the

Caregiver Module: "People may provide regular care or assistance to a friend or family member who has a health problem or disability. During the past 30 days, did you provide regular care or assistance to a friend or family member who has a health problem or disability?" (CDC, 2018). Within all caregivers, the study identified caregivers who reported experiencing some cognitive decline. These respondents responded "YES" to Question 1 in the Caregiver Module, and responded “YES” to Question 1 in the Cognitive Decline Optional Module: “During the past 12 months, have you experienced confusion or memory loss that is happening more often or is getting worse?” (CDC, 2018).

As subjective cognitive decline is a potential outcome with far-reaching effects of caregiver-related stress and burden related to caregiving tasks ADLs and IADLs, the study explored this particular facet of caregiver health. The Cognitive Decline module from BRFSS allowed an analysis of the individuals who identified as caregivers and how their self-reported cognitive decline impacts their activities and relationships. Exploring Cho's adapted model addresses the type and characteristics of informal caregivers reporting subjective cognitive decline. Typically, only care recipients are assessed for functional impacts in most research.

### ***Study Variables:***

In exploring differences between caregivers reporting subjective cognitive decline or not, using the adapted model from Cho, we addressed the type and characteristics of informal caregivers, which included demographic responses and the caregiver's relationship to the care recipient. The model also addressed caregiving tasks, the time spent caregiving, and caregiver unmet needs-needed supports, which are all factors contributing to caregiver burden.

## Functional Impacts of Subjective Cognitive Decline on Informal Caregivers

The study also asked, among caregivers who reported subjective cognitive decline, what specific deficits were reported?

Because of the nature of the caregiving relationship, spousal dyads, aging caregivers, elevated stress, there are physical and mental impacts. This study examined one of those impacts, subjective cognitive decline and analyzed the individuals who identified as caregivers and how their self-reported cognitive decline impacted their activities and relationships.

### *I. Variables Related to Subjective Cognitive Decline*

Variables were defined as (1) experiencing memory loss within the last 12 months, yes/never, (2) given up household tasks within the last 30 days because of memory loss, yes/never, (3) needing assistance with household tasks within the last 30 days because of memory loss, yes/never, (4) received assistance when needed within the last 30 days because of memory loss, yes/never, (5) memory loss interfering with social or out of home activities, yes/never. This section of the analysis examined the functional impacts of subjective cognitive decline among caregivers, specifically among caregivers who report subjective cognitive decline, and what specific deficits are reported?

## Demographic Characteristics, the Nature of the Caregiving Relationship, and Caregiver Unmet Needs

### *II. Independent Variables*

The independent variables were the type and characteristics of informal caregivers, the nature of the caregiving relationship, and the caregivers' unmet needs—needed supports. The demographic variables are defined as (1) sex, male/female, (2) age, 18-34, 35-44, 45-54, 55-64, 65 and over, (3) race, Non-Hispanic White, Non-Hispanic African-American, Non-Hispanic American Indian, Alaska Native, Non-Hispanic Asian, Native Hawaiian, or Pacific Islander, Hispanic, (4) marital/relationship status, living together/ not living together, (5) educational attainment, not completed high school, completed high school, some technical school/ college, college graduate, (6) employment status, employed, unemployed, homemaker, retired, unable to work, (7) income, less than $25K, $25K-$45K, $46K-$60K, $61K-$75K, more than $75K, (8) insurance coverage, have coverage/no coverage, (9) medical provider, only one, more than one, no provider. Additionally, the independent variable also includes the relationship to the care recipient, defined as parent/grandparent, spouse/partner, mother/father-in-law, sibling or brother/sister-in-law, child/grandchild, other relative, or a non-relative. Independent variables further explored were defined as the (1) length of time providing care, less than 30 days, one month to less than six months, six months to less than two years, two years to less than five years; more than five years; (2) hours per week providing care, up to 8 hours per week, 9 to 19 hours per week, 20 to 39 hours per week, 40 hours or more, (3) caregiving tasks, referred to as activities of daily living, (ADLs), yes/no, (4) caregiving tasks, instrumental activities of daily living (IADLs), yes/no, (5) support needed for caregiver, classes about giving care, help in getting access to services, support groups, individual counseling to help cope with giving care, respite care, no help needed.

All independent variables were converted to categorical variables for the study.

III. *Dependent Variables*

The dependent variable is the presence of subjective cognitive decline. BFRSS respondents were asked if they had experienced confusion or memory loss that is happening more often or is getting worse within the last 12 months. Respondents answering yes or no were included in the study.

## ***Analytic Approach***

First, we examined the functional impacts of subjective cognitive decline on caregivers who reported subjective cognitive decline. We conducted a chi-square test for a descriptive analysis of the functional ability of the study sample to determine the impact of subjective cognitive decline on caregivers.

Then, we examined the type and characteristics of informal caregivers, the nature of the caregiving relationship, and caregiver unmet needs, and compared those elements with caregivers who report experiencing subjective cognitive decline compared to those who do not report any subjective cognitive decline. Chi-square tests (ɑ = 0.05) were conducted to assess whether the type and characteristics of informal caregivers, the nature of the caregiving relationship, or caregiver unmet needs differed if caregivers are reporting or not reporting subjective cognitive decline. Additionally, logistic regression models (ɑ = 0.05) were conducted to measure associations, demographic differences, the nature of the caregiving relationship, or caregiver needs for caregivers reporting subjective cognitive decline.

All statistical analyses followed BRFSS used complex survey weights, guidance, and instructions for weighting responses and were conducted using SAS statistical software, version 9.4 (SAS Institute Inc., Cary, NC). Approval from the University of South Carolina Institutional Review Board was granted on March 21, 2022. The study was categorized as "exempt status," as de-identified secondary data were utilized for this study.

## Results

Respondents were principally female (59.7%), non-Hispanic White (78.5%), evenly divided across the three age groups, and most were in a romantic relationship (67.3%). Additionally, the participants in the study had completed high school and/or technical school/some college (62.6%), were employed or retired (79.2%), and most of study subjects had an income level of

$75,000 or greater (32.7%). Also, the majority of the respondents had insurance (93.3%), and had at least one medical provider (81.8%).

In terms of caregiving, the respondents were mostly either the spouse/partner (26.7%) or the parent/grandparent (31.9%) to the person receiving care, had provided care for more than five years (32.4%), worked 8 hours or less providing care (56.0%), and had a relatively even distribution of providing ADLs (50.2% and 50.0%), and mostly provided assistance with IADLs (76.8%), and reported they did not need assistance (81.8%).

### ***Functional Impacts (ADLs and IADLs) of Self-Reported Subjective Cognitive Decline on Individuals Identifying as Caregivers***

The functional impacts and the specific issues reported (ADLs and IADLs) of subjective cognitive decline in individuals identifying as caregivers (n=2665) are shown in Table 4.1. Among caregivers who reported having subjective cognitive decline and memory loss/confusion, 53.0 % have given up daily household tasks, 49.5% need assistance with daily activities, and 8.3 % are able to access assistance with daily activities. More than half of caregivers (55.5%) reported memory loss/confusion has interfered with daily activities: work, volunteer, or social activities, and nearly half (48.1%) of caregivers have discussed memory loss with the physician.

### ***Type and Characteristics of Informal Caregivers***

Following the adapted framework to examine the type and characteristics of informal caregivers, we found female caregivers were less likely than male respondents to report experiencing subjective cognitive decline (11.7% versus 14.4%, p=.0005, Table 4.2). Caregivers not living together with a spouse or partner were more likely to report subjective cognitive decline than caregivers living with a spouse or partner (16.4% and 11.0%, p= <.0001, respectively). Additionally, caregivers who had not completed high school were more likely to report subjective cognitive decline (22.3%) than those caregivers who had completed college or technical school. Caregivers completing college or technical school were the least likely (8.5%) to report subjective cognitive decline (p= <.0001), About 37.5% of caregivers who were unable to work reported subjective cognitive decline compared to 8.3% of caregivers who were employed (p= <.0001). Caregivers reporting $75,000 in income or more were the least likely (7.1%) to report subjective cognitive decline, while caregivers reporting $25,000 or less were the most likely (22.1%) to report subjective cognitive decline (p= <.0001). Caregivers with more than one medical provider or no medical provider were more likely to report subjective cognitive decline when compared to caregivers with one medical provider (15.7%, 15.2%, and 12.2%, (p= <.0001), respectively). All other factors related to the type and characteristics of informal caregivers showed no statistically significant association with subjective cognitive decline.

Table 4.2 also shows the factors related to the nature of the caregiving relationship, continuing to follow the adapted Cho's adapted model. None of the factors showed any statistically significant association with subjective cognitive decline except for those caregivers providing care—ADLs. Caregivers providing care—ADLs were slightly more likely (13.6%) to report subjective cognitive decline compared to caregivers not providing ADLs (12.0%, p=.0331). Finally, when examining caregiver unmet needs-needed support, caregivers who reported needing individual counseling and classes about care were more likely (28% and 22.7%, respectively) to report subjective cognitive decline, while caregivers indicating no help needed were the least likely (11.2%) to report subjective cognitive decline (p= <.0001).

### *Unadjusted Model: Factors Associated with Reported Cognitive Decline Among Caregivers, Type and Characteristics of Informal Caregivers.*

Table 4.3 shows the factors associated with reported cognitive decline among caregivers guided by Cho's adapted theoretical framework. In the unadjusted model (Model 0), all the demographic characteristics based on the type and characteristics of informal caregivers were significantly associated with cognitive decline except age, race, and insurance coverage. For example, compared to female caregivers, male caregivers had 1.3 times the odds of reporting subjective cognitive decline. Additionally, caregivers who reported $75,000 or more were 23.0% less likely to report cognitive decline than caregivers who made $25,00 or less.

### *Nature of the Caregiving Relationship.*

The relationship to the care recipient and providing care-ADLs were the only factors describing the nature of the caregiving relationship as significantly associated with cognitive decline. For example, compared to caregivers of non-relatives of the care recipient to those who were parents or grandparents (OR= .82, 95% CI, 0.680-0.997, p <.05), spouses or mothers/fathers-in-law were less likely to report cognitive decline (OR= .82, 95% CI, 0.667-1.000, p <.05).

### ***Caregiver Unmet Needs.***

All factors associated with caregiver unmet needs were associated with cognitive decline except those caregivers who reported needing respite. Mainly, caregivers needing individual counseling had three times the odds of reporting cognitive decline as compared to those not needing any help in the unadjusted model.

### ***Adjusted Models for Factors Associated with Reported Cognitive Decline Among Caregivers***

In the model (Model 1) adjusted for the type and characteristics of informal caregivers, all demographic characteristics were statistically significantly associated with cognitive decline except for age, marital/relationship status, insurance coverage, and medical providers. Additionally, after adjusting for informal caregivers' type and characteristics, the results did not significantly alter the association between sex and cognitive decline. Also, only the comparison between Non-Hispanic White caregivers and Non-Hispanic African-American caregivers was significantly associated with cognitive decline, and no other racial categories differed from Non-Hispanic White. Specifically, compared to Non-

Hispanic White caregivers, Non-Hispanic African-American caregivers were 24.0% less likely to report subjective cognitive decline.

In the model adjusted for the type and characteristics of informal caregivers and the nature of the caregiving relationship (Model 2), all the demographic factors were significantly associated with subjective cognitive decline except age, marital/relationship status, insurance coverage, and medical providers, which differs only slightly compared to the previous model. Providing care-ADLs was the only factor related to the nature of the caregiving relationship significantly associated with cognitive decline. In particular, those caregivers providing care—ADLs had 1.2 times the odds of reported cognitive decline compared to those caregivers not providing care.

When examining the model (Model 3), adjusted for the type and characteristics of informal caregivers, the nature of the caregiving relationship, and caregiver unmet needs, insurance and age were now associated with cognitive decline after adjusting for all the other factors. Factors related to the nature of the caregiving relationship significantly associated with cognitive decline were hours per week providing care and providing care—ADLs.

Specifically, caregivers providing care for 8 hours a week were significantly associated with cognitive decline (OR=1.4, 95% CI, 1.104-1.798, $p < .05$)**.** All factors related to caregiver unmet needs had significant associations with cognitive decline except for those caregivers needing respite or support groups. Caregivers needing individual counseling had 3.4 times the odds of having a significant association with cognitive decline.

## Discussion

There are limited studies exploring the relationships between informal caregiving and subjective decline. As such, we believe this is the first study to explore the relationship of caregivers and subjective cognitive decline. While there is a great deal of research on caregiver burden and its consequences, there is limited research on this impairment in caregivers. Of the current studies specifically exploring cognitive decline in caregivers, most studies focus on care for individuals with dementia and/or Alzheimer's disease. Also, many of the studies were conducted in other countries and were centered around spousal dyads. The most recent US research, while related, does not explore the same elements based on a theoretical framework. We can surmise this research does corroborate the existing knowledge that caregiver burden and stress can negatively impact the caregiver and the quality of care an individual receives.

Firstly, we investigated the functional impacts of subjective cognitive decline on informal caregivers. We found that about half of the caregivers' daily lives were affected by subjective cognitive decline. Then the relationship between informal caregivers and subjective cognitive decline was explored; and we hypothesized there would be a difference in the demographic characteristics, the nature of the caregiving relationship, and caregiver unmet needs of caregivers who report subjective cognitive decline compared to caregivers who do not report any subjective cognitive decline. The findings suggest significant differences in demographic characteristics, the nature of the caregiving, and caregiver unmet needs. Of those caregivers reporting subjective decline, more than half of the respondents reported they had given up daily household tasks, needed assistance with daily activities, and interfered with daily activities: work, volunteer, or social activities, all due to memory loss/confusion. Also, nearly half of them had discussed their memory loss with their physician, which is interesting to note; however, almost all respondents reporting no cognitive decline also reported not being able to receive assistance when needed. We found among caregivers reporting subjective decline, there were associations between memory loss and the ability to complete daily tasks. Also, more females provide care, and more males report having cognitive decline, which is in support of the current literature on caregiving and subjective cognitive decline. These findings, particularly the strong associations, indicate caregivers may have experiences with subjective cognitive decline while providing care. A caregiver's current health condition can further suggest associations with subjective cognitive decline. As evidenced by this study, caregivers with cognitive decline are experiencing limitations in their own daily and social activities, which merits exploration of how those challenges might impact the care they are responsible for providing.

## Policy Implications

If caregivers are experiencing stress or burden then the care provided can be affected in both quality and safety. These findings support the need for further exploration of informal caregivers and, in this instance, subjective cognitive decline. According to AARP, public policies regarding eldercare and care for individuals with disabilities have not been responsive to the changing care landscape. The current caregiving model appears to be unsustainable—with longer lives, shorter hospitalizations, healthcare workforce shortages, the rising costs of care, and the shifting demographics require a focused nationwide approach (2020). Data shows that caregivers may not be focused on their own health and therefore may miss regular check-ups and screenings. Unfortunately, when care recipients have medical visits or assessments, they are the sole focus of the visit. Physicians and other healthcare workers do not receive payment for the caregiver unless the caregiver is the actual patient nor for patient education and training. The Family Caregiver Alliance has developed a "Family Caregiver Screening Toolkit: A Resource for Health Care Providers" as a response to the need for better caregiver screening (caregiving.org, nd). The failure to identify the care conditions and needs of the caregivers places both the care recipient and the caregiver at risk. It is vital to continue to explore their experiences and the consequences of caregiving. Effective interventions and policies cannot be developed without a complete understanding of the caregivers themselves.

The health care system must include caregiver health in the care plans of those care recipients, especially with chronic, long-term health concerns, including Alzheimer's and dementia. Care recipients with dementia-related conditions require more complex care over a longer period of time, and more formal care options might not be available due to costs and geographical location. The lack of a consistent, comprehensive nationwide approach to care provision means that states choose their level of involvement in meeting the unmet needs of both the recipient and the caregivers, so service availability differs from state to state (AARP, 2020). Some care recipients may be able to receive Medicaid, but the funding is limited based on eligibility requirements and the income of care recipient (AARP, 2020). Other policy areas include the need for workplace policies to support caregivers and programs or access to financial resources to offset the economic impacts of providing care (AARP, 2020). Additionally, ensuring the long-term availability of Social Security, paid family leave programs, caregiver education and screening are just some of the policies needing further exploration to ensure informal caregivers are supported in their work caring for loved ones. While the study illustrated a clear relationship between caregiving and subjective decline, the clear indication is that caregivers need assistance to provide quality care for themselves, and the family members and friends under their care, and the health care system must respond.

### *Limitations*

The study has several limitations. There is no causal relationship between caregiving and subjective cognitive decline because of the study's cross-sectional design. Also, the data from the BRFSS is all self-reported. As with all self-reported data, there may be issues with recalling or remembering information, and if participants have ideas about what are appropriate responses to questions, those attitudes can influence what and how the respondents decide to share. The BRFSS is administered at a point in time and contextualizes questions, for instance, "in the last 30 days" or "within the last 12 months, so that caregivers' status could have been different before or after those time frames.

## Conclusion

As the US population continues to age, providing care becomes a more significant and important issue. Informal caregivers are the quiet backbone of the care industry, sometimes isolated and invisible. While caregiving can be rewarding and purposeful, providing care can also negatively impact the caregiver. Caregiver burden is a collective term to describe the financial, physical, and mental difficulties some caregivers experience. One such difficulty is cognitive decline among the caregivers themselves. Informal caregiving typically occurs within familial relationships, for example, spousal or partner dyads and/or with the parent/child/grandparent dynamic. Subjective cognitive decline can have negative impacts on physical and mental health and inhibit the ability to complete everyday activities. There are significant implications for caregivers with subjective cognitive decline providing care—ADLs and IADLs to someone dealing with illness themselves. Having subjective cognitive decline can influence the quality of care and enhance safety complications for the care recipient. There are policy implications on multiple levels, for example, are clinicians/ physicians providing care, is the caregiver being asked about whether or not they are dealing with memory loss and need assistance. From a public health perspective, additional research is needed to further study the relationship between subjective cognitive decline and caregiving. There are several key questions needing additional study, is the care being received affected by the subjective cognitive decline; what additional resources are needed to support the caregivers, the intersection of informal caregiving, subjective cognitive decline, and caregiver health. Given the growing aging community, there is an imperative to explore the experiences of informal caregivers. Moreover, the findings also suggest a need for more comprehensive policy responses for ensuring caregiver health.

Table 4.1. Functional Self-Reported Effects (ADLs and IADLs) of Cognitive Decline on Individuals Identifying as Caregivers: Behavioral Risk Factor Surveillance System (BRFSS) Participants, 2015-2018

**Caregivers with Subjective Cognitive Decline (n=2665)**

| **Functional Impact of Subjective Cognitive Decline** | | **Observations** | **Weighted Column Percent** | **Weighted Standard Error of Column Percent** |
|---|---|---|---|---|
| **Characteristics of Functional Impact of Subjective Cognitive Decline** | | | | |
| **Given Up Daily Household Tasks (Due to Memory Loss/Confusion)** | | | | |
| | Yes | 1413 | 53.0 | 1.5 |
| | Never | 1221 | 47.0 | 1.5 |
| **Needs Assistance with Daily Activities (Due to Memory Loss/Confusion)** | | | | |
| | Yes | 1288 | 49.5 | 1.5 |
| | Never | 1354 | 50.5 | 1.5 |
| **Ability to Access Assistance with Daily Activities** | | | | |
| | Yes | 73 | 8.3 | 1.2 |
| | Never | 730 | 91.7 | 1.2 |
| **Interference with Daily Activities: Work, Volunteer, or Social Activities** | | | | |
| | Yes | 1425 | 55.5 | 1.5 |
| | Never | 1205 | 44.5 | 1.5 |
| **Discussed Memory Loss with Physician** | | | | |
| | Yes | 1299 | 48.1 | 1.5 |
| | Never | 1421 | 51.9 | 1.5 |

Table 4.2. Characteristics of Caregivers, by Cognitive Decline Status: Behavioral Risk Factor Surveillance System (BRFSS) Participants, 2015-2018

| | **Cognitive Decline (n=2665)** | | | **No Cognitive Decline (n=18608)** | | | **Total (n=21273)** | | | **P-value*** |
|---|---|---|---|---|---|---|---|---|---|---|
| | Observations | Weighted Row Percent | Weighted Standard Error of Row Percent | Observations | Weighted Row Percent | Weighted Standard Error of Row Percent | Observations | Weighted Column Percent | Weighted Standard Error of Column Percent | |
| Female | 1593 | 11.7 | 0.5 | 12171 | 88.3 | 0.5 | 13764 | 59.7 | 0.6 | **0.0005** |
| Male | 1071 | 14.4 | 0.6 | 6435 | 85.6 | 0.6 | 7506 | 40.3 | 0.6 | |
| 25-54 | 730 | 13.3 | 0.7 | 4603 | 86.7 | 0.7 | 5333 | 34.1 | 0.6 | 0.4714 |
| 55-64 | 921 | 12.2 | 0.7 | 6540 | 87.8 | 0.6 | 7461 | 34.0 | 0.6 | |
| 65 and over | 1014 | 12.9 | 0.7 | 7465 | 87.1 | 0.7 | 8479 | 32.0 | 0.5 | |
| Non-Hispanic White | 1970 | 12.6 | 0.4 | 14345 | 87.4 | 0.4 | 16315 | 78.5 | 0.5 | 0.2751 |
| Non-Hispanic African-American | 302 | 12.9 | 1.1 | 1936 | 87.2 | 1.1 | 2238 | 11.8 | 0.4 | |
| Non-Hispanic American Indian or Alaskan Native | 62 | 18.2 | 4.2 | 207 | 81.7 | 4.2 | 269 | 1.04 | 0.1 | |

| | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|
| Non-Hispanic Asian, Native Hawaiian, or Pacific Islander | 87 | 11.1 | 2.9 | 628 | 88.9 | 2.9 | 715 | 2.5 | 0.2 | |
| Non-Hispanic Multiracial and Other | 135 | 16.9 | 2.9 | 778 | 83.1 | 2.9 | 913 | 2.26 | 0.1 | |
| Hispanic | 72 | 15.4 | 2.3 | 437 | 84.6 | 2.3 | 509 | 3.9 | 0.4 | |
| **Marital/Relationship Status** | | | | | | | | | | |
| | 1515 | 11.0 | 0.4 | 11936 | 89.0 | 0.4 | 13451 | 67.3 | 0.6 | **<.0001** |
| | 1137 | 16.4 | 0.8 | 6568 | 83.6 | 0.8 | 7705 | 32.7 | 0.6 | |
| **Educational Attainment** | | | | | | | | | | |
| Not Completed High School | 289 | 22.3 | 1.8 | 991 | 77.7 | 1.8 | 1280 | 10.0 | 0.4 | **<.0001** |
| Completed High School | 822 | 12.8 | 0.6 | 5098 | 87.2 | 0.6 | 5920 | 29.9 | 0.6 | |
| Some Technical School/College | 856 | 13.5 | 0.7 | 5482 | 86.5 | 0.7 | 6338 | 32.7 | 0.6 | |
| Completed Technical School/College | 693 | 8.5 | 0.5 | 7006 | 91.5 | 0.5 | 7699 | 27.5 | 0.5 | |

| | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|
| **Employment Status** | | | | | | | | | | |
| Employed | 745 | 8.3 | 0.5 | 8456 | 91.7 | 0.5 | 9201 | 48.1 | 0.6 | **<.0001** |
| Unemployed | 180 | 18.8 | 2.1 | 750 | 81.2 | 2.1 | 930 | 5.2 | 0.3 | |
| Homemaker | 125 | 9.3 | 1.2 | 1034 | 90.1 | 1.2 | 1159 | 6.0 | 0.3 | |
| Retired | 915 | 11.9 | 0.6 | 6994 | 88.1 | 0.6 | 7909 | 31.1 | 0.5 | |
| Unable to Work | 687 | 37.5 | 1.7 | 1273 | 62.5 | 1.7 | 1960 | 9.6 | 0.3 | |
| **Income** | | | | | | | | | | |
| Less than $25K | 966 | 22.1 | 1.0 | 3820 | 77.9 | 1.0 | 4786 | 25.5 | 0.6 | **<.0001** |
| $26K to Less than $50K | 589 | 12.5 | 0.8 | 4250 | 87.5 | 0.8 | 4839 | 25.2 | 0.6 | |
| $50K to Less than $75K | 336 | 11.2 | 1.0 | 2801 | 88.8 | 1.0 | 3137 | 16.6 | 0.5 | |
| Greater than $75K | 408 | 7.1 | 0.6 | 5060 | 93.0 | 0.6 | 5468 | 32.7 | 0.6 | |
| **Any Type of Insurance Coverage** | | | | | | | | | | |
| Have Coverage | 2461 | 12.7 | 0.4 | 17501 | 87.3 | 0.4 | 19962 | 93.3 | 0.3 | 0.1443 |
| No Coverage | 198 | 14.7 | 1.4 | 1077 | 85.2 | 1.4 | 1275 | 6.7 | 0.3 | |

| | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|
| **Medical Provider** | | | | | | | | | | |
| One Provider | 2035 | 12.2 | 0.4 | 15206 | 87.8 | 0.4 | 17241 | 81.8 | 0.5 | **<.0001** |
| More than One Provider | 379 | 15.7 | 1.2 | 1736 | 84.3 | 1.2 | 2115 | 8.8 | 0.3 | |
| No Provider | 246 | 15.2 | 1.5 | 1621 | 84.8 | 1.5 | 1867 | 9.4 | 0.3 | |
| **Factors Describing the Nature of Caregiving Relationship** | | | | | | | | | | |
| **Relationship to Care Recipient** | | | | | | | | | | |
| Parent/Grandparent | 675 | 11.9 | 0.7 | 5697 | 88.1 | 0.7 | 6372 | 31.9 | 0.6 | 0.1328 |
| Spouse, Partner, or M/F in-law | 699 | 12.0 | 0.7 | 4969 | 88.0 | 0.7 | 5668 | 26.7 | 0.5 | |
| Sibling or B/S in-law | 255 | 13.8 | 1.2 | 1659 | 86.2 | 1.2 | 1914 | 8.7 | 0.3 | |
| Child/Grandchild | 296 | 14.2 | 1.2 | 1733 | 85.8 | 1.2 | 2029 | 10.2 | 0.4 | |
| Other Relative | 189 | 14.4 | 1.7 | 1210 | 85.6 | 1.7 | 1399 | 6.6 | 0.3 | |
| Non-Relative | 540 | 14.2 | 0.9 | 3175 | 85.8 | 0.9 | 3715 | 16.0 | 0.4 | |
| **Length of Time Providing Care** | | | | | | | | | | |
| Less than 30 Days | 442 | 11.9 | 0.9 | 3288 | 88.1 | 0.9 | 3730 | 17.4 | 0.5 | 0.4148 |

| | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|
| 1 Month to Less than 6 Months | 306 | 12.3 | 1.1 | 2183 | 87.7 | 1.1 | 2489 | 11.1 | 0.3 | |
| 6 Months to Less than 2 Years | 500 | 13.5 | 1.0 | 3450 | 86.5 | 1.0 | 3950 | 18.9 | 0.5 | |
| 2 Years to Less than 5 Years | 532 | 12.0 | 0.7 | 3921 | 88.0 | 0.7 | 4453 | 20.1 | 0.4 | |
| More than 5 Years | 836 | 13.5 | 0.7 | 5466 | 86.5 | 0.7 | 6302 | 32.4 | 0.6 | |
| **Hours per Week Providing Care** | | | | | | | | | | |
| 8 Hours or Less | 1355 | 12.6 | 0.5 | 10050 | 87.4 | 0.5 | 11405 | 56.0 | 0.6 | 0.4144 |
| 9 to 19 Hours | 337 | 12.1 | 0.9 | 2221 | 87.9 | 0.9 | 2558 | 12.8 | 0.4 | |
| 20 to 39 Hours | 280 | 13.2 | 1.1 | 1747 | 86.7 | 1.1 | 2027 | 10.8 | 0.4 | |
| 40 Hours or more | 518 | 14.0 | 0.9 | 3352 | 86.0 | 0.9 | 3870 | 20.3 | 0.5 | |
| **Provide Care—giving medications, feeding, dressing, or bathing (ADLs)#** | | | | | | | | | | |
| Yes | 1318 | 13.6 | 0.6 | 8929 | 86.4 | 0.6 | 10247 | 50.2 | 0.6 | **0.0331** |
| No | 1329 | 12.0 | 0.5 | 9560 | 88.0 | 0.5 | 10889 | 50.0 | 0.6 | |

|  |  |  |  |  |  |  |  |  |  |  |
|---|---|---|---|---|---|---|---|---|---|---|
| **Provide Care—managing household tasks-cleaning, managing money, or preparing meals (IADLs)[##]** |  |  |  |  |  |  |  |  |  |  |
| Yes | 2024 | 13.0 | 0.4 | 14106 | 87.0 | 0.4 | 16130 | 76.8 | 0.5 | 0.2350 |
| No | 622 | 12.0 | 0.7 | 4393 | 88.0 | 0.7 | 5015 | 23.2 | 0.5 |  |
| **Factors Describing Caregiver Unmet Needs** |  |  |  |  |  |  |  |  |  |  |
| **Support Needed for Caregivers** |  |  |  |  |  |  |  |  |  |  |
| Classes about Care | 64 | 22.7 | 3.6 | 226 | 77.3 | 3.6 | 290 | 1.3 | 0.1 | **<.0001** |
| Help Access to Services | 365 | 18.7 | 1.3 | 1505 | 81.3 | 1.3 | 1870 | 9.7 | 0.4 |  |
| Individual Counseling | 97 | 28.0 | 3.4 | 307 | 72.0 | 3.4 | 404 | 1.9 | 0.1 |  |
| Support Groups | 111 | 15.9 | 2.1 | 473 | 84.1 | 2.1 | 584 | 2.7 | 0.2 |  |
| Respite | 84 | 14.1 | 2.1 | 538 | 85.9 | 2.1 | 622 | 2.6 | 0.2 |  |
| No Help Needed | 1820 | 11.2 | 0.4 | 15017 | 88.8 | 0.4 | 16837 | 81.8 | 0.4 |  |

*Bold indicates a significant P-value at an alpha level of 0.05

[#] ADLs are defined as Activities of Daily Living

[##] IADLs are defined as Instrumental Activities of Daily Living

Table 4.3. Logistic Regression--Factors Associated with Reported Cognitive Decline Among Caregivers: Behavioral Risk Factor Surveillance System (BRFSS) Participants, 2015-2018

| | **Model 0: Unadjusted Model** | | | **Model 1: Adjusted for Type and Characteristics of Informal Caregivers†** | | | **Model 2: Adjusted for Type and Characteristics of Informal Caregivers† and Nature of the Caregiving Relationship††** | | | **Model 3: Adjusted for Type and Characteristics of Informal Caregivers†, the Nature of the Caregiving Relationship††, and Caregiver Unmet Needs†††** | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| **Demographic Characteristics of Caregivers** | **OR** | **95% CI** | **P-Value*** | **OR** | **95% CI** | **P-Value*** | **OR** | **95% CI** | **P-Value*** | **OR** | **95% CI** | **P-Value*** |
| **Sex** | | | | | | | | | | | | |
| Male vs. Female | **1.271** | **1.111-1.455** | **0.0005** | **1.280** | **1.092-1.500** | **0.0023** | **1.266** | **1.072-1.495** | **0.0053** | **1.253** | **1.055-1.488** | **0.0101** |
| **Age** | | | | | | | | | | | | |
| 25-54 vs. 65 and over | 1.041 | 0.880-1.233 | 0.6371 | 1.021 | 0.776-1.344 | 0.8808 | 1.000 | 0.744-1.343 | 0.9984 | 0.910 | 0.672-1.233 | 0.5438 |
| 55-64 vs. 65 and over | 0.942 | 0.806-1.101 | 0.4496 | 0.838 | 0.664-1.059 | 0.1385 | 0.788 | 0.614-1.011 | 0.0614 | **0.728** | **0.563-0.942** | **0.0159** |

| | | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| **Race** | | | | | | | | | | | | |
| Non-Hispanic African-American vs. Non-Hispanic White | 1.022 | 0.836-1.250 | 0.8323 | **0.762** | **0.601-0.966** | **0.0246** | **0.742** | **0.578-0.953** | **0.0196** | **0.731** | **0.565-0.944** | **0.0165** |
| Non-Hispanic American Indian or Alaskan Native vs. Non-Hispanic White | 1.555 | 0.889-2.719 | 0.1217 | 1.056 | 0.530-2.107 | 0.8762 | 1.114 | 0.555-2.254 | 0.7630 | 1.061 | 0.512-2.198 | 0.8736 |
| Non-Hispanic Asian, Native Hawaiian, or Pacific Islander vs. Non-Hispanic White | 0.867 | 0.488-1.541 | 0.6262 | 1.125 | 0.574-2.204 | 0.7317 | 1.054 | 0.525-2.116 | 0.8815 | 1.023 | 0.495-2.111 | 0.9518 |
| Non-Hispanic Multiracial and Other vs. Non-Hispanic White | 1.412 | 0.939-2.123 | 0.0973 | 1.323 | 0.827-2.115 | 0.2427 | 1.303 | 0.799-2.126 | 0.2890 | 1.262 | 0.753-2.113 | 0.3770 |
| Hispanic vs. Non-Hispanic White | 1.262 | 0.879-1.813 | 0.2072 | 0.943 | 0.637-1.394 | 0.7676 | 1.000 | 0.674-1.484 | 0.9993 | 0.835 | 0.552-1.263 | 0.3934 |
| **Marital/Relationship Status** | | | | | | | | | | | | |
| Living Together vs. Not Living Together | **0.628** | **0.546-0.723** | **<.0001** | 0.904 | 0.748-1.092 | 0.2965 | 0.943 | 0.767-1.159 | 0.5779 | 0.895 | 0.725-1.106 | 0.3044 |

| | | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| **Educational Attainment** | | | | | | | | | | | | |
| Completed High School vs. Not Completed High School | **0.510** | **0.403-0.644** | **<.0001** | 0.745 | 0.549-1.011 | 0.0591 | 0.755 | 0.548-1.039 | 0.0846 | 0.760 | 0.541-1068 | 0.1144 |
| Some Technical School/College vs. Not Completed High School | **0.544** | **0.431-0.687** | **<.0001** | 0.859 | 0.630-1.172 | 0.3389 | 0.846 | 0.610-1.171 | 0.3131 | 0.810 | 0.573-1.144 | 0.2318 |
| Completed Technical School/College vs. Not Completed High School | **0.322** | **0.252-0.411** | **<.0001** | **0.688** | **0.484-0.977** | **0.0368** | 0.701 | 0.484-1.014 | 0.0594 | **0.661** | **0.447-0.979** | **0.0389** |
| **Employment Status** | | | | | | | | | | | | |
| Unemployed vs. Employed | **2.579** | **1.913-3.476** | **<.0001** | **2.078** | **1.477-2.922** | **<.0001** | **2.185** | **1.554-3.072** | **<.0001** | **2.260** | **1.589-3.215** | **<.0001** |
| Homemaker vs. Employed | 1.132 | 0.824-1.555 | 0.4433 | 1.178 | 0.812-1.708 | 0.3873 | 1.097 | 0.741-1.624 | 0.6437 | 1.027 | 0.699-1.510 | 0.8926 |
| Retired vs. Employed | **1.502** | **1.271-1.776** | **<.0001** | 1.243 | 0.960-1.608 | 0.0986 | 1.243 | 0.961-1.608 | 0.0981 | 1.206 | 0.924-1.574 | 0.1686 |
| Unable to Work vs. Employed | **6.672** | **5.491-8.107** | **<.0001** | **4.752** | **3.736-6.045** | **<.0001** | **4.666** | **3.636-5.987** | **<.0001** | **4.586** | **3.539-5.943** | **<.0001** |

|  |  |  |  |  |  |  |  |  |  |  |  |  |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| **Income** |  |  |  |  |  |  |  |  |  |  |  |  |
| $26K to Less than $50K vs. Less than $25K | **0.502** | **0.419-0.601** | **<.0001** | **0.755** | **0.609-0.935** | **0.0099** | **0.753** | **0.605-0.937** | **0.0111** | **0.768** | **0.614-0.961** | **0.0207** |
| $50K to Less than $75K vs. Less than $25K | **0.446** | **0.355-0.561** | **<.0001** | **0.738** | **0.564-0.967** | **0.0276** | **0.722** | **0.547-0.952** | **0.0210** | 0.761 | 0.572-1.012 | 0.0606 |
| Greater than $75K vs. Less than $25K | **0.269** | **0.220-0.330** | **<.0001** | **0.503** | **0.380-0.667** | **<.0001** | **0.473** | **0.351-0.638** | **<.0001** | **0.504** | **0.371-0.684** | **<.0001** |
| **Any Type of Insurance Coverage** |  |  |  |  |  |  |  |  |  |  |  |  |
| Have Coverage vs. No Coverage | 0.839 | 0.663-1.062 | 0.1445 | 1.343 | 0.989-1.824 | 0.0585 | 1.342 | 0.978-1.840 | 0.0685 | **1.408** | **1.013-1.957** | **0.0414** |
| **Medical Provider** |  |  |  |  |  |  |  |  |  |  |  |  |
| One Provider vs. No Provider | **0.779** | **0.612-0.991** | **0.0421** | 0.812 | 0.600-1.099 | 0.1776 | 0.819 | 0.598-1.122 | 0.2131 | 0.824 | 0.589-1.152 | 0.2568 |
| More than One Provider vs. No Provider | 1.040 | 0.779-1.388 | 0.7928 | 0.944 | 0.659-1.353 | 0.7552 | 0.954 | 0.658-1.384 | 0.8040 | 0.988 | 0.669-1.461 | 0.9532 |

**Factors Describing the Nature of Caregiving Relationship**

| | | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| **Relationship to Care Recipient** | | | | | | | | | | | | |
| Parent/Grandparent vs. Non-Relative | **0.817** | **0.667-1.000** | **0.0496** | | | | 0.883 | 0.678-1.151 | 0.3566 | 0.902 | 0.684-1.188 | 0.4618 |
| Spouse or M/F in-law vs. Non-Relative | **0.823** | **0.680-0.997** | **0.0462** | | | | 0.806 | 0.613-1.060 | 0.1222 | 0.851 | 0.640-1.133 | 0.2696 |
| Sibling or B/S in-law vs. Non-Relative | 0.967 | 0.758-1.235 | 0.7898 | | | | 0.895 | 0.660-1.214 | 0.4762 | 0.899 | 0.656-1.231 | 0.5055 |
| Child/Grandchild vs. Non-Relative | 1.000 | 0.787-1.272 | 0.9983 | | | | 1.021 | 0.747-1.397 | 0.8944 | 0.990 | 0.715-1.369 | 0.9494 |
| Other Relative vs. Non-Relative | 1.016 | 0.745-1.385 | 0.9208 | | | | 1.022 | 0.702-1.487 | 0.9111 | 1.040 | 0.704-1.538 | 0.8423 |
| **Length of Time Providing Care** | | | | | | | | | | | | |
| Less than 30 Days vs. More than 5 Years | 0.862 | 0.704-1.054 | 0.1471 | | | | 0.855 | 0.661-1.106 | 0.2322 | 0.895 | 0.686-1.167 | 0.4120 |
| 1 Month to Less than 6 Months vs. More than 5 Years | 0.897 | 0.707-1.138 | 0.3713 | | | | 0.951 | 0.711-1.271 | 0.7329 | 0.907 | 0.671-1.226 | 0.5263 |
| 6 Months to Less than 2 Years vs. More than 5 Years | 0.998 | 0.815-1.221 | 0.9825 | | | | 1.091 | 0.860-1.383 | 0.4739 | 1.068 | 0.835-1.365 | 0.6020 |
| 2 Years to Less than 5 Years vs. More than 5 Years | 0.870 | 0.729-1.039 | 0.1241 | | | | 0.937 | 0.757-1.161 | 0.5539 | 0.902 | 0.723-1.125 | 0.3598 |

**Hours per Week Providing Care**

| | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|
| 8 Hours or Less vs. 40 Hours or More | 0.884 | 0.739-1.058 | 0.1789 | 1.259 | 0.997-1.590 | 0.0531 | **1.409** | **1.104-1.798** | **0.0059** |
| 9 to 19 Hours vs. 40 Hours or More | 0.846 | 0.676-1.059 | 0.1451 | 1.049 | 0.800-1.375 | 0.7286 | 1.111 | 0.840-1.469 | 0.4601 |
| 20 to 39 Hours vs. 40 Hours or More | 0.939 | 0.738-1.196 | 0.6102 | 1.059 | 0.813-1.379 | 0.6729 | 1.069 | 0.808-1.414 | 0.6404 |

**Provide Care-giving medications, feeding, dressing, or bathing (ADLs)[#]**

| | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|
| Yes vs. No | **1.156** | **1.011-1.322** | **0.0334** | **1.244** | **1.040-1.489** | **0.0170** | **1.248** | **1.034-1.506** | **0.0207** |

**Provide Care-managing household tasks-cleaning, managing money, or preparing meals (IADLs)[##]**

| | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|
| Yes vs. No | 1.099 | 0.940-1.284 | 0.2356 | 1.166 | 0.945-1.438 | 0.1522 | 1.184 | 0.950-1.475 | 0.1331 |

**Factors Describing Caregiver Unmet Needs**

| | | | | | | |
|---|---|---|---|---|---|---|
| **Support Needed for Caregivers** | | | | | | |
| Classes about Care vs. No Help Needed | **2.338** | **1.557-3.509** | **<.0001** | **2.596** | **1.557-4.327** | **0.0003** |
| Help Access to Services vs. No Help Needed | **1.826** | **1.505-2.216** | **<.0001** | **1.698** | **1.346-2.141** | **<.0001** |
| Individual Counseling vs. No Help Needed | **3.091** | **2.194-4.354** | **<.0001** | **3.386** | **2.234-5.131** | **<.0001** |
| Support Groups vs. No Help Needed | **1.506** | **1.091-2.077** | **0.0127** | 1.288 | 0.901-1.840 | 0.1648 |
| Respite vs. No Help Needed | 1.307 | 0.920-1.857 | 0.1355 | 1.142 | 0.901-2.232 | 0.1314 |

*Bold indicates a significant P-value at an alpha level of 0.05

[#] ADLs are defined as Activities of Daily Living

[##] IADLs are defined as Instrumental Activities of Daily Living

[†] Type and Characteristics of Informal Caregivers include: age, sex, race, gender, marital/relationship status, education, employment, income, medical providers, insurance coverage

[††] Nature of the Caregiving Relationship includes: the caregiver's relationship to the care recipient and the direct care provided to the care recipient

[†††] Caregiver Unmet Needs include: assistance a caregiver may need but is not receiving

# CHAPTER 5

## MANUSCRIPT TWO

## HEALTH-RELATED OUTCOMES FOR CAREGIVERS WITH COGNITIVE DECLINE

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# ABSTRACT

*Purpose.* The United States is experiencing unprecedented demographic shifts as the population continues to age. More than 53 million Americans are caregivers and that number is continuing to grow. Caregiving has become a significant societal and public health issue to be addressed. The purpose of this research was to provide a population-based national perspective to examine whether caregivers who report cognitive decline have worse health status than other caregivers.

*Methods.* The study used the Behavioral Risk Factor Surveillance System (BRFSS) years 2015-2018 pooled to gather information about caregivers and subjective cognitive decline. We conducted chi-square tests ($\alpha = 0.05$) to measure differences in the health-related outcomes of caregivers reporting or not reporting cognitive decline. Next logistic regression models ($\alpha = 0.05$) were used to measure associations of health-related outcomes with reported cognitive decline among caregivers.

*Results.* The findings conclude there is an association between caregivers with subjective cognitive decline and reported poorer health outcomes. This is a significant finding as caregivers are providing care ADLs (personal care, such as feeding, bathing, dressing, toileting, and transferring) and IADLs (related to care and function, including medication management, scheduling, and if required, transportation to medical visits, shopping, housekeeping, money and household

financial management, meal preparation, transportation, and communications) to the recipient in various stages of health.

*Conclusion.* As evidenced by this study, caregivers with cognitive decline are experiencing poorer health outcomes, which merits exploration of how those outcomes might impact the care being provided. Moreover, these findings support the need for further exploration of informal caregivers and in this instance, subjective cognitive decline. The health care system must include caregiver health in the care plans of care recipients and policies need to be developed to support the work of the caregiver or the current model will continue at its current unsustainable pace.

## Introduction

Caregiving, particularly by unpaid family members or friends is an important trend deserving of exploration. Van Durme, et al. (2012) reported that caregiving and the role of caregivers are important issues at the political, sociological, and economic levels. The AARP Public Policy Institute in Valuing the Invaluable: 2020 reports the estimated economic value of $470 billion in 2017 for unpaid caregiving. The aging US population is increasing both the importance and need for informal caregivers (family members, spouses, siblings, children, parents, etc. that provide unpaid care (AARP, 2020). According to Jeffers et al. (2021), informal caregivers make up about 20% of adults in the US. Before the advent of medical technologies and medications, like antibiotics, for instance, life expectancy in the US was about 45-50 years old (Talley and Crews, 2007, Schulz et al., 2018). Talley and Crews (2007) note further the increase in life expectancy, which is currently nearly 80 years old. With longer life expectancies, there are large segments of the population moving into advanced age; thus, caregiving has become more frequent and requires a longer commitment. Advancements in medical technology and diseases being more chronic, as opposed to acute infections, have resulted in not only individuals living longer but also a reshaping of caregiving needs and requirements. Talley and Crews (2007), Choi and Seo (2019), Kasper et al. (2015), as well as other studies, state that the need for caregiving is not only a function of an aging population but also related to the costs and shortages in healthcare.

Caregiving can be emotionally, financially, and physically demanding. Informal caregiving provides opportunities for individuals who are aging and/or have a chronic illness to receive care at home. Caregivers are often responsible for providing physical care and maintenance, emotional support, and social interaction for those in their care, often at the expense of their own health and need for social activities (Bastarowos, 2013). If caregivers have significant social support within their families and the community, the impact of the stress and anxiety, caregiver burden, is lessened, but without that support, the effects on the health, financial, and psychological well-being of caregivers can be severely compromised. How caregivers are able to manage their own experiences and health has an effect on the care they are able to provide as well (Bastarowos, 2013).

Caregiving is not a new phenomenon. Families have been the primary caregivers, particularly of aging parents or spouses since the beginning of time. In *Valuing the Invaluable* (2019), the challenges with caregiving now are "more complex, costly, stressful, and demanding than any other time in human history (p. 6)," and the challenges are related to the constant and everchanging pace of social, health and financial issues. Informal caregiving is an unpaid role, and while many may find it emotionally fulfilling, it is also difficult. The systems engaged in caregiving, health care, social services, etc., are notoriously hard to navigate, leaving many caregivers trying to figure out where and how to get help and, at a minimum, what to do (Valuing the Invaluable, 2019). *Valuing the*

*Invaluable* (2019) reports a study that found 9 in 10 individuals with middle-income in the midlife stage of life reported being a caregiver was significantly more challenging than anticipated and requiring more time, patience, and emotional stability than was initially thought. The *Valuing the Invaluable* report continues by describing "family caregivers as an 'invisible, isolated army' carrying out increasingly complicated tasks and experiencing challenges and frustrations without adequate recognition, support, or guidance, and at great personal cost (p.5)."

Even though caregivers are intimately and extensively involved in the daily care of the care recipients, caregivers are not usually recognized by healthcare providers and/or payers (Schulz et al., 2018). The system is not actively assessing the needs, capabilities, and well-being nor acknowledging how intertwined and interdependent the lives of care recipients are with the caregivers (Valuing the Invaluable, 2015).

## Caregiving and Physical Health

Caregiving has been shown to influence physical health negatively. Studies report issues such as fatigue, back issues, low appetite, and insomnia. Often caregivers forgo their own self-care, health maintenance, and treatment for their own health conditions when caregiving (Sullivan & Miller, 2015; Choi and Seo, 2019). The CDC (2020) reports 17.6% of those identified as caregivers experienced 14 or more physically unhealthy days within the last 30 days.

Caregivers are frequently required to complete physical tasks, such as transferring the care recipient to locations, bathing, dressing, or basic lifting.

Most caregivers have not received any formal training in how to safely complete their necessary care tasks, which may increase the risk for injuries (Sullivan & Miller, 2015). If caregivers find it difficult to manage their own care, it is likely they are also not being proactive about their health in general, which can have negative impacts on the caregivers' quality of life (Choi and Seo, 2019; Sullivan & Miller, 2015).

### Caregiving and Physiological and Mental Health

Positive responses to caregiving are related to caregivers feeling their role has given their lives meaning and purpose. Yet, in many caregivers, those positive perspectives occur simultaneously with stress and strain (AARP, 2020). Caregiving can be rewarding, but over time the decline in the recipient's condition, financial strain and stress, and isolation can present significant challenges (Sullivan and Miller, 2015). Among current studies, caregivers are dealing with depression or anxiety (Choi and Seo, 2019; Riffin et al., 2018). A particular struggle unique to the caregiving experiences is anticipatory grief, which also contributes to depression and anxiety. Also, anticipatory grief can last the length of the caregiving duration, which can last years (Choi and Seo, 2019; Sullivan and Miller, 2015). Increased stress, depression, and anxiety can lead to other illnesses, such as cognitive impairment, particularly in spouses caring for a spouse with dementia, Alzheimer's disease, and related diseases (Vitaliano et al., 2009; Dassel et al. 2017).

## Caregiving and Subjective Cognitive Decline and Cognitive Impairment

The CDC (2019) defines cognitive decline as a broad term encompassing impairment related to brain processes. Cognitive decline can be mild or as advanced as dementia and/or Alzheimer's disease. Cognitive decline is characterized by impairment in the "ability to learn, remember, and make judgments" (p.1). *Subjective Cognitive Decline* refers to individuals self-reporting experiencing issues with memory or other cognitive processes (CDC, 2019).

Cognitive impairment is characterized by problems up to the inability to learn, remember, and make decisions or judgments. Impairment can significantly influence one's health and well-being (CDC, 2019).

Cognitive impairment can occur in individuals with chronic diseases, especially those not managed well (CDC, 2020). It is not uncommon for caregivers to forgo their own care, which can place them at higher risk for cognitive impairment and challenges with pre-existing conditions (Dassell, 2017). Also, the stress related to caregiving is linked to poor health outcomes, and cognitive impairment may result (AARP, 2019; Choi and Seo, 2019; Schulz et al., 2018). Physical and psychological health may be compromised when the caregiving needs are high-intensity and long-lasting (Schulz et al., 2018). While there is a great deal of research on caregiver burden and its consequences, there is limited research on subjective cognitive impairment in caregivers.

The purpose of this study is to assess whether caregivers who reported subjective cognitive decline have worse health status—general, physical, and mental health than other caregivers. When compared to caregivers without subjective cognitive decline, are the  caregivers who reported subjective cognitive decline differing in their health status?

## Methodology

### *Theoretical Model*

The analysis is grounded in an adapted model of Cho's (2007) proposed framework for evaluating the effects of informal caregiving on health-related outcomes for elderly care recipients (Figure 1). Since caregiving and receiving care are parallel processes affecting the individual providing care and the individual receiving care, the adapted model shifts the focus from care recipients to caregivers. The elements of the model developed by Cho are (1) Type of Informal Caregivers, (2) Nature of Caregiving Relationship, (3) Caregiving, (4) Internal Processes of a Care Recipient, which ultimately impacts the (5) Health-Related Outcomes of a Care Recipient.

This study will focus on caregivers' experiences and will use an adapted version of Cho's model: Adapted Framework Addressing the Experiences of Informal Caregivers on their own Health-Related Outcomes (Figure 5.2). Both caregivers and care recipients are experiencing life changes simultaneously and can experience significant changes in their health outcomes. The elements of Cho's model have been adapted and redefined to examine the caregiver's perspective. The elements in the new model are (1) Type and Characteristics of Informal Caregivers, (2) Nature of the Caregiving Relationship, (3) Caregiver Unmet Needs, (4) Internal Processes of Caregiver (Caregiver Burden), which leads to the (5) Health-Related Outcomes of a Caregiver (Figure 2). The literature on caregiving informed the adapted definitions (CDC, 2019, 2020, Cook and Cohen, 2018, Bastarowas, 2013, Choi and Seo, 2019, Leow and Chan, 2011).

The purpose is to provide a population-based national perspective regarding informal caregivers to identify differences between caregivers' self-reporting cognitive decline and those caregivers' self-reporting no cognitive decline in health outcomes. Using the adapted framework, we examined the type and characteristics of informal caregivers, the nature of the caregiving relationship, caregiver unmet needs, and health-related outcomes, and compared those elements with caregivers who report experiencing subjective cognitive decline compared to those who do not report any subjective cognitive decline. We hypothesize that caregivers without cognitive decline will report better health status than caregivers with cognitive decline.

### ***Data Sources***

We used the Behavioral Risk Factor Surveillance System (BRFSS) years 2015-2018 pooled to gather information about caregivers and caregivers reporting subjective cognitive decline. The BFRSS is collected via landlines,

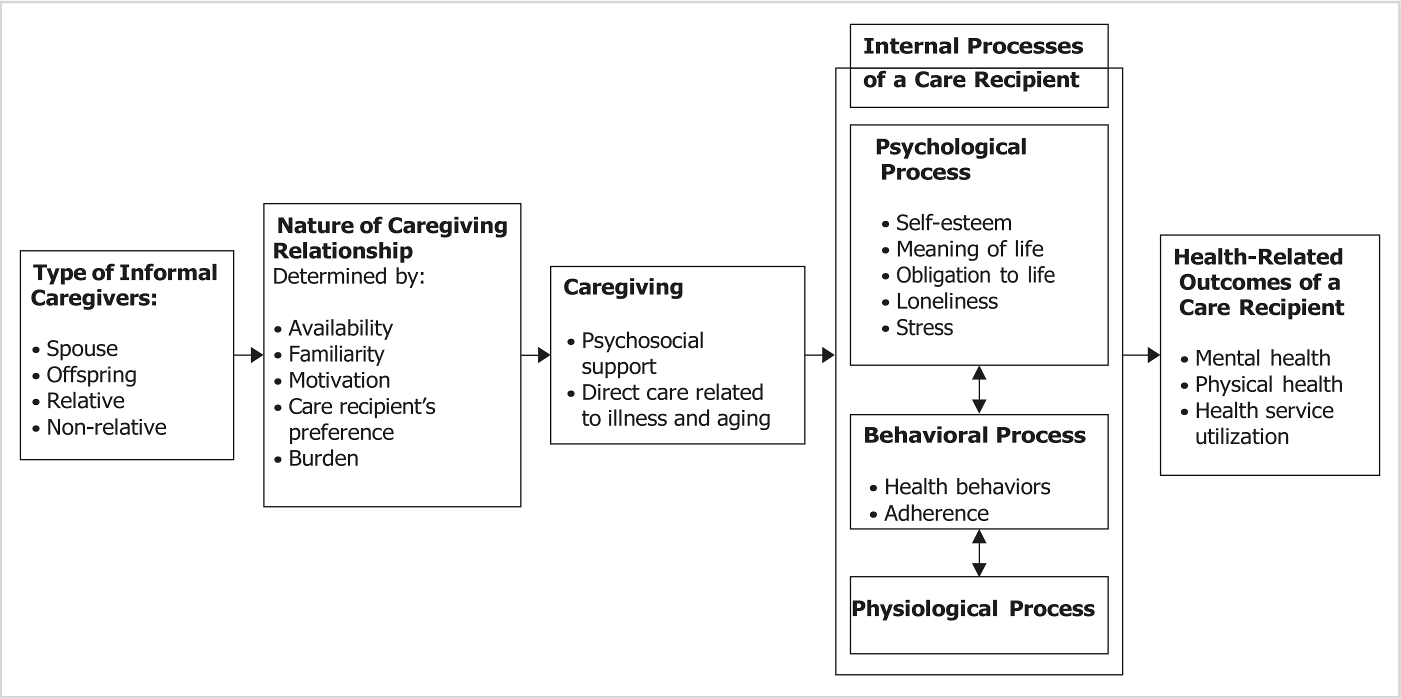

Figure 5.1 Cho’s Framework oAddressing the Effects of Informal Caregivers on Health-Related Outcomes of Elderly Recipients in Home Health Care.

*Cho, Eunhee. (2007). "A Proposed Theoretical Framework Addressing the Effects of Informal Caregivers on Health-Related Outcomes of Elderly Recipients in Home Health Care." Asian Nursing Research,1(1), 23–34. https://doi.org/10.1016/S1976-1317(08)60006-7.*

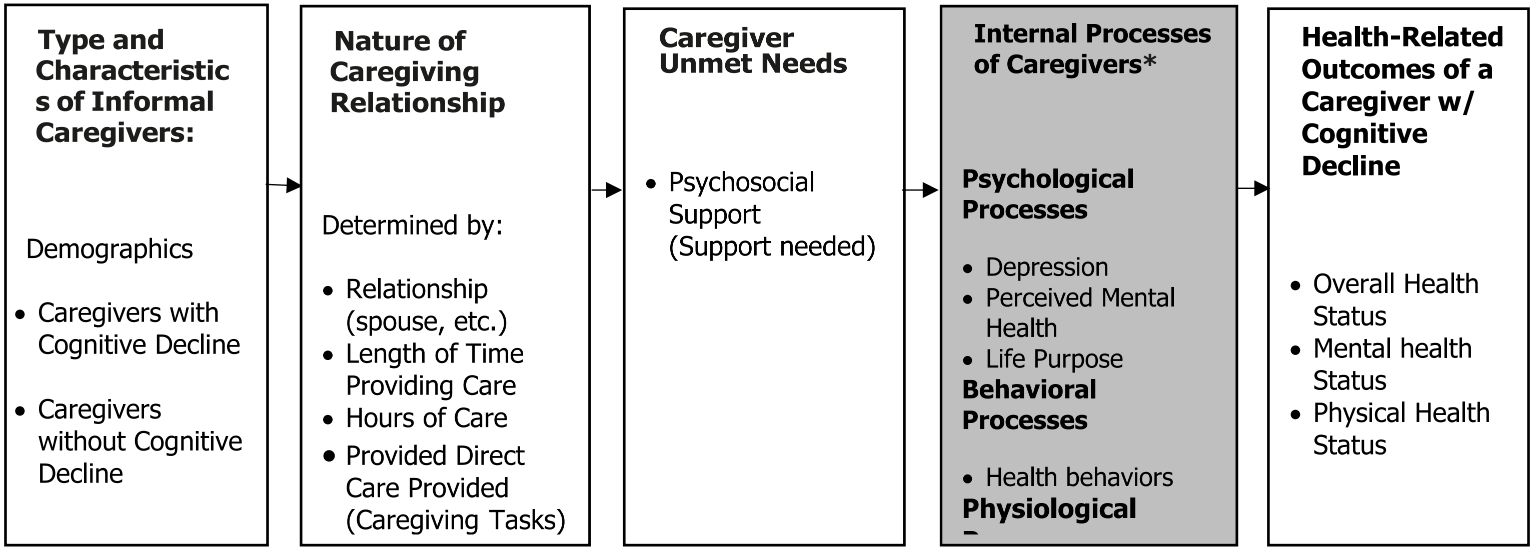

Figure 5.2 Adapted Framework Addressing the Experiences of informal Caregivers on Their Own Health-Related Outcomes

Note. *Adapted from Cho, Eunhee. (2007). A Proposed Theoretical Framework Addressing the Effects of Informal Caregivers on Health-Related Outcomes of Elderly Recipients in Home Health Care." Asian Nursing Research,1(1), 23–34. https://doi.org/10.1016/S1976-1317(08)60006-7.*

cellular, the mail, and collects more than 400,00 interviews yearly (CDC, 2018). Currently, all 50 states administer the survey through state health departments with guidance from the CDC.

The BRFSS collects data on health status, health conditions, and preventive care. The yearly surveys are comprised of three components: the core sections (fixed core, rotating core, and emerging core), optional modules, and questions added at the state level. The fixed core is the questions required to be administered by all the states. The fixed core covers demographic questions and health behaviors. The rotating core questions are asked in alternating years, and the emerging core focuses on current trends. Optional modules are administered yearly by the state. State responses to state-added questions are available if requested. In this study, state-added questions and responses will not be analyzed.

The cross-sectional study design uses BRFSS data from pooled 2015-1018 and questions from the following Core Sections: Demographics, Health Care Access, Health Status, and Healthy Days, and two Optional Modules—the Caregiver Module: gathers information about caregivers' activities and experiences to assess caregiver status and health. The Cognitive Decline Module: collects data to ascertain how subjective cognitive decline affects the lives of respondents aged 45 years and older, including people with difficulties performing activities or caring for themselves.

### ***Study Sample***

The study sample is comprised of respondents answering two sets of questions, from the Caregiver Module and the Cognitive Decline Module in the years 2015-2018, who reported they were caregivers in the Caregiver Module (n=47227). Also, the respondents completed the Cognitive Decline Modules, and if they answered "YES" to Question 1 in the Caregiver Module: "People may provide regular care or assistance to a friend or family member who has a health problem or disability. During the past 30 days, did you provide regular care or assistance to a friend or family member who has a health problem or disability?" (CDC, 2018); they were identified as caregivers with subjective cognitive decline. These respondents will have responded "YES" to Question 1 in the Caregiver Module and will have responded "YES" to Question 1 in the Cognitive Decline Optional Module: "During the past 12 months, have you experienced confusion or memory loss that is happening more often or is getting worse?" (n=21273) (CDC, 2018). As subjective cognitive decline is a potential outcome with far-reaching effects of caregiver-related stress and burden, the study will explore this particular facet of caregiver health. The Cognitive Decline module from BRFSS allowed an analysis of the individuals who identified as caregivers and how their self-reported cognitive decline impacts their activities and relationships. Exploring Cho's adapted model addresses the type and characteristics of informal caregivers and their health outcomes reporting subjective cognitive decline.

### ***Study Variables***

In exploring differences between caregivers reporting subjective cognitive decline or not, using the adapted model from Cho, we addressed the health-related outcomes of caregivers reporting cognitive decline. The model also addressed the type and characteristics of informal caregivers, caregiving tasks, the time spent caregiving, and caregiver unmet needs-needed supports, which are all factors contributing to caregiver burden which can cause physical and mental health consequences.

#### *I. Independent Variables*

In exploring differences between caregivers reporting cognitive decline or not, in the adapted model from Cho, this study addresses the health-related outcomes and subjective cognitive decline. The independent variable is the presence of cognitive decline. BFRSS respondents were asked if they had experienced confusion or memory loss that is happening more often or is getting worse within the last 12 months. Respondents answering yes or no were included in the study.

#### *II. Dependent Variables*

The dependent variables are the health-related outcomes of caregivers. The variables are the self-reported responses for general health, poor/fair or excellent/very good/good, physical health within the last 30 days, yes, none, and mental health within the last 30 days, yes or no.

All independent variables were converted to categorical variables for the study.

### *Analytic Approach*

First, we conducted chi-square tests ($\alpha = 0.05$) to measure differences in the general health-related outcomes of caregivers reporting or not reporting cognitive decline. Next, we conducted three logistic regression models ($\alpha = 0.05$) were used to measure associations of general health-related outcomes, physical health outcomes, and mental health outcomes with reported cognitive decline among caregivers. The analytic approach was guided by the theoretical framework adapted for the study.

All statistical analyses followed BRFSS used complex survey weights, guidance, and instructions for weighting responses and were conducted using SAS statistical software, version 9.4 (SAS Institute Inc., Cary, NC). Approval from the University of South Carolina Institutional Review Board was granted on March 21, 2022. The study was categorized as "exempt status," as de-identified secondary data was utilized for this study.

## Results

The study respondents were principally female (59.8%), non-Hispanic White (78.5%), and most between the ages of 55 and over (66.0%), and most of the participants were in a romantic relationship (67.3%). Additionally, most of the participants in the study had completed high school and/or technical school/some college (90%), were employed or retired (79.3%), and predominantly had an income level of $75,000 or greater (32.7%). Also, the majority of the respondents had insurance (93.3%), and had at least one medical provider (81.8%). In terms of caregiving, the respondents were mostly either the spouse/partner (26.7%) or the parent/grandparent (31.9%) to the person receiving care, had provided care for more than five years (32.4%), worked 8 hours or less providing care (56.1%), evenly provided ADLs, caregiving tasks, referred to as activities of daily living,yes/no (50.2% and 49.8%), and mostly provided assistance with IADLs, instrumental activities of daily living (76.8%), and reported they did not need assistance (81.8%).

### ***Characteristics of Caregivers, by Health-Related Outcomes***

Subjective cognitive decline was the main predictor for general health-related outcomes. The analysis found a significant association ($p <.0001$) between subjective cognitive decline and general health status (Table 5.1). Caregivers reporting subjective cognitive decline were less likely to report excellent/very good/good health as compared to caregivers who did not report cognitive decline (50% vs 81%). When examining the caregiving relationship, all factors had a statistically significant relationship associated with fair/poor general health except for IADLs. For example, the highest proportion of caregivers reporting excellent health (80.9%) has been providing care for less than 30 days while the lowest proportion has been providing care for more than five years (72%). There was a statistically relationship associated with caregiver unmet needed and general health outcomes. Of the caregivers reporting excellent/very good/ good health, the highest proportion reported needing no help or assistance (78.2%). When analyzing demographic characteristics, all factors of demographic characteristics were significantly associated with health outcomes and subjective cognitive decline, except sex and age. For instance, caregivers who were employed had the highest proportion of excellent to good health (86.9%), while caregivers who reported being unable to work had the lowest proportion (69.7%) of reporting excellent or good health.

### ***Adjusted analysis of factors associated with self-reported Good to Excellent Health among individuals providing caregiving***

Factors related to general health with caregivers with and without cognitive decline are provided in Table 5.2. In the unadjusted model (model 0), caregivers reporting memory loss have four times the odds of reporting fair to poor health as compared to caregivers not reporting memory loss (OR=4.26, 95% CI, 3.69-4.91, p <.0001). After adjusting for the type and characteristics of informal caregivers (Model 1), the association between memory loss and general health was significantly reduced (OR=2.58, 95% CI, 2.18-3.06, p <.0001). However, when adding factors related to the nature of the caregiving relationship (Model 2), the association increased slightly (OR=2.63, 95% CI, 2.21-3.06, p <.0001). Yet, when adjusting for all the previous factors and adding in caregiver unmet needs (Model 3), the association was not significantly altered (OR=2.61, 95% CI, 2.18-3.13, p <.0001).

### ***Adjusted analysis of factors associated with self-reported Good to Excellent Physical Health among individuals providing caregiving***

Physical health outcomes for individuals providing care and dealing with memory loss are illustrated in Table 5.3. Similar to the results for general health, in the unadjusted model (model 0), caregivers reporting memory loss have four times the odds of reporting fair to poor health as compared to caregivers not reporting memory loss (OR=4.26, 95% CI, 3.69-4.91, p <.0001). After adjusting for the type and characteristics of informal caregivers (Model 1), the association between memory loss and general health was significantly reduced (OR=2.91, 95% CI, 2.46-3.44, p <.0001). When adjusting for the type and characteristics of caregivers and adding in factors related the nature of the caregiving relationship (Model 2) the association continued the slight decrease (OR=2.84, 95% CI, 2.39-3.40, p <.0001). After adjusting for the type and characteristics of informal caregivers, the nature of the caregiving relationship, and adding in caregiver unmet needs (Model 3), the association again slightly decreased (OR=2.74, 95% CI, 2.28-3.29, p <.0001).

### ***Adjusted analysis of factors associated with self-reported Good to Excellent Mental Health among individuals providing caregiving***

Factors related to mental health with caregivers with and without memory loss are provided in Table 5.4. Initially, the results were similar for both general health and physical health in exploring the mental health for caregivers. In the unadjusted model (model 0), caregivers reporting memory loss have four times the odds of reporting fair to poor health as compared to caregivers not reporting memory loss (OR=4.36, 95% CI, 3.80-5.01, p <.0001). After adjusting for the type and characteristics of informal caregivers (Model 1), the association between memory loss and mental health was significantly reduced (OR=3.77, 95% CI, 3.21-4.44, p <.0001), but stronger than the association for both general and physical health. Yet when adding factors related the nature of the caregiving relationship (Model 2), the association increased slightly (OR=3.84, 95% CI, 3.24-4.55, p <.0001). After adjusting for all the previous factors, the characteristics and type of informal caregivers, and the nature of the caregiving relationship, then and adding in caregiver unmet needs (Model 3), the association was not significantly changed (OR=3.60, 95% CI, 3.02-4.30, p <.0001).

## Discussion

As there is a dearth of studies examining informal caregivers, subjective cognitive decline, and associations with health on multiple levels, we believe we are one of the few, if not the first study to explore this intersection for informal caregivers. While there is a great deal of research on caregiver burden and its consequences, there is limited research on this impairment in caregivers and its relationship on the actual health outcomes of caregivers. Of the current studies specifically exploring cognitive decline in caregivers, most studies focus on care for individuals with dementia and/or Alzheimer's disease. Also, many of the studies were conducted in other countries and were centered around spousal dyads. The most recent US research, while related, does not explore the same elements based on a theoretical framework, nor do the studies examine both physical, mental, and general health status. We can surmise this research does corroborate the existing knowledge that caregiver burden and stress can negatively impact the caregiver and their health outcomes and the quality of care an individual receives.

We hypothesized there would be a difference in the self-reported health outcomes (Fair/Poor vs. Excellent/Very Good/ Good) of caregivers reporting memory loss (subjective cognitive decline) and those caregivers without a self-report of subjective cognitive decline. The findings conclude there is an association between caregivers with subjective cognitive decline and reported poorer health outcomes.

This is a significant finding as caregivers are providing care ADLs (personal care, such as feeding, bathing, dressing, toileting, and transferring) and IADLs (related to care and function, including medication management, scheduling, and if required, transportation to medical visits, shopping, housekeeping, money and household financial management, meal preparation, transportation, and communications) to the recipient in various stages of health. If caregivers are experiencing poorer general, physical and mental health then the care provided can be affected in both quality and safety.

Our findings are consistent with current research, Brown and Cohen (2020) found potential associations with informal caregiving, poor mental health, and subjective cognitive decline. Jeffers et al. (2021) reported that of the participants in their study about 12.5% of the caregivers reported some cognitive decline. Informal caregiving, while purposeful can provide challenges and negative experiences, for example, stress, physical, mental, emotional, and financial demands. Caregivers are often responsible for providing physical care and maintenance, emotional support, and social interaction for those in their care, often at the expense of their own health and need for social activities (Bastarowos, 2013).

## Policy Implications

These findings support the need for further exploration of informal caregivers and in this instance, subjective cognitive decline. The health care system must include caregiver health in the care plans of those care recipients, especially with chronic, long-term health concerns including Alzheimer's and dementia. Those care recipients require more complex care over a longer period of time and more formal care options might not be available due to cost and geographical location.

The intersection of informal caregiving, subjective cognitive decline, and caregiver health requires more study. Moreover, the findings also suggest a need for more comprehensive policy responses for ensuring caregiver health. According to AARP, public policies regarding eldercare and care for individuals with disabilities have not been responsive to the changing care landscape. The current caregiving model appears to be unsustainable—with longer lives, shorter hospitalizations, healthcare workforce shortages, the rising costs of care, and the shifting demographics require a focused nationwide approach (2020). Data shows that caregivers may not be focused on their own health and therefore may miss regular check-ups and screenings. Unfortunately, when care recipients have medical visits or assessments, they are the sole focus of the visit. Physicians and other healthcare workers do not receive payment for the caregiver unless the caregiver is the actual patient nor for patient education and training. The Family Caregiver Alliance has developed a "Family Caregiver Screening Toolkit: A Resource for Health Care Providers" as a response to the need for better caregiver screening (caregiving.org, nd). The failure to identify the care conditions and needs of the caregivers places both the care recipient and the caregiver at risk. It is vital to continue to explore their experiences and the consequences of caregiving. Effective interventions and policies cannot be developed without a complete understanding of the caregivers themselves.

The lack of a consistent, comprehensive nationwide approach to care provision means that states choose their level of involvement in meeting the unmet needs of both the recipient and the caregivers, so service availability differs from state to state (AARP, 2020). Some care recipients may be able to receive Medicaid, but the funding is limited based on eligibility requirements and the income of care recipient (AARP, 2020). Other policy areas include the need for workplace policies, i.e., paid leave or amended FMLA to support caregivers and programs or access to financial resources to offset the economic impacts of providing care, like tax credits (AARP, 2020). Additionally, ensuring the long-term availability of Social Security, paid family leave programs, caregiver education and screening are just some of the policies needing further exploration to ensure informal caregivers are supported in their work caring for loved ones. While the study illustrated a clear relationship between caregiving and subjective decline, the clear indication is that caregivers need assistance to provide quality care for themselves, and the family members and friends under their care, and the health care system must respond.

Subjective cognitive decline can be in some cases, a precursor to dementia-related illness. If the caregivers are not well, then how effectively can care be provided to those currently ill.

## Limitations

The study has several limitations. No causal relationship between caregiving and subjective cognitive decline can be established because of the study's cross-sectional design. Also, the data from the BRFSS is all self-reported. As with all self-reported data, there may be challenges with recall or memory. This is an even greater concern with this population as individuals with memory loss may be asked questions they simply do not remember. The BRFSS is administered at a point in time and contextualizes questions, for instance, "in the last 30 days" or "within the last 12 months, so that caregivers' status could have been different before or after those time frames. Also, while the caregiver and cognitive decline modules within the BRFSS, the modules are optional and all states are not required to include those sections in the administration of the BRFSS in their communities.

## Conclusion

The US population is continuing to age. The number of individuals moving into older age is not decreasing, and not everyone will be healthy enough to live independently and without assistance. About 20% of the US adult population are caregivers, and caregiving comes with rewards and challenges. Currently, caregiving is influenced dramatically by the combination of longer lives, more chronic diseases, medical technology advances, shortages in the health care industry, and fewer available numbers of caregivers. Therefore caregiving, informal unpaid caregiving is becoming increasingly necessary as family members and friends live longer. Caregivers need to be healthy to care for their loved one who is possibly living with chronic, and sometimes complex conditions. Caregivers need to be screened and assessed, so they are more available to be and continue to serve as informal caregivers.

Table 5.1 Characteristics of Caregivers, by Health-Related Outcomes, Behavioral Risk Factor Surveillance System (BRFSS) Participants, 2015-2018

| | **Fair/Poor Health** | | | **Excellent/Very Good/Good Health** | | | **Total** | | | |
|---|---|---|---|---|---|---|---|---|---|---|
| **Characteristics** | **Observations** | **Weighted Row Percent** | **Weighted Standard Error of Row Percent** | **Observations** | **Weighted Row Percent** | **Weighted Standard Error of Row Percent** | **Observations** | **Weighted Column Percent** | **Weighted Standard Error of Column Percent** | **P-value*** |
| **Factors Affecting Health Status** | | | | | | | | | | |
| **Cognitive Decline** | | | | | | | | | | |
| Yes | 1275 | 50.2 | 1.6 | 1382 | 49.8 | 1.6 | 2657 | 12.8 | 0.4 | **<.0001** |
| No | 3344 | 19.1 | 0.6 | 15222 | 80.9 | 0.6 | 18566 | 87.2 | 0.4 | |

| | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|
| **Factors Describing the Nature of Caregiving Relationship** | | | | | | | | | | |
| **Relationship to Care Recipient** | | | | | | | | | | |
| Parent/Grand parent | 1133 | 18.7 | 0.8 | 5227 | 81.3 | 0.8 | 6360 | 31.9 | 0.6 | **<.0001** |
| Spouse or M/F in-law | 1309 | 24.7 | 1.1 | 4345 | 75.3 | 1.1 | 5654 | 26.7 | 0.5 | |
| Sibling or B/S in-law | 481 | 26.9 | 1.7 | 1430 | 73.1 | 1.7 | 1911 | 8.7 | 0.3 | |
| Child/ Grandchild | 508 | 27.8 | 2.4 | 1514 | 72.2 | 2.4 | 2022 | 10.2 | 0.4 | |
| Other Relative | 319 | 23.3 | 2.0 | 1075 | 76.7 | 2.0 | 1394 | 6.5 | 0.3 | |
| Non-Relative | 839 | 24.7 | 1.4 | 2867 | 75.3 | 1.4 | 3706 | 15.9 | 0.4 | |
| **Length of Time Providing Care** | | | | | | | | | | |
| Less than 30 days | 707 | 19.4 | 1.2 | 3018 | 80.6 | 1.2 | 3725 | 17.4 | 0.5 | **<.0001** |
| 1 mo to less than 6 mo | 499 | 20.4 | 1.3 | 1985 | 79.6 | 1.3 | 2484 | 11.1 | 0.3 | |
| 6 mo to less than 2 yrs | 824 | 21.6 | 1.3 | 3116 | 78.4 | 1.3 | 3940 | 18.9 | 0.5 | |
| 2 yrs to less than 5 yrs | 922 | 21.8 | 1.0 | 3522 | 78.2 | 1.0 | 4444 | 20.1 | 0.4 | |
| More than 5 yrs | 1566 | 27.6 | 1.2 | 4717 | 72.4 | 1.2 | 6283 | 32.4 | 0.6 | |

| | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|
| **Hours per Week Providing Care** | | | | | | | | | | |
| 8 hrs or less | 2165 | 19.8 | 0.7 | 9223 | 80.2 | 0.7 | 11388 | 56.1 | 0.6 | **<.0001** |
| 9 to 19 hrs | 543 | 21.6 | 1.3 | 2010 | 78.4 | 1.3 | 2553 | 12.8 | 0.4 | |
| 20 to 39 hrs | 470 | 22.4 | 1.4 | 1552 | 77.6 | 1.4 | 2022 | 10.8 | 0.4 | |
| 40 hrs or more | 1085 | 32.9 | 1.6 | 2769 | 67.1 | 1.6 | 3854 | 20.3 | 0.5 | |
| **Provide Care-giving medications, feeding, dressing, or bathing (ADLs)#** | | | | | | | | | | |
| Yes | 2338 | 24.4 | 0.7 | 7884 | 75.6 | 0.7 | 10222 | 50.2 | 0.6 | **0.0259** |
| No | 2260 | 21.9 | 0.8 | 8605 | 78.1 | 0.8 | 10865 | 49.8 | 0.6 | |
| **Provide Care-managing household tasks-cleaning, managing money, or preparing meals (IADLs)##** | | | | | | | | | | |
| Yes | 3498 | 22.9 | 0.6 | 12593 | 77.1 | 0.6 | 16091 | 76.8 | 0.5 | 0.4312 |
| No | 1097 | 24 | 1.2 | 3907 | 76.0 | 1.2 | 5004 | 23.2 | 0.5 | |

**Factors Describing Caregiver Unmet Needs**

| | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|
| **Support Needed for Caregivers** | | | | | | | | | | |
| Classes about Care | 83 | 29.7 | 4.1 | 207 | 70.3 | 4.1 | 290 | 1.3 | 0.1 | **<.0001** |
| Help Access to Services | 523 | 27.4 | 1.7 | 1346 | 72.6 | 1.7 | 1869 | 9.7 | 0.4 | |
| Individual Counseling | 122 | 31.6 | 3.6 | 281 | 68.4 | 3.6 | 403 | 1.8 | 0.1 | |
| Support Groups | 162 | 25.9 | 2.7 | 421 | 74.1 | 2.7 | 583 | 2.7 | 0.2 | |
| Respite | 142 | 26.6 | 3.0 | 478 | 73.4 | 3.0 | 620 | 2.6 | 0.2 | |
| No Help Needed | 3385 | 21.8 | 0.6 | 13412 | 78.2 | 0.6 | 16797 | 81.8 | 0.4 | |
| **Demographic Characteristics of Caregivers** | | | | | | | | | | |
| **Sex** | | | | | | | | | | |
| Female | 2858 | 22.4 | 0.7 | 10881 | 77.6 | 0.7 | 13739 | 59.8 | 0.6 | 0.1285 |
| Male | 1760 | 24.1 | 0.8 | 5721 | 75.9 | 0.8 | 7481 | 40.3 | 0.6 | |
| **Age** | | | | | | | | | | |
| 25-54 | 1156 | 22.6 | 1.1 | 4171 | 77.4 | 1.1 | 5327 | 34.1 | 0.6 | 0.5944 |
| 55-64 | 1680 | 23.9 | 0.8 | 5768 | 76.1 | 0.8 | 7448 | 34 | 0.6 | |
| 65 and over | 1783 | 22.9 | 0.9 | 6665 | 77.1 | 0.9 | 8448 | 32 | 0.5 | |

|  |  |  |  |  |  |  |  |  |  |  |
|---|---|---|---|---|---|---|---|---|---|---|
| **Race** |  |  |  |  |  |  |  |  |  |  |
| Non-Hispanic White | 3244 | 21.5 | 0.6 | 13036 | 78.5 | 0.6 | 16280 | 78.5 | 0.5 | **<.0001** |
| Non-Hispanic African-American | 658 | 28 | 1.6 | 1574 | 72 | 1.6 | 2232 | 11.8 | 0.4 |  |
| Non-Hispanic American Indian or Alaskan Native | 109 | 34.4 | 5.6 | 160 | 65.6 | 5.6 | 269 | 1.04 | 0.1 |  |
| Non-Hispanic Asian, Native Hawaiian, or Pacific Islander | 123 | 16.4 | 4.9 | 592 | 83.6 | 4.9 | 715 | 2.5 | 0.2 |  |
| Non-Hispanic Multiracial and Other | 264 | 36 | 3.5 | 644 | 64 | 3.5 | 908 | 2.3 | 0.1 |  |
| Hispanic | 159 | 32.1 | 3.2 | 349 | 67.9 | 3.2 | 508 | 3.9 | 0.3 |  |
| **Relationship Status** |  |  |  |  |  |  |  |  |  |  |
| Living Together | 2504 | 19.4 | 0.6 | 10920 | 80.6 | 0.6 | 13424 | 67.3 | 0.6 | **<.0001** |
| Not Living Together | 2089 | 30.7 | 1.1 | 5593 | 69.3 | 1.1 | 7682 | 32.7 | 0.6 |  |

| | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|
| **Educational Attainment** | | | | | | | | | | |
| Not Completed High School | 625 | 48.7 | 2.2 | 650 | 51.3 | 2.2 | 1275 | 10 | 0.4 | **<.0001** |
| Completed High School | 1661 | 27 | 1.2 | 4242 | 73 | 1.2 | 5903 | 29.8 | 0.6 | |
| Some Technical School/College | 1430 | 21.7 | 0.8 | 4893 | 78.3 | 0.8 | 6323 | 32.7 | 0.6 | |
| Completed Technical School/College | 896 | 11.3 | 0.6 | 6790 | 88.7 | 0.6 | 7686 | 27.5 | 0.5 | |
| **Employment Status** | | | | | | | | | | |
| Employed | 1135 | 13.1 | 0.7 | 8054 | 86.9 | 0.7 | 9189 | 48.2 | 0.6 | **<.0001** |
| Unemployed | 277 | 37.8 | 3.6 | 649 | 62.1 | 3.6 | 926 | 5.2 | 0.3 | |
| Homemaker | 224 | 22.2 | 2.1 | 930 | 77.8 | 2.1 | 1154 | 5.9 | 0.3 | |
| Retired | 1635 | 22.1 | 0.8 | 6253 | 77.9 | 0.8 | 7888 | 31.1 | 0.5 | |
| Unable to Work | 1327 | 69.7 | 1.6 | 627 | 30.1 | 1.6 | 1954 | 9.5 | 0.3 | |

| | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|
| **Income** | | | | | | | | | | |
| Less than $25K | 1924 | 43.5 | 1.2 | 2850 | 56.5 | 1.2 | 4774 | 25.2 | 0.6 | **<.0001** |
| $26K to less than $50K | 1066 | 24.3 | 1.4 | 3762 | 75.7 | 1.4 | 4828 | 25.1 | 0.6 | |
| $50K to less than $75K | 458 | 16 | 1.1 | 2670 | 84.0 | 1.1 | 3128 | 16.6 | 0.5 | |
| Greater than $75K | 476 | 10.1 | 0.8 | 4989 | 89.9 | 0.8 | 5465 | 32.7 | 0.6 | |
| **Any Type of Insurance Coverage** | | | | | | | | | | |
| Have Coverage | 4216 | 22.6 | 0.6 | 15700 | 77.4 | 0.6 | 19916 | 93.3 | 0.3 | **0.0002** |
| No Coverage | 392 | 29.8 | 2.0 | 879 | 70.2 | 2.0 | 1271 | 6.7 | 0.3 | |
| **Medical Providers** | | | | | | | | | | |
| One Provider | 3579 | 22.1 | 0.6 | 13631 | 77.9 | 0.6 | 17210 | 81.8 | 0.5 | **<.0001** |
| More than One Provider | 622 | 33 | 2.1 | 1484 | 67 | 2.1 | 2106 | 8.8 | 0.3 | |
| No Provider | 402 | 22.2 | 1.5 | 1455 | 77.8 | 1.5 | 1857 | 9.4 | 0.3 | |

*Bold indicates a significant P-value at an alpha level of 0.05

[#]ADLs are defined as Activities of Daily Living

[##] IADLs are defined as Instrumental Activities of Daily Living

Table 5.2. Adjusted analysis of factors associated with self-reported Fair to Poor General Health among individuals providing caregiving, 2015-2018 BRFSS

| | **Model 0: Unadjusted Model** | | | **Model 1: Adjusted for Type and Characteristics of Informal Caregivers†** | | | **Model 2: Adjusted for Type and Characteristics of Informal Caregivers† and Nature of the Caregiving Relationship††** | | | **Model 3: Adjusted for Type and Characteristics of Informal Caregivers†, the Nature of the Caregiving Relationship††, and Caregiver Unmet Needs†††** | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| **Characteristics** | **OR** | **95% CI** | **P-Value*** | **OR** | **95% CI** | **P-Value*** | **OR** | **95% CI** | **P-Value*** | **OR** | **95% CI** | **P-Value*** |
| **Memory Loss** | | | | | | | | | | | | |
| Yes vs. No | **4.259** | **3.693-4.910** | **<.0001** | **2.581** | **2.177-3.061** | **<.0001** | **2.629** | **2.205-3.134** | **<.0001** | **2.609** | **2.175-3.130** | **<.0001** |
| **Factors Describing the Nature of Caregiving Relationship** | | | | | | | | | | | | |
| **Relationship to Recipient** | | | | | | | | | | | | |
| Parent/Grandparent vs. Non-Relative | **0.702** | **0.586-0.840** | **0.0001** | | | | **0.749** | **0.579-0.969** | **0.0280** | **0.746** | **0.574-0.970** | **0.0289** |
| Spouse or M/F in-law vs. Non-Relative | 1.001 | 0.834-1.202 | 0.9914 | | | | **1.301** | **1.013-1.670** | **0.0392** | **1.298** | **1.007-1.674** | **0.0440** |
| Sibling or B/S in-law vs. Non-Relative | 1.125 | 0.901-1.405 | 0.2995 | | | | 1.011 | 0.755-1.354 | 0.9394 | 0.980 | 0.727-1.321 | 0.8927 |
| Child/Grandchild vs. Non-Relative | 1.174 | 0.894-1.541 | 0.2493 | | | | 1.192 | 0.797-1.783 | 0.3914 | 1.169 | 0.768-1.781 | 0.4661 |

|  |  |  |  |  |  |  |  |  |  |
|---|---|---|---|---|---|---|---|---|---|
| Other Relative vs. Non-Relative | 0.926 | 0.712-1.203 | 0.5625 | 0.820 | 0.581-1.158 | 0.2597 | 0.867 | 0.612-1.226 | 0.4184 |
| **How long have you provided care** |  |  |  |  |  |  |  |  |  |
| Less than 30 days vs. More than 5 yrs | **0.631** | **0.521-0.765** | **<.0001** | **0.741** | **0.585-0.940** | **0.0134** | **0.731** | **0.573-0.933** | **0.0120** |
| 1 mo to less than 6 mo vs. More than 5 yrs | **0.674** | **0.557-0.817** | **<.0001** | **0.740** | **0.584-0.939** | **0.0131** | **0.724** | **0.568-0.924** | **0.0095** |
| 6 mo to less than 2 yrs vs. More than 5 yrs | **0.723** | **0.602-0.868** | **0.0005** | 0.852 | 0.686-1.058 | 0.1475 | 0.862 | 0.691-1.075 | 0.1872 |
| 2 yrs to less than 5 yrs vs. More than 5 yrs | **0.731** | **0.623-0.858** | **0.0001** | 0.832 | 0.683-1.012 | 0.0660 | 0.820 | 0.672-1.002 | 0.0526 |
| **How many hours per week do you provide care** |  |  |  |  |  |  |  |  |  |
| 8 hrs or less vs. 40 hrs or more | **0.505** | **0.428-0.595** | **<.0001** | **0.718** | **0.568-0.908** | **0.0056** | **0.744** | **0.579-0.956** | **0.0206** |
| 9 to 19 hrs vs. 40 hrs or more | **0.561** | **0.455-0.691** | **<.0001** | 0.799 | 0.606-1.054 | 0.1124 | 0.793 | 0.595-1.056 | 0.1120 |
| 20 to 39 hrs vs. 40 hrs or more | **0.590** | **0.476-0.733** | **<.0001** | **0.681** | **0.523-0.886** | **0.0043** | **0.678** | **0.516-0.891** | **0.0053** |
| **Tasks of Activities of Daily Living (ability to) #** |  |  |  |  |  |  |  |  |  |

| | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|
| Yes vs. No | **1.151** | **1.017-<br>1.303** | **0.0256** | 1.009 | 0.815-<br>1.250 | 0.9310 | 0.983 | 0.790-<br>1.223 | 0.8769 |
| **Tasks of Instrumental Activities of Daily Living (ability to) ##** | | | | | | | | | |
| Yes vs. No | 0.942 | 0.812-<br>1.093 | 0.4313 | **0.782** | **0.641-<br>0.955** | **0.0160** | **0.787** | **0.641-<br>0.966** | **0.0223** |
| **Factors Describing Caregiver Unmet Needs** | | | | | | | | | |
| **Support Needed for Caregivers** | | | | | | | | | |
| Classes about Care vs. No Help Needed | **1.517** | **1.027-<br>2.241** | **0.0361** | | | | 1.469 | 0.830-<br>2.599 | 0.1863 |
| Help Access to Services vs. No Help Needed | **1.357** | **1.133-<br>1.624** | **0.0009** | | | | 1.212 | 0.942-<br>1.560 | 0.1342 |
| Individual Counseling vs. No Help Needed | **1.662** | **1.189-<br>2.324** | **0.0030** | | | | 1.144 | 0.737-<br>1.776 | 0.5489 |
| Support Groups vs. No Help Needed | 1.252 | 0.943-<br>1.663 | 0.1207 | | | | 1.055 | 0.757-<br>1.472 | 0.7511 |
| Respite vs. No Help Needed | 1.303 | 0.960-<br>1.769 | 0.0896 | | | | **1.541** | **1.020-<br>2.327** | **0.0399** |
| **Demographic Characteristics of Caregivers** | | | | | | | | | |

|  |  |  |  |  |  |  |  |  |  |  |  |  |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| **Sex** |  |  |  |  |  |  |  |  |  |  |  |  |
| Male vs. Female | 1.098 | 0.974-1.237 | 0.1277 | 1.077 | 0.917-1.264 | 0.3662 | 1.062 | 0.902-1.251 | 0.4715 | 1.067 | 0.902-1.262 | 0.4485 |
| **Age** |  |  |  |  |  |  |  |  |  |  |  |  |
| 25-54 vs. 65 and over | 0.985 | 0.841-1.154 | 0.8524 | 1.038 | 0.785-1.372 | 0.7936 | 1.256 | 0.943-1.673 | 0.1196 | 1.237 | 0.922-1.659 | 0.1556 |
| 55-64 vs. 65 and over | 1.059 | 0.927-1.210 | 0.3967 | 1.020 | 0.829-1.255 | 0.8537 | 1.175 | 0.948-1.455 | 0.1408 | 1.180 | 0.951-1.466 | 0.1333 |
| **Race** |  |  |  |  |  |  |  |  |  |  |  |  |
| NH African-American vs. NH White | **1.421** | **1.201-1.681** | **<.0001** | 1.040 | 0.811-1.332 | 0.7580 | 1.021 | 0.797-1.308 | 0.8676 | 1.059 | 0.823-1.363 | 0.6564 |
| NH American Indian or Alaskan Native vs. NH White | **1.914** | **1.173-3.125** | **0.0094** | 1.102 | 0.650-1.867 | 0.7185 | 1.087 | 0.604-1.955 | 0.7819 | 1.207 | 0.666-2.187 | 0.5353 |
| NH Asian, Native Hawaiian, or Pacific Islander vs. NH White | 0.719 | 0.358-1.447 | 0.3556 | 1.090 | 0.521-2.282 | 0.8190 | 1.016 | 0.493-2.094 | 0.9650 | 1.015 | 0.490-2.101 | 0.9683 |
| NH Multiracial and Other vs. NH White | **2.053** | **1.512-2.788** | **<.0001** | **1.960** | **1.431-2.686** | **<.0001** | **1.873** | **1.366-2.568** | **<.0001** | **1.857** | **1.350-2.555** | **0.0001** |
| Hispanic vs. NH White | **1.726** | **1.278-2.332** | **0.0004** | 1.443 | 0.969-2.148 | 0.0712 | **1.556** | **1.026-2.361** | **0.0374** | **1.564** | **1.017-2.406** | **0.0417** |
| **Marital Status** |  |  |  |  |  |  |  |  |  |  |  |  |

| | | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| Living Together vs. Not Living Together | **0.546** | **0.480-0.620** | **<.0001** | 0.942 | 0.762-1.164 | 0.5807 | **0.783** | **0.630-0.972** | **0.0269** | 0.800 | 0.640-1.001 | 0.0506 |
| **Educational Attainment** | | | | | | | | | | | | |
| Completed High School vs. Not Completed High School | **0.390** | **0.317-0.480** | **<.0001** | **0.666** | **0.516-0.860** | **0.0018** | **0.707** | **0.543-0.920** | **0.0100** | **0.679** | **0.517-0.892** | **0.0054** |
| Some Technical School/College vs. Not Completed High School | **0.292** | **0.240-0.355** | **<.0001** | **0.559** | **0.435-0.719** | **<.0001** | **0.618** | **0.476-0.802** | **<.0001** | **0.578** | **0.442-0.756** | **<.0001** |
| Completed Technical School/College vs. Not Completed High School | **0.133** | **0.108-0.165** | **<.0001** | **0.379** | **0.284-0.505** | **<.0001** | **0.437** | **0.323-0.591** | **0.0003** | **0.400** | **0.292-0.546** | **<.0001** |
| **Employment Status** | | | | | | | | | | | | |
| Unemployed vs. Employed | **4.026** | **2.915-5.560** | **<.0001** | **2.487** | **1.637-3.777** | **<.0001** | **2.385** | **1.558-3.652** | **<.0001** | **2.422** | **1.567-3.743** | **<.0001** |
| Homemaker vs. Employed | **1.891** | **1.441-2.482** | **<.0001** | **1.422** | **1.037-1.952** | **0.0291** | **1.392** | **1.006-1.926** | **0.0457** | 1.356 | 0.968-1.899 | 0.0763 |
| Retired vs. Employed | **1.872** | **1.600-2.190** | **<.0001** | **1.479** | **1.182-1.851** | **0.0006** | **1.466** | **1.159-1.855** | **0.0014** | **1.486** | **1.171-1.885** | **0.0011** |
| Unable to Work vs. Employed | **15.191** | **12.540-18.402** | **<.0001** | **7.128** | **5.701-8.911** | **<.0001** | **7.102** | **5.639-8.944** | **<.0001** | **7.008** | **5.530-8.882** | **<.0001** |
| **Income** | | | | | | | | | | | | |

| | | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| $26K to less than $50K vs. Less than $25K | **0.417** | **0.349-0.497** | **<.0001** | **0.714** | **0.575-0.886** | **0.0022** | **0.724** | **0.586-0.893** | **0.0026** | **0.735** | **0.592-0.911** | **0.0050** |
| $50K to less than $75K vs. Less than $25K | **0.248** | **0.206-0.299** | **<.0001** | **0.497** | **0.392-0.628** | **<.0001** | **0.498** | **0.391-0.634** | **<.0001** | **0.509** | **0.398-0.651** | **<.0001** |
| Greater than $75K vs. Less than $25K | **0.146** | **0.119-0.179** | **<.0001** | **0.368** | **0.273-0.497** | **<.0001** | **0.390** | **0.287-0.528** | **<.0001** | **0.389** | **0.285-0.531** | **<.0001** |
| **Any Type of Insurance Coverage** | | | | | | | | | | | | |
| Have Coverage vs. No Coverage | **0.688** | **0.566-0.838** | **0.0002** | 1.045 | 0.782-1.398 | 0.7646 | 1.099 | 0.829-1.456 | 0.5123 | 1.140 | 0.852-1.527 | 0.3770 |
| **Medical Provider** | | | | | | | | | | | | |
| One Provider vs. No Provider | 0.997 | 0.829-1.198 | 0.9717 | **1.391** | **1.075-1.800** | **0.0120** | **1.392** | **1.067-1.816** | **0.0149** | **1.390** | **1.055-1.833** | **<.0001** |
| More than One Provider vs. No Provider | **1.727** | **1.345-2.218** | **<.0001** | **2.383** | **1.705-3.332** | **<.0001** | **2.463** | **1.739-3.489** | **<.0001** | **2.628** | **1.839-3.756** | **0.0193** |

*Bold indicates a significant P-value at an alpha level of 0.05

#ADLs are defined as Activities of Daily Living

## IADLs are defined as Instrumental Activities of Daily Living

†Type and Characteristics of Informal Caregivers include: age, sex, race, gender, marital status, education, employment, income, medical providers, insurance coverage

†† Nature of the Caregiving Relationship includes: the caregiver's relationship to the care recipient, and the direct care provided to the care recipient

†††Caregiver Unmet Needs include: assistance a caregiver may need but is not receiving

Table 5.3. Adjusted analysis of factors associated with self-reported Fair to Poor Physical Health among individuals providing caregiving, 2015-2018 BRFSS

| | **Model 0: Unadjusted Model** | | | **Model 1: Adjusted for Type and Characteristics of Informal Caregivers†** | | | **Model 2: Adjusted for Type and Characteristics of Informal Caregivers† and Nature of the Caregiving Relationship††** | | | **Model 3: Adjusted for Type and Characteristics of Informal Caregivers†, the Nature of the Caregiving Relationship††, and Caregiver Unmet Needs†††** | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| **Characteristics** | **OR** | **95% CI** | **P-Value*** | **OR** | **95% CI** | **P-Value*** | **OR** | **95% CI** | **P-Value*** | **OR** | **95% CI** | **P-Value*** |
| **Memory Loss** | | | | | | | | | | | | |
| Yes vs. No | **4.259** | **3.693-4.910** | **<.0001** | **2.915** | **2.464-3.448** | **<.0001** | **2.845** | **2.385-3.395** | **<.0001** | **2.735** | **2.279-3.282** | **<.0001** |
| **Factors Describing the Nature of Caregiving Relationship** | | | | | | | | | | | | |
| **Relationship to Recipient** | | | | | | | | | | | | |
| Parent/Grandparent vs. Non-Relative | **0.795** | **0.687-0.920** | **0.0021** | | | | **0.820** | **0.677-0.993** | **0.0420** | **0.794** | **0.654-0.965** | **0.0204** |
| Spouse or M/F in-law vs. Non-Relative | 0.884 | 0.761-1.028 | 0.1101 | | | | 1.025 | 0.840-1.252 | 0.8069 | 1.028 | 0.840-1.258 | 0.7868 |
| Sibling or B/S in-law vs. Non-Relative | 0.902 | 0.742-1.096 | 0.2984 | | | | 0.847 | 0.671-1.069 | 0.1610 | 0.824 | 0.651-1.044 | 0.1094 |

| | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|
| Child/Grandchild vs. Non-Relative | 1.087 | 0.884-1.336 | 0.4275 | 0.967 | 0.742-1.260 | 0.8031 | 0.926 | 0.706-1.216 | 0.5812 |
| Other Relative vs. Non-Relative | 0.979 | 0.785-1.220 | 0.8509 | 0.912 | 0.697-1.194 | 0.5029 | 0.895 | 0.681-1.177 | 0.4285 |
| **How long have you provided care** | | | | | | | | | |
| Less than 30 days vs. More than 5 yrs | **0.825** | **0.708-0.962** | **0.0140** | 0.945 | 0.776-1.150 | 0.5709 | 0.971 | 0.795-1.186 | 0.7741 |
| 1 mo to less than 6 mo vs. More than 5 yrs | **0.818** | **0.695-0.962** | **0.0154** | **0.793** | **0.656-0.958** | **0.0139** | **0.786** | **0.649-0.953** | **0.0143** |
| 6 mo to less than 2 yrs vs. More than 5 yrs | **0.757** | **0.652-0.879** | **0.0003** | **0.808** | **0.682-0.958** | **0.0128** | **0.817** | **0.687-0.971** | **0.0220** |
| 2 yrs to less than 5 yrs vs. More than 5 yrs | **0.816** | **0.714-0.932** | **0.0027** | 0.909 | 0.777-1.062 | 0.2292 | 0.906 | 0.773-1.062 | 0.2251 |
| **How many hours per week do you provide care** | | | | | | | | | |
| 8 hrs or less vs. 40 hrs or more | **0.762** | **0.663-0.876** | **0.0001** | 0.985 | 0.806-1.204 | 0.8839 | 0.996 | 0.806-1.230 | 0.9686 |
| 9 to 19 hrs vs. 40 hrs or more | **0.755** | **0.632-0.902** | **0.0020** | 0.927 | 0.743-1.157 | 0.5019 | 0.917 | 0.730-1.152 | 0.4556 |
| 20 to 39 hrs vs. 40 hrs or more | 0.875 | 0.723-1.059 | 0.1707 | 1.026 | 0.814-1.292 | 0.8298 | 1.027 | 0.809-1.304 | 0.8256 |
| **Tasks of Activities of Daily Living (ability to)#** | | | | | | | | | |
| Yes vs. No | 1.046 | 0.948-1.154 | 0.3733 | 0.936 | 0.819-1.069 | 0.3292 | 0.918 | 0.801-1.052 | 0.2177 |

| | | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| **Tasks of Instrumental Activities of Daily Living (ability to) ##** | | | | | | | | | | | | |
| Yes vs. No | 1.112 | 0.985-1.254 | 0.0856 | | | | 1.099 | 0.941-1.283 | 0.2348 | 1.092 | 0.932-1.280 | 0.2774 |
| **Factors Describing Caregiver Unmet Needs** | | | | | | | | | | | | |
| **Support Needed for Caregivers** | | | | | | | | | | | | |
| Classes about Care vs. No Help Needed | **1.527** | **1.069-2.183** | **0.0201** | | | | | | | **1.610** | **1.062-2.439** | **0.0249** |
| Help Access to Services vs. No Help Needed | **1.546** | **1.312-1.821** | **<.0001** | | | | | | | **1.464** | **1.213-1.768** | **<.0001** |
| Individual Counseling vs. No Help Needed | **1.767** | **1.281-2.436** | **0.0005** | | | | | | | 1.401 | 1.136-2.086 | 0.0788 |
| Support Groups vs. No Help Needed | 1.275 | 0.973-1.669 | 0.0776 | | | | | | | 1.138 | 0.804-16.10 | 0.4670 |
| Respite vs. No Help Needed | **1.548** | **1.203-1.991** | **0.0007** | | | | | | | **1.539** | **1.136-2.086** | **0.0054** |
| **Demographic Characteristics of Caregivers** | | | | | | | | | | | | |
| **Sex** | | | | | | | | | | | | |
| Male vs. Female | **0.814** | **0.738-0.899** | **<.0001** | **0.784** | **0.697-0.883** | **<.0001** | **0.772** | **0.684-0.873** | **<.0001** | **0.780** | **0.689-0.884** | **0.0001** |

| | | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| **Age** | | | | | | | | | | | | |
| 25-54 vs. 65 and over | **1.204** | **1.063-1.363** | **0.0034** | **1.254** | **1.036-1.519** | **0.0204** | **1.372** | **1.124-1.674** | **0.0019** | **1.339** | **1.091-1.642** | **0.0051** |
| 55-64 vs. 65 and over | **1.129** | **1.010-1.261** | **0.0323** | 1.078 | 0.920-1.265 | 0.3525 | 1.127 | 0.953-1.333 | 0.1635 | 1.107 | 0.932-1.314 | 0.2471 |
| **Race** | | | | | | | | | | | | |
| NH African-American  vs. NH White | 1.140 | 0.974-1.333 | 0.1027 | 0.911 | 0.747-1.111 | 0.3563 | 0.916 | 0.747-1.124 | 0.4013 | 0.911 | 0.738-1.24 | 0.3838 |
| NH American Indian or Alaskan Native vs. NH White | **1.834** | **1.103-3.049** | **0.0195** | 1.497 | 0.736-3.048 | 0.2654 | 1.487 | 0.726-3.048 | 0.2718 | 1.622 | 0.777-3.389 | 0.1979 |
| NH Asian, Native Hawaiian, or Pacific Islander vs. NH White | 0.690 | 0.471-1.010 | 0.0564 | 0.771 | 0.499-1.190 | 0.2396 | 0.757 | 0.471-1.215 | 0.2483 | 0.739 | 0.456-1.199 | 0.2206 |
| NH Multiracial and Other vs. NH White | **1.533** | **1.171-2.007** | **0.0019** | **1.425** | **1.063-1.911** | **0.0179** | **1.433** | **1.057-1.944** | **0.0207** | **1.387** | **1.015-1.805** | **0.0398** |
| Hispanic vs. NH White | **1.336** | **1.000-1.785** | **0.0497** | 1.201 | 0.853-1.690 | 0.2937 | 1.367 | 0.957-1.953 | 0.0854 | 1.337 | 0.925-1.934 | 0.1223 |
| **Marital Status** | | | | | | | | | | | | |
| Living Together vs. Not Living Together | **0.647** | **0.582-0.719** | **<.0001** | 0.922 | 0.801-1.060 | 0.2538 | 0.892 | 0.766-1.037 | 0.1371 | 0.891 | 0.763-1.039 | 0.1417 |

| | | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| **Educational Attainment** | | | | | | | | | | | | |
| Completed High School vs. Not Completed High School | **0.580** | **0.476-0.706** | **<.0001** | 0.870 | 0.682-1.110 | 0.2626 | 0.962 | 0.746-1.240 | 0.7644 | 0.895 | 0.690-1.159 | 0.3995 |
| Some Technical School/College vs. Not Completed High School | **0.603** | **0.498-0.731** | **<.0001** | 1.012 | 0.793-1.290 | 0.9243 | 1.115 | 0.864-1.439 | 0.4029 | 1.020 | 0.787-1.323 | 0.8801 |
| Completed Technical School/College vs. Not Completed High School | **0.407** | **0.335-0.494-** | **<.0001** | 0.932 | 0.722-1.203 | 0.5906 | 1.041 | 0.797-1.361 | 0.7667 | 0.928 | 0.706-1.219 | 0.5906 |
| **Employment Status** | | | | | | | | | | | | |
| Unemployed vs. Employed | **2.609** | **2.015-3.378** | **<.0001** | **2.187** | **1.586-3.017** | **<.0001** | **2.535** | **1.843-3.487** | **<.0001** | **2.580** | **1.866-3.567** | **<.0001** |
| Homemaker vs. Employed | **1.288** | **1.050-1.580** | **0.0151** | 1.104 | 0.865-1.409 | 0.4255 | 1.117 | 0.863-1.445 | 0.4015 | 1.116 | 0.857-1.453 | 0.4159 |
| Retired vs. Employed | **1.193** | **1.069-1.332** | **0.0017** | 1.121 | 0.953-1.319 | 0.1692 | 1.154 | 0.973-1.368 | 0.1009 | 1.151 | 0.966-1.371 | 0.1153 |
| Unable to Work vs. Employed | **9.993** | **8.170-12.222** | **<.0001** | **5.935** | **4.677-7.531** | **<.0001** | **6.273** | **4.913-8.010** | **<.0001** | **6.213** | **4.839-7.977** | **<.0001** |

| | | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| **Income** | | | | | | | | | | | | |
| $26K to less than $50K vs. Less than $25K | **0.518** | **0.445-0.604** | **<.0001** | **0.754** | **0.635-0.895** | **0.0012** | **0.757** | **0.635-0.901** | **0.0018** | **0.783** | **0.655-0.936** | **0.0073** |
| $50K to less than $75K vs. Less than $25K | **0.426** | **0.363-0.499** | **<.0001** | **0.641** | **0.529-0.777** | **<.0001** | **0.627** | **0.515-0.763** | **<.0001** | **0.644** | **0.528-0.786** | **<.0001** |
| Greater than $75K vs. Less than $25K | **0.316** | **0.275-0.364** | **<.0001** | **0.515** | **0.425-0.624** | **<.0001** | **0.518** | **0.426-0.630** | **<.0001** | **0.531** | **0.435-0.648** | **<.0001** |
| **Any Type of Insurance Coverage** | | | | | | | | | | | | |
| Have Coverage vs. No Coverage | 0.928 | 0.769-1.120 | 0.4346 | **1.334** | **1.040-1.710** | **0.0232** | **1.399** | **1.098-1.783** | **0.0065** | **1.440** | **1.123-1.846** | **0.0040** |
| **Medical Provider** | | | | | | | | | | | | |
| One Provider vs. No Provider | 1.155 | 0.983-1.358 | 0.0806 | **1.379** | **1.136-1.674** | **0.0012** | **1.373** | **1.123-1.678** | **0.0020** | **1.364** | **1.108-1.679** | **0.0034** |
| More than One Provider vs. No Provider | **1.590** | **1.273-1.988** | **<.0001** | **1.755** | **1.346-2.287** | **<.0001** | **1.679** | **1.271-2.218** | **0.0003** | **1.700** | **1.281-2.258** | **0.0002** |

*Bold indicates a significant P-value at an alpha level of 0.05

[#] ADLs are defined as Activities of Daily Living

[##] IADLs are defined as Instrumental Activities of Daily Living

[†] Type and Characteristics of Informal Caregivers include: age, sex, race, gender, marital status, education, employment, income, medical providers, insurance coverage

[††] Nature of the Caregiving Relationship include: the caregiver's relationship to the care recipient, and the direct care provided to the care recipient

[†††] Caregiver Unmet Needs include: assistance a caregiver may need but is not receiving

Table 5.4. Adjusted analysis of factors associated with self-reported Fair to Poor Mental Health among individuals providing caregiving, 2015-2018 BRFSS

| | **Model 0: Unadjusted Model** | | | **Model 1: Adjusted for Type and Characteristics of Informal Caregivers†** | | | **Model 2: Adjusted for Type and Characteristics of Informal Caregivers† and Nature of the Caregiving Relationship††** | | | **Model 3: Adjusted for Type and Characteristics of Informal Caregivers†, the Nature of the Caregiving Relationship††, and Caregiver Unmet Needs†††** | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| **Characteristics** | **OR** | **95% CI** | **P-Value*** | **OR** | **95% CI** | **P-Value*** | **OR** | **95% CI** | **P-Value** | **OR** | **95% CI** | **P-Value*** |
| **Memory Loss** | | | | | | | | | | | | |
| Yes vs. No | **4.358** | **3.792-5.009** | **<.0001** | **3.774** | **3.208-4.440** | **<.0001** | **3.843** | **3.244-4.553** | **<.0001** | **3.600** | **3.016-4.298** | **<.0001** |
| **Factors Describing the Nature of Caregiving Relationship** | | | | | | | | | | | | |
| **Relationship to Recipient** | | | | | | | | | | | | |
| Parent/Grandparent vs. Non-Relative | **1.184** | **1.024-1.614** | **0.0224** | | | | 1.075 | 0.886-1.304 | 0.4610 | 1.023 | 0.841-1.246 | 0.8193 |
| Spouse or M/F in-law vs. Non-Relative | 1.063 | 0.913-1.237 | 0.4345 | | | | 1.200 | 0.974-1.479 | 0.0862 | 1.182 | 0.955-1.464 | 0.6437 |
| Sibling or B/S in-law vs. Non-Relative | 1.130 | 0.924-1.382 | 0.2337 | | | | 1.087 | 0.845-1.399 | 0.5138 | 1.063 | 0.821-1.377 | 0.1246 |
| Child/Grandchild vs. Non-Relative | **1.303** | **1.051-1.614** | **0.0156** | | | | 1.108 | 0.851-1.443 | 0.4461 | 1.052 | 0.796-1.390 | 0.7217 |

| | | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| Other Relative vs. Non-Relative | 0.954 | 0.763-1.193 | 0.6774 | 0.814 | 0.622-1.064 | 0.1312 | 0.807 | 0.616-1.059 | 0.1219 |
| **How long have you provided care** | | | | | | | | | |
| Less than 30 days vs. More than 5 yrs | **0.786** | **0.671-0.919** | **0.0026** | 0.925 | 0.759-1.126 | 0.4349 | 0.973 | 0.796-1.190 | 0.7920 |
| 1 mo to less than 6 mo vs. More than 5 yrs | 0.877 | 0.745-1.033 | 0.1153 | 0.907 | 0.746-1.102 | 0.3250 | 0.889 | 0.725-1.089 | 0.2549 |
| 6 mo to less than 2 yrs vs. More than 5 yrs | **0.847** | **0.728-0.986** | **0.0321** | 0.893 | 0.750-1.062 | 0.2005 | 0.896 | 0.750-1.072 | 0.2304 |
| 2 yrs to less than 5 yrs vs. More than 5 yrs | **0.866** | **0.755-0.994** | **0.0410** | 0.914 | 0.779-1.072 | 0.2691 | 0.890 | 0.755-1.050 | 0.1660 |
| **How many hours per week do you provide care** | | | | | | | | | |
| 8 hrs or less vs. 40 hrs or more | **0.669** | **0.581-0.772** | **<.0001** | 0.833 | 0.692-1.001 | 0.0515 | 0.895 | 0.736-1.089 | 0.2670 |
| 9 to 19 hrs vs. 40 hrs or more | 0.971 | 0.813-1.161 | 0.7488 | 1.157 | 0.932-1.436 | 0.1862 | 1.168 | 0.933-1.463 | 0.1752 |
| 20 to 39 hrs vs. 40 hrs or more | **0.778** | **0.644-0.941** | **0.0096** | 0.882 | 0.714-1.090 | 0.2466 | 0.880 | 0.703-1.101 | 0.2630 |
| **Tasks of Activities of Daily Living (ability to)#** | | | | | | | | | |
| Yes vs. No | **1.254** | **1.133-1.389** | **<.0001** | 0.995 | 0.871-1.136 | 0.9379 | 0.959 | 0.836-1.100 | 0.5485 |

| | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|
| **Tasks of Instrumental Activities of Daily Living (ability to)$^{\#\#}$** | | | | | | | | | |
| Yes vs. No | **1.339** | **1.181-1.517** | **<.0001** | 1.124 | 0.956-1.321 | 0.1569 | 1.096 | 0.931-1.291 | 0.2719 |
| **Factors Describing Caregiver Unmet Needs** | | | | | | | | | |
| **Support Needed for Caregivers** | | | | | | | | | |
| Classes about Care vs. No Help Needed | 1.245 | 0.870-1.781 | 0.2314 | | | | 1.216 | 0.798-1.853 | 0.3632 |
| Help Access to Services vs. No Help Needed | **2.215** | **1.881-2.609** | **<.0001** | | | | **1.997** | **1.636-2.439** | **<.0001** |
| Individual Counseling vs. No Help Needed | **3.865** | **2.730-5.472** | **<.0001** | | | | **3.207** | **2.141-4.804** | **<.0001** |
| Support Groups vs. No Help Needed | **2.415** | **1.824-3.197** | **<.0001** | | | | **2.647** | **1.916-3.659** | **<.0001** |
| Respite vs. No Help Needed | **2.128** | **1.655-2.737** | **<.0001** | | | | **1.998** | **1.485-2.689** | **<.0001** |

**Demographic Characteristics of Caregivers**

| | | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| **Sex** | | | | | | | | | | | | |
| Male vs. Female | **0.619** | **0.558-0.688** | **<.0001** | **0.568** | **0.501-0.644** | **<.0001** | **0.565** | **0.497-0.642** | **<.0001** | **0.578** | **0.506-0.659** | **<.0001** |
| **Age** | | | | | | | | | | | | |
| 25-54 vs. 65 and over | **1.878** | **1.647-2.141** | **<.0001** | **1.850** | **1.528-2.240** | **<.0001** | **1.977** | **1.616-2.418** | **<.0001** | **1.933** | **1.572-2.377** | **<.0001** |
| 55-64 vs. 65 and over | **1.737** | **1.540-1.960** | **<.0001** | **1.638** | **1.387-1.933** | **<.0001** | **1.709** | **1.438-2.032** | **<.0001** | **1.684** | **1.411-2.009** | **<.0001** |
| **Race** | | | | | | | | | | | | |
| NH African-American vs. NH White | 0.969 | 0.827-1.136 | 0.6979 | **0.739** | **0.607-0.899** | **0.0026** | **0.728** | **0.593-0.894** | **0.0025** | **0.705** | **0.567-0.876** | **0.0017** |
| NH American Indian or Alaskan Native vs. NH White | 1.572 | 0.926-2.670 | 0.0942 | 1.325 | 0.731-2.404 | 0.3537 | 1.179 | 0.637-2.185 | 0.5999 | 1.251 | 0.665-2.355 | 0.4871 |
| NH Asian, Native Hawaiian, or Pacific Islander vs. NH White | 0.635 | 0.387-1.042 | 0.0721 | 0.761 | 0.435-1.333 | 0.3404 | 0.735 | 0.415-1.303 | 0.2914 | 0.706 | 0.385-1.296 | 0.2614 |
| NH Multiracial and Other vs. NH White | 1.267 | 0.961-1.670 | 0.0932 | 1.030 | 0.745-1.423 | 0.8595 | 1.062 | 0.746-1.512 | 0.7394 | 1.022 | 0.697-1.499 | 0.9098 |
| Hispanic vs. NH White | 0.911 | 0.683-1.216 | 0.5272 | **0.689** | **0.498-0.953** | **0.0243** | 0.732 | 0.520-1.028 | 0.0720 | **0.634** | **0.444-0.906** | **0.0124** |

|  |  |  |  |  |  |  |  |  |  |  |  |  |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| **Marital Status** |  |  |  |  |  |  |  |  |  |  |  |  |
| Living Together vs. Not Living Together | **0.710** | **0.636-0.791** | **<.0001** | 0.938 | 0.808-1.089 | 0.3992 | 0.894 | 0.764-1.046 | 0.1615 | 0.899 | 0.763-1.058 | 0.2009 |
| **Educational Attainment** |  |  |  |  |  |  |  |  |  |  |  |  |
| Completed High School vs. Not Completed High School | **0.686** | **0.560-.840** | **0.0003** | 0.868 | 0.678-1.111 | 0.2617 | 0.915 | 0.701-1.194 | 0.5142 | 0.860 | 0.653-1.132 | 0.2817 |
| Some Technical School/College vs. Not Completed High School | **0.766** | **0.631-0.931** | **0.0073** | 1.065 | 0.833-1.361 | 0.6163 | 1.141 | 0.876-1.487 | 0.3278 | 1.019 | 0.776-1.339 | 0.8922 |
| Completed Technical School/College vs. Not Completed High School | **0.565** | **0.465-0.686** | **<.0001** | 0.971 | 0.753-1.253 | 0.8226 | 1.044 | 0.793-1.375 | 0.7571 | 0.910 | 0.685-1.208 | 0.5137 |
| **Employment Status** |  |  |  |  |  |  |  |  |  |  |  |  |
| Unemployed vs. Employed | **2.061** | **1.574-2.699** | **<.0001** | **1.680** | **1.183-2.385** | **0.0038** | **1.787** | **1.246-2.564** | **0.0016** | **1.783** | **1.240-2.566** | **0.0018** |
| Homemaker vs. Employed | **1.430** | **1.161-1.761** | **0.0008** | 1.205 | 0.944-1.538 | 0.1337 | 1.148 | 0.893-1.477 | 0.2815 | 1.180 | 0.910-1.529 | 0.2116 |
| Retired vs. Employed | **0.762** | **0.679-0.855** | **<.0001** | 0.923 | 0.779-1.093 | 0.3534 | 0.940 | 0.789-1.120 | 0.4900 | 0.932 | 0.779-1.114 | 0.4387 |
| Unable to Work vs. Employed | **3.817** | **3.220-4.525** | **<.0001** | **2.143** | **1.722-2.667** | **<.0001** | **2.089** | **1.669-2.615** | **<.0001** | **2.029** | **1.602-2.571** | **<.0001** |

| | | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| **Income** | | | | | | | | | | | | |
| $26K to less than $50K vs. Less than $25K | **0.603** | **0.513-0.708** | **<.0001** | **0.823** | **0.685-0.989** | **0.0373** | **0.825** | **0.683-0.996** | **0.0456** | 0.849 | 0.698-1.032 | 0.0998 |
| $50K to less than $75K vs. Less than $25K | **0.552** | **0.471-0.648** | **<.0001** | **0.732** | **0.602-0.891** | **0.0018** | **0.728** | **0.596-0.890** | **0.0019** | **0.737** | **0.601-0.905** | **0.0036** |
| Greater than $75K vs. Less than $25K | **0.451** | **0.393-0.517** | **<.0001** | **0.604** | **0.492-0.742** | **<.0001** | **0.601** | **0.486-0.742** | **<.0001** | **0.602** | **0.484-0.749** | **<.0001** |
| **Any Type of Insurance Coverage** | | | | | | | | | | | | |
| Have Coverage vs. No Coverage | **0.720** | **0.594-0.873** | **0.0008** | 1.068 | 0.827-1.379 | 0.6155 | 1.100 | 0.847-1.430 | 0.4746 | 1.157 | 0.875-1.531 | 0.3071 |
| **Medical Provider** | | | | | | | | | | | | |
| One Provider vs. No Provider | **0.848** | **.0720-0.997** | **0.0463** | 0.962 | 0.790-1.172 | 0.7015 | 0.946 | 0.772-1.160 | 0.5958 | 0.962 | 0.777-1.190 | 0.7210 |
| More than One Provider vs. No Provider | 0.933 | 0.742-1.173 | 0.5505 | 1.055 | 0.796-1.400 | 0.7078 | 1.044 | 0.781-1.395 | 0.7704 | 1.082 | 0.800-1.464 | 0.6088 |

*Bold indicates a significant P-value at an alpha level of 0.05

#ADLs are defined as Activities of Daily Living

## IADLs defined as Instrumental Activities of Daily Living

†Type and Characteristics of Informal Caregivers include: age, sex, race, gender, marital status, education, employment, income, medical providers, insurance coverage

†† Nature of the Caregiving Relationship includes: the caregiver's relationship to the care recipient, and the direct care provided to the care recipient

†††Caregiver Unmet Needs include: assistance a caregiver may need but is not receiving

# CHAPTER 6

# CONCLUSION

Informal, unpaid caregiving is a critical facet of the individual health status and the US health system, albeit informal, as the population in the United States continues to age. Caregiving is influenced dramatically by the combination of longer lives, more chronic diseases, medical technology advances, shortages in the health care industry, and fewer available numbers of caregivers. Caregiving can have both positive and negative consequences. The negative consequences are a combination of experiences leading to stress and, in many instances, caregiver burden. Increased levels of caregiver burden have been associated with subjective cognitive decline. This dissertation research examined the intersection between informal caregivers and subjective cognitive decline to determine who the caregivers were and what were the impacts of cognitive decline on caregiver health and function.

Manuscripts one and two (chapters 4 and 5, respectively) were based on analyses of data collected from the Behavioral Risk Factor Surveillance System (BRFSS) from 2015 through 2018, the core survey, and the optional caregiver and the optional cognitive decline modules. Chapter 4 used a cross-sectional analysis to provide a population-based national perspective regarding informal caregivers to identify associations between caregivers' self-reporting cognitive decline and those caregivers' self-reporting no cognitive decline. Chapter 5 provided a cross-sectional study to measure the associations between informal caregivers' self-reporting cognitive decline and their health outcomes.

The results from Chapter 4 indicated that the demographic characteristics, the nature of the caregiving relationship, and caregivers' unmet needs were associated with cognitive decline. Regression analysis showed significantly higher odds of subjective cognitive decline among males and in individuals who were unemployed and unable to work. Chapter 5 indicated similar results in the analysis related to health-related outcomes. Subjective cognitive decline is strongly associated with self-reported fair/poor health when examining general health. Regression analysis showed higher odds of subjective cognitive decline for caregivers with self-reported fair/poor for general health and physical health, and the highest odds were in the association between subjective cognitive decline and mental health.

In the results for each chapter, we examined differences between caregivers with cognitive decline compared to those reporting no cognitive decline. The findings indicated associations at multiple levels. The study also examined the functional impacts of subjective cognitive decline and informal caregivers. More than half of caregivers with self-reported cognitive had difficulties completing their day-to-day activities. The cross-sectional design of the studies prevented any causal inferences between subjective cognitive decline and caregiving. Further research will more thoroughly examine policy implications and needed changes to better provide services to informal caregivers.

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