THE RELATIONSHIP BETWEEN DEPRESSION AND DYAD RELATIONSHIP STRAIN IN CAREGIVING DYADS OF VETERANS WITH DEMENTIA

KELLY MARTINCIK

Bachelor of Arts in Psychology
Ohio Dominican University
December 2007

Master of Science in Clinical Psychology
Cleveland State University
May 2010

submitted in partial fulfillment of requirement for the degree

DOCTOR OF PHILOSOPHY IN URBAN EDUCATION, COUNSELING

PSYCHOLOGY

at the

Cleveland State University

JUNE 2016
We hereby approve the dissertation of
Kelly Martincin

Candidate for the Doctor of Philosophy in Urban Education, Counseling Psychology Degree

This Dissertation has been approved for the Office of Doctoral Studies,
College of Education and Human Services and
CLEVELAND STATE UNIVERSITY, College of Graduate Studies by:

______________________________
Dissertation Chairperson: Graham B. Stead, Ph.D.

______________________________
Curriculum and Foundations
Department & Date

______________________________
Methodologist: Karla R. Hamlen Mansour, Ph.D.

______________________________
Curriculum and Foundations
Department & Date

______________________________
Sarah M. Toman, Ph.D.

______________________________
C.A.S.A.L.
Department & Date

______________________________
Elizabeth R. Welfel, Ph.D.

______________________________
C.A.S.A.L.
Department & Date

______________________________
Katherine S. Judge, Ph.D.

______________________________
Psychology
Department & Date

______________________________
Ilya Yaroslavsky, Ph.D.

______________________________
Psychology
Department & Date
       June 29, 2016
       Student’s Date of Defense
Dedication

This dissertation is dedicated first and foremost to my grandmother, Mary Margaret, and grandfather, Barney, who not only shaped me as a person and future clinician, but also provided my most formative experiences related to caregiving. This dissertation is a direct result of their daily example of love, commitment, and positive outcomes related to superior caregiving. Though they did not live to see this day, I dedicate to them not only my dissertation, but also my career in healthcare, my passion for work with older adults, and my commitment to social justice and advancing outcomes for dementia patients.

I would also like to dedicate this dissertation to my husband, Matt. His amazing support throughout my graduate training has been unending, and I would not have been able to complete my degree without him. Additionally, I would like to thank my wonderful family, Mom, Dad, and Kristen, for their endless support and understanding during this very long process. I vow to never again bring a text book on a family vacation! Next, I would like to thank my many mentors who have spent countless hours shaping me in ways that go far beyond clinical work and research skills. Their tireless example and commitment to excellence has left an indelible mark on me both as a person and a clinician. Finally, I would like to thank my impressive cohort and all the close friends who have supported me through this process. They made this experience unforgettable, and I will treasure the bond forged during our time in grad school always. Thank you, everyone, for all your love and support!
THE RELATIONSHIP BETWEEN DEPRESSION AND DYAD RELATIONSHIP STRAIN IN CAREGIVING DYADS OF VETERANS WITH DEMENTIA

KELLY MARTIN CIN

ABSTRACT

Partners in Dementia Care (PDC) was a multi-site telephone intervention for dementia patients and their caregivers. Participants were 508 veterans and 486 caregivers of at least 50 years of age with various dementia diagnoses. The aim was to investigate the impact that care partners have on one another’s depression and used each care partner’s appraisal of dyadic relationship strain to predict depression in both the individual as well as his or her care partner. Results indicated there was a significant positive relationship between caregiver’s dyad relationship strain and the caregiver’s depression ($\beta = .26, p < .001$). For caregivers, $R^2 = .07$. In regards to the IWD, there was a positive relationship between the IWD’s dyad relationship strain and depression ($\beta = .31, p < .001$). For IWDs, $R^2 = .11$. For both care partners, increased strain was related to increased depression, thus rejecting the first null hypothesis. It was determined that for the IWD’s dyad relationship strain’s effect on caregiver’s depression, results were $\beta = 0.065, p = 0.247$. The results for the caregiver’s dyad relationship strain effect on the IWD’s depression, results were $\beta = -0.004, p = .985$. Thus, the second and third null hypotheses were retained. This means that the caregiver’s dyad relationship strain was not predictive of the IWD’s reported depression and vice versa. Additionally, though there were no hypotheses regarding the relationship between dyad relationship strain of
the care partners and relationship of depression between the care partners, this was examined as part of the model. There was a significant positive relationship between dyad relationship strain of the care partners \((r = .25, p < .001)\), as well as a significant positive relationship between depression of the care partners \((r = .19, p < .001)\). These findings highlight the intricate balance of the partnership within the caregiving dyad, and suggest that each care partner responds to the mood and emotions of the other care partner. This emphasizes the need for dyadic intervention and working with both care partners to improve outcomes for the dyad.
# TABLE OF CONTENTS

<table>
<thead>
<tr>
<th>ABSTRACT</th>
<th>iv</th>
</tr>
</thead>
<tbody>
<tr>
<td>CHAPTER</td>
<td></td>
</tr>
<tr>
<td>I. INTRODUCTION</td>
<td>1</td>
</tr>
<tr>
<td>Purpose of the Study</td>
<td>4</td>
</tr>
<tr>
<td>Significance of the Study</td>
<td>4</td>
</tr>
<tr>
<td>History of Dementia</td>
<td>5</td>
</tr>
<tr>
<td>Impact of Dementia</td>
<td>10</td>
</tr>
<tr>
<td>Needs of Veterans</td>
<td>11</td>
</tr>
<tr>
<td>Statement of the Problem</td>
<td>15</td>
</tr>
<tr>
<td>Significance of the Problem</td>
<td>16</td>
</tr>
<tr>
<td>Partners in Dementia Care</td>
<td>17</td>
</tr>
<tr>
<td>Summary and Conclusion</td>
<td>18</td>
</tr>
<tr>
<td>II. LITERATURE REVIEW</td>
<td>19</td>
</tr>
<tr>
<td>Stress Process Models</td>
<td>19</td>
</tr>
<tr>
<td>Original Stress Process Model</td>
<td>20</td>
</tr>
<tr>
<td>Stress Process Model for Caregivers</td>
<td>22</td>
</tr>
<tr>
<td>Stress Process Model for Individuals With Dementia</td>
<td>23</td>
</tr>
<tr>
<td>Section</td>
<td>Page</td>
</tr>
<tr>
<td>------------------------------------------------------------------------</td>
<td>------</td>
</tr>
<tr>
<td>Objective and subjective stressors</td>
<td>24</td>
</tr>
<tr>
<td>Secondary strains</td>
<td>24</td>
</tr>
<tr>
<td>Mediators</td>
<td>26</td>
</tr>
<tr>
<td>Outcomes</td>
<td>27</td>
</tr>
<tr>
<td>Illness Experience of Individuals With Dementia</td>
<td>27</td>
</tr>
<tr>
<td>Depression in individuals with dementia</td>
<td>28</td>
</tr>
<tr>
<td>Caregivers – Demographic Considerations</td>
<td>33</td>
</tr>
<tr>
<td>Caregiving ethnicity</td>
<td>33</td>
</tr>
<tr>
<td>Caregiving gender</td>
<td>35</td>
</tr>
<tr>
<td>Age of the caregiver</td>
<td>36</td>
</tr>
<tr>
<td>Education level of the caregiver</td>
<td>38</td>
</tr>
<tr>
<td>Depression in Caregivers</td>
<td>39</td>
</tr>
<tr>
<td>Dyad Relationship Strain</td>
<td>44</td>
</tr>
<tr>
<td>Summary</td>
<td>52</td>
</tr>
<tr>
<td>Aims and Hypotheses</td>
<td>54</td>
</tr>
<tr>
<td>III. METHOD</td>
<td>55</td>
</tr>
<tr>
<td>Participants</td>
<td>56</td>
</tr>
<tr>
<td>Demographic information</td>
<td>56</td>
</tr>
<tr>
<td>Attrition</td>
<td>57</td>
</tr>
<tr>
<td>Research Design</td>
<td>57</td>
</tr>
<tr>
<td>Measures</td>
<td>58</td>
</tr>
<tr>
<td>Center for Epidemiologic Studies Depression Scale (CES-D)</td>
<td>58</td>
</tr>
<tr>
<td>Dyad Relationship Strain</td>
<td>62</td>
</tr>
</tbody>
</table>
LIST OF TABLES

Table 1. Correlation matrix for depression and dyad relationship strain .............. 73
LIST OF FIGURES

Figure 1. Stress Process Model for Individuals with Dementia.......................... 106
Figure 2. Actor Partner Interdependence Model.............................................. 107
Figure 3. Final Results..................................................................................... 108
CHAPTER I

INTRODUCTION

Dementia is a neurocognitive disorder that causes impairment in one or more cognitive domains (these include attention, executive function, memory, language, perceptual-motor, or social cognition), and is significant enough to interfere with one’s ability to independently perform everyday activities (American Psychiatric Association, 2013). Alzheimer’s disease (AD) is one form of dementia, but is the most prevalent type of dementia worldwide (Alzheimer’s Association, 2016). While AD can only definitively be diagnosed post-mortem, probable AD can diagnosed if there is evidence of the gene from family history or genetic testing and there is evidence of a decline in memory and learning and at least one other cognitive domain, a steady progression of symptoms, and no evidence of other conditions that may be causing the decline (American Psychiatric Association, 2013). The majority of people with AD receive informal care from family members and friends, resulting in a great deal of stress being placed on both the caregivers and care recipients to ensure that the individual with
dementia’s daily needs are met. An estimated 83% of care provided to patients with AD is provided by family, friends, or other unpaid caregivers (Alzheimer’s Association, 2016).

The first risk factor for AD include being over the age of 65 (Alzheimer’s Association, 2016). Though younger people can develop AD, it is rare and they likely have other significant risk factors. In the United States, 4% of people with AD are under the age of 65, 15% of people with AD are ages 65-74, 44% of people with AD are ages 75-84, and 37% of people with AD are over the age of 85 (Alzheimer’s Association, 2016). In the general population, 11% of people over the age of 65 have AD and 32% of people over the age of 85 have AD (Alzheimer’s Association, 2016). The second risk factor is having a first degree relative with AD, namely a parent or sibling who had the disease. The third major risk factor is having the APOEε4 gene (Alzheimer’s Association, 2016; Karlsson et al., 2015). Approximately 20-30% of the population has one copy of this gene, and nearly 2% of the population has two copies, creating the greatest genetic risk for developing AD. Having the APOEε2 gene is thought to decrease risk, and approximately 10-20% of the population has one or two copies of this gene. Karlsson and colleagues (2015) also note that being a carrier of the APOEε4 gene is a risk factor in developing depression later in the dementia disease process as opposed to IWDs who have depression premorbid to AD. The fourth risk factor to developing AD is to have mild cognitive impairment (MCI), with small but measurable declines in cognitive ability that are noticeable to family and close friends. MCI can frequently, but not always, progress to become AD or another form of dementia. A fifth risk factor is cardiovascular disease. Cardiovascular disease likely impacts health of the brain as the
brain has a complicated network of blood vessels. This risk factor is also a modifiable risk factor, so taking care of one’s overall health can decrease the likelihood that one will develop AD (Alzheimer’s Association, 2016). Smith (2016) reviewed relevant literature on this topic and echoed these findings. He discussed how antihypertensives and other medications can help protect brain health as people age. A sixth risk factor is lack of social and mental activity. This is another modifiable risk factor, and being socially engaged and mentally active in daily life can protect against one’s likelihood that one will develop AD (Alzheimer’s Association, 2016). Smith (2016) reviewed relevant literature on this topic and echoed these findings, discussing how mental activity (e.g., ‘brain games) can be helpful in prevention of cognitive decline. A seventh risk factor is lower education level. For people who are highly educated, it is hypothesized that they have developed a “cognitive reserve” (Alzheimer’s Association, 2016, p. 12) that protect the brain from AD and similar diseases; however, people with higher education levels are also likely higher socio-economic status (SES) and have other health benefits associated with higher SES. An eighth risk factor for developing AD is traumatic brain injury (TBI). Having a moderate TBI is associated with double the risk of developing AD, and a severe TBI is associated with 4.5 times the risk (Alzheimer’s Association, 2016). Another consideration, though this is not considered by the Alzheimer’s Association (2016) to be a risk factor, is that two-thirds of people with AD are women. Some argue that this is because women are known to live longer than men; however there has been other forms of dementia that have no observed difference in prevalence rates by gender (Alzheimer’s Association, 2016).
Purpose of the Study

The purpose of this study is to investigate how dyadic relationship strain of both the caregiver and IWD relates to depression of both care partners is a systemic fashion. The Stress Process Model for individuals with dementia as outlined by Judge, Menne, and Whitlatch (2009) was used to guide design of the study (see Figure 1 on page 103). It aims to address related deficits in the literature and better understand the illness experiences of IWDs and caregiving experiences of their caregivers, and how these experiences impact one another’s depression. By helping understand the complex relationships of the numerous variables at play in caregiving dyads, healthcare professionals can continue to improve interventions for optimal psychosocial outcomes for both care partners.

Significance of the Study

Clinical trials with the size and scope of Partners in Dementia Care (PDC) tend to be few and far between. Such studies have the potential to change national policy on healthcare and possibly shape the way entities such as the Veterans Administration (VA) approach home healthcare. This study intends to investigate an aspect of the research that the PDC research has not yet addressed. Previous to this, the PDC team has mainly focused on the outcomes for the caregivers, so research on the care recipient is just beginning. This project investigated some of the most significant constructs of the care recipient’s experience, their relationship with their care partner and psychosocial outcomes, specifically depression. This study could potentially significantly add a great deal to the literature on caregiving and experience of being a care recipient, as limited information is available on the experience of the patient in dementia caregiving, and even
less is available on the experience of Veterans with dementia. Additionally, it specifically investigates the impact each care partner has on one another’s depression, which is a gap in the current body of literature. A discussion of the history of dementia, followed by information on the impact of dementia and the needs of Veterans will follow.

**History of Dementia**

Cognitive decline in elderly persons has been documented as early as 2000 BC, when the ancient Egyptians were aware that old age could be accompanied by memory difficulties; however, the ancient Egyptians believed the heart and diaphragm controlled mental faculties (Boller & Forbes, 1998). The earliest known scientific studies of dementia come from Greco-Roman times, with the earliest reference attributed to a Greek physician, Pythagoras, in the 7th Century BC (Berchtold & Cotman, 1998). He and other early scientists, including Hippocrates, Plato, and Aristotle, all believed that this was not a disease, but rather a symptom of aging. The earliest documentation that dementia could possibly be a preventable condition was by the philosopher Cicero (332 BC – 395 AD), who noted that older men who are actively involved in intellectual pursuits are less likely to suffer the effects of dementia than less active men (Berchtold & Cotman, 1998; Boller & Forbes, 1998; Castellani, Rolston, & Smith, 2010). Even the Roman physician, Galen (150-200 AD), who is considered by some to be the father of modern medicine, viewed aging a disease process; however, he was also the first to correctly classify dementia as a mental disease (Berchtold & Cotman, 1998). The majority of writers from this period believed that the heart, not the brain, was the organ of the soul and mental processes, and it would take centuries for science to better understand the role of the brain in all cognitive processes.
Little advancement was made in the study of aging and dementia between the Greco-Roman period (i.e. approximately 200 AD) and the 17th century. Up until this time, many people who suffered from dementia were at best imprisoned as a criminal, or at worst, executed for witchcraft (Berchtold & Cotman, 1998). During this period, people began searching for evidence of physiological changes in the brain that may be the origin of mental disorders. Of note, an English physician, Matthew Baille (1761-1823) was the first to note increased ventricle size people with dementia (Berchtold & Cotman, 1998). He did not understand that this was in fact a sign of atrophy, now considered a hallmark of the most common form of dementia, Alzheimer’s disease (AD), but he was the first to document the important changes that underlie symptoms of AD. In this same time period, the work of a French physician, Phillippe Pinel (1745-1826), became highly influential in the study of dementia. He was one of the first to lobby for changes in the treatment of individuals with dementia, and established a view that dementia was a disease and not a crime (Berchtold & Cotman, 1998). Pinel led reforms for patients to be treated in hospital settings, as opposed to incarceration. Pinel’s student, Esquirol, went on to create the first classification system for mental disease, allowing for more systematic study and improved scientific discourse regarding the symptoms and physiologic changes in individuals with dementia (Berchtold & Cotman, 1998).

The study of syphilis in particular created much advancement in understanding the brain and cognitive impairment associated with disease. Syphilis was well known as early as the 15th century, and was considered one of the major causes of “insanity” (Boller & Forbes, 1998, p. 128). The disease was common across Europe and the Middle East, and even brought to America by sailors under the command of Christopher
Columbus. Up until the mid-20th century, syphilis was thought to be responsible for up to half of all admissions to psychiatric care facilities (Boller & Forbes, 1998), and thus was a primary driver in research to better understand the brain and illness impacting cognition. Related to this, advancements came in understanding changes within the brain related to AD and dementia. By the 1860s, it was well documented that changes in brain weight accompanied many symptoms of dementia (Berchtold & Cotman, 1998). As a direct result of study of diseases such as syphilis and chronic alcoholism, it became understood that the changes in weight were in fact brain atrophy. Through the study of stroke victims, it was learned that this atrophy was due to cell death and later, it would be discovered that synaptic loss in the hippocampus heralds the transition between mild cognitive impairment and AD (Jellinger, 2006).

In the 1890s and early 1900s, advancements in staining techniques allowed physicians to begin documenting evidence of what is now known as amyloid plaques and neurofibrillary tangles in the brains of elderly patients with dementia (Berchtold & Cotman, 1998). One physician using the new staining techniques and studying the symptoms of dementia was German physician, Alois Alzheimer (1864-1915) (Berchtold & Cotman, 1998). In 1901, Alzheimer treated a 51 year old woman suffering from symptoms of dementia named Auguste D. Her symptoms included memory impairment, hallucinations, delusions, paranoia, apraxia, speech difficulties, and behavioral disturbances (Jellinger, 2006). Her disease was clearly severe, progressed rapidly, and she died quickly (Berchtold & Cotman, 1998; Jellinger, 2006). Upon autopsy, Alzheimer noted that her brain contained widespread plaque (originally called ‘miliary foci’), significant neuronal degeneration, and marked neurofibrillary tangles. He documented
these three significant findings that went on to become the hallmark of the form of dementia that bears his name (Berchtold & Cotman, 1998; Jellinger, 2006; Castellani et al., 2010).

Even today, it is difficult to diagnose AD before death, and AD can only be confirmed upon autopsy (Berchtold & Cotman, 1998). Further advancement in understanding AD and all forms of dementia were made when dementia was first classified in DSM-1 as “organic brain syndrome” (Jellinger, 2006 p. 1607). In 1980, the DSM-III went on list AD by name, and cited it as the cause of most age-related dementias (Jellinger, 2006).

Research within the last several decades has established that genetics can play a role in the development of AD in some individuals. Of all patients with AD, 15-35% have a first degree relative with the condition (Castellani et al., 2010). Specific genetic variants and mutations account for 30-50% of cases of early onset AD and 20% of late onset cases (Jellinger, 2006). This research was largely driven by the observations that many individuals with trisomy 21 have early onset AD, and further research led to relationships noted on variants of chromosomes 1, 14, 19, and 21 (Castellani et al., 2010; Jellinger, 2006). While having no family history of AD reduces the likelihood that one will develop AD, other protective factors include being highly educated, use of anti-inflammatory medications, and lack of head trauma (Castellani et al., 2010).

Today, it is known that AD is the most common neurodegenerative disease worldwide, and accounts for 65-70% of known dementia cases (Castellani et al., 2010; Jellinger, 2006). For individuals over age 65, the risk for men developing AD is 33% and 45% for women (Jellinger, 2006). Prevalence increases with age, with up to 50% of people over
the age of 85 suffering from AD (Castellani et al., 2010). AD typically has an insidious onset and a progressive course that typically leads to death in 10-15 years. Though presentations of AD can vary dramatically, diagnostic criteria include memory impairment and difficulty in at least one other cognitive domain, with disturbance in social or occupational function (Castellani et al., 2010). AD typically has an insidious onset and a progressive course that typically leads to death in 10-15 years (Jellinger, 2006). Patients typically die in a vegetative state, and cause of death is frequently a comorbid condition, such as pneumonia (Castellani et al., 2010).

Though AD can only be definitively diagnosed post-mortem (Berchtold & Cotman, 1998; Jellinger, 2006), today’s medical professionals can use a variety of brief cognitive screeners, such as the Blessed Test, to diagnose the severity and progressive course of dementia (Jellinger, 2006). While there is no cure for AD and many other forms of dementia, treatment is available in the form of medications such as acetylcholinesterase inhibitors (e.g., Aricept) and NMDA-agonists (e.g., Namenda), but these medications currently only slow the rapid progression of AD. Many dementia symptoms can be managed with antipsychotic medications and antidepressants, but again, this is only symptoms management as opposed to a cure for AD (Castellani et al., 2010; Jellinger, 2006). Recently, clinical trials have been conducted for vaccines or immunotherapy that would reduce amyloid plaque in the brain, but these were halted due to extreme side effects (Castellani et al, 2010; Jellinger, 2006). Despite the limited number of treatments currently available, it is important to remember that only 30 years ago AD was widely considered to be an untreatable condition. Today, with continued
medical advancement, hope for a cure is renewed and improved treatment options are possible for those currently living with AD and other forms of age-related dementias.

**Impact of Dementia**

Dementia impacts the lives of millions of individuals worldwide. In the United States, 13 to 15 million people have conditions that impair cognitive function (Whitlatch, 2008). Alzheimer’s disease (AD), which is the most common kind of dementia, affects roughly 5.2 million Americans. By 2050, this number is estimated to be 13.8 million Americans. Currently, 11% of people over the age of 65 and up to 32% of people who are over the age of 85 suffer from AD (Alzheimer’s Association, 2016). While AD is the most common form of dementia, it is still only one kind, so there are still millions more individuals suffering from other forms of dementia. There is evidence that the rates of dementia will double every five years once an individual reaches age 60 (Krishnan et al., 2005). More women than men have AD and other forms of dementia, and women account for 65% of caregivers to Individuals with Dementia (IWDs) (Alzheimer’s Association, 2016). In 2015, Americans provided 18.1 billion hours of unpaid care to IWDs, which is worth $221.3 billion and is equal to eight times the total value of McDonald’s sales in 2014 ($27.4 billion) (Alzheimer’s Association, 2016). Fifty-nine percent of caregivers rate the emotional stress of caregiving as ‘high’ or ‘very high,’ and 38% rate the physical stress of caregiving as ‘high’ or ‘very high,’ (Alzheimer’s Association, 2016). Medicare alone is expected to pay $160 billion in healthcare related expenses of IWDs, while costs to Medicaid, out of pocket, and other expenses for this population is estimated to be $236 billion in 2016 (Alzheimer’s Association, 2016). Roughly $46 billion, or 19%, of these costs are paid out of pocket, causing a huge burden
on IWDs and their families (Alzheimer’s Association, 2016). When one considers that AD is only one form of dementia, it is staggering to contemplate the number of older adults that are suffering from this condition, and in turn the numbers of family members who are now charged with their care. As individuals continue to live longer than previous generations and survival rates of many major illnesses rise, informal caregiving rates will continue to increase (Sharpe, Butow, Smith, McConnell, & Clark, 2005). Caregiving for dementia patients has been widely studied. Roughly 50% of published studies on caregiving are with dementia populations, and this research suggests that populations of caregivers within a specific illness category can vary greatly with regard to stressors, styles of caregiver, styles of coping, and more (Pinquart & Sorenson, 2005). As the Baby Boomer generation (born from 1946-1964) in America ages, rates of dementia will most likely continue to rise and caregivers within this age cohort will require additional aid to cope with the demands of caregiving. Belle and colleagues (2006) stated that the ramifications of caregiving are not limited to physical and psychological stress to caregivers; caregiving can result in significant increases in risk of death for caregivers. What has been studied insufficiently is the impact that caregiving can have on IWDs, especially from their own perspective, despite it being established that many IWDs can accurately report their own feelings and subjective emotional experiences in the earlier portions of their disease process (Snow et al., 2005).

**Needs of Veterans**

For numerous reasons, Veterans are a unique population with unique needs, so it is important that they be properly researched so appropriate interventions can be designed. The health of thousands of Americans and their families are counting on the
VA to continue doing research and providing the best care. Veterans comprise a huge portion of the American population, and many elderly individuals rely on the VA for healthcare and other benefits. Cooley and Asthana (2010) state that 562,058 veterans have been diagnosed with dementia. Of these individuals, 307,474 people were enrolled in the VA healthcare system, and 184,578 of these individuals actually received care at a VA medical facility in 2004. These numbers are anticipated to rise over the next several years (Cooley & Asthana, 2010). With this information, one can see that investigations are needed into how to best care for these individuals, primarily to maintain the highest levels of health and quality of life.

Krishnan and colleagues (2005) examined the overall prevalence rates of dementia in consumers of medical care in the VA medical system. They found that of patients 65 and older, 7.3% had some form of dementia. Broken down into smaller age categories, ages 65-74 had a prevalence of 4.6%, 75-84 had a prevalence of 9.5%, and 85 or older had a prevalence 18.1%. Broken down by race, 9.7% of those identifying as Caucasian were diagnosed with dementia, 14.7% of those identifying as Black, and 10.2% of ‘others’ (Krishnan et al., 2005). Geographically, the highest rates of dementia in VA patients were found in the following states: Maryland, Virginia, southern areas of West Virginia, Kentucky, Tennessee, North Carolina, South Carolina, Georgia, Alabama, Mississippi, Louisiana, Arkansas, Texas, and Oklahoma. The areas with the lowest rates of dementia in VA patients were found in the following states: Delaware, New York, New Jersey, Pennsylvania, northern areas of West Virginia, North Dakota, South Dakota, Nebraska, Iowa, and Minnesota. Prevalence rates of various types of dementia were also examined. Of the sample of veterans, 44.6% had Alzheimer’s disease, 11.9% had
vascular dementia, 2.3% had alcohol related dementia, 0.37% had Pick’s disease, and 40.77% had other forms of dementia (Krishnan et al., 2005). The aims of Krishnan et al.’s study were to examine trends, but not necessarily identify reasons for these trends. However, from the data compiled it is clear that there is a great deal of need within the veteran community for proper care and support of not only the patients, but also their families and loved ones.

In a study of data from VA centers nationwide, Byers et al. (2012) investigated if depression or dysthymia were associated with increased risk of dementia and death in older Veterans. They found at baseline, over 10% of veterans studied had depression or dysthymia diagnoses. After seven years, rates of dementia were significantly higher in both the depressed and dysthymic groups than those Veterans without depression or dysthymia. Higher incidence rates of death were also found in both these groups. The risk of death was 40% higher for veterans with depression or dysthymia than for those without (Byers et al., 2012).

Kalkonde and colleagues (2009) stated that minorities, in general, report underuse of medical interventions for a variety of medical issues including Alzheimer’s disease. They stated that African Americans are 40% less likely to be taking appropriate medication for Alzheimer’s disease. In their sample of Veterans, only 50% of African Americans were likely to use medication while 86% of other ethnicities used medication. They also found that Caucasians were more likely to undergo neuropsychological testing than their African American counterparts (43.8% and 24.8% respectively; Latinos, 32.4% received testing), and that African Americans were more likely to be screened for depression than Caucasians and Latinos (71.6%, 60.4%, and 64.7% respectively)
(Kalkonde et al., 2009). It is unclear if these options were not prescribed to African American patients or if they were recommended and the veteran chose not to utilize these services. It is unlikely that any individual in the study could not afford medication or neuropsychological testing, as all would have VA benefits. To some degree, this study raised more questions than answers, but again highlights the need for increased care and education of healthcare providers and consumers.

Also of note, there may be significant stigma in the military to report mental health symptoms. Warner et al. (2011) found in their study of 3502 US Army soldiers that anonymous surveys of mental health symptoms yielded much higher rates of reporting of symptoms of PTSD, depression, and suicidal ideation (two to four times higher than surveys with identifiable information). Additionally, 20.3% of soldiers who screened positive to depression or PTSD noted that they were not comfortable answering honestly on these screenings (Warner et al., 2011). Because military service often becomes part of a Veteran’s identity, these feelings of discomfort with mental health symptoms and stigma of reporting mental health concerns may remain with Veterans long after their military service, so it is possible that Veterans may underreport symptoms of depression and dementia.

In sum, Veterans have slightly different needs and presentations than the mainstream population for numerous reasons. This group of individuals has different presentations of psychopathology, different experiences and rates of trauma that can precipitate mood disorders, and also exposure to different environments and chemicals that have been linked to different physical illnesses (e.g., Agent Orange exposure in Vietnam Era Veterans). Ignoring these differences does a disservice to both Veterans and
clinicians, which highlights the need for further research and specialized treatment for
veterans. This study is significant in that it can add to a growing body of literature that
directly examines and serves the needs of Veterans.

**Statement of the Problem**

There is an established body of knowledge on how IWDs negatively impact their
caregivers (Moon & Dilworth-Anderson, 2015; Ornstein & Gaugler, 2012). With this
comes the assumption that the caregiving dyad is a team, bonded together with the health
and behavior of one directly impacting the other care partner. While much research has
been conducted on negative outcomes for caregivers created by IWDs and their illness
experiences, the inverse of this relationship is lacking in the literature.

A key question remains – how do caregivers impact their patients? If a caregiver
is highly depressed, how does this manifest in psychosocial outcomes for the IWD? Or,
alternatively, if the caregiver is experiencing dyad relationship strain (defined as
relationship strain between the two care partners of the caregiving dyad) (Connor et al.,
2008), how does this manifest in outcomes for the patient? There are many reasons
questions of this nature need to be answered. First, achieving the highest quality of life
for both IWD and caregiver is of the utmost importance in that respect of all human lives
is a primary tenet of the fields of psychology and medicine. Second, quality treatment of
IWDs becomes a social justice prerogative as individuals suffering cognitive impairment
are already an at-risk population. They suffer from bias on two fronts, the first being
ageist attitudes of society and additional bias related to their cognitive impairment. By
understanding what caregiving factors relate to both negative and positive outcomes for
IWDs, ideal caregiving environments can be facilitated. Third, by creating better
outcomes for IWDs, one is also creating better outcomes for caregivers because IWD symptoms, such as depression, are known to create many of the situations that provide the most burden and stress for caregivers (Givens, Mezzacappa, Heeren, Yaffe, & Fredman, 2013). However, this is a difficult task. The outcomes for the IWD cannot be studied in isolation because the IWD is tied in many ways to the caregiver. The two must work together for the IWD’s health, safety, and survival. Typically, it is far more likely that the dyad share many bonds of family or friendship, and live together in the same home. Because of this, the relationship is more than one partner providing care for the other. There is usually love, history, and frequently many frustrations that come with any close relationship.

Significance of the Problem

In addition to wanting the best mental and physical healthcare outcomes for all individuals, there is the practical matter of the current managed care environment in healthcare for not only the United States, but also other nations. Increasingly, psychologists and other health care providers are expected to achieve better outcomes for their patients in shorter amounts of time and at a reduced cost than what was previously considered standard. By understanding how the caregiver impacts the IWD, one could potentially create a pathway to intervene with the caregiver and more quickly and cost-effectively create better outcomes for the IWD.

Previous research has established that caregivers have an impact on IWDs’ behaviors. A study by Riviere et al. (2002) found that IWDs with caregivers who are experiencing greater levels of burden and caregivers who were at a more advanced age tended to develop greater amounts of aversive behaviors than their less burdened and
younger counterparts. Additional research has established that certain caregiver characteristics provide a worse quality of care for dementia patients. For example, Sternberg, Bentur, and Shuldiner (2014) found that caregivers with a physical disability, caregivers reporting higher levels of burden, caregivers with higher rates of depression, and those with lower education levels provided worse quality of care for their dementia patients than those with higher education. When it is established that these factors provide a low quality of care, it can be assumed that worse psychosocial outcomes are found in the patients of these caregivers.

Understanding the emotional experience of caregivers is important because the emotional health of caregivers can directly impact the health of IWDs. Studies suggest that poor emotional health can have direct consequences, such as abuse of the care partner (MacNeil et al., 2009). Thus it becomes a social justice prerogative to better understand the struggles of caregiving dyads to help both care partners achieve the highest quality of both physical and mental health and also to help confront ageist attitudes of society.

**Partners in Dementia Care**

Partners in Dementia Care (PDC) was a joint venture between the Veteran’s Administration and the Alzheimer’s Association to develop and test the efficacy of an intervention for Veterans with dementia and their caregivers (Bass et al., 2014). This non-pharmacologic, yearlong intervention was designed to improve psychosocial outcomes including unmet needs, embarrassment about memory problems, isolation, relationship strain, and depression. Structured interviews were completed with participating Veterans and their caregivers at baseline, six months, and 12 months of
intervention. The major goals of this intervention were found to be partly successful, with a reduction in unmet needs ($\beta = -0.52; p = 0.08$), embarrassment about memory problems ($\beta = -0.24; p = 0.08$), relationship strain ($\beta = -0.09; p = 0.05$), and depression ($\beta = -0.10; p = 0.03$) (Bass et al., 2014). Isolation was not found to be statistically significant ($p = .15$).

**Summary and Conclusion**

In summary, this research intends to fill a significant gap in the literature regarding caregiving experience and the illness experience of IWDs. It intends to investigate the illness experience of IWDs, specifically the impact of the caregiver and caregiver experiences on mental health outcomes of IWDs. It has the added benefit of addressing how the IWD can also impact mood symptoms of the caregiver. In addition, this research will also add to the limited body of knowledge available on the illness experience of Veterans with dementia. This has powerful social justice implications in that it addresses the needs of marginalized population in hopes that IWDs will become more respected and active partners in their own care. IWDs are a marginalized population in that the face discrimination on two fronts, first from ageism in society, and second from bias against those with cognitive disabilities. In addition, by better understanding how caregivers impact their care partners, the increasing demands on medical and mental health professions to provide quality interventions quickly and effectively may be eased by designing interventions that can act with the caregiver to create positive outcomes for the individual with dementia.
CHAPTER II

LITERATURE REVIEW

The purpose of this literature review is to further investigate the relationship between dyadic relationship strain and depression in both care partners. The Stress Process Model for Individuals with Dementia (Judge, Menne, & Whitlatch, 2009) will be used to guide this review. Research questions include the following: Does the dyad relationship strain of individuals with dementia (IWD) relate to their level of depression? Does the dyad relationship strain of caregivers relate to their level of depression? Does the dyad relationship strain of the caregiver relate to depression in the IWD? And finally, does the dyad relationship strain of the IWD relate to depression in the caregiver?

Stress Process Models

Stress process models are widely used in caregiving research (Judge et al., 2009; Moon & Dilworth-Anderson, 2015; Pearlin, Menaghan, Lieberman, & Mullan, 1981; Pearlin, Mullan, Semple, & Skaff, 1990). These models are ideal for conceptualizing both caregiver and care receiver in that they account for how stressors and strains are both inter-related and how these stressors and strains combine with the distinct context of the individual to create various outcomes. They consider the environment as well as the
strengths and weaknesses of each individual care partner when considering psychosocial outcomes, such as depression.

The following stress process models will be discussed, namely the original Stress Process Model (Pearlin, Menaghan, Liberman, & Mullan, 1981), the Stress Process Model for Caregivers (Pearlin, Mullan, Semple, & Skaff, 1990), and the Stress Process Model for Individuals with Dementia (Judge et al., 2009), which is the guide for the present study.

**Original Stress Process Model.** The stress process model was originally the work of Pearlin, Menaghan, Lieberman, and Mullan in 1981. Their original study used “longitudinal data to observe how life events, chronic life strains, self-concepts, coping, and social supports come together to form a process of stress” (p. 337). In general, the model posits that primary stressors are stressors that arise directly from the situation and secondary stressors are other related strains, such as stress from work or other social roles unrelated to the primary stressor. This is placed within the context of the individual, which include factors such as age, race, and socioeconomic status. These elements combine to create the outcomes for the individual.

Pearlin et al. (1981) suggested that there are two major sources of stress in one’s life: a) a specific event that causes stress or b) on-going stressors referred to as ‘chronic strains.’ When these two types of stressors combine, they can either cause one to gain new understanding of pre-existing problems or they may exacerbate current stressors. With either path, the two types of stressors combine so that they may provide new perspectives on their stress.
When one is perceiving one’s stress, one’s self-concept acts as a lens or filter that can potentially alter the way one perceives stress. The two items of one’s self-concept that Pearlin et al. (1981) focused on are mastery and self-esteem. Mastery serves the purpose of helping one decide how capable one is of handling the stressor, while self-esteem acts to help one determine one’s own worth. High sense of mastery and high self-esteem typically improve one’s appraisal of the stressor while low sense of mastery and low self-esteem typically magnify the impact of the stressor in one’s life. Also of importance are situations where one can have a high sense of mastery and low self-esteem, and vice-versa. Different situations may elicit different appraisals of mastery and self-esteem in different situations. In addition, appraisals of self-esteem and mastery can change over time. If one is dealing well with the stressor, then one’s sense of mastery and self-esteem can improve; whereas if the stressor is on-going and the individual does not feel he or she is dealing with the problem, then that individual’s sense of mastery and self-esteem can erode.

Next, Pearlin et al. (1981) discussed the important role of mediating resources. Of particular importance are social supports and coping. Pearlin et al. (1981) acknowledge that there is a great deal of ambiguity in a definition for what ‘social support’ is, but they utilize a working definition that suggests social support is more than merely having people in one’s life. Having beneficial social support is having people in one’s life that care about one’s well-being and have a certain level of intimacy and trust within that relationship.

The next mediator is coping (Pearlin et al., 1981). Coping is defined as adaptive behavior that is learned from one’s environment, not necessarily personal inborn
characteristics. Pearlin et al. (1981) also stated that coping serves three functions: “The modification of the situation giving rise to stressful problems; the modification of the meaning of problems in a manner that their threat; and the management of stress symptoms” (p. 341). They further defined coping as behaviors specific to the situation and acknowledge that coping can have its limitations when dealing with problems resulting from a larger system and that it is most effective when dealing with face-to-face problems, e.g., difficulty with a family member.

**Stress Process Model for Caregivers.** In 1990, Pearlin, Mullan, Semple, and Skaff built on the original Stress Process Model (SPM) (Pearlin et al., 1981) and applied it specifically to caregivers. When testing their model, the original sample ($n = 555$) was caregivers of individuals with Alzheimer’s disease. The original domains of the caregiving SPM may include the following: Background and context (individual characteristics of the caregiver that may influence their caregiving, such as ethnicity, SES, education level, and more); Primary Stressors (includes objective and subjective indicators of the stress of the caregiving situation); Secondary Role Strains (includes other conflicts, such as dealing with work-life balance); Secondary Intrapsychic Strains (includes global sense of self such as mastery and self-esteem, and situational sense of self such as role captivity); Mediators (using coping and social support to either enhance or better deal with the various strains and stressors); and finally these domains all interact and work in concert to produce Outcomes (indicators of the impact of stress on physical and mental well-being, such as depression, anxiety, and physical health declines).

In 1998, Goode and colleagues tested Pearlin et al.’s (1990) SPM of caregiving with 122 family caregivers of individuals with Alzheimer’s disease. These caregivers
reported on physical health, mental health, and variables of the stress process model, and the authors used hierarchical regression to determine that increases in primary stressors (e.g., impairment of activities of daily living (ADLs, basic self-care tasks such as bathing and dressing) and instrumental activities of daily living (IADLs, tasks required to live independently such as cooking and paying bills), increase in problem behaviors) did not directly relate to physical and mental health. They identified "psychosocial resource factors" (p. 191) that act as mediators of stress including appraisals of the primary stressor, coping responses, and social support. They found that more positive appraisals, stronger coping skills, and healthier social support will typically predict improved physical and mental outcomes for the caregiver.

**Stress Process Model for Individuals with Dementia.** Judge and colleagues (2009) furthered research of SPMs when they created the Stress Process Model for Individuals with Dementia. One of their goals in applying this model to individuals with dementia was to emphasize the individual experience of people with dementia as a result of personality, personal history, physical health, and other factors (Judge et al., 2009). This emphasis is highly important because people with dementia are frequently marginalized due to their lack of cognitive abilities. For their model, Judge et al. (2009) list age, gender, race, education level, socioeconomic status, health history, social network, and living arrangements as background and context. Background and context of the individual is highly important because a great deal of research suggests that factors such as race, SES, and living arrangements can have a great deal of impact on one's dementia and caregiving experience. The Stress Process Model for IWD aims to highlight the individual illness experience of each person, so beginning with background
and context highlights this individuality and accounts for the many differences within the population of IWDs.

**Objective and subjective stressors.** Judge et al. (2009) divide primary stressors into objective stressors and subjective stressors. Objective primary stressors include cognitive status, functional status, and behavior problems. These stressors are deemed as objective because they can be measured using various assessment techniques, and can quantitatively be compared to the symptoms and experiences of other IWDs. Subjective primary stressors include role captivity, perceived distress, and perceived dependency. These are subjective in that the individual’s appraisal of the IWD is key. While there are assessments to quantitatively measure these variables by clinicians, the individuals’ perception of these items is more important than the clinician’s valuation of these variables because individual distress is highly subjective and influenced by many factors. While these variables are divided into objective and subjective stressors, one cannot infer that one or the other category is more important or more impactful on the illness experience of the IWD. The SPM for IWDs is designed to highlight that each of these items and all the various categories and classifications act in concert to produce a highly individual illness experience with highly individual outcomes. Change to any one variable can produce drastic variations to the entire model and any singular outcome variable.

**Secondary strains.** Secondary strains are divided into role strains and intrapsychic strains. Secondary role strains highlight how the IWD functions as part of a family, a social network, and society at large. These include family role strain, job/work role, social/recreational role, and dyad strain. Having an illness such as dementia can

24
produce drastic changes in one’s relationships and roles. If the IWD is still working, this may quickly become an impossible or even dangerous task because by nature of the diagnosis of dementia, one is cognitive impaired. For example, if the IWD worked in a job that required use of complex machinery, this could quickly become problematic, as the ability to remember step-by-step instructions declines. There are numerous ways this could become very dangerous in a factory type setting. If the IWD has a family, his or her role in the family will typically change, as other family members must begin overseeing tasks that were typically done by the IWD. While most IWDs are able to help with household chores well into their illness, eventually chores such as cooking and paying bills become more difficult and are typically taken over by a caregiver. Friendships will also change as the IWD’s abilities decline. Again, this is an area that typically is not immediately impacted by a dementia diagnosis, however social events such as a weekly card club may soon become a challenge for the IWD. Sometimes social relationships will change as the IWD’s needs change, but sometimes these relationships will die off as the IWD is no longer able to provide transportation for him or herself, or as he or she becomes less likely to call and make plans. All of these changes to the IWD’s lifestyle can create huge stress in not only the IWD’s life, but the life of many others as well.

Secondary intrapsychic strains include self-esteem, mastery, and self-efficacy. While strong self-esteem, mastery of different areas, and self-efficacy can help buffer the initial changes of one’s lifestyle following cognitive decline, these items are all likely to change as the IWD realizes that he or she is no longer able to do things they once could. Retiring or taking medical leave from a job they were once quite good at, ruining a meal
they used to be able to cook from memory, and forgetting plans with friends that had once been a usual occurrence are all examples of things that can profoundly change one’s sense of self and one’s sense of one’s lifestyle. How one manages these changes can greatly impact the overall illness experience.

**Mediators.** Mediators that can affect the relationship between primary stressors and secondary strains are divided into internal mediators and external mediators (Judge et al., 2009). Internal mediators include personality, hardiness, life orientation, spirituality, and core values. Each of these items are personal coping mechanisms that help the IWD make sense of and cope with his or her cognitive decline. They represent factors that come from within the individual, and are typically indicative of lifelong patterns of feelings and behaviors. These each can be strengths or weakness, helping or hurting the well-being of the IWD. For example, a person with a typically optimistic personality may be better able to find positive aspects of the situation, whereas someone who has traditionally been a pessimist may focus on the many losses associated cognitive decline. Another example is spirituality. For many people, faith in a higher power can be a great comfort in the face of serious illness; whereas for others, they may view serious illness as a punishment by God.

External mediators include social support, knowledge of the illness, and financial resources. While these are still unique to the individual, they are not coming from within the individual, rather they come from the IWD’s environment. For example, a person who has worked in the medical field may have better knowledge of the typical process of dementia as well as treatment options, and this may make coping a bit easier for them. Another example is a person with a strong social network. This can provide not only
emotional comfort and support, but also physical support in helping the caregiver with the many tasks related to caregiving, providing support for the dyad, and reducing strain in other areas. Judge et al. (2009) stated that items such as interventions would fit within this category, which opens the door to examine what other factors could be included as mediators, including the influence of caregivers. For example, research has suggested that the emotional health of caregivers can predict changes in outcomes of the quality of care that they provide for their patients (MacNeil et al., 2009). If an intervention for caregivers, such as counseling to address depression and anxiety, could predict better emotional health for the caregiver, it could potentially make caregiving a positive mediator for the IWD creating better mental health outcomes for the patient.

Outcomes. Outcomes resulting from the background, primary stressors, secondary strains, and mediators are encompassed under the heading of well-being. Well-being includes quality of life, depression, anxiety, and psychological reactions (Judge et al., 2009). The previous domains work in concert to either alleviate or increase negative mental health symptoms. It has been well established that depression and anxiety are very common in IWD’s, adding a second blow to an already devastating disease. While there is little that can be done for dementia currently, creating better outcomes for these patients can be as simple as a better understanding of what drives depression within this population and helping to create better emotional outcomes for those who already suffer.

Illness Experience of Individuals with Dementia

Stress process models help researchers better understand the illness experiences of IWDs and the experiences of caregivers, but these only provide an overview of what is a
highly individualized experience for each person, patient or caregiver. Exploration of each of the domains with the SPMs guiding this research, however this literature review is limited to the scope of dyad relationship strain and depression. Depression was selected as the outcome variable because it is very common in IWDs as well as in caregivers (e.g., Alzheimer’s Association, 2016; Aranda & Knight, 1997; Baronet, 1999; Byers et al., 2012), and has the potential to substantially decrease one’s quality of life (e.g., Belle et al., 2006; Dunkin & Anderson-Hanley, 1998; Joling et al., 2012). Though these experiences are also highly individualized, a review of the available literature is helpful in understanding basic trends and commonalities. As highlighted in the SPM of IWDs (Judge et al., 2009), depression is a key outcome for IWDs and is an important facet of understanding their overall illness experience.

Understanding the experiences and stresses of caregivers is quite obviously not the only component to understanding how caregiving can impact outcomes for the dementia patient. One needs to understand how dementia itself can create negative psychosocial outcomes, including high rates of depression and caregiving dyad relationship strain within this population. Because this population is already at risk of negative psychosocial outcomes, stresses placed on them by caregivers can cause or further exacerbate the mood disturbances that frequently predict problem behaviors and other things that become stressors to caregivers. A discussion of the literature on depression in IWDs follows, as this is the focus of the investigation.

**Depression in individuals with dementia.**

Depression is one of the key outcomes of wellbeing in the SPM. Incidence rates of depression for IWDs are disturbingly high and this creates very serious negative
outcomes for both patient and caregiver. A study by Ballard et al. (2000) found that 36% of IWDs experienced at least one major depressive episode after the onset of dementia symptoms, and 15% experienced an episode lasting more than six months. Type of dementia may also play a role, as this study compared 92 individuals with Vascular Dementia and 92 individuals with Alzheimer’s disease. They found that individuals diagnosed with Vascular Dementia experienced depression at rates 2.8 times that of those with Alzheimer’s disease. They also found that older age was predictive of depression, though they did not specify what age ranges were at great greater risk. Previous depressive episodes were not predictive of depression in their sample. In addition, the presence of depressive symptoms predicted more severe impairment of memory, attention, and concentration as compared to those not experiencing depressive symptoms (Ballard et al., 2000).

Spira et al. (2012) supported some of Ballard et al.’s (2009) findings in their study. They found that women in their 9th and 10th decades of life (n = 302) who experience depression are also at higher risk of experiencing cognitive impairment and lower cognitive functioning.

Alexopoulos et al. (1995), in their study of depression patients (n = 67), found that those with mild to moderate dementia were less like to experience comorbid anxiety than their cognitively intact counterparts. There appeared to be little difference in the way older patients (n = 52) experienced symptoms of depression compared to the younger participants (n = 15). There also appeared to be little difference in age of those experiencing comorbid depression and anxiety, with cognitive impairment being the only differentiating factor between those experiencing both conditions and those with only
depression. This study raises more questions than answers such as why IWDs were less likely to experience comorbid anxiety, but it provides significant evidence to suggest that those with dementia experience mood symptoms differently, and therefore additional research is needed to better understand this phenomenon and the illness experience of IWDs.

Dawson, Powers, Krestar, Yarry, and Judge (2013) collected self-report data from 131 IWDs, which is a departure from many other studies that use caregivers to report on IWD mood symptoms. This highlights evidence that strongly suggests that many IWDs can accurately report on their own mood symptoms and subjective emotional experiences well into their disease process. Dawson et al. (2013) found that physical health strain and role captivity were found to be significant predictors of depressive symptoms in IWDs ($\beta = 0.36, p < .001$, and $\beta = 0.23, p < .01$ respectively, $R^2 = .56, F(14,99) = 9.03, p < .001$). They also found that the Mini Mental Status Exam (a common cognitive screen) (Folstein, Folstein, & McHugh, 1975) score was not predictive of depressive symptoms, suggesting that cognitive abilities are not predictive of depression.

One unanswered question about depression and dementia is whether depression can precede dementia, and if so, does it contribute to the causation of dementia. Many studies have established a strong link between the two conditions, but whether one is causing or driving the other remains unclear. In a study by Richard et al. (2013) they examined rates of depression in conjunction with progression from MCI to dementia. They did a longitudinal study of 2160 healthy older adults (age 65 and older) to study whether depression or dementia precede one another and found that dementia risk was higher in individuals who presented with depression at baseline. The odds ratio (i.e. the
odds that an event will occur) for those who presented with depression and developed mild cognitive impairment (MCI) was 1.4 (95% CI, 1.1-1.9). The odds ratio for those who presented with depression and developed dementia was 2.2 (95% CI, 1.2-2.3). This pattern was also prevalent in participants that progressed from MCI to dementia during the study (odds ratio 2.0, 95% CI, 1.2-3.4). Richard et al (2013) state that depression continues to develop as people move from normal cognition to impaired cognition and link this to other studies suggesting that depression may have a vascular component, as vascular risk factors have also been established in some types of dementia.

Snowden et al., (2015) conducted a longitudinal examination of depression in IWDs (n = 27,776). They found that rates of depression were statistically significantly higher in IWDs and people with MCI as compared to a normal population at initial evaluation. For those with MCI and dementia that did not have depression at the initial evaluation, they were more like to develop depression within two years as compared to people with normal cognition. Rates of depression at two years post evaluation for IWDs was 24.7%, 21.7% for people with MCI, and 10.5% for those with normal cognition (Snowden et al., 2015). They cited previous research that notes depression typically precedes dementia, but note that even if people who are early in their disease process and do not yet have depressive symptoms, that clinicians should still be aware that these individuals are at high risk for developing depression.

Karlsson et al. (2015) also investigated the development of depression in IWDs over time and specifically examined a possible association with the APOEε4 gene. In their sample of 804 IWDs and 1600 matched controls, they found that the gene was not predictive of having depression at the onset of AD, but there was a statistically significant
relationship with the gene and those that developed depression later in their disease process. Depression was closely related to having dementia regardless of whether someone had the gene at onset of dementia (Karlsson et al., 2015).

Mirza et al., (2014) found similar results to Snowden et al. (2015) and Karlsson et al., (2015) in their longitudinal study, though they did not examine genetic factors. They followed 4393 individual who did not have dementia for 13.7 years, during which 582 individuals developed dementia. They found that depressive symptoms were associated with an 8% increased risk of developing dementia (Mirza et al., 2014).

Gracia-Garcia and colleagues (2015) found similar results in a Spanish sample of 3,864 individuals who were cognitively intact at baseline. They followed-up with their sample at 2.5 and 4.5 years, and during that time, 70 individuals developed dementia. Those with severe depression at baseline were statistically significantly more likely to develop dementia (Gracia-Garcia et al., 2015).

In summary, there are many studies that link depression and dementia, but little is known as to how or why this link exists. It is known that many IWDs can accurately report their mood and subjective emotional symptoms well into the disease process, and that IWDs have incredibly high rates of depression. While there are still more questions than answers about the illness experience of IWDs, research is beginning to shed light on these questions by establishing key evidence, such as premorbid depression as a possible factor, and that individuals with different types of dementia experience depression differently. What has not been firmly established is what environmental factors play a roll. Dawson et al. (2013) begin to explore this by establishing that factors such as role
captivity play a role, but little to no data exists on the relationship quality of the dyad’s impact on the IWDs depressive symptoms.

Next, the experience of caregivers will be examined. First, the literature on the overall caregiving experience and various factors that can impact the caregiving experience will be reviewed, and this will then followed by a review of the literature on depression in caregivers.

Caregivers – Demographic Considerations

Caregiving ethnicity. Many studies suggest that individual caregiver differences, known as background and context within the SPM, result in differences in caregiving experiences. Many studies focus on how these differences impact caregiving burden for the individual, and higher levels of burden are known to produce decreased quality of care for dementia patients (Riviere et al., 2002). Ethnicity is one demographic variable that has been widely studied. Many variables can affect the construct of caregiver burden including ethnicity. Being Caucasian is frequently associated with the highest levels of burden (Aranda & Knight, 1997; Baronet, 1999; Belle et al., 2006; Chenier, 1997; Dunkin & Anderson-Hanley, 1998). The reason for this is unclear, and many theories have been put forward. One theory is that African Americans in particular tend to utilize more informal sources of help than their Caucasian counterparts and may have more effective coping strategies (Dunkin & Anderson-Hanley, 1998). Quite similar to this are findings that older African Americans tend to have better social support than their Caucasian elderly peers, which for African Americans tends to include a large kinship network not always seen in Caucasian populations (Chenier, 1997; Horwitz & Reinhard, 1995). Another hypothesis is the relationship between Caucasian caregivers
and their care recipients as opposed to minority groups. Caucasian caregivers are more likely to be the spouse of the patient, whereas in most minority groups it is another family member, frequently adult children, who are caring for the ill person. Spouses tend to report more burden than other family members, so relationship (another important demographic variable), not ethnicity, may be what the studies are finding (Dunkin & Anderson-Hanley, 1998; Horwitz & Reinhard, 1995). In a meta-analysis of 168 articles on caregiving that included data from 28,980 spouses as caregivers, 30,739 adult children as caregivers, and 4,627 adult children-in-law as caregivers, Pinquart and Sorenson (2011) also found that spouses as caregivers, as opposed to children or children-in-law, tend to experience more depression as well as greater levels of financial and physical burden. While literature on Latino caregivers is limited, some research finds that Latinos score higher than African Americans and higher than or equal to Caucasians on burden inventories (Aranda & Knight, 1997).

In a meta-analysis of 116 studies on caregiver burden, Pinquart and Sorenson (2005) found some key similarities and differences between Asians, Latinos, African Americans, and Caucasians. They found that in general, all minorities have greater levels of illness and impairment of ADLs than Caucasians, and that formal service use (such as in-home nursing aides) tend to be less accessible for minorities and attribute this to a potential language barrier, resulting in more informal caregiving. All minority groups also tended to have extended family as caregivers, whereas Caucasian populations were more like to have spouses as caregivers. Non-Caucasian caregivers performed more care related tasks, and only Asian caregivers spent fewer hours providing care than Caucasians. All minority caregivers also found more uplifts in caring, had higher levels
of subjective wellbeing, lower levels of perceived burden, and poor physical health in comparison to Caucasians. Pinquart and Sorenson (2005) also found that Latinos and Asians more frequently consider symptoms of dementia to be ‘normal’ aging. Latinos and Asians also reported worse relationships with the care recipient than Caucasians. Asian Americans were more likely to use more emotion-focused coping than Caucasians, which is known to not improve the situation in ways that other forms of coping, such as instrumental coping, usually would. Finally, Asian American caregivers tended to show higher levels of depression than Caucasians, which is counterintuitive considering they display lower levels of burden and the two are considered to be closely linked in other literature (Pinquart & Sorenson, 2005). Other contextual factors in caregiving that may be somehow related to ethnic differences include but are not limited to gender, age, and education level of the caregiver.

**Caregiving gender.** Females tend to report significantly higher levels of caregiver burden as opposed to men (Chio et al., 2005; Croog et al., 2006; Papastavrou et al., 2007; Parks & Pilisuk, 1991). This is important because in the literature, samples of caregivers tend to be overwhelmingly female (Baronet, 1999; Parks & Pilisuk, 1991). Papastavrou et al. (2007) found that women experience more burden because their social restrictions while in the caring role appear to be greater than that of men. Chio et al. (2005) have evidence to suggest that this is because men tend to receive gratification for their roles as caregivers. Parks and Pilisuk (1991) found similar data supporting this finding, and stated that women’s overall higher rates of depression are due to the role-strain that results from unappreciated social obligations to family, and their undervalued social role. It is also possible that men tend to have internal motivation for their
caregiving while women may feel they have a duty to their families and then struggle to balance the needs the care recipient with the needs of other family members and additional social roles such as employment (Chio et al., 2005).

In a study of spouses as caregivers \( (n = 199) \), Croog et al. (2006) found interesting results regarding gender differences. They found that caregiving husbands tend to experience more depression than caregiving wives, and caregiving wives tend to experience more anxiety than caregiving husbands. Curiously, husbands counter-intuitively displayed a statistically significant negative correlation between depressive symptoms and personal time restriction while wives displayed a statistically significant positive correlation between depressive symptoms and personal time restriction. Husbands also tended to experience the 'need to do more' over wives, and wives typically expressed more 'anger and resentment' than husband caregivers. In the overall model of regression for this study, the authors noted that there was an interaction between 'destructive behavior of the patient' and the results of gender based 'anger and resentment,' so it is unclear if perhaps male Alzheimer's patients tend to display greater amounts of destructive behavior than their female equivalents and this hypothesis was not addressed by Croog et al. (2006). Morimoto et al. (2003) found similar results among stroke caregivers \( (n = 100) \), with wives showing more burden when caring for their husbands than husbands caring for wives.

**Age of the caregiver.** There are differing results on how the age of the caregiver can moderate burden. While the data seem decidedly mixed on the impact of age on burden, Pinquart and Sorenson's (2005) meta-analysis found that in comparison to African Americans, Asians, and Latinos, Caucasian caregivers tended to be older than
minority caregivers. Chenier (1997) performed an extensive literature review and found trends that older individuals tend to experience more physical and emotional burden, and cites other research finding similar results. Baronet (1999), in a thorough review of the literature, found trends suggesting the opposite; younger people were worse off because they tend to experience higher levels of stigma and fear when caring for a mentally ill relative, and cites additional research that had similar findings of younger people experiencing greater overall burden.

Morimoto and colleagues (2003), using a Japanese sample of stroke caregivers ($n = 100$), found that younger people tended to experience greater levels of burden, but out of the married couples studied, wives tended to be younger than their husbands in both caregiver roles and care recipient roles, so gender may be more important than age in this instance. It should also be noted that their sample was of caregivers for stroke survivors, not dementia patients, and while there are likely many commonalities between caregiving for a stroke patient as opposed to a dementia patient, there are likely many differences, so the experience may be similar but not equal.

Croog and colleagues (2006) did not find any statistically significant results related to age ($n = 199$), but did note that their sample of Alzheimer’s patients ranged from middle to late age and so did their caregivers, suggesting little disparity of age in the caring dyads for this population. Aranda and Knight (1997), in a thorough review of available literature, suggested that older African American caregivers experience less burden than Caucasian caregivers, whereas older Caucasian caregivers tend to experience more burden than African American caregivers when caring for Alzheimer’s Disease patients, so it is possible that the intersection between age and other factors, such as
ethnicity, may also be important. It is possible that the age of the caregiver may have different effects on the caring relationship depending on race, illness of the care recipient, or numerous other variables, but literature specifically investigating age of caregivers was not found for this review. Also, specific literature on the intersectionality of demographic variables and caregiving was not found for this review.

**Education level of the caregiver.** A final demographic variable that may play a role in the caregiving experience is level of education. Though this variable is not nearly as well studied as other demographic information about caregivers, Riviere et al. (2002), in a study of 224 Alzheimer’s disease patients and their caregivers, found that caregivers with lower education was associated with decreased quality of care outcomes in their dementia patients. Unrelated to educational level of the caregiver, but highly significant in conceptualizing caregiving and illness experience of IWDs, this study also found that disease severity, emotional burden (e.g., depression and anxiety related to caregiving), and material burden (e.g., financial strain of caregiving), are predictive of developing aversive feeding behaviors in Alzheimer’s patients. This behavior can cause further stress on the caregiver, reinforcing a cycle of stress for both caregiver and IWD.

An additional study that included education level of the caregiver was Moon and Dilworth-Anderson’s 2015 study using the National Study of Caregiving data, which included 650 caregivers of people with dementia (138 caregivers) and caregivers of other illness (512 caregivers). They found that caregivers with higher education levels had statistically significantly lower levels of depression and statistically significantly higher levels of perceived overall health than their less educated counterparts. Notably, Moon and Dilworth-Anderson (2015) provided no discussion as to what might be related to this
outcome, but one could hypothesize that more highly educated caregivers may have higher socio-economic status and great access to resources and less financial burden than people with lower education levels. Another hypothesis would be that more highly educated individuals may have jobs in healthcare (e.g., doctors, nurses, etc.) and may be more adept at navigating the United States’ complex healthcare system to more easily address the needs of the IWD and obtain principle caregiving support. However these are hypotheses and much more research on education level and caregiving would be required to elucidate the reasons for this relationship.

**Depression in Caregivers**

It is also important to examine the literature on depression of the caregiver. Mood disorders are highly problematic for caregivers, as the following literature will discuss. In a study of 209 Brazilian caregivers of IWDs, caregivers were more likely to experience major depression, anxiety, insomnia, chronic pain, and diabetes than non-caregivers \( (n = 10,644) \) (Laks, Goren, Duenas, Novik, & Kahle-Wrobleski, 2016). This link between higher rates of not only mood disorders, but also major physical health implications is likely indicative of the high rates of stress a caregiver experiences when their loved one is ill and also the amount of stress related to the tasks of caregiving. The odds ratio for developing depressive symptoms in their sample of caregivers was 2.008, and the odds ratio for developing a major depressive disorder was 1.483. This was statistically significantly higher than their non-caregiving sample, and cites a clear need to address these concerns for caregivers. (Laks et al., 2016).

Rates of depressive symptoms vary within the literature. Mahoney, Regan, Katona, and Livingston (2005) found that 10.5% of caregivers experience significant
depression. Mahoney et al. (2005) studied 153 individuals with Alzheimer’s disease and their caregivers as part of a larger study. They found, most notably, that having a poor quality of relationship with the IWD was related to depression (Mann-Whitney U = 1494.5, p < .05). This is helpful because it lends further evidence to the hypothesis that the quality of the relationship can impact mental health symptoms, but it only represents the perspective of the caregiver. Having the perspective of the other half of the caregiving dyad could further the understanding of both parties illness experience, and further contribute to designing interventions.

A study of spousal caregivers of hospice patients with dementia (n = 40) or lung cancer (n = 40) found that being a caregiving wife (as opposed to a husband) was associated with experiencing more negative social interactions with their social circle (Haley, LaMonde, Han, Burton, & Schonwetter, 2003). In addition, it was found that poor caregiver health was associated with higher rates of depression. This is of concern because caregivers are under a great deal of stress, so maintaining both the physical and mental health of caregivers is important to maintain a high quality of life for both caregivers and IWDs. This study was also interesting in that it compared caregivers of patients with dementia and caregivers of patients with lung cancer. They found that the patient’s diagnosis and symptoms, duration of caregiving, or hours spent each week engaged in caregiving tasks, all were not significant in predicting depression, while physical health status of the caregiver and being a wife as opposed to being a husband was predictive of depression (Haley et al., 2003). This is contrary to many common assumptions, such as that depression would be problematic for both caregiving husband and wives, but consistent with other literature on the topic (e.g., Alzheimer’s
Association, 2016) and reiterates a need to consider holistic health of body and mind for caregivers.

Several studies have examined the rates of medication prescribed to caregivers. A study of 218 spousal caregivers found that caregivers were statistically significantly more likely to experience depression than the 353 non-caregiving matched controls (Jolting, van Hout, Schellevis, van der Horst, Scheltens, Knol, & Marwijk, 2010). Perhaps more importantly, they found that antidepressants and anxiolytic medications were far more likely to be prescribed to this group (Jolting et al, 2010).

Related to this, a different study (n = 40) found that use of escitalopram (Lexapro) was effective in treating symptoms of depression in caregivers of dementia patients, and that symptoms of anxiety, burden, distress, and resilience all improved with medication as opposed to placebo (Lavretsky, Siddarth, & Irwin, 2010). While it is encouraging that there are pharmaceutical interventions that can be helpful to caregivers, it is also important to note that these medications frequently have negative side effects, so in an ideal caregiving situation, other interventions could be used to improve the mental health of the caregiver. Also of note is that this study did not compare pharmaceutical treatment to any kind of psychotherapeutic intervention, and a head-to-head comparison of the two would help researchers better understand how to best alleviate affective symptoms in caregivers.

Depression can also impact the way caregivers experience caregiving, predicting other negative outcomes. A study by Springate and Tremont (2014) found that caregivers who were older and experiencing greater levels of depression than their younger, less depressed peers, had a greater, more direct impact of caregiving on their lives as well as
experiencing guilt, frustration, and embarrassment. The authors did not specify what specific age ranges are considered ‘older’ and ‘younger.’

Similarly, a study of German caregivers of frontotemporal dementia patients found that depression predicts lower quality of life in caregivers (Roche, Croot, MacCann, Cramer, & Diehl-Schmid, 2015). Ninety-four caregivers participated in their study of the caregiving experience of caregivers for patients with frontotemporal dementia. The majority of caregivers were female and spouses of the IWDs. Approximately 34% of caregivers endorsed moderate to severe depression, and this was predictive of lower perceived quality of life. It was also found that caregiving strain specifically exacerbated levels of depression, which in turn impacted quality of life, so caregiving strain specifically caused a cascade of negative effects for the caregiver including both increased depression and decreased quality of life (Roche et al., 2015).

A study by MacNeil et al. (2009) investigated anger of 417 dementia caregivers as both a mediator and moderator of depression, resentment, and anxiety with potentially harmful behavior against their elderly care recipients. The authors define potentially harmful behavior as either psychological (yelling, screaming, threatening the care recipient) or physical (shaking, slapping, or handling the care recipient roughly). They found statistically significant correlations between potentially harmful behavior and caregiver anger \( (r = .44) \), anxiety \( (r = .27) \), depression \( (r = .32) \), and resentment \( (r = .46) \). In addition, caregiver anger mediated the relationship between caregiver anger and potentially harmful behavior, partially mediated the relationship between depression and potentially harmful behavior, and partially mediated the relationship between resentment and potentially harmful behavior. Finally, anger moderated the relationship between both
depression and resentment and potentially harmful behavior, but was not found to be a moderator for caregiver anxiety. This study clearly establishes a link between the emotions of the caregiver and direct outcomes for the patient. It highlights the need to consider the mental health of the caregiver with potentially dire outcomes for the IWD. IWDs are an at-risk population given their cognitive disabilities, so it is a social justice prerogative to protect this population from abuse and other harmful behavior. This can be achieved by promoting wellness for caregivers. Further evidence related to this includes studies by Mahoney et al. (2005), who found that poor physical health and poor relationship quality predicted experiencing depression in 153 caregivers, and Joling et al. (2012) found that being Latino and poor physical health predicted depression in their study of 725 dementia caregivers.

Conversely, positive emotions and positive appraisals of caregiving may have protective factors for caregivers. Kajiwara, Nakatani, Ono, and Miyakoshi (2015) investigated a positive appraisal of caregiving and continuation of caregiving in 405 Japanese caregivers of IWDs. In their study, a positive appraisal of caregiving made the caregiver more likely to continue caring for the IWD as opposed to placing the IWD in a nursing home. Caregiver burden negatively related to continuity of care within the home, making it more likely for caregivers to place the IWD in a nursing home (Kajiwara et al., 2015).

In sum, every aspect of caregivers and caregiving has been examined in detail, namely race, age, relationship to the IWD, gender, mood symptoms and others, and research has established that many individuals experience and cope with the stresses of caregiving in dramatically different ways. The common thread in this research is that all
caregivers experience stress and negative emotions related to caregiving and the illness of their care partner. What is not widely studied is how this impacts the IWD. Because it is clear that the partners of the dyad are intricately linked, it is possible that the experience and emotions of one directly impact the experience and emotions of the other. Further research is needed to establish this hypothesis and further investigate the details of the relationship of these factors.

**Dyad Relationship Strain**

Dyad relationship strain is one of the secondary strains; specifically it is a role strain. It refers to stress and conflict within the care partnership (Judge et al., 2009). Frequently, the care partnership arises out of a previously intimate relationship; caregivers are most often a spouse or an adult-child of the IWD. The illness experience dramatically changes the roles of both care partners. This change is sometimes difficult to navigate, especially in a caregiving environment that already carries a great deal of stress for both care partners. Because of this, there is frequently strain within this relationship. This is another area where caregivers can be highly influential in the experience of the IWD, because the mental health of the caregiver can influence strain in this relationship. If a caregiver is not managing their stress properly, this can cause further rifts between the two members of the dyad. Conversely, a caregiver who is managing their stress level well may not bring extraneous stressors into his or her relationship with the IWD.

There is limited research available on dyadic relationship strain specifically, but one such study examined dyadic relationship strain as a component of overall caregiver strain (Bass, McClendon, Deimling, & Mukherjee, 1994). This study of 576 caregivers
examined whether a diagnosis of mental impairment impacted levels of strain for the family. They found that when a formal diagnosis of mental impairment had been made, dyadic relationship strain increased with evidence of increased tension and conflict between care recipient and caregiver. Bass and colleagues (1994) hypothesized that this may be due to several factors, including elevating the importance of the illness within the family, the patient’s formal diagnosis resulting in role-reversal and placing the care recipient in a new, dependent role, or that the diagnosis accentuates the demands of the caregiving role, which may result in further role conflicts. Other variables that caused increase caregiver strain included activity restriction and social isolation of the caregivers (Bass et al., 1994).

Caregiver burden has been found to be related to relationship satisfaction. Steadman, Tremont, and Davis (2007) investigated the relationship between relationship satisfaction and caregiver burden. Participants included 72 spouse or adult-child caregivers of IWDs. It was found that poorer relationship satisfaction was associated with higher levels of burden \( r = -0.38, p = 0.01 \), and that frequency of memory or behavioral problems was significantly related to caregiver’s perception premorbid relationship satisfaction \( r = -0.39, p = 0.01 \). In addition, impairment of ADLs and frequency of memory and behavioral problems were found to also correlate with caregiver burden, which is greatly supported in previous literature (e.g., Dunkin & Anderson-Hanley, 1998). Also of interest, disease severity did not have a significant positive relationship with caregiver burden. This is contrary to most other literature, including Simonelli et al. (2008). The most interesting of these findings is that behavioral problems are related to caregiver’s perception of relationship quality. One can
assume that the IWD and his or her caregiver may have a similar appraisal of the relationship quality, and this may somehow be related to the behavior problems. In the literature, behavior problems of IWD have been linked to depression of the caregiver and other mood disorders such as anxiety (e.g., Dunkin & Anderson-Hanley, 1998), so it can by hypothesized that relationship quality may be contributing to the mood disorder, which may in turn result in behavior problems.

Related to the previous study, caregiver burden has been found to impact many aspects of relationship quality, such as marital satisfaction and sexual intimacy. Simonelli et al.’s (2008) investigated the impact of caregiver burden on marital satisfaction and sexual intimacy. One hundred spousal caregivers of a partner with AD participated in the study. Both affective and sexual relationship satisfaction negatively correlated with caregiver burden ($r = -.448, p = .001$, and $r = -.374, p = .001$ respectively). This could lead one to believe that relationship strain could increase caregiver burden. Less importantly, but still of interest, is that AD dyads reported less affective and sexual relationship satisfaction than their age matched controls. No statistically significant difference was found between in control couples and AD couples in reports of feelings of love toward their partners.

Relationship quality can impact many variables, including the desire to place IWDs in a nursing facility. Spitznagel, Tremont, Davis, and Foster (2006) investigated the relationship between desire to institutionalize and relationship factors. Of the 72 caregivers in the study, those who reported no desire to institutionalize their care partners also reported lower levels of family dysfunction ($F (1,70) = 6.42, p = .05$). Interestingly, they found that the relationship between spousal relationship and desire to institutionalize
was not statistically significant, which could be viewed in contrast to other literature that suggests that a poor spousal relationship is related to increased burden (Campbell et al., 2008), and increased burden was found in this study to be related to an increased desire to institutionalize the IWD ($F(1,70) = 9.46, p = .01$).

Premorbid family functioning can impact caregiver burden. In a study of 38 caregivers of dementia patients, Heru, Ryan, and Iqbal (2004) found that impaired family functioning increased caregiver burden. The majority of the caregivers were either spouses or adult children. The authors assessed multiple domains of family functioning. Analyses suggested that poor family function was significantly associated with increased caregiver burden ($t(32) = -2.56, p = .02$) as perceived by the caregiver. Of the specific family function domains, those most closely associated with increased burden were communication ($t(32) = -6.94, p = .0001$), problem solving ($t(32) = -5.78, p = .0001$), and affective responsiveness, or the range of affect expressed by family members including anger, criticism, and sadness (on this scale, a higher score means more anger, criticism, and sadness) ($t(32) = -5.04, p = .0001$). Causality cannot be inferred, so one could hypothesize that increased burden is causing poor family function or that pre-existing poor family function is causing increased burden. Quite possibly, it is either one of these, or even both, depending on the individual family system and disease process of the IWD. In any event, these findings are significant because literature has previously established that increased burden is related to increased depression in caregivers. This study is significant because it can be assumed that family function and relationship strain are highly similar constructs, and with a dearth of literature available on this topic, this is
helpful in directing further inquiry in the relationship between relationship strain and depression in both care partners.

Related to family functioning, family adaptability may play a role in relationship satisfaction in married couples of hemodialysis patients (Jiang et al., 2015). Though these are not caregiving dyads of dementia, many aspects of caregiving for other chronic illnesses overlap with the caregiving experience for dementia. Their study included a sample of 38 Chinese hemodialysis patients and their 38 spouses, as well as 38 healthy controls for comparison. They found that family adaptability was a statistically significant predictor of relationship satisfaction in the married couples of the patients. Another statistically significant predictor was social support outside the marriage (Jiang et al., 2015). Again, this study did not address dementia caregiving specifically, but it raises interesting ideas as to how families can cope with the stress of serious illness in a healthy manner. Jiang et al. (2015) defined family adaptability as the ability to adjust to the family system, including changing rules, structure, and typical behaviors to changes in the health of family members. When considered in this light, it is clear that families experiencing dementia would also need a high level of adaptability to cope effectively with stresses presented by dementia. Dementia is also a progressive disease, so the symptoms experienced by the IWD continually worsen and change until the ultimate death of the patient. This requires ongoing adaptability and change on the part of caregivers as they address each new concern for the patient.

Many factors have been found to be related to relationship strain, including caregiver mastery. Connor and colleagues (2008) investigated whether a care management activity intervention impacted levels of caregiver mastery and relationship
strain. Using data from the Alzheimer’s Disease Coordinated Care for San Diego Seniors study, 181 caregiving dyads received the intervention, which included services from nursing and social work care managers who recognized concerns, established care plans, and initiated care plan activities with the dyad. While there was a difference on levels of mastery with those receiving the intervention improving caregiver mastery, there was no significant difference in level of relationship strain ($p = .10$). There are many reasons that this could have happened, of which the most probable is that change in relationship strain would require a different style of intervention, and possibly addressing the mood symptoms of one or both care partners. One limitation of this study was that it did not account for other factors that could have related to relationship strain, such as mood disorders of one or both care partners.

Some research already suggests a link between relationship satisfaction and depression in caregivers. Lawrence et al. (1998) stated that “The quality of the relationship can be viewed not only as a product of the stressors, but also as providing a lens though which stressors are interpreted or appraised” (p. 150). In their study of 118 family caregivers, they found that current relationship quality mediated associations between caregiving stress and caregiver depression. This is helpful as it provides a link between relationship quality and mood symptoms; however it is limited because it is only providing the point of view of the caregiver. It would be helpful to have the perspective of the IWD to add to the understanding of this relationship.

Similarly, a study by Adams, McClendon, and Smyth (2008) specifically investigated the relationship between relationship quality and depression among 428 caregivers of dementia patients. The majority of the caregivers were spouses (72.9%),
and all other caregivers were adult children or other relatives. Both relationship quality prior to diagnosis and present quality of relationship were investigated, and both were found to be related to depression among the caregivers ($r = .088, p = .05$; and $r = -.197, p = .001$, respectively). Also of note, previous and current relationship quality had a moderate correlation with one another ($r = .479, p = .001$), which helped the authors develop a path model for their analysis. The path model suggested that within the context of other variables analyzed, that previous relationship quality predicted current relationship quality, which then predicted depressive symptoms in caregivers. This information is highly useful in that it suggests that there is the potential to intervene early on to improve relationship quality, and perhaps in turn improve depressive symptoms in caregivers; however, this study did not investigate how this impacts IWDs. It would be helpful to have the perspective of the IWD to see if this intervention could also improve their appraisal of relationship quality within the caregiving dyad.

An earlier study investigated how relationship quality impacted caregiver depression, and in turn, how that directly related to outcomes for the IWD. Williamson and Shaffer (2001) investigated if relationship quality predicted caregiver depression and care receiver maltreatment. They attempted to investigate relationships between premorbid relationship quality, present relationship quality, and caregiver outcomes. To address this goal, they conducted a longitudinal study with 142 spousal caregivers of dementia patients and found that caregivers with better relationships pre-illness were more likely to view their current relationship as more rewarding ($r = .50, p = .001$) than those with poorer relationship pre-illness. These caregivers were less depressed ($r = -.26, p = .01$) than those with poorer relationships pre-illness, and were less likely to engage in
potentially harmful behaviors toward their care partner ($r = -.29, p = .001$) than caregivers with poorer relationships pre-illness. They then conducted a path analysis and found that pre-illness relationship quality predicted current relationship quality, which then predicted caregiver depression, and which in turn predicted potentially harmful behaviors. This study provided a clear link between relationship quality and caregiver depression, but perhaps more importantly, it provided an opportunity to intervene before caregivers become abusive toward IWDs. If clinicians can provide assistance early on with the relationship or even caregiver depression, then well-being of the IWD can be enhanced through an intervention focused on the caregiver, which can save both time and resources. Similar to other literature, it addresses the possibility for protection of the IWD as an already at-risk population due to their cognitive disabilities.

Interventions for both care partners have been found effective in reducing dyadic relationship strain. Judge, Yarr, Looman, and Bass (2013) investigated whether a strength-based dyadic intervention could impact several caregiving dimensions, including dyadic relationship strain. They found that their intervention significantly reduced dyadic relationship strain amongst caregivers ($t(109) = 2.51, p = .01$), and also significantly reduced caregiver depression ($t(109) = -2.12, p = .04$). The intervention was six 90 minute sessions that combined education with cognitive rehabilitation skills into a single intervention that worked simultaneously with both care partners, so several factors could have impacted the decrease in relationship strain. Overall, it was found to increase general well-being of the caregiver, so this alone could have impacted how they viewed strain with their care partner (Judge et al., 2013). One strength of this intervention was that it included both care partners, allowing both the caregiver and IWD to contribute
their thoughts and opinions on how to best improve outcomes for the dyad as a whole. Related to this, a theoretical article by Mendes (2015) discusses the importance of relationships in the overall health of IWDs and how healthcare professionals can enhance relationships for caregiving dyads. She highlights the need to improve communication between care partners and the importance of acceptance of the disease process for each care partner. She also discussed how healthcare professionals can help improve these things for the caregiving dyad (Mendes, 2015). This is in line with Judge et al.'s (2012) work, taking a strength-based approach involving both care partners to improve relationships for caregiving dyads.

In sum, there is an established relationship between mood symptoms of the caregiver and dimensions of the relationship. Noticeably absent from the literature are studies of dyadic relationship from the perspective of the IWD. This leaves many questions unanswered. Do they perceive their relationship has changed? If so, is this frustrating, and what specifically about the change is most frustrating to them? And finally, perhaps most importantly, how does this relate to their mood symptoms and overall quality of life? While research is limited in this area, there is room for growth and better understanding of the IWD illness process. With that comes potentially enhanced emotional health for both care partners.

**Summary**

In sum, the literature on caregiving experiences and the illness experience of individuals with dementia suggests that numerous variables can impact both caregivers and IWDs, including mental health, age, education level, gender, and more. While there is a wealth of data on caregiving experiences, there is a great deal less literature on the
illness experience of IWDs, despite clear evidence that suggests that these individuals can accurately report on their subjective mood symptoms earlier in their disease process (Dawson et al., 2013). Depression is known to be closely associated with dementia, and many studies have found that depression symptoms commonly occur prior to onset of cognitive decline (Gracia-Garcia et al., 2015; Karlsson et al., 2014; Snowden et al., 2015); however, it is unclear what role the relationship with the caregiver or other variables related to caregiving may be impacting depression. The SPM of IWDs (Judge et al., 2009) suggests that family/friend network, role captivity, distress, dependency, family role strain, and dyadic relationship strain all can influence psychosocial outcomes of the IWD, and these are all factors that can conceivably be influenced by caregiving. The present analysis will focus on one of these items, dyadic relationship strain, as it relates to depression in both care partners.

Much more literature is needed to clear up disparities in the current literature and also to fill gaps of what is yet unknown to improve outcomes for both caregivers and IWDs. Specifically, more needs to be known on how the IWD experiences his or her illness, and what aspects of caregiving can impact the illness experience. Research has established that relationship factors can impact depression for the caregiver, and also that the caregiver can impact the IWD (Judge et al., 2013). However, research has not clearly established how relationship quality or relationship strain impacts the IWD, and there is little research available on the best ways to improve relationship quality and depression in both caregivers and IWDs. As illustrated by the Stress Process Models for Caregivers and IWDs (Judge et al., 2009; Pearlin et al., 1990), many factors contribute to emotional
outcomes, and relationship strain has been selected because it is not widely studied in the literature, but it is integral to the welfare and illness experience of each care partner.

Aims and Hypotheses

The aim of this study is to investigate the impact that care partners have on one another’s depression. Specifically, each care partner’s perception of relationship strain within the caregiving dyad is being used as a predictor of depression not only within that individual, but also within their care partner.

The first hypothesis is that the relationship strain of each care partner will predict levels of depression for that care partner. The second hypothesis is that the relationship strain for the caregiver will predict the level of depression in the IWD. The third hypothesis is that the level of relationship strain for the IWD will predict the level of depression for the caregiver.
CHAPTER III

METHOD

Partners in Dementia Care (PDC) was a multi-site telephone intervention for dementia patients and their caregivers, funded through the Veterans Administration, the Alzheimer’s Association, the Robert Wood Johnson Foundation, and the Houston Center for Quality Care and Utilization Studies. Participants were 508 veterans and 486 caregivers of at least 50 years of age with various dementia diagnoses. Five locations nationwide (each a VA Medical Center) were used to administer the intervention, which sought to provide information about services available, help motivate family members of patients, and provide various forms of support for the families and Veterans. Results of the intervention were examined at 6 and 12 months post intervention, and information was collected in a structured interview by trained nursing and social work staff. Data from this study were selected for the present analysis to address gaps in the literature on how caregivers can potentially impact their patients. Studies as large as the PDC project are rare, and this dataset had many desirable qualities. First, it included measures of the relationship of the dyad as well as psychosocial measures for both care partners. Second, it had self-report data completed by each care partner, while in many
other studies, caregivers report symptoms and other outcomes for the IWD. Having self-report data from the IWD provides unique insight into the illness experience of the IWD. Third, the data were collected from five different locations nationwide, providing and more generalizable view of caregiving and illness experiences of caregiving dyads. Finally, the PDC project was designed and implemented by a team of researchers, psychologists, and medical professionals at each VA location, ensuring that the data used is of the highest caliber in terms of quality design and rigorous data collection procedures.

**Participants**

**Demographic information.** Initially, 508 Veterans consented to participation in the Partners in Dementia Care study. Of these, 333 (66%) completed the baseline interview; and of these individuals, 263 (79.0%) completed the six month interview, and 194 (58.3%) completed the twelve month (Bass et al., 2014). The vast majority of Veterans were men (97.5%) and the vast majority of caregivers were women (94.9%). The mean age of the Veterans was 78.5 (Bass et al., 2014) and the mean age of caregivers was 66.2 (Bradford, Upchurch, Bass, Judge, Snow, Wilson, and Kunik, 2011). The majority of the Veterans identified their race as White (84.9%), which was similar to caregivers, 84.4% of whom identified as White (Judge et al., 2011). Most Veterans had completed high school (76.4%), and 24.8% had a college degree (Bass et al., 2014). Caregivers had lower educational attainment. For highest educational attainment of caregivers, 21% completed high school, 38% had some college, and 18% completed a college degree (Bradford et al., 2011). On average, Veterans had been diagnosed with dementia for two years prior to the study (Bass et al., 2014). For relationship between
caregiver and patient, the majority of the caregivers were wives of the IWD (66.7%), 20.0% were a daughter, 2.2% were a husband, 3.3% were a son, and 7.8% identified as “other” (Judge et al., 2011).

**Attrition.** Bass et al. (2014) previously studied some components of the data that were used in the present analysis. They completed an attrition analysis and found “(V)eterans who completed baseline interviews but who did not complete six- and/or twelve-month follow-ups indicated that those who stopped participating were significantly more likely to be members of a minority group, more impaired in personal care at baseline, and more isolated from others at baseline,” (p. 5). This suggests that the study may not be entirely representative of the experiences of all Veterans.

**Research Design**

The aim of this study was to investigate the impact of the relationship between care partners, and how relationship can impact the dyad’s depression. For the analysis, each care partner’s perception of relationship strain within the caregiving dyad was being used as a predictor of depression not only within that individual, but also for their care partner. The present study was a quantitative, theory-driven analysis of proximal factors impacting illness and caregiving experiences of caregiving dyads with dementia using the SPM of IWDs (Judge et al., 2009). As with most quantitative research, the study was closely aligned with a post-positivist paradigm and is person-centered and descriptive in nature (Heppner, Wampold, Owen, Thompson, & Heppner, 2015), and used the Stress Process Model for Individuals with Dementia (Judge et al., 2009) to guide exploration of the illness experience of IWDs as well as the caregiving experience for the caregivers of each dyad. The present study was non-experimental due to the use of secondary data, but
the data were drawn from a longitudinal study of an intervention for caregiving dyads of IWDs. Partners in Dementia Care was a true experimental design in that it had a control group that received usual care and random assignment for intervention sites (Bass et al., 2015; Heppner et al., 2015). Data were analyzed using the actor-partner interdependence model (APIM) for distinguishable dyads using structural equation modeling (Kashy & Kenny, 1999; Kenny & Cook, 1999; Kenny, Kashy, & Cook, 2006), and this is discussed later in greater detail in the Data Analysis section.

Measures

The following measures were employed: Center for Epidemiologic Studies Depression Scale (CES-D) (Kohout, Berkman, Evans, & Cornoni-Huntley, 1993) and the Measure of Dyadic Relationship Strain Dyad (Deimling, Bass, Townsend, & Noelker, 1989).

**Center for Epidemiologic Studies Depression Scale (CES-D)** (Kohout et al., 1993). The aim of measuring depression was to examine one outcome, noted in the SPMs of caregivers (Pearlin et al., 1990) and IWDs (Judge et al., 2009). Depression was measured by the 11-item Center for Epidemiologic Studies Depression Scale (CES-D) (Kohout et al., 1993). This is a widely used measure of depression that is available in the public domain.

When the original CES-D (Kohout et al., 1993) was created, it drew items from previously validated measures of depression that had assessed the primary symptoms of depression and had been established by both clinical and factor-analytic studies (Kohout et al., 1993; Markush & Favero, 1973; Radloff, 1977). The CES-D was somewhat novel in that it only assessed current symptoms of depression, and did not focus on previous
experiences related to depression. Unlike other inventories, it only asked patients to rate their symptoms over the last seven days as opposed to a longer period of time. Another benefit of the CES-D over other measures was that it could be broken down into four major domains of depressive symptoms including depressed affect, positive affect, somatic complaints, and interpersonal problems (Kohout et al., 1993). The original CES-D was 20 items with some being reverse scored. Respondents could answer with 0 (indicating no symptoms over the past week) to 3 (indicating great difficulty with symptoms over the past week), for a total score of 0-60 on the measure (Radloff, 1977). Kohout and colleagues developed a shorter 11 item version in 1993 with the expressed aim of ease of use with elderly populations (Kohout et al., 1993). They developed both a 0-2 Likert scale 11 item version and a forced choice 11 item version that provided satisfactory validity and reliability when compared to the original 20 item version. The main advantage of the new version was ease of use with older adult populations including IWDs, as older adults with symptoms of cognitive impairment sometimes have difficulty with Likert scales; however a secondary advantage was that the new versions can be administered in half the time of the original (Kohout et al., 1993). The shorter time is ideal for older adults who may struggle with attention on longer measures, but it is also beneficial for ease of use in large-scale studies when it may be administered with other measures, creating a shorter battery for study participants.

Caregivers and IWDs were asked the same questions drawn directly from the CES-D (Kohout et al., 1993), with the only difference being that caregivers were asked Likert-type questions, and IWDs were given forced choice questions (Bass et al., 2014).
Caregivers were asked how many times in a week do they experienced the following, and IWDs were asked if they had felt this way in the past week:

a. Not feel like eating?
b. Feel depressed?
c. Feel that everything you did was an effort?
d. Sleep restlessly?
e. Feel happy? (reverse scored item)
f. Feel lonely?
g. Feel people were unfriendly?
h. Enjoy life? (reverse scored item)
i. Feel sad?
j. Feel people disliked you?
k. Not seem to be able to ‘get going?’

For caregivers, the CES-D (Kohout et al., 1993) questions were administered using a Likert scale of 0-2, where zero represents ‘hardly or never’ experiencing the symptom, one represents ‘sometimes (1-3 days a week)’ experiencing the symptom, and two represents ‘often (4-7 days a week)’ experiencing the symptom (Bass et al., 2014). Higher scores represent more severe depressive symptoms, and lower scores represent less severe depressive symptoms. For IWDs, the questions were identical, but reduced a force choice answer of ‘yes’ or ‘no’ to whether the IWD had experienced the symptom in the past week (Bass et al., 2014). This was done because IWDs generally have difficulty
responding to more complex questions, and Likert items can be difficult for this population to understand.

Radloff (1977) investigated reliability and validity for the original 20 item version of the CES-D (Kohout et al., 1993). They randomly sampled individuals ages 18+ from Kansas City, Missouri \((n = 1173)\) and Washington County, Maryland \((n = 1673)\) to obtain a diverse sample, and also obtained clinical samples from psychiatric facilities in Washington County, Maryland \((n = 70)\) and New Haven, Connecticut \((n = 35)\) (Radloff, 1977). Test-retest reliability was deemed acceptable at all time points \((r = .67\) comparing initial interview and re-assessment at four weeks). The test scores were also found to demonstrate concurrent validity when compared to other depression measures of that era \((r = .51, .60, .61, \text{and} .54)\). The test also demonstrated discriminant validity with a test of positive affect \((r = -.21)\).

Kohout et al. (1993) provided evidence that supports the use of both the forced choice and Likert-type scale versions of the 11 item CES-D (Kohout et al., 1993). In a sample of three sites that comprised 10,296 participants over the age of 65, the two new 11 item measures provided reliability evidence in comparison with the original 20 item version (Likert \(r = .95\), forced choice \(r = .88\)). Factor analysis findings from this study suggested that both forms also measure the same four domains of depression symptoms including depressed mood, positive mood, somatic, and interpersonal symptoms of depression. In this study, both versions were specifically tested with adults over age 65, providing further evidence that this measure was an ideal choice for use in this study (Kohout et al., 1993). For the present analysis, final scores on the CES-D of both patients and caregivers were converted to \(z\)-scores for comparison of IWD to caregiver.
Bass et al. (2014), using the same data that will be used in the present analysis, found that this measure had acceptable reliability at all three data-collection waves of the PDC trial (Cronbach’s alpha of .76, .79 and .78 at baseline, six months and twelve months, respectively).

**Dyad Relationship Strain** (Deimling, Bass, Townsend, & Noelker, 1989). The aim of using a measure of relationship strain was to explore the quality of the relationship between care partners. Dyad relationship strain was assessed using an adapted measure from a published family caregiving measure (Bass, McClendon, Deimling, & Mukherjee, 1994; Deimling et al., 1989). It was the sum of six questions focused on perceptions of the quality of the relationship with their care partners. Questions asked whether the care partner believed they were being manipulated by their care partner, if their care partner made more requests than needed, had feelings of anger, resentment, or depression related to their care partner, and about interpersonal strain (Bass et al., 1994).

This measure’s questions were administered in a Likert-type scale for caregivers and forced choice of ‘agree’ or ‘disagree’ for IWDs (Bass et al., 2014). For caregivers, the Likert scale was as follows: A score of three was given if the caregiver stated they ‘strongly agree,’ a score of two for ‘agree,’ a score of one for ‘disagree,’ and a score of zero for ‘strongly disagree.’ Higher scores on this measure represent increased relationship strain, and a lower score represents lower levels of relationship strain. Questions asked whether, because of health problems and need for assistance, care partners felt that their care partner tried to manipulate them, felt that the relationship with the care partner was strained, felt resentful toward the care partner, felt angry toward the care partner, felt appreciated for what they do (reverse scored), or felt close to their care
partner (reverse scored) (Bass et al., 2014). Similar to the CES-D (Kohout et al., 1993), the scores for IWDs and caregivers were converted to z-scores to allow for comparison of each member in the dyad in the present analysis.

Bass et al. (2014) evaluated reliability using the same data that was used in this analysis. They found this measure had good reliability across all waves of data-collection during the PDC intervention (Cronbach’s alpha .78, .77 and .84 at baseline, six months and twelve months, respectively) (Bass et al., 2014). A similar study used the PDC data for just the caregivers (IWDs were not included), and found good reliability across all periods of data collection (Cronbach’s alpha .79, .80 and .82 at baseline, six months and twelve months, respectively) (Bass et al., 2013). Previous studies using other data sources have also found this measure’s scores to be highly reliable, including Bass et al. (1994) which had a Cronbach’s alpha .86, and Deimling et al. (1989), which had a Cronbach’s alpha of .96, with similar findings in Bass et al., 2012 (Cronbach’s alpha of .78) and Bass et al., 2014 (Cronbach’s alpha of .78, .77, and .84 at three data collection time points). Bass et al. (2014) demonstrated construct validity in that their sample from the PDC intervention showed improvement on this measure in the expected direction when compared to participants who received usual care. Patients in the PDC intervention group reduced their dyad relationship strain scores by a mean of 80%, whereas the usual care group reduced their dyad relationship strain scores by 25% during the same time period Bass et al., 2014. Similarly, Bass et al. (2013) demonstrated a reduction in dyad relationship strain using the PDC intervention. For this study, when comparing change from 6 to 12 months post-intervention, the intervention group decreased their dyad relationship strain by 14.9% and the usual care group increased their relationship strain.
by 4.8% (Bass et al., 2013). An additional study by Bass, McClendon, Brennan, and McCarthy (1998) used a computer support network to improve outcomes for dementia caregivers. In this study, the intervention group decreased their dyad relationship strain by a mean .78 points, whereas the control group demonstrated no change in scores (Bass et al., 1998). Another study by Bass, Clark, Looman, McCarthy, and Eckert (2003) investigated possible reductions in relationship strain using a care consultation intervention for dementia caregivers. This study found that their intervention reduced dyad relationship in non-spouse caregivers ($r = -.33, p = .02$), but not for spousal caregivers ($r = .06, p = .56$) when compared to a control group (Bass et al., 2003). Similar results were found in Judge et al’s (2013) intervention Project ANSWERS, in which the intervention group had significant improvement in dyad relationship strain as compared to the control group as measured by the current measure.

Bass et al. (1994) noted the measure’s similarity to other popular measures of burden, but did not expressly examine validity with statistical comparison. Sebern and Whitlatch (2007), expressly examined validity of this measure and found it to be reliable and valid for patients and caregivers using a sample of 66 IWDs and 65 of their caregivers. Factor analysis revealed that the items loaded into two factors, positive dyadic interaction and dyadic relationship strain, and the factor loadings were similar for IWD and caregiver groups. Concurrent validity was examined when the dyadic relationship scale was compared with the CES-D (Kohout et al., 1993), and found to be acceptable.
Procedure

Data for this project were selected from a larger dataset of the Partners in Dementia Care (PDC) study. PDC was a joint project between the Veteran’s Administration and the Alzheimer’s Association to develop and test the efficacy of an intervention for Veterans with dementia and their caregivers (Bass et al., 2014). This non-pharmacologic, yearlong intervention was designed to improve various psychosocial outcomes including unmet needs, embarrassment about memory problems, isolation, relationship strain, and depression. Structured interviews were completed via phone by trained staff (nursing, social workers, and other healthcare professionals) with participating veterans and their caregivers at baseline, six months, and 12 months of intervention. Measures including assessment for depression and dyadic relationship strain were collected at that time (Bass et al., 2014). Initially, data from the 12 month interview were considered for the analysis, but due to the sample size at that time point being small, data from the initial interview were used for the present analysis. The advantage of using data from the first time point was a larger sample size, but a drawback for using data from this point is that the Veterans and their caregivers did not have the benefit of the PDC intervention, and thus possibly displayed higher levels of dyadic relationship strain and depression, though comparison studies were not conducted to verify this (Bass et al., 2014).

Prior to study implementation, PDC was granted Institutional Review Board (IRB) approval at each Veteran’s Administration Medical Center used for the intervention, as well as by the Benjamin Rose Institute’s IRB. Prior to examination of
the data for the present analysis, IRB approval at Cleveland State University was sought and granted.

**Statistical Analysis**

Data were analyzed using the actor-partner interdependence model (APIM) for distinguishable dyads using structural equation modeling (Kashy & Kenny, 1999; Kenny & Cook, 1999; Kenny, Kashy, & Cook, 2006). This method was selected to address the aim of investigating the impact of each care partner’s perception of relationship strain and the relationship to depression not only within that individual, but also within their care partner.

The literature suggests that the APIM is commonly used in research with couples and families because it accounts for a systems approach (Momtaz, Hamid, Masud, Haron, & Ibrahim, 2013). This is consistent with the Stress Process Model for Caregivers of Dementia Patients (Pearlin et al., 1990) and the Stress Process Model for Individuals with Dementia (Judge et al., 2009), which are theoretical underpinning for the present analysis, because the stress process models take a systems approach in examining psychosocial outcomes for the patient and caregiver. The APIM can "explore how individuals' independent variables simultaneously and independently contribute to their own dependent variables and to their partner's dependent variables," (Momtaz et al., 2013, p. 1415). This model accounts for each care partner’s perception of relationship strain influencing his or her own depression, but also influencing the other care partner’s depression as well as influencing the other care partner’s perception of relationship strain.

Because the members of the caregiving dyad are interlinked in many ways, the sets of data from each care partner cannot be treated as independent observations. As
seen in Figure 2, located on page 104, the illustration, which is adapted from that of Kenny, Kashy, and Cook (2006), shows how this interdependence is accounted for. It also illustrates the way the model allows one to retain the individual measurements while nesting the measurements within the context of the dyad, allowing for comparison of scores with the care partner. For the present analysis, using Kenny, Kashy, and Cook’s (2005) guidance for the current model, there are boxes highlighting the variables for each care partner’s dyadic relationship strain and depression. The horizontal arrows indicate actor effects, or how much impact one person has on their own outcomes. The diagonal arrows indicate partner effects, or how much impact one’s care partner has on one’s outcomes. Partner effects are the interdependent portion of this analysis. Examination of partner effects is useful because the dyadic nature of the present analysis does not allow for independent observations, but rather accounts for a systemic approach to the problem. As stated by Cook and Kenny (2005), “Actor effects are estimated controlling for the partner effects, and partner effects are estimated controlling for actor effects” (p. 103). Finally, Kenny, Kashy, and Cook (2006) note the presence of residuals, or error, for this analysis, because it is highly unlikely that the selected variables would account for all the variance of this analysis. In the model for this analysis, $R^2$ will reflect this and note how much variance was accounted for by the present model.

This approach has advantages over other statistical options such as regression in several ways (Cook & Kenny, 2005). First, it can test the differences between two actor effects and two partner effects simultaneously, reducing the possibility of error. Next, it can answer whether the actor or the partner has a larger effect, which would be difficult to determine with independent observations. Finally, it can pool effects across dyad
members, e.g., tests may not reach significance when each care partner is evaluated separately, but may be significant when combined with the impact of the other care partner (Cook & Kenny, 2005). Regression would be a better choice for examining independent observations, but the APIM is preferable to consider the analysis within the theoretical model of Judge et al.'s (2009) Stress Process Model for IWDs.

There are several ways to use the APIM, and the structural equation modeling (SEM) format for distinguishable dyads was employed (Kenny, Kashy, & Cook, 2006). While Kenny, Kashy, and Cook (2006) use the term SEM for their guidance in how to conduct this analysis, it should be noted that while this analysis is very similar to traditional SEM, it is not in fact SEM given that use of SEM requires latent (i.e. inferred) variables, and the variables for this analysis are observed variables. The advantage of using this form of analysis was that all hypotheses of the study could be conducted simultaneously. The statistical analysis software M+ was used to run the analysis.

Measures were selected from the pre-existing options of the PDC intervention, and were chosen to reflect the goal of investigating the impact care partners have on one another’s health and how their relationship can effect psychosocial outcomes. The Center for Epidemiologic Studies Depression Scale (CES-D) (Kohout et al., 1993) was used as the psychosocial outcome and the Measure of Dyadic Relationship Strain Dyad (Deimling et al., 1989) was used as the measure of the relationship between care partners. The relationships between the variables were similarly selected to investigate these relationships and these decisions were guided by the SPM for IWDs (Judge et al., 2009) and then applied to APIM for distinguishable dyads framework (Cook & Kenny, 2005). Using this framework allowed the analysis to both investigate the impact that the
relationship between care partners has one the other partner’s mental health, but also investigate how the relationship impacts the individual’s mental health, which directly links to a portion of the SPM for IWDs (Judge et al., 2009) with dyad relationship strain being a secondary strain/role strain, and depression being an outcome.

When attempting to model real world situations, there are frequently many intricate causal networks between numerous variables (Gefen, Straub, & Boudrea, 2000). SEM allows researchers to examine these intricate networks in a single statistical analysis that is systematic and all-inclusive analysis. SEM presents a complete model, whereas earlier statistical methods, such as regression and ANOVA, only allow for one layer of relationships to be examined at a time. A large part of the advantage of SEM is that it permits one model both independent and dependent constructs concurrently, enabling one to conduct more complicated analyses. It also reduces the likelihood of error that is inherent in multiple analyses.

Prior to analysis, scores from all four variables were converted to z-scores to allow for comparison between caregiver and IWD variables. Both caregivers and IWDs were asked the same questions, however caregivers’ questions were administered as a Likert scale and IWDs’ questions were forced choices, so the raw scores of the scales were slightly different and converting to z-scores allowed comparison between caregiver and IWD variables. Robust Maximum likelihood estimation (ML) was used for this analysis (Yuan, Yang-Wallentin, & Bentler, 2012). Robust ML is known to be particularly useful for sample sizes over 50, and also helpful when data has significant skew or kurtosis (Yuan et al., 2012). The sample size was over 50, so robust ML was a
good match for this analysis (Yuan et al., 2012), and this is further discussed in the following section. Data were analyzed using M-plus software.
CHAPTER IV

RESULTS

Aims and Hypotheses

The aim of this study was to investigate the impact that care partners’ relationship has on one another’s depression. Specifically, each care partner’s perception of relationship strain within the caregiving dyad was used as a predictor of depression not only within that individual, but also within their care partner.

The first hypothesis was that the relationship strain of each care partner would predict levels of depression for that care partner. The second hypothesis was that the relationship strain for the caregiver would predict the level of depression in the IWD. The third hypothesis was that the level of relationship strain for the IWD would predict the level of depression for the caregiver.

Results

Structural equation modeling requires the assumption of multivariate normality (McDonald & Ho, 2002). To assess for univariate normality, skew and kurtosis were examined (Hair, Black, Babin, Anderson, & Tatham, 2006). For IWD depression, skewness = 0.36 and kurtosis = -0.15. For IWD dyadic relationship strain, skewness =
2.84 and kurtosis = 11.41. For caregiver depression, skewness = 1.20 and kurtosis = 1.51. For caregiver relationship strain, skewness = -0.02 and kurtosis = 1.15. This demonstrates that for some of the variables, assumptions of univariate normality was violated, so multivariate normality may also have been violated; however robust maximum likelihood estimation (ML) was used in the analysis, which allows for the analysis to overcome these violations (Yuan et al., 2012). Robust ML was used because the sample size was over 50 and it was possible that there would be violations of normality. Robust ML is able to overcome the violations in normality found in the present sample.

The caregiver’s dyad relationship strain mean was 6.91 (SD = 2.64) out of a possible score of 0-18 on the measure. The IWD’s dyad relationship strain mean score was 0.79 (SD = 3.75) out of a possible score of 0-6. For depression, the caregiver mean score was 3.90 (SD = 3.41) out of a possible score of 0-22 (a score of 10 or more is considered significant depression (Radloff, 1977), and for IWDs, the mean score was 2.40 (SD = 2.72) out of a possible 0-11 (no official cutoffs were found for depression diagnosis in the literature, but this is not likely to be clinically significant depressive symptoms). For additional information, see Table 1 for Correlation Matrix found below.
Table 1.

**Correlation Matrix for Depression and Dyadic Relationship Strain**

<table>
<thead>
<tr>
<th></th>
<th>IWD Depression</th>
<th>CG Depression</th>
<th>IWD Strain</th>
<th>CG Strain</th>
</tr>
</thead>
<tbody>
<tr>
<td>IWD Depression</td>
<td>1.000</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>CG Depression</td>
<td>.212**</td>
<td>1.000</td>
<td></td>
<td></td>
</tr>
<tr>
<td>IWD Strain</td>
<td>.321**</td>
<td>.063</td>
<td>1.000</td>
<td></td>
</tr>
<tr>
<td>CG Strain</td>
<td>.141*</td>
<td>.262**</td>
<td>.245**</td>
<td>1.000</td>
</tr>
</tbody>
</table>

* = p < .05, ** = p < .01

IWD n = 298, CG n = 298

IWD = Individuals with Dementia, CG = Caregivers

There were three hypotheses. The first hypothesis was that there would be a relationship between relationship strain of each care partner and levels of depression for that care partner (actor effects). The second hypothesis was that there would be a relationship between levels of relationship strain for the caregiver and levels of depression in the IWD. The third hypothesis was that there would be a relationship between levels of relationship strain for the IWD and levels of depression for the caregiver. The second and third hypotheses referred to partner effects for the model.
Overall, the actor effects for the model were significant, whereas the partner effects were not (see Figure 3 found on page 105). The actor effects were related to hypothesis one, which examined the relationship between relationship strain and depression in each care partner. There was a statistically significant positive relationship between caregiver’s dyad relationship strain and the caregiver’s depression ($\beta = .26, p < .001$), where $\beta$ describes how strongly a predictor variable influences the outcome variable and $p$ represents significance level. For caregivers, $R^2 = .07$, suggesting that while the variance accounted for was small, it was significant as $R^2$ describes the percentage of variance accounted for in the model.

In regards to the actor effects of the IWD, there was a similar statistically significant positive relationship between the IWD’s dyad relationship strain and depression ($\beta = .31, p < .001$). Similarly for IWDs, $R^2 = .11$, also suggesting that while the variance accounted for by the model was small, it was statistically significant. For both care partners, increased strain was related to increased depression, thus rejecting the first null hypothesis. This means that for both care partners, the individual’s reported dyad relationship was significantly predictive of that individual’s reported depression.

The partner effects were not statistically significant, which related to the second and third hypotheses that examined the impact of the one care partner’s strain on the other care partner’s depression. It was determined that for the IWD’s dyad relationship strain’s effect on caregiver’s depression, results were $\beta = 0.065, p = .247$. The results for the caregiver’s dyad relationship strain effect on the IWD’s depression, results were $\beta = -0.004, p = .985$. Thus, the second and third null hypotheses were retained. This meant
that the caregiver’s dyad relationship strain was not predictive of the IWD’s reported depression and vice versa.

Additionally, though there were no hypotheses regarding the relationship between dyad relationship strain of the care partners nor regarding relationship of depression between the care partners, this was examined as part of the model. There was a statistically significant positive relationship between dyad relationship strain of the care partners \(r = .25, p < .001\), as well as a statistically significant positive relationship between depression of the care partners \(r = .19, p < .001\). This meant that there was a statistically significant relationship of both dyad relationship strain and depression, so when one care partner reported increased relationship strain, it is likely the other partner was reporting the same, and when one care partner reported increased depression, it is likely that the other care partner also reported increased depression.
CHAPTER V

DISCUSSION

The aim of this study was to investigate the impact that care partners have on one another’s depression. The analysis used the Actor Partner Interdependence Model (Cook & Kenny, 2005) to examine each care partner’s perception of relationship strain within the caregiving dyad and used relationship strain as a predictor of depression not only for that individual, but also for their care partner. Hypotheses included the following: 1. The relationship strain of each care partner would predict levels of depression for that care partner. 2. The relationship strain for the caregiver would predict the level of depression in the IWD. 3. The level of relationship strain for the IWD would predict the level of depression for the caregiver.

The analysis found that the relationship strain of each care partner was predictive of that individual’s depression, and this confirmed hypothesis one. This suggested that as dyadic relationship strain increases, so did depression, and this was true for both care partners. These findings were not particularly surprising as logic follows that relationship strain and depressive symptoms would be related, and literature supported these findings (e.g., Adams, McClendon, & Smyth, 2008; Lawrence et al., 1998;
Mahoney, et al., 2005; Williamson & Shaffer, 2001). To review, Adams, McClendon, and Smyth (2008) found that both premorbid relationship quality as well as relationship quality post-diagnosis were both related to depression in caregivers. Similarly, Lawrence et al. (1998) found that relationship quality mediated the relationship between caregiver stress and caregiver depression. Mahoney et al. (2005) had similar findings for caregivers in that relationship quality predicted depression. None of these studies discussed how relationship quality or relationship strain may impact IWDs, so the present analysis is significant in that it not only supports previous literature findings for caregivers, but also establishes a link between relationship strain and depression in the IWD. Furthermore, this is significant because Williamson and Shaffer (2001) found that not only did relationship quality predict depression in their sample of caregivers, but perhaps more importantly, depression then predicted care receiver maltreatment. This suggests that the current findings have important consequences for both caregiver and care recipient.

Next, it was found that the relationship strain for the caregiver was not predictive of depression for the IWD, nor was the relationship strain of the IWD predictive of depression for the caregiver, so hypotheses two and three were not confirmed. While this pathway was not itself statistically significant, it may be related to other mediators that might explain the relationship, and this would be a great possibility for future research such as caregiver burden. The reason there is an assumed relationship between caregiver variables and psychosocial outcomes for the patient is based on previous literature from authors such as Riviere et al. (2002), who found that IWDs with caregivers who are experiencing greater levels of burden develop greater amounts of aversive behaviors than IWDs with caregivers who reported less burden. Aversive behaviors can often be a result
of strain that the IWD is unable to verbally express and/or unmet needs, so it is likely that the burden experienced by the caregiver in negatively interpreted by the IWD, thus the IWD is experiencing negative emotions that manifest as aversive behavior. A mediator such as the caregiver’s appraisal of burden may be significant, and so it should be investigated in future analyses.

In addition, there was a statistically significant relationship between the dyad relationship strain of the care partners, as well as the depression of the care partners, suggesting that when one partner is experiencing more strain or depression than peers in a similar situation, the other care partner is also experiencing more strain or depression than their peers and vice versa. This finding highlights the intricate balance of the partnership within the caregiving dyad, and suggests they similarly appraise the stress in their relationship. Even when cognitive decline is present, the IWD still likely understands and responds to the relationship, though perhaps not in the same way they had previously (Dawson et al., 2013). This highlights the need for dyadic intervention and working with both care partners to improve outcomes for the dyad. The work of Judge et al. (2012) highlights how dyadic intervention can be successful in improving both dyadic relationship and depressive symptoms of both care partners.

The present analysis supports the current Stress Process Model for Individuals with Dementia (Judge et al., 2009). To review, Judge et al. (2009) created the model to emphasize the individual experience of IWDs as a result of personality, personal history, physical health, and other factors (see Figure 1 on page 103). The SPM for IWDs creates a graphical representation of the complex interplay of many variables broken down into background and context (including demographic variables as well as health history, social
network, and living arrangements), primary strains (including object stressors: cognitive status, functional status, and behavior problems; and subjective stressors: role captivity, perceived distress, perceived dependency), secondary strains (including role strains: family role strains, work role, social roles, and dyad strain; and intrapsychic strains: self-esteem, mastery, and self-efficacy), mediators (including internal mediators: personality, hardiness, life orientation, spirituality, and care values; and external mediators: social support, knowledge of illness, and financial resources), and outcomes (including quality of life, depression, anxiety, and physiological reactions) (Judge et al., 2009). Dyadic relationship strain is a secondary strain and depression is an outcome. The present analysis supports the SPM for IWDs (Judge et al., 2009) in that the dyad relationship strain was predictive of depression for each individual (see Figure 3 on page 105, and note the statistically significant relationship demonstrated in the directional arrows between the dyad relationship of each individual and his or her depression). The SPM for IWDs (Judge et al., 2009) does not reference how the dyad relationship strain of the caregiver impacts psychosocial outcomes of the IWD, so it can be inferred that the non-significant finding of how the caregiver’s relationship strain relates to the IWD’s depression being not significant also supports the current model. While these variables are only two of the many variables accounted for in the SPM for IWDs, it would be helpful to have additional information to better understand the relationships described in the model (e.g., measures of burden and other aspects of the SPM for IWDs). Also consistent with the model, the dyad relationship strain of the caregiver was not significantly predictive of depression in the IWD, which also supports the model as this is not listed as a secondary strain. The SPM of IWDs is also very similar to the SPM for
caregivers (Pearlin et al., 1990), so the similar results for caregivers also align with the findings of the SPM of IWDs.

IWDs are noted to have high rates of depression. The literature review highlighted a study by Ballard et al. (2000) that found 36% of IWDs experienced at least one major depressive episode after the onset of dementia symptoms, and 15% experienced an episode lasting more than six months. The present study’s findings were similar, with IWDs mean depression score of 2.40 (SD = 2.72) out of a possible score of 0-11 on the CES-D (Kohout et al., 1993). This suggests that the majority of respondents were reporting mild to moderate depressive symptoms at baseline of the PDC intervention. Richard et al. (2013), Snowden et al. (2015), Karlsson et al. (2015), Mirza et al. (2014), and Gracia-Garcia et al. (2015) all conducted longitudinal analyses of depression in older adults and found a significant relationship between premorbid depression symptoms and later development of dementia. While the present analysis did not examine premorbid depression in IWDs, it may be important future research as Byers et al. (2012) specifically examined rates of depression in Veterans and found that Veterans with depression were twice as likely to develop dementia later in life. They also found that 10% of Veterans had depression or dysthymia, and the risk of death was 40% higher for this group (Byers et al., 2012). This highlights that depression is not only a risk factor for developing dementia, but also a risk factor for other dire consequences. Given that relationship strain was related to depression in the present sample of IWDs, it should be investigated if this finding is similar in populations of Veterans who do not have dementia.
Caregivers are also known to experience high rates of depression, along with many other dire health consequences (e.g., Aranda & Knight, 1997; Baronet, 1999; Bass et al., 2012; Campbell et al., 2008; Givens et al., 2013). The literature review highlighted a study that found caregivers were more likely to experience major depression, anxiety, insomnia, chronic pain, and diabetes than non-caregivers (Laks et al., 2016). This link of higher rates of not only mood disorders, but also major physical health implications is likely indicative of the high rates of stress a caregiver experiences and requires the attention of the medical community. The odds ratio for developing depressive symptoms in their sample of caregivers was 2.008, and the odds ratio for developing a major depressive disorder was 1.483. This was statistically significantly higher than their non-caregiving sample (Laks et al., 2016). For the present analysis, the caregiver depression mean score was 3.90 ($SD = 3.41$) out of a possible score of 0-22, suggesting that the sample’s caregivers were mostly endorsing mild symptoms of depression. This is significant in that depressive symptoms in caregivers can impact the caregiving experience. Springate and Tremont (2014) found the caregivers with higher levels of depression had an impact on their caregiving and experienced more guilt, frustration, and embarrassment about caregiving as compared to their less depressed counterparts. Similarly, Roche et al. (2015) found that depression predicted a lower quality of life in caregivers, and caregiving strain exacerbated depressive symptoms. This literature is important because depression has been found to be related harmful behavior against OA care recipients by their caregivers, and anger was found to be a mediator and moderator of this relationship (MacNeil et al., 2009).
Also of note, the present analysis fills a significant gap in the literature. As highlighted in the literature review, the views of the IWD are often not considered. Many times, the caregiver speaks for the patient, and the caregiver’s view could likely be colored by their own stress related to the demands of caregiving for someone with a serious illness. Though it has been established that IWDs can reliably report their own subjective mood experiences earlier in their disease process (Whitlatch, 2008), their thoughts and opinions often go unreported or uninvestigated. This has social justice implications because elder abuse frequently goes unreported (Castle, Ferguson-Rome, & Teresi, 2015), often because the victim is not even asked what his or her thoughts and experiences are on their care. Additionally, perpetrators of elder abuse are typically a caregiver, whether that is a friend or family member or a paid care provider (Roberto, 2016), so directly asking an IWD about their experience (as opposed to asking a caregiver) may be the only way to detect abuse.

Poor relationships are associated with increased burden, which is then associated in the literature with increased depressive symptoms in caregivers. Steadman, Tremont, and Davis (2007) found that poor relationship satisfaction was associated with higher levels of burden ($r = -.38, p = .001$), and that frequency of memory or behavioral problems was significantly related to caregiver’s perception premorbid relationship satisfaction ($r = -.39, p = .01$). For the present analysis, the caregiver’s dyad relationship strain mean was 6.91 ($SD = 2.64$) out of a possible score of 0-18 on the measure, suggesting that many caregivers were reporting mild to moderate dyadic relationship strain. This gives rise to the hypothesis that caregiver burden may be a mediator of the
relationship between dyadic relationship strain and depressive symptoms in caregivers of IWDs, which would be helpful to explore in a future analysis.

Though there is little research available to review on dyad relationship strain with IWDs, one can infer that increased relationship strain results in increased stress for the IWD. The IWD’s dyad relationship strain mean score was 0.79 ($SD = 3.75$) out of a possible score of 0-6, so the scores on this measure appear to be somewhat varied between individuals, but this suggests that certain individuals were experiencing some distress related to dyadic relationship strain.

**Implications for Counselors**

The findings of the present analysis are significant for counseling practice in that they firmly establish the need for dyadic intervention IWDs and their caregivers. Partners in Dementia Care (PDC) is one such intervention, and the present study supports the need for expanded implementation of PDC or similar programs to address the needs of IWDs and caregivers. Furthermore, clinicians should conceptualize their work with IWDs, caregivers, or caregiving dyads as a systems approach. Both the Stress Process Model (SPM) for IWDs (Judge et al., 2009) and for caregivers (Pearlin et al., 1990) highlight the many factors that contribute to psychosocial outcomes for both IWDs and caregivers, a many of these factors are related to the relationship of the dyad. As counselors work with IWDs and caregivers individually or as a dyad, they are encouraged to strive to conceptualize these cases within the SPM for IWDs (Judge et al., 2009) and/or SPM for caregivers (Pearlin et al., 1990) frameworks to better understand the illness experience of IWDs and caregiving experience of caregivers. These experiences
are quite complex, and the present analysis highlights one small part of these experiences and how they relate to the experiences of the care partner.

Another implication for counseling practice that cannot be understated is the need for counselors to be acutely aware of high rates of depression in older adults (OAs). The present analysis supports that caregivers and IWDs experience depression and provides a partial explanation for this. Counselors would be encouraged to directly assess for depression symptoms at regular intervals for the welfare and safety of their patients, but also to assess for problems in relationships for OAs, as strained relationships could possibly lead to depressive symptoms later, even if these symptoms are not present in the current moment.

Limitations

Secondary data. The most significant limitation of this study was the use of secondary data. The measures were pre-selected by a committee of highly qualified medical professionals, which is a strength in many respects, but were not selected by the author. In addition, the author did not participate in data collection. This clearly limits many aspects of the study from a design standpoint, including what predictors and outcomes could be examined. Information on other secondary strains for IWDs would have been helpful in more fully understanding the illness experience of the IWDs in the sample.

Gender depression rates. Another important drawback of this study is the high incidence of depression rates in women as compared to men (Piccinelli & Wilkinson, 2000) This is notable for the present analysis because the majority of the caregivers in the study are women, and the majority of the IWDs in the study are men.
Relatedly, as discussed in the literature review, females tend to report markedly higher levels of caregiver burden as opposed to men (Chio et al., 2005; Croog et al., 2006; Papastavrou et al., 2007; Parks & Pilisuk, 1991), and higher levels of caregiver burden has also been related to higher rates of depression. One example includes Mahoney, Regan, Katona, and Livingston (2005), who found that 10.5% of caregivers experience significant depression. This is important because in the literature, samples of caregivers tend to be overwhelmingly female (Baronet, 1999; Parks & Pilisuk, 1991). While the literature reflects a gender imbalance in caregiving with women providing care more frequently than men, this is complicated by the well-established fact that women are diagnosed with depression at far greater rates than men. A thorough review of the literature on this topic by Piccinelli and Wilkinson (2000) suggests there may be many reasons for this. Possible reasons include the following: Women are more likely to seek help, possible gender-bias in diagnostic criteria, possible differences by gender in ability to recall symptoms, and more. Piccinelli and Wilkinson (2000) note that there has been little support for a biological explanation as to why women experience depression at greater rates than men, but there are many cultural and environmental explanations for this difference. Included in these cultural and environmental explanations are the notable disparities in gender role expectations in caring for the home and family, which may relate to women being more prone to experience depression (Piccinelli & Wilkinson, 2000). This relates to the present study because the sample used, like the majority of studies on caregiving of IWDs, has women as the majority of caregivers. This results in a complicated presentation of women being more likely to be caregivers and more likely to
experience or report depression, and high rates of depression amongst caregivers regardless of gender.

**Relationship strain variable.** An additional possible limitation of the study is related to the relationship strain variable. While one assumes that a large portion of the dyadic relationship strain may be related to the illness of IWD and required care associated with the illness, it is highly likely that within high-strain dyads there is a long standing history of relationship strain related to other factors. Caregiving dyads are typically comprised of individuals with strong familial and/or friendship ties, which results in long history that could account for strain due to previous relational riffs that predate the onset of dementia. Dementia symptoms would likely exacerbate any pre-existing relationship strain, however there is no easy way to assess or control for this with any study. A pre-morbid estimate of relationship strain and/or relationship quality would have been helpful in examining this possibility, however this would be difficult to accomplish, and the use of secondary data made exploring this important aspect of the data impossible.

**Lack of diversity.** Also of consideration is the lack of diversity in the sample. For the present analysis, the IWDs were mostly White males, and the caregivers were mostly White females (Judge et al., 2011). This limits generalizability and does not further the understanding of the unique illness and caregiving experiences of minority populations. Related to this, Bass et al.’s (2014) attrition study of the data suggested that participants who identified as an ethnic minority were less likely to follow-up in later phases of the study. The present analysis used the first wave of data to lessen the impact of this possible threat to validity, but it suggests there may be something different about
the experience of ethnic minorities that is not fully explained by this study and thus limits generalizability (Heppner et al., 2015).

**Unique sample.** An additional limitation of this study was that the IWDs were Veterans. While it is helpful to better understand the experiences of this unique population, Veterans may have unique experiences inherent to military service that complicate their dementia presentation, and thus limit generalizability to an average population.

**Relationships of caregivers.** The majority of caregivers were spouses of IWDs; however, a significant portion of caregivers were also adult children, which is a very different relationship, and this could change appraisal of dyad relationship strain. It is also unclear how many non-spousal caregivers lived with the IWDs, which could also change appraisals of dyad relationship strain. Previous literature has established that relationship type of the caregiver can influence appraisal of constructs such as caregiver burden even when the difference is as simple as the differences between husband and wives as caregivers (e.g. Chio et al., 2005; Croog et al., 2006; Papastavrou et al., 2007; Parks & Pilisuk, 1991), so it should be assumed that the relationship type may influence constructs such as dyad relationship strain as well.

**Implications for Future Research**

The present analysis was limited in its scope and design due to the use of secondary data. Future research should expand upon this topic in several areas. First, the results for hypothesis one (dyadic relationship strain of each individual predicting depression) were statistically significant, however, the results for hypotheses two and three (dyadic relationship strain of one care partner predicting depression of the other)
were not. In addition to this interesting finding, there were statistically significant relationships between dyadic relationship strain of both care partners and depression of both care partners. Despite the lack of statistical significance for hypotheses two and three, in light of additional results, one could consider future research of various mediator or moderator variables and how this may impact pathways of strains of the dyad influencing psychosocial outcomes such as anxiety, caregiver burden, and also demographic information such as age, gender, and education of both caregivers and IWDs. It should be noted that it is very likely that there is no significant relationship between the dyad relationship strain of one care partner and depression in the other, however future research could further enhance understanding of this topic.

A significant limitation to understanding the illness experience of IWDs is limited research on dyadic relationship strain as a construct as well as the measure of this construct for use with dementia caregiving dyads. Relationship quality and relationship satisfaction research is similar, but not the same. Further research would benefit the understanding of dyadic relationship strain and how this relates to the many stresses and outcomes in caregiving and well as the illness experience for IWDs. It would also be of interest to have additional information on premorbid estimates of possible relationship strain for the caregiving dyads, as the literature review noted that premorbid relationship satisfaction can impact relationship satisfaction when one partner becomes ill. It would be interesting to see if similar outcomes arise from dyads in this sample or a similar sample.

Another area for possible future research includes repeating this study with other samples. The present sample is of American Veterans, so they may have unique
experiences that shape their illness experience and relationships with their caregivers. This analysis did not examine possible comorbid mental illness (e.g., PTSD), so it would be interesting to repeat this study with a civilian population. In addition, the literature review noted that ethnicity and culture clearly plays a role in the caregiving experience. The present sample was not overly diverse in terms of ethnicity, so this may have impacted outcomes. Related to this, the IWDs were predominately men and their caregivers were predominately women. This is consistent with the majority of caregiving research, as in many cultures, American culture included, the principle tasks of caregiving commonly falls to female family members, however due to women more commonly reporting depressive symptoms, this has the potential to skew the data. It would be interesting to repeat the study with a sample of predominantly female IWDs and a more mixed-gender group of caregivers. One advantage of the present analysis is that it was somewhat geographically diverse, so this should be repeated in future studies. Similarly, the sample of both IWDs and caregivers was predominately White individuals (Judge et al., 2011). It would be helpful to repeat this study with a more racially diverse sample to better understand the illness and caregiving experiences of people of different ethnicities.

The most important area for future research is of possible interventions for caregiving dyads. Currently, there are few interventions that address the needs of both members of the caregiving dyad (Judge and colleagues Project ANSWERS being one notable exception (Judge et al., 2012)). As literature highlighted in the review states, the stress and emotional burden of caregiving can cause caregivers to become abusive to IWD (MacNeil et al., 2009). While this is clearly one of the worst possible outcomes,
stress and low mood of caregivers can also impact quality of life and emotional outcomes within the dyad. While the data did not explicitly establish a link between dyad relationship strain of one partner and depression of the other, future research could further examine a path model where dyad relationship strain increases depression of that individual, which in turn is related to depression of the other partner.

Summary and Conclusion

In brief, the present analysis found that there was a significant relationship between dyadic relationship strain of each care partner and his or her depression. There was also a significant relationship between the dyadic relationship strain of both care partners, as well as a significant relationship between the depression symptoms of both care partners. The dyadic relationship strain of the caregiver was not found to be predictive of depression in the IWD, nor was the dyadic relationship strain of the IWD found to be predictive of depression in the caregiver.

These findings fill a significant gap in the literature in that they explore the illness experience of the IWD from his or her perspective, and examines how relationship strain with his or her caregiver can influence depressive symptoms. The findings also highlight the importance of the relationship between caregiver and IWD, and how this special relationship is related to potential mental health outcomes for these individuals. This highlights the need for dyadic interventions and for the IWD to be included in his or her care and care decisions for the best possible outcomes for both care partners. By finding pathways that help explain psychosocial outcomes for IWDs and caregivers, psychologists and other healthcare professionals have additional information and tools to help provide quality care and improve the mental health of both caregivers and IWDs.
REFERENCES


Bass, D. M., Judge, K. S., Maslow, K., Wilson, N. L., Morgan, R. O., McCarthy, C.,
“Partners in Dementia Care” on veteran’s hospital admissions and emergency
department visits. *Alzheimers & Dementia: Translational Research & Clinical
Interventions, 1*, 13-22. doi: 10.1016/j.trci.2015.03.003

Kunik, M. E. (2012). Negative caregiving effects among caregivers of veterans
with dementia. *American Journal of Geriatric Psychiatry, 20*(3), 239-247. doi:
10.1097/JGP.0b013e31824108ca

Dementia Care: Effect of a care coordination program for veterans with dementia
and their family members and friends. *Journal of the American Geriatrics
Society, 61*, 1377-1386. doi: 10.1111/jgs.12362

Randazzo, R., … Kunik, M. E. (2014). A controlled trial of Partners in Dementia
Care: Veteran outcomes after six and twelve months. *Alzheimer’s Research and
Therapy, 6*(9), 1-12. doi:10.1186/alzrt242

effect of a computer support network on caregiver strain. *Journal of Aging and
Health, 10*(1), 20-43.


relationship between depression and dementia. *Neurobiology of Aging, 36*, 1751-1756. doi: 10.1016/j.neurobiolaging.2015.01.008


Ornstien, K., & Gaugler, J. E. (2012). The problem with “problem behaviors”: A systematic review of the association between individual patient behavioral and psychological symptoms and caregiver depression and burden within the dementia patient-caregiver dyad. *International Psychogeriatrics, 24*(10), 1536-1552. doi: 10.1017/S1041610212000737


Williamson, G. M., & Shaffer, D. R. (2001). Relationship quality and potentially harmful behavior by spousal caregivers: How were we then, how we are now. *Psychology and Aging, 12*(2), 217-226. doi: 10.1037//0882-7974.16.2.217

Permission for use of figure obtained from copyright holder. See Appendix A on page 109.
FIGURE 2. Actor partner independence model for the present analysis.

Original model by Kenny, Kashy, & Cook (2006), adapted by author for present analysis under fair use guidelines. See Appendix B on page 110.

IWD = Individual with dementia
FIGURE 3. Structural equation model of the actor independence partner model with final results

Original model by Kenny, Kashy, & Cook (2006), adapted by author for present analysis under fair use guidelines. See Appendix B on page 110.
APPENDICES
APPENDIX A. Permission by copyright holder to use the Stress Process Model for Individuals with Dementia (Judge et al., 2009).

Welcome to Rightslink

Oxford University Press has partnered with Copyright Clearance Center’s Rightslink service to offer a variety of options for reusing Oxford University Press content. Select the "I would like to ..." drop-down menu to view the many re-use options available to you.

Papers published under Creative Commons Open Access licences may not require permissions for re-use. Please check the copyright line and licence used for this paper before requesting permission. Copyright lines can be found on the abstract of all OUP journal articles and information on CC licences can be found here. If you are unsure if the material is covered by open access or if your reuse requires permissions then please contact journals.permissions@oup.com.

Reuse Permitted Free of Charge

Reuse of Figures/Table in quantities of one or two are free of charge provided they are not used for pharmaceutical or commercial purposes. Oxford University Press grants a license for all orders, including $0 orders. Please select the Continue button and place an order for this reuse.

Oxford University Press grants a license for all orders, including $0 orders. Please select the Continue button and place an order for this reuse.
APPENDIX B. Fair use analysis for use of model by Kenny, Kashy, & Cook (2006) that was then adapted by author for present analysis under fair use guidelines (Brewer & ALA Office for Information Technology Policy, 2008).

Fair Use Evaluation Documentation


<table>
<thead>
<tr>
<th>Name:</th>
<th>Kelly Martinson</th>
</tr>
</thead>
<tbody>
<tr>
<td>Job Title:</td>
<td>Doctoral Student</td>
</tr>
<tr>
<td>Institution:</td>
<td>Cleveland State University</td>
</tr>
<tr>
<td>Title of Work Used:</td>
<td>Dyadic data analysis</td>
</tr>
<tr>
<td>Copyright Holder:</td>
<td>Kenny, D. A., Kashy, D. A., &amp; Cook, W. L.</td>
</tr>
<tr>
<td>Publication Status:</td>
<td>Published</td>
</tr>
<tr>
<td>Publisher:</td>
<td>Guilford Press</td>
</tr>
<tr>
<td>Place of Publication:</td>
<td>New York</td>
</tr>
<tr>
<td>Publication Year:</td>
<td>2006</td>
</tr>
<tr>
<td>Description of Work:</td>
<td>Text book</td>
</tr>
<tr>
<td>Date of Evaluation:</td>
<td>May 25, 2016</td>
</tr>
<tr>
<td>Date of Intended Use:</td>
<td>May 25, 2016</td>
</tr>
</tbody>
</table>

Describe the **Purpose** and Character of Your Intended Use:

[+] Use is for "criticism, comment, news reporting, teaching, (including multiple print copies for classroom use), scholarship or research"
[+] Use is socially beneficial (promotes the creation of new knowledge, learning, etc.) [define how]
[+] Use is not-for-profit
[+] Use is one-time, or is only occasional or spontaneous
[+] Use creates a derivative work of the original (full translation, adaptation, abridged version, etc.)

![Fair Use Scale]

111
Describe the **Nature** of Your Intended Use of the Copyrighted Work:

- [ ] Work to be used has been previously PUBLISHED
- [ ] Work to be used contains limited new knowledge, content, or creative expression (in relation to previously copyrighted works)
- [ ] Work to be used is primarily of a factual nature (non-fiction, collection of facts, etc.)

Fair [ ] [ ] [ ] [ ] [ ] Unfair

Describe the **Amount** of Your Intended Use in Relation to the Copyrighted Work as a Whole:

- [ ] Only limited and reasonable portions will be used
- [ ] The portion used is not the "heart" of the work (the portion considered most central to the work as a whole)
- [ ] Only the amount required to achieve the stated, socially-beneficial purpose or objective will be used (be that educational, artistic, scholarly, journalistic, etc.)
- [ ] The amount used falls within widely recognized fair use guidelines* vetted by key stakeholder groups [reference guidelines]

Fair [ ] [ ] [ ] [ ] [ ] Unfair

Describe the **Effect** of Your Intended Use on the Potential Market or Value of the Copyrighted Work:

- [ ] Use of the work has the potential to create or improve the market for the work
- [ ] Proper attribution will be given with the intended use

Fair [ ] [ ] [ ] [ ] [ ] Unfair
The Average "Fairness Level," Based on Your Rating of Each of the 4 Factors, Is:

[see tool disclaimer for important clarifying information]

Fair

Unfair

Based on the information and justification I have provided above, I, Kelly Martinin, am asserting this use is FAIR under Section 107 of the U.S. Copyright Code.

Signature:

Date of Signature:

*Disclaimer: This document is intended to help you collect, organize & archive the information you might need to support your fair use evaluation. It is not a source of legal advice or assistance. The results are only as good as the input you have provided by are intended to suggest next steps, and not to provide a final judgment. It is recommended that you share this evaluation with a copyright specialist before proceeding with your intended use.*