DEMENTIA CAREGIVING AND DISRUPTIVE BEHAVIORS: THE AFRICAN AMERICAN EXPERIENCE

by

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"So don't get tired of doing what is good. Don't get discouraged and give up, for we will reap a harvest of blessing at the appropriate time." (Galatians 6:9)

DEDICATION

To my family, person’s with dementia, their caregivers, and the many families affected by dementia.

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First, I give thanks and all praise to God because without Him, none of this would be possible.

I want to thank my grandmother who has been my inspiration for researching, helping, and serving older adults. We have shared many adventures and laughs by ourselves, with your friends, and with your siblings. I guess it was only natural to develop the passion I have for the elderly. Thank you for being my best friend and always listening. You have been a constant blessing to my life in so many ways, but without your prayers, support, and unconditional love, I can't begin to imagine where I would be. Your examples of patience, strength, and faith have encouraged me during some of my weakest moments. This achievement represents what our ancestors could not imagine and I'm thankful you have been able to share and witness the journey. I love you.

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ABSTRACT

Dementia Caregiving and Disruptive Behaviors: The African American Experience

by

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The purpose of this study was to examine the African American (AA) dementia caregiving experience for community dwelling caregivers in the context of disruptive behaviors. A secondary analysis, utilizing the Aging and Demographics Study (N=742) was performed to examine background and proximal factors influencing disruptive behaviors among White and AA subjects. The Need Driven Dementia Compromised Behavior Model (NDB) was used as a framework. Logistic regression models examined associations among behavioral outcomes (hallucinations, delusions, agitation, and depression). Significant differences pertaining to background factors of the NDB model and variables associated with dementia/behavioral risk as well as behavioral outcomes were found between AA and White subjects for type of dementia, education, number of medications, number of conditions/procedures, MMSE scores, and the behavioral outcome of depression ($p<0.05$). Background factors demonstrated that disruptive behaviors were associated with increased odds of occurring if subjects with dementia had increased age (OR=1.02, 95%CI=1.00-1.05), cognitive impairment (OR=0.92, 95% CI=0.84-1.00), functional impairment (OR=1.16, 95%CI=1.10-1.22), were female (OR=2.81, 95% CI=1.41-5.61), were White (OR=0.37, 95%CI=0.20-0.67), and had increased number of medical diagnoses or conditions (OR=1.16, 95% CI=1.09-1.24). Significant differences pertaining to proximal factors of the NDB model for care recipients and variables associated with behavioral risk were found between AA and White subjects for sleep changes, type of relationship with caregiver, and frequency of contact with caregiver ($p<0.05$). Proximal analyses revealed disruptive behaviors were associated with increased odds of occurring if subjects were White (OR=0.14 95% CI=0.04-0.50), with increasing age (OR=1.04 (1.00-1.08)], with decreased frequency of contact [OR 3.92 (1.20-12.77)], increased hours/day of care [OR 1.05 (1.01-1.09)], and non-family caregiver provision [OR 7.33 (1.26-42.64)]. Decreased odds of disruptive behaviors occurring were associated with the absence of hunger changes [OR 0.31 (0.21-0.47)] and sleep changes [OR 0.67 (0.46-1.00)].

Recommendations for future research, practice, and policy include revisiting the literature, expanding research strategies, community based interventions, increased education of caregivers/care recipients, reimbursements for caregivers, and the initiation and continuation of local, state, and federal funding for research.

CHAPTER 1: INTRODUCTION

Background

In general, dementia describes a syndrome of neurodegenerative diseases affecting memory/recall, executive function, and daily activity performance (Cotter, 2007; Harwood & Ownby, 2000). The Diagnostic and Statistical Manual of Mental Disorders (APA, 2000) characterize dementia by intellectual decline, such as problems with abstract thinking or complex behavior, and memory. However, before a diagnosis of dementia can be made, significant difficulty in memory in combination with one or more of the disturbances of aphasia (loss of language), apraxia (loss of intentional movement), and agnosia (inability to recognize objects) must be present.

There are numerous causes and multiple risk factors involved related to irreversible dementia syndromes. Alzheimer's disease (AD) and vascular dementia (VaD) are the most common irreversible forms of dementia representing 50% and 15% respectively (Cotter, 2007; Dugue, Neugroschl, Sewell, & Marin, 2003). AD is the third costliest disease with reported projections upwards of $100 billion dollars and national expenditures projected to triple over the next 40 years (Sanders & Morano, 2008; Nichols, Chang, Lummus, Burns, Martindale-Adams, Graney, et al., 2008; Algase, 2007; Cotter, 2007; Messinger-Rapport, McCallum, & Hujer, 2006). Approximately 5 million individuals are affected by dementia and projections for the 85 years and older group are expected to quadruple by the year 2050 (Cotter, 2007; Day, 1996). A major risk factor is age, where people over 85 have a 40-50% chance of developing AD (Thompson, Lewis, Murphy, Hale, Blackwell, Acton, et al., 2004; Hubbell & Hubbell, 2002; Shanks-McElroy & Strobino, 2001). In addition to exponential increases nationally in the older adult population, minority populations will increase, particularly African American elders whose population will quadruple by the year 2050 (McKinnon & Bennett, 2005). Recently, emerging literature has suggested higher prevalence and risk for racially diverse elders where the combination of geriatric population growth and dementia risk are of concern (Sink, Covinsky, Newcomer, & Yaffe, 2004; Harwood & Ownby, 2000; Picot, Struther, & Humphrey, 1995).

Disruptive behaviors raise safety concerns, interfere with everyday functioning, and generally occur within mid-to-late stages of dementia (Logsdon, McCurry, & Teri, 2007; Senanarong, Cummings, Fairbanks, Mega, Masterman, O'Connor, et al., 2004). However they consume up to 30% of all dementia related costs and are associated with community caregiver burden and reduced income or employment (Cotter, 2007; Sink, et al., 2004; Sink, Holden, & Yaffe, 2005). Two-thirds of all persons with dementia reside in the community receiving care from over 10 million caregivers (Nichols, et al., 2008; Cotter, 2007; Messinger-Rapport, et al., 2006; Schulz & Martire, 2004; Langa, Chernew, Kabeto, Herzog, Ofstedal, Willis, et al., 2001). Informal caregivers, such as family members, comprise 75% of caregivers, where informal expenditures increase with dementia progression and are higher than formalized care (Nichols, et al., 2008; Cotter, 2007; Messinger-Rapport, et al., 2006; Schulz & Martire, 2004; Langa, et al., 2001). Despite increased cost and physical and mental health demands placed on caregivers, families prefer to maintain relatives in the home (Nichols, et al., 2008).

Conceptual Model

The Need Driven Dementia Compromised Behavior model, a middle range nursing framework, introduces background (personal) factors and proximal (dynamic) factors as influential determinants of behavioral manifestations.

Statement of the Problem

In the African American community, due in part to cultural and historical influences, the reluctance to institutionalize elders, utilize formalized services, as well as disproportionate health risks and outcomes associated with chronic illnesses are of concern. In particular, lack of dementia research participation and underutilized health care services resulting in under diagnosis or late diagnosis of dementia have contributed to diminished health outcomes and limited effectiveness of treatment options. Simultaneous and more frequent disruptive behaviors have been reported among African Americans, yet the African American experience of dementia caregiving has only recently begun to emerge in the literature. Although some information has been generated regarding the management of behaviors by African American caregivers, the perception of dementia caregiving and factors which may influence them remain largely unknown (Belle, Burgio, Burns, Coon, Czaja, Gallagher-Thompson, et al., 2006). Further, few studies have demonstrated the types of dementia, behavioral manifestations, the experience of caregivers with behaviors over time, or intervention strategies to aide caregivers as well as care recipients. Further, persistently low sample sizes, cross sectional designs, and conceptualization issues have increased the difficulty with exploring this topic adequately.

Significance

The importance of this dissertation concerns the lack of representation regarding minorities in dementia care research in general, and nursing research in particular. Little information exists regarding the impact of dementia and associated behaviors among these groups, particularly African Americans; this is especially the case for those residing in the community. This under-representation has limited the effectiveness, and relevance of current nursing interventions for disruptive behaviors in dementia among African Americans. The persistent under-representation, and therefore understudy, in dementia research, poor health outcomes, and limited applicability/utility of research findings, represents a challenge for African American caregivers and care recipients affected by dementia.

Purpose

This dissertation will provide a descriptive overview of the African American dementia caregiving experience for community dwelling caregivers in the context of disruptive behaviors. Following the introduction, an adaptation of Broome's Integrative Literature Review (Broome, 2000) will be incorporated as 28 years of literature chronicling dementia, community caregiving, and disturbing behaviors, and the African American experience is presented.

Chapter three presents a cross sectional descriptive exploratory secondary data analysis of the Aging Demographics and Memory Study (ADAMS) utilizing the Need-Driven-Dementia Compromised (NDB) model to explore background factors. A description of the study, NDB model, sample, methods, results, and discussion conclude the chapter. The fourth chapter extends the secondary data analysis of the ADAMS, through the expansion of the NDB model utilizing theory derivation (Walker & Avant, 2005) to explore proximal factors. A description of the study, NDB model, brief overview and application of theory derivation, sample, methods, results, and discussion are presented. The final chapter provides a summary of the contribution of this thesis work to the literature, utility and expansion of the NDB model, and recommendations for policy, practice, and future research.

CHAPTER 2: AN INTEGRATIVE LITERATURE REVIEW OF THE AFRICAN AMERICAN COMMUNITY DWELLING DEMENTIA CAREGIVING EXPERIENCE

INTRODUCTION

Dementia is an umbrella term describing progressive neuro-degeneration with numerous causes where Alzheimer's disease, the most common form, has increased prevalence and incidence projections in the elderly population (Sanders & Morano, 2008; Hubbell & Hubbell, 2002) as well as the minority elder population (McKinnon & Bennett, 2005). Dementia care represents a significant strain on the healthcare system, yet the majority of those diagnosed with dementia reside at home where they receive care from informal caregivers who absorb/deflect the majority of the financial impact. For the growing number of informal dementia caregivers, the early stages of dementia may be mild. However, as cognitive function declines, behavioral disturbances manifest resulting in care recipients who become increasingly difficult to manage.

The dementia literature presents numerous behavioral manifestations and their frequency, which jeopardize patient and caregiver safety. Despite this literal abundance of articles, these studies have occurred within institutional settings resulting in a paucity of recent articles detailing community dwelling persons with dementia behaviors. In fact, little information exists as to what types of dementia exist in the community as well as the different types and frequencies of behavioral manifestations in community dwelling elders. Additionally, within the dementia literature, many of the samples utilized for study lack diversity or possess low sample sizes.

The importance of this paper concerns the lack of representation regarding minorities in dementia care research in general, and nursing research in particular. Little information exists regarding the impact of dementia and associated behaviors among these groups, particularly African Americans; this is especially the case for those residing in the community. This under-representation has limited the effectiveness, and relevance of current nursing interventions for disturbing behaviors in dementia among African Americans. The persistent under-representation, and therefore understudy in dementia research, poor health outcomes, and limited applicability/utility of research findings, represents a challenge for African American caregivers and care recipients affected by dementia.

Purpose

Through an examination of the literature, this paper will describe dementia caregivers, caregivers and disturbing behaviors, and will conclude by highlighting the experience of African American community dwelling dementia caregivers and disruptive behaviors. Incorporating the steps of Broome's Integrative Literature Review as a guide (Broome, 2000), this paper is organized into three sections. The first section briefly provides a broad illustration of the African American experience by defining terms and highlighting African American culture and values, specifically those regarding the family and church. The first section continues with the identification of health concerns, including chronic illnesses/disparities, institutionalization, involvement in research, and the influence of racism, as they pertain to dementia. The importance of the African

American experience depicts the unique characteristics and factors which have shaped, strengthened and contributed to the evolution of the culture. However, these characteristics and experiences also influence participation, in terms of recruitment, and representation in dementia research.

The second section of this paper provides an overview of dementia, comprehensive review of disruptive behaviors, and African American involvement in dementia research. The final section introduces the role of community dementia caregivers, including formal/informal, caregivers and disruptive behaviors, African American community dementia caregivers, and African American community dementia caregivers and disruptive behaviors. A summary of findings and recommendations conclude this paper.

This literature review utilizes Broome's Integrated Literature Review (Broome, 2000), which offers five steps in the integrative review process. The first three steps, identification of the concept, identification of research questions, and the search process, are outlined here and incorporated throughout, in sections one through three of this paper. The remaining steps of the integrative review process, information extraction, as well as synthesis and summary, are found specifically within section three, which describes community caregivers.

The first step involves the identification of the concept: Disruptive behaviors of dementia and the African American (AA) community dwelling caregiving experience. Following the identification of the concept, Broome suggests explicitly outlining research questions to guide and influence study selection and information to be extracted.

Research questions included: What is the AA cultural experience; What is dementia; What types of disruptive behaviors occur in dementia; How are AA represented in the dementia research literature; What is dementia caregiving in the general community; How do disruptive behaviors influence the community dwelling dementia caregiving experience; What is dementia caregiving for African Americans in the community; and How do disruptive behaviors influence the community dwelling dementia caregiving experience?

The third step of the integrated literature review, the search process, involved multiple database searches (MEDLINE, Proquest, Web of Science, EBSCOhost, Search Tools, CINAHL, Pub Med, PsycInfo, Ageline, Sociological Abstracts, Social Services Abstracts, Social Work Abstracts, Anthropology Plus) of research and review articles published between 1980-2008 using the key words *dementia, caregiving, caregivers, disruptive behaviors,* and *African Americans/Blacks*. Combination terms included *dementia and caregivers, dementia and behaviors/disruptive behaviors, dementia and African Americans/Blacks, caregivers and African Americans/Blacks, African Americans/Blacks and dementia and behaviors/disruptive behaviors*. Results incorporating the combination terms were selected and extracted for review.

THE AFRICAN AMERICAN EXPERIENCE

Definition

According to the Census Bureau, the categorization of "African American/Black" refers to anyone who originated from a Black race group in Africa (McKinnon & Bennett, 2005). Based on this definition, 36.2 million individuals self-identify as Black representing almost 13% of the total population. Individuals whose racial composition includes Black alone, or in combination with another major race category are also considered Black. Further, according to Arthur and Katkin (2006), Black refers to descendents of slaves, or free Blacks, as well as foreign born immigrants from the Caribbean, Africa, Central and South America, or Hispanic Blacks. The important distinction here is to recognize that the term Black is not limited to African American and is inclusive of other minority groups/cultures and within these groups considerable variation exists.

Although the term African American is increasingly gaining acceptance in the research/scientific literature, with some consideration for Black American or American Black, preference is for the term Black, although its usage in scientific literature is cautiously advised (Aspinall, 2008; Williams & Jackson, 2000). As Williams and Jackson (2000) explain, over time terms change, however, the utilization of preferred terms interchangeably is of importance as is the periodic assessment and revision of categorizations. Although terminology has evolved due in part to the middle class Black population, preferences vary within segments of the population contributing to the interchangeability of terms (Aspinall, 2008).

Aspinall (2008) reviewed several studies examining the usage of AA and Black finding those who preferred “African American” were young, highly educated, residents of large cities, living outside of the South, who had higher incomes, had attended integrated schools, and valued racial identification. In contrast, individuals who preferred “Black” were less educated, poor, older residents of the South (Aspinall, 2008). In addition, amongst foreign born Blacks, Black is also the preferred term as they do not relate to or identify with African American (Aspinall, 2008). For this reason, it has been suggested that usage of African American be limited under specific circumstances, and the 2010 census include an "other Black" option to describe Black immigrants who do not identify as African American (Aspinall, 2008). For the purpose of this paper the term African American (AA) will be utilized to distinguish from other minority groups.

Culture and Values

Culture is "the shared language, behavior, customs, symbols, knowledge, and pattern of comprehending reality and the ability to create or determine history" (Arthur & Katkin, 2006, p. 28). Like any ethnic group, AA possess a rich history with experiences unique to the culture. As Arthur and Katkin (2006) describe, "Culture provides individuals with guidelines that are transmitted from one generation to the next and that inform the individual about how to view the world, how to experience it emotionally, how to behave in it in relation to other people, to supernatural forces or Gods, and to the natural environment" (p. 28). Within the AA community there are many facets which preserve and disseminate these values, as well as provide social support, particularly the family and the church.

Family

The socialization process of an individual is initiated by the family, which simultaneously reinforces and continues cultural history and traditions. Generally, the standardized representation of family is that of the nuclear family, however, within the AA community, the structure differs (Taylor, Chatters, & Mays, 1988). The AA family is a strong influence and source of support in the lives of individuals, particularly the extended family whose sense of obligation to support relatives is intended to help promote stability through such characteristics as material support and mutual aid system exchange (Martin & Martin, 1978). Intergenerational relationships and living arrangements are common among AA families due to divorce, financial hardships, single parenthood, adolescent parenthood, or major family problems including substance abuse, domestic violence, and incarceration (Taylor, Chatters, & Jackson, 1993). Further, due in part to higher incidence of male mortality, the head of households is primarily a female matriarch (Taylor, et al., 1993).

Social support between AA family members could be financial, emotional, spiritual/cognitive, or instrumental although financial exchanges are less likely due to disparities in wealth, or financial resources (Taylor, et al., 1993; Taylor, et al., 1988). In crises, as well as management of routine activities, relatives such as aunts/uncles or grandparents are sought for assistance, but generally immediate family members such as parents, siblings or children are the primary support sources (Taylor, et al., 1988).

In a decade review of the literature (Taylor, Chatters, Tucker, & Lewis, 1990), extended families were more common among women, AA, and singles where proximity to relatives, affective bonds, increased satisfaction, and interaction were critical elements in the social support networks of AA. For elderly AA, children, other relatives, or friends/neighbors, and their proximity, were essential sources of support (Taylor, et al., 1993; Taylor, et al., 1990). In the absence of children, particular reliance upon other relatives, friends, neighbors, or church members were paramount to establishing and maintaining support among AA elders (Taylor, et al., 1990).

Although the extended family network includes biological relatives, it is not limited to blood relationships. This aspect of the extended family network includes friends, neighbors or church members (Taylor, et al., 1988). “Fictive kin” describes relationships which are neither biologically, nor matrimonially associated, yet voluntarily regarded as familial (Chatters, Taylor, & Jayakody, 1994, p. 297). Such relationships were established during slavery where an extension of traditional biological ties and involvement or membership of a family was necessary for survival due to the prospect of familial separation by death, sale, or desertion (Chatters, et al., 1994). Originally, children were socialized by parents and other adults to address older persons unrelated to them as “aunt”or “uncle” but has evolved into the designation of “play” mother/father, brother/sister, or son/daughter and also extends the “god-child/parent” relationship (Chatters, et al., 1994).

The deep rooted nature and history of these relationships supports their endurance, often spanning such extensive time periods that family members are unable to recall the relationship origins (Chatters, et al., 1994). While these relationships are not distinctive to American slave culture and have in fact been found in Spanish and English cultures, relative to AA culture, such relationships are incorporated with less prevalence (Chatters, et al., 1994).

In the AA community, family caregiving is a longstanding cultural tradition, particularly for elders, where various experiences, resources, and social expectations play a pivotal role in its perception (Dilworth-Anderson, Williams, & Gibson, 2002; Dilworth-Anderson, Brummett, Goodwin, Williams, Williams, & Siegler, 2005). Generally regarded in positive terms such as rewarding, caregiving has been associated with greater satisfaction, decreased burden, decreased stress, increased social support, and health outcomes (Dilworth-Anderson & Anderson, 1994; Zauszniewski, Picot, Roberts, Debanne, & Wykle, 2005; Picot, Debanne, Namazi, & Wykle, 1997; Picot, Zauszniewski, & Delgado, 1997; Dilworth-Anderson, et al., 2005). Dilworth Anderson and colleagues (Dilworth-Anderson, Williams, & Cooper, 1999), identified multiple caregiving structures, and their influence on the flow of caregiving. Caregiving structures were dependent on the situation or condition of care recipients where proximity of family members was also an important factor in the determination and implementation of the caregiving composition (Dilworth-Anderson, et al., 1999; Picot, et al., 1997).

Caregivers, chiefly female, have been shown to be resourceful although emotional costs such as depression or strain due to competing role demands, have been found (Picot, et al., 1997; Williams, Dilworth-Anderson, & Goodwin, 2003; Zauszniewski, et al., 2005). Overall, caregiver strain has illustrated wide variance among AA. Typically, caregivers who possess higher education report more strain due to extensive financial support, although they are less likely to be caregivers but more likely to use support systems (Williams & Dilworth-Anderson, 2002; Williams, et al., 2003). Additionally, when both the health of the caregiver and care recipient are perceived as poor, caregivers report more strain (Williams, et al.,2003). Further, increases in activities of daily living (ADLs), such as toileting, and cognitive impairment have been associated with lower role strain and decreased usage of formalized support among caregivers who are less educated and more likely to function in the caregiving role (Williams, et al., 2003; Williams & Dilworth-Anderson, 2002).

Church

Second only to family, the church is a significant contributor of support both informally (spiritual, informational, emotional, or material) and formally (organized community programs) to assist families or individuals in crisis as well as through daily struggles (Williams & Dilworth-Anderson, 2002; Taylor & Chatters, 1986). Picot and colleagues (Picot, et al., 1997) demonstrated the influence of prayer, church attendance, and religiosity in decreasing stress associated with caregiving, although Williams and Dilworth-Anderson (2002) showed less utilization of church support in caregiving with the receipt of Medicaid services.

The church has remained a stronghold in the AA community because of its historical accessibility to members of the community denied elsewhere, and its self sufficiency (Taylor & Chatters, 1986). Although the church provides numerous instances of support, of importance are prayer, and advisement or encouragement, particularly during bereavement or illness (Taylor, Chatters, Hardison, & Riley, 2001). According to Taylor and Chatters (1986), based on the tenant of pastoral care, which is "to provide fellowship, spiritual sustenance, and to ensure the mental and physical well being of those members in need" (p. 194), it was found that membership, attendance, religiosity, and affiliation were related to the amount and frequency of support provided. Further, younger and male participants were more likely to receive support, whereas divorced individuals were less so. Although high income and rural residences received some form of assistance, they were less likely to require assistance. More recently, support from church members was more likely amongst older females who were closely affiliated with the church due to frequency of interactions, thus receiving greater support (Taylor, Lincoln, & Chatters, 2005).

Health

Chronic Illnesses/Disparities

Due in part to changes in the health care system and length of stay, many more individuals are discharged home with chronic illnesses and to that end many individuals are living longer with their chronic illnesses, especially AA. However, the health risks and outcomes associated with chronic illnesses, when compared to White groups, disproportionately affect AA, particularly cancer, diabetes, and cardiovascular disease.

Disparities in health outcomes have been established among AA, particularly in terms of life expectancy, with cardiovascular disease, diabetes, and cancer. These disparities disproportionately impact AA, however, such disproportionate disparities have persisted for years (Arthur & Katkin, 2006; Williams & Rucker, 2000). Williams (1997) provided an adaptive framework explicating the relationship between race and health and the importance of considering the combined influence of environmental, social, behavioral, and biological factors which increase the risk of illness. Although disparities in health are primarily influenced by socioeconomic status and affect both AA men and women, men have been found to possess more elevated risks and engage in health damaging behaviors (Williams, 2003; Williams, 2002).

The influence of residential segregation as a major factor in health disparities has been demonstrated due to limited access to resources including education and employment; lack of control over environment; and increased hazard exposure, which affect behavioral choices such as physical activity, and dietary patterns (Williams & Collins, 2004; Schulz, Williams, Israel, & Lempert, 2002; Williams & Collins, 2001). Dovidio and colleagues (Dovidio, Kawakami, & Gaertner, 2002) have utilized the term “aversive racism”, a subtle duality of deliberate responses, or embedded unconscious attitudes, which can be attributed to health disparities. The denial of racism or prejudice, coupled with persistent discriminatory and biased practices in structural and institutional resources, explicates in part the perpetual marginalization of AA.

Since the publishing of the Institute of Medicine’s (IOM) report (Smedley, Stith, & Nelson, 2003) highlighting the persistence of numerous disparities, the variation in health status among AA has received increasing attention (Arthur & Katkin, 2006). The leading Healthy People 2010 initiatives include the reduction or elimination of disparities and the increase of access to health care (DHHS, 2000). However, in efforts to eliminate disparities, new challenges including methodological limitations of racial categorizations, acculturation/immigration factors, geographic differences, as well as the presentation of racial data require additional consideration to foster the minimization of discrepancies in health care and health outcomes among racial and ethnic populations (Williams, 1997).

Institutionalization

Chronic illnesses pose a significant impact on AA, with health disparities at the helm (Smedley, et al., 2003). Despite this knowledge, in combination with the increased likelihood that chronic illnesses and consequential functional limitations represent a common reason to utilize institutionalization for AA, AA are consistently reluctant to institutionalize elderly family members (Diwan, Hougham, & Sachs, 2004; Gaugler, Leach, Clay, & Newcomer, 2004; Belgrave, Wykle, & Choi, 1993). In a qualitative study Winslow and Flaskerud (2009) found that cultural expectations and shame played a contributing role. Further, the lack of culturally sensitive care functioned as a perceived barrier.

African Americans have been shown to prefer the usage of informal care, home care, or none at all when compared to Whites for reasons which include feelings of obligation, guilt, or failure, in addition to racial discrimination, financial limitations, and cultural values (Gaugler, et al., 2004; Kosloski, Schaefer, Allwardt, Montgomery, & Karner, 2002; Kelley, 1994; Belgrave, et al., 1993). Further, a perception of reduced necessity, decreased likelihood of receiving an appropriate level of care, racial segregation within institutions, or a reduction in quality of care have been reported, lending preferential support for the nurturing environment of home (Belgrave, et al., 1993). However, positive attitudes toward placement and formal service usage have been shown to be predictive of institutionalization in addition to reduced instrumental activities of daily living (IADLs), such as grocery shopping or paying bills, and prior long term care (LTC) usage (Gaugler, et al., 2004). In some circumstances, the recommendation by health care providers or the church may assist in influencing the decision to consider the option/utilization of institutionalization (Belgrave, et al., 1993).

Involvement in medical/health research

African Americans have been underrepresented in various types of health research including clinical trials and mental health research, with few exceptions (Thompson, Neighbors, Munday, & Jackson, 1996). Yet, any research including human subjects must include women and minorities, or justification for their exclusion, because of the pervasive historical absence of representation in research literature (Picot, Tierney, Mirpourian, Ericsson, Wright, & Powell, 2002; Shavers-Hornaday, Lynch, Burmeister, & Torner, 1997; Thompson, et al., 1996). Numerous factors influence the willingness of AA to participate in research including mistrust, lack of knowledge, perceived quality of health care, and fear (Shavers-Hornaday, et al., 1997; Thompson, et al., 1996).

However, in light of these challenges, investigators perpetuate existing barriers or create new barriers affecting AA research participation as well. Shavers-Hornaday and colleagues (1997) demonstrated that actions such as not extending participatory invitations, and failing to establish relationships in communities or with ethnic/minority health professionals/researchers, are critical to potential subject recruitment and avoidable. Although numerous strategies have been recommended, and in many cases implemented, to improve representation, much remains to be done to increase their research participation (Picot, et al., 2002; Shavers-Hornaday, et al., 1997; Thompson, et al., 1996).

Racism

When discussing race, “broad groupings of people based on an area of descent” (Harwood & Ownby, 2000, p. 40), it is also important to illuminate racism as well. Although instances of racism are no longer as overt as once reported, they continue to persist in pockets throughout the country and manifest either behaviorally or attitudinally in a variety of regions and settings including education, housing, and employment (Clark, Anderson, Clark, & Williams, 1999). The extensive history of racism and its disproportionate impact on AA is perceived physiologically as either an acute or chronic stressor, with deleterious consequences influencing physical and psychological health outcomes (Williams & Williams-Morris, 2000; Clark, et al., 1999). Few racial groups have contended with similar effects of racism and its consequences as AA (Arthur & Katkin, 2006; Clark, et al., 1999).

Clark and colleagues (1999) define racism as “beliefs, attitudes, institutional arrangements, and acts that tend to denigrate individuals or groups because of phenotypic characteristics or ethnic group affiliation” (p. 805). Williams & Williams-Morris (2000) defined racism as “an organized system that leads to the subjugation of some human population groups relative to anothers” (p.244). As a result, certain groups regarded as inferior to others perpetuates the development of prejudice, or “negative attitudes and beliefs toward racial outgroups” (Williams & Williams-Morris, 2000, p. 244) and discrimination, the “differential treatment of members of these groups by both individuals and societal institutions” (Williams & Williams-Morris, 2000, p. 244). Such persistent behaviors have reinforced the reluctance of some Latino groups to identify as Black due to the pervasive undertones and negative connotations (Golash-Boza & Darity, 2008). In fact, as Williams and Jackson (2000) highlight, racism has been negatively attributed to numerous societal outcomes reflecting disparities in power and access to resources in society.

The impact of racism and its associates, discrimination and prejudice, are not limited to outside groups, but also include within group racism where such things as hair texture and variations of skin tone (with darker hues attributed to inferiority) were perpetuated within major strongholds in the AA community including social organizations, businesses, religious institutions, and educational infrastructures (Clark, et al., 1999). As a result intragroup and intergroup racism have been shown to contribute to many aspects of AA well being, overall health, stress and health care utilization (Williams & Williams-Morris, 2000; Clark, et al., 1999).

The unique challenges within the AA experience such as racism, prejudice, and discrimination, have impacted numerous aspects of daily life. However, these influences combined with longstanding cultural beliefs/values impact the perception and attitudes of many individuals, particularly the elderly or their adult children, in health care decisions including institutionalization, or other formal services, and engagement in health research. Supporting evidence demonstrates disparities in chronic illnesses where discriminatory practices including unequal access to care, quality of care provision/resources, and health outcomes reinforce feelings of mistrust, and reliance on the family and the church, which are primary and influential informal support networks.

Dementia is an ever increasing chronic illness which does not discriminate in its victims. Although historical instances have reinforced feelings of mistrust in the AA community, lack of dementia research participation limits the ability of findings to consider unique AA factors which influence the effectiveness of services, interventions, or medications. With the lack of research in this population, the needs of AA will remain unknown and generalized treatments, strategies, recommendations will continue to be applied. An overall cultural reluctance to seek treatment for chronic illness can contribute to under diagnosis or late diagnosis of dementia where effective or applicable treatment options are minimized and health outcomes reduced. Due to the pervasive cultural reluctance to institutionalize for a variety of factors, the AA elderly are at increased risk due to transitions within the disease process and reliance on informal support systems which may become overwhelmed by behavioral changes, or be insufficient to accommodate such changes, thereby increasing demand of the caregiving role.

Nursing as a professional science/discipline draws attention not only to the presenting illness but also incorporates a holistic perspective which considers the uniqueness of each individual’s response as it relates to their quality of life, during the restoration of their health status or maintenance of their level of functioning. Taking into account the collective uniqueness of the AA culture and community, nursing is poised to offer insight into the physiological needs of caregivers and care recipients while simultaneously considering the psychological aspects necessary to enhance quality of life through patient advocacy and the fostering of collaborative interdisciplinary relationships. Further, the integration of cultural sensitivity, clinical skill, and a holistic perspective equip nurses with an advantage necessary to initiate the development, improvement, and implementation of interventions to address the challenges associated with the AA experience in regards to dementia care.

DEMENTIA

An integrated literature review chronicling the years 1980-2008 is now presented describing trends in dementia, including types and prevalence, disruptive behaviors, and AA involvement in research. The time period of 1980 was selected because according to Sanders & Morano (2008) this was the beginning of the acceptance of dementia as a diagnosis where it increased in prevalence in the scientific literature, particularly around the middle of the decade. Additionally, a trend in the documentation of the progression and evolution of dementia began (Harwood & Ownby, 2000).

Increased attention and advanced knowledge have occurred within Alzheimer’s disease (AD) dementia research contributing to current understanding of implications and consequences due to its longstanding history and scientific inquiry. However, the implications of other forms of dementia are of equal importance as increasing evidence of their impact emerges in the literature and society. Although the documented prevalence of AD is more robust, this section will portray dementia collectively followed by a discussion of common types and their characteristics, eventually narrowing down specifically to AD. However, broad connections with other dementias are illustrated when possible.

Review of Dementia

Dementia is a general term to refer to a syndrome of neurodegenerative diseases where memory/recall, executive function, and the performance of daily activities are impacted (Cotter, 2007; Harwood & Ownby, 2000). The Diagnostic and Statistical Manual (APA, 2000) defines dementia as “the development of multiple cognitive deficits that include memory impairment and at least 1 of the following cognitive disturbances: aphasia, apraxia, agnosia, or a disturbance in executive functioning. The cognitive deficits must be sufficiently severe to cause impairment in occupational or social functioning and must represent a decline from a previously higher level of functioning” (p. 376).

Anywhere between 50-70 causes of dementia, including reversible and irreversible, have been identified where despite the common denominator of memory loss, other factors such as progression, impact, and treatments vary (Sanders & Morano, 2008; Cotter, 2007; Dugue, et al., 2003; Harwood & Ownby, 2000). The most common irreversible dementias include Alzheimer's disease (AD), vascular dementia (VaD), mixed dementia (combination of AD and VaD), Lewy body, and Pick's disease/frontotemporal dementia (FTD) (Cotter, 2007; Dugue, et al., 2003; Harwood & Ownby, 2000).

Alzheimer's disease and VaD are the two most common types of dementia. Alzheimer's disease, characterized by insidious progression of memory impairment, results in the deterioration of functional, cognitive, and behavioral abilities, ultimately impairing social and occupational function. Alzheimer's disease represents over 50% of all dementias, but can only definitively be diagnosed post mortem (Cotter, 2007; Sano & Weber, 2003; Dugue, et al., 2003; Gormley, Rizwan, & Lovestone, 1998). In recent years, clinicians have been able to reliably distinguish between normal aging, mild cognitive impairment, and the early stages of AD with up to 90% accuracy based on improved history taking as well as advances in neuropsychological testing (Dugue, et al., 2003). In one comprehensive study it was suggested that perhaps many diagnoses of AD were in fact combinations of other post mortem dementias over-representing AD and may prove to be a methodological error in frequency of diagnoses (Shadlen, Larson, & Yukawa, 2000).

Vascular dementia, characterized by dramatic impairments in executive function early in the disease, represents 15% of all dementias (Cotter, 2007; Dugue, et al., 2003; Harwood & Ownby, 2000). Following AD and VaD are Lewy body dementia, characterized by visual hallucinations with fluctuations in cognition and attention, and Pick's disease/Frontotemporal lobe dementia, characterized by personality changes and impaired language, where both comprise 5% of dementia diagnoses (Cotter, 2007; Dugue, et al., 2003).

Mild cognitive impairment (MCI), another diagnosis associated with dementia, particularly the risk of transitioning to dementia, has recently been suggested as a predisposing factor in individuals before advancing to AD (Dugue, et al., 2003). In mild cognitive impairment, cognitive functions remain intact with memory impairment only (Dugue, et al., 2003). Although discussions surrounding dementia warrant mention of MCI, it is important to emphasize that variation exists in the literature regarding MCI progression to dementia, particularly because not all MCI progresses to a dementia (Albert & Blacker, 2006; Winblad, Palmer, Kivipelto, Jelic, Fratiglioni, Wahlund, Nordberg, et al, 2004; Morris, Storandt, Miller, McKeel, Price, Rubin, & Berg, 2001; Peterson, Smith, Waring, Ivnik, Kokmen, & Tangelos, 1997).

Although the benefits of physical activity, antioxidant rich foods and cognitive exercises are highly encouraged due to evidence supporting their cognitive benefit including increased focus/attention, decreased depression, and neurogenesis, or the creation of pathways in the brain to transfer information, research continues as to what extent these mechanisms reduce, or whether or not they eliminate, the risk of dementia development (Middleton & Yaffe, 2009). Despite a lack of concrete evidence supporting the prevention /cessation, inhibition, elimination, or reversal of dementia, research is ongoing and is responsible for the refutation of previous theories such as exposure to elements of aluminum or magnesium, originally believed to be a causative factor of dementia development (Perl, 1985).

Currently, approximately 4-5 million older adults are affected by AD at a cost exceeding $100 billion with projected national expenditures expected to more than triple by the year 2050, making it the third costliest disease (Sanders & Morano, 2008; Nichols, et al., 2008; Algase, 2007; Cotter, 2007; Messinger-Rapport, et al., 2006). Approximately ten percent of individuals 65 years of age and older are affected, however, among those 85 years of age and older the prevalence rate soars to 50% (Thompson, et al., 2004; Hubbell & Hubbell, 2002; Shanks-McElroy & Strobino, 2001). With age as a major AD risk factor, decreasing birth rates, and census projections quadrupling the 85 years of age and over group by the year 2050, the impact of AD will increase exponentially (Cotter, 2007; Day, 1996). Further, the Census Bureau projects older adult ethnic and minority populations to increase significantly compared to White elders (McKinnon & Bennett, 2005). Although the White elderly population is projected to double between 2000 and 2050, African American elders will quadruple, Hispanic elders will increase seven times, Asian/Pacific Islander elders will increase 6.5 times and Native American elders will increase 3.5 times that of present levels (McKinnon & Bennett, 2005).

Projections for the older adult population are expected to reach 20% by 2050, yet by 2020, it is projected that 22% of the elderly population will be comprised of ethnic elders, and the African American composition is expected to double, to 44%, within the same year (McKinnon & Bennett, 2005; Harwood & Ownby, 2000). As the geriatric population rapidly increases in combination with dementia risk, the impact on ethnic elders cannot be ignored. In fact, in recent years supporting data has emerged suggesting higher prevalence and heightened risk for dementia among ethnically diverse elders compared with non-Hispanic whites (Sink, et al., 2004; Harwood & Ownby, 2000; Picot, et al., 1995).

Review of Disruptive Behaviors

Disruptive behaviors consume up to 30% of dementia related costs (Cotter, 2007) and have been shown to represent a common reason for institutionalization, neglect, abuse, disability, and increased financial and caregiving demands (Messinger-Rapport, et al., 2006; Hubbell & Hubbell, 2002; Finkel, 2001). In long term care settings disruptive behaviors have been shown to occur in over 50% of cases (Cohen-Mansfield & Libin, 2005; Kolanowski & Garr, 1999) contributing to high turnover rates, injury, restraint usage, and burnout (Lyketsos, Steele, Galik, Rosenblatt, Steinberg, Warren, et al., 1999). In the community setting, prevalence rates have been reported as high as 98% contributing to additional caregiver stress, burden, and depression; increased institutionalization; and reduced income or employment (Sink, et al., 2005; Sink, et al., 2004).

The description of dementia behaviors has existed in the literature for many years although in various forms. Cohen-Mansfield and Billig (1986) in a seminal work operationalized the term "agitation" to describe all behaviors of dementia which were "inappropriate verbal, vocal or motor activity not explained by needs or confusion" (p. 712) and included such behaviors as wandering, pacing, screaming, fighting, cursing, and biting. Prior to this body of work, according to a review of the literature, the term agitation had been used to describe numerous behaviors beginning in the mid 60's with increasing reporting during the 80's (Cohen-Mansfield & Billig, 1986). Following the example of Cohen-Mansfield and Billig (1986), agitation in the elderly became accepted in the literature (Chrisman, Tabar, Whall, & Booth, 1991). Since then other terms including psychosis (Broadway & Mintzer, 2007), catastrophic reactions (Tiberti, Sabe, Kuzis, Garcia Cuerva, Leiguarda, & Starkstein, 1998), disturbing behaviors (Kolanowski, 1995), inappropriate behaviors (Cohen-Mansfield, 2001), aggressive behaviors (Salzman, Jeste, Meyer, Cohen-Mansfield, Cummings, Grossberg, et al., 2008; O'Leary, Jyringi, & Sedler, 2005; Lyketsos, et al., 1999; Cohen-Mansfield & Werner, 1998; Aarsland, Cummings, Yenner, & Miller, 1996; Hamel, Gold, Andres, Reis, Dastoor, Grauer, et al., 1990; Ryden, 1988), neuropsychiatric symptoms (Ayalon, Gum, Feliciano, & Arean, 2006; Sink, et al., 2005; Livingston, Johnston, Katona, Paton, & Lyketsos, 2005; Aarsland, et al., 1996), behavioral disorders (Stoppe, Brandt, & Staedt, 1999), behavioral symptoms (Volicer & Hurley, 2003), problem behaviors (Davis, Buckwalter, & Burgio, 1997), behavioral disturbances (Logsdon, et al., 2007; Kunik, Huffman, Bharani, Hillman, Molinari, & Orengo, 2000; Gormley & Rizwan, 1998; Gormley, et al., 1998), and behavioral and psychological symptoms in dementia (BPSD) (Robert, Verhey, Byrne, Hurt, De Deyn, Nobili, et al., 2005; Finkel, 2001) have been used and often interchangeably.

Logsdon and colleagues (2007) utilized the term behavioral disturbances and define them as “behaviors that are disruptive and distressing, that create safety concerns, and/or interfere with necessary care for the individual with dementia or his or her caregiver” (p. 29). In addition, DSM-IV (TR) has utilized the term behavioral disturbances (APA, 2000). Although behaviors are designated as disruptive, they are often subjectively identified according to social acceptance and are not necessarily perceived as such by the person with dementia (Cohen-Mansfield & Billig, 1986).

Further, although many behaviors are attributed to disease progression alone, often times overlooked factors such as infection or illness, medications, environmental changes, or underlying needs are contributing factors when verbalization is not possible (Cotter, 2007; Stoppe, et al., 1999).

Generally, disruptive behaviors occur within mid-to late stages of dementia (Senanarong, et al., 2004). However, given the numerous etiologies of dementia, behavioral manifestations will vary in onset and progression, especially early in the disease. Later, behaviors will become more similar (Sanders & Morano, 2008; Volicer & Hurley, 2003). Further, progressive dementias present differently from chronic or otherwise non-progressive dementias both in behavior and in management (Volicer & Hurley, 2003). For example, some behaviors occur early with increased frequency, gradually disappearing, while other behaviors emerge later in the disease progression (Finkel, 2001; Stoppe, et al., 1999). In addition, some individuals will develop behavioral manifestations and others will not, but the explanatory research is still developing with potential genetic, biochemical, personality, and neuroanatomical associations playing a role (Finkel, 2001).

Many behaviors are represented in the dementia literature as disruptive, including depression (Jorm, 2000), apathy/passivity (Colling, 1999), sleep disturbances (Vitiello & Borson, 2001), hyper-sexuality (Robinson, 2003), hoarding (Hogstel, 1993), and incontinence (Skelly & Flint, 1995). However, the most frequently occurring include agitation, aggression, delusions, hallucinations, wandering, and vocalizations (Finkel, 2001; Stoppe, et al., 1999).

Delusions are very common in AD occurring in up to 73% of patients (Finkel, 2001). Aggression/agitation, which may be precipitated by delusions, occur in patients anywhere between 20-90% of the time (Stoppe, et al., 1999). Hallucinations, particularly common in Lewy body dementia, possess a frequency reporting of 80% (Finkel, 2001). Wandering, a frequently occurring behavior in up to 70% of dementia patients, has numerous health benefits including increased exercise, circulation, and decreased contracture formation. However, it is also of considerable concern because of excess weight loss associated with increased caloric consumption and inadequate replenishment due to the diminished capacity of individuals to recognize hunger, feed themselves, or communicate needs, as well as elopement or death (Cotter, 2007; Beattie, Algase, & Song, 2004; Finkel, 2001; Stoppe, et al., 1999). Vocalizations have been reported as the most annoying, persistent and frequent behaviors occurring in approximately 20-30% of nursing home residents and include screaming, repetitious verbalizations, or cursing (Beck & Vogelphl, 1999).

Treatment of disruptive behaviors falls into one of two categories: pharmacological treatment or non-pharmacological treatment. According to a 2005 article, (Sink, et al., 2005) it was reported that pharmacological treatments of behaviors at one time were inclusive of typical antipsychotics, however, no evidence unequivocally supported their usefulness. While haloperidol demonstrated a slight benefit in treating aggression, countering the risks associated with the side effects could not be shown to justify the benefit. However, more recently, the off label usage of atypical antipsychotics demonstrated modest effectiveness with behaviors particularly in individuals diagnosed with AD or VaD. Although side effects were generally low, some concerns remained and recently the FDA has begun including Black Box warnings due to increased cardiac risk or death (Salzman, et al., 2008). Further, despite clinical trials, atypical antipsychotics were unable to demonstrate the treatment of disruptive behaviors more efficaciously than placebo (Salzman, et al., 2008).

Non-pharmacological treatments are generally the first option implemented to control disruptive behaviors as they do not involve the risk of medications, address underlying psychosocial or environmental justifications of behaviors, remove the risk of medications masking an actual need, and allow affected individuals to remain in the community for longer periods of time (Logsdon et al., 2007; Cohen-Mansfield, 2001). Some non-pharmacological/psychosocial interventions are provided in the long term care setting and have been reported in the literature to aid in the reduction of behaviors, however, exploration of their effectiveness in the community setting has only recently begun to receive attention (Fitzsimmons & Buettner, 2002).

Non-pharmacological treatments, or behavioral therapy, can include a wide array of options designed to reduce disruptive behaviors. Despite varied reports of efficacy pertaining to behavioral outcomes (Ayalon, et al., 2006; Livingston, et al., 2005; Cohen-Mansfield, 2001), a variety of interventions exist including light therapy (e.g. Lyketsos, Veiel, & Baker, 1999), music therapy (e.g. Tabloski, McKinnon-Howe, & Remington, 1995), reminiscence therapy (e.g. Haight, Bachman, Hendrix, Wagner, Meeks, & Johnson, 2003), and pet therapy (e.g. Zisselman, Rovner, & Shmuely, 1996). Nursing interventions have also emerged to address disruptive behaviors utilizing massage therapy (e.g. Snyder, Egan, & Burns, 1995), natural environments (Whall, Black, Groh, Yankou, Kupferschmid, & Foster, 1997; Whall, 1991), preserved implicit memory

(Harrison, Son, Kim, & Whall, 2007; Parahoo, Whall, Colling, & Nusbaum, 2006), behavioral analysis (Boehm, Whall, Cosgrove, Locke, & Schlenk, 1995), multi-sensory environment (Riley-Doucet, 2009), progressively lowered stress threshold (Hall & Buckwalter, 1986), simple pleasures (Colling & Buettner, 2002), and exercise therapy (Buettner, Lundegren, & Farrell, 1996). As a result of such varied usage/efficacy, pharmacological treatments are eventually sought, either in combination or alone. However, all possible influential factors should be exhausted and non-pharmacological treatments should prove unsuccessful before implementation of pharmacological regimens (Stoppe, et al., 1999).

African Americans and Dementia Research

Despite evidence supporting increased incidence and prevalence of dementia among ethnic groups, particularly African Americans, they consistently remain under-represented and therefore understudied in dementia research resulting in poor health outcomes, limited applicability/utility of research findings or interventions (Sink, et al., 2004; Lampley-Dallas, 2002). In fact, in spite of the emergence and acceptance of a dementia diagnosis and attention to the dementia trajectory, in general, limited research was available on the role, or impact of ethnicity (Harwood & Ownby, 2000). Following AD, which is the most commonly diagnosed dementia in African Americans, VaD is the second most common dementia affecting the elderly and tends to occur more often in African Americans (Dugue, et al., 2003; Harwood & Ownby, 2000). In addition, emerging evidence has associated diabetes and atherosclerosis, also prevalent within AA communities, with VaD risk (Harwood & Ownby, 2000; Shadlen, et al., 2000). Due to the documented prevalence among AA for cardiovascular illnesses including hypertension, stroke, and heart disease, VaD is of significant concern (Harwood & Ownby, 2000; Shadlen, et al., 2000; Day, 1996).

Research has demonstrated conditional willingness of elders to participate in research, however, there is evidence indicating that many willing subjects are ineligible for a variety of reasons (Picot, et al., 1995). In addition to ineligibility, numerous obstacles such as financial burden, or transportation have prevented the participation of African Americans (Ballard, Nash, Raiford & Harrell, 1993). For other individuals, regardless of the type of research proposed, historical evidence of misconduct, factored with a belief of inequitable quality care, and general governmental and medical distrust, poses a significant deterrent to participation (Picot, et al., 1995). Further, evidence has demonstrated the influence of other family members in decisions of participation (Picot, et al., 1995; Taylor & Chatters, 1986).

In response to some of the identified barriers, however, successful researchers have made suggestions to increase participation such as the inclusion of AA recruiters or data collectors; consistency of interviewers; involvement of community resources; scheduling/rescheduling flexibility; cultural awareness /knowledge including norms, values, family dynamics, social issues, and patterns of communication; establishing trust before recruitment; including family members; and conducting studies in the homes, neighborhoods, or other culturally accessible locations to ease comfort and intimidation (Dilworth-Anderson, et al., 2005; Dilworth-Anderson, Goodwin, & Williams, 2004; Picot, et al.,, 2002; Picot, Stuckey, Humphrey, Smyth, & Whitehouse, 1996).

Much of the dementia literature presented includes expertise and contributions from multiple disciplines, particularly medicine and psychology, illuminating the presence and differentiation of dementia, in addition to the challenge of disturbing behaviors. However, nursing has been instrumental with nurse scientists noting the absence of AA in dementia research (e.g. Picot, et al. 1995), communication in dementia (Whall, 1989), identifying the influence of personality on behaviors (Kolanowski & Whall, 1996), highlighting behaviors in nursing homes (Whall, Gillis, Yankou, Booth, & Beel-Bates, 1992), identifying behaviors commonly associated with dementia (Beck & Vogelpohl, 1999; Colling, 1999; Beattie, et al., 2004), consequences of dementia behaviors (Kolanowski & Garr, 1999), defining dementia behaviors (Kolanowski, 1995; Davis, et al., 1997), as well as offering non-pharmacological interventions to decrease behaviors (Riley-Doucet, 2009; Harrison, et al.,, 2007; Parahoo, et al., 2006; Fitzsimmons & Buettner, 2002; Colling & Buettner, 2002; Whall, et al., 1997; Snyder, et al., 1995; Boehm, et al., 1995; Whall, 1991; Hall & Buckwalter, 1987; Buettner, et al., 1986). Nursing has begun to establish itself as a versatile discipline, able to recognize a pressing need and respond accordingly.

COMMUNITY DEMENTIA CAREGIVERS

Step four of Broome's Integrative Review, information extraction, involves the summarization and documentation of relevant information from each selected article. The following section discusses trends in the literature surrounding community dementia caregiving and disruptive behaviors as well as AA dementia caregivers within the community and the occurrence of disruptive behaviors. The final step of the integrative review, synthesis and summary, encompasses the culmination of research literature and provides an overview of dementia caregiving research presently, what is missing, and future directions.

Dementia caregiving has gained increasing attention due to the unique burden associated with functional impairment, the economic impact on caregivers, and the strain on the health care system (Schulz & Martire, 2004; Aneshensel, Pearlin, Mullan, Zarit, & Whitlatch, 1995). However, much of the attention and focus can be attributed to the introduction of The Stress Process Model. This model revolutionized the dementia caregiving approach and experience through the presentation of a multifaceted interplay of stressors influencing the dementia caregiving process diverting attention to the caregiver, in addition to the care recipient (Pearlin, Mullan, Semple, & Skaff, 1990).

Approximately one third of persons with dementia reside in long term care settings, while the remaining majority reside in the home or community setting receiving care from over 10 million caregivers (Cotter, 2007; Messinger-Rapport, et al., 2006). One quarter of the care services provided are performed by formal caregivers, including professionals, whereas 75% of care is provided by informal caregivers, such as family members (Schulz & Martire, 2004). Informal care expenditures are higher than formalized care, where cost increases with dementia progression (Nichols, et al., 2008; Langa, et al., 2001). To illustrate, compared with mild dementia, informal caregiving costs for severe dementia are nearly double with recent annual estimates in excess of $35,000/year (Nichols, et al., 2008).

Dementia caregiving can be very demanding on caregivers due to extensive amounts of time, energy, and effort expended to retain persons with dementia in the home resulting in social isolation and self neglect (Shanks-McElroy & Strobino, 2001; Cox, 1997). In addition, health related outcomes such as stress, depression, anxiety, fatigue, and insomnia continue to emerge in the literature (Messinger-Rapport, et al., 2006; Thompson, et al., 2004; Shanks-McElroy & Strobino, 2001). Despite the significantly increased cost and stress associated with informal care provision many families prefer to maintain relatives in the home (Nichols, et al., 2008,).

Formal Caregivers

Formal caregivers represent any individual receiving payment or monetary compensation for the provision of care to an individual (Schulz, & Martire, 2004). Although formal caregivers are found in a variety of settings including hospitals, long term care (LTC) settings, or assisted living facilities (ALFs), for individuals with dementia, there are a large group of professional caregivers who are certified and credentialed to provide skilled dementia care required by patients in the home or community (McCarty & Drebing, 2003). Respite care is an umbrella term describing numerous supportive services that help caregivers maintain independence in the community, and offer them the opportunity to temporarily relinquish the care provider role (Robinson, Buckwalter, & Reed, 2005; Larkin & Hopcraft, 1993). While it is not a new phenomenon, respite exists in several capacities including home health care and temporary institutional placement such as hospitals, residential care facilities, or adult day care centers (Gaugler, Jarrott, Zarit, Stephens, Townsend, & Greene, 2003; Larkin & Hopcroft, 1993). The length of time for respite care services can range from several hours per day with home health care or day care services, to two weeks in a nursing home or hospital setting (Gaugler, et al., 2003; Larkin & Hopcroft, 1993).

Despite the benefits and availability of services, respite care is underutilized by dementia caregivers (Robinson, et al., 2005; Kosloski, et al., 2002; Cox, 1997). Underutilization has been attributed to feelings of guilt regarding a sense of abandonment, feelings of separation or loss, and possible anger or resentment from the care recipient (Robinson, et al., 2005; Larkin & Hopcroft, 1993). In addition, spouses, particularly men, have been found to be reluctant to relinquish care of a spouse to another person where utilization of respite care involves the perception of failing to uphold marital and caregiving responsibilities, giving up on the spouse or relationship, as well as an apparent sign of weakness (Hubbell & Hubbell, 2002; Larkin & Hopcroft, 1993). However, Robinson, Buckwalter, and Reed (2005) refute the perception of weakness and suggest that because spouses have cared for loved ones for several years, the spouse may feel resilient and capable of providing care alone and therefore does not require or want additional assistance (Shanks-McElroy & Strobino, 2001).

Conversely, evidence has shown that adult child caregivers tend to utilize formal services more often in combination with informal services, particularly when not residing with a parent or when juggling the competing demands of caring for their own family (Tully & Sehm, 1994). However the cost, particularly insurance reimbursement, is often a deterrent where caring for a loved one at home is a more viable alternative. Edwards and Morris (2007) presented an exception to this standard demonstrating the pervasiveness of older adults who live alone with dementia, and utilize formal services more frequently, particularly African Americans who are in earlier stages of dementia, possess a case worker, and services are certified by Medicaid. Gaugler and colleagues (2004) found some evidence supporting the notion that compared to persons without

Medicaid coverage, Medicaid influenced formal service utilization and at earlier rates. However, it should also be noted that according to findings from a 2004 study, (Diwan, et al., 2004) higher income reduces the ability to qualify for free or low cost services, making already costly services unrealistic/impractical/unattainable, thereby impacting their overall usage.

Informal Caregivers

Informal caregivers generally are persons not receiving payment or reimbursement for care provision and may include spouses, children, other relatives, or friends (Schulz & Martire, 2004). Traditionally, the informal caregiver role has been fulfilled by women - spouses, daughters, or daughters in law - where the sacrifice involved to meet caregiving needs, has influenced productivity and altered composition of the workforce through such mechanisms as early retirement, resignation from employment, absenteeism, or conversion to part time status (Nichols, et al., 2008; Covinsky, Eng, Lui, Sands, Sehgal, Walter, et al., 2001). More recently, the predominantly female "sandwich generation," adult children who are providing care for aging parents and families/children of their own, simultaneously juggle/balance the demands of competing roles, imposing additional sacrifice or compromise (Tully & Sehm, 1994).

Although females consistently comprise the majority of caregivers, males are increasing with approximately 20 percent represented and these numbers continue to rise precipitously (Messinger-Rapport, et al., 2006; Thompson, et al., 2004). Men are perceived as stoic or controlling, thereby experiencing less effects of stress and incidence of depression, yet, they are more at risk for burnout because of societal role expectations, their assumption of a role not traditionally associated with masculinity, and its perception as a burden (Thompson, et al., 2004; Hubbell & Hubbell, 2002). In addition, men are equally as likely to experience depression or anxiety as women are, although they are less likely to report it (Hubbell & Hubbell, 2002). However, according to Thompson et al. (2004) spousal men derive pleasure from the caregiving experience of the AD spouse, whereas women are more susceptible to caregiver-related depression, due to differences in gender coping strategies and likely additional role demands. Brodie and Gadling-Cole (2003) report men rely on external services, whereas women lack this propensity and thus impose unrealistic standards, which may offer one explanation for gender differences.

One aspect of caregiving which does not receive much attention is the impact of conflicts within families. These conflicts may involve decisions to institutionalize family members (Gaugler, Zarit, & Pearlin, 1999) or to provide care in the home (Davis, 1997), as well as preexisting strains which manifest during the stress of dementia caregiving (Gwyther, 1995; Semple, 1992) and appear to have more of an impact on adult child caregivers rather than spouses (Strawbridge & Wallhagen, 1991). Although not in the forefront of attention, such instances impact caregiving in terms of potential stressors experienced by caregivers.

Alzheimer’s disease is the most common dementia, however, other dementia forms, although uncommon in some instances, impact families when individuals are affected at a younger onset and children or spouses are suddenly thrust into a caregiver role (LoGiudice & Hassett, 2005). If the family member affected of early onset dementia is a parent or spouse, family members become resentful due to lack of transition (LoGiudice & Hassett, 2005). For a young spousal caregiver, although they are less likely to experience the physical burden associated with caregiving, in comparison to older caregivers, caring for a counterpart who contributed to financial and parental responsibilities becomes daunting (LoGiudice & Hassett, 2005). However, when an older spouse, grandparent, or parent is diagnosed with dementia the transition of increasing dependency can be viewed as preparatory for the role of caregiver (LoGiudice & Hassett, 2005). In addition, when an older loved one resides with family, the level of responsibility facilitates maturation and empathy in children and increases overall family cohesion, countering initial feelings of resentment (LoGiudice & Hassett, 2005).

Caregivers and Disruptive Behaviors

Dementia is a progressive illness where gradual, and at times, dramatic changes tend to occur. As has been presented, disruptive behaviors are the most common changes with disease progression, presenting most commonly within the middle to late stages. For caregivers this presents an enormous challenge as the occurrence of behaviors continues to rise. Typically behavior research involve persons with dementia residing in nursing homes, which is where most statistical reporting is generated. However, some studies have offered the prevalence of behaviors in the community as well as offered predictors of such behaviors.

In a Canadian study (Hamel, et al., 1990), authors assessed caregiver reactions to aggression in the community. Aggression, predicted by frequency of behaviors, pre-existing aggression, and pre-existing social relationship between patient and caregiver were found in the majority of the sample (57%) and were comprised primarily of verbal aggression. Although Eustace and colleagues. (Eustace, Kidd, Greene, Fallon, Bhrain, Cunningham, et al., 2001) found lower prevalence of verbal aggression in 30% of the population, significant associations between paranoid and delusional ideation, male gender, and agitation were found. Similarly, other studies determined associated factors of physical and verbal aggression including activity disturbances, hallucinations and delusional ideation (Gormley & Rizwan, 1998; Aarsland, et al., 1996).

Whereas other studies were limited in their cross sectional design, Cohen-Mansfield and Werner (1998) performed a longitudinal analysis of predictors of aggressive behaviors identifying cognitive impairment, depression, and poor quality of relationships between caregiver and care recipient. In addition, they also determined that verbally aggressive older adults suffered from depressed affect and poor health. Another longitudinally designed study (Holtzer, Tang, Devanand, Albert, Wegesin, Marder, et al., 2003) found wandering, agitation, and delusions to be common behaviors where wandering and agitation increased over time from 39% to 57%.

Of equal consideration/importance are the distribution of behaviors where one study (Shahar, Snow, Souchek, Ashton, & Kunik, 2004), found over one-third of patients exhibited at least one aggressive behavior several times per week, with the majority of aggressive behaviors (57%) exhibited less than once/week. O'Leary and colleagues (O'Leary, et al., 2005) found that one-quarter of patients exhibiting physical aggression did so against a caregiver within the last year, whereas over one-third had engaged in some form of physical aggression toward a person in the last two weeks. In addition, physical aggression was more likely to occur in the middle stages of disease and was more likely if patient had a history of conduct disorder symptoms (O'Leary, et al., 2005). Further, similar to previous literature, authors also found that delusions/paranoia were associated with general physical aggression and verbal aggression, however, not aggression toward a caregiver (O'Leary, et al., 2005).

Some studies have attempted to assess the relationship with behaviors and other manifestations to determine precipitating factors. Extending findings linking aggression with depression, one study (Lyketsos, et al., 1999), demonstrated aggressive behaviors were associated with moderate to severe depression, male gender, and greater functional impairment after adjusting for delusions, hallucinations, sleep disturbance and severity of cognitive impairment. Lopez and colleagues (Lopez, Becker, Sweet, Klunk, Kaufer, Saxton, et al., 2003) examined the relationship between depression, agitation, aggression, and psychosis in AD patients as a function of AD severity. Findings revealed that gender race and level of education appear to contribute to behavioral development where, except for depression, psychiatric symptoms increase in frequency with disease stage progression (Lopez, et al., 2003).

While these studies focused on the association of depression and behaviors among persons with dementia, another (Danhauer, McCann, Gilley, Beckett, Bienias, & Evans, 2004) conducted a longitudinal study examining behaviors and the occurrence of depression among caregivers. Behaviors increased over an 18-month span, however, distress/depression among caregivers did not, which was believed to be an adaptive process thereby incrementally decreasing depression (Danhauer, et al., 2004). Over time depression was found to be consistent with disturbing behaviors, however, more consistent with aggressive behaviors than psychomotor (Danhauer, et al., 2004).

Oftentimes, in efforts to reduce the strain associated with caring for loved ones with behavioral challenges, interventions targeting behavior management skills of caregivers, and behavior reduction for care recipients have been implemented. Corcoran and colleagues (Corcoran, Gitlin, Levy, Eckhardt, Earland, Shaw, et al., 2002) developed an occupational therapy intervention using an environmental framework proposed for dementia care. Findings demonstrated that when applied to problematic behaviors of wandering, catastrophic reactions, and burden, the intervention enhanced caregiver's ability to adapt the needs of the care recipient with the environment (Corcoran, et al., 2002). Another study (Farran, Gilley,McCann, Bienias, Lindeman, & Evans, 2007), found that when comparing two interventions targeting disruptive behaviors over time, the caregiver skill building (CSB) intervention was more effective than the information and support only (ISO) intervention in the reduction of caregiver distress. However, both were equally effective in the improvement of behavior management over time. Nichols and colleagues (Nichols, et al., 2008) examined the cost effectiveness of a multi-component psychosocial intervention to reduce caregiver stress and burden and enhance the management of care recipient behaviors. Over a six month time period results demonstrated that caregivers receiving the intervention had more time to attend to non caregiver related activities compared with caregiver controls (Nichols,et al., 2008). Table 1 provides an overview of articles with a focus on community dementia caregivers and disruptive behaviors.

In general more emphasis defining community caregivers and the impact of dementia caregiving is highlighted predominately within social work (e.g. Edwards & Morris, 2007; Cox, 1997) although nursing has examined spousal caregivers and family conflict in caregiving (Robinson, et al., 2005; Davis, 1997; Strawbridge & Wallhagen, 1991). When examining the caregiving experience of disruptive behaviors in the community, medicine and psychology are more prevalent in the literature. However, extending beyond the examination of prevalence/incidence or relationships of behaviors in the community, nursing has targeted the management of behaviors by caregivers and reducing behaviors through the testing/implementation of interventions (Farran, et al., 2007; Farran, et al., 2003; Corcoran, et al., 2002). The contribution of nursing to the development and implementation of an intervention was spearheaded by qualitative interviews regarding caregiver needs and has the potential to stimulate future nursing research which will enhance the quality of life of caregivers and care recipients over time.

Table 1

Table 1 - Community Dementia Caregivers and Disturbing Behaviors, 1990-2008

Author, Year	Purpose	Framework	Concepts/Definitions	Methods	Results	Strengths	Limitations
Hamel et al, 1990	To examine cg reactions to pt aggression		Aggression Caregiver Burden	RAS, GHQ, Burden Interview, HDS SIQ, NEO Personality Inventory, HDS Convenience sample – referral N=213 cg, M age 63.10 (145 female; 68 male N=213 care recipient, M age75.16 (128 female; 85 male)	57% of pts displayed aggression, majority verbal Predictors of aggression : Greater frequency of memory/behavior problems, pre-morbid aggression, troubled pre-morbid social relationship between pt and caregiver	Community sample Varied dementia types Introduces CG/recipient relationship factor in aggressive behavior Examines personality as contributor to behaviors	Not randomized, limited generalizability, no report of ethnic/racial breakdown Used NEO personality on caregivers versus care recipient
Aarsland et al, 1996	To explore relationships between aggressive behaviors & other neuropsychiatric symptoms		Aggressive Behavior Neuropsychiatric Symptoms	GDS, HDS, BEHAVE-AD, MMSE Convenience sample from CA dementia clinic N=75 pts, M age75.2yrs (38 male; 37 female) MMSE score (M 14.1, SD 7.8)	33% of pts verbally aggressive, 17% physically aggressive; AB more frequent with hallucinations; physical aggression associated with activity disturbance and hallucinations; verbal aggression associated with delusional ideation	Explored relationship between depression and aggressive behavior in AD	No ethnic/racial No random Generalizability Young sample may represent other dementia with different behavioral manifestations Pts on different medications may have confound results in behavioral outcomes

CG= Caregiver; RAS=Ryden Aggression Scale; GHQ = General Health Questionnaire; SIQ= Social Interaction Questionnaire; HDS=Hierarchic Dementia Scale; GDS=Global Deterioration Scale; HDS =Hamilton Depression Scale; BEHAVE-AD= Behavioral Pathology in Alzheimer's Disease Rating Scale; MMSE= Mini-Mental Status Examination

Author, Year	Purpose	Framework	Concept Definition	Methods	Results	Strengths	Limitations
Gormley et al, 1998	To examine the level and clinical correlates of aggressive behaviors		Aggressive Behavior	RAGE, BEHAVE-AD, HRSD, DSS, CDR, MMSE; convenience sample – referrals N=70 (45 female, 25 male) 58% in community	AB occur frequently in patients (nearly half of sample) and associated with delusion Delusions increases the risk of depression	Insight into behaviors in UK Use of valid/reliable measures Examined other relationships/ behaviors	No ethnic/racial Combined sample locations (inpt, outpt), LImited generalizability No random Cross sectional
Eustace et al, 2001	To determine the prevalence of verbal aggression		Verbal Aggression – verbal outbursts including unaccustomed use of foul/abusive language which may or may not be accompanied by anger or directed at a person	BEHAVE-AD, BLESSED, CAMCOG, MMSE, N=150 (M age 76.5 years) MMSE score (M19.3 SD 4.67) convenience recruited through Mercer's Institute on Aging (MIRA)	paranoid delusions/ ideation significantly associated with presence of verbal aggression; male gender and agitation significantly associated with verbal aggression	Provides prevalence and correlative data looking at verbal aggression Irish study Standardized measures	No racial/ethnic No random Convenience Cross sectional No generalizability
Corcoran et al, 2002	To explicate the role of occupational therapy in dementia care by presenting an OT intervention	Competence Environmental Press Theory	Wandering Catastrophic Reactions – emotional and physical responses to stress typically associated with dementia crying agitation cursing and physical abuse Caregiver Concerns	Intervention study N=1220 caregivers of dementia persons in the community from the Resources for Enhancing Alzheimer's Caregivers Health (REACH)	Caregivers' ability to fit the environment to the needs of care recipients enhanced; standardized the use of caregiver driven treatment applied to wandering catastrophic reactions and caregiver burden	Provides OT perspective of care intervention Large sample size Intervention empowers caregivers Utilized available data/sample	No additional sample description Cross sectional Convenience

RAGE-Rating Scale for Aggressive Behavior in the Elderly; BEHAVE-AD= Behavioral Pathology in Alzheimer's Disease Rating Scale; HRSD= Hamilton Rating Scale for Depression; DSS = Depressive Signs Scale; CDR = Clinical Dementia Rating Scale; MMSE= Mini-Mental Status Exam; BLESSED= Blessed Dementia Rating Scale; CAMCOG=Cambridge Cognitive Examination

Author, Year	Purpose	Framework	Concepts/Definitions	Methods	Results	Strengths	Limitations
Holtzer et al, 2003	To examine relationships between cognitive status and psychopathological features longitudinally		Wandering, Agitation, Physical Aggression Delusions, Hallucinations	CUSPAD, MMSE, N=236 (59% female, majority White)	Wandering, agitation and delusions are common	Longitudinal design (5 yrs) Large sample Generalizable findings Good exclusionary criteria	No racial breakdown MMSE only cognitive measure utilized Psych meds not controlled for Convenience from Predictor Study Sites (Hopkins, Columbia, Mass General)
Shahar et al, 2004	To examine use of the CMAI using several cut point to describe agitated behaviors		Agitation	CMAI, N=99 VA sample (100% male- 43% White, 40% Black, 15% other)	At least one aggressive behavior1-2x/week exhibited by almost half the sample	Usage of CMAI in community Provides data on the frequency & severity of agitation in dementia patients	All male sample Cross sectional Convenience Small AA sample
Danhauer et al, 2004	To assess behavioral symptoms and caregiver depression longitudinally		Agitated, Aggressive Behaviors Depressive Symptoms	MMSE, CES-D, PBC, CMAI-SF, N=90 clients/caregivers, convenience sample, 63% female, severe CI; 83% female caregivers – 30% spouse, 59% children (in law), 11% other relatives/friends	Increased dementia symptoms no distress increase; behaviors associated w/ higher rates of depressive symptoms	Intensive measurement protocol Good follow-up Evaluated different types of behavior and caregiver distress Reported dementia severity Longitudinal design Included different types of CG	Restricted participation Convenience Limited generalizability Limited behavior measurement (only agitation) No ethnic/racial sample reported

CUSPAD=Columbia University Scale for Psychopathology in Alzheimer's Disease; MMSE=Mini Mental Status Examination; CMAI= Cohen-Mansfield Agitation Inventory; CES-D = Center for Epidemiologic Studies Depression Scale; PBC= Patient Behavior Checklist; CG= Caregiver

Author, Year	Purpose	Framework	Concepts/Definitions	Methods	Results	Strengths	Limitations
O'Leary et al, 2005	To assess the prevalence of physical aggression against caregivers		Physical Aggression	MMSE, ADLS, CMAI-LF, Family History Interview for Personality Disorders, MBPC, Physical Self Maintenance Scale, IADLS, mMMSE; GDS, CG interview N=198 dyads (65 male pts M age, 77.2 yrs; 133 female pts M age,79.4 yrs) 62% of caregivers children, 19% partners	25% of dementia sample were aggressive to caregivers Physical aggression more likely during middle stages of dementia Pts with history of conduct disorder or physical aggression more likely to be aggressive Delusions/paranoia associated with physical aggression and verbal aggression	Examined risk of abuse/ aggressive behaviors against caregivers (safety) Examined different stages of dementia Different types of cg Good standardized measures	No race/ethnicity Not random Convenience sample Many pts in sample had behaviors and were referred for medications/adjustments to manage behaviors
Lyketsos et al, 1999	To determine the frequency of physically aggressive behavior and relationship to depression		Physically Aggressive Behavior-"an overt act involving delivery of a noxious stimulus to another person which was clearly not accidental"	Case control investigation N=541, M age 75.2 yrs; majority female, white; MMSE, Psychogeriatric Dependency Rating Scale, General Medical Health Rating, Cornell Scale for Depression	Aggressive behavior associated with moderate to severe depression, male gender, and ADL impairment	2nd study to examine relationship between depression and aggressive behavior Good sample size Concise, operationalized definition	Non-exhaustive examination of aggression variables, consecutive series of clinical sample limits ability to estimate physical aggression prevalence Cross sectional Convenience No evidence of ethnic/racial sample

MMSE = Mini-Mental Status Exam; ADLS = Activities of Daily Living Scale; CMAI-LF = Cohen Mansfield Agitation Inventory Long Form; MBPC= Memory and Behavioral Problem Checklist; mMMSE = Modified Mini-Mental Status Exam; GDS = Geriatric Depression Scale; IADLS = Instrumental Activities of Daily Living Scale

Author, Year	Purpose	Framework	Concepts/Definitions	Methods	Results	Strengths	Limitations
Lopez et al, 2003	To examine the relationship between depression agitation aggression and psychosis		Agitation – emotional distress with increased motor activity Aggression- pts displayed verbal/physical aggressive behavior Wandering- pts attempting to leave home and actually walked away Sundowning – pts exhibited increased confusion @ dusk/early night hours Delusions/Hallucinations	Descriptive N =1155 pts with AD; 349 male, 806 female; 438 mild, 563 moderate, 154 severe; convenience sample; 6% AA MMSE, CERAD-BRS, HDRS, BDRS, MDRS, CDR, HRS, NYU scale	Gender race and level of education appear to contribute to the development of psychiatric syndromes; psych syndromes increase in frequency as disease stages increase in severity (except depression)	Use of good standardized measures Expands literature on agitation and depression Introduces influence of race/education on psychotic syndromes Large sample Dementia severity description	Small minority sample Convenience Cross-sectional
Cohen-Mansfield et al, 1998	To longitudinally investigate the predictors of aggressive behaviors		Aggressive Behaviors	N=200 community residing residents from 5 senior day care centers in MD; 132 (66%) female; 87.5% White, 9.5% AA, 1% Hispanic, 1% Asian American, 1% other ethnicity CMAI-C, BCRS, MMSE, Raskin Depression Scale, SF-McGill Pain Questionnaire	Physically aggressive behaviors predicted by CI, depressed affect, and poor quality relationship; verbal aggression associated with depressed affect and poor health	Longitudinal design First study to examine aggressive behaviors and their predictors in the community over time Good standardized measures	High attrition rate (68% due to death) Convenience Low ethnic/racial sample

MMSE = Mini-Mental Status Exam; CERAD-BRS = Consortium to Establish a registry for Alzheimer's Disease Behavioral Rating Scale; HDRS = Hamilton Depression Rating Scale; BDRS = Blessed Dementia Rating Scale; MDRS= Mattis Dementia Rating Scale; CDR=Clinical Dementia Rating; HRS= Hachinski Rating Scale; New York University Scale; CMAI-C= Cohen Mansfield Agitation Inventory for Community; BCRS= Brief Cognitive Rating Scale

Author, Year	Purpose	Framework	Concepts/Definitions	Methods	Results	Strengths	Limitations
Alessi, 1999	To review behavioral management in persons with dementia		Behaviors r/t memory disturbance, restlessness/agitation, catastrophic reactions, day/night disturbances, wandering, physical violence	Review	Most common behaviors and triggers/ in addition to treatment strategies (pharmacologic and non-pharmacologic) are presented	Presents general overview of strategies caregivers can implement in the home to manage dementia behaviors	
Farran et al, 2003	To identify content and skills needed by dementia caregivers in addressing behavior and emotional responses, personal and IADLS, and cognitive decline in persons with dementia			Purposive sampling Descriptive study N=272 caregiver/recipient dyads; CG-majority female, White (80%), married, living with care recipient	The following themes emerged in order of importance to CG: Managing behaviors and emotional responses Responding to care recipient needs surrounding ADLs/IADLs Dealing with cognitive decline	Qualitative study to examine what caregivers needed Nursing research	Cross sectional Convenience Not taped, interviewers provided summaries from memory (limits accuracy) Low ethnic/racial sample

ADLS= Activities of Daily Living; IADLS= Instrumental Activities of Daily Living; CG = caregiver

Author, Year	Purpose	Framework	Concepts/Definitions	Methods	Results	Strengths	Limitations
Farran et al, 2007	To test the efficacy of a cg skill building intervention in reducing emotional distress of agitated behaviors	Self Efficacy Theory Stress Process Model	Information Support Oriented Therapy (ISO) Caregiver Skill Building Treatment (CSB) Distress Self-Efficacy Agitated Behaviors	RCT N=143; 27AA, 116 White cg dyads CG M age 62.8, female PWD M age78.8, female MMSE, RMBPC, BMS-R	CSB more effective than ISO in reducing CG distress with agitated behaviors Equally as effective in cg behavior management skill over time	RCT Longitudinal design Behavior mgmt increased in both groups Recruitment strategies Low attrition Treatment integrity Nursing research	Small sample Cross sectional Subgroup analysis doesn't compare groups Low AA sample
Nichols et al, 2008	To examine the cost-effectiveness of a RCT of a home based intervention for caregivers of people with dementia		Stress Burden Behavior Management	REACH II – multisite RCT June 02-Dec 04 N=55 Black and White intervention cg dyads, 47% AA; N=57 Black and White control cg dyads, 54% AA Zarit Burden Interview, CES-D, RMBPC, MMSE, ADLS, IADLS,	Significant differences between intervention/control caregivers in care provision hrs CG intervention group greater time to spend on non-cg related activities	First cost-effectiveness analysis of a RCT of a home based intervention for CG of PWD using a control condition Good AA sample Utilized available sample data Usage of standardized measures	Lack of follow-up data after end of intervention Lack of objective healthcare utilization data

RCT= Randomized Clinical Trial; CG= Caregiver; PWD= Person with Dementia; MMSE= Mini Mental Status Examination; RMBPC= Revised Memory and Behavioral Problem Checklist; BMS-R= Behavior Management Scale-Revised; AA= African American; REACH= Resources for Enhancing Alzheimer's Caregivers Health; CES-D= Center for Epidemiological Studies-Depression Scale; ADLS= Activities of Daily Living Scale; IADLS= Instrumental Activities of Daily Living Scale

AFRICAN AMERICAN COMMUNITY DEMENTIA CAREGIVERS

When examining the caregiving literature it is of importance to focus on the needs/health outcomes of various ethnic dementia caregivers, particularly AA. Many similarities exist among dementia caregivers as well as AA dementia caregivers, particularly the fact that they are primarily female. Subsequent differences presented in the literature over time warrant special attention. For example, AA are less commonly found to be spousal caregivers, the incidence of depression or stress related to care giving is typically lower, and care giving is more positively viewed (Messinger-Rapport, et al., 2006; Connell & Gibson, 1997; Lawton, Rajagopal, Brody, & Kleban, 1992). However, for adult child caregivers the balance of caregiving is unique in that they may be caring for an aging parent(s), other elderly relatives with dementia, as well as children or grandchildren, and may repeat the dementia caregiving role with a spouse in later years (Lampley-Dallas, 2002).

In general, the dementia literature is not lacking on caregivers, however, little attention was given to AA dementia caregivers, let alone those residing in the community. In the mid-90’s, two review articles were produced discussing dementia caregiving among AA. Both articles mentioned the methodological limitations of studies during that time involving AA dementia caregivers, which included design and small, non-representative samples (Connell & Gibson, 1997; Gonzales, Gitlin, & Lyons, 1995). However, Connell and Gibson (Connell & Gibson, 1997), who reviewed articles between 1985 and 1995, also highlighted a lack of theoretical framework testing. Gonzales, Gitlin, and Lyons (1995), who examined articles between 1987 and 1994, noted the lack of conceptualized definitions, lack of strategies aimed at recruitment and sampling, and inconsistent or absent variable clarification.

Eight articles identified during the 1990's examined a range of caregiving experiences for AA including caregiving appraisal (Lawton, Moss, Kleban, Glicksoman, & Rovine, 1991); caregiving dynamics (Lawton, et al., 1992); institutionalization decisions (Kelley, 1994); perceived rewards (Picot, 1994); caregiver stress (Cox, 1995); caregiving rewards, costs, and coping (Picot, 1995); and well-being (Haley, West, Wadley, Ford, White, Barrett, et al., 1995). Despite informative findings, indicative of the limitations noted by Connell and Gibson (1997) and Gonzales, Gitlin and Lyons (1995), all of the studies reported convenience samples and very low AA samples which limited generalizability.

In a review article, Janevic and Connell (2001) examined articles between 1996 and 2000, which compared the caregiving experiences for ethnic/racial caregivers. Overall, their findings demonstrated differences in the stress process, psychosocial outcomes, and factors related to formal service utilization. However, they noted limited generalizability of findings beyond samples studied and recommended that consideration of terms utilized be applicable to all cultures, examination of the influence of immigration and acculturation on the caregiving experience be considered, and increased qualitative/ethnographic research on the dementia caregiving experience be integrated.

Five articles identified since 2000 examined the state of dementia research in ethnic populations (Lampley-Dallas, 2002), stressful caregiving situations (Davis, Weaver, Zamrini, Stevens, Kang, & Parker, 2004), health outcomes in AA caregivers

(Dilworth-Anderson, et al., 2004), contrasts and commonalities among caregivers across different ethnic groups (Vickrey, Strickland, Fitten, Adams, Ortiz, & Hays, 2007), and differences in caregiving experiences among Black or White rural caregivers (Kosberg, Kaufman, Burgio, Leeper, & Sun, 2007). Although the studies reported continued to extend the literature and addressed many of the limitations noted in the previous decade, small, convenient samples persisted, limiting the generalizability of findings.

During the new millennium, increasing attention was focused on caregivers' decisions to institutionalize demented elders and the factors that influenced or inhibited such decisions. One study found that although over 20% of all caregivers reduced employment or quit altogether when providing community based informal care, AA and Hispanic caregivers were most likely to reduce the number of employment hours to accommodate the caregiving role (Covinsky, et al., 2001). Based on these findings authors theorized this may support why AA utilize nursing homes with decreased frequency (Covinsky, et al., 2001). In a 2004 study, (Gaugler, et al., 2004), aimed at predicting factors determining nursing home placement among AA, authors findings also supported this propensity. Throughout the 3 year study, findings revealed over 70% of the sample with dementia were not institutionalized, caregiver emotional response was a predictor of early institutionalization, caregivers experiencing higher levels of burden were likely to institutionalize, and care recipient gender, age, level of cognitive impairment and Medicaid eligibility predicted expedited institutionalization. Table 2 provides an overview of the literature detailing AA community dementia caregivers.

Table 2

Table 2 - African American Community Dementia Caregivers, 1991-2008

Title, Author	Purpose	Framework	Concepts/ Definitions	Methods	Results	Strengths	Limitations	Implications
Connell & Gibson, 1997	To review articles between 1985-1995 examining differences in race, culture and/or ethnicity in the dementia caregiving experience			Database review, examined peer-reviewed published articles looking at dementia caregiving differences among racial, cultural, ethnic groups	Methodological limitations: small non representative samples, lack of multivariate analyses, lack of control groups, lack of framework/theory testing Non-white cg less likely to be spouses, greater occurrence of adult child, friend or other family member	Offered strategies to improve methodological errors Introduced new techniques when considering ethnic/racial groups Thorough literature review with well defined, rationalized exclusionary criteria Attention to dementia caregiving across varying groups		Consider examining differences among cg groups within/between Examine race, culture, ethnicity impact on cg research constructs/measures Increase sample size/representativeness, increase diversity
Gonzales et al, 1995	To describe articles examining AA caregiving of individuals with dementia between 1987-1994			Systematic literature search of selected databases, major journals from varied disciplines	Lack of consistent conceptualized definition of burden; methodological limitations of comparative designs Lack of recruitment and sampling Clarification of variables	Inclusion/Exclusion criteria of articles reviewed Organization and summarization of findings Specific attention to AA dementia caregiving Strategies to improve methodological limitations Offers expansion of strategies for recruitment Nursing research		ID valid/reliable concepts and measures for AA Develop/implement innovative recruitment strategies Utilize systematic sampling procedures More descriptive studies of AA cg experiences

Author, Year	Purpose	Framework	Concepts/Definitions	Methods	Results	Strengths	Limitations
Lawton et al, 1991	To test a model of caregiver appraisal for spouses and adult children	Lazarus' stress model; Two factor view of Psychological Well being	Caregiving Appraisal Caregiving satisfaction/burden	From respite care study on caregiver well being Positive affect scale, Zarit burden interview, CES-D, MAI; N=285 spouses; N=244 adult-child	Spouses- caregiver satisfaction significant determinant of positive affect Adult children- higher levels of caregiver behavior related to greater caregiver satisfaction and burden Burden r/t depression in both groups but adult children cg positive affect not affected by cg satisfaction	Expands model for CG application Usage of model to describe and focus on differences between spousal/child caregivers Model usage guides research	Recruitment – local agencies Convenience sample Low "non-white" sample Cross sectional data
Lawton et al, 1992	To examine dementia caregiving dynamics of Black and White caregivers	Two factor psychological well being	Traditional Caregiving Ideology	N=632, 472 White, 157 Black MSQ; PBC; MAI; Zarit Burden Scale; CES-D; PAS From 1st wave of respite care study	Greater non-spouse, non-child cg among Blacks v Whites Black and White cg who provided greater care had increased satisfaction/burden simultaneously	Examines caregiving among greater AA sample Introduced cultural differences among AA cg compared to White Identifies variance in AA culture in identification of caregiving	Selective recruitment Convenience sample Cross sectional Aggregation of "Black" sample

CES-D= Center for Epidemiological Studies-Depression Scale; MAI= Multilevel Assessment Instrument; CG=Caregiver; AA=African American; MSQ= Mental Status Questionnaire; PBC= Problem Behaviors Checklist; PAS= Positive Affect Scale (Bradburn's Affect Balance Scale)

Author, Year	Purpose	Framework	Concepts/Definitions	Methods	Results	Strengths	Limitations
Picot, 1994	To explore relationship of rewards to demographic variables among AA caregivers	Choice and Social Exchange Theory	Perceived Rewards Internal Rewards External Rewards Short term Rewards Long term Rewards	Convenience, purposive snowball sampling , non-experimental cross sectional design N=83 AA female caregivers PCRS, TRIMS BPC	Perceived rewards internal/external in source external/internal in timing Rewards minimally influenced by SES or characteristics of cg/recipient (except for age/education) Young more educated cg perceive fewer rewards than older less educated cg	AA sample Usage of theory to guide research Demonstrates perception of reward system in AA caregivers Nursing research	Cross sectional
Cox, 1995	To examine caregiving of Black and White dementia caregivers	The Stress Process	Caregiver Stress	Purposive sample of primary caregivers N=76 Black N=88 White convenience sample MBPC	Perceived lack of informal support and sense of incompetency exacerbate stress for Black cg, no effect on White cg White cg affected by pt impairment	Factors affecting cg stress varies across groups Highlight the complexity of social suppose	Small sample size Voluntary contact Cross sectional design

PCRS= Picot Caregiver Rewards Scale; TRIMS-BPC= Texas Research Institute of Mental Sciences Behavioral Problem Checklist; AA= African American; SES= Socio-economic Status; CG= Caregiver; MBPC= Memory and Behavioral Problems Checklist

Author, Year	Purpose	Framework	Concepts/Definitions	Methods	Results	Strengths	Limitations
Picot, 1995	Explore the relationships of appraisals in coping of AA dementia caregivers	Stress and Coping Model Choice and Social Exchange Theory	Perceived Rewards Perceived Costs Caregiving Demands Coping strategies Perceived quality of social support	Convenience sample N=83 AA female caregivers PCRS, CCI, TRIMS-BPC, JCS, MWSSQ	AA use various types of coping depending on what's at stake for them and coping resources	Specific focus on coping of AA dementia caregivers AA sample size Usage of written media in recruitment Expanded inclusion of CG beyond blood relative/living with care recipient Nursing research	Cross sectional Convenience
Haley et al, 1995	Compare four groups Black and White dementia caregivers; Black and White non-dementia caregivers on psychosocial and physical well being		Psychological Distress Physical Health Social support and activity – Well Being	Convenience from Memory Clinic N = 175 70 Black, 105 White N=70 Black, 105 White (non-caregiver) MMSE, ADLS, IADLS, CES-D, LSI-Z, BSI, CMI, RMBPC, SSQRS; MAI	Cg and non-cg no difference within race on demographic variables, similar social consequences for both groups White cg increased depression and decreased life satisfaction Race associated with physical health variables	Pts carefully diagnosed and well characterized Comprehensive set of psych, social, and physical health measures	"Family" designation ambiguous Category deletion until cg/non cg did not differ significantly within race on targeted demographic variable Unknown representativeness
Janevic & Connell, 2001	To review studies that compare two or more racial, ethnic national or cultural groups on caregiving experiences				Differences may exist in the stress process, psychosocial outcomes, and in variable r/t service utilization among cg of different racial ethnic national and cultural groups		Unclear origin of differences within studies Unclear of generalizations beyond study sample

PCRS= Picot Caregiver Reward Scale; CCI= Cost of Care Index; JCS= Jalowiec Coping Scale; TRIMS-BPC= Texas Research Institute of Mental Sciences Behavioral Problem Checklist; MWSSQ= Modified Wood Social Support Questionnaire; MMSE= Mini Mental Status Examination; ADLS= Activities of Daily Living Scale; IADLS= Instrumental Activities of Daily Living Scale; CES-D= Center for Epidemiological Studies-Depression Scale; LSI-Z= Life Satisfaction Index-Z; BSI= Brief Symptom Inventory; CMI= Cornell Medical Index; RMBPC= Revised Memory and Behavioral Problem Checklist; SSQRS= Social Support Questionnaire Short Form-Revised; MAI= Multilevel Assessment Instrument

Author, Year	Purpose	Framework	Concepts/ Definitions	Methods	Results	Strengths	Limitations
Davis et al, 2004	To identify specific cg situations that are stressful			University Medical Center memory clinic Home care agencies N=30 (23 White, 7 Black) female caregivers PSM, IADL, RMBPC-A&B, CHS, SCB-B, CES-D, GDS, MMSE	CG had increased (statistically significant) cortisol production compared to non-cg	Offers physiological evidence of stress in caregivers Demonstrated feasibility of subject initiated bio-psychological data in the home setting Good standardized measures Nursing research	Young sample >60 Interpretation of findings complicated by verification of pt adherence w/ data collection protocols and omission of possible confounding variables Convenience from memory clinic Cross sectional Low AA sample
Dilworth-Anderson et al, 2004	To longitudinally examine health outcomes of AA dementia caregivers	The Stress Model	Psychosocial Health Physical Functioning Stressors Resources	Longitudinal data analysis, N=107 recruited from Duke EPESE ADLS, SPMSQ, MOS-36, OARS	Cultural beliefs/values helped explain health outcomes for AA cg	Introduces cultural influence on health outcomes Longitudinal AA sample	Sample size Rural/urban sample-unknown
Vickrey et al, 2007	To explore similarities and differences across four ethnic groups: AA, HA, EA, CA			6 focus groups of non-professional cg of pwd in L.A. from memory clinic N=47; 34 female, 13 male	Responsibilities, worrying about care recipient, unmet information needs, and stigma common to all groups AA identified more benefits to dementia caregiving (more tolerant, spiritual, better life perspective), used religion/spirituality as comfort, and identified discrimination in care/receipt of services	Qualitative Informal CG Ethnic group diversity	Convenience Cross sectional

PSM= Physical Self-Maintenance; IADL= Instrumental Activities of Daily Living; RMBPC= Revised Memory and Behavior Problem Checklist- Scale A & B; CHS= Caregiving Hassles Scale; SCB-B; Screen for Caregiver Burden-Scale B; CES-D= Center for Epidemiological Studies-Depression; GDS= Geriatric Depression Sale; MMSE= Mini Mental Status Examination; CG= Caregiver; EPESE= Established Populations for Epidemiologic Studies of the Elderly; ADLS= Activities of Daily Living Scale; SPMSQ= Short Portable Mental Status Questionnaire; OARS= Older Americans Resources and Services; PWD= Person with Dementia; AA=African American; HA= Hispanic American; EA= European American; CA= Chinese American

Author, Year	Purpose	Framework	Concepts/Definition	Methods	Results	Strengths	Limitations
Kosberg et al, 2007	To explore differences between rural White and Black caregivers	The Stress Process Model		Cross sectional survey w/ structured interview using random digit telephone dialing 39/45 rural counties in AL N=141; 67 AA, 74 White SPSMQ, DSRS, RMBPC, PSM, IADLS, ISEL, DRI, COPE Scale, CCI, QOLI	AA gave more hrs of care, used religion/denial as coping mechanism, were less burdened and participate in organized religion	Good AA sample Random digit dialing Representative of rural cg in AL	Cross sectional Structured interviews Survey data Sample size Probability sampling
Kelley, 1994	To obtain cg perceptions of the AA dementia pt and factors influencing decision to institutionalize pt			Non-randomized Descriptive (Qualitative with structure questionnaire N=72 pt/cg dyads 34 Black ,37 White, 1 Hispanic 52% AD; 18% VaD; 3.2% mixed,;26% secondary to PD/ETOH abuse	Informal support systems alternative to institutionalization with structured supportive framework, where lack of concrete resources may hasten institutionalization Majority of caregivers are daughters, among spouses- female	Provides qualitative data to describe the cg situation from viewpoint of AA caregiver Good AA sample Nursing research	Small sample size Lack of multivariate stats Convenience Cross sectional

SPSMQ= Short Portable Mental Status Questionnaire; DSRS= Dementia Severity Rating Scale; RMBPC= Revised Memory and Behavior Problem Checklist; PSM= Physical Self Maintenance; IADLS= Instrumental Activities of Daily Living Scale; ISEL= Interpersonal Support Evaluation List; DRI= Duke Religious Index; CCI=Consequences of Care Index; QOLI= Quality of Life Inventory; PWD Person with Dementia; AD= Alzheimer's Disease; VaD= Vascular dementia; PD= Parkinson's Disease; CI= Cognitively Impaired; ETOH= Alcohol; AA= African American

Author, Year	Purpose	Framework	Concepts/Definitions	Methods	Results	Strengths	Limitations
Gaugler et al, 2004	To determine predictors of institutionalization for CI AA	The Stress Process Model	Objective Stress Subjective Stress	Experimental Design 3 yr longitudinal study N=667 AA and primary cg from MADDE study RMBPC, MMSE, Zarit Burden Scale	70% of AA did not enter NH during 3-yr study CG emotional response predictor of earlier AA institutionalization Male gender, cg burden, severity of impairment, and Medicaid eligibility predictors of earlier institutionalization	ID risk factors for NH placement in MADDE population of AA pwd Includes attn to caregiver in addition to care recipient	CG/care recipient not representative or generalizable to entire population
Stevens et al, 2004	To determine racial differences in rates of nursing home placement	The Stress Process Model		Prospective sample from UAB memory disorder clinic N=215 cg dyads; 80 AA (recipient age –M 75.5, SD 8.5; cg age – M 56.7, SD 56.7) AA (MMSE- M 11.5, SD 8.7) Nam powers index of occupational status, MMSE, ADLS, IADLS, MBPC, CES-D, LSI-Z, SSQSR, CRI	Race a significant predictor of institutionalization – Whites institutionalize sooner AA recipients more likely to remain in the home until death SES of family, age of recipient, quality of relationship between cg/care recipient, behavioral/functional characteristics, cg appraisal, and cg burden increase likelihood of NHP	Extends research on AA delay of institutionalization Analyzed projections over time of placement	Cross sectional Convenience sample
Winslow & Flaskerud, 2008	To determine placement decision making between minority and white caregivers			Qualitative study; 12 CG – 3AA, 8 Hispanic/Latino, 1 Middle Eastern	Unique perspectives on LTC placement decisions: decision to place based on cultural expectations/norms, professionals advice, loneliness of placement decision making, proximity issues in care provision, lack of culturally sensitive care	Qualitative study Concerns flushed out to inform health professionals of importance of culturally competent care Nursing reseaqrch	Small sample Cross sectional

MMSE= Mini Mental Status Exam; ADLS= Activities of Daily Living Scale; IADLS= Instrumental Activities of Daily Living Scale; MBPC= Memory and Behavioral Problems Checklist; CES-D= Center for Epidemiological Studies – Depression Scale; LSI-Z= Life Satisfaction Index; SSQSR= Social Support Questionnaire, Short Form-Revised; AA= African American; CRI= Coping Response Inventory; NHP= Nursing Home Placement; AA= African American; MADDE= Medicare Alzheimer's Disease Demonstration Evaluation; RMBPC= Revised Memory and Behavioral Problem Checklist; MMSE= Mini Mental Status Exam; PWD= person with dementia

African American Caregivers and Disruptive Behaviors

Providing care to loved ones with dementia is demanding on caregivers in terms of emotional, physical, and mental health. Further, dementia caregiving combined with disturbing behaviors exacerbates the impact on caregivers. Although the impact of behaviors has been demonstrated, the influence of disruptive behaviors on AA dementia caregivers deserves attention. For AA caregivers in the reported literature, behaviors have been shown to have additional consequences. In a study by Sink, Covinsky, Newcomer, and Yaffe (2004) authors found that 92% of community dwelling ethnic groups with dementia presented with disruptive behaviors. Residents had at least one dementia behavior although ethnic groups sampled presented multiple behaviors simultaneously and with greater frequency (Sink, et al., 2004). The median number of behaviors was three, but of the three racial groups analyzed, Blacks and Latino's possessed significantly more behaviors than Whites, where 61% of Blacks possessed four or more behaviors.

Such findings lend support to instances of increased strain and stress among AA caregivers. One article found that behaviors significantly contributed to the experience of strain (personal, emotional, and role) with adult children more commonly reporting strain than spouses or other caregivers (Diwan, Hougham, & Sachs, 2004). Although not explicitly stated, this could possibly be due to competing role demands and differences in family structure and function. In 1998, Picot explored caregiver behavioral upset among hypertensive and non-hypertensive Black female caregivers. Although both groups reported comparable levels of daily hassles, hypertensive caregivers had increased caregiver demands and greater upset with recipient behaviors.

Toth-Cohen (2004) also explored influences affecting caregivers perception of upset in response to behavioral and memory problems and identified four influential factors. Social support and religious orientation, consistent with the literature, were found to buffer the influence of upset (Toth-Cohen, 2004). However, additional findings, which included making sense of memory/behavioral issues, and strategies to manage issues, were also found to affect the perception of upset and offer additional explanations illuminating AA caregivers' management of behaviors. However, the utilization of such findings to develop and implement interventions for AA has mixed effects. A randomized control trial multi-component intervention was found to improve caregiver quality of life based on burden, depression, self care, problem behaviors and social support for White and Latino's, but was ineffective for AA (Belle, et al., 2006). However, for AA spousal caregivers quality of life improvements did occur (Belle, et al., 2006). Table 3 provides an overview of the research literature describing AA community dementia caregivers and disturbing behaviors.

African American caregivers have received increasing attention in the dementia caregiving literature, although relatively recently, and by a variety of disciplines including public health (Connell & Gibson, 1997; Janevic & Connell, 2001), psychology (Lawton, et al., 1991, 1992; Haley, et al., 1995), medicine (Covinsky, et al., 2001; Covinsky, et al., 2004; Lampley-Dallas, 2002; Vickrey, et al., 2007), sociology (Dilworth-Anderson, et al., 2004), occupational health (Toth-Cohen, 2004), and social work (Kosberg, et al., 2007;C ox, 1995). However, nursing has been instrumental in shifting attention to specific challenges encountered by AA community dwelling dementia caregivers and disruptive behaviors identifying study limitations (Gonzales, et al, 1995), the physiological impact of caregiver stress (Davis, et al., 2004), institutionalization decisions (Kelley, 1994), rewards and coping (Picot, 1994, 1995), and behavioral upset (Picot, 1998). Further, the REACH study (Resources for Enhancing Alzheimer's Caregiver Health) was funded in collaboration with the National Institute of Nursing Research (NINR) with the intention of developing interventions for caregivers (REACH I and II) demonstrating the initiation and sustained commitment of nursing to contribute to the well being of dementia caregivers and the AA community through interdisciplinary collaboration (Belle, et al., 2006; Toth-Cohen, 2004).

Table 3

Table 3 - African American Community Dementia Caregivers and Disturbing Behaviors, 1998-2006

Author, Year	Purpose	Framework	Concept	Methods	Results	Strengths	Limitations
Picot & Genet, 1998	To explore the levels of cg behavioral upset among Black female cg with normal blood pressure and high blood pressure		Daily Hassles Resourcefulness Blood Pressure	Face-to-face interviews subsample from larger study N=10 hypertensive CG; N=8 normal b/p CG TRIMS-BPC, Hassles Scale, Self Control Schedule	Both cg (normal and high b/p) equal levels of hassles and resources but differed significantly in emotional reactions to behaviors CG w/ high b/p had higher demands and upset with behaviors	Qualitative study Unique perception of cg reactions to behaviors Nursing research	Convenience sample Cross sectional No indications of behaviors seen as upsetting Small sample size
Sink et al, 2004	To determine prevalence of caregiver reported common dementia behaviors		Dementia Related Behaviors: psychomotor agitation; constantly talkative; hallucinations; paranoia; unreasonable anger; combativeness; wandering; waking caregiver	Cross sectional from MADDE study N =5776 pwd and cg dyads 469 (8%) AA Pt age (M 79.1; SD 7.5) CG age (M 57.3; SD 14.1) 70% female pts, 82% female cg, 88% mod-severe dementia MMSE for AA v 66% of White subjects	90% of pts had at least one behavior (median 3) AA/Hispanics had more behaviors than Whites 61% of AA had 4 or greater behaviors AA more likely to be talkative, have hallucinations, unreasonable anger, wander or wake caregiver AA cg report less burden despite greater behaviors	Large sample Demonstrated increased likelihood of behaviors in minority populations Compared behaviors across minority groups Includes CG characteristics as a confounder in outcome relationship between ethnicity and behavior	Cross sectional design Oversampling of Latino's limits generalizability Dementia diagnosis based on treating physician Reported behaviors by CG not directly observed

CG= caregiver; TRIMS-BPC= Texas Research Institute of Mental Sciences Behavioral Problem Checklist; B/P= Blood Pressure AA= African American; MADDE= Medicare Alzheimer's Disease Demonstration and Evaluation Study; PWD= person with dementia; MMSE= Mini Mental Status Examination

Author, Year	Purpose	Framework	Concepts/ Definitions	Methods	Results	Strengths	Limitations
Toth-Cohen, 2004	To explore factors influencing appraisal of upset in Black cg		Social support Religious Orientation Making Sense Using Strategies	Convenience sample from REACH study N=15 Black cg, 12 female, 3 male Descriptive study (content analysis) in-home interviews, transcripts RMBPC	Social support and religious orientation influence upset in response to behavioral issues Making sense of behavioral issues and use of specific strategies to manage behaviors	AA sample Mixed methods Strict inclusion criteria Supports, extends past research Highlights how behaviors are managed Demonstrate blending/integration of knowledge	Small sample Participants also part of REACH study and had access to resources and education not otherwise available to general population
Diwan et al, 2004	To examine the predictors of types of cg strain among PEACE caregivers	The Stress Process Model	Caregiver Strain	N=150 pt/cg dyads Convenience: outpatient Geriatric Center @ Univ of Chicago and Sr. Health Center Pt (82% AA) CG (79% AA) Pt age (M82;SD6.8) CG age (M61.9; SD 13.5) Caregiver Strain Index, RMBPC, ADLS, IADLS, VDS	Behaviors predicted all types of role strain (role, personal, emotional) Perceived lack of support from health care team predicted personal/emotional strain Higher income predicted role strain Pt functional limitations predicted personal and role strain	Examined strain associated with end-of-life caregiving Large AA representation Standardized measures used	Cross sectional Oversampling of AA not representative of population Convenience Recruitment at Geriatric center not typical

REACH= Resources for Enhancing Alzheimer's Caregiver Health; RMBPC= Revised Memory and Behavioral Problem Checklist; PEACE= Palliative Excellence in Alzheimer's Care Efforts; ADLS= Activities of Daily Living Scale; IADLS= Instrumental Activities of Daily Living Scale; DVS= Verbal Descriptor Scale

Author, Year	Purpose	Concepts/Definitions	Methods	Results	Strengths	Limitations
Belle et al, 2006	To test an intervention on QOL and cg depression and rates of institutionalization	QOL – depression, burden, self-care, social support, problem behaviors CG Depression Institutionalization	RCT N=642; 211 AA, 212 Latino, 219 White Convenience recruited from 5 REACH sites (memory clinics, primary care clinics, social service agencies, physicians offices, churches, community centers, brochures, PSA's radio, newspaper articles, TV, newsletter, community presentations MMSE, CES-D, RMBPC, Zarit CG Burden Interview	Intervention effects improved across all groups but more statistically significant for Latino's and Whites, none for AA cg Significant interaction between relationship dyad and intervention for AA – spouses statistically significant improvement in intervention than control	RCT Excluded REACH participants/other intervention study participants Detailed exclusion criteria Rigorous recruitment efforts	6 mth follow-up Broad combination of ethnic groups – doesn't account for heterogeneity No inclusion of other ethnic groups (API/AI) No explanation for possible differences between AA No control condition

QOL= Quality of Life; CG= Caregiver; RCT= Randomized Controlled Trial; AA= African American; API= Asian/Pacific Islander; AI=American Indian; REACH= Resources for Enhancing Alzheimer's Caregiver Health; PSA= Public Service Announcement; MMSE= Mini Mental Status Examination; CES-D= Center for Epidemiological Studies-Depression Scale; RMBPC= Revised Memory and Behavioral Problem Checklist;

SUMMARY OF FINDINGS

Overall, this literature review demonstrated the challenge of disruptive behaviors of dementia in the community. Dementia in any form can be especially troubling for community caregivers, particularly family members. Further when combined with behavioral disruptions, the challenges of caregiving are exacerbated. In general, more severe dementia stages and resultant large number/percentages of behaviors are present in the community with increased frequency and have been found to be associated with increased cognitive impairment, memory problems, decreased activity/health status, relationship between care recipient and caregivers, pre-morbid personality, conduct disorder, depression, male gender, race, and education level. Because behaviors tend to occur during the mid stages of dementia and have increased with disease progression, more interventions have been developed to equip caregivers with skills more effective in managing behaviors and have allowed for engagement in non-caregiver related activities. Despite numerous strengths surrounding studies including clear conceptualization of terms, standardized measures, and increased attention to caregivers, the majority of study weaknesses included cross sectional designs, convenience samples and low minority participation.

African American older adults represent a rapidly growing minority group in the US who are not only at increased risk for dementia, but have been found to have increased prevalence of AD and disproportionate risk factors for VaD. With increased demand placed on the caregiver, frequently little attention was devoted to AA caregivers. Few studies existed with focus on AA caregivers and those which did possessed methodological limitations and low sample sizes. However, with increasing attention to minority involvement, differences in caregiving experiences according to race and type of relationship emerged and illuminated the importance of religion and social support networks on decision in the AA community. The major strengths of these studies were the identification of the influence of cultural as well as emerging regional differences as they related to various aspects of dementia caregiving in the AA community. However, despite significant advances many weaknesses including low sample sizes, cross sectional designs, recruitment techniques, low qualitative studies, and the exclusion of extended family members in the role of caregiver or primary caregiver persisted.

Although the emergence of AA dementia caregiving lagged behind the mainstream, the attention segued into continued research which shifted its focus onto the challenges of disruptive behaviors for this community. Findings began to collectively reveal that AA care recipients with dementia were more impaired resulting in more frequent behaviors yet were remaining in the home, often until death. While caregivers navigated behaviors additional research emerged suggesting religion and informal social support influenced caregiver perceptions of behaviors. Further the type of relationship between caregiver and care recipient influenced intervention effectiveness of behavior management. As researchers began to increase AA participation, several strengths were observed, such as increasing attention to the incorporation of qualitative studies, standardized measures used with minority/AA populations, and introducing caregiver characteristics including ethnicity as potential confounders in behavioral outcomes. Unfortunately, some weaknesses remained including persistent low participation, cross sectional data, and recruitment strategies

Due to a variety of factors including medical mistrust and cultural influences, low participation in dementia research has resulted in underrepresentation and understudy, which has limited generalizability of findings, treatments, or interventions and resulted in declining health outcomes for both care recipients as well as caregivers. Although increasing research has acknowledged the inadequate representation of AA despite varied attempts at recruitment and retention the numbers remain low.

The contribution of nursing, a holistic, individually focused professional discipline, possesses the sensitivity, compassion, cultural competence, and clinical skill necessary to assess and incorporate unique strategies to encourage/increase research participation and exploration of the caregiving experience of disturbing behaviors for the development of beneficial interventions. As has been demonstrated, the profession of nursing has offered a perspective that has been a significant contributor to the expansion of dementia research and associated challenges in terms of identifying and defining behaviors, intervention development for caregivers/care recipients, as well as recognizing the limitations of AA involvement in dementia research. In addition, nursing has been a proponent for methodological improvements in AA dementia caregiving research, the identification of unique challenges experienced by AA caregivers, and a partnering contributor encouraging interdisciplinary collaborative research with the intention of developing and implementing interventions for racial dementia caregiver groups.

This body of work contributes to future nursing research regarding dementia caregiving and will expand knowledge pertaining to the AA dementia caregiving experience over time, elucidate the caregiver experience with disturbing behaviors including the identification of specific behavioral management strategies utilized by caregivers, foster the exploration of caregiver/care recipient relationships (type, structure, length, proximity), encourage formal resource utilization and research participation, including clinical trials, and enhance the identification of specific needs of AA caregivers in order to guide future intervention studies. Further, the encouragement of collaborative efforts between informal and formal services in the AA community and the enhancement of informal resources, while simultaneously incorporating/acknowledging/recognizing the influence of culturally specific needs/tactics/techniques/norms and values is an endeavor the profession of nursing is prepared to continue.

RECOMMENDATIONS

In an attempt to guide researchers and encourage participation of AA subjects and their caregivers, some recommendations surrounding conceptualization of terms and research strategies, particularly recruitment, sample selection, design, and measurements, are presented.

Definitions

Disruptive Behaviors

Research surrounding behaviors of dementia has continued for many years, however, a consistent definition has eluded researchers as many are exploring particular dementia associated behaviors in depth or dementia behaviors in general, where definitions have varied. At the outset of a research study recruiting AA a broad definition may better capture the numerous behaviors which may emerge. In addition, the usage of loaded/judgemental terms such as disturbing or problematic may not be an accurate reflection of the caregivers experience, which may illuminate/provide insight into reported levels of increased tolerance/decreased burden among AA caregivers. As has been shown, AA person's with dementia possess a tendency to manifest multiple behaviors simultaneously which are perceived as disruptive. For this reason, limiting a study to a single behavior (wandering) or a general group of behaviors (agitation) may exclude other behaviors which manifest.

In addition, qualitative studies exploring behaviors that are considered disruptive, the frequency of such behaviors, and their severity, may not match the researcher's definition. Inappropriate dress several times a week may be "disruptive" to a researcher or other outside individual, but not a family caregiver. Further, exploring the meaning of a term is particularly important with behavioral changes over the course of the disease where depression or apathy/passivity may be perceived as more disruptive or of concern to caregivers due to lack of engagement. Consideration of expanding commonly recognized disruptive behaviors seen early in dementia in combination with additional behaviors which emerge later are suggested to better capture the experience of AA when not institutionalizing family members despite behaviors. In future research endeavors, as consistent terms emerge, the utilization of standardized definitions across studies involving AA may be of benefit in comparing studies and developing interventions to enhance the strategies/techniques already incorporated in the AA community.

Caregivers

In early research, the definition of caregivers was based on the family structure of majority groups where a family member such as a spouse or child was delegated as the primary caregiver. However as has been demonstrated not only are AA caregivers less likely to be spouses but the AA family is an extensive network where individuals not biologically related are considered family sharing all the rights and privileges entailed.

For this reason, the expansion of family members to include non-biological relatives, extended family members, neighbors, or church members should be considered. In addition, blended families may reside in the same residence, where caregivers who are still employed share the role of caregiving and no "primary" caregiver is present. Instead the number of hours of care is shared between children, siblings, extended family, spouses, in-laws, or grandchildren in addition to other outside members and the designated head of household or primary caregiver may shoulder a large amount of care on weekends or after work hours.

For this reason, the term primary caregiver should not be utilized as it may exclude caregivers who are in fact providing a significant amount of care. Further, consideration of dual caregiving demands which may be an emerging trend in AA communities warrants additional attention. Also exploring the length of time in the caregiving role, whether minimal or longstanding/substantial helps to validate the sense of importance for the caregiver and illuminates the significant contribution they offer.

Research Strategies

Recruitment

Although memory clinics, referral, support groups and Alzheimer's Disease Research Centers (ADRCs) represent ideal resources for recruiting caregivers and care recipients, recruitment strategies should not be limited to these outlets as many minority populations may not participate in the research studies which track participants, may not be/have enrolled in registries, seek diagnosis later where referrals are less common, and tend not to utilize formal services/resources such as support groups. Further rural environments decrease likelihood of participation in the above mentioned venues as access becomes a significant factor in difficulty. As has been demonstrated recruitment efforts should take under consideration flyers, home health care agencies/referrals, community partnerships, media usage, and mainstays within the community such as churches, beauty salons/barber shops, grocery stores, AA organizations, gyms, schools, libraries, and community sponsored programs (health fairs, workshops/seminars) to boost recruitment efforts.

In addition, the inclusion of minority researchers/health professionals for participation in data collection may enhance trust. Other factors that can help to establish trust include maintaining an attitude of openness to considering locations in the community and engaging in an honest dialogue with participants about the research. Further, continuity in providing incentives such as monetary/gift cards, free parking, and accommodations for children, show appreciation for patient and caregiver participation in research.

Sample

First, although in the AA community, the majority of caregivers and care recipients are female, maximal effort to include both genders should be incorporated. The model of caregiving tends to focus on female caregivers, but as has been demonstrated, the gradual increase of male caregivers, and potential AA male caregivers, warrants consideration, where targeted recruitment efforts should be incorporated to aid in the exploration of gender differences. African Americans are a heterogenous population where the aggregation of caregiver and/or care recipient data may minimize differences or overstate similarities of gender, or regional/urban residence/location within the diverse AA population, (which may also include Caribbean Blacks). Comparative studies between groups is encouraged, but when possible, within group comparisons with disaggregated data may yield potential differences and explanatory information or prompt further questions for future research.

In addition, expanding inclusion criteria to include various types of dementia and stages will likely capture additional potential participants. Caregivers have unique needs throughout the disease process and often are providing care on their own and may not understand the changes expected and need guidance to cope with changes and progression as well as when/how to care for themselves. Including this group of caregivers/recipients may capture these needs previously underexplored and shape (guide) varied interventions of benefit across the disease spectrum. Finally, the availability of large interdisciplinary collaborative study sites possess large samples where the AA composition may be beneficial to conduct further research with or provide opportunities to analyze available data and guide future research or interventional studies. When conducting additional research, caution is advised against caregivers who have participated in research studies previously as they may confound/introduce bias into outcomes. Although the AA sample composition may be expanded from the exploration of interdisciplinary collaborative efforts or available data, another benefit is the potential to design future studies which represent a broad perspective of challenges and solutions in the creation and implementation of interventions.

Design

Working with an elderly population raises some difficulty with attrition due to death, where cross sectional data is likely most feasible. However, longitudinal designs with mixed methods approaches to account for change in behaviors, disease progression, caregiver management strategies and experiences/perceptions allow for the quantification of subtle changes in combination with caregiver reports of changes over time, presenting more robust data. While some studies did investigate behaviors longitudinally these studies unfortunately were limited in their sample composition where observing changes over time in minority populations, such as African Americans, was not possible. Further, these above mentioned studies only observed changes in behaviors but room may have been available to identify disease progression or stability, as well as caregiver strategies.

When incorporating intervention studies, although intensive interventions have been shown to be a useful tactic, with dementia progression, interventions should be repeated or reassessed as needs will change over time and behaviors/strategies may return to baseline or be ineffective (especially in terms of education/access to resources). To include more AA this demonstrates a vested interest over time, provides additional support, and allows the development/representation/implementation of new strategies or behavioral changes from overt to subtle. Further, changes with the caregiver and care recipient can determine re-evaluation, adjustments, new education and new interventions.

Measures

The usage of measures which have been developed and have been tested in community settings with established psychometric properties should be used for the expansion of utility in minority populations and to identify strengths and weaknesses as a guide in the development of additional tools which accurately capture/depict behavioral outcomes (overt - behavioral, subtle - functional) and caregiver management strategies (religious measures). Further, this action aids in comparisons and drawing conclusions across studies over time as well as establishing concurrent validity in the expansion of measures in the literature and utilized in research.

Due to a variety of factors including medical mistrust and cultural influences, low participation of AA in dementia research has resulted in underrepresentation and understudy, which has limited generalizability of findings, treatments, or interventions and resulted in declining health outcomes for both care recipients as well as caregivers. While research among community dwelling AA with dementia and their caregivers has increased over time, acknowledging inadequate representation of AA through varied attempts at recruitment and retention, the occurrence of disturbing behaviors and its influence on the caregiving experience among AA has only recently emerged where additional research is necessary.

Incorporating many of the proposed recommendations, defining caregiving, defining dementia behaviors, and redefining or expanding methodological approaches in recruitment strategies, sample representation, design, and measurement will be a preliminary step in the mixed methodological approach to the development and implementation of future interventions to maximize the caregiving experience for both caregiver and care recipient, increase quality of life, as well as continue to contribute to the expansion of the dementia caregiving literature.

CHAPTER 3: A COMPARATIVE PROFILE OF BACKGROUND FACTORS AND DISRUPTIVE BEHAVIORS BETWEEN AFRICAN AMERICAN AND WHITE COMMUNITY DWELLING PERSONS WITH DEMENTIA

INTRODUCTION

Nearly 5 million older adults are affected by Alzheimer's disease (AD), the most prevalent dementia and the third costliest disease, with national expenditures upwards of $100 billion and projections expected to triple by the year 2050 (Sanders & Morano, 2008; Nichols, et al., 2008; Algase, 2007; Cotter, 2007; Messinger-Rapport, et al., 2006). Progressive memory loss, the most common characteristic, and everyday functioning are impaired, with ten percent of the 65 years of age and older population affected (Cotter, 2007; Hubbell & Hubbell, 2002; Harwood & Ownby, 2000). However, the prevalence rate increases dramatically, up to 50%, among the 85 years of age and older cohort (Thompson, et al., 2004; Hubbell & Hubbell, 2002; Shanks-McElroy & Strobino, 2001). Further, census projections quadruple for those 85 years of age and over by the year 2050 where the impact of AD, factored with age and decreasing birth rates, will increase (Cotter, 2007; Day, 1996). As the geriatric population is projected to reach 20% by 2050, the minority elder population will comprise 22% as early as 2020, with African Americans doubling the same year, increasing dementia risk for elders, and minority elders in particular (McKinnon & Bennett, 2005; Harwood & Ownby, 2000). For the purpose of this paper the term African American (AA) will be utilized to distinguish from other Black minority groups, where considerable heterogeneity exists (Aspinall, 2008; Arthur & Katkin, 2006; McKinnon & Bennett, 2005; Williams & Jackson, 2000).

Supporting data has recently emerged suggesting higher prevalence and heightened risk for dementia among minority elders (Sink, et al., 2004; Harwood & Ownby, 2000; Picot, et al., 1995). However, AA in particular despite increased incidence and prevalence, remain understudied and under-represented in research leading to poor health outcomes, limited applicability of findings or interventions, and little research on the influence of culture/ethnicity (Sink, et al., 2004; Lampley-Dallas, 2002; Harwood & Ownby, 2000). The most commonly diagnosed dementia in AA is AD, and vascular dementia (VaD), the second most common dementia affecting the elderly, tends to occur more often in AAs (Dugue, et al., 2003; Harwood & Ownby, 2000). Vascular dementia is of significant concern due to documented prevalence among AAs for cardiovascular illnesses, including hypertension, stroke, and heart disease, in combination with emerging evidence associating diabetes and atherosclerosis, also prevalent within AA communities, with VaD risk (CDC, 2006, Harwood & Ownby, 2000; Shadlen, et al., 2000).

Disruptive behaviors, which are subjectively perceived, interfere with daily activities including care provision or pose safety concerns, and generally occur within mid-to-late stage dementia (Logsdon, et al., 2007; Senanarong et al., 2004; Cohen-Mansfield & Billig, 1986). Disruptive behaviors consume up to 30% of dementia related costs (Cotter, 2007) with reported community prevalence rates as high as 98% contributing to caregiver stress, burden, reduced income or employment and represent a common reason for institutionalization, neglect, or abuse (Messinger-Rapport, et al., 2006; Sink, et al., 2005; Sink, et al., 2004; Hubbell & Hubbell, 2002; Finkel, 2001). Many behaviors are represented in the dementia literature as disruptive (Robinson, 2003; Vitiello & Borson, 2001; Jorm, 2000; Colling, 1999; Skelly & Flint, 1995; Hogstel, 1993), however, the most frequently occurring include agitation, aggression, delusions, hallucinations, wandering, and vocalizations (Finkel, 2001; Stoppe, et al., 1999).

With over two-thirds of persons with dementia residing in the community receiving care from 10 million caregivers, 75% of whom are informal caregivers such as family members, informal expenditures increase with dementia progression (Nichols, et al., 2008; Cotter, 2007; Messinger-Rapport, et al., 2006; Schulz & Martire, 2004; Langa, et al., 2001). Despite the economic impact, physical and mental health demands, and increased prevalence of behaviors in the community, families prefer to maintain relatives in the home (Nichols, et al., 2008).

In the AA community, due in part to cultural and historical influences, reliance on informal social supports, including the church and family, have contributed in part to an overall reluctance to institutionalize elders or utilize formalized services (Dilworth-Anderson & Anderson, 1994; Picot, et al., 1997; Belgrave, et al., 1993). Further, disproportionate health risks and outcomes associated with chronic illnesses, which affect AAs, lack of dementia research participation, as well as under diagnosis or late diagnosis of dementia, limit effective treatment options (Arthur & Katkin, 2006; Sink, et al., 2004; Smedley, et al., 2003; Lampley-Dallas, 2002). The AA experience of caregiving has only recently begun to emerge in the literature (Lawton, et al., 1991), where in light of simultaneous and more frequent disturbing behaviors among AA, the emerging trend is necessary. Although some information has been generated regarding the management of behaviors by AA caregivers, the perception of dementia caregiving and factors which may influence them remain largely unknown (Belle, et al., 2006; Toth-Cohen, 2004). Further, few studies have demonstrated the types of dementia, behavioral manifestations, the experience of caregivers with behaviors over time, and intervention strategies to aide caregivers as well as care recipients. The persistence of low sample sizes, cross sectional designs, and conceptualization issues have also increased the difficulty with exploring this topic adequately.

Recognizing the dearth of information detailing the experience of caregiving for AA dementia caregivers and acknowledging the cultural influences contributing to the uniqueness of the AA experience, the Need-Driven Dementia-Compromised Behavior (NDB) model is presented to aid in the exploration of the AA experience of dementia caregiving in the context of disturbing behaviors.

Purpose

The purpose of this study was to examine background factors of the NDB model to address the following research questions: 1) What relationships exist between cognitive factors and behaviors among AAs; 2) What relationships exist between health status factors and behaviors among AAs; 3) What relationships exist between demographic variables and behaviors among AAs and; 4) How do background factors associated with behaviors differ between AAs and Whites?

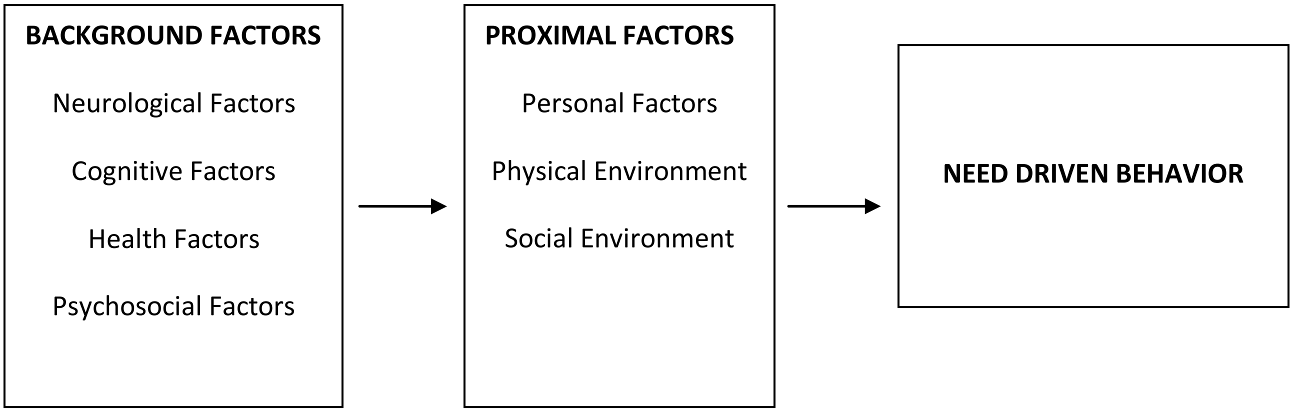
NEED DRIVEN DEMENTIA COMPROMISED BEHAVIOR (NDB) MODEL

Model Description

Although numerous middle range theories and models have been developed throughout the years (e.g. Cohen-Mansfield) based on the classification and treatment of behavioral interventions, this paper will focus on the NDB model. The NDB is a middle range, holistic, conceptual nursing framework which suggests that objectively perceived behaviors characterized as disruptive or problematic are the manifestation of preserved primary behaviors, which are based on goal pursuit or need expressions but are dementia compromised (Algase, Beck, Kolanowski, Whall, Berent, Colling, et al., 1996). The NDB model represents the interaction between background and proximal factors which influence the manifestation of various dementia behaviors. Simultaneously, it considers the comprehensive assessment of the person and their environment (Algase, et al., 1996).

Background factors are static, or unchanging, individual characteristics which portray a risk profile of persons with dementia that is comprised of - neurological factors, cognitive factors, health status, and psychosocial factors (Algase, et al., 1996). Proximal factors are more dynamic and are represented as - personal, physical environmental, and social environmental factors-triggers-which precipitate behaviors (Algase, et al., 1996). Figure 1 presents a schematic of the NDB model and factors affecting NDB.

Figure 1 The Need-Driven Dementia-Compromised Behavior (NDB) Model



Usage

The NDB model has demonstrated and reported methodological strengths surrounding dementia behavior in terms of observation and inter-rater reliability to improve measurement challenges, received endorsement for its utility, and interdisciplinary collaboration to increase and expand its sophistication has been suggested (Burgio, 1999; Whall, 1999). The NDB model has also functioned to assist with the development of interventions aimed at decreasing behaviors. Kolanowski & Whall (2000) provided a holistic overview of how the NDB can be utilized in the development of interventions to manage behaviors. According to the authors, by identifying background factors for individuals at risk, combined with the identification of proximal factors to be addressed, representing a need state, tailored individual interventions matched to skill level can be developed, creating an appropriate yet comprehensive intervention designed for the person with dementia behavior.

Kolanowski, Richards, and Sullivan (2002) utilized background factors to illustrate an individualized intervention for dementia behaviors. Whall (2002) also illustrated how interventions can be developed and expanded utilizing the NDB model through the process of theory synthesis, allowing the merging of additional theories outside of nursing to guide intervention development. Yao & Algase (2008) utilized theory synthesis to extend dementia behaviors combining the NDB model with a model of locomoting responses to environment in elders with dementia (LRE-EWD).

Richards, Lambert, & Beck (2000) also examined the influence of the NDB model in the development of interventions for behavior management by highlighting selected proximal factors (hunger, sleep, and social environment) and discussing targeted interventions to minimize behaviors. Selected intervention studies demonstrated varied degrees of success, but collectively, techniques addressing sleep, hunger and environment helped to reduce NDB's (Richards, et al., 2000).

In a series of intervention studies examining activities matched on skill level and interest in behaviors of persons with dementia, overall findings demonstrated behaviors were of shorter duration or reduced frequency (Colling & Buettner, 2002); effective for wide spectrum of behaviors (Kolanowski, Litaker, & Buettner, 2005); and less behaviors were exhibited while engaged with activities (Kolanowski, Buettner, Costa, & Litaker, 2001; Kolanowski, Litaker, & Baumann, 2002), or when individually selected (Fitzsimmons & Buettner, 2002).

The NDB model has been utilized to understand the relationship of premorbid personality to wandering (Song, 2003); to explore medication usage in nursing homes and behavioral outcomes (Kim & Whall, 2006; Kim, 2005) to guide dementia care according to Korean nursing standards (Whall, Shin, & Colling, 1999); served as a guiding framework for the development of a wandering scale tested in US, Canadian, and Australian nursing homes (Algase, Beattie, Song, Milke, Duffield, & Cowan, 2004); and has been suggested as a framework supporting person-centered care (Mitty & Flores, 2007; Penrod, Yu, Kolanowski, Fick, Loeb, & Hupcey, 2007). However, most notably, the NDB model has been incorporated in numerous studies as a guiding framework to understand various dementia behaviors including aggression, wandering, problematic vocalizations, passivity, and sleep disturbances.

AGGRESSIVE BEHAVIORS

Kolanowski and Garr (1999) utilized the NDB model in a descriptive cross sectional study to determine if premorbid characteristics predicted aggressive physical behaviors in nursing home residents with AD or VaD, or if pre-morbid factors as a group predicted aggressive physical behaviors in dementia. In a convenience sample of 84 demented elders residing in four nursing homes in northeastern Pennsylvania, the majority of the sample was female (69%), with a mean age of 84.95 and mean Mini Mental Status Examination (MMSE) score of 4.99 demonstrating severe cognitive impairment. In comparison to an earlier pilot study, findings did not support that pre-morbid factors predicted aggressive physical behaviors. Overall the sample was consistent with the general public except on openness scores and the sample was average in terms of emotional stability and responses to stress. Authors hypothesized that factors such as lower mean mental status scores, less physical aggression across the sample, and loss of physical ability, and lack of measurements for subtle aggression contributed to results.

Whall, et al. (2008) in a multivariate, cross sectional descriptive study, used background and proximal factors from the NDB model to describe the occurrence of aggressive behaviors among nursing home residents in the development of interventions and to improve dementia care. Nine randomly selected nursing homes, ranging between small and medium size, in 4 counties in the Midwest were selected revealing a sample size of 107 participants (5.6% AA). Findings revealed that shower baths were the only care event monitored during the study which triggered aggressive behaviors. The background factors which predicted aggressive behaviors during bathing were gender, stage of dementia, and personality profile, including four other care observations. The proximal factor of amount of sleep predicted the occurrence of aggressive behaviors.

WANDERING BEHAVIORS

Algase (1999) suggested use of the NDB model to aid in the understanding of wandering behaviors, through a perspective looking “within” a behavior, especially with consideration of neurocognitive factors in designing and implementing future interventions. Beattie and Algase (2002) described the successful development of a method, substruction, to guide an intervention to improve feeding impairment of wanderers within nursing homes. Shortly after this article, Beattie, et al., (2004) in an embedded experimental convenience sample of three residents – 2 in nursing homes (NH) and 1 in an assisted living facility (ALF) – extended this research and utilized the NDB model to determine the effect of the systematic use of a behavioral nursing intervention on mealtime behaviors of wanderers. Despite a small sample size, long term care setting, and a non randomized mealtime intervention, structured communication and behavioral reinforcement helped to maintain wanderers at the table during meals for longer periods of time.

Beattie, Song and Lagore (2005) explored background and proximal variables of the NDB model to identify wandering in long term care (LTC) (NH and ALFs) utilizing the Revised Algase Wandering Scale-Nursing Home Version tool (RAWS-NH). Although no differences were found in behaviors between the two settings, safety precautions were emphasized due to the variation in staffing and regulations, in efforts to prevent elopement and other sentinel events (Beattie, et al., 2005)

PASSIVITY

Colling (1999) utilized the NDB model to discuss passive behaviors as a problematic behavior, which although not disruptive, are disturbing to caregivers, and generally are unresponsive to interventions. Colling (2004) also utilized a qualitative semi-structured interview on a purposive sample of 50 Midwestern caregiver and care recipient dyads residing in the community, recruited from a cognitive impairment clinic to illustrate the impact of passivity. Care recipients ranged in cognitive impairment between mild to severe, were primarily female, with a mean age of 77 years. The care recipient sample was 92% White and eight percent AA. Caregivers were evenly distributed by gender although the majority were spouses, followed by children. The mean age was 63 years. Findings revealed that although passive behaviors were emotionally distressing to family caregivers, caregivers were able to understand and respond to the needs of loved ones to encourage engagement with people, the environment, and activities.

SLEEP DISTURBANCES

Sullivan & Richards (2004) utilized the NDB model to compare a convenience sample of 171 nursing home residents from 7 nursing homes in the central southeastern US with dementia who maintained normal circadian rhythms to those with altered circadian rhythms to explain disruptive behaviors. The sample included subjects with probable AD, VaD, mixed dementia, alcohol related dementia, dementia related to trauma, and unspecified dementia. The majority of the sample was female, White, with some AA (11%) and Latino (0.6%) subjects, possessed a mean age of 80.64, and mean MMSE score of 8.41 demonstrating severe cognitive impairment. Findings demonstrated that psychosocial activity and physical activity were predictors of the development of circadian disturbances offering insight into the development of interventions to engage subjects and decrease alterations in sleep wake cycles/patterns. A major strength of the study was that it was the largest study of sleep wake cycles in elders with dementia.

PROBLEMATIC VOCALIZATIONS

Beck and Vogelpohl (1999) introduced problematic vocalizations and the incorporation of the NDB model in understanding the motivations behind such behaviors in efforts to promote well being by targeting effective management techniques. In a non-random sample of 97 nursing home residents from one central Arkansas nursing home and 2 nursing homes from the Baltimore MD/Washington DC areas, were examined longitudinally and their relationship to each other and with selected background/proximal variables (Beck & Vogelpohl, 1999). The majority of the sample was female, White, with 13.2% AA, mean age was 82.5 years, mean MMSE score 7.77 indicating severe cognitive impairment and mean activities of daily living (ADL) scores of 29.43 indicative of moderate functional impairment (Beck & Vogelpohl, 1999). Findings revealed residents presented an average of 2 behaviors in each 8 hour videotaped/observational episode and out of total behaviors 48% were some variation of problematic vocalizations. Gender, fragmented sleep, and affect were significantly related to aggressive vocal behaviors where aggression and vocalizations explained 39% of variance. Further, cognitive impairment and fragmented sleep were significantly associated with agitated vocal behaviors, where agitation and vocalizations explained 28% of variance (Beck & Vogelpohl, 1999).

Woods, Rapp, & Beck (2004) conceptualized the terms escalation and de-escalation when referring to BPSD (Behavioral and Psychological Symptoms of Dementia) and utilized the NDB model as a theoretical framework to guide an intervention in examining the escalation/de-escalation of behaviors of nursing home residents with dementia. The first study was a descriptive convenience sample comprised of 19 cognitively impaired nursing home residents. The sample was primarily female and White, with a mean age of 81 years, and a mean MMSE of 6 indicating severe dementia.

Findings from this study revealed behaviors which oscillated between two categories rather than escalating linearly and then deescalating.

Study two, an interventional study, included 57 long term facility residents. Subjects were primarily female, White, with one Asian male, and had mean MMSE scores of 5.85 indicated severe cognitive impairment (Woods, et al., 2004). Overall findings demonstrated that the escalation of behaviors and vocalizations, persisted without intervention. With a therapeutic touch intervention vocalization behaviors de-escalated although authors cautioned that behaviors and escalation/de-escalation are individualized contributing to variance within an individual and across individuals thereby necessitating tailoring of interventions (Woods, et al., 2004).

Kovach, Noonan, Schlidt, & Wells (2005) extended the NDB model to reflect consequences. Overall, authors supported the importance of addressing underlying needs of persons with dementia to prevent a cascade of events resulting in negative outcomes, prevent or delay transitions from home or hospital visits, and improving the environment for all persons with behaviors by attending to specific underlying needs.

Strengths/Limitations

The NDB model represents a methodologically sound model and exceptional work in uncovering premises explaining behaviors in dementia. However, despite its varied utility and strengths one of the major limitations is that it has not been adequately tested with an AA population. Further, with the exception of Colling's (2004) study of passivity among community dwelling residents, the NDB model has been limited to usage within the nursing home setting. In addition, although the influence of the social environment, one of the proximal factors identified within the NDB model, has been examined (Richards, et al., 2000), it was conceptualized and utilized primarily in relation to the nursing home environment.

Dementia and its behavioral manifestations have numerous implications within the community dwelling AA older adult population and among caregivers, due in large part to its understudy. This research provides additional data to extend this aspect of the model to include and consider influential factors within the community setting/home environment. To provide an understanding of the unique experiences and needs of AA person's with dementia (PWD) and their caregivers, the NDB model was utilized, expanded, and examined in efforts to offer culturally appropriate strategies to safely maintain residents in the home, improve the quality of life and health outcomes for PWD and their caregivers, and simultaneously reinforce the caregiver and patient relationship.

METHODS

The Aging, Demographics, and Memory Study (ADAMS) is a supplement to the Health and Retirement Study (HRS) which is sponsored by the National Institute of Aging (grant number NIA U01AG009740). It was conducted jointly by Duke University and the University of Michigan. Designed as a community based assessment of dementia, ADAMS sought to provide information on risk factors and outcomes of Cognitive Impairment Not Demented (CIND) and Dementia. In the literature, study design, methodology, and sample characteristics of the ADAMS has been described (Langa, Plassman, Wallace, Herzog, Heeringa, Ofstedal, et al., 2005) as well as sample design, analysis and weighting (Heeringa, Fisher, Hurd, Langa, Ofstedal, Plassman, et al., 2006). ADAMS data has been used to estimate dementia prevalence in the US (Plassman, Langa, Fisher, Heeringa, Weir, Ofstedal, et al., 2007); estimate cognitive impairment without dementia prevalence in the US (Plassman, Langa, Fisher, Heeringa, Weir, Ofstedal, 2008); explore parental educational influence on dementia development in late-life (Rogers, Plassman, Kabeto, Fisher, McArdle, Llewellyn, et al., 2009); prevalence of depression among US older adults (Steffens, Fisher, Langa, Potter, & Plassman, 2009); and psychometrics of alternative scales assessing cognitive impairment (Fong, Fearing, Jones, Shi, Rudolph, Yang, et al., 2009).

This is a secondary analysis utilizing the ADAMS dataset where the behavioral outcomes of delusions, hallucinations, agitation, and depression were selected based on frequencies and support in the literature. The NDB model was utilized to organize selected variables according to background factors related to the behavioral outcomes. Demographic variables including age, race, gender, education, region of residence, employment status, and marital status were selected to provide a description of the sample. Original data categorized education as: no degree, GED, high school, 2 yr degree, 4 yr degree, master's degree, or professional degree. Education was collapsed into three categories, less than high school, high school completion, or greater than high school for analyses.

Additional data was selected based on risk profile for dementia development or behavioral manifestations. Selected variables included: current smoking status, current problem drinking, conditions, type of dementia, number of behaviors, and medications. Type of dementia was categorized as Alzheimer's dementia, Normal, and other (which included other dementia types including vascular dementia, and CIND). Five condition categories were created based on associated dementia and behavioral risk factors and included neurological, cardiovascular, cancer, psychiatric, and other. The "neurological" condition included reported history of Parkinson’s disease, brain injury, head injury, and epilepsy. The “cardiovascular” condition included reported history of hypertension/high blood pressure, heart attack/MI, high cholesterol/triglycerides, stroke, and diabetes. The condition labeled “psychiatric” included reported history of mood disorder, schizophrenia, bipolar disorder, hallucinations, and delusions. Finally, “other” included reported history of thyroid or respiratory problems, which in the dataset included asthma, bronchitis, COPD, and emphysema.

Four medication categories were created to identify those most influential on the presence of behavioral manifestations. Categories included Alzheimer’s medications, sleep medications, pain medications, or psychiatric medications. The list of reported medications were reviewed and assigned to the appropriate category.

Subjects

A random subsample of 1,770 individuals over the age of 70, from the year 2000 of the larger Health and Retirement Study (HRS), were selected to comprise the Aging, Demographics, and Memory Study (ADAMS). Of the original subjects targeted, 227 (13%) died before assessments and 687 (39%) refused/other non-participatory reason, resulting in 856 individuals who were assessed. For data analysis, 742 AA and White subjects who answered questions regarding behavioral outcomes were included.

Procedures

ADAMS study procedures were explained in depth to subjects and written informed consent was obtained. Prior to individual HRS interviews, informed consent was obtained from all respondents. The University of Michigan Institutional Review Board approved the HRS and both the University of Michigan and Duke University

Institutional Review Boards approved ADAMS. Structured 3-to-4 hour assessments were conducted within the homes of subjects by a nurse and neuropsychology technician. A knowledgeable and reliable informant provided respondent information which included: a) chronological history of cognitive symptoms; b) medical history; c) current medications; d) current neuropsychiatric symptoms; e) measures of severity of cognitive and functional impairment; f) family history of memory problems; and g) caregiving questionnaire. Respondents completed a) neuropsychological measures battery; b) self-report depression measure; c) standardized neurological examination; d) blood pressure measure; e) collection of DNA sample for APOE genotyping; and f) videotaped segment covering sections of the cognitive status and neurological examination. Neuroimaging and laboratory results were also reviewed.

Three general categories of diagnoses-normal cognitive function, CIND, and dementia-were assigned. To denote the etiology of cognitive impairment, several subcategories within the categories of CIND and dementia, were utilized. Prior to the initiation of the ADAMS, diagnostic criteria based on published criteria such as the DSM-III-R and DSM-IV, were established. To capture the range of etiologies and clinical presentations, CIND was broadly defined as, "functional impairment reported by the ADAMS subject or informant that did not meet criteria for dementia, or performance on neuropsychological measures that was below expectation and >1.5 standard deviations below published norms on any test within a cognitive domain (e.g. memory, orientation, language, executive function, praxis)" (Langa, et al., 2005, p. 186). An expert consensus panel comprised of neuropsychologists, geropsychiatrists, internists, and neurologists assigned final diagnoses.

Measures

The ADAMS utilized several objective measures, however, for the purpose of this analysis and remaining consistent with background factors included in the NDB model, four measures were selected. The Mini-Mental Status Examination, the Clinical Dementia Rating scale, and the Dementia Severity Rating Scale were selected for the analysis of cognitive status factors. Health status factors were analyzed with the Blessed Dementia scale.

Cognitive Status

The Mini-Mental Status Examination (MMSE) (Folstein, Folstein, & McHugh, 1975) is a commonly used screening tool to quickly assess cognitive impairment in the elderly and intellectual changes over time. The MMSE consists of 11 items where a total score of 30 is assessed in the seven domains of orientation to time (5 points), orientation to place (5 points), registration of three words (3 points), attention and calculation (5 points), recall of three words (3 points), language (8 points), and visual construction (1 point). The MMSE was developed to differentiate between neurologic and psychiatric patients (organic v. functional organic) with no intention to be utilized as a diagnostic measure. Through the evolvement of research findings over time, a score of 23 or less has been generally accepted to indicate the presence of cognitive impairment (Tombaugh & McIntyre, 1992).

The severity classification has been divided into three levels: 24-30 = no cognitive impairment; 18-23 = mild cognitive impairment; and 0-17 = severe cognitive impairment (Tombaugh & McIntyre, 1992). Original validity and reliability reports based on 206 psychiatric patients found correlation of 0.78 with the Weschler Adult Intelligence Scale for verbal IQ and 0.66 for performance IQ. Test/retest reliability was 0.89 and a combination of test/retest and inter-rater reliability was 0.83 (Folstein, et al., 1975). Subsequently, Tombaugh & McIntyre (1992) performed a comprehensive review of the MMSE's usage over 26 years finding moderate-to-high levels of reliability, and validity demonstrating high levels of sensitivity for moderate-to-severe levels of dementia. However, for older AA false-positive rates have been found to be higher than Whites (Fillenbaum, Heyman, Williams, Prosnitz, & Burchett, 1990; Gurland, Cross, Teresi, & Barrett, 1992).

Further, intercorrelations between the Comprehensive Assessment and Referral Evaluation (CARE) diagnostic, Mental Status Questionnaire, Short Portable Mental Status Questionnaire, Blessed Memory-Information-Concentration test, and MMSE were worse when administered to AA than White patients (Gurland, et al., 1992). In addition, the impact of age (Brayne & Calloway, 1990) and education have been shown to be contributing factors to low cognitive measurement scores, including the MMSE, among AA, where cut point adjustments have been recommended when administered to subjects with low levels of education (Murden, McRae, Kaner, & Bucknam, 1991). However, more recently, Ford, Haley, Thrower, West, & Harrell (1996) demonstrated that race, age, and education do not influence MMSE scores in the presence of a dementia diagnosis.

The Clinical Dementia Rating Scale (CDR) (Hughes, Berg, Danziger, Coben, & Martin, 1982), a global dementia measure, describes dementia in six categories of memory, orientation, judgement/problem solving, community affairs, home/hobby, and personal care. The five-point scale has ratings of 0 (no cognitive impairment), 0.5

(questionable), 1 (mild) 2 (moderate) and 3 (severe) with total scores ranging between 0 – 5 based on algorithm calculation (Morris, 1993; Hughes, et al., 1982). Inter-rater reliability correlation coefficient was originally reported at .89 (Hughes, et al., 1982) with subsequent videotaped design reports of .91 (Burke, Miller, Robin, Morris, Coben, Duchek, et al., 1988). Validity against other neuropathologic conditions with 100% specificity has been reported (Morris, McKeel, Fulling, Torack, & Berg, 1988), although strict exclusionary criteria, limited generalizability and sensitivity findings.

The Dementia Severity Rating Scale (DSRS) (Clark & Ewbank, 1996) is an 11-item questionnaire completed by caregivers which assesses memory, orientation, judgement, social interaction, home activities, personal care, language, recognition, eating, continence, and mobility. Each category descriptor increases in severity with sequential numbering, where zero represents normal functioning. Caregivers indicate the subjects' average level of functioning where zero in all 11 categories represents no impairment and the maximum score of 53 represents the most severe impairment. The DSRS has demonstrated high concurrent validity with correlations between the MMSE of 0.74 and selected components of the CERAD battery of 0.73. In addition, test re-test reliability has a correlation of 0.90 and inter-rater reliability >0.87.

Health Status

The Blessed Dementia Scale (Blessed, Tomlinson, & Roth, 1968) is a cognitive and behavioral quantitative assessment of daily functioning, habits, personality, orientation, memory, and concentration in dementia. The test is divided into two sections where the first section includes daily activities, habits, and personality with scores ranging between 0-17. The second section of the test includes orientation, memory, and concentration and was completed with advanced dementia subjects.

Statistical Analysis

Between-group comparisons (AA compared with Whites) were made with use of independent *t* tests or chi-square tests. Multiple regression models using logistic regression were utilized to describe associations between behavior outcomes. Analyses were conducted with a combination of SAS version 9.2 (SAS Institute Inc., North Carolina) and SPSS version 18 (SPSS Inc., Chicago).

RESULTS

Sample Characteristics

The White sample (n=594) had an average age of 81.41 years (SD=6.88 years). The majority were female (57.20%), widowed (50.20%), or married (42.20%), and retired (85.40%). The AA subjects (n=148) had an average age of 81.49 years (SD=6.83 years). Similarly, the majority were female (61.50%), widowed (62.70%), or married (26.90%), and retired (86.70%). The majority of Whites were almost evenly distributed across the, S. Atlantic region (27.10%), the Midwest (24.30%), and the West (20.30%), whereas the majority of AAs were concentrated in the south (68.90%). The education for Whites revealed the majority of subjects possessed less than HS education (44.30%), although this was followed closely by White subjects with a HS diploma (35.40%). However, education for AAs revealed a large majority of subjects had less than HS education (82.40%). Table 4 presents additional demographic data (psychosocial factors of the NDB model) pertaining to the sample.

Table 4 - Sample Demographics

Variable	Overall (N=742) N or Mean (% or SD)	White (N=594) N or Mean (% or SD)	AA (N=148) N or Mean (% or SD)	p-value (α=0.05)
Age (yrs)	81.42 (6.87)	81.41 (6.88)	81.49 (6.83)	0.90
Range	[70-110]	[70-105]	[70-110]	
Education				***<0.01**
Less than HS	358 (48.30)	236 (44.30)	122 (82.40)	
HS	283 (38.10)	263 (35.40)	20 (13.50)	
More than HS	101 (13.60)	95 (16.00)	6 (4.10)	
Gender				0.35
Male	311 (41.90)			
Female	431 (58.10)	340 (57.20)	91 (61.50)	
Ethnicity				
White	594 (80.00)			
AA	148 (20.00)			
Marital Status				***<0.01**
Single	19 (2.50)	15 (2.60)	3 (2.20)	
Married	278 (39,30)	242 (42.20)	36 (26.90)	
Divorced	36 (5.10)	28 (4.90)	8 (6.00)	
Separated	4 (0.60)	1 (0.20)	3 (2.20)	
Widowed	372 (52.50)	288 (50.20)	84 (62.70)	
Region				***<0.01**
NW	100 (14.10)	81 (14.10)	19 (14.10)	
MW	157 (22.10)	140 (24.30)	17 (12.60)	
S. Atlantic	214 (30.10)	156 (27.10)	58 (43.00)	
S. Central	116 (16.30)	81 (14.10)	35 (25.90)	
West	123 (17.30)	117 (20.30)	6 (4.40)	
Employment				0.57
Working	19 (2.70)	18 (3.10)	1 (0.70)	
Retired	608 (85.60)	491 (85.40)	117 (86.70)	
Semi-retired	36 (5.10)	29 (5.00)	7 (5.20)	
Disabled	15 (2.10)	11 (1.90)	4 (3.00)	
Unemployed	32 (4.50)	26 (4.50)	6 (4.40)	

Tables 5, 6, and 7 present descriptive statistics of the sample pertaining to background factors of the NDB model and selected variables associated with dementia/behavioral risk and selected behavioral outcomes. Of the proportions reported, chi-square tests showed there were significant differences between Whites and AA subjects for education, cancer diagnosis, "other" diagnosis, type of dementia, marital status, region of residence, and the proportion of individuals with a display of depressed behavior. T-tests indicated significant differences by race/ethnicity for the mean number of drugs reported, mean number of conditions or procedures reported, and MMSE score.

Table 5 - Descriptive Statistics by Variable and Race (Health Status)

Variable	Overall (N=742) N or Mean (% or SD)	White (N=594) N or Mean (% or SD))	AA (N=148) N or Mean (% or SD)	p-value (α=0.05)
Condition (Cardiovascular)				0.64
No	116 (15.60)	91 (15.30)	25 (16.90)	
Yes	626 (84.40)	503 (84.70)	123 (83.10)	
Condition (Cancer)				**<0.01**
No	518 (69.80)	398 (67.00)	120 (81.10)	
Yes	224 (30.20)	196 (33.00)	28 (18.90)	
Condition (Other)				**<0.01**
No	497 (67.00)	381 (64.10)	116 (78.40)	
Yes	245 (33.00)	213 (35.90)	32 (21.60)	
Condition (Neurological)				0.24
No	591 (79.70)	468 (78.80)	123 (83.10)	
Yes	151 (20.40)	126 (21.20)	25 (16.90)	
Condition (Psychiatric)				0.65
No	712 (96.00)	569 (95.80)	143 (96.60)	
Yes	30 (4.00)	25 (4.20)	5 (3.40)	
Type of Dementia				**<0.01**
Normal	275 (37.10)	237 (39.90)	38 (25.70)	
AD	199 (26.80)	152 (25.60)	47 (31.80)	
Other	268 (36.10)	205 (34.50)	63 (42.60)	
Current Problem Drinker				0.67
No	729 (98.25)	583 (98.15)	146 (98.65)	
Yes	13 (1.75)	11 (1.85)	2 (1.35)	
Current Smoker				0.36
No	676 (91.10)	544 (91.60)	132 (89.20)	
Yes	66 (8.90)	50 (8.40)	16 (10.80)	
Medications (AD)				0.21
No	660 (93.00)	538 (93.60)	122 (90.40)	
Yes	50 (7.00)	37 (6.40)	13 (9.60)	
Medications (Sleep)				0.52
No	666 (93.80)	538 (93.60)	128 (94.80)	
Yes	44 (6.20)	37 (6.40)	7 (5.20)	
Medications (Pain)				0.64
No	244 (34.40)	196 (34.10)	48 (35.60)	
Yes	466 (65.60)	379 (65.90)	87 (64.40)	
Medications (Psychiatric)				0.20
No	492 (69.30)	392 (68.20)	100 (74.10)	
Yes	218 (30.70)	183 (31.80)	35 (25.90)	
No. of Medications	6.89 (4.31)	7.31 (4.39)	5.20 (3.53)	**<0.01**
Range	[0-27]	[0-27]	[0-17]	
No. of Conditions/Procedure	7.11 (3.70)	7.51 (3.72)	5.49 (3.14)	**<0.01**
Range	[0-23]	[0-23]	[0-20]	
Blessed Score	2.57 (4.32)	2.59 (4.38)	2.48 (4.09)	0.78
Range	[0-17]	[0-17]	[0-17]	

Table 6 - Descriptive Statistics by Variable and Race (Cognitive Status Factors)

Variable	Overall Sample Mean (SD)	White Mean (SD)	AA Mean (SD)	p-value (α=0.05)
CDR Score	0.81 (1.01)	0.79 (1.02)	0.90 (0.95)	0.25
Range	[0-5]	[0-5]	[0-5]	
DSRS Score	10.63(13.06)	10.25(13.07)	12.26 (12.95)	0.12
Range	[0-53]	[0-53]	[0-52]	
MMSE Score	22.41 (6.83)	23.32 (6.64)	18.61 (6.27)	**<0.01**
Range	[0-30]	[0-30]	[0-30]	

Table 7 - Descriptive Statistics by Variable and Race (Behaviors)

Variables	Overall (N=742) N (%)	White (N=594) N (%)	AA (N=148) N (%)	p-value (α=0.05)
Behavior (Depression)				**<0.01**
No	601 (81.00)	467 (78.60)	134 (90.50)	
Yes	141 (19.00)	127 (21.40)	14 (9.50)	
Behavior (Delusions)				0.08
No	683 (92.55)	551 (93.40)	132 (89.20)	
Yes	55 (7.45)	39 (6.60)	16 (10.80)	
Behavior(Hallucinations)				0.94
No	701 (94.50)	561 (94.40)	140 (94.60)	
Yes	41 (5.50)	33 (5.60)	8 (5.40)	
Behavior (Agitation)				0.42
No	637 (85.85)	513 (86.40)	124 (83.80)	
Yes	105 (14.15)	81 (13.60)	24 (16.20)	
Number of Behaviors Exhibited				0.12
0	521 (70.20)	409 (68.90)	112 (75.70)	
1	130 (17.50)	114 (19.20)	16 (10.80)	
2	65 (8.80)	51 (8.60)	14 (9.50)	
3	22 (3.00)	16 (2.70)	6 (4.00)	
4	4 (0.50)	4 (0.70)	0 (0.00)	

Logistic Regression

Logistic regression analyses of the background variables in relation to each behavior were conducted using three models. All models were controlled for age and race. The cognitive factor model included subject age, race, CDR score, DSRS score, and MMSE score. The health status model included subject age, race, total number of medications reported, total number of conditions/procedures reported, type of dementia (categorized as AD, other dementia, or normal), and Blessed score. The psychosocial factor model included subject age, race, gender, and education level (categorized as less than high school, high school completion, or more than high school). Referents within the models included White, other, men, and greater than high school according to the corresponding variable.

In the analysis of delusions as the behavioral outcome, the cognitive factors model displayed significant results to suggest decreased odds of delusional behavior was associated with higher individual MMSE scores (OR=0.92, 95% CI=0.84-1.00). The health status model demonstrated that increased odds of delusional behavior were associated with increased Blessed score (OR=1.15, 95% CI=1.08-1.23). In the psychosocial model the odds of delusions were higher if subjects were women compared to men (OR=2.81, 95% CI=1.41-5.61).

When examining hallucinations as the outcome, the cognitive factors model indicated that increased odds of hallucinations were associated with increased CDR scores (OR=3.59, 95% CI=1.51-8.53). In the health status model, increased odds of hallucinations were associated with increased Blessed scores (OR=1.18, 95% CI=1.11-1.27). Finally in the psychosocial model increased odds of hallucinations were associated with increased age (OR=1.05, 95% CI=1.01-1.10) and women had increased odds of hallucinations compared to men (OR=2.65, 95% CI=1.19-5.89).

When examining agitation in the models, cognitive factors indicated increased DSRS score to be associated with increased odds of agitation (OR=1.12, 95% CI=1.07-1.17). Health status factor results showed increased Blessed scores to be associated with increased odds of agitation (OR=1.16, 95% CI=1.10-1.22) and decreased odds of agitation were associated with persons without dementia (OR=0.18, 95% CI=0.08-0.43). Psychosocial factors demonstrated increased age to be associated with increased odds of agitation (OR=1.05, 95% CI=1.01-1.08).

Analyses with depressed behavior as the outcome demonstrated that AA subjects had decreased odds of depression compared to White subjects. In the cognitive status model increased DSRS scores were associated with increased odds of depression (OR=1.09, 95% CI=1.05-1.14). The health status model indicated that individuals with more conditions had increased odds of depression (OR=1.16, 95% CI=1.09-1.24) and person's without dementia demonstrated decreased odds of depression (OR=0.40, 95% CI=0.24-0.68). In the psychosocial factor model, increased odds of depression were associated with increased age (OR=1.02, 95% CI=1.00-1.05).

Table 8 - Logistic Regression

Behavior	Model	Variable	OR (95% CI)
DELUSIONS			
		Age	**1.04 (1.00-1.08)**
		Race (AA v. White)	1.71 (0.93-3.17)
	Cognitive Factors	Age	0.97 (0.92-1.02)
		Race (AA v. White)	0.98 (0.39-2.48)
		CDR	1.42 (0.66-3.05)
		DSRS	1.05 (0.99-1.12)
		MMSE	**0.92 (0.84-1.00)**
	Health Status Factors	Age	0.96 (0.91-1.01)
		Race (AA v. White)	1.44 (0.70-2.93)
		Number of Medications	1.03 (0.95-1.13)
		Number of Conditions	0.93 (0.83-1.03)
		Dementia Type (AD v. Other)	1.91 (0.88-4.16)
		Blessed	**1.15 (1.08-1.23)**
	Psychosocial Factors	Age	1.03 (0.99-1.07)
		Race (AA v. White)	1.31 (0.68-2.52)
		Gender (Women v. Men)	**2.81 (1.41-5.61)**
		Education (<HS v. >HS)	1.57 (0.44-5.58)
		Education (HS v. >HS)	2.72 (0.80-9.27)
HALLUCINATIONS			
		Age	**1.06 (1.02-1.11)**
		Race (AA v. White)	0.97 (0.44-2.15)
	Cognitive Factors	Age	1.01 (0.94-1.07)
		Race (AA v. White)	1.15 (0.38-3.52)
		CDR	**3.59 (1.51-8.53)**
		DSRS	1.02 (0.95-1.10)
		MMSE	1.03 (0.93-1.13)
	Health Status Factors	Age	0.97 (0.91-1.02)
		Race (AA v. White)	0.99 (0.41-2.41)
		Number of Medications	0.96 (0.86-1.06)
		Number of Conditions	1.10 (0.99-1.23)
		Dementia Type (AD v. Other)	1.47 (0.60-3.58)
		Blessed	**1.18 (1.11-1.27)**
	Psychosocial Factors	Age	**1.05 (1.01-1.10)**
		Race (AA v. White)	0.83 (0.36-1.93)
		Gender (Women v. Men)	**2.65 (1.19-5.89)**
		Education (<HS v. >HS)	2.43 (0.54-10.91)
		Education (HS v. >HS)	2.82 (0.64-12.51)

Table 9 - Logistic Regression (continued))

Behavior	Model	Variable	OR (95% CI)
AGITATION			
		Age	**1.05 (1.02-1.08)**
		Race (AA v. White)	1.23 (0.74-2.02)
	Cognitive Factors	Age	0.98 (0.94-1.03)
		Race (AA v. White)	0.99 (0.47-2.07)
		CDR	0.78 (0.42-1.43)
		DSRS	**1.12 (1.07-1.17)**
		MMSE	0.99 (0.92-1.06)
	Health Status Factors	Age	0.99 (0.96-1.03)
		Race (AA v. White)	1.16 (0.66-2.03)
		Number of Medications	1.01 (0.95-1.08)
		Number of Conditions	1.00 (0.92-1.08)
		Dementia Type (Normal v. Other)	**0.18 (0.08-0.43)**
		Dementia Type (AD v. Other)	0.90 (0.50-1.65)
		Blessed	**1.16 (1.10-1.22)**
	Psychosocial Factors	Age	**1.05 (1.01-1.08)**
		Race (AA v. White)	1.10 (0.65-1.88)
		Gender (Women v. Men)	1.13 (0.73-1.76)
		Education (<HS v. >HS)	1.79 (0.80-4.01)
		Education (HS v. >HS)	2.00 (0.90-4.45)
DEPRESSION			
		Age	**1.02 (1.00-1.05)**
		Race (AA v. White)	**0.38 (0.21-0.69)**
	Cognitive Factors	Age	1.00 (0.96-1.03)
		Race (AA v. White)	**0.31 (0.14-0.70)**
		CDR	0.90 (0.52-1.58)
		DSRS	**1.09 (1.05-1.14)**
		MMSE	1.05 (0.99-1.12)
	Health Status Factors	Age	0.98 (0.95-1.01)
		Race (AA v. White)	**0.44 (0.24-0.81)**
		Number of Medications	1.00 (0.95-1.05)
		Number of Conditions	**1.16 (1.09-1.24)**
		Dementia Type (Normal v. Other)	**0.40 (0.24-0.68)**
		Dementia Type (AD v. Other)	1.66 (0.95-2.89)
		Blessed	0.98 (0.93-1.04)
	Psychosocial Factors	Age	**1.02 (1.00-1.05)**
		Race (AA v. White)	**0.37 (0.20-0.67)**
		Gender (Women v. Men)	0.84 (0.57-1.24)
		Education (<HS v. >HS)	1.33 (0.73-2.44)
		Education (HS v. >HS)	1.40 (0.76-2.56)

DISCUSSION

Psychosocial

Overall sample findings are consistent in terms of the composition where retired, White elderly females, falling into the middle-old age range are represented. However, statistically significant differences between White and AA subjects related to marital status, region of residence, and education may be reflective of several things.

Marital Status

First, in terms of marital status, although the majority of both AA sample subjects and White sample subjects reported being “widowed”, over half of the AA sample reported being widowed. According to recent literature (Arthur & Katkin, 2006; Smedley, et al., 2003), the documentation of health status/chronic illness prevalence in the AA community disproportionately impacting AAs may be a contributing factor in widowhood. Additional literature has highlighted gender differences in the AA community related to mortality, which have been associated with decreased health risks, likely contributing to women living longer than men (Williams, 2003; Williams, 2002). Following widowed, the second most prevalent marital status was “married”. Proportionately higher percentages were reported among AA sample subjects and White sample subjects, however, overall fewer AA subjects were married compared to Whites. Supportive literature suggests the influence of higher divorce rates, increased incarceration rates, and other social behaviors in the AA community resulting in female headed households (Taylor, et al., 1993) and fewer marriages.

Dementia behaviors have been shown to be decreased in marital relationships where the ability to recognize behavioral triggers or identify appropriate de-escalation techniques have been influential factors (Steadman, Tremont, & Davis, 2007), perhaps due to familiarity with subjects or the length of relationships. However, for AA subjects who are less likely to be married, behaviors may tend to occur more frequently where education regarding the disease process, respite services, and management strategies are critical for caregivers.

Region

Second, a greater proportion of the AA subject sample was found to be more concentrated in the South. The White subject sample was also concentrated in the south, followed by the Midwest, or West. According to the literature, despite migration patterns to the North during the early-to-middle 19th century for employment, many AAs, particularly elderly AAs, remained in the South, or returned, with increasing evidence supporting preference for rural southern environments (Longino & Smith, 1991). Due to lack of resources including support groups, health professionals, or adult services, rural care recipients may have increased incidence of behaviors, which is of concern. However, limited data supports this where further research is warranted (Kosberg, et al., 2007).

Education

Finally, findings revealed the majority of AA sample subjects possessed less than a high school education, as did White subjects. Early literature suggested southern AAs possessed lower educational attainment due to restricted options as a result of segregationist practices, or a preponderance of blue collar, agricultural, or service positions (e.g. maid, housekeeper, butler, doorman, driver) (Anderson, 1978). The de-emphasis on education created a culture which encouraged engaging in employment sooner (Anderson, 1978). Subsequent findings demonstrated that inequalities in education, which were common, also translated into the perpetuation of unequal employment practices (Braddock & McPartland, 1987).

Although not significant in the data analysis, the vast majority of subjects were retired. However, according to the literature, decreased levels of educational attainment, related to type of employment/occupation options has been associated with increased dementia risk and behavioral manifestations (Ngandu, von Strauss, Kala, Winbled, Nissinen, Tuomilento, et al, 2007; Callahan, Hall, Hui, Musick, Unverzagt, & Hendrie, 1996).

Health Status

Several items related to subject's health status, including number of medications, number of conditions/procedures reported, cancer, and "other" conditions, were indicative of statistical significance.

Number of Medications

White sample subjects had an average of medications compared to AA sample subjects. Literature has reported that AAs may be reluctant to see physician's where there is a decreased likelihood of medications being prescribed, or used (Boulware, Cooper, Ratner, LaVeist, & Powe, 2003). Further, lower physician visits decrease diagnoses of medical conditions, which may be related to physician distrust. Thereby, late diagnosis or underdiagnosis, result in the perpetuation of the disproportionate impact of chronic illnesses on AAs (Arthur & Katkin, 2006; Sink, et al., 2004; Smedley, et al., 2003; Boulware, et al., 2003; Lampley-Dallas, 2002). In addition, compliance, a major concept associated with medication usage places judgement on subjects and may not accurately reflect the willingness of elderly subjects to take medications, but is instead an issue of adherence, or the implementation of the recommended medication regimen (Murray, Morrow, Weiner, Clark, Tu, Deer, et al., 2004). However, in dementia, medication refusal has been shown to increase with disease progression due to increasing paranoia/suspicion (Finkel, 2001).

The number of medications reported may reflect a discrepancy between the actual number of medications prescribed versus what is actually being taken because of the impact of poverty influencing the ability to fill medications or cost-cutting techniques such as altering the frequency of dosages (i.e. every other day v. every day) or cutting pills to conserve money by extending the longevity of medications (Sarver, Sudano, & Baker, 2000). For elderly AAs, where pensions are primary sources of income, the decision to prioritize where/how money is spent is often negotiated between other needs including bills, food, rent, other caregiving responsibilities, as well as medications, where medications are of great importance, but may be the highest expense/ most inconvenient expense (Murray, et al., 2004).

To demonstrate, although almost a third of the sample reported AD or another dementia, few White or AA subjects reported AD medication usage, with AAs significantly lower than Whites. It is worth mentioning that in the entire ADAMS sample of those diagnosed with dementia, few were given this diagnosis by a specialist and instead the diagnosis was provided by general practitioners, which according to reported literature, increases the propensity of overdiagnosis, inappropriate medication prescription, over prescribing medications, and limited knowledge about effective treatments in dementia (Shadlen, et al., 2000).

Generally, medications are of most benefit in delaying AD progression and preserving quality of life with early diagnosis and treatment (Burns, Bernabei, Bullock, Cruz-Jentoft, Frolich, Hoch, et al., 2009; Farlow & Cummings, 2007). However, under medication negates potential improvement or disease maintenance by exacerbating disease progression and minimizing quality of life. Further, medications have been shown to decrease dementia behaviors (Sink, et al., 2005), although recent warnings have emerged associating adverse outcomes with usage of some medications (Salzman, et al., 2008). If AAs are using medications less, there may be more frequent behaviors, while on the other hand White subjects who are using more medications may have decreased the representation of behaviors, or may be associated with more behaviors as polypharmacy, common in the elderly, may increase behaviors due to the varying actions or side effects of medications.

Although not significant, high percentages of pain medication usage were reported by both White and AA sample subjects. Pain is also a catalyst to disruptive behaviors due to inadequate management, or lack of treatment, which may precipitate behaviors, whereas when properly managed behaviors are less likely to occur (Algase, et al., 1996). With disease progression, behaviors are more likely where the benefit of medications delaying disease progression possess potential benefits.

Number of Conditions/Procedures

White sample subjects had a mean of conditions/procedures compared to AA sample subjects. There is a propensity for the number of illnesses and procedures to increase over time with age where some illnesses may require more medications or procedures, however, the emergence of polypharmacy increases the vulnerability of older adults as both groups were on greater than 15 medications. Polypharmacy has become a problematic occurrence in the elderly population not only due to numerous self prescribed over-the-counter medications, but also medications prescribed by varying specialists. When prescribed and over-the-counter medications are not reconciled to eliminate redundancy or determine necessity they may result in side effects, which include behavioral manifestations (Kroenke & Pinholt, 1990).

Types of Conditions

When examining the types of conditions, cancer was significant between the White and AA subject sample. Cancer risk increases with age, and while AAs may have higher mortality due to late diagnosis or lack of treatment in cancer, Whites have been found to have higher incidence of cancer overall (Williams & Jackson, 2005; Howard, Hankey, Greenberg, Austin, Coma, Chen, et al., 1992). Different forms of cancer have been found to metastasize to other areas of the body, including the brain, where dementia or therapy induced dementia (chemotherapy, radiation) may occur, thereby triggering behaviors.

The "other" category (respiratory illnesses and thyroid problems) was more significant among White subjects than AA subjects however, this was an unexpected finding. According to recent literature, the impact of poverty and environmental factors in urban areas, traditionally inhabited by AAs, increases the incidence and occurrence of respiratory illnesses (Hegewald & Crapo, 2007). Further, thyroid dysfunction has been found to be associated with dementia (Ganguli, Burmeister, Seaberg, Belle, & DeKosky, 1996), although recent findings have refuted this evidence where further research is ongoing (de Jong, den Heijer, Visser, de Rijke, Drexhage, Hofman, et al., 2006). Similarly, respiratory function has been shown to influence dementia development over time (Higgs, 2010; Guo, Waern, Sjogren, Lissner, Bengtsson, Bjorkelund, et al., 2007), where behavioral manifestations are possible.

Cognitive

Dementia type was significant between the White and AA subject sample, with the majority of Whites and AAs impacted by either AD or “other” dementia. According to the literature, across dementia types, higher prevalence of dementia is present in the community, particularly in AA populations (Sink, et al., 2004; Harwood & Ownby, 2000; Picot, et al., 1995). However, after data analysis, a surprising finding was that AD was not the most prevalent dementia among either group, particularly for AAs. As has been highlighted in the literature, this may demonstrate a trend in over-diagnosis (Shadlen, et al., 2000), or the gradual emergence of other dementias and improved technology to differentiate diagnoses (Dugue, et al., 2003). Vascular dementia had a much lower representation than expected particularly with such a high portion of the sample experiencing numerous cardiovascular risk factors.

Some behavioral manifestations are more common to various forms of dementia, however, the majority are found in AD. Although the number of selected dementia behaviors exhibited was not significant in the sample between groups findings contrasted with literature demonstrating increased numbers of concurrent behaviors in the community and among AAs (Sink, et al., 2005; Sink, et al., 2004). Although the majority of White subjects and AA subjects did not experience behaviors, due to the lower subject sample size of AAs, this may not be an accurate reflection. However, of the subjects who displayed behaviors, Whites and AAs subjects displayed between one and three behaviors simultaneously, which contributes to caregiver burden, stress, and strain. Further, it is of importance to note that many White subjects experienced hallucinations, increasing demand on caregivers.

Dementia severity, as evidenced by MMSE scores, was also statistically significant. Between AAs mean score and Whites mean score, Whites were less impaired than AAs. Although both White and AA subjects were in the mild dementia range, AAs were approaching the gradation cut off between mild and moderate (Tombaugh & McIntyre, 1992). As literature has suggested, due to late diagnosis, AAs possess the propensity to be farther along in disease progression (Arthur & Katkin, 2006; Sink, et al., 2003; Boulware, et al., 2003; Lampley-Dallas, 2002). Not only are behaviors more common among cognitively impaired elders, particularly AAs, but there is increased burden associated with caregiving for dementia caregivers in the community (Diwan, et al., 2004; Toth-Cohen, 2004; Picot, 1998). African Americans have been found to be more severely impaired, and may thereby manifest more behaviors (Sink, Covinsky, et al., 2004).

Behaviors

Among outcome behaviors, a statistically significant finding was that depression was more significant among Whites than AAs. Delusional behavior was approaching significance. The significance of depression among White subjects could be related to the higher prevalence of psych medication usage reported by White subjects compared to AAs. Research continues to emerge highlighting the common underdiagnosis of depression in the elderly (Garrard, Rolnick, Nitz, Luepke, Jackson, Fischer, et al., 1998). Further, depression is related to behaviors such as withdrawn/disinterested behavior which are often perceived as most bothersome compared to others due to lack of engagement (de Vugt, Stevens, Aalton, Lousberg, Jaspers, Winkins, et al, 2003; Colling, 1999). While depression was found to be more common in the White subject sample, literature surrounding the issue of taboo/stigma in the AA community involving depression may result in underreporting despite higher prevalence/incidence of mental illness among AAs (Corrigan, 2004; Williams 1986).

With the White population showing such a significant increase in depression, this raises concern for suicide which is higher in Whites, and an increasing trend among elderly males (NIMH, 2003; Yin, 2006). With decreased functional ability, declining cognition, other associated age-related changes, and grief/loss contributing to stress of projected decline, the propensity to initiate and implement a plan places them at increased risk.

Logistic Regression

Across most behavior outcomes (hallucinations, agitation, and depression), increased age was associated with increased odds of behaviors occurring. This finding is somewhat inconsistent with the literature, which has demonstrated that increased age, likely correlated with advancing stages of dementia, results in a reduced tendency for behavioral occurrence (Senanarong, et al., 2004). Analyses further revealed that both delusions and hallucinations were shown to have increased odds of occurring in women compared to men. A possible explanation, as evidenced by the literature, has demonstrated that sleep architecture changes occur with increasing age as well as in dementia, where altered dream states spilling over into consciousness may result in hallucinations, triggering an agitated state (Boeve, Silber, & Ferman, 2002). Further, there is evidence supporting the propensity of males to display physical behavioral outbursts in comparison to women, who tend to demonstrate less overt behaviors, instead demonstrating higher verbalizations/vocalized behaviors, of which delusions and hallucinations may be related (Lyketsos, et al., 1999).

Across the behavioral outcomes of delusions, hallucinations, and agitation, increased odds of behaviors occurring was associated with increased Blessed scores. Although functional impairment is related to behavioral outcomes, greater impairment related to advancing disease may reflect a reduction in behaviors. Senanarong and colleagues (2004) have demonstrated that behaviors are more likely to occur during mid-to-late stage dementia where circumstances are more favorable for behavioral exhibitions, but with increasing severity or functional impairment behaviors are decreased.

Among the behaviors of hallucinations, agitation, and depression, increased odds of behavioral occurrences were associated with increased scores on either the CDR or the DSRS. Although decreased scores on the MMSE represent greater impairment or dementia severity, consistent with other overall behavioral findings and measurements, decreased odds of delusional behavior was associated with increased MMSE scores.

Decreased odds of the behaviors of agitation and depression were found in persons without dementia. Although literature has demonstrated that various types of dementia present with different behavioral manifestations, longstanding personality characteristics and the influence of environmental factors/ have also been found to contribute to the manifestation of behaviors in dementia (de Vugt, Riedijk, Aalton, Tibben, van Swicten, & Verhey, 2006; O'Leary, et al., 2005; Eustace, et al., 2001; Gormley & Rizwan, 1998; Aarsland, et al., 1996).

White subjects were associated with increased odds of displaying depression than AAs and depression was associated with increased odds of occurring as the number of conditions increased. Differences between White and AA elders in the display of depression are consistent with findings in the literature relating depression and suicide in older Whites (NIMH, 2003; Yin, 2006). However, associated stigma within the AA community may result in lowered reporting (Corrigan, 2004; Williams 1986) and cultural differences in the presentation of depression may not be reflected. Further, particularly with a dementia diagnosis, many elderly associate declining health, numerous ailments, or medications with impending death and are often subject to depression (Waern, Rubenowitz, Runeson, Skoog, Wilhelmson, & Allebeck, 2002).

LIMITATIONS

This was a cross sectional analysis, which limits the ability to see changes over time, although data within the data set were collected longitudinally. Also, as with any secondary analysis, data availability and further exploration of questions is a primary limitation. For example, an inability to verify reported data (medical diagnosis, medications, length of time), limited the interpretation of findings.   Further, within-group analysis may have provided additional insight into differences or introduced new information. In addition, length of dementia diagnosis may have also provided additional information regarding the transition of disease progression and manifestation of behaviors.

A significant limitation, however, was the inability to examine the influence of pain on the behavioral manifestations of subjects, as a large proportion of the sample, both AA and White subjects reported taking pain medications. Pain has become widely recognized as the sixth vital sign and has repeatedly been reported to be under treated in the elderly population. According to Herr (2002) older adults tend to under-report pain or not request pain medication based on the belief that increased pain is associated with death, worsening of illness, increased need for testing or hospitalization, or that reporting pain will be perceived as bothersome. For AAs, pain is also under-reported or delayed, with symptoms qualified as related to the aging process or equated with weakness (Taylor & Herr, 2003). In the dementia patient, under treatment of pain is very common due to increased difficulty determining presence and quality, however, although more severe dementia is associated with a higher pain tolerance it does not suggest the complete absence of pain (Scherder, Herr, Pickering, Gibson, Beredeth, & Lautenbacher, 2009).

Information pertaining to the previous occupation of subjects as well as personality characteristics may also have yielded insightful data in the manifestation of behaviors as well as a risk profile. In addition, the collapsing of variables (conditions and medications) combined conditions/medications associated with dementia risk in general categories where individual differences according to conditions or medications may have been overlooked. While this research was exploratory in nature to examine any associations or patterns which might be present in the data, the exclusion of missing values was a limitation that warrants future attention. Further, the decision to collapse dementia types and the specific behaviors selected may have obscured valuable information. However, initial analyses revealed low frequencies where the collapsing and selection was warranted. Finally, this data analysis did not examine gender or ethnic (Hispanic) differences where the literature reports differences between genders and variations with ethnic groups, which influence caregiving experiences and behavioral manifestations, potentially overlooking additional insight.

RECOMMENDATIONS

Include the implementation of intervention strategies over time to assist spousal and adult-child caregivers, as well as promote education regarding the disease process, respite services, and behavioral management techniques. Sampling efforts to include additional nationally representative samples from various regions across the country have proven beneficial but are difficult in terms of resources, collaborations, the time involved, and are limited in number and participants. African Americans tend to reside more in the Southern region where increased recruitment strategies to target these populations, particularly rural residents to obtain a more descriptive picture of dementia in this relatively understudied area would be useful. It should be noted, however, that the establishment of trust is of crucial importance because of the historical impact of Tuskegee, a notorious example of research misconduct, which occurred in the south where many elderly residents remain.

Educational differences highlight the importance of measures which take into account educational attainment/literacy and the development of recruitment strategies and data collection techniques which are specific to a level of understanding appropriate to subjects and their level of comprehension based on dementia stage/severity. Research consents, questionnaires, and recruitment tactics developed at an 8th grade level should continue to be utilized and implemented as educational differences, including illiteracy, persist where to deviate from such tactics may alienate/discourage/intimidate participants from future research continuing lack of participation.

Future research should include valid tests to assess pain in cognitively impaired persons that are applicable to minority populations not only for the presence of pain but the severity, where Faces has been found to meet these criteria (Taylor & Herr, 2003). In addition, education for caregivers to identify context clues belying the indication or presence of pain should be included in research studies and interventions. Additional education should be targeted toward caregivers not only in the recognition of signs of dementia and not attributing them to age, as well as the importance of early diagnosis, but also the benefits of some medications. However, with increased paranoia/suspicion this may be a challenge if some subjects are on several medications and there is increasing difficulty in administering/convincing subjects when newer drugs in the medication repertoire are not recognized and refused, while more longstanding/familiar medications are taken more easily.

Finally, although medication categories were collapsed into four broad categories associated with dementia and behavioral manifestations, it should be noted that some medications which appear on Beer's list of inappropriate medications for the elderly (Beers, 1997; Beers, Ouslander, Rollingher, Reuben, Brooks, & Beck, 1991) were reported in usage, although in low numbers. The associated side effects demonstrate not only a need for patient and caregiver education, but suggest that primary care providers inquire further about medication usage and improve medication reconciliation due to chronic illnesses and specialist referrals.

General attention should be given to thorough patient health histories as well as attention to assessment data. Although across both groups, very low reports of current drinking problems were reported, both samples reported having problems with drinking in the past (i.e., DUI's, interference with work, etc) where excessive alcohol intake has been shown to have numerous health consequences and in relation to dementia has an increased association with development and associated behaviors. Future work should also incorporate measures, particularly the CAGE questionnaire with reported valid/reliable findings among older adults, to briefly assess for problem drinking, increased education among caregivers and subjects when applicable, and resource assistance to help those with problem drinking. It should be noted, however, that given behaviors and increased resistance to change during the dementia illness, this may not be an easy task.

Another non significant finding surrounds the cardiovascular condition category, which was statistically the same across groups, but places both AA and White elderly at increased risk for cardiovascular illnesses. The cardiovascular category was collapsed to include the majority of illnesses associated with dementia risk. Although this analysis did not analyze separate cardiovascular illnesses, due to increased vascular risk for AA this should be explored further in future research and researchers should obtain a thorough health history of subject participants.

It is also important to note that among current smokers AA were approaching 11%, which contributes to respiratory illnesses and in addition to documented pulmonary consequences, has also been associated with increased vascular dementia risk and may be associated with behavioral manifestations. Numerous risks are associated with smoking where varied risk is correlated with the products and patterns of usage (Fagerstrom, 2002). Thorough health histories and assessments are critical for this population as well as the encouragement of smoking cessation and providing resources/referrals to aid in abolishing the habit.

Increased assessment for depression and properly addressing the needs of the elderly to preserve the quality of life and relationships between care recipients and caregivers. Encourage seeking of early assessment and treatment associated with observed memory changes or changes in daily functioning. The importance of early assessment and diagnosis to preserve function should be stressed by educating caregivers and even care recipients about signs of dementia as well as the utility of medications which delay progression. Attention must be paid to the longevity of females who are aging and living longer with increased dementia risk and behavioral developments.

Education for management of disease progression where less overt behaviors begin to emerge, including incontinence or depression is of great importance. Continued research surrounding the differences in behavioral manifestation for different stages and dementia types where appropriate education and behavioral strategies can be implemented. Within group comparisons are also warranted for the extension of research to identify other behavioral differences and behavioral management strategies.

CHAPTER 4: COMPARATIVE PROFILE OF PROXIMAL FACTORS AND DISRUPTIVE BEHAVIORS BETWEEN AFRICAN AMERICAN AND WHITE COMMUNITY DWELLING PERSONS WITH DEMENTIA

INTRODUCTION

Approximately 5 million older adults are affected by Alzheimer’s disease (AD), the third costliest disease, where national expenditures are projected to triple by the year 2050, from current costs which exceed $100 billion (Sanders & Morano, 2008; Nichols, et al., 2008; Algase, 2007; Cotter, 2007; Messinger-Rapport, et al., 2006). Ten percent of individuals 65 years of age and older are currently affected, however, after the age of 85 years, prevalence rates soar to 50% (Thompson, et al., 2004; Hubbell & Hubbell, 2002; Shanks-McElroy & Strobino, 2001). The impact of dementia will increase exponentially due to several factors including age, a major risk factor for AD, and projected quadrupling of the 85 years of age and over group by 2050 (Cotter, 2007; Day, 1996).

Although the White elderly population is expected to double between 2000 and 2050, Census Bureau projections among ethnic and minority populations will increase significantly in comparison (McKinnon & Bennett, 2005). By 2050, the population of African American elders is projected to quadruple, and by 2020, when the elderly population will reach 22% African Americans are expected to double (McKinnon & Bennett, 2005; Harwood & Ownby, 2000). Emerging evidence reporting higher prevalence and increased risk for ethnic elders, especially African Americans, in combination with a rapidly aging population, raise concerns for this vulnerable group (Sink, et al., 2004; Harwood & Ownby, 2000; Picot, et al., 1995). The term African American (AA) is utilized for the purpose of this paper to distinguish from other Black minority groups where considerable heterogeneity exists (Aspinall, 2008; Arthur & Katkin, 2006; McKinnon & Bennett, 2005; Williams & Jackson, 2000).

Alzheimer's disease is the most commonly diagnosed dementia in AAs, yet vascular dementia (VaD), the second most common dementia tends to occur more often in AAs (Dugue, et al., 2003; Harwood & Ownby, 2000). In addition, prevalent cardiovascular illnesses within the AA community associated with increased vascular dementia risk, (e.g. hypertension, diabetes, stroke, atherosclerosis, and heart disease) are of significant concern (Harwood & Ownby, 2000; Shadlen, et al., 2000; CDC, 2000). However, lack of participation in dementia research, demonstrated by under-representation and understudy of AA as well as under diagnosis or late diagnosis of dementia, have limited interventions or other treatment options (Arthur & Katkin, 2006; Sink, et al., 2004; Smedley, et al., 2003; Lampley-Dallas, 2002; Harwood & Ownby, 2000).

Over 10 million caregivers, 75 % of whom are family members, provide care to two-thirds of persons with dementia who reside in the community (Cotter, 2007; Messinger-Rapport, et al., 2006; Schulz & Martire, 2004). Informal caregiving is demanding physically, socially, mentally, and financially, where cost increases with disease progression (Nichols, et al., 2008; Messinger-Rapport, et al., 2006; Thompson, et al., 2004; Langa, et al., 2001; Shanks-McElroy & Strobino, 2001; Cox, 1997). Yet, despite the associated stress and economic burden, families prefer to maintain relatives in the home (Nichols, et al., 2008). For AAs, cultural and historical influences factored in with reliance on informal social supports have contributed further to an overall reluctance to institutionalize elders and pursue formal service utilization (Dilworth-Anderson & Anderson, 1994; Picot, et al., 1997; Belgrave, et al., 1993).

Disruptive behaviors, often interfere with care, or raise safety issues, but are subjectively identified behaviors generally occurring during mid-to-late stages of dementia (Logsdon, et al., 2007; Senanarong, et al., 2004; Cohen-Mansfield & Billig, 1986). Disruptive behaviors consume up to 30% of dementia related costs with community-dwelling prevalence rates reported as high as 98% contributing to increased institutionalization and reduced income or employment (Cotter, 2007; Sink, et al., 2004; Sink, et al., 2005). Many behaviors are represented in the dementia literature as disturbing (Robinson, 2003; Vitiello & Borson, 2001; Jorm, 2000; Colling, 1999; Skelly & Flint, 1995; Hogstel, 1993), however, the most frequently occurring include agitation, aggression, delusions, hallucinations, wandering, and vocalizations (Finkel, 2001; Stoppe, et al., 1999).

In addition to these common behaviors, physiological need states, hunger and sleep, are affected by disease progression. Due to changes in the brain and disease progression, especially during mid-to-late stages, the ability to recognize items to aid in eating, control amount of consumption, or initiate volitional food consumption is altered (Amella, 2004). In addition, the inability to recognize hunger produces challenges, where even attempts at prompting will not trigger eating (Amella, 2004). In the AA culture food is equated with fellowship and health, and food aversion may be misinterpreted as an insult or purposeful/intentional, rather than advanced disease progression (Amella, 2004).

Similarly, as dementia severity increases, sleep patterns are interrupted due to architectural changes where sleep is prolonged or fragmented (Ancoli-Israel, 1997). Hyper-somnolence (sleeping too much) has begun to emerge in other dementias (Parkinson's Disease [PD], Dementia w/ Lewy Bodies [DLB], Fronto-temporal dementia [FTD]) and findings have emerged demonstrating that dreams transitioning into wakefulness has resulted in hallucinations in AD, PD, DLB, and FTD (Boeve, et al., 2002). Due to the inability to verbalize/express or rationalize behaviors, institutionalization may result (Boeve, et al., 2002).

In the absence of dementia, racial differences have been found where AAs have increased risk of decreased sleep duration due to residing in metropolitan areas or areas with large populations (Hale & Do, 2007). Further, the influence of life stressors and urban environments (social factors, noise/light, structural/living conditions) have contributed to unhealthy sleep patterns found in city residents leading to differences in health outcomes (Hale & Do, 2007). The challenge in dementia is in understanding or recognizing the underlying reasons, needs, or causes for disruptive behaviors where such need states could represent the causative factors.

The AA experience of caregiving has only recently begun to appear in the literature (Lawton, et al., 1991), where in light of simultaneous and more frequent disturbing behaviors among AAs, the emerging trend is critical. Although some information has been generated regarding the management of behaviors by AA caregivers, the perception of dementia caregiving and factors which may influence them remain largely unknown (Belle, et al., 2006; Toth-Cohen, 2004). Further, few studies have demonstrated the types of dementia, behavioral manifestations, the experience of caregivers with behaviors over time, and intervention strategies to aide caregivers as well as care recipients. The persistence of low sample sizes, cross sectional designs, and conceptualization issues have also increased the difficulty with exploring this topic adequately.

Due to the under-representation of AAs in the dementia literature surrounding the caregiving experience and disruptive behaviors, the Need-Driven Dementia-Compromised Behavior (NDB) Model will be presented to examine the influence of selected variables on behaviors. The NDB model is presented and expanded through theory derivation (Walker & Avant, 2005) to aid in the exploration of the AA experience of dementia caregiving in the context of disturbing behaviors.

Purpose

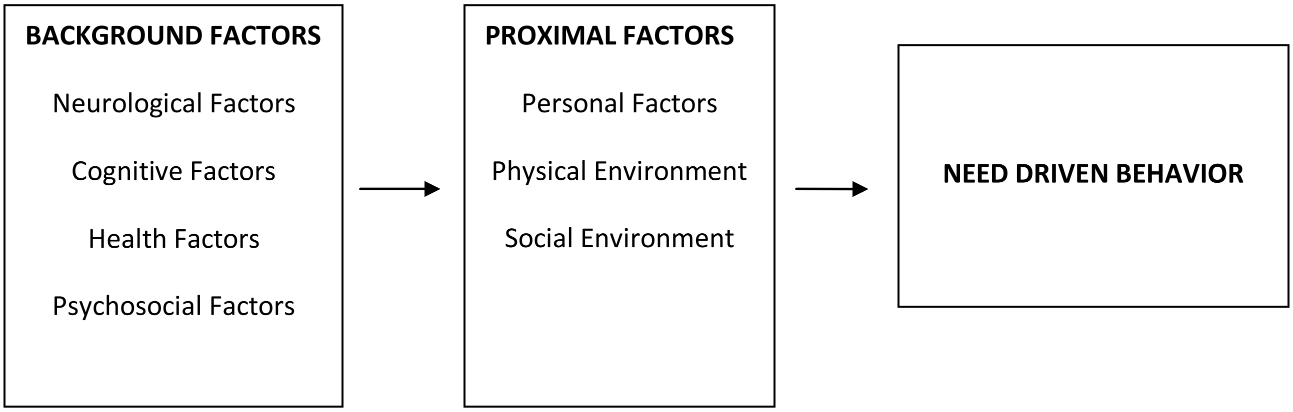
The purpose of this study was to examine the expansion of proximal factors of the NDB model to address the following research questions: 1) What relationships exist between personal factors and behaviors among AA; 2) What relationships exist between social environment factors and behaviors among AA; 3) How do proximal factors associated with behaviors differ between African Americans and Whites?

NEED DRIVEN DEMENTIA COMPROMISED BEHAVIOR (NDB) MODEL

Model Description

Despite other models developed to classify and treat behavioral manifestations (e.g. Cohen Mansfield), this paper focuses on the nurse driven middle range theory of the NDB model. The NDB model posits that subjectively labeled behaviors as disruptive or problematic are the manifestations of preserved primary behaviors which are fueled by goal pursuit or need expression, but are dementia compromised (Algase, et al., 1996). The NDB model, a holistic nursing conceptual framework, considers the individual and their environment, depicting an interaction between background and proximal factors, which influence the manifestation of various dementia behaviors (Algase, et al., 1996). Background factors are static, or unchanging, individual characteristics and portray a risk profile of persons with dementia that is comprised of neurologic factors; cognitive factors; health status; and psychosocial factors (Algase, et al., 1996). Proximal factors, or triggers, are more dynamic and are represented as personal, physical environmental, or social environmental factors, which precipitate behaviors (Algase, et al., 1996). Figure 1 presents a schematic of the NDB model and factors affecting this model.

Figure 2 - The Need-Driven Dementia-Compromised Behavior (NDB) Model



Since its development, the NDB model has been found to have psychometrically sound properties and been endorsed for interdisciplinary collaboration (Burgio, 1999; Whall, 1999). In addition, the NDB model has aided in the development of interventions (Yao & Algase, 2002; Kolanowski, et al., 2005; Colling & Buettner, 2002; Fitzsimmons & Buettner, 2002; Kolanowski, Richards, & Sullivan, 2002; Kolanowski, Litaker, & Baumann, 2002; Whall, 2002; Kolanowski, et al., 2001; Kolanowski & Whall, 2000; Richards, et al., 2000); examined relationships between constructs and behaviors (Song, 2003); explored medication usage in nursing homes and behavioral outcomes (Kim & Whall, 2006; Kim, 2005); guided Korean nursing care in dementia (Whall, et al., 1999); served as a guiding framework for the development of a wandering scale (Algase, et al., 2004); been suggested as a framework supporting person-centered care (Mitty & Flores, 2007; Penrod, et al., 2007); and has been extended to study consequences of behaviors (Kovach, et al., 2005).

However, most notably, the NDB model has been incorporated in numerous studies as a guiding framework to understand various dementia behaviors including aggression (Whall, et al., 2008; Kolanowski & Garr, 1999); wandering (Beattie, et al., 2005; Beattie, et al., 2004; Beattie & Algase, 2002; Algase, 1999); problematic vocalizations (Woods, et al., 2004; Beck & Vogelpohl, 1999); passivity (Colling, 2004; 1999); and sleep disturbances (Sullivan & Richards, 2004). An in-depth discussion of the NDB model can be found elsewhere (Cothran, 2010).

Although the NDB model represents a methodologically sound framework and has done exceptional work in uncovering premises explaining behaviors in dementia it has not been adequately tested with an AA population. Further, with the exception of

Colling's (2004) study of passivity among community dwelling residents, the NDB model has been limited to usage within the nursing home setting. In fact, the social environment, one of the proximal factors identified within the NDB model, was originally defined according to the environment of the nursing home. To illustrate, although Richards, Lambert, and Beck's (2000) study was the only study found which explicitly examined the influence of proximal factors, including the social environment, on the reduction of behaviors, this too was conducted within the nursing home setting.

Dementia and its behavioral manifestations have numerous implications within the community dwelling AA older adult population and among caregivers, due in large part to its understudy. This research will provide additional data to extend this aspect of the model to include and consider influential factors within the community setting/home environment. To provide an understanding of the unique experiences and needs of community dwelling AA persons with dementia (PWD) and their caregivers, the NDB model will be expanded, utilizing theory derivation, in efforts to offer culturally appropriate strategies to safely maintain residents in the home, improve the quality of life and health outcomes for person's with dementia and their caregivers, and simultaneously reinforce the caregiver and patient relationship.

THEORY DERIVATION

For the purposes of developing novice theoretical frameworks, Walker and Avant (2005) describe a useful technique-theory derivation. Theory derivation is the incorporation or adaptation of a theory and its constructs, either conceptual, structural, or both, from one field translated into another field, which creates a new theory. Theory derivation involves the creative interpretation of phenomenological dimensions across disciplines to identify similarities and restructure findings in a way that adds significance. In general, theory derivation is used when no information exists about a phenomenon, to develop new insight into a phenomenon, to adopt a structural representation for concepts and relationships, or to adopt concepts to an existing structural representation. There are six steps involved in the process of theory derivation, which include: 1) becoming familiar with the phenomenon; 2) conducting a large amount of reading across disciplines to create analogies; 3) selecting a “parent” theory; 4) identifying content/structure from parent theory to be adapted; 5) modifying/refining concepts/statements as they relate to the phenomenon; and 6) testing for validity.

Although adopting a theory from one discipline and applying it to another creates a new theory, utilizing only concepts, structure, or modifying certain components of an original theory also qualifies. Theory derivation is simple and efficient, where its appeal is often the encouragement of creative thinking in the development, expansion, and modification of an area of interest. The main disadvantages involve vigilance in remaining current and familiar with emerging trends in the literature across disciplines and failure to account for dissimilarities in the original theory.

Theory derivation will be utilized to examine disturbing behaviors in community dwelling AA elders with the NDB model, maintaining its original structure and constructs. However, the social environment, a proximal factor, will be extended from the nursing home setting to application and utility within the community-dwelling environment.

METHODS

The ADAMS is a supplement to the HRS which is sponsored by the National Institute of Aging (grant number NIA U01AG009740). It was conducted jointly by Duke University and the University of Michigan. Designed as a community based assessment of dementia in a nationally representative elderly sample, ADAMS sought to provide information on risk factors and outcomes of Cognitive Impairment Not Demented (CIND) and Dementia.

This is a secondary analysis utilizing the ADAMS dataset where the behavioral outcomes of delusions, hallucinations, agitation, and depression were selected based on frequencies and support in the literature. The NDB model was utilized to organize selected variables according to proximal factors related to the behavioral outcomes. Demographic variables of care recipients included age, race, gender, education, region of residence, employment status, and marital status. Demographics of caregivers included education, race, marital status, gender, and age. Four dichotomous questions pertaining to sleep: frequent waking, trouble sleeping, early awakening, and trouble sleeping were combined to create a new dichotomous category “change in sleep pattern”. Similarly the dichotomous category “change in hunger” was created by combining four original dichotomous questions pertaining to hunger: appetite increase, appetite decrease, lost weight, and gained weight.

Additional data was selected based on the influence of factors within the social environment and the risk profile for behavioral manifestations of care recipients. Selected variables included: days/month helped, caregiver work hrs/week, hours/day helped, how long known caregiver (years), relationship, frequency of contact, length of time helped, paid helper, reason for no helper, caregiver health, caregiver stress, lives with caregiver, and positive caregiver experience. Relationship between caregiver and care recipient was originally categorized as spouse, child grandchild, child-in-law, sibling, niece, nephew, sibling-in-law, parent-in-law, other relative, professional, or other non-relative. Relationship was collapsed into four groups: spouse, child, other relative, or other non-relative. Frequency of contact data originally included lives with, daily contact, several times/week, once a week, one to three times a month, or less than once a month. Frequency of contact was collapsed into four categories to include daily, several times/week, several times/month, and once/month. The dichotomous category of positive caregiver experience was created by combining six caregiver questions: useful, closer to care recipient, good, new skills, able to handle new problems, prevent worsening.

Subjects

A random subsample of 1,770 individuals over the age of 70, from the 2000 Health and Retirement Study (HRS), were selected to comprise the Aging, Memory, and Demographics Study (ADAMS) sample. Of the 856 individuals assessed, the total sample analyzed (N=755) possessed a mean age of 81.42 years (SD=6.87), were retired, female, White, widowed, lived in the S. Atlantic region, had either a form of dementia, or AD, and had less than a HS education. Additional sample characteristics are reported elsewhere (Cothran, 2010).

Procedures

Written informed consent was obtained from all respondents and Institutional Review Board approval was obtained from both the University of Michigan and Duke University for the ADAMS. Structured assessments were conducted in the residence of subjects by a nurse and neuropsychologist technician where informants provided detailed subject information on a variety of domains, as well as information measuring caregiving experiences and employment/demographic information. Respondents completed a) neuropsychological measures battery; b) self-report depression measure; c) standardized neurological examination; d) blood pressure measure; e) collection of DNA sample for APOE genotyping; and f) videotaped segment covering sections of the cognitive status and neurological examination. Laboratory and neuroimaging results were also reviewed. A detailed explanation of ADAMS study procedures can be found elsewhere (Cothran, 2010; Langa, et al., 2005).

Statistical Analysis

Between-group comparisons (AAs compared with Whites) were made with use of independent *t* tests or chi-square tests. Multiple regression models using logistic regression were utilized to describe associations between behavior outcomes. Analyses were conducted with a combination of SAS version 9.2 (SAS Institute Inc., North Carolina) and SPSS version 18 (SPSS Inc., Chicago).

RESULTS

Sample Characteristics

Among the White subjects in the sample (n=594) the majority were female with an average age of 81.41 years (SD=6.88 years). AA subjects (n=148) were primarily female with an average age of 81.49 years (SD=6.83 years). White subjects primarily received care from spouses (40.50%) whereas AAs primarily received care from children (44.40%). White caregivers were female (63.50%), and married (65.80%) with an average age of 65.11 years (SD=13.45 years). Among AA caregivers the average age was 59.88 (SD=15.44), where the majority were female (64.20%) and married (41.20%). The majority of both White (29.10%) and AA caregivers (21.60%) had at least a two year degree. Tables 10 and 11 provide additional demographic information describing the White and AA subject/caregiver sample.

Table 10 - Sample Demographics (Care Recipient)

Variable	Overall (N=742) N or Mean (% or SD)	White (N=594) N or Mean (% or SD)	AA (N=148) N or Mean (% or SD)	p-value (α=0.05)
Age (yrs)	81.42 (6.87)	81.41 (6.88)	81.49 (6.83)	0.90
Range	[70-110]	[70-105]	[70-110]	
Education				**<0.01**
Less than HS	358 (48.30)	236 (44.30)	122 (82.40)	
HS	283 (38.10)	263 (35.40)	20 (13.50)	
More than HS	101 (13.60)	95 (16.00)	6 (4.10)	
Gender				0.35
Male	311 (41.90)			
Female	431 (58.10)	340 (57.20)	91 (61.50)	
Ethnicity				
White	594 (80.00)			
AA	148 (20.00)			
Marital Status				**<0.01**
Single	19 (2.50)	15 (2.60)	3 (2.20)	
Married	278 (39,30)	242 (42.20)	36 (26.90)	
Divorced	36 (5.10)	28 (4.90)	8 (6.00)	
Separated	4 (0.60)	1 (0.20)	3 (2.20)	
Widowed	372 (52.50)	288 (50.20)	84 (62.70)	
Region				**<0.01**
NW	100 (14.10)	81 (14.10)	19 (14.10)	
MW	157 (22.10)	140 (24.30)	17 (12.60)	
S. Atlantic	214 (30.10)	156 (27.10)	58 (43.00)	
S. Central	116 (16.30)	81 (14.10)	35 (25.90)	
West	123 (17.30)	117 (20.30)	6 (4.40)	
Employment				0.57
Working	19 (2.70)	18 (3.10)	1 (0.70)	
Retired	608 (85.60)	491 (85.40)	117 (86.70)	
Semi-retired	36 (5.10)	29 (5.00)	7 (5.20)	
Disabled	15 (2.10)	11 (1.90)	4 (3.00)	
Unemployed	32 (4.50)	26 (4.50)	6 (4.40)	

Table 11 - Sample Demographics (Caregivers)

Variable	Overall (N=742) N or Mean (% or SD)	White (N=594) N or Mean (% or SD)	AA (N=148) N or Mean (% or SD)	p-value (α=0.05)
Education				**<0.01**
No HS degree	2 (0.30)	1 (0.20)	1 (0.70)	
GED	38 (5.10)	20 (3.40)	19 (12.20)	
HS diploma	60 (8.10)	36 (6.10)	24 (16.20)	
2-yr degree	205 (27.60)	173 (29.10)	32 (21.60)	
4-yr degree	179 (24.10)	150 (25.20)	29 (19.60)	
Master's degree	82 (11.00)	71 (11.90)	11 (7.40)	
Professional degree	78 (10.50)	76 (12.80)	2 (1.30)	
Race/Ethnicity				**<0.01**
White	499 (67.20)			
AA	112 (15.10)			
Marital Status				**<0.01**
Married	452 (60.90)	391 (65.80)	61 (41.20)	
Never married	32 (4.30)	19 (3.20)	13 (8.80)	
Living with Partner	18 (2.40)	15 (2.50)	3 (2.00)	
Separated	7 (0.90)	5 (0.80)	2 (1.30)	
Divorced	62 (8.30)	47 (7.90)	15 (10.10)	
Widow	74 (10.00)	51 (8.60)	23 (15.50)	
Gender				**0.03**
Male	162 (25.60)	142 (27.40)	20 (17.40)	
Female	472 (74.40)	377 (72.60)	95 (82.60)	
Age (yrs)	63.32 (14.48)	65.11 (13.45)	59.88 (15.44)	**<0.01**
[Range]	[20-98]	[25-95]	[20-98]	

Tables 12 and 13 present descriptive statistics pertaining to proximal factors of the NDB model and selected variables associated with behavioral risk. Of the proportions reported, chi-square tests showed there were significant differences between White and AA care recipients for sleeping pattern changes, relationship to caregiver, frequency of contact with caregiver, caregiver utilization of paid helpers, caregiver health, caregiver gender, caregiver education, race/ethnicity of caregiver, and caregiver marital status. T-tests indicated significant differences by race/ethnicity for caregiver age only.

Table 12 - Descriptive Statistics by Variable and Race (Personal Factors)

Variable	Overall (N=742) N (%)	White (N=594) N (%)	AA (N=148) N (%)	p-value (α=0.05)
Change in Sleep Pattern				**<0.01**
No	401 (54.00)	301 (50.70)	96 (64.90)	
Yes	345 (46.50)	293 (49.30)	52 (35.10)	
Change in Hunger				0.20
No	397 (53.50)	328 (55.20)	73 (49.30)	
Yes	341 (46.00)	266 (44.80)	75 (50.70)	

Table 13 - Descriptive Statistics by Variable and Race (Social Environment)

Variables	Overall (N=742) N or Mean (% or SD)	White (N=594) N or Mean (% or SD)	AA (N=148) N or Mean (% or SD)	p-value (α=0.05)
Relationship to Caregiver				**<0.01**
Spouse	240 (32.30)	212 (40.50)	28 (23.90)	
Child	241 (32.50)	189 (36.10)	52 (44.40)	
Other relative	90 (12.10)	65 (12.40)	25 (21.40)	
Non-relative	70 (9.40)	58 (11.10)	12 (10.30)	
Frequency of Contact w/ Caregiver				**0.03**
Daily	375 (50.50)	294 (49.50)	81 (54.73)	
Several/week	249 (33.50)	194 (32.70)	55 (37.20)	
Several/month	110 (14.80)	98 (16.50)	12 (8.10)	
Once/month	8 (1.10)	8 (1.30)	0 (0.00)	
Length of Time Helped by Caregiver				0.82
<1 month	6 (0.80)	5 (0.80)	1 (0.70)	
1-6 months	18 (2.40)	14 (2.30)	4 (2.70)	
6 months-1 year	27 (3.60)	24 (4.00)	3 (2.00)	
1-2 years	49 (6.60)	39 (6.60)	10 (6.80)	
>2 years	100 (13.50)	79 (13.30)	21 (14.10)	
Paid Helper				**<0.01**
No	201 (57.80)	149 (52.80)	52 (78.80)	
Yes	147 (42.20)	133 (47.20)	14 (21.20)	
Reason for no Helper				0.08
Unnecessary	94 (60.30)	71 (61.70)	23 (56.10)	
Too expensive	13 (8.30)	7 (6.10)	6 (14.60)	
Not of good enough quality	2 (1.30)	1 (0.90)	1 (2.40)	
Not available	4 (2.60)	1 (0.90)	3 (7.30)	
Care recipient not comfortable	24 (15.40)	20 (17.40)	4 (9.80)	
Other	19 (12.20)	15 (13.00)	4 (9.80)	
Caregiver Health				**0.02**
Excellent	105 (16.50)	93 (17.90)	12 (10.30)	
Very Good	201 (31.60)	172 (33.10)	29 (25.00)	
Good	206 (32.40)	163 (31.30)	43 (37.10)	
Fair	105 (16.50)	79 (15.20)	26 (22.40)	
Poor	19 (3.00)	13 (2.50)	6 (5.20)	
Caregiver Stress				0.37
No	308 (49.80)	249 (48.90)	59 (53.60)	
Yes	311 (50.20)	260 (51.10)	51 (46.40)	
Lives with Caregiver				0.30
No	312 (48.75)	261 (49.70)	51 (44.35)	
Yes	328 (51.25)	264 (50.30)	64 (55.65)	
Positive Caregiver Experience				0.30
No	484 (65.20)	393 (66.20)	91 (61.50)	
Yes	258 (34.80)	201 (33.80)	57 (38.50)	
Days/month helped	17.37(12.99)	17.43 (12.84)	18.11 (13.79)	0.76
[Range]	[0-31]	[0-31]	[0-31]	
Work hrs/week	35.75 (16.60)	35.58 (16.21)	34.07 (17.30)	0.60
[Range]	[2-120]	[2-120]	[2-80]	
Hours/day helped	7.65 (8.51)	7.35 (8.36)	8.79 (9.09)	0.35
[Range]	[0-24]	[0-24]	[0-24]	
How long known caregiver (years)	48.29 (17.43)	48.16 (18.01)	48.82 (14.89)	0.68
[Range]	[1-85]	[1-85]	[6-82]	

Logistic Regression

Logistic regression analyses of proximal variables in relation to the odds of each behavior were conducted using two models with both models controlled for age and race. The personal factors model included subject age, race/ethnicity, changes in hunger, and changes in sleep. Social environmental factors included subject age, race/ethnicity, relationship to caregiver, frequency of contact with caregiver, hours per day of care, and years known. Referents within the models included White, changes, spouse, and daily according to the corresponding variable.

Results from the personal factors model showed increased age to be associated with increased odds of delusions (OR=1.04, 95%CI=1.00-1.08), hallucinations (OR=1.05, 95%CI=1.01-1.10), and agitation (OR=1.04, 95%CI=1.01-1.07). No changes in hunger was associated with decreased odds of hallucinations (OR=0.27, 95%CI=0.12-0.58), agitation (OR=0.41, 95% CI=0.26-0.65), and depression (OR=0.31, 95%CI=0.21-0.47). No changes in sleep was associated with decreased odds of delusions (OR=0.52, 95% CI=0.29-0.94) and depression (OR=0.67, 95%CI=0.46-1.00). African American subjects had decreased odds of depression compared to White subjects (OR=0.42, 95%CI=0.23-0.77).

The social environmental model indicated that increased hours per day of care was associated with increased odds of delusions (OR=1.05, 95% CI=1.00-1.10) and agitation (OR=1.05, 95% CI 1.01-1.09). Frequency of contact, less than several times/week, compared to daily, was found to be associated with increased odds of agitation (OR=3.92, 95% CI=1.20-12.77). African American subjects had decreased odds of depression compared to White subjects (OR=0.14, 95%CI=0.04-0.50), and compared to being cared for by spouses, subjects cared for by non-family caregivers had increased odds of depression (OR=7.33, 95%CI=1.26-42.64). Tables 14 and 15 present additional results regarding regression analyses according to proximal factor and behavioral outcomes.

Table 14 - Logistic Regression

Behavior	Model	Variable	OR (95% CI)
DELUSIONS			
	Personal Factors	Age	**1.04 (1.00-1.08)**
		Race (AA v. White)	1.77 (0.94-3.31)
		Sleep (No Changes v. Changes)	**0.52 (0.29-0.94)**
		Hunger (No Changes v. Changes)	0.67 (0.38-1.20)
	Social Environment	Age	0.97 (0.91-1.04)
		Race (AA v. White)	1.32 (0.48-3.63)
		Relationship (Non-Family v. Spouse)	1.16 (0.08-16.61)
		Relationship (Other Family v. Spouse)	3.07 (0.57-16.37)
		Relationship (Child v. Spouse)	2.94 (0.71-12.15)
		Frequency of Contact (<Several/Wk v. Daily)	0.77 (0.14-4.12)
		Frequency of Contact (Several/Wk v. Daily)	1.32 (0.49-3.52)
		Hrs/Day of Care	**1.05 (1.00-1.10)**
		Years Known	1.01 (0.98-1.04)
HALLUCINATIONS			
	Personal Factors	Age	**1.05 (1.01-1.10)**
		Race (AA v. White)	1.14 (0.50-2.59)
		Sleep (No Changes v. Changes)	0.56 (0.28-1.11)
		Hunger (No Changes v. Changes)	**0.27 (0.12-0.58)**
	Social Environment	Age	1.03 (0.95-1.11)
		Race (AA v. White)	0.56 (0.14-2.20)
		Relationship (Other Family v. Spouse)	1.45 (0.25-8.54)
		Relationship (Child v. Spouse)	1.29 (0.32-5.18)
		Frequency of Contact (<Several/Wk v. Daily)	0.34 (0.04-3.05)
		Frequency of Contact (Several/Wk v. Daily)	0.61 (0.19-2.00)
		Hrs/Day of Care	1.04 (0.98-1.09)
		Years Known	1.01 (0.98-1.05)

Table 15 - Logistic Regression (continued)

Behavior	Model	Variable	OR (95% CI)
AGITATION	**Personal Factors**	Age	**1.04 (1.01-1.07)**
		Race (AA v. White)	1.38 (0.82-2.31)
		Sleep (No Changes v. Changes)	0.67 (0.43-1.03)
		Hunger (No Changes v. Changes)	**0.41 (0.26-0.65)**
	Social Environment	Age	0.99 (0.93-1.04)
		Race (AA v. White)	1.27 (0.53-3.04)
		Relationship (Non-Family v. Spouse)	2.07 (0.38-11.41)
		Relationship (Other Family v. Spouse)	0.99 (0.26-3.77)
		Relationship (Child v. Spouse)	1.40 (0.50-3.91)
		Frequency of Contact (<Several/Wk v. Daily)	**3.92 (1.20-12.77)**
		Frequency of Contact (Several/Wk v. Daily)	1.25 (0.54-2.85)
		Hrs/Day of Care	**1.05 (1.01-1.09)**
		Years Known	1.01 (0.98-1.03)
DEPRESSION	**Personal Factors**	Age	1.02 (0.99-1.04)
		Race (AA v. White)	**0.42 (0.23-0.77)**
		Sleep (No Changes v. Changes)	**0.67 (0.46-1.00)**
		Hunger (No Changes v. Changes)	**0.31 (0.21-0.47)**
	Social Environment	Age	0.97 (0.92-1.03)
		Race (AA v. White)	**0.14 (0.04-0.50)**
		Relationship (Non-Family v. Spouse)	**7.33 (1.26-42.64)**
		Relationship (Other Family v. Spouse)	0.70 (0.17-2.85)
		Relationship (Child v. Spouse)	1.96 (0.74-5.17)
		Frequency of Contact (<Several/Wk v. Daily)	1.12 (0.35-3.54)
		Frequency of Contact (Several/Wk v. Daily)	0.70 (0.31-1.57)
		Hrs/Day of Care	0.99 (0.95-1.03)
		Years Known	1.02 (0.99-1.05)

DISCUSSION

Statistically significant differences were found between White and AA subjects sleep pattern changes, relationships with caregivers, frequency of contact, age of caregivers, caregiver usage of a paid helper, health of caregivers, gender of caregivers, education of caregivers, caregiver race, and caregiver marital status, which warrant discussion.

Social Environment

Caregiver/recipient relationship

The majority of the sample received care from either a spouse, or child, however, AA subjects were more likely to receive care from children followed by spouses, a consistent finding with the literature (Messinger-Rapport, et al., 2006; Connell & Gibson, 1997). Of note in the sample is the increasing proportion of AA "other relatives" providing care. According to the literature, AAs possess a strong family commitment to caregiving which involves the inclusion of extended family members (Chatters, et al., 1994; Taylor, et al., 1993).

The likelihood of behavioral manifestations may be impacted by the type of relationship, where certain relationship types can either decrease or increase behaviors, particularly if longstanding strain/conflict has been pervasive in such relationships (Gwyther, 1995; Semple, 1992). Further, as the literature highlights the influence of various caregivers fulfilling the caregiving role, the dissemination of caregiving may be shared amongst family members (Dilworth-Anderson, et al., 1999). Due to changes in caregiving where the care is shared among variable family members behaviors may also manifest due to the inconsistency or frequent changes. Although consistency may remain in terms of selected family members who are providing care/fulfilling the caregiver role, the shift between who is caregiving day-to-day may exacerbate behaviors due to anxiety, fear, and declining recognition.

Frequency of Contact

Both samples were in frequent contact with their caregivers, primarily on a daily basis. However, AA subjects were in more frequent contact either on a daily basis or several times per week. Literature has suggested the combination of increasing age and decreasing functional ability increases susceptibility to loss of independence for older adults (Gill, Williams, & Tinetti, 1995). With a demonstrably aged sample, frequent contact becomes a necessity. Further, frequency of contact in the AA subject sample is exemplified by the absence of monthly contact. In the AA family, caregiving has been shown to represent a cultural norm (Dilworth-Anderson, et al., 2002; Dilworth-Anderson, et al., 2005). These findings lend further support to the cohesiveness and commitment discussed in the literature surrounding the AA family.

Due to increased stimulation and decreased time alone there is a decreased likelihood of behaviors, possibly related to the relationship and contact frequency. Under stimulation has been found to trigger increased behaviors (Cohen-Mansfield) and consistency in contact is related to findings which demonstrate that processing and adjustment to change is problematic in dementia (Ornell, Bergman, Elton, O'Brien, & Bebbington, 1990). Although length of time known between the sample of White and AA caregivers/care recipients is not statistically significant, the average duration for AAs was slightly longer, 49.25 years (range 6-82 years). The longstanding relationships of family members (either spouses or children), lends support to the notion that frequency of contact may reflect the dynamic nature and composition of the relationship and be a factor relating to behavioral manifestations.

Caregiver age

The ages of caregivers also were statistically significant. While the mean age of White caregivers fell in the retirement range, AA caregivers were younger and likely still employed. However, literature has presented a depiction of minority caregivers who reduce or eliminate employment to meet dementia caregiving needs (Covinsky, et al., 2001). Interestingly findings have also demonstrated that AA adults have been found to extend employment beyond retirement age, due to inability to retire, financial challenges, or insufficient pensions, (Mermin, Johnson, & Murphy, 2007; Gendell & Siegel, 1992; Social Security Retirement Planner), where reducing or terminating employment poses a risk of forfeiting full retirement benefits with early out options. For AA adult-child caregivers who may be approaching retirement age, but remain employed, the literature suggests the influence of various roles including spouse, child, parent, and employee (Tully & Sehm, 1994; Lampley-Dallas, 2002) as well as other caregiving roles (Belle, et al., 2006) which are simultaneously balanced.

While findings were not significant, it should be noted that both AA and White caregivers in the sample worked less than full-time, with White caregivers working slightly more than AA caregivers. AA caregiver ages ranged between 20-98 years of age, revealing a younger cohort of caregivers. This finding introduces the prospect of grandchildren sharing the caregiving responsibility. With the emergence of grandparent caregivers in the literature (Fuller-Thomson, Minkler, & Driver, 1997), perhaps over time the caregiving role shifts such that the grandchild assumes a caregiving role with a dementia compromised grandparent. Further, considering the age distribution of the AA sample, in addition to the possibility of grandchildren as caregivers, and the simultaneous demands of adult-child caregivers, spousal caregivers may also experience the burden of caregiving and are themselves at risk for dementia due to increased age according to the risk profile in the literature (Thompson, et al., 2004; Hubbell & Hubbell, 2002; Shanks-McElroy & Strobino, 2001).

Age of caregivers may be associated with the frequency of behaviors as well as the ability of caregivers to adapt to behavioral manifestations. Further, the varied ages of caregivers illuminate differences in experiences. As LoGiudice & Hassett (2005) suggest, younger caregivers perceptions may vary from an adult-child, or spouse, particularly if that younger caregiver is a grandchild who has witnessed the progression of the disease and transition of the care recipient into the home environment. Shared caregiving demands become the norm, and changes are expected due to longer diagnosis of dementia (LoGiudice & Hassett, 2005). However, older adult caregivers may be less physically and emotionally capable of handling the stress of behaviors where the risk of neglect or abuse increases (Messinger-Rapport, et al., 2006; Hubbell & Hubbell, 2002; Finkel, 2001).

Service Utilization

AA caregiver subjects' utilization of formalized services was significantly less than White caregiver subjects, which may also be related to the increased hours of employment of White caregivers, and to that end increased service utilization or institutionalization. For AAs, both reluctance as well as generalized lack of knowledge/awareness have been found to be contributing factors to decreased service utilization (Gaugler, et al., 2004) and reliance on informal support systems including family and the church (Williams & Dilworth-Anderson, 2002; Taylor, et al., 1993; Taylor, et al., 1988; Taylor & Chatters, 1986; Martin & Martin, 1978).

Although findings were not significant between groups, a caregiver question explored in the data set inquired about the reasoning behind White and AA caregivers decision not to utilize paid helpers. The majority response for both groups was that it was “not necessary”. This may be due to findings that AA and White caregivers did not differ in hours of care/day or days of care/month provided to care recipients, although AA caregivers provided slightly more than an hour/day of care and an additional day of care/month compared to White caregivers. However, this is consistent with the literature, which suggests that AA tend to provide greater care, institutionalize or utilize formalized services less, and have known care recipients longer (Gaugler, et al., 2004; Kosloski, et al., 2002; Kelley, 1994; Belgrave, et al., 1993).

Another notable finding, although not significant, revealed that both White and AA caregivers provided greater than two years of care. In light of caregiving differences among AAs, the length of time in the caregiving role may be related to findings in the literature demonstrating the reluctance to relinquish care in any capacity (Robinson, et al., 2005; Hubbell & Hubbell, 2002; Shanks-McElroy & Strobino, 2001; Larkin & Hopcroft, 1993).

Without the aid of additional supports, formal or informal, the ability to manage behaviors is further compromised for AA caregivers due to a combination of competing demands which increase the risk of neglect or abuse due to stress overload/burden (Messinger-Rapport, et al., 2006; Sink, et al., 2005; Sink, et al., 2004; Hubbell & Hubbell, 2002; Finkel, 2001). Further lack of service utilization, including respite, perpetuate underusage and decreased awarenesss of behavioral management strategies. As AA caregivers maintain loved ones in the home longer, through advanced stages and often until death, disease progression and variable behaviors will occur. Greater assistance to manage behaviors or increase stimulation with varied day-to-day activities, may aid in familiarity with triggers and strategies to de-escalate or recognize impending behavioral escalation, thereby decreasing caregiver burden and preserving the caregiver and quality of relationships with the care recipient.

Caregiver Health

White and AA caregivers health was another statistically significant finding observed. Overall, White caregivers rated their health better than AA caregivers. This could be attributed to the availability of time to focus on health, as White caregivers in the sample also reported increased usage of formalized services. Recent literature has demonstrated that utilization of formalized services provides time to attend to personal and health needs (Robinson, et al., 2005; Larkin & Hopcraft, 1993). However, in contrast, the literature highlights that AA caregivers who are reluctant to utilize formalized services and have a tendency to maintain family members in the home longer, are at increased risk for health consequences in combination with prevalent chronic illnesses (Gaugler, et al., 2004; Covinsky, et al., 2001) where behaviors become perceived as more disruptive. Caregiver stress, such as that related to health status, has also been found to be related to the perception of burden, increased institutionalization, burnout, neglect, and abuse (Messinger-Rapport, et al., 2006; Schulz, Belle, Czaja, McGinnis, Stevens, & Zhang, 2004; Hubbell & Hubbell, 2002; Finkel, 2001) .

Although AA caregivers in this sample reported less stress with caregiving over the last year compared to White caregivers it should be noted that literature findings have also shown caregivers who are less educated, perceived themselves to have better health and report lower stress with caregiving (Williams, et al., 2003; Williams & Dilworth-Anderson, 2002). Further, although not significant, it should be noted that reporting from both AA and White caregivers in the sample viewed the caregiving experience negatively. This is inconsistent with the literature where most AA caregivers commonly report more positive experiences with caregiving (Dilworth-Anderson & Anderson, 1994; Zauszniewski, et al., 2005; Picot, Debanne, Namazi, & Wykle, 1997; Picot, Zauszniewski, & Delgado, 1997; Dilworth-Anderson, et al., 2005).

The reluctance of AAs to institutionalize family members in combination with the prevalence of dementia and related behaviors cause concern regarding stress management tactics of caregivers and the documented influence of stress on health outcomes. A positive caregiving experience and successful techniques or strategies to manage behaviors may contribute to the caregiving experience. However, at least in this sample, AA caregivers perceptions are no longer positive. Stress, burden, and lack of caregiving help, particularly when multiple behaviors are occurring more frequently, are associated with the perception of the caregiving experience. Transitions in the disease process, where new behaviors are emerging, or previously effective strategies are ineffective, further influence perceptions and experiences.

Caregiver gender

The gender of caregivers, predominantly female for both AA and White caregivers, was an additional statistically significant finding. Generally, caregiving has been highlighted as a role fulfilled by women (Nichols, et al., 2008; Covinsky, et al., 2001). For AA caregivers a similar trend has been demonstrated (Williams, et al., 2003; Picot, Zauszniewski, & Delgado, 1997). Female caregivers have reduced likelihood to request assistance of services/support which exacerbates stress and burden. Further, the behaviors manifested by male care recipients, generally more physical overt behaviors, are more difficult or overwhelming for female caregivers to manage.

Caregiver Education

Next, education was demonstrated to be statistically significant between AA and White caregivers. Although the majority of AA caregivers in the sample completed high school and had some college, compared to Whites, an educational gap is evident. Education is indicative of resourcefulness and access and although AA caregiver subjects had greater education than care recipients, Whites being more educated have access to greater resources or possess the knowledge or networks to access more resources. Although both caregivers and care recipients resided in the same region, unlike care recipients where educational discrepancies were reflective of segregationist practices in the South and an era where high school educational attainment was the standard for that generation, caregivers had greater educational opportunities.

Adult-child caregivers benefitted from desegregation of schools and affirmative action practices, which presented significant opportunities for educational pursuits. However, as evidenced by the data, differences persisted. Increased knowledge/awareness to access/utilize resources for management of behaviors is a key factor in educational attainment. In addition, greater education may be associated with access to care and increased likelihood of seeking medical advice, including multiple medical professional/specialist opinions, and increase the likelihood of research participation.

Caregiver race

Data analysis also demonstrated statistical significance in the race of caregivers, where a higher number of White v AA caregivers were present in the sample. The literature has highlighted the trend that AA subjects and caregivers are underrepresented in dementia research (Sink, et al., 2004; Lample-Dallas, 2002; Connell & Gibson, 1997; Gonzales, et al., 1995). Numerous reasons have been offered as explanations including ineligibility, financial burden, transportation, historical misconduct, and distrust (Picot, et al., 1995; Ballard, et al., 1993). However, despite underrepresentation in dementia research, evidence persists demonstrating higher prevalence of AA in the homes receiving care (Sink, et al., 2004).

With decreased participation represented by low sample sizes, this under-representation has limited the effectiveness, and relevance of interventions for disruptive behaviors in dementia among African Americans. The persistent under-representation, and understudy, in dementia research, can be attributed to poor health outcomes, limited applicability/utility of research findings, and poses a barrier to understanding the efficacy of treatments and interventions, which represents a challenge for African American caregivers and care recipients affected by dementia. With reports of increased behavioral frequency among AA care recipients and multiple behaviors, the perpetuation and continued usage of tactics/techniques of unknown benefit to AA care recipients and caregivers, exacerbates burden on caregivers and raises safety issues for care recipients.

Caregiver marital status

The majority of both AAs and Whites were married, yet statistical significance was found between AA and White married caregiver as there were fewer AA caregivers reporting being married. This could be explained by literature findings which have demonstrated higher divorce rates in the AA community (Tucker & Mitchell-Kernan, 1995). Because of the tendency for fewer AA sample subjects to be married, followed by widowed, or single, this draws attention to literature highlighting the family structure of

AA caregivers where intergenerational and extended family relationships are not only common due to a variety of experiences in the AA family (Taylor, et al., 1993), but may influence the caregiver composition where finding have demonstrated differing caregiving structures in AA families (Dilworth-Anderson, et al., 1999; Picot, Zauszniewski, & Delgado, 1997).

The marital status of caregivers may influence the manifestation of behaviors where the reliance on multiple family members (children and other extended family) may result in inconsistency/change, which is problematic in dementia, or increased time alone due to employed caregivers where behaviors are known to increase. Further, the manifestation of behaviors may be more likely between a care recipient and an adult-child caregiver versus that of a spousal caregiver, although the quality of the relationship in either case may be an influential factor.

Personal Factors

The physiological need state of sleep was significant between groups, with the majority of White subjects reporting changes in sleep. Overall, both AAs and Whites experienced some sleep changes. Supporting literature has offered that sleep disruption has been associated with hallucinations or agitated behaviors and associated unmet need states, which may be the cause. Yet the inability to verbalize or express needs may result in behavioral manifestations.

Logistic Regression

Logistic regression findings overall demonstrated increased odds of behaviors as age increased. This is somewhat contrary to the literature which has associated decreased behaviors with simultaneous increases in age and dementia severity/stage progression

(Senanarong, et al., 2004). AAs had lower odds of depression versus Whites, which is consistent with supporting literature, which suggests White older adults tend to have greater incidence of depression than AAs (NIMH, 2003; Yin, 2006). No change in hunger or sleep resulted in decreased odds of behaviors. This finding supports literature which has demonstrated that unattended physiological need state changes have been associated with increased behaviors, due in part to the inability to communicate such needs. However, this finding may also indicate that the need states examined, in relation to the sample size, do not influence behaviors, although other need states (elimination, pain) may offer additional insight. Decreased frequency of contact was associated with increased odds of agitation, which is another consistent finding with the literature as less contact has been associated with increased behaviors, although the type of relationship between caregiver and care recipient may also precipitate behaviors if there is a history of conflict. Increased hours of care was associated with increased odds of agitation and delusions. Literature has suggested that increased stimulation during care provision reduces the likelihood of behavioral manifestations, however, in this instance, a possible explanation may be greater caregiver strain or burden perceived by the care recipient possibly influencing behaviors. In addition, it is also possible that greater care provision is necessary due to the manifestation of disruptive behaviors. Finally, non-family caregivers were associated with increased odds of depression. This finding lends support to the notion that a relationship with a caregiver who is not family may encourage depression as contact with loved ones is reduced, thereby inducing a depressed state.

LIMITATIONS

This analysis was cross-sectional in nature limiting the ability to observe changes longitudinally and, as with any secondary analysis, data availability and further exploration of questions is another limitation. Similarly, as this research was exploratory in nature to examine any associations or patterns which might be present in the data, the exclusion of missing values was a limitation that warrants future attention. Gender or ethnic (Hispanic) differences were not explored in this analysis further limiting additional insight into their influence on caregiving experiences and behavioral manifestations. The ability to verify self-reported responses with chart data or physician report was another limitation where generalizations could not be made. Further, within-group analysis of spousal and adult-child caregiver differences may have yielded additional insight into behavioral manifestations. Next, the exploration of past behaviors, what they were, what stopped the behaviors as well as past medications used to manage behaviors, psychiatric illness, pain, or sleeping, but due to side effects, efficacy, or cost were no longer utilized, may have presented an additional role to explore in the occurrence of behaviors.

The length of dementia diagnosis to evaluate subtle changes over time as well as the progression of behaviors may have yielded additional insight into the presentation of behaviors. Information pertaining to the previous occupation of subjects as well as personality characteristics may also have yielded insightful data in the manifestation of behaviors as well as a risk profile. Also the influence of religious support for AA coping with dementia and behaviors may have been useful to describe behavioral management strategies as well as the under-utilization of formal services. In addition, the collapsing of variables (sleep, hunger, relationship, frequency of contact; and caregiver experience) may have overshadowed individual differences in responses across caregivers. The selection of specific behaviors from the original number available may have overlooked the influence of other behaviors, although it should be noted that preliminary analysis did not reveal significant frequencies with other behaviors.

RECOMMENDATIONS

Future research should explore not only the types of relationships (spouse, child, etc) but also endeavor to assess the quality of relationships. Behaviors can be triggered by longstanding issues between caregiver and care recipient such as the influence of divorce, estrangement, substance abuse, or incarceration, and the obligation, or resentful undertaking of caregiver could result in increased burden/stress for caregivers, or abuse/ neglect of the care recipient.

Encourage the inclusion of residents on errands when possible, engagement in appropriate level and personality appropriate activities (Fitzsimmons & Buettner, 2002), which not only enhance the quality of relationships, but also provide stimulation. Future research should involve inclusion criteria pertaining to length of caregiving relationships extending beyond six months (Wisniewski, Belle, Marcus, Burgio, Coon, Ory, et al., 2003), which although sufficient will likely capture the quality of relationships and their relation to behavioral manifestations. Additional questions surveying length of relationships can help shed insight into the bond and nature of these relationships. Finally, recognition and sensitivity to extensive relationships between caregiver and care recipient where as disease progresses and death occurs, grief support and support for role transitioning for caregivers may also be an intervention/educational need.

Both groups can benefit from increased recruitment strategies to include caregivers who deviate from the spousal/adult-child caregiver commonly represented and their experiences as well as definitions of caregivers and increased disturbing behaviors, considering shared caregiving, and redefining primary caregivers. Assessment and screening of spousal caregivers or older adult caregivers may help detect and identify burden stress, and other psychosocial needs. Educate families on respite services, and appropriate stimulating activities. Sensitivity attached to working caregivers who are either unable to retire or have reentered the work force would be of benefit. Variable factors such as limited time may be addressed with strategies to reduce/maximize the amount of time expended with the inclusion of phone interviews or convenient recruitment efforts.

Further, sensitivity to the caregiver role by recognizing grandchildren and the obligations or responsibilities they posses, spousal caregivers and the influence of challenges related to aging/chronic illness, or memory, as well as adult child caregivers who juggle multiple demands, can be of benefit (Lampley-Dallas, 2002; Tully & Sehm, 1994). This is of importance to future research where attention to differences in work schedules or commitments of caregivers, shared caregiving, and increased potential for time alone may be factors to consider among the AA. Also, the caregiving role may shift between a “primary” caregiver who works full-time during the week, resuming primary care after work or on the weekend, and by a child after school or other relative during the day.

Increased attention should continue to be given to AA caregivers due to risk of burnout, stress, and burden, where interventions and education should be the focus to highlight the changes in dementia over time and strategies to manage behaviors.

Future research exploring knowledge/awareness of resources and services offered and their benefits, as well as exploring what supports are offered informally and how sufficient these supports are in meeting caregiving needs may be useful. Exploring the barriers to formal service utilization, what services/resources are used, under what circumstances, and what methods are needed to enhance formal and informal services is essential. In addition, the exploration of what necessitates the solicitation of assistance and what prompts the decision to do so is warranted.

Future research should include questions regarding the health of caregivers, including stress perception, and how they attend to their own health, particularly as research has demonstrated reduced self care among caregivers, especially spouses (Gallant & Connell, 1997). Research examining what factors contribute to a positive/negative caregiving experience and what resources or supports can be implemented and increased to facilitate, encourage, or ensure this is critical. Resources to encourage participation in formal services, dementia research, clinical trials and heightened educational efforts to maintain the experience of closeness and value of the caregiving experience is also critical.

Increased support and education for female caregivers is of importance, particularly for spousal females who are older and managing dementia behaviors, as well as adult-child caregivers who are likely to juggle multiple demands. In addition, with literature suggesting an increase in male caregivers (Messinger-Rapport, et al., 2006; Thompson, et al., 2004), there is an increasing need to explore male caregiving experiences. Across White and AA racial groups, women have higher life expectancies than males and with the associated risk of dementia with increased age, it is not surprising the predominance of women primarily affected by dementia where over time an increase in male caregivers (husbands or sons) is imminent. Increased efforts to explore the experiences and perceptions of male dementia caregivers, as well as the inclusion of targeted recruitment strategies to encourage participation, is highly encouraged. With an increase in male caregivers, although perceived as stoic, they are at risk for burnout, anxiety, depression (Thompson, et al., 2004; Hubbell & Hubbell, 2002), and are particularly reluctant to utilize services (Hubbell & Hubbell, 2002; Larkin & Hopcroft, 1993) where attention to their needs and perceptions is of great importance.

For AA men, little information exists regarding their role in caregiving. However, the influence of cultural expectations of masculinity, stoicism, and John Henryism - extreme coping mechanisms for chronic stressors (Bennett, Merritt, Sollers, Edwards, Whitfield, Brandon, et al., 2004) - place male caregivers at risk for negative health outcomes. Raising awareness of elusive, yet critical issues pertaining to men, and particularly AA men, are pivotal to illuminate the unique experiences and decisional influences, where development of culturally tailored interventions that may be useful to male caregivers can occur.

Considering the varying levels of caregiver educational attainment, increasing efforts to provide education to caregivers regarding disease transition and promotion of resources and strategies for behavior management, as well as recognizing that all caregivers may not endeavor to explore other options or be at identical levels of educational attainment where education strategies may need to be expanded.

Encourage cultural sensitivity to the experiences of caregivers and increase the ability of minority researchers to establish trust with this population. Expanding recruitment strategies to encourage research participation can be done by providing accommodations for participants (financial incentives, free parking, convenient locations, baby-sitting/adult day-care services). Future research should consider qualitative data to identify the barriers identified by caregivers, and if possible care recipients, which prevent research participation. Further, identifying the specific needs and experiences of caregivers/recipients, where proposed research may not meet the needs of this population, or have interest in their experiences.

Also, expanding inclusion criteria to include varying types and severity of dementia, as well as types of caregivers, may have an influence on the eligibility of potential subjects. Further, increasing recruitment efforts and qualitative research may illuminate differences in caregiver experiences or definitions, where perhaps caregiving may be perceived differently if caring for a family member is an obligation or expectation.

Sensitivity is paramount to the needs of caregivers who may juggle multiple demands (parent, spouse, employee), may be single parents providing care, or may also have multiple caregiving roles (young children, aging parents, grandchildren). Consider the composition of the caregiving structure where various members of family may be contributing to the role. Increased research should inquire about the marital status of caregivers and the role it plays, if any, in the caregiving experience.

Maintaining consistent sleep schedules and reducing environmental stimuli, such as noise or light, and providing consistent sleep aids for dementia subjects are encouraged. However, education of caregivers is critical to understand the delicate balance between increased behaviors and sleep disturbances or overstimulation. It is important to encourage the participation of loved ones with dementia in appropriate activities during the day, recognizing that too much stimulation may exacerbate sleep disturbances due to frequent napping throughout the day, and too little sleep may increase behaviors.

While no statistical differences were found, almost half of the White sample and slightly over half of the AA sample experienced changes in hunger, another physiological need state. Behavioral manifestations are likely to occur due to dementia compromise and the inability of subjects to express needs. Further, with dementia progression, the awareness of needs change where special attention must be given to ensure adequate dietary needs are met for both Whites and AAs. Future interventions and research should target caregiver education and strategies to encourage eating as well as preparatory counseling or coping strategies for AA caregiver who will transition out of the caregiver role. As dementia progresses aversion to eating is part of the dying process, but may be interpreted differently. Further, typically education or interventions only are targeted in their intensity and focus on one time period , yet caregivers receive most benefit with strategies over time, particularly related to disease transitions and behavioral management strategies.

Educate caregivers regarding the transition of dementia where, as age and dementia severity increase, behaviors will likely decrease, although the importance of support systems to cope with less overt behavioral manifestations or advancing disease states are necessary. Encourage stimulation of care recipients where care provision is less likely to result in behaviors but also enhances the quality of relationships.

CHAPTER 5: CONCLUSION

Summary of Findings

This dissertation highlighted the escalating prevalence and incidence of dementia and disruptive behaviors in older adults, as well as the inevitable, multifaceted impact on caregivers, particularly AA, by presenting the AA dementia caregiving experience. An integrated literature review detailed the unique cultural aspects of the AA experience and the influential role these aspects play in the underrepresentation of AA in the dementia literature including diagnosis, clinical trial and intervention study participation, as well as formalized service utilization and institutionalization.

Within the last 20 years attention to AA dementia caregivers has emerged with a focus on composition, differential experiences, psychosocial determinants, and health outcomes. More recently attention to disruptive behaviors in dementia and AA caregivers has become prominent where multiple behaviors have been found. These behaviors tend to occur with greater frequency in the AA community where increasingly disruptive behaviors exacerbate stress and burden.

Secondary data analysis utilizing the Need-Driven Dementia-Compromised Behavior (NDB) model as a guide examined background and proximal factors in the manifestation of the selected behaviors of delusions, hallucination, agitation, and depression. Exploration of background factors by race found significant differences in education, cancer/other diagnosis, dementia type, marital status, region of residence and display of depressed behavior. Regression analysis demonstrated that behaviors were less likely to occur with increasing age, in men, White subjects, increased functional/cognitive impairment, with dementia, and increased number of conditions. Behaviors were more likely to occur with decreased functional/cognitive impairment. Essentially when considering a profile of risk for AA community dwelling elders, based on findings from the data analysis, greater cognitive impairment, greater functional impairment, presence of dementia, greater number of conditions, and gender are associated with increased odds of behaviors.

Exploration of proximal factors by race found significant differences in subjects changes in sleep, relationship to caregiver, frequency of contact with caregiver, caregiver age, caregiver health, caregiver gender, caregiver education, caregiver marital status, and caregiver race. Regression analysis demonstrated that behaviors were less likely to occur with increasing age, in men, with decreased frequency of contact, increased hours/day of care, and non-family caregiver provision. In the absence of hunger or sleep changes, behaviors were less likely to occur. Factors which may influence behavior reduction include caregivers anticipating hunger or sleep needs of care recipients, decreasing hours/day of care, increasing frequency of contact, and encouraging family caregiver participation when possible.

Conclusions

Although unique strategies incorporating informal supports have been helpful in reducing the influence of behaviors, intervention studies have demonstrated inconsistencies. Caregiving experiences and interventional benefit may be dependent upon the type of caregiver relationship (spousal versus adult-child). However, persistent under-representation and ultimately understudy have limited the utility, relevance, and effectiveness of interventions and perpetuated their overgeneralization and incorporation in the management of disturbing behaviors of dementia for AA. As a result, the true benefit cannot be ascertained representing a pervasive challenge for caregivers and care recipients.

Defining disruptive behaviors prior to research engagement as well as allowing caregivers to provide their own definition, redefining the term primary caregiver/caregiver to be inclusive of differences within the AA family/extended family/ informal support network, and consideration of research strategies in terms of recruitment, sample, design, and measures, may help encourage additional AA participation in research and provide additional insight into the AA dementia caregiving experience. Education for caregivers and care recipients is of great importance in the early recognition and diagnosis of AA elders, medication usage/reconciliation, dementia types, progression, behaviors and management strategies, as well as recognizing the variance in educational or literacy levels with dissemination. Further, assessing pain, depression, and other risk factors is critical for researchers as well as medical professionals.

Caregiver education regarding disease progression, including physiological need state changes, and resource utilization may be of great benefit. However, increasing attention to caregiver demographics, barriers to utilization, recruitment strategies, caregiver experiences-(especially male caregivers)-sensitivity to caregiver needs and cultural sensitivity have emerged as factors which may minimize or exacerbate behaviors. Future research is necessary.

Numerous researchers have proposed various middle range theories examining disruptive behaviors, however, within nursing several interventions have been developed based on the underlying theory of the NDB model. Utilization of the NDB model as a guiding framework in this dissertation has demonstrated promise in the expansion of the social environment from the nursing home to the community. While findings require further analysis, preliminary data suggests the influence of the social environment, particularly community caregivers, on the manifestation of dementia behaviors. Further research examining caregiver /community characteristics in depth, the inclusion of additional characteristics not available/analyzed in this data set (personal factors/physical environment), as well as the inclusion of multiple behavioral manifestations will continue to expand this model. Ultimately, this framework can be utilized for the identification of triggers in the environment to aid caregivers and health professionals in the minimization of behaviors where expansion of this model can contribute to its usage in various racial, cultural, and environmental contexts.

Limitations

Self-reported data, the cross-sectional nature of this study, and secondary analysis of the data limited the verification and interpretation/generalization of data. Despite the exploratory nature of this research, missing data and the unavailability of additional economic data may have influenced results, which warrant future examination. In addition, the inability to perform within group comparisons, unavailable details about dementia diagnosis, medication usage, past behaviors, and the influence of pain on behavioral outcomes also were limitations of this dissertation. Selection of different behaviors, exploration of gender/ethnic differences, and exploration of characteristics of participants including personality and past occupations, may have provided additional insight. Further, the collapsing of variables may have overshadowed individual differences, and lack of information regarding religious support limited the ability to determine the influence of such support on managing behaviors and usage of formalized services. Finally, the influence of delirium and post traumatic stress, particularly among an age cohort of possible veteran's, were unable to be examined or extracted from the data in their influence on the manifestation of behaviors.

Recommendations for Future Research

Revisiting the literature systematically because of the growing significance of this problem and the continued understudy/inadequate representation is a primary recommendation. Caregivers who may either be older and managing chronic illness trajectories of their own, or juggling competing demands of various roles including child/parent/spouse, highlights the need to focus on caregivers over time due to health changes, behavioral management strategies, and role transitions. Similarly, the needs of care recipients warrant further attention as well due to disease progression and cognitive changes, behavioral manifestations, and changes/transitions in caregivers.

Future research expanding research strategies such as the expansion of recruitment, sampling, design, and measurement strategies are needed to encourage participation and add insight into the needs of AA dementia caregivers/care recipients. Such techniques may capture the experience and progression of AA elders with AD and dementia behaviors as well as the experience of dementia caregivers particularly with baseline behavioral management strategies and strategy changes over time. In addition, careful screening of caregivers and care recipients to determine immediate needs, interventions, or follow-up should be a responsibility shared between researchers and primary care professionals. Further, increased attention to caregiver characteristics, which emerged as associated factors in the minimization or exacerbation of behaviors, warrants additional research.

Finally, future research utilizing the ADAMS dataset can include the utilization of additional behavioral scales not only for the depiction of the types and frequency of behaviors seen, but also for continued validation of measurements in various settings and with various populations. In addition, further exploration/examination of factors which may have influenced the manifestation of behaviors such as pain, pre-existing personality, medications, past and/or recent behaviors, the stage/length of dementia, and additional economic factors may yield useful information in future data collection waves.

Recommendations for Practice

In practice, the implementation of community based interventions through the combination of formal and informal support resources to better meet the culturally specific needs of caregivers and care recipients are critical. Education is important to aid in early recognition, medication benefits and usage, dementia types and progression, behavioral management strategies, and formalized resource options and usage. Additionally, practitioners should be culturally sensitive when providing education. Recognizing the magnitude of information, being attentive to the timing of delivery, the most effective method of delivery, and awareness of the variance in educational or literacy levels can promote a beneficial exchange. Finally, focused assessments of care recipients for disease progression and behavioral manifestations as well as caregiver assessments pertaining to health changes and behavioral management strategies are necessary.

Recommendations for Policy

At the policy level, local, state, and federal funding endorsing research for either a dementia cure or effective intervention strategies should continue and are necessary. Many clinical trials are often financed by pharmaceutical companies, however continued and increased governmental funding for AD research including clinical trials, as well as government supported initiatives for intervention studies or stem cell research can continue to push research endeavors until a cure is found or effective interventions to manage AD can be created. In addition, policies mandating training, initiatives outlining educational strategies, and reimbursements for formalized services to decrease caregiver burden are essential. Federal and state policies to address the lack of health care providers and resources, as well as funding to conduct research, are needed in rural environments as the influence of dementia and associated behaviors are likely higher with increased burden upon caregivers. Finally, governmental endorsement of the Alzheimer's Association and other agency groups, and increasing financial support for initiatives promoting dementia education and training can assist caregivers and care recipients.

The hidden costs of caregiving, not fully covered by governmental programs such as Medicare are often supplemented by private insurance, Medigap insurance, or in some circumstances, Medicaid. However, fixed incomes, alternative financial obligations, and rising insurance premiums still pose a burden despite enacted policies designed to be of assistance. Policies regulating the extension of benefits or the offering of reimbursements to cover respite or day care services, aid caregivers by enhancing usage and eliminating/minimizing out-of-pocket costs, and improve the quality of life of care recipients.

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