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THE PRESENCE, NATURE, AND IMPACT OF CAREGIVER STRESS AND SELF-CARE IN INFORMAL CAREGIVERS FOR VETERANS WITH ALZHEIMER'S OR OTHER DEMENTIA

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SUSAN K. LESHER
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THE PRESENCE, NATURE, AND IMPACT OF CAREGIVER STRESS AND SELF-CARE IN INFORMAL CAREGIVERS FOR VETERANS WITH ALZHEIMER'S OR OTHER DEMENTIA

A DISSERTATION APPROVED FOR THE
DEPARTMENT OF EDUCATIONAL PSYCHOLOGY

BY

_____
Dr. Paula McWhirter, Chair

_____
Dr. Calvin Stoltenberg

_____
Dr. Rockey Robbins

_____
Dr. Hairong Song

_____
Dr. Barbara Greene

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To Robin Lesher, the World's Greatest Mom. Thank you for always having my back, no matter what life kicks my way.

To Dan Lesher, the World's Greatest Dad. Thank you for your never-ending support in the form of love, encouragement, and care packages.

To Dustin Kerman, my best friend and soulmate. Thank you for believing in me, and for always helping me find the positive.

I love you all.

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Abstract

This preliminary research explores the relationships between caregiver stress, self-care, and overall quality of life (QOL) in adult informal caregivers providing care for veterans with dementia. Demographic and care-related factors were also described, and investigated as potential risk/protective factors for caregiver stress. Results indicated that both caregiver stress and self-care were significant predictors of overall QOL ($p \leq .001$). Interestingly, no relationship was found between caregiver stress and self-care. Many demographic and care-related differences were found between the study sample and a nationally representative sample of caregivers, suggesting the experiences and circumstances of the study population, and therefore the best interventions for the study population, may be meaningfully different. The only demographic or care-related factor to achieve statistical significance with regards to levels of stress or self-care was hours of care provided per week. Notably, all of these factors demonstrated large effect sizes. Though the small sample size makes generalizability somewhat difficult, these results indicate that caregiver self-care may be a target domain for interventions designed to improve QOL.

Chapter 1: Introduction

Caregivers play a crucial role in supporting the health and well-being of individuals who are unable to care for themselves. Professional caregivers, such as doctors, nurses, psychologists, and social workers, provide the vast majority of inpatient and acute care, however, post-discharge many of the caregiving responsibilities are shifted to informal caregivers such as friends and family members. The National Alliance for Caregiving (NAC, 2009) in cooperation with AARP published data from a national survey estimating that 65.7 million people in the United States had been in the role of family caregiver within the previous year. Alzheimer's or other dementia was identified as one of the most common conditions requiring care (10%), and when prompted, an additional 16% of caregivers reported loved ones struggle with mental confusion (NAC, 2009). Alzheimer's/dementia was second only to old age (12%). Interestingly, advanced aging has been identified as the most significant risk factor for the development of Alzheimer's (Alzheimer's Association, 2012). In fact, within the general population, approximately one in 70 people ages 65-70 is affected by dementia. Within the next decade, these rates double (to one in five people) among those ages 80 or older (The Alzheimer's Society of Ireland, n.d.). The Alzheimer's Association (2014), reports the number of people diagnosed with Alzheimer's is projected to almost triple from 4.7 million in 2004 to 13.8 million in 2050. Therefore, with the average age of care recipients increasing (66.5 in 2004 to 69.3 in 2009; NAC, 2009), and rates of diagnosed Alzheimer's almost tripling, it is likely to expect a subsequent increase in the number of informal caregivers for individuals affected by Alzheimer's or other dementia.

Dementia is an umbrella term used to describe a decline in cognitive functioning significant enough to impact daily living, including problems with memory, language, attention, reasoning, visual perception, and judgment (Alzheimer's Association, 2015d). Alzheimer's disease is the most common form of dementia, comprising 60-80% of all dementia cases (Alzheimer's Association, 2015d). Because of the numerous possibilities for patterns of decline, the activities involved in caregiving are considerably diverse, and can include assisting with both activities of daily living (ADLs) such as transitions, dressing, bathing, toileting, and feeding, and instrumental activities of daily living (IADLs) such as transportation, finances, medication management, housework, and emotional/behavior support. Being able to receive informal care of this nature can be very positive for the individual receiving care for many reasons, including the likelihood of lower frequencies and/or shorter lengths of institutionalization. However, research evidence suggests that assuming the role of caregiver has wide-reaching negative impacts on the health and well-being of the caregiving individuals (Watanabe, Shiel, Asami, Taki, & Tabuchi, 2000; Hasson et al., 2010; Simon, Kumar, & Kendric, 2009; Whittingham, Barnes, & Gardiner, 2013). Many different constructs and terms have been investigated in association with this well-established presence of negative health effects for informal carers, including burden (Zarit, Todd, & Zarit, 1986), strain (Teasdale et al., 2014), and stress (Riley, 2007; Greene, Smith, Gardiner, & Timbury, 1982). Despite the differences in terminology, and the slight differences in operationalization that accompany them, the research in this area has produced consistent findings. For the purposes of consistency, the current research will use the term "caregiver stress," or simply "stress."

One of the most significant ways in which caregiving negatively affects caregiver quality of life is through the increased demands on their time. In a 2009 survey (National Alliance for Caregiving), over half of caregivers surveyed admitted that their responsibilities as a caregiver reduced the amount of time they were able to spend with friends and family. This also has the potential to reduce the amount of time spent in pleasurable and relaxing activities, in other words limiting the amount of self-care that takes place. This could help to explain why in that same survey (National Alliance for Caregiving, 2009) 47% of the caregivers reported feeling high levels of emotional stress as a result of their caregiving. More frequent and/or more effective use of self-care strategies by caregivers could serve to significantly reduce caregiver stress and the negative effects this stress has on the health and well-being of caregivers.

The need for research and informed practice focused on this population is compelling. However, informal caregivers are challenging to research. It is a population comprised of individuals with an extremely wide range of characteristics, providing care for a similarly diverse group of individuals. Because of this heterogeneity, it is difficult to draw conclusions about "caregivers" as a whole, and most research in the field focuses on caregivers who share an important characteristic, frequently the diagnosis or condition of their care recipients. Therefore, in order to address a more homogenous group of caregivers, the current study is specifically focused on informal (non-professional) adult caregivers for veterans with Alzheimer's disease or another form of dementia.

The large national study performed by the National Alliance for Caregiving found that 17% of their respondents were caring for a veteran (National Alliance for

Caregiving, 2010). This means that an estimated 11,169,000 informal caregivers in the United States are providing care for a veteran. Caregivers for veterans is a group that has been identified as a "special set of caregivers" (National Alliance for Caregiving, 2010, p. 11) with unique challenges. However, very little research has been done with the population, and the research that does exist tends to focus mainly on caregivers for veterans whose diagnosis or condition is directly related to their service such as PTSD or TBI. This research aims to fill the knowledge gaps regarding the unique challenges, risk factors, and protective factors for adult informal caregivers providing care for veterans with dementia. Specifically this study will be looking at caregiver stress, health-promoting behaviors (self-care), and overall quality of life. The information gained in this study could be useful in not only better understanding the challenges faced by these informal caregivers, but also in beginning to devise more effective and targeted interventions to increase their quality of life, as well as the quality of life for the recipients of their care.

Chapter 2: Literature Review

Types of Dementia

The Alzheimer's Association (2014) defines dementia as "an overall term for diseases and conditions characterized by a decline in memory or other thinking skills that affects a person's ability to perform everyday activities" (p. 5). The symptoms of dementia arise from damage to the brain that can take place in a variety of areas and can result from a variety of factors. Due to the diversity of symptom presentations, dementia has been broken down into different types, with each subtype usually based on the underlying cause.

Alzheimer's disease. Alzheimer's disease is the most common form of dementia, and is estimated to account for 60 to 80 percent of dementia cases (Alzheimer's Association, 2014). A single cause of Alzheimer's disease has not yet been identified, but there is a pattern of changes in the brain that is characteristic of the disease. Specifically, accumulations of the beta-amyloid protein (plaques) form outside of neurons, and accumulations of an abnormal form of the tau protein (tau tangles) form inside neurons (Alzheimer's Association, 2014). These brain changes interfere with interneuronal communication and molecular transport, and contribute to the cell death that causes the characteristic brain shrinkage seen in Alzheimer's disease. The hallmark symptom of Alzheimer's disease is memory loss, especially for recent events, as the part of the brain responsible for encoding and storing new information is usually the first part of the brain to be affected (Manning & Ducharme, 2010). Other common symptoms of Alzheimer's disease include disorientation, poor judgment, significant decline in activities of daily living and instrumental activities of daily living, language

difficulties, poor visuospatial skills, apraxia, and apathy (Alzheimer's Association, 2014).

Because these problems arise gradually over time, individuals may experience Alzheimer's-like symptoms for years prior to diagnosis. On average, individuals live between four and eight years after the diagnosis is made (Alzheimer's Association, 2014). Alzheimer's disease is ultimately fatal. It is one of the leading causes of poor health and disability, and is the fifth leading cause of death for individuals ages 65 and older (Alzheimer's Association, 2014).

Vascular dementia. The second most common dementia is vascular dementia (Manning & Ducharme, 2010). This type of dementia, sometimes referred to as "post-stroke dementia," is highly associated with cerebrovascular disease, and is usually the result of either microscopic bleeding or blockage of blood vessel(s) in the brain (Alzheimer's Association, 2012). Vascular dementia can result in many different impairments depending on the location and severity of the vascular problem. However, the most common deficit is related to executive functioning including attention, processing speed, and problem solving (Manning & Ducharme, 2010). In contrast to Alzheimer's disease and most other types of dementia, the onset of vascular dementia tends to be sudden followed by a plateau, rather than gradual worsening.

Dementia with Lewy bodies and Parkinson's disease dementia. Dementia with Lewy bodies, the third most common type of dementia, is caused by abnormal alpha-synuclein protein aggregations in the cortex (Alzheimer's Association, 2015a). Similarly, Parkinson's disease is associated with alpha-synuclein protein aggregations in the substantia nigra, and eventually leads to dementia in 50 to 80 percent of cases

(Alzheimer's Association, 2015c). Dementia with Lewy bodies and Parkinson's disease have many overlapping symptoms including balance problems, visual hallucinations, sleep disturbances, and day-today variability in confusion and alertness (Alzheimer's Association, 2015a). The key difference between dementia with Lewy bodies and Parkinson's disease dementia is the timeframe of symptom onset; if dementia symptoms appear within one year of the motor symptoms, then the diagnosis is dementia with Lewy bodies. However, if the dementia symptoms do not appear until more than one year after the onset motor symptoms, then the diagnosis is Parkinson's disease dementia (Alzheimer's Association, 2015c).

Frontotemporal dementia. A less common type of dementia is frontotemporal dementia, which is comprised of three subtypes, each of which encompasses a number of disorders. The first subtype, behavioral variant frontotemporal dementia, is characterized by changes in personality and behavior, frequently accompanied by disinhibition (Alzheimer's Association, 2015b). The second subtype is best described as primary progressive aphasia, and is characterized by difficulty with language problems, including comprehension, generation, and meaningful communication (Alzheimer's Association, 2015b). The final subtype is labeled frontotemporal dementia movement disorder. The disorders of this subtype primarily affect automatic muscle function, but can also affect language and behavior (Alzheimer's Association, 2015b). Although these subtypes differ somewhat in initial presentation, as the disorders progress there is increasing overlap in symptom presentation (Alzheimer's Association, 2015b). One unique aspect of all frontotemporal dementias is that their

age of onset tends to be 50s to early 60s; much earlier than other dementias (Alzheimer's Association, 2015b).

Other dementia. There are other, less common conditions that are also known to cause dementia, such as normal pressure hydrocephalus and Creutzfeldt-Jakob disease (Alzheimer's Association, 2014). It is also possible to have a mixed dementia, in which Alzheimer's characteristics are present alongside another type of dementia (Alzheimer's Association, 2012). Though symptoms from a singular dementia may predominate, it is estimated that up to half of all dementias are of mixed etiology (Alzheimer's Association, 2014).

Diagnosing Dementia

When the Diagnostic and Statistical Manual of Mental Disorders, fifth edition (DSM-5) was published in 2013, the terminology used to describe dementia changed. The diagnostic categories of "dementia" and "amnestic disorder" were replaced with "major neurocognitive disorder," and a new category called "mild neurocognitive disorder" was added to recognize less severe levels of impairment (American Psychiatric Association, 2013b). The differentiation between etiological subtypes (e.g., Major neurocognitive disorder due to Alzheimer's disease) is still an important component of diagnosis for both major and mild neurocognitive disorders, and each etiological subtype has a separate set of diagnostic criteria.

Major neurocognitive disorder. There are two main diagnostic criteria for the diagnosis of major neurocognitive disorder. Criterion A states that there must be "evidence of significant cognitive decline from a previous level of performance in one or more cognitive domains" (American Psychiatric Association, 2013a, p. 602). This

evidence usually consists of two components; (a) substantial impairment on neuropsychological testing or other quantified clinical assessment, and (b) concern regarding cognitive function on the part of the individual, an informed friend/family member, and/or the clinician. Criterion B states that the cognitive decline (Criterion A) must interfere with the individual's ability to independently perform ADLs and/or IADLs (American Psychiatric Association, 2013a). To be diagnosed with major neurocognitive disorder, it must also be determined that the cognitive deficits do not occur solely within a delirium (Criterion C), and are not better explained by another mental disorder (Criterion D).

Mild neurocognitive disorder. Similar to major neurocognitive disorder, there are two main diagnostic criteria. In contrast to Criterion A for major neurocognitive disorder which requires "significant cognitive decline," Criterion A for mild neurocognitive disorder only requires evidence of "modest cognitive decline from a previous level of performance in one or more cognitive domains" (American Psychiatric Association, 2013a, p. 605). Criterion B states that these cognitive deficits do not interfere with independence in ADLs or IADLs, but note that increased effort, compensatory strategies, and/or accommodation may be necessary to successfully complete these tasks (American Psychiatric Association, 2013a). Exactly like in major neurocognitive disorder, it must be determined that the cognitive deficits do not occur exclusively during a delirium (Criterion C), or as the result of another mental disorder (Criterion D).

Differential diagnosis. As alluded to in the diagnostic criteria (C&D), there are other conditions and disorders that mimic the symptoms of dementia. The most

significant difference between true dementia and the disorders that mimic its symptoms is that dementia is not curable or reversible (Alzheimer's Association, 2014). Some of the most common causes of dementia-like symptoms are delirium, depression (or other mood disorders), polypharmacy/medication side effects, sensory deficits, metabolic problems, and chronic sleep impairment. Each of these can cause problems with attention, executive function, processing speed, and memory, but each of these also has a treatment that can reverse or eliminate the symptoms. Because dementia does not currently have a treatment that can reverse the symptoms (Alzheimer's Association, 2014), it is important to rule out these reversible causes of dementia, so that individuals do not needlessly endure these potentially life-altering symptoms.

Meta-analytic reviews from the last quarter century indicate that the diagnosis of dementia in cases with underlying reversible causes has decreased dramatically from an estimated 11 percent prior to 1988 (Clarfield, 1988) to less than one percent in 2003 (Clarfield, 2003). However, there is some variability in the research, with other studies showing much higher prevalence rates ranging from seven percent (Muangpaisan, Petcharat, & Srinonprasert, 2012) to 19 percent (Eboli Bello & Schultz, 2011). There are many reasons hypothesized for these differences including hospital-based versus community-based studies (Eboli Bellow & Schultz, 2011), variability in clinician knowledge and objective testing, updated diagnostic criteria, (Clarfield, 2003), inconsistent definitions of reversible dementia (Takada et al., 2003), and short term or non-existent follow-up. The commonly accepted range reported for reversible dementia is zero to 30 percent (Takada, et al., 2003; Arnold & Kumar, 1993; Piccini, Bracco, & Amaducci, 1998).

The current research. Because the current research relies solely on self-report information from caregivers for these individuals, it is beyond the scope of this study to differentiate between the many etiologies of dementia. However, because this research focuses on caregiving and caregiver well-being, the precise cause of symptoms/behaviors for which the caregivers are providing care is much less important than the symptoms/behaviors themselves. The next section examines these symptoms/behaviors in more depth, and discusses the ways they can affect caregivers.

Caregiving

Though there are endless possibilities for areas in which caregivers can provide assistance, these activities are usually grouped into two categories; activities of daily living (ADLs) and instrumental activities of daily living (IADLs). The five common ADLs are transfers (getting in and out of bed, chairs, etc.), dressing, bathing, feeding, and toileting. The seven common IADLs are transportation, housework, grocery shopping, preparing meals, managing finances, managing medication, and interfacing with healthcare or other assistive services. Caregiver responsibilities vary widely in regard to both the types of activities with which they assist their care recipients. The most recent, large national study (NAC, 2009) found that 56 percent of all caregivers assist with least one ADL, with the most common being transfers (40%), dressing (30%), and bathing (26%). It is even more common for the caregivers to assist with IADLs. The NAC (2009) found that on average, caregivers for adults assisted with 4.4 out of the seven IADLs (NAC, 2009), with the most common being transportation (83%), housework (75%), grocery shopping (75%), meal preparation (65%), and managing finances (64%).

Caregivers also significantly differ on the amount of time spent in the caregiving role. The National Alliance for Caregiving (NAC, 2009) found that about half of caregivers are in roles that require eight or fewer hours per week, but that about 13 percent are caregivers spend more than 40 hours per week in their caregiving role. The average for all caregivers with adult care recipients was 19.9 hours per week (NAC, 2009), though notably this number is significantly different for different groups of caregivers and care recipients. For example, caregivers age 65 or older provide significantly more care on average (30.6 hours per week) than their younger counterparts (18.8 hours per week). The particular groups of interest for this study include caregivers caring for veteran care recipients, and caregivers caring for care recipients with dementia.

Caregivers for veterans. One of the most comprehensive studies focusing on caregivers for veterans was conducted by the NAC (2010b), but caregivers were only included in this study if the condition(s) for which care is required were related to military service. The most commonly reported conditions were mental illness (70%), post-traumatic stress disorder (60%), traumatic brain injury (29%), and diabetes (28%), but others included Parkinson's disease (6%) and multiple sclerosis (4%). This special set of caregivers caring for veterans seems to differ from the population of caregivers in general in several ways.

A particularly relevant finding from the NAC (2010b) shows that 65 percent of caregivers for veterans reported a high burden of care, but nationally only 31 percent of other caregivers report a high burden. The duration of care is substantially longer for caregivers of veterans, with 56 percent being in the caregiving role for at least five

years, and 30 percent for at least ten years (NAC, 2010b). On the other hand, only 30 percent of the larger population of caregivers has been caregiving for at least five years, and only 15 percent for at least ten years (NAC, 2009). There is also a significant difference in gender and age, with caregivers for veterans being nearly all female (96%; NAC, 2010b), while caregivers in general were only two thirds (66%) female (NAC, 2009), and over 60 percent of caregivers for veterans were age 50 or older (NAC, 2010b), whereas only 48 percent of caregivers from the general survey were age 50 or older (NAC, 2009). The relationship between the caregiver and care recipient is yet another area in which large differences are seen, with 70 percent of caregivers for veterans caring for a spouse, while only five percent of caregivers in general are caring for a spouse or partner (NAC, 2010b; NAC 2009). Among others, these primary differences clearly differentiate caregivers for veterans from the population of caregivers for non-veterans.

Caregivers for dementia patients. Demographically, individuals providing care for patients with dementia are somewhat similar to caregivers for non-dementia patients. The average age of the dementia caregiver is 48 years old, and most (59%) are women (Alzheimer's Association & NAC, 2004). Also similar to non-dementia caregivers, caregivers for individuals with dementia are usually providing care to a relative (87%). Of note, 35% of dementia care recipients are 85 years of age or older, while only 20% of non-dementia care recipients are similarly aged (Alzheimer's Association & NAC, 2004). Despite some demographic similarities, dementia caregivers are considerably different from the non-dementia caregivers in terms of the care they provide.

Similar to the disproportionate burden of care for veterans, caregivers for people with dementia also reported a disproportionately high burden of care (61%) relative to non-dementia caregivers (46%; Alzheimer's Association & NAC, 2004). For instance, a greater percentage (65%) of dementia caregivers assist with at least one ADL (Alzheimer's Association & NAC, 2004), relative to non-dementia caregivers (56%; NAC, 2009). Also, dementia caregivers are much more likely than non-dementia caregivers to be assisting with the more difficult ADLs including toileting (32% versus 13%), bathing (35% versus 25%) and eating (28% versus 18%). Almost one quarter (23%) of dementia caregivers report that they spend at least 40 hours a week in caregiving activities (Alzheimer's Association & NAC, 2004).

Both the types of activities involved in caregiving, and the amount of time involved in caregiving, along with many other factors can contribute to caregiver stress, a known risk factor for negative effects on both the caregiver (Schulz & Sherwood, 2008; Simon, Kumar, & Kendrick, 2009;) and the care recipient (Kuzuya et al., 2011). The following section presents what is already known about caregiver stress, and the effects it has on the caregiver.

Caregiver Stress and Quality of Life

It is well established that informal caregivers have high needs regarding both instrumental and psychological/emotional support (McKeown, Porter-Armstrong, & Baxter, 2003; O'Callaghan, McAllister, & Wilson, 2011; Moules & Chandler, 1999). The transactional model of stress and coping (Lazarus & Folkman, 1984), conceptualizes stress not as an inherent response to the presence of stressors, but rather the result of an imbalance between burden and coping ability. In other words, when the

demands that accompany the role of caregiver outweigh the support and coping ability of the caregiver, the result is stress. This concept has been supported specifically in the context of caregiving (Smith et al., 2006;), and the observed stress has manifested in many different ways including family distress (Sander & Kreutzer, 1999; Chen & Boore, 2008), anger (Perlesz, Kinsella, & Crowe, 2000; Lezak, 1978), physical health problems (McPherson, Pentland, & McNaughton, 2000) and anxiety or depression (Watanabe et al., 2000; O'Connor & McCabe, 2011).

There are noted differences in stress across different types of caregivers. For example, primary caregivers (individuals who are the main, or only, caregiver) report significantly worse physical health than non-primary caregivers (NAC, 2009). Longer-term caregivers are also more likely to say that caregiving has negatively impacted their health (NAC, 2009). Other caregiver characteristics that are associated with negative health include female gender and living with the care recipient (Pinquart & Sorensen, 2003; NAC, 2009). Interestingly, the negative psychological effects of caregiving, including depression are usually more impactful than the negative physiological effects (Schulz & Sherwood, 2008). Approximately 31 percent of caregivers report feeling highly stressed (NAC, 2009), and not surprisingly, many of the caregiver characteristics that are associated with poor physical health are also associated with poor mental health. Factors that seem to place caregivers at the greatest risk of negative mental health include providing care for 20 or more hours per week, female gender, caring for a spouse, and more advance age (Schulz & Sherwood, 2008; NAC, 2009; Pinquart & Sorenson, 2003).

Although caregiver characteristics clearly have a significant impact on the level of stress resulting from being a caregiver, factors related to the care recipient also are very significant, and potentially even more impactful.

Veteran care recipients. As noted earlier, the vast majority of the limited research that exists on informal caregivers for veterans focuses on the impact of PTSD and/or TBI. Although not directly relevant to the current research, it is worth noting that the few studies involving caregivers for these individuals show that the presence and severity of these issues tend to correlate with increased caregiver stress (Beckham, Lytle, & Feldman, 1996; Calhoun, Beckham, & Bosworth, 2002; Phelan et al., 2011). When these conditions are not the focus of the research, the findings are not dissimilar from other caregiving studies. For example the NAC (2010b) found caregivers for veterans are at risk for interrupted/poor quality sleep, decreased self-care, strained family/marital relationships, and life upset such as delays in retirement or education. These are fairly common experiences among caregivers, regardless of the condition of their care recipient. However, caregivers for veterans describe their situation as highly stressful more than twice as frequently as other caregivers nationally (68% versus 31%; NAC, 2010b). Heightened levels of caregiver stress occur at even greater rates if the veteran care recipient has a mental health condition such as depression or PTSD (91%; NAC, 2010b); particularly common conditions in veterans (Tanielian & Jaycox, 2008; Patel, 2014).

Care recipients with dementia. The Alzheimer's Association and NAC (2004) released the following statement to summarize the situation of dementia caregivers:

> Caregivers of persons with Alzheimer's disease and other dementias shoulder a particularly heavy burden of care. Compared with other caregivers, the type of care

> they provide is more physically and emotionally demanding and more time-consuming, and it takes a heavier toll on work and family life. But they are not getting the help and support they need. (p. i)

Multiple national studies have concluded that caregiving has much greater negative effects on dementia caregivers than on non-dementia caregivers (Ory, Hoffman III, Lee, Tennstedt, Schulz, 1999; NAC, 2010a; NAC, 2009), and these effects can be seen in many domains of health and wellbeing. While most (60%) dementia caregivers consider their physical health to be either "excellent" or "very good," it appears that over time caregiver health deteriorates; 67 percent of caregivers within their first four years of caregiving describe their health as "excellent"/"very good," but only 48 percent of caregivers who have been providing care for four years or more rate their health as "excellent"/"very good" (NAC, 2010a). The negative impact of dementia caregiving on emotional health is even more pronounced with 41 percent of dementia caregivers rating their situation as highly stressful, whereas only 13 percent of non-dementia caregivers rate their situation similarly (Alzheimer's Association & NAC, 2004). This emotional stress for the caregiver seems to persist even after their care recipient has been moved to an assisted living facility or a nursing home (NAC, 2010a). Research has also shown that dementia caregivers are more likely to experience symptoms of depression (Baumgarten et al., 1992).

Veteran care recipients with dementia. The NAC (2010a) study revealed that 23 percent of individuals receiving care for dementia also served in the armed forces. However, this is an under-studied population, so not much is known about this group. A recent study (Bass et al., 2012) found that the care recipients required assistance for an average of three ADLs, and most IADLs. Similar to other studies conducted with a

less specific caregiving population, it was found that some caregivers experience negative effects of caregiving including social isolation and depression. The only other study that could be found that investigated caregivers for veterans with dementia (Liu, Wang, Tan, Ji, & Gauthier, 2012) was conducted in China, with veterans of the Chinese armed forces. However, similar results were found.

Self-Care

Self-care, broadly defined, is any behavior that promotes the health and wellbeing of the individual performing that behavior. There has been an abundance of research demonstrating that the health and health-related quality of life of caregivers is significantly worse than that of comparable non-caregivers (McPherson, Pentland, & McNaughton, 2000; McLaughlin et al., 2010; Scuffham, Synnott, Turkstra, & Hegney, 2010). Some research has demonstrated that caregivers undergo fundamental changes to their nervous systems (Rohleder, Marin, Ma, & Miller, 2009; Lucini et al., 2008), which may indicate a direct link between the chronic stress/arousal that accompanies the caregiving role, and the observed negative health outcomes. Research has also demonstrated that the behaviors and lifestyles of caregivers change significantly in response to the demands of caregiving, and that it is these changes (e.g. fewer health-promoting behaviors) that contribute to the negative health outcomes (Mochari-Greenberger & Mosca, 2012; Williams, 2007). Ross, Sundaramurthi, and Bevans (2013) recently completed a review related to changes in health behavior for cancer caregivers, which concluded that though the association between caregivers and poor health outcomes is strong, the research needed for us to understand the mechanism responsible does not yet exist.

Self-care and caregiver stress. Despite the lack of clarity regarding the underlying mechanism, it has been established that high levels of caregiver stress are associated with poor health and quality of life (QOL) for caregivers (Khan, Pallant, & Brand, 2007; Kate, Grover, Kulhara, & Nehra, 2013; Ozdilek & Gunal, 2012). However, it has also been established that self-care behaviors seem to protect caregivers from experiencing the negative effects of caregiving (Gallagher, Wagenfeld, Baro, & Haepers, 1994) and increase QOL (Lo, 2009). Research consistently shows that the implementation of self-care behaviors, including positive social integration (Rodakowski, Skidmore, Rogers, & Schulz, 2012), exercise (Castro, Wilcox, O'Sullivan, Bauman, & King, 2002), and mindfulness/meditation (Oken et al., 2010), serves to decrease caregiver stress. One study even demonstrated that something as simple as having care recipients with dementia listen to an MP3 player can provide significant benefits for caregivers in terms of decreased psychological distress and improved mental health and wellbeing by providing a period of time during which the caregiver could rest from the high level of vigilance that is normally required (Lewis, Bauer, Winbolt, Chenco, & Hanley, 2015). However, the time and energy necessary for self-care are frequently sacrificed when an individual becomes a caregiver.

Caregivers and self-care. The idea that caregivers have a difficult time balancing their own needs with the needs of their care recipient has been around for decades (Bunting, 1989). With the average caregiver spending 20.4 hours per week providing care, and most (73%) of caregivers being employed on top of their caregiving responsibilities, it is easy understand how time becomes strained and self-care frequently falls by the wayside (Mochari-Greenberger & Mosca, 2012; NAC, 2009).

Being able to have time for friends and/or family outside of the caregiving relationship appears to be an important aspect of self-care, as almost half (47%) of caregivers who have sacrificed this time feel high levels of emotional stress, while only 14 percent of caregivers who continue to spend time with friends and family report similarly high levels of emotional stress (NAC, 2009). Dementia caregivers are even more likely to experience significant decrease or complete loss of time to spend with family and friends than non-dementia caregivers (NAC, 2010a). Two-thirds of dementia caregivers say they have sacrificed vacations, hobbies, social activities, exercise, or some combination of these things in order to fulfill their caregiving responsibilities (Alzheimer's Association & NAC, 2004). In short, caregivers have a tendency to sacrifice their own health and wellbeing by limiting their self-care, in favor providing care for their care recipient.

The Current Research

This study will contribute to the sparse existing literature on informal caregivers for veterans with dementia, by describing the nature and prevalence of caregiver stress and self-care behaviors in this population. This research will also investigate the relationships of caregiver stress to demographic and care-related variables in order to identify possible risk factors. Lastly, the impact of caregiver stress on overall quality of life will be explored, as well as the potential mediating role that self-care behaviors may play in this relationship. Specifically, it is hypothesized that (a) caregivers with higher levels of stress will report lower qualities of life; (b) caregivers with higher levels of self-care will report higher qualities of life; and (c) self-care will mediate the relationship between caregiver stress and quality of life. The information gained from

this study could be useful in better understanding the experiences of informal caregivers for veterans with dementia, and could also provide valuable insight into important elements of effective interventions for this relatively unstudied population.

Chapter 3: Method

Participants and Procedure

Participants were adult, informal caregivers providing care to veteran patients being seen in a memory disorders or dementia day clinic at a Veterans Affairs (VA) hospital. All patients at these clinics have been referred by a physician, psychiatrist, or a similar medical provider due to concern regarding their cognitive functioning. The patients' presenting problems range from new-onset memory loss that may indicate early stages of dementia, to known, late-stage Alzheimer's disease. Due to the nature of this clinic, patients are brought to their appointments frequently by an informal caregiver, usually a spouse or an adult child. It was during these appointments, while the veteran patient was engaged in other clinical activities for which the caregiver was not needed, that informal caregivers were given the opportunity to complete the questionnaire packet. All information collected was self-report, using well-validated instruments.

Power. Prior to data collection, a power analysis was conducted in order to determine the sample size needed to conduct the mediation analysis with a power level of .80 and alpha of .05. This analysis indicated a sample size of 79 individuals would be sufficient. However, challenges arose during data collection. Many individuals presenting to these clinics did not present with a caregiver who met criteria for inclusion in this study. For example, many individuals were brought to their appointments by Disabled American Veteran (DAV) vans, or by formal (paid) caregivers. There were also some patients in attendance at these clinics that did not have dementia at all. In order to maintain the homogeneity of the sample and the focus of the study, these

individuals were not included in the study. Because of these challenges, the sample size was limited to 31 participants, and the more complex analyses (e.g., mediational analysis) were not able to be completed.

Instruments

Caregiver stress. Due to the numerous definitions and operationalizations of caregiver stress, there are many different instruments designed to measure this construct. One review (Van Durme, Macq, Jeanmart, & Gobert, 2012) compared over 100 different measures of caregiver stress, 70 of which were published in the last 25 years. The Relative Stress Scale (Greene, et al., 1982) was one of the few identified that (a) specifically measures caregiver stress, and (b) is normed on a population of informal caregivers for individuals with dementia. This scale is widely used in both clinical practice and research (Thommessen et al., 2002), and is especially useful because its subscales allow the examination of different dimensions of caregiver stress (Ulstein, Wyller, & Engedal, 2007b).

The Relative Stress Scale (RSS) has demonstrated good construct validity (Van Durme, Macq, et al., 2012), and reliability (Greene, et al., 1982). It is a 15-item scale, comprised of questions asking the respondent to rate the frequency or severity of symptoms on 5-point Likert scales (e.g. "never," "rarely," "sometimes," "frequently," "always"). The original developers of the RSS reported three total factors; personal distress (Cronbach's alpha = .96), degree of life upset (Cronbach's alpha = .96), and negative feelings toward care recipient (Cronbach's alpha = .88). The overall measure showed a three week, test-retest reliability of .85 (Greene, et al., 1982). Other research has supported this same factor structure, and yielded similar subscale internal

consistency (Ulstein, Wyller, & Engedal, 2007b). The RSS was used to measure multiple dimensions of subjective caregiver stress.

Self-care. Measuring self-care behavior can be difficult due to the incredible variety of behaviors that could be considered self-care. For the purposes of this study, a measure that tapped into the frequency of diverse behaviors was ideal, so the Health-Promoting Lifestyle Profile II (HPLP-II) was chosen (Walker & Hill-Polerecky, 1996). This scale is comprised of the following six dimensions: spiritual growth (e.g. "I feel I am growing and changing in positive ways"); interpersonal relations (e.g. "I discuss my problems and concerns with people close to me"); nutrition (e.g. "I eat 6-11 servings of bread, cereal, rice, and pasta each day"); physical activity (e.g. "I take part in light to moderate physical activity…5 or more times a week"; health responsibility (e.g. "I report any unusual signs or symptoms to a physician or other health professional"); and stress management (e.g. "I take some time for relaxation each day"). The respondent ranks the frequency with which they engage in each behavior as "never," "sometimes," "often," or "routinely." The responses are scored such that higher scores indicate high frequency of the health promoting behaviors. Scale scores and overall score are obtained by averaging the items that comprise the scale.

The creators of the scale report that the construct validity was confirmed via factor analysis, and that the internal consistency for all of the subscales and the overall scale were between .79 and .89 (Walker & Hill-Polerecky, 1996). Other research has reported similar consistencies ranging from .75 to .93 (Callaghan, 2003). In the interest of minimizing burden on the participants, the nutrition subscale has been dropped. The information that could be gained from this subscale is thought to be the least likely to

accurately reflect self-care. The other five subscales of the HPLP-II were used to measure self-care.

Quality of life. Quality of life can be defined in many ways, and there is not a consensus among either clinicians or researchers regarding its definition (Skevington, Lotfy, & O'Connell, 2004). The World Health Organization (WHO) defines quality of life as "an individual's perception of their position in life in the context of their culture and value systems, and their personal goals, standards, and concerns." (WHO, 2015) In the early 1990s, the WHO started a project that aimed to develop an instrument that could measure quality of life, as defined this way, and the WHOQOL-100, a 100-item instrument, was developed as a result. The WHOQOL-BREF (WHO, 2004) is a newer, 26-item version of the WHOQOL-100 that measures four broad domains; physical health, psychological health, social relationships, and environment. Each of the 26 items is based on a five-point Likert scale.

This instrument has been studied extensively and has been shown to have to have good internal consistency at the subscale level (Skevington, Lofty, & O'Connell, 2004). In a sample from the United States, three of the four subscales have Cronbach's alphas between .84 and .87. The final subscale (social relationships) had a marginal Cronbach's alpha of only .69. However, systematic analyses indicated that each of the 26 items on the WHOQOL-BREF made a significant contribution to the overall scale (Skevington, Lofty, & O'Connell, 2004). It was also determined that the WHOQOL-BREF had sufficient construct and discriminant validity (Skevington, Lofty, & O'Connell, 2004). Additional research (Vahedi, 2010) also provides support for both

the validity and reliability of this scale. The WHOQOL-BREF was used to measure global quality of life.

Variables related to caregiving. In order to balance the subjective information regarding caregiver stress with less subjective domains of caregiver burden, a portion of the questionnaire was designed to gather information about the caregiver role that is based in objective fact, though data collected is self-report. The type of information collected includes, but is not limited to, demographic information, length of time in the role of caregiver, relationship to care recipient, average number of hours spent providing care, specific activities involved in caregiving, other caregivers' contributions, and living arrangement for the care recipient.

Chapter 4: Results

Measures

Table 1 presents the means, standard deviations, and Cronbach alphas for each measure and all subscales. The Relative Stress Scale (RSS) was found to have good internal consistency for the personal distress subscale (Cronbach alpha = .87), the degree of life upset subscale (Cronbach alpha = .92, and the negative feelings subscale (Cronbach alpha = .86). The overall measure's Cronbach alpha was .95. The subscales for the Health Promoting Lifestyles Profile (HPLP-II) also demonstrated good internal consistency, ranging from .79 to .87. The HPLP-II overall Cronbach alpha was .94. Most of the World Health Organization Quality of Life – BREF (WHOLQOL-BREF) four subscales produced sufficient internal consistency. Physical QOL was .89, Psychological QOL was .73, and environmental QOL was .75. Social QOL was marginal, with only .68. However, this study utilizes overall QOL as the primary dependent variable, and the internal consistency for the overall scale was high (.93).

Table 1. Means, standard deviations, and Cronbach alphas

	Mean	SD	Cronbach alpha
RSS	21.79	14.16	.95
Personal Distress	8.97	5.44	.87
Life Upset	8.41	6.29	.92
Negative Feelings	4.41	3.35	.86
HPLP-II	104.79	21.34	.94
Spiritual Growth	25.39	5.41	.87
Interpersonal	24.74	4.79	.79
Physical Activity	15.00	5.75	.80
Health Responsibility	21.48	5.30	.81
Stress Management	18.64	5.21	.85
WHOQOL-BREF	54.57	10.65	.93
Physical	54.93	16.54	.89
Psychological	67.96	12.31	.73
Environmental	70.69	14.04	.75
Social	62.07	18.44	.68

Participants

Demographic information. Table 2 presents a summary of caregiver demographic information. Thirty-one informal caregivers for veterans with Alzheimer's or other dementia participated in the current research, and 29 participants completed the measures (one withdrew, and one returned half-complete measures that could not be interpreted). Of the 29 participants who completed the measures, most were married (79.3%) women (86.2%). The majority of respondents were Caucasian (79.3%), though African American (17.2%) and Asian (3.4%) individuals participated as well. The participants' ages ranged from 36 to 77, with an average age of 64.9 (standard deviation of 8.8 years). More than half (62.1%) of the participants were retired, and the rest were either employed (27.6%) or unemployed/seeking work (10.3%).

Table 2. Summary of demographic information

	N	Percent		N	Percent
Gender			**Employment Status**		
Male	4	13.8	Unemployed	3	10.3
Female	25	86.2	Employed	8	27.6
Race			Retired	18	62.1
Caucasian	23	79.3	**Education**		
African American	5	17.2	<12 yrs.	2	6.9
Asian	1	3.4	High school	10	34.5
Marital Status			Some college	9	31.0
Married	23	79.3	Associate	2	6.9
Separated	2	6.9	Bachelor's	2	6.9
Widowed	2	6.9	Graduate/Professional	4	13.8
Divorced	2	6.9			

Care-related information. Table 3 provides a summary of care-related information. Most caregivers were providing care for either a spouse/significant other (55.2%) or a parent (27.6%). There was one participant each caring for a sibling

(3.4%), friend (3.4%), uncle (3.4%), and mother-in-law (3.4%). A majority (62.1%) of the caregivers were residing with the care recipient, and almost half (44.8%) said they were the only person providing care for their care recipient. The duration of care ranged from less than six months to more than 20 years, with the following distribution: 13.8 percent less than one year, 48.2 percent between one and five years, 17.2 percent between six and ten years, and 17.2 percent more than ten years. Over the length of their caregiving, some reported that they continued to provide the same level of care (20.7%), but most indicated that they are providing either "somewhat more" (37.9%) or "much more" (37.9%) care now than when they first became a caregiver. When considering their current caregiving responsibilities, most (65.5%) reported daily caregiving, and many (34.5%) reported spending more than 12 hours a day providing care. More than half of all respondents (55.2%) reported spending an average of 20 or more hours per week providing care.

Table 3. Summary of care-related information

	N	Percent		N	Percent
Recipient			**Frequency**		
Spouse	16	55.2	Daily	19	65.5
Parent	8	27.6	>1x weekly	4	13.7
Sibling	1	3.4	Weekly	1	3.4
Friend	1	3.4	<1x weekly	4	13.7
Other	2	6.9	**Hours/Day**		
Location			>12 hours	10	34.5
With Caregiver	18	62.1	8-12 hours	2	6.9
Within 10 miles	5	17.2	4-7 hours	6	20.7
Within 30 miles	3	10.3	1-3 hours	8	27.6
>30 miles	1	3.4	<1 hour	3	10.3
Nursing Home	1	3.4	**Other Caregivers**		
Duration			Family	13	44.8
<1 year	4	13.8	Friends	0	0.0
1-5 years	14	48.2	Professionals	4	13.8
6-10 years	5	17.2	No one	13	44.8
>11 years	5	17.2			

ADLs and IADLs. Overall, 69 percent of participants assisted with at least one ADL and 100 percent assisted with at least one IADL. The most common ADL assistance provided was with transfers (58.6%), followed by dressing (48.3%), bathing (379%), toileting (27.6%), and eating (17.2%). Caregivers provided care with each of the IADLs, except medication management, in at least 75% of cases. The most common IADL assistance was with managing healthcare or other outside services (89.7%), followed by housework (82.8%), transportation (79.3%), managing finances (79.3%), grocery shopping (75.9%), preparing meals (75.9%), and managing medication (69%).

Caregiver Stress

All caregivers included in this research reported experiencing some caregiver stress, though the amount of stress reported ranged from minimal (score of 5/60) to very high (51/60). The mean overall stress score was 21.8 with a standard deviation of 14. 2. The subscale that was most highly endorsed was the life upset subscale. The mean life upset score was 8.4 (out of 20 possible points) with a standard deviation of 6.3 points. The personal distress subscale was a close second as far as endorsement, with a mean raw score of 9.0 (out of 24 possible points), and a standard deviation of 5.4 points. The final subscale, negative feelings toward the person, was endorsed much less, and had a mean score of 4.4 (out of 16 possible points) with standard deviation 3.4.

Caregiver Self-Care

The creators of the scale recommend using averages for scale scores rather than sums, so that scores can be meaningfully compared across subscales despite the uneven number of items in each subscale. The average subscale scores discussed in this section

are for descriptive purposes only, and should be interpreted with some caution as they are averages of ordinal data. The following metric should be used for interpretation of the average scores: 1=Never, 2=Sometimes, 3=Often, 4=Routinely. For example, an average score of 1.5 would indicate that the respondent engages in that particular type of self-care behavior (e.g. stress management) more than never, but less than sometimes (on average).

The most performed self-care behaviors were in the categories of spiritual growth (2.8) and interpersonal relations (2.7). Somewhat less common self-care behaviors were related to health responsibility (2.4) and stress management (2.3). By far, the least common self-care behavior was physical activity (1.9). When looking at overall self-care, a total score of 86 would indicate an average rating of "sometimes" and a score of 129 would indicate an average score of "often." For this sample, the mean total score was 104.8 (out of 172 possible points) with a standard deviation of 21.3.

Possible Risk Factors

The following four factors were selected for analysis as potential risk factors, due to previous research indicating that these characteristics are associated with negative outcomes: caregiving for a spouse or significant other, providing 20 hours of care or more per week, providing care for six or more years, and being the only caregiver. The characteristic of living with the care recipient was not explored as a separate factor because in this sample, the group of caregivers caring for a spouse and the group of caregivers living with their care recipient overlapped too much to merit separate analyses. ANOVA was used to investigate the differences between these

groups in regards to caregiver stress and self-care. Tables 4 and 5 present a summary of these analyses.

Increased caregiving stress. Levene's test was not significant (F=1.011, p = .472). Of the characteristics listed above, the only one to achieve statistical significance was providing 20 hours of care or more per week (F=4.861, p=.038). Cohen's d is 3.43, indicating a very large effect size. Although being the only caregiver was not a statistically significant characteristic (F=2.854, p=.105), the estimated effect size was very large (d=2.59). Similarly, caring for 6 or more years (F=1.367, p=.255) was not significant, but produced a very large effect (d=1.60). Caring for a spouse/significant other was not significant (F=2.24, p=.149) and produced a very large effect (d=2.57). However, this effect was opposite of what has been observed in previous studies; caregivers caring for spouses/significant others in this sample reported consistently lower levels of stress than individuals caring for other family members/friends.

Table 4. Factors affecting caregiver stress

	F	*p*	d
Caring for Spouse	2.24	.149	2.57
Caring ≥20 hrs./week	4.861	.038*	3.43
Caring >5 years	1.367	.255	1.60
Only caregiver	2.854	.105	2.59

Decreased self-care. Levene's test was not significant (F=0.548, p=.833). None of the characteristics were significant in terms of self-care. Caring for a spouse was approaching significance (F=3.79, p=.065) and did produce a very large effect size (d=3.35). Notably, individuals caring for their spouse/significant other engaged in less self-care. Similarly, neither providing care for 20 or more hours per week (F=2.705, p=.114), nor being a long-term caregiver (F=0.547, p=.468) were significant, but both

yielded large effect sizes (d=2.56 and d=1.00). Being the only caregiver was not significant (F=.004, *p*=.951), and only produced a very small effect size (d=0.09).

Table 5. Factors affecting caregiver self-care

	F	*p*	d
Caring for Spouse	3.790	.065	3.35
Caring ≥20 hrs./week	2.705	.114	2.56
Caring >5 years	0.547	.468	1.00
Only caregiver	0.004	.951	0.09

Caregiver QOL

Caregiver QOL was found to be highly correlated with both stress (*r*= -.64, *p*=.000) and self-care (*r*=.61, *p*=.000). Interestingly, stress and self-care were not correlated with each other (*r*= -.124, *p*=.522). Table 6 shows the correlation matrix for these variables.

Table 6. Self-care, stress, and QOL correlation matrix

		1	2	3
1	**Stress**	***		
2	**Self-Care**	-.124	***	
3	**QOL**	-.640	.610	***

Stress was most highly correlated with the physical QOL domain (*r*= -.688, *p*=.000), closely followed by the psychological QOL domain (*r*= -.631, *p*=.000). Self-care was most highly correlated with the environmental QOL domain (*r*=.639, *p*=.000), followed by psychological QOL (*r*=.561, *p*=.002) and social QOL (*r*=.501, *p*=.006). Self-care was the least correlated with physical QOL (*r*=.374, *p*=.045). Table 7 presents a summary of the self-care and stress correlates with both domain-specific and overall QOL.

Table 7. QOL domain-specific stress and self-care correlates

	Physical	Psych	Social	Environ.	Overall
Stress	-.688	-.631	-.505	-.306	-.640
p	<.001	<.001	.005	.106	<.001
Self-Care	.374	.561	.501	.639	.610
p	.045	.002	.006	<.001	<.001

A simple regression analysis showed that stress was a highly significant and meaningful predictor of overall QOL (R square = .410, Beta = -.640, *p*=.000). Self-care was also shown to be a highly significant and meaningful predictor of overall QOL (R square = .365, Beta= .604, *p*=.001). Table 7 summarizes these predictors.

Table 8. QOL Predictors

	R Square	Beta	*p*
Stress	.410	-6.40	<.001
Self-care	.365	6.04	<.001

Mediation. It was hypothesized that self-care would play a mediating role in the relationship between stress and QOL, such that self-care would temper the negative impact that stress has on QOL. However, because stress and self-care had no measurable relationship to each other (R square = .017, Beta = -.129, *p*=.506), this hypothesis is not supported. Table 7 shows the correlation matrix for these three variables.

Chapter 5: Discussion

The results from this preliminary research provide much needed information regarding the unique and understudied population of informal caregivers for veterans with dementia. The following sections highlight important similarities and differences between this population and other caregiver populations, and discuss implications for intervention and clinical practice.

Limitations

This study's relatively small sample size is an important limitation to consider. The sample size limited the power, which likely resulted in an artificial decrease in statistical significance. This is thought to explain why factors that are consistently significant in the existing literature (e.g., duration of caregiving, primary caregiver status, relationship to care recipient) were not found to be significant in the current research. Because this study was conducted with caregivers for veterans enrolled in VA services, the generalizability of results to caregivers for veterans not enrolled in VA services may also be limited.

Who Are the Caregivers?

Results show that the typical caregiver for a veteran with dementia is a 65 year old, retired female who provides at least four hours of daily care for her spouse. This is in stark contrast to the typical caregiver from a nationally representative sample (NAC, 2009) who is a 48 year old, employed female who provides up to eight hours of care per week for a parent or other relative. Even when considering a specific sample of caregivers for dementia, the typical caregiver (51 year old, employed female who provides up to eight hours of care per week for a parent/parent-in-law; NAC, 2010a) is

notably different from the typical caregiver for a veteran with dementia as seen in the current research. Further research on a larger scale is required to confirm that these differences are not coincidental due to a limited sample size, but these preliminary results suggest that the two populations of caregivers most utilized in caregiver research (general family caregivers, and caregivers for dementia) are substantially different than the population of caregivers for veterans with dementia.

Caregiver Responsibilities

Results also indicate that caregivers for veterans with dementia have more caregiving responsibilities than other populations of caregivers. About 26 percent of general family caregivers (NAC, 2009) and 27 percent of dementia caregivers (NAC, 2010a) spend 20 or more hours per week providing care, but 55 percent of the current sample reported spending 20 or more hours per week providing care. Also of note, caregivers for veterans with dementia seem to provide somewhat more assistance with ADLs (average 1.9 out of 5 versus 1.6 out of 6) and much more assistance with IADLs (5.5 out of 7 versus 4.4 out of 7) than general caregivers (NAC, 2009). Of note, managing healthcare or other outside services was the least common IADL in caregiving samples of general caregivers (34%; NAC, 2009), dementia caregivers (46%; NAC, 2010b), and caregivers for veterans (46%; NAC, 2010a), but was the most common (90%) in the current research. It is thought that this percentage is so high in the current research because all participants were providing care for an established VA patient, meaning a multitude of healthcare and other assistive services are available to these patients, whereas many comparable services are either not available, or not financially feasible for many individuals not receiving services through the VA.

Caregiver Stress

The results of this study are well-aligned with the existing research that suggests some caregivers experience a great deal of stress while others do not. Prior research with dementia caregivers (Ulstein, Wyller, & Engedal, 2007a) found that stress as measured by the RSS was a powerful discriminatory factor with regards to risk for caregiver psychiatric illness such as depression. RSS scores of 22 or lower were considered the low-risk group, scores of 23-30 were considered intermediate-risk, and scores 31 or higher were high-risk. In the current sample, 62.0 percent of caregivers would have been in the low-risk group, 6.9 percent in the intermediate risk group, and 31.0 percent into the high-risk group. In other words, almost one-third of the caregivers sampled are so overwhelmed by their caregiving responsibilities that they are likely to have (or soon develop) symptoms severe enough to meet full criteria for a psychiatric disorder.

Effect on quality of life. Results showed that the more stress experienced by the caregiver, the lower their reported quality of life. One commonly proposed mechanism for this relationship is that the demands of caregiving limit opportunities for caregivers to engage in positive self-care behaviors and social interactions (Connell, Janevic, & Gallant, 2001). In fact, empirical studies have consistently suggested that the presence of stress can negatively influence self-care (McCann, Warnick, & Knopp, 1990; Burton, Newsom, Schulz, Hirsch, & German, 1997) and social life (Haley et al., 1995). The finding of the current research that caregivers spending 20 or more hours per week providing care reported significantly higher levels of stress than those spending less than 20 hours per week (d=3.43) is also cohesive with the idea that more time spent caregiving leads to less time spent in self-care which in turn leads to higher

stress levels. However, in the current research absolutely no relationship was found between stress and self-care (r=-.124, p=.522).

This complete lack of a relationship was very unexpected, and the underlying reason for this apparent contradiction with prior research is unknown. The possibility of a curvilinear relationship in which caregivers at the extremes (not stressed and highly stressed) do not engage in self-care was explored, and dismissed after visual examination of the plotted data. Another possibility is that the nature of the items on the HPLP-II (face-valid, socially and personally desirable) inadvertently created a bias that skewed the results to look as though caregivers are engaging in more self-care behaviors than they actually are. It is also possible that stress and self-care are truly unrelated in the population of caregivers for veterans with dementia. Whatever the reason for this apparent non-relationship, it is worth noting that self-care was a significant predictor (R square = .365, Beta= .604, p=.001) of quality of life. This is important because it establishes self-care and stress as independent factors predicting quality of life, meaning that either one could be the basis for initial intervention with the goal of improving caregiver quality of life.

Interventions for Caregivers

The three primary areas that are targeted by interventions for dementia caregivers are usually social support, caregiving skills, and/or managing negative emotions (Schulz, Gallagher-Thompson, William, & Czaja, 2000). These focus areas are well-aligned with the results of this study that indicate the two most predominant types of caregiver stress were life upset (social distress) and emotional distress. Though some caregivers endorsed negative feelings toward the care recipient, this type of caregiver stress was endorsed much less frequently.

There are four commonly accepted modalities of dementia caregiver intervention; (a) support groups, (b) education and skills training, (c) respite care, and (d) multicomponent interventions (Bourgeois, Schulz, & Burgio, 1996). However, empirical studies looking at the efficacy of these caregiver interventions have yielded mixed results at best. The general consensus seems to be that most caregiver interventions have some benefit for some caregivers, but these benefits are not consistently observed, and more targeted and comprehensive (multicomponent) intervention strategies are needed (Etters, Goodall, & Harrison, 2008; Torti, Gwyther, Reed, Friedman, & Schulman, 2004; Brodaty & Donkin, 2009; Schulz et al., 2002).

Resources for Enhancing Alzheimer's Caregiver Health (REACH). One of the largest, and most successful, randomized trials investigating interventions for dementia caregivers was Resources for Enhancing Alzheimer's Caregiver Health (REACH; Gitlin et al., 2003; Schulz et. al, 2003). REACH was a multisite project that tested different interventions at each site including skills training, support group, coping class, information, and family-based home interventions. Interventions were implemented by a range of professionals (e.g., social workers, psychologists, occupational therapists) over the course of six months to two years. This study yielded a statistically significant reduction in caregiver stress and depression, but effect sizes were quite modest (d=.15, d=.23), and no treatment modality was shown to be more effective than the rest (Gitlin, et al., 2003).

A clinical translation of the REACH project (Nichols, Martindale-Adams, Burns, Graney, & Zuber, 2011) resulted in the REACH VA program; an intervention to be used in the VA consisting of nine individual home sessions, three individual telephone sessions, and five monthly telephone support group sessions, over the course

of six months. In its current form, REACH VA consists of four, one hour sessions over two to three months focused on psychoeducational and cognitive-behavioral interventions (Nichols & Martindale-Adams, 2012). Aside from the original translational study (Nichols, et al, 2011), no empirical research regarding the efficacy of REACH VA could be found. Given the change in caregiving population from REACH to REACH VA, the seemingly limited scope (and modality) of intervention in REACH VA, the nontrivial format adjustments, and the fact that effect sizes were modest to begin with ($.02<d<.34$), it is reasonable to anticipate that outcomes could be improved with the implementation of more targeted, individualized, and comprehensive interventions.

Conclusions

Caregivers for veterans with Alzheimer's or other dementia experience caregiver stress, particularly in the form of emotional and social distress. In the last decade a number of new caregiver interventions have been developed, and while many of them have shown some beneficial effects, these effects have been small and inconsistent. Caregiver interventions that are personalized and multimodal have shown the most promising results. Due to the many observed differences between a nationally representative sample of caregivers, and a sample of caregivers for veterans with dementia, it is important that this specific population be studied further so that targeted interventions can be developed. This preliminary research indicates that participating in good self-care, creating and maintaining social relationships, and reducing the number of hours spent providing care could be beneficial goals to work toward. Results also suggest that individuals with certain characteristics, such as being the only caregiver

and being a long-term caregiver, may predispose caregivers to experience increased stress, and as such these individuals may benefit the most from supportive intervention.

Future Research

Future research should seek to reconcile some of the substantial differences between result found in this study, and those found in previous studies. Examples of these differences include the relationship (or lack of relationship) between caregiver stress and self-care, and being a spousal caregiver as a risk versus a protective factor with regard to stress and decreased quality of life. Conducting studies that also include caregivers for veterans not receiving services through the VA would also be beneficial, as this group would likely have a significantly different experience. Similarly, looking at how caregivers and care recipients are or are not supported by the military (i.e., financially, access to resources), and how stage of dementia affects stress, self-care, and quality of life could also be interesting avenues for further investigation. This will provide a clearer picture of caregivers for veterans with dementia, and will help guide the development of more personalized, relevant, and effective interventions.

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Appendix A: Relative Stress Scale

Please rate the frequency or severity that you experience each of the following thoughts/feelings with regards to your caregiving.

1	2	3	4	5
Never or Not At all	**Rarely or A little**	**Sometimes or Moderately frequently**	**Frequently or Quite a lot**	**Always or Considerably**

Do you ever feel you can no longer cope with the situation?	1	2	3	4	5
Do you ever feel that you need a break?	1	2	3	4	5
Do you ever get depressed by the situation?	1	2	3	4	5
Has your own health suffered at all?	1	2	3	4	5
Do you worry about accidents happening to the person you're caring for?	1	2	3	4	5
Do you ever feel that there will be no end to the problem?	1	2	3	4	5
Do you find it difficult to get away on holiday/vacation?	1	2	3	4	5
How much has your social life been affected?	1	2	3	4	5
How much has the household routine been upset?	1	2	3	4	5
Is your sleep interrupted by the person you're caring for?	1	2	3	4	5
Has your standard of living been reduced?	1	2	3	4	5
Do you ever feel embarrassed by the person you're caring for?	1	2	3	4	5
Are you at all prevented from having visitors?	1	2	3	4	5
Do you ever get cross or angry with the person you're caring for?	1	2	3	4	5
Do you ever feel frustrated at times with the person you're caring for?	1	2	3	4	5

Appendix B: Health-Promoting Lifestyle Profile – II
With Nutrition Subscale Removed

This questionnaire contains statements about your PRESENT way of life or personal habits. Please respond to each item as accurately as possible, and try not to skip any item. Indicate the frequency with which you engage in each behavior on the following scale.

1	2	3	4
Never	**Sometimes**	**Often**	**Routinely**

Discuss my problems and concerns with people close to me.	1	2	3	4
Report any unusual signs or symptoms to a physician or other health professional.	1	2	3	4
Follow a planned exercise program.	1	2	3	4
Get enough sleep.	1	2	3	4
Feel I am growing and changing in positive ways.	1	2	3	4
Praise other people easily for their achievements.	1	2	3	4
Read or watch TV programs about improving health.	1	2	3	4
Exercise vigorously for 20 or more minutes at least three times a week (such as brisk walking, bicycling, aerobic dancing, using a stair climber).	1	2	3	4
Take some time for relaxation each day.	1	2	3	4
Believe that my life has purpose.	1	2	3	4
Maintain meaningful and fulfilling relationships with others.	1	2	3	4
Question health professionals in order to understand their instructions.	1	2	3	4
Take part in light to moderate physical activity (such as sustained walking 30-40 minutes) 5 or more times a week.	1	2	3	4
Accept those things in my life which I can not change.	1	2	3	4
Look forward to the future.	1	2	3	4
Spend time with close friends.	1	2	3	4

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1 Never	2 Sometimes	3 Often	4 Routinely

Get a second opinion when I question my health care provider's advice.	1	2	3	4
Take part in leisure-time (recreational) physical activities (such as swimming, dancing, bicycling).	1	2	3	4
Concentrate on pleasant thoughts at bedtime.	1	2	3	4
Feel content and at peace with myself.	1	2	3	4
Find it easy to show concern, love, and warmth to others.	1	2	3	4
Discuss my health concerns with health professionals.	1	2	3	4
Do stretching exercises at least 3 times per week.	1	2	3	4
Use specific methods to control my stress.	1	2	3	4
Work toward long-term goals in my life.	1	2	3	4
Touch and am touched by people I care about.	1	2	3	4
Inspect my body at least monthly for physical changes/danger signs.	1	2	3	4
Get exercise during usual daily activities (such as walking during lunch, using stairs instead of elevators, parking car away from destination and walking).	1	2	3	4
Balance time between work and play.	1	2	3	4
Find each day interesting and challenging.	1	2	3	4
Find ways to meet my needs for intimacy.	1	2	3	4
Ask for information from health professionals about how to take good care of myself.	1	2	3	4
Check my pulse rate when exercising.	1	2	3	4
Practice relaxation or medication for 15-20 minutes daily.	1	2	3	4
Am aware of what is important to me in life.	1	2	3	4
Get support from a network of caring people.	1	2	3	4

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1	2	3	4
Never	**Sometimes**	**Often**	**Routinely**

Attend educational programs on personal health care.	1	2	3	4
Reach my target heart rate when exercising.	1	2	3	4
Pace myself to prevent tiredness.	1	2	3	4
Feel connected with some force greater than myself.	1	2	3	4
Settle conflicts with others through discussion and compromise.	1	2	3	4
Seek guidance or counseling when necessary.	1	2	3	4
Expose myself to new experiences and challenges.	1	2	3	4

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Appendix C: WHOQOL-BREF

How would you rate your quality of life?

Very Poor	Poor	Neither poor nor good	Good	Very Good
○	○	○	○	○

How satisfied are you with your health?

Very Dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very Satisfied
○	○	○	○	○

The following questions ask about how much you have experienced certain things in the last two weeks. Please use the following scale when responding.

1	**2**	**3**	**4**	**5**
Not at all	**A little**	**A moderate amount**	**Very much**	**An extreme amount**

To what extent do you feel that physical pain prevents you from doing what you need to do?	1	2	3	4	5
How much do you need any medical treatment to function in your daily life?	1	2	3	4	5
How much do you enjoy life?	1	2	3	4	5
To what extent do you feel your life to be meaningful?	1	2	3	4	5
How well are you able to concentrate?	1	2	3	4	5
How safe do you feel in your daily life?	1	2	3	4	5
How healthy is your physical environment	1	2	3	4	5

The following questions ask about how completely you experience or were able to do certain things in the last two weeks. Please use the following scale when responding.

1	2	3	4	5
Not at all	**A little**	**Moderately**	**Mostly**	**Completely**

Do you have enough energy for everyday life?	1	2	3	4	5
Are you able to accept your bodily appearance?	1	2	3	4	5
Have you enough money to meet your needs?	1	2	3	4	5
How available to you is the information that you need in your day-to-day life?	1	2	3	4	5
To what extent do you have the opportunity for leisure activities?	1	2	3	4	5

How well are you able to get around?

Very Poor	Poor	Neither poor nor well	Well	Very Well
○	○	○	○	○

The following questions ask you to say how good or satisfied you have felt about various aspects of your life over the last two weeks. Please use the following scale when responding.

1	2	3	4	5
Very dissatisfied	**Dissatisfied**	**Neither satisfied nor dissatisfied**	**Satisfied**	**Very satisfied**

How satisfied are you with your sleep?	1	2	3	4	5
How satisfied are you with your ability to perform your daily living activities?	1	2	3	4	5
How satisfied are you with your capacity for work?	1	2	3	4	5
How satisfied are you with yourself?	1	2	3	4	5
How satisfied are you with your personal relationships?	1	2	3	4	5
How satisfied are you with your sex life?	1	2	3	4	5
How satisfied are you with the support you get from your friends?	1	2	3	4	5
How satisfied are you with the conditions of your living place?	1	2	3	4	5
How satisfied are you with your access to health services?	1	2	3	4	5
How satisfied are you with your mode of transportation?	1	2	3	4	5

How often do you have negative feelings, such as blue mood, despair, anxiety, or depression?

Never	**Seldom**	**Quite Often**	**Very Often**	**Always**