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ASSOCIATION BETWEEN BEHAVIORAL AND PSYCHOLOGICAL SYMPTOMS IN PERSONS WITH ALZHEIMER’S DISEASE AND DEPRESSION IN CAREGIVERS FROM LOW INCOME FAMILIES

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DEDICATION

In loving memory of my mother, Yiyiing Zhou (1961-2013).
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I am deeply indebted to my mentor and dissertation chair Dr. Sue Levkoff for her fundamental role in my doctoral work. When I felt ready to conduct research on my own, Dr. Levkoff gave me the freedom to do whatever I wanted, at the same time continuing to contribute valuable feedback, advice, and encouragement. Dr. Levkoff provided me every bit of guidance, assistance, and expertise that I needed to complete my dissertation research. She has shown me, by her example, what a good researcher (and person) should be.

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Nobody has been more important to me in the pursuit of doctoral degree than my family members. I would like to thank my father, Kaijian Tang, whose love and guidance are with me in whatever I pursue. I dedicate this dissertation to the memory of my mother, Yiying Zhou, whose role in my life was, and remains, immense. This last word of acknowledgement I have saved for my dear husband Xinchu Zhao, who provides unending encouragement and inspiration to me. We met in the summer of 2013 at University of South Carolina and got married during our PhD program. I really appreciate him for being a part of my life.
ABSTRACT

Alzheimer’s disease (AD) is the most common neurodegenerative disease and is a leading cause of dementia. Behavioral and psychological symptoms (BPS) represent a heterogeneous group of non-cognitive symptoms and behaviors occurring in persons with Alzheimer’s disease (PwAD), and they are often associated with negative outcomes for AD caregivers. Evidence indicates differences in caregivers’ mental health across race/ethnic groups. However, there is a lack of research that compares racial differences in the association between BPS in PwAD and caregiver depression. The aims of this dissertation, which are grounded in the Stress Process Model, include: 1) To compare racial differences in BPS in PwAD both as disparate symptoms and as symptoms that co-occur together; 2) To assess how BPS in PwAD impact depressive symptoms in caregivers of PwAD; and 3) To assess whether the impact of BPS on caregiver depressive symptoms differs across race.

The data used in the study were from the South Carolina Alzheimer’s Disease Registry, which included PwAD who were eligible for a Medicaid waiver program and their unpaid informal caregivers. The final sample for this study included 635 dyads, with 313 African Americans and 322 whites. Four clusters of PwAD were identified including Cluster 1: Minimally Symptomatic; Cluster 2: Apathetic; Cluster 3: Psychotic & Hyperactive; and Cluster 4: Highly Symptomatic. White PwAD exhibited more severe symptoms than African Americans, and white caregivers reported a higher level of
depressive symptoms than African Americans. Both caregiver level of burden and
distress mediated the relationship between BPS in PwAD and caregiver level of
depressive symptoms. However, there were no racial differences in the relationship
between BPS in PwAD and caregiver level of depressive symptoms.

The findings of this study highlight the importance of developing more effective
and targeted treatment options and therapies for neuropsychiatric symptoms and
delivering cultural relevant education programs/interventions to ethnic groups. Future
studies can benefit from profiling PwAD over the course of the disease and examining
the longitudinal effects of BPS in PwAD on caregiver depression.
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LIST OF ABBREVIATIONS

AD .......................................................... Alzheimer’s Disease

ADL .......................................................... Activities of Daily Living

ADRD ......................................................... Alzheimer’s or Other Dementias

BPS .......................................................... Behavioral and Psychological Symptoms

CDC .......................................................... Centers for Disease Control and Prevention

CESD-10 .................................................. Center for Epidemiological Studies Depression Scale-10

DV .......................................................... Dependent Variable

FWER .......................................................... Familywise Error Rate

IV .......................................................... Independent Variable

MAR .......................................................... Missing at Random

NPI .......................................................... The Neuropsychiatric Inventory

PwAD .......................................................... Persons with Alzheimer’s Disease

REACH .................................................. Resources for Enhancing Alzheimer’s Caregiver Health

SD .......................................................... Standard Deviation

ZBI .......................................................... Zarit Burden Interview
CHAPTER 1

INTRODUCTION

Alzheimer’s disease (AD) is the most common neurodegenerative disease and is a leading cause of dementia. In 2018, an estimated 5.8 million Americans were living with AD, and by 2050, that number will be doubled (Alzheimer’s Association, 2019). Recent studies show that African Americans have the highest prevalence of AD and related dementias (Matthews et al., 2019; Steenland, Goldstein, Levey, & Wharton, 2016). Older African Americans are about twice as likely to have AD as older whites, though there are more non-Hispanic whites living with the disease (Alzheimer’s Association, 2019; Gurland et al., 1999; Potter et al., 2009). The majority (70-80%) of persons with AD (PwAD) live in the community until late in the progression of the disease (Alzheimer’s Association, 2019; Alzheimer’s Association and National Alliance for Caregiving, 2004; Kasper, Freedman, Spillman, & Wolff, 2015; Schulz & Martire, 2004). For the majority of PwAD, care is provided by informal caregivers including family members and friends (Alzheimer’s Association, 2019; Alzheimer’s Association and National Alliance for Caregiving, 2004; Friedman, Shih, Langa, & Hurd, 2015; Schulz & Martire, 2004). Currently, more than 16 million Americans provide unpaid care or caregiving for people with Alzheimer’s or other dementias (ADRD) (Alzheimer’s Association, 2019). Approximately one third (34%) of ADRD caregivers are 65 years of age or older (Alzheimer’s Association, 2019), with the majority (two thirds) female (Bouldin &
Andresen, 2014; Kasper, Freedman, & Spillman, 2014). About 70% of caregivers are non-Hispanic white while 10% are African American (Alzheimer’s Association, 2019).

While caregivers for PwAD are able to identify positive experiences of caregiving such as feeling appreciated and feelings of accomplishment (Carbonneau, Caron, & Desrosiers, 2010; Cheng, Mak, Lau, Ng, & Lam, 2015; Roth, Fredman, & Haley, 2015), caregiving can be time consuming and emotionally and physically draining, resulting in greater risk for caregivers and negative effects on their quality of life (Goren, Montgomery, Kahle-Wrobleski, Nakamura, & Ueda, 2016; Kasper, Freedman, & Spillman, 2014; NAC & AARP, 2015; Richardson, Lee, Berg-Weger, & Grossberg, 2013). According to a national report, about 35% of AD caregivers reported that their physical health has gotten worse due to caregiving responsibilities (NAC & AARP, 2016). Fifty-nine percent of AD caregivers rated the emotional stress of caregiving as high to very high (Alzheimer’s Association, 2019). Approximately 40% of AD caregivers suffered from depressive symptoms (Mausbach, Chattillion, Roepke, Patterson, & Grant, 2013; Sallim, Sayampanathan, Cuttilan, & Ho, 2015). Depression not only reduces the quality of life of AD caregivers, but also leads to a reduction in the quality of care provided for PwAD (Wiglesworth, Mosqueda, Mulnard, Liao, Gibbs, & Fitzgerald, 2010), puts PwAD at greater risk of health problems (Li & Lewis, 2013; Joling et al., 2010), and increases the likelihood of institutionalization for PwAD (Cohen-Mansfield & Wirtz, 2011; Hébert, Dubois, Wolfson, Chambers, & Cohen, 2001).

**Behavioral and Psychological Symptoms in PwAD**

Behavioral and psychological symptoms (BPS), also known as neuropsychiatric symptoms, represent a heterogeneous group of non-cognitive symptoms and behaviors
occurring in PwAD. BPS are frequent amongst PwAD, affecting nearly all PwAD at some point in the illness (Lyketsos et al., 2011). Irrespective of the severity of the disease, the most frequently encountered BPS in AD is apathy, followed by depression, aggression, anxiety, and sleep disorders (Karttunen et al., 2011; Reynish et al., 2007; Selbæk & Engedal, 2012; Tschanz et al., 2011; Zhao et al., 2016). Studies also show that PwAD experience other symptoms such as aberrant motor behavior and appetite/eating abnormalities (Charernboon & Phanasathit, 2014; Chow et al., 2002).

Recent evidence in BPS research suggests that AD symptoms “cluster,” (Canevelli et al., 2013; Lyketsos, Lopez, Jones, Fitzpatrick, Breitner, & DeKosky, 2002; Lyketsos et al., 2001; Tun, Murman, Long, Colenda, & Von Eye, 2007; Youn et al., 2011), meaning that there is a recognized phenomenon of co-occurrence of BPS in AD. Research show that the majority of PwAD exhibited two or more BPS (Lyketsos et al., 2001; Youn et al., 2011). BPS can be grouped into factors in which there are core nuclear syndromes such as a psychotic syndrome (hallucinations, delusions), an affective syndrome (depression, anxiety, irritability, agitation), and a behavior syndrome (euphoria, disinhibition, apathy, aberrant motor behavior) (Garre-Olmo, Lopez-Pousa, Vilalta-Franch, de Gracia Blanco, & Vilarrasa, 2010). Previous studies have attempted to classify PwAD according to their presence and severity of BPS (Spalletta et al., 2010; Vilalta-Franch et al., 2010), and different clusters have been found in previous studies (Canevelli et al., 2013; Lyketsos et al., 2002; Tun et al., 2007). For example, Lyketsos and his colleagues (2002) found three clusters based on the presence of BPS in PwAD including a group with affective symptoms (e.g., anxiety, depression), a group with psychotic symptoms (e.g., hallucinations), and a group with no disturbances or a single
symptom. Tun et al. (2007) identified four distinct symptom profiles based on the severity and frequency of symptoms: minimally symptomatic (PwAD have few symptoms), affective symptoms (i.e., depression, anxiety, and apathy), predominantly apathetic (emergence of apathy as a distinct profile), and highly symptomatic with psychotic features (high symptoms with high Neuropsychiatric Inventory score).

**BPS’ Impact on AD Caregiver**

BPS in PwAD are often associated with negative outcomes for caregivers including increased caregiver burden, distress, and depressive symptoms (Feast, Moniz-Cook, Stoner, Charlesworth, & Orrell, 2016; Ornstein & Gaugler, 2012; Vaingankar et al., 2016). Specifically, BPS such as irritability, agitation, apathy and delusions in PwAD have been found to adversely impact caregiver perceived level of burden (Mohamed, Rosenheck, Lyketsos, & Schneider, 2010; Ornstein & Gaugler, 2012; Rymer et al., 2002; Terum et al., 2017), distress (Black & Almeida, 2004; Fauth & Gibbons, 2014; Lima-Silva et al., 2015), depression (Covinsky et al., 2003; Mohamed et al., 2010; Ornstein & Gaugler, 2012), and quality of life (Miguel et al., 2016). In addition, an extensive body of literature suggests that it is the non-cognitive, or the BPS associated with AD that are the most burdensome to caregivers and have the greatest impact on decisions to institutionalize patients such as irritability, agitation/aggression, apathy, and delusions (Ballard, Lowery, Powell, O’Brien, & James, 2000; Black & Almeida, 2004; Coen, Swanwick, O’Boyle, & Coakley, 1997; Machnicki, Allegri, Dillon, Serrano, & Taragano, 2009; Pinquart & Sörensen, 2003; Porter et al., 2016; Schulz, O’Brien, Bookwala, & Fleissner, 1995; Steffens, Maytan, Helms, & Plassman, 2005).
Racial Differences

In 2002, the Alzheimer’s Association referred to AD as a “silent epidemic” in the African American community due to its increased prevalence, scope, and nature (Alzheimer’s Association, 2002). Previous studies found differences in BPS among PwAD and caregiver’s health between African Americans and whites as reviewed below.

Racial Differences of BPS in PwAD. Findings are limited and mixed regarding racial differences in the presence of BPS among PwAD. Some studies found higher rates of psychotic symptoms such as hallucination and delusions among African Americans versus white (Bassiony, Steinberg, Warren, Rosenblatt, Baker, & Lyketsos, 2000; Cohen & Magai, 1999; Lopez et al., 2003; Sink, Covinsky, Newcomer, & Yaffe, 2004). Other studies found lower depression in PwAD among African Americans than Hispanics (Chen, Borson, & Scanlan, 2000; Cothran et al., 2015).

BPS in PwAD is often observed and reported by caregivers. Inconsistent findings are shown related to whether African-American caregivers report more BPS than white caregivers (Logsdon, McCurry, & Teri, 2007). Underreporting BPS may be related to not understanding symptoms, accepting them as symptoms of normal aging process, misinterpreting them, or ignoring or minimizing them (Dilworth-Anderson & Gibson, 2002; Jett, 2006; Pinquart & Sörensen, 2011). African-American caregivers have been found to have lower levels of factual knowledge about AD (Cahill, Pierce, Werner, Darley, & Bobersky, 2015; Scott, Clay, Epps, Cothran, & Williams, 2018) and they seek out fewer information sources of the disease (Roberts, Connell, Cisewski, Hipps, Demissie, & Green, 2003; Samson, Parker, Dye, & Hepburn, 2016). Psychiatric
symptoms including anxiety and hallucinations are often attributed to the normal process of having lost one's mind due to age among African Americans (Jett, 2006).

**Racial Differences in Caregivers’ Health.** Previous research findings suggest differences in caregivers’ mental health across race/ethnic groups, with African-American caregivers reporting less burden and depression than white caregivers (Cothran et al., 2015; Janvic & Connell, 2001; Pinquart, & Sörensen, 2005; Roth, Ackerman, Okonkwo, & Burgio, 2008; Roth, Haley, Owen, Clay, & Goode, 2001). This may be explained by racial differences in the appraisal of the subjective stressfulness of caregiving tasks such as managing BPS of the patient. African-American caregivers have generally lower appraisals of the stressfulness of caregiving than white caregivers, leading to lower levels of depression (Haley et al., 2004). Family-oriented values may also play a role leading to African-American caregivers viewing caregiving as a blessing, or with family members expected to provide whatever care is, no matter what the care recipient’s needs or circumstances (Scharlach, et al., 2006).

Despite African-American caregivers reporting less burden and depression than white caregivers regarding the adverse psychological consequences of providing care to PwAD, both groups of caregivers are vulnerable to impaired physical health over time (Roth, Haley, Owen, Clay, & Goode, 2001). A recent study found that problems with physical health and health maintenance were two of the five most commonly reported caregiver problems among African American dementia caregivers (Wells et al., 2017).
Limitation of Previous Studies and Current Research

**Small Sample Size and Homogeneity.** Most available studies have small and homogenous samples (mostly white or unreported; sample size smaller than 200 patient-caregiver dyads) (Black & Almeida, 2004; Chappell & Penning, 1996; Covinsky et al., 2003; Danhauer et al., 2004; Fauth & Gibbons, 2014; Feast, Moniz-Cook, Stonder, Charlesworth, & Orrell, 2016; Hooker et al., 2002; Ornstein et al., 2013). The percentages of presence of certain BPS vary. For example, Prado-Jean et al. (2010) reported 18.2% of their sample displayed apathy whereas Craig et al. (2005) reported 75% of their sample displayed apathy. Likewise, prevalence of depression in AD reported in thirty studies ranges from 19% to 78% (Zhao et al., 2016). These inconsistencies in the presentation of symptoms across research studies may be due to sampling methods, e.g., small sample size, different samples recruited from the community or nursing homes (Fauth & Gibbons, 2014). There is a research gap on examining BPS in AD using a large sample size and including PwAD from ethnic minority groups.

**Focus on Dementia.** Many studies examining presence of BPS focus on ADRD including AD, vascular dementia, Parkinson’s disease dementia, and frontotemporal dementia etc. (Covinsky et al., 2003; Feast, Moniz-Cook, Stonder, Charlesworth, & Orrell, 2016; Prado-Jean et al., 2010). However, examining a specific type of dementia is important as there are differences in BPS within dementia subtypes. For example, individuals with behavioral-variant frontotemporal dementia have been found to have higher presence and severity of BPS than those with AD (Lima-Silva et al., 2015). Individuals with Parkinson’s dementia have been rated as being more apathetic than those with AD (Cahn-Weiner, Grace, Ott, Fernandez, & Friedman, 2002).
Limited Research on Race and Income. Race and ethnicity are accepted as fundamental determinants that shape exposure to, and experience of, risk factors for health (Williams, Priest, & Anderson, 2016). However, there is a lack of research with a balanced sample size regarding race and ethnicity, and that compares racial differences on the association between BPS in PwAD and caregiver depression. Danhauer et al. (2004) examined the association between BPS in PwAD and caregiver depressive symptoms, but no information is provided regarding race.

Most research on the topic has no information on the SES or income level of the caregivers or patients, and no study has focused on low income families specifically. A previous study examining patient and caregiver characteristics associated with depression found that caregivers’ low levels of financial resources (income) predicted depression (Covinsky et al., 2003). PwAD and their caregivers from low income families are likely to have limited access to resources and support, information related to caregiving, and that may lead to poorer health.

Symptoms Groups vs Clustered PwAD. Previous research examining the relationship between BPS and caregiver depression has inconsistent findings. Some studies found that among all BPS, the presence of patient depressive symptoms was the only one that had significant effect on caregiver depressive symptoms (Donaldson, Tarrier, & Burns, 1998; Harwood et al., 1998; Neundorfer, McClendon, Smyth, Stuckey, Strauss, & Patterson, 2001; Ornstein et al., 2013), while a study by Covinsky et al. (2003) identified that aggression was a strong individual predictor of caregiver depression. Studies show that both individual symptoms and a combination of different symptoms can predict outcomes related to caregiver and PwAD such as caregiver burden (Rocca et
al., 2010) and nursing home placement (Tun et al., 2007). Researchers have used different statistical methods to empirically identify classifications of BPS in AD including principal component analysis (Spalletta et al., 2010; Vilalta-Franch et al., 2010), classic factor analysis (Garre-Olmo et al., 2010), and latent class analysis (Lyketsos et al., 2001). These approaches disregard homogeneous subgroups of PwAD based on BPS when studying their impact on caregivers’ mental health. Limited research has been conducted that identifies profiles of PwAD with combinations of symptoms that predict caregiver depressive symptoms. The current research aimed to determine whether there were homogeneous subgroups of PwAD that would be identified by their co-occurred BPS. These neuropsychological subgroups might evince different outcomes (e.g., caregiver depression, burden, distress). As the goal of this study was to separate PwAD into groups based on the actual BPS measured, cluster analysis is generally considered the best approach. Not like classification based on factor scores, cluster analysis directly uses the actual variables, thus can avoid loss of information. Based on cluster analysis results, we can describe each case in terms of his/her assigned group. This will be valuable when we want to deliver specialized interventions to a specific group. In addition, the data used in this study was not a random sample and the results cannot be generalized to the population, it is more important to provide a description of the sample and provide practical implications to this sample using cluster analysis method.

The current study aimed at overcoming the limitations of previous studies by 1) using a dataset including 635 dyads of PwAD and their caregivers that comprises a sample of both African Americans and whites who are from low-income families.
(enrolled in the Medicaid waiver program); 2) focusing specifically on PwAD and their caregivers; 3) examining the association between BPS in PwAD and depression in caregivers among whites and African Americans; and 4) using cluster analysis to explore possible clusters of PwAD, and to understand the association between those identified clusters and caregiver depression.

**Objectives and Significance of the Current Study**

This study aimed at understanding the relationship between BPS in PwAD and caregiver depression among white and African Americans who are from low income families. Specifically, there were three aims for this study: 1) To compare racial differences in BPS in PwAD both as disparate symptoms and as symptoms that co-occur together; 2) To assess how BPS in PwAD impact depressive symptoms in caregivers of PwAD; and 3) To assess whether the impact of BPS on caregiver depressive symptoms differs across race.

The current study relies on a sample from South Carolina (SC). The prevalence of AD is growing in SC. The projected percentage increase in the total number of adults aged 65 and older with AD between 2017 and 2025 is 39.5% in SC, which ranks in the top 5 states. SC also had the highest age-adjusted death rate (362.8) for AD in the U.S. in 2015 as reported by the CDC (2015). Currently, there are 313,000 caregivers for persons with ADRD in SC, providing about 357 million hours of unpaid care (Alzheimer’s Association, 2019).

The data used in the study are from the South Carolina Alzheimer’s Disease Registry (The Registry), which includes unpaid informal caregivers of PwAD in SC who
are eligible for a Medicaid waiver program. Medicaid pays for nursing home and other long-term care services for people with very low income. According to a recent report by Alzheimer’s Association (2019), 27% of older individuals with ADRD had Medicaid coverage, compared with 11% of individuals without the disease. Average annual Medicaid payments per person for Medicare beneficiaries with ADRD were about 23 times as great as average Medicaid payments for those without the disease (Alzheimer’s Association, 2019).

The current study is the first to the investigator’s knowledge examining the relationship between BPS in PwAD and caregiver depression using a dataset with a sample of African-American caregivers and white caregivers who are from low-income families.
CHAPTER 2

CONCEPTUAL FRAMEWORK AND RESEARCH QUESTION

This chapter introduces concepts used in the study and a conceptual framework developed and adapted from Pearlin’s Stress Process Model (Pearlin et al., 1990). Four research questions and a series of hypotheses guided by the framework for this study are proposed.

Conceptualization of Key Concepts

Informal Caregivers and Caregiving. The Merriam Webster dictionary (2019) defines caregiver as “a person who provides direct care, as for children, elderly people, or the chronically ill”. This definition provides the basic and general meaning of the caregiver. Informal caregivers, defined by Schulz & Martier (2004), are persons not receiving payment for care provision and may include spouses, children, other relatives, or non-relatives such as friends. Defining caregiver can be discussed together with the term “caregiving”, which generally means the activity or the process that a caregiver provides to the care recipient. According to a definition of caregiving by Drentea (2007), that “act of providing unpaid assistance and support to family members or acquaintances who have physical, psychological or developmental needs”, caregiving activities performed are outside of normal expectations (e.g., parenting). To be noted, Pearlin et al.’s definition (1990) on caregiving underscores an emotional component and
commitment to the relationship as the basis for actions. They suggest that caregiving is not a role but entails identified actions within the context of a relationship and involves an emotional connection between caregiver and care recipient (Pearlin, Menaghan, Lieberman, & Mullan, 1981). For example, African Americans identified love and affection as reasons for fulfilling caregiver responsibilities (Nkongho & Archbold, 1995), while some groups did not report similar reasons for providing care (Wallhagen & Yamamoto-Mitani, 2006). Understanding the reasons for caregiving may help researchers understand the influence caregiving experiences have on caregiver outcomes. This element of caregiving definition is important in caregiving research, especially in studies comparing caregivers or caregiving outcome among different ethnic groups. In this study, we define an informal caregiver as a partner, relative, friend or neighbor who has a significant personal relationship with, and provides a holistic (physically, mentally, emotionally, and socially) assistance for, an individual with AD.

**Behavioral and Psychological Symptoms.** AD or other dementias typically present with two syndromes, cognitive and behavioral or psychological. In 1996, the International Psychogeriatric Association (IPA) called a consensus conference to examine the available knowledge on noncognitive symptoms of dementia. The researchers and experts agreed on a term that would include all behavioral symptoms observed in the dementia: “Behavioral and Psychological Signs and Symptoms of Dementia”, defined as “signs and symptoms of disturbed perception, thought content, mood or behavior that frequently occur in patients with dementia” (Finkel, e Silva, Cohen, Miller, & Sartorius, 1997). According to the Consensus Statement (Finkel et al., 1997), symptoms can be grouped into 1) those symptoms usually and mainly assessed on
the basis of interviews with individuals with dementia and relatives including anxiety, depressive mood, hallucinations, and delusions; 2) those symptoms usually identified on the basis of observation of behaviors from the individual with dementia including aggression, screaming, restlessness, agitation, wandering, culturally inappropriate behaviors, sexual disinhibition, hoarding, cursing, and shadowing. These symptoms are integral elements of the disease process and present severe problems to both caregivers and care recipients.

The assessment of BPS requires a thorough examination to collect specific and detailed information about the history, patient’s subjective experiences, and objective behavior. And a reliable family member or caregiver is often needed to obtain information (Cerejeira, Lagarto, & Mukaetova-Ladinska, 2012). The interview with caregivers is an opportunity to characterize the BPS and to recognize which BPS are of greatest concern to them as these may not necessarily coincide with the patient’s own complaints or with the clinician’s priorities (Cerejeira, Lagarto, & Mukaetova-Ladinska, 2012). There are several validated instruments developed to quantify BPS such as BEHAVE-AD (Reisberg et al., 1987) assessing the presence and severity of 25 behavioral symptoms in 7 categories (paranoid and delusional ideation, hallucination, activity disturbances, aggressiveness, sleep disturbances, affective symptoms, and anxieties and phobias); and the Neuropsychiatric Inventory (NPI; Cummings et al., 1994) evaluating 12 symptoms based on the caregiver information (delusions, hallucinations, agitation, depression, anxiety, apathy, irritability, euphoria, disinhibition, aberrant motor behavior, night time behavior disturbances, and eating behavior abnormalities).
**Caregiver Depression and Burden.** Depression, known as major depressive disorder or clinical depression is a common and serious mood disorder, and is a major mental health concern for informal caregivers. Symptoms of depression include decreased interest or pleasure, change in sleep, appetite, weight and in activity, fatigue or loss of energy, guilt/worthlessness, diminished ability to think or concentrate, and suicidality (American Psychiatric Association, 2013). Caregiver depression can be considered as the cumulative results of responses to long-term caregiving. According to Pearlin et al. (1981), depression is one of the global indicators of stress. In this study, caregiver depression is conceptualized as a cumulative outcome of stress process that AD informal caregivers experience and feel during caregiving.

There is no International Classification of Diseases, Ninth Revision (ICD-9) or ICD-10 code for caregiver burden. A review of the burden literature suggests that there is disagreement regarding the conceptual and operational definition of caregiver burden. For example, Baillie et al. (1988) view caregiver burden as almost interchangeable with perceived stress of caregiving. Zarit et al. (1980) defined caregiver burden as caregiver’s perceived emotional, social, and financial consequences of care provision. This definition emphasizes the multidimensional aspects caregiving may exact on caregivers and also that caregiving is a highly individualized experience. Researchers suggest that burden refer only to subjective perceptions of and reactions to the experience of caregiving (Poulshock & Deimling, 1984). In general, most definitions of burden refer to negative reaction, attitude, or feeling on the part of the caregiver.

**Caregiver Competence.** The definition and theoretical origin of competence has its roots in social cognitive learning theories. It is a concept that is similar to self-
efficacy. Self-efficacy was defined as an individual’s perception of his/her ability to perform competently in a specific situation (Bandura, 1977). Perceived self-efficacy represents the confidence that one can employ the skills necessary to cope with stress and mobilize one’s resources required to meet the situational demands (Bandura, 1977). According to social cognitive theory, self-efficacy influences the appraisal of stressful stimuli (threat, harm or challenge). In this way it may affect subsequent emotional states of an individual. Thus, the concept of competence is important in examining caregiver stress and its role on influencing caregiver depression. Caregiver competence can be defined as the perceived adequacy of one’s performance as a caregiver (Pearlin et al., 1990). Adapted from the self-efficacy definition and definitions of caregiver competence by Schepers et al. (2012) and Pearlin et al. (1990), we define it as one’s perceived adequacy to care for PwAD across a range of AD-specific roles and responsibilities in the current study.

**Conceptual Framework Based on Stress Process Model**

The relationship between caregiving and health is described generally in terms of stress. In 1989, Pearlin developed the Stress Process Model and subsequently modified it for different purposes and situations, including examining the stress of caring for persons with ADRD (Pearlin et al., 1990; Ranney & Aranda, 2001), AIDS (Pearlin et al., 1997; Turner, Pearlin, & Mullan, 1998), and older adults (Cairney & Krause, 2005; Milkie, Bierman, & Schieman, 2008). The Stress Process Model has been widely used in research examining stress and coping for family caregivers of PwAD (Aneshensel et al., 1995; Pearlin, Mullan, Semple, & Skaff, 1990). The notion of “the stress process” was first used in 1981, and Pearlin et al. suggested that stress be studied as a process starting from
sources of stress or stressors, the mediators of stress, and to the manifestations of stress (Pearlin, Menaghan, Lieberman, & Mullan, 1981). In studies applying the stress process to family caregiving, Pearlin and colleagues conceptualized four components of caregiver stress: the background and context of stress; the stressors; the mediators/moderators of stress; and the outcomes or manifestations of stress (Pearlin, Mullan, Semple, & Skaff, 1990).

**BPS as Primary Stressor**

Stressors are at the heart of the stress process. Stressors are the conditions, experiences, and activities that are problematic for caregivers, and threaten or fatigue them (Pearlin et al., 1990). In Pearlin’s model, stressors are divided into two groups: primary stressors and secondary stressors, both of which stem directly from the needs of the patient and the nature and magnitude of the care demanded by these needs. Primary stressors emerge directly from the caregiving situation, such as care recipient’s problem behaviors, cognitive status, and number of activities for which the patient is dependent on the caregiver and the extent of dependency for each activity. Stressors can be viewed differently in terms of their characteristics. For example, clinical cognitive status evaluation is considered as an objective stressor assessed by a specialist like a geriatrician, neurologist, geriatric psychiatrist, or neuropsychologist. However, some stressors including BPS are based on caregiver’s observation and report. In the current study, presence and severity of BPS in PwAD is conceptualized as the primary source of stress, which is continuously present and influencing caregivers’ daily life. Assessment of BPS in PwAD is dependent on the ability of care providers/caregivers to accurately
monitor and describe behavior changes in the care recipients (Logsdon, McCurry, & Teri, 2007).

While primary stressors are viewed as driving the stress model (Pearlin et al., 1990), Pearlin also identifies secondary stressors not directly related to caregiving duties, such as family conflict, work difficulties, and financial difficulties. The current study did not focus on these secondary stressors, though some related variables were included as context factors: employment and marital status in the context of stressors.

**Caregiver Burden and Caregiver Distress as Mediator of Stress**

Mediator of stress are those behaviors, perceptions, and cognitions that can mediate the stressor’s impact on outcome (Pearlin et al., 1981). Mediators help provide explanations for outcome variability. The usual mode of analysis is to determine if the strength of the relationship between a stressor and an outcome is reinforced or attenuated under different mediating conditions (Wheaton, 1985). According to the Transactional Theory of Stress by Lazarus & Folkman (1984), stressors are not the direct precipitating cause of a stress reaction, but rather it is the individual’s appraisal of the challenge/threat that determines the response. This theory suggests that appraisal is important and is one of the main ways by which a person evaluates the meaning and significance of a situation. Stress thus is conceptualized as a relationship between the person and the environment that is appraised by the person as exceeding his or her resources and as endangering the well-being (Lazarus & Folkman, 1984). There are two types of appraisal: primary and secondary. In primary appraisal, the person evaluates whether he or she has anything at stake in this encounter. Specific to this study, the caregiver experiences and appraises the stressor coming from the PwAD and caregiving tasks and evaluates if the
stressor endangers or exceeds his or her resources thus impacts an outcome such as mental health. Previous studies using the Stress Process Model (Pearlin et al., 1990) report that the association between BPS and mental health outcomes of caregivers is mediated by subjective stress appraisal (Goode, Haley, Roth, & Ford, 1998; Hooker et al., 2002; Son et al., 2007). Studies also considered caregiver’s appraisal of burden as a key mediator of those stressors (behavior problems in the PwAD), and found higher levels of burden appraisal associated with worse mental and physical health outcomes (Chun, Knight, & Youn, 2007; Kim, Knight, & Longmire, 2007; Sörensen & Pinquart, 2005). In the current study, caregiver’s appraisal of distress related to BPS and caregiver’s perceived level of burden on caregiving were considered and examined as mediators. Caregiver distress related to BPS is viewed as a direct appraise of the stressor, while caregiver perceive level of burden is considered as caregiver’s appraisal of the general caregiving experience.

**Caregiver Competence as Moderator of Stress**

Moderator of stress are those behaviors, perceptions, and cognitions that can alter the impact on outcome (Pearlin et al., 1981). According to Lazarus & Folkman (1984), in secondary appraisals, the person evaluates what can be done to overcome or prevent harm. For example, caregiver’s perceived level of competence in providing care to PwAD is one of the factors that is capable of altering the condition of negative health outcomes. Caregiver competence, defined in terms of self-perception, is the perceived adequacy of one’s performance as a caregiver (Pearlin et al., 1990). This is one of the important elements in the model of caregiving stress process.
Bandura’s (1982) self-efficacy theory explains how self-perceptions of efficacy influence an individual’s thought patterns, behaviors, and emotions. Expectations of personal efficacy determine whether coping behavior will be initiated, the amount of effort will be expended, and how long it will be sustained (Bandura, 1977). In this study, caregiver competence is considered as a moderator in the model.

In summary, as shown in Figure 2.1, caregiver’s level of burden and level of distress (mediating the relationship between stressor and outcome) and caregiver’s level of competence (moderating the relationship between stressor and outcome) were examined in the current study.

**Caregiver Depression as Manifestation of Stress**

According to Pearlin et al. (1981), there is general agreement that stress refers to “a response of the organism to conditions that, either consciously or unconsciously, are experienced as noxious.” Elements of emotional distress are likely to present first and persist, and they may be eventually inimical to physical well-being. Pearlin (1981) limited the manifestation of stress to a single, global indicator, depression. The assessment of depression is based on respondents’ report of depressive symptoms. Depression is well suited to the current study concerned with social and economic antecedents. It is known to vary with sex, race, marital status, and income in caregivers of individuals with ADRD (Covinsky et al., 2003).

**Contextual Factors of Stress**

Caregiving and its consequences are potentially influenced by key characteristics of the caregiver (Pearlin, Mullan, Semple, & Skaff, 1990). The effects of caregiver’s age,
SES status, race, and gender are expected to be threaded throughout the entire stress process, influencing stressors, mediators, and outcomes (Pearlin, 1989; Pearlin, Mullan, Semple, & Skaff, 1990). Therefore, it is important to include and examine effects of contextual variables on the components of the stress process.

In Pearlin’s conceptual model of Alzheimer’s caregivers, SES characteristics, caregiving history (e.g., relationship of the caregiver to the patient, physical health of the patient, and the length of time the patient has required care), family and network composition (e.g., nature and frequency of contacts with family members and others), and program availability (e.g., use of community-based programs, cost, duration) were examined within background and context of stress (Pearlin, Mullan, Semple, & Skaff, 1990). For the current study, caregiver’s characteristics (age, gender, race, education level, employment, and general health), and relationship of the caregiver to the patient are considered as contextual factors of stress and included in the framework. In addition to those variables included in the Pearlin’s model, the current study also included a variable indicating whether the PwAD was institutionalized within 6 months of the study initiation.

Overall, the conceptual model, as can be seen in Figure 2.1, suggests that when confronted with BPS in PwAD, caregivers cognitively appraise their situations. Caregivers appraise BPS as more distressful to themselves are more likely to have higher level of depressive symptoms. Caregiver’s appraisal of caregiving as a burden also have influence on their depression level, with a higher level of perceived burden leading to a higher level of depressive symptoms. In addition, self-perceived caregiving competence is hypothesized to influence caregiver’s appraisal of the stressor (BPS) that will affect
caregiver depression. Specifically, caregivers with high perceived adequacy to care for PwAD are less likely to assess BPS as stressful events, which leads to a lower level of depressive symptoms. Conversely, caregivers who have a low level of competence may be more likely to perceive BPS in PwAD as a threat to their mental well-being. These particular caregivers may go through the appraisal process repeatedly, and they are often faced with excessive stress, which would overwhelm their ability to cope with BPS and other caregiving responsibilities. This persistent perceived threat would be exhausting and could lead to negative mental health outcomes such as depression.

Among those contextual factors that influence the stressors, mediators, and outcomes, race is a key factor that is studied in the current study. Dilworth-Anderson and Anderson (1994) suggest that ethnicity provides a context for caregiving. The influence of ethnicity on psychological outcomes of caregivers occurs through ethnic differences in background variables, such as the proportion of female and spousal caregivers; the risk for exposure to stressors, including the types and severity of the care recipient’s illness; social support and coping processes; and appraisals of caregiving experiences (as gain or burden) and related cultural values (Aranda & Knight, 1997; Knight, Silverstein, McCallum, & Fox, 2000). For example, ethnic minority caregivers may be less likely than their white peers to view BPS in AD as cause of embarrassment or social unease, because of the high respect for elders (Dilworth-Anderson & Gibson, 2002). In this study, it is hypothesized that the key elements in the stress process model (BPS in PwAD, caregiver perceived level of burden and distress, caregiver competence, and caregiver depression) are different between white and African Americans.
Figure 2.1 Conceptual Framework.

**Contextual Factors**
- *Caregiver*: race, education, age, gender, employment, general health
- *Caregiving related*: relationship to the care recipient, received help, living in nursing home or community

**Stress Source** (Primary Stressor)
- BPS in care recipient

**Mediators of Stress**
- Caregiver appraisal of stress (distress) from BPS
- Caregiver appraisal of burden

**Depression**
- Caregiver depressive symptoms

**Moderator**
- Caregiver appraisal of competence
Research Questions

In the following section, main research questions and hypotheses are proposed based on the aims of the study and the conceptual framework.

**Aim 1:** To compare racial differences in BPS in PwAD both as disparate symptoms and as symptoms that co-occur together.

**Research Question 1:** For the BPS that commonly accompany AD, are there any racial differences associated with their presence and severity?

RQ 1.1: What is the identified BPS (both Frequency and Frequency*Severity) in PwAD reported by caregivers?

Hypothesis 1.2: BPS in PwAD reported by the caregiver are different by race.

RQ 1.3: What are possible clusters of PwAD based on their co-occurring BPS?

Hypothesis 1.4: There is a significant relationship between the identified clusters of BPS in PwAD and race.

**Aim 2:** To assess how BPS in PwAD impact depressive symptoms in caregivers of PwAD.

**Research Question 2:** What is the relationship between caregivers’ reported BPS in PwAD and caregiver level of depressive symptoms?

Hypothesis 2.1: BPS in PwAD is associated with caregiver level of depressive symptoms.

Hypothesis 2.2: Caregiver level of depressive symptoms among clustered groups of PwAD identified in RQ 1.3 are different.
**Research Question 3:** To what extent are caregiver psychosocial variables associated with their depressive symptoms? What are the roles of caregivers’ level of distress, burden, and competence in the relationship between BPS in PwAD and caregivers’ depressive symptoms?

Hypothesis 3.1: Caregiver level of distress, burden, and competence are significant predictors of caregiver level of depressive symptoms.

Hypothesis 3.2: Caregiver level of burden mediates the relationship between BPS in PwAD and caregiver level of depressive symptoms.

Hypothesis 3.3: Caregiver level of distress mediates the relationship between BPS in PwAD and caregiver level of depressive symptoms.

Hypothesis 3.4: Caregiver level of competence moderates the relationship between BPS in PwAD and caregiver level of depressive symptoms.

**Aim 3:** To assess whether the impact of BPS on caregiver depressive symptoms differs across race.

**Research Question 4:** Are there any racial differences in caregiver depressive symptoms and in the association between BPS in PwAD and caregiver depressive symptoms?

Hypothesis 4.1: Caregiver level of depressive symptoms between white and African Americans are different.

Hypothesis 4.2: There are racial differences in the relationship between BPS in PwAD and caregiver level of depressive symptoms.
CHAPTER 3

RESEARCH DESIGN AND METHODOLOGY

This chapter presents the research design and methodology used to address the research questions proposed above. In brief, this study adopted secondary data analysis using data provided by the South Carolina AD Registry. Information about the dataset, measures used in the analysis, and the analytic plan for answering each research question are presented.

Data Source and Sampling

The data used in the current study were from the South Carolina AD Registry, which is one of only three statewide population-based registries of ADRD in the U.S. The South Carolina AD Registry has collected data on South Carolinians with ADRD since 1988 and has identified 251,416 cases of ADRD in South Carolina (Office for the Study of Aging, 2018). The Registry includes multiple sources containing administrative data including inpatient hospitalizations, mental health records, Medicaid claims, emergency department visits, memory clinics, vital records, and sources that contain clinical data such as long-term care evaluations.

The current study analyzed a subsample of the Registry data that were collected for a previous study examining the influence of caregiver characteristics and BPS in
PwAD on nursing home placement (Porter et al., 2016). Inclusion criteria for PwAD and their caregivers included: 1) There was a self or caregiver-reported physician-diagnosis of AD, and a verification of the AD diagnosis using ICD-9 codes by the study team of the previous study (Office for the Study of Aging, 2016); 2) The PwAD was enrolled in a Medicaid waiver program; 3) The PwAD was eligible for nursing home level of care; 4) The PwAD was living in the community or had been admitted to a nursing home within 6 months of the assessment; 5) There was an informal or family caregiver, who spent at least 4 hours per day at least 4 days per week with the individual with AD; and 6) The informal or family caregiver was available for an interview. More detailed information can be found in a published paper using the same data source by Porter et al. (2016). A total of 1,159 individuals were initially deemed eligible for the study by Porter et al. (2016). Of these, 705 individuals’ caregivers agreed to be interviewed and completed the interview. The overall response rate was 72%. Characteristics of the 705 individuals whose caregivers completed interviews were similar to the 454 individuals whose caregivers did not complete interviews based on gender, race, and age of the PwAD (Porter et al., 2016). Prior to the interview, individuals diagnosed with AD identified as living in the nursing home and community were matched on race (African American versus white), gender, age (within 5 years), and long-term care assessment date (within 120 days). The long-term care assessment date was chosen as a matching variable to assure that those living in the nursing home and community had a level of care assessment within a similar time frame. There were 641 individuals matched with replacement. As the current research only focused on African-American and white caregivers, 6 individuals were excluded from the 641 participants (3 Hispanic cases, 1
Asian/Pacific Islander, and 2 other). The final sample for this study included 635 dyads, with 313 African-American caregivers and 322 white caregivers. Figure 3.1 presents a consort flow diagram of study enrollment (Porter et al., 2016).

Figure 3.1 Project Flow Diagram (Porter et al., 2016).
Survey and Interview Procedure

As reported by Porter et al. (2016), interviews were completed by 5 trained interviewers from the Office for the Study of Aging, Arnold School of Public Health, University of South Carolina over the telephone. The interviews lasted between 30 minutes and 1 hour and took place between January and September 2010. The interview survey consisted of questions about caregiver’s relationship to the care recipient, household size, and other demographics. The Neuropsychiatric Inventory-Questionnaire (NPI) was used to identify BPS. The NPI consists of 12 domains of behavioral and psychological symptoms and assesses BPS with respect to caregivers’ reported frequency and severity of each domain (See Measures section below about specific questions and items used in the current study). Caregivers were asked to answer the questions using different reference points. Caregivers of those individuals living in nursing homes were asked to think back to the month before admitting their care recipient to a nursing home (maximum 7 months recall period). Caregivers of those individuals living in the community were asked to think back to the month prior to the interviewer’s call. Caregivers were mailed a letter with information about the study, along with $2 as an incentive for participation in the survey. Verbal informed consent was obtained from all subjects before the study by phone. Interviewers called caregivers and conducted the interview over the telephone or scheduled an appointment to conduct the interview at a later time by phone. After completing the interview, caregivers were mailed a letter thanking them for their participation and additional incentive, a $10 gift card, for their time and assistance.
Ethical Issues and IRB Approval for the Study

In August 2017, the researcher received IRB approval from the University of South Carolina to conduct the current study and submitted a data application form to the South Carolina AD Registry Manager (Dr. Maggi Miller, Office for the Study of Aging). The data were then sent via Email by the Registry Manager in October 2017. For security purposes, the data and relevant SAS syntax and output were stored on a password-protected laptop. Only the researcher knows the password to unlock the laptop. After completing the study, the data were removed and deleted from the laptop.

Measures

Caregiver Depressive Symptoms. Caregiver depressive symptoms was measured using the 10-item screening questionnaire, the Center for Epidemiological Studies Depression Scale–10 (CESD-10) (Andresen, Malmgren, Carter, & Patrick, 1994). This scale is a self-report measure of depressive symptoms, which is widely used in different population groups including caregivers (Björgvinsson, Kertz, Bigda-Peyton, McCoy, & Aderka, 2013; Finkel, Czaja, Martinovich, Harris, Pezzuto, & Schulz, 2007; Gallagher et al., 2011). There is a total of 10 items (e.g., “You felt fearful”, “You felt lonely”) and caregivers’ self-report frequency level for each statement (See detailed information about 10 items of the scale in Appendix A). In scoring the scale, a value of 0, 1, 2 or 3 is assigned to a response depending upon whether the item is worded positively or negatively. For items 1-4, 6-7, 9-10, the scoring is: rarely/none of the time=0, some of the time=1, occasionally=2, most of the time=3. Items 5 and 8 are reverse scored as follows: most of the time=0, occasionally=1, some of the time=2, rarely/none of the time=3. The total score was calculated by the sum of 10 items (range: 0-30), with a
higher score indicating the presence of more symptomatology and level of depression. If one or more of the 10 items are missing for a case, CESD score would not be calculated and it was treated as missing value (not included in the statistical analysis). Any score equal to or above 10 indicates a person is at risk for clinical depression (Andresen, Malmgren, Carter, & Patrick, 1994). Internal consistency for the scale in the current study was high (Cronbach’s alpha=0.80).

**Behavioral and Psychological Symptoms (BPS).** The Neuropsychiatric Inventory (NPI) (Cummings et al., 1994) was used to assess AD-related BPS for PwAD in the community dwelling sample and those in the nursing home sample one month prior to institutionalization. The NPI is designed to be self-administered questionnaire completed by family caregivers of PwAD. There are 10 domains of behavioral functioning: delusions, hallucinations, agitation/aggression, dysphoria, anxiety, euphoria, apathy, disinhibition, irritability/lability, and aberrant motor activity (original scales), with 2 more domains added since its development: night-time behavioral disturbances and appetite and eating abnormalities (Cummings, 1997). A screening question is asked about each domain first. If the response indicates that the patient has problems with a particular domain of behavior, the caregiver is only then asked all the individual questions in that domain, rating the frequency of each symptom on a 4-point scale and the severity on a 3-point scale (Cummings, 1997). The total score of NPI ranges from 0-144 (12 domains * 4-point frequency * 3-point severity), with a higher score indicating the presence of more severe BPS of the person. Internal consistency for the total score of NPI in the current study was high (Cronbach’s alpha=0.81). Cronbach Coefficients for each of 12 domains ranged from 0.79 to 0.81.
Caregiver Distress from BPS. Caregiver distress was measured by distress the behavior disturbance causes in NPI. Caregivers were asked “How emotionally distressing do you find this behavior?” and rated on a 5-point scale, from “Not at all” (0) to “Very severely or extremely” (5). The NPI provides distress ratings for each individual symptom of BPS reported. Total score for caregiver distress ranges from 0-60 (12 domains * maximum 5 points for each behavior). Cronbach’s alpha for the scale in the current study was 0.90.

Caregiver Burden. Caregiver burden was measured by 4-item screening version of Zarit Burden Interview (ZBI; Bédard et al., 2001). The short and simple 4-item version has been formed to be valid and reliable with results comparable to those of the full version (Bédard et al., 2001). Reducing the number of items did not affect the properties of the ZBI and was suggested that it might have easier administration of the instrument (Bédard et al., 2001). Caregivers are asked to report the frequency of 4 feeling related questions on a 4-point scale from “Never” (0) to “Nearly Always” (4). Questions are as follows: 1) Did you feel that because of the time you spent with patient, that you did not have enough time for yourself? 2) Did you feel stressed between caring for patient and trying to meet other responsibilities for your family or work? 3) Did you feel strained (tense) when you were around patient? 4) Did you feel uncertain about what to do about patient? Total score ranges from 0-16, with a score of 8 indicating high burden level. Cronbach’s alpha for the short screening version in the current study was 0.77.

Caregiver Competence. Caregiving competence was measured by a 4-item scale developed by Pearlin et al. (1990) in the stress and coping model for family caregiving. Caregivers are asked to report the frequency of following questions on a 4-point scale
from “Not at all” (1) to “Very/Very much” (4): How much do you 1) Believe that you’ve learned how to deal with a very difficult situation? 2) Feel that all in all, you are a good caregiver? Think how of all the things we’ve been talking about: the daily ups and downs that you face as a caregiver; the job you are doing; and the ways you deal with the difficulties. Putting all these things together, 3) How successful do you feel? 4) How self-confident do you feel? Reponses for the first 2 items are “Very much”, “Somewhat”, “Just a little”, and “Not at all”; responses for item 3 and 4 are “Very”, “Fairly”, “Just a little”, and “Not at all”. Total score ranges from 4-16, with a higher score indicating higher level of competence in caring the PwAD. Cronbach’s alpha for the scale in the current study was 0.65.

**Demographic and Contextual Variables**

**Gender.** Caregiver gender was a dichotomous variable with male coded as 1 and female coded as 2. PwAD gender had same categories and coding.

**Race.** The study only focused on African American (1) and white (0) caregiver in the Registry. Race of PwAD had same categories and coding.

**Age.** Age of both caregiver and PwAD was calculated from their date of birth from the original data, and both were continuous variables. Age of PwAD ranged from 53 to 101 (SD=8.17). Caregiver’s age ranged from 20 to 94 (SD=11.12).

**Relationship to the PwAD.** The original question asking about caregiver relationship to the person included 13 response options (e.g., daughter, son, wife, husband, daughter in law, son in law, parent, sister, brother, grandchild, niece or nephew, no blood relationship, and other). Categories of the variable in the current study were
reorganized for analytic purpose as follows: spouse (either husband or wife) (1),
children/children in law (including daughter, son, daughter in law, and son in law) (2),
other relatives (including parent, sister, brother, grandchild, and niece or nephew) (3),
and non-relative or other (including no blood relationship and other) (4).

**Employment.** Caregiver employment status was measured by one question: What
is your employment status? Original response options included: retired but working part
time, fully retired, unemployed, homemaker, employed full time, employed part time,
and other. For the analytic purpose, this variable was re-categorized as follows: retired
(fully retired and retired but working part time) coded as “1”, not working (unemployed
and homemaker) coded as “2”, employed either full time or part time coded as “3”, and
other coded as “4”.

**Education Level.** Caregiver education level was measured by their highest level
of education. Original response options include 7 levels: less than 8th grade, 8th-12th
grade, high school graduate/GED, some college, college graduate, some graduate
courses, and graduate degree. The final variable for analysis included three levels: high
school or below coded as “1”, some college or college graduate coded as “2”, and some
graduate or graduate degree coded as “3”.

**Received Help.** Whether the caregiver received help from others aside from paid
assistance was coded as a dichotomous variable with “0” indicating No and “1”
indicating Yes.

**Nursing Home Placement or Community Living.** Whether the PwAD is living
in a nursing home or in the community was measured by the following question: Where
is the patient staying now: nursing home or private home. This variable for analysis is a
dichotomous variable with “0” indicating living in the community and “1” indicating
living in a nursing home.

Statistical Analysis

Cluster analysis was executed using the “pam” function in the 'cluster' package in
R. Other analyses were executed in SAS v9.1.3 (SAS Institute Inc., 2003). Descriptive
univariate statistics were examined to gain an understanding of the data distribution and
bivariate correlational analyses were conducted to gain a better understanding of how the
variables of interest were interrelated. Specific analytic plan for each research question is
introduced as below.

Research Question 1: For the BPS that commonly accompany AD, are there any racial
differences associated with their presence and severity?

RQ 1.1: What is the identified BPS (both Frequency and Frequency*Severity) in
PwAD reported by caregivers?

To answer RQ 1.1, descriptive analyses were used to examine the total score of
BPS (e.g., mean, SD), and individual domain of BPS (e.g., frequency, score).

Hypothesis 1.2: BPS in PwAD reported by the caregiver are different by race.

To test Hypothesis 1.2, Mann-Whitney U-tests (hereafter U-tests) were used to
examine whether the total score of BPS and the score for each domain between African-
American and white caregivers are different. Chi-square test was used to examine
differences in the frequency of BPS presence as reported by African-American and white caregivers.

**RQ 1.3: What are possible clusters of PwAD based on their co-occurring BPS?**

Cluster analyses were conducted to identify clusters of PwAD based on their co-occurring BPS. The analysis considered BPS as continuous variable (frequency*severity score). K-medoids approach (Kaufman & Rousseeuw, 1987) was used to identify groups of PwAD. K-medoids is a classical partitioning technique of clustering, which clusters the data set of n objects into k clusters, with the number k of clusters assumed known a priori. To choose an optimal k, the researcher specified k (e.g., 2,3,4) before the execution of the algorithm using “average silhouette width” method. The researcher ran PAM multiple times with increasing k and select k such that it maximizes with average silhouette width of the resultant clusters. The choice of k was made for each initial classification and the original classes do not need to be partitioned into the same number of clusters. After the classification, descriptive analyses (e.g., BPS) were used to profile each cluster.

**Hypothesis 1.4: There is a significant relationship between the identified clusters of BPS in PwAD and race.**

Chi-square test was used to verify the relationship between race and identified cluster groups.

**Research Question 2: What is the relationship between caregivers’ reported BPS in PwAD and caregiver level of depressive symptoms?**
Hypothesis 2.1: BPS in PwAD is associated with caregiver level of depressive symptoms.

To test Hypothesis 2.1, general linear regression was conducted to examine if the total score of BPS is associated with caregiver depressive symptoms (controlling contextual factors).

Hypothesis 2.2: Caregiver level of depressive symptoms among clustered groups of PwAD identified in RQ 1.3 are different.

As the score of caregiver level of depressive symptoms was not normally distributed, Kruskal-Wallis test (a non-parametric version of ANOVA) was conducted to examine if caregiver level of depressive symptoms among clustered groups of PwAD identified in RQ 1.3 were different.

Research Question 3: To what extent are caregiver psychosocial variables associated with their depressive symptoms? What are the roles of caregivers’ level of distress, burden, and competence in the relationship between BPS in PwAD and caregivers’ depressive symptoms?

Hypothesis 3.1: Caregiver level of distress, burden, and competence are significant predictors of caregiver level of depressive symptoms.

General linear regression was used to test Hypotheses 3.1 and examine if the total score of BPS, caregiver’s level of distress, burden, and competence were associated with caregiver level of depressive symptoms (controlling contextual factors).
Hypothesis 3.2: Caregiver level of burden mediates the relationship between BPS in PwAD and caregiver level of depressive symptoms.

Hypothesis 3.3: Caregiver level of distress mediates the relationship between BPS in PwAD and caregiver level of depressive symptoms.

Hypothesis 3.4: Caregiver level of competence moderates the relationship between BPS in PwAD and caregiver level of depressive symptoms.

For Hypothesis 3.2 & 3.3, procedures described by Baron and Kenny (1986) were used to determine mediation effects. Sobel’s (1982) test of significance was performed to determine the extent to which a mediator contributes to the total effect on the dependent variable (caregiver depressive symptoms). An interaction term competence * total score of BPS was added to test if caregiver competence was a moderator on the relationship between BPS and caregiver depressive symptoms (Hypothesis 3.4).

Research Question 4: Are there any racial differences in caregiver depressive symptoms and in the association between BPS in PwAD and caregiver depressive symptoms?

Hypothesis 4.1: Caregiver level of depressive symptoms between white and African Americans are different.

U-tests were conducted to test Hypothesis 4.1.

Hypothesis 4.2: There are racial differences in the relationship between BPS in PwAD and caregiver level of depressive symptoms.

To test Hypothesis 4.2, an interaction term race * total score of BPS was added to the general linear regression model to examine if the total score of BPS is associated with
caregiver level of depressive symptoms across race.

**Missing Data**

In order to understand the dataset and make sure it can be used to answer all the research questions, data management including missing mechanism examination and data cleaning were conducted. Based on the study sample of 635 dyads, the amount of missing data for each dyad ranged from 0 to 13 items (M=0.49, SD=1.43). Overall, 527 dyads (82.99%) had no missing data, 8 dyads (1.26%) had 1 missing item, 65 dyads (10.24%) had 2 missing items, 15 dyads (2.36%) had 3 missing items, 10 dyads (1.57%) had 4 missing items, and 10 dyads (1.57%) had missing data on 5 items or more. The total number of missing values accounted for 0.86% of all values in the sample. Most of the phi coefficients (i.e., the correlations between missingness) were within an acceptable range of -0.04 to 0.4 (90.32%); A few (n=45, 9.68%) stronger correlations were observed (0.41-0.82). Those strong correlations were between individual items of scales (e.g., BPS, caregiver distress, burden, competence), and the variables that would be used in the final analyses were scale score instead of individual items. No strong correlations between missingness and observed values were found; correlation coefficients ranged from -0.17 to 0.15. The assumption that the missing was at random (MAR) can be made.

When data are missing completely at random and less than 30% of data are missing, listwise deletion yields less biased regression parameter estimates than do other common imputation methods (Kromrey & Hines, 1994). Thus, limiting the sample to those with complete data on all variables of interest (i.e., listwise deletion) was an appropriate missing-data treatment. After checking the missingness of the data, we were able to retain 635 dyads.
Assumptions for Statistical Tests

Tests for Comparing Two Groups. Independent t-tests require that variables are normally distributed. Variables including BPS in PwAD, caregiver burden, caregiver distress, caregiver competence, and caregiver depressive symptoms were checked. As most of the variables were ordinal with skewness, the normality assumption did not hold for t-tests. Therefore, Mann-Whitney U-tests were used to compare group means. Mann-Whitney U-tests do not have assumption on normality. Plots indicated that the shapes of the distributions being compared were similar to each other.

To control the familywise error rate (FWER) for multiple hypothesis tests in the study (e.g., Hypothesis 1.2, Hypothesis 4.1), the Holm-Bonferroni Method (Holm, 1979) was used. It is a modification of the Bonferroni correction, which reduces the possibility of getting a statistically significant result when performing multiple tests. As a result, an alpha smaller than or equal to .0006 was considered statistically significant for tests related to Hypothesis 1.2 and Hypothesis 4.1.

General Linear Regression. Prior to performing the regression analysis to answer the research questions, assumptions were examined by following the procedures described by Cohen, Cohen, West, and Aiken (2003). Assumptions about regression models were examined through the visual analysis of data, and the assumptions were met. For example, in all models, the linearity assumption was examined by reviewing a plot of residuals versus predicted values. Points were symmetrically distributed around a horizontal line with a roughly constant variance. Homoscedasticity of errors was examined through a plot of residuals versus predicted values; errors did not systematically increase in one direction by a significant amount. The normality
assumption was met, as points on a normal quantile plot were close to the diagonal reference line. Lastly, independence of errors was also met, because a random display of points was observed in the plot without any patterns. In respect to outliers, no outlier was detected using studentized residuals (> 3) and Cook’s D (> 1). Multicollinearity was measured by variance inflation factors (VIF) and tolerance. If VIF value exceeds 10, there is a strong multicollinearity (Yoo et al., 2014). In this study, all VIF values were lower than 10. The following figures did not show obvious violations of assumptions for whole sample, nursing home, and community living subsample.

![Diagnostic Plots for Assumptions (Whole Sample)](image)

Figure 3.2 Diagnostic Plots for Assumptions (Whole Sample).
Figure 3.3 Diagnostic Plots for Assumptions (Nursing Home Subsample).

Figure 3.4 Diagnostic Plots for Assumptions (Community Living Subsample).
Before conducting regression analysis, continuous variables were centered by subtracting the mean of each variable from the data to improve interpretation of the resulting regression equations as well as reduce multicollinearity (Kromrey & Foster-Johnson, 1998). An alpha of .05 was used as the cutoff for statistical significance in general linear regression analysis results.

**Nursing Home vs Community Living.** Before conducting a multiple regression for inferential statistics, U-tests were conducted to see if the subsample of PwAD living in nursing home and the subsample of PwAD living in community were comparable across all main variables. Mean comparisons of nursing home subsample and community subsample indicated significant group differences on BPS in PwAD [statistic=80664.50, p<.0001], caregiver burden [statistic=81521.00, p<.0001], caregiver distress [statistic=73626.50, p<.0001], and caregiver depressive symptoms [statistic=83837.50, p=.0012]. Caregivers of those living in the nursing home reported higher mean of BPS in PwAD (35.88 vs 26.97), caregiver burden (7.35 vs 5.93), caregiver distress (17.34 vs 13.07), and caregiver depressive symptoms (11.39 vs 9.80), and the lower mean scores on caregiver competence (14.74 vs 15.00). For this reason, results for the two groups were reported separately for each research question.
CHAPTER 4

RESULTS

This chapter presents a summary of the characteristics of the study participants and results from descriptive analyses, bivariate analyses, multivariate analyses, and cluster analyses that examine the following research questions and hypotheses:

Research Question 1: For the BPS that commonly accompany AD, are there any racial differences associated with their presence and severity?

RQ 1.1: What is the identified BPS (both Frequency and Frequency*Severity) in PwAD reported by caregivers?

Hypothesis 1.2: BPS in PwAD reported by the caregiver are different by race.

RQ 1.3: What are possible clusters of PwAD based on their co-occurring BPS?

Hypothesis 1.4: There is a significant relationship between the identified clusters of BPS in PwAD and race.

Research Question 2: What is the relationship between caregivers’ reported BPS in PwAD and caregiver level of depressive symptoms?

Hypothesis 2.1: BPS in PwAD is associated with caregiver level of depressive symptom
Hypothesis 2.2: Caregiver level of depressive symptoms among clustered groups of PwAD identified in RQ 1.3 are different.

Research Question 3: To what extent are caregiver psychosocial variables associated with their depressive symptoms? What are the roles of caregivers’ level of distress, burden, and competence in the relationship between BPS in PwAD and caregivers’ depressive symptoms?

Hypothesis 3.1: Caregiver level of distress, burden, and competence are significant predictors of caregiver level of depressive symptoms.

Hypothesis 3.2: Caregiver level of burden mediates the relationship between BPS in PwAD and caregiver level of depressive symptoms.

Hypothesis 3.3: Caregiver level of distress mediates the relationship between BPS in PwAD and caregiver level of depressive symptoms.

Hypothesis 3.4: Caregiver level of competence moderates the relationship between BPS in PwAD and caregiver level of depressive symptoms.

Research Question 4: Are there any racial differences in caregiver depressive symptoms and in the association between BPS in PwAD and caregiver depressive symptoms?

Hypothesis 4.1: Caregiver level of depressive symptoms between white and African Americans are different.

Hypothesis 4.2: There are racial differences in the relationship between BPS in PwAD and caregiver level of depressive symptoms.
Results for the total sample (N=635), subsample of nursing home (n=348, 54.80%), and subsample of community (n=287, 45.20%) are reported separately.

**Characteristics of PwAD**

Descriptive characteristics of the PwAD in the study (N=635) are depicted in Table 4.1. Most PwAD in the total sample were female (n=462, 72.76%). Almost half of PwAD were above 85 years (n=291, 46.78%), followed by those aged 75-84 years (n=242, 38.91%), 65-74 (n=75, 12.06%), and below 65 (n=14, 2.25%). PwAD age ranged between 53 and 101, with an average of 83.70 years (SD=8.16). There were 321 (50.55%) whites and 314 (49.45%) African Americans.

**Nursing Home Sample.** More than 70% of PwAD living in the nursing home at the time of being interviewed were female (n=252, 72.41%; Table 4.2). About half of PwAD were above 85 years (n=171, 50.44%), followed by those aged 75-84 years (n=126, 37.17%), 65-74 (n=38, 11.21%), and below 65 (n=4, 1.18%). PwAD age ranged between 54 and 101, with an average of 84.19 years (SD=7.85). There were 195 (56.03%) whites and 153 (43.97%) African Americans.

**Community Living Sample.** Similar to the nursing home subsample, most of the PwAD living in the community at the time of being interviewed were female (n=210, 73.17%). There were 120 (42.40%) PwAD above 85 years, followed by those aged 75-84 years (n=116, 40.99%), 65-74 (n=37, 13.07%), and below 65 (n=10, 3.53%). PwAD age ranged from 53 to 101, with an average of 83.10 years (SD=8.50). There were 126 (43.90%) whites and 161 (56.10%) African Americans.
A higher percentage of African American PwAD (51.27% vs 39.25%) than whites were living in the community (p=.002).

**Characteristics of Caregivers**

Most caregivers for PwAD in the total sample were female (n=514, 80.94%). Caregiver’s age ranged between 20 and 94 years, with an average of 59.86 years and standard deviation 11.12; more than a third caregivers aged 60-74 years (n=247, 38.90%), followed by those aged 45-59 (n=230, 36.22%), 44 or below (n=105, 16.54%), and 75 or above (n=53, 8.35%). There were 322 (50.71%) white caregivers and 313 (49.29%) African-American caregivers. In terms of caregivers’ highest level of education, almost half of the sample (n=309, 49.20%) had a degree of high school or below, 269 (42.83%) caregivers had some college or college graduate, and 50 (7.96%) caregivers had some graduate education or a graduate degree. More than half of all caregivers (n=359, 56.54%) were married at the time of interview. About 41% of all caregivers were employed full-time or part-time (n=263, 41.48%), while 33.6% of caregivers were retired (n=213). Caregivers’ relationship to the PwAD included mostly children/children in law (n=428, 67.4%), followed by other relative (n=94, 14.8%), spouse (n=71, 11.18%), and non-relative (n=42, 6.61%).

As for the place of residence, 348 (54.80%) PwAD were living in the nursing home at the time of interview while 287 (45.20%) were staying in their communities. Among those staying in the communities, 225 (78.95%) were living with their caregivers in the same household.
Nursing Home Sample. Most caregivers for PwAD living in the nursing home were female (n=267, 76.72%). Caregiver age ranged between 29 and 94 years, with an average of 61.12 years and standard deviation 11.49; 41.09% of caregivers were aged 60-74 years (n=143), followed by those 45-59 (n=113, 32.47%), 44 or below (n=55, 15.80%), and 75 or above (n=37, 10.63%). There were 196 (56.32%) white caregivers and 152 (43.68%) African-American caregivers. In terms of caregivers’ highest level of education, almost half of the subsample (n=162, 47.51%) had some college or college graduate, 43.99% (n=150) caregivers had high school or below, and 29 (8.50%) caregivers had some graduate education or a graduate degree. More than half of caregivers in the subsample (n=225, 64.66%) were married at the time of interview. There were 151 (43.52%) caregivers employed either full-time or part-time, while 132 (38.04) caregivers were retired. Caregivers’ relationship to the PwAD included mostly children/children in law (n=226, 64.94%), followed by other relative (n=61, 17.53%), spouse (n=36, 10.34%), and non-relative (n=25, 7.18%).

Community Living Sample. Most caregivers for PwAD living in the community were female (n=247, 86.06%). Caregiver age ranged between 20 and 86 years, with an average of 58.30 years and standard deviation 10.46; 40.77% of caregivers were aged 45-59 years (n=117), followed by those 60-74 (n=104, 36.24%), 44 or below (n=50, 17.42%), and 75 or above (n=16, 5.57%). There were 126 (43.90%) white caregivers and 161 (56.10%) African-American caregivers. In terms of caregivers’ highest level of education, more than half of the subsample (n=159, 55.40%) had a degree of high school or below, 107 (37.28%) caregivers had some college or college graduate, and 21 (7.32%) caregivers had some graduate education or a graduate degree. There were 134 (46.69%)
caregivers married at the time of interview. More than a third of caregivers were employed either full time or part time (n=112, 39.02%), while 28.22% of caregivers were retired (n=81). Caregivers’ relationship to the PwAD included mostly children/children in law (n=202, 70.38%), followed by spouse (n=35, 12.20%), other relative (n=33, 11.50%), and non-relative (n=17, 5.92%).

There were significant differences regarding the following caregiver demographics between those living in a nursing home and in the community: caregiver gender (p=.003), race (p=.002), marital status (p<.0001), employment status (p=.0004), and education level (p=.017). Specifically, comparing to caregivers of PwAD living in the nursing home, there were higher percentage of female (86.06% vs 76.72%), African American (56.10% vs 43.68%) caregivers of those PwAD living in community, and higher percentage of caregivers in the community had high school or below education level (55.4% vs 43.99%).

Table 4.1

Demographic Information (N=635)

<table>
<thead>
<tr>
<th>PwAD Demographic</th>
<th>All (n=635)</th>
<th>White (n=321)</th>
<th>African American (n=314)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>462 (72.76)</td>
<td>235 (73.21)</td>
<td>227 (72.29)</td>
</tr>
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<td>Male</td>
<td>173 (27.24)</td>
<td>86 (26.79)</td>
<td>87 (27.71)</td>
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<tr>
<td>Age Group</td>
<td>All (n=635)</td>
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<td>African American (n=313)</td>
</tr>
<tr>
<td>-----------</td>
<td>-------------</td>
<td>---------------</td>
<td>--------------------------</td>
</tr>
<tr>
<td>&lt;65</td>
<td>14 (2.25)</td>
<td>10 (3.17)</td>
<td>4 (1.30)</td>
</tr>
<tr>
<td>65-74</td>
<td>75 (12.06)</td>
<td>38 (12.06)</td>
<td>37 (12.05)</td>
</tr>
<tr>
<td>75-84</td>
<td>242 (38.91)</td>
<td>123 (39.05)</td>
<td>119 (38.76)</td>
</tr>
<tr>
<td>85 and above</td>
<td>291 (46.78)</td>
<td>133 (45.71)</td>
<td>147 (47.88)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Living in Nursing Home</th>
<th>All (n=635)</th>
<th>White (n=322)</th>
<th>African American (n=313)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>348 (54.8)</td>
<td>195 (60.75)</td>
<td>153 (48.73)</td>
</tr>
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<td>287 (45.2)</td>
<td>126 (39.25)</td>
<td>161 (51.27)</td>
</tr>
</tbody>
</table>

Caregiver Demographic

<table>
<thead>
<tr>
<th>Caregiver Demographic</th>
<th>All (n=635)</th>
<th>White (n=322)</th>
<th>African American (n=313)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>514 (80.94)</td>
<td>248 (77.02)</td>
<td>266 (84.98)</td>
</tr>
<tr>
<td>Male</td>
<td>121 (19.06)</td>
<td>74 (22.98)</td>
<td>47 (15.02)</td>
</tr>
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</table>

<table>
<thead>
<tr>
<th>Education Level</th>
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<th>African American (n=313)</th>
</tr>
</thead>
<tbody>
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<td>High school or below</td>
<td>309 (49.20)</td>
<td>146 (46.20)</td>
<td>163 (52.24)</td>
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<td>Some college or college</td>
<td>269 (42.83)</td>
<td>149 (47.15)</td>
<td>120 (38.46)</td>
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<td>Some graduate or graduate</td>
<td>50 (7.96)</td>
<td>21 (6.65)</td>
<td>29 (9.29)</td>
</tr>
<tr>
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<td>Count (Percentage)</td>
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<td></td>
</tr>
<tr>
<td>-----------------</td>
<td>--------------------</td>
<td></td>
<td></td>
</tr>
<tr>
<td>44 or below</td>
<td>105 (16.54)</td>
<td></td>
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</tr>
<tr>
<td>45-59</td>
<td>230 (36.22)</td>
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<td></td>
</tr>
<tr>
<td>60-74</td>
<td>247 (38.90)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>75 and above</td>
<td>53 (8.35)</td>
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<table>
<thead>
<tr>
<th>Marital Status</th>
<th>Count (Percentage)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Married</td>
<td>359 (56.54)</td>
</tr>
<tr>
<td>Single</td>
<td>88 (13.86)</td>
</tr>
<tr>
<td>Divorced</td>
<td>76 (11.97)</td>
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<tr>
<td>Widowed</td>
<td>77 (12.13)</td>
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<tr>
<td>Other</td>
<td>35 (5.51)</td>
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<table>
<thead>
<tr>
<th>Employment Status</th>
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</thead>
<tbody>
<tr>
<td>Retired</td>
<td>213 (33.60)</td>
</tr>
<tr>
<td>Employed full/part time</td>
<td>263 (41.48)</td>
</tr>
<tr>
<td>Not working</td>
<td>93 (14.67)</td>
</tr>
<tr>
<td>Other</td>
<td>65 (10.25)</td>
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<table>
<thead>
<tr>
<th>Relationship</th>
<th>Count (Percentage)</th>
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<tr>
<td>Spouse</td>
<td>71 (11.18)</td>
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51
<table>
<thead>
<tr>
<th>Relationship</th>
<th>Count</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Children/children in law</td>
<td>428 (67.40)</td>
<td>228 (70.81)</td>
</tr>
<tr>
<td>Other relative</td>
<td>94 (14.80)</td>
<td>30 (9.32)</td>
</tr>
<tr>
<td>Non-relative</td>
<td>42 (6.61)</td>
<td>21 (6.52)</td>
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**General Health**

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<th>Health Status</th>
<th>Count</th>
<th>Percentage</th>
</tr>
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<tbody>
<tr>
<td>Excellent</td>
<td>63 (9.95)</td>
<td>37 (11.53)</td>
</tr>
<tr>
<td>Very good</td>
<td>161 (25.43)</td>
<td>95 (29.60)</td>
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<tr>
<td>Good</td>
<td>197 (31.12)</td>
<td>89 (27.73)</td>
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<tr>
<td>Fair</td>
<td>152 (24.01)</td>
<td>65 (20.25)</td>
</tr>
<tr>
<td>Poor</td>
<td>60 (9.48)</td>
<td>35 (10.90)</td>
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**Total**

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<tr>
<th></th>
<th>Count</th>
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<tr>
<td></td>
<td>635 (100)</td>
<td>322 (50.71)</td>
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</table>

Note. 1Age group variable has 13 missing cases; 2Education level variable has 7 missing cases; 3Employment variable has 1 missing case; 4General health variable has 2 missing cases; 5Chi-square test results showed significant differences regarding gender (p=.011), marital status (p<.0001), employment status (p=.030), relationship with the care recipient (p=.001), general health (p=.008), and nursing home/community (p=.002) by race.
Table 4.2

Demographic Information for Nursing Home and Community Living Subsample

<table>
<thead>
<tr>
<th>PwAD Demographic</th>
<th>All (n=635)</th>
<th>Nursing Home (n=348)</th>
<th>Community Living (n=287)</th>
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<td><strong>Gender</strong></td>
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<td></td>
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<td>Male</td>
<td>173 (27.24)</td>
<td>96 (27.59)</td>
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<tr>
<td><strong>Race</strong></td>
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</tr>
<tr>
<td>White</td>
<td>321 (50.55)</td>
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<td>African American</td>
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<td>153 (43.97)</td>
<td>161 (56.10)</td>
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<td><strong>Age Group</strong></td>
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<td>65-74</td>
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<td>291 (46.78)</td>
<td>171 (50.44)</td>
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<tr>
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<td>465</td>
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<td>(49.29)</td>
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<td>(47.51)</td>
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<td>Age Group</td>
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<td>(15.80)</td>
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<td>343</td>
</tr>
<tr>
<td></td>
<td>(36.22)</td>
<td>(32.47)</td>
<td></td>
</tr>
<tr>
<td>60-74</td>
<td>247</td>
<td>143</td>
<td>390</td>
</tr>
<tr>
<td></td>
<td>(38.90)</td>
<td>(41.09)</td>
<td></td>
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<tr>
<td>75 and above</td>
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<td>37</td>
<td>90</td>
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<td></td>
<td>(8.35)</td>
<td>(10.63)</td>
<td></td>
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<tr>
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<tr>
<td>Married</td>
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<td>225</td>
<td>584</td>
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<tr>
<td></td>
<td>(56.54)</td>
<td>(64.66)</td>
<td></td>
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<tr>
<td>Single</td>
<td>88</td>
<td>33</td>
<td>121</td>
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<tr>
<td></td>
<td>(13.86)</td>
<td>(9.48)</td>
<td></td>
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<tr>
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<td>Count (Percentage)</td>
<td>Count (Percentage)</td>
<td>Count (Percentage)</td>
</tr>
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<td>--------------</td>
<td>--------------------</td>
<td>--------------------</td>
<td>--------------------</td>
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<tr>
<td>Divorced</td>
<td>76 (11.97)</td>
<td>32 (9.20)</td>
<td>44 (15.33)</td>
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<tr>
<td>Widowed</td>
<td>77 (12.13)</td>
<td>42 (12.07)</td>
<td>35 (12.20)</td>
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<tr>
<td>Other</td>
<td>35 (5.51)</td>
<td>16 (4.60)</td>
<td>19 (6.62)</td>
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<table>
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<th>Employment Status(^3)</th>
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<tr>
<td>Retired</td>
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<td>Employed full/part time</td>
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<tr>
<td>Not working</td>
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<td>Other</td>
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<table>
<thead>
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<tr>
<td>Spouse</td>
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<td>Children/children in law</td>
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<tr>
<td>Other relative</td>
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<tr>
<td>Non-relative</td>
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<table>
<thead>
<tr>
<th>General Health(^4)</th>
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<tr>
<td>Excellent</td>
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<tr>
<td>Very good</td>
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<tr>
<td>Good</td>
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<tr>
<td>Fair</td>
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</table>
Table 4.3 shows descriptive statistics of the primary continuous variables in the study: caregiver depressive symptoms, BPS in PwAD, caregiver distress, caregiver burden, and caregiver competence. This study used indices for acceptable limits of skewness (±2) and kurtosis (±4), respectively. The mean score of caregiver depressive symptoms was 10.67 (SD=6.48), which is above the cutoff point of 10. Individuals whose CESD-10 score is ≥10 are identified as at risk for clinical depression. Higher scores indicate a higher level of depressive symptoms. The mean value of BPS score in PwAD was 31.85 (SD=24.63). Regarding caregiver distress related to BPS, the mean value was 15.43 (SD=11.45). Caregiver burden was also examined, and results showed that the
mean value of it was 6.71 (SD=4.15). Lastly, the average caregiver competence score was 14.86 (SD=1.55).

U-tests for comparing nursing home subsample and community subsample indicated significant group differences on BPS in PwAD [statistic=80664.50, p<.0001], caregiver burden [statistic=81521.00, p<.0001], caregiver distress [statistic=73626.50, p<.0001], and caregiver depressive symptoms [statistic=83837.50, p=.0012]. Caregivers of those living in the nursing home reported higher mean of BPS in PwAD (35.88 vs 26.97), caregiver burden (7.35 vs 5.93), caregiver distress (17.34 vs 13.07), and caregiver depressive symptoms (11.39 vs 9.80).

Table 4.3

Descriptive Statistics of Continuous Variables

<table>
<thead>
<tr>
<th>All Sample (N=635)</th>
<th>M (SD)</th>
<th>Sk</th>
<th>Ku</th>
<th>Range</th>
</tr>
</thead>
<tbody>
<tr>
<td>Caregiver depressive symptoms (CESD-10)</td>
<td>10.67 (6.48)</td>
<td>.56</td>
<td>-.16</td>
<td>0-30</td>
</tr>
<tr>
<td>Behavioral and psychological symptoms (NPI)</td>
<td>31.85 (24.63)</td>
<td>.95</td>
<td>.50</td>
<td>0-125</td>
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<tr>
<td>Caregiver distress</td>
<td>15.43 (11.45)</td>
<td>.83</td>
<td>.15</td>
<td>0-53</td>
</tr>
<tr>
<td>Caregiver burden</td>
<td>6.71 (4.15)</td>
<td>.15</td>
<td>-.77</td>
<td>0-16</td>
</tr>
<tr>
<td>Caregiver competence</td>
<td>14.86 (1.55)</td>
<td>-1.54</td>
<td>2.30</td>
<td>8-16</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Nursing Home (n=348)</th>
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<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Caregiver depressive symptoms (CESD-10)</td>
<td>11.39 (6.53)</td>
<td>.45</td>
<td>-.28</td>
<td>0-30</td>
</tr>
<tr>
<td>Behavioral and psychological symptoms (NPI)</td>
<td>35.88 (25.77)</td>
<td>.84</td>
<td>.30</td>
<td>0-125</td>
</tr>
<tr>
<td>Caregiver distress</td>
<td>17.34 (12.02)</td>
<td>.72</td>
<td>-.08</td>
<td>0-53</td>
</tr>
<tr>
<td>Caregiver burden</td>
<td>7.35 (4.26)</td>
<td>.01</td>
<td>-.88</td>
<td>0-16</td>
</tr>
</tbody>
</table>
Caregiver competence 14.74 (1.64) -1.52 2.32 8-16

Community (n=287)

Caregiver depressive symptoms (CESD-10) 9.80 (6.32) .70 .12 0-29
Behavioral and psychological symptoms (NPI) 26.97 (22.25) 1.07 .66 0-95
Caregiver distress 13.07 (10.25) .91 .30 0-45
Caregiver burden 5.93 (3.88) .26 -.55 0-16
Caregiver competence 15.00 (1.41) -1.49 1.74 10-16

**Correlation Analysis of Key Study Variables**

Correlational analyses were performed on 8 key study variables for all caregivers (N=635). The results showed that caregiver depressive symptoms was positively correlated to caregiver distress (r=.514, p<.0001), BPS (frequency*severity) in PwAD (r=.435, p<.0001), and caregiver burden (r=.596, p<.0001); and it was negatively correlated with caregiver competence (r=-.252, p<.0001), caregiver general health (r=-.270, p<.0001), and relationship between caregiver and PwAD (r=-.194, p<.0001). BPS (frequency*severity) in PwAD was positively correlated with caregiver distress (r=.858, p<.0001) and caregiver burden (r=.446, p<.0001), and negatively correlated with caregiver competence (r=-.132, p=.0009). Detailed description of the correlation analysis is presented in Table 4.4.

**Nursing Home Sample.** Correlational analyses were performed on 8 key study variables for caregivers of PwAD living in the nursing home (n=348). Results were similar as the whole sample. Caregiver depressive symptoms was positively correlated to caregiver distress (r=.514, p<.0001), BPS (frequency*severity) in PwAD (r=.444,
p<.0001), and caregiver burden (r=.621, p<.0001); and it was negatively correlated with caregiver competence (r=-.221, p<.0001), caregiver general health (r=-.216, p<.0001), and relationship between caregiver and PwAD (r=-.223, p<.0001). BPS (frequency*severity) in PwAD was positively correlated with caregiver distress (r=.867, p<.0001) and caregiver burden (r=.487, p<.0001), and negatively correlated with caregiver competence (r=-.126, p=.019).

**Community Living Sample.** Correlational analyses were performed on 8 key study variables for caregivers of PwAD living in the community (n=287). Results were similar as in the nursing home subsample. Caregiver depressive symptoms were positively correlated to caregiver distress (r=.490, p<.0001), BPS (frequency*severity) in PwAD (r=.395, p<.0001), and caregiver burden (r=.544, p<.0001); and it was negatively correlated with caregiver competence (r=-.281, p<.0001), caregiver general health (r=-.365, p<.0001), and relationship between caregiver and PwAD (r=-.181, p=.0021). BPS (frequency*severity) in PwAD was positively correlated with caregiver distress (r=.828, p<.0001) and caregiver burden (r=.338, p<.0001).

**Research Question 1:** For the BPS that commonly accompany AD, are there any racial differences associated with their presence and severity?

**RQ 1.1: What is the identified BPS (both Frequency and Frequency*Severity) in PwAD reported by caregivers?**

According to all caregivers in the sample, the most frequently reported BPS in PwAD was agitation/aggression (n=455, 72.11%), followed by irritability/lability (n=385, 61.60%), apathy/indifference (n=373, 60.06%), depression/dysphoria
Table 4.4

Correlational Analysis of Key Study Variables (N=635)

<table>
<thead>
<tr>
<th>Variables</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Relationship</td>
<td></td>
<td>1</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. General health</td>
<td>.057</td>
<td>1</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Received help</td>
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<td>.026</td>
<td>1</td>
<td></td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>4. Caregiver distress</td>
<td>-.114**</td>
<td>-.161***</td>
<td>-.075</td>
<td>1</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. Caregiver burden</td>
<td>-.090*</td>
<td>-.153***</td>
<td>.045</td>
<td>.542***</td>
<td>1</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. Caregiver competence</td>
<td>.054</td>
<td>.162***</td>
<td>-.017</td>
<td>-.173***</td>
<td>-.298***</td>
<td>1</td>
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<td></td>
</tr>
<tr>
<td>7. BPS (frequency*severity)</td>
<td>-.056</td>
<td>-.100*</td>
<td>-.044</td>
<td>.858***</td>
<td>.446***</td>
<td>-.132***</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>8. Caregiver depressive symptoms</td>
<td>-.194***</td>
<td>-.270***</td>
<td>-.026</td>
<td>.514***</td>
<td>.596***</td>
<td>-.252***</td>
<td>.435***</td>
<td>1</td>
</tr>
</tbody>
</table>

Note. *p<.05. **p<.01. ***p<.001
(n=328, 53.16%), and sleep and nighttime behavior disorders (n=322, 50.71%; Table 4.5). Over half of all PwAD exhibited BPS mentioned above (agitation/aggression, irritability/lability, apathy/indifference, depression/dysphoria, and sleep and nighttime behavior disorders).

In terms of both frequency and severity of BPS, agitation/aggression (mean=4.02, SD=3.98) had the highest mean score, followed by apathy/indifference (mean=3.60, SD=4.04), irritability/lability (mean=3.47, SD=3.86), sleep and nighttime behavior disorders (mean=3.33, SD=4.12), and aberrant motor behavior (mean=3.20, SD=4.09).

Table 4.5

*BPS in PwAD (N=635)*

<table>
<thead>
<tr>
<th>BPS Domain</th>
<th>Frequency</th>
<th>Frequency*Severity Mean</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>(Percentage)</td>
<td>(SD)</td>
</tr>
<tr>
<td>Agitation/Aggression</td>
<td>455 (72.11%)</td>
<td>4.02 (3.98)</td>
</tr>
<tr>
<td>Irritability/Lability</td>
<td>385 (61.60)</td>
<td>3.47 (3.86)</td>
</tr>
<tr>
<td>Apathy/Indifference</td>
<td>373 (60.06)</td>
<td>3.60 (4.04)</td>
</tr>
<tr>
<td>Depression/Dysphoria</td>
<td>328 (53.16)</td>
<td>2.57 (3.52)</td>
</tr>
<tr>
<td>Sleep and Nighttime Behavior</td>
<td>322 (50.71)</td>
<td>3.33 (4.12)</td>
</tr>
<tr>
<td>Disorders</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Aberrant Motor Behavior</td>
<td>315 (49.61)</td>
<td>3.20 (4.09)</td>
</tr>
<tr>
<td>Behavior</td>
<td>Count (%)</td>
<td>Mean (SD)</td>
</tr>
<tr>
<td>--------------------------</td>
<td>-----------</td>
<td>-----------</td>
</tr>
<tr>
<td>Hallucinations</td>
<td>285 (45.75)</td>
<td>2.32 (3.47)</td>
</tr>
<tr>
<td>Appetite and Eating Changes</td>
<td>271 (44.14)</td>
<td>2.56 (3.70)</td>
</tr>
<tr>
<td>Delusions</td>
<td>258 (41.35)</td>
<td>2.43 (3.67)</td>
</tr>
<tr>
<td>Disinhibition</td>
<td>250 (40.26)</td>
<td>1.77 (2.94)</td>
</tr>
<tr>
<td>Anxiety</td>
<td>233 (37.46)</td>
<td>2.01 (3.33)</td>
</tr>
<tr>
<td>Elation/Euphoria</td>
<td>104 (16.48)</td>
<td>.56 (1.56)</td>
</tr>
<tr>
<td>Total</td>
<td>635 (100)</td>
<td>31.85 (24.63)</td>
</tr>
</tbody>
</table>

*Note: Missing cases for each BPS: Agitation/Aggression (n=4), Irritability/Lability (n=10), Apathy/Indifference (n=14), Depression/Dysphoria (n=18), Sleep and Nighttime Behavior Disorders (n=28), Aberrant Motor Behavior (n=20), Hallucinations (n=12), Appetite and Eating Changes (n=21), Delusions (n=11), Disinhibition (n=14), Anxiety (n=13), Elation/Euphoria (n=4).*

**Nursing Home Sample.** According to caregivers of PwAD living in the nursing home, the most frequently reported BPS in PwAD was agitation/aggression (n=270, 77.81%), followed by irritability/lability (n=229, 66.57%), apathy/indifference (n=218, 63.19%), and sleep and nighttime behavior disorders (n=199, 58.88%). In terms of both frequency and severity of BPS, agitation/aggression (mean=4.66, SD=4.09) had the highest mean score, followed by irritability/lability (mean=4.01, SD=3.98), apathy/indifference (mean=3.99, SD=4.18), sleep and nighttime behavior disorders (mean=3.87, SD=4.22), and aberrant motor behavior (mean=3.39, SD=4.28).
Community Living Sample. For the subsample of PwAD living in the community, the most frequently reported BPS in PwAD was agitation/aggression (n=185, 65.14%), followed by irritability/lability (n=156, 55.52%), apathy/indifference (n=155, 56.16%), and aberrant motor behavior (n=142, 52.01%). In terms of both frequency and severity of BPS, agitation/aggression (mean=3.24, SD=3.69) had the highest mean score, followed by apathy/indifference (mean=3.11, SD=3.82), aberrant motor behavior (mean=2.98, SD=3.84), irritability/lability (mean=2.82, SD=3.61), and sleep and nighttime behavior disorders (mean=2.67, SD=3.89).

Hypothesis 1.2: BPS in PwAD reported by the caregiver are different by race.

Among all PwAD, higher percentage of whites than African Americans exhibited apathy/indifference (67.52% vs 52.44%, p=.0001), depression/dysphoria (61.54% vs 44.59%, p<.0001), and anxiety (45.08% vs 29.64%, p<.0001). For other BPS, no significant differences were found between whites and African Americans (Table 4.6).

In terms of both frequency and severity of BPS, there were significant differences in the total BPS score between whites and African Americans with White PwAD having higher scores (Mean=35.49, SD=24.75) than African American PwAD (Mean=28.13, SD=23.97; p<.0001). There were also differences in the following domains of BPS: apathy/indifference (p=.0003), depression/dysphoria (p<.0001), and anxiety (p<.0001). Specifically, whites had higher mean scores of all the above BPS. This result confirmed the first hypothesis pertaining to the association between NPI scores and race.
Table 4.6

*Racial Differences in BPS in PwAD (N=635)*

<table>
<thead>
<tr>
<th>BPS Domain</th>
<th>Frequency (Percentage)</th>
<th>Mean (SD)</th>
<th>p-value</th>
<th>Mean (SD)</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>African American</td>
<td>White</td>
<td>African American</td>
<td>White</td>
</tr>
<tr>
<td>Agitation/Aggression</td>
<td>219</td>
<td>236</td>
<td>.2887</td>
<td>3.58</td>
<td>4.44</td>
</tr>
<tr>
<td></td>
<td>(70.19)</td>
<td>(73.98)</td>
<td>(3.85)</td>
<td>(4.06)</td>
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<tr>
<td>Irritability/Lability</td>
<td>174</td>
<td>211</td>
<td>.0097</td>
<td>2.98</td>
<td>3.95</td>
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<tr>
<td></td>
<td>(56.49)</td>
<td>(66.56)</td>
<td>(3.71)</td>
<td>(3.95)</td>
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<tr>
<td>Apathy/Indifference</td>
<td>161</td>
<td>212</td>
<td><strong>.0001</strong></td>
<td>3.06</td>
<td>4.12</td>
</tr>
<tr>
<td></td>
<td>(52.44)</td>
<td>(67.52)</td>
<td>(3.89)</td>
<td>(4.12)</td>
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</tr>
<tr>
<td>Depression/Dysphoria</td>
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<td>192</td>
<td><strong>&lt;.0001</strong></td>
<td>1.82</td>
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<tr>
<td></td>
<td>(44.59)</td>
<td>(61.54)</td>
<td>(2.92)</td>
<td>(3.90)</td>
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<tr>
<td>Sleep and Nighttime</td>
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<td>160</td>
<td>.8334</td>
<td>3.27</td>
<td>3.38</td>
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<td>Behavior Disorders</td>
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<td>(52.46)</td>
<td>(4.07)</td>
<td>(4.17)</td>
<td></td>
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<tr>
<td>Aberrant Motor Behavior</td>
<td>150</td>
<td>165</td>
<td>.3571</td>
<td>2.96</td>
<td>3.45</td>
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<td>(53.05)</td>
<td>(4.02)</td>
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<td>Hallucinations</td>
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<tr>
<td></td>
<td>(45.13)</td>
<td>(46.35)</td>
<td>(3.45)</td>
<td>(3.50)</td>
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### Appetite and Eating Changes

<table>
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<th>Sample SD</th>
<th>t-value</th>
<th>p-value</th>
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<tbody>
<tr>
<td>Appetite and Eating Changes</td>
<td>314</td>
<td>28.13</td>
<td>23.97</td>
<td>&lt;.0001</td>
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<tr>
<td>Changes</td>
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<td>2.65</td>
<td>2.26</td>
<td>2.86</td>
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### Delusions

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<td>2.12</td>
<td>2.74</td>
<td>.0390</td>
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### Disinhibition

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<th>Sample SD</th>
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<td>Disinhibition</td>
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<td>1.54</td>
<td>2.00</td>
<td>.319</td>
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### Anxiety

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<tbody>
<tr>
<td>Anxiety</td>
<td>91</td>
<td>1.52</td>
<td>2.48</td>
<td>&lt;.0001</td>
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</table>

### Elation/Euphoria

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<th>Sample SD</th>
<th>t-value</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Elation/Euphoria</td>
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<td>0.77</td>
<td>0.36</td>
<td>0.012</td>
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### Total

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<th>p-value</th>
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<td>Total</td>
<td>314</td>
<td>28.13</td>
<td>23.97</td>
<td>&lt;.0001</td>
</tr>
</tbody>
</table>

**Nursing Home Sample.** Among PwAD living in the nursing home, higher percentage of whites than African Americans exhibited depression/dysphoria (65.45% vs 43.71%, p < .0001), and anxiety (46.11% vs 28.10%, p = .0006). For other BPS, no significant differences were found between whites and African Americans.

In terms of both frequency and severity of BPS, there were no significant differences in the total score between whites and African Americans in the nursing home subsample (p = .0265). However, there were differences in depression/dysphoria.
(p<.0001). Specifically, whites had higher mean score of depression/dysphoria (3.51 vs 1.75) than African Americans.

Community Living Sample. Among PwAD living in the community, no significant differences were found between whites and African Americans in the presence of all 12 BPS domains.

In terms of both frequency and severity of BPS, there were no significant differences in the total NPI score between whites and African Americans in the community living subsample (p=.0013). However, there were significant differences in the score of apathy/indifference (p=.0006). Specifically, whites had higher mean score of apathy/indifference (3.92 vs 2.48) than African Americans.

RQ 1.3: What are possible clusters of PwAD based on their co-occurring BPS?

BPS co-occurred in PwAD. The mean number of BPS domains exhibited in PwAD was 5.65 (SD=2.92; Table 4.7). There were over half (n=340, 53.71%) of PwAD exhibiting 6 or more domains of BPS.

Comparing PwAD living in the nursing home and in the community (Table 4.8), the mean number of BPS domains exhibited in PwAD living in the nursing home was 6.01 (SD=2.90) while the mean number for those living in the community was 5.22 (SD=2.89). There were significant differences in the mean number of BPS presence between PwAD living in the nursing home and in the community (p=.0006). In addition, there were over half (n=208, 59.77%) of PwAD living in the nursing home exhibiting 6
or more domains of BPS. However, less than half (n=132, 46.32%) of PwAD living in the community exhibiting 6 or more domains of BPS.

Table 4.7

*Number of Co-occurring BPS Domains in PwAD (African American vs White)*

<table>
<thead>
<tr>
<th>Number of BPS Domains</th>
<th>Total</th>
<th>African American</th>
<th>White</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>23 (3.63)</td>
<td>17 (5.43)</td>
<td>6 (1.88)</td>
</tr>
<tr>
<td>1</td>
<td>36 (5.69)</td>
<td>20 (6.39)</td>
<td>16 (5.00)</td>
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<tr>
<td>2</td>
<td>46 (7.27)</td>
<td>26 (8.31)</td>
<td>20 (6.25)</td>
</tr>
<tr>
<td>3</td>
<td>60 (9.48)</td>
<td>33 (10.54)</td>
<td>27 (8.44)</td>
</tr>
<tr>
<td>4</td>
<td>60 (9.48)</td>
<td>34 (10.86)</td>
<td>26 (8.13)</td>
</tr>
<tr>
<td>5</td>
<td>68 (10.74)</td>
<td>35 (11.18)</td>
<td>33 (10.31)</td>
</tr>
<tr>
<td>6</td>
<td>83 (13.11)</td>
<td>45 (14.38)</td>
<td>38 (11.88)</td>
</tr>
<tr>
<td>7</td>
<td>78 (12.32)</td>
<td>23 (7.35)</td>
<td>55 (17.19)</td>
</tr>
<tr>
<td>8</td>
<td>67 (10.58)</td>
<td>34 (10.86)</td>
<td>33 (10.31)</td>
</tr>
<tr>
<td>9</td>
<td>44 (6.95)</td>
<td>14 (4.47)</td>
<td>30 (9.38)</td>
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<tr>
<td>10</td>
<td>40 (6.32)</td>
<td>15 (4.79)</td>
<td>25 (7.81)</td>
</tr>
<tr>
<td>11</td>
<td>22 (3.48)</td>
<td>14 (4.47)</td>
<td>8 (2.50)</td>
</tr>
<tr>
<td>Number of BPS Domains</td>
<td>Total</td>
<td>Nursing Home</td>
<td>Community Living</td>
</tr>
<tr>
<td>-----------------------</td>
<td>-------</td>
<td>--------------</td>
<td>------------------</td>
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<tr>
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<td>12 (3.45)</td>
<td>11 (3.86)</td>
</tr>
<tr>
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<td>14 (4.02)</td>
<td>22 (7.72)</td>
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<tr>
<td>4</td>
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<td>5</td>
<td>68 (10.74)</td>
<td>34 (9.77)</td>
<td>34 (11.93)</td>
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<tr>
<td>6</td>
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<tr>
<td>7</td>
<td>78 (12.32)</td>
<td>51 (14.66)</td>
<td>27 (9.47)</td>
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<td>8</td>
<td>67 (10.58)</td>
<td>38 (10.92)</td>
<td>29 (10.18)</td>
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<tr>
<td>9</td>
<td>44 (6.95)</td>
<td>29 (8.33)</td>
<td>15 (5.26)</td>
</tr>
<tr>
<td>10</td>
<td>40 (6.32)</td>
<td>25 (7.18)</td>
<td>15 (5.26)</td>
</tr>
</tbody>
</table>

*Note:* 2 cases were missing (1 African American, 1 white).
K-medoids, a classical partitioning technique of clustering, was used to group PwAD into k clusters known a priori. To choose the number of clusters (k), average silhouette width method was adopted. Over a range of possible values for the number of clusters k, the one that maximizes the average silhouette is considered as optimal (Kaufman & Rousseeuw, 1987). Table 4.9 showed silhouette score results when k ranges from 2 to 8. When k=2, the average silhouette score is the highest (.247), PwAD was clustered into 2 (high and low in BPS frequency*severity score). For better interpretation of the data, we chose k=4 (average silhouette score was similar to that when k=3 and was higher than other scores).

Cluster analysis identified four clusters: cluster 1 (n=223), cluster 2 (n=198), cluster 3 (n=148), and cluster 4 (n=66). The description of clusters and the cluster mean score of caregiver level of depressive symptoms are reported in Table 4.10.

Table 4.9

Average Silhouette Width (k=2-8)

<table>
<thead>
<tr>
<th>k choice</th>
<th>Average Silhouette Width</th>
</tr>
</thead>
<tbody>
<tr>
<td>2</td>
<td>.247</td>
</tr>
<tr>
<td>3</td>
<td>.127</td>
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</table>
### Table 4.10

*Cluster Profiles for the Frequency and Severity of BPS*

<table>
<thead>
<tr>
<th>Variables</th>
<th>Cluster 1 (Minimally symptomatic)</th>
<th>Cluster 2 (Apathetic)</th>
<th>Cluster 3 (Psychotic &amp; Hyperactive)</th>
<th>Cluster 4 (Highly symptomatic)</th>
</tr>
</thead>
<tbody>
<tr>
<td>N</td>
<td>223</td>
<td>198</td>
<td>148</td>
<td>66</td>
</tr>
<tr>
<td>Age</td>
<td>83.76 (8.54)</td>
<td>83.52 (7.97)</td>
<td>84.60 (7.98)</td>
<td>82.00 (7.74)</td>
</tr>
<tr>
<td>Race (White %)</td>
<td>89 (39.91)</td>
<td>120 (60.61)</td>
<td>69 (46.62)</td>
<td>43 (65.15)</td>
</tr>
<tr>
<td>Gender (Female %)</td>
<td>155 (69.51)</td>
<td>146 (73.74)</td>
<td>117 (79.05)</td>
<td>44 (66.67)</td>
</tr>
<tr>
<td>Location (Nursing Home %)</td>
<td>95 (42.60)</td>
<td>116 (58.59)</td>
<td>89 (60.14)</td>
<td>48 (72.73)</td>
</tr>
<tr>
<td>Total NPI score</td>
<td>9.43 (7.23)</td>
<td>29.02 (10.31)</td>
<td>48.25 (14.67)</td>
<td>79.30 (16.71)</td>
</tr>
<tr>
<td>Delusions</td>
<td>.38 (1.19)</td>
<td>1.80 (2.81)</td>
<td>3.55 (3.70)</td>
<td><strong>8.77 (3.52)</strong></td>
</tr>
<tr>
<td>Category</td>
<td>Mean (SD)</td>
<td>Median (SD)</td>
<td>Mode (SD)</td>
<td>Min (SD)</td>
</tr>
<tr>
<td>---------------------------</td>
<td>-----------</td>
<td>-------------</td>
<td>-----------</td>
<td>----------</td>
</tr>
<tr>
<td>Hallucinations</td>
<td>0.71 (1.52)</td>
<td>1.24 (2.13)</td>
<td>4.53 (4.13)</td>
<td>6.00 (4.47)</td>
</tr>
<tr>
<td>Agitation/Aggression</td>
<td>1.52 (2.38)</td>
<td>3.70 (3.30)</td>
<td>5.44 (3.64)</td>
<td>10.23 (2.57)</td>
</tr>
<tr>
<td>Depression/Dysphoria</td>
<td>0.74 (1.56)</td>
<td>3.25 (3.45)</td>
<td>2.54 (2.98)</td>
<td>6.82 (5.05)</td>
</tr>
<tr>
<td>Anxiety</td>
<td>0.43 (1.16)</td>
<td>2.01 (3.06)</td>
<td>2.82 (3.66)</td>
<td>5.50 (4.72)</td>
</tr>
<tr>
<td>Elation/Euphoria</td>
<td>0.30 (1.02)</td>
<td>0.34 (1.25)</td>
<td>0.82 (1.71)</td>
<td>1.55 (2.67)</td>
</tr>
<tr>
<td>Apathy/Indifference</td>
<td>0.86 (1.60)</td>
<td>4.53 (3.90)</td>
<td>4.55 (4.07)</td>
<td>7.92 (4.16)</td>
</tr>
<tr>
<td>Disinhibition</td>
<td>0.44 (1.28)</td>
<td>1.83 (2.78)</td>
<td>2.06 (2.88)</td>
<td>5.45 (4.05)</td>
</tr>
<tr>
<td>Irritability/Lability</td>
<td>0.71 (1.38)</td>
<td>4.06 (3.52)</td>
<td>4.16 (3.49)</td>
<td>9.53 (2.85)</td>
</tr>
<tr>
<td>Aberrant Motor Behavior</td>
<td>1.08 (2.29)</td>
<td>1.96 (2.84)</td>
<td>6.54 (4.41)</td>
<td>6.64 (4.41)</td>
</tr>
<tr>
<td>Sleep and Nighttime</td>
<td>1.55 (2.69)</td>
<td>1.53 (2.46)</td>
<td>6.81 (4.15)</td>
<td>6.94 (4.66)</td>
</tr>
<tr>
<td>Appetite and Eating Changes</td>
<td>0.72 (1.55)</td>
<td>2.79 (3.31)</td>
<td>4.43 (4.77)</td>
<td>3.95 (4.35)</td>
</tr>
<tr>
<td>Caregiver depressive symptoms</td>
<td>8.10 (5.80)</td>
<td>10.93 (6.38)</td>
<td>11.65 (5.65)</td>
<td>16.41 (6.37)</td>
</tr>
<tr>
<td>Caregiver distress</td>
<td>5.89 (5.16)</td>
<td>14.72 (8.25)</td>
<td>21.10 (9.17)</td>
<td>33.14 (8.98)</td>
</tr>
<tr>
<td>Caregiver burden</td>
<td>4.61 (3.55)</td>
<td>7.29 (3.89)</td>
<td>7.51 (3.72)</td>
<td>10.30 (4.12)</td>
</tr>
<tr>
<td>Caregiver competence</td>
<td>15.17 (1.28)</td>
<td>14.68 (1.68)</td>
<td>14.85 (1.58)</td>
<td>14.35 (1.66)</td>
</tr>
</tbody>
</table>
Note. A target symptom was considered to be present and clinically significant if its item score was 4 or higher (highlighted; Ismail et al., 2013; Lyketsos et al., 2002). The twelve neuropsychiatric symptoms were identified as four sub-syndromes, namely hyperactivity (aggression, disinhibition, irritability, aberrant motor behavior and euphoria), psychosis (delusion, hallucination and sleep disorder), affective (depression and anxiety), and apathy (apathy and appetite disorder) (Aalten et al., 2007).

PwAD in Cluster 1 had least average score of BPS (mean=9.43, SD=7.23), and exhibiting least severity of almost all domains compared with PwAD in other clusters (except sleep and nighttime behavior disorders), thus was named as “Minimally Symptomatic”. More than half of the PwAD (n=128, 57.4%) in Cluster 1 were living in the community at the time of being interviewed. In addition, caregivers of PwAD had lowest level of depressive symptoms (mean=8.10, SD=5.80), burden (mean=4.61, SD=3.55), and distress (mean=5.89, SD=5.16), but highest level of competence (mean=15.17, SD=1.28) than caregivers of PwAD in other clusters.

PwAD in Cluster 2 had higher average score of BPS (mean=29.02, SD=10.31) than those in Cluster 1 (mean=9.43, SD=7.23), but lower than those in Cluster 3 (mean=48.25, SD=14.67) and Cluster 4 (mean=79.30, SD=16.71). Generally, PwAD in Cluster 2 exhibited apathetic syndromes (mean of apathy=4.53). To be noted, PwAD in Cluster 2 exhibited more severe depression/dysphoria symptom (mean=3.25, SD=3.45) than those in Cluster 3 (mean=2.54, SD=2.98). For other symptoms, PwAD in Cluster 2 had lower score than those in Cluster 3 and Cluster 4. Cluster 2 was named as “Apathetic”. More than half of PwAD in Cluster 2 were white (n=120, 60.61%), female (n=146, 73.74%), and living in a nursing home (n=116, 58.59%). In addition, caregivers
of PwAD in Cluster 2 had lower level of depressive symptoms (mean=10.93, SD=6.38), burden (mean=7.29, SD=3.89), distress (mean=14.72, SD=8.25), and competence (mean=14.68, SD=1.68) than caregivers of PwAD in Cluster 3. However, their level of competence was higher than caregivers of PwAD in Cluster 4 (14.68 vs 14.35).

For PwAD in Cluster 3, they had highest score on appetite and eating changes (mean=4.43, SD=4.77), but had lowest score on depression/dysphoria (mean=2.54, SD=2.98). Generally, they exhibited more severe symptoms (higher mean score of BPS) than those in Cluster 1 and Cluster 2, but less severe than those in Cluster 4. They had both psychosis (delusions, hallucinations) and hyperactive syndromes (irritability, aggression, aberrant motor behavior), thus was named as “Psychotic & Hyperactive”.

More than half of PwAD in Cluster 3 were African Americans (n=79, 53.38%), female (n=117, 79.05%), and living in a nursing home (n=89, 60.14%). Regarding their caregivers, they had lower level of depressive symptoms (mean=11.65, SD=5.65), burden (mean=7.51, SD=3.72), distress (mean=21.10, SD=9.17), but had higher level of competence (mean=14.85, SD=1.58) than caregivers of PwAD in Cluster 4.

PwAD in Cluster 4 had most severe symptoms with highest average score of BPS (mean=79.30, SD=16.71) among all clusters. They exhibited all symptoms except elation/euphoria and was named as “Highly Symptomatic”. More than half of PwAD in Cluster 4 were white (n=43, 65.15%), female (n=44, 66.67%), and living in a nursing home (n=48, 72.73%). Regarding their caregivers, they had highest level of depressive symptoms (mean=16.41, SD=6.37), burden (mean=10.30, SD=4.12), distress (mean=33.14, SD=8.98), but lowest level of competence (mean=14.35, SD=1.66) than caregivers of PwAD in other clusters.
Post hoc analysis results showed that the relation between the identified clusters and whether PwAD was in nursing home or community was significant, $\chi^2(3, N=635) = 24.81$, $p<.0001$. Higher percentage of PwAD living in nursing home were in Cluster 2 (33.33% vs 28.57%), Cluster 3 (25.57% vs 20.56%), and Cluster 4 (13.79% vs 6.27%) than those living in the community.

**Hypothesis 1.4: There is a significant relationship between the identified clusters of BPS in PwAD and race.**

A chi-square test of independence was performed to examine the relation between identified clusters and race. The relation between the two variables was significant, $\chi^2(3, N=635) = 24.65$, $p<.0001$. PwAD who were African Americans were less likely to be in Cluster 2 (24.84% vs 37.38%) and Cluster 4 (7.32% vs 13.40%) than whites. This result supported Hypothesis 1.4 pertaining to the association between identified clusters of PwAD and race.

**Research Question 2:** What is the relationship between caregivers’ reported BPS in PwAD and caregiver level of depressive symptoms?

**Hypothesis 2.1: BPS in PwAD is associated with caregiver level of depressive symptoms.**

General linear regression results (Table 4.11) showed that the model with all predictors (contextual factors and BPS frequency*severity in PwAD) can explain 28% ($R^2$) of variability in caregiver depressive symptoms [$F(10, 543) = 21.36$, $p<.0001$]. There was a main effect for BPS in PwAD ($b=.09$, $p<.0001$), where higher scores of BPS
were associated with the presence of greater symptoms of depression. This result supported Hypothesis 2.1.

**Nursing Home Sample.** In terms of the subsample of caregivers of PwAD living in the nursing home, general linear regression results showed that the model with all predictors (contextual factors and BPS frequency*severity in PwAD) can explain 27% ($R^2$) of variability in caregiver depressive symptoms [$F(9, 292) = 11.89, p<.0001$]. There was a main effect for BPS in PwAD (b=.10, $p<.0001$), where higher scores of BPS were associated with the presence of greater symptoms of depression.

**Community Living Sample.** General linear regression results from the community living subsample were similar to that of nursing home subsample. The model with all predictors (contextual factors and BPS frequency*severity in PwAD) can explain 31% ($R^2$) of variability in caregiver depressive symptoms [$F(9, 242) = 11.92, p<.0001$]. There was a main effect for BPS in PwAD (b=.08, $p<.0001$), where higher scores of BPS were associated with the presence of greater symptoms of depression.

Table 4.11

*General Linear Regression Analysis for Predicting Caregiver Depressive Symptoms*

<table>
<thead>
<tr>
<th>Variable</th>
<th>Parameter</th>
<th>Standardized Error</th>
<th>t</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Intercept</td>
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<td>2.80</td>
<td>8.49</td>
<td>&lt;.0001***</td>
</tr>
<tr>
<td>Caregiver age</td>
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<td>.03</td>
<td>-2.03</td>
<td>.043*</td>
</tr>
<tr>
<td>Caregiver gender</td>
<td>-.03</td>
<td>.63</td>
<td>-.05</td>
<td>.962</td>
</tr>
</tbody>
</table>
Hypothesis 2.2: Caregiver level of depressive symptoms among clustered groups of PwAD identified in RQ 1.3 are different.

Kruskal-Wallis test results showed significant differences on caregiver level of depressive symptoms among four clustered groups of PwAD identified in RQ 1.3, $\chi^2(3, N=635) = 89.16, p<.0001$. Caregivers of PwAD in Cluster 4 had the highest mean level of depressive symptoms (mean=16.41), followed by those in Cluster 3 (mean=11.65), and Cluster 2 (mean=10.93). Caregivers of PwAD in Cluster 1 had the lowest mean level of depressive symptoms (mean=8.10). Hypothesis 2.2 was supported by this result.

Research Question 3: To what extent are caregiver psychosocial variables associated with their depressive symptoms? What are the roles of caregivers’ level of distress, burden, and competence in the relationship between BPS in PwAD and caregivers’ depressive symptoms?
Hypothesis 3.1: Caregiver level of distress, burden, and competence are significant predictors of caregiver level of depressive symptoms.

General linear regression results (Table 4.12) showed that the model with all predictors (contextual factors, BPS frequency*severity in PwAD, caregiver distress, caregiver burden, and caregiver competence) can explain 47% ($R^2$) of variability in caregiver depressive symptoms [$F(13, 518) = 34.71, p<.0001$]. There was a main effect for caregiver burden ($b=.69, p<.0001$), with higher level of caregiver burden associated with the presence of greater symptoms of depression. However, caregiver distress and caregiver competence were not significant predictors of caregiver depressive symptoms. Hypothesis 3.1 was not fully supported by this result.

Table 4.12

*General Linear Regression Analysis for Predicting Caregiver Depressive Symptoms*

<table>
<thead>
<tr>
<th>Variable</th>
<th>Parameter Estimate</th>
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<td>9.22</td>
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<td>.020*</td>
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Nursing home/community

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<th></th>
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<th>Caregiver distress (c)</th>
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<th>Caregiver competence</th>
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<td>10.85</td>
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<td>.319</td>
<td>.196</td>
<td>.055</td>
<td>&lt;.0001***</td>
<td>.153</td>
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</table>

Note. C in parenthesis indicates that the variable was centered at the mean. *p < .05. **p < .01. ***p < .001.

Nursing Home Sample. For the nursing home subsample, general linear regression results showed that the model with all predictors (contextual factors, BPS frequency*severity in PwAD, caregiver distress, caregiver burden, and caregiver competence) can explain 43% ($R^2$) of variability in caregiver depressive symptoms [$F(12, 278) = 17.75, p<.0001$]. There was a main effect for caregiver burden (b=.68, $p<.0001$), where higher level of caregiver burden was associated with the presence of greater symptoms of depression. However, caregiver distress and caregiver competence were not significant predictors of caregiver depressive symptoms.

Community Living Sample. Similar to the results of the nursing home subsample, general linear regression results of the community living subsample showed that the model with all predictors (contextual factors, BPS frequency*severity in PwAD,
caregiver distress, caregiver burden, and caregiver competence) can explain 52% ($R^2$) of variability in caregiver depressive symptoms [$F(12, 228) = 20.27, p<.0001$]. There was a main effect for caregiver burden ($b=.74, p<.0001$), where higher level of caregiver burden was associated with the presence of greater symptoms of depression. Similar to the nursing home subsample, caregiver distress and caregiver competence were not significant predictors of caregiver depressive symptoms.

**Hypothesis 3.2: Caregiver level of burden mediates the relationship between BPS in PwAD and caregiver level of depressive symptoms.**

Mediation effect was conducted using procedures described by Baron and Kenny (1986). Mediation is tested through three regressions: (1) Independent variable (IV) predicting the dependent variable (DV); (2) IV predicting the mediator; (3) IV and mediator predicting the DV. In this study, IV is BPS (frequency*severity) in PwAD; DV is caregiver depressive symptoms; and mediator is caregiver burden. The following conditions must be met in the results to support mediation: (1) The IV is shown to significantly influence the DV in the first regression equation; (2) IV is shown to significantly influence the mediator in the second regression equation; and (3) Mediator must significantly influence the DV in third equation (both IV and mediator are entered as predictors).

The total effect of BPS on caregiver depressive symptoms was significant on average ($b=.11, p<.0001$). BPS was significantly predictive of the hypothesized mediating variable, caregiver burden ($b=.08, p<.0001$). When regressing caregiver depressive symptoms simultaneously on the BPS and caregiver burden, there were significant relationships between BPS and caregiver depressive symptoms ($b=.06,$
p<.0001), and between caregiver burden and caregiver depressive symptoms (b=.78, p<.0001). Caregiver depressive symptoms was predicted well by BPS and caregiver burden, with R²=.39 (p<.0001).

By using the Sobel’s test, the indirect effect was 9.48 (p<.0001). While the direct path from BPS to caregiver depressive symptoms was statistically significant, the effects of BPS on caregiver depressive symptoms were partially mediated by caregiver burden. Table 4.13 and Figure 4.1 presents detailed information about the mediation effect results. Therefore, Hypothesis 3.2 was fully supported by this result.

Table 4.13

*Caregiver Burden Mediation Effect*

<table>
<thead>
<tr>
<th>Variable</th>
<th>Parameter Estimate</th>
<th>Standardized Error</th>
<th>t</th>
<th>p</th>
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<td><strong>First step</strong></td>
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</tr>
<tr>
<td>Intercept</td>
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<td>.38</td>
<td>18.54</td>
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</tr>
<tr>
<td>BPS</td>
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<td>.01</td>
<td>12.15</td>
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<tr>
<td><strong>Second step</strong></td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
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<td>&lt;.0001***</td>
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<tr>
<td><strong>Third step</strong></td>
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<td></td>
</tr>
<tr>
<td>Intercept</td>
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<td>9.02</td>
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</tr>
<tr>
<td>BPS</td>
<td>.06</td>
<td>.01</td>
<td>6.08</td>
<td>&lt;.0001***</td>
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</table>
Caregiver burden \( b = .78 \) *** 

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<td></td>
<td>.78</td>
<td>.05</td>
<td>14.48</td>
<td>(&lt;.0001)***</td>
</tr>
</tbody>
</table>

*Note.* \*p < .05. **p < .01. ***p < .001.

**Note.** The regression coefficient between BPS and caregiver depressive symptoms, controlling for caregiver burden is in parentheses.

**Nursing Home Sample.** Mediation tests for the nursing home subsample showed similar results as whole sample. The total effect of BPS on caregiver depressive symptoms was significant on average \( (b=.11, \ p<.0001) \). BPS was significantly predictive of the hypothesized mediating variable, caregiver burden \( (b=.08, \ p<.0001) \). When regressing caregiver depressive symptoms simultaneously on the BPS and caregiver burden, the result indicated that there were significant relationships between BPS and caregiver depressive symptoms \( (b=.05, \ p=.0001) \), and between caregiver burden and caregiver depressive symptoms \( (b=.81, \ p<.0001) \). Caregiver depressive symptoms was predicted well by BPS and caregiver burden, with \( R^2 = .41 \) \( (p<.0001) \). By using the Sobel’s test, the indirect effect was 7.62 \( (p<.0001) \). While the direct path from BPS to caregiver depressive symptoms was statistically significant, the effects of BPS on caregiver depressive symptoms were partially mediated by caregiver burden.
Community Living Sample. Mediation tests for the community living subsample showed similar results as whole sample and nursing home subsample. The total effect of BPS on caregiver depressive symptoms was significant on average (b=.11, p<.0001). BPS was significantly predictive of the hypothesized mediating variable, caregiver burden (b=.06, p<.0001). When regressing caregiver depressive symptoms simultaneously on the BPS and caregiver burden, the result indicated that there were significant relationships between BPS and caregiver depressive symptoms (b=.07, p=.0001), and between caregiver burden and caregiver depressive symptoms (b=.76, p<.0001). Caregiver depressive symptoms was predicted well by BPS and caregiver burden, with $R^2=.35$ (p<.0001). By using the Sobel’s test, the indirect effect was 5.05 (p<.0001). While the direct path from BPS to caregiver depressive symptoms was statistically significant, the effects of BPS on caregiver depressive symptoms were partially mediated by caregiver burden.

Hypothesis 3.3: Caregiver level of distress mediates the relationship between BPS in PwAD and caregiver level of depressive symptoms.

Using the same steps as RQ3.2, BPS was a significant predictor of caregiver distress (b=.41, p<.0001). When regressing caregiver depressive symptoms simultaneously on the BPS and caregiver distress, the result indicated that the previously significant relationship between BPS and caregiver depressive symptoms became non-significant (b=−.00, p=.816). Caregiver distress was significantly associated with caregiver depression (b=.30, p<.0001). Caregiver depressive symptoms was predicted well by BPS and caregiver distress, with $R^2=.26$ (p<.0001). By using the Sobel’s test, the indirect effect was 7.65 (p<.0001). Therefore, there is almost complete mediation effect
for caregiver distress in the relationship between BPS and caregiver depressive symptoms (Table 4.14, Figure 4.2). Hypothesis 3.3 was fully supported by this result.

Table 4.14

*Caregiver Distress Mediation Effect*

<table>
<thead>
<tr>
<th>Variable</th>
<th>Parameter Estimate</th>
<th>Standardized Error</th>
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<th>p</th>
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<td><strong>First step</strong></td>
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</tr>
<tr>
<td>Intercept</td>
<td>7.03</td>
<td>.38</td>
<td>18.54</td>
<td>&lt;.0001***</td>
</tr>
<tr>
<td>BPS</td>
<td>.11</td>
<td>.01</td>
<td>12.15</td>
<td>&lt;.0001***</td>
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<tr>
<td><strong>Second step</strong></td>
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<td><strong>Third step</strong></td>
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<tr>
<td>Intercept</td>
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<td>BPS</td>
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<td>.816</td>
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<tr>
<td>Caregiver distress</td>
<td>.30</td>
<td>.04</td>
<td>7.78</td>
<td>&lt;.0001***</td>
</tr>
</tbody>
</table>

Note. *p < .05. **p < .01. ***p < .001.
Note. The regression coefficient between BPS and caregiver depressive symptoms, controlling for caregiver distress is in parentheses.

**Nursing Home Sample.** BPS was a significant predictor of caregiver distress (b=.41, p<.0001). When regressing caregiver depressive symptoms simultaneously on the BPS and caregiver distress, the result indicated that the previously significant relationship between BPS and caregiver depressive symptoms became non-significant (b=-.00, p=.853). Caregiver distress was significantly associated with caregiver depression (b=.28, p<.0001). Caregiver depressive symptoms was predicted well by BPS and caregiver distress, with $R^2=.26$ (p<.0001). By using the Sobel’s test, the indirect effect was 5.51 (p<.0001). Therefore, there is almost complete mediation effect for caregiver distress in the relationship between BPS and caregiver depressive symptoms.

**Community Living Sample.** BPS was a significant predictor of caregiver distress (b=.39, p<.0001). When regressing caregiver depressive symptoms simultaneously on the BPS and caregiver distress, the result indicated that the previously significant relationship...
between BPS and caregiver depressive symptoms became non-significant (p=.852). Caregiver distress was significantly associated with caregiver depression (b=.31, p<.0001). Caregiver depressive symptoms was predicted well by BPS and caregiver distress, with R²=.24 (p<.0001). By using the Sobel’s test, the indirect effect was 5.21 (p<.0001). Therefore, there is almost complete mediation effect for caregiver distress in the relationship between BPS and caregiver depressive symptoms.

**Hypothesis 3.4: Caregiver level of competence moderates the relationship between BPS in PwAD and caregiver level of depressive symptoms.**

To test the moderation effect of caregiver competence between BPS (frequency*severity) in PwAD and caregiver depressive symptoms, an interaction term (caregiver competence * BPS) was added into the regression model. General linear regression results showed that the interaction term (caregiver competence * BPS) was not significant (p=.348). Therefore, this finding did not demonstrate the support for Hypothesis 3.4.

**Nursing Home Sample.** Moderation tests of caregiver competence between BPS in PwAD and caregiver depressive symptoms in the nursing home subsample showed the interaction term (caregiver competence * BPS) was not significant (p=.101).

**Community Living Sample.** Moderation tests of caregiver competence between BPS in PwAD and caregiver depressive symptoms in the community living subsample showed the interaction term (caregiver competence * BPS) was not significant (p=.852).

**Research Question 4:** Are there any racial differences in caregiver depressive symptoms and in the association between BPS in PwAD and caregiver depressive symptoms?
Hypothesis 4.1: Caregiver level of depressive symptoms between white and African Americans are different.

U-tests were conducted to compare caregiver depressive symptoms between whites and African Americans. Mean comparisons indicated significant group differences on caregiver depressive symptoms \[\text{statistic}=89013.00, p<.0001\]. White caregivers reported the higher mean of depressive symptoms (mean=11.89, SD=6.90) than African-American caregivers (mean=9.41, SD=5.77). Therefore, Hypothesis 4.1 was supported by the results.

**Nursing Home Sample.** For caregivers of PwAD living in the nursing home, U-tests results showed that there were no significant group differences on caregiver depressive symptoms (p=.0081) between African Americans and whites, though white caregivers reported higher mean of depressive symptoms (mean=12.26, SD=6.87) than African-American caregivers (mean=10.28, SD=5.90).

**Community Living Sample.** For caregivers of PwAD living in the community, there were no significant group differences on caregiver depressive symptoms (p=.001) between African Americans and whites. White caregivers reported the higher mean of depressive symptoms (mean=11.33, SD=6.92) than African-American caregivers (mean=8.61, SD=5.54).

Hypothesis 4.2: There are racial differences in the relationship between BPS in PwAD and caregiver level of depressive symptoms.

To test the moderation effect of racial differences in the relationship between BPS (frequency*severity) in PwAD and caregiver depressive symptoms, an interaction term
(race * BPS) was added into the regression model. General linear regression results showed that the interaction term (race * BPS) was not significant (p=.061). This analysis results did not support for the study hypothesis.

**Nursing Home Sample.** General linear regression results showed that the interaction term (race * BPS) for the nursing home subsample was not significant (p=.245).

**Community Living Sample.** General linear regression results showed that the interaction term (race * BPS) for the community living subsample was not significant (p=.126).
CHAPTER 5

DISCUSSION

The purpose of this study was to investigate the relationship between BPS in PwAD and caregiver depression among white and African Americans who are from low income families. This research also aimed to compare white and African-American caregivers on the key study variables and on the relationship between BPS in PwAD and caregiver depression. It was hypothesized that there would be a positive association between BPS in PwAD and caregiver level of depressive symptoms; caregiver level of distress and burden were hypothesized to mediate the relationship between BPS in PwAD and caregiver level of depressive symptoms; the relationship between BPS in PwAD and caregiver level of depressive symptoms would vary depending on caregiver level of competence; and there would be racial differences in BPS in PwAD, caregiver level of depressive symptoms, and on the relationship between the two. These hypotheses were tested through general linear regression models, mediation tests, and a series of Mann-Whitney U-tests. Included in this chapter are a summary of the study findings, limitations of the study, as well as implications for social work practice and social work research.

Summary of Study Findings

BPS in PwAD. This study aimed to identify BPS exhibited in PwAD. Findings showed that the most frequently reported BPS in PwAD included agitation/aggression,
irritability/lability, apathy/indifference, and depression/dysphoria, and the least common symptoms included elation/euphoria, delusions, and disinhibition, which is similar to the findings from a meta-analysis study on 48 AD studies published from 1964 to September 30, 2014 (Zhao et al., 2016). The only difference was that irritability was less prevalent according to the meta-analysis results. The prevalence of BPS may vary widely across studies and possible reasons for the differences on irritability prevalence may be related to sample characteristics including age, disease duration, study setting (Zhao et al., 2016). Irritability was found to be one of the BPS that is associated with severity of the AD (D’Onofrio et al., 2012) and can predict nursing home placement (Fauth & Gibbons, 2014; Porter et al., 2016). All individuals with AD included in this study were eligible for nursing home level of care, which may explain the reason why irritability presence was high in PwAD in the current study.

Study findings confirmed co-occurrence of BPS domains in AD that the mean number of BPS domains exhibited in PwAD was about 6, meaning that on average a PwAD in the sample exhibited 6 domains at the same time. PwAD can be meaningfully grouped based on the severity and frequency of BPS. Four clusters were identified in this study including Cluster 1: Minimally Symptomatic (n=223); Cluster 2: Apathetic (n=198); Cluster 3: Psychotic & Hyperactive (n=148); and Cluster 4: Highly Symptomatic (n=66). PwAD in Cluster 1 exhibited least severity of almost all BPS (had least average score of BPS frequency*severity), and more PwAD were grouped in Cluster 1. Cluster 2 composed of PwAD exhibiting apathy with higher mean score on the apathy domain. Cluster 3 composed of PwAD with psychotic (hallucinations, delusions)
and hyperactive (irritability, agitation/aggression, aberrant motor behavior) symptoms. PwAD in Cluster 4 had most severe symptoms with highest average score of BPS and exhibited almost all clinical symptoms (except elation). Only 66 PwAD were in Cluster 4. Our results included minimally symptomatic, apathetic, and highly symptomatic were similar to previous studies that adopted cluster analysis to group AD patients. For example, Tun and his colleagues (2007) found four clusters including “minimally symptomatic”, “affective symptoms”, “predominantly apathetic”, and “highly symptomatic with psychotic features”. Another study by Lyketsos et al (2001) identified three clusters including minimally symptomatic, affective disturbance (depression, irritability, anxiety euphoria), and psychotic disturbance (delusions, hallucinations). Rocca et al (2010) also found three clusters including the minimally symptomatic cluster; the psychotic/behavioral cluster (patients with predominantly psychotic and behavioral symptoms including delusions, hallucinations, agitation, euphoria, disinhibition, irritability and aberrant motor behavior); and the depressive cluster (patients with predominantly depressive symptoms such as depression and anxiety). Different from previous cluster analysis findings, our results did not include a group with affective symptoms. Affective symptoms like anxiety in PwAD were less exhibited in our study sample (37.46%), and the mean score of anxiety (frequency*severity) was low. For depression, although more than half the sample presented the symptom, but regarding both the frequency and severity, this symptom had a lower mean score compared to other symptoms. To be noted, our results showed significant differences between African Americans and whites on both anxiety and depression, with more percentages of whites exhibiting both domains and having higher mean scores of them. Previous studies
focused on white primarily, which may explain the differences on the finding about affective symptoms. Future work is needed to focus on the affective symptoms on African Americans and understand how caregivers perceive depression and anxiety symptoms on PwAD.

According to a review study by Van der Linde et al (2014), the studies using the NPI as a measure of BPS suggest the following symptom groups: affective symptoms (depression/dysphoria, anxiety, sometimes also including apathy), psychosis (delusions, hallucinations, sometimes also including sleeping problems and aberrant motor behavior), hyperactivity (irritability, agitation/aggression, sometimes also including aberrant motor behavior), and euphoria. Results from the review also indicated that symptoms include apathy, eating disturbances, nighttime behavior disorders, disinhibition, and aberrant motor behavior did not show consistent results. Findings in the current study profiling PwAD in Cluster 3 who exhibited hallucinations, delusions, nighttime behavior disorders, and aberrant motor behavior showed similar patterns as the review study (Van der Linde et al., 2014) and some other studies (Selbæk & Engedal, 2012; Van der Linde et al., 2014). Moreover, our results showed that apathy was commonly exhibited in PwAD across three clusters, whereas delusions, hallucinations, and aggression were more exhibited in Cluster 4. As suggested by Lyketsos et al (2011), apathy is commonly reported across all stages of dementia and tends to worsen over time, whereas delusions, hallucinations, and aggression are more episodic and more common in moderate to severe stages of the disease.

**BPS in PwAD and Caregiver Depression.** This study aimed to examine the relationship between BPS in PwAD and caregiver depression among white and African-
American caregivers guided by the Stress Process Model (Pearlin et al., 1990). Results from the regression model that included contextual factors, BPS in PwAD, and caregiver depression confirmed a positive association between BPS in PwAD and caregiver level of depressive symptoms. Higher scores of BPS in PwAD predicted higher levels of caregiver depressive symptoms. This result was consistent with previous review studies examining BPS and AD caregiver depression (Black & Almeida, 2004; Ornstein & Gaugler, 2012) and may pertain to challenges that many caregivers confront when coping with BPS in PwAD. As hypothesized, caregiver level of depressive symptoms among clustered groups of PwAD identified in the study were different. There were significant differences on caregiver level of depressive symptoms among four clustered groups of PwAD. Caregivers of PwAD in Cluster 4 had the highest mean level of depressive symptoms, followed by those in Cluster 3 and Cluster 2. Caregivers of PwAD in Cluster 1 had the lowest mean level of depressive symptoms. Symptoms of PwAD in Cluster 3 and Cluster 4 were more serious (higher mean score of BPS frequency*severity) and included psychosis (hallucination and delusions) and agitation/aggression, and the mean scores of caregiver level of depressive symptoms for caregivers of Cluster 3 and Cluster 4 were both above 10. Previous research findings suggest that aggression (Covinsky et al., 2003; Danhauer et al., 2004), psychosis (Donaldson, Tarrier, & Burns, 1998; Harwood et al., 1998), and agitation symptoms (Asada, Kinoshita, & Kakuma, 2000; Victoroff, Mack, & Nielson, 1998) are directly associated with caregiver depression. These symptoms may result in higher level of depression for the caregiver than others because they may be more difficult to manage, may be taken more personally by the caregiver, or may serve as more dramatic reminders of loss of a loved one (Ornstein & Gaugler, 2012).
Overall, findings from the cluster analysis showed that BPS can be categorized based on the presence and severity of symptoms and that such grouping has predictive validity of caregiver depression. Understanding whether specific clusters of PwAD and the BPS characteristics of these clusters have more negative impact on caregiver depression and the mechanism by which this occurs can help target treatment and intervention efforts more effectively for both PwAD and their caregivers.

**Caregiver Burden and Distress as Mediators.** Our findings support the Stress Process Model, suggesting that both caregiver level of burden and distress mediate the relationship between BPS in PwAD and caregiver level of depressive symptoms. When adding both mediators into the regression model, the previous significant variable BPS in the model without these two mediators became insignificant. Caregiver level of burden was found to be a significant variable of caregiver depression. Mediation tests confirmed the role of caregiver level of burden as a mediator that the impact of BPS in PwAD on caregiver depression is made through caregiver’s perceive level of burden. This finding that caregiver level of burden works as a mediator in the relationship between BPS in PwAD and caregiver level of depressive symptoms has been found in previous studies (Chun, Knight, & Youn, 2007; Clyburn, Stones, Hadjistavropoulos, & Tuokko, 2000; Kim, Knight, & Longmire, 2007). Caregivers experience challenging BPS exhibited in PwAD and evaluate how the situation may endanger their well-being and caregiving performance, and thus has impact on their mental health outcomes. Regarding the second mediator caregiver distress, it was measured in terms of BPS in PwAD, and caregivers were asked to rate their level of distress regarding each specific BPS domain exhibited in PwAD, analyses results showed that it fully mediated the relationship between BPS in
PwAD and caregiver level of depressive symptoms. Findings of the mediation tests suggest BPS may result in higher level of depression for the caregiver because caregivers perceive it as distressful or feel the tasks of managing BPS are burdensome. Caregiver appraisal of BPS is important and is one of the main ways by which a caregiver evaluates the meaning and significance of BPS. In order to alleviate caregiver depression, it is important to understand how caregivers perceive BPS in PwAD, how they consider BPS as a burden, and reduce their distress related to BPS. Findings of this study suggests that capturing the impact of the behaviors from a caregiver perspective is important. Therefore, future research is needed to conceptualize BPS from caregivers’ perspective. Specifically, it is important to know how caregivers understand BPS they encounter, how they manage BPS, and how those BPS might impact care recipient and themselves differently. Ornstein and Gaugler (2012) suggested that psychosis may have relatively little effect on the care recipient but may have huge implication for the well-being of the overwhelmed caregiver. Understanding caregivers’ appraisal of BPS and other caregiving tasks is important in order to improve their mental health and overall well-being.

Caregiver Competence as Moderator. It was hypothesized that caregiver perceived level of competence would play a moderating role between BPS in PwAD and caregiver level of depressive symptoms. Caregivers with high perceived adequacy to care for PwAD were hypothesized to less likely assess BPS as stressful events, which would lead to a lower level of depressive symptoms. However, in the study results, the relationship between BPS in PwAD and caregiver level of depressive symptoms did not differ depending on the level of competence reported by caregivers. Possible explanations for this may relate to how caregiver competence was measured in the current study.
Caregiver competence was defined in the study as one’s perceived adequacy to care for PwAD across a range of AD-specific roles and responsibilities. However, this variable was measure by questions such as “How successful do you feel”, and “How much do you feel that all in all, you’re a good caregiver”. These questions are not specific to reflect how caregivers perceive themselves as competent to deal with the stressor BPS or a range of specific caregiving tasks. The validity of this scale (0.65) is relatively low compared to other variables included in this study. Limited efforts have been made to measure efficacy related concepts in informal caregivers of AD, and most of these efforts have not been domain specific (Fortinsky, Kercher, & Burant, 2002). Future research is needed to use more valid measurement of caregiver competence and understand the role of caregiver competence in the relationship between BPS in PwAD and caregiver mental health. Another possible explanation about our findings not supporting caregiver competence as a moderator is related to caregivers’ socially desirable answers to the questions. Descriptive analysis results showed that the mean score of caregiver level of competence was 14.86 (SD=1.55), meaning that all caregivers in the sample perceived themselves as highly competent. It is possible that caregivers felt comfortable to provide socially desirable answers to the questions about caregiving competence, but they did not really feel that competent to take care of the care recipient. Also, caregivers generally perceived themselves as good, responsible, and successful caregivers in taking care of PwAD, however, this level of competence is not able to attenuate the effect of BPS on caregiver depression. In addition, caregiver competence in the general regression model was not a significant predictor of caregiver depressive symptoms, and the correlation
coefficients to caregiver depressive symptoms and BPS in PwAD were low (-.252 with caregiver depressive symptoms; -.132 with BPS in PwAD).

**Racial Differences in BPS and Caregiver Depression.** It was hypothesized that BPS in PwAD differed between African Americans and whites. The study findings confirmed that the overall BPS (frequency*severity score) between whites and African Americans were different, and white PwAD had higher score than African Americans meaning that white PwAD exhibited more severe symptoms as reported by their caregivers. More specifically, higher percentage of whites exhibited apathy, depression, and anxiety, and whites had higher mean scores of these three BPS domains. Part of our results is consistent with previous studies that lower depression in PwAD were found among African Americans (Chen, Borson, & Scanlan, 2000; Gothran et al., 2015). However, we did not find differences in either severity or presence of hallucinations and delusions between whites and African Americans, which is inconsistent with previous literature findings that African Americans had higher rates of psychotic symptoms (hallucinations and delusions) than whites (Bassiony et al., 2000; Lopez et al., 2003; Sink et al., 2004). One possible reason is that those studies had very few African Americans in the sample (Bassiony et al., 2000; Lopez et al., 2003). Sample size is important because of its relationship to effect size and power in statistical analyses. Sink et al. (2004) in their study included 469 (8%) African Americans, however, they were all dementia patients. In addition, the measurement of BPS used previously also differed from the current study. For example, the study by Sink et al. (2004) only included one question about hallucination (please tell me if client named typically does seeing or hearing things that are not there). This one-item measurement may cause different results compared to
studies using a more valid scale. Furthermore, factors of age, population origin, and disease duration can explain the differences in prevalence of delusions in AD (Zhao et al., 2016). Prior evidence had indicated that delusional patients were older than those without psychotic symptoms (Bassiony et al., 2000). In the current study, we did not find significant differences in age between African Americans and whites. Since the current study did not have information about disease duration and stage of AD, future research is needed to gain insight into the mechanisms underlying the association between patient characteristics (e.g., race, age, disease duration, as well as severity) and BPS.

Results showed significant differences on caregiver depressive symptoms between white and African-American caregivers, with white caregivers reporting higher mean level of depressive symptoms than African Americans, which is consistent with previous literatures (Cothran et al., 2015; Dilworth-Anderson, William, & Gibson, 2002; Roth, Ackerman, Okonkwo, & Burgio, 2008). This may be explained from a cultural perspective about how African Americans perceive differently from whites on caregiver burden and general caregiving experiences. First, cultural values would operate through African Americans’ cognitive appraisals of caregiving as less burdensome (Dilworth-Anderson, Williams, & Gibson, 2002; Haley et al., 2004). Our results showed perceived level of burden and distress mediated the relationship between BPS in PwAD and caregiver depressive symptoms, and African Americans reported lower level of burden and distress. African-American caregivers have generally lower appraisals of the stressfulness of caregiving than white caregivers, which might lead to lower levels of depression. Several factors may contribute to this finding, such as high levels of intrinsic motivation to provide care based on familism, the use of cognitive coping strategies that
help caregivers to find personal and spiritual meaning in the caregiving experience, and greater availability of informal support (Pinquart, & Sörensen, 2005). Also, African-American caregivers may be less likely than whites to view BPS as cause of embarrassment or social unease, because of the high respect for elders (Dilworth-Anderson & Gibson, 2002).

Familism, defined as strong identification and solidarity of individuals with their family (nuclear and extended) as well as attachment, mutual support, family obligation, and familial interconnectedness (Sabogal, Marin, Otero-Sabogal, Marin, & Perez-Stable, 1987), could be important factors that lead to lower perceptions of caregiving as burdensome (Aranda & Knight, 1997). African Americans were found to have higher cultural justification for caregiving ratings (an operationalized familism that reflects cultural reasons and expectations in providing care) than whites, which had a curvilinear relationship with caregivers' psychological well-being over time (Dilworth-Anderson et al., 2005). This also suggests that they differ from whites regarding why they give care to older relatives and thus influences their appraisal of caregiving. African-American caregivers strongly identify with traditional values that encourage providing care to older dependent people in the family than white caregivers. Within African-American community, family is beyond a standardized representation of the nuclear family (Taylor, Chatters, & Mays, 1988). African Americans have been influenced by the extended family whose sense of obligation to support relatives is intended to help promote stability through material support and mutual aid exchange (Martin & Martin, 1980). The extended family network is not limited to blood relationships, but includes friends, neighbors, or church members (Taylor, Chatters, & Mays, 1988). For elder African
Americans, children, other relatives, or friends/neighbors are essential sources of support. It is also important to discuss individualism versus familism values that influence caregivers’ perceptions about caregiving. Western majority culture tends to emphasize individualism and perceive caregiving as a burden because it disrupts the caregiver's life, while filial piety and values concerning family supportiveness may have more positive health effects for African-American caregivers (Knight & Sayegh, 2010). Last but not least, previous research indicates that African-American caregivers are more likely to report more positive caregiving experiences, i.e. “a more positive attitude toward life” and “appreciate life more” (Roth, Dilworth-Anderson, Huang, Gross, & Gitlin, 2015), which may lead to a lower appraisal of the negative aspects of caregiving.

Although we found significant differences in both BPS in PwAD and caregiver depressive symptoms between African Americans and whites, there were no racial differences in the relationship between BPS in PwAD and caregiver level of depressive symptoms. This means that the effect of BPS in PwAD on caregiver depressive symptoms was same for white and African-American caregivers. According to Feldman & Rosenthal (1994), there are two types of ethnic differences: positioning effects and patterning effects. Positioning effects are those differences in the mean levels of caregiver variables, while patterning effects are differences in the association of caregiver variables. Ethnic differences in mean levels of stressors and resources may lead to differences in psychological health outcomes of caregivers (e.g., caregiver depressive symptoms), but the effects of stressors and resources may also vary by ethnicity. Although results of the current study confirmed positioning effects between African Americans and whites including differences in contextual factors (gender, marital status,
employment status, relationship with the care recipient, and general health) and BPS in PwAD. However, the patterning effects were not confirmed in the study. Knight and colleagues (2000) proposed that the influence of ethnicity on psychological outcomes of caregivers occurs through ethnic differences in background variables (e.g., proportion of female and spousal caregivers), the risk for exposure to stressors (types and severity of BPS), social support and coping processes, and appraisals of caregiving experiences (as gain or burden). Future research is needed to examine the patterning effects on caregiver mental health outcomes. Approaches that take into account ethnic differences in both the mean levels of variables and in the interrelation between them would help us better understand why African-American caregivers’ mental health is better than that of whites.

**Nursing Home and Community Sample Differences.** As the sample used in the study included both PwAD living in nursing homes and those living in their own community, results for each research question were reported separately to see if there were differences between the two subsamples. Findings showed similar results for all RQs as the whole sample and between the two subsamples, but the two subsamples had differences in main variables of the study that caregivers of those living in the nursing home reported higher mean of BPS (frequency*severity) in PwAD, had higher level of caregiver burden, caregiver distress, and caregiver depressive symptoms, but had lower level of caregiver competence. This implies that caregivers of those living in the nursing home, when recalling back about their caregiving experiences, reported negative feelings (i.e., caregiver burden, distress, and depression) and felt less competent to take care of the care recipient. In addition, we found that higher percentage of PwAD living in the nursing home were in Cluster 2, 3, and 4, and PwAD living in the nursing home had
higher mean number of BPS presence as well as higher mean score of BPS (frequency*severity). More symptoms and high severity level of the symptoms in PwAD, as well as caregiver lower level of competence might be important determinants of a nursing home placement. Those caregivers of PwAD living in the community, who reported least severe symptoms in PwAD and had higher level of competence, could still manage the caregiving tasks at home with a lower level of burden and depressive symptoms. This finding is consistent with previous literature about BPS and caregiver level of burden as predictors of institutionalization (Cepoiu-Martin, Tam-Tham, Patten, Maxwell, & Hogan, 2016; Coehlo, Hooker, & Bowman, 2007; Gaugler et al., 2003; Luppa et al., 2008; Porter et al., 2016). These findings suggest that it may be important to develop programs/interventions where caregivers are trained in behavioral management of BPS symptoms, which has the potential to decrease caregiver distress and perceived burden through increasing their confidence in their abilities to manage symptoms experienced by PwAD, thus delays institutionalization.

Limitations

This study has several limitations related to survey research, sampling methods, and the population under study. First, data were collected through caregiver self-report which is subject to recall bias. Especially, the recall period of 7 months (maximum) for the nursing home group might have impacted the data as caregivers of PwAD living in the nursing home may have forgotten about the symptoms exhibited in PwAD several months prior to the interview, and it might be difficult for them to recall their level of distress, burden, and depressive symptoms months back. There also might be cultural differences in reporting BPS between African-American and white caregivers. For
example, African Americans might not want to admit that caring for their loved one is burdensome. Second, when using secondary data, the researcher is limited to the variables available in the dataset and the manner in which they were measured. For example, information about stage of AD, other types of stressors such as activities of daily living (ADL) dependency, and length of care/days since diagnosis provided were not collected. They may also influence caregiver depression. However, the general linear regression model used in the current study with all predictors (contextual factors, BPS in PwAD, caregiver distress, caregiver burden, and caregiver competence) can explain 47% of variability in caregiver depressive symptoms which is high for this kind of study. In addition, participants in the Registry limited to persons who are Medicaid eligible, thus they were not representative of all PwAD and their caregivers across all income groups. The data used in the study were all from one southern state, so generalization cannot be made across the U.S.

**Implications for Social Work**

The examination of BPS in PwAD and caregiver depression among African American and white caregivers holds several implications for social work research and practice. Specific recommendations for social work practitioners and social work researchers are provided below.

First and foremost, it is important to develop more effective and targeted therapies for neuropsychiatric symptoms that may be able to relieve the non-cognitive symptoms of AD and thus improve caregiver’s mental health. The study findings reflect the symptoms profile of PwAD and identify four clusters that include minimally symptomatic, severely symptomatic, apathetic, and psychotic and hyperactive PwAD. This profile of PwAD is
important and useful for professionals to develop therapies and interventions to alleviate symptoms, as different interventions will be provided to different groups of PwAD within which they exhibit similar symptoms. For example, for PwAD in cluster 3, intervention focus will be on alleviating symptoms including hallucinations, agitation/aggression, apathy, aberrant motor behavior, and sleep and nighttime behavior disorders. The intervention will be slightly different for those PwAD in cluster 4, that additional focus on disinhibition, anxiety, and delusions are needed. As PwAD had minimally symptomatic in cluster 1, preventions are important to delay their experiences of BPS. Public health efforts have focused on developing effective pharmacologic and nonpharmacologic therapies to ameliorate the wide range of BPS (Epperly, Dunay, & Boice, 2017; Lanctôt et al., 2017; Lyketsos, 2007). There are also different types of psychosocial interventions (e.g., music, dancing, reminiscence, exercise) found to be helpful in treating certain BPS domains including anxiety (Sung, Chang, & Lee, 2010), agitation and aggression (Livingston et al., 2005), and improving mood or communication (Hamill, Smith, & Röhricht, 2012). A combination of different components targeting to treating different BPS domains are needed. In addition, evidence show that psychosocial interventions involving informal caregivers are designed to ameliorate BPS (Livingston et al., 2005). For example, one psychoeducation group program for informal caregivers is found to be effective in improving neuropsychiatric symptoms (Hébert et al., 2003). Considering caregiving settings, different interventions may need for PwAD living in nursing homes and those living in their own communities to relieve the non-cognitive symptoms of AD as findings of this study indicate that BPS in PwAD living in the nursing home are more severe than those living in the community.
Recent review studies of nonpharmacological interventions to reduce BPS in general dementia suggest that the majority of studies focus on interventions on individuals with dementia residing at long term care facilities, and their application to home-based support remains uncertain (O’Connor, Ames, Gardner, & King, 2009; de Oliveira et al., 2015). In a residential care setting such as nursing home, multicomponent interventions that incorporate psychological principles, environmental modifications, and education of direct care providers may be the most feasible and effective approach to decrease BPS (Logsdon, McCurry, & Teri, 2007). For PwAD living in the community and their caregivers, tailored interventions are currently being considered as more effective than standardized interventions (de Oliveira et al., 2015). Activities tailored specifically to a person’s own interests and functional level generate greater levels of engagement and effectiveness and minimize the occurrence of behaviors that commonly associated with nursing home placement such as agitation (Gitlin et al., 2008).

It is also important to provide unique education programs to caregivers of PwAD to help them understand and manage certain behaviors that they have experienced or will experience. Previous meta-analysis provides the strongest evidence to date that caregiver interventions have a twofold advantage: they reduce distress in caregivers, and they reduce BPS in individuals with dementia (Gitlin, 2012). Findings from a review study suggested that caregiver training and educational programs focused on managing BPS, promoting competence and coping strategies for challenging behavior reduce family caregiver perceived level of burden and depression (Trivedi et al., 2018). Specifically, REACH (Resources for Enhancing Alzheimer’s Caregiver Health) carer interventions promoted a problem-focused approach to behavioral management and evidence showed
some success with lessening the impact of behavioral symptoms and protecting caregiver health (Belle et al., 2006; Elliott, Burgio, & DeCoster, 2010). Considering that a great proportion of informal caregivers of PwAD are older people themselves and they are likely to have an informal caregiver as well, it becomes necessary to focus intervention and programs on the specific needs and perceptions of BPS of this specific age group, as younger and older family caregivers may not form a homogenous group (de Oliveira, Vass, & Aubeeluck, 2015). It is vital to provide the older caregivers support interventions at the individual level to reduce the physical and psychological burden of caregiving. Interventions such as creating network for caregiver support may also be beneficial to this group of caregivers.

The findings of this study also highlight the importance of delivering cultural relevant education programs/interventions to ethnic groups from low-income families. Psychosocial interventions for depression in ethnic minority caregivers of PwAD could be enhanced through cultural adaptations (Akarsu, Prince, Lawrence, & Das-Munshi, 2019). Evidence from REACH studies suggests that family therapy targeted at culturally different groups in five US sites reduced distress about BPS and caregiver depression (Elliott, Burgio, & Decoster, 2010). However, limited family interventions are available targeted for, or included diverse low-income families (Gitlin, Cigliana, Cigliana, & Pappa, 2017). People with coexisting risk factors (low income, low perceived health) may benefit most from interventions (Andrén & Elmståhl, 2007). Future work targeting caregivers from low-income families are needed and valuable.

Lastly, for social work researchers, this study exposes a gap in the research on examining BPS in PwAD between different ethnic groups. More research is needed to
compare BPS in PwAD among Asians, Hispanics, and other minority groups. Future studies can also benefit from profiling PwAD over the course of the disease and examining longitudinal effects of BPS in PwAD on caregiver depressive symptoms. There is some evidence showing that there were differences in the longitudinal courses of different BPS domains, and apathy was the only symptom with high baseline prevalence, persistence and incidence during the disease course (Van Der Linde et al., 2016). As this study did not have information about AD stage or length of days since diagnosis, we cannot compare profiles of PwAD at different stages. In addition, more research is needed to examine caregiver’s understanding about BPS in PwAD, how they manage those symptoms, and their perceptions on how BPS influence their life and health. Investigating these topics will deepen our understanding of BPS from a caregiver perspective and help us design useful educational programs and interventions for them to manage AD related symptoms.
REFERENCES


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APPENDIX A

MEASUREMENTS

Caregiver Depression: CESD-10 items

CESD1: You were bothered by things that usually don’t bother you.

CESD2: You had trouble keeping your mind on what you were doing.

CESD3: You felt depressed.

CESD4: You felt that everything you did was an effort.

CESD5: You felt hopeful about the future.

CESD6: You felt fearful.

CESD7: Your sleep was restless.

CESD8: You were happy.

CESD9: You felt lonely.

CESD10: You could not “get going”.

Response options:

- Rarely/none of the time (0)

- Some of the time (1)
- Occasionally (2)
- Most of the time (3)

**Behavioral and Psychological Symptoms: Neuropsychiatric Inventory (NPI)**

*Domains*: delusions, hallucinations, agitation/aggression, depression/dysphoria, anxiety, apathy/indifference, irritability/lability, elation/euphoria, disinhibition, aberrant motor behavior, sleep and nighttime behavior disorders, appetite and eating changes

If the screening question is confirmed, determine the frequency and severity of the domain.

*Frequency*:

- Rarely (1) – less than once per week
- Sometimes (2) – about once per week
- Often (3) – several times per week but less than every day
- Very often (4) – once or more per day

*Severity*: mild (1), moderate (2), severe (3)

**Caregiver Distress** (included in the NPI questionnaire)

How emotionally distressing do you find this behavior?

Response options:

- Not at all (0)
- Minimally (almost no change in work routine) (1)
- Mildly (almost no change in work routine but little time rebudgeting required) (2)

- Moderately (disrupts work routine, requires time rebudgeting) (3)

- Severely (disruptive, upsetting to staff and other residents, major time infringement) (4)

- Very severely or extremely (very disruptive, major source of distress for staff and other residents, requires time usually devoted to other residents or activities) (5)

**Caregiver Burden: ZBI-4 items**

ZBI1: Did you feel that because of the time you spent with patient, that you did not have enough time for yourself?

ZBI2: Did you feel stressed between caring for patient and trying to meet other responsibilities for your family or work?

ZBI3: Did you feel strained (tense) when you were around patient?

ZBI4: Did you feel uncertain about what to do about patient?

Response options:

- Never (0)

- Rarely (1)

- Sometimes (2)

- Quite frequency (3)

- Nearly always (4)
Caregiver Competence-4 items

Item 1: How much do you believe that you’ve learned how to deal with a very difficult situation?

Item 2: How much do you feel that all in all, you’re a good caregiver?

Item 3: How successful do you feel?

Item 4: How self-confident do you feel?

Response options:

- Not at all (1)

- Just a little (2)

- Fairly (3)

- Very (4)
library(haven)

library(forecast)

library(EnvStats)

library(cluster)

library(sjmisc)

forfinalanalysis2019 <- read_sas("data/forfinalanalysis2019.sas7bdat", NULL)

cluster_data=forfinalanalysis2019[196:(196+11)]

# Choosing the number of clusters k using the average silhouette width criterion.

my.k.choices <- 2:8

avg.sil.width <- rep(0, times=length(my.k.choices))

for (ii in 1:length(my.k.choices)) {
  avg.sil.width[ii] <- pam(cluster_data, k=my.k.choices[ii])$silinfo$avg.width
}

print( cbind(my.k.choices, avg.sil.width) )
# Cluster Analysis

npi.4.clust <- lapply(1:4, function(nc)
forfinalanalysis2019$id[npi.kmed.4$clustering==nc])
npi.4.clust  # printing the clusters

# Create a Variable for Each Individual Cluster

npi.kmed.4$clustering
data_with_cluster=cbind(forfinalanalysis2019,npi.kmed.4$clustering)
colnames(data_with_cluster)[230]="cluster"

# Mean NPI Score for Each Cluster

aggregate(data_with_cluster[, c(196:(196+11),211)], list(data_with_cluster$cluster), mean)
aggregate(data_with_cluster[, c(196:(196+11),211)], list(data_with_cluster$cluster), sd)
aggregate(data_with_cluster[, "cesdscore"], list(data_with_cluster$cluster), mean)
aggregate(data_with_cluster[, "cesdscore"], list(data_with_cluster$cluster), sd)
aggregate(data_with_cluster[, "patient_age"], list(data_with_cluster$cluster), mean,na.rm=TRUE)
aggregate(data_with_cluster[, "patient_age"], list(data_with_cluster$cluster), sd,na.rm=TRUE)
aggregate(data_with_cluster[, "distscore"], list(data_with_cluster$cluster), mean, na.rm=TRUE)
aggregate(data_with_cluster[, "distscore"], list(data_with_cluster$cluster), sd, na.rm=TRUE)
aggregate(data_with_cluster[, "compscore"], list(data_with_cluster$cluster), mean, na.rm=TRUE)
aggregate(data_with_cluster[, "compscore"], list(data_with_cluster$cluster), sd, na.rm=TRUE)
aggregate(data_with_cluster[, "zbiscore"], list(data_with_cluster$cluster), mean, na.rm=TRUE)
aggregate(data_with_cluster[, "zbiscore"], list(data_with_cluster$cluster), sd, na.rm=TRUE)

# Chi-Square tests
chisq.test(data_with_cluster$cluster, data_with_cluster$patient_race)
chisq.test(data_with_cluster$cluster, data_with_cluster$patient_gender)
chisq.test(data_with_cluster$cluster, data_with_cluster$location)
table(data_with_cluster$cluster, data_with_cluster$patient_race)
table(data_with_cluster$cluster, data_with_cluster$patient_gender)
table(data_with_cluster$cluster, data_with_cluster$location)
prop.table(table(data_with_cluster$cluster, data_with_cluster$patient_race), 1)
prop.table(table(data_with_cluster$cluster, data_with_cluster$patient_race), 2)
prop.table(table(data_with_cluster$cluster, data_with_cluster$location), 2)

# As data is non-normal, use a non-parameteric version of ANOVA: Kruskal-Wallis

kruskal.test(npiscore ~ cluster, data = data_with_cluster)
kruskal.test(cesdscore ~ cluster, data = data_with_cluster)