AGGRESSIVE BEHAVIORS IN DEMENTIA: PREVALENCE AND CAREGIVER REACTIONS

by
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the requirements for the degree of Doctor of Philosophy

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Abstract

Purpose

The purpose of this dissertation study was to describe and explore the prevalence of aggressive behavior types (verbal aggression, destroying property, and threatening to hurt others) and their relationship with caregiver reactions (upset and confidence) among diverse, community-dwelling persons with dementia and their caregivers.

Methods

This study used both secondary data analyses and semi-structured interviews. Baseline data from 630 participants in the NIH Resources for Enhancing Alzheimer's Caregiver Health II (REACH II) initiative was analyzed. Then, thirteen Black/African-American caregivers were purposively recruited and interviewed.

Results

More than a third ($N = 241$) of caregivers reported one or more aggressive behaviors in one week. Verbal aggression was most frequently reported ($N = 217$), then threatening to hurt others ($N = 54$), and destroying property ($N = 45$). Black/African-Americans were more than twice as likely as White/Caucasians to report threatening to hurt others, after controlling for covariates (AOR=2.26, p=0.035, 95% CI [1.06-4.84]). Over two-thirds of caregivers reported dichotomous upset with each behavior type. A statistically significant negative correlation with a medium strength of association between upset and confidence was found for total behaviors, verbal aggression, and threatening to hurt others. Caregivers differed statistically significantly by race/ethnicity in reporting upset with (p=0.003) and confidence managing (p=0.006) verbal aggression,

as well as confidence managing behaviors overall (p=0.001). In interviews with Black/African-American caregivers, two overarching themes emerged: *Care Challenges*, including subthemes *Taking care of a stranger*, *Hurtful interactions*, *Overcoming the past*, and *Social and financial strain* and *Success Strategies*, including subthemes “*It’s the disease….not the person,” “I got to do what I gotta do,” “We didn’t argue….we didn’t insist,”* and *“Don’t put her in a position to fail.”*

Conclusion

Prevalence of aggressive behaviors in dementia was high, differing only slightly by race/ethnicity. Caregivers overall were challenged by aggressive behaviors in terms of their level of upset and confidence, differing somewhat by race/ethnicity. Themes emerging from interviews suggested caregivers used cognitive and behavioral strategies to address caregiving challenges. Cultural and contextual factors may be key to understanding why aggressive behaviors occur and to developing effective interventions to help families effectively prevent and manage them.

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Dedication

For Celia…

“Love is still the answer, and the questions never really change…”

—Jamie Huling

With my immense gratitude…

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I will be able to emulate her effectiveness in advancing her passion of attaining a world in which every person has the freedom to live unmolested by interpersonal violence.

My academic journey from the first days of undergraduate work through the last days of graduate work has been marked by a multitude of new, collegial relationships. Each member of the faculties of North Hennepin Community College, St. Cloud State University, Morningside College, and Johns Hopkins University, have contributed uniquely to my development. I owe, in turn, a debt of gratitude to each, and will throughout my career. I hope that I have adequately expressed my thankfulness to each of you individually when I had the opportunity, as I am keenly aware that I cannot do it sufficiently here. My doctoral colleagues are also an outstanding group. I have been privileged to share this journey with several cohorts as we overlapped at different times. You have each been an inspiration in a special way and I am proud to be included as a member of this community of scholars.

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Finally, I would like to thank my family and friends. I considered listing each of you here; but, I cannot. I do not know where to end, and to describe what you each mean to me would be too personal. So, I conclude with my love to Celia, Dad, Mom, Bruce, Maria, Kayli, and Caden. You have seen me at the worst, and at the best. I love you.

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Chapter 1: Introduction

Dementia is an emerging public health crisis of historic proportions, with the number of people with dementia estimated to nearly double every twenty years between 2010 and 2050, from 35.6 million people in 2010 to 115.4 million in 2050 (Prince & Jackson, 2009). The impact on persons with dementia, their caregivers, the healthcare system, and the world's economies is already substantial and is expected to become even more immense as these numbers increase (Prince, Prina, & Guerchet, 2013). One of the most challenging aspects of dementia for caregivers are neuropsychiatric symptoms (Gauthier et al., 2010), which are behaviors that frequently develop as part of the neuropsychiatric pathologic processes (Miyoshi & Morimura, 2010). Nearly every person with dementia will experience one or more neuropsychiatric symptoms over the entire course of the disease process (Jost & Grossberg, 1996; Lyketsos et al., 2001; Steinberg et al., 2008).

Aggressive behaviors are among the most difficult neuropsychiatric symptoms for caregivers to manage (Hall & O'Connor, 2004). Aggressive behaviors in dementia have been associated with increased long-term care institutional placement, a 10-fold increase in caregiver and person with dementia injury rates, and increased psychotropic medication use, all of which substantially magnify the personal, social, and economic impact for persons with dementia over the course of the illness (Hamel et al., 1990; Kunik, Snow, Davila, McNeese, et al., 2010). Approximately 30 to 50% of all persons with dementia have aggressive behaviors of some kind, with potentially over 90% experiencing aggressive behavior at some point in the dementia course (Cipriani, Vedovello, Nuti, & Di Fiorino, 2011; Hamel, et al., 1990; Kunik, Snow, Davila, Steele, et al., 2010). This is concerning, not only because of the personal impact of aggressive behaviors on caregivers and persons with dementia, but also to society at large as aggressive behaviors are a frequent trigger for hospitalization and institutionalization, which are associated with substantially higher costs (Alzheimer's Association, 2015; Beeri, Werner, Davidson, & Noy, 2002; Hurd, Martorell, Delavande, Mullen, & Langa, 2013).

Aggressive behavior in persons with dementia has also been associated with poorer caregiver outcomes (Eastley & Wilcock, 1997; Fauth & Gibbons, 2014; Gauthier, et al., 2010; Kunik, Snow, Davila, McNeese, et al., 2010; Ryden, 1988). Further research is needed to explore at greater depth the context in which caregivers experience aggressive behaviors in the person with dementia if modifiable factors are to be identified and targeted for future intervention development. Therefore, the purpose of this dissertation study was to explore the relationship between caregiver reactions and aggressive behaviors in community-dwelling persons with dementia in three racial/ethnic groups (Hispanic/Latino, Black/African-American and White/Caucasian).

Defining aggressive behavior within the context of dementia has been the subject of considerable debate but Patel and Hope (1992) provide the following succinct definition: "Aggressive behavior is an overt act, involving the delivery of noxious stimuli to (but not necessarily aimed at) another object, organism or self, which is clearly not accidental." Two components of this definition in particular are helpful to understand how aggressive behaviors are defined operationally in this dissertation study. The first component of aggressive behavior as defined here is the willfulness of the action, which means that the noxious stimulus is not incidental to some other action. For example, a person demonstrating agitated behaviors may knock a glass of water on the ground as s/he attempts to keep moving, but a person who is demonstrating aggressive behaviors may take the glass and throw it on the floor. The second component is the directionality of the action. Aggressive behavior may be directed toward "another object, organism, or self." Within this study aggressive behaviors include specifically those actions directed toward others and toward objects.

Factors Associated with Aggressive Behavior in Dementia

The risk factors for aggressive behavior in dementia are complex and, in some cases, remain unclear. Living arrangements, familial relationship within the dyad, declining dyadic mutuality, functional limitations of both the caregiver and person with dementia, and depression in caregivers have been identified as risk factors strongly associated with increased aggression in persons with dementia and increased conflict in dyads of caregivers and persons with dementia (Cassie, 2012; Kunik, Snow, Davila, Steele, et al., 2010; Menon et al., 2001; Morgan et al., 2013; Paveza et al., 1992). Persons with dementia in dyads with a spousal or partner relationship are more likely to become aggressive toward their caregiver than those persons with dementia who are not spouses or partners of their caregivers (Cipriani, et al., 2011). Additionally, problem behaviors, such as aggression, have also been associated with increased caregiver burden, with females caring for males at greatest increased risk (Bedard et al., 2005; Eastley & Wilcock, 1997). The literature also suggests that there may be a relationship between premorbid personality and aggressive behavior but the nature of the associations remains somewhat unclear (Hamel, et al., 1990; Kolanowski & Garr, 1999; Low, Brodaty, & Draper, 2002; Osborne, Simpson, & Stokes, 2010; Pulsford & Duxbury, 2006; Whall et al., 2008).

Differences by Race/Ethnicity

A review of the literature on ethnicity and dementia found that: 1) the prevalence and incidence of dementia among Black/African-Americans and Hispanic/Latinos was higher than among White/Caucasians, 2) the frequency of different types of neuropsychiatric symptoms appeared to differ by race/ethnicity, and 3) differences were found by race/ethnicity both in how family caregivers provided care and in their psychological outcomes (Harwood & Ownby, 2000). In addition to having higher prevalence rates of dementia and neuropsychiatric behaviors, both Black/African-Americans and Hispanic/Latinos tend to be diagnosed with dementia later in the disease process than White/Caucasians, delaying supportive interventions for both caregivers and persons with dementia (Alzheimer's Association, 2015; Chin, Negash, & Hamilton, 2011; Schrauf & Iris, 2011).

Patterns of prevalence and incidence of specific neuropsychiatric behaviors, including aggressive behavior, have also been shown to differ across racial/ethnic groups (Harwood & Ownby, 2000; Ortiz, Fitten, Cummings, Hwang, & Fonseca, 2006; Sink, Covinsky, Newcomer, & Yaffe, 2004), which suggest that the experiences of both the person with dementia and the caregiver for the person with dementia may also differ by race/ethnicity (Alzheimer’s Association, 2015; Connell & Gibson, 1997; Janevic & Connell, 2001; Pinquart & Sorensen, 2005; Roff et al., 2004; Vickrey et al., 2007).

Several studies point toward race/ethnic differences in prevalence rates of neuropsychiatric behaviors but findings are not consistent among studies (Chen, Borson, & Scanlan, 2000; Cohen & Magai, 1999; Hargrave, Stoeklin, Haan, & Reed, 2000; Lachs et al., 2013; Ortiz, et al., 2006; Sink, et al., 2004). For example, Sink, et al. (2004) found that Black/African-Americans and Hispanic/Latinos demonstrated more dementia-related behaviors than did White/Caucasians and Hispanic/Latinos were more likely than White/Caucasians to demonstrate combative behaviors. However, Lachs, et al. (2013) found that Hispanic/Latinos were less likely than White/Caucasians to exhibit aggressive behaviors toward staff in an institutional setting. Ortiz, et al. (2006) found that at the first assessment for dementia, Hispanic/Latinos tended to present more neuropsychiatric symptoms than White/Caucasians. On the other hand, Chen, et al. (2000) found that the prevalence of aggressive behavior was not significantly different by stage of dementia or by race/ethnicity. It remains unclear, therefore, if differences in prevalence rates between groups in the literature are an artifact of sampling, setting, measurement, or other factors such as disease stage or disparities in accessing healthcare.

As caregivers from different race/ethnic backgrounds experience the caregiving role differently, these differences in neuropsychiatric symptoms between race/ethnicities may be key to understanding more about how caregivers’ experiences differ in managing these symptoms in the person with dementia. To our knowledge no study has examined caregiver reactions to different aggressive behavior types in persons with dementia by race/ethnicity. Thus, to begin to address this gap in the scientific literature, the purpose of this dissertation study was to describe prevalence rates of aggressive behavior and to explore the relationship between caregiver reactions (upset and confidence) and aggressive behaviors (verbal aggression, destroying property, and threatening to hurt others) in community-dwelling persons with dementia in Black/African-American, Hispanic/Latino, and White/Caucasians.

Conceptual Model

The conceptual framework underlying this dissertation study arises from the Stress Process Models, for both the person with dementia and for the caregiver. The Stress Process Model for Persons with Dementia was developed by Judge, Menne, and Whitlatch (2010) and built upon the Stress Process Model for caregiver (Haley, Lane Brown, & Levine, 1987; Lazarus & Folkman, 1989; Pearlin, Mullan, Semple, & Skaff, 1990) for use with caregivers of persons with dementia (Appendix 1). These two models provide an understanding of variables of interest for the person with dementia and the caregiver.

The Stress Process Model for Persons with Dementia provides the framework for understanding the factors associated with aggressive behaviors. The associations delineated within the framework provide the theoretical basis for selecting covariates of interest in the illness experience of the person with dementia, such as declining cognitive status, psychological threats, and physiological needs (Judge, et al., 2010).

The Stress Process Model for Caregivers was developed to provide a framework to understand the relationships between multiple components that ultimately lead to outcomes of interest for the caregiver, such as indicators of physical and mental health. It is used in this study to understand the theoretical basis for the relationship between types of aggressive behaviors by the person with dementia (verbal aggression, destroying property, and threatening to hurt others) and caregiver reactions (upset and confidence). Aggressive behaviors demonstrated by the person with dementia can be described as Primary Stressors according to the model, leading to negative caregiver outcomes, and by extension, negative outcomes for the person with dementia (Haley, et al., 1987; Lazarus & Folkman, 1989; Pearlin, et al., 1990).

Together, these complementary Stress Process Models, combined with relevant variables identified by literature review, provide a solid theoretical underpinning for this dissertation study.

Specific Aims

Aim 1

Describe prevalence rates of aggressive behaviors in persons with dementia in a diverse, community-dwelling sample.

Aim 2

Examine associations between types of aggressive behaviors in persons with dementia and caregiver reactions in a diverse, community-dwelling sample.

Aim 3

Compare associations by race/ethnicity (Hispanic/Latino, Black/African-American, and White/Caucasian) between types of aggressive behaviors in persons with dementia and caregiver reactions in a diverse, community-dwelling sample.

Aim 4

Explore how caregivers describe their own experiences with aggressive behaviors in persons with dementia, including the strategies they may use to prevent or manage the behaviors, in a diverse, community-dwelling sample.

Significance

This dissertation study represents one preliminary yet essential step toward understanding the racial and ethnic differences in caregiving responses to aggressive behaviors. As a cure is not imminent, this dissertation research addressed the critical need to assist caregivers in managing the most distressing behavioral symptoms among dementia patients. This study adds to the state of the science and provides greater understanding as to how caregivers in these different racial/ethnic groups handle aggressive behaviors in persons with dementia. This knowledge may be useful for future intervention development designed to provide caregivers with additional resources to deal with some of the most difficult neuropsychiatric behaviors in persons with dementia.

Innovation

This study is the first that we know of to examine relationships between different types aggressive behaviors (verbal aggression, destroying property, and threatening to hurt others) in persons with dementia and caregiver reactions (upset and confidence) to these behaviors in a racially, ethnically, and geographically diverse community-dwelling sample of Hispanic/Latinos, Black/African-Americans, and White/Caucasians.

Organization of Dissertation

This dissertation consists of five chapters.

Chapter 1: Introduction

This section provides an overview of the study, a brief literature review, the conceptual framework, specific aims, significance, and innovation.

Chapter 2: Manuscript 1

This section includes manuscript 1, entitled, "Prevalence of Aggressive Behaviors in Persons with Dementia in a Diverse, Community-Dwelling Sample." It is an examination of the prevalence of specific types of aggressive behaviors in a large, diverse, community-dwelling sample of persons with dementia. It has been prepared submission to The Gerontologist.

Chapter 3: Manuscript 2

This section includes manuscript 2, entitled, "Caregiver Reactions to Aggressive Behaviors in Persons with Dementia in a Diverse, Community-Dwelling Sample." It is an examination of the relationships between specific types of aggressive behaviors and caregiver reactions in a large, diverse, community-dwelling sample of caregivers of persons with dementia. It has been prepared for submission to The Gerontologist.

Chapter 4: Manuscript 3

This section includes manuscript 3, entitled, "African-American Caregivers' Perspectives on Aggressive Behaviors in Dementia." It is an exploration of Black/African-American caregivers' experiences with aggressive behaviors in persons with dementia using semi-structured, focused, in-depth interviews with a purposively recruited sample. It has been prepared for submission to The Gerontologist.

Chapter 5: Conclusion

This section includes a concise summary of the preceding chapters, including results, study strengths and limitations, study implications, and conclusion. It is followed by appendices, a complete list of references, and the author's curriculum vitae.

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Chapter 2: Manuscript 1

FOR SUBMISSION TO THE GERONTOLOGIST

Title

Prevalence of Aggressive Behaviors in Persons with Dementia in a Diverse, Community-Dwelling Sample

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Abstract

Purpose

We describe prevalence of aggressive behaviors and examine differences by race/ethnicity (White/Caucasian, Black/African-American, and Hispanic/Latino) among persons with dementia in a community-dwelling sample.

Design and Methods

Secondary analysis of baseline data (prior to randomization) from Resources for Enhancing Alzheimer's Caregiver Health II (REACH II) initiative to examine prevalence of three types of aggressive behaviors (verbal aggression, destroying property, and threatening to hurt others).

Results

Of 630 participants (216 White/Caucasian, 207 Black/African-American, 207 Hispanic/Latino) enrolled in the REACH II trial, 38.3% (*N*=241) of caregivers of persons with dementia reported one or more aggressive behaviors experienced by persons with dementia in the preceding week and 10.1% (*N*=64) reported two or more behaviors. Hispanic/Latino caregivers were more likely to report only one behavior and Black/African-American caregivers two or more behaviors within one week (*p*=0.020). Overall, verbal aggression was most frequently reported (34.4%, *N*=217), followed by threatening to hurt others (8.6%, *N*=54), and destroying property (7.1%, *N*=45). In a binary logistic regression, after controlling for covariates, only threatening to hurt others had significantly different adjusted odds by race/ethnicity. Black/African-American caregivers were more likely than White/Caucasians (*AOR*=2.26, *p*=0.035, 95% CI [1.06-4.84]) and Hispanic/Latinos were not significantly different from White/Caucasians (*AOR*=1.30, *p*=0.532, 95% CI [0.57-2.95]) in reporting threatening to hurt

others behavior.

Implications

Aggressive behaviors in dementia were high among all three race/ethnic groups, although prevalence of different types varied. Interventions to reduce or prevent aggressive behaviors may need to consider its expression in different race/ethnic groups.

Introduction

Aggressive behaviors are among the most challenging, complex, and costly neuropsychiatric behaviors for persons with dementia, their caregivers, and health providers (Fauth & Gibbons, 2014; Gauthier et al., 2010; Hall & O'Connor, 2004; Miyoshi & Morimura, 2010). Aggressive behaviors, within the context of dementia, have been defined as "…an overt act, involving the delivery of noxious stimuli to (but not necessarily aimed at) another object, organism or self, which is clearly not accidental (Patel & Hope, 1992b, p. 212)." These behaviors have been associated with increased long-term care institutional placement, a 10-fold increase in caregiver and person with dementia injury rates, and increased psychotropic medication use, all of which substantially magnify the personal, social, and economic impact for persons with dementia over the course of the illness (Hamel et al., 1990; Kunik, Snow, Davila, McNeese, et al., 2010). As these behaviors have been associated with increased hospitalization, and hospitalization is associated with substantially higher costs, there is a pressing need to more fully understand aggressive behaviors in dementia from which to develop effective preventive and management strategies (Beeri, Werner, Davidson, & Noy, 2002; Hurd, Martorell, Delavande, Mullen, & Langa, 2013).

The prevalence of aggressive behavior is difficult to estimate as studies have used different definitions and varying measurement periods (Keene et al., 1999). Between 30% to 50% of persons with dementia are estimated to be experiencing aggressive behavior at any one time, with more than 90% potentially experiencing aggression over the course of dementia (Argyle, Jestice, & Brook, 1985; Cipriani, Vedovello, Nuti, & Di Fiorino, 2011; Eastley & Wilcock, 1997; Gibbons, Gannon, & Wrigley, 1997; Gormley, Rizwan, & Lovestone, 1998; Hamel, et al., 1990; Hope, Keene, Fairburn, Jacoby, & McShane, 1999; Keene, et al., 1999;

Kunik, Snow, Davila, Steele, et al., 2010; Lyketsos et al., 2002; Reisberg et al., 1987; Ryden, 1988; Zhao et al., 2015). For example, Patel and Hope (1992a) reported that 45% (N=44) of a sample of older psychiatrically hospitalized adults demonstrated at least mild aggression over a 3-day period. However, in a 10-year longitudinal study following persons with dementia until death, from the community to the institutional setting, Keene, et al. (1999) found that 96% (N=95) of persons with dementia demonstrated some type of severe or persistent aggressive behavior at some point during the dementia course.

There are many risk factors associated with aggressive behavior in dementia that have been identified in the literature such as caregiver burden, premorbid agreeableness, health status, cognitive status, and depression (Gruber-Baldini, Boustani, Sloane, & Zimmerman, 2004; Kunik, Snow, Davila, Steele, et al., 2010; Whall et al., 2008). Race and ethnicity are also among the factors that have been identified as having potential to impact risk for aggressive behaviors in persons with dementia. However, further study is needed with large, diverse samples and controlling for appropriate covariates to identify how or if race/ethnicity is associated with different types of aggressive behaviors.

While a number of studies have examined neuropsychiatric symptoms, overall and a few specifically at aggressive behavior by race/ethnicity, to our knowledge no studies have been conducted to examine types of aggressive behaviors by race/ethnicity with a large geographically and racially/ethnically diverse community-dwelling sample. In a literature review, Harwood and Ownby (2000) found that the prevalence and incidence of dementia among Black/African-Americans and Hispanic/Latinos was higher than among White/Caucasians and that the frequency of different neuropsychiatric symptoms also differed by race/ethnicity. Other studies also point toward race/ethnic differences in prevalence rates of neuropsychiatric behaviors but findings are not consistent among studies (Chen, Borson, & Scanlan, 2000; Cohen & Magai, 1999; Hargrave, Stoeklin, Haan, & Reed, 2000; Lachs et al., 2013; Ortiz, Fitten, Cummings, Hwang, & Fonseca, 2006; Sink, Covinsky, Newcomer, & Yaffe, 2004). For example, in a large sample of community-dwelling, Medicare patients, Sink, et al. (2004) found that 61% of Black/African-Americans and 57% of Hispanic/Latinos demonstrated four or more dementia-related behaviors, compared to 46% of White/Caucasians reporting four or more. Also, Hispanic/Latinos were more likely than White/Caucasians to demonstrate combative behaviors. However, Lachs, et al. (2013) found that in an institutional setting, Hispanic/Latinos were less likely than White/Caucasians to exhibit aggressive behaviors toward staff. Ortiz, et al. (2006) found that Hispanic/Latinos tended to present more neuropsychiatric symptoms than White/Caucasians did at the first neuropsychiatric assessment. On the other hand, Chen, et al. (2000) found that the prevalence of aggression was not significantly different by stage of dementia or by race/ethnicity (Black, Asian/Pacific Islander, Hispanic, Native American). It remains unclear if differences in prevalence rates reported in the literature between these groups are an artifact of sampling, setting, measurement of behaviors, or other factors such as disease stage or disparities in accessing healthcare.

Therefore, the purpose of this cross-sectional, descriptive study is to examine three types of aggressive behaviors (verbal aggression, destroying property, and threatening to hurt others) in a community-dwelling sample of White/Caucasian, Black/African-American, and Hispanic/Latino persons with dementia. Three descriptive, fundamental questions are posed: What is the prevalence of aggressive behavior in persons with dementia, both in the overall sample and by race/ethnicity? What is the prevalence of each type of aggressive behavior (verbal aggression, destroying property, and threatening to hurt others), both in the overall sample and by race/ethnicity? Is the prevalence of aggressive behavior (overall aggression and aggression by individual type) different by race/ethnicity?

The conceptual framework guiding the study is the Stress Process Model for Persons with Dementia, developed by Judge, Menne, and Whitlatch (2010) and which builds upon previous Stress Process Models for caregivers (Haley, Lane Brown, & Levine, 1987; Lazarus & Folkman, 1989; Pearlin, Mullan, Semple, & Skaff, 1990). Applied to aggressive behaviors, this model would suggest that social and environmental stressors may be perceived as threats by the person with dementia and overwhelm his or her coping mechanisms. This in turn may lead to behaviors that the caregiver may report as aggression as the person with dementia uses his or her remaining resources to attempt to communicate a desire to decline participation in caregiving activities, such as hygiene care. The associations delineated within the framework provide the theoretical basis for selecting covariates of interest in the illness experience of the person with dementia (Judge, et al., 2010).

Research Design and Methods

The Resources for Enhancing Alzheimer's Caregiver Health II (REACH II) initiative was an innovative, NIH-funded study with the purpose of designing and testing a multi-component intervention for family caregivers of persons with dementia. It was one of the first multi-site intervention studies to recruit and enroll a large sample of geographically diverse caregivers and persons with dementia from Black/African-American, Hispanic/Latino, and White/Caucasian racial/ethnic groups and was conducted from 2001 to 2004. The publicly available, de-identified, REACH II dataset provides a unique opportunity to examine caregiver-reported aggressive behaviors of persons with dementia among these groups. The data included in this study was collected during the baseline interviews, which occurred prior to randomization and receipt of the REACH II intervention.

Sample

REACH II included a convenience sample of 642 caregiver and person with dementia dyads from five U.S. cities (Birmingham, Alabama; Memphis, Tennessee; Miami, Florida; Palo Alto, California; and Philadelphia, Pennsylvania). Both Hispanic/Latinos and Black/African-Americans were oversampled to allow for a more robust investigation of race/ethnic differences, with 212 Hispanic/Latino, 211 Black/African-American, and 219 White/Caucasian dyads recruited. For this study, 12 participant dyads were eliminated because of ambiguity as to their self-identified race/ethnicity in the publically available dataset, resulting in a total sample of 630 dyads.

Caregivers. Caregivers were included if they were a family member over 21 years old living with the person with dementia and had been providing four hours or more care per day for the previous six months. Caregivers also had to report at least two signs of caregiver distress, such as reporting moderate to high levels of stress or feeling like they often needed to cry. Other inclusion criteria concerned logistical considerations (e.g., have telephone, will remain in area).

Caregivers were excluded if they were non-English or non-Spanish speaking, in active treatment for cancer, reported imminent institutional placement of the person with dementia, or were cognitively impaired.

Persons with dementia. Persons with dementia were included in the study if they had a diagnosis of dementia or cognitive impairment (Mini-Mental State Examination (MMSE) score $\leq$23). Persons with dementia were excluded from the study if they were non-English or non-

Spanish speaking, had a history of Parkinson's Disease or stroke, were in active treatment for cancer, had a severe mental illness, had dementia secondary to head trauma, or were bedbound.

Recruitment procedures and eligibility criteria for REACH II have been reported in greater detail elsewhere (Belle et al., 2006).

Data Collection

If possible, both caregivers and persons with dementia provided written consent. Caregivers of persons with dementia who could not provide consent did so on their behalf. Participants enrolled and consented in the REACH II study participated in a face-to-face interview involving behavioral occurrences and their frequency. Participants were provided with response cards to aid in responding to standardized instruments. All materials were translated into Spanish using forward-and-back translation (Belle, et al., 2006). Interviewer training was extensive and standardized across all sites.

The REACH II data are housed at and accessed from the Inter-University Consortium for Political and Social Research (ICPSR), which is part of the Institute for Social Research at the University of Michigan. ICPSR data undergo a confidentiality review and are altered when necessary to limit the risk of disclosure. All data for this study underwent ICPSR review and are publicly available. None of the data required special permission for use. ICPSR created ready-to-go data files along with setups in the major statistical software formats as well as standard codebooks to accompany the data. In addition to these procedures, ICPSR created an online analysis version with question text for this data collection. All data for this study were already cleaned and converted for immediate use in statistical modeling.

Measures

Race/ethnicity. Race/ethnicity was determined by first grouping all participants who indicated Hispanic/Latino as their ethnicity, regardless of any other race selection. Then the remaining participants were designated as either non-Hispanic Black/African-American or non-Hispanic White/Caucasian, with each category exclusive of the other.

Dependent Variables. The Revised Memory and Behavior Checklist (RMBC) was used to assess problems of memory and behavior in three domains: memory, depression, and disruption, of which the latter included three aggressive behaviors, verbal aggression, destroying property, and threatening to hurt others (Teri et al., 1992). The full scale has adequate reliability, with Cronbach's alpha coefficient of 0.84 for patient behavior (Roth et al., 2003; Teri, et al., 1992). Aggressive behaviors were described both at the individual item level and with total composite scoring. For each specific aggressive behavior, the frequency of occurrence was rated None, 1-2 times, 3-6 times, Daily or more over the preceding week, as reported by the caregiver. For analysis, aggressive behavior types were measured in two ways. First, the highest two categories were combined, leaving three categories (None, 1-2 times, and 3 or more times). Second, for binary analysis, if a behavior had occurred at least once, it was scored as present. Similarly, total behaviors were measured in two ways. First, if any one of the three behavior types was present at least once, aggressive behavior was scored as present. Secondly, a summative composite score of the presence of behaviors was created, with each behavior type measured as present or absent, giving possible scores of 0, 1, 2, or all 3 aggressive behavior types present.

Covariates. Covariates were initially selected for inclusion in analyses based on a literature review of studies exploring the causes and correlates of aggressive behavior in dementia and the stress process model. The stress process model was helpful to guide selection of factors that may affect the person with dementia's ability to cope with stress, including both intrinsic and extrinsic variables (i.e. relating to the caregiver and caregiving environment). For caregivers, covariates included gender, age, education level, marital status, ability to pay for basics, income level, depression score, and health status. For persons with dementia, covariates included gender, age, education level, marital status, cognitive status, depression score, and health status. In addition, also included were the spousal relationship between caregiver and person with dementia, the total years living together, and the years the caregiver lived with the person with dementia to provide care. All covariates were first examined in univariate analysis for their relationship to the dependent variable. Those covariates for which there was a statistically significant relationship were next examined for collinearity. Covariates removed from subsequent analyses were caregiver education level, marital status, and income level, person with dementia age and marital status, and total years living together. Subsequently, covariates retained in univariate analyses were selected for the final, most parsimonious model only if they contributed significantly to the final model in backward-stepwise logistic regression. Intrinsic variables included as covariates in the final model were the person with dementia's health status, depression index score, as measured by the RMBC depression subscale, and cognitive status, as measured by the Mini-Mental State Examination (MMSE) score. Extrinsic variables included as covariates were the caregiver's ability to pay for basics, as a proxy measure for socioeconomic status, and level of depression, as measured by the Centers for Epidemiological Studies – Depression (CES-D) scale score.

Sociodemographic characteristics. The caregiver's ability to pay for basics served as a proxy measure for economic status and was on a four point Likert-type scale (not difficult at all, not very difficult, somewhat difficult, very difficult). The level of education for both the caregiver and person with dementia were measured from zero, indicating no formal education, to seventeen, indicating doctoral preparation. The health status of both the caregiver and the person with dementia, as reported by the caregiver, were on a Likert-type scale along five points (poor, fair, good, very good, excellent).

Cognitive status. The cognitive status of persons with dementia was assessed using the MMSE. This scale has been demonstrated to have an adequate Cronbach's alpha coefficient at 0.78 when used as screening test for dementia (Tombaugh & McIntyre, 1992). It also has a demonstrated test-retest reliability coefficient of 0.89 when using the same test administrator and 0.83 when using two different test administrators, and has been validated in a wide array of settings (Folstein, Folstein, & Fanjiang, 2001; Folstein, Folstein, & McHugh, 1975).

Depression. The measure of depression in the person with dementia used in this study is comprised of a simple summative index of the responses to the 8 items from the depression sub-scale in the RMBC.

Caregivers were also assessed for depression, with the 10-item CES-D scale. This scale has been demonstrated to have good reliability with Cronbach's alpha coefficients ranging from of 0.85 to 0.90 and strong evidence of construct and concurrent validity (Radloff, 1977).

Physical function. Function was measured in the person with dementia using the Katz Activities of Daily Living scale (Katz, Ford, Moskowitz, Jackson, & Jaffe, 1963) and the Lawton Instrumental Activities of Daily Living (Lawton & Brody, 1969). Both scales were combined into one instrument with a summative index score and with a reported Cronbach's alpha coefficient of 0.84 (Schulz et al., 2002).

Statistical Analyses

Continuous variables were described using mean, and standard deviation, or median and interquartile range, depending on the distribution, while frequency and percentage were used to describe categorical variables. Psychosocial and sociodemographic variables were also descriptively analyzed both within and across groups using a Chi-square test, Fisher's Exact test, Kruskal-Wallis test, or Analysis of Variance (ANOVA), as appropriate.

Differences in aggressive behaviors by race/ethnicity were analyzed using a Chi-square test, post-hoc standardized residuals comparison, binary logistic regression, and multinomial logistic regression. Pairwise comparisons used the Bonferroni correction.

All analyses were conducted using IBM SPSS software (IBM Corp., 2015).

Results

Study Participants

[Insert Table 1 about here]

Study participants included caregivers and persons with dementia, as demonstrated by Table 1. Demographic characteristics of study participants that are continuous variables and are non-normally distributed have both median and mean values reported in table 1. For comparison with existing literature, mean values are reported here.

Caregivers. For the total sample, the mean caregiver age was 62.1 (*SD*=13.22) years, with most caregivers being female (80.3%, *N*=506). Only 27.7% (*N*=174) of caregivers reported very good or excellent health. Over half (52.3%, *N*=329) of caregivers reported that it was somewhat or very difficult to pay for basics and had cared for the person with dementia for a mean of 6.1 (*SD*=9.88) years. Most caregivers (55.1%, *N*=347) were caring for persons with dementia who were not their spouses and most did not screen positive for depression (76.7%, *N*=483), with a mean CESD score of 10.0 (*SD*=6.46) out of a possible 60. Most caregivers had at least some post-secondary education (*M*=12.6, *SD*=3.15).

Caregivers differed significantly by race/ethnicity on most key characteristics. Black/African-American caregivers were more likely to be male ($p=0.032$) and older in years on average ($M=65.0$, $SD=12.61$, $p<0.001$) than either White/Caucasian caregivers ($M=61.3$, $SD=13.88$) or Hispanic/Latino caregivers ($M=60.0$, $SD=12.61$). Black/African-American caregivers had, on average, lower depression scores ($M=9.1$, $SD=6.02$, $p=0.049$) than White/Caucasians ($M=10.5$, $SD=6.18$). Black/African-Americans also had cared for the person with dementia longer in years ($M=9.3$, $SD=14.01$, $p<0.001$) than White/Caucasians ($M=5.0$, $SD=7.89$) or Hispanic/Latinos ($M=4.2$, $SD=4.61$). Hispanic/Latino caregivers reported the lowest level of education ($M=10.9$, $SD=4.12$, $p<0.001$), the greatest difficulty paying for basic needs ($p<0.001$), and the worst physical health for both the person with dementia ($p=0.001$) and caregiver ($p<0.001$).

Persons with dementia. Persons with dementia were 56.5% ($N=356$) female with a mean age of 78.7 ($SD=8.63$) years. They had a lower mean education level than their caregivers ($M=9.7$, $SD=4.51$) and lower health level than their caregivers, with only 15.9% ($N=100$) of persons with dementia having very good or excellent health. The mean MMSE score of the persons with dementia was 12.4 ($SD=7.30$) out of a possible 30, indicating moderate to severe dementia. The mean functional limitation index score was 10.6 ($SD=3.51$) out of a possible 15, with higher scores indicating greater function. The mean depression index score was 4.9 ($SD=4.48$) out of 8, with lower scores indicating fewer depressive symptoms.

White/Caucasian persons with dementia had higher MMSE scores ($M=14.3$, $SD=7.48$, $p<0.001$) than Black/African-Americans ($M=11.4$, $SD=7.09$) or Hispanic/Latinos ($M=11.3$, $SD=6.94$). As with caregivers, Black/African-American persons with dementia had lower depression scores ($M=4.2$, $SD=4.00$) than Hispanic/Latinos ($M=5.7$, $SD=5.08$, $p=0.009$). The proportion of caregivers and persons with dementia with a spousal relationship trended toward a statistically significant difference by race/ethnicity (*p*=0.053). Gender, age, and functional limitation scores were not significantly different by race/ethnicity for persons with dementia.

Prevalence of Overall Behaviors

[Insert Table 2 about here]

Total sample. Over one-third (38.3%, *N*=241) of caregivers in the total sample reported the presence of one or more aggressive behavior type in the preceding week. When the total number of behaviors present was divided into three categories, by number of behavior types present (*one, two, or three behavior types*), 28.1% (*N*=177) of caregivers reported one behavior type, 8.4% (*N*=53) reported two, and 1.7% (*N*=11) reported three in the total sample.

By race/ethnicity. When examined by race/ethnicity, there was a significant difference (*p*=0.050) for caregivers reporting one or more aggressive behaviors in the preceding week, with 44.0% (*N*=91) of Hispanic/Latinos, 38.6% (*N*=80) of Black/African-Americans, and 32.4% (*N*=70) of White/Caucasians reporting. In pairwise comparisons, Hispanic/Latinos were significantly more likely to report one or more behaviors than were White/Caucasians. The proportions of caregivers reporting one, two, or three behaviors in the preceding week differed by race/ethnicity (*p*=0.020). In pairwise comparisons, more Black/African-American (11.6%, *N*=24) caregivers reported two aggressive behavior types than did White/Caucasians (4.6%, *N*=10).

Prevalence of Aggressive Behavior Types

[Insert Table 3 about here]

Total sample. Of the three aggressive behavior types, verbal aggression occurred most frequently in the total sample (34.4%, *N*=217), followed by threatening to hurt others (8.6%, *N*=54), and destroying property (7.1%, *N*=45).

By race/ethnicity. The unadjusted prevalence of the three types of aggressive behavior appeared to vary by race/ethnic group, as demonstrated in Table 3. Based on descriptive statistics, Hispanic/Latino caregivers were most likely to report verbal aggression (40.1%, *N*=83), followed by Black/African-Americans (34.3%, *N*=71) and White/Caucasians (29.2%, *N*=63). More than twice as many Hispanic/Latino (8.2%, *N*=17) and Black/African-American (9.7%, *N*=20) caregivers reported destroying property than did White/Caucasians (3.7%, *N*=8). More Black/African-Americans also reported threatening to hurt others (12.1%, *N*=25), when compared to Hispanic/Latinos (7.7%, *N*=16) or White/Caucasians (6.0%, *N*=13).

Adjusted Analysis by Race/Ethnicity

[Insert Table 4 about here]

While differences appeared to exist between race/ethnic groups in unadjusted analyses, after adjusting for selected covariates (person with dementia: cognitive status, depression, health status; caregiver: economic status, depression) in binary logistic regression analyses, only one significant difference remained between race/ethnic groups. Black/African-Americans were more than twice as likely to report threatening to hurt others in the preceding week as White/Caucasians over the same time period (*AOR*=2.26, *p*=0.035, 95% CI [1.06-4.84]), while Hispanic/Latinos were not when compared to White/Caucasians (*AOR*=1.30, *p*=0.532, 95% CI [0.57-2.95]).

Discussion

The purpose of this study was to describe the prevalence of aggressive behavior types and examine differences by race/ethnicity among persons with dementia in a community-dwelling sample. We found that the overall prevalence rate of three aggressive behavior types (verbal aggression, destroying property, threatening to hurt others) over the preceding 1-week was 38.3%. This represents over a third of caregivers reporting aggressive behavior within a brief time frame of 1-week. It is possible that if a longer time frame is used, prevalence might be higher.

We found that the total number of aggressive behaviors reported by caregivers differed by race/ethnicity with Hispanic/Latino persons with dementia more likely than White/Caucasians or Black/African-Americans to have only one behavior type, while Black/African-Americans were more likely than White/Caucasians or Hispanic/Latinos to have two or more behavior types. Having more than one aggressive behavior type may present as greater complexity in the care environment and that interventions are needed to address multiple types of aggressive behaviors that may occur, especially among Black/African-Americans.

To our knowledge, this is the first study to examine prevalence rates for these specific types of aggressive behaviors among these race/ethnic groups using a large, geographically diverse sample. However, we found a difference by race/ethnicity for only one behavior type, with Black/African-Americans having over twice the odds of threatening to hurt others than did White/Caucasians or Hispanic/Latinos, after controlling for covariates, but no differences by race/ethnicity for the other two behaviors.

In this study, nearly all initial differences in aggressive behaviors by race/ethnicity in univariate analyses were no longer significant after adjusting for covariates including person with dementia depression, health status, and cognitive status as well as caregiver depression and difficulty paying for basics. This suggests that other factors may be more important to consider when examining prevalence of aggressive behaviors in dementia than race/ethnicity. Four of the five covariates included in the adjusted analysis (depression in the caregiver and the person with dementia, the health status of the person with dementia, and paying for basics) may be amenable to intervention and subsequently reduce aggression.

The factors remaining significant in our final model also represent stressors at different levels of the stress and coping framework. Depression, cognitive decline, and health status of the person with dementia all are primary stressors for the caregiver while difficulty paying for basics serves as a proxy for the larger background context of socioeconomic constraints. Difficulty paying, though, is not only part of the social context but also is a secondary role strain, contributing directly to the increased burden of the caregiver. Caregiver depression in the stress process model, however, is an outcome attributable, at least in part, to the stressors that have overwhelmed the coping capacity and social support of the caregiver. This suggests that simultaneously focusing intervention efforts at the sources of stress, such as depression and poor health status of the person with dementia, may be as important as directly intervening with the caregiver.

As depression is under-recognized and under-treated (Barry, Abou, Simen, & Gill, 2012), it is important that both persons in the dyad are targeted for screening and intervention. As the person with dementia's health status is also a significant contributor to the final regression model of aggressive behaviors, a complimentary step for intervention may be designing a more robust, holistic, and thorough primary care experience for older adults to address depression and other comorbidities. Improving the health status of the person with dementia could also be considered as a step toward reducing aggressive behaviors. In addition, depression screening in primary care visits for both the caregiver and the person with dementia may also have a systemic impact by reducing the risk for or occurrence of aggressive behaviors in the person with dementia while also increasing the ability of the caregiver to respond effectively to the needs of the person with dementia. Financial difficulties are also amenable to intervention by providing caregivers financial advice and counseling and access to social services to offset the economic burden of caregiving. The importance of these interventions is also supported by the stress process model as it posits that increasing coping resources mediates the effect of stressors on caregiver outcomes. Interventions targeted at decreased depression of the person with dementia and the caregiver's increased ability to meet basic economic needs may help to reduce both primary and secondary role stressors. The model would suggest that a reduction in caregiver depression may follow, which in turn would increase caregiver coping capacity and tolerance of social interaction. In an iterative cycle, improving caregiver outcomes may feedback to the person with dementia, further attenuating behavioral symptoms as their needs are more fully met.

There are other contextual factors, both in the demonstration of the behavioral symptoms and their interpretation, in this study that were not measured, which may also contribute to these findings. For example, when considering the difference in prevalence of threatening to hurt others by race/ethnicity, it should be noted that there may be regional variations in the expression of aggressive behaviors which we could not detect as we did not stratify our analysis by region of the country, given sample sizes that were too small for such comparisons. In addition, Black/African-American caregivers were more likely in our sample to be male and to be older than White/Caucasians or Hispanic/Latinos. Though these factors were not significant in our analyses, it is possible that they may play some role in how dyadic relationships differ which may in turn impact the expression of aggression by the person with dementia or how it is interpreted and reported by the family caregiver.

Further, although there appears to be some differences in the presentation of aggressive behavior in persons with dementia by race/ethnicity, this study did not examine how caregivers perceive aggressive behaviors. As the RMBPC is based on caregiver appraisals of behavioral occurrences, observed differences may be due to caregiver reactions to these behaviors by race/ethnicity versus objective determinations of behavioral manifestations. Thus, further research in this area is warranted to tease out the respective contributions to behavioral reporting. There is a need for greater precision and clarity in measurement approaches, both to capture specific types of behaviors and the context in which they are manifested in dementia as well as the ways that caregivers perceive, interpret and report behaviors. One possible explanation for our finding that Black/African-American caregivers represented in this sample were more likely to report the behavior of threatening to hurt others is that these caregivers were more highly sensitized to recognize behaviors by the person with dementia that signaled distress or discomfort. If signaling behaviors were unrecognized and unaddressed by the caregiver, it is possible that the behaviors escalate to aggressive-type behaviors. This is a hypothesis that should be explored in future studies that can more carefully examine the context in which caregivers experience the different forms of aggressive behaviors in dementia.

In-depth, qualitative exploration of the experience of caregivers is also needed to understand how caregivers may anticipate, prevent, and respond to aggressive behaviors. As the experience in preventing and managing behaviors remains poorly understood, this research could help advance an understanding of the context in which behaviors occur and the impact on caregiving. Understanding the cultural factors contributing to the manifestation and management of these behaviors may be helpful for designing and tailoring interventions to address the underlying causes of aggressive-type behaviors and reduce their occurrences.

Limitations

As this was a secondary analysis of data, this study was dependent upon the variables included in the original REACH II study. Factors previously identified in the literature that may increase risk for aggressive behaviors, such as pain, symptoms of psychosis, and severe hearing or vision difficulties in the person with dementia (Aarsland, Cummings, Yenner, & Miller, 1996; Hall & O'Connor, 2004; Husebo, Ballard, Sandvik, Nilsen, & Aarsland, 2011; Proitsi et al., 2011), were not included in the original REACH II data set. However, it would be important to include these factors in future research in this area. Further research is needed to determine how or if these and other risk factors influence prevalence rates and whether they differ by caregiver race/ethnicity.

Another potential limitation is that the reporting of behavioral symptoms is dependent upon the family caregiver, which may introduce bias. It is possible that caregiver depression or poor health status, as others have shown (Sink, Covinsky, Barnes, Newcomer, & Yaffe, 2006), may affect how the caregiver perceives and reports aggressive behaviors. Also contributing to this possible bias is that the REACH II sample was a convenience or volunteer sample, rather than a population-based study. Additionally, caregivers had to report some level of distress in caregiving in order to be eligible for the study. Thus, the caregivers in this sample may not be representative of the larger population from which they were drawn. Further studies with large population-based samples representing a broader range of levels of caregiver distress and satisfaction levels are needed to further build on the prevalence results of this study.

There are some indications in the literature that male gender of the person with dementia and a spousal dementia caregiving relationship are risk factors for aggressive behavior in dementia (Hall & O'Connor, 2004; Hamel, et al., 1990; Ott, Tate, Gordon, & Heindel, 1996; Zuidema, de Jonghe, Verhey, & Koopmans, 2009). We initially considered these variables for inclusion as covariates in the multivariate analyses for this study. However, neither gender nor relationship were significantly associated with aggressive behaviors in univariate analyses, and were thus subsequently excluded in the multivariate analyses. Nonetheless, both gender and relationship would be important factors to consider in future research examining differences in the prevalence of aggressive-type behaviors.

Finally, it must be noted that only White/Caucasian, Black/African-American, and Hispanic/Latino race/ethnic groups were represented in the REACH II multi-site initiative. As this was a secondary analysis of data, it was not possible to include other race/ethnicities, including Asian-Americans, who are the fastest growing race/ethnic group in the United States (Brown, 2014), further limiting the generalizability of the findings.

Conclusion

Regardless of race/ethnicity, more than one third of dementia caregivers report aggressive behaviors in the past week. Though Black/African-American persons with dementia had greater odds of threatening to hurt others than White/Caucasians or Hispanic/Latinos, the small sample size makes it difficult to definitively conclude this to be the case. It may be that other factors than race/ethnicity account for this difference as shown by the covariates in this study. Race/ethnicity does not appear to be as important as a risk factor for developing aggressive behaviors overall in dementia as do other modifiable factors such as caregiver or person with dementia depression, caregiver health status, and financial strain.

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Table 2.1: Demographic Characteristics of Caregivers (1A) and Persons with Dementia (1B)

1A. Caregivers	Total Sample (630)	White/ Caucasian (216)	Black/ African-American (207)	Hispanic/ Latino (207)	*p*	Pairwise, by Race/ Ethnicity
Age, years (*M*, *SD*)	62.1 (13.22)	61.3 (13.88)	65.0 (12.66)	60.0 (12.61)	*<0.001 (A)	B>W,H (older)
Gender (%, *N*)					*0.032 (x^2)	B<W,H (fewer female)
Male	19.7 (124)	17.1 (37)	25.6 (53)	16.4 (34)		
Female	80.3 (506)	82.9 (179)	74.4 (154)	83.6 (173)		
Level of Education [a]					*<0.001 (K)	W>B>H (higher level)
(*Mdn*, *IQR*)	14.0 (3.0)	14.0 (3.0)	13.0 (2.0)	12.0 (6.0)		
(*M*, *SD*)	12.6 (3.15)	13.7 (2.06)	13.0 (2.17)	10.8 (4.07)		
Ability to pay for basics (%, *N*)					*<0.001 (x^2)	H>B>W (more difficulty)
Refused	0.5 (3)	0.5 (1)	0.5 (1)	0.5 (1)		
Not difficult at all	26.0 (164)	43.5 (94)	20.8 (43)	13.0 (27)		
Not very difficult	21.3 (134)	19.9 (43)	24.2 (50)	24.2 (50)		
Somewhat difficult	38.3 (241)	28.7 (62)	40.6 (84)	40.6 (84)		
Very difficult	14.0 (88)	7.4 (16)	14.0 (29)	14.0 (29)		
Center for Epidemiological Studies Depression (CES-D) score [e]					*0.049 (K)	B<W (fewer symptoms)
(*Mdn*, *IQR*)	9.0 (9.0)	10.0 (10.0)	8.0 (8.0)	9.0 (10.0)		
(*M*, *SD*)	10.0 (6.46)	10.5 (6.18)	9.1 (6.02)	10.5 (7.09)		
Years caring for person with dementia					*<0.001 (K)	B>W,H (more years)
(*Mdn*, *IQR*)	3.0 (4.0)	3.0 (3.0)	4.0 (6.0)	3.0 (3.0)		
(*M*, *SD*)	6.1 (9.88)	5.0 (7.89)	9.2 (14.06)	4.2 (4.61)		

Spousal relationship to person with dementia (%, *N*)					0.053 (x^2)	
Spouse	44.9 (283)	47.2 (102)	49.3 (102)	38.2 (79)		
Non-Spouse	55.1 (347)	52.8 (114)	50.7 (105)	61.8 (128)		
Physical health (%, *N*)					*<0.001 (*F*)	H<B,W (poorer health)
Poor	9.4 (59)	4.6 (10)	3.4 (7)	20.3 (42)		
Fair	29.2 (184)	21.8 (47)	30.9 (64)	35.3 (73)		
Good	33.8 (213)	34.3 (74)	41.5 (86)	25.6 (53)		
Very Good	20.2 (127)	28.2 (61)	20.3 (42)	11.6 (24)		
Excellent	7.5 (47)	11.1 (24)	3.9 (8)	7.2 (15)		

1B. Persons with dementia	Total Sample (630)	White/ Caucasian (216)	Black/ African-American (207)	Hispanic/ Latino (207)	*p*	Pairwise, by Race/ Ethnicity
Age, years					0.642 (K)	
(*Mdn*, *IQR*)	80.0 (11.0)	79.0 (12.0)	80.0 (12.0)	80.0 (10.0)		
(*M*, *SD*)	78.7 (8.63)	78.2 (9.13)	79.2 (8.54)	78.9 (8.19)		
Gender (%, *N*)					0.230 (x^2)	
Male	43.5 (274)	48.1 (104)	40.6 (84)	41.5 (86)		
Female	56.5 (356)	51.9 (112)	59.4 (123)	58.5 (121)		
Level of Education [a]					*<0.001 (K)	W>B>H (higher level)
(*Mdn*, *IQR*)	11.0 (8.0)	12.0 (4.0)	10.0 (7.0)	6.0 (9.0)		
(*M*, *SD*)	9.7 (4.51)	12.2 (3.08)	9.7 (4.03)	7.0 (4.66)		
Mini-Mental State Exam (MMSE) score [b]					*<0.001 (A)	W>B,H (higher score)
(*M*, *SD*)	12.4 (7.30)	14.3 (7.48)	11.4 (7.09)	11.3 (6.94)		
Depression index score [c]					*0.009 (K)	H>B (more symptoms)

(*Mdn*, *IQR*)	4.0 (5.0)	4.0 (6.0)	3.0 (4.0)	4.0 (6.0)		
(*M*, *SD*)	4.9 (4.48)	5.0 (4.21)	4.2 (4.00)	5.7 (5.08)		
Functional limitation index score [d]					0.672 (K)	
(*Mdn*, *IQR*)	11.5 (6.0)	11.0 (6.0)	12.0 (5.0)	12.0 (6.0)		
(*M*, *SD*)	10.6 (3.51)	10.5 (3.50)	10.6 (3.43)	10.7 (3.61)		
Physical health (%, *N*)					*0.001 (*F*)	W>H (better health)
Poor	20.0 (126)	21.3 (46)	15.0 (31)	23.7 (49)		
Fair	36.5 (230)	30.1 (65)	38.2 (79)	41.5 (86)		
Good	27.6 (174)	27.3 (59)	33.8 (70)	21.7 (45)		
Very Good	11.0 (69)	12.0 (26)	11.1 (23)	9.7 (20)		
Excellent	4.9 (31)	9.3 (20)	1.9 (4)	3.4 (7)		

Notes.

[a] Likert scale 0-17: 0 = No education to 17 = Doctoral education

[b] MMSE reference range: 0-30; higher scores indicate better cognition

[c] Depression index: 8 items, 1 point per item; higher scores indicate more depressive symptoms

[d] Functional limitation index: 7 ADL and 8 IADL items, 1 point per item; higher scores indicate greater limitation

[e] CES-D reference range: 0-60; higher scores indicate more depressive symptoms

*Statistically significant at $p<0.05$

A = ANOVA

K = Kruskal-Wallis test

F = Fisher's exact test

W = White/Caucasian, B = Black/African-American, H = Hispanic/Latino

Table 2.2: Total Aggressive Behavior by Person with Dementia Race/Ethnicity

Within the past week… % (*N*)	Total Sample (630)	White/ Caucasian (216)	Black/ African-American (207)	Hispanic/ Latino (207)	*p* (value, *df*)	Pairwise, by Race/ Ethnicity
Any aggressive behavior present[a]					0.050 (6.00, 2) x^2	
No	61.7 (389)	67.6 (146)	61.4 (127)	56.0 (116)		
Yes	38.3 (241)	32.4 (70)	38.6 (80)	44.0 (91)		H>W (more PwD with behavior present)
Number of behavior types present[a]					*0.020 (14.36) *F*	
1 aggressive behavior	28.1 (177)	26.9 (58)	24.2 (50)	33.3 (69)		
2 aggressive behaviors	8.4 (53)	4.6 (10)	11.6 (24)	9.2 (19)		B>W (more PwD with 2 behaviors present)
3 aggressive behaviors	1.7 (11)	0.9 (2)	2.9 (6)	1.4 (3)		

Notes.

[a] Total aggressive behaviors includes *verbal aggression*, *destroying property*, and *threatening to hurt others* present at least once or more in the preceding week.

*Statistically significant at $p<0.05$

F = Fisher's exact test

W = White/Caucasian, B = Black/African-American, H = Hispanic/Latino

Table 2.3: Frequency of Aggressive Behavior Types by Person with Dementia Race/Ethnicity

Within the past week… % (*N*)	Total Sample (630)	White/ Caucasian (216)	Black/ African-American (207)	Hispanic/ Latino (207)
Verbal Aggression				
Behavior present				
No	65.6 (413)	70.8 (153)	65.7 (136)	59.9 (124)
Yes[a]	34.4 (217)	29.2 (63)	34.3 (71)	40.1 (83)
Behavior frequency				
1-2 times	20.0 (126)	17.1 (37)	20.8 (43)	22.2 (46)
3 or more times	14.4 (91)	12.0 (26)	13.5 (28)	17.9 (37)
Destroying Property				
Behavior present				
No	92.9 (585)	96.3 (208)	90.3 (187)	91.8 (190)
Yes[a]	7.1 (45)	3.7 (8)	9.7 (20)	8.2 (17)
Behavior frequency				
1-2 times	3.8 (24)	1.4 (3)	4.3 (9)	5.8 (12)
3 or more times	3.3 (21)	2.3 (5)	5.3 (11)	2.4 (5)
Threatening to Hurt Others				
Behavior present				
No	91.4 (576)	96.3 (208)	97.6 (202)	96.1 (199)
Yes[a]	8.6 (54)	6.0 (13)	12.1 (25)	7.7 (16)
Behavior frequency				
1-2 times	5.2 (33)	4.6 (10)	7.7 (16)	3.4 (7)
3 or more times	3.3 (21)	1.4 (3)	4.3 (9)	4.3 (9)

Notes.
[a] Dichotomous: Present = 1 or more times

Table 2.4: Adjusted Odds Ratios of Aggressive Behavior by Person with Dementia Race/Ethnicity, Using Binary Logistic Regression

Within the past week…	Black/ African-American+ *AOR*^{a,b} (*p* [95% CI])	Hispanic/ Latino+ *AOR*^{a,b} (*p* [95% CI])	Final Model *p* (x^2, *df*)
Any aggression present	1.32 (0.222 [0.85-2.06])	1.39 (0.154 [0.88-2.18])	*<0.001 (71.29, 12)
Verbal Aggression present	1.37 (0.177 [0.87-2.16])	1.47 (0.105 [0.92-2.33])	*<0.001 (74.82, 12)
Destroying Property present	2.28 (0.073 [0.93-5.61])	1.61 (0.309 [0.64-4.05])	*0.006 (27.92, 12)
Threatening to Hurt Others present	*2.26 (0.035 [1.06-4.84])	1.30 (0.532 [0.57-2.95])	*0.003, (29.94, 12)

Notes.

[a] Adjusted for the following covariates: CG CES-D score, difficulty paying for basics; PwD depression index score, health status, MMSE score
Covariates dropped for collinearity or non-significance: CG gender, age, education level, marital status, income level, and health status; PwD gender, age, education level, and marital status; CG and PwD spousal relationship, total years living together, and years caregiving

[b] Reference group: White/Caucasian (*N*=216) with no behaviors present in preceding week

[+] Black/African-American (*N*=207); Hispanic/Latino (*N*=207)

*Statistically significant at $p<0.05$

Chapter 3: Manuscript 2

FOR SUBMISSION TO THE GERONTOLOGIST

Title

Caregiver Reactions to Aggressive Behaviors in Persons with Dementia in a Diverse, Community-Dwelling Sample

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Abstract

Purpose

We describe caregiver reactions (upset and confidence) to three aggressive behavior types (verbal aggression, destroying property, threatening to hurt others) in persons with dementia and whether differences vary by race/ethnicity (White/Caucasian, Black/African-American, Hispanic/Latino) in a regionally diverse, community-dwelling sample.

Design and Methods

Secondary analysis of baseline data from the Resources for Enhancing Alzheimer's Caregiver Health II (REACH II) initiative, which tested an intervention for caregivers of persons with dementia. Caregiver reactions to three aggressive behavior types were examined.

Results

Of 630 caregivers, 241 (38.3%) (68 White/Caucasian, 80 Black/African-American, 93 Hispanic/Latino) identified one or more aggressive behaviors occurring in past week. Over two-thirds of caregivers expressed upset to overall aggressive behavior and for each aggressive behavior type. However, only 60.4% (*N*=32) of caregivers expressed confidence managing threatening to hurt others, 56.7% (*N*=123) managing verbal aggression and 42.2% (*N*=19) managing destroying property. While upset level did not differ by race/ethnicity, Hispanic/Latinos reported lower confidence managing aggressive behaviors than Black/African-Americans or White/Caucasians (*p*=0.001). Verbal aggression was the only behavior type that differed by race/ethnicity for upset (*p*=0.003) and confidence (*p*=0.006) Most White/Caucasians caregivers expressed upset (83.6%, *N*=51), followed by Hispanic/Latinos (69.4%, *N*=59) and Black/African-Americans (56.3%, *N*=40) for verbal aggression. Hispanic/Latinos (43.5%, *N*=37) had the fewest caregivers that expressed confidence, compared to White/Caucasians (62.3%,

N=38) and Black/African-Americans (67.6%, *N*=48) managing verbal aggression.

Implications

Aggressive behaviors challenge caregivers, with reactions varying by behavior type and race/ethnicity. Findings suggest need to tailor interventions to cultural and contextual factors to effectively support families.

Introduction

Aggressive behaviors are common and among the most discomfiting aspects of dementia, implicated in increased institutionalization, increased neuroleptic medication use, and poorer health outcomes for caregivers and persons with dementia (Bedard et al., 2005; Cohen, Luchins, Eisdorfer, & Paveza, 1990; Gauthier et al., 2010; Hamel et al., 1990; Kochhann et al., 2011; Kunik, Snow, Davila, McNeese, et al., 2010). These behaviors are part of a larger constellation of neuropsychiatric symptoms that may occur with the progression of dementia and that have been shown to be among the greatest contributors to caregiver burden (Miyoshi & Morimura, 2010; Nowrangi, Lyketsos, & Rosenberg, 2015; van der Lee, Bakker, Duivenvoorden, & Droes, 2014).

Patel and Hope (1992) defined aggression as “an overt act, involving the delivery of noxious stimuli to (but not necessarily aimed at) another object, organism or self, which is clearly not accidental” (p. 212), which can include verbal abuse, destroying property, threats to harm others, and even physical assault (Hall & O'Connor, 2004). It has been estimated that the prevalence of aggressive behavior in dementia is between 30% to 50%, with possibly more than 90% of persons with dementia demonstrating these behaviors over the dementia course (Cipriani, Vedovello, Nuti, & Di Fiorino, 2011; Keene et al., 1999; Kunik, Snow, Davila, Steele, et al., 2010; Lyketsos et al., 2002; Zhao et al., 2015). Though conceptual and operational definitions of aggressive behavior have not been consistent and longitudinal studies have been limited, making prevalence estimates difficult, it is clear that aggressive behavior is a substantial source of distress to family caregivers (Fauth et al., 2012; Truzzi, Valente, Engelhardt, & Laks, 2013).

As most people with dementia live in the community, family caregivers are in the forefront of providing hands-on care to persons with dementia. Unfortunately, while the majority of persons with dementia are cared for at home by family members or close friends, most caregivers do not receive specialized training in dementia care and have limited knowledge about how to prevent or manage aggressive behaviors (Prince, Prina, & Guerchet, 2013). While it is clear that caregiver management of aggressive behaviors is important (Gauthier, et al., 2010) and many caregivers are not formally prepared for the caregiving role, the ways that caregivers perceive and address aggressive behaviors are not clear.

Caregivers experience caregiving differently. Outcomes that have been shown to differ include caregiver burden, satisfaction, depression, and physical health. These differences have been associated with socioeconomic factors, behavioral symptoms in dementia, and care recipient characteristics associated with these differences (Covinsky et al., 2003; Smith, Williamson, Miller, & Schulz, 2011). Several studies have also found that there are differences in how people experience caregiving depending on their cultural, ethnic, and/or racial background (Cherry et al., 2013; Dilworth-Anderson, Williams, & Gibson, 2002; Heo & Koeske, 2013; Hilgeman et al., 2009; Kim, Chang, Rose, & Kim, 2012; O'Connor, 2012; Prince, et al., 2013; Sorensen & Pinquart, 2005). For example, studies have consistently shown that Black/African-Americans tend to be less depressed and Hispanic/Latinos more depressed than their White/Caucasian counterparts (Covinsky, et al., 2003; Sorensen & Pinquart, 2005). Both Hispanic/Latinos and Black/African-Americans tend to report higher caregiver satisfaction, more positive caregiving outcomes, and lower caregiver burden than do White/Caucasians (*Evercare study of Hispanic family caregiving in the U.S.: Findings from a national study*, 2008; Roth et al., 2003; Roth, Dilworth-Anderson, Huang, Gross, & Gitlin, 2015; Sorensen & Pinquart, 2005).

Other studies have examined aggressive behavior but few have examined the impact on caregivers by specific types of aggressive behavior, and fewer yet have looked at how the impact may differ by race/ethnicity. To our knowledge no study has examined differences between race/ethnic groups with regard to caregiver reactions to specific types of aggressive behaviors in persons with dementia in a large, diverse, community-dwelling sample. Given that aggressive behaviors can be a trigger for hospitalization and relocation to NH, it is important to understand caregiver reactions and whether they differ by race/ethnicity from which to design appropriate caregiver education and supportive interventions.

We previously showed that over a third of the REACH II sample reported one or more aggressive behaviors and there was only slight variation by race/ethnicity in the type of aggressive behavior reported (Hansen, Hodgson, Budhathoki, & Gitlin, 2015). The purpose of this study is to build on this previous effort and examine how caregivers in this sample reported their reactions to occurrences of aggressive behaviors. Reactions include caregivers' upset with and confidence managing three types of aggressive behaviors: verbal aggression, destroying property, and threatening to hurt others. Three descriptive questions are posed: What is the caregiver-reported level of upset with overall aggressive behavior and each aggressive behavior types? What is the caregiver-reported level of confidence managing overall aggressive behaviors and each aggressive behavior type? Do the levels of upset and confidence for each aggressive behavior type differ by race/ethnicity for this sample?

The Stress Process Model for caregivers provides the theoretical foundation for this study (Haley, Lane Brown, & Levine, 1987; Lazarus & Folkman, 1989; Pearlin, Mullan, Semple, & Skaff, 1990). This model suggests that stressors, such as providing care while managing aggressive behavior in persons with dementia, may be appraised as threats by the caregiver and overwhelm his or her coping mechanisms, eventually leading to poorer caregiver outcomes. Drawing upon this framework, we posit that a relationship may exist between caregiver upset with aggressive behaviors and their confidence managing the behaviors. Further extrapolating from this model, it is possible that the relationship may differ depending on caregiver perception of threat for each aggressive behavior type and how they respond to these behaviors within the context of their background and caregiving situation.

Research Design and Methods

Funded by the National Institute on Aging, the 2001 to 2004 REACH II initiative was designed to test an innovative multi-component intervention for caregivers of community-dwelling persons with dementia and was among the first multi-site caregiver trial to recruit a large geographically and racially/ethnically diverse sample. The REACH II de-identified dataset is publicly available, allowing for exploration and examination of caregiver reactions to aggressive behavior in persons with dementia. The data included in this study was collected during the baseline interviews, which occurred prior to randomization and receipt of the REACH II intervention.

Sample

REACH II consisted of a convenience sample of 642 dyads of persons with dementia and their family caregiver (219 White/Caucasian, 212 Hispanic/Latino, and 212 Black/African-American). They were recruited from five U.S. cities (Birmingham, Alabama; Memphis, Tennessee; Miami, Florida; Palo Alto, California; and Philadelphia, Pennsylvania), with both Hispanic/Latinos and Black/African-Americans oversampled so differences by race/ethnicity could be investigated. In a previous study, 630 of these dyads were examined for the caregiver-reported presence of aggressive behaviors, with twelve dyads not included due to ambiguous race/ethnicity designation in the publicly available dataset (Hansen, et al., 2015). Of these, 241 caregivers (68 White/Caucasian, 93 Hispanic/Latino, and 80 Black/African-American) reported that the person with dementia for whom they provided care demonstrated any aggressive behavior and were thus included in this study.

Caregivers. Caregivers in REACH II were eligible for inclusion if they were a family member older than 21 living with person with dementia and in a caregiving role for more than six months, providing four or more hours of assistance. To be included, caregivers also needed to endorse experiencing at least two signs of caregiver distress, such as feeling angry or frustrated or feeling their health had declined. Additional inclusion criteria addressed logistical concerns, such as telephone accessibility and an intent to remain in the area where recruited.

Caregivers were excluded if they were non-English or non-Spanish speaking, in treatment (chemotherapy, radiation therapy) for cancer, anticipating imminent institutional placement of the person with dementia, or cognitively impaired.

Persons with dementia. Persons with dementia were eligible for inclusion if they had diagnosis of dementia or cognitive impairment (MMSE score $\leq$23). Persons with dementia were excluded if they were non-English or non-Spanish speaking, in treatment for cancer, had severe mental illness, or were bedbound.

Further recruitment procedures and eligibility criteria for REACH II have been described in more detail elsewhere (Belle et al., 2006).

Data Collection

Where possible, both caregivers and persons with dementia provided written consent. However, caregivers did provide consent on behalf of persons with dementia who could not consent on their own. Following consent and enrollment, all REACH II participants across all sites were interviewed face-to-face in English or Spanish by interviewers who had been trained extensively using a standardized protocol. All materials, including response cards, were translated into Spanish from English, using forward-and-back translation (Belle, et al., 2006).

The Inter-University Consortium for Political and Social Research (ICPSR), part of the Institute for Social Research at the University of Michigan, houses the online repository for REACH II data. All ICPSR data undergo a confidentiality review and are altered when necessary to limit the risk of disclosure before being made publicly available. ICPSR provides clean data files in major statistical software formats and codebooks, all of which require no special permissions to access or use.

Measures

Race/ethnicity. All participants who indicated Hispanic/Latino as their ethnicity were designated as an exclusive group regardless of any other race/ethnicity selection. Then the remaining participants were divided into exclusive groups as either non-Hispanic Black/African-American or non-Hispanic White/Caucasian.

Dependent Variable. The Revised Memory and Behavior Checklist (RMBC) was used to assess memory and behavior difficulties and includes three aggressive behavior types (verbal aggression, destroying property, threatening to hurt others) (Roth, et al., 2003; Teri et al., 1992). For this study, we examined caregiver reactions to each aggressive behavior type, which was defined as caregivers' level of upset with and confidence managing each aggressive behavior type. For upset and confidence, responses were recorded on a 5-point Likert-type scale (*not at all*, *a little*, *somewhat*, *very much*, *extremely*). For analyses in this study, the full range was used to describe levels of both the upset and confidence scales, but then reduced to a dichotomous variable to examine differences between groups (upset/confidence *not present* = *not at all*, *a little*; upset/confidence *present* = *somewhat*, *very much*, *extremely*).

Descriptive variables. The stress process model was helpful to guide selection of factors for further description that may affect caregivers' ability to cope with the stress of encountering aggressive behaviors in dementia. These include both intrinsic (e.g. depression) and extrinsic variables (e.g. education level, socioeconomic status) that may affect caregivers' threat appraisal and perceived ability to cope with stress. Variables selected here have also previously been identified in a large body of literature as being implicated in caregiver outcomes (Hughes et al., 2014; van der Lee, et al., 2014).

The four factors included for description were all caregiver specific variables. Caregiver education was measured on an 18-point Likert-type scale, with zero indicating no formal education and 17 indicating doctoral preparation. Economic status was measured using a proxy called caregiver ability to pay for basics, with a 4-point Likert-type scale (not difficult at all, not very difficult, somewhat difficult, very difficult). Caregiver health was also measured on a Likert-type scale, with five points (poor, fair, good, very good, excellent). Caregivers were also assessed for depression, with the 10-item Center for Epidemiologic Studies Depression Scale (CES-D). This scale has good reliability with Cronbach's alpha coefficients ranging from of 0.85 to 0.90 and evidence of good construct and concurrent validity (Radloff, 1977).

Statistical Analyses

Mean and standard deviation or median and interquartile range were used to describe continuous variables. Categorical variables were described using frequency and percentage. Aggressive behaviors and caregiver reactions were described individually by type and as a composite score of overall aggressive behavior. Sociodemographic variables were described and analyzed across groups using a Chi-square test, Fisher's Exact test, Kruskal-Wallis test, Analysis of Variance (ANOVA), or logistic regression, as appropriate. Pairwise comparisons used the

Bonferroni correction. Similar statistical methods were used to evaluate differences in caregiver reactions by race/ethnicity. Bivariate correlations between upset and confidence were examined using Spearman’s rho correlation coefficient.

All statistical analyses were conducted using IBM SPSS software (IBM Corp., 2015).

Results

Study participants included caregivers, as demonstrated by Table 1. Variables that are continuous and non-normally distributed have both median and mean values reported in table 1. For comparison with existing literature, mean values are reported throughout this section.

Study Participants

[Insert Table 1 about here]

Total sample. Caregivers were, on average, 62.9 years old (*SD*=13.50) and largely female (77.2%, *N*=186). The majority had a non-spousal relationship to the person with dementia (54.4%, *N*=131). The mean level of education indicated that caregivers had attended at least some vocational training after high school on average and the largest percentage reported that their ability to pay for basics was somewhat difficult (40.7%, *N*=98). The mean number of years that caregivers had provided care was 5.6 (*SD*=8.57). Most caregivers rated their physical health as good or better (60.1%, *N*=145) and the mean score of the Center for Epidemiological Studies Depression scale was 11.1 out of 60.0 (*SD*=6.5), with higher scores indicating more symptoms of depression.

By race/ethnicity. Analyzed by race/ethnicity, the demographic characteristics of caregivers reflected several differences. Hispanic/Latinos (16.1%, *N*=15) were more likely to be female than Black/African-American caregivers (*p*=0.016; 33.8%, *N*=27). Black/African-Americans provided care for more years (*p*=0.013; *M*=7.7, *SD*=11.7) than White/Caucasians

(*M*=4.4, *SD*=6.6) in pairwise associations. White/Caucasians had a higher mean level of education (some college or Associate's degree) than Hispanic/Latinos (high school) (*p*=0.002). Hispanic/Latino caregivers had significantly worse physical health than Black/African-American caregivers and White/Caucasian counterparts (*p*=<0.001). Hispanic/Latinos and Black/African-Americans also had significantly more difficulty paying for basics than did White/Caucasians (*p*=0.021).

Prevalence of Aggressive Behaviors

[Insert Table 2 about here]

Total sample. As detailed in Hansen, et al. (2015), 38.3% (*N*=241) of the larger sample of 630 persons with dementia in REACH II demonstrated at least one aggressive behavior in the preceding week. The most prevalent behavior type in the total sample was verbal aggression (34.4%, *N*=217), followed by threatening to hurt others (8.6%, *N*=54) and destroying property (7.1%, *N*=45).

By race/ethnicity. Based on descriptive statistics, the unadjusted analysis demonstrated that Hispanic/Latinos had the highest percentage of caregivers reporting verbal aggression (44.0%, *N*=91), followed by Black/African-Americans (38.6%, *N*=80) and White/Caucasians (32.4%, *N*=70). For destroying property behavior, Black/African-Americans led with 9.7% (*N*=20), Hispanic/Latinos came next with 8.2% (*N*=17), and White/Caucasians were lowest with 3.7% (*N*=8). The same order of prevalence was found for threatening to hurt others, with Black/African-Americans having 12.1% (*N*=25), Hispanic/Latinos 7.7% (*N*=16), and White/Caucasians 6.0% (*N*=13). After adjusting for covariates, only verbal aggression was significantly different by race/ethnicity, with Black/African-American caregivers having an adjusted odds ratio of 2.26 (*p*=0.035, 95% CI [1.06-4.84]) greater likelihood than

White/Caucasian caregivers of reporting this behavior type in a one-week time period (Hansen, et al., 2015).

Caregiver Reactions to Aggressive Behaviors

[Insert Table 3 about here]

[Insert Table 4 about here]

[Insert Table 5 about here]

Total sample. When described using the full 5-point Likert-type scale, caregivers had a mean level of upset for all behaviors of 2.3, in a range of zero to four (*SD*=1.26). Caregivers' level of confidence was lower than their level of upset for all types, with a mean level of confidence managing aggressive behavior of 1.8, also in a range of zero to four (*SD*=1.24).

Described dichotomously, over two-thirds of caregivers were upset with all aggressive behaviors combined and with each aggressive behavior type, with the largest percentage upset with destroying property (73.3%, *N*=33), followed by threatening to hurt others (72.2%, *N*=39) and by verbal aggression (69.1%, *N*=150). Described dichotomously, a little over half of caregivers were confident managing all aggressive behaviors combined, with 60.4% (*N*=32) confident managing threatening to hurt others, 56.7% (*N*=123) confident managing verbal aggression, and 42.2% (*N*=19) confident managing destroying property.

By race/ethnicity. Upset levels to overall aggressive behaviors did not differ significantly, with Black/African-Americans having a mean level of upset of 2.0 (*SD*=1.27), White/Caucasians having 2.47 (*SD*=1.13), and Hispanic/Latinos having 2.27 (*SD*=1.33). Confidence levels did differ statistically significantly by race/ethnicity (*p*=0.001) across all behaviors, with Hispanic/Latinos reporting lower levels (*M*=1.46, *SD*=1.29) than either Black/African-Americans (*M*=2.12, *SD*=1.19) or White/Caucasians (*M*=1.71, *SD*=1.24).

For aggressive behavior types, caregiver upset with verbal aggression was the only behavior which differed significantly by race/ethnicity (p=0.003). White/Caucasians had the highest percentage of caregivers upset with verbal aggression (83.6%, N=51), followed by Hispanic/Latinos 69.4% (N=59), and with Black/African-Americans having the lowest percentage of caregivers upset, although even for this group, more than half expressed some level of upset (56.3%, N=40). Caregiver confidence managing verbal aggression also differed statistically significantly by race/ethnicity (p=0.006), with a lower percentage of Hispanic/Latino caregivers expressing confidence (43.5%, N=37), than White/Caucasians 62.3% (N=38), and Black/African-Americans 67.6% (N=48).

Associations between Caregiver Upset and Confidence

[Insert Table 6 about here]

[Insert Table 7 about here]

Total sample. Overall, a statistically significant negative correlation with a weak to medium strength of association was found between upset and confidence for all combined aggressive behavior types (r_s=-0.345, p=<0.001), for verbal aggression (r_s =-0.396, p=<0.001), and for threatening to hurt others (r_s =-0.316, p=0.021). No statistically significant correlation was found between upset and confidence for destroying property.

By race/ethnicity. A statistically significant negative correlation with a weak to medium strength of association between upset and confidence was found for overall aggressive behavior, in both White/Caucasians (r_s=-0.397, p=0.001) and Black/African-Americans (r_s=-0.461, p=<0.001). By aggressive behavior type, all three race/ethnic groups had statistically negative correlations between upset and confidence for verbal aggression (White/Caucasians: r_s =-0.389, p=0.002; Black/African-Americans: r_s =-0.551, p=<0.001; Hispanic/Latinos: r_s =-0.246, *p*=0.023). Only threatening to hurt others in White/Caucasians had a strong association between upset and confidence (r_s =-0.731, *p*=0.007). No statistically significant correlations between upset and confidence were found for destroying property in any of the race/ethnic groups.

Discussion

This study is the first to our knowledge to examine the reactions of a large, ethnically and geographically diverse sample of caregivers to specific types of aggressive behaviors in community-dwelling persons with dementia. We previously found that over two-thirds of persons with dementia experienced one or more aggressive behaviors in this sample (Hansen, et al., 2015); however, little is known about how caregivers react to specific types of aggressive behaviors, and whether those reactions differ by race/ethnicity. This is important as it can help inform the development of culturally sensitive and tailored interventions to support family caregivers of persons with dementia who encounter these common, highly distressing behaviors.

Caregivers in this sample were primarily female, with a non-spousal relationship to the person with dementia; however, Black/African-Americans were more likely to be male and to have cared for the person with dementia longer. While caregivers overall reported good or better physical health, Hispanic/Latinos were more likely to be in poorer physical health than White/Caucasians or Black/African-Americans. Though most caregivers reported finding it somewhat difficult to pay for basics, both Black/African-American and Hispanic/Latinos found it more difficult that White/Caucasians. White/Caucasians also reported a higher average level of education than the other two groups. These differences support findings in other studies of the disparity between race/ethnicities in terms of socioeconomic and caregiving resources (Lines & Wiener, 2014).

Overall, more caregivers in this sample were upset than were confident with all aggressive behaviors. Though not rising to statistical significance, fewer Black/African-Americans reported upset to all aggressive behaviors, than either White/Caucasians or Hispanic/Latinos. Statistically significantly fewer Black/African-Americans also reported upset with verbal aggression than Hispanic/Latinos and White/Caucasians. White/Caucasians had the most caregivers of the race/ethnic groups who reported upset with verbal aggression. Hispanic/Latinos had the lowest percentage of caregivers who reported being confident managing all behaviors combined as well as verbal aggression alone, compared to Black/African-Americans and White/Caucasians. Statistically significant findings were not present for two aggressive behavior types, destroying property and threatening to hurt others, which may be in part due to the small number of occurrences of these events in this sample.

All statistically significant correlations between upset and confidence were negative, though the presence of correlation and strength of association differed by race/ethnicity, gender, and spousal relationship. This suggests that the relationship between upset and confidence may be bound within the context of race, ethnicity, dyadic relationship, and/or culture. However, all of the significant correlations were only weak to medium in strength of association, except for the reactions of White/Caucasians to threatening to hurt others behavior. Within the framework of the stress and coping framework, these negative associations may suggest that as caregivers appraise the potential threat of aggressive behavior, they may be at increased risk of upset if their evaluation of their ability to manage the behavior is low. In other words, having little confidence may predispose caregivers to feeling easily overwhelmed and to experience this as upset with the behavior. Especially for White/Caucasians reporting threatening to hurt others behavior, interventions to increase their sense of confidence in managing the behavior may increase their coping and decrease their upset.

In this sample, Hispanic/Latino caregivers had the lowest level of confidence and also the lowest levels of education and the poorest health, echoing previous reports by the National Hispanic Caregiver study and other studies (*Evercare study of Hispanic family caregiving in the U.S.: Findings from a national study*, 2008; Karlin, Weil, & Gould, 2012; Llanque & Enriquez, 2012). In the context of the stress and coping framework, this suggests that having limited resources, such as lower education and less access to health care, may contribute to Hispanic/Latinos appraising threats in their environment as more stressful and overwhelming than groups who have easier access to these resources. For example, caregivers who perceive behaviors as threatening may be more easily overwhelmed because of the cumulative effect of the primary stressors, including dementia-related behaviors, and secondary role strain, including economic constraints, which are greater than their capacity to cope with them. As the coping capacity is overwhelmed, the perceived ability to manage aggressive behavior may be decreased and confidence may lag. If this hypothesis is true, it suggests that intervening by addressing education, health care, and economic disparities may affect the confidence with which these caregivers can approach persons with dementia who have aggressive behavior.

Hispanic/Latinos also bring strengths to the caregiving experience (Hodge & Sun, 2012; Napoles, Chadiha, Eversley, & Moreno-John, 2010) that may influence their perception of behaviors. Hispanic/Latinos did not have the highest level of upset to all behaviors, which is again consistent with literature suggesting that these caregivers have lower caregiver burden and greater satisfaction in the caregiving experience than White/Caucasians, despite being more likely to live with and spend more time caring for the person with dementia (Coon et al., 2004; *Evercare study of Hispanic family caregiving in the U.S.: Findings from a national study*, 2008). Intervention development to potentially increase their confidence managing aggressive behaviors may benefit by focusing and capitalizing on those strengths. For example, building on their lower perceived burden and greater satisfaction overall, Hispanic/Latinos may benefit from targeted interventions to increase confidence in this specific aspect of providing care for persons with dementia. As their confidence increases, the threat posed by aggressive behavior may decrease and they may experience even greater satisfaction in caregiving.

The differences in caregiver reactions raise a number of questions for future study. More research is needed to understand the context and factors associated with the differential reactions to specific types of aggressive behaviors, such as Black/African-Americans' lower upset and Hispanic/Latinos' lower confidence. It may be that perspectives shaped by cultural influences and social networks lead some aggressive behavior types to be more challenging to caregivers than others. Understanding which specific factors contribute to these differences may allow for intervention development to enhance caregiver skill and confidence in managing these behaviors.

One example of these differences is our finding that fewer Black/African-Americans reported upset with verbal aggression and more reported confidence managing it, when compared to White/Caucasians and Hispanic/Latinos. This is consistent with the findings of Roth, et al. (2003) that Black/African-Americans were less upset than White/Caucasians by dementia-related behaviors overall, though that study also found that Hispanic/Latinos were similarly less upset. Further exploration of how Black/African-American caregivers frame verbal aggression may be helpful in advancing intervention development in this area. Cultures, or even families, differ in how patterns of communication are expressed and perceived (Hecht, Jackson, & Ribeau, 2002). In some cultures, verbal expressions of frustration and anger are considered both normal and healthy, while in other cultures these same communication styles could potentially be perceived as aggressive and frightening. It is conceivable that these differences in perception could heavily influence how caregivers perceive verbal expressions of anger, frustration, or distress in dementia as well.

Little is known about strategies that caregivers use to cope and adapt to these specific behaviors and whether strategies may differ among race/ethnic groups. Intervention development may also benefit by examining strategies that are commonly and successfully used in one culture for potential modification or adaptation for use in other cultural contexts. Strategies that may seem obvious or commonplace in one culture may be surprising and novel in another culture. Research to potentially adapt successful strategies in one culture for use by another cultural group may be well-served by more closely examining how caregivers of differing race/ethnicities approach the prevention and management of aggressive behaviors in persons with dementia.

Stress and coping models (Folkman, Lazarus, Dunkel-Schetter, DeLongis, & Gruen, 1986; Haley, et al., 1987; Pearlin, et al., 1990) may also be helpful when considering possible hypotheses regarding the relationship between caregiver upset and confidence. Caregivers who have lower confidence managing aggressive behaviors may perceive the behaviors as a greater threat, leading eventually to a higher level of upset. On the other hand, caregivers who have higher upset with aggressive behaviors may in turn assess their own ability to manage the behaviors as inadequate and thus report lower confidence. In either case, behavioral interventions may be especially helpful in reframing the aggressive behavior for the caregiver and decreasing upset and/or increasing confidence.

Limitations

As this was a secondary data analysis, this study was necessarily limited by the questions included in the original multi-site trial. Consequently, future research needs to examine other factors concerning the context in which specific aggressive behaviors occurred and caregivers manage those behaviors. Further research is needed to provide insight into how caregivers respond to and cope with these specific behaviors in order to advance intervention development that incorporates these strategies on a broader, more replicable scale.

Another limitation of this secondary analysis is that White/Caucasian, Black/African-American, and Hispanic/Latino race/ethnic groups were represented in this study, but not other race/ethnicities. For example, Asian-Americans are the fastest growing race/ethnic group in the United States (Brown, 2014) and their exclusion potentially limits the generalizability of the findings. Future studies should include a more representative population-based sample of race/ethnic groups to allow for further examination of how dementia caregiving may be similar or different across cultural contexts.

It also must be noted that this study relied on caregiver report for all measures used. It is unknown if there may be recall or response bias, in part due to a perceived social stigma that may accompany these specific types of behaviors. Cultural influences may affect both how the behaviors are perceived and how they are reported, with race/ethnic minorities at particular risk for misinterpretation of caregiver reported information (Fox, Hinton, & Levkoff, 1999). Further research into how caregivers view these behaviors and how they impact social relationships may help to provide further elucidation. Additionally, measuring caregiver reactions to specific dementia-related behaviors continues to be a challenge. Much of the context related to caregiver reactions to these behaviors was not captured by the measurements used in this study. Future research is needed to develop instruments that are more robust and that can capture the subtleties in caregiver response to the range of aggressive behaviors in persons with dementia.

Caregivers' higher upset than confidence to combined aggressive behavior leads to further questions. The nature of the relationship between caregivers' upset with and confidence managing the combined aggressive behaviors cannot be determined in this cross-sectional sample. This study did not examine the factors associated with confidence or upset which would be an important direction for future research. It may be that caregivers with lower confidence have fewer resources, social support, or poor relationship quality.

In addition to behavioral symptoms in dementia, female gender and a spousal dementia caregiving relationship have been found to be associated with greater burden and lower satisfaction with caregiving (Chiao, Wu, & Hsiao, 2015; Kim, et al., 2012; Poysti et al., 2012). Similarly, it is possible that gender and relationship shape caregiver reactions to aggressive behaviors. Future research should consider the contribution of these factors to appraisals of specific to aggressive behaviors.

Finally, we must acknowledge the importance of the context in which aggressive behavior occurs. While the variables in this study did not include many contextual factors related to aggressive behavior, it is helpful to contemplate their influence as part of this discussion. Behavior that is lower risk to the caregiver, like shaking a fist, and behavior that is higher risk, like swinging a cane at the caregiver's head, would both be classified in this study as threatening to harm another. However, the context of that behavior, including its duration, accompaniment by other actions, severity, and so on, form an important aspect of understanding how the caregiver reacts to the behavior. Previous trauma experienced by either the caregiver or the person with dementia may also have a profound effect on how these events are perceived; this is particularly true if the trauma consisted of abusive behaviors that were part of the dyadic relationship at some point in the past. Differences in size, weight, age, strength, and gender can also all conceivably have a substantial impact on the caregiver's reaction, including levels of upset and confidence. These are important areas for further exploration in other studies that may help to guide the development and tailoring of supportive interventions in the future.

Conclusion

Aggressive behavior in persons with dementia poses a substantial challenge to caregivers. Caregiver reactions vary depending on the specific type of behavior and these differences extend to differential levels of upset with and confidence managing these behavior types among the three race/ethnic groups in this sample. Total aggressive behavior was upsetting to over two-thirds of the sample suggesting that caregivers may benefit from learning strategies for addressing these behaviors. It is unclear why Black/African-Americans had the least caregivers upset with these types of behavior and Hispanic/Latinos had the lowest number reporting confidence managing all behavior types. These differences should be further explored for the cultural and contextual factors that influence both upset and confidence in these race/ethnic groups. Identifying modifiable factors that contribute to upset and confidence would provide further opportunities to design interventions to enhance caregiver ability and skill in managing these behaviors.

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Table 3.1: Demographic Characteristics of Caregivers

	Total Sample (241)	White/ Caucasian (68)	Black/ African-American (80)	Hispanic/ Latino (93)	*p*	Pairwise, by Race/ Ethnicity
Age (*M*, *SD*)	62.9 (13.50)	62.8 (14.92)	65.2 (13.05)	61.1 (12.56)	0.217 (A)	
Gender (%, *N*)					*0.016 (x^2)	H>B (more female)
Male	22.8 (55)	19.1 (13)	33.8 (27)	16.1 (15)		
Female	77.2 (186)	80.9 (55)	66.3 (53)	83.9 (78)		
Level of Education[a]					*0.002 (K)	*W>H (higher level of education)
(*Mdn*, *IQR*)	13.0 (2.0)	14.0 (3.0)	13.0 (2.0)	12.0 (4.0)		
(*M*, *SD*)	12.7 (2.67)	13.6 (1.77)	13.0 (1.95)	11.7 (3.40)		
Ability to pay for basics (%, *N*)					*0.021 (x^2)	H,B>W (more difficulty paying)
Not difficult at all	21.2 (51)	33.8 (23)	15.0 (12)	17.2 (16)		
Not very difficult	24.1 (58)	23.5 (16)	30.0 (24)	19.4 (18)		
Somewhat difficult	40.7 (98)	36.8 (25)	40.0 (32)	44.1 (41)		
Very difficult	14.1 (34)	5.9 (4)	15.0 (12)	19.4 (18)		
Center for Epidemiological Studies Depression (CES-D) score[b]					0.197 (K)	
(*Mdn*, *IQR*)	10.0 (9.0)	10.0 (7.0)	8.5 (8.0)	11.0 (12.0)		
(*M*, *SD*)	11.1 (6.54)	11.1 (6.09)	9.8 (5.80)	12.1 (7.33)		
Years caring for person with dementia					*0.013 (K)	B>W (more years caring)
(*Mdn*, *IQR*)	3.0 (4.0)	2.4 (3.4)	4.0 (5.8)	3.0 (3.0)		
(*M*, *SD*)	5.6 (8.57)	4.4 (6.53)	7.7 (11.72)	4.6 (6.06)		
Spousal relationship to person with dementia (%, *N*)					0.497 (x^2)	

Spouse	45.6 (110)	48.5 (33)	48.8 (39)	40.9 (38)		
Non-Spouse	54.4 (131)	51.5 (35)	51.2 (41)	59.1 (55)		
Physical health (%, *N*)					*<0.001 (*F*)	H<B,W (poorer health)
Poor	10.0 (24)	4.4 (3)	3.8 (3)	19.4 (18)		
Fair	29.9 (72)	17.6 (12)	30.0 (24)	38.7 (36)		
Good	34.0 (82)	41.2 (28)	43.8 (35)	20.4 (19)		
Very Good	19.5 (47)	26.5 (18)	17.5 (14)	16.1 (15)		
Excellent	6.6 (16)	10.3 (7)	5.0 (4)	5.4 (5)		

Notes.

[a] Likert scale 0-17: 0 = No education to 17 = Doctoral education

[b] CES-D reference range: 0-60; higher scores indicate more depressive symptoms

*Statistically significant at $p<0.05$

A = ANOVA

K = Kruskal-Wallis test

F = Fisher's exact test

W = White/Caucasian, B = Black/African-American, H = Hispanic/Latino

Table 3.2: Prevalence of Aggressive Behavior by Person with Dementia Race/Ethnicity

Present within the past week… % (*N*)	Total Sample (630)	White/ Caucasian (216)	Black/ African-American (207)	Hispanic/ Latino (207)
Any aggressive behavior(s)				
No	61.7 (389)	67.6 (146)	61.4 (127)	56.0 (116)
Yes	38.3 (241)	32.4 (70)	38.6 (80)	44.0 (91)
Verbal Aggression				
No	65.6 (413)	70.8 (153)	65.7 (136)	59.9 (124)
Yes	34.4 (217)	29.2 (63)	34.3 (71)	40.1 (83)
Destroying Property				
No	92.9 (585)	96.3 (208)	90.3 (187)	91.8 (190)
Yes	7.1 (45)	3.7 (8)	9.7 (20)	8.2 (17)
Threatening to Hurt Others				
No	91.4 (576)	96.3 (208)	97.6 (202)	96.1 (199)
Yes	8.6 (54)	6.0 (13)	12.1 (25)	7.7 (16)

Table 3.3: Caregiver Confidence and Upset for All Aggressive Behavior by Caregiver Race/Ethnicity

Within the past week…	Total Sample (241^a)	White/ Caucasian (68^a)	Black/ African-American (80^a)	Hispanic/ Latino (93^a)	*p* (value, *df*)	Pairwise, by Race/ Ethnicity
Upset					0.114 (4.35, 2) K	
Mdn (*IQR*)[b]	2.5 (2.0)	3.0 (1.0)	2.0 (2.0)	3.0 (2.0)		
M (*SD*)[b]	2.2 (1.26)	2.5 (1.11)	2.0 (1.27)	2.3 (1.34)		
Confidence					*0.001 (13.46, 2) K	B>H (more confidence)
Mdn (*IQR*)[b]	2.0 (2.0)	2.0 (2.0)	2.0 (2.0)	1.0 (2.0)		
M (*SD*)[b]	1.7 (1.24)	1.7 (1.14)	2.1 (1.21)	1.5 (1.29)		

Notes.

[a] *N* = Number of persons with dementia demonstrating any aggressive behavior(s)

[b] Range: 0 (Not at all upset/confident) – 4 (Extremely upset/confident)

*Statistically significant at $p<0.05$

K = Kruskal-Wallis test

W = White/Caucasian, B = Black/African-American, H = Hispanic/Latino

Table 3.4: Presence of Caregiver Upset with Aggressive Behavior Types by Caregiver Race/Ethnicity

Within the past week… % (*N*)	Total Sample	White/ Caucasian	Black/ African-American	Hispanic/ Latino	*p* (value, *df*)	Pairwise, by Race/ Ethnicity
Verbal Aggression	217[a]	61[a]	71[a]	85[a]	*0.003 (11.44, 2) x^2	No significant pairs
Upset present						
No[b]	30.9 (67)	16.4 (10)	43.7 (31)	30.6 (26)		
Yes[c]	69.1 (150)	83.6 (51)	56.3 (40)	69.4 (59)		
Destroying Property	45[a]	8[a]	20[a]	17[a]	0.297 (2.77) *F*	
Upset present						
No[b]	26.7 (12)	12.5 (1)	20.0 (4)	41.2 (7)		
Yes[c]	73.3 (33)	87.5 (7)	80.0 (16)	58.8 (10)		
Threatening to Hurt Others	54[a]	12[a]	25[a]	17[a]	>0.999 (0.15) *F*	
Upset present						
No[b]	27.8 (15)	25.0 (3)	28.0 (7)	29.4 (5)		
Yes[c]	72.2 (39)	75.0 (9)	72.0 (18)	70.6 (12)		

Notes.

[a] *N* = Number of persons with dementia demonstrating behavior

[b] Sum of *confidence level* categories "None at All" and "A Little."

[c] Sum of *confidence level* categories "Moderately," "Very Much," and "Extremely."

*Statistically significant at $p<0.05$

F = Fisher's exact test

W = White/Caucasian, B = Black/African-American, H = Hispanic/Latino

Table 3.5: Presence of Caregiver Confidence Managing Aggressive Behavior Types by Caregiver Race/Ethnicity

Within the past week… % (*N*)	Total Sample	White/ Caucasian	Black/ African-American	Hispanic/ Latino	*p* (value, *df*)	Pairwise, by Race/ Ethnicity
Verbal Aggression	217[a]	61[a]	71[a]	85[a]	*0.006 (10.22, 2) x^2	B>H (more confidence)
Confidence present						
No[b]	43.3 (94)	37.7 (23)	32.4 (23)	56.5 (48)		
Yes[c]	56.7 (123)	62.3 (38)	67.6 (48)	43.5 (37)		
Destroying Property	45[a]	8[a]	20[a]	17[a]	0.317 (2.51) *F*	
Confidence present						
No[a]	57.8 (26)	62.5 (5)	45.0 (9)	70.6 (12)		
Yes[b]	42.2 (19)	37.5 (3)	55.0 (11)	29.4 (5)		
Threatening to Hurt Others	54[a,d]	12[a]	25[a]	16[a,d]	0.078 (4.95) *F*	
Confidence present						
No[a]	38.9 (21)	50.0 (6)	24.0 (6)	56.3 (9)		
Yes[b]	59.3 (32)	50.0 (6)	76.0 (19)	43.8 (7)		

Notes.

[a] *N* = Number of persons with dementia demonstrating behavior

[b] Sum of *confidence level* categories “None at All” and “A Little.”

[c] Sum of *confidence level* categories “Moderately,” “Very Much,” and “Extremely.”

[d] One participant declined response to confidence level in managing Hurt Others behavior

*Statistically significant at $p<0.05$

F = Fisher’s exact test

W = White/Caucasian, B = Black/African-American, H = Hispanic/Latino

Table 3.6: Association between Caregiver Upset and Confidence by Caregiver Race/Ethnicity

Spearman's rho (p)	Total Sample	White/ Caucasian	Black/ African-American	Hispanic/ Latino
Overall Aggression	*-0.345 (<0.001)	*-0.397 (0.001)	*-0.461 (<0.001)	-0.201 (0.053)
Verbal Aggression	*-0.396 (<0.001)	*-0.389 (0.002)	*-0.551 (<0.001)	*-0.246 (0.023)
Destroying Property	-0.261 (0.084)	-0.503 (0.203)	-0.273 (0.244)	-0.370 (0.144)
Threatening to Hurt Others	*-0.316 (0.021)	*-0.731 (0.007)	-0.281 (0.174)	-0.018 (0.946)

Notes.

*Statistically significant at $p<0.05$

Chapter 4: Manuscript 3

FOR SUBMISSION TO THE GERONTOLOGIST

Title

African-American Caregivers' Perspectives on Aggressive Behaviors in Dementia

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Abstract

Purpose

Though African-American dementia caregivers report less upset and more confidence managing aggressive behaviors when compared to whites, their contextual experience remains unclear. Thus, this study explores African-American caregivers' perspectives on aggressive behaviors in dementia.

Methods

Transcripts of semi-structured interviews with thirteen African-American family caregivers were analyzed using content analysis with descriptive, process, holistic, and pattern coding approaches in multiple coding cycles.

Results

Two overarching themes emerged, *Care Challenges* and *Success Strategies*. *Care Challenges,* reflecting specific concerns and affective caregiver experience, included four sub-themes. Managing aggressive behaviors felt like *Taking care of a stranger* and involved *Hurtful interactions*. This required participants to focus on *Overcoming the past* of premorbid dyadic conflict, while simultaneously contending with *Social and financial strain*. *Success Strategies*, reflecting cognitive and behavioral strategies to prevent and manage aggressive behavior, also included four sub-themes. Participants remembered "*It's the disease….not the person"* to reframe aggressive behavior and prioritized caregiving over other commitments by reminding themselves *"I got to do what I gotta do."* Preventing aggressive behaviors was most successful when *"We didn't argue….we didn't insist"* and caregivers remembered *"Don't put her in a position to fail"* when

involving the person with dementia in activities.

Implications

African-American caregivers described substantial challenges when confronted by aggressive behaviors. Strategies employed by caregivers enabled them to maintain a caring perspective and the person with dementia to maintain calm. Interventions that help caregivers manage aggressive behaviors may benefit by considering the challenges, cultural values, and effective strategies used by African-Americans.

Introduction

Aggressive behaviors in dementia, defined by Patel and Hope (1992a) as "…an overt act, involving the delivery of noxious stimuli to (but not necessarily aimed at) another object, organism or self, which is clearly not accidental (p. 212)," are among the most challenging of all the neuropsychiatric behaviors (Fauth & Gibbons, 2014; Gauthier et al., 2010; K. A. Hall & O'Connor, 2004; Miyoshi & Morimura, 2010) These behaviors have been found to increase rates of hospitalization, institutionalization, psychotropic medication use, and increase rates of physical injury in both caregivers and persons with dementia (Hamel et al., 1990; Kunik, Snow, Davila, McNeese, et al., 2010). These consequences are costly, both in terms of the human toll and in economic value (Beeri, Werner, Davidson, & Noy, 2002; Hurd, Martorell, Delavande, Mullen, & Langa, 2013).

The prevalence of aggressive behavior in dementia has been difficult to estimate as definitions of aggressive behavior have varied, approaches to measurement have differed, and longitudinal studies have been limited (Keene et al., 1999). Current estimates suggest somewhere between 30% to 50% of all people experiencing dementia have some type of aggressive behavior and possibly more than 90% of those with dementia may demonstrate these behaviors over the dementia course (Cipriani, Vedovello, Nuti, & Di Fiorino, 2011; Keene, et al., 1999; Kunik, Snow, Davila, Steele, et al., 2010; Lyketsos et al., 2002; Zhao et al., 2015). As most people with dementia live at home and are cared for by their family (Alzheimer's Association, 2012; Gitlin & Schulz, 2012), caregivers are likely to encounter these behaviors at some point in their experience. Unfortunately, caregivers infrequently receive any type of formal disease-related preparation, and thus have little exposure to skills training in preventing or managing aggressive behaviors (Prince, Prina, & Guerchet, 2013).

Previous research has indicated that caregivers from different race/ethnic backgrounds experience the caregiving role differently (Alzheimer's Association, 2015; Janevic & Connell, 2001; Vickrey et al., 2007). One of the consistent differences that have been identified is that African-American caregivers have been shown to report higher levels of satisfaction and lower levels of burden in caregiving when compared to whites (Bekhet, 2015; Haley et al., 1996; Miller, Campbell, Farran, Kaufman, & Davis, 1995; Roth, Dilworth-Anderson, Huang, Gross, & Gitlin, 2015; Skarupski, McCann, Bienias, & Evans, 2009; Toth-Cohen, 2004). Supporting these findings, a recent study found that African-Americans reported the lowest level of upset to verbal aggression and were more confident managing aggressive behaviors overall when compared to whites and Hispanic/Latinos (Hansen, Hodgson, Budhathoki, & Gitlin, 2015). The context in which these caregivers experience aggressive behaviors by persons with dementia, however, remains largely unexplored and it is unknown why African-American caregivers have reported lower upset and greater confidence when confronted with aggressive behaviors than other race/ethnicities. This is an important area to explore as understanding caregivers' perspectives on aggressive behaviors may offer direction for future intervention development. Therefore, the purpose of this study was to explore how African-American caregivers describe their own experiences with aggressive behaviors in persons with dementia, including their reactions and management strategies.

Underpinning this study is the conceptual framework, the Stress Process Model (Haley, Lane Brown, & Levine, 1987; Lazarus & Folkman, 1989; Pearlin, et al., 1990). This model suggests primary stressors, such as caregiving for a person with dementia who is exhibiting aggressive behavior, and secondary stressors, such as integrating role-relationship changes into the caregiver's sense of self, may overwhelm the caregiver, eventually leading to negative health outcomes. However, this model would also suggest that strong coping mechanisms may provide a type of buffer, decreasing the stress. For example, though a caregiver may experience some upset when encountering aggressive behavior, the coping strategies used may increase confidence and decrease the level of threat that the caregiver experiences.

Research Design and Methods

Sample and Recruitment

Participants were recruited from a large metropolitan area in the Eastern United States. Potential participants were purposively identified from a database securely maintained by the Johns Hopkins University School of Nursing's Center for Innovative Care in Aging. This database included only those individuals who had previously agreed to be contacted for inclusion in future research and had either been screened for or participated in the Dementia Behavior Study (principal investigator, senior author L.N.G.). Initial inclusion criteria included self-identification as African-American and caregiving for a person with dementia within the previous two years. Next, baseline data gathered for the Dementia Behavior Study was used to identify those participants who had reported aggressive behaviors by the person with dementia and these were included in the first tier to be contacted for this study. Similarly, those in the second tier for contact were individuals who had indicated the person with dementia had demonstrated agitated, but not aggressive, behaviors. Finally, in the third tier, were individuals for whom behaviors of the person were unknown or were not present at the time of the baseline. All participants were notified by postal mail that the first author (B.R.H.) would be contacting them, followed by a recruitment telephone call approximately two weeks later. Seventeen individuals were contacted for recruitment, with four declining and thirteen agreeing to participate in this research study, a 76.5% rate of recruitment. Recruitment continued until no new themes were emerging in concurrent data analysis.

Data Collection

Participants were interviewed in their own homes using semi-structured interviews during the summer of 2015. The interviews used a vignette approach with three separate vignettes presenting specific types of aggressive behaviors commonly observed in dementia. The vignette approach was chosen as it has been shown to be an effective method for eliciting data about a range of topics, including socially sensitive topics such as aggressive behaviors (Barter & Renold, 1999; R. Hughes & Huby, 2002; Spalding & Phillips, 2007). The interview guide was developed in a collaborative and iterative process with input from all authors (see supplemental materials); however, all interviews were conducted by the first author alone. Interviews were digitally audio-recorded and subsequently transcribed by a qualified, third-party transcription service. Digital transcriptions were then double-checked for accuracy.

Ethical Considerations

Study procedures for this research with human subjects were reviewed and approved by the Johns Hopkins Medical Institutions Institutional Review Board (IRB). Informed consent procedures were conducted as approved by the IRB and participant confidentiality was protected by having all data securely encrypted and stored on an institutionally-approved remote server. Participants were assigned an identification number and the transcripts were de-identified. The key linking the transcripts and identities was stored in an encrypted file on the remote server. Participant information and signed informed consent forms were stored in a locked facility provided by the Center for Innovative Care in Aging. Following transcription, all audio-recordings were permanently deleted.

Analysis

Interview transcripts were imported into MAXQDA 13 analytic software (Verbi Software - Consult - Sozialforschung GmbH, 1989). The data analysis was conducted as described by Saldaña (2009). During the First Cycle, in which codes are developed and assigned to data, the first author initially used descriptive coding (Miles & Huberman, 1994; Saldaña, 2003) to capture individual topic areas arising line-by-line from the data. To complete the First Cycle, the first author used process coding (Corbin & Strauss, 2008; Strauss & Corbin, 1998), to focus specifically on the processes by which caregivers addressed aggressive behaviors, and holistic coding (Dey, 1993), to assign macro-level codes to larger passages of cohesive narrative. Moving into the Second Cycle, in which codes are combined into larger categories, pattern coding (Miles & Huberman, 1994) was used to describe the higher-level patterns emerging as earlier codes were combined under an emerging conceptual schema. To complete the Second Cycle, themes were developed and expanded to adequately represent the totality of the constituent parts. During the process, the codes and categories were jointly reviewed and reconciled in discussion with co-authors. When discrepancies of interpretation or coding nomenclature occurred, review and discussion continued until consensus was reached by co-authors.

Results

Participants

[Insert Table 1 about here]

Participants were all African-American (*N*=13), with most being female (92.3%, *N*=12), and a mean age of 65.5 years (*SD*=8.39; *Mdn*=67, *IQR*=9). Participants had provided care for a mean of 6.35 years (*SD*=3.86; *Mdn*=5, *IQR*=7), with a range of 2.5 years to 15 years, and most were caregivers for a parent (84.6%, *N*=11). At the time of the interview, most participants were currently caring for a person with dementia (61.5%, *N*=8), with the remainder having been the primary caregiver of a person with dementia within the previous two years (38.5%, *N*=5).

Themes

[Insert Table 2 about here]

In this exploration of African-American caregivers’ perspectives on aggressive behaviors in dementia, themes emerged in two main areas. The first theme addressed the contextual factors surrounding the behaviors and the caring experience. These *Care Challenges* were comprised of four sub-themes, including *Taking care of a stranger*, *Hurtful interactions*, *Overcoming the past*, and *Social and financial strain*. The second theme described strategies caregivers used to prevent or manage aggressive behavior. These *Success Strategies* were comprised of four sub-themes, including "*It's the disease….not the person," "I got to do what I gotta do…*," "*We didn't argue….we didn't insist*," and "*Don't put her in a position to fail*."

Care Challenges. Participants in this study reported encountering a wide array of challenges in caregiving but from among them sub-themes emerged that shared commonality among participants.

Taking care of a stranger. As aggressive behaviors and other symptoms of dementia made their appearance, participants struggled to reconcile the internal image of the healthy person they had known and the person with dementia in the moment. Though participants described feeling love and a sense of responsibility to care for the person with dementia, it was as though they were constantly trying to "see through" the symptoms of dementia to reconnect with the person they had known and loved before dementia changed their relationship. As one participant stated, "There's the lady that raised me…there's the lady that I'm lookin' at now. In there somewhere is that woman" (QE, 56). The same participant explained further, making explicit the connection between her struggle to recognize her mother through the dementia and the aggressive behaviors that her mother exhibited.

> My mother, in all of my years, I had never seen her curse or cuss at people or use profanity….she did that… 'I don't want this shit. Goddamn this. Damn that.' My mother was never like that, never like that, and to see her change and say those behaviors, she became a different person. (QE, 56)

The slowly-changing nature of the relationship between the caregiver and the person with dementia was distressing and the distress intensified when aggressive behaviors appeared. Dealing with this distress proved to be especially challenging as it was often not possible for these caregivers to take any extended time out from caregiving in order to integrate these changes into their own self-concept or their view of the relationship. At times it seemed that the internal dissonance became so sharp between the person the caregiver remembered and the person they cared for that the caregiver began to dissociate the two. As one participant explained,

> You don't believe that your mother would actually fight you or hit you. You don't believe that your mother would take her fist and hit you, because you're trying to clean her, or you're trying to give her a bath. You don't think that they would do that… I see it as this way. This is a completely change in the personality. My mother was never that kind of person. She would never ever hit a—she wouldn't even hit us. I've never in her life heard her use bad language, and she was always kind and pleasant. To see her like that, that was not the mother that I know. Wasn't the mother I know, but this was her body. (DI, 68)

Hurtful interactions. Though participants described many challenges related to caregiving, encounters with aggressive behaviors seemed to be the most unexpected and disconcerting. These encounters were acutely difficult for them and they frequently described them as sad or hurtful. One participant struggling to find words to explain her first experience with the person with dementia demonstrating these behaviors, stated, "It's frustrating and scary, and confusing, and overwhelming…" (RJ, 50). Another participant, framing her own reactions to similar experiences within the context of a vignette, said,

> The first couple of times, when you don't recognize—when you don't know this is part of the illness—the part of the progression of the illness—if you don't recognize that at the beginning, you would feel crazy… If you knew that these were the kinds of behaviors that were going to come [you could] prepare yourself. Still, I think the first time it happens it's still a shock. (AT, 56)

These interactions seemed to demonstrate dissimilarity from their view of the person with dementia as a stranger. The caregivers seemed to feel that the behaviors were directed toward them in a personal way that was not reflected in other behaviors. As one participant stated, "I don't take it personal, but sometime it's hard not to take it personal" (EP, 70). Another participant described her experience with her mother like this,

> …Then, I realized she doesn't realize what she's saying. Then, I guess the first thing you felt is heartbroken. I guess for her to think that I would take from her, and I think that was really the most heartbreaking thing, that somebody you've been helping out and taking care of for years. Then all of a sudden, it seemed like she was beginning to turn on me. Yeah, I think that was the worst part. Yeah. (PN, 67)

Overcoming the past. Some participants described difficult relationships with the person with dementia that dated back to earlier points in their lives. These caregivers described an additional layer of complexity surrounding the aggressive behavior and their reactions to it. As the dementia progressed, these caregivers also went through the same type of differentiation process between the dementia symptoms and the real person.

However, this was made more difficult because some of the symptoms attributable to dementia were similar to behaviors that the person had demonstrated before dementia. As one participant described about her relationship with her mother,

> …I always felt all my life like I couldn't please my mother…She didn't see the good thing we did…I'm carrying over from childhood into adulthood. I'm responding still like the child that nothing I do can please you. I said that to her but then when the light came on and I realized that, '…you can't take this personally this is not 1950, 1945 and she is not who she was then.'…I would think to myself, 'Yeah she may have Alzheimer's but that's who she always been.' Well that personality don't change but you've gotta realize that…now she's at the point where she just, she don't know better, she can't do better. When my mind set changed then things changed…This is not a power struggle because that is what it was for mother and me for a long time, it was a power struggle. She's not gonna give up the power struggle so I have to give it up. (WB, 73)

Another participant, who had a tumultuous premorbid history with the person with dementia, described how she tried to come to terms with the verbal aggression that was new to their relationship and accompanied the dementia.

> *Interviewee:* You can forgive, but you may not forget. You got a lot of stuff under your belt. I'm sure then that the person that has dementia also has a lot of stuff under their belt…I don't know whether you still call it love. It's another word for it. Maybe it could be respect, but during certain bouts, I have actually

> lost the respect and told him so. “I have lost respect for you when you treat me like that…”
>
> *Interviewer:* It sounds like it's difficult to separate out the person from the behavior that you're experiencing.
>
> *Interviewee:* Yes…Yes. As time goes on, and they get better, then you forgive. You don’t forget, but you forgive. Because then you have something to blame it on. You say, “That was what that was all about.” (SL, 80)

Social and financial strain. The situational stress of caregiving was also exacerbated for several caregivers by the limited nature of the resources available to them. For some participants, the financial burden was acute because not only were they needed in constant caregiving, but they were unable to use that time for income generation. For other participants, social support was present, but none was available that could fill the role of caregiver. For a few others, a combination of the two made their lives especially difficult. One participant explained that though she had other family to help her, they were not able to help with direct caregiving activities.

> I can’t even take a vacation. I can’t go anywhere, but for a few hours because I got to come back and change mom’s diaper and clean her up. We can’t afford to have somebody to come in, and pay them $20.00 an hour or whatever they charge to come in, for a couple of hours and do those kind of things for her. (EP, 70)

Another participant related her experience with caring for her mother and, in distress, having to make difficult decisions in order to continue to care for her at home.

> I'm in tears, always fighting tears and I said look I can't do it, I can't do it anymore but I don't want to put her in an institution. I don't want to. I promised myself after my father…I said I'll hire help. I'll work an extra job. Anyhow the Lord answered my prayer…I said, "I just can't keep this up, I just can't, I can't do it, I need help." …Because it got to the point where I just could not. It was too much on my nerves and everything else… (WB, 73)

Success Strategies.

"It's the disease….not the person". A cognitive strategy used by caregivers was to identify behaviors that are part of the dementia syndrome and to frequently recall that the behaviors were a result of the disease process, which allowed them not to take it personally. Some caregivers described dementia as the "other" person but occasionally the "real" person makes an appearance, allowing for connection. A few caregivers reported that even their exposure to items from the Neuropsychiatric Inventory (Cummings, 1997) in a previous study helped them to differentiate between dementia and the real person. When describing their reactions to aggressive behavior, caregivers frequently attributed these behaviors to the other person or to the disease. Though expressing personal hurt and dismay, they would use that cognitive approach to allow them to continue to provide compassionate care by assigning the hurtful behavior to the dementia while they continued to care for the real person.

For example, one participant described her insight into the real person that still inhabited the stranger's body.

> …my mother was highly intelligent, highly articulate, highly verbal, well read, self-educated and self-aware. She, even now, contains to be all of that in there within, underneath, round the side…she's in there. You see flashes of it. There are moments when she knows what she's done. She just says, 'I don't know why I can't stop this. I know I ask you this. I asked you this already but what did you tell me?' Then, your heart breaks because you can see that she doesn't want to be doing this thing and if she could stop it, she would but she can't. She's compelled, if you will. (AT, 56)

Another participant described the internal conflict she had until she realized that even though her mother had a premorbid personality that she found abrasive, the behaviors she was now encountering were different, and arising from the progression of dementia. Coming to this realization allowed her to cognitively reframe the entire caregiving experience and the aggressive behaviors of her mother in the caregiving interactions.

> When the light came on I realized, when I accepted the fact that this is the disease, see it as the disease as opposed to she's striking out at me…Then even if the thought or emotion came up I could talk to myself real quick and say, 'Uh-uh, that's the disease.' … As I change…she may still do the same thing but it's like the story of the child on the airplane…crying…disturbing all the passengers. Then the steward just told the passengers about who this child was and they're bringing her from another country and stuff –then their whole attitude changed and they became empathetic toward the kid… As I accepted the fact that, 'This is

> not personal against you…this is the disease.' Then I began handling it differently. (WB, 73)

"I got to do what I gotta do…". Caregivers reported that it was important to them to rearrange all other activities to make time with the person with dementia their utmost priority. Whether rearranging work schedules, getting up earlier in the morning, or forgoing favorite activities, the caregivers stated that it was important to give the person with dementia the space and time to maintain their equanimity. Not rushing the person with dementia was one aspect that informed this perspective and hurrying the person with dementia for one's own convenience was viewed as highly disrespectful. Participants indicated that it was the caregiver's responsibility to make time for the needs of the person with dementia, even despite competing priorities. This making time for caregiving was exemplified by one participant who described her approach to melding her work life with her caregiving responsibilities.

> The thing I think you have to do when you—when you're caring for someone with dementia is…let your employer know, because there will be times that you might be late. I think that's the first thing you need to do. You need to let your employer know that I'm dealing with a parent, a husband, whatever, a relative with dementia, and sometimes I may need to be late. Because they [persons with dementia] need to follow a routine, and if you get them off of the routine—. (DI, 68)

Another participant echoed this approach and explained why she felt compelled to rearrange her life for her father, stating, "I wanna help 'em because this is—

I'm looking at this is my dad. I need to do whatever I can because he was an excellent person in my life” (AE, 61). Later, she went on to expand on the urgency she felt to make caregiving the priority activity in her life, despite personal cost.

> But it was my father. My job knew the situation. I told 'em, ‘My dad come first.’ I got to do what I gotta do for my father. That job is gonna be there. I done drop dead, the day after tomorrow you'll find somebody to take my place and do the job. My dad needs me here now. I'll be at work when I can. (AE, 61)

“We didn’t argue….we didn’t insist”. Caregivers in this study frequently provided examples of nonconfrontational approaches to caregiving. They explained that this was more respectful of the person with dementia and more likely to prevent aggressive behavior. Several participants also described this approach as being more productive and less time-intensive than confrontation, with many reporting that they learned this as a matter of trial and error. One participant described her morning routine with her mother, demonstrating the way she approached the hygiene and dressing aspects of caregiving.

> …there would be times when it would take me two hours to get her dressed in the morning. Starting at five o’clock, it would take two hours. The first thing you do is you wake her up, and you just let her relax, ‘We’re going to get up.’ Then you sit her up on the side of the bed. ‘Let’s stretch out our arm here, stretch an arm there.’ …You take her to the bathroom, put her on the toilet, let her sit there. You go out of the room, you come back, because you never know… It was a back and forth… Sit her down, put on the stockings, go out, come back. ‘Are you

> ready now?' … It gave her time to get herself together. I would go do something else while I waited for her to get ready. For me, it was more productive for me…It gave me time to do other things…. (DI, 68)

Some participants described times when they could see that the caregiving tasks were contributing to increasing agitation for the person with dementia. Several reported that pausing the caregiving task for even five minutes was reported as being sufficient to completely change the dynamic and allow for successful completion of caregiving activities without further conflict. As one caregiver said, often the person with dementia "was a completely different person" (DI, 68) when allowed a brief break from the caregiving activity and was subsequently agreeable to completing the resisted activity. One participant described a typical interaction with her mother, and the way she used time, space, and even physical affection to provide an environment where her mother could return to a state of calm.

> I ask, I say, 'Miss Smith.'
>
> [*mimicking mother's angry, loud voice*] 'What?'
>
> I say, 'Oh,' so I knew just leave that alone for a minute. Come back. I ask Miss Smith again,
>
> [*mimicking mother's calm, quiet voice*] 'What, baby?'
>
> See, whole new turn around. But you can't foul 'em up. When I see Miss like that I leave her alone. I'll come by and maybe hug 'er, hug 'er and kiss 'er, and just like nothing had happened. (IB, 65)

Caregivers also identified these mini-breaks as important times for the caregivers to regain their perspective and to approach caregiving in a calmer and patient state of mind.

> I might go sit out on the porch to get myself calm, and especially when I'm trying to get her to do somethin' like eat. She would spit it out or she'd say eat it yourself. When I felt my blood pressure going up, I would just go some place and do something. I might go do laundry. Go sit on the porch. Just go do something, and then I calm—I'm calmed down. I come back, and approach her again. Sometimes when I came back, she was better too. I found out that the more you try to push her to do something, and she was determined she wasn't gonna do it, you just making yourself worse, so you might as well just let it go. Give her some time, and come back, and try it later. (EP, 70)

"Don't put her in a position to fail". Being present and intimately familiar with the needs, behaviors, and interests of the person with dementia seemed key to preventing and addressing aggressive behaviors for these caregivers. Many described small details in their care that addressed specific preferences or aspects of the person's character that were important to preventing situations that were triggers for aggressive behavior. For example, one participant related how she tried to anticipate ways to encourage independence while also providing necessary assistance in the least intrusive way possible.

> I was assuring her independence but assuring her ability to succeed… Why put her in that position to fail or to get frustrated or not to be able to do it and then

> you come and do it for her and she'll be upset. Even cutting up her food, I would cut up her food rather than put the whole chicken leg…she couldn't do things but she wanted that bone…I would cut the meat off and leave a little on the bone and put the bone on the plate. (WB, 73)

Another caregiver explained that paid caregivers in an institutional setting who cared for her mother briefly did not use the same type of patient technique and her mother's reaction was markedly different.

> She hadn't did it with me, but she did threaten to kill one of the caregivers. She had never did that as long as she was with me. I think with my mom, you have to know her breakin' point. You have to know when to step back. …I guess they didn't realize that she could blow off. That she really could come out and curse you out really. I guess they kept—I felt like they didn't really handle the situation at the time correctly. She just blew up. (PN, 67)

She explained further, describing how her approach differed from other caregivers' who were not as attuned to her mother's individual needs.

> …they went back and forward with her, which I don't do…I have been there recently, and I saw she opened the door…because she saw me at the door. The caregiver came and said, "You know you're not supposed to open that door." She turned around and looked and said, "Don't you think I got sense enough to know who to open the door for. That's my daughter." He said, "You're not supposed to answer." I told the caregiver like that, "Don't go—you have already told her not to open the door. She knows she not supposed to open the door…" …You

> back off, she backs off right away. Less than five minutes, she's already forgotten about it. Why you keep goin' on and on? Because she's not gonna remember this anyway. I don't care how many times you might tell her not to open the door, if she sees somebody at that door, and she know you, she's gonna run and open the door. That's her… (PN, 67)

Discussion

To our knowledge, this is the first study of its kind to specifically explore African-American caregivers' experiences with and reactions to aggressive behavior types experienced by persons with dementia. This study identified two themes, comprised of four sub-themes each, which describe these caregivers' perspectives on these behaviors. The two overarching themes that emerged were *Care Challenges* and *Success Strategies*. *Care Challenges* reflected specific concerns as well as affective caregiver experience. The four subthemes included *Taking care of a stranger*, *Hurtful interactions*, *Overcoming the past*, and *Social and financial strain*. Participants felt like they were *Taking care of a stranger* when managing aggressive behaviors, as these often involved *Hurtful interactions*. In cases where dyadic conflicts had existed before dementia onset, aggressive behaviors added to the difficulty of caregiving, which required *Overcoming the past*. Further, these challenges were all set within the context of *Social and financial strain*. *Success Strategies* reflected cognitive and behavioral strategies for preventing and managing aggressive behavior. The four sub-themes included "*It's the disease….not the person*," "*I got to do what I gotta do*," "*We didn't argue….we didn't insist*," and "*Don't put her in a position to fail*." Remembering "*It's the disease….not the person*" helped participants to reframe the behavior and to continue to provide care. As participants tried to balance priorities, a frequent refrain was "*I got to do what I gotta do*," which helped them to keep caregiving as most important. Participants reported that prevention of aggressive behaviors was more successful when "*We didn't argue….we didn't insist*." Additionally, caregivers who "*Don't put her in a position to fail*" were able to engage persons with dementia in activities without aggressive behaviors occurring. These themes demonstrate that while caregivers were constantly confronted by difficulties, they were also actively developing and practicing methods to address both the symptoms in the person with dementia and their own reactions to the symptoms.

Caregivers in this study developed two different kinds of *Success Strategies* that helped them to continue to provide care after encountering these disconcerting behaviors. Of the four *Success Strategies* sub-themes, two describe cognitive strategies and two describe behavioral strategies developed by caregivers. "*It's the disease….not the person*" and "*I got to do what I gotta do*" were both cognitive reframing strategies that the caregivers used to internally cope with the rigors of caregiving when troublesome dementia symptoms were present. "*We didn't argue….we didn't insist*" and "*Don't put her in a position to fail*" were active strategies that the caregivers used in their relationship with the person with dementia to primarily prevent, but occasionally to manage, aggressive behaviors.

Both the challenges and the strategies these African-American caregivers presented provide valuable insight into the complex interplay between the caregiver and the person with dementia, as novel and troubling symptoms of dementia appear and reappear, fundamentally altering long-established patterns in the relationship. The perplexing and distressing nature of the changes shared by participants in this study echo the findings of previous studies (Evans & Lee, 2014; Gottlieb & Gignac, 1996; Large & Slinger, 2015; Lindauer & Harvath, 2015; Toth-Cohen, 2004; Wuest, Ericson, & Stern, 1994). Taken together, these studies suggest that as the person with dementia becomes increasingly impaired, caregivers experience profound grief and a struggle to redefine and reintegrate their shifting reality. At the same time, caregivers also strive to provide care that remains centered on the essential personhood of the person with dementia, despite the feelings of increasing estrangement that may simultaneously be occurring. The findings from our study add to the literature by demonstrating that aggressive behaviors can exacerbate this internal conflict and that caregivers may struggle to adjust their caregiving strategies to accommodate new realities.

It is important to again note in light of these caregivers' struggle to adapt to the disease-related changes in the persons with dementia that previous studies with African-American caregivers have consistently found that they report lower burden than other race/ethnic groups (Bekhet, 2015; Haley, et al., 1996; Miller, et al., 1995; Skarupski, et al., 2009; Toth-Cohen, 2004). This has been challenged as a simplistic and stereotypical view of African-Americans' experiences with caregiving that does not capture their full experience (Dilworth-Anderson, Williams, & Gibson, 2002; Fox, Hinton, & Levkoff, 1999; Kingsberry, Saunders, & Richardson, 2010). It is possible that the degree to which burden has been associated with caregiving overall has been more broadly over-estimated than has been generally accepted in the caregiving literature, perhaps in part due to an overreliance on convenience or purposive sampling rather than on probabilistic sampling methods (R. M. Brown & Brown, 2014; Pruchno et al., 2008). This view is supported by several recent studies that suggest that caregivers have better, rather than worse, outcomes than non-caregivers on several variables (S. L. Brown et al., 2009; Roth, Dilworth-Anderson, et al., 2015; Roth, Fredman, & Haley, 2015; Roth et al., 2013). Further research to assess whether a more balanced and consistent measurement approach that captures both the positive and negative aspects of caregiving may eventually yield a more nuanced understanding of the caregiving experience than measuring burden alone. This may also have implications for understanding reported differences by race, ethnicity, or culture.

Participants' desire to maintain love, respect, and empathy for the person with dementia was evident in this study; however, their struggle to not depersonalize the person with dementia was acutely heightened when confronted with aggressive behavior. This was even the case when the pre-dementia relationship between the caregiver and the person with dementia had been troubled. This is consistent with recent research with a different sample of African-American caregivers that found participants tended to focus on what remained of the personalities of the persons with dementia, rather than on what was lost (Lindauer, Harvath, Berry, & Wros, 2015). This perspective may be a strength that African-American caregivers draw upon to remain person-centered in their caregiving activities. Appraisal of the threat of aggressive behavior, and the subsequent reaction, may be attenuated by a conscious, holistic view of the person with dementia that counts what remains of the person's personality as a resource that can be leveraged to manage the behavior. By maintaining a holistic view that focuses on the remaining aspects of personality, these caregivers may have been successfully overcoming the challenge they had identified of depersonalizing the person with dementia by seeing them as a stranger.

These findings suggest that interventions designed to support caregivers of persons with dementia should be sensitive to how symptoms of dementia challenge caregivers' person-centered focus. Emphasizing the concept of personhood and clearly delineating symptoms of dementia may by themselves be potent components of a supportive intervention as they may provide the caregiver with tools to feel less threatened and to regain positive regard for the person. This confirms findings from a study by Toth-Cohen (2004), conducted with a demographically-similar sample, that recognizing behavioral symptoms and being able to attribute them to the pathologic processes underlying dementia helped participants to reconcile a sense of who the person with dementia was and the caregiving role. Additionally encouraging, participants' experiences in this study suggest that the same strategies of emphasizing personhood and differentiating dementia-related behaviors may be successful even in relationships burdened by a long history of discord predating the onset of dementia. As participant WB (73) explained, "I would think to myself, 'Yeah she may have Alzheimer's but that's who she always been.' Well that personality don't change but you've gotta realize that…now she's at the point where she just, she don't know better, she can't do better."

It was notable that almost all of these participants had a strong internal sense of how to construct their caregiving approach in ways that were specifically tailored to the needs and preferences of the person with dementia. As these participants described, they placed a strong emphasis on knowing the person with dementia well and setting them up to succeed in their daily activities. Several participants reported doing this by a trial-and-error method in which they would attempt a strategy and watch the person with dementia for signs of distress, discomfort, or displeasure. One possible explanation for this attentiveness to disequilibrium of the person with dementia could be explored in the context of the stress and coping framework. These caregivers may have developed a method of frequent and careful appraisal as way to manage and minimize stress that may otherwise overwhelm their coping resources. When a person with dementia begins to experience discomfort or displeasure, a cascade of events may be triggered that is manifested in aggressive behaviors, as is suggested by the unmet needs model of dementia behaviors (Algase et al., 1996; Kovach, Noonan, Schlidt, & Wells, 2005). By frequently appraising the behavior of the person with dementia, it is possible that these caregivers adjusted their reactions to accommodate and address the person's needs, thereby preventing overwhelming stress to both the caregivers and persons with dementia.

While these participants described challenges to caregiving both within themselves and within the changing relationship with the person with dementia, it is important to recognize that they were happening within the larger socioeconomic context, which they identified as an additional stressor and the stress process model includes as both part of the background in which stress is experienced as well as contributing to secondary role strain in the form of economic pressure. In addition, the lack of caregiving-related resources, participants in our study also identified their inability to take time away from the caregiving role as a challenge, which has also been shown to be an independent contributor to caregiver burden (Losada et al., 2010).

These results in our study are supported by research by Black et al. (2013) and T. B. Hughes et al. (2014) that, at baseline, found most caregivers in the MIND at Home intervention study had unmet needs related to caregiving role support and that those needs, along with behavioral symptoms in the person with dementia, contributed significantly to the level of caregiver burden. Within the stress coping framework, these unmet needs represent different levels of stressors that are both internal and external, which together are posited to contribute to negative caregiver outcomes, such as depression and declining health status. However, in the stress process model, coping and social support have the potential to mediate negative outcomes. This mediation was suggested by how participants described using mini-breaks by stepping into another room or out onto the porch to sit for a few minutes to help them rejuvenate. This strategy, though easy to overlook, may signal an important aspect of how these caregivers bolstered their coping resources, and thus mediating negative outcomes. This may be helpful to inform intervention development focused on supporting caregivers with limited access to social or economic resources. It is possible that even small, incremental approaches to regaining leisure time for caregivers may be helpful in decreasing distress and improving caregiver psychological outcomes.

Giving the person with dementia space to recover their equanimity was also frequently cited as an effective behavioral management strategy by participants in this study. This strategy fits well into the Stress Process Model for Individuals with Dementia proposed by Judge, Menne, and Whitlatch (2010) and that built upon the caregiver stress process model (Haley, et al., 1987; Lazarus & Folkman, 1989; Pearlin, et al., 1990). Little is known about the person with dementia's lived experience of having behavioral symptoms in dementia, especially in the mid- to late-stages of the dementia course when communication abilities are increasingly disrupted. However, the model proposed by Judge and colleagues would point to the immense scope of the challenges that the person with dementia is likely experiencing concurrently with the caregiver's challenges. Another model that may be helpful to consider in light of these caregivers' successful use of this strategy is the Progressively Lowered Threshold Model which posits that persons with dementia have a reduced ability to cope with intrinsic and extrinsic stressors (G. R. Hall & Buckwalter, 1987). Stressors, such as hygiene care and other caregiving activities, are likely to place stress on the coping abilities of the person with dementia and mini-breaks during such activities may serve a restorative purpose for the person with dementia.

Caregivers in this sample did express that they placed a high priority on caregiving, even at great personal cost. This emphasis on the needs of the person with dementia may be important to the person-centered approach that they consistently reported using in caregiving activities. Even when it meant early morning awakening, staying awake overnight, and working extra shifts, these participants described an approach that allowed the person with dementia sufficient time and space during caregiving activities to remain calm and relatively undisturbed. This may speak to a larger ethos in this race/ethnic community but it is unclear exactly why this might be. The Cultural Justifications for Caregiving Scale (CJCS) is one instrument that may be helpful in future research for elucidating this area further, building upon the work of Dilworth-Anderson et al. (2005), Powers and Whitlatch (2014), and others.

A contrary view to the stress process model that may help to explain these caregivers approach to caregiving may be found in the healthy caregiver hypothesis. This hypothesis suggests that healthier people may be self-selected to be caregivers and remain in that capacity for longer periods of time because they have well developed self-care approaches as well as strong prosocial tendencies (R. M. Brown & Brown, 2014; S.L. Brown, Brown, & Preston, 2012; Fredman et al., 2010; Roth, Fredman, et al., 2015). It follows then that these caregivers may have developed coping strategies well before assuming a caregiving role, and have since incorporated these strategies into the role. In the context of this model, the caregiving strategies that emerged from these caregiver interviews may reflect a lifelong approach to social interactions and attentiveness to their own needs that has prepared them well for both the demands of caregiving. Further qualitative in-depth exploration of this hypothesis in similar samples may be helpful to better understand if caregivers previously adopted approaches to interpersonal communication that laid the groundwork for the strategies identified here.

Limitations

This study had limitations, in addition to its strengths. As the purpose of this research was not to provide population estimates, but rather to do an in-depth exploration of a phenomenon, the sample size was fairly small. African-American caregivers were purposively selected as our previous research had suggested that African-American caregivers reported greater confidence managing aggressive behaviors. However, an important next step in this research would be to explore caregiver reactions to these behaviors in other race, ethnic, and cultural contexts. For example, Asian-Americans are the fastest growing race/ethnic group in the U.S. (A. Brown, 2014) and little research exists that examines the experiences of any segment of this group in regard to aggressive behaviors in dementia. Though the findings in this study cannot be represented as generalizable to the population of dementia caregivers as a whole, this research does provide valuable information about care challenges and strategies that this sample used dementia caregiving that may be useful to explore in other settings and samples.

The generalizability of this study may also be limited by the previous exposure these participants had to an intervention study specifically focused on behaviors in dementia. Though a few of the participants in this study had only been screened for the intervention study, the remainder had been randomly assigned and completed either the attention control protocol or the intervention protocol. For those in the attention control group, home safety and dementia education were provided by trained interventionists and for those in the intervention group, occupational therapist interventionists trained caregivers to use activities specifically tailored to the interests and abilities of the person with dementia. The exposure to dementia care best practices and caregiver resources that some of these participants may have influenced the way in which they responded to the vignettes posed in this study. However, it is important to also note that even with this previous exposure to these resources, the analysis reflected that these caregivers continued to perceive a substantial burden related to aggressive behaviors. In addition, many of the challenges and strategies they discussed appear to have predated their participation in either the intervention study or this study.

It should be noted that there was little diversity in this study as it concerns gender and relationship. There was only one male and one spousal caregiver and thus it was not possible to compare viewpoints between males and females or spouses and non-spouses. As both female gender and a spousal dementia caregiving relationship have been associated with increased caregiver burden (Chiao, Wu, & Hsiao, 2015; Kim, Chang, Rose, & Kim, 2012; Poysti et al., 2012), it would be important to consider these factors in future studies on caregiver reactions to and management of aggressive behavior in dementia.

Another potential limitation of this study is that the one person conducted both the interviews and the initial data analysis. However, subsequent to the initial phases of the data analysis, co-authors provided review and independent analysis of the data, with ongoing discussion between all co-authors, which was designed to increase the trustworthiness of the final results.

Conclusion

In this study of Black/African-American caregivers of persons with dementia, participants described both barriers they encountered in caregiving and facilitators that they used to prevent and manage aggressive behaviors. Under the first overarching theme *Care Challenges*, four sub-themes emerged: *Taking care of a stranger*, *Hurtful interactions*, *Overcoming the past*, and *Social and financial strain*. Under the second overarching theme *Success Strategies*, four sub-themes also emerged: "*It's the disease….not the person*," "*I got to do what I gotta do*," "*We didn't argue….we didn't insist,"* and "*Don't put her in a position to fail*." *Care Challenges* describes participants' specific concerns and affective experience with aggressive behaviors. While participants reported that dementia caregiving sometimes felt like *Taking care of a stranger*, this was exacerbated when aggressive behaviors occurred. Frequently they described aggressive behaviors as personally *Hurtful interactions* between caregiver and person with dementia. Participants also reported that *Overcoming the past,* including premorbid conflict with the person with dementia, was necessary for caregiving but especially difficult with the occurrence of aggressive behaviors. Further, *Social and financial strain* was a common backdrop to caregiving that participants suggested formed a barrier. *Success Strategies* describes both cognitive and behavioral that participants used to prevent and manage aggressive behavior. Differentiating dementia-related behavior from the person underneath required participants frequently remind themselves that "*It's the disease….not the person*." "*I got to do what I gotta do*" was the rationale participants used to prioritize caregiving needs of the person with dementia. "*We didn't argue….we didn't insist*" refers to participants' person-centered approach that required they use the response of the person with dementia to guide the timing and execution of caregiving activities. Additionally, "*Don't put her in a position to fail*" was an important concept used to describe how participants helped the person with dementia to be as independent as possible, while being mindful of limitations. These insights provide important information that may be helpful to guide intervention development that is supportive of caregivers and that encourages a person-centered approach to caring for persons with dementia.

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Table 4.1: Participant Demographic Characteristics

	(*N*=13)
Age, years	
Mdn (*IQR*)	67 (9)
M (*SD*)	65.5 (8.39)
Gender % (*N*)	
Female	92.3 (12)
Male	7.7 (1)
Relationship of person with dementia to caregiver % (*N*)	
Mother	69.2 (9)
Father	15.4 (2)
Other	15.4 (2)
Years caring for person with dementia	
Mdn (*IQR*)	5 (7)
M (*SD*)	6.4 (3.86)

Table 4.2: Major Themes and Sub-Themes

1. Care Challenges
    a. Taking care of a stranger
    b. Hurtful interactions
    c. Overcoming the past
    d. Social and financial strain
2. Success Strategies
    a. “It’s the disease…not the person”
    b. “I got to do what I gotta do”
    c. “We didn’t argue…we didn’t insist”
    d. “Don’t put her in a position to fail”

Supplemental Material: Interview Guide

My name is *** and I will be talking with you today about your perspectives on specific behaviors in dementia and any experiences you have had with them. As we discussed before you signed the consent, you may stop this interview at any time or decline to answer any questions you would not like to answer. Before we start, as we discussed a little bit ago, I would like to record our conversation so the recording can help me to remember what was said. Would it be ok if I started the recording now?

I am going to start with a few basic questions first:

- What is your full name?
- What is your age?
- Where were you born?
- Are you currently caring for a person with dementia?
    - If no: Did you care for a person with dementia?
- What is (his/her) name?
- What is (his/her) age?
- When was (he/she) diagnosed with dementia?
    - Alternative: When did (he/she) find out (he/she) had (Alzheimer's disease or other dementia)?
- How long have you been caring for (PwD)?

- Alternative: How long did you care for (PwD)?
    - You indicated you are no longer caring for (PwD). How long has it been since you were caring for (him/her)?

Thank you. Now I would like to tell you three different stories and then ask you some questions about each one.

[Vignette #1: Mrs. Jones

Behavior: Verbal aggression

Subjects: Male (husband) caring for female (wife)

Antecedent: Redirecting]

‘Mrs. Jones is a 75-year old female with dementia living at home with her husband of 47 years. Her husband has been providing care for Mrs. Jones since she began to have difficulty taking care of herself about 2 years ago. Before the onset of dementia, Mrs. Jones’ prepared all the meals in the house, taking great pride in it and becoming known among their friends as an outstanding cook. Mrs. Jones’ husband has now taken over preparation of meals but he tries to involve Mrs. Jones as much as he can in activities she can manage, such as stirring ingredients and setting the table. Today Mrs. Jones attempted to pick up a hot pan from the stove and her husband, concerned she might be burned, gently removed the pan from her hand and set it back on the stove. Mrs.

Jones began yelling at him, saying, “I hate you! You are mean. Get away from me. You are a bad, bad man!”’

- *Why do you think Mrs. Jones is behaving this way?*
- *How do you think Mrs. Jones’ husband should respond to her next?*
- *What do you think Mrs. Jones’ husband is feeling?*
- *What do you think Mrs. Jones’ husband might have done differently to avoid this situation?*
- *What do you think was most upsetting about this episode for Mrs. Jones?*
- *What do you think was most upsetting about this episode for Mrs. Jones’ husband?*

- Since (PwD) has had dementia, have you ever experienced (him/her) behaving like Mrs. Jones?
    - If no, proceed to Vignette #2.
    - If yes, proceed to following questions.
- How upsetting did you find it when (PwD) was behaving that way?
- How confident did you feel about dealing with (PwD) when (he/she) was behaving that way?
- How did you deal with (PwD) behaving that way when you were at home? In public?

[Vignette #2: Mr. Smith

Behavior: Destroying property

Subjects: Female (sister) caring for male (brother)

Antecedent: Pain and being rushed]

‘Mr. Smith is a 68-year old male with dementia who moved in with his younger sister in her home about 4 years ago when he became very forgetful. Shortly after moving in, he was diagnosed with dementia, and over the last year has slowly lost his ability to speak. Mr. Smith also uses a walker to walk as he has severe arthritis in his knees and hips that causes him a great deal of pain, especially when he tries to move too quickly. During the week Mr. Smith’s sister takes him to an Adult Daycare while she is at work as a secretary. This morning, she was in a hurry to take Mr. Smith to Daycare so she could get to work. Just as she was walking to the front door with Mr. Smith, he began to pull at his pants, which she has learned means he needs to use the toilet. Becoming frustrated and worried she will be late for work, Mr. Smith’s sister begins pulling on his arm to hurry him towards the bathroom. Mr. Smith pulls back from her, then after a few more steps with her still pulling his arm, stops, shouts, “Aaaaah,” then picks up his walker and swings it against a table lamp which falls and shatters.

- *Why do you think Mr. Smith is behaving this way?*
- *How do you think Mr. Smith’s sister should respond to him?*

- *What do you think Mr. Smith's sister is feeling?*
- *What do you think Mr. Smith's sister might have done differently to avoid this situation?*
- *What do you think was most upsetting about this episode for Mr. Smith?*
- *What do you think was most upsetting about this episode for Mr. Smith's sister?*

- Since (PwD) has had dementia, have you ever experienced (him/her) behaving like Mr. Smith?
    - If no, proceed to Vignette #2.
    - If yes, proceed to following questions.
- How upsetting did you find it when (PwD) behaved that way?
- How confident did you feel about dealing with (PwD) when (he/she) behaved that way?
- How did you deal with (PwD) behaving that way when you were at home? In public?

[Vignette #3: Ms. Brown

Behavior: Threatening to hurt others

Subjects: Female (daughter) caring for female (mother)

Antecedents: Intimate personal hygiene care]

‘Mrs. Brown is an 86-year old female living in her apartment with her daughter, who has lived with her for 10 years. Mrs. Brown has had dementia for several years and is now unable to care for herself in any way. Every morning Mrs. Brown’s daughter gives her a sponge bath as there is only a bathtub in the apartment and it has become too difficult for her to get Mrs. Brown in and out of it. This morning Mrs. Brown’s daughter is almost done with the sponge bath and the bath water has become cool as she begins to wash between Mrs. Brown’s legs. Suddenly Mrs. Brown begins shouting, “I’ll kill you!” over and over while attempting to scratch her daughter’s face and arms.

- *Why do you think Mrs. Brown is behaving this way?*
- *How do you think Mrs. Brown’s daughter should respond to her?*
- *What do you think Mrs. Brown’s daughter is feeling?*
- *What do you think Mrs. Brown’s daughter might have done differently to avoid this situation?*
- *What do you think was most upsetting about this episode for Mrs. Brown?*
- *What do you think was most upsetting about this episode for Mrs. Brown’s daughter?*

- Since (PwD) has had dementia, have you ever experienced (him/her) behaving like Mrs. Brown?
    - If no, proceed to Vignette #2.
    - If yes, proceed to following questions.

- How upsetting did you find it when (PwD) behaved that way?
- How confident did you feel about dealing with (PwD) when (he/she) behaved that way?
- How did you deal with (PwD) behaving that way when you were at home? In public?

Follow-up Questions:

- In the stories we just talked about there are several examples of what is sometimes called aggressive behavior, which can be a symptom that occurs as dementia progresses. Are there any other behaviors you have seen in your experience with (PwD) that you think might not be exactly the same but be similar to the behaviors in the stories?
    - ***If no aggressive behaviors identified, proceed to next question.***
    - ***If aggressive behaviors are identified, proceed to following questions.***
        - You have identified aggressive behavior(s) that you have experienced with (PwD). Is there anything you have identified that helps you to know when aggressive behavior is likely to occur?
        - What strategies did you try to prevent aggressive behavior from occurring with (PwD)?
            - Probe: You mentioned (strategy). Were there any other strategies you tried?

    - When aggressive behavior occurred, what strategies did you use to calm (PwD)?
      - Probe: You mentioned (strategy). Were there any other strategies you tried?
    - Have you sought help or thought of seeking help for caring with (PwD) by using an institution (like nursing home or other skilled care facility)?
      - Probe: How has aggressive behavior affected these thoughts?
- Do you think that (PwD) ever has pain?
  - Probe: How do you know when (PwD) is in pain?
  - Probe: How often do you check if (PWD) has pain?
  - Probe: If you decide (PWD) has pain, what kinds of things do you usually do as a result?
    - Probe: For example, distraction, over-the-counter medications, home remedies?

Chapter 5: Discussion

The purpose of this dissertation study was to describe prevalence rates of aggressive behaviors and to explore the relationship between caregiver reactions (upset and confidence) and the occurrences of three types of aggressive behaviors: verbal aggression, destroying property, and threatening to hurt others. The study involved community-dwelling persons with dementia and their caregivers who were Black/African-American, Hispanic/Latino, and White/Caucasians. The main findings are summarized here by the following specific aims:

Summary of Results

Aim 1

Aim 1: Describe prevalence rates of aggressive behaviors in persons with dementia in a diverse, community-dwelling sample.

In this cross-sectional secondary analysis of the NIH REACH II initiative, we found that the caregiver-reported prevalence of at least one type of aggressive behavior within the preceding week was 38.3%, similar to prevalence ranges previously reported in the literature (Cipriani, Vedovello, Nuti, & Di Fiorino, 2011; Kunik et al., 2010; Lyketsos et al., 2002; Zhao et al., 2015). This differed significantly by race/ethnicity (p=0.050), with 44.0% (N=91) for Hispanic/Latinos, 38.6% (N=80) for Black/African-Americans, and 32.4% (N=70) for White/Caucasians. Analyzed by number of behavior types present (*one, two, or three*), 28.1% (N=177) of caregivers reported one behavior type, 8.4% (N=53) reported two, and 1.7% (N=11) reported three. These proportions also differed by race/ethnicity (p=0.020), with 33.3% (N=69) of Hispanic/Latinos, 26.9%

(*N*=58) of White/Caucasians, and 24.2% (*N*=50) of Black/African-Americans reporting only one aggressive behavior type present. More Black/African-Americans (11.6%, *N*=24) and Hispanic/Latinos (9.2%, *N*=19) reported two or more aggressive behavior types than did White/Caucasians (4.6%, *N*=10).

Verbal aggression occurred most frequently (34.4%, *N*=217), followed by threatening to hurt others (8.6%, *N*=54), and destroying property (7.1%, *N*=45). Hispanic/Latino caregivers were most likely to report verbal aggression (40.1%, *N*=83), followed by Black/African-Americans (34.3%, *N*=71) and White/Caucasians (29.2%, *N*=63). About half as many White/Caucasians (3.7%, *N*=8) reported destroying property as did Hispanic/Latinos (8.2%, *N*=17) and Black/African-Americans (9.7%, *N*=20). More Black/African-Americans (12.1%, *N*=25) than Hispanic/Latinos (7.7%, *N*=16) or White/Caucasians (6.0%, *N*=13) reported threatening to hurt others.

Unadjusted analyses of aggressive behavior type prevalence by race/ethnicity suggested differences; however, after adjusting for selected covariates (person with dementia: cognitive status, depression, health status; caregiver: economic status, depression) in binary logistic regression analyses, only one significant difference remained. Compared to White/Caucasians, Black/African-Americans were more than twice as likely to report threatening to hurt others (*AOR*=2.26, *p*=0.035, 95% CI [1.06-4.84]), while Hispanic/Latinos were not (*AOR*=1.30, *p*=0.532, 95% CI [0.57-2.95]).

Aims 2 and 3

Aim 2: Examine associations between types of aggressive behaviors in persons with dementia and caregiver reactions in a diverse, community-dwelling sample.

Aim 3: Compare associations by race/ethnicity (Hispanic/Latino, Black/African-American, and White/Caucasian) between types of aggressive behaviors in persons with dementia and caregiver reactions in a diverse, community-dwelling sample.

The second and third aims of this dissertation are combined in this concise summary. Using the full 5-point Likert-type scale, ranging from *Not at all* (0) to *Extremely* (4), caregivers had a mean level of upset for all behaviors of 2.3 (SD=1.26; *Mdn*=2.5, *IQR*=2.0). Confidence level was lower than upset level, with a mean of 1.8, (*SD*=1.24; *Mdn*=2.0, *IQR*=2.0).

Coded dichotomously, with *not at all* and *a little* coded as *not present* and *somewhat*, *very much*, and *extremely* coded as *present*, over two-thirds of caregivers were upset with aggressive behavior overall, with almost three-fourths upset with destroying property (73.3%, *N*=33), followed by threatening to hurt others (72.2%, *N*=39) and verbal aggression (69.1%, *N*=150). A little over half of caregivers were confident managing aggressive behavior, with 60.4% (*N*=32) confident managing threatening to hurt others, followed by verbal aggression (56.7%, *N*=123) and destroying property (42.2%, *N*=19).

We also found a statistically significant negative correlation with a medium strength of association between upset and confidence for overall aggressive behavior (r_s=-0.345, *p*=<0.001), for verbal aggression (r_s =-0.396, *p*=<0.001), and for threatening to hurt others (r_s =-0.316, *p*=0.021). There was no statistically significant correlation between upset and confidence for destroying property.

Examined by race/ethnicity, upset did not differ significantly when analyzed using the full Likert-type scale. Black/African-Americans had a median level of upset of

2.0 (*IQR*=2.0; *M*=2.03, *SD*=1.27), White/Caucasians had a median level of 3.0 (*IQR*=1.0; *M*=2.47, *SD*=1.13), and Hispanic/Latinos had a level of 3.0 (*IQR*=2.0; *M*=2.27, *SD*=1.33). Confidence levels did differ statistically significantly (*p*=0.001), with Hispanic/Latinos reporting the lowest levels (*Mdn*=1.0, *IQR*=2.0; *M*=1.46, *SD*=1.29), when compared to Black/African-Americans (*Mdn*=2.0, *IQR*=2.0; *M*=2.12, *SD*=1.19) or White/Caucasians (*Mdn*=2.0, *IQR*=2.0; *M*=1.71, *SD*=1.24).

When analyzed by race/ethnicity, verbal aggression was the only behavior type for which caregiver upset differed significantly (*p*=0.003). The highest percentage of caregivers upset with verbal aggression were White/Caucasians (83.6%, *N*=51), followed by Hispanic/Latinos 69.4% (*N*=59), and Black/African-Americans (56.3%, *N*=40). Confidence managing verbal aggression also differed statistically significantly by race/ethnicity (*p*=0.006), with a lower percentage of Hispanic/Latino caregivers expressing confidence (43.5%, *N*=37), than White/Caucasians 62.3% (*N*=38), or Black/African-Americans 67.6% (*N*=48).

Fewer caregivers were confident managing aggressive behaviors than were upset with them, both overall and by specific type of aggressive behavior. Only verbal aggression differed by race/ethnicity in both upset and confidence. More White/Caucasians reported upset to verbal aggression than did Black/African-Americans or Hispanic/Latinos. Hispanic/Latinos, however, had the fewest caregivers reporting being confident managing verbal aggression, compared to Black/African-Americans and White/Caucasians. The relatively small numbers expressing the other two types of behaviors may account for the lack of significant differences, making it difficult to draw conclusions about race/ethnicity difference in reactions for those behavior types.

Aim 4

Aim 4: Explore how African American caregivers describe their own experiences with aggressive behaviors in persons with dementia, including the strategies they may use to prevent or manage the behaviors, in a diverse, community-dwelling sample.

The fourth aim of this study was to purposively explore how one group of caregivers, African-Americans, described their own experiences with aggressive behaviors demonstrated by persons with dementia, including the strategies they may use to prevent or manage the behaviors. In our previous aims, we found this group to have lower upset and higher confidence than White/Caucasians and Hispanic/Latinos, which was consistent with literature that indicates Black/African-Americans report low burden and high satisfaction in caregiving overall (Bekhet, 2015; Haley et al., 1996; Miller, Campbell, Farran, Kaufman, & Davis, 1995; Skarupski, McCann, Bienias, & Evans, 2009; Toth-Cohen, 2004). As deepening our understanding of their insights and strategies may be helpful for other groups as well, we purposively recruited a sample of Black/African-American caregivers with whom to conduct semi-structured, focused interviews. We found that these caregivers shared common challenges in caregiving as well as strategies to prevent and manage aggressive behaviors. This study identified two themes, comprised of four sub-themes each, which describe these caregivers' perspectives on these behaviors. The two overarching themes that emerged were *Care Challenges* and *Success Strategies*. *Care Challenges* encompassed specific concerns as well as affective caregiver experience. The four subthemes included *Taking care of a stranger*, *Hurtful interactions*, *Overcoming the past*, and *Social and financial strain*. Aggressive behavior exacerbated participants' feeling that they were *Taking care of a stranger*, often leading to *Hurtful interactions* that were deeply distressing. Caregivers who had experienced conflict with the person with dementia premorbidly described *Overcoming the past* in order to provide care. *Social and financial strain* further challenged participants as they attributed long periods of unrelieved, high intensity caregiving to resource deficits and socioeconomic factors. *Success Strategies* described cognitive and behavioral strategies for preventing and managing aggressive behavior. The four sub-themes included "*It's the disease….not the person*," "*I got to do what I gotta do*," "*We didn't argue….we didn't insist*," and "*Don't put her in a position to fail*." Participants reframed behavior by differentiating "*It's the disease….not the person*" while prioritizing caregiving with the rationale "*I got to do what I gotta do*." Participants who were successful in preventing aggressive behavior described how "*We didn't argue….we didn't insist*," but rather would delay completing an activity until the person with dementia was ready. "*Don't put her in a position to fail*" reflected participants' sensitivity to person-centered care that accounted for the abilities and preferences of the person with dementia when planning activities. These themes demonstrate that while caregivers met many difficulties, they were actively adapting and addressing the needs of the person with dementia, while managing their own reactions to the symptoms.

Limitations and Strengths

This study had a number of strengths, as well as limitations. First, this is the first study of which we are aware that examines both different types of aggressive behaviors and caregiver reactions to those behaviors in a large, diverse, community-dwelling sample of caregivers and persons with dementia. This is also the first study to our knowledge to explore Black-African-American caregiver experiences with and reactions to different types of aggressive behaviors demonstrated by community-dwelling persons with dementia.

Another strength of this dissertation study is that it provides insight as to the contextual experiences of Black/African-American caregivers' with aggressive behavior in dementia. Lacking in the secondary analysis was the larger context around aggressive behaviors. That is, it is not possible to identify the context in which such behaviors occur, in terms of precipitating factors, risk factors, and also how reactions by caregivers either minimize or amplify such behaviors. The qualitative interviews provided insight as to how these behaviors are experienced.

Both a potential strength and limitation to this dissertation study is that the Black/African-American caregivers purposively sampled for in-depth interviews were not from the same sample with whom baseline interviews were conducted and from whom the data for the secondary data analysis was gathered. The Resources for Enhancing Alzheimer's Caregiver Health (REACH II) initiative was conducted in five U.S. cities from 2001 to 2006. Baltimore, Maryland, from which the study participants were recruited for the semi-structured interviews for this study, was not one of those 5 cities.

Using two different samples to examine the same phenomenon can be helpful in triangulation as the findings from both can complement and enhance one another to provide a clearer understanding. On the other hand, two different samples can make it more difficult to draw inferences from the combined results than would be the case if a true mixed methods approach were to be used.

In addition, nearly ten years elapsed between the conclusion of the REACH II intervention study and in-depth interviews were conducted with participants in this study, therefore we do not know the context in which behaviors occurred for the REACH II sample for which prevalence data is reported. Though there is more reason than not to believe that aggressive behaviors in dementia continue to pose substantial burden and distress to caregivers, there may have been temporal changes that affect the way in which caregivers experience aggressive behaviors in the intervening years, such as expanded access to healthcare resources under the Affordable Care Act. Nonetheless, as there is no known proven treatment for these types of behaviors, and no disease altering drug solutions, the experience of the caregivers involved in REACH II may very well be similar to those who were interviewed under our fourth aim. Our findings would support this as it was clear in both the secondary analyses and in the semi-structured interviews that caregivers then and now continue to find aggressive behaviors upsetting and that supportive interventions are needed.

A limitation of this dissertation study is that race/ethnic diversity was limited to White/Caucasians, Black/African-Americans, and Hispanic/Latinos. As the first part of this work was a secondary analysis of data, it was not possible to include other race/ethnicities, including Asian-Americans, further limiting the generalizability of the findings. In addition, gender and relationship were not included in the final analytic models of the secondary analyses and there was also little diversity in the qualitative study as it concerns gender and relationship. Both gender and relationship would be important factors to consider in future research examining differences in the prevalence of aggressive-type behaviors and caregiver reactions to those behaviors.

As with most in-depth, qualitative explorations of phenomena, the small sample size of participants under the fourth aim in this study potentially limits the generalizability of those findings as the sample may not be representative of a larger population. However, as the purpose of qualitative interviewing is to obtain an in-depth perspective versus generalization – this may not be a limitation.

Another potential limitation associated with the fourth aim is that the participants, primarily comprised of daughters of the person with dementia, were recruited after having either been screened for or a participating in a large intervention trial targeting neuropsychiatric behaviors. Participants in the intervention trial were randomly assigned to either the attention control or intervention groups, however both groups received exposure to resources about dementia and dementia care than they otherwise might have. Thus, caregivers participating in the qualitative interviewing may not reflect caregivers in the population who have not been exposed to dementia education. This may have biased the results of the qualitative interviews, as caregivers in either of these conditions may have been more aware of and sensitive to the needs of the person with dementia.

In both samples for this study, the stage of dementia and cognitive status of the person with dementia was not well-described, which is another limitation. The Mini-Mental State Exam was used as a proxy measure but that is insufficient to establish linkages between prevalence, disease stage, and etiology.

In both samples we also relied on caregiver report, which may have introduced bias, as caregiver depression and perceived burden has been shown to increase reporting of behavioral symptoms (Fauth & Gibbons, 2014). While triangulation of data, such as including clinician assessment or direct observation of caregiver interactions with the person with dementia, may possibly attenuate this bias, caregiver report continues to be the primary means by which behavioral symptoms are examined in the literature. Our study is consistent with this approach and as our primary interest was to examine how caregivers perceive and react to behaviors in persons with dementia, caregiver report provided valuable information that may be helpful in the development of supportive interventions in future research.

Implications

This research has a number of implications. First, aggressive behaviors in dementia are experienced by a substantial number of persons with dementia and their caregivers. With over a third of caregivers reporting at least one aggressive behavior with the preceding week in our study, it is clear that there is a pressing need for interventions to support the caregiver in preventing and managing the behaviors and to support the person with dementia to mitigate risk factors for aggressive behavior.

As nearly all initial differences in prevalence of types of aggressive behavior between race/ethnicities were not significant after adjusting for covariates, aggressive behaviors appear to occur across all race/ethnic groups similarly. Modifiable factors such as depression in the caregiver and in the person with dementia, as well as the health status of the person with dementia, were statistically significant covariates under our first aim. Thus, interventions that address these two factors, depression and health, may also result in reducing risk for aggressive behaviors.

There was significant variation in caregiver reactions by race/ethnicity to some types of aggressive behaviors under our third aim. Hispanic/Latinos experienced high upset and low confidence managing aggressive behaviors; interventions for this group that increase confidence with behavioral management may be especially helpful to these caregivers. White/Caucasians experienced high upset with aggressive behaviors and further exploration is needed to understand why their upset was significantly elevated compared to the other two groups although prevalence of behavioral occurrences were similar. Further, under our third aim, Black/African-Americans reported lower upset and higher confidence managing aggressive behavior types in this study, compared to White/Caucasians and Hispanic/Latinos. We investigated this finding further under our fourth aim and future research is needed to explore whether the strategies that emerged under that aim can be applied panculturally, informing future intervention development. For example, one finding is that Black/African-Americans appeared to be able to successfully integrate the rapidly changing dynamics of the dyadic relationship impacted by dementia. This may have implications for the development of more broadly generalizable supportive interventions that may help caregivers to decrease upset and refocus on person-centered care.

Another area of exploration that is potentially promising for intervention development is the inverse relationship between caregiver upset and confidence in managing these behaviors that we found under our second and third aims. It may be possible that supportive caregiver interventions to increase caregiver confidence in addressing different types of aggressive behaviors can lead to decreases in caregiver upset with these behaviors.

Caregiver upset associated with aggressive behaviors in dementia is concerning and provides some window into the experience of providing care in these situations. Under our fourth aim, participant descriptions of their reactions to aggressive behaviors indicate that a number of factors are involved in how caregivers experience the aggressive behavior. For example, premorbid history of conflict between the caregiver and the person with dementia may increase caregiver upset as caregivers attempt to reconcile their caregiving responsibilities with interactions that continue to echo those earlier conflicts. Interventions that help to heighten caregiver awareness of how dementia potentially can limit the ability of persons to change dementia-related patterns of behavior may decrease caregiver upset.

Conclusion

This study was the first to our knowledge that examined the prevalence of different types of aggressive behaviors in a large, diverse, community-dwelling sample of persons with dementia and their family caregivers. It is also the first to our knowledge to examine the relationships between caregiver reactions to three specific types of aggressive behavior by race/ethnicity. Previous research has tended to focus on behaviors as monolithic categories; however, our findings would suggest that caregiver reactions differ depending on the specific manifestation of these behavioral categories. Thus, this dissertation research adds to the body of knowledge on behavioral symptoms and highlights the need to deconstruct behaviors and understand the contextual factors of the environment in which they occur. Key findings under our first three aims include that behaviors overall occur in over a third of families and that caregivers reported high upset and low confidence managing aggressive behaviors, with some significant variation by type of aggressive behavior and by race/ethnicity. Under our fourth aim, Black/African-American caregivers reported challenges and strategies that suggested that these families used an ongoing active process for addressing both aggressive behaviors of the person with dementia and managing the caregivers' own reactions associated with the behaviors.

As this study suggests overall that different behavioral manifestations trigger different reactions, determining which types of aggressive behaviors are most problematic to caregivers can help us to refine our intervention approaches. Further study is needed to understand how and why caregivers may differ in reporting high upset for one type of aggressive behavior but not for another. Research is also needed to explore if the challenges and strategies that emerged under our fourth aim are common or translatable beyond this small, fairly homogeneous sample. This is important as caregiving strategies identified in this study may have the potential to be integrated into targeted interventions with caregivers from diverse backgrounds. The prevention and successfully management of aggressive behavior in dementia has the potential to greatly increase the quality of life for both caregivers and persons with dementia, and as interventions are urgently needed, it is imperative that future research in this area is prioritized.

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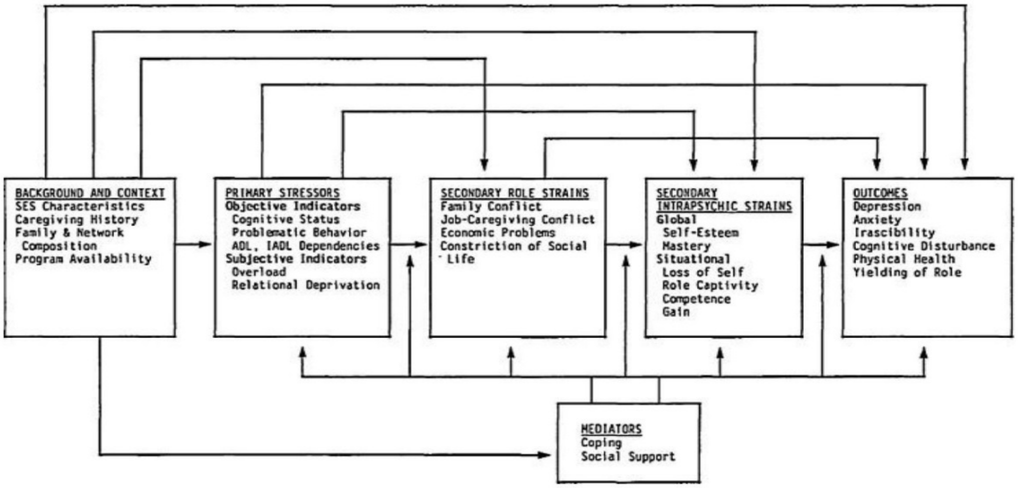
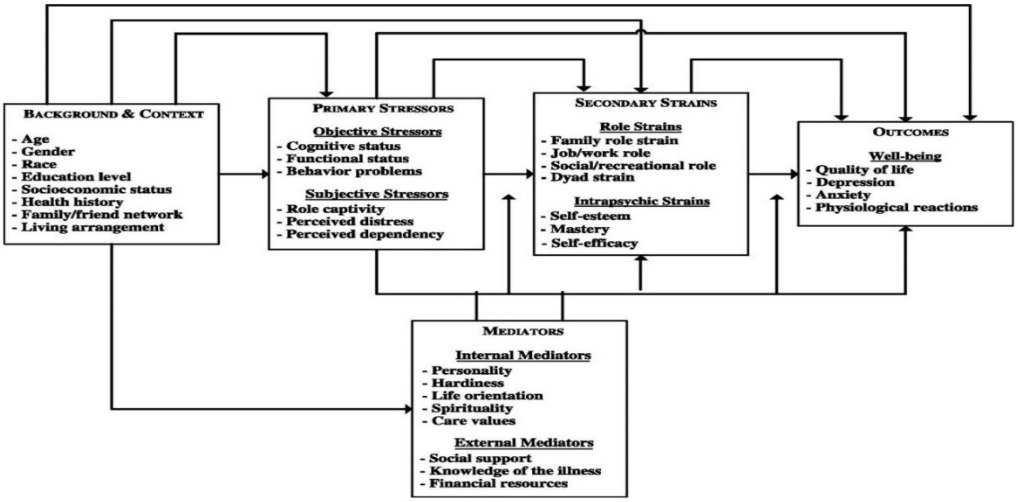
Appendix 1: Stress Process Models

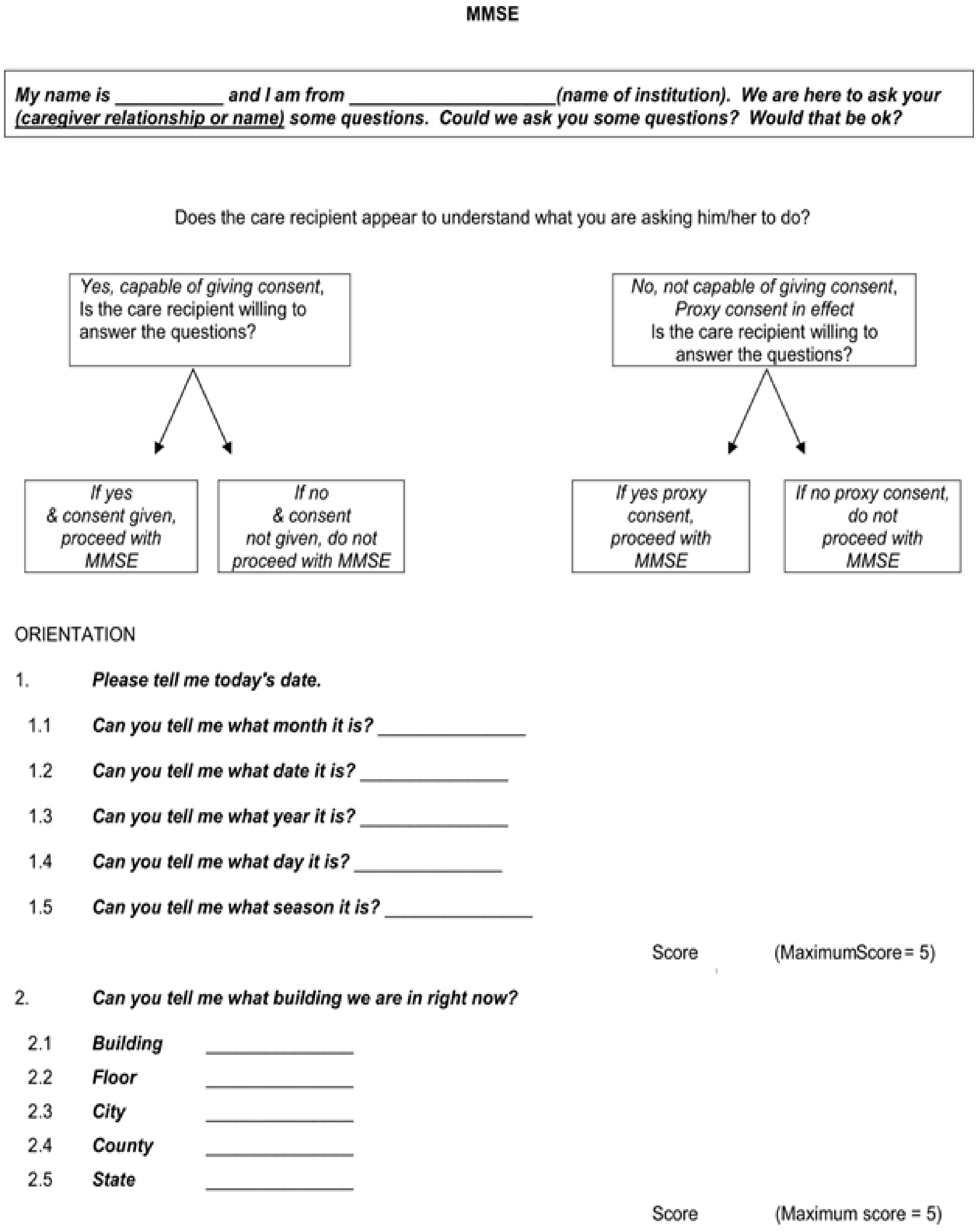
Stress Process Model for Alzheimer's Caregivers' Stress (Pearlin et al., 1990)



Stress Process Model for Individuals with Dementia (Judge et al., 2009)



Appendix 2: Mini-Mental State Exam (MMSE) (from REACH II)



MMSE

My name is ___________ and I am from ____________________(name of institution). We are here to ask your <u>(caregiver relationship or name)</u> some questions. Could we ask you some questions? Would that be ok?

Does the care recipient appear to understand what you are asking him/her to do?

Yes, capable of giving consent,
Is the care recipient willing to answer the questions?

If yes & consent given, proceed with MMSE

If no & consent not given, do not proceed with MMSE

No, not capable of giving consent,
Proxy consent in effect
Is the care recipient willing to answer the questions?

If yes proxy consent, proceed with MMSE

If no proxy consent, do not proceed with MMSE

ORIENTATION

1. ***Please tell me today's date.***

1.1 ***Can you tell me what month it is?*** _______________

1.2 ***Can you tell me what date it is?*** _______________

1.3 ***Can you tell me what year it is?*** _______________

1.4 ***Can you tell me what day it is?*** _______________

1.5 ***Can you tell me what season it is?*** _______________

Score (MaximumScore = 5)

2. ***Can you tell me what building we are in right now?***

2.1 ***Building*** _______________
2.2 ***Floor*** _______________
2.3 ***City*** _______________
2.4 ***County*** _______________
2.5 ***State*** _______________

Score (Maximum score = 5)

REGISTRATION

3. ***I'm going to name three objects, and I'd like you to repeat them after me, ok?*** (Name three objects, allotting one second to say each.)

APPLE ... TABLE ... PENNY

Give 1 point for each correct answer on the first trial only. Repeat the objects until the participant can name them all - maximum of 6 trials. Stop after 6 unsuccessful trials and enter a 7 for number of trials to indicate that they never learned the succession.

3.1 Number of trials _____

Score (Maximum score = 3)

ATTENTION AND CALCULATION

4. ***I'm going to ask you to do some subtraction. Think of the number 7. I want you to subtract 7 from 100. Now subtract 7 from that and keep going until I stop you.*** (Enter numbers given by respondent below.)

100,
4. 1 __________
4. 2 __________
4. 3 __________
4. 4 __________
4. 5 __________ (Stop)

Score *(Maximum score = 5)* ✱

5. ***I want you to spell a word forward and then backward. The word is 'WORLD.'***

5.1 ***Spell it forward.*** ____ ____ ____ ____ ____
(If incorrect, then correct the participant and allow him/her to respell it until he/she spells it correctly.)

5.2 ***Spell it backward.*** ____ ____ ____ ____ ____
(Write exact letters given by respondent in blanks.)

Score (Max score = 5) ✱

RECALL

6 . ***Do you remember a few minutes ago I had you repeat some words after me? Can you tell me what they were?*** (Give 1 point for each correct answer)

____

Score (Maximum score = 3)

LANGUAGE

7. ***Please name these for me.*** (Show the participant a wooden pencil and a watch, preferably worn on the wrist. Score 1 point for each correct answer.)

____

Score (Maximum score = 2)

8. ***I'm going to read a sentence and I want you to repeat it after me. Say exactly what I say, ok?***

NO IFS, ANDS, OR BUTS.

____

Score (Maximum score = 1;
Score 1 point only if every word is repeated correctly.)

9. ***Now I'm going to ask you to do something for me. I'm only going to say it once, so listen carefully.***

Take this paper in your right hand;
Fold the paper in half with both hands;
and put the paper in your lap.

Score (Maximum score = 3;
Score 1 point for each stage.)

10. ***Read this card, and do what the card tells you to do.*** (Show the card (RC 2) with close your eyes on it. One prompt allowed after initial instructions. Score 1 point.)

Score (Maximum score = 1)

11. ***Now please write a sentence for me on this blank piece of paper.*** (Do not dictate a sentence or provide a subject; it must be written spontaneously. Prompt as often as you like. The sentence must contain a subject and verb and be sensible. Correct grammar and punctuation not necessary. Score 1 point.)

Score (Maximum score = 1)

12. ***Please copy this design exactly as it is for me.*** (Hold the card (RC 3) with the design on it in front of the participant; do not let the participant trace the design. All 10 angles must be present and 2 must intersect to score 1 point. Tremor and rotation are ignored.)

Score (Maximum score = 1)

13. Total score

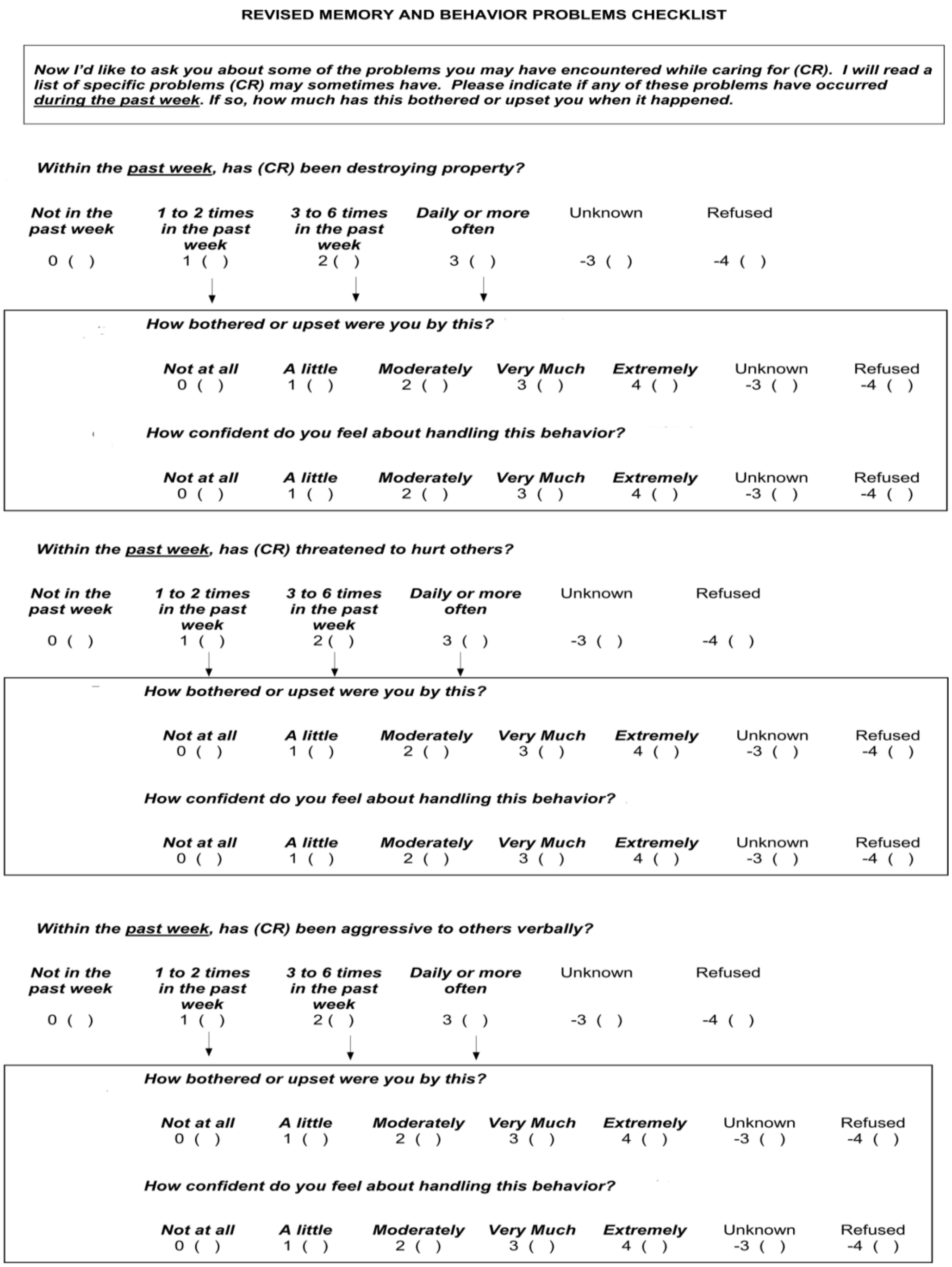
14. Is the MMSE Total Score = 0?

0 ( ) No

1 ( ) Yes

Appendix 3: Revised Memory and Behavior Checklist – Aggressive Behavior Items

(from REACH II)



REVISED MEMORY AND BEHAVIOR PROBLEMS CHECKLIST

Now I'd like to ask you about some of the problems you may have encountered while caring for (CR). I will read a list of specific problems (CR) may sometimes have. Please indicate if any of these problems have occurred <u>during the past week</u>. If so, how much has this bothered or upset you when it happened.

Within the <u>past week</u>, has (CR) been destroying property?

Not in the past week	***1 to 2 times in the past week***	***3 to 6 times in the past week***	***Daily or more often***	Unknown	Refused
0 ( )	1 ( )	2 ( )	3 ( )	-3 ( )	-4 ( )

How bothered or upset were you by this?

Not at all	***A little***	***Moderately***	***Very Much***	***Extremely***	Unknown	Refused
0 ( )	1 ( )	2 ( )	3 ( )	4 ( )	-3 ( )	-4 ( )

How confident do you feel about handling this behavior?

Not at all	***A little***	***Moderately***	***Very Much***	***Extremely***	Unknown	Refused
0 ( )	1 ( )	2 ( )	3 ( )	4 ( )	-3 ( )	-4 ( )

Within the <u>past week</u>, has (CR) threatened to hurt others?

Not in the past week	***1 to 2 times in the past week***	***3 to 6 times in the past week***	***Daily or more often***	Unknown	Refused
0 ( )	1 ( )	2 ( )	3 ( )	-3 ( )	-4 ( )

How bothered or upset were you by this?

Not at all	***A little***	***Moderately***	***Very Much***	***Extremely***	Unknown	Refused
0 ( )	1 ( )	2 ( )	3 ( )	4 ( )	-3 ( )	-4 ( )

How confident do you feel about handling this behavior?

Not at all	***A little***	***Moderately***	***Very Much***	***Extremely***	Unknown	Refused
0 ( )	1 ( )	2 ( )	3 ( )	4 ( )	-3 ( )	-4 ( )

Within the <u>past week</u>, has (CR) been aggressive to others verbally?

Not in the past week	***1 to 2 times in the past week***	***3 to 6 times in the past week***	***Daily or more often***	Unknown	Refused
0 ( )	1 ( )	2 ( )	3 ( )	-3 ( )	-4 ( )

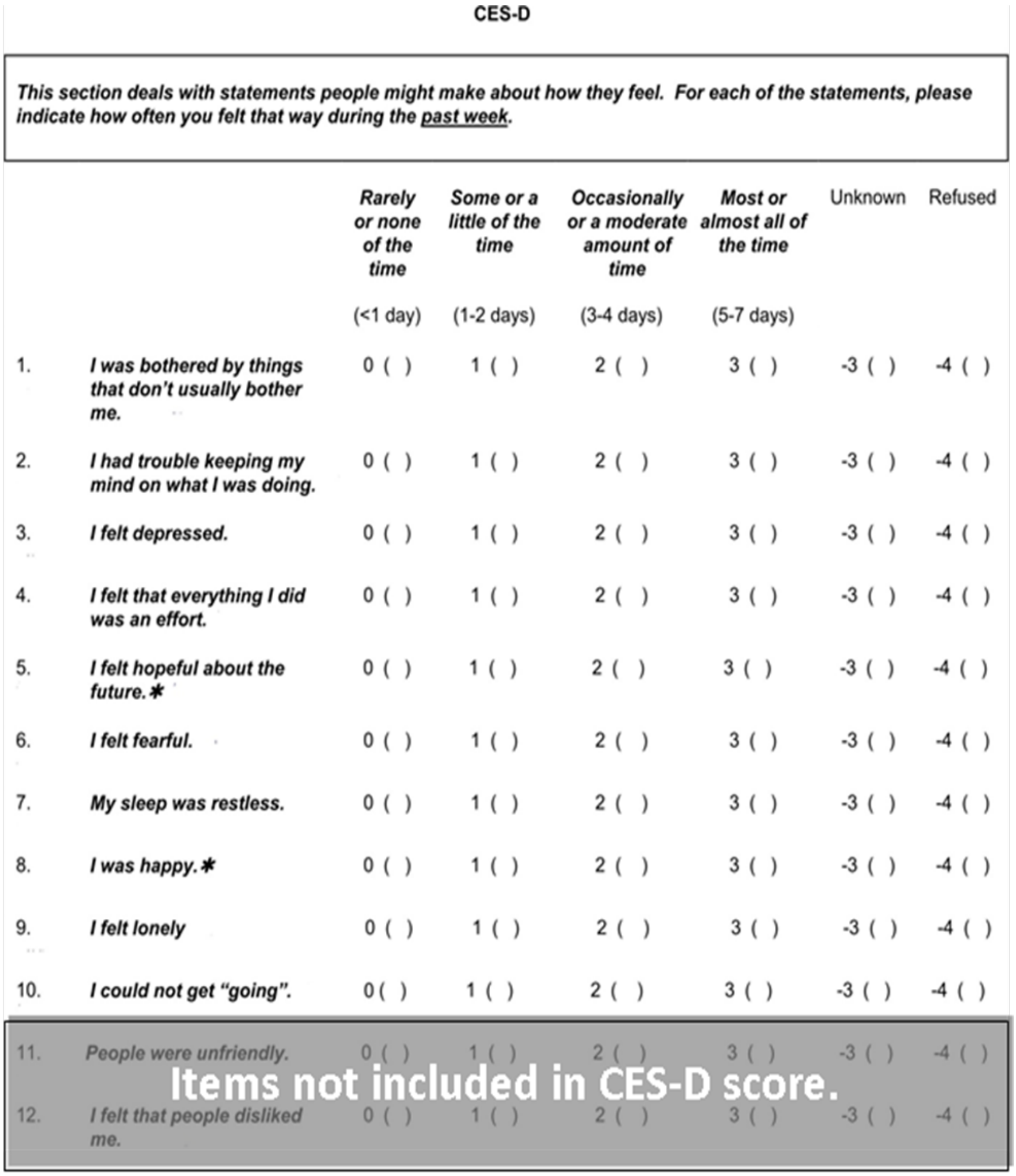
How bothered or upset were you by this?

Not at all	***A little***	***Moderately***	***Very Much***	***Extremely***	Unknown	Refused
0 ( )	1 ( )	2 ( )	3 ( )	4 ( )	-3 ( )	-4 ( )

How confident do you feel about handling this behavior?

Not at all	***A little***	***Moderately***	***Very Much***	***Extremely***	Unknown	Refused
0 ( )	1 ( )	2 ( )	3 ( )	4 ( )	-3 ( )	-4 ( )

Appendix 4: Center for Epidemiological Studies on Depression (CES-D) (from REACH II)

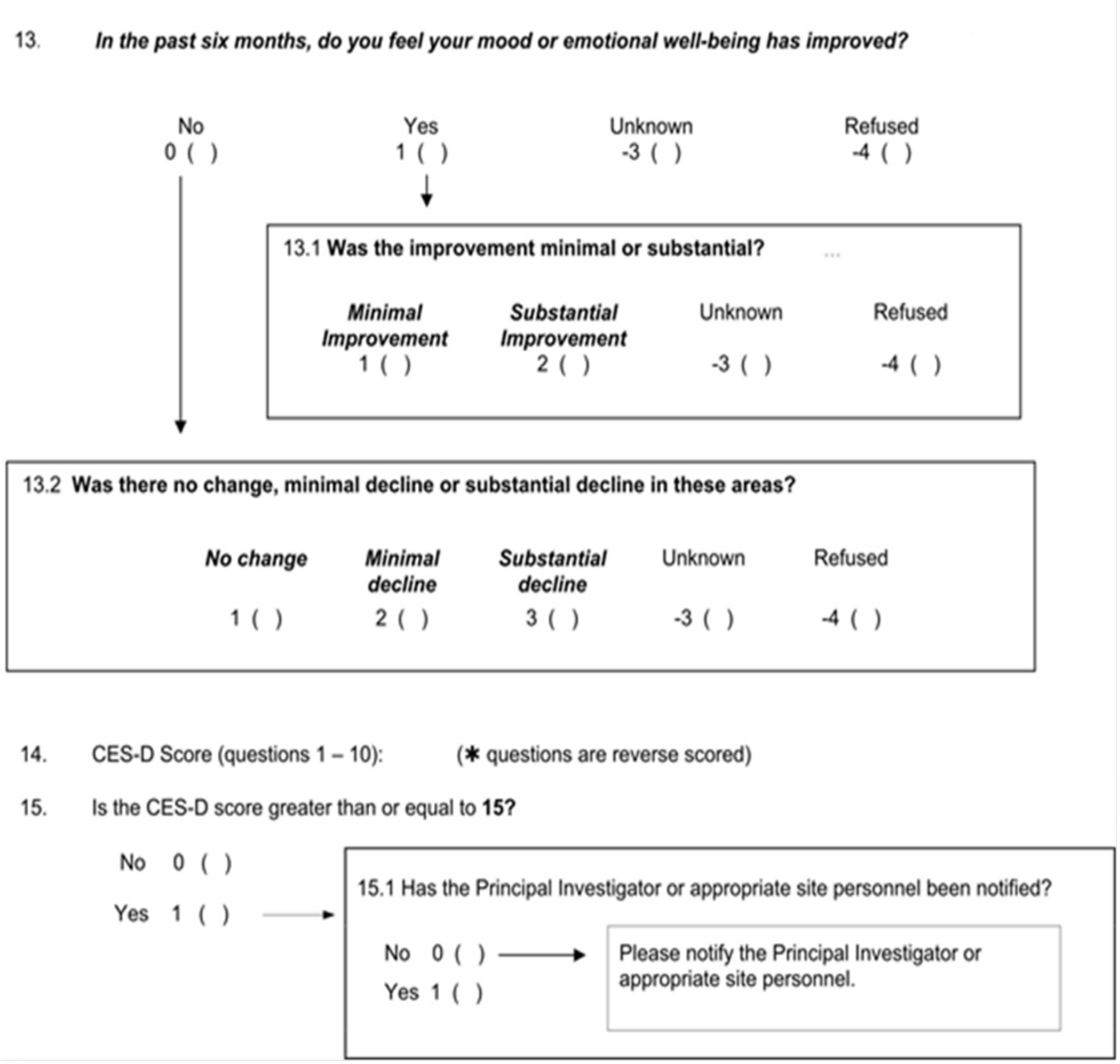


CES-D

This section deals with statements people might make about how they feel. For each of the statements, please indicate how often you felt that way during the past week.

		Rarely or none of the time (<1 day)	***Some or a little of the time*** (1-2 days)	***Occasionally or a moderate amount of time*** (3-4 days)	***Most or almost all of the time*** (5-7 days)	Unknown	Refused
1.	***I was bothered by things that don't usually bother me.***	0 ( )	1 ( )	2 ( )	3 ( )	-3 ( )	-4 ( )
2.	***I had trouble keeping my mind on what I was doing.***	0 ( )	1 ( )	2 ( )	3 ( )	-3 ( )	-4 ( )
3.	***I felt depressed.***	0 ( )	1 ( )	2 ( )	3 ( )	-3 ( )	-4 ( )
4.	***I felt that everything I did was an effort.***	0 ( )	1 ( )	2 ( )	3 ( )	-3 ( )	-4 ( )
5.	***I felt hopeful about the future.*** ✱	0 ( )	1 ( )	2 ( )	3 ( )	-3 ( )	-4 ( )
6.	***I felt fearful.***	0 ( )	1 ( )	2 ( )	3 ( )	-3 ( )	-4 ( )
7.	***My sleep was restless.***	0 ( )	1 ( )	2 ( )	3 ( )	-3 ( )	-4 ( )
8.	***I was happy.*** ✱	0 ( )	1 ( )	2 ( )	3 ( )	-3 ( )	-4 ( )
9.	***I felt lonely***	0 ( )	1 ( )	2 ( )	3 ( )	-3 ( )	-4 ( )
10.	***I could not get "going".***	0( )	1 ( )	2 ( )	3 ( )	-3 ( )	-4 ( )
11.	*People were unfriendly.*	0 ( )	1 ( )	2 ( )	3 ( )	-3 ( )	-4 ( )
12.	*I felt that people disliked me.*	0 ( )	1 ( )	2 ( )	3 ( )	-3 ( )	-4 ( )

Items not included in CES-D score.



13. ***In the past six months, do you feel your mood or emotional well-being has improved?***

No	Yes	Unknown	Refused
0 ( )	1 ( )	-3 ( )	-4 ( )

13.1 **Was the improvement minimal or substantial?**

Minimal Improvement	***Substantial Improvement***	Unknown	Refused
1 ( )	2 ( )	-3 ( )	-4 ( )

13.2 **Was there no change, minimal decline or substantial decline in these areas?**

No change	***Minimal decline***	***Substantial decline***	Unknown	Refused
1 ( )	2 ( )	3 ( )	-3 ( )	-4 ( )

14. CES-D Score (questions 1 – 10): (✱ questions are reverse scored)

15. Is the CES-D score greater than or equal to **15?**

No 0 ( )

Yes 1 ( ) →

15.1 Has the Principal Investigator or appropriate site personnel been notified?

No 0 ( ) → Please notify the Principal Investigator or appropriate site personnel.

Yes 1 ( )

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Curriculum Vitae

Part I

PERSONAL DATA

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EDUCATION

2009-2015	Doctor of Philosophy (PhD), The Johns Hopkins University School of Nursing, Baltimore, Maryland
2009-2012	Master of Science in Nursing (MSN), The Johns Hopkins University School of Nursing, Baltimore, Maryland
2009-2012	Post-Master's Certificate in Forensic Nursing, The Johns Hopkins University School of Nursing, Baltimore, Maryland
2006-2009	Bachelor of Science in Nursing (BSN), Morningside College, Sioux City, Iowa

CURRENT LICENSE AND CERTIFICATION

2009-Present	Maryland Board of Nursing, Registered Nurse, License #R186586

EXPERIENCE

Professional

2015-Present	Research Assistant, Reducing Agitation in People with Dementia: The Customized Activity Trial (Study # NIH 1 R01 AG041781-01A1) (Tailored Activity Program), Laura N. Gitlin, Ph.D., Principal Investigator, Center for Innovative Care in Aging, The Johns Hopkins University School of Nursing, Baltimore, Maryland.
2014-Present	Consultant, Forensic Nurse Examiner Program, Mercy Medical Center, Baltimore, Maryland

2012-2014	Research Assistant, Reducing Agitation in People with Dementia: The Customized Activity Trial (Study # NIH 1 R01 AG041781-01A1) (Tailored Activity Program), Laura N. Gitlin, Ph.D., Principal Investigator, Center for Innovative Care in Aging, The Johns Hopkins University School of Nursing, Baltimore, Maryland.
2012-2014	Forensic Nurse Examiner-Adult (FNE-A), Mercy Medical Center, Baltimore, Maryland
2012-2013	Psychiatric Clinical Instructor, The Johns Hopkins University School of Nursing, Baltimore, Maryland
2009-2011	Nurse Clinician I (NCI), Department of Psychiatry, The Johns Hopkins Hospital, Baltimore, Maryland
2008-2009	Hospice Volunteer, Hospice of Siouxland, Sioux City, Iowa
2007-2009	Court Appointed Special Advocate (CASA) for Children and Guardian ad litem, Woodbury County Child Advocacy Board, Sioux City, Iowa
2007-2009	Tutor, Department of Nursing, Morningside College, Sioux City, Iowa
2007-2008	Volunteer Advocate, Council on Sexual Assault and Domestic Violence, Sioux City, Iowa
2005-2006	Tutor, North Hennepin Community College, Brooklyn Park, Minnesota
2005-2006	Assistant to Death Investigator, Death Investigation Unit, Hennepin County Medical Examiner's Office, Minneapolis, Minnesota
1993-2004	Missionary and Ministry Worker, Nondenominational Christian Fellowship, United States and Canada
1990-1991	Certified Nursing Assistant, Buena Vista Care Manor, Storm Lake, Iowa

Clinical Training

Fall, 2011	Fall Semester MSN Clinical with Chief Nurse and Medical Director, Office of Health Care Quality (OHCQ), Maryland Department of Health and Mental Hygiene, Baltimore, Maryland
Summer, 2011	Summer Semester MSN Clinical with Nurse Analyst, Abuse and Neglect Investigations, Medicaid Fraud Control Unit (MFCU), Maryland Office of the Attorney General, Baltimore, Maryland
Summer, 2011	Summer Semester MSN Clinical with Nurse Surveyor, Complaint Surveys, Long-Term Care Unit, Office of Health

	Care Quality (OHCQ), Maryland Department of Health and Mental Hygiene, Baltimore, Maryland
Spring, 2011	Spring Semester MSN Clinical with Clinical Nurse Specialist, University of Maryland Shock Trauma Center, Baltimore, Maryland
Summer, 2008	Summer III Clinical Nurse Extern, Mayo Clinic, Rochester, Minnesota

RESEARCH

2013-2014	Research residency, Reducing Agitation in People with Dementia: The Customized Activity Trial (NIH 1 R01 AG041781-01A1), Laura N. Gitlin, Ph.D., Principal Investigator, Center for Innovative Care in Aging, The Johns Hopkins University School of Nursing, Baltimore, Maryland.
2012-2013	Research residency, Managing Behavior in Nursing Homes: Innovative Intervention and Methods (Alzheimer's Association), Laura N. Gitlin, PhD, Principal Investigator, Center for Innovative Care in Aging, The Johns Hopkins University School of Nursing, Baltimore, Maryland.
2012	Research residency, Secondary Analysis of Qualitative Interviews with African-American Older Adults, (NIH R24 MH074779, RO1 MH079814, Laura N. Gitlin, PhD, RN, Principal Investigator), Nancy A. Hodgson, PhD, RN, Principal Investigator, The Johns Hopkins University School of Nursing, Baltimore, Maryland.
2011-2012	Predoctoral Health Disparities Research Fellow, Institutional NRSA for Interdisciplinary Health Disparities Research, (NIH T32NR007968), Jerilyn K. Allen, ScD, RN, FAAN, Principal Investigator, The Johns Hopkins University School of Nursing, Baltimore, Maryland.

HONORS AND AWARDS

2014	Graduate Teaching Award, The Johns Hopkins University School of Nursing
2014	School of Nursing Informers and Educators (SONIE) Award, The Johns Hopkins University School of Nursing
2013-2015	John A. Hartford National Hartford Center of Gerontological Nursing Excellence Patricia G. Archbold Scholar
2012-2013	Ellen Levi Zamoiski Fellow, The Johns Hopkins University School of Nursing

2011-2012	Predoctoral Health Disparities Research Fellow, Institutional NRSA for Interdisciplinary Health Disparities Research (NIH T32NR007968)
2010-2012	Jonas Scholar, Jonas Center for Nursing Excellence
2009-2010	Predoctoral Fellow, Dr. Scholl Foundation
2009-2010	Caylor Fellow, The Johns Hopkins University School of Nursing
2009	Summa Cum Laude, Morningside College
2009	Lorraine E. Knepper Award in Nursing for Academic Excellence, Morningside College
2009	First Place, Palmer Student Research Symposium, Morningside College
2009	Inductee, Sigma Theta Tau International
2008	Inductee, Omicron Delta Kappa
2008	Inductee, Psi Chi
2007	Professional Development and Achievement Award, Department of Nursing, Morningside College

SCHOLARSHIP (*data-based)

Research

1. ***Hansen, B.R.**, Hodgson, N.A. & Gitlin, L.N. (in press, 2015). It's a matter of trust: Older African-Americans speak about health care encounters. *Journal of Applied Gerontology*.
2. *Marx, K.A., Stanley, I.H., Van Haitsma, K., Moody, J., Alonzi, D., **Hansen, B.R.** & Gitlin, L.N. (2014). Knowing versus doing: Education needs of staff in a chronic care hospital unit for persons with dementia. *Journal of Gerontological Nursing, 40*(12), 26-37.
3. *Draughon, J. E., Anderson, J. C., **Hansen, B. R.**, & Sheridan, D. J. (2014). Nonoccupational postexposure HIV prophylaxis in sexual assault programs: A survey of SANE and FNE program coordinators. *Journal of the Association of Nurses in AIDS Care*, *25*(1), S90-S100.

Reviews

1. Gitlin, L.N., Marx, K.A., Stanley, I.H., **Hansen, B.R.** & Van Haitsma, K. (2014). Assessing neuropsychiatric symptoms in people with dementia: A systematic review of measures. *International Psychogeriatrics, 26*(11), 1805-48.

Non-Peer Reviewed

1. **Hansen, B.R.** (Apr, 2015). Presenting a professional image in a crowded social media world. *Advances in Nursing Doctoral Education & Research, 3*(1), 20-21.

1. **Hansen, B.** & Sheridan, D.J. (Winter, 2011). Assessing for injuries from physical abuse. *Kentucky Association of Health Care Facilities Newsletter*, 6-7.

Presentation Abstracts

1. ***Hansen, B.R.**, Hodgson, N.A., Budhathoki, C., & Gitlin, L.N., (2015). Caregivers' reactions to aggressive behaviors in persons with dementia in a geographically and racially/ethnically diverse community-dwelling sample. In **B.R. Hansen** (Chair), *Exploring Highly Challenging Behavioral Symptoms in Dementia: Restlessness, Rejection of Care, and Aggression.* Symposium conducted at the Gerontological Society of America, 68th Annual Scientific Meeting, Orland, FL.
2. ***Hansen, B.R.** & Hodgson, N.A., (2014). "The work of our hands": Qualitative analysis of a caregiver discussion board. In N. Hodgson (Chair), *The impact of creative and meaningful activities on neuropsychiatric symptoms in persons with dementia*. Symposium conducted at the Gerontological Society of America, 67th Annual Scientific Meeting, Washington, D.C.
3. ***Hansen, B.R.**, Hodgson, N.A., & Gitlin, L.N., (2014). Prevalence of aggressive behaviors in persons with dementia by caregiver report in a diverse, community-dwelling sample. In **B.R. Hansen** (Chair), *Understanding Behavioral Symptoms in Persons with Dementia: Characteristics, Associations, and Measurement.* Symposium conducted at the Gerontological Society of America, 67th Annual Scientific Meeting, Washington, D.C.
4. Gitlin, L.N., Marx, K.A., Van Haitsma, K., **Hansen, B.R.**, & Kolanowski, A.M., (2013). Assessing behavioral health: A review of measures. In M. Trahan (Chair), *Activity as a therapeutic modality in dementia care: Theoretical and applied.* Symposium conducted at the Gerontological Society of America, 66th Annual Scientific Meeting, New Orleans, Louisiana.
5. Gitlin, L.N., Marx, K.A., Van Haitsma, K., **Hansen, B.R.**, Alonzi, D., Wentlejeski, D., & Gentile, T., (2013). Can activity reduce behavioral symptoms in hospitalized dementia patients? In A. Kolanowski (Chair), *Toolbox for improving behavioral health in nursing homes.* Symposium conducted at the Gerontological Society of America, 66th Annual Scientific Meeting, New Orleans, Louisiana.
6. *Marx, K.A., Gitlin, L.N., Goldhammer, T., **Hansen, B.R.**, & Sodero, J., (2013). Home hazards and mood in an older Latino population. In S. Szanton (Chair), *Reducing risk factors at home to improve function: Findings of studies from 3 continents.* Symposium conducted at the Gerontological Society of America, 66th Annual Scientific Meeting, New Orleans, Louisiana.
7. *Draughon, J.E., Anderson, J., **Hansen, B.R.** & Sheridan, D.J. (2012). Sexual assault program HIV PEP practices survey. Paper presented at the Scientific Assembly of the International Association of Forensic Nursing. San Juan, Puerto Rico.

Poster Abstracts

1. ***Hansen, B.R.**, Hodgson, N.A., & Gitlin, L.N., (2014). Caregiver upset with and confidence managing aggressive behaviors in persons with dementia in a community-dwelling sample. Poster presented at the 2014 National Hartford Center of Gerontological Nursing Excellence Academic Leadership Conference, Washington D.C.
2. *Marx, K.A., Gitlin, L.N., Van Haitsma, K., **Hansen, B.R.**, Nelson, A., Alonzi, D., & Moody, J., (2013). Caring for older adults with dementia in a chronic care hospital: Staff knowledge and unmet needs. Poster presented at the 8th Annual Bayview Research Symposium, Johns Hopkins Bayview Hospital, Baltimore, Maryland.
3. *Marx, K.A., Gitlin, L.N., Van Haitsma, K., **Hansen, B.R.**, Nelson, A., Alonzi, D., & Moody, J., (2013). Caring for older adults with dementia in a chronic care hospital: Staff knowledge and unmet needs. Poster presented at the Gerontological Society of America, 66th Annual Scientific Meeting, New Orleans, Louisiana.
4. ***Hansen, B.R.**, Hodgson, N.A. & Gitlin, L.N., (2013). It's a matter of trust: Older African Americans speak about health care encounters. Poster presented at the Gerontological Society of America, 66th Annual Scientific Meeting, New Orleans, Louisiana.
5. **Hansen, B.R.** & Sheridan, D.J., (2012). Early identification of pressure ulcers using assistive technologies: A systematic review. Poster presented at the Scientific Assembly of the International Association of Forensic Nursing. San Juan, Puerto Rico.

Blog Posts

1. **Hansen, B.R.** (2014, June 26). Aggressive behaviors in dementia: Delivering care while perceiving threat. Retrieved from http://nyceac.com/elder-justice-dispatchaggressive-behaviors-in-dementia-delivering-care-while-perceiving-threat/

In Preparation

1. ***Hansen, B.R.**, Hodgson, N.A., & Gitlin, L.N. (dissertation manuscript, in preparation). Perspectives on aggressive behaviors in dementia among African-American caregivers.
2. ***Hansen, B.R.**, Hodgson, N.A., Budhathoki, C., & Gitlin, L.N. (dissertation manuscript, in preparation). Caregiver Reactions to aggressive behaviors in persons with dementia in a diverse, community-dwelling sample.
3. ***Hansen, B.R.**, Hodgson, N.A., Budhathoki, C., & Gitlin, L.N. (dissertation manuscript, in preparation). Prevalence and correlates of aggressive behaviors in persons with dementia in a diverse, community-dwelling sample.
4. **Hansen, B.R.**, & Holbrook, D. (in preparation). Therapeutic nursing presence in forensic examinations: Respect, dignity, and healing.

5. **Hansen, B.R.**, Hodgson, N.A, & Gitlin, L.N. (in preparation). Defining the boundaries of dueling roles: The clinician as researcher and interventionist.

EDITORIAL ACTIVITIES

2014-2015	Gerontological Society of America, Conference Abstract Reviewer
2013	Journal of Interpersonal Violence, Ad-Hoc Reviewer
2013	Journal of the American Geriatrics Society, Ad-Hoc Reviewer
2012	The Gerontologist, Ad-Hoc Reviewer

PROFESSIONAL ACTIVITIES

Society/Association Membership

2012-Present	Gerontological Society of America, Member
2011-Present	American Geriatrics Society, Member
2010-Present	National Committee for the Prevention of Elder Abuse, Member
2010-Present	Sigma Theta Tau International, Nu Beta Chapter (312), Member
2009-Present	Sigma Theta Tau International, Theta Gamma-at-Large Chapter (193), Member
2009-Present	American Nurses Association, Member
2006-Present	International Association of Forensic Nursing, Member

Professional Meetings

International

2013	Attendee, International Association of Forensic Nursing, 21st International Conference on Forensic Nursing Science and Practice, Anaheim, California, October 21-25
2012	Presenter, International Association of Forensic Nursing, 20th Annual Scientific Assembly, Fajardo, Puerto Rico, October 11-14
2011	Attendee, International Association of Forensic Nursing, 19th Annual Scientific Assembly, Pittsburgh, Pennsylvania, October 19-22

2010	Attendee, International Association of Forensic Nursing, 18th Annual Scientific Assembly, Montreal, Quebec, Canada, October 27-30

National

2014	Presenter, Gerontological Society of America, 67th Annual Scientific Meeting, Washington, D.C., November 5-9
2014	Presenter, National Hartford Center for Geriatric Nursing Excellence Leadership Conference, Washington, D.C., November 4-5
2014	Invited Attendee, Dementia Action Alliance 2014 Dementia Thought Leaders Invitational Summit, Washington D.C., June 30
2014	Student Assistant, Elder Justice Roadmap Project, Project Planning Group meeting, U.S. Department of Justice, Washington D.C., February 18-19
2013	Presenter, Gerontological Society of America, 66th Annual Scientific Meeting, New Orleans, Louisiana, November 20-24
2013	Invited Attendee, National Hartford Centers for Geriatric Nursing Excellence Leadership Conference, New Orleans, Louisiana, November 18-20
2012	Attendee, Gerontological Society of America, 65th Annual Scientific Meeting, San Diego, California, November 14-18
2010	Invited Attendee, Jonas Leaders Scholar Conference, American Association of Colleges of Nursing, Washington, D.C., October 31-November 2

Regional

2011	Attendee, Disaster Mortuary Operational Response Team, Region III Training, Gettysburg, Pennsylvania, March 25-27
2008	Delegate, Iowa Association of Nursing Students, Annual Convention, Coralville, Iowa, October 27-28
2007	Delegate, Iowa Association of Nursing Students, Annual Convention, Des Moines, Iowa, October 22-23
2006	Delegate, Iowa Association of Nursing Students, Annual Convention, Des Moines, Iowa, October 5-6

Curriculum Vitae

Part II

TEACHING ACTIVITIES

Fall, 2015	Guest Lecturer, Topic: Elder Abuse, NR.110.305.0101/.0201 Nursing Care for Older Adults across the Continuum, Prelicensure, 120 students, The Johns Hopkins University School of Nursing, Baltimore, MD
Spring, 2015	Guest Lecturer, Topic: Elder Abuse, NR.110.305.0101/.0201 Nursing Care for Older Adults across the Continuum, Undergraduate, 180 students, The Johns Hopkins University School of Nursing, Baltimore, MD
Fall, 2014	Guest Presenter, Topic: Reducing Use of Seclusion and Restraint in Acute Psychiatric Care as a New Nurse, NR.110.312 Psychiatric Mental Health Nursing, Undergraduate, 8 students, The Johns Hopkins University School of Nursing, Baltimore, MD
Fall, 2014	Guest Lecturer, Topic: Elder Abuse, NR.110.305.0101/.0201 Nursing Care for Older Adults across the Continuum, Undergraduate, 180 students, The Johns Hopkins University School of Nursing, Baltimore, MD
Summer, 2014	Guest Lecturer, Topic: Healthcare Reform, NR.110.306.0201 Professional Role Development in Nursing, Undergraduate, 60 students, The Johns Hopkins University School of Nursing, Baltimore, MD
Summer, 2014	Teaching Resident, NR.110.306.0201 Professional Role Development in Nursing, Undergraduate, 60 students, The Johns Hopkins University School of Nursing, Baltimore, MD
Spring, 2014	Invited Presenter, Topic: Elder Abuse: Research and Policy Developments, NR.110.818 Special Topics in Violence Research, 10 students, The Johns Hopkins University School of Nursing, Baltimore, MD
Spring, 2014	Invited Presenter, Topic: Elder Abuse, NR.110.593 Family Violence, Graduate and Undergraduate, 30 students, The Johns Hopkins University School of Nursing, Baltimore, MD
Spring, 2014	Guest Lecturer, Topic: Elder Abuse, NR.110.305.0101/.0201 Nursing Care for Older Adults across the Continuum, Undergraduate, 159 students, The Johns Hopkins University School of Nursing, Baltimore, MD

Spring, 2014	Teaching Resident, NR.110.305.0201 Nursing Care for Older Adults across the Continuum, Undergraduate, 80 students, The Johns Hopkins University School of Nursing, Baltimore, MD
Fall, 2013	Guest Lecturer, Topic: Elder Abuse, NR.110.305.0101/.0201/.0301 Nursing Care for Older Adults across the Continuum, Undergraduate, The Johns Hopkins University School of Nursing, Baltimore, MD
Fall, 2013	Teaching Resident, Coursera Massive Open Online Course: Care of Elders with Alzheimer's Disease and other Major Neurocognitive Disorders, Open Enrollment, 20,000+ students, The Johns Hopkins University School of Nursing, Baltimore, MD
Fall, 2013	Guest Lecturer, Topic: Characterizing Neuropsychiatric Symptoms in Dementia using a Case Study Approach, Coursera Massive Open Online Course: Care of Elders with Alzheimer's Disease and other Major Neurocognitive Disorders, Open Enrollment, 20,000+ students, The Johns Hopkins University School of Nursing, Baltimore, MD
Spring, 2013	Teaching Resident, NR.110.305.0101/.0201 Nursing Care for Older Adults across the Continuum, Undergraduate, 150 students, The Johns Hopkins University School of Nursing, Baltimore, MD
Spring, 2013	Guest Lecturer, Topic: Delirium, Depression, Dementia, NR.110.305.0101/0201 Nursing Care for Older Adults across the Continuum, Undergraduate, 150 students, The Johns Hopkins University School of Nursing, Baltimore, MD
Spring, 2013	Guest Lecturer, Topic: Delirium, Depression, Dementia, NR.110.305.0301 Nursing Care for Older Adults across the Continuum, Undergraduate, 4 students, The Johns Hopkins University School of Nursing, Baltimore, MD
Spring, 2013	Clinical Instructor, NR.110.312 Psychiatric Mental Health Nursing, Undergraduate, 8 students, The Johns Hopkins University School of Nursing, Baltimore, MD
Spring, 2013	Invited Presenter, Topic: Elder Abuse, NR.110.593 Family Violence, Graduate and Undergraduate, 25 students, The Johns Hopkins University School of Nursing, Baltimore, MD
Spring, 2013	Clinical Instructor, NR.110.312 Psychiatric Mental Health Nursing, Undergraduate, 7 students, The Johns Hopkins University School of Nursing, Baltimore, MD
Fall, 2012	Clinical Instructor, NR.110.312 Psychiatric Mental Health Nursing, Undergraduate, 7 students, The Johns Hopkins University School of Nursing, Baltimore, MD

Spring, 2012	Invited Presenter, Topic: Elder Abuse, NR.110.593 Family Violence, Graduate and Undergraduate, 20 students, The Johns Hopkins University School of Nursing, Baltimore, MD
Spring, 2011	Teaching Resident, NR.110.312 Psychiatric Mental Health Nursing, Undergraduate, 75 students, The Johns Hopkins University School of Nursing, Baltimore, MD
Spring, 2011	Guest Lecturer, Topic: Managing Aggressive Behaviors in Patients in Psychiatric Treatment Settings, NR.110.312 Psychiatric Mental Health Nursing, Undergraduate, 75 students, The Johns Hopkins University School of Nursing, Baltimore, MD

SERVICE AND LEADERSHIP ACTIVITIES

2015	Student Ambassador, Basic and Advanced Summer Research Institute, Center for Innovative Care in Aging, The Johns Hopkins University School of Nursing, Baltimore, MD, June 8-12
2015	Invited Participant, United States Young Leaders Discussion Series for Innovative Ideas to Address Dementia, United Kingdom Science and Innovation Network, American Association for the Advancement of Science, Washington, DC, February 9
2014-2015	Member, Elder Justice Roadmap National Training Plan Working Group, Washington, DC
2014-2015	Student Representative, Strategic Planning Initiative, Professional Development Office, The Johns Hopkins Medical Institutions, Baltimore, MD
2014	Student Ambassador, Summer Research Institute, Center for Innovative Care in Aging, The Johns Hopkins University School of Nursing, Baltimore, MD, June 11-13
2013-2015	Representative, Mentoring Committee, Emerging Scholar and Professional Organization (ESPO), The Gerontological Society of America, Washington, DC.
2013	Student Ambassador, Summer Research Institute, Center for Innovative Care in Aging, The Johns Hopkins University School of Nursing, Baltimore, MD, June 12-14
2012	Student Ambassador, Summer Research Institute, Center for Innovative Care in Aging, The Johns Hopkins University School of Nursing, Baltimore, MD, June 14-16

2011-2012	PhD Curriculum Committee Representative, Doctoral Students Organization, The Johns Hopkins University School of Nursing, Baltimore, MD
2011	Invited Presenter, Introductory Workshop, Robert Wood Johnson New Careers in Nursing, The Johns Hopkins University School of Nursing, Baltimore, MD, May 20
2010-2011	Secretary, Doctoral Students Organization, The Johns Hopkins University School of Nursing, Baltimore, MD
2009	Invited Presenter, Doctoral Program Donor Seminar, The Johns Hopkins University School of Nursing, Baltimore, MD, October 26
2008-2009	Student Representative, Nurse Faculty Search Committee, Morningside College, Sioux City, IA
2006-2009	Class Representative, Department of Nursing Faculty Council, Morningside College, Sioux City, IA