The Impact of Dementia Caregiving on Caregiver Cognitive Health

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This dissertation titled
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Abstract

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The Impact of Dementia Caregiving on Caregiver Cognitive Health

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Providing care for individuals with dementia (IWD) is associated with significant burden and negative health outcomes. While it is well-documented that caregiving has negative effects on physical and psychological health, relatively few studies have examined the cognitive impact of caring for IWD. In the present study, we sought to expand existing literature on caregiver stress and burden into the domain of cognitive functioning. We hypothesized that caregivers for IWD would demonstrate worse cognitive functioning and report lower perceived cognitive ability. We also explored whether physical and psychological health outcomes were related to cognitive outcomes of caregivers and controls. Other potential correlates of caregiver cognitive health outcomes were also examined. As expected, caregivers performed worse than their non-caregiving peers in memory, but not psychomotor processing speed. Caregivers and non-caregivers did not differ in perceived cognitive ability. Consistent with prior research, caregivers generally reported worse physical and psychological health. Correlates of poorer cognitive outcomes for caregivers included higher anxiety, more sleep disturbance, higher caregiver burden and more distress about neuropsychiatric symptoms in IWD. These correlates may help to identify caregivers who are at greatest risk for negative outcomes so that interventions can be targeted to buffer the negative impact of
caregiver stress. Limitations include small sample size and the non-representative nature of the sample.
This dissertation is dedicated to my husband, parents, and grandmother, and in honor of my sister, Amanda Kinzer.
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Introduction

In the U.S., around 14.9 million adults care for someone with Alzheimer disease or another type of dementia (The National Alliance for Caregiving and AARP, 2009). Of the approximately 3 million Americans with dementia being cared for at home, about 75% of care is provided by informal caregivers, such as family and friends (Schulz & Martire, 2004). Providing care for individuals with dementia (IWD) is often associated with significant burden and negative health outcomes (Kang et al., 2014; Pinquart & Sörensen, 2003). In addition, among care recipients aged 50 and older, the average age of their caregivers ranges from 50-64. Of those caring for someone aged 65+, the average age of their caregivers is 63, with approximately one-third of caregivers in fair to poor health themselves. This implies that most IWD will be cared for by an older adult, who may be experiencing their own (pathological or normal) age-related declines in physical and cognitive health. Thus, caregiver burden presents a significant public health concern.

Existing evidence indicates that providing care for IWD may be associated with higher levels of caregiving stress than providing care for individuals with other types of illnesses. For example, a national survey of over 1,500 family caregivers of IWD revealed that they viewed their caregiving responsibilities as more stressful than caregivers of physically-impaired older adults without dementia; caregivers for IWD also reported giving up vacations or hobbies to a greater extent, spending more hours providing care, and experiencing more work-related difficulties than other types of caregivers (Ory et al., 1999). According to the national survey conducted by the National Association for Caregiving and the American Association of Retired Persons (AARP),
caregivers for IWD report providing more assistance and experiencing higher levels of stress relative to caregivers of physically-impaired older adults who do not have dementia (The National Alliance for Caregiving and AARP, 2009).

Conceptual models of caregiving, such as the Stress Process Model for Family caregiving (Pearlin et al., 1990), assume that the impact of caring for someone with a chronic illness and functional decline is stressful for caregivers, and thus can be studied within the framework of traditional models of stress and health. Consistent with the tenets of these models, stress experienced over a long period of time leads to wear and tear due to continued adaptation; this process has been found to result in damaging consequences, mediated, at least in part, by hypothalamic-pituitary-adrenal (HPA) imbalances (e.g. De Andrés-García et al., 2012). More specifically, chronic HPA disturbances have been related to autoimmunity and immune-suppression and a down-regulation in salivary immunoglobulin A (IgA) levels, among other immune parameters (De Andrés-García et al., 2012). Caregiving is often perceived as a source of significant stress, and the caregiving experience often persists over long periods of time, placing caregivers at increased risk for these physiological consequences.

In addition to the physiological changes indicative of stress, chronic stress may also be associated with increased risk for poor health behaviors, such as substance use and poor sleep, diet, and exercise habits (e.g. Krueger & Chang, 2008; Ng & Jeffrey, 2003). Poor health behaviors may be related to negative outcomes for caregiver physical and psychological health and cognition. Thus, the behavioral impact of chronic stress represents another potential pathway through which caregiving stress might place
caregivers at increased risk for health problems.

Overall, caregivers for IWD consistently have poorer physical health relative to non-caregivers, as judged by objective measures, such as higher daily cortisol levels (e.g. Wahbeh et al., 2008), higher blood pressure (e.g. Fonareva & Oken, 2014), higher number of chronic diseases (e.g. Pinquart and Sörensen, 2003), higher risk for developing diseases (e.g. Shaw, Patterson, Semple, et al., 1997; Schulz & Beach, 1999; Fonareva & Oken, 2014), and greater health service utilization (e.g. Kiecolt-Glaser et al., 1991; Schubert et al., 2008). Further, caregivers for IWD report lower levels of subjective physical health and well-being (e.g. Pinquart & Sörensen 2003, 2007; Richardson, Lee, Berg-Weger, & Grossberg, 2013).

One purported mechanism for these physical health differences, consistent with models of stress and health, involves physiological changes indicative of stress and associated with health problems. Caregivers for IWD differ from non-caregivers in many physiological markers of health, such as sympathetic nervous system activity, coagulant activity, hypothalamic-pituitary-adrenal axis activity, immune function, and cellular aging (de Vugt et al., 2005; Fonareva & Oken, 2014; Kiecolt-Glaser et al., 1991; Vitaliano, Zhang, & Scanlan, 2003; Wahbeh et al., 2008).

In addition to differences in physical health outcomes and physiological indices of stress, caregivers for IWD are at increased risk for negative psychological health outcomes relative to their non-caregiving peers (e.g. Cuijpers, 2005; Vitaliano et al., 2009). For example, caregivers for IWD show a higher prevalence of Major Depressive Disorder relative to control participants (Cuijpers, 2005), and spousal caregivers report
higher levels of depressed mood than demographically-similar non-caregiver spouses (Caswell et al., 2003). Caregivers for IWD may also be at greater risk for developing depressive symptoms over time; in longitudinal studies, caregivers have reported a higher prevalence of depressive disorders relative to control participants at intake and an increasingly higher prevalence at follow-up (e.g. Kiecolt-Glaser et al., 1991). Caregiver psychological distress may also be related to physical health outcomes. For example, caregiver psychological distress, including depression, is associated with negative hormonal changes and declines in immune functioning (e.g. Shaw et al., 1997; Vitaliano et al., 2003) and with caregiver report of physical symptoms (Pinquart & Sörensen, 2007). This is consistent with the pathophysiological mechanisms of stress.

**Correlates of Caregiver Health Concerns**

Caregivers for IWD generally report high levels of burden, stress, and physical and psychological health problems; however, not all caregivers experience negative health impacts to the same extent and there may also be positive aspects associated with the caregiving experience. Positive aspects of caregiving, such as satisfaction derived from the caregiving relationship and rewarding appraisals of caregiving, may be associated with reduced stress and greater emotional well-being, including less depression and caregiver burden (e.g. Hilgeman, Allen, DeCoste, & Burgio, 2007; Tarlow et al., 2004). Other factors associated with the degree to which caregivers for IWD are likely to experience burden and negative health impacts include variables associated with the IWD, such as dementia severity and presence/absence of behavioral problems, and sociodemographic characteristics of caregivers, such as age, gender, and
Regarding factors related to the IWD, dementia symptom severity and behavioral and psychological symptoms of dementia are the factors most often associated with caregiver physical well-being (e.g. Schubert et al., 2008; Shaw et al., 1997). In a meta-analysis, Pinquart and Sörensen (2007) found that 57.5% of caregivers caring for IWD who had above-median levels of behavior problems had above-median impairments in physical health as compared with 42.5% of caregivers with fewer behavior problems.

In addition to caregiver physical health problems, caregiver psychological concerns are often associated with characteristics of the IWD. For example, higher dementia severity and more cognitive and functional impairment were significantly associated with higher caregiver burden in a recent cross-sectional study (Kang et al., 2014). This was one of the few studies that utilized multimethods for assessment (caregiver ratings and neuropsychological battery); in most studies examining the relationship between characteristics of IWD and caregiver psychological concerns, studies are limited by use of the same methods (caregiver self-report) to assess both behavior problems in IWD and caregiver psychological distress (e.g. Baumgarten et al., 1991).

Researchers examining sociodemographic characteristics of caregivers, such as age, gender, and spousal status, have found that spousal caregivers endorse higher levels of burden relative to adult offspring caregivers of IWD (Baumgarten et al., 1991; Pinquart & Sörensen, 2003). Differences between caregivers and non-caregivers tend to be larger in samples with higher proportions of female participants (e.g. Yee & Schulz,
Age differences appear to be inconsistent; in Pinquart and Sörensen’s meta-analysis, differences in self-efficacy and depression were larger among older samples, but differences in stress were larger in younger samples. The authors theorized that younger caregivers are likely to have more competing roles and caregiving demands that exceed their personal resources.

**The Cognitive Impact of Caregiving**

While it is well documented that caregiving has negative effects on physical and psychological health, which may be related to characteristics of both IWD and caregivers, relatively few studies have examined the cognitive impact of caring for IWD. This is a considerable oversight, given that caregivers for IWD have been shown to experience high levels of stress and that stress may impact cognitive health via numerous pathways, such as the impact of stress hormones upon regions of the brain relevant to cognitive functioning (e.g. Vitaliano, 2009). In addition to being under chronic stress, spousal caregivers of IWD tend to be older adults and may already be at increased risk for cognitive changes associated with normal aging (e.g Bondi et al., 2009; Schoenberg & Duff, 2011). Further, chronic medical conditions such as hypertension and diabetes tend to be more common among older adults generally and among caregivers and may contribute to impairments in cognitive functioning (e.g. Caswell et al., 2003). Poor cognitive functioning might have a negative impact on a caregiver’s ability to provide adequate care and may be associated with increased anxiety among caregivers regarding their own risk for dementia.
Authors of existing studies suggest that caring for IWD may be associated with decreased cognitive performance (e.g. Caswell et al., 2003; Vitaliano et al., 2005, 2009; de Vugt et al., 2006; Fonareva & Oken, 2014). Fonareva and Oken (2014) reviewed many studies of health outcomes among caregivers for IWD and non-caregiver peers, including seven studies examining objective measures of cognition. Four out of seven studies in the review (de Vugt et al., 2006; Oken et al., 2011; Caswell et al., 2003, Vitaliano et al., 2009) found that caregivers for IWD performed worse on cognitive measures than age-matched non-caregiving control participants, with effects ranging from $d = 0.38$ to $d = -0.77$ on measures of processing speed, attention, and concentration. The strongest effect sizes were for processing speed (Caswell et al., 2003, $d = -0.62$; de Vugt et al., 2006, $d = -0.77$) and attention ($d = 0.60$; Oken et al., 2011).

Existing studies of cognitive functioning in caregivers for IWD have been limited by numerous methodological issues. For example, most studies recruited only females, limiting the applicability of these results to the general population of caregivers for IWD. Further, some prior studies (e.g. Vitaliano et al., 2005) assessed cognitive functioning using only a single measure, or used measures of cognitive constructs (such as intelligence or vocabulary) that are not related to aging and dementia (processing speed and learning/delayed recall). In addition, prior studies generally did not examine the relationship of cognitive outcomes to physical or mental health outcomes in caregivers. Further, no studies to date have explored potential correlates of caregiver cognitive health, such as those that have been examined in studies of physical and mental health of caregivers.
The purpose of the present study was to further expand the existing literature on caregiver stress/burden into the domain of cognitive functioning, addressing these limitations. We hypothesized that caregivers for IWD would demonstrate worse cognitive functioning relative to controls, particularly in the domains of memory and processing speed, and would report lower perceived cognitive ability relative to controls. In addition, we explored whether physical and psychological health outcomes were related to the cognitive outcomes of caregivers and controls. Finally, other potential correlates of caregiver cognitive health outcomes, such as demographic variables, IWD variables, perceived social support, and caregiver burden, were examined.
Method

Participants

Caregivers for IWD (N = 29) and control participants (N = 48) aged 50 and older were recruited from the southeast and central Ohio communities. Participants were recruited through posters placed in the community, newspaper ads, and social media (see Appendix A). A subset of these individuals previously participated in studies on cognitive impairment in older adults and had signed consent to be invited to participate in follow-up studies; they were invited to participate in the present study via phone call or email. The definition of caregiver for the present study was any individual over 50 years of age who reported currently caring for IWD for at least 5 hours per week.

Among the entire sample, 56 (73.7%) participants identified as female. Age in the total sample ranged from 51 to 90 years (M = 68.27, SD = 8.998), 92.3% reported having completed at least high school, and 93.6% identified as white (non-Hispanic/Latino).

Of the twenty-nine participants who reported that they currently provide care for an individual with dementia, 61.5 percent cared for a first-degree relative. The mean duration of caregiving was 36.80 months (range 4 – 120 months) and the mean number of hours spent providing care was 16.91 hours per week (range 5 - 60). Eight caregivers (27.6%) reported living with their care recipient. See Appendix C for supplemental descriptive information about caregivers.

Due to potential effects on cognitive functioning, participants who reported a history of loss of consciousness above 30 minutes due to head injury or stroke (N = 4) were excluded from analyses of the study hypotheses, leaving a final sample of 25
caregivers for IWD and 48 control participants. See Appendix C for further medical and psychological history of participants in both groups.

**Procedure**

Following informed consent, participants completed a brief clinical interview to assess medical and psychological history and then completed a battery of cognitive tests. They completed electronic measures of demographics, depressive symptoms, subjective cognition, anxiety, perceived stress, sleep disturbance, positive and negative affect, social support, dementia severity and caregiver distress, caregiver burden, positive aspects of caregiving, and service utilization. Dementia symptom severity and associated caregiver distress, caregiver burden, positive aspects of caregiving, and service utilization were measured only among participants who identified as caregivers. Research assistants measured all participants’ blood pressure and instructed them on how to measure their waist circumference in inches. All participants then received feedback on their cognitive performance. Some \((N = 22)\) also received 20 dollar Walmart gift cards as compensation.

**Materials**

Measures of interest for the present study are described briefly below; other measures were also administered but were not germane to study hypotheses and are not included here. Copies of all non-copyrighted measures and more detailed psychometrics for each measure appear in Appendix B.

**Objective cognitive performance.** Participants completed the Repeatable Battery for the Assessment of Neuropsychological Status (RBANS; Randolph, 1998), a brief measure of neuropsychological status across several cognitive domains. The RBANS has
been found to have good test-retest reliability over a mean interval of about 40 weeks (Groth-Marnat, 2009). The overall pattern of correlations between the index scores suggests that the different index scores measure relatively distinct cognitive constructs, and there is ample support for the construct validity of this measure as a measure of several cognitive domains and as a measure of general neuropsychological status in diverse neurological conditions, including dementia (Groth-Marnat, 2009). Variables of interest to test the present study’s main hypothesis were age-corrected scores on the Delayed Memory Index and the coding subtest.

Participants also completed the Trail Making Test (TMT; Reitan, 1955), a measure of psychomotor processing speed and mental flexibility. Test-retest reliability varies with the age range and the population being studied but is generally adequate, at least for Part B, over a period of about 11 months (Dikmen et al., 1999). Parts A and B correlate moderately well with each other, indicating that they measure similar, yet somewhat distinct functions. The test correlates moderately well with other measures of attentional abilities as well as speed. The TMT is sensitive to detecting cognitive impairment associated with dementia (Chen et al., 2000). The dependent variable to test our main hypothesis was the age-corrected scaled score on TMT part B.

Participants also completed the Controlled Oral Word Association Test (COWA; Benton & Hamsher, 1989), a measure of verbal fluency. This measure has good 6-month test-retest reliability (Ruff et al., 1996). Reduced performance on this test is seen among individuals with dementia (Strauss, Sherman, & Spreen 2006). The dependent variable used to test the main hypothesis was the age-corrected scaled score.
**Subjective cognition.** Two scores were used to test the second part of our main hypotheses (perceived cognitive ability). Participants responded to the following question: “Have you noticed a decline in your memory over the past year?” with a yes/no response. Participants also completed the Everyday Memory Questionnaire – revised (EMQ, Royle & Lincoln, 2008), a subjective measure of memory failure in everyday life. The internal consistency of the EMQ was good in the current sample ($\alpha = 0.867$). The total score was used in tests of the main study hypotheses.

**Physical health.** Participants completed a brief clinical interview designed to assess medical history, including number of physical health conditions, number of recent illnesses, medications used over the past 3 months, and number of doctor visits in the past 3 months. They also provided ratings of their perceived current health status on a 5-point Likert scale, ranging from 1 (poor) to 5 (excellent). Researchers measured participants’ blood pressure using the American Diagnostic Corporation’s Digital Blood Pressure Monitor Plus (model6022N). Researchers recorded the average of three consecutive measurements of systolic and diastolic blood pressure. Researchers instructed participants on how to measure their own waist circumference in inches. Participants also reported their height and weight; body mass index (BMI) was calculated by converting weight into kilograms and height into centimeters and dividing weight in kilograms by height in centimeters squared. Participants rated sleep disturbance and sleep-related impairments using the short forms of the Sleep Disturbance (SD) and Sleep-Related Impairment (SRI) domains from the Patient-Reported Outcomes Measurement Information System (PROMIS) short form (Yu et al., 2011). The internal consistency of this scale was
excellent in the current sample ($\alpha = 0.926$). Dependent variables used in exploratory analyses included systolic and diastolic blood pressure, number of medical diagnoses, number of recent illnesses, number of current medications, number of recent doctor visits, BMI, SD/SRI total score, and waist circumference.

**Psychological health.** Depression was assessed using the Center for Epidemiologic Studies Depression Scale Revised (CESD-r; Eaton, Smith, Ybarra, Muntaner, & Tien, 2004), a self-report measure of depressive symptoms for use in the general population. The internal consistency for the total score, used as a dependent variable in exploratory analyses, was excellent in the current sample ($\alpha = 0.929$). Anxiety and worry were assessed using an abbreviated, 8-item version of the Penn State Worry Questionnaire (PSWQ-A; Hopko, Stanley, Reas, Wetherell, Beck, Novy, et al., 2003). The total score was used as a dependent variable in exploratory analyses; internal consistency was excellent in the current sample ($\alpha = 0.957$). Perceived stress was assessed using the 10-item version of the Perceived Stress Scale (Cohen, Kamarck, & Mermelstein, 1983), a self-report measure of the degree to which individuals appraise life situations as stressful. Internal consistency was excellent in the current sample ($\alpha = 0.905$). The dependent variable used in exploratory analyses was the total score on this measure. Participants also completed the Positive and Negative Affect Schedule-Expanded Form (PANAS-X, Watson & Clark, 1994) to assess various aspects of current positive and negative affect, particularly hostility; the dependent variables were the hostility subscale, which had internal consistency of $\alpha = 0.571$ for the current sample, the positive affect subscale ($\alpha = 0.912$), and the negative affect subscale ($\alpha = 0.918$), which
were used in supplemental analyses only.

**Caregiver burden, positive aspects of caregiving, and service utilization.**

Participants who identified as caregivers for IWD completed a checklist of activities of daily living (Katz, Down, Cash, & Grotz, 1970) and instrumental activities of daily living (Lawton & Brody, 1969) with which they help the care recipient and rated the frequency which with they assist with each behavior. The results of this checklist were used to describe the caregiving experience (see Appendix C). They also completed the Caregiver Burden Inventory (Novak & Guest, 1989), a 24-item, five-subscale, diverse multidimensional instrument that measures the impact of caregiving on caregivers. The internal consistency in the present sample was $\alpha = 0.931$ for the total score, $\alpha = 0.844$ for the time-dependence burden subscale, $\alpha = 0.901$ for the developmental burden subscale, $\alpha = 0.854$ for the physical burden subscale, $\alpha = 0.858$ for the social burden subscale, and $\alpha = 0.852$ for the emotional burden subscale. Variables used in exploratory analyses included the total caregiver burden score and each subscale score. Caregivers also reported positive aspects of caregiving along two dimensions (Tarlow et al., 2004). In the current sample the internal consistency for both dimensions was good ($\alpha = 0.891$ for the Self-affirmation component, $\alpha = 0.890$ for the Outlook on Life component, and 0.898 for the entire scale). The score for the total positive aspects of caregiving scale was used in exploratory analyses. Finally, caregivers completed a checklist of health and human resources they currently use (McCallion, Toseland, Gerber, & Banks, 2004), as well as listing personal barriers to utilizing available resources (e.g. cost, transportation, etc.). This checklist was used to describe the caregiving experience (see Appendix C).
Neuropsychiatric symptom severity and associated caregiver distress. Only participants who identified as caregivers for IWD completed a brief form of the Neuropsychiatric Inventory (NPI-Q; Kaufer, Cummings, Ketchel, Smith, MacMillan et al., 2000), an informant-based assessment of neuropsychiatric symptoms and associated caregiver distress. Each of 12 symptom domains (delusions, hallucinations, agitation/aggression, dysphoria/depression, anxiety, euphoria/elation, apathy/indifference, disinhibition, irritability/lability, aberrant motor behaviors, nighttime behavioral disturbances, and appetite/eating disturbances) is assessed. The dependent variables used in exploratory analyses included one total score based on the number of symptoms endorsed and another total score for the level of associated distress with the symptoms. The internal consistency of this measure in the current sample was $\alpha = 0.778$ for severity and $\alpha = 0.787$ for distress.

Social support. To assess perceived social support, participants completed an 11-item measure of social support received from others and a 4-item measure of negative social interactions (Krause, 1995). The internal consistency of social support received from others was good in the current sample ($\alpha = 0.855$). The internal consistency of negative social interactions was acceptable in the current sample ($\alpha = 0.781$). Both positive social support and negative social interactions were used in exploratory analyses.

Demographics. All participants completed a brief electronic survey of demographic information, including age, gender, marital status, race/ethnicity, occupation, perceived socioeconomic status (SES), educational attainment, and caregiver status; those who reported being a caregiver also provided demographic information.
about the care recipient (age, gender, race/ethnicity, and co-residence with the caregiver). Demographic variables used in the exploratory analyses include age and gender of the caregiver and caregiver relationship to the IWD.

**Analyses**

We first examined the dependent variables for extreme outliers (values more than 3 times the interquartile range below the first quartile or above the third quartile), as well as skewness and kurtosis, to determine if non-parametric tests were indicated or whether variables should be transformed. There was a significant outlier for systolic and diastolic blood pressure that we removed. We also removed substantial outliers from number of medications, BMI, hostility, the CESD-R, and the EMQ. After removing the outliers, the EMQ and CESD-R were moderately positively skewed; we ran square root transformations on those variables. See Appendix C, Table 1 for a detailed summary of these analyses. Prior to testing hypotheses, we compared the two groups on demographic variables to make sure they did not differ significantly on relevant factors (age, gender, race, education).

To test whether dementia caregivers received lower scores on measures of cognitive performance relative to their non-caregiving peers, we conducted a MANCOVA comparing mean differences between caregivers and non-caregivers on age-corrected scores on the Delayed Memory Index of the RBANS, the TMT part B, the Coding subtest of the RBANS, and COWA, with age as a covariate. Because the overall model was significant, we followed up this up with ANCOVAs ($p<.02$ to correct for multiple comparisons).
To test the hypothesis that caregivers report worse subjective cognitive functioning relative to non-caregivers, we conducted an ANCOVA with caregiver status as the independent variable, total scores on the EMQ as the dependent variable, and age as a covariate, as age was significantly correlated with scores on the EMQ. We also conducted a chi-square analysis to test whether dementia caregivers were more likely to respond “yes” to the question: “Have you noticed a decline in your memory over the past year?”

To explore potential physical and mental health correlates of cognitive test outcomes, we first tested for group differences in physical and mental health variables to confirm findings from prior literature examining the effect of caregiver stress on physical and mental health outcomes. We used ANCOVAs with age as a covariate to explore these differences. Then, we examined whether these variables correlated with cognitive test outcomes for each group separately and the sample as a whole.

Finally, we examined correlations of other caregiver-specific measures (caregiver burden, positive aspects of caregiving, social support, dementia neuropsychiatric symptom severity and associated distress, and demographic factors including age, gender, and relationship to the IWD) to cognitive performance in the subset of participants who identified as caregivers.
Results

Among caregivers for IWD, 21 (72.4%) participants identified as female. Caregiver age ranged from 51 to 90 years ($M = 64.62, SD = 10.493$), 93.1% had completed at least a high school education, and 89.7% identified as white (non-Hispanic/Latino). Among control participants, 35 (72.9%) participants identified as female. Age ranged from 54 to 87 years ($M = 70.48, SD = 7.22$) and 93.8% reported having completed at least high school. Among control participants, 97.9% identified as white (non-Hispanic/Latino). Caregivers were significantly younger than non-caregivers, $t(72)=-3.545, p = 0.001$; thus, age was included as a covariate in subsequent analyses.

There were no group differences observed in race/ethnicity (white/non-white), $\chi^2(1) = 2.949, p = 0.086$, gender, $\chi^2(1) = 0.081, p = 0.776$, or formal education (less than high school vs. high school or more), $\chi^2(1) = 0.529, p = 0.467$.

Main Hypotheses: Cognitive Differences between Groups

Consistent with predictions, caregivers were worse in cognitive performance relative to non-caregiver controls when examining the full model with all cognitive variables, even when controlling for age $F(4, 64) = 2.924, p = 0.028$. Caregivers specifically performed worse on the Delayed Memory Index, $F(1, 67) = 10.729, p = 0.002$, partial $\eta^2 = 0.138$, but not on TMT Part B, $F(1, 67) = 2.445, p = 0.123$, partial $\eta^2 = 0.035$, Coding, $F(1, 67) = 0.932, p = 0.338$, partial $\eta^2 = 0.014$, or COWA, $F(1, 67) = 0.203, p = 0.654$, partial $\eta^2 = 0.003$. See Table 1 for means and standard deviations for all groups on the cognitive variables.

Contrary to predictions, caregivers and controls did not differ in subjective
cognitive functioning on the EMQ $F(1, 70) = 2.540, p = 0.116$, partial $\eta^2 = 0.035$, controlling for age, although group means were in the expected direction. Further, caregivers were not more likely to respond “yes” to the question: “Have you noticed a decline in your memory over the past year?” $\chi^2 (1) = 0.194, p = 0.660$; 16 (61.5%) caregivers and 27 (56.25%) non-caregivers endorsed this item. See Table 1.

**Exploratory Analyses of the Relationship of Cognitive Outcomes to Physical and Psychological Outcomes**

To explore whether cognitive findings would be related to physical and psychological health factors, we first explored whether groups differed in physical or psychological health. Consistent with prior research, caregivers reported worse physical health than non-caregivers when examining the full model with all of the physical variables, $F(8, 60) = 2.625, p = 0.016$, partial $\eta^2 = 0.259$, and had higher systolic blood pressure, $F(1, 67) = 4.306, p = 0.042$, partial $\eta^2 = 0.060$, but reported a lower number of current medications, $F(1, 67) = 4.769, p = 0.032$, partial $\eta^2 = 0.066$, even after controlling for age. Groups were not significantly different on any other health variables: self-reported medical diagnoses, $F(1, 67) = 0.269, p = 0.606$, partial $\eta^2 = 0.004$, number of self-reported recent illnesses, $F(1, 67) = 1.199, p = 0.277$, partial $\eta^2 = 0.018$, diastolic blood pressure $F(1, 67) = 0.002, p = 0.965$, partial $\eta^2 = 0.000$, number of recent doctor visits $F(1, 67) = 2.306, p = 0.134$, partial $\eta^2 = 0.033$, BMI, $F(1, 67) = 0.332, p = 0.566$, partial $\eta^2 = 0.005$, waist circumference, $F(1, 67) = 1.308, p = 0.257$, partial $\eta^2 = 0.019$, or sleep disturbance, $F(1, 67) = 1.960, p = 0.167$, partial $\eta^2 = 0.032$. See Table 2 for descriptive statistics.
Table 1

*Group Differences in Cognitive Variables*

<table>
<thead>
<tr>
<th></th>
<th>Caregivers</th>
<th></th>
<th>Controls</th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>M</td>
<td>SD</td>
<td>M</td>
<td>SD</td>
<td>p</td>
<td>d</td>
</tr>
<tr>
<td>TMT</td>
<td>11.870</td>
<td>3.270</td>
<td>12.468</td>
<td>2.330</td>
<td>0.123</td>
<td>0.211</td>
</tr>
<tr>
<td>COWA</td>
<td>10.960</td>
<td>3.052</td>
<td>11.319</td>
<td>2.775</td>
<td>0.654</td>
<td>0.123</td>
</tr>
<tr>
<td>DMI</td>
<td>101.913</td>
<td>10.453</td>
<td>108.809</td>
<td>12.019</td>
<td>0.002</td>
<td>0.612</td>
</tr>
<tr>
<td>Coding</td>
<td>11.913</td>
<td>2.610</td>
<td>11.893</td>
<td>3.389</td>
<td>0.338</td>
<td>0.006</td>
</tr>
<tr>
<td>EMQ</td>
<td>21.458</td>
<td>7.454</td>
<td>20.575</td>
<td>5.282</td>
<td>0.116</td>
<td>0.189</td>
</tr>
</tbody>
</table>

*Note.* TMT = Trail Making Test Part B scaled score; COWA = Controlled Oral Word Association Test; DMI = Delayed Memory Index; EMQ = Everyday Memory Questionnaire.

With regard to psychological health, caregivers reported more depressive symptoms on the CESD-R, \( F(1, 72) = 4.025, p = 0.049, \) partial \( \eta^2 = 0.054 \), and reported more anxiety on the PSWQ-A, \( F(1, 73) = 9.598, p = 0.003, \) partial \( \eta^2 = 0.118 \), controlling for age.

Groups did not differ in the positive affect or hostility PANAS subscales, but did differ regarding negative affect, with caregivers reporting higher levels of negative affect than non-caregivers; see supplemental Table 2 in Appendix C.

We then explored whether physical and psychological factors correlated with cognitive performance in each group. Among the entire sample, higher systolic blood pressure was associated with lower scores on the Delayed Memory Index, \( r = -0.268, p = 0.026 \), the coding subtest, \( r = -0.286, p = 0.017 \), and the TMT, \( r = -0.264, p = 0.030 \).
Table 2

*Group Differences in Physical and Psychological Variables*

<table>
<thead>
<tr>
<th></th>
<th>Caregivers</th>
<th>Controls</th>
<th>p</th>
<th>d</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>M</strong></td>
<td>135.640</td>
<td>132.156</td>
<td>0.042</td>
<td>0.21</td>
</tr>
<tr>
<td><strong>SD</strong></td>
<td>17.325</td>
<td>15.788</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Systolic Blood Pressure</strong></td>
<td>78.840</td>
<td>79.600</td>
<td>0.965</td>
<td>0.07</td>
</tr>
<tr>
<td><strong>Diastolic Blood Pressure</strong></td>
<td>2.440</td>
<td>2.533</td>
<td>0.606</td>
<td>0.05</td>
</tr>
<tr>
<td><strong>Number of Diagnoses</strong></td>
<td>1.520</td>
<td>1.333</td>
<td>0.277</td>
<td>0.38</td>
</tr>
<tr>
<td><strong>Number of Illnesses</strong></td>
<td>3.680</td>
<td>5.822</td>
<td>0.032</td>
<td>0.83</td>
</tr>
<tr>
<td><strong>Number of Medications</strong></td>
<td>3.240</td>
<td>1.533</td>
<td>0.134</td>
<td>0.39</td>
</tr>
<tr>
<td><strong>BMI</strong></td>
<td>28.501</td>
<td>27.486</td>
<td>0.566</td>
<td>0.19</td>
</tr>
<tr>
<td><strong>Waist Circumference</strong></td>
<td>38.940</td>
<td>37.256</td>
<td>0.257</td>
<td>0.27</td>
</tr>
<tr>
<td><strong>Sleep</strong></td>
<td>18.741</td>
<td>12.479</td>
<td>0.003</td>
<td>0.85</td>
</tr>
<tr>
<td><strong>CESD-r</strong></td>
<td>8.810</td>
<td>5.230</td>
<td>0.049</td>
<td>0.45</td>
</tr>
<tr>
<td><strong>PSWQ-A</strong></td>
<td>18.741</td>
<td>12.479</td>
<td>0.001</td>
<td>0.93</td>
</tr>
<tr>
<td><strong>Stress</strong></td>
<td>20.926</td>
<td>17.375</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>4.341</td>
<td>3.210</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*Note.* M = Mean. SD = Standard Deviation. BMI = Body Mass Index; CESD-r = Center for Epidemiologic Studies Depression Scale Revised; PSWQ-A = Penn State Worry Questionnaire – Abbreviated; Stress = Perceived Stress Scale scores. Caregivers also reported higher levels of perceived stress on the perceived stress scale, $F(1, 72) = 12.599, p = 0.001$, partial $\eta^2 = 0.149$, controlling for age.
Among non-caregivers, no physical or psychological variable correlated with any of the cognitive outcomes. Among caregivers, lower scores on the coding test were related to higher scores on the PSWQ-A, \( r = -0.515, p = 0.012 \), and to greater sleep disturbance, \( r = -0.491, p = 0.020 \). See Table 3.

We explored whether physical and psychological factors correlated with subjective cognitive performance in each group. Among the entire sample, a larger number of medical diagnoses was associated with higher scores on the EMQ, \( r = 0.273, p = 0.021 \). This was also true among the caregivers, \( r = 0.457, p = 0.025 \). Among non-caregivers, no physical or psychological variables related to subjective cognitive performance. See Table 4.

**Exploratory Hypotheses: Correlates of Cognitive Outcomes among Caregivers**

We examined correlations of other caregiver-specific measures, including caregiver burden, positive aspects of caregiving, and neuropsychiatric symptom severity and associated distress to cognitive performance among participants who identified as caregivers. See Table 5 for correlations. Higher total caregiver burden was related to worse performance on the coding subtest, \( r = -0.418, p = 0.037 \). Higher distress about neuropsychiatric symptoms related to worse performance on TMT, \( r = -0.520, p = 0.009 \).

We also examined relationships among caregiver demographic variables and cognitive performance. Higher caregiver age was related to worse performance on the Delayed Memory Index, \( r = -0.373, p = 0.043 \), and coding tests, \( r = -0.435, p = 0.014 \). There were no gender differences among caregivers in terms of cognitive outcomes, including TMT Part B, \( t(21) = -0.723, p = 0.478 \), COWA, \( t(21) = 0.402, p = 0.691 \),
Table 3

Correlations of Physical and Psychological Variables with Cognition among the Total Sample, Caregivers, and Non-caregivers

<table>
<thead>
<tr>
<th>Delayed Memory Index</th>
<th>Coding</th>
<th>TMT</th>
<th>COWA</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total</td>
<td>Caregiver</td>
<td>Control</td>
<td>Total</td>
</tr>
<tr>
<td>BMI</td>
<td>-.128</td>
<td>-.219</td>
<td>-.034</td>
</tr>
<tr>
<td>Waist</td>
<td>-.127</td>
<td>-.061</td>
<td>-.138</td>
</tr>
<tr>
<td>Systolic</td>
<td>-.268*</td>
<td>-.287</td>
<td>-.228</td>
</tr>
<tr>
<td>Diastolic</td>
<td>-.174</td>
<td>-.196</td>
<td>-.193</td>
</tr>
<tr>
<td>Dx</td>
<td>.006</td>
<td>-.032</td>
<td>.021</td>
</tr>
<tr>
<td>Illness</td>
<td>-.101</td>
<td>-.237</td>
<td>-.046</td>
</tr>
<tr>
<td>Meds</td>
<td>.103</td>
<td>.001</td>
<td>.107</td>
</tr>
<tr>
<td>Doctor</td>
<td>-.101</td>
<td>-.192</td>
<td>.012</td>
</tr>
<tr>
<td>CESD-r</td>
<td>-.080</td>
<td>-.005</td>
<td>.004</td>
</tr>
<tr>
<td>PSWQ-A</td>
<td>.051</td>
<td>-.139</td>
<td>.197</td>
</tr>
<tr>
<td>Stress</td>
<td>-.029</td>
<td>-.135</td>
<td>.193</td>
</tr>
<tr>
<td>Sleep</td>
<td>-.100</td>
<td>-.286</td>
<td>.054</td>
</tr>
</tbody>
</table>

Note. BMI = Body Mass Index; Dx = number of medical diagnoses; Illness = number of illnesses (Spearman’s ρ), Doctor = number of doctor visits (Spearman’s ρ); CESD-r = Center for Epidemiologic Studies Depression Scale-Revised; PSWQ-A = Penn State Worry Questionnaire – Abbreviated; Stress = Perceived Stress Scale scores; TMT = Trail Making Test Part B; COWA = Controlled Oral Word Association Test. * p < 0.05
Coding, \( t(21) = -0.956, p = 0.349 \), or Delayed Memory Index scores, \( t(21) = -1.419, p = 0.170 \). See Table 6. There were also no gender differences in measures of caregiver burden, \( t(21) = -0.608, p = 0.550 \), worry, \( t(20) = -0.016, p = 0.987 \), or depression \( t(19) = -0.207, p = 0.838 \), among caregivers. Gender differences were difficult to examine, however, given the small number of male caregivers in the study.

There were no differences in cognitive outcomes based on relationship to the IWD (genetically-related vs. not genetically related) for TMT Part B, \( t(21) = 0.337, p = 0.740 \), COWA, \( t(21) = -0.341, p = 0.736 \), coding, \( t(21) = -0.038, p = 0.970 \), or Delayed Memory Index, \( t(21) = 1.518, p = 0.145 \). See Table 6 for descriptive statistics.
**Discussion**

Overall, the present findings lend partial support to the hypothesis that caregivers perform worse than their non-caring peers on measures of cognitive functioning. The results of this study are also consistent with other literature examining differences in health and mental health outcomes between caregivers for IWD and non-caregivers.

**Group Differences in Objective and Subjective Cognition**

As hypothesized, caregivers performed worse on an objective measure of delayed memory, relative to non-caregiving controls, even when controlling for age. This is consistent with findings from one prior study that demonstrated worse performance among caregivers on measures of delayed verbal recall (e.g. Fonareva & Oken, 2014).

Contrary to predictions, caregivers did not differ from controls on measures of psychomotor speed. This is inconsistent with prior literature finding relative deficits on measures of processing speed in caregivers (Caswell et al., 2003; de Vugt et al.; 2006).

Although we did not find significant differences on these measures in the current sample, the group means were generally in the expected directions, with caregivers scoring lower (though not significantly lower) than controls on most measures; these non-significant findings may be explained by small sample size in the current study. However, because the overall effect sizes we found were generally lower than those reported in prior studies using similar measures (e.g. Caswell et al., 2003; de Vugt et al., 2006), it is also likely that our study had reduced variance in cognitive performance due to the characteristics of the sample such as high levels of education. Given the effect sizes we obtained for processing speed, we would have needed a sample of 714, with 357 in
Table 4

Correlations of Physical and Psychological Variables with Subjective Memory among the Total Sample, Caregivers, and Non-caregivers

<table>
<thead>
<tr>
<th></th>
<th>Total</th>
<th>Caregivers</th>
<th>Control</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>EMQ</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>BMI</td>
<td>-.069</td>
<td>-.174</td>
<td>-.011</td>
</tr>
<tr>
<td>Waist</td>
<td>0.105</td>
<td>0.070</td>
<td>0.124</td>
</tr>
<tr>
<td>Systolic</td>
<td>0.172</td>
<td>0.053</td>
<td>0.263</td>
</tr>
<tr>
<td>Diastolic</td>
<td>0.117</td>
<td>0.016</td>
<td>0.189</td>
</tr>
<tr>
<td>Dx</td>
<td>0.273*</td>
<td>0.457*</td>
<td>0.094</td>
</tr>
<tr>
<td>Illness</td>
<td>0.121</td>
<td>0.063</td>
<td>0.158</td>
</tr>
<tr>
<td>Meds</td>
<td>-.052</td>
<td>0.104</td>
<td>-.121</td>
</tr>
<tr>
<td>Doctor</td>
<td>0.121</td>
<td>0.205</td>
<td>0.069</td>
</tr>
<tr>
<td>CESD-r</td>
<td>0.114</td>
<td>0.265</td>
<td>0.088</td>
</tr>
<tr>
<td>PSWQ-A</td>
<td>0.047</td>
<td>0.129</td>
<td>0.032</td>
</tr>
<tr>
<td>Stress</td>
<td>0.054</td>
<td>0.227</td>
<td>-.005</td>
</tr>
</tbody>
</table>

Note. BMI = Body Mass Index; Dx = number of medical diagnoses; Illness = number of illnesses (Spearman’s ρ); Doctor = number of doctor visits (Spearman’s ρ); CESD-r = Center for Epidemiologic Studies Depression Scale-Revised; PSWQ-A = Penn State Worry Questionnaire – Abbreviated; Stress = Perceived Stress Scale scores; EMQ = Everyday Memory Questionnaire

* p < 0.05

each group, to find a significant effect. Although caregivers did not differ from non-caregivers in processing speed, the differences in delayed recall have clinical implications in that caregivers for IWD may be more likely to have memory problems of their own. This would be problematic because decreased memory functioning could compromise caregivers’ abilities to provide care for the IWD and to care for themselves well. However, it should be noted that although we identified relative differences in memory
Table 5

*Relationships among Caregiver-Specific Measures and Cognition*

<table>
<thead>
<tr>
<th></th>
<th>Memory</th>
<th>Coding</th>
<th>TMT</th>
<th>COWA</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total Burden</td>
<td>-.372</td>
<td>-.418*</td>
<td>-.142</td>
<td>-.215</td>
</tr>
<tr>
<td>Time Dependence Burden</td>
<td>-.285</td>
<td>-.412*</td>
<td>-.131</td>
<td>-.260</td>
</tr>
<tr>
<td>Developmental Burden</td>
<td>-.286</td>
<td>-.436*</td>
<td>-.328</td>
<td>-.104</td>
</tr>
<tr>
<td>Physical Burden</td>
<td>-.276</td>
<td>-.337</td>
<td>-.089</td>
<td>-.124</td>
</tr>
<tr>
<td>Emotional Burden</td>
<td>-.412*</td>
<td>-.341</td>
<td>-.091</td>
<td>-.066</td>
</tr>
<tr>
<td>Positive Aspects of Caregiving</td>
<td>.256</td>
<td>.201</td>
<td>.138</td>
<td>.254</td>
</tr>
<tr>
<td>Dementia Severity</td>
<td>.077</td>
<td>.243</td>
<td>-.227</td>
<td>-.035</td>
</tr>
<tr>
<td>Caregiver Distress</td>
<td>-.241</td>
<td>-.300</td>
<td>-.520**</td>
<td>-.275</td>
</tr>
<tr>
<td>Age</td>
<td>-.373*</td>
<td>-.435*</td>
<td>-.360</td>
<td>-.104</td>
</tr>
<tr>
<td>Positive Social Support</td>
<td>-.263</td>
<td>.280</td>
<td>-.021</td>
<td>.327</td>
</tr>
<tr>
<td>Negative Social Interactions</td>
<td>-.102</td>
<td>-.067</td>
<td>.242</td>
<td>.199</td>
</tr>
</tbody>
</table>

*Note. TMT = Trail Making Test Part B; COWA = Controlled Oral Word Association Test.*

*p < 0.05   **p < 0.01

between caregivers and controls, the data suggests that, on average, controls were above average in memory while the caregivers were average in memory, not in the impaired range. Given the higher level of physical and psychological health problems among caregivers, it is important that caregivers are able to establish and maintain good health behaviors to provide adequate care for themselves and the IWD that they care for.

Increased cognitive difficulties, in addition to increased burden, anxiety, and depression, could make this difficult to accomplish.

Contrary to our expectations, caregivers did not differ from non-caregivers in terms of their own perceptions of their cognitive functioning. This is inconsistent with
Table 6

*Relationships among Caregiver Gender and Relationship with IWD and Cognition*

<table>
<thead>
<tr>
<th></th>
<th>Delayed Memory Index</th>
<th>Coding</th>
<th>TMT</th>
<th>COWA</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>$M$</td>
<td>$SD$</td>
<td>$M$</td>
<td>$SD$</td>
</tr>
<tr>
<td>Male ($N = 6$)</td>
<td>98.800</td>
<td>9.311</td>
<td>10.833</td>
<td>2.137</td>
</tr>
</tbody>
</table>

*Note.* TMT = Trail Making Test; Controlled Oral Word Association Test
prior findings that individuals with greater exposure to IWD tend to report greater subjective cognitive decline, although their perceptions of this are generally less accurate than those with less exposure to dementia (Kinzer & Suhr, 2016). While we speculated that caregivers are likely to have more exposure to IWD, and thus may be more likely to worry about their own cognitive functioning, which could result in overly negative estimations of their own subjective cognitive decline, it is possible that non-caregivers in the study may also have personal exposure to dementia, outside of a caregiving role. Unfortunately, we did not assess for general exposure to IWD among the non-caregivers in our study. Further, because there is general public knowledge of dementia, both caregivers and non-caregivers may be sensitive to perceived signs of cognitive decline.

**Physical and Psychological Health Correlates of Cognitive Outcomes**

Consistent with prior caregiver research, we found that caregivers reported worse physical health, which is consistent with prior literature (e.g. Kang et al., 2014; Pinquart & Sörensen, 2007), with higher systolic blood pressure than controls, which is also consistent with prior literature (e.g. Fonareva & Oken, 2014). Overall, perceptions of negative health and blood pressure findings indicate a need for increased focus on preventative healthcare for caregivers, who may struggle to balance their own physical health needs with that of the IWD they are caring for. Interestingly, caregivers reported taking a significantly lower number of prescription and over-the-counter medications, including vitamins and supplements, relative to non-caregivers. This cannot be fully explained by age because we accounted for age in our analyses. Despite a significant difference in the number of medications, caregivers and non-caregivers did not differ
significantly in terms of self-reported physical health conditions, number of recent illnesses, or number of recent doctor visits.

Caregivers reported more depressive symptoms and anxiety relative to non-caregivers. They also endorsed higher levels of general negative affect. This is consistent with many prior studies examining mental health variables in caregivers with IWD (e.g. Cuijpers, 2005; Vitaliano et al., 2009). According to existing literature, caregiver characteristics such as burden and distress are associated with nursing home placement (e.g. Yaffe, Fox, & Newcomer, 2002), and interventions designed to improve caregiver well-being may successfully delay nursing home placement for IWD (Mittelman, Haley, Clay, & Roth, 2006). Implications of these findings include the importance of screening for mental health disorders among caregivers, as these may be targets for intervention, and referring caregivers with high levels of anxiety, depression, and/or negative affect to the appropriate mental health resources.

Generally, physical and mental health variables were not related to cognitive outcomes. In the sample as a whole, higher levels of reported anxiety were related to worse performance on a measure of psychomotor processing speed. We also found that higher systolic blood pressure was associated with lower scores on several measures of cognitive functioning. This is consistent with the known relationship between chronic medical conditions such as hypertension and impairments in cognitive functioning (e.g. Caswell et al., 2003). We were unable to determine the mechanisms of these relationships in the current study, as systolic blood pressure was not related to levels of anxiety and levels of perceived stress in our sample, though caregivers reported higher stress levels in
general. Also, although caregivers reported higher levels of stress and performed worse on some measures of cognitive performance, perceived stress was not related to cognitive performance in our sample. Among caregivers, more physical and mental health variables were related to cognitive outcome; specifically, higher anxiety, more sleep disturbance, higher caregiver burden and more distress about neuropsychiatric symptoms in IWD were associated with poorer cognitive outcomes among caregivers.

**Caregiver-Specific Correlates of Cognitive Outcome**

Caregiver burden was related to worse cognitive performance, specifically in terms of performance on the coding test, a measure of processing speed. Higher caregiver distress regarding neuropsychiatric symptom severity was also related to performance on a different measure of processing speed, the TMT Part B. However, most other caregiver-specific measures were not related to cognitive outcome. This may have been due to insufficient statistical power to detect significant differences. For example, to detect a significant effect of $r = 0.20$, we would have needed a sample of 80 caregivers; to find a significant effect of 0.25 with statistical power of 0.8, we would have needed 64 caregivers, and for an effect size of $r = 0.37$, we would have needed to recruit 43 caregivers. Many of our non-significant correlations ranged from about $r = 0.20$ (e.g. coding and positive aspects of caregiving) to $r = 0.25$ and higher, up to about $r = 0.37$ (e.g. Delayed Memory Index and caregiver burden, Delayed Memory Index and social support, Delayed Memory Index and positive aspects of caregiving, coding and social support, coding and caregiver distress). With a larger sample of caregivers, these results likely would have been significant.
In general, however, findings indicate that the burden and distress associated with caregiving might impact caregivers’ own cognitive performance. It is important to note that the data was cross-sectional and we cannot make causal attributions without longitudinal data. It could also be possible that caregivers’ own cognitive problems contributed to their sense of caregiver burden. However, in general, these findings have implications for caregiver’s abilities to provide appropriate care for the IWD and suggest a need for resources that might buffer the negative effects of caregiver burden.

We also found that higher caregiver age was associated with worse cognitive performance, as expected. We did not find gender differences in cognitive or psychological outcomes, but this may have been due to the small sample size, particularly the small number of male caregivers in our sample. Relationship to the IWD was not significantly related to any of our outcomes, although the vast majority of caregivers were genetically related to the IWD, making it difficult to draw any conclusions about the influence of having a genetic relationship with the IWD.

**Limitations**

This study was characterized by several limitations, one being the size of the sample, as previously noted. We had difficulty recruiting our caregiver sample, despite running the study for about 2 years, recruiting in three different rural and urban communities, offering a monetary incentive in addition to the clinical feedback, and using a variety of recruitment methods including posters in medical and public places, free talks to older adult groups, and newspaper advertisements. Ultimately, we were not able to collect enough data from caregivers to power all of our analyses.
In addition to the small sample size, the sample might not have been representative of the general population of caregivers and non-caregiving older adults for several reasons. First, our control sample was primarily composed of individuals who had previously participated in studies in the same research laboratory, in which they had received neuropsychological feedback. This might have influenced their subjective perceptions of their cognitive functioning. Further, caregivers who are more burdened or spend more hours caregiving/live with the IWD may have been less likely to participate in our study, limiting our ability to examine the full range of the impact of caregiver burden. Future studies should explore ways to recruit from these groups, for example by going to caregivers’ homes to collect data.

The sample was also not representative of the older adult population in terms of demographic characteristics. For example, fewer than 7% of the total sample identified as non-white, limiting our ability to draw conclusions regarding the potential effects of racial/ethnic status. Also, the sample was highly educated; over 30% of the sample had previously obtained a college degree and 47.3% had obtained an advanced degree. Educational attainment is particularly relevant when examining cognitive outcomes, as cognitive performance is related to level of education (e.g Vitaliano et al., 2009). Because our data was cross-sectional, we were unable to draw conclusions about causal relationships. Future studies should address this limitation by recruiting a more diverse sample and utilizing a longitudinal design.

Further, the way in which we defined the criteria for caregivers for IWD was broad. We identified caregivers as anyone providing at least 5 hours of care per week,
and caregivers were not required to reside with the IWD. This definition allowed us to recruit a larger number of caregivers than we would have been able to otherwise, but left us with a heterogeneous sample of caregivers with regard to amount of care they were providing. However, existing studies have used equally broad definitions of caregivers, and overall there is a lot of inconsistency in who is defined as a caregiver in this area of research (e.g. Cuijpers, 2005; Kang et al., 2014). Future studies should seek to recruit more diverse and representative samples using narrower criteria to define caregivers.

**Implications and Directions for Future Research**

The current study provides further evidence that providing care for an IWD is associated with worse physical, psychological, and cognitive outcomes, although there was little relationship of cognitive outcomes to the physical and psychological outcomes in caregivers. The few relationships with cognitive outcomes that did emerge (relationships with higher anxiety, more sleep disturbance, higher caregiver burden and more distress about neuropsychiatric symptoms in IWD) were consistent with prior literature. Further, results suggest that cognitive performance in caregivers is associated with caregiver age, caregiver burden, and caregiver distress associated with neuropsychiatric symptom severity. Given the limitations of the study, however, more research is needed before drawing stronger conclusions regarding the impact of caregiving on caregiver cognitive health and the correlates of cognitive outcomes in caregivers. As previously discussed, the present study suffered from numerous limitations that should be addressed in future research, and findings from this sample cannot be generalized at this point. Future studies should seek to address the limitations of the
current study and further examine the correlates of caregiver health outcomes, including protective factors such as social support, positive beliefs about caregiving, and service utilization. Future studies should focus specifically on cognitive outcomes, as this area has been relatively neglected in literature to date. It is important to identify caregivers who are at greatest risk for negative outcomes so that interventions can be developed to buffer the negative impact of caregiver stress.
References


neuropsychology: A syndrome-based approach (pp. 357-403). New York: Springer Science + Business Media, LLC.


Appendix A: Recruitment Materials

Do you help care for someone with dementia?
Researchers at Ohio University are studying how serving as a caregiver for a patient or patients with dementia can affect the caregiver. In exchange for participating, you will receive free cognitive screening with feedback on your cognitive performance and a $20 Walmart gift card!

You May Be Eligible To Participate if:
You are over 50
You provide at least 5 hours of care per week to an individual with dementia; you do not need to live with this person.
You are able to read and write in English

Your participation will include answering questions about your physical and mental health, your general background, your experience as a caregiver, and your thoughts about your cognitive abilities. You will also complete a brief battery of cognitive tests, about which you will receive feedback at the end of the study.

For more information, contact:
Alex Woody, 740-593-0910, ww064211@ohio.edu
ARE YOU INTERESTED IN A FREE COGNITIVE SCREENING?

Researchers at Ohio University are studying how serving as a caregiver for a patient or patients with dementia can affect the caregiver. We are comparing caregivers with non-caregivers; you do not need to be a caregiver to participate.

In exchange for participating, you will receive a free cognitive screening and feedback on your cognitive performance!

For more information, contact:
Anna Kinzer, M.S., 740-593-0910, ak143911@ohio.edu

You May Be Eligible To Participate if:
You are over 50
You are able to read and write in English

Your participation will include answering questions about your physical and mental health, your general background, your experience as a caregiver, and your thoughts about your cognitive abilities. You will also complete a brief battery of cognitive tests, about which you will receive feedback at the end of the study.
Appendix B: Measures

Repeatable Battery for the Assessment of Neuropsychiatric Status (RBANS)

The RBANS consists of five indexes (immediate memory, visuospatial/constructional, language, attention, and delayed memory). Subtests include List Learning, Story Memory, Figure Copy, Line Orientation, Picture Naming, Semantic Fluency, Digit Span, and Coding. Subtest scores are used to calculate index scores, which include Immediate Memory, Visuospatial/Constructional, Attention, Language, and Delayed Memory. The Total Scale Index is created by taking the sum of the final index scores. The RBANS normative data is based on a representative standardization sample of 540 U.S. adults aged 20-89. Average reliability coefficients for the subtests range from 0.50 for Figure Copy to 0.85 for List Learning. For index scores, average reliability coefficients range from 0.80 for Language to 0.93 for the Total Scale Index. Index test-retest correlations ranged from $r = 0.68$ for Visuospatial/Constructional to 0.84 for the Total Scale Index. Subtest correlations range from 0.49 to 0.75 and subtests measuring similar constructs correlate more strongly than subtests measuring different constructs. To examine convergent and divergent construct validity, the RBANS was compared with external measures grouped into five areas: general intellectual ability, memory, spatial processing, attention, and language/achievement.

Trail Making Test

The Trail Making Test (TMT) is a measure of attention, speed, and mental flexibility. The TMT is divided into two parts, each consisting of one page. Part A consists of 25 circles distributed over the entire page and numbered from 1 to
25. Participants are required to connect the circles as quickly as possible with a pencil line, beginning with 1 and continuing in numerical sequence. Part B consists of 25 circles numbered 1 to 13 and lettered from A to L. Participants are instructed to connect the circles with a pencil line by alternating between letters and numbers in ascending sequence. The normative sample included 1,212 adults aged 20-85 from various states in the United States and Manitoba, Canada (Strauss, Sherman, & Spreen, 2006). Test-retest reliability varies with the age range and the population being studied but is generally adequate, at least for Part B. Parts A and B correlate moderately well with each other ($r = 0.31-6$), indicating that they measure similar, yet somewhat distinct functions. The test correlates moderately well with other measures of attentional abilities as well as speed. There is evidence that TMT measures more than psychometric intelligence and is sensitive to neurocognitive deficits. It has been found to be sensitive to a variety of disorders and closed head injury, although the test’s utility in cases of mild head injury is questionable. Cross-sectional and longitudinal studies have revealed that performance on the TMT declines with age. The test is sensitive to disorders such as Alzheimer’s disease. Both Parts A and B appear useful for predicting instrumental activities of daily living in community-dwelling older adults (Strauss et al., 2006).

**Controlled Oral Word Association Test (COWA)**

Examiner instructions for the COWA test: "I am going to say a letter of the alphabet, and I want you to say as quickly as you can all the words you can think of which begin with that letter. You may say any word at all except proper names, such as names of people or places. So you would not say "Rochester" or "Robert." Also, do not
use the same words again with a different ending, such as "eat" and "eating." "For example, if I say "S," you could say, "sun," "sit," "shoe," or "slow." Can you think of other words beginning with the letter "S?" Wait for the subject to give a word, indicate if the word is correct, and ask the subject to give another word beginning with the letter "S." Once two appropriate words beginning with the demonstration letter are given, say, "That is fine. Now I'm going to give you another letter, and again say all the words beginning with that letter that you can think of. Remember, no names of people or places, just ordinary words. Also, if you should draw a blank, I want you to keep on trying until the time limit is up. You will have a minute for each one." The first letter is C, and 1 minute is allowed, and the same applies for the letters F and L of Version A. In Version B, the same procedure is used with the alternate letters PRW.

Ruff and colleagues (1996) updated the normative data in a sample of 360 normal volunteers aged 16-70, with education ranging from 7 to 22 years. Internal consistency in this sample was high (r = 0.83) as was 6-month retest reliability (r = 0.74). Performance was influenced by education, but the impact of education was influenced by gender; males with some college performed significantly better than males with no college. Females, however, demonstrated significant differences across three educational groups (12 years or less, 13-15 years, and 16 years or more).

Medical History (clinical interview)

Have you ever lost consciousness due to a blow to the head or other injury? YES   NO

IF YES... If YES, when?

For how long did you lose consciousness? _________
Did you see a doctor?  

Were you hospitalized?  

What was your diagnosis, if any?  

Did you have any form of treatment?  

Have you ever had seizures?  YES  NO  

Have you ever had a brain tumor?  YES  NO  

Have you ever had a stroke?  YES  NO  

Have you ever had a heart attack?  YES  NO  

Please report all of your medical diagnoses (including hypertension or high blood pressure, diabetes or high blood sugar, and high cholesterol – please report your cholesterol number if you know it):  

Please rate your perception of your current health status:  

<table>
<thead>
<tr>
<th>Poor</th>
<th>Fair</th>
<th>Good</th>
<th>Very Good</th>
<th>Excellent</th>
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Have you ever seen a mental health professional (psychiatrist, psychologist, counselor)?  

YES  NO  

If YES, for what diagnosis or purpose?  

When  

Please think back to each month over the past three months. List any specific illnesses you had and tally the number of doctor’s visits you can recall. This list refers to illnesses and doctor’s visits you had yourself.
Current Prescription and Over-the-Counter Medications Used

<table>
<thead>
<tr>
<th>Medication</th>
<th>Frequency</th>
<th>Date Last Taken</th>
<th>Taken Regularly?</th>
<th>Purpose</th>
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Prescription and Over-the-Counter Medications not being used currently, but used anytime in the past 3 months

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<th>Medication</th>
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<th>Date Last Taken</th>
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Subjective Socioeconomic Status (SES)

The MacArthur Scale of Subjective Social Status measures subjective social status using a numbered stepladder image (Adler, Stewart et. al., 2007).
This scale was developed to measure the common sense of social status across SES indicators and is predicted by traditional indicators of SES such as material wealth and educational attainment, as well as subjective feelings of financial security.
Sleep disturbance and sleep-related impairment

In the past 7 days…

My sleep was restless. (Not at all, a little bit, somewhat, quite a bit, very much)

I was satisfied with my sleep. (Not at all, a little bit, somewhat, quite a bit, very much)

My sleep was refreshing. (Not at all, a little bit, somewhat, quite a bit, very much)

I had difficulty falling asleep. (Not at all, a little bit, somewhat, quite a bit, very much)

I had trouble staying asleep. (Never, rarely, sometimes, often, always)

I had trouble sleeping. (Never, rarely, sometimes, often, always)

I got enough sleep. (Never, rarely, sometimes, often, always)

My sleep quality was… (very poor, poor, fair, good, very good)

I had a hard time getting things done because I was sleepy. (Not at all, a little bit, somewhat, quite a bit, very much)

I felt alert when I woke up. (Not at all, a little bit, somewhat, quite a bit, very much)

I felt tired. (Not at all, a little bit, somewhat, quite a bit, very much)

I had problems during the day because of poor sleep. (Not at all, a little bit, somewhat, quite a bit, very much)

I had a hard time concentrating because of poor sleep. (Not at all, a little bit, somewhat, quite a bit, very much)

I felt irritable because of poor sleep. (Not at all, a little bit, somewhat, quite a bit, very much)

I was sleepy during the daytime. (Not at all, a little bit, somewhat, quite a bit, very much)
I had trouble staying awake during the day. (Not at all, a little bit, somewhat, quite a bit, very much)

Participants provided ratings on sleep quality using the Sleep Disturbance (SD) and Sleep-Related Impairments (SRI) item banks, short forms from the Patient-Reported Outcomes Measurement Information System (Yu, Buysse, Germain, Moul, Stover, Doods, et al., 2011). The short forms correlate strongly with the longer forms and have greater measurement precision than other measures of sleep quality as judged by larger information values across severity levels.

Center for Epidemiologic Studies Depression Scale Revised (CESD-r)

Below is a list of the ways you might have felt or behaved. Please select options that reflect how often you have felt this way in the past week or so.

1. My appetite was poor.
2. I could not shake off the blues.
3. I had trouble keeping my mind on what I was doing.
4. I felt depressed.
5. My sleep was restless.
6. I felt sad.
7. I could not get going.
8. Nothing made me happy.
9. I felt like a bad person.
10. I lost interest in my usual activities.
11. I slept much more than usual.
12. I felt like I was moving too slowly.
13. I felt fidgety.
14. I wished I were dead.
15. I wanted to hurt myself.
16. I was tired all the time.
17. I did not like myself.
18. I lost a lot of weight without trying to.
19. I had a lot of trouble getting to sleep.
20. I could not focus on the important things.

The CESD-r (Eaton, Smith, Ybarra, Muntaner, & Tien, 2004) is an updated version of the CESD (Radloff, 1977), a screening test for depression and depressive disorder in the general population. It contains 20 items reflecting diagnostic criteria for depression. Five response items are provided, ranging from “not at all or less than one day” to “nearly every day for 2 weeks.” This measure shows strong psychometric properties, including internal consistency ($\alpha = 0.975$), strong factor loadings, and convergent and divergent validity. See items above.

**Penn State Worry Questionnaire Abbreviated (PSWQ-A)**

1. My worries overwhelm me.
2. Many situations make me worry.
3. I know I should not worry about things, but I just cannot help it.
4. When I am under pressure, I worry a lot.
5. I am always worrying about something.
6. As soon as I finish one task, I start worrying about everything else I must do.
7. I have been a worrier all my life.
8. I have been worrying about things.

Each item of the Penn State Sorry Questionnaire is rated on a scale of 1 (not at all typical of me) to 5 (very typical of me). Eleven of the items are positive for the presence of worry, and five are reverse coded, indicating an absence of worry (Knight, McMahon, Skeaff, & Green, 2008). Among the original normative sample (405 introductory psychology students), the mean score was 48.8 (SD = 13.8), with scores ranging from 16-80 (the entire range of possible scores). Females scores significantly higher than males, t(404)= 3.24, P < 0.002. The coefficient α was 0.93 for the total group. Test-retest reliability using a subset of the original sample over an 8-10 week interval was quite high, r(45) = 0.92, P < 0.001. In college samples, the measure correlates positively with other measures of emotional disturbance, assessments of other relevant psychological constructs such as perfectionism and self-esteem, and with specific maladaptive coping strategies. Responses did not seem to be influenced by social desirability. In clinical samples, the PSWQ distinguished levels of diagnosable Generalized Anxiety Disorder (GAD), and produced higher scores for those with GAD than for those with diagnosable Posttraumatic Stress Disorder (Meyer et al., 1990)

Although the PSWQ was shown to be a reliable and valid instrument in a normative sample, it was developed using younger to middle aged adults, and its psychometric properties appear to be inadequate for assessing worry in older adults (Crittendon & Hopko, 2006). Crittendon and Hopko showed that the PSWQ can be
effectively modified for use with older adults by excluding all five of the reverse coded items and three of the positively worded items. This modification results in the eight-item Penn State Worry Questionnaire-Abbreviated (Hopko, Stanley, Reas, Wetherell, Beck, Novy, et al., 2003). The PSWQ-A has high internal consistency ($\alpha = .87$) and adequate test-retest reliability ($r = .63$) when used with older adults. The measure also demonstrated good convergent and divergent validity with other measures of anxiety and worry ($r = .39-.49$) (Crittendon & Hopko, 2006). Because the PSWQ-A appears to be more appropriate for assessing worry among older adults than the original PSWQ, the PSWQ-A was used in the current study.

**Perceived Stress Scale**

The questions in this scale ask you about your feelings and thoughts during the last month. In each case, you will be asked to indicate *how often* you felt or thought a certain way. For each question, choose from the following alternatives:

0 Never  
1 Almost Never  
2 Sometimes  
3 Fairly Often  
4 Very Often

1. In the last month, how often have you been upset because of something that happened unexpectedly?  
2. In the last month, how often have you felt that you were unable to control the important things in your life?
3. In the last month, how often have you felt nervous and “stressed”?

4. In the last month, how often have you felt confident about your ability to handle your personal problems?

5. In the last month, how often have you felt that things were going your way?

6. In the last month, how often have you found that you could not cope with all the things you had to do?

7. In the last month, how often have you been able to control irritations in your life?

8. In the last month, how often have you felt that you were on top of things?

9. In the last month, how often have you been angered because of things that happened that were outside of your control?

10. In the last month, how often have you felt difficulties were piling up so high that you could not overcome them?

The Perceived Stress Scale, 10-item version (PSS-10; Cohen & Williamson, 1988) was derived from the 14-item Perceived Stress Scale (PSS; Cohen, Kamarck, & Mermelstein, 1983). Scores on this measure are obtained by reversing the scores on the four positive items (items 4, 5, 7, and 8) and then summing across all 10 items. The 14-item version of PSS was designed for use with community samples with at least a junior high school education. Among the first normative sample (332 freshman college students living in dormitories at the University of Oregon), the mean score on the PSS was 23.18 (SD = 7.55). Among the second normative sample (114 members of a class in introductory personality psychology), the mean score was 23.67 (SD = 7.79). Mean scores for females were 23.57 (SD = 7.55) and 25.71 (SD = 6.20) in the two samples.
respectively; mean scores for males were 22.38 (SD = 6.79) and 21.73 (SD = 8.42). The difference between males and females in the normative samples did not approach statistical significance. Age was unrelated to PSS scores in the normative samples. Coefficient alpha reliability was .84 in the first sample and .85 in the second sample, suggesting good internal consistency. Two-day test-retest correlation was .84 and six-week retest reliability was .55. There was a small to moderate correlation between PSS and number of stressful life events; these correlations generally increased when accounting for the respondent’s perceived impact of these events. The PSS was a better predictor of depressive and physical symptomology in the normative sample than stressful life-event scores (Cohen, Kamarck, & Mermelstein, 1983). Roberti and colleagues (2006) found support for normative results, internal consistencies, and construct validity in the 10-item version, revealing that the PSS-10 is a reliable and valid instrument for assessing perceived stress.

Positive and Negative Affect Schedule – Expanded Form (PANAS-X)

This scale consists of words and phrases that describe different feelings and emotions. For each item, indicate to what extent you have felt this way during the past few weeks.

Afraid
Scared
Nervous
Jittery
Irritable
Hostile
The positive and negative affect and hostility items from the Positive and Negative Affect Schedule-Expanded Form (PANAS-X, Watson & Clark, 1994) assess various aspects of positive and negative affect, particularly hostility. Participants rate each item on a five-point scale ranging from Very little or not at all to Extremely. Internal consistency reliabilities are high, ranging from 0.83 to 0.90 for Positive Affect and from
0.85 to 0.90 for Negative Affect. The correlation between the Positive and Negative Affect scales is generally low, ranging from -0.05 to -0.35. Both scales demonstrate convergent/divergent validity, with convergent correlations ranging from 0.89 to 0.95 and discriminant correlations ranging from -0.02 to -0.18.

**Everyday Memory Questionnaire (EMQ)**

Below are listed some examples of things that happen to people in everyday life. Some of them may happen frequently and some may happen very rarely. We should like to know how often on average you think each one has happened to you over the past month.

1. Having to check whether you have done something that you should have done.
2. Forgetting when it was that something happened; for example, whether it was yesterday or last week.
3. Forgetting that you were told something yesterday or a few days ago, and maybe having to be reminded about it.
4. Starting to read something (a book or an article in a newspaper, or a magazine) without realizing you have already read it before.
5. Finding that a word is ‘on the tip of your tongue.’ You know what it is but cannot quite find it.
6. Completely forgetting to do things you said you would do, and things that you planned to do.
7. Forgetting important details of what you did or what happened to you the day before.
8. When talking to someone, forgetting what you have just said. Maybe saying ‘what was I talking about?’
9. When reading a newspaper or magazine, being unable to follow the thread of a story, losing track of what it is about.

10. Forgetting to tell somebody something important, perhaps forgetting to pass on a message or remind someone of something.

11. Getting the details of what someone told you mixed up and confused.

12. Forgetting where things are normally kept or looking for them in the wrong place.

13. Repeating to someone what you have just told them or asking someone the same question twice.

Participants respond to each item on a five point scale ranging from once or less in the past month to once or more in a day. Royle and Lincoln examined the internal consistency, factor structure, and construct validity of this measure in healthy participants (N = 98). They also examined the measure’s sensitivity to differences between 160 patients with memory problems and healthy participants. Cronbach’s alpha was high (0.89), suggesting strong internal consistency. Total scores summed over 13 items ranged from 0-41 with a mean of 9.75 (SD = 8.6). A principle components analysis suggested 3 factors explaining 62% of the variance. There were significant differences between groups, with stroke patients scoring the highest.

Neuropsychiatric Inventory Questionnaire (NPI-Q)

For each of the following items, please answer the questions based on the changes that have occurred since the individual that you are caring for first began to experience memory problems. Click “yes” only if the symptom has been present in the past month. Otherwise click “no.”
Delusions: Does the person you are caring for believe that others are stealing from him or her, or planning to harm him or her in some way?

Hallucinations: Does the person you are caring for act as if he or she hears voices? Does he or she talk to people who are not there?

Agitation or aggression: Is the person you care for stubborn and resistive to help from others?

Depression or dysphoria: Does the person you care for act as if he or she is sad or low in spirits? Does he or she cry?

Anxiety: Does the person you care for become upset when separated from you? Does he or she have any other signs of nervousness, such as shortness of breath, sighing, being unable to relax, or feeling excessively tense?

Elation or euphoria: Does the person you care for appear to feel too good or act excessively happy?

Apathy or indifference: Does the person you care for seem less interested in his or her usual activities and the activities or plans of others?

Disinhibition: Does the person you care for seem to act impulsively? For example, does he or she talk to strangers as if he or she knows them, or does he or she say things that may hurt people’s feelings?

Irritability or lability: Is the person you care for impatient and cranky? Does he or she have difficulty coping with delays or waiting for planned activities?
Motor disturbance: Does the person you care for engage in repetitive activities, such as pacing around the house, handling buttons, wrapping string, or doing other things repeatedly?

Nighttime behaviors: Does the person you care for awaken you during the night, rise too early in the morning, or take excessive naps during the day?

Appetite and eating: Has the person you care for lost or gained weight, or had a change in the food he or she likes?

The Neuropsychiatric Inventory (NPI-Q; Kaufer, Cummings, Ketchel, Smith, MacMillan et al., 2000) is an informant-based assessment of neuropsychiatric symptoms and associated caregiver distress. Each of 12 symptom domains (delusions, hallucinations, agitation/aggression, dysphoria/depression, anxiety, euphoria/elation, apathy/indifference, disinhibition, irritability/lability, aberrant motor behaviors, nighttime behavioral disturbances, and appetite/eating disturbances) is assessed by a written screening question and informants are asked to circle “yes” or “no.” Informants proceed to the next question if the answer is “no” or rate the symptoms present in the last 4 weeks if the answer is “yes.” Informants rate the severity of symptoms on a 3-point scale (1-mild, 2-moderate, 3-severe); the total severity score represents the sum of individual symptom scores and ranges from 0-36. The level of caregiver distress associated with each symptom is rated on a 6-point scale (not distressing at all to extreme) with the distress score (range = 0-60) representing the sum of individual symptom scores.

The initial validation study (Kaufer et al., 2000) included 31 women and 29 men of which 43 were spouses, 14 were sons or daughters, and 1 each was a grandson, friend,
or sister. Participants were stratified by MMSE scores to examine the effects of dementia severity. The NPI-Q demonstrated adequate test-retest reliability (0.80 for total symptom and 0.94 for distress scores over an interval of a few hours) and convergent validity with respect to total and individual symptom domain scores and caregiver distress ratings on the NPI. Scores were correlated to MMSE scores in the Low MMSE group, but not in the High MMSE group, suggesting that neuropsychiatric symptoms in community-dwelling AD patients may become more consistent as the disease progresses and/or that informants become better able to observe and report these symptoms as they gain more experience in the caregiving role. Specific dependent variables that will be used in exploratory analyses of the correlates of physical, mental, and cognitive health outcomes are the total severity score to test the exploratory hypothesis that greater dementia symptom severity will be associated with worse caregiver health and the distress score to test the exploratory hypothesis that caregivers who experience greater caregiving distress related to patient behavioral and psychiatric symptoms will report worse physical, psychological, and cognitive health.

**Caregiver Burden Inventory (CBI)**

Choose the item that best represents how often each statement describes your feelings about the person you care for.

1. He/she needs my help to perform many daily tasks.

2. He/she is dependent on me.

3. I have to watch him/her constantly.

4. I have to help him/her with many basic functions.
5. I don’t have a minute’s break from his/her chores.
6. I feel embarrassed over his/her behavior.
7. I feel ashamed of him/her.
8. I resent him/her.
9. I feel uncomfortable when I have friends over.
10. I feel angry about my interactions with him/her.
11. I feel that I am missing out on life.
12. I wish I could escape from this situation.
13. My social life has suffered.
14. I feel emotionally drained due to caring for him/her.
15. I expected that things would be different at this point in my life.
16. I don’t get along with other family members as well as I used to.
17. My care giving efforts aren’t appreciated by others in my family.
18. I’ve had problems with my marriage or other significant relationship.
19. I don’t get along as well as I used to with others.
20. I feel resentful of others relatives who could but do not help.
21. I’m not getting enough sleep.
22. My health has suffered.
23. Care giving has made me physically sick.
24. I’m physically tired.

The Caregiver Burden Inventory (CBI, Novak & Guest, 1989) is a 24-item, five-subscale, diverse multidimensional instrument that measures the impact of burden on
caregivers. Responses to each item range from 0 (not at all descriptive) to 4 (very descriptive). The CBI includes 5 interpretable factors: time-dependence burden (burden due to restriction on the caregiver’s time), developmental burden (caregivers’ feelings of being “off-time” in their development with respect to their peers), physical burden (feelings of chronic fatigue and damage to physical health), social burden (feelings of role conflict), and emotional burden (negative feelings toward care recipients).

A major strength of this measure is the fact that it measures five dimensions of burden, including one dimension that represents a developmental aspect of burden (Caserta, Lund, & Wright, 1996). Caserta and colleagues examined 160 primary caregivers (82% female) with an average age of 62.5 ($SD = 13.3$). Fifty-two percent were spousal caregivers. In addition to the CBI, participants completed a checklist of patient memory and behavior problems, the CES-D to assess caregiver depression, a checklist of caregiver tasks, and a scale examining caregiver satisfaction. They also collected data on caregiver perceived health and the number of days sick in the past three months. They reported the following reliability coefficients for each subscale: Time dependence (.85), development (.87), physical (.86), social (.69), and emotional (.81). Each dimension of burden appeared to be independent of caregiver age, gender, or length of time spent in the caregiving role. Spousal caregivers were more likely to report high levels of time dependence, developmental, and physical burden. Higher levels of developmental burden were associated with greater depression, lower satisfaction, higher levels of patient impairment, and more days of caregiver illness. Physical burden was associated with perceived health and days sick. The strongest correlation for depression was with
physical burden. The findings of this study support the use of the CBI as a measure of the multidimensional construct of burden (Caserta et al., 1996).

**Katz Index of Independence in Activities of Daily Living**

Please indicate the extent to which the person you care for requires assistance with each of the activities listed below:

- Bathing
- Dressing
- Toileting
- Transferring
- Continence
- Feeding
- Ability to use the telephone
- Shopping
- Food preparation
- Housekeeping
- Laundry
- Transportation
- Medications
- Finances

Caregivers rated each activity on a four-point scale, ranging from no supervision, direction, or personal assistance required to total supervision, direction, or personal assistance needed.
Positive Aspects of Caregiving

Caregiving has...

1.) Made me feel useful.
2.) Made me feel good about myself.
3.) Made me feel needed.
4.) Made me feel appreciated.
5.) Made me feel important.
6.) Made me feel strong and confident.
7.) Enabled me to appreciate life more.
8.) Enabled me to develop a more positive attitude towards life.
9.) Strengthened my relationships with others.

This measure (Tarlow et al., 2004) was developed and administered to 1,229 participants. Each item was rated on a 5-point scale ranging from 1 (disagree a lot) to 5 (agree a lot). An exploratory factor analysis identified two components, Self Affirmation and Outlook on Life. The inter-item reliability for the Self Affirmation component was $\alpha = 0.86$ and the internal consistency for the Outlook on Life component was $\alpha = 0.80$. The correlation between the two components was 0.69 and the overall reliability of the nine items was $\alpha = 0.89$. There was moderate convergent and discriminant validity with other measures; all correlations were in the hypothesized directions although the magnitude of these correlations was smaller than anticipated. Tarlow and colleagues found support for construct validity given variability among subgroups that were expected to vary. See items above.
Social Support and negative social interactions

1. Others provided transportation.

2. Others helped with housework chores and yardwork.

3. Others helped with shopping.

4. Others were right there with you during a difficult time.

5. Others provided comfort.

6. Others listened to you talk about private feelings.

7. Others showed interest and concern.

8. Others suggested some action you could take to solve a problem.

9. Others made difficult situations easier to understand.

10. Others helped you understand why you didn’t do something well.

11. Others told you what they did in a similar stressful situation.

1. Others made too many demands.

2. Others were critical.

3. Others pried into affairs.

4. Others took advantage.

Participants responded to the items above (Krause, 1995) on a 4-point scale (never, once in a while, fairly often, very often).
Appendix C: Supplemental Tables

Table C1

Tests of Skewness and Kurtosis

<table>
<thead>
<tr>
<th>Variable</th>
<th>Mean</th>
<th>SD</th>
<th>Range</th>
<th>Skewness</th>
<th>Kurtosis</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>68.27</td>
<td>8.998</td>
<td>51-90</td>
<td>1.42</td>
<td>0.318</td>
</tr>
<tr>
<td>Systolic</td>
<td>134.96</td>
<td>18.95</td>
<td>106-216</td>
<td>4.45</td>
<td>6.15</td>
</tr>
<tr>
<td>Diastolic</td>
<td>79.97</td>
<td>11.065</td>
<td>54-114</td>
<td>1.77</td>
<td>0.676</td>
</tr>
<tr>
<td>Waist</td>
<td>38.16</td>
<td>6.35</td>
<td>26.50-56.0</td>
<td>3.05</td>
<td>1.38</td>
</tr>
<tr>
<td>Medications</td>
<td>5.44</td>
<td>3.51</td>
<td>0-19</td>
<td>4.68</td>
<td>4.95</td>
</tr>
<tr>
<td>TMT</td>
<td>12.04</td>
<td>2.77</td>
<td>5.00-17.00</td>
<td>1.38</td>
<td>0.21</td>
</tr>
<tr>
<td>COWA Scaled</td>
<td>11.17</td>
<td>2.858</td>
<td>3.00-16.00</td>
<td>2.205</td>
<td>0.708</td>
</tr>
<tr>
<td>Delayed Memory Index</td>
<td>105.65</td>
<td>12.4</td>
<td>75-127</td>
<td>1.91</td>
<td>0.193</td>
</tr>
<tr>
<td>Coding Scaled</td>
<td>11.58</td>
<td>3.19</td>
<td>6.00-18.00</td>
<td>0.325</td>
<td>1.63</td>
</tr>
<tr>
<td>CESD-r</td>
<td>7.15</td>
<td>9.26</td>
<td>0-56</td>
<td>9.62</td>
<td>18.44</td>
</tr>
<tr>
<td>PSWQ-A</td>
<td>14.73</td>
<td>8.13</td>
<td>8.00-37.00</td>
<td>4.41</td>
<td>0.662</td>
</tr>
<tr>
<td>Perceived Stress</td>
<td>18.653</td>
<td>4.012</td>
<td>11.00-31.00</td>
<td>1.899</td>
<td>1.338</td>
</tr>
<tr>
<td>BMI</td>
<td>28.3</td>
<td>6.2</td>
<td>15.47-51.70</td>
<td>4.46</td>
<td>4.85</td>
</tr>
<tr>
<td>Social Support</td>
<td>38.76</td>
<td>6.13</td>
<td>27-57</td>
<td>2</td>
<td>0.418</td>
</tr>
<tr>
<td>EMQ</td>
<td>21.4</td>
<td>6.898</td>
<td>13-47</td>
<td>5.06</td>
<td>3.897</td>
</tr>
<tr>
<td>Severity</td>
<td>9.71</td>
<td>6.57</td>
<td>0-23</td>
<td>0.406</td>
<td>0.828</td>
</tr>
<tr>
<td>Distress</td>
<td>17.54</td>
<td>12.167</td>
<td>0-41</td>
<td>0.46</td>
<td>1.31</td>
</tr>
<tr>
<td>Burden</td>
<td>57.64</td>
<td>15.78</td>
<td>34-109</td>
<td>2.596</td>
<td>3.266</td>
</tr>
<tr>
<td>Positive Aspects</td>
<td>27.07</td>
<td>8.33</td>
<td>9.00-42</td>
<td>0.286</td>
<td>0.167</td>
</tr>
<tr>
<td>Sleep</td>
<td>32.35</td>
<td>10.48</td>
<td>17-78</td>
<td>5.13</td>
<td>6.996</td>
</tr>
</tbody>
</table>

*Note.* Systolic/Diastolic = Blood pressure; Medications = current number of medications; TMT = Trail Making Test Part B scaled score; COWA = Controlled Oral Word Association Test; CESD-r = Center for Epidemiologic Studies Depression Scale – Revised; PSWQ-A = Penn State Worry Questionnaire – Abbreviated; Perceived Stress = Perceived Stress Scale scores; BMI = Body Mass Index; EMQ = Everyday Memory Questionnaire. Sleep = short forms of the Sleep Disturbance and Sleep-Related Impairment domains.
A few of the scales contained significant outliers, which we removed before running analyses. These included systolic and diastolic blood pressure (one outlier each, the same individual), number of medications (two outliers), CESD-R (one outlier), BMI (one outlier), hostility (one outlier), sleep disturbance (one outlier) and EMQ (one outlier). After removing these outliers, PSWQA, CESD-R, and EMQ remained positively skewed. We ran square root transformations on these variables and used the transformed scales in our analyses.

**Supplemental Descriptive Analyses**

Among the total sample, 18 participants reported their cholesterol levels, which ranged from 120 to 237 ($M = 181.944$, $SD = 31.948$). The most common medical diagnoses reported by participants included hypertension ($N = 30$), high cholesterol ($N = 24$), arthritis ($N = 11$), and diabetes ($N = 6$). Thirty-five participants (47.3%) reported a history of treatment for one or more mental health conditions, including anxiety disorders, adjustment, depression, bipolar disorder, ADHD, and alcohol use disorder. Eight participants (10.3%) reported that they currently have a mental health diagnosis.

Notably, caregivers differed significantly from non-caregivers on the subjective SES measure, $t(73) = 2.134, p = 0.036$, with caregivers scoring significantly lower ($M = 6.04, SD = 1.825$) than non-caregivers ($M = 6.85, SD = 1.444$). When examining the outcome measures and controlling for SES, the MANCOVAs for cognitive $F(4, 61) = 1.626, p = 0.179$, and physical health, $F(10, 49) = 1.609, p = 0.132$, were no longer significant, likely because of reduced sample size as some values were missing for the SES measure. The pattern remained the same, however, with differences pointing
towards greater impairments in caregivers with respect to the Delayed Memory Index and systolic blood pressure.

With regard to rates of service utilization among caregivers for IWD, the most common services utilized were outpatient health services, inpatient health services, religious organizations, and nursing homes. See Table C2 for the frequencies with which other services were utilized by study caregivers. Scores on the measure of assistance with ADLs (Katz, et al. 1970) ranged from 24 – 56 ($M = 41.562$, $SD = 9.718$).
Table C2  
*Service Utilization among Caregivers*

<table>
<thead>
<tr>
<th>Service</th>
<th>N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Outpatient Health</td>
<td>13 (44.8%)</td>
</tr>
<tr>
<td>Inpatient Health</td>
<td>8 (27.6%)</td>
</tr>
<tr>
<td>Home Health Aide</td>
<td>5 (17.2%)</td>
</tr>
<tr>
<td>Visiting Nurse</td>
<td>6 (20.7%)</td>
</tr>
<tr>
<td>Emergency Response System</td>
<td>6 (20.7%)</td>
</tr>
<tr>
<td>Outpatient Mental Health</td>
<td>4 (13.8%)</td>
</tr>
<tr>
<td>Inpatient Mental Health</td>
<td>2 (6.9%)</td>
</tr>
<tr>
<td>Alzheimer’s Disease Assistance Center</td>
<td>4 (13.8%)</td>
</tr>
<tr>
<td>Personal Medical Alert System</td>
<td>3 (10.3%)</td>
</tr>
<tr>
<td>Nursing Home</td>
<td>7 (24.1%)</td>
</tr>
<tr>
<td>Homemaker</td>
<td>3 (10.3%)</td>
</tr>
<tr>
<td>Legal</td>
<td>5 (17.2%)</td>
</tr>
<tr>
<td>Informal Referral</td>
<td>3 (10.3%)</td>
</tr>
<tr>
<td>Church, Mosque, or Synagogue</td>
<td>8 (27.6%)</td>
</tr>
<tr>
<td>Home Modification Assistance</td>
<td>4 (13.8%)</td>
</tr>
<tr>
<td>Library</td>
<td>6 (20.7%)</td>
</tr>
<tr>
<td>Transportation</td>
<td>8 (27.6%)</td>
</tr>
<tr>
<td>Alzheimer’s Association</td>
<td>6 (20.7%)</td>
</tr>
<tr>
<td>In-Home Respite Care</td>
<td>2 (6.9%)</td>
</tr>
<tr>
<td>Agency on Aging</td>
<td>3 (10.3%)</td>
</tr>
</tbody>
</table>
Table C2 Continued

<table>
<thead>
<tr>
<th>Service</th>
<th>Count</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adult Day Care</td>
<td>2</td>
<td>6.9%</td>
</tr>
<tr>
<td>Senior Center</td>
<td>3</td>
<td>10.3%</td>
</tr>
<tr>
<td>Financial Assistance</td>
<td>4</td>
<td>13.8%</td>
</tr>
<tr>
<td>Meals on Wheels</td>
<td>1</td>
<td>3.4%</td>
</tr>
<tr>
<td>Individual Counseling</td>
<td>2</td>
<td>6.9%</td>
</tr>
<tr>
<td>Educational Programs</td>
<td>2</td>
<td>6.9%</td>
</tr>
<tr>
<td>Support Group</td>
<td>5</td>
<td>17.2%</td>
</tr>
<tr>
<td>Recreational Facilities</td>
<td>6</td>
<td>20.7%</td>
</tr>
<tr>
<td>Home Energy Assistance</td>
<td>1</td>
<td>3.4%</td>
</tr>
<tr>
<td>Out-of-Home Respite Care</td>
<td>1</td>
<td>3.4%</td>
</tr>
<tr>
<td>Telephone Reassurance</td>
<td>1</td>
<td>3.4%</td>
</tr>
<tr>
<td>Family Counseling</td>
<td>2</td>
<td>6.9%</td>
</tr>
<tr>
<td>Caregiver Resource Center</td>
<td>2</td>
<td>6.9%</td>
</tr>
</tbody>
</table>

The most common perceived barriers to service utilization included lack of awareness of available services ($N = 12$), high cost ($N = 8$), poor ease of access ($N = 5$), lack of assistance from other informal helpers ($N = 5$), and inconvenient location ($N = 5$).
Table C3

Supplemental Analyses of PANAS-X Scales

<table>
<thead>
<tr>
<th></th>
<th>Caregivers</th>
<th>Controls</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>M</td>
<td>SD</td>
</tr>
<tr>
<td>Positive</td>
<td>35</td>
<td>8.207</td>
</tr>
<tr>
<td>Negative</td>
<td>23.966</td>
<td>10.602</td>
</tr>
<tr>
<td>Hostility</td>
<td>10.464</td>
<td>2.365</td>
</tr>
</tbody>
</table>

We used a one-way ANCOVA to compare scores between groups on the subscales of the PANAS, controlling for age. Groups did not differ on positive affect, $F(2, 74) = 1.671, p = 0.200$, partial $\eta^2 = 0.022$, or hostility, $F(2, 73) = 2.196, p = 0.143$, partial $\eta^2 = 0.029$, but did differ in terms of negative affect, $F(2, 73) = 8.213, p = 0.005$, partial $\eta^2 = 0.101$ with caregivers reporting much higher negative affect than controls.