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ASSOCIATION BETWEEN CAREGIVING-RELATED FACTORS AND EXHAUSTION AMONG INFORMAL CAREGIVERS OF A LOVED ONE WITH ALZHEIMER'S DISEASE OR A RELATED DEMENTIA

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AN ABSTRACT OF A THESIS SUBMITTED TO THE FACULTY OF THE ROLLINS SCHOOL OF PUBLIC HEALTH OF EMORY UNIVERSITY IN PARTIAL FULFILLMENT OF THE REQUIREMENTS FOR THE DEGREE OF MASTER OF PUBLIC HEALTH IN GLOBAL HEALTH
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ABSTRACT

ASSOCIATION BETWEEN CAREGIVING-RELATED FACTORS AND EXHAUSTION AMONG INFORMAL CAREGIVERS OF A LOVED ONE WITH ALZHEIMER'S DISEASE OR A RELATED DEMENTIA

OBJECTIVE

Informal caregivers provide assistance without monetary compensation. Do people who take on an informal caregiving role have high frequencies of adverse health outcomes? This study aimed to assess whether caregiving-related factors were correlated with being exhausted at night.

METHODS

Utilizing the nationally representative 2017 National Study of Caregiving (NSOC) interviews, data were analyzed for 506 informal caregivers. Being exhausted at night was the outcome of interest. Caregiving-related factors were the number of hours per day spent in caregiving, financial difficulty associated with the caregiving role, the physical difficulty associated with the role, and the relationship to the care recipient. Socio-demographic factors of caregivers were included to assess whether any additional factors were associated with feeling of exhaustion. I estimated descriptive statistics and six ordinal logistic regressions. All analyses were adjusted using survey weights, to be able to generalize to caregivers of Medicare beneficiaries with ADRD.

RESULTS

Among the caregiving related factors included caregiving hours per day, the perceived financial difficulty, and perceived physical difficulty were significantly associated with caregiver's being exhausted at night. Once covariates were introduced, caregiving helping hours were no longer significantly associated with being exhausted at night, although financial difficulty and physical difficulty associated with the caregiving role remained significant. Further, caregivers who were emotionally distressed and those who were women had a significantly higher likelihood of reporting being either somewhat or very much exhausted at night.

CONCLUSIONS

More than half of ADRD caregivers report being exhausted at night. This research indicates that there are differences in being exhausted at night related to components of the caregiving experience, such as the number of caregiving hours per day, financial difficulty, and physical difficulty. These findings indicate the need for resources and coping strategies to address the factors that contribute to caregiver exhaustion.

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Chapter I: Introduction

More than 46 million U.S. adults are at least 65 years old; national demographic trends and projections indicates this number will approach 90 million by the year 2050. [24] Concerns about the health, ability to function, and quality of life are of the utmost concern when studying the health and wellbeing of older adults. One of the most important factors associated with higher quality of life in older adults is cognitive wellbeing. [4, 37] “Cognitive health is a major factor in ensuring the quality of life of older adults and preserving their independence”. [13] Once cognitive health declines, the fear that the individual with develop some form of dementia increases. Dementia refers to the “loss of cognitive functioning— thinking, remembering, and reasoning— and behavioral abilities to such an extent that it interferes with a person’s daily life and activities”. [3]

Throughout this paper, the challenges placed upon one’s quality of life as they an informal caregiving role for someone with Alzheimer’s Disease or a Related Dementias (ADRD) will be discussed. Under this ADRD umbrella term are four specific forms of dementia— Alzheimer’s disease, frontotemporal dementia, Lewy body dementia, and vascular dementia. Each of these diseases impairs the memory, thought processes, and overall brain functioning of those diagnosed with either one or a combination of the dementia forms. In 2014 the burden of ADRD in the United States was estimated at 5 million adults aged 65 and older, which was 1.6% of the American population, which is half of the projected 2060 ADRD burden which is projected to reach 3.3% of the population, or 13.9 million Americans. [78]

Contributing to nearly 60% of all dementia cases, Alzheimer’s disease (AD) is the most common form of dementia and is often the cause of disability and dependency in older adults worldwide. [27, 36, 100, 122] Neurologically speaking, Alzheimer’s disease is characterized by “two hallmark pathologies: β-amyloid plaque deposition and neurofibrillary tangles of hyperphosphorylated tau”. [125] Additionally, the presence of fluids, imaging biomarkers, and the presentation of other clinical criteria result can be clear hallmarks of the presence of AD. [125] Cognitively, those with Alzheimer’s, whether in the predementia or dementia phase, experience changes in memory, are cognitively slower than they may have been before the disease progressed, and a loss of general awareness. [68] Revisions and additional research on Alzheimer's disease allows for better distinction between AD and other common forms of dementia.

Trailing Alzheimer's disease, vascular dementia is the second-most common form of dementia, accounting for somewhere between 15% and 30% of all dementia cases, largely depending on the population. [100, 116] Blood flow to the brain is reduced when someone has vascular dementia, resulting in the damage and destruction of brain cells. "Vascular dementia refers to any dementia that is primarily cause by cerebrovascular disease or impaired cerebral blood flow and falls within the spectrum of vascular cognitive impairment…".[128] Accurate diagnosis of this form of dementia often requires brain imagining which allows clinicians to quantify the degree of cognitive impairment present. While some caveats exist, vascular dementia can often be classified based on the presence of substantial burdens of white matter lesions (i.e., >25%), lacunes, strategic infarcts. [116]

The NINDS-AIREN criteria has been established to accurately diagnose vascular dementia, noting a diagnosis of *probable* vascular dementia can be made with when the following clinical features are present: "early presence of gait disturbance; a history of unsteadiness and frequent, unprovoked falls; early urinary frequency, urgency, and other urinary symptoms not explained by urologic disease; pseudobulbar palsy; and personality and mood changes, abulia, depression, emotional incontinence, or other subcortical deficits".[103] Sudden cutoffs of blood supply to the brain, as well as the blockage and narrowing of blood vessels inside the brain, which describe the occurrence of a stroke, often make individuals susceptible to developing vascular dementia, hence the reason why vascular dementia is sometimes called "Post Stroke Dementia".

Metaphorically, the way Lewy bodies accumulate and effect the brain is like the way a dam acts in a river. When the dam is placed in the river, it becomes an effective way to hold back the water and block the river flow. Similarly, the Lewy bodies, small protein particles, present in the brain gather and clot the neurons, preventing them from functioning and causing them to fail. [28, 64] Lewy bodies, known as alpha-synucleins, are notable causes of both Lewy bodies dementia (DLB) and Parkinson's disease with dementia (PDD). Often academic literature and research studies discuss DLB and PDD together as they overlap in symptoms and manifestation. However, the difference lies in the timing of the events and the onset of symptoms. When dementia symptoms arise and develop prior to the motor disorder the individual is diagnosed with Lewy bodies dementia. Contrary, when the individual develops a motor disorder and then begins to develop dementia, they are diagnosed with Parkinson's disease with dementia.

The prevalence of this disease is often difficult to determine as both Lewy bodies dementia and Parkinson's disease with dementia are lumped together. Further, individuals diagnosed with DLB often have a comorbidity between both DLB and Alzheimer's disease. Dementia with Lewy Bodies, a term synonymous to Lewy body dementia, is often distinguished from other forms of dementia based on the presence visual hallucinations, slowness and rigidity with reference to their movements and mobility, sleep disturbance, and mood changes which can result in heightened feelings of depression, apathy, paranoia, and agitation. [3, 68] It seems the rate of Lewy bodies dementia in the ADRD population is somewhere between 10% and 25%.[68]

Frontotemporal dementia is estimated to be prevalent in some ten to fifteen percent of the dementia population.[89, 97] In the Lund and Manchester groups in 1994, the diagnostic characteristics of frontotemporal dementia were settled with distinguishing features including "behavioral disorder, affective symptoms, a speech disorder, preservation of spatial orientation and praxis, some physical signs, normal EE, predominant frontal or anterior temporal abnormality on imaging, and frontal dysfunction at neuropsychic testing". [92] When looking at the neurological breakdown of the disease, the frontal and temporal lobes of the brain are affected and deteriorated because of an abnormal collection of proteins in the brain, which prevent the brain from effectively functioning. The nerve cells begin to shrink, eventually disappearing entirely. [33, 68] "Frontotemporal lobar degeneration is the second most prevalent form of early-onset neurodegenerative dementia, after Alzheimer's disease", that is amongst those between the ages of 45 and 64 years old. [8]

An overwhelming majority (~80%) of those with dementia live in residential, community settings, meaning assistance and care comes from individuals outside of clinical settings. [22, 70] Eighty-three percent of help and assistance provided to an older adult in the United States comes from family members, friends, or some other unpaid caregiver. [42] Of those unpaid, informal caregivers providing care for an older adult, nearly half (48%) are providing care for someone with Alzheimer's disease or some related dementia. [114] In 2015, nearly 16 million Americans were providing informal care for a family member with Alzheimer's disease or a related dementia. [6] With scarce availability and eligibility to receive government assistance or funding services as an informal caregiving, the caregiving role can be difficult and burdensome for many. Caregivers responsible for provisioning care for a loved one with ADRD often compromise their own health under the pressure of not only caring for the individual with ADRD, but also as must also perform and be accountable for other duties and responsibilities — other dependents, employment, your own health, and wellbeing. The wellbeing and health of informal caregiver is ever more important alongside the projected increase in the aging community, and subsequentially an increased prevalence of older adults with ADRD, as anticipated, meaning the demand for informal caregivers will only surge.

Research Question

This research study aims to better understand the physical and psychological outcomes of being a caregiver for someone with Alzheimer's disease or a related dementia (ADRD). Specifically, the study aims to assess whether a relationship exists between caregiving related factors and being exhausted at night among ADRD caregivers. Notably, caregiving related factors include the relationship between the caregiver and care recipient, the perceived physical and financial difficulty associated with being a caregiving, and the number of hours spent as a caregiver helping the recipient. Being 'exhausted at night' will be assessed based on the degree of agreement to the statement "you [the caregiver] feel exhausted when you go to bed at night".

Each caregiving related factor will be assessed independently, meaning this study will test four unique hypotheses. If the null hypothesis is true, there will not be an association between the caregiving related factor and being exhausted at night. If, instead, the alternative hypothesis is true for the given caregiving related factor, which we expect to be true, there will be a statistically significant association between being exhausted at night as a caregiver and caregiving related factors. The hypotheses being tested in this study are:

H_1: The number of caregiving helping hours spent assisting the care recipient daily effects how exhausted ADRD caregivers are at night.

H_2: Perceiving the caregiving role as a financial difficult one will result in differences among ADRD caregivers regarding how exhausted they are at night.

H_3: Perceiving the caregiving role as a physically difficult one will result in differences among ADRD caregivers regarding how exhausted they are at night.

H_4: Differences in how exhausted caregivers of those with ADRD are will be affected by the whether the caregiver is the spouse, child, or of some other relation to the care recipient.

Conversely, the null hypothesis for each of the hypotheses listed below would be the caregiving related factor listed would not have an effect nor be associated with being exhausted at night.

Chapter II: Review of Relevant Literature

Dementia is a term used to describe several diseases where the affected individual experiences a decline in their cognitive abilities. Alzheimer's disease (AD) is the most common form of dementia amongst the more than 400 types, afflicting nearly 6 million Americans, and 50 million people worldwide.[101,125] As the sixth leading cause of death in the United States, Alzheimer's disease is the one of the few diseases in the top 10 leading causes of death that cannot be cured, prevented, or slowed, claiming the life of one in three seniors within four to eight years following an AD diagnosis. [6, 96, 118] Alongside Alzheimer's disease, there are several related forms of dementia often studied with AD, including vascular, Lewy body, and frontotemporal dementia. Using resources, including the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-5) and the National Institute of Health (NIH) criteria, physicians and researchers can better distinguish which form of dementia patients have based on the symptoms they present. As described in the Introduction of this paper, each form of Alzheimer's disease and related dementias (ADRD) have unique presentations and biomarkers which distinguish them from one another.

Epidemiology of ADRD

Alzheimer's Disease

A progressive neurodegenerative disorder, Alzheimer's disease (AD) occurs in two forms — early onset Alzheimer's disease (EOAD) and the more common late-onset form. [9] Early-onset Alzheimer's disease (EOAD) is rare, usually progressing because of genetic changes, presenting in those between the ages of 30 and 60 years old. Signs and symptoms of late-onset Alzheimer's disease (LOAD) begin exhibiting in those in their mid-60's or older. Between the two forms, those with LOAD have the greatest levels of memory impairment, perform more poorly on language tests, and are slightly better at motor behavior tasks; additionally, they display more frequent psychiatric and behavioral symptoms related to their condition. [66, 112, 119] Across both forms of AD, different areas of the brain begin to shrink, resulting in impairments like those previously described. Neurons stop functioning, resulting in memory-loss and delayed response, beginning in the hippocampus region until atrophy sets in, affecting the entire brain. Countless research studies have attempted to better understand the etiology of AD by determining risk factors for disease, however few have been conclusive. While age and genetics have been established as factors associated with a higher likelihood of developing Alzheimer's disease, sex, history of head injuries, level of education, and trisomy 21 have also been suspected as risk factors for Alzheimer's disease, as well. [18, 46, 50, 56, 106, 109, 134]

Vascular Dementia

Ischemic white-matter brain lesions have been noted as a biomarker for vascular dementia, distinguishing it from the general white matter changes found in Alzheimer's patients.[23, 47, 86] Cerebrovascular diseases, those disorders where some area of the brain is affected by bleeding or ischemia for a temporary or permanent amount of time, were once considered to be the primary cause of age-related dementia.[72] Up to 20% of all dementia cases are related to some underlying vascular cause, including conditions such as stroke and atherosclerosis, however, the presence of these conditions do not always cause dementia.[63] "Cerebrovascular disease will be present in most individuals with dementia, but—just like other causes—rarely a cause on its own". [127] Reasoning, planning, memory, and judgement are all processes effected by the presence of vascular dementia. [62] Increased age, as is the case with many similar forms of dementia, is a substantial risk factor for vascular dementia. Further, a history of heart attacks, strokes or ministrokes, high cholesterol and high blood pressure, diabetes, smoking, obesity, and atrial fibrillation have been shown to increase an individual's risk for vascular dementia in a number of research studies. [47, 58, 102, 110, 132]

Lewy Body Dementia

Memory loss is one of the earliest symptoms of Lewy body dementia. [45] Lewy body dementia is characterized by the presence and accumulation of Lewy body proteins in the brain.[45, 53] This accumulation results in chemical changes and ultimately changes in the way those affected think, behave, and move. Affecting the cerebral and limbic cortex, along with the brain stem and the hippocampus, midbrain and basal ganglia, Lewy body dementia often results in widespread decline in overall abilities in those diagnosed with the condition.[45, 94] Similar to the other forms of ADRD, age, sex, and family history are risk factors for developing Lewy body dementia. Specifically, those older than 60 years old, as well as those with a family history of the disease or Parkinson's disease, are at greater risk for developing Lewy body dementia.[52, 124] Evidence also indicates women are at an increased risk for Lewy body dementia or Parkinson's disease with dementia, although some cohort studies have challenged these results. [67, 123]

Frontotemporal Dementia

Frontotemporal dementia is distinguished by "atrophy of prefrontal and anterior temporal cortices", which occurs in somewhere between 5-15% of all dementia patients.[83]Abnormal growth of proteins cause damage to the nerves in either the frontal or temporal regions of the brain, resulting in frontotemporal dementia.[83] Often referred to as a presenile dementia, frontotemporal dementia mostly affects people younger than 65 years old; most cases are diagnosed in those 45 to 65 years old, although some patients have been diagnosed as young as 21 years old.[10, 108] Besides family history, the only other established risk factor for frontotemporal dementia has been genetic markers, notably genes for proteins (*MAPT* and *TBK1*) and progranulin (*GRN* and *PGRN*), as well as the chromosome 9 gene *C9orf72*. [48, 83, 89]

Informal Caregiver Role

The socioeconomic costs of providing necessary care for someone with Alzheimer's disease or a related dementia is abundant. "In 2015, [worldwide] dementia costs were estimated at US$818 billion, equivalent to 1.1% of global gross domestic product—a staggering cost that had grown by 35% since 2010". [38] High-income countries, with a dementia population totaling 19.5 million, allocated US$487.1 billion in 2015 towards direct medical and social costs for those with ADRD.[126] Direct medical expenditures included physician visits, hospital and emergency room costs, pharmacy pick-ups, and short-term skilled nursing facilities. Non-medical, social ADRD costs include transportation, paid formal home-health care, and any costs that go towards paying for food, house, and car payments, as well as any other necessities.[32] Not included in the staggering US$487.1 billion quoted price of indirect costs were the efforts provided by informal caregivers. *Informal caregivers*— unpaid individuals who assist and provide care to family members, friends, and others with ADRD— from high-income countries contributed more than 30 billion hours of unpaid care in 2015, which, based on conservative estimates, is valued at US$271.1 billion.[126]

Caregiver Demographics

Informal caregiver research, also referred to as *familial caregivers, unpaid caregiver,* or just *caregivers*, indicates more than 40% of ADRD caregivers in the United States have a household income of $50,000 or less.[56, 59] Income and financial means of caregivers is an important measure to include in such research since research has demonstrated informal caregivers who are from higher income brackets have better health outcomes and a more positive perception of the caregiving experience.[56, 59] Addition statistics show two-thirds of ADRD caregivers are younger than 65 years old; further, more than half of ADRD caregivers are caring for their parent, and two-thirds of these caregivers are womens. [2, 41, 70, 96, 99] Non-Hispanic whites make up nearly two-thirds of the informal ADRD caregiver group, followed by African Americans at 17%, the 14% of Hispanics/Latinos, and 5% of Asians; other racial and ethnic groups make up the remaining 3% of informal caregivers.[2, 69, 96] One-fourth of informal ADRD caregivers fall into the sandwich generation, caring not only for someone with Alzheimer's or a related dementia, but also a dependent child or grandchild.[1, 81] Two-thirds of these informal caregivers are living with the care recipient, meaning they are constantly on-call when they are home and often are overworked by their caregiving duties. [96]

Responsibilities of Caregiver

"More than 16 million family members and other unpaid caregivers provided an estimated 18.5 billion hours of care to people with Alzheimer's or other dementias" [6] in the United States during 2018.[38] Responsibilities include assistance with hearing, mobilization, decision making. Those without the financial means to offset their duties by employing help elsewhere, as well as those who continue to be employed while also being a caregiver are overworked and stressed. Caregivers provide companionship for those with dementia and the ability to serve as a mode of communication and a source of information for physicians and professionals caring for the care recipient. Although caregivers often struggle as a informal caregiver, research demonstrates the ADRD caregiver and recipient relationship is often still a mutually beneficial one.

Rewarding Role as Informal Caregiver

A number of positive outcomes and feelings are often reported in those who are an informal caregiver. Positive experiences, or the overall thought that their caregiving role was a positive and rewarding one, was reported by 83% of respondents in a National Opinion Survey Center (2014) report.[40] Unsurprisingly, those who mention higher benefits from their caregiving experience also had lower levels of depression and higher degrees of life satisfaction than did those who subjectively appraised their caregiving role as an overall stressful one.[51, 98] A Swiss sample of 159 informal caregivers of patients with schizophrenia sought to understand not only the negative consequences of taking on an informal caregiving role, but also the ways this role can provide a positive experience for someone responsible for caring for a patient with severe mental illness. [17] As imagined, "negative experience of caregiving can be explained by a greater perception of coping with stress and the perception of more difficulties".[17] Similar perceptions of the caregiving role have been observed among ADRD caregivers.

Main findings from the Harmell report (2011) found dementia caregivers with higher levels of self-efficacy and mastery in their caregiving duties also had increased use of positive coping strategies, including the use of spirituality. Most dementia caregiving research notes positive aspects which fall into one of following three categories: "i) personal and social affirmation of role fulfillment, ii) effective cognitive emotional regulation, and iii) contexts which favour finding meaning in the caregiving process".[95, 133] Caregivers for those with ADRD who report positive aspects of their caregiving role often mention boosts to their satisfaction and meaning of life, which in turn are associated with better mental health outcomes, self-efficacy, and overall quality of life. While one may mention feeling as though their life has more meaning as a caregiver, they often find themselves between strain and happiness from their role.

Burnout in Informal ADRD Caregivers

Unpaid ADRD caregivers are 2.5 times more likely to have mental or emotional challenges than caregivers for individuals with non-dementia conditions; further, one in every three caregivers reported their health had worsened or was compromised due to their caregiving role and responsibilities.[6, 32, 85, 111] *Caregiver burnout* expounds the "psychological syndrome that appears in response to chronic and interpersonal stressors" within the caregiving environment.[120] Signs of caregiver burnout often resemble those of stress and depression in other individuals; **emotional exhaustion**, poorer physical health (e.g., getting sick more often), **changes in sleep patterns**, irritability, and withdrawal from friends and family often accompany the caregiver role as individuals begin dedicating their time and efforts to caring for someone else, often making their own wants and needs secondary to those of their care recipient.[21, 93] Since this paper will discuss and assess the sleep outcomes and emotional wellbeing of ADRD caregivers, we will take time to discuss the findings relating to these two aspects of caregiver burnout below.

Emotional Wellbeing

"After that point her health had quickly gone downhill, and she developed new chronic conditions and old ones worsened. I've always considered caregiving the culprit".[115] Caregivers of loved ones with ADRD display high levels of strain, feelings of loneliness and disappointment, and higher frequencies of depressive disorders and anxiety than non-dementia caregivers, as well as burnout and other forms of emotional and physical strain.[34, 51, 65, 131] As the severity of the dementia symptoms worsen and the dementia progresses, caregiver burden along with the other adverse health outcomes are exacerbated. Supporting individuals with Alzheimer's or a related dementia "comes at a cost of caregiver distress and poorer quality of life".[15]

Research studies often aim to understand and quantify the burden placed on caregivers in ADRD caregiver populations. Schulz (2003) assessed the emotional effects and bereavement felt by 217 family caregivers who were caring for a loved one towards the end of the recipient's life. Half of Schulz's (2003) participants felt as if they were 'on caregiving duty' 24 hours a day; half of the study's participants stated they provided care for more than 45 hours a week! While caregivers display remarkable resilience, the extensive hours and work required because of their role often fosters high levels of stress and *caregiver burden*- defined by Pearlin (1990) as “the all-encompassing challenges felt by caregivers with respect to their physical and emotional well-being, family relations, and work and financial status”.

Emotional exhaustion has been quantified and measured in other studies using methods including the *Maslach Burnout Inventory (MBI)*, a 22-item survey designed to effectively measure emotional exhaustion, depersonalization, and personal accomplishment amongst informal caregivers.[77] The inventory uses a seven-point Likert scale to assess the outcomes and feelings of emotional exhaustion. In Salama’s 2012 cross-sectional study, 63.9% of caregivers for impaired elderly patients in rural Lower Egypt experienced severe degrees of burden.

Amongst caregivers of family members with Alzheimer’s disease, nearly 15% of caregivers displayed some form of caregiver burnout.[7] Further, the presence of emotional exhaustion in caregivers was significantly associated with anxiety, depersonalization, and depressive symptomology. [7, 131] Truzzi (2012) found 42.1% of dementia caregivers, amongst a sample of 145 caregivers providing care for someone with dementia who was treated in Rio de Janeiro, had high levels of emotional exhaustion, based on the use of the MBI scale. In an Istanbul sample, 25% of dementia caregivers displayed high levels of emotional exhaustion with the use of the Maslach Burden Inventory.[130] Caregivers with high levels of emotional exhaustion experienced negative perceptions of health and often delirium and depression.[120, 121]

Pines Burnout Measure (PBM) is also commonly used to evaluate the physical and emotional burden placed on caregivers.[76] This 21-point item scale uses a 7-point Likert scale, similar to that of the MBI. In studies using PBM to evaluate caregiver stress and emotional wellbeing, similar results were found to those described above where caregiver’s quality of life was significantly associated with their distress measures; caregiver burnout was significantly predicted by high degrees of caregiver aggression, depression, abnormal motor behavior, hallucinations, and irritability. [61, 117]

Sleep Patterns

Nocturnal sleep disturbances are frequent in those diagnosed with Lewy bodies dementia, but across both Lewy’s bodies dementias (i.e., dementia with Lewy bodies and Parkinson's disease dementia) and Alzheimer’s disease sleep disturbances were higher than the public and corresponded with delusions, apathy, and agitation in the dementia patient. [14, 104] In the Rongve (2010) sample of mild dementia patients, the most reported sleep disturbance was insomnia, which was reported 29.9% of the time. “Approximately one-quarter of adults with dementia experience sleep disturbances”. [105] Further, Lewy bodies dementia, compared to other forms of dementia, had the highest prevalence of circadian and sleep disturbances, which includes episodes of nightmares, generalized exhaustion during the day, early-morning awakenings, fragmented sleep, and sleep latency.[5, 90]

Vascular dementia and Alzheimer’s disease patients also commonly experience obstructive sleep apnea. In one Welsh cohort study, 20% of vascular dementia patients had reported disturbed sleep and another 30% reported *severe* daytime sleepiness. [39] Frontotemporal dementia patients often experience comorbidities with their dementia diagnosis and sleep disorders, including insomnia and excessive daytime sleepiness. This “significantly contribute[s] to caregiver burden and burnout”. [79] While battling these two comorbidities between poor sleep and dementia status, many informal caregivers often also experience similar symptoms as they are kept awake or experience disrupted sleep while caring for the recipient who awakes throughout the night, leaving them exhausted throughout the daytime.

Non-caregivers report significantly more hours of sleep during the week, clocking in somewhere between 2.42 to 3.50 extra hours of sleep each week compared to their caregiver counterparts.[44, 75] Those dedicating more hours a week to caregiving duties report shorter hours of sleep than do those who spend less hours a week dedicated to caregiving duties.[75] Interestingly, antidepressant use has been associated with longer sleep time in Alzheimer’s caregivers, which demonstrates depression and other mental health concerns may also explain poor sleep quality in caregivers.[16, 80]

An epidemiological study found amongst family caregivers for a loved one with dementia, Chalder fatigue scale (CFS) scores were significantly higher than were scores observed in the non-caregiver group.[91] Zvěřová (2012) quantified chronic fatigue amongst Alzheimer’s caregivers in Prague and found the following frequencies with relation to how fatigued the caregivers were: 9.59% (*never*), 23.29% (*seldom*), 45.20% (*sometimes*), and 21.92% (*often*). Similar studies observed sleep problems in three-fourths of the sample.[135] One such study report 72.5% of Alzheimer's disease caregivers had difficulty falling asleep.[29, 90] Twenty-five percent of informal caregivers of either an Alzheimer's or Parkinson's disease patient reported using sleep medication.[30]

Extant literature has assessed the relationship between emotional wellbeing sleep quality in ADRD caregivers. In Smyth's (2020) sample, nearly all (94%) dementia caregivers were poor sleepers "with 84% [having] difficulty initiating sleep and 72% reporting having difficulty maintaining sleep".[113] Further, these outcomes were significantly associated with psychological distress and high levels of severe depression, anxiety, and stress. [113] To date, there has only been one journal published article which assessed the relationship between several psychological, contextual, and physical health outcomes of dementia caregivers using the National Study of Caregiving (NSOC) sample. The paper looked at the frequency of nighttime awakenings and found 16% of caregivers reported experiencing awakenings nearly every night, which was significantly associated with higher fall risk in care recipients, as well has more chronic conditions and emotional difficulty related to their caregiving role.[74]

Demographic Differences in Caregiver Burden

Age

Millennial caregivers are an often-overlooked subpopulation of informal caregivers. Findings demonstrate high degrees of stress, strain, and attitudes of ageism within this young population of caregivers. Among millennial caregivers for someone with ADRD 79% experience emotional distress, as well as difficulties with accessing affordable care, and 52% are in need of resources to mitigate their emotional and physical distress. [2]

Research surrounding sleep outcomes and caregiver age has not been conclusive. Whereas some studies conclude older caregivers have poorer sleep outcomes, others report older caregivers staying in bed for longer periods of time and having overall better sleep efficiency when compared to younger caregivers. [12, 44, 80] Much of this is the result of differing definitions for the outcomes and different measures being utilized to quantify sleep outcomes. One particular meta-analysis of all research comparing sleep outcomes to caregiver age found when all of the studies are combined the significance between the variables no longer exists. However, with the limited inclusion of caregivers from younger generations in research studies there is a gap in knowledge and additional studies must be conducted.

Gender

Various research studies have demonstrated that women are more likely to be informal caregivers for dementia patients than men; these estimates for the gender difference between ADRD caregivers roughly ranges from 58 to 70 percent in favor of women.[19, 87, 129] Caregiver burden is also different based on the caregiver's gender, as well. Women caregivers have displayed significantly higher levels of depression when compared to their male counterparts, as well as "greater psychological stress, more family conflicts, higher guilt, lower psychological quality of life, sense of coherence and ability to control disturbing thoughts". [25, 43, 117, 129] Overall, women who are caregivers are at greater risks for emotional challenges and higher degrees of stress associated with their informal caregiving role.

Greater depressive symptoms have been associated with poorer health outcomes, a connection which may explain some of the reasons why female dementia caregivers have poorer sleep outcomes than males. "Caregivers reported more depressive symptoms, and depression [were] strongly correlated with longer sleep latency".[20] Age may also confound this relationship. "Dementia caregivers [who] are older women … are at risk for age-related sleep disturbances, including sleep latency, decreased sleep maintenance, decreased slow wave and REM sleep…".[80] Each of these disruptions lead to exhaustion and generalized fatigue throughout the day. While there is some evidence to indicates female caregivers are likely to report poorer sleep quality outcomes than male caregivers, there also is evidence pointing in the opposite direction. Men who were caregivers caring for a spouse with dementia, specifically moderate or severe dementia cases, reported waking up again after sleep onset 64% of the time, compared to the 48% of women who were caring for their spouse with dementia. [82]

Race and Ethnicity

There are considerable racial differences within the informal caregiving population, especially when focusing on dementia caregivers in the United States. Most dementia caregiver in the United States are White, followed by 17% of Black caregivers, 14% of Latinos, 5% of Asian caregivers, and 3% of

Native American or Alaska Native caregivers. [2, 69, 96] When studying psychological wellbeing of caregivers, non-Hispanic Whites reported higher burdens of caregiver stress, burden, and depression than did African American and Hispanic/Latinx caregivers.[26, 51, 75] Racial minorities also report using psychosocial coping resources (i.e., religion, faith, and prayer) more than non-Hispanic Whites; minority caregivers endorsed stronger beliefs relating to familial support, as well, when compared to non-Hispanic Whites.[26, 51, 73] This indicates, despite the injustice and discrimination racial minorities face on a daily basis, psychosocial support and familial ties may help mitigate the difficulties and challenges associated with being an informal, ADRD caregiver.

This research will add to the bodies of evidence described as it considers the associations between caregiving related factors, socio-demographic factors of caregivers, and caregiver symptoms to poor sleep outcomes.

Chapter III: Research Study

Data Section

This study utilizes information from two datasets, the National Health & Aging Trends Study (NHATS) and the National Study on Caregiving (NSOC). All caregiver variables of interest discussed in this paper came from the NSOC. However, participation in the study in contingent on the ADRD status of care recipients, which was gathered from the NHATS. Since 2011 NHATS has annually collected information from their nationally representative sample of Medicare beneficiaries who are 65 years or older through interviews. Participation in NHATS is also contingent on living in one of the contiguous United States, that is all U.S. states excluding Alaska and Hawaii. The study is designed to capture the changes in daily life and functioning as individuals get older. Participation in the NHATS is not conditional based on an Alzheimer's or related dementia diagnosis, therefore analysis took place to remove those who do not have some form of what was deemed *probable* dementia.

Those in the original 2011 cohort have been interviewed annually, if they are still alive, for follow-up interviews. Each new year of the NHATS interviews corresponds with a round. For example, this study looked at information from the Round 7 interviews, which took place during 2017. Since NHATS has established a cohort of older adults, replenishment of the sample size has been conducted. During the Round 5 study the older adult sample in NHATS was replenished to replace those original 2011 older adults in the sample who may have died, lost contact, or wished to no longer be a part of the study. Of the 19,530 individuals who completed the Round 7 NHATS interview, 12,411 of them were from the original 2011 cohort, meaning 7,119 participants were replacements who were recruited during the 2015 replenishment.

Those older adults who completed the NHATS Round 6 interviews were mailed information asking them whether they would like to setup an appointment to participate in the upcoming 2017 interviews. If the NHATS participant had died between completing the 2016 interview and the 2017 interviews taking place the proxy identified as the best respondent to answer questions about the last month of the NHATS participant would be asked to participate in the last month of life interview.

Importantly, all of the caregivers included in this sample were caring for an older adult at the time of the interview. None of the care recipients had died prior to the interviews. Both studies are nationally representative, but methods were put in place to oversample older adults, as well as those who are Black, which explains the higher frequencies of these groups in the NHATS samples compared to the frequencies observed in the general population. More information about the NHATS and NSOC sampling design, along with the weights used during the analysis of this research study, can be obtained from the DeMatteis, Freedman, and Kasper 2018 paper.

To explore the role being a caregiver for one of these older adults included in the NHATS cohort, the supplemental National Study on Caregiving (NSOC) was developed. Caregivers were only included in analysis during Rounds 1, 5, and 7 of the corresponding NHATS study. All caregivers included in the NSOC are informal caregivers, meaning they are not compensated for the work they do as a caregiver to the older adult. Participants included in the NSOC answer questions about themselves, as well as details about the behaviors and activities they provide and assist with for their care recipients.

There were 6,312 Medicare beneficiaries who completed the NHATS Round 7 interviews, and 2,652 informal caregivers were identified among those Medicare beneficiaries who completed the NHATS interviews. For this project, analysis was conducted to extract only those NHATS older adults who, either by their own account or from the response of their proxy who was used to answer questions on behalf of the older adult, were diagnosed with dementia or were displayed a number of symptoms associated with probable dementia. Kasper, Freedman, & Spillman (2013) have created methodology to be used specifically for the NHATS dataset to best characterize participants who have probable dementia. Following the deletion of participants based on the *probable* dementia criteria laid forth by Kasper, Freedman, & Spillman (2013), 802 NHATS participants were left. These 802 participants, therefore, were those who either were reported as being diagnosed with dementia or showed signs of probable dementia. Of those 802 NHATS participants, 583 ADRD caregivers were identified as having completed the NSOC interview. It is important to note not all the 802 NHATS participants had an informal caregiver.

Listwise deletion was employed to account for missing data from the 583 caregivers identified. Since the study was only collecting information about the care recipients as it related to their probable dementia symptoms or having been diagnosed with Alzheimer's disease or a related dementia, we were only interested in assessing complete responses from the caregivers. Beyond being exhausted at night, we were interested in socio-demographic factors of caregivers, along with caregiver symptoms of distress. Caregivers who failed to respond to any variable included in the analysis were excluded from the study. This deletion ensured all participants had complete responses to all questions, allowing us to better make conclusions about the interplays between the variables and being exhausted at night. In total, 77 participants were deleted due to missing data, leaving the final analysis sample at 506 participants.

Methodology

Procedures and Sample

Care recipients who had probable dementia participated in the Round 7 National Health & Aging Trends Study (NHATS). Probable or possible dementia status was determined based on the criteria provided by Kasper et. al (2013) and the responses given by either the Medicare beneficiary or their interview proxy during the Round 7 NHATS interview. In total, 42% of care recipients were deemed as having possible or probable dementia, which accounted for 2,652 participants in the Round 7 NHATS database. Each care recipient was cared for by an informal caregiver who participated in the National Study of Caregivers (NSOC). The NSOC database houses the responses to the caregiver factors of interest in this study.

Caregivers of NHATS participants were eligible for the NSOC if the NHATS participant interviews indicated they had an informal or unpaid family caregiver who assisted them with mobility, household chores, and/or self-care activities. Caregivers were identified by NHATS participants or their proxies during the NHATS interview, and those identified were then asked to participate in the NSOC interviews. Of the 2,652 NHATS participants with probable or possible dementia, 583 informal or unpaid caregivers were identified. Following listwise deletion which removed caregivers who did not complete or respond to all questions that correspond to the variables of interest for the study. Of the 583 caregivers identified, 77 were removed leaving the final analytic sample at 506 informal caregivers for an NHATS older adult with probable or possible dementia.

Measures

Outcome of Interest

Caregivers were asked to what extent, either *very much*, *somewhat*, or *not so much*, they agreed with the statement 'you are exhausted when you go to bed at night'. Responses to this question were used to quantify whether the ADRD caregivers were, and to what degree, exhausted at night.

Caregiving Related Factors

Questions used to gather information about the caregiving related factors of the ADRD caregivers are detailed in the Appendix. Caregiving related variables included in the primary analyses were the relationship between the caregiver and care recipient, the physical and financial difficulty associated with the caregiving role, and the number of caregiving hours spent per day helping assist the recipient. The caregiver relationship to the care recipient was classified as either *spouse, child,* or *other*. Those included in the 'other' group included neighbors and friends, stepchildren or in-laws, and extended family members. Both the financial and physical difficulty questions had response options of either yes or no. Responses of 'yes' meant the caregiver found the role to be difficult, either financially or physically based on the question. Caregivers estimated the number of hours per day, ranging from one to 24 hours, they spent providing direct assistance to the care recipient.

Socio-demographic Factors of Caregivers & Emotional Distress

Caregiver socio-demographic factors and emotional distress were used to assess whether demographic factors and psychological distress confounded the relationship between being exhausted at night and caregiving related factors amongst caregivers for someone with ADRD. The following variables were included as socio-demographic factors of caregivers in this study: caregiver gender, age of the caregiver, the caregiver's highest level of completed education, and their race. While the caregiver gender options were coded as *female* and *male*, which typically are sex categories of individuals, this study and those prior refer to these as the gender identities of participants because the response was largely based on how the caregiver presented during the interview and often interviewers answered the question themselves. Interviewers only asked the question when they were unsure about the gender identity (i.e., how the caregiver presented themselves physically) of the ADRD caregiver. Education levels included were *less than high school*, *greater than some high school*, and *college degree or higher*. A caregiver who graduated from high school or received a GED and then went on to complete trade schooling would be included in the 'greater than some high school' group, distinguished from a caregiver who received an associate degree. Caregivers were either identified racially as either *White*, *African American*, or *Other*. Races included in the other category include those who identify as either Latino, Native American or Pacific Islander, Asian, or as more than one race. Age was calculated based on the caregiver's date of birth.

The psychological wellbeing of caregivers was measured based on their experience of emotional distress in the last month. Emotional distress amongst caregivers was determined based on their response to two emotional wellbeing questions. The first question asked how often in the past month the caregiver felt either anxious or nervous. Similarly, participants were asked how often in the past month they experienced feelings of depression or being down. For this research study, responses to both questions were totaled and an average score across both questions was established and used to quantify emotional distress amongst participants. Before establishing the composite score as an accurate measure of emotional distress, a logistic regression test was performed to determine whether responses to the anxiety question were predictive and significantly associated to those responses to the question about depressive symptoms. The graphical results from this test are presented in Figure 2. Overall, these two questions are highly predictive of one another and the relationship between the two is statistically significant ($\beta = 0.88$, $p < 0.0001$). Average scores for the composite emotional distress variable ranged from 1 to 4, and responses were relabeled so that 1= *never,* 2= *rarely*, 3= *several days*, and 4= *nearly every day*, now depicting how often during the last month caregivers have experienced emotional distress, defined as feelings of anxiety, nervousness, depression, and/or being down.

Statistical Analysis

Before conducting the statistical analyses, listwise deletion was completed, resulting in the removal of 77 participants due to missing data. The analytic sample of this study, as a result, included 506 ADRD caregivers. Descriptive statistics of all variables included in the study were assessed and detailed in Table 1. Ultimately, an ordinal logistic regression model was fit using cumulative link models to the data, examining the relationship between the various included variables and being exhausted at night, the outcome of interest, using RStudio version 1.4.1103. [49] Analytic weights provided by the NSOC were applied to the model, as well. Details about the survey weights can be accessed in the technical document of the Round 7 interviews for both NHATS and NSOC.[35] A conceptual model, used as a framework for the analysis and research study, was also developed based on a model presented by the Kim et al., 2012 paper.

Our analysis was framed to assess the associations described in our conceptual framework (Figure 1). The primary analyses assessed the bivariate correlations between each *caregiving related factor* and being exhausted at night. All of the caregiving related factors were included in a multivariate analysis in Model 5. *Socio-demographic factors of caregivers*, as well as the *anxiety and depression* measure, were included in the secondary multivariate analysis (Model 6). Model 6 was used to assess whether confounding factors explained some of the variation observed in responses to being exhausted at night based on the caregiving related factors assessed in Models 1 through 5. An ordinal logistic regression test was used throughout all the models, outside of the descriptive analysis which was tested to get an understanding of the responses and characteristics of caregivers being analyzed.

Results

This section details the findings of the quantitative analysis for this study. The primary objective of the study was to assess whether caregiving related factors amongst caregivers caring for someone with Alzheimer’s disease or a related dementia (ADRD) — relationship between caregiver and care recipient, number of hours per day spent helping care recipient, the physical difficulty associated with the caregiving role, and the financial difficulty associated with the caregiving role— are significantly correlated with being exhausted at night.

Descriptive Analysis

Table 1 references the findings from the descriptive analysis of the caregiving related factors, socio-demographic factors of caregivers, and the outcome of interest. Figure 3 is a pie chart which shows the level of agreement respondents had when presented with the statement they felt exhausted at night when they went to sleep. Many participants stated the lowest level of agreement, not so much, with the statement *you felt exhausted when they went to bed at night*.

Descriptive statistics demonstrated more than 70% of caregivers were women. On average, caregivers were in their early 60's, and most were caring for a parent with ADRD. More than three-quarters of caregivers were White. For approximately 53% of caregivers the highest level of education completed was some schooling beyond high school, which includes trade schooling and some college courses. Forty-six percent of caregivers indicated never experiencing emotional distress (i.e., anxiety and depression symptoms) in the past month.

Caregiving related factors were also assessed. Most caregivers did not find their role financially nor physically difficult. Caregivers, on average, dedicated 4.35 hours each day to helping as a caregiver, although responses ranged from 1 to 24 hours per day.

Caregiving Related Factors & Being Exhausted at Night

Model 1 assessed the correlation between the number of hours a caregiver dedicated to helping the recipient during the day and the degree of caregiver's agreement with the statement "you felt exhausted when you went to bed at night". The findings, presented in Table 2, show each additional hours a caregiver helped the recipient during the day was associated with a 6% increased proportional odds of a higher exhaustion category (i.e., not so much vs. somewhat and somewhat vs. very much). This association between caregiver's hours per day and being exhausted at night was significant, meaning the alternative hypothesis 1 ($H_{A:1}$) for our research question was true for this specific caregiving related factor.

Model 2 assessed the relationship between perceived financial difficulty of the caregiving role and the agreement with feeling exhausted at night. The relationship between the variables in Model 2 was statistically significant. Notably, finding the role financially difficult was associated with a more than four-time increased proportional odds of a higher exhaustion category. Similarly, Model 3, focuses on whether caregiver exhaustion is related to their perceived physical difficulty of the role. The regression model determined this relationship was also statistically significant. In the ordinal logistic regression model, physical difficulty associated with the role was correlated with a nearly four time increase in proportional odds of being in a higher exhaustion category. Alternative hypotheses two ($H_{A:2}$) and three ($H_{A:3}$) are supported by the results of Model 2 and 3, respectively.

Model 4 presents association between the caregiver's relationship to the care receiver and being exhausted at night. The analysis demonstrated there that this association was not significant for caregivers who were the child of the recipient. However, there was a significant association between the 'other' category of caregivers and the outcome. The regression results demonstrated caregivers included in the 'other' relationship group, caring for an extended family member or friend with ADRD, were associated with a 49% lower proportional odds of a higher exhaustion category. Since this model is insignificant, the null hypothesis for this model is true, noting there is no difference in response to the 'exhausted at night' variable based on caregiver's relationship to the recipient.

Following the independent analyses of the caregiving related factors, Model 5 aimed to assess, when included together, which caregiving related factors better explain the differences in being exhausted at night observed in ADRD caregivers. In Table 2 we can see the three caregiving related factors- caregiving helping hours, financial difficulty, and physical difficulty- are associated with caregiver exhaustion (i.e., caregivers being exhausted at night). However, when comparing the findings from Model 5 to the independent models prior, the level of significance observed between caregiving hours and caregiver exhaustion decreases in Model 5. Whereas in Model 1 caregiving helping hours was statistically significant at the less than 0.1% level of significance, Model 5 shows the level of significance has decreased, indicating there is a 4% chance the differences observed in caregiver exhaustion is due to chance alone rather than the number of helping hours for the recipient, per day. The odds of being in an increased exhaustion category has decreased from the single independent variable models (i.e., Model 2 and Model 3) to Model 5 for both financial difficulty and physical difficulty, although the level of significance remained the same.

Caregiving Related Factors, Socio-demographic Factors, Emotional Distress and Exhausted at Night

When socio-demographic factors of caregivers and emotional distress were added and analyzed in Model 6, only two of the caregiving related factors contributed significantly to exhaustion in ADRD caregivers. Financial difficulty, as well as physical difficulty associated with the role, remained significantly associated with caregiver's exhaustion outcomes. Caregivers who found the role to be financially difficult were associated with nearly three times increased proportional odds of a higher exhaustion category (i.e., not so much vs. somewhat and somewhat vs. very much). Similarly, reports of physical difficulty were also associated with increased odds of a higher exhaustion category in ADRD caregivers. Caregiving helping hours per day was no longer associated with caregiver exhaustion which demonstrates the introduction of caregiver socio-demographic factors, as well as emotional wellbeing, better explain the differences observed amongst caregivers for those with ADRD.

Experiences with anxiety and depression in caregivers, along with being a woman, were significantly associated with being in a higher exhaustion category. Caregivers who were emotionally distressed several days were associated with a nearly three times the proportional odds of a higher exhaustion category when compared to caregivers who never experienced emotional distress. As emotional distress frequency increased to nearly every day caregivers increased their odds to more than three times the proportional odds of a higher exhaustion category than those observed in those who never experienced emotional distress.

While insignificantly associated with exhaustion levels amongst ADRD caregivers, other socio-demographic factors of caregivers in the analysis did provide important insight. One such socio-demographic factor was the racial identity of caregivers. Caregivers in the ‘other’ racial category (i.e., Latinx, American Indian & Alaska Native, and Asian) displayed a positive coefficient between the race category and exhaustion. This indicates that those caregivers in the other racial group are associated, although not significantly so, with increased proportional odds of a higher exhaustion category ($\beta = 0.88$, $p = 0.08$). The other insignificantly associated socio-demographic factors-caregiver age and the highest level of completed education- did not demonstrate any correlation with differential outcomes between ADRD caregivers based on these variables.

Additional patterns can be observed relating to socio-demographic covariates that, although insignificant, may contribute to different sleep outcomes in dementia caregivers. Having completed more levels of education was associated with lower proportional odds of a higher exhaustion category when compared to those who only completed some schooling less than high school. Caregiver age only slightly changed the outcome of being exhausted at night. For each one unit increase in caregiver age there was a one percent lower proportional odds of higher exhaustion category. Once again, these correlations and odds were not significantly associated, based on the *p*-value.

Robustness of Ordinal Logistic Regression Test

The homoscedasticity, which is the same variance across the variable groups, is central to using the logistic regression model for this analysis. Homoscedasticity is necessary for ordinal logistic regression models to be run, which was conducted for this research paper. A Brant Test was conducted to observe whether the deviations from the ordinal logistic regression model are statistically significant (i.e., $p \leq 0.05$). This test determined none of the assumptions were violated since none of the p-values from the Brant Test were significant. Therefore, the use of ordinal logistic regressions across the models are valid.

Chapter IV: Discussion

The objective of this research was to determine whether being exhausted at night was related to caregiving related factors among those caring for someone with Alzheimer's disease or a related dementia (ADRD). Our analysis demonstrates that some caregiving related factors explained the variation in being exhausted at night and the alternative hypotheses were accepted in most cases. Caregiving helping hours per day, financial difficulty associated with the caregiving role, and the physical difficulty associated with the caregiving role were significantly associated with differential exhaustion outcomes. We then aimed to see whether these significant relationships were confounded by socio-demographic factors of caregivers, as well as emotional distress. When socio-demographic factors and emotional wellbeing were also included in the model, the odds ratios associated with the caregiving related factors decreased. Additionally, emotional distress and the gender of the caregiver were significantly associated with being exhausted at night, and caregiving helping hours was no longer significant.

We found that being exhausted at night was common among caregivers for someone with Alzheimer's disease or a related dementia. Notably, a few caregiving related factors were significantly associated with reports of being exhausted at night among dementia caregivers. Caregivers being exhausted at night was significantly associated with reporting physical difficulty, as well as financially difficult. These two independent factors, financial difficulty, and physical difficulty were the only caregiving related factors in this model that remained significant throughout the analyses. Reports of caregiver financial burden were shown to be associated with sleep outcomes in previous literature, which supports the findings of this study. [16] Similarly, caregiver perceived physical difficulty of the caregiving role was associated with poorer caregiver sleep outcomes. [16]

However, once all caregiving related factors were added in Model 5, and emotional distress and socio-demographic factors of caregivers in Model 6, the odds associated with being in a higher exhaustion group among caregivers based on their response to either physical difficulty or financial difficulty decreased. The odds ratio produced by the ordinal logistic regression model between financial difficultly and being exhausted at night shifted from a ratio of 4.2 in the bivariate analysis down to 2.9 in the multivariate analysis in Model 6. Similarly, the odds ratio produced by the analysis between physical difficulty and being exhausted at night decreased from a ratio of 4.0 in the bivariate analysis to 2.2 in Model 6. The decrease in odds ratios described previously shows caregivers perceived financial difficulty and physical difficulty are correlated with other caregiving related factors, as well as socio-demographic factors of caregivers and caregiver symptoms of emotional distress. The findings, nonetheless, support the hypothesis that caregiving related factors, notably the perceived financial and physical difficulty of the role, are associated with caregivers being exhausted at night.

As the number of caregiving hours for someone battling dementia increases so do reports of sleep disturbances and poor sleep outcomes in caregivers.[43,75] Paralleling extant literature, we determined dementia caregivers who reported dedicating more caregiving hours to their recipients also had increased odds of reporting being exhausted at night. However, once socio-demographic factors of caregivers and caregiver emotional distress were added to the model, seen in Model 6, the association between being exhausted at night and caregiving helping hours per day was no longer significant. Further, in Model 6 emotional distress and caregiver gender were significantly associated with being exhausted at night. This indicates the bivariate association observed between caregiving helping hours and being exhausted at night was better explained by either emotional distress or caregiver gender.

One potential explanation for the observed drop in significance between caregiving helping hours and being exhausted at night could be the confounding relationship between caregiving helping hours per day and financial difficulty. Perhaps caregivers do not have the funds or means to afford formal care services for the care recipient. Without some other source providing care for the care recipient, thus offsetting the number of hours the caregiver must spend helping the recipient, caregivers often find themselves missing work and limiting the number of hours they can spend at their jobs. Ultimately, this results in financial struggles as they are unpaid for their lost time spent caring for their recipient. Rearranging work schedules, decreasing the number of hours they work, having to take unpaid leave to meet the needs and responsibilities of their caregiving role, and/or losing a job completely are the harsh realities for more than 60% of caregivers.[2] We imagine similar trends can be observed in studies like this one, with increased numbers of caregiving helping hours being associated with a higher likelihood of finding the role financially difficulty, however, follow-up studies should be conducted to assess whether this relationship is true.

Looking at the socio-demographic factors, our study determined the gender of the caregiver was the only factor in its group that was significantly associated with being exhausted at night in, detailed in Model 6 (Table 2). Notably, the study found females were more exhausted at night than male caregivers. Although the literature is conflicted on these grounds, most research indicates that women who are dementia caregivers have poorer sleep outcomes than their male counterparts.[12,80] McCurry (2009) reported findings that support this trend, whereas Mills (2009) found that males report a higher frequency of sleep disruptions than females. The gender related findings from our study are consistent with literature on other forms of caregiving, for instance among caregivers of cancer patients.[16] Further, this study supports conclusions from other studies which report an association between socio-demographic factors of caregivers and caregiving related factors. As noted previously, the introduction of socio-demographic factors in the analysis was followed by a decreased odds ratio produced by the association between being exhausted at night and physical difficulty, as well as between being exhausted at night and financial difficulty. [16, 43, 80]

Contrary to other literature, this study did not find a significant association between caregiver race and being exhausted at night. Other literature reported differences in burden based on the caregiver's race, with minorities reporting significantly higher levels of caregiver burden.[16] One explanation for this pattern not being observed in this study may be based on the mismatch between the prevalence of Latino, Asian, and Native American and Alaska Native dementia caregivers in this study compared to the established rates of these minority groups by the American Association of Retired Persons. The 2015 American Association of Retired Persons (AARP) Report indicate nearly 20% of dementia caregivers are Latino, and 6% are Asian. However, less than 0.1% of the caregivers in this study were either Latino, Asian, or Native American or Alaska Native.

One of the reasons for this mismatch in representation could be due to the lack of oversampling for all minority populations by the National Health and Aging Trends Study (NHATS). While NHATS oversamples African American/Black Medicare beneficiaries in their sampling design, they do not employ methods to oversample other minority groups. [35] In follow-up studies, we recommend establishing methodology to increase the number of minorities across all racial groups to better understand how caregiver health outcomes may be confounded by diverse racial identities. Further, including racially diverse dementia caregivers in research allows us to assess whether the relationships between race and coping strategies is supported as has been demonstrated in other research studies. [26, 51, 73] The sample size of Latino, Asian, or Native American or Alaska Native caregivers is much too small to test the hypothesis of caregiver race being related to being exhausted at night in this sample.

Further analysis regarding the financial impact of dementia caregiving is needed in light of this employment state of the country. We can only imagine the financial difficulty associated with the caregiving role is more prevalent considering the COVID-19 pandemic. Whereas previously dementia caregivers with the means of doing so were able to offset some of their caregiving responsibilities and financial troubles by working additional jobs and relying on others to help care for the care recipient while they worked, this may not be the case for many caregivers today. Millions of Americans in the United States were laid off at the start of the pandemic, leaving many to survive on stimulus checks or other sporadic methods of receiving funding. Older adults are tremendously vulnerable to becoming infected with COVID-19, leaving many caregivers with no choice but to quarantine and social distance with their elderly family members. Some did not work as a result, trying to keep themselves and their elderly loved ones safe. While dealing with the lack of financial support and having to increase the number of caregiving hours, one can only imagine the adverse effects of caregiving were exacerbated during the pandemic. Whether in a pandemic or not, we need to consider the needs of caregivers and provide them with resources and care so they can continue to help one of the most vulnerable groups of the population.

Limitations

While this study utilized standardized methodology proposed from Kasper et al.'s 2013 paper to assess whether the care recipients had probable dementia, in combination with those who were reported as having been diagnosed with Alzheimer's disease or dementia, we cannot be sure all care recipients included in this study actually had dementia. This study took advantage of the large and nationally representative National Study of Caregiving (NSOC), which is not specifically aimed at surveying caregivers of individuals with dementia. We were only able to determine which care recipients had probable dementia, outside of those who were formally diagnosed with the disease by a physician. This means the findings from this study may only explain the outcomes of caregivers for those who display a number of cognitive and functional disabilities rather than those who have some form of Alzheimer's disease or a related dementia. However, with the findings aligning those observed in research studies with care recipients who have been diagnosed with ADRD, which indicates that most of the care recipients did, in fact, have ADRD. Beyond being unsure whether all participants are caring for someone with dementia, the measures used in this research were not standardized or validates, namely emotional distress and exhaustion.

All the measures of interest in this study wee subjective, which introduces several biases into the results. Ideally, objective measures of exhaustion and the number of hours spent per day helping as a caregiver would be measured by the researchers, allowing them to standardize and measure the outcomes and variables the same across participants, allowing for an accurate reading of the study aims. Further, along the note of how the outcome of interest was analyzed, researchers cannot be sure all participants respond similarly with relation to how they interpreted the question. Additionally, researchers are not sure all respondents have a similar belief or understanding of what categorizes as 'not so much' versus 'somewhat' or even 'very much'. One way to address this concern and the limitations associated with the ambiguity subjective measures bring to research surveys is to create and utilize objective measures that aim to quantify participant experiences with health outcomes, including measures similar to the Maslach Burnout Inventory, the Pines Burnout Scale, and the Chalder fatigue scale. [76, 77, 91] While subjective measures can introduce some ambiguity to the research study, we must remain confident that individuals are able to accurately note and report their health outcomes.

Future Directions

Findings from this study add to the growing body of literature linking sleep outcomes to caregiving related factors, socio-demographic factors of caregivers, and emotional distress. Luckily, many of these caregiving related factors can be modified and the stress and burden of the caregiving role managed. Since this study did not assess how coping strategies and interventions, like social support and religion, effect these outcomes or associations, there is a need for additional studies to be conducted. Further, because this study was novel and addressed a gap in the understanding of how the perceived financial difficulty of the caregiving role effected outcomes of being exhausted at night among ADRD caregivers, future research is needed to further establish this relationship and to support the findings of this study. Hopefully, current research is being conducted to assess how this pandemic effect the health outcomes of dementia caregivers, and further those with dementia, considering the health concerns and economic changes the virus has brought to the United States.

As research aims to address the gaps described above, researchers should aim to include racially and ethnically diverse samples, as well as including caregivers from different generations and with different relationships to the caregiver. Millennial caregivers are often underrepresented, as they were in this sample. Little is known about how millennial caregivers cope with the stresses of being a caregiver. Millennial caregivers introduce new, understudied aspects of caregiving to the forefront, including the additional stress of having to not only care for an older adult with ADRD but also a child or dependent. What are the effects on exhaustion and other health outcomes, including emotional distress, when you are responsible for providing essential care to multiple people at once, including one with a progressive disease? Are there unique barriers to access of resources or a lack of understanding present amongst younger ADRD caregivers? Better understanding how demographic features of caregivers, whether age, gender, or race, intersect with the caregiving role will facilitate effective interventions and better health outcomes amongst informal ADRD caregivers.

While this study, and most studies to date, focus on the adverse outcomes of being a dementia caregiver, we hope more studies are conducted to demonstrate the rewarding aspects of being an informal caregiver. Few studies included in the literature review demonstrated caregiving is a rewarding experience and a fulfilling role for many. It is human nature to want to help and care for those who need us. Research needs to highlight the advantages of dementia caregiving, the happiness and joy it truly brings. With projections showing an increase in the prevalence of ADRD throughout the next few decades, the demand for informal caregivers will also increase, meaning we must foster a better understanding of what it means to be a caregiver on both sides of the coin. Bring light to the difficult aspects of being a caregiver for someone with some form of dementia and provide resources and strategies on how to get out of these pits, but also show how satisfying and the amount of gratitude that can be gained from a role so important as this. We must use this research, and the ones to follow, to support and empower informal caregivers.

Conclusion

This study established and supported findings of an association between caregiving related factors, as well as socio-demographic factors and emotional wellbeing, and being exhausted at night. Of the caregiving related factors included in the analysis, caregiving helping hours per day, the perceived financial difficulty of the role, and the perceived physical difficulty of the role were all associated with caregivers being exhausted at night. These findings supported three of the four alternative hypotheses presented at the start of the study. Among dementia caregivers, caregiver gender and emotional distress, covariates added in the last model of the analysis, were also correlated with being exhausted at night. These results demonstrated women caregivers, as well as those who were emotionally distressed, had an increased likelihood of being exhausted at night.

This study adds to the growing body of evidence surrounding informal caregivers for someone with Alzheimer's disease or a related dementia, providing a better understanding of the caregiving related factors effecting sleep outcomes in caregivers. We hope this promotes researchers to conduct additional analyses aimed at understanding factors contributing to ADRD caregiver's sleep outcomes, as well as encouraging efforts needed to improve the overall quality of life of informal caregivers. Aware of the caregiving related factors, socio-demographic factors, and caregiver symptoms which contribute to poor health outcomes, public health professionals can develop programs and interventions aimed at improving the wellbeing and quality of life of ADRD caregivers while targeting those factors leading to poorer sleep outcomes.

Chapter V: Public Health Implications

Caregiver research is important, especially when thinking about those caring for an older adult with dementia. In the absence of a cure, a way to slow the progression of the disease, or effective ways of preventing ADRD from developing, we must ensure their health is maintained to the best of our ability while they struggle through the disease. As has been discussed throughout this paper, the number of people with Alzheimer's disease or a related dementia (ADRD) is projected to increase throughout the next few decades, further increasing the demand for informal caregivers. The work of these informal caregivers often remains unknown and misunderstood. Caregiving related factors were associated with more adverse health outcomes, notably being exhausted at night, amongst informal caregivers helping a recipient with ADRD. Healthcare providers must be aware of these associations and the findings because many caregivers may not be aware of their poor health themselves or may not be willing to seek care for it.

Caregiver exhaustion show inequalities based on the emotional distress experienced by caregivers, how difficult they find their role to be, and their gender. These findings are not unique to this project, and there are many caregiver and caregiving related factors that were not discussed and assessed in this research. With established patterns or correlations between caregiving related factors, emotional wellbeing, and socio-demographic factors of caregivers to physical wellbeing and exhaustion outcomes we must move to a place of mediating these outcomes and improving the health of caregivers. This is where public health work is most important. Public health professionals and researchers have placed a framework, as was done in this research, to better understand the links between poor health outcomes and wellbeing in specific groups. We now know and understand that being exhausted is correlated, to some degree, with being emotionally distress, being a women caregiver, and finding the role financially and physically difficult. Now we must move to the next steps in addressing this issue.

Would ADRD caregivers respond they *never* feel exhausted if they had increased access to support resources? Are ADRD caregivers who utilize religious and family support networks less likely to report themselves as being exhausted at night? These are questions left to be answered by public health research. While we have some evidence that indicates support networks and the use of resources are Further, this study should be used in public health to show public health professionals what additional characteristics may be explaining the poor health outcomes they observe in their caregiver patients. Rather than simply assuming the experience of exhaustion are what are expected amongst ADRD caregivers, we now have evidence that shows this is not the case. There are stressors and aspects of caregiving that increase the frequency of being exhausted. Further, this study shows questions about exhaustion should be asked more readily when caring for caregivers of someone with dementia. Exhaustion may help explain caregiver symptoms being observed and may describe the presence of other adverse health outcomes, including emotional distress.

Lastly, this research and information provided will hopefully motivate for the adoption of larger-scale policy changes and the initiation of subsequent research and funding for dementia caregivers. National initiatives, including those being pushed by the CDC's Healthy Aging Branch, are important in addressing the concerns not only of caregivers but also of their care recipients. Training and workforce developments need to be addressed to support caregivers, as well as emergency preparedness efforts to allow caregivers to access resources and funding during situations like the COVID-19 pandemic. The absence of these resources during emergency situations increases caregiver burden and burnout. "Public health strategies at the systems, policies, and environmental levels, including conducting public health education campaigns, improving core competencies for health professionals, and utilizing population-based data" can help address the adverse health outcomes observed in this study for the long run.[88] As public health professionals the worries presented in the study should not merely be addressed when they arise, but resources and interventions should always be present to reduce the chances of these outcomes throughout the caregiver's time. Public health is tasked with providing outlets and resources to effectively educate, empower, and encourage dementia caregivers. We have presented the issues needing to be addressed in this research, now we must begin our work.

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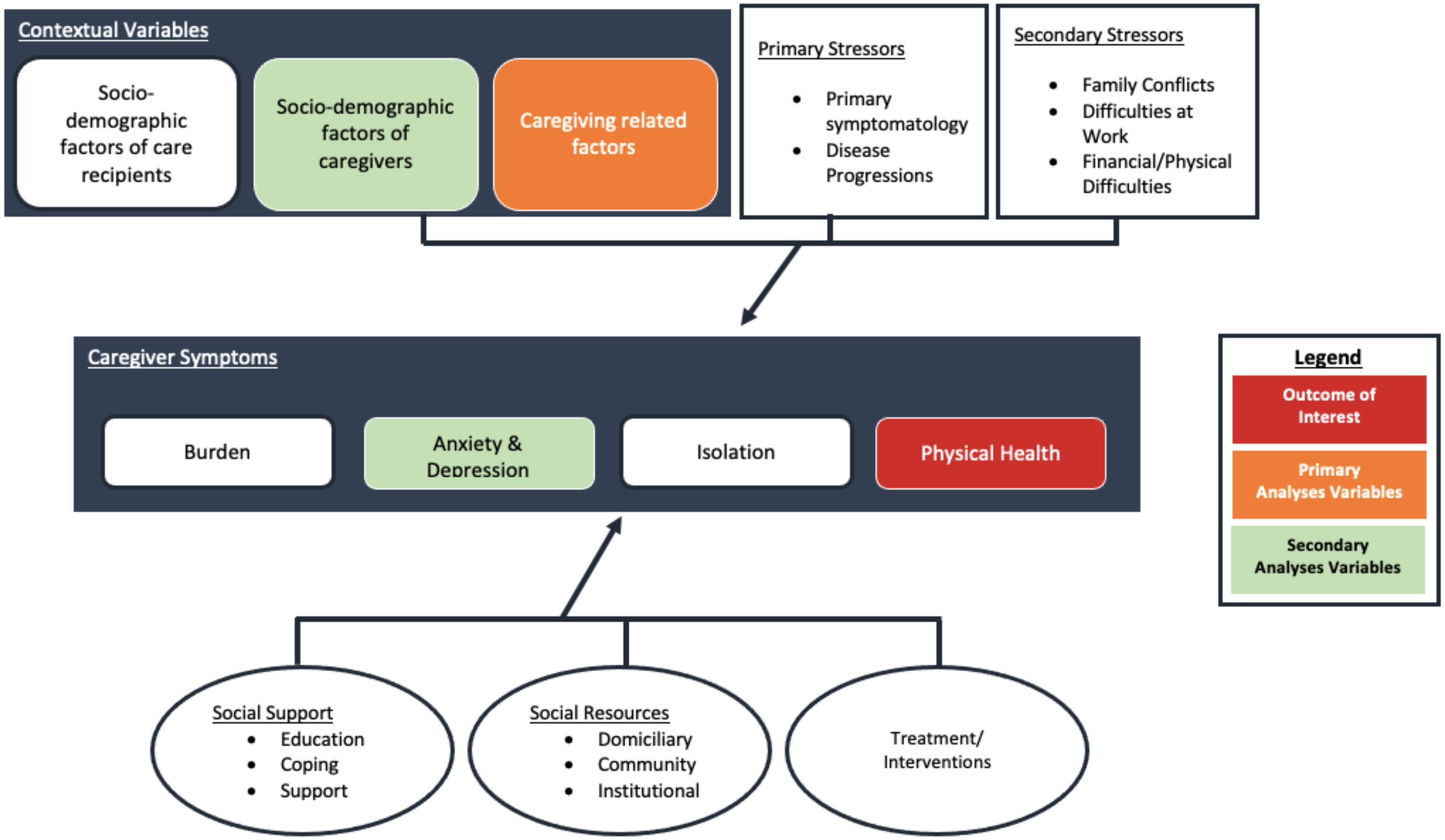
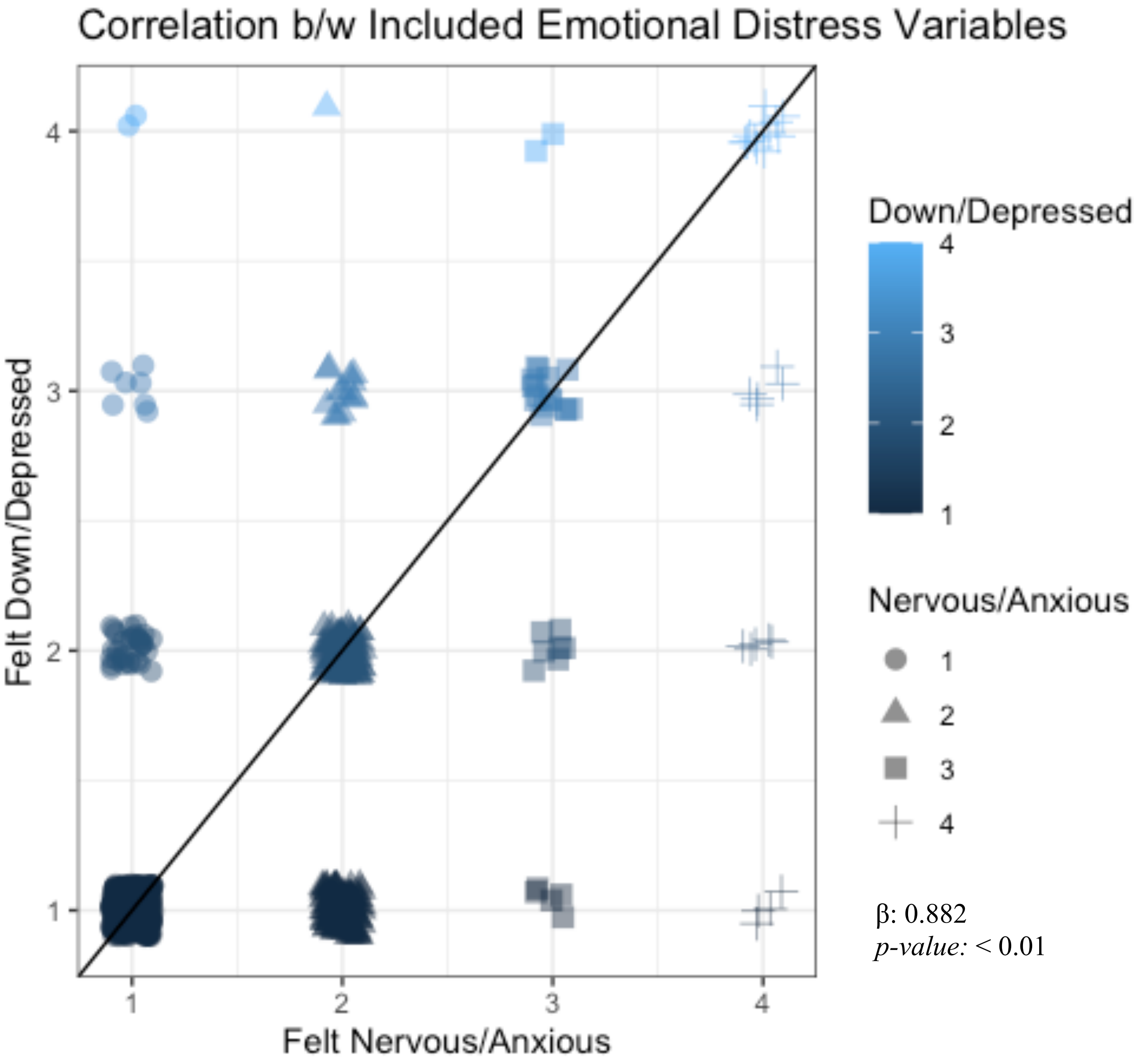
Figures and Tables

Figure 1: Representation of conceptual framework



Note: Primary analyses include results from Models One, Two, Three, and Four. Models Five and Six include the outcome of interest and the primary analyses variables, as well as the secondary analyses variables which are introduced during Model Six. Model Five assesses the relationship between the Outcome of Interest and all Primary Analyses Variables, whereas the first four models look at the independent relationship of each Caregiving related factor and its relationship to the Physical Health outcome.

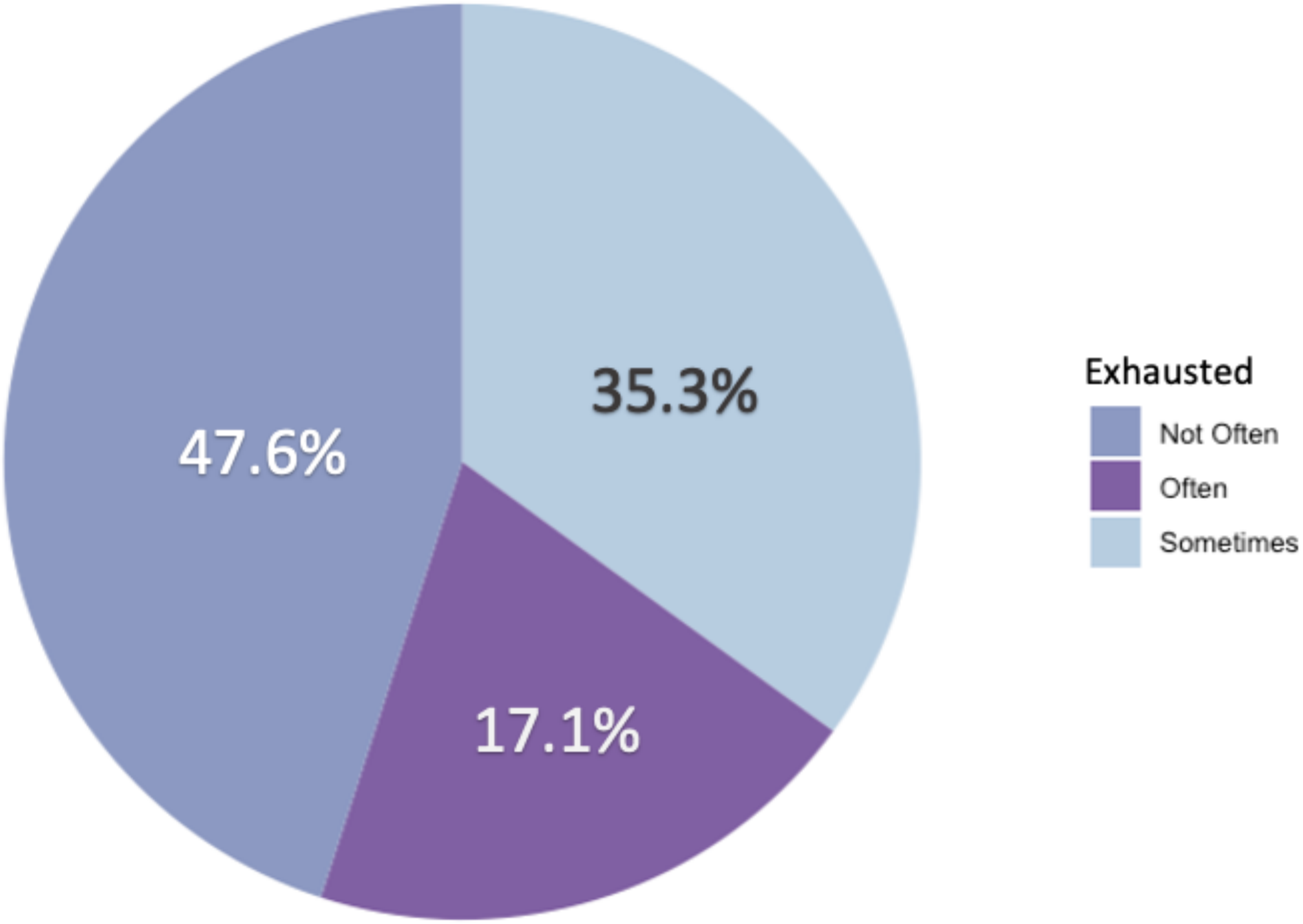
Figure 2: Validating combination of depression variable and anxiety variable to new emotional distress variable



β: 0.882
p-value: < 0.01

Note: Respondent answers were coded for both questions with a number ranging from 1 to 4. Responses coded as **1** for either question (i.e., feeling down/depressed or feeling nervous/anxious) denoted never experiencing these emotions. Responses of **4**, on the other hand, meant respondents felt either set of emotions every day. Survey weighted. Source: National Study of Caregiving (NSOC), 2017

Figure 3: Frequency of being 'exhausted at night' responses in caregivers, United States (*N*=506)



Note: Survey weighted. Source: National Study of Caregiving (NSOC), 2017

Table 1: Demographic, psychological, and health attributes of caregivers, United States (*N*=506)

Caregiver Population Attributes	**Frequency (%)**	**Mean (SE)**	**Range**
Age (yrs)		60.46 (0.80)	17 - 93
Caregiving Helping Hours/Day		4.35 (0.22)	1 - 24
Gender			
Male	29.70%		
Women	70.30%		
Race			
White	82.90%		
African American	14.10%		
Other	0.03%		
Highest Level of Education			
Less than High School	6.10%		
Greater than Some High School	52.50%		
College Degree or Higher	41.40%		
Relationship to Care Recipient			
Spouse	16.30%		
Child	53.20%		
Other	30.50%		
Financial Difficulty			
No	82.50%		
Yes	17.50%		
Physical Difficulty			
No	73.40%		
Yes	26.60%		
Emotional Distress			
Never	46.30%		
Rarely	21.50%		
Several Days	20.70%		
Nearly Every Day	11.50%		
Exhausted at Night			
Not So Much	47.60%		
Somewhat	35.30%		
Very Much	17.10%		

Note: Survey weighted. Source: National Study of Caregiving (NSOC), 2017. SE = standard error. Physical and Financial Difficulty based on perceived difficulty associated with caregiving role. 'Other" caregivers include extended family and friends of those with ADRD

Table 2: Results from survey-adjusted ordinal logistic regression, of caregivers reporting higher agreeance with being exhausted at night based on caregiving related factors (*N*= 506)

	Model 1			**Model 2**			**Model 3**			**Model 4**			**Model 5**		
Variables															
	OR	**SE**	***p*-value**	**OR**	**SE**	***p*-value**	**OR**	**SE**	***p*-value**	**OR**	**SE**	***p*-value**	**OR**	**SE**	***p*-value**
Caregiving Helping Hours/Day	1.1	0	0.001***										1	0	0.04*
Financial Difficulty				4.2	0.2	< 0.001***							2.7	0.2	< 0.001***
Physical Difficulty							4	0.3	< 0.001***				3	0.2	< 0.001***
Relationship to Care Recipient															
Spouse										*Ref.*			*Ref.*		
Child										0.9	0.2	0.59	1	0.2	0.88
Other										0.5	0.3	0.01**	0.7	0.3	0.18
Dependent Constants															
Not So Much | Somewhat		0.1	0.69		0.3	< 0.001***		0.3	< 0.001***		0.2	0.02*		0.4	< 0.001***
Somewhat | Very Much		0.2	< 0.001***		0.3	< 0.001***		0.3	< 0.001***		0.2	< 0.001***		0.4	< 0.001***

Note: *** $p \leq 0.001$. ** $0.001 < p \leq 0.01$ Ref. = Reference. Outcome variable is frequency of being exhausted at night. Model 1 null hypothesis states helping hours are the same across exhaustion at night categories. Model 2 null hypothesis states perceived financial difficulty is the same across exhaustion at night categories. Model 3 null hypothesis states perceived physical difficulty is the same across exhaustion at night categories. Model 4 null hypothesis states caregiver relationships to care recipient are the same across exhaustion at night categories. Model 4 uses the spouse relationship as the group of reference. Caregivers who were the child of the care recipient fell between the age ranges of 19 and 86 years old. Survey weighted. Source: National Study of Caregiving (NSOC), United States, 2017.

Table 3: Results from survey-adjusted ordinal logistic regression of caregivers reporting higher agreeance with being exhausted at night based on caregiving related factors, socio-demographic factors, and emotional distress of caregivers (*N*= 506)

	Model 6		
Caregiving Related Factors			
	OR	**SE**	***p*-value**
Caregiving Helping Hours/Day	1.02	0.02	0.22
Financial Difficulty	2.92	0.25	< 0.001 ***
Physical Difficulty	2.2	0.21	< 0.001 ***
Relationship to Care Recipient			
Spouse	*Ref.*		
Child	0.91	0.29	0.73
Other	0.57	0.34	0.09
Socio-demographic Factors of Caregivers			
	OR	**SE**	***p*-value**
Age	0.99	0.01	0.28
Gender			
Male	*Ref.*		
Women	2.55	0.01	< 0.001 ***
Race			
White	*Ref.*		
African American	1.15	0.21	0.5
Other	2.43	0.5	0.08
Highest Level of Education			
Less than High School	*Ref.*		
Greater than Some High School	0.82	0.34	0.53
College Degree or Higher	0.79	0.35	0.48
Caregiver Symptoms			
	OR	**SE**	***p*-value**
Emotional Distress			
Never	*Ref.*		
Rarely	1.79	0.24	< 0.01*
Several Days	2.41	0.25	< 0.001 ***
Nearly Every Day	3.29	0.3	< 0.001***
Dependent Constants			
Not So Much | Somewhat		0.93	< 0.001***
Somewhat | Very Much		0.96	< 0.001 ***

Note: *** $p \leq 0.001$. * $0.01 < p < 0.05$ Ref. = Reference. Outcome variable is frequency of being exhausted at night. Greater than some high school indicates caregiver graduated high school with a diploma or obtained a GED but did not obtain any degrees higher than that (e.g., Associates, Bachelors, Masters), but they may have attended a trade school. Caregivers in the 'other' relationship category include extended family members and friends. Emotional distress is a measure of anxiety and depression symptoms in the caregiver. Survey weighted. Source: National Study of Caregiving (NSOC), United States, 2017.

Appendix: National Study of Caregiving (NSOC) interview questions of interest

NSOC Interview Questions

Age (yrs): What is your date of birth?

Caregiving Hours/Day: On days when you helped SP, about how many hours did you spend helping?

Education: What is the highest degree or level of school you completed?

No Schooling Completed; 1st-8th Grade; 9th-12th Grade (No Diploma); High School Graduate (High School Diploma or Equivalent); Vocational, Technical, Business, Or Trade School Certificate Or Diploma (Beyond High School Level); Some College but No Degree; Associate degree; Bachelor's Degree; Master's, Professional, Or Doctoral Degree {**recoded as**: Less than High School, Greater than Some High School, or College Degree or Higher}

Emotional Distress: Over the last month, how often have you felt down, depressed, or hopeless?

Not at All, Several Days, More than Half the Days, Nearly Every Day {**recoded as**: Never, Rarely, Several Days, Nearly Every Day}

Emotional Distress: Over the last month, how often have you felt nervous, anxious, or on edge?

Not at All, Several Days, more than Half the Days, Nearly Every Day {**recoded as**: Never, Rarely, Several Days, Nearly Every Day}

Exhaustion: You are exhausted when you go to bed at night.

Very Much; Somewhat; or Not So Much

Financial Difficulty: Is helping {SP}/Has helping {SP} been financially difficult for you?

Physical Difficulty: Is helping {SP}/Has helping {SP} been physically difficult for you?

Race: What race do you consider yourself to be:

White; Black or African American; American Indian; Alaska Native; Asian; Native Hawaiian or Pacific Islander? {**recoded as:** White, African American, or Other}

Relationship to SP: What is your relationship to {SP}?

Gender: We have you listed as {*male/women*}. Is that correct?