

Racial and Ethnic Disparities Among Individuals with Alzheimer's Disease in the United States: A Literature Review

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Racial and Ethnic Disparities Among Individuals with Alzheimer’s Disease in the United States: A Literature Review

Lisa M. Lines, Noha A. Sherif, and Joshua M. Wiener

Abstract

This study reviews the published literature on racial and ethnic disparities among people with Alzheimer’s disease (AD) and related dementias in the United States. To identify relevant studies, we searched electronic sources for peer-reviewed journal articles and unpublished research reports that were published through July 2014; related to the AD population and their caregivers; and provided evidence of racial and ethnic disparities, discussed reasons for disparities, or described interventions to address disparities. The literature shows consistent and adverse disparities among blacks and Hispanics compared with non-Hispanic whites concerning AD, including the disease’s prevalence and incidence, mortality, participation in clinical trials, use of medications and other interventions, use of long-term services and supports, health care expenditures, quality of care, and caregiving. The literature suggests numerous underlying causes, including factors related to measurement of the disease, genetics, socioeconomic factors, cultural differences, lack of culturally competent clinicians, and discrimination. Although these disparities are well known, little is known about the effectiveness of various strategies, such as cultural competence training, to address these differences, and very few studies evaluate possible interventions.

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Introduction

According to the Institute of Medicine (IOM) report *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care* (Smedley, Stith, & Nelson, 2003), disparities in health care are racial or ethnic differences in the quality of health care that are not due to clinical needs, preferences, or the appropriateness of an intervention (Smedley et al., 2003). A large body of evidence suggests that across racial and ethnic groups in the United States, significant differences exist in prevalence, incidence, treatment, and mortality for Alzheimer's disease (AD) and related dementias.¹ Substantial differences exist in participation in clinical trials, use of services, and disease-related expenditures. Disparities across racial and ethnic groups in diagnosis and treatment rates and in the use of services are concerns from both ethical and policy perspectives. In an ideal world, the burden of disease and access to services would not vary based on a person's racial or ethnic background.

As the US population ages and minorities become a higher proportion of the older population, a higher percentage of people with AD will be minorities. Among the population aged 85 or older, which is the age group most likely to have AD, the proportion that is Hispanic (of any race) is projected to increase from 5 percent in 2010 to 15 percent in 2050; the proportion that is black will increase from 7 to 10 percent, while the proportion that is Asian will rise from 2 to 6 percent (Vincent & Velkoff, 2010).

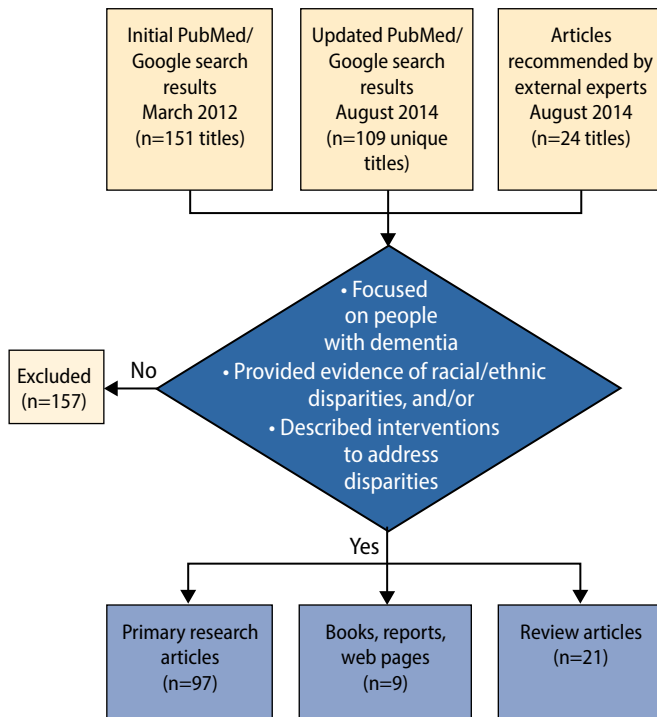
This research report describes evidence from the literature of racial and ethnic disparities in AD. We explore possible reasons for these disparities, including factors related to measurement of AD, genetics, cardiovascular and cerebrovascular disease, socioeconomic factors, cultural differences, and racial and ethnic discrimination. We also review interventions that have attempted to reduce disparities in this population.

Methods

To identify relevant studies related to the AD population and their caregivers, we searched PubMed, Google Scholar, and our in-house electronic library (an EndNote library containing dementia-related references collected for prior studies) for peer-reviewed articles and research reports published in English through July 2014. We also searched the Internet for gray literature using similar search terms. We included studies and reports that focused on people with dementia or their caregivers, compared at least two racial and ethnic groups to provide evidence of racial and ethnic disparities, discussed reasons for disparities, or described interventions to address disparities. We included reviews, books, government and nonprofit research reports, and research studies published in peer-reviewed journals. We included several systematic reviews, but we did not separately review the articles cited within those reviews.

Our searches of the peer-reviewed literature combined free text and Medical Subject Heading (MeSH) terms, such as "disparities," "disparity," and "discrimination," with free text and MeSH terms for AD and dementia ("dementia" OR "Alzheimer disease" OR "cognitive impairment") and terms for individual ethnic and racial groups. Journal articles were required to have an abstract and pertain to human subjects. Our initial search in March 2012 located 151 article abstracts. An updated search conducted in August 2014 identified 109 unique additional article abstracts, and another 24 articles were located through discussions with expert reviewers. After excluding articles that were clearly irrelevant on the basis of their title or abstract, we reviewed the full texts of 118 refereed articles and 9 other sources (books, reports, web pages, etc.). Figure 1 shows the flow of articles through the search process.

¹ In this report, "Alzheimer's disease (AD)" is used when the available data pertain specifically to that disease. The term "dementia" is used when the data pertain more generally to AD and other diseases and conditions that cause dementia.

Figure 1. Search process and results

Results

Evidence of Racial and Ethnic Disparities

Prevalence, Incidence, Diagnosis, and Phenotypes

Prevalence describes the proportion of a population with a disease at a specific point in time, whereas incidence describes the proportion of the population that develops a disease over a specific time period. Reported AD prevalence rates among older adults range from 14 percent to 500 percent higher among African Americans than among whites (Froehlich, Bogardus, & Inouye, 2001), although some researchers have found no significant differences in prevalence between black and white elders (Fillenbaum et al., 1998; Livney et al., 2011). The most frequently cited estimates are that blacks are about two times more likely than whites to have AD and Hispanics are about 1.5 times more likely than non-Hispanic whites to have AD (Alzheimer's Association, 2011, 2014).

Prevalence studies in New Haven, Connecticut; Copiah County, Mississippi; Houston, Texas; New York, New York; Dade County, Florida; and East

Baltimore, Maryland, have all found higher rates of dementia among elderly ethnic minority people—specifically African Americans and Hispanics—than among whites and Asians (Demirovic et al., 2003; Harwood & Ownby, 2000; Perkins et al., 1997). Among African Americans, prevalence estimates have been as high as 56 percent, although rates of diagnosed disease have been more in the 5 to 16 percent range (Teresi, Holmes, Ramirez, Gurland, & Lantigua, 2002).

The Indianapolis-Ibadan study was established in 1991 to investigate the prevalence and incidence of dementia and AD among African Americans in Indianapolis, Indiana ($n = 2,147$), and Yoruba in Ibadan, Nigeria ($n = 2,459$), and to compare rates across these populations (Hendrie et al., 2001; Hendrie et al., 1995; Ogunniyi et al., 2000). Baseline interviews were conducted in 1992 to 1993, and participants were invited to participate in two waves of follow-up (1994–1995 and 1997–1998). Baseline age-adjusted prevalence rates were significantly different between the two samples: among Yoruba, dementia prevalence was 2.3 percent, and AD prevalence was 1.4 percent, whereas prevalence among African Americans was 4.8 percent and 3.7 percent, respectively; in the overall sample, prevalence of dementia was 8.2 percent, and the prevalence of AD was 6.2 percent. According to follow-up analyses, the age-adjusted prevalence of dementia in the Indianapolis sample was not significantly different between 1992 and 2001, although researchers did observe a slight increase over time (from around 6.8 percent in 1992 to 7.5 percent in 2001).

Prevalence rates among Hispanics have been less commonly measured, but one study estimated dementia prevalence of 8 percent of Caribbean Latinos in the 65 to 74 age group, 28 percent in the 75 to 84 age group, and 63 percent in those aged 85 or older (Gurland et al., 1999). Another, more recent study found that Mexican-American men had significantly higher prevalence of cognitive impairment than did non-Hispanic white men (Samper-Ternent et al., 2012).

An analysis of 2006 Medicare claims data found that older African Americans and Hispanics were more

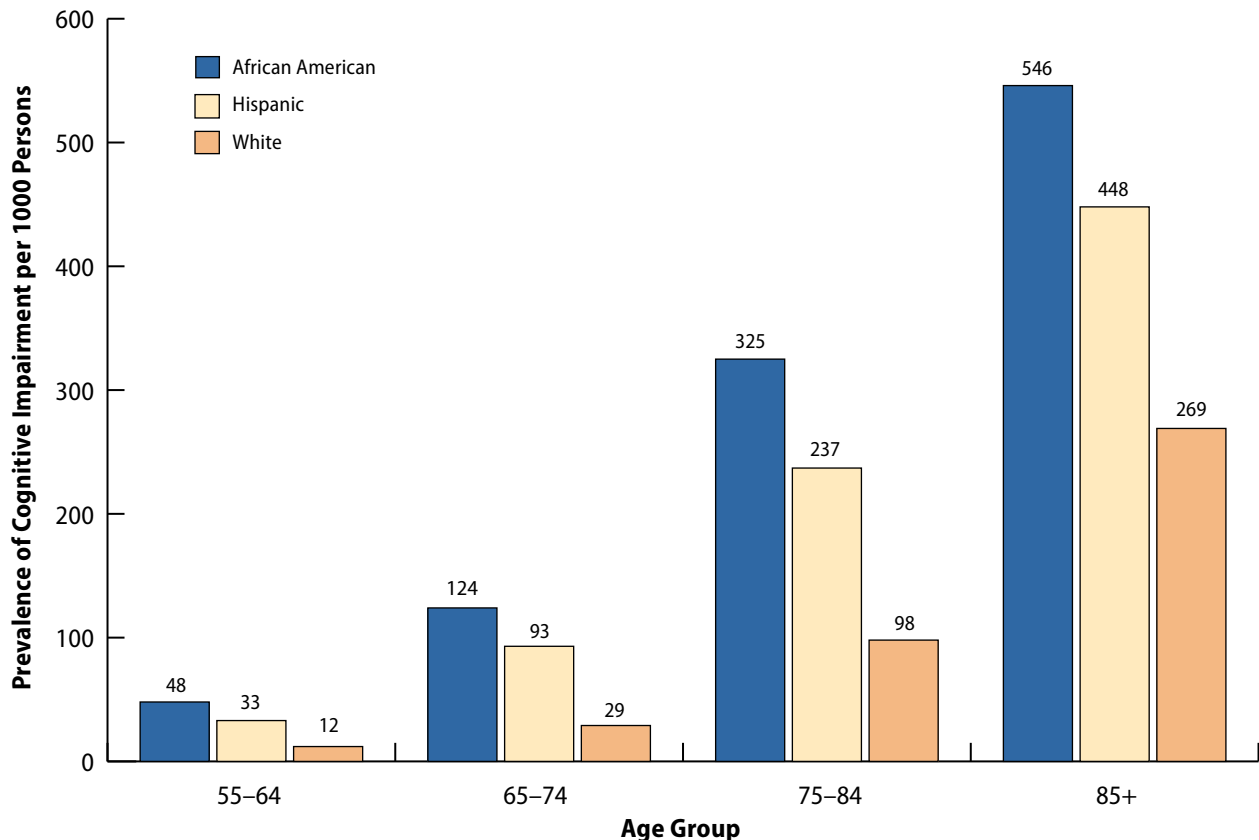
likely than older whites to have a diagnosis of AD. Rates were 14 percent for Hispanics, 13 percent for African Americans, 10 percent for whites, 9 percent for Native Americans, and 8 percent for Asians (Alzheimer's Association, 2011). The report's authors cautioned that prevalence rates based on diagnosis codes may reflect varying levels of underdiagnosis across populations. They also pointed out that Health and Retirement Study data shows that among those aged 55 or older with independently confirmed cognitive impairment, 46 percent of whites reported being told by a physician that they had a memory-related disease, compared with 34 percent of Hispanics and 34 percent of African Americans (Alzheimer's Association, 2011).

In terms of the prevalence of cognitive impairment, the 2006 Health and Retirement Study shows a marked difference by age and race or ethnicity, as shown in Figure 2. Overall prevalence is about

105 per 1,000 Americans aged 55 or over; African Americans are approximately 2 to 3 times more likely than whites to have cognitive impairment (Alzheimer's Association, 2011).

Incidence estimates also suggest higher risk of AD among nonwhite populations. In a 7-year study in the Washington Heights and Inwood communities of New York City, overall adjusted incidence rates for probable and possible AD (excluding vascular and other dementias) among whites were 0.4 percent per person-year for ages 65 to 74, 2.6 percent for ages 75 to 84, and 4.2 percent for ages 85 and over (Tang et al., 2001). Incidence was higher among African Americans (1.7 percent, 4.4 percent, and 11.4 percent, respectively) and Caribbean Hispanics (1.4 percent, 4.4 percent, and 8.8 percent, respectively) in the same community. In the Cardiovascular Health Study, a multisite observational study of elderly US residents from four communities in North Carolina,

Figure 2. Prevalence of cognitive impairment among Americans aged 55 or older (rate per 1,000 persons) by age and race or ethnicity, 2006 Health and Retirement Study



Source: Adapted from Alzheimer's Association (2011).

Maryland, California, and Pennsylvania ($n = 3,602$), the age-adjusted incidence of dementia was 34.7 per 1,000 person-years for white women, 35.3 for white men, 58.8 for African-American women, and 53.0 for African-American men. After researchers adjusted for age and education, racial differences were only borderline statistically significant (Fitzpatrick et al., 2004).

One more recent study found that the unadjusted hazard ratio for developing dementia over 12 years was 1.44 for black participants compared with white, but after demographics, apolipoprotein E4, comorbidities, lifestyle factors, and socioeconomic status were adjusted for, the black-white difference was reduced to 1.09 and was no longer statistically significant (Yaffe et al., 2013). In contrast, others have found that, even when they control for education, vascular disease, age, and other confounding variables, blacks are still at higher risk for dementia than are their white counterparts (Shadlen, Larson, Gibbons, McCormick, & Teri, 1999).

In the previously described Indianapolis-Ibadan study, age-standardized incidence rates of dementia were significantly lower among Yoruba (1.4 percent) than among African Americans (3.2 percent); AD prevalence rates were also significantly different (1.2 percent and 2.5 percent, respectively) (Hendrie et al., 2001). This study, which used identical research methods at each location, provides unique evidence of the differences in dementia and AD incidence between people of African descent residing in the United States and Africans residing in Nigeria.

Researchers have described two distinct phenotypes (observable characteristics) of dementia: type 1 is characterized by impaired executive function and posterior cortical function, and type 2 involves impaired executive function with relatively preserved function in the posterior cortex (Schillerstrom et al., 2007). According to a study of 433 African Americans and 477 whites aged 65 or older in Birmingham, Alabama, 33 percent had the type 1 phenotype, and it was 2.5 times more common among African Americans than among whites; 15 percent had the type 2 phenotype, and there were no significant differences between groups (Schillerstrom et al., 2007).

Health Outcomes and Symptom Burden

Mortality and other health outcomes among people with AD vary by race and ethnicity. Despite a lower prevalence and incidence rate, whites have a higher overall mortality rate from AD (Gillum & Obisesan, 2011; Mehta et al., 2008; Moschetti, Cummings, Sorvillo, & Kuo, 2012). In two recent studies, whites had dementia listed as the underlying or contributing cause of death on their death certificates slightly more often than blacks: from 1999 through 2004, the age-adjusted death rate per 100,000 was 64.7 for whites and 62.8 for blacks, a 3 percent difference (Gillum & Obisesan, 2011), and from 1999 through 2008, the age-adjusted mortality rate per 100,000 was 52.1 for whites, 44.3 for blacks, 32.3 for Hispanics, 26.8 for Native Americans, and 19.4 for Asians and Pacific Islanders (Moschetti et al., 2012). It should be noted that cause-of-death studies may be confounded by reporting bias, variations in diagnostic customs, and differences in access to diagnostic technologies. In another study, African Americans and Latinos had a lower adjusted risk of AD-related mortality than their white counterparts, whereas Asians and Native Americans had a mortality risk similar to that of whites (Mehta et al., 2008).

Rates vary by geographic region, with higher rates among whites than blacks in New England, the Mid-Atlantic, and in the East and West South Central census regions. In the East and West North Central, South Atlantic, Mountain, and Pacific regions, rates were higher among blacks than whites. In six of the nine regions, the differences were less than 10 percent, but in the Mid Atlantic and East and West South Central regions, white death rates were 12 to 26 percent higher than black death rates (Gillum & Obisesan, 2011).

In another study, blacks and whites born in the so-called stroke belt states (Alabama, Arkansas, Georgia, Mississippi, North Carolina, South Carolina, and Tennessee) were at higher age- and sex-adjusted risk of dementia mortality—29 percent higher for blacks and 19 percent higher for whites—than those born in other states, even among those who no longer lived in those states at the time of death (Glymour, Kosheleva, Wadley, Weiss, & Manly, 2011).

In a large epidemiological study aimed at identifying the prevalence of behavioral and psychotic symptoms of dementia among patients with dementia, after researchers adjusted for age, sex, education, income, Mini-Mental Status Examination (MMSE) score, activities of daily living, and caregiver characteristics, blacks were at increased risk (relative to whites) of being constantly talkative, having hallucinations, expressing unreasonable anger, wandering, and waking the caregiver, whereas Hispanics were at increased risk (relative to whites) of having hallucinations, expressing unreasonable anger, being combative, and wandering. Whites were at increased risk (relative to Hispanics) of being paranoid (Sink, Covinsky, Newcomer, & Yaffe, 2004).

Older African Americans with AD consistently describe themselves as more impaired, with greater need for health services, than whites—despite a lack of measured differences in the number of recent sick days, number of reported chronic conditions, cognitive status, and mortality (Froehlich et al., 2001). Whether this difference is a result of unmeasured comorbidities or different types of comorbidities, cultural differences in the perception and description of cognitive disability, or some other factor is not known.

A study in Philadelphia, using data collected from 1989 through 2008 on 1,341 people, found that Latinos with AD ($n = 154$) had younger age at onset, more cognitive impairment at the time of initial presentation, and more depressive symptoms than did whites or African Americans (Livney et al., 2011). In a Northern California study involving 1,573 patients (12 percent African American and 4 percent Hispanic), African American and Hispanic patients had lower rates of depression than whites; African Americans had a lower rate of anxiety than whites; and Hispanics with mixed dementia had a lower rate of apathy than whites after age, sex, education, and disease severity were controlled for (Hargrave, Stoeklin, Haan, & Reed, 2000). In a sample of 240 dementia outpatients residing in Brooklyn, New York, African Americans had significantly higher rates of psychotic symptoms than whites, whereas whites had higher rates of depressive symptoms after researchers controlled for 14 potential confounding factors;

interestingly, there were no significant differences in symptom burden between US-born African Americans and African Caribbeans (Cohen & Magai, 1999).

Sleep disturbances, which are common among people with AD, have been shown in a South Florida study to be more common among African American and Hispanic individuals with AD than among whites with AD (Ownby et al., 2010). Ethnic and racial differences persisted in multivariable mixed-effects regression models that controlled for patient cognitive and functional status, age, sex, and depression, as well as caregiver sex and depression. In a study in Seattle, Washington, being African American was significantly associated with affective symptoms, anxiety, and sleep disturbances after dementia severity, age, sex, and education were controlled for (Chen, Borson, & Scanlan, 2000).

Evidence comparing agitation behaviors in Taiwanese, Italian, and US dementia populations also exists (Fuh et al., 2002). Taiwanese individuals experienced more frequent hallucinations than the other two groups, and Italian patients experienced more apathy than either the Taiwanese or American participants, with agitation and disease severity controlled for. Further evidence from cross-cultural studies in China and the United States shows that Chinese people with AD have higher rates of anxiety and delusions, whereas white US residents have higher rates of appetite changes and apathy (Chow et al., 2002). These results point to influences of culture rather than innate neuropathological factors, further validating the importance of context in disparities research (Fuh et al., 2002).

Participation in Research Studies

Medical research to test disease-altering drugs and other interventions is an important component of the effort to reduce the burden of the disease. Minorities are underrepresented in clinical trials and other medical research studies (Cooper, Tandy, Balamurali, & Livingston, 2010; Wendler et al., 2006). Some researchers attribute this underrepresentation to a higher level of comorbidity among minorities (disqualifying them from participating), as well as language requirements (many clinical trials require

English fluency) (Cooper et al., 2010). Others believe that past abuses, such as the Tuskegee syphilis study, have soured the relationship between researchers and racial and ethnic minorities (Wendler et al., 2006). This belief is reinforced by evidence from focus groups with African Americans with AD and their caregivers (Connell, Shaw, Holmes, & Foster, 2001; Lambe, Cantwell, Islam, Horvath, & Jefferson, 2011).

In a study of 3,470 older adults with possible or probable AD who were selected on the basis of their potential eligibility to participate in one of two clinical trials, less than 8 percent qualified; most (60 percent) were disqualified because of major behavioral problems. Black and Hispanic adults were less likely than whites to qualify for inclusion (Schneider, Olin, Lyness, & Chui, 1997).

A 2006 review of the literature found that the underrepresentation of minorities in clinical research was not related to a lower consent rate, with no clear directionality or patterns (Wendler et al., 2006). The authors concluded that willingness to enroll in research studies is more a function of the characteristics of individual studies than of racial or ethnic attitudes as a whole. Examples of factors other than willingness to participate that may be important in determining multiethnic participation include the choice of study site and proximity of research locations to places where minorities live and work; recruitment disparities, such as differences in knowledge about trials and invitations to participate; language barriers; and other barriers to participation, such as child or elder care and travel expenses.

A qualitative study to investigate barriers to participation in clinical research among Latinos found that Latinos often do not meet clinical trial eligibility guidelines because of underdiagnosis; many studies require participants to have a physician's diagnosis of AD to participate. Underdiagnosis stemmed from several factors, including a perception of AD-related symptoms as a natural part of aging, barriers to access, and a lack of information about AD and available services. In addition, many caregivers may also be overburdened, making participating in a research study too onerous (Gelman, 2010).

Use of Long-Term Services and Supports and Other Health Services Utilization

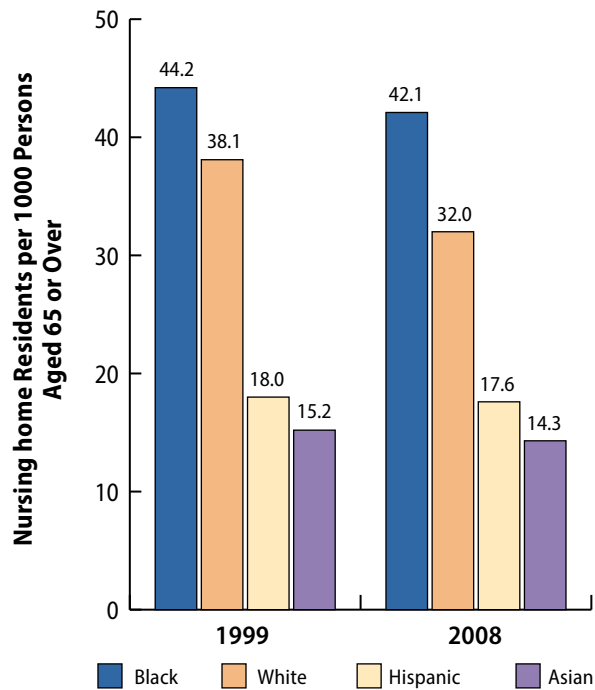
AD is associated with a substantial burden in terms of negative health events, such as infections and falls, as well as hospitalizations, institutionalization, and use of psychotropic medications (Malone et al., 2009). In a large, three-state study, Gilligan, Malone, Warholak, and Armstrong (2013a) found that, after controlling for demographics and pharmacotherapy exposure, African-American Medicaid beneficiaries with dementia were significantly more likely than their white counterparts to be hospitalized.

Approximately 40 percent of persons who died in a nursing home from 1999 through 2006 had dementia (22 percent with mild to moderately severe dementia and 20 percent with advanced dementia) (Miller, Lima, & Mitchell, 2010). Historically, disparities in access to nursing homes and other formal long-term care services contributed to lower rates of use of such services by elderly members of minority groups than by elderly whites (Belgrave, Wykle, & Choi, 1993). However, as nursing home occupancy rates have declined in most markets, and assisted living and other home- and community-based options have proliferated, access to nursing home care may now be less of a problem for elderly minorities (Feng, Fennell, Tyler, Clark, & Mor, 2011).

In both 1999 and 2008, rates of nursing home residency per 1,000 persons aged 65 or older were highest among blacks, followed by whites, Hispanics, and Asians (Figure 3). From 1999 through 2008, the absolute number of elderly Hispanics and Asians living in US nursing homes grew by 55 percent and 54 percent, respectively, while the number of elderly black residents increased 11 percent (Feng et al., 2011). During the same period, the number of white nursing home residents declined by 10 percent. However, on a population basis, the rates per 1,000 persons declined in all four groups (Figure 3).

A meta-analysis of seven studies showed that, in the United States, minorities were 40 percent less likely than whites to enter a long-term care facility (Cooper et al., 2010). Insurance status, poverty, level of impairment (e.g., activities of daily living, instrumental activities of daily living, and gait), and social support/caregiver willingness to provide care

Figure 3. Nursing home residents per 1,000 persons aged 65 or over by race or ethnicity, 1999 and 2008



were the main determinants of institutionalization in that study. More recently, Gilligan and colleagues (2013a) found that nonwhite dually eligible beneficiaries (Medicaid/Medicare) with AD in Florida, New Jersey, and New York were significantly less likely than their white counterparts to be institutionalized.

A study of 215 individuals with dementia in Alabama (of which 37 percent were African American) found that whites were placed in nursing homes at nearly 2.5 times the rate of African Americans (Stevens et al., 2004). The authors observed that, in addition to race, family socioeconomic status and care recipient age were also significant predictors of time to nursing home placement (Stevens et al., 2004). In contrast, a study in Maryland of 2,285 persons newly admitted to nursing homes found that African Americans were significantly more likely to have dementia than were whites (77 percent and 57 percent, respectively) (Weintraub et al., 2000).

Although minority use of nursing homes has grown in recent years, evidence shows that they tend to live in lower-quality facilities. For example, a national study of 516,082 nursing home residents found

that residents in facilities with a higher proportion of African Americans had higher odds of being hospitalized, a possible marker of poor quality (Gruneir, Miller, Feng, Intrator, & Mor, 2008). In another study, nonwhites residing in nursing homes were 4.3 percentage points less likely than whites to receive special dementia care services, which was attributed to the fact that more nonwhites lived in facilities that were less likely to have special dementia care services or dementia care units (Sengupta, Decker, Harris-Kojetin, & Jones, 2012).

Although nursing home use by people with dementia is important, the long-term services and supports system is increasingly oriented toward home and community-based services. A meta-analysis of seven studies found that the use of community social services did not differ by race or ethnicity after controlling for dementia severity and socioeconomic status (Cooper et al., 2010). However, in their study of respite care provided through the Administration on Aging-funded Alzheimer's Disease Demonstration Grants to States program, Montgomery and colleagues (2001) found that use patterns differed by racial and ethnic groups. For example, blacks tended to use small amounts of care for a longer period of time, whereas Hispanics used a lot of care for a shorter period of time.

A recent systematic review of 20 studies on ethnic and racial disparities at the end of life among people with dementia found that attitudes toward end-of-life care were similar in different ethnic and racial groups, but evidence on hospice use was conflicting. Artificial nutrition and other life-sustaining treatments (such as intensive care unit use and mechanical ventilation) were more frequently used, and decisions to withhold treatment less common, among African Americans and Asians (Connolly, Sampson, & Purandare, 2012). Additionally, the use of percutaneous endoscopic gastrostomy tube feeding, which is discouraged by physicians and lacks evidence of its benefits, is more commonly used for African Americans than for whites (Braun et al., 2005).

Finally, African-American older people are less likely than their white counterparts to be referred for psychiatric evaluations, which may indicate undertreatment, differences in help-seeking

behaviors, or both (Leo, Narayan, Sherry, Michalek, & Pollock, 1997).

Use of Medications

Multiple studies have shown that whites are generally more likely than nonwhites to be prescribed acetylcholinesterase inhibitors (AChEIs) and other dementia medications. A meta-analysis and literature review by Cooper and colleagues (2010) that pooled the results of three studies found that African Americans were 30 percent less likely to be prescribed AChEIs than whites, whereas Hispanics had a likelihood of prescriptions similar to that of whites. Three other studies of medication use by race and ethnicity that were not included in the above meta-analysis also found that African Americans were less likely to use or to be prescribed dementia medications (Gruber-Baldini, Stuart, Zuckerman, Simoni-Wastila, & Miller, 2007; Hernandez, McClendon, Zhou, Sachs, & Lerner, 2010; McClendon, Hernandez, Smyth, & Lerner, 2009). One analysis of data using the 2000 to 2002 Medicare Current Beneficiary Survey found the opposite: community-dwelling African-American and Hispanic Medicare beneficiaries were more likely to be prescribed one type of AChEI, donepezil (Aricept), than were whites (Perryman, Lewis, & Rivers, 2009). In an analysis of four states' Medicaid populations, Gilligan, Malone, Warholak, and Armstrong (2012) found significant disparities in medication use (AChEIs and memantine) between Hispanics and non-Hispanics in Florida and California, with greater use in Hispanics. However, in New York, non-Hispanics had greater use than Hispanics. Zuckerman and colleagues (2008) found that even after they adjusted for socioeconomic status, health care access and utilization, demographics, and other confounding variables, disparities in the utilization of antidementia medications persisted between non-Hispanic whites and other minority groups, with whites having a 30 percent higher usage rate. Specifically, these disparities persisted for blacks and non-Hispanic others, but diminished among Hispanics when these control variables were accounted for (Zuckerman et al., 2008). Although African Americans are often less likely to be prescribed medications, there is evidence that antidementia medications such as donepezil are safe and moderately effective for African-American and Hispanic patients with mild to moderate AD

(Griffith, Lichtenberg, Goldman, & Payne-Parrish, 2006; Lopez et al., 2008).

Among dementia patients with depression, access to and use of antidepressant medication also varies by race. Whites are more likely than nonwhites to be given antidepressant medications. Depression screening has been shown to significantly increase the number of nonwhite depressed dementia patients receiving antidepressant medications (Cohen, Hyland, & Kimhy, 2003).

Studies have also documented racial differences in medication adherence among white, black, and Hispanic dementia patients. Poon, Lal, Ford, and Braun (2009) found that African-American patients were less likely than whites to adhere to their medication regimens, except when prescribed angiotensin receptor blockers and diuretics. Hispanic participants also had lower adherence rates than whites for two medication classes: calcium-channel blockers and angiotensin-converting enzyme (ACE) inhibitors. The study also found disparities in the numbers and types of medications prescribed to these two racial groups. African Americans were less likely than whites to receive prescriptions in five different classes, and Hispanic participants were less likely than whites to be prescribed medications in six different classes. Although this study indicates less medication adherence among nonwhites, developing better strategies to support medication compliance (rather than not prescribing) may lead to better health outcomes within these groups.

Health Care Expenditures

Published literature on disparities in expenditures for health care and long-term services and supports is very sparse. We found only two peer-reviewed studies; one used data from the early 1990s, and the other used Medicaid data from 2004. In the first, in Tennessee, blacks with vascular dementia had higher total expenditures than did whites with the same diagnosis (\$17,359 and \$12,904, respectively) (Husaini et al., 2003). In the second study, blacks had significantly higher expenditures than whites, Hispanics, and patients of other racial and ethnic backgrounds, and Hispanics and whites had significantly higher expenditures than others (Gilligan, Malone, Warholak, & Armstrong, 2013b).

In a study funded by the Alzheimer's Association, total Medicare costs were substantially higher for older African Americans and Hispanics diagnosed with AD than for whites with a similar diagnosis (Table 1). These estimates were not adjusted and therefore may be biased because of group-level differences in age, sex, and comorbidity burden.

Harrow and colleagues (2004) have reported that the estimated costs of informal care (services provided by families and friends) are substantially higher than the costs of formal care (services provided by agencies such as home health aides, visiting nurses, and meal deliveries). This finding suggests that minority populations, who often depend more on informal care, may experience an even greater burden associated with dementia when the indirect costs of caregiving are taken into account.

Caregiving

Dementia care is influenced by all the members of what may be termed the “health care triad”—physicians and other clinicians, caregivers, and people with dementia (Fortinsky, 2001). The caregiver role is often assumed by an adult child, friend, or other family member in black families and

by an adult daughter in Hispanic families (Janevic & Connell, 2001). However, the concept of the “primary caregiver” may not be equally applicable in all cultures; interventions that are aimed at the family, rather than just the primary caregiver, may be more culturally appropriate in some cases (Janevic & Connell, 2001). For example, Korean and Korean-American caregivers are less likely to be spouses and more likely to be other family members (Janevic & Connell, 2001).

In a 2010 survey conducted on behalf of the Alzheimer's Association, 70 percent of AD caregivers were white, 15 percent were African American, 12 percent were Hispanic, 1 percent were Asian American, and 2 percent were from other ethnic groups (Alzheimer's Association, 2012). Compared with caregivers of other races, African-American and Hispanic caregivers were more likely to be single/never married and more likely to have incomes of less than \$50,000 per year. Asian-American caregivers were as likely to be male as female, in contrast to caregivers of other races, who were predominantly female. Asian-American caregivers were more likely to be highly educated.

Table 1. Use of and Medicare payments for health care services among Medicare beneficiaries with a dementia diagnosis, by race or ethnicity, 2006

	Overall	White	African American	Hispanic
Total mean Medicare payment per beneficiary	\$15,333	\$14,498	\$21,044	\$19,933
Mean Medicare payment for hospital care per beneficiary	\$4,964	\$4,563	\$7,687	\$6,632
Mean hospital discharges per 1,000 beneficiaries	660	632	887	731
Mean number of hospital days per beneficiary	4.2	3.9	6.4	5.2
Mean Medicare payment for physician visits per beneficiary	\$1,018	\$956	\$1,390	\$1,411
Mean number of physician visits per beneficiary	12.7	12.1	16.4	17.1
Mean Medicare payment for home health care per beneficiary	\$1,118	\$1,025	\$1,591	\$2,453
Percentage of beneficiaries with at least one home health claim	18.8%	18.2%	22.1%	25.9%
Mean Medicare payment for hospice per beneficiary	\$1,732	\$1,789	\$1,514	\$1,225
Percentage of beneficiaries with at least one hospice claim	13.7%	14.2%	11.3%	8.8%

Source: Adapted from Alzheimer's Association (2011).

Compared with non-Hispanic whites, Mexican-American caregivers of persons with dementia report greater distress, poorer self-rated health, more somatic complaints, and increased levels of sensitivity to patient problem behaviors (Harwood & Ownby, 2000). Similarly, depression is more common in Hispanic family caregivers than in whites (Janevic & Connell, 2001). In a review of the literature, 7 studies found evidence of worse mental health among Hispanic caregivers than among whites, whereas among African-American caregivers, 11 studies found evidence of better mental health compared with whites (Napoles, Chadiha, Eversley, & Moreno-John, 2010).

Some studies of caregiving interventions for people with dementia suggest that African Americans find some aspects of caregiving less stressful and get more emotional benefit from the experience than do whites (Janevic & Connell, 2001). For example, in the Resources for Enhancing Alzheimer's Caregiver Health (REACH) study, African Americans had higher scores than whites on the Positive Aspects of Caregiving scale and lower anxiety and fewer feelings of bother by the care recipient's behavior (Roff et al., 2004). In some cultures, caregiving is more expected, which may be protective against stress. Baseline differences between groups in psychological distress may account for differences in the impact of AD on caregivers (Janevic & Connell, 2001).

African-American and white caregivers have notable differences in coping mechanisms, as well as in monetary costs and time commitments (Kosberg, Kaufman, Burgio, Leeper, & Sun, 2007). White caregivers are more likely to cope by relying on humor and acceptance, whereas African-American caregivers reportedly rely more on religion and denial to maneuver through the caregiving experience. Additionally, white caregivers experience less financial burden, and African-American caregivers contribute more time to caring for the care recipient (Kosberg et al., 2007).

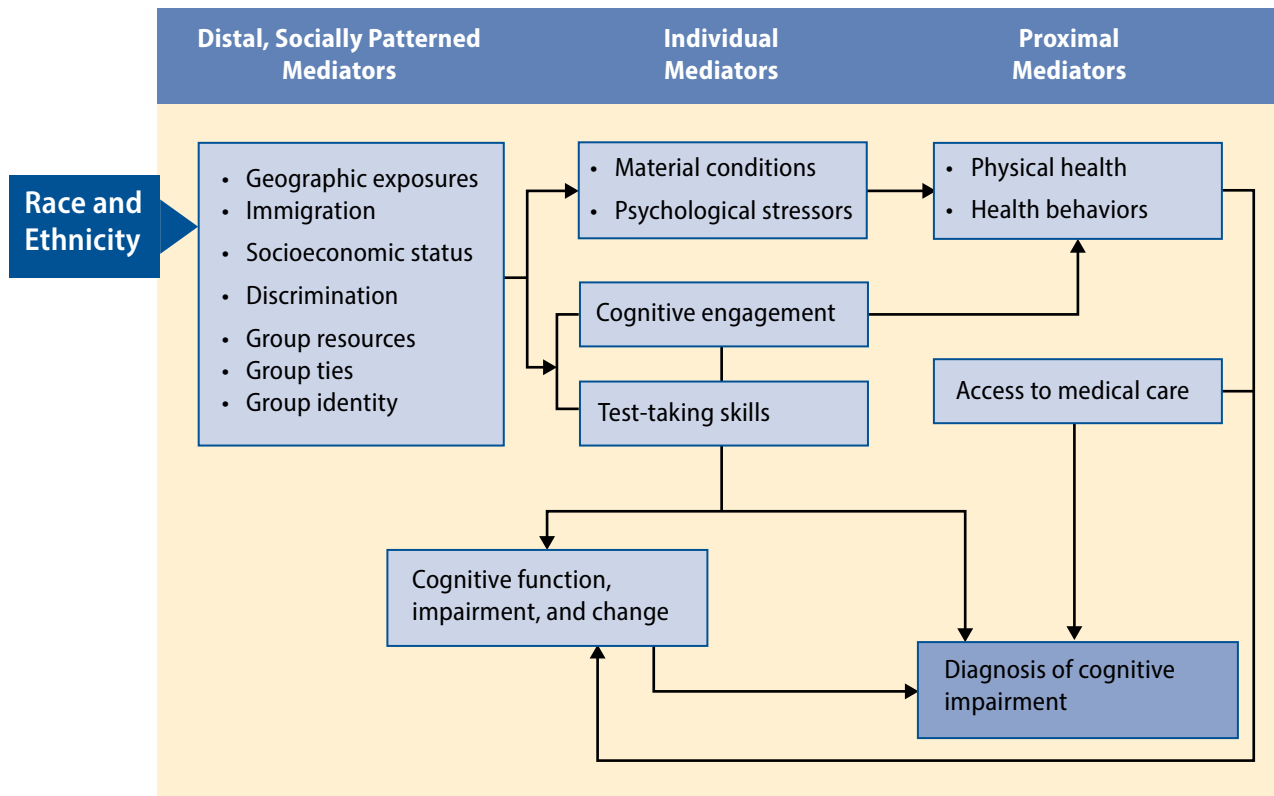
Evidence on the psychological impact of caregiving on African-American and white caregivers is inconsistent. For example, Knight, Longmire, Dave, Kim, and David (2007) found no differences in mental and physical health between African-American and white caregivers caring for people with dementia. Any identified differences in physical health, such as higher blood pressure in African Americans, were attributed to group-specific behaviors and not to caregiver status (Knight et al., 2007). Conversely, Williams found that African-American caregivers reported high levels of depressive symptoms when caring for AD patients with memory and behavioral difficulties, whereas this association was not found for white caregivers (Williams, 2005). More generally, perceived and received social support, time for leisurely activities, and other psychosocial experiences are inversely related to depressive symptomology, indicating that context, perception, and lived social experiences influence caregiver health.

Disparities also exist in how caregivers respond to depressive symptoms, with African-American caregivers being less likely than their white counterparts to use antidepressant and anti-anxiety medications (Sleath, Thorpe, Landerman, Doyle, & Clipp, 2005).

Possible Reasons for Racial and Ethnic Disparities

Possible reasons for racial and ethnic disparities include factors related to measurement of AD, genetics, the prevalence of cardiovascular and cerebrovascular diseases, socioeconomic factors, cultural differences, and racial and ethnic discrimination. Several pathways, some of which have implications for disparities, link race and ethnicity with cognitive impairment (Figure 4) (Glymour & Manly, 2008). In this section, we describe the evidence underlying selected factors, mediators, and pathways associated with disparities in this population.

Figure 4. Pathways linking race and ethnicity to cognitive impairment



Source: Adapted from Glymour and Manly (2008).

Factors Related to Measurement of Alzheimer's Disease Prevalence and Incidence

The higher prevalence rates for community-dwelling African Americans than for whites that were found in many studies may be partially attributable to the measurement of disease prevalence and incidence. For example, the lower institutionalization rates among African Americans in the past left more people with dementia in the community, whereas similar white individuals were in nursing homes (Froehlich et al., 2001). The institutionalization rate of people with dementia would affect estimated prevalence rates because most studies are of the community-based population.

The effects of education on cognitive test results, as well as cultural differences in how cognitive impairment is perceived and reported, are likely to affect prevalence estimates substantially (Chin, Negash, & Hamilton, 2011). The number of years

of education may not be equivalent between racial and ethnic groups because of disparities in school quality, particularly in older cohorts. Therefore, even prevalence studies that control for education may not be able to adequately adjust for differences in educational quality (Glymour & Manly, 2008).

Cognitive testing instruments—including the most widely used instrument, the MMSE—perform differently among individuals of different educational levels and racial and ethnic groups (Chin et al., 2011; Teresi et al., 2002). Instrument bias can result from lower literacy and education, lack of test-taking experience and stress related to test taking, varying degrees of acculturation, and language issues such as poor translation. In addition, Froehlich et al. (2001) note that greater score variability within African Americans on standard cognitive tests makes establishing cutpoints for abnormal results difficult.

Minorities seeking care are often more impaired at the time of their diagnosis, which suggests that they may be accessing services later in the disease process (Cooper et al., 2010), although some researchers have found no significant differences between ethnic and racial groups in the delay between symptom onset and diagnosis (Livney et al., 2011). Several factors can delay seeking of treatment, including caregivers' lack of knowledge about when to seek treatment; lack of effective treatments; and interactions between patients, families, and caregivers (Boise, Camicioli, Morgan, Rose, & Congleton, 1999). Some community physicians may be reluctant to diagnose AD because of inadequate reimbursement for evaluation and management, lack of time to provide appropriate follow-up care, lack of knowledge of when and to whom to refer, lack of information about diagnostic criteria, cultural resistance, belief that there is no treatment, and perceived lack of importance to diagnose the disease (Boise et al., 1999). Anecdotally, this reluctance is more prevalent in minority communities (National Institute on Aging, 2010). Moreover, one study shows some evidence that caregivers of black elders with cognitive impairment report less cognitive decline in the care receiver than do their white peers, despite no significant differences in impairment, suggesting that black caregivers may perceive cognitive changes differently (Rovner, Casten, Arenson, Salzman, & Kornsey, 2012).

Issues of cultural framework, perception, and understanding of disability are important when interpreting scales that include items with different cultural connotations. Diagnosis is clearly problematic when physicians and patients do not speak the same language or do not share the same cultural perspective (Borson, Scanlan, Watanabe, Tu, & Lessig, 2006). Moreover, some diagnostic instruments also contain items that may have different implications for various ethnic and racial groups. For example, a hangman's noose, one of the items on the Boston Naming Test, may have very different implications for elderly African Americans than for white respondents (Jett, 2006).

Genetics

Recent advances in our understanding of the human genome have uncovered a number of genetic risk factors for dementia. Apolipoprotein E (APOE) is a gene that comes in a normal or neutral form (allele), known as E3, and two variants, E2 and E4, which have been implicated in vascular and Alzheimer's dementias. The E4 variant is the most important known genetic risk factor for AD, although the majority of the population does not carry the allele.

In a recent review and meta-analysis, E4 has been shown to be associated with about 65 to 75 percent of cases of non-Mendelian-inherited AD and up to 20 percent of all dementias (Crean et al., 2011). The meta-analysis found that 39 percent of AD patients from Asian countries carried the APOE4 allele, as did 43 percent of patients from southern Europe and the Mediterranean, 54 percent from central Europe, 59 percent from North America, and 64 percent from northern Europe.

Having one or two E4 alleles or forms of the APOE gene is a major predictor of AD, although the evidence is somewhat inconsistent for African Americans (Chin et al., 2011; Crean et al., 2011; Graff-Radford et al., 2002; Logue et al., 2011; Tang et al., 1996). The E4 allele is associated with increased risk of AD among African Americans, but not among Yoruba (Hendrie et al., 2006). According to an earlier meta-analysis, the prevalence of E4 among those with AD was highest in whites (37 percent), followed by African Americans (32 percent), Japanese (28 percent), and Hispanics (19 percent) (Farrer et al., 1997). A recent case-control study found that, compared to the E3/E3 genotype, the E4/E4 genotype is associated with 8-fold higher odds of AD, whereas having the E2/E2 or E2/E3 genotype is protective and having either the E2/E4 or E3/E4 genotype is associated with a smaller, but still significant, increase in odds of 2.1 (Logue et al., 2011). Other genetic studies have found that the E4/E4 genotype is more likely to be associated with dementia in African Americans than in whites (Maestre et al., 1995). Green and colleagues (2002) found that the E2/E4 and E3/E4 genotypes were associated with an increased risk of AD in whites, but not in African Americans.

Other genes are also involved in development of AD. Recently, in a study using a relatively large sample ($n = 3,100$), the C9ORF72 gene was shown to be associated with AD, frontotemporal dementia, and amyotrophic lateral sclerosis among individuals of European descent, but African Americans in the sample did not have any expansions of the gene (Kohli et al., 2013). However, less than 1 percent of the sample had the genetic marker; thus, the new finding explains only a small proportion of risk differences. Other recent studies have proposed several novel candidate genes as having a role in AD pathogenesis, including *PROX1* (OMIM *601546) and *CNTNAP2* (OMIM *604569), as well as *ABCA7*, *CR1*, *BINI*, *EPHA1*, *TREM2*, *SORL1*, and *CD33* (Reitz et al., 2013).

A potential marker for AD risk, the Saitohin gene, has been investigated, but subsequent studies have found no significant differences in genotype or allele frequency in whites, African Americans, or Hispanics (Clark et al., 2003).

AD occurrence is clustered within families, with ethnic and racial differences noted in the degree of familial clustering. In a New York study of 435 people with probable or possible AD and 1,577 siblings and parents, the lifetime risk of AD in relatives of people with AD was 26 percent and was 19 percent in relatives of controls. The risk of AD was significantly higher among relatives for whites and Hispanics, but it was not statistically significant in African Americans (Devi et al., 2000).

Cardiovascular and Cerebrovascular Disease and Other Comorbidities

Vascular factors and conditions that may be associated with cognitive decline and dementia include stroke, diabetes, hypertension, congestive heart failure, high fat intake, high cholesterol, smoking, alcohol misuse, atrial fibrillation, low folate, and obesity (Glymour & Manly, 2008). Although no definitive evidence links cardiovascular disease and AD, several studies have found associations between cognitive impairment and cardiovascular disease (Purnell, Gao, Callahan, & Hendrie, 2009).

Most of the cardiovascular disease risk factors are more common in African Americans and Hispanics (Glymour & Manly, 2008). Geographic variation in the prevalence of cardiovascular disease risk factors may be related to differences in regional dietary patterns. More than 80 percent of blacks aged 65 or over in 2000 were born in the South, and southern-born individuals have significantly higher rates of circulatory disease mortality (Glymour & Manly, 2008).

Vascular dementia accounts for a larger proportion of cases of late-onset dementias in African Americans than in whites (Froehlich et al., 2001). However, as with other dementia disorders, it is unclear whether differences in the prevalence of vascular dementia reflect true differences or are a result of measurement bias because of differences in education, socioeconomic status, or other cultural factors. One recent study found that reducing ethnic and racial disparities in the incidence of type 2 diabetes could reduce the incidence of cognitive impairment and dementia by 17 percent (Noble, Manly, Schupf, Tang, & Luchsinger, 2012). Conversely, a different study found that even when black and white patients with probable AD were matched on four variables (age at presentation to the clinic, age at AD onset, duration of illness, and MMSE scores), black patients had higher rates of hypertension than white patients, and white patients had higher rates of atrial fibrillation and cancer than black patients (Zamrini, Parrish, Parsons, & Harrell, 2004). The authors suggest that these results are a product of differences between these racial groups and are not statistical errors; however, this study did not describe differences in educational attainment, socioeconomic status, or other sociocultural factors, which may have more significant impacts on health outcomes, knowledge of preventative treatments, and health care access than race alone.

Some studies suggest that differences in AD prevalence cannot be attributed to differences in underlying cardiovascular disease rates. In one study, black AD patients had higher crude rates of hypertension than did whites, but other differences in rates of diseases (heart disease, stroke, diabetes)

were not significantly different between the groups (Hargrave, Stoeklin, Haan, & Reed, 1998). In another study, although the cumulative incidence rate of AD was twice as high among African Americans and Caribbean Hispanics, the presence of cardiovascular or cerebrovascular disease did not contribute to increased risk (Tang et al., 2001). Finally, a systematic review of the English-language literature published from 2000 through 2007 concluded that hypertension and diabetes were not significantly associated with increased risk for AD, although interactions between risk factors, including APOE4 status, exercise, alcohol use, physical function, and cholesterol, modified risk for the disease (Purnell et al., 2009).

Socioeconomic Factors

Parental or early life socioeconomic position, childhood IQ, measures of early growth (such as infant head circumference and childhood height), educational attainment, occupational characteristics, and various measures of social integration have all been linked to cognitive function and neurocognitive disorders in adulthood and old age (Glymour & Manly, 2008). Individual socioeconomic position may affect cognitive status or diagnoses through (1) material conditions, (2) psychosocial conditions (such as status), (3) direct cognitive stimulation, or (4) test-taking skills (Glymour & Manly, 2008).

Geronimus, Hicken, Keene, and Bound (2006) attributed many racial and ethnic disparities in health to “weathering,” the accumulated consequences of chronic exposure to economic and social adversity. Having financial resources leads to health-enhancing conditions such as healthy housing, high-quality food, safe working conditions, and access to high-quality medical care (and the reverse is true as well). Occupation can negatively influence health through stress and material deprivation as well as through toxic work conditions (Glymour & Manly, 2008).

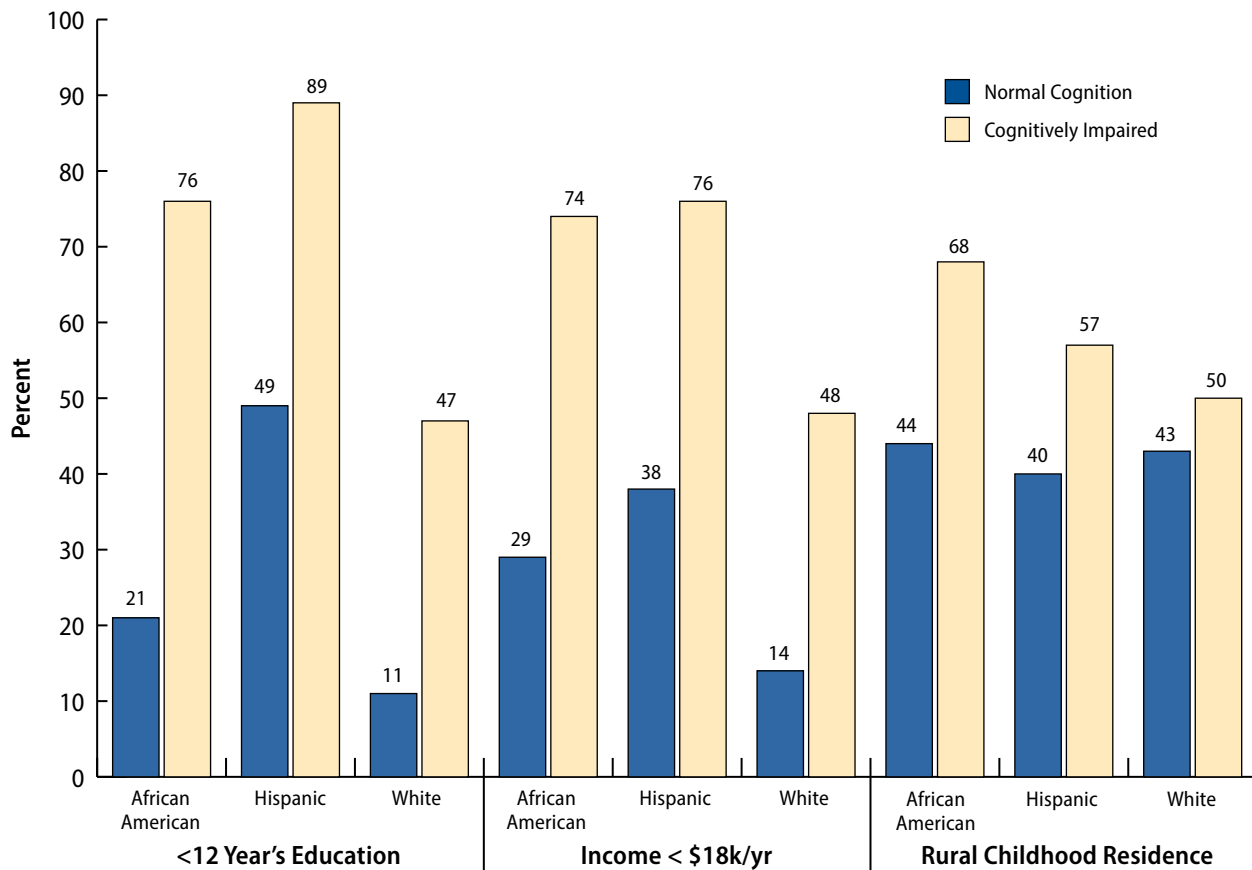
Poverty often reduces access to educational opportunities or is associated with poor-quality education, thereby increasing the likelihood of adult

poverty, which may increase the risk of depression and cognitive impairment (Glymour & Manly, 2008). If the effect of education on cognitive aging is primarily through material advantages, then credentials may be more important than the quality of the education. However, if education's effect is because of cognitive skills or engagement, then school quality is potentially more important. Resources available to parents are also very important to a child's cognitive development, and differences in parental socioeconomic status predict dementia. Extra schooling appears to have substantial benefits for memory function in the elderly (Glymour & Manly, 2008). As a protective factor, education also may work in concert with innate cognitive ability, as evidence from the Nun Study suggests that early-life linguistic ability also may be associated with lower risk of AD in later life (Riley, Snowdon, Desrosiers, & Markesbery, 2005).

Additional evidence links cognitive impairment risk with low income, less education, and having lived in a rural area (Hall, Gao, Unverzagt, & Hendrie, 2000). These socioeconomic characteristics are more common among older people with cognitive impairment, as shown in Figure 5 (Alzheimer's Association, 2011). For example, 89 percent of Hispanics aged 55 or over with cognitive impairment possess less than 12 years of education, compared with 49 percent of those with normal cognition.

Several studies have examined the effects of racial inequalities in education on long-term consequences for cognitive functioning. Lower levels of educational attainment are associated with lower levels of cognitive functioning (Sachs-Ericsson & Blazer, 2005; Zsembik & Peek, 2001). Education can mediate racial disparities in cognitive decline, but it alone does not eliminate those disparities.

Figure 5. Socioeconomic characteristics among Americans aged 55 or older by cognitive impairment and race and ethnicity, 2006 Health and Retirement Study



Cultural Differences

Culture has been defined as a group's values, beliefs, traditions, symbols, language, and social organization (Harwood & Ownby, 2000). The US model of health care, which values autonomy in medical decision making, contrasts with preferences for more family-based, physician-based, or shared physician- and family-based decision making in other cultures. Moreover, although US culture emphasizes full disclosure by clinicians, it is common for health care professionals in other countries to conceal serious diagnoses from patients because disclosure can be viewed as disrespectful, impolite, or even harmful to the patient (Searight & Gafford, 2005).

Cultural differences in how people respond to diagnoses suggest that physicians should tailor their approach to sharing diagnostic information to patient and family preferences (e.g., direct

disclosure or building expectations to disclosure) (Connell, Boise, Stuckey, Holmes, & Hudson, 2004). Organized physician training can help physicians learn techniques for communicating diagnoses in a compassionate, emotionally sensitive, and informative manner and to use the opportunity to increase knowledge and utilization of other resources and services that would support and cater to the needs of patients and their families (Connell & Gallant, 1996).

Cultural influences on African Americans that may cause disparities in treatment or access to medical care include the legacies of slavery, Jim Crow laws, and the Tuskegee syphilis study; the influence of religious beliefs on care-seeking behaviours; the use of home remedies; distrust of the medical system; being of a different or the same race as one's medical provider; and health literacy (Eiser & Ellis, 2010). Strong religious beliefs, including the belief that

illnesses can be cured or are controlled by God, may lead to delayed or forgone care. Strong spirituality has been correlated with lower medication adherence and later-stage cancer diagnosis (Eiser & Ellis, 2010). Similarly, some elderly African Americans and other nonwhite patients are more likely to use traditional or herbal medicines instead of, before, or alongside allopathic medicines.

Many individuals and cultures perceive dementia-related symptoms as a natural part of aging (Ayalon & Arean, 2004; Chow et al., 2002; Eiser & Ellis, 2010; Gelman, 2010; Gray, Jimenez, Cucciare, Tong, & Gallagher-Thompson, 2009; Jett, 2006). For example, Gray et al. (2009) asked participants whether the following statement is true: "Significant loss of memory/mental ability, commonly known as senility, is a normal part of aging." Of whites, 23 percent agreed, compared with 55 percent of Hispanics and 33 percent of Chinese. A 2004 study used a similar sentence: "Alzheimer's disease is a normal process of aging, like graying of hair or wrinkles" (Ayalon & Arean, 2004). In this study, 66 percent of whites, 50 percent of African Americans, 24 percent of Latinos, and 17 percent of Asians agreed with the statement. Individuals who perceive memory loss as a natural part of aging may be more likely to overlook behavioral and cognitive symptoms of dementia and thus less likely to seek medical care. In addition to delaying medical care, minority groups tend to experience other barriers, including less knowledge about dementia and less access to health services (Sayegh & Knight, 2013).

Studies have been conducted to understand differences in beliefs, knowledge, and perceptions about AD across different racial and ethnic groups. One study found that, after controlling for education, having a family member with AD, medical comorbidity, and other variables, (1) black participants were more likely than their white counterparts to identify genetics as a risk factor for AD; (2) both blacks and Latinos were more likely than whites to identify stress as a risk factor for AD; and (3) Latinos were least likely to identify mental activity as a preventive factor for AD (Ayalon, 2013). Another study found that black participants' perceived risk of AD is lower than non-Hispanic whites' perceived risk of AD (Chung, Mehta,

Shumway, Alvidrez, & Perez-Stable, 2009). Other differences between black and non-Hispanic whites' beliefs about AD include differences in the level of factual knowledge about AD, number of information sources, belief about putative causes, and concerns about developing the disease (Connell, Scott Roberts, McLaughlin, & Akinleye, 2009; Roberts et al., 2003). Despite these differences, blacks and whites share similarities in their understanding of treatment effectiveness and recognition of common AD symptoms (Roberts et al., 2003).

Lack of accurate knowledge and information about AD significantly limits opportunities for care that meets the needs of caregivers and care recipients. Latino caregivers often prefer family-based care, and they may not identify external services as necessary to support their caregiver roles; however, they do identify lack of knowledge about AD as a barrier to effective diagnosis and ongoing care for their care recipient (Neary & Mahoney, 2005). Differences in knowledge about AD and, consequently, differences in perceptions and behaviors toward AD risks and treatments are problematic because they have the potential to negatively influence people's planning for the course of the disease.

Numerous cultural differences related to caregiving for patients with AD may also contribute to racial and ethnic disparities (Gray et al., 2009; Napoles et al., 2010). The most frequently documented cultural differences for both African-American and Hispanic caregivers compared with white caregivers are more positive views of caregiving, greater spirituality, a stronger sense of duty to family, and higher value placed on extended family networks (Napoles et al., 2010). African-American caregivers of people with AD also appear to have more social support than white caregivers. Despite receiving more social support, however, a perceived lack of that support, combined with feeling incompetent, increases stress for black caregivers, but not for whites (Cox, 1995).

Caregiver differences occur both between and within different racial and ethnic groups. Losada and colleagues compared the relationship between familism (i.e., the primacy of the family over individual interests), burden symptoms, and depressive symptoms among Hispanic caregivers

from Los Angeles, California, and Madrid, Spain (Losada et al., 2006). The results were significant and uniquely different: the association between familism and depressive symptoms was statistically significant for Spanish caregivers but not for the US caregiver population. Similarly, the association between familism and burden was significant for US caregivers but not for Spanish caregivers, pointing out the relevance of context and culture in understanding differences in caregiver health outcomes (Losada et al., 2006).

Research focused on Asian-American caregivers is more limited, but evidence suggests a strong sense of filial responsibility in individual family units (Napoles et al., 2010). Confucian-influenced cultures have a tradition of first-born sons and their wives being responsible for elder care (Janevic & Connell, 2001); people from these cultures also may be less likely to seek outside help in dealing with their family members because of community stigmatization of AD (Mahoney, Cloutterbuck, Neary, & Zhan, 2005).

Studies have found cultural differences in knowledge levels and beliefs about AD in the general population as well. Connell, Scott Roberts, and McLaughlin (2007) conducted a national study of white, black, and Hispanic public opinions about AD and treatment. Blacks and Hispanics were more likely to view cognitive decline and AD as a normal experience of aging and also were more optimistic about the prospects of future developments in AD treatments. Another difference was the preparedness for handling a diagnosis: Hispanic participants reported feeling equipped to navigate diagnostic disclosure situations, whereas blacks and whites did not (Connell et al., 2007).

Racial and Ethnic Discrimination

Although discrimination by clinicians against racial and ethnic minorities in the United States is commonly asserted as the cause of racial and ethnic disparities, we were unable to find any empirical studies on this topic that focused on people with AD. Indeed, few empirical studies have been conducted on this topic in health care.

A rare study of discrimination in health care used the implicit association test to assess the degree to which

implicit racial bias affected physicians' decisions on thrombosis (Green et al., 2007). A total of 287 internal and emergency medicine residents from four hospitals in Boston and Atlanta participated in an online study. Half of the physicians received information about a white patient, and the other half received the same information but were told that the patient was African American. Although physicians self-reported that they did not prefer treating one patient or the other and did not see either patient as more cooperative, the test found a preference for treating whites and the perception that African Americans were less cooperative. Similarly, Blanchard and Lurie (2004) found that minorities were more likely than whites to report being looked down upon or treated disrespectfully. Specifically, after the researchers adjusted for sex, language, income, insurance coverage, and education, 20 percent of Asians, 19 percent of Hispanics, and 14 percent of blacks reported that their medical provider treated them disrespectfully or looked down upon them, compared with 9 percent of whites.

Although not specifically about AD, the IOM's *Unequal Treatment* report (Smedley et al., 2003) identified racial bias and prejudice (conscious and unconscious) as obvious potential reasons for differences in treatment for a number of diseases. Clinicians' lack of empathy and limited contact with people of other races and ethnicities were identified as potential factors. The IOM report also cites the theory that the pressures of the health care environment can lead to clinicians stereotyping patients as a cognitive shortcut, which reduces the amount of time they need to spend with patients. Consequently, the common tendency to see the patient-clinician relationship as one of a lower-status person coming to a higher-status person for assistance, rather than a relationship between collaborators—regardless of race or ethnicity—could be a barrier to quality care (Smedley et al., 2003).

Lampléy-Dallas, Mold, and Flori (2001) conducted a study that highlighted African-American caregivers' dissatisfaction with health care services and providers. Specifically, African-American caregivers pointed to two main problem areas: (1) their interactions with physicians, in which they reported experiences of racism; and (2) the absence of social support groups

in their communities (Lampléy-Dallas et al., 2001). This study highlights the biopsychosocial impact of perceived or experienced racism and social support on long-term health consequences for caregivers and caregiver burden.

Interventions to Reduce Racial and Ethnic Disparities

In seeking to address ethnic and racial disparities, the IOM's *Unequal Treatment* report stated that matching needs to services is a more important goal than providing equal amounts of services to different groups (Smedley et al., 2003). Both undertreatment and overtreatment can be problems, and it would be undesirable to insist that all patients were equally overtreated. Instead, the goal should be the right care, delivered to the right patient, at the right time, in the right setting (Fowler, Levin, & Sepucha, 2011).

Race and ethnicity are heterogeneous factors influenced by socioeconomic status, environment, diet, education, and other external variables. Moreover, because race and ethnicity are social constructs and are not biologically defined, considerable variations exist within and among ethnic and racial groups in terms of ancestral heritage. Thus, some studies have suggested that researching differences between families with and without a history of AD may be more effective than the current racial and ethnic approach (Weiner, 2008). Although extensive evidence documents disparities among different racial and ethnic groups with AD, few studies evaluate interventions to address disparities in this population. Almost all interventions designed to explicitly address racial and ethnic disparities focus on the cultural competency of the health care provider, health system, or both. Interventions not specific to the AD population include care coordination, care management, community health workers, and culturally tailored education interventions (Quinones et al., 2011).

Cultural Competence

Cultural competency is especially important in the health care setting, where barriers to communication and access to quality care can result in delayed diagnosis, inappropriate treatment, or worse. Cultural competence involves both awareness and knowledge

about other cultures and skill in relating to people of other cultures. Cultural competence requires acknowledging that culture and ethnicity guide and affect behavior and that all people are cultural beings (Betancourt, Green, Carrillo, & Ananeh-Firempong, 2003).

A culturally competent health care environment includes the following characteristics (Anderson, Scrimshaw, Fullilove, Fielding, & Normand, 2003): a culturally diverse staff that reflects the communities served; bilingual staff or interpreters for the clients' languages; culture- and language-specific training for clinicians; and signs and communication materials that are both in the clients' languages and are sensitive to cultural norms.

One example of a policy designed to address disparities at the systems level is the Culturally and Linguistically Appropriate Services standards issued in 2001 by the US Department of Health and Human Services' Office of Minority Health (2001). This policy requires certain activities, such as competent language-assistance services and signage and materials in different languages, and encourages others, such as culturally competent care and staff diversity. The general evidence for improved outcomes as a result of interpreter services is mixed, but a few studies suggest that patients with limited English proficiency who receive language assistance are more satisfied with their care and have better clinical outcomes (Smedley et al., 2003).

Cultural competence education is mandated as part of medical licensure or continuing medical education requirements in New Jersey, Washington, and California, and other states have considered similar rules (Eiser & Ellis, 2010). The accrediting authority for medical schools in the United States also has standards for cross-cultural curricula as part of undergraduate medical education (Liaison Committee on Medical Education, 2012).

Many studies of cultural competence training, not specific to AD, have found that it has a beneficial effect on the attitudes, knowledge, and skills of physicians and on patient satisfaction (Beach et al., 2005). For example, 17 of 19 studies of cultural competence training for health professionals found a beneficial effect in terms of knowledge; 21 of 25

studies found that such training improved attitudes; and 14 of 14 studies showed benefits of training in improving skills. In addition, studies have found that cultural competence training of health professionals improves patient satisfaction. No definitive evidence has yet linked this training to improved health outcomes (Beach et al., 2005; Betancourt et al., 2003). One study of counseling of black female patients showed that cultural competence improved patient adherence (Beach et al., 2005).

One of the goals of the Administration for Community Living–funded Alzheimer’s Disease Supportive Services Program is to provide or expand support services for traditionally underserved or hard-to-serve AD patients and their caregivers, especially minorities and rural residents. An Illinois grant focused on older persons who spoke Arabic, Assyrian, Bosnian, Hindi, and Urdu (Wiener & Mitchell, 2007). The grant worked with the Coalition of Limited English Speaking Elderly (CLESE), an organization representing 45 Chicago-area ethnic organizations that provide services to older people. Under the grant, CLESE organizations translated materials into the appropriate languages, identified home care clients with memory loss, made home visits to try to enroll elderly people into the program, conducted caregiver training, and trained clinicians to screen for dementia.

Four additional grants were recently described by Shuman, Yuen, Gordon, and Wiener (2014). In one project, grantees engaged Chinese and Japanese communities in Southern California and Chinese and Vietnamese communities in Northern California. Georgia’s project included a target population from 11 rural counties in central and west-south Georgia. A project in New Mexico focused on reaching veterans, particularly Hispanic and American Indian families. South Carolina’s project targeted primarily the African-American rural population in the southeastern part of the state. Several common themes emerged from all four grantees: recognizing cultural and community-specific norms, building trusting relationships, finding a local champion, tailoring services to suit the needs of the community, and using outreach strategies that are meaningful to the community (Shuman et al., 2014).

A systematic review of interventions focused on caregivers of persons with AD and related disorders found 18 studies that reported outcomes by caregiver ethnicity, of which 11 considered cultural factors in their design. Eight of these 11 studies were from the Resources for Enhancing Alzheimer’s Caregiver Health (REACH) initiative (Napoles et al., 2010). Cultural tailoring addressed familism, language, bicultural and bilingual staffing, health literacy, the need for advocacy, protecting elders, and logistical barriers.

Quality of care is related to cultural competence and diversity among health care providers (Daker-White, Beattie, Gilliard, & Means, 2002). When service providers are matched to dementia clients according to ethnicity and language, patient outcomes may be improved (Braun & Browne, 1998). Similarly, training staff in cultural awareness and sensitivity and conducting language-appropriate cognitive testing may help address some disparities (Daker-White et al., 2002).

Caregiver interventions may be more effective when delivered by staff who are bilingual and bicultural (Napoles et al., 2010). For example, the REACH and REACH II projects—multisite studies to evaluate culturally tailored interventions—were effective at reducing depression and improving quality of life among caregivers (Belle et al., 2006). Among REACH’s strengths are the tailoring of the intervention materials to individual caregivers and the involvement of bilingual and bicultural staff. Another study focusing on REACH participants, however, found inconclusive evidence for the association between racial concordance and caregiver participation rates or outcomes (McGinnis, Schulz, Stone, Klinger, & Mercurio, 2006). In that setting, racial concordance between caregivers and interventionists had no impact on caregiver participation rates, caregiver depression rates, or caregiver burden. The study reported that African-American caregivers who interacted with African-American interventionists had decreased rates of depression, but the finding was statistically inconclusive because the study only included two African-American interventionists (McGinnis et al., 2006).

Outreach to Minority Communities

Another approach to addressing disparities involves targeting programs and outreach to minority populations. The Alzheimer's Disease Demonstration Grants to States program provided demonstration grants to Florida, Kentucky, and Washington, DC, that focused on African Americans (Wiener & Mitchell, 2007). For example, in Washington, DC, the intervention focused on educational efforts conducted within church communities. The communities also held awareness events and developed caregiver respite programs. More recently, several of the current Alzheimer's Disease Supportive Services Program grantees, including South Carolina, California, Florida, North Carolina, and Puerto Rico, are targeting individuals in diverse ethnic and racial groups.

Another intervention aimed at reaching minority populations is the Alzheimer's Disease Research Center Satellite Diagnostic and Treatment Clinics program (National Institute on Aging, 2010). Begun in 1990, the program established satellite clinics linked with 1 of 30 existing Alzheimer's Disease Centers. In recent years, satellite clinics have been established on the Choctaw Nation reservation, in Harlem, at Grady Hospital in Atlanta, and in St. Louis. The Alzheimer's Disease Centers are actively involved in formulating strategies and plans to recruit diverse populations to their clinics, including for participation in clinical trials. Successful strategies include improved patient coordination and personal attention, home visits, and support groups (National Institute on Aging, 2010).

Changes in Screening Practices and Policies

Using "culture-blind" cognitive screening tests can significantly improve detection rates and consequently can support early intervention for people with dementia. The Mini-Cog, a short screening tool for dementia, was created to assist

primary care physicians in detecting dementia in a timely and accurate manner (Borson et al., 2006). This tool also is meant to address physicians' difficulties in identifying dementia because of sociodemographic factors and other patient-specific characteristics. Results show that the Mini-Cog successfully identified 84 percent of cognitively impaired subjects. Physicians who did not use the Mini-Cog identified 41 percent of cognitively impaired subjects. Factors such as low education levels, low literacy levels, language barriers, non-Alzheimer type dementia, and ethnic differences did not affect the performance of the Mini-Cog (Borson et al., 2006).

Discussion and Conclusions

This paper reviews the research literature on ethnic and racial disparities among individuals with AD. The current literature shows consistent and adverse disparities among blacks and Hispanics compared with non-Hispanic whites in the following areas: the prevalence and incidence of AD, mortality, participation in clinical trials, use of medications and other interventions, use of long-term services and supports, health care expenditures, quality of care, and caregivers.

The reasons for these disparities are not well understood, but they include possible genetic differences, prevalence of other diseases that may increase the risk of AD, higher rates of poverty, lower levels of education, and experiences of racial and ethnic discrimination. In addition, differences in service use and expenditures may be related to cultural differences and racial and ethnic discrimination. Although these disparities are well known, little is known about the effectiveness of various strategies, such as cultural competence training, to address these differences within the context of AD, with almost no studies available that evaluate possible interventions.

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