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**A COMPREHENSIVE ANALYSIS ON THE DEMOGRAPHICS AND HEALTH CHARACTERISTICS  
OF CAREGIVERS TO PERSONS WITH DEMENTIA IN THE UNITED STATES**

A Thesis in

Public Health Sciences

by

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## ABSTRACT

With an aging population, the prevalence of Alzheimer's disease (AD) and other dementias is increasing worldwide. In the United States, informal caregivers currently provide millions of hours of unpaid care annually, the assumed costs of which would approximately double the \$214 billion in current annual estimated healthcare expenditures. This study aims to compare the demographics, health variables, and caregiving status of caregivers to persons with dementia versus other caregivers and non-caregivers.

Data on caregivers was collected using 2012 Behavioral Risk Factor Surveillance System (BRFSS) responses from select states that completed the state-added Caregiver Module. Variables were analyzed for significant differences between populations using chi-square analysis, with additional analysis on select stratification of gender and type of care by AD/dementia caregivers. Finally, modeling was performed to identify significant predictors of caregiver-reported difficulties associated with caregiving responsibilities.

Significant differences were found between rates of self-reported mental distress and difficulties experienced by the caregiver, dependent upon certain caregiving status and demographic variables. These associations provide further insight into the AD/dementia population, which may serve towards increasing awareness of existing insurance policy gaps and the importance of further investment into public outreach programs that would lessen the individual and growing societal impacts of providing care to persons with Alzheimer's disease and other dementias.

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## Chapter 1. INTRODUCTION

### 1.1 Characteristics of Alzheimer's and Other Dementias

Dementia is a neurodegenerative process that causes deterioration in memory, thinking, and behavior, progresses to an inability to perform daily life functions, and leads to eventual death.<sup>1,2</sup> Worldwide, there are 35.6 million people with dementia, and approximately 7.7 million new cases arise every year.<sup>3</sup> Alzheimer's disease (AD) is the most common form of dementia, accounting for 60-70% of all dementia cases worldwide.<sup>3</sup> This form of dementia alone is the sixth leading cause of death in the United States, causing approximately 85,000 deaths per year, and totaling to more annual deaths than breast cancer and prostate cancer combined.<sup>4,5</sup> One recent study suggests that this number is grossly underestimated, and that the true number of annual deaths due to AD alone totals closer to 500,000, making it the third leading cause of death in the nation, and falling closely behind all cancers.<sup>6</sup> Of the ten leading causes of death in the United States, it is the only one that cannot be prevented, cured, or even slowed, and it is expensive<sup>4,7</sup>; it is estimated that 2014 healthcare costs due to Alzheimer's alone will be approximately \$214 billion, making it more expensive than care for heart disease or cancer.<sup>7</sup>

After Alzheimer's disease, the other most common forms of dementia are Lewy body dementia and vascular dementia.<sup>8</sup> The most common risk factor for both Lewy Body dementia and Alzheimer's disease is increased age; onset is generally seen in patients greater than 65 years of age, and the National Institute on Aging suggests that the risk of developing Alzheimer's doubles every five years after age 65.<sup>9</sup> While Alzheimer's is

characterized by a gradual disease progression beginning with impaired memory and decision-making,<sup>10</sup> Lewy Body is characterized by symptoms of cognitive dysfunction relieved by intermittent moments of lucidity; Lewy body dementia is also often accompanied by hallucinations.<sup>11</sup> Vascular dementia results from a lack of sufficient blood flow to the brain, which damages and eventually kills brain cells.<sup>12</sup> Changes in cognition may occur suddenly after a stroke has blocked major brain vessels, or it may occur gradually over time with a cumulative effect from prolonged oxygen and nutrient deprivation or multiple small strokes.

Aside from demographic and health risk factors, Alzheimer's disease also has been associated with certain genetic mutations. A mutation in one of three determinant genes, Amyloid beta precursor protein (*APP*), Presenilin-1 (*PS-1*), or Presenilin-2 (*PS-2*), is known to cause Alzheimer's in 100% of carriers. These gene mutations are associated with the less common early-onset form of the disease, and account for less than five percent of Alzheimer's cases.<sup>13,14</sup> A fourth protein, Apolipoprotein E e4 allele (*APOE-e4*) is considered a risk gene for the most common late-onset form of Alzheimer's; approximately 20% of cases have at least one copy of the *APOE-e4* allele that is associated with AD.<sup>14-15</sup>

No similar determinant or risk gene associations have been identified with certainty for Lewy body dementia or vascular dementia.<sup>8</sup>

The statistics above revolve mostly around Alzheimer's, mainly because this is the most prevalent form of dementia. While the number estimations are astounding for annual deaths, costs, and significant risk increases in Alzheimer's disease as a function of aging in particular, it is important to remember that these numbers represent only a fraction of overall dementia cases. The true impact of dementia is an extrapolation beyond these

numbers, and the currently known main causes of dementia, aging and genes, are unalterable.

## **1.2 Caregiving For Dementia Patients and Others**

For each person with dementia, there are approximately one to four caregivers.<sup>7</sup> In 2013, it is estimated that 15.5 million family and friends of dementia patients provided 17.7 billion hours of unpaid care, equating to over \$220 billion dollars.<sup>7</sup> These numbers, as an estimation of caregivers in combination with AD patients, demonstrate the far-reaching effects of this disease, giving a total population of over 20 million people in the United States significantly affected by Alzheimer's disease. Because of the emotional and physical tolls of providing care to a person with dementia, caregivers incurred an additional \$9.3 billion dollars in healthcare costs of their own, with 60% rating the emotional stress of caregiving as high or very high, and greater than 33% reporting symptoms of depression.<sup>7,16</sup> Recent studies suggest that the rate of psychological and emotional burden is higher when compared to caregivers of other health problems, and shows an even greater difference when compared to non-caregivers.<sup>17,18</sup> A separate study, after controlling for sociodemographic factors, prevalent disease, and subclinical disease, found an increased mortality rate of 63% for elderly spousal caregivers that were experiencing strain versus noncaregiving controls<sup>19</sup>; this study measured impact on caregivers in general, without focus on caregivers of dementia, and strain was self-reported in terms of mental, emotional, and physical measures.

Aside from the mental and physical health implications on the caregiver population as a whole, the societal impact of the caregiver burden is readily apparent. Aside from high healthcare costs for caregivers, the 2010 business productivity loss estimated for employed caregivers was approximately 8% higher than versus non-caregivers, costing U.S. employers approximately \$13.4 billion annually as a health differential from non-caregivers.<sup>20</sup> As a net productivity loss due to caregiving, the 2006 estimated total cost of caregiving to U.S. employers was approximately \$33.6 billion.<sup>20</sup> Additionally, as the population ages and as people become more mobile and live further from their families of origin, fewer caregivers will be able to provide the same level of care to the increasing elderly population. This may impact care recipients in different ways. Care recipients may continue to live at home and receive less care, possibly leading to poorer overall health outcomes and increased healthcare costs, or they may require increased utilization of formal care services, creating more individual financial burden and subsequent social financial burden associated with institutionalized care.

The burden of caregivers can be discussed as one of two different types: Objective burden, and subjective burden. Objective burden is an estimation of the dependence of the dementia patient on the caregiver, and provides information on the level of daily disturbance experienced by the caregiver through time or activities. Subjective burden is a rating by the caregiver of the emotional, physical, psychological, and financial burden felt, due to the task of caregiving. According to a 2008 study, these two burden types are only loosely correlated.<sup>21</sup> Additionally, caregivers may be considered in one of two ways: Care providers, or care managers. Care providers provide physical care to the patient and assist

with daily activities. Care managers arrange for others to provide specific care, such as a financial advisor to assist with asset management.

There are several care options available to support those acting as either care providers or care managers. These include adult day care centers, in-home care by a paid provider, residential care, respite care, and hospice care. However, many caregivers are financially unable to utilize these resources, or feel guilt at the prospect of placing a loved one into a stranger's care.<sup>22,23</sup> This leads to underutilization of care options, and not necessarily by choice of the care provider. A study by Labra et. al suggests that caregivers are even more likely to feel burden if they feel that they have no choice in providing care, which leads to further propagation of increased health risks to the care providers.<sup>24</sup>

### **1.3 The Behavior Risk Factor Surveillance System and the Caregiving Module**

The Behavioral Risk Factor Surveillance System (BRFSS) is the world's largest on-going telephone health survey system, using annual surveys to estimate health risk behaviors among US adult populations.<sup>25,26</sup> The survey initiative was driven by research in the 1980s indicating that personal health behaviors greatly influenced an individual's risk for premature morbidity and mortality. Data collected by the National Center for Health Statistics (NCHS) provided national estimates on risk behaviors, but the applicability of this data to health initiatives was considered limited. It was acknowledged that national data may not be representative of state-specific data, and it was therefore not feasible to implement state-wide public health policy based on national health statistics. Started in 1984 by the Centers for Disease Control (CDC), 15 states initially participated in BRFSS

monthly data collection. By 1993, the survey was being performed nationwide with a CDC-developed standard core questionnaire that could be used across states for data collection and analysis. Today, monthly data collection for the BRFSS occurs in all 50 states, the District of Columbia, American Samoa, Palau, Puerto Rico, the U.S. Virgin Islands, and Guam. Aside from the nationally used core questions, optional modules were additionally introduced to be included in the questionnaire at a state's discretion. To better understand the effects of caregiving on persons providing care, and the amount and type of care being provided, a module containing a series of questions regarding caregiving was introduced to the BRFSS as the Caregiver Module. The concept for the Caregiver Module began modestly as two questions regarding caregiving that were added to the core BRFSS questions in 2000.<sup>27</sup> Select states ran pilots for additional questions in a state-added module in subsequent years, building on these questions. In 2009, the Caregiver Module was introduced as a standardized optional module for states, with all questions cognitively-tested and CDC-approved. By 2012, 27 states and the District of Columbia had completed the module for at least one year. See **Figure 1**, below, for a map of all state participation in the Caregiver Module from 2005-2013.

Although the Caregiver Module was first used in 2005, it was not formally standardized until 2009. For this reason, this study focused on state data obtained in years 2009 and later. See **Table 1** below for a list of states that have used the Caregiver Module since 2009. It is important to note that the list in Table 1 is not intended to be fully comprehensive; additional states are known to have completed the module in 2013, but the full list is not currently known due to an extensive process for data collection. Further explanation of the data collection process is detailed in **Section 2.1**.

Figure 1: Map of State Participation in Caregiver Module, 2005-2013

### BRFSS Caregiver Module 2005 - 2013

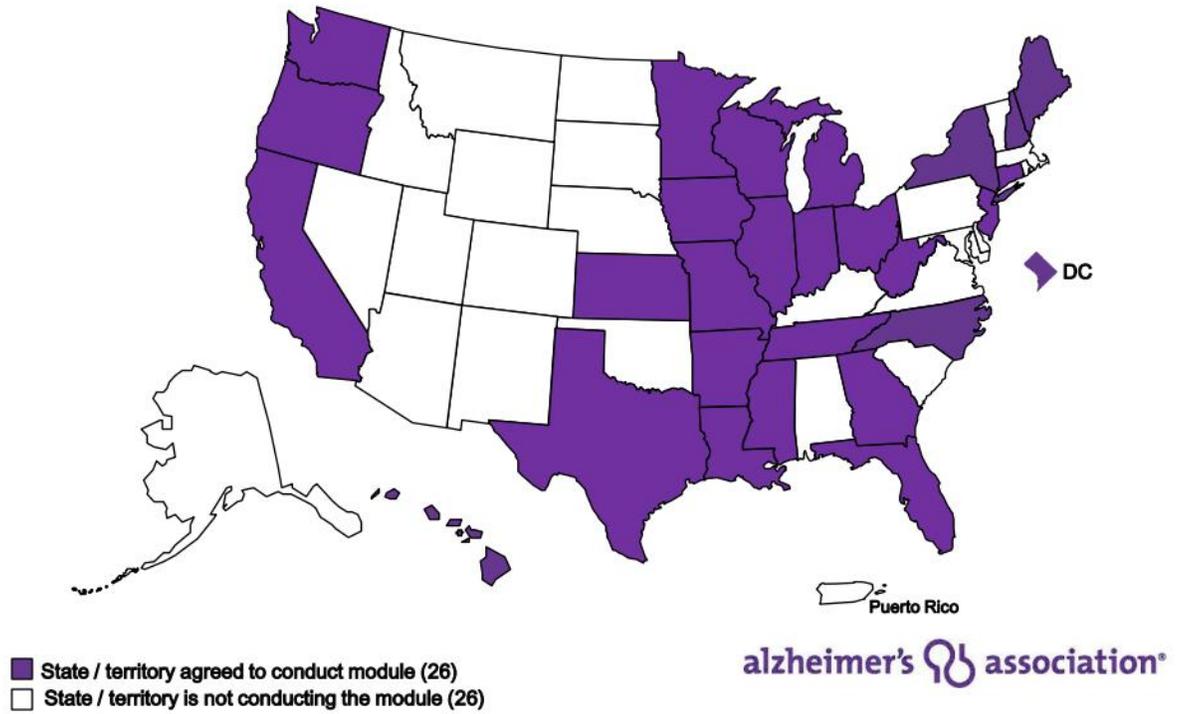


Table 1: State Caregiver Module Data Inclusion, by Year

2009	2010	2011	2012	2013
District of Columbia Illinois Louisiana Ohio	Connecticut New Hampshire New Jersey New York Tennessee Virginia Texas	New Jersey North Carolina	California Georgia Indiana Iowa Maine Mississippi Missouri Oregon Wisconsin West Virginia	Oregon

## 1.4 Literature Review

A limited number of peer-reviewed studies have been published to date on caregivers of dementia patients. Much of the research has been in reports published by various dementia associations, which are not peer reviewed. Additionally, many studies by these different organizations report results in various ways using the same shared data set, leading to fewer independent studies than is immediately apparent. This creates some difficulty in referring to prior studies for statistically significant evidence of potential associated variables. Discussion below focuses on the most prevalent findings in existing reports and publications, and on previous publications using BRFSS caregiving data.

Multiple studies indicate that dementia caregivers tend to be middle aged and female, and are often caring for parents or parent-in-laws.<sup>28-29</sup> Greater than two-thirds of dementia caregivers are white non-Hispanic, with black non-Hispanic, other non-Hispanic, and Hispanic race subgroups comprising the remainder of caregivers, trending from greatest to smallest in typical population frequency.<sup>30,31</sup>

A number of studies indicate that caregiving responsibilities are often associated with decreased physical and psychological health of the caregivers,<sup>32-33</sup> with dementia caregiving causing more severe health effects than other types due to the care being particularly challenging.<sup>33</sup> Other studies suggest few effects on physical or general health, but generally confirm negative effects on mental health, citing emotional and behavioral problems of dementia patients as primary predictors of distress, versus physical problems of patients.<sup>34,35</sup> Women caregivers are more likely to report feeling mentally distressed due to caregiving than men, although reasons for this are not well understood; it is unclear

whether a social paradigm makes women feel more comfortable sharing feelings of distress, or whether certain caregiving factors or other variables cause a higher level of distress.<sup>36</sup>

It is important to note that there are differences in the way studies evaluate health status; some studies use self-reported health measures, such as BRFSS studies, while others use standardized health interview scores or third-party ratings. It's possible that the method for reporting health variables may influence differences found in associations between caregiving status and physical or mental health distress. One study suggested a tendency by caregivers to self-rate poorer general health than their peers, while third-party ratings often do not reveal the same pattern.<sup>36</sup> While this discrepancy is a possibility to consider, this explanation does not appear to be general consensus at this time. Additionally, the hypothesis is not inclusive of all methods of evaluating health status, leaving comparison of some methods unexplored, and it does not reflect findings of a definite pattern evident across multiple studies at this time.

Using regression analysis, a study funded by the National Alliance of Caregiving (NAC) and American Association of Retired Persons (AARP) reported that increased age, being female, caring for a spouse, increased hours of care per week, greater impairment of the recipient's activities of daily living, and living with the care recipient were all factors that increased caregiver burden, with burden measured as a composite score from three self-reported ratings on physical strain, emotional stress, and financial hardship.<sup>36</sup>

Very few published studies have used data from the Caregiver Module of the BRFSS. Three studies were found in total. One study, published in 2009, used single-state 2005 data from North Carolina.<sup>30</sup> The 2005 questionnaire was executed prior to standardization of the Caregiver Module, so questions and formatting were different from the most recent

version, and caregivers of interest were identified as caring for a person “with cognitive impairment” versus a person with “Alzheimer’s disease or dementia”. No significant differences were found between caregivers to patients with cognitive impairment versus other caregivers in demographic variables such as age, race, sex, level of education, annual household income, self-reported number of health days, self-rated general health, availability of social support, and life satisfaction. The analysis did find that length of time providing care and care recipient age were significantly different between caregivers to cognitively impaired patients versus caregivers of non-cognitively impaired patients, with dementia caregivers providing care for longer term than other caregivers, and care recipients being older. A significantly higher percentage of caregivers to cognitively impaired patients reported providing the care recipient with help in “learning, remembering, confusion” than non-cognitively impaired care providers.

A second study, published in 2010, used 2007 BRFSS pilot data from three states to examine relationships between health behaviors (e.g. diet, physical activity) and caregiving status, in all caregivers 65 years or older.<sup>37</sup> Although some reports suggest that caregivers report less time for routine health care and report poorer overall health,<sup>38,39</sup> this study found no significant differences between caregivers and non-caregivers in modifiable health behaviors or health indicators, such as influenza and pneumococcal immunization participation, or weight. The study did find that caregivers were significantly more likely to meet physical activity recommendations than non-caregivers; the same association was reported in a 2006 study, in which the authors suggested that caregivers may have higher rates of physical activity than non-caregivers due to certain caregiving responsibilities.<sup>40</sup>

A third study used 2009 BRFSS data to identify demographic characteristics of caregivers of all persons (not specific to patient age or dementia status), and to compare health variables of caregivers to non-caregivers. The authors of this study reported that select caregiving status variables and caregiver age were associated with self-rated health, frequency of physical and mental health distress reporting, and life satisfaction, confirming other findings suggesting higher rates of physical and mental health distress in caregivers than in non-caregivers,<sup>29</sup> although contrasting in some ways with the other two BRFSS study findings as listed above.

## **1.5 Study Purpose**

The prevalence of dementia is increasing, and the impact is significant. Many caregivers to dementia patients report feeling overwhelmed by, and underprepared for, the care required for the care recipient.<sup>41</sup> For caregivers that would prefer professional assistance, professional care services are often not covered by insurance,<sup>42,43</sup> leading to health and financial implications for both the patient and caregiver, and in-turn, leading to larger societal implications as well.<sup>44</sup>

The purpose of this study is to better understand the demographics of dementia caregivers, and to identify any significant risk factors for increased subjective caregiver burden. This may help to identify target populations for expanded outreach programs. It also may act as one further step towards increasing awareness of caregiving difficulties in order to continue efforts towards realizing effective solutions for insurance coverage, and

towards increasing provider awareness to the importance of providing support and education to informal caregivers.

To date, no peer-reviewed studies have used BRFSS Caregiver Module data from years 2010 or later. A report issued by the Alzheimer's Association used combined BRFSS data from 2009-2010 to evaluate demographics, health, and caregiving variables of dementia caregivers as compared to non-dementia caregivers of all ages and to non-dementia caregivers for care recipients aged 60 or older, investigating associations that have been discussed in prior studies.<sup>31</sup> This thesis will investigate similar familiar variables from 2012 BRFSS responses, in addition to investigating other potential patterns of association.

## Chapter 2. METHOD

### 2.1 Data Collection

Responses for core questions to the BRFSS are publicly available on the CDC's website. However, responses to optional modules may be available through CDC or may be maintained solely by the state, at the state's discretion. Responses to state-added modules are maintained by each respective state.

Because the CDC does not dedicate resources to maintaining a log of states using optional modules, and has no oversight or reporting of states that choose to use state-added modules, there was no single repository for determining states that had completed the Caregiver Module. A map generated by the Alzheimer's Association notes which states had completed the module in years 2009-2013,<sup>25</sup> but it does not provide information on the years in which states completed the module. For further assistance in determining the potential data set population, authors of the Alzheimer's Association BRFSS report were contacted for insight into state participation. Erin D. Bouldin, MPH, PhD, and Elena Andresen, PhD, subsequently provided a list of known states and years in which the Caregiving Module was executed.

From here, state BRFSS coordinators were identified via the CDC publicly available coordinators listing and were individually contacted for data set collection. Data sets were eventually collected from 15 states. As research progressed, it was learned that the BRFSS had undergone a fundamental design change beginning in 2011. Instead of using only landline telephones for respondent interviews, the survey population included both landline and cellular phone subjects. This change led to a very different sample population, and

therefore, data collected prior to 2011 could not be combined with 2010 data or earlier. Because the number of states using the Caregiver module was greater in later years, data collected from 2011 and later became the primary focus. Data from 2009 and 2010 were not used. Further, a list of specific states completing the Caregiver module in 2013 was not well-established, as this was years after the Alzheimer's Association BRFSS report was written and the authors had little access to this information at the time. For those states that were known and those that were contacted for prior data and asked about 2013 data, no states had 2013 data yet available. This narrowed the focus to 2011 and 2012 data sets. Some states requested monetary compensation for providing data, and because of a lack of funding, these states were excluded from the final data set. In total, data from 2011 or later was eventually received from eight of twelve states. Upon evaluation of data obtained, it was discovered that some states had chosen to alter questions from the original standardized module format to provide more state-suitable information. However, because of these changes to a different format, the data set was no longer able to be combined with the standardized format, so data from these state-altered sets could not be used. In addition, some states did not use core variables that other states used, based on annual rotation of core variables and within-state version differences. Variables that were not used by all states were not included in final data sets.

After narrowing the scope and performing data frequency analyses, data from five states in total (*California, Iowa, Maine, Missouri, and Wisconsin*) was refined and finalized with variable name agreement using state and CDC reference materials (see **BIBLIOGRAPHY** for material source listings)<sup>45-46</sup> and merged to create one data set. Observations containing missing data, or containing responses coded to indicate that the respondent refused to

respond or did not know an answer, were eliminated from the data set. The removed observations generally totaled less than one percent of total responses, with some variables' missing observations totaling less than five percent of total responses, and one exception variable ("Household annual income") totaling closer to nine percent of total responses. The finalized data set had a total sample population of 16,677 classified as either caregivers or non-caregivers; from this, 2,870 of the respondents were classified as caregivers, and 390 of those caregivers provided care to persons with Alzheimer's disease or other dementias. Because of the process of acquiring the respective state data sets, and further, merging them based on availability and agreement of specific variables of interest, this data set is considered to be a wholly unique data source.

## **2.2 Measures**

Responses provided as numerical variables were aggregated into ordinal variables for the purpose of this study. In some cases, this categorization was provided as a separate calculated variable within the BRFSS study design. In other cases, numerical variables were aggregated within this study as part of the data analysis process. In addition, some variables in ordinal or nominal form were further aggregated for better statistical power, or to better explore extreme non-normal subpopulation distribution and anticipated differences in caregiving population subtypes.

Respondents were screened to determine caregiving status. The questionnaire explained "People may provide regular care or assistance to a friend or family member who has a health problem, long-term illness or disability." Those that answered "yes" to the

question “During the past month, did you provide any such care or assistance to a friend or family member?” were classified as *Caregivers*.

Identified caregivers were then asked a number of additional questions, including the care recipient’s *age* (numerical), *gender*, and *relationship* (nominal) to the caregiver. Caregivers were then asked the *major health problem* or disability of the care recipient, and asked to choose from a list of mutually exclusive choices. Those caregivers that chose “Alzheimer’s Disease or Dementia” as the major health problem were classified as “Caregivers of people with AD/dementia” for the purposes of this study; caregivers choosing any other health problem were classified as “Caregivers of people without AD or dementia” within this study. Caregivers were additionally asked how *long they have provided care* to that person, and asked to respond in days, weeks, months, or years; the area in which the *care recipient needs most help*, and asked to choose from a list of choices (mutually exclusive); the number of *hours per week* that the caregiver provides care to that person in an average week, with numerical response provided in hours; the *greatest difficulty* the caregiver faces, as a caregiver, and asked to choose from a list of choices (mutually exclusive); and whether the care recipient has experienced *changes in thinking or memory* in the past year (binary). The variables used in analysis, and respective response descriptions, are summarized in **Table 2** below.

As part of the core demographic variables, respondents (caregivers and non-caregivers) answered questions regarding *age* (ordinal), *gender*, and *level of education*. They were also asked about *employment status*, and asked to choose from a list of choices; *marital status*, and asked to choose from a list of choices; and *number of children* under the age of 18 residing in the household, as a numerical response. *Disability status* was assessed

as whether the respondent was “limited in any way in any activities because of physical, mental, or emotional problems,” with responses reported as yes or no.

Table 2: Caregiving Analysis Variables

Category	Variable Type	Category*	Original Variable Name	Aggregated Variable Name
Care recipient's Gender	Binary	Male	crgvgnr	
Care recipient's Age	Ordinal	4 Age ranges	crgvage	crgvage_cat
Care recipient's relationship to Caregiver	Nominal	3 Categories of family, and 1 "non-relative" choice	crgvrelt	crgvrelt2
Care recipient's major health problem	Binary	Alzheimer's disease or dementia	crgvprob	addementia
Cognitive status change	Binary	Care recipient experienced a change in thinking or remembering in past year	crgvchnr	
Hours of care provided per week	Ordinal	4 Different choices, as ranges	crgvhrs	crgvhrs_cat
Hours of care provided per week	Binary	0-8 Hours	crgvhrs	crgvhrs_8
Area in which care recipient needs most help	Nominal	9 Choices pertaining to physical, mental, or emotional areas of help	crgvmst1	
Area in which care recipient needs most help	Binary	"Taking care of self (eating, bathing, etc.)"	crgvmst1	selfcare
Great difficulty faced by Caregiver	Nominal	9 Different ways in which caregiving affects the caregiver's personal life, including a "No difficulty" option	crgvdif	
Great difficulty faced by Caregiver	Binary	"Creates stress"	crgvdif	crgvdif_5
Great difficulty faced by Caregiver	Binary	Includes any difficulty choice for "greatest difficulty", except "No difficulty"	crgvdif	crgvdif_cat2

\*For Binary variables, the Category description describes "Event='1'."

NOTE: See Results table for Caregiving variables (Table 4, page 22) for full category response choices.

*Race* and *income* were reported categorically. *Mental distress* was reported as a numerical value, responding to the question “thinking about your mental health, which includes stress, depression, and problems with emotions, for how many days during the past 30 days was your mental health not good?” The numerical responses were aggregated into a binary variable of “1 or more days of poor mental health in the last 30 days.” *Physical activity* was asked as “During the past month, other than your regular job, did you participate in any physical activities or exercises such as running, calisthenics, golf, gardening, or walking for exercise?” and reported as a yes or no response. *General health* was a self-rated measure, with the questionnaire reading “Would you say your general health is” and choices listed as “Excellent,” “Very good,” “Good,” “Fair,” or “Poor.” This variable was aggregated into a binary variable in which a positive event was defined such that health was rated as “Good” or better. Respondents were also asked about most recent *checkup*, with the question reading “About how long has it been since you last visited a doctor for a routine checkup?” and ordinal response choices listed. The demographic variables used in analysis, and respective response choices, are listed below in **Table 3**.

**Table 3: Demographic Analysis Variables**

Category	Variable Type	Category*	Original Variable Name	Aggregated Variable Name
Gender	Binary	Female	sex	
Age	Ordinal	5 Age ranges (beginning age 18)	age	_age_g
Education	Ordinal	4 Choices of highest education level completed	educa	_educag
Education	Binary	"Some college or beyond"	educa	_educa_cat2
Employment status	Nominal	3 Employment status categories	employ	employ_new
Marital status	Binary	Married/Coupled	marital	marital_new
Children in household	Binary	At least one child under age 18 lives in household	_chldcnt	_chldcnt_any
Disability status	Binary	Respondent has a disability	qlactlm2	
Race/ethnicity	Nominal	4 Different Race Categories	race2	race_new
Household annual income	Ordinal	4 Income ranges	income2	income_cat
Income	Binary	"\$75,000 or more"	income2	income_cat2
Income	Binary	\$50,000 or more	income2	income_cat50
Mental distress	Binary	1 or more days of poor mental health in the past 30 days	menthlth	mntlhlth_new
Physical activity	Binary	Engage in physical activity outside of work	exerany2	
General health	Binary	"Excellent", "Very good", or "Good"	genhlth	genhlth_good
Checkup	Binary	Respondent had a routine checkup within the last year	checkup1	checkup_new

\*For Binary variables, the Category description describes "Event='1'."

NOTE: See Results table for Demographic variables (**Table 5**, page 25) for full category response choices.

## 2.3 Data Analysis

Data were analyzed using SAS software version 9.4. Two-tailed chi-square tests were performed to establish statistically significant relationships between variables, using Rao-Scott chi-square test statistic. Separately, logistic regression ("SURVEYLOGISTIC")

procedure) was used to create a model for multivariate analysis. In both cases, significance was inferred at a level of 0.05.

In both types of analyses, strata, cluster, and weight variables were applied, as per standard procedure for survey analysis. The strata variable is CDC provided, and accounts for state, geographic region, and household density differences. BRFSS uses random digit dialing that is not geographically or otherwise clustered; because of this, there are no true cluster groups of respondents, and each observation is treated as a unique cluster. Because BRFSS uses disproportionate stratified sampling, weight variables are necessary for frequency adjustment. Each state has its own derived weight variable, representative of the within-state population, and these unique variables were applied to the respective data sets within the final combined data set. Final results are reported as weighted frequencies. Because weights are state-representative, results reported in this analysis are not statewide or nationwide estimations, but are estimations based on a sample population of the five included states.

## Chapter 3. RESULTS

### 3.1 Chi-square Analyses of Caregiving Variables

As an initial measure, caregiving variables were evaluated for significant differences between caregivers to persons with AD or dementia (AD/DEM) as compared to caregivers of all ages of persons without AD or dementia (NOAD-ALL), and as compared to caregivers of persons over 60 years of age without AD or dementia (NOAD>60). While it is important to consider the differences between caregivers of dementia patients with other caregivers in general, it's also important to consider whether these differences are due simply to caring for an older population, or are due to inherent differences in caregiving experiences. This was the reason for including both alternative populations for comparison. A table of results for all analyses is displayed below in **Table 4**; p-values are listed for significant variables.

The proportion of AD/DEM care recipients that are female was found to be significantly greater than in the NOAD-ALL group (AD/DEM=72.2%; NOAD-ALL=58.8%, p-value=0.0045). Care recipient's age and proportion of reported cognitive change were both significantly different in AD/DEM versus both NOAD-ALL and NOAD>60 groups (NOAD-ALL: p-value Age<0.0001, Cognitive change<0.0001; NOAD>60: p-value Age=0.0010, Cognitive change<0.0001).

**Table 4: Results of chi-square analysis: Caregiving variables**

Variable	Category	Caregivers of people with AD/dementia	Caregivers of people without AD or dementia	
		Care recipients of all ages (n=390) (AD/DEM)	Care recipients of all ages (n=2480) (NOAD-ALL)	Care recipients >=60 years (n=1858) (NOAD>60)
		Weighted Frequency (95% CI)	Weighted Frequency (95% CI)	Weighted Frequency (95% CI)
Care recipient's Gender <sup>1</sup>	Female	72.2 (64.2, 80.2)	58.5 (54.4, 62.5)	64.7 (60.1, 69.2)
	p-value		*0.0045	0.12
Care recipient's Age <sup>1,2</sup>	0-64	3.9 (0.2, 7.6)	41.1 (37.1, 45.0)	11.2 (8.15, 14.2)
	65-74	15.9 (9.2, 22.7)	16.7 (13.8, 19.7)	25.2 (21.1, 29.3)
	75-84	31.4 (23.3, 39.4)	21.4 (18.3, 24.5)	32.2 (28.0, 36.5)
	85 or older	48.8 (39.6, 58.1)	20.8 (17.9, 23.8)	32.3 (27.3, 35.5)
	p-value		*<0.0001	*0.0010
Care recipient's relationship to caregiver	Parent or Parent-in-law	50.7 (41.5, 60.0)	42.8 (38.8, 46.8)	55.3 (50.8, 59.8)
	Spouse	9.4 (4.0, 14.9)	10.1 (8.1, 12.0)	10.3 (8.0, 12.5)
	Other relative	29 (20.0, 38.1)	30.2 (26.5, 33.9)	21.1 (17.3, 24.9)
	Non-relative	10.8 (5.9, 15.7)	16.9 (14.0, 19.8)	13.4 (10.5, 16.2)
Cognitive status change <sup>1,2</sup>	Care recipient experienced a change in thinking or remembering in past year	92.9 (88.0, 97.7)	48.7 (44.8, 52.6)	55.7 (51.2, 60.3)
	p-value		*<0.0001	*<0.0001
Hours of care provided per week	0-8	57.3 (48.1, 66.5)	55.0 (51.0, 58.9)	56.2 (51.6, 60.8)
	9-19	10.4 (5.5, 15.3)	16.2 (13.4, 18.9)	17.9 (14.3, 21.6)
	20-39	11.6 (5.7, 17.5)	13.7 (10.8, 16.5)	12.9 (9.7, 16.0)
	40 or more	20.7 (12.6, 28.8)	15.2 (12.3, 18.0)	13.0 (9.8, 16.2)

(Table 4 continued on page 23)

(Table 4 continued from page 22)

Variable	Category	Caregivers of people with AD/dementia	Caregivers of people without AD or dementia	
		Care recipients of all ages (n=390) (AD/DEM)	Care recipients of all ages (n=2480) (NOAD-ALL)	Care recipients >=60 years (n=1858) (NOAD>60)
		Weighted Frequency (95% CI)	Weighted Frequency (95% CI)	Weighted Frequency (95% CI)
Area in which care recipient needs most help <sup>1,2</sup>	Taking care of self (eating, bathing, etc.)	24.9 (16.5, 33.2)	16.5 (13.5, 19.5)	15.8 (12.5, 19.1)
	Taking care of residence	30.5 (21.7, 39.4)	31.1 (27.4, 34.8)	32.3 (28.9, 36.5)
	Communicating with others	1.2 (0.5, 2.0)	2.8 (1.4, 4.3)	1.7 (0.6, 2.9)
	Learning or remembering	13.5 (7.7, 19.3)	2.2 (1.0, 3.3)	2.4 (0.7, 4.0)
	Seeing or hearing	0.3 (0.0, 0.8)	1.1 (0.5, 1.7)	1.1 (0.5, 1.7)
	Mobility within the home	1.2 (0.0, 2.7)	4.8 (3.2, 6.4)	4.6 (2.9, 6.4)
	Transportation outside the home	18.1 (10.6, 25.6)	24.0 (20.7, 27.2)	27.2 (23.4, 31.0)
	Getting along with people	0.2 (0.0, 0.4)	0.3 (0.1, 0.6)	0.3 (0.0, 0.6)
	Relieving anxiety or depression	1.5 (0.4, 2.7)	6.3 (4.5, 8.0)	5.1 (3.0, 7.2)
	Something else	8.5 (4.7, 12.4)	10.9 (8.4, 13.5)	9.5 (6.6, 12.3)
		p-value		*<0.0001
Great difficulty faced by caregiver <sup>1,2</sup>	Creates financial burden	1.9 (0.6, 3.1)	6.1 (4.5, 7.7)	4.0 (2.4, 5.6)
	Doesn't leave enough time for yourself	8.5 (3.3, 13.7)	8.8 (6.5, 11.1)	9.5 (6.7, 12.3)
	Doesn't leave enough time for your family	8.6 (2.4, 14.8)	4.8 (2.8, 6.7)	4.7 (2.3, 7.2)
	Interferes with work	5.8 (0.4, 11.2)	5.4 (3.4, 7.5)	5.5 (2.8, 8.1)
	Creates stress	32.3 (23.7, 41.0)	20.5 (17.3, 23.8)	20.1 (16.3, 23.9)
	Creates or aggravates health problems	1.9 (0.2, 3.6)	1.7 (0.8, 2.6)	1.6 (0.7, 2.5)
	Affects family relationships	10.5 (4.9, 16.2)	3.4 (2.1, 4.7)	3.3 (1.6, 6.1)
	Other difficulty	14.7 (7.5, 21.9)	33.3 (29.4, 37.3)	32.4 (28.1, 36.7)
	No difficulty	15.8 (11.1, 20.4)	16.1 (14.7, 17.4)	18.9 (17.2, 20.7)
		p-value		*<0.0001

1: AD/DEM group is significantly different from NOAD-ALL group

2: AD/DEM group is significantly different from NOAD&gt;60 group

\* Statistically significant

Other caregiving variables in which the AD/DEM group differed significantly from the NOAD groups included the area in which the care recipient needs the most help (NOAD-ALL: p-value<0.0001 NOAD>60: p-value<0.0001) and greatest difficulty faced by the caregiver (NOAD-ALL: p-value<0.0001; NOAD>60: p-value=0.0001). Most notably, the AD/DEM response frequencies differed most from NOAD groups for “area in which the care recipient needs the most help” in selections “Taking care of self” (AD/DEM=24.9%; NOAD-ALL=16.5%; NOAD>60=15.8%), and in “Learning or remembering” (AD/DEM=13.5%; NOAD-ALL=2.2%; NOAD>60=2.4%). In the “greatest difficulty faced by caregiver” category, the AD/DEM group differed from the NOAD groups most in “Creates stress” (AD/DEM=32.3%; NOAD-ALL=20.5%; NOAD>60=20.1%) and “Other difficulty” (AD/DEM=14.7%; NOAD-ALL=33.3%; NOAD>60=32.4%).

### 3.2 Chi-square Analyses of Demographic Variables

In addition to evaluating differences in caregiving status of AD/dementia caregivers in comparison to other types of caregivers, demographic variables were also analyzed for differences between the AD/DEM group and other caregiving groups (NOAD-ALL, NOAD>60), and non-caregivers (NONCARE). Variables analyzed were chosen based on potential significance as suggested by literature review findings in previous studies and reports. Results of all demographic variables analyzed are summarized in **Table 5** below; p-values are listed for significant variables.

Table 5 : Results of chi-square analysis: Demographic variables

Variable	Category	Caregivers of people with AD/dementia	Caregivers of people without AD or dementia		Non-caregivers
		Care recipients of all ages (n=390) (AD/DEM)	Care recipients of all ages (n=2480) (NOAD-ALL)	Care recipients >=60 years (n=1858) (NOAD>60)	(n=13807) (NONCARE)
		Weighted Frequency (95% CI)	Weighted Frequency (95% CI)	Weighted Frequency (95% CI)	Weighted Frequency (95% CI)
Gender <sup>3</sup>	Female	67.6	65.5	66.4	47.7
	p-value		0.64	0.79	*<0.0001
Age <sup>3</sup>	18-34	14.3 (6.9, 21.8)	19.9 (16.4, 23.4)	14.3 (10.7, 17.9)	33.4 (31.6, 35.1)
	35-44	11.4 (4.8, 18.0)	18.6 (15.1, 22.2)	17.5 (13.5, 21.5)	18.5 (17.2, 19.8)
	45-54	27.6 (19.4, 35.8)	25.1 (21.6, 28.6)	26 (21.8, 30.1)	17.5 (16.3, 18.7)
	55-64	26.7 (19.1, 34.2)	19.5 (16.9, 22.1)	22.1 (18.8, 25.3)	14.4 (13.5, 15.4)
	65+	20.0 (13.0, 27.0)	16.9 (14.7, 19.1)	20.1 (17.2, 22.9)	16.2 (15.3, 17.0)
	p-value		0.13	0.59	*<0.0001
Education <sup>3</sup>	Less than high school	6.4 (2.0, 10.8)	8.4 (6.0, 10.7)	8.1 (5.2, 10.9)	13.0 (11.8, 14.2)
	High school degree or equivalent	18.7 (11.8, 25.5)	22 (18.8, 25.2)	22.3 (18.7, 25.9)	24.7 (23.2, 26.1)
	Some college or technical school	30.7 (22.4, 39.1)	32 (28.3, 35.6)	30.6 (26.6, 34.6)	28 (26.4, 29.5)
	4+ years of college (grad or higher)	44.2 (34.9, 53.5)	37.7 (33.8, 41.5)	39.0 (34.4, 43.6)	34.4 (32.8, 36.0)
	p-value		0.55	0.68	*0.03
Employment status	Employed, student, or homemaker	74.6 (67.0, 82.2)	67.3 (63.8, 70.9)	63.9 (59.6, 68.2)	72.8 (71.4, 74.2)
	Retired	16.9 (11.4, 22.3)	18.4 (16.0, 20.8)	22.7 (19.5, 25.8)	14.9 (14.1, 15.7)
	Out of work or unable to work	8.5 (2.4, 14.7)	14.3 (11.2, 17.3)	13.4 (9.9, 16.9)	12.3 (11.1, 13.6)
Disability status	Respondent is limited in some way in some activities because of physical, mental, or emotional problems	18.4 (12.0, 24.9)	24.1 (20.8, 27.4)	23.2 (19.5, 27.0)	16.2 (15.1, 17.3)

(Table 5 continued on page 26)

(Table 5 continued from page 25)

Variable	Category	Caregivers of people with AD/dementia	Caregivers of people without AD or dementia		Non-caregivers
		Care recipients of all ages (n=390) (AD/DEM)	Care recipients of all ages (n=2480) (NOAD-ALL)	Care recipients >=60 years (n=1858) (NOAD>60)	(n=13807) (NONCARE)
		Weighted Frequency (95% CI)	Weighted Frequency (95% CI)	Weighted Frequency (95% CI)	Weighted Frequency (95% CI)
Race / ethnicity <sup>3</sup>	White only, non-Hispanic	76.5 (67.0, 86.0)	67.0 (62.8, 71.2)	68.4 (63.5, 73.4)	57.9 (56.2, 59.7)
	Black only, non-Hispanic	4.6 (1.2, 8.1)	7.8 (5.3, 10.3)	7.8 (4.8, 10.9)	5.3 (4.6, 6.1)
	Other, non-Hispanic	11 (3.2, 18.9)	16.1 (12.8, 19.4)	15.5 (11.6, 19.5)	24.1 (22.5, 25.8)
	Any race, Hispanic	7.8 (1.2, 14.5)	9.1 (5.5, 12.7)	8.2 (4.2, 12.1)	12.6 (11.0, 14.2)
	p-value		0.40	0.52	*0.0106
Household annual income <sup>3</sup>	Less than \$25,000	17.3 (10.6, 23.4)	26.2 (22.7, 29.7)	25.0 (20.9, 29.1)	28.1 (26.5, 29.7)
	\$25,000-\$49,999	23.2 (16.0, 30.4)	26.6 (22.9, 30.3)	23.4 (19.7, 27.1)	24.1 (22.6, 25.5)
	\$50,000-\$74,999	20.1 (12.7, 27.6)	17.3 (14.6, 20.1)	18.3 (15.0, 21.6)	15.0 (13.9, 16.2)
	\$75,000 or more	39.4 (30.2, 48.7)	29.8 (26.3, 33.4)	33.4 (29.0, 37.8)	32.8 (31.2, 34.3)
	p-value		0.07	0.31	*0.04
Mental distress	1 or more days of mental health "not good" in the past 30 days (stress, depression, emotional problems)	42.7 (33.3, 52.0)	44.7 (40.8, 48.7)	42.9 (38.3, 47.4)	35.6 (34.0, 37.3)
Physical activity <sup>1,2,3</sup>	Outside of work, engage in any physical activity for exercise in past month?	93.1 (90.3, 95.9)	83.8 (80.8, 86.7)	85.2 (82.1, 88.3)	81.1 (79.8, 82.4)
	p-value		*<0.0001	*0.0006	*<0.0001
General health <sup>1,2,3</sup>	Excellent, very good, or good	94.0 (91.2, 96.7)	84.5 (81.4, 87.5)	85.4 (81.7, 89.0)	84.1 (82.9, 85.4)
	p-value		*<0.0001	*0.0003	*<0.0001
Length of time since visited doctor for routine checkup	Less than 1 year	67.6 (58.5, 76.7)	67.3 (63.4, 71.2)	68.3 (63.8, 72.7)	62.6 (60.9, 64.3)
	1 year to less than 5 years	22.9 (14.6, 31.2)	24.6 (21.0, 28.2)	24.0 (20.1, 28.0)	27.3 (25.7, 28.9)
	5 years or more	9.5 (3.4, 15.5)	8.1 (5.5, 10.7)	7.7 (4.4, 11.0)	10.1 (9.0, 11.1)

1: AD/DEM group is significantly different from NOAD-ALL group

2: AD/DEM group is significantly different from NOAD&gt;60 group

3: AD/DEM group is significantly different from NONCARE group

\* Statistically significant

Several demographic variables showed significant differences between the AD/DEM group and NONCARE group. These include: Gender (as % Female, AD/DEM=67.6%, NONCARE=47.7%; p-value<0.0001), Age (p-value<0.0001), Education (p-value=0.03), Race/ethnicity (p-value=0.01), and Household annual income (p-value=0.04). Overall, the AD/DEM population is more often female, older, more educated, higher income, and has a greater percentage of white, non-Hispanic population than non-caregivers.

In addition, two demographic variables showed significance between the AD/DEM group and all three remaining comparative groups. These included participation in physical activity, and general health, with the AD/DEM group showing a higher proportion of its population participating in physical activity (AD/DEM=93.1%; NOAD-ALL=83.8%, p-value<0.0001; NOAD>60=85.2%, p-value=0.0006; NONCARE=81.1%, p-value<0.0001) and reporting better overall general health (AD/DEM=94.0%; NOAD-ALL=84.5%, p-value<0.0001; NOAD>60=85.4%, p-value=0.0003; NONCARE=84.1%, p-value<0.0001).

### **3.3 Chi-square Analyses of Different AD/Dementia Caregiver Populations**

Some further parameters of interest were evaluated within the AD/DEM group to investigate significant associations. Statistical power was limited due to creating subpopulations within an already relatively small sample size.

Because there is some evidence that gender differences exist in reporting distress associated with caregiving, select caregiving and health variables were evaluated for significant differences between men and women. Frequencies of mental distress and reported caregiving difficulties (“greatest difficulty”) were analyzed to evaluate any differences in subjective burden. Additionally, other factors that may contribute to

increased feelings of distress were evaluated; in this case, hours of care per week and the caregiver’s relationship to the recipient were examined to understand whom men and women are caring for, and also whether they are contributing different amounts of time to providing care. Results obtained are summarized in **Table 6** below.

**Table 6: Chi-square analysis of AD/Dementia Caregivers: Gender Differences**

Variable	Category	Men	Women	p-value
		Weighted Frequency (95% CI)	Weighted Frequency (95% CI)	
Mental distress *	1 or more days of mental health "not good" in the past 30 days (stress, depression, emotional problems)	25.2 (13.0, 37.3)	51.1 (39.0, 63.1)	*0.0032
Greatest difficulty faced by caregiver	Any difficulty reported	78.6 (69.7, 87.4)	86.9 (82.3, 91.6)	0.10
	Creates stress	24.1 (10.4, 37.8)	36.2 (25.4, 47.1)	0.2028
Hours of care per week	0-8 hours of care	61.6 (47.0, 76.1)	55.2 (43.5, 67.0)	0.5123
Care recipient's relationship to Caregiver	Parent or Parent-in-law	46.6 (32.3, 61.0)	52.7 (40.2, 65.2)	0.4244
	Spouse	9.7 (0.9, 18.5)	9.3 (2.1, 16.5)	
	Other relative	26.4 (12.7, 40.0)	30.3 (19.0, 41.6)	
	Non-relative	17.3 (5.5, 29.0)	7.7 (3.9, 11.4)	

\* Statistically significant

This data suggests that, of caregivers to AD/dementia patients, a significantly greater percentage of women than men report one or more days of mental distress (women=51.1%; men=25.2%; p-value=0.0032). Similarly, the data indicate that a higher percentage of woman also reported a greatest difficulty of “creates stress” (women=36.2%; men=24.1%), and report some difficulty associated with caregiving responsibilities (women=86.9%; men=78.6%), as opposed to reporting “no difficulty”; however, these two additional parameters were not statistically significantly different from men (creates stress,

p-value=0.20; any difficulty, p-value=0.10). There were no significant gender differences in caregivers that provided 0-8 hours of care per week (versus nine or more hours per week) or in the caregiver's relationship to the care recipient.

In order to roughly evaluate whether the health variable of "mental distress" was due simply to gender differences in the general population, and not unique to AD/dementia caregivers, a subsequent analysis was performed on non-caregivers. Analysis of non-caregivers revealed that 40.7% of women and 31.1% of men report one or more days of mental distress. Although the frequency of women reporting mental distress is still greater, the difference between men in women in the AD/DEM group versus the NONCARE group appears to be more exaggerated in general.

It has also been suggested in previous studies that caregiver burden increases as the caregiver's role in recipients' Activities of Daily Living (ADLs) increase.<sup>47</sup> For this reason, a number of parameters were examined to better understand the profiles of those caregivers that reported "Taking care of self (eating, bathing, etc.)" as the area in which they provide the most help to the care recipient, versus those that reported other listed choices. Additionally, a notably greater proportion of people in the AD/DEM group reported this "self-care" response versus those in the NOAD-ALL and NOAD>60 groups, making it a somewhat unique level-of-care measure for the AD/DEM group. Results of analyses are summarized in **Table 7** below.

**Table 7: Chi-square Analysis of AD/Dementia Caregivers: Self-care Differences**

Variable	Category	Area in which recipient needs most help = Self-care (eating, bathing, etc.)	Area in which recipient needs most help <b>NOT</b> = Self-care (eating, bathing, etc.)	p-value
		<b>Weighted Frequency (95% CI)</b>	<b>Weighted Frequency (95% CI)</b>	
Caregiver's household annual income	\$50,000 or more	47.9 (29.0, 66.9)	63.4 (54.7, 72.1)	0.14
Hours of care per week	0-8 hours of care	49.2 (30.1, 68.3)	60.0 (49.6, 70.3)	0.32
Caregiver's employment status	Employed, student, or homemaker	78.8 (65.2, 92.4)	73.2 (63.9, 82.5)	0.76
	Retired	12.6 (5.2, 20.0)	18.3 (11.7, 24.8)	
	Out of work or unable to work	8.6 (0.0, 20.7)	8.5 (1.1, 15.9)	
Greatest difficulty for caregiver *	Creates Stress	19.5 (8.1, 30.8)	36.6 (26.5, 46.7)	*0.03
Caregiver's mental distress	1 or more days of mental health "not good" in the past 30 days (stress, depression, emotional problems)	54.2 (35.7, 72.6)	38.9 (28.4, 49.4)	0.13

\* Statistically significant

Income was analyzed in the stratified self-care groups to understand whether those with higher income may be more able or likely to hire professional care to assist with self-care as the disease progresses, resulting in a greater proportion of lower-income caregivers providing self-care than higher-income caregivers. This general trend was observed within this data set. While the variable does approach significance (p-value=0.14), the difference is not statistically significant.

It was then hypothesized that a difference associated with income may be due to higher income caregivers being more likely to be employed, and thus less able to commit time to providing self-care. However, no significant differences were found in rates of employment or hours of care per week between the two groups. This may support the theory that higher income caregivers are simply better able to afford additional care,

although other confounders are possible. Finally, stress variables were analyzed in the stratified self-care groups. It was found that a significantly lower percent of AD/dementia caregivers listing self-care as the main area of assistance reported “creates” stress as the greatest difficulty than those that did not list self-care as the main area of assistance (Self-care=19.5%; NOT self-care=36.6%; p-value=0.03). Mental distress was also evaluated; although the difference approached significance, with p-value=0.13, it was not found to be statistically significant (Self-care=54.2%; NOT self-care=38.9%). It is interesting to note that while “creates stress” is negatively associated with reporting “self-care”, mental distress appears slightly positively associated.

### 3.4 Regression Model for Caregiver Burden

Using the data available, caregiver subjective burden was analyzed as a binary outcome variable, using respondents’ choices to the question regarding “greatest difficulty for caregiver.” Because caregiver burden may be used as an inclusive term for multiple types of stress experienced by a caregiver (financial, emotional, physical, etc.), the binary variable chosen was “crgvdiff\_cat2,” which includes all difficulty response choices, except “No Difficulty.” While a specific “creates stress” choice is listed, it is assumed that other difficulty choices likely also cause stress, and additionally, may simply be more descriptive characterizations for the derivation of stress, and not categorically mutually exclusive.

From here, independent variables were chosen that reflected potential associations suggested either from previous studies or from chi-square analyses performed as a part of this thesis. **Table 8** below shows the variable description, variable name (Effects), degrees of freedom (DF), and respective significance (Pr>ChiSq).

**Table 8: Full Model Description**

SAS: Type 3 Analysis of Effects on Binary Outcome Variable=crgvdiff_cat2			
Variable Description	Effects	DF	Pr > ChiSq
Care recipient's Gender	crgvgndr	1	0.4713
Caregiver's relationship to the care recipient	crgvrelt2	3	0.0204
Care recipient's Age	crgvage_cat	3	0.0906
Hours of Care per week (0-8)	crgvhrs_8	1	<.0001
Self-care	selfcare	1	0.3492
Any child under 18 in the household	_chldcnt_any	1	<.0001
Employment status	employ_new	2	0.6493
Exercise	EXERANY2	1	0.4141
Age	_age_cat5	4	0.1692
Education: Some college or beyond	_educa_cat2	1	0.3112
Income: \$50,000 or more	income_cat2	1	0.5292
Married/coupled	marital_new	3	0.2395
> 1 poor mental health day in past 30 days	menthlth_new	1	0.1572
Race	race_new	3	0.5588
Gender	SEX	1	0.2417

Subsequent backwards elimination was performed until all remaining variables were significant. The overall model yielded three significant variables: caregiver’s relationship to the care recipient, hours of care provided per week (0-8, or more than 8), and whether the caregiver had children under age 18 living in the household. **Table 9** below shows significant variables and respective odds ratios.

**Table 9: Final Model Description with Odds Ratios**

Description	Type 3 Analysis of Effects			Odds Ratio Estimates			
	Effect	Wald Chi-Square	Pr > ChiSq	Effect	Point Estimate	95% Wald Confidence Limits	
Caregiver's relationship to care recipient	crgvrelt2	13.8359	0.0031	crgvrelt2 2 vs 1	0.415	0.102	1.684
				crgvrelt2 3 vs 1	0.2	0.08	0.5
				crgvrelt2 4 vs 1	0.261	0.08	0.855
Hours of care per week (0-8)	crgvhrs_8	13.0673	0.0003	crgvhrs_8 0 vs 1	4.371	1.964	9.724
Any child under 18 in the household	_chldcnt_any	29.378	<.0001	_chldcnt_any 0 vs 1	0.123	0.058	0.263

This data suggests that caregivers to parents and parent-in-laws are more likely to report some difficulty than caregivers to “other relatives” or non-relatives. The odds of a caregiver to a parent or parent-in-law reporting a difficulty are approximately 5.0 times the odds of a caregiver to an “other relative” reporting a difficulty, and 3.8 times the odds of a caregiver to a non-relative reporting a difficulty. The odds of a caregiver reporting a difficulty are not significantly different between caregivers to parents/parent-in-laws and spouses.

The likelihood of a caregiver reporting any difficulty also increases as hours of care per week rises above 8 hours; caregivers that provide care more than 8 hours per week are 4.4 times more likely to report any difficulty than caregivers providing 0-8 hours of care per week.

Finally, caregivers with children in the home are 8.1 times more likely to report any difficulty than caregivers without children in the home. This indicates agreement with studies suggesting that the “sandwich generation”, involving adults who are caring for both children and parents, report higher levels of stress than other caregivers.

## Chapter 4. DISCUSSION

Many significant variables identified in this study confirm findings in previous studies. Care recipient gender frequency is in agreement with Alzheimer's disease statistics suggesting that females are disproportionately afflicted, whether this is due to a longer life expectancy or due to a higher risk of disease. In this case, gender is only significantly different from the NOAD-ALL group, and not significantly different from the older NOAD>60 group. This may lend credibility to the theory that disease prevalence differences are due to life expectancy; however, limited statistical power to easily distinguish between different populations should be acknowledged.

The variable for care recipient's age exhibits a steadily growing proportion of recipients in each subsequent age group for the AD/dementia group. This is in agreement with statistics indicating a substantial dementia prevalence increase with increasing age. No similar increasing pattern is evident in the remaining groups. Cognitive change is also significantly different in the AD/DEM group than the NOAD groups. It is expected that cognitive change would occur more frequently in AD/dementia patients than in the NOAD groups, due to AD/dementia manifestation. In addition, the statistically significant differences in variables measuring the "area in which the care recipient needs most help" and the "greatest difficulty faced by the caregiver" do seem to confirm that caregiving for AD/dementia patients presents a unique set of responsibilities and challenges in comparison to other caregiving roles.

The significance of certain demographic variables is also in agreement with previous studies. This analysis yielded results suggesting that AD/dementia caregivers, in comparison

to non-caregivers, tend to be female, older, have higher education and annual household income, and tend to be white race/ethnicity. Physical activity was suggested in some studies to be lower in caregivers, and AD/dementia caregivers in particular, due to factors such as lack of time because of caregiving responsibilities, or lack of effort due to caregiving stressors.<sup>48,38</sup> Other studies, however, found that physical activity may be higher in caregivers, because caregiving responsibilities kept caregivers active.<sup>40</sup> This study confirmed the latter finding, showing that caregivers to AD/dementia patients had higher reported levels of physical activity than did NOAD and NONCARE groups. Additionally, many studies suggest poorer overall health in caregivers, with AD/dementia caregivers suffering particularly more due to burdens of caregiving and lack of time and effort into keeping up with their own healthcare. However, this study found that the self-reported general health of AD/dementia caregivers was significantly higher than that reported by NOAD caregivers and non-caregivers. This is in agreement with two previous BRFSS studies that did not find negative association between AD/dementia caregiving status and general health. It's possible that the AD/dementia caregiver population that is willing to participate in phone surveys is in better overall health than the general AD/dementia caregiver population, although this difference would seemingly no longer be relevant when applied to the NOAD and NONCARE groups as well. It's also difficult to understand whether the general health parameter is truly reflective of a respondent's better health status, or is based on an inherent difference in subjective reporting.<sup>40,49</sup> Maybe only those in better health are able to provide the rigorous caring needed by AD/dementia patients, or maybe the caregiver's perspective of his or her own health is subconsciously being compared to the health of the person they care for, which is generally viewed as relatively negative for

an AD/dementia diagnosis. Many other explanations are possible as well. In tandem with the general health variable, the idea of lack of caregiver self-care was explored further by analyzing for differences in time since last routine checkup; however, no significant differences were found between the AD/DEM group and any other groups. Mental distress was also evaluated for differences. While all caregiving groups appear to trend higher than non-caregivers in proportion of respondents experiencing one or more days of mental distress in the past 30 days, no significant differences were found between the AD/DEM group and any other groups.

Analyses were also performed on differences of characteristics within the AD/dementia caregiver population. Reasons for stratifying by gender and by self-care, and for choosing the specific variables of interest for each stratified analysis, are outlined above in **Section 3.3**. Despite statistical power being limited due to subgrouping of a relatively small sample size, the tests were chosen for interest in analysis, regardless of obtaining statistical significance.

The significantly higher reporting of mental distress in women than in men is consistent with evidence in other studies.<sup>50,51</sup> In line with this finding, women also reported “creates stress” ,and separately, any difficulty, in response to the question asking about greatest difficulty for caregiver, although these two variables were not significantly different from men. Again, it is unclear whether the mental distress variable truly reflects differences in mental distress, or in willingness to self-report mental distress. Women are more often encouraged to share emotional stresses than men; these results may be a reflection of this difference.<sup>52</sup> It’s also possible that women find the same responsibilities of caring for an AD/dementia patient more stressful than men do, have less effective coping strategies, or

possibly that women have a harder time physically fulfilling certain roles related to dementia caregiving, which causes greater rates of mental distress.<sup>51,53,54</sup> One study suggests that men, in general, are better able to tolerate stress over time and thus maintain lower levels of depression.<sup>54</sup>

In self-care stratified analyses, although the income disparity was not statistically significant, it did approach significance, with p-value=0.14. Although the variable association does not appear to be prominently explored in previous publications, the relationship was informally suggested by a subject matter expert experienced with facilitating dementia caregiver support groups, Dr. Claire Flaherty, Clinical Neuropsychologist and Associate Professor of Neurology at the Penn State College of Medicine. Surprisingly, a lower frequency of “creates stress” was reported as the caregivers’ greatest difficulty in those that reported self-care than those that did not. A previous study suggested that increased participation in providing this type of self-care to recipients generally led to increased feelings of burden.<sup>47</sup> However, in contrast to the “creates stress” response difference, a greater proportion of caregivers reporting self-care noted one or more days of mental distress in the past 30 days than those that did not, although this parameter was not significant. It’s possible that some other difficulty types are more highly applicable specifically to providing self-care, causing a greater likelihood of mental distress than the non-specific “creates stress” difficulty frequency implies. The “creates stress” variable may not be fully indicative of the total level of stress affecting the caregiver.

In line with this, the regression model binary outcome variable chosen was “any difficulty” versus “creates stress”, for reasons described directly above and as outlined in

**Section 3.4.** A caregiving variable was chosen, as opposed to a general demographic variable like mental distress, for the purpose of ensuring that the variable was specific to caregiving. The significant variables remaining after backwards elimination included caregiver relationship to care recipient, hours of care per week, and children in the household. Although little research explores stress differences between different types of caregiving relationships, evidence of spousal caregiving stress is well-established.<sup>47,50</sup> There was no significant difference in frequencies of reporting difficulty between spousal caregivers and caregivers to parents or parent-in-laws. Caregivers of parents/parent-in-laws appear to have greater likelihood of reporting difficulty than caregivers of other relative and non-relatives. It is likely that a closer relationship existed between spouses and between parents/adult children than between caregivers and other relatives or non-relatives, causing greater stress for the caregiver and resulting in greater subjective burden as the disease progresses.<sup>55</sup> It's also possible that the extent of care may be inherently different between these different relationship groups, which causes a higher rate of reporting difficulties in certain relationships than others.<sup>55</sup>

Hours of care per week, measured in terms of zero to eight hours or greater than eight hours, was a second significant factor, with those reporting greater than eight hours more frequently reporting a difficulty than those providing care for eight or fewer hours per week. It may be that the overall time commitment itself more frequently creates difficulties, or it may be that disease progression necessitates a greater time commitment, and that reported difficulties are related to the caregiver's greater exposure to the recipient's failing health. As Dr. Flaherty explains, "For the spouse or adult child, in particular, progression of caregiving demands to advanced stage responsibilities can be an

emotionally painful transition, representing as it does the impending demise of their loved one.”

Finally, caregivers with a child under 18 in the household were significantly more likely to report any difficulty than caregivers without a child in the household. Multiple studies suggest that the “sandwich generation”, in which a person is providing care to both a child and a parent, frequently report higher rates of stress than other care providers.<sup>56</sup> Other studies indicate that one significant predictor of stress in caregivers is having more roles than the provider can perform, and that discordance between roles in general may increase feelings of stress.<sup>57,58</sup> This would help to explain the significant relationship identified in this population. Although some caregivers reporting a child in the household are older and may not personally be members of the sandwich generation, it is reasonable to assume that these caregivers may still be filling multiple roles and experiencing the same type of resulting stress. It is also possible that, in addition to filling the role of caregiver, these older caregivers are filling the role of a grandparent raising a child, a growing phenomenon leaving a total 5.8 million children living with grandparents as of 2010.<sup>59</sup> Studies have shown that this subpopulation experiences decreased well-being in general,<sup>60</sup> and adding the dementia caregiving responsibilities serves to promote the same multiple-role difficulties experienced by the sandwich generation.

## Chapter 5. CONCLUSION

This study both confirmed many previous findings in the literature regarding significant differences between dementia caregivers and other caregivers, and also failed to find significant differences in some expected parameters. However, even results which contrasted the most prevalent notions about dementia caregivers versus other caregivers still found agreement with select publications suggesting alternative patterns.

The main points prominent in this report highlight the gender differences in caregivers' levels of mental distress, and the significance of the caregiver's relationship to the recipient, hours of care provided per week, and having children in the household as predictors of increased rates of reporting difficulties associated with caregiving. While the general health variable did not indicate significant health disparities of the AD/dementia caregiver population requiring further public action, and some studies agree with a lack of disparity in general or physical health, this specific parameter asked participants to self-report on their "health" in general. It's a very non-descript variable that may be missing a larger picture. While 94% of AD/dementia respondents reported "good" or better health, a contrasting 42% reported one or more days of mental distress in the past 30 days.

Other variables that may have been useful in assessing an overall health picture, including numerical measures of depressed days, anxious days, nervous or hopeless days, or "poor health" days, had very low response rates (50%) or were not asked in all state questionnaires. While this is an unintended repercussion of the functional design of the study that allows states to appropriately tailor the study to their needs and keep total questions below a certain threshold, it creates disagreement in variables. This disagreement creates difficulties in producing a sample population inclusive of all variables,

or large enough to identify statistical significance in some subpopulations, which subsequently limits the degree to which further analyses can be performed for a more in-depth population analysis.

In total, this study indicates that nearly 85% of AD/dementia caregivers report some difficulty associated with caregiving. Almost 21% of dementia caregivers are providing 40 or more hours of care per week. Approximately 60% of caregivers are providing care to parents/parent-in-laws or spouses, which have higher rates of reporting difficulties than other caregiver relationships. Over 50% of female AD/dementia caregivers report one or more days of mental distress, which is twice that of men.

In general, these difficulty-associated variables are not modifiable factors. Although hours of care per week may be viewed as a possible modifiable factor, many caregivers feel a lack of options regarding their participation in providing care, and some of this is due to financial concern.<sup>24</sup> This variable in particular helps to stress the importance of implementing insurance policy changes to include coverage for some type of professional care assistance. In support of this, a European study found that countries providing greater governmental assistance were positively correlated with caregiver well-being.<sup>61</sup> These findings also provide direction for health care providers and other potential caregiving outreach groups on which factors contribute most to reporting difficulties, and which types of populations may be at increased risk of mental distress or subjective difficulties related to caregiving.

As an extension to the purpose of this study, websites for caregiving resources specific to patients with Alzheimer's Disease and dementias are included in the **APPENDIX** on page 42.

## **APPENDIX: Links to Dementia Caregiver Resources**

1. Helpguide.org: <http://www.helpguide.org/articles/caregiving/support-for-alzheimers-and-dementia-caregivers.htm>.<sup>62</sup>
2. Homewatch Caregivers: <https://www.homewatchcaregivers.com/home-care-resources/dementia/care-tips>.<sup>63</sup>
3. Alzheimer's Association: <http://www.alz.org/care/>.<sup>64</sup>
4. Family Caregiver Alliance: <https://caregiver.org/>.<sup>48</sup>

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