



U.S. Department of Health and Human Services  
Assistant Secretary for Planning and Evaluation  
Office of Disability, Aging and Long-Term Care Policy

# **RACIAL AND ETHNIC DISPARITIES IN ALZHEIMER'S DISEASE: A LITERATURE REVIEW**

February 2014

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# **RACIAL AND ETHNIC DISPARITIES IN ALZHEIMER'S DISEASE: A Literature Review**

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## ABSTRACT

This study aimed to describe and characterize the published literature on disparities between racial and ethnic groups among individuals with Alzheimer's disease and related dementias. To identify relevant studies, we searched electronic sources for peer-reviewed articles and research reports published through 2014 related to the Alzheimer's population and their caregivers that 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 to non-Hispanic Whites in the prevalence and incidence of Alzheimer's disease, 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 providers, 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 within the context of Alzheimer's disease, with almost no studies available that evaluate possible interventions.

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## ACRONYMS

The following acronyms are mentioned in this report.

AChEI	Acetylcholinesterase Inhibitors
APOE	Apolipoprotein E E3 is the normal/neutral form; E2 and E4 are variants
CLESE	Coalition of Limited English Speaking Elderly
ICU	Intensive Care Unit
IOM	Institute of Medicine
IQ	Intelligence Quotient
MeSH	Medical Subject Heading
MMSE	Mini-Mental Status Examination
REACH	Resources for Enhancing Alzheimer's Caregiver Health

# INTRODUCTION

Existing evidence for Alzheimer's disease and related dementias suggests that there are significant differences in prevalence, incidence, treatment, and mortality of Alzheimer's disease across racial and ethnic groups. There are also substantial differences in participation in clinical trials, the 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 an ethical and policy perspective. In an ideal world, the burden of disease and access to services would not vary based on a person's race or ethnic background.

As the population ages and minorities become a higher proportion of the older population, a higher percentage of people with Alzheimer's disease will be minorities. Among the population aged 85 and older, which is the age group most likely to have Alzheimer's disease, the proportion of the population that is White is projected to decline from 90% in 2010 to 81% in 2050 (Vincent & Velkoff, 2010). The proportion of the 85 and older population that is non-Hispanic White is projected to decline from 85% in 2010 to 67% in 2050. During the same time period, the proportion of the population aged 85 and older that is Hispanic is projected to increase from 5% to 15%.

This research report describes evidence from the literature of racial and ethnic disparities in Alzheimer's disease, explores possible reasons for these disparities, and reviews interventions that have attempted to reduce disparities in this population.



## METHODS

To identify relevant studies, we searched PubMed, Google Scholar, and our in-house electronic library for peer-reviewed articles and research reports published in English through 2014 related to the Alzheimer's population and their caregivers. We also searched the Internet for gray literature using similar search terms. We included studies and reports that provided evidence of racial and ethnic disparities, discussed reasons for disparities, or described interventions to address disparities, including other reviews, books, government and non-profit research reports, and research studies published in peer-reviewed journals. 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 Alzheimer's disease and dementia ("dementia" OR "alzheimer disease" OR "cognitive impairment"). Journal articles were required to have an abstract and pertain to human subjects. Our initial search located 151 article abstracts. After excluding articles that were clearly irrelevant based on their title or abstract, we reviewed the full texts of 35 refereed articles and 15 other sources (books, reports, web pages, etc.).

# EVIDENCE OF RACIAL AND ETHNIC DISPARITIES

## Prevalence, Incidence, and Diagnosis

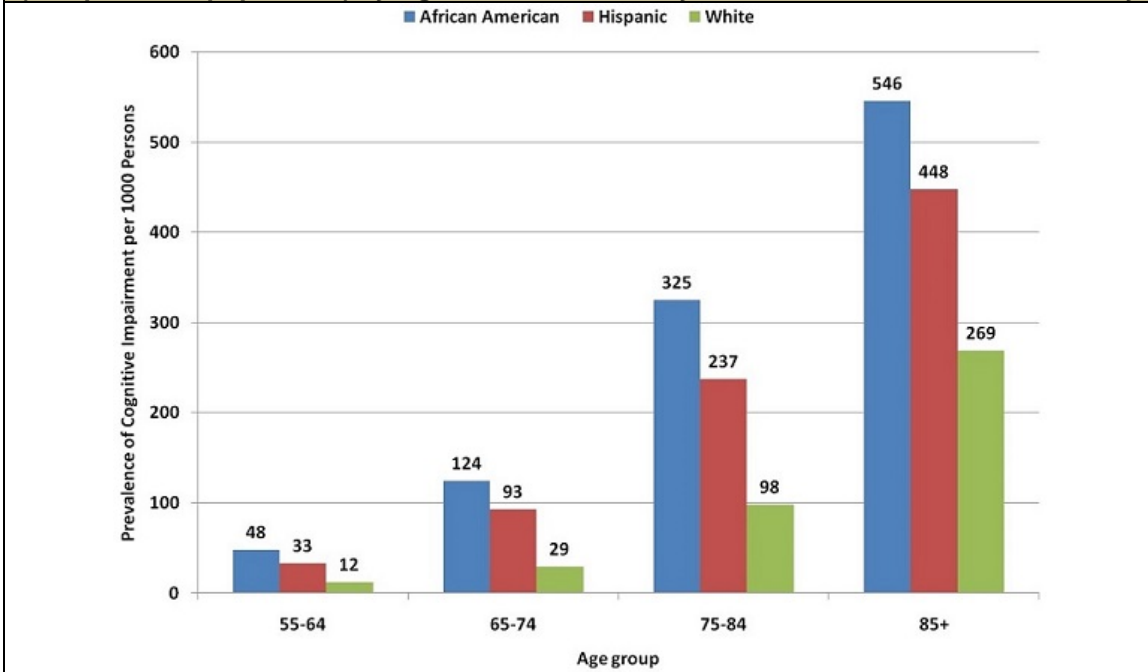
Prevalence describes the proportion of a population with a disease at a specific point in time, while incidence describes the proportion of the population that develops a disease over a specific time period. Reported Alzheimer's disease prevalence rates range from 14% to 50% higher among African Americans than among Whites (Froehlich et al., 2001). The most frequently cited estimates are that Blacks are about two times more likely than Whites to have Alzheimer's disease and Hispanics are about 1.5 times more likely than Whites to have Alzheimer's disease (Alzheimer's Association, 2011, 2014).

Prevalence studies in New Haven, Connecticut; Copiah County, Mississippi; Houston, Texas; New York, New York; the Piedmont region of North Carolina; and East Baltimore, Maryland, have all found higher rates of dementia among ethnic minority elderly--specifically African Americans and Hispanics--compared to Whites and Asians (Harwood & Ownby, 2000). Among African Americans, prevalence estimates have been as high as 56%, although rates of diagnosed disease have been more in the range of 5%-16% (Teresi et al., 2002; Gurland & Lantigua, 2002). Prevalence rates among Hispanics have been less commonly measured, but one study estimated dementia prevalence of 8% of Caribbean Latinos in the 65-74 age group, 28% in the 75-84 age group, and 63% in those aged 85 and 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 Whites to have a diagnosis of Alzheimer's disease. Rates were 14% for Hispanics, 13% for African Americans, 10% for Whites, 9% for Native Americans, and 8% 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 the Health and Retirement Study has found that among those with cognitive impairment, 46% of Whites over age 55 had been told by a physician that they had a memory-related disease, compared to 34% of Hispanics and 34% of African Americans.

In terms of the prevalence of cognitive impairment, the 2006 Health and Retirement Study shows a marked difference by age and race/ethnicity, as shown in **Figure 1**. Overall prevalence is about 105 per 1,000 Americans aged 55 or over. African Americans are approximately 2-3 times more likely than Whites to have cognitive impairment, and these differences are greater in the younger age groups (Alzheimer's Association, 2011).

**FIGURE 1. Prevalence of Cognitive Impairment among Americans Aged 55 and Older (rate per 1,000 population) by Age and Race/Ethnicity, 2006 Health and Retirement Study**



**SOURCE:** Adapted from Alzheimer's Association, 2010.

Incidence estimates also suggest higher risk of Alzheimer's disease among non-White 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 Alzheimer's disease (excluding vascular and other dementias) among Whites were 0.4% per person-year for ages 65-74, 2.6% for ages 75-84, and 4.2% for ages 85+ (Tang et al., 2001). Incidence was higher among African Americans (1.7%, 4.4%, and 11.4%) and Caribbean Hispanics (1.4%, 4.4%, and 8.8%) in the same community. One recent study found that the unadjusted hazard ratio for developing dementia over 12 years was 1.44 for Black participants compared to White, but after adjusting for demographics, apolipoprotein (APOE) E4, comorbidities, lifestyle factors, and socioeconomic status, the Black-White difference was reduced to 1.09 and was no longer significant (Yaffe et al., 2013).

## Health Outcomes

Mortality and other health outcomes among people with Alzheimer's disease vary by race and ethnicity. Despite a lower prevalence and incidence rate, Whites have a higher overall mortality rate from Alzheimer's disease (Gillum & Obisesan, 2011; Mehta et al., 2008). In a recent study, Whites had dementia listed as the underlying or contributing cause of death on their death certificates more often than Blacks during 1999-2004: the age-adjusted rate per 100,000 was 647 for Whites versus 628 for Blacks (Gillum & Obisesan, 2011). Rates were higher 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. African Americans and Latinos with Alzheimer's disease had a lower adjusted risk of mortality than their White counterparts. Asians and American Indians had similar mortality risk as Whites (Mehta et al., 2008).

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-adjusted and sex-adjusted risk of dementia mortality--29% higher for Blacks and 19% higher for Whites--than those born in other states, even among those who did not live in those states at death (Glymour et al., 2011).

In a large epidemiological study aimed at identifying the prevalence of specific behaviors among patients with dementia, after adjusting 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. Hispanics were at increased risk (relative to Whites) of having hallucinations, expressing unreasonable anger, being combative, and wandering. Whites were at increased risk of being paranoid relative to Hispanics (Sink et al., 2004). Older African Americans with Alzheimer's disease 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.

## Participation in Clinical Trials

Minorities are underrepresented in clinical trials and other research studies (Cooper et al., 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/ethnic minorities (Wendler et al., 2006).

A 2006 review of the literature investigated whether the underrepresentation of minorities in clinical research was related to a lower consent rate, and found that the differences between racial groups were small and non-significant, with no clear directionality or patterns (Wendler et al., 2006). The authors conclude that willingness to enroll in research studies is more a function of the characteristics of individual studies than a function of racial or ethnic attitudes as a whole. Examples of factors other than willingness to participate that may be important in determining multi-ethnic 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 care or elder care and travel expenses.

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

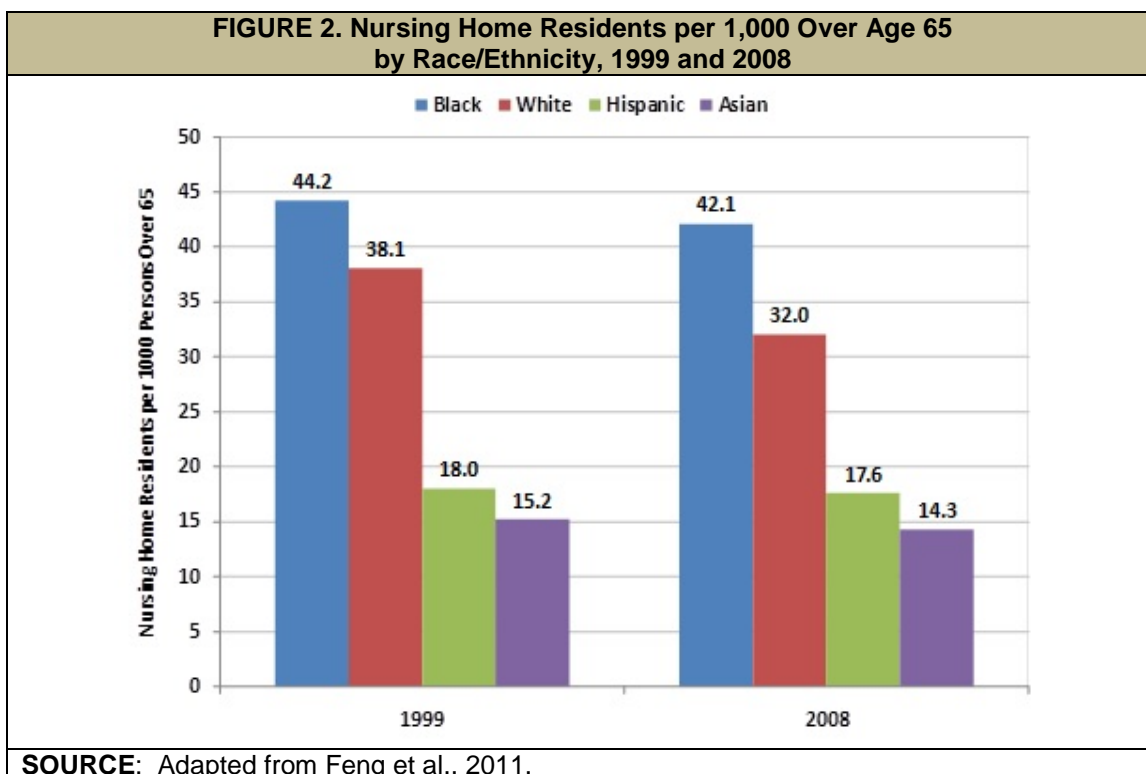
## Use of Long-Term Services and Supports

Approximately 40% of persons who died in a nursing home between 1999 and 2006 had dementia (22% with mild to moderately severe dementia and 20% with advanced dementia) (Miller et al., 2010). Historically, disparities in access to nursing homes and other formal long-term care services contributed to the lower rates of use of such services by elderly members of minority groups, compared to elderly Whites (Belgrave et al., 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 be less of a problem for elderly minorities (Feng et al., 2011). In both 1999 and 2008, rates of nursing home residency were highest among Blacks, followed by Whites, Hispanics, and Asians (**Figure 2**). Between 1999 and 2008, the absolute number of elderly Hispanics and Asians living in United States nursing homes grew by 55% and 54%, respectively, while the number of elderly Black residents increased 11% (Feng et al., 2011). During the same period, the number of White nursing home residents declined by 10%. However, on a population basis, the rates per 1,000 persons declined in all four groups (**Figure 2**). A meta-analysis of seven studies showed that minorities were 40% less likely to enter a long-term care facility than Whites in the United States. Insurance status, poverty, level of impairment (activities of daily living, instrumental activities of daily living, gait, etc.) and social support/caregiver willingness to provide care are the main determinants of institutionalization (Cooper et al., 2010).

Although use of nursing homes by minorities has grown in recent years, there is evidence that minorities tend to live in lower quality facilities (Smith et al., 2007). 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 et al., 2008).

A meta-analysis of seven studies found that the use of community social services did not differ by race/ethnicity after controlling for dementia severity and socioeconomic status (Cooper et al., 2010). On the other hand, in their study of respite care provided

through the Alzheimer’s Disease Demonstration Grants to States program, Montgomery et al. (2001) found that use patterns differed by racial and ethnic groups. For example, Blacks tended to use small amounts of care for a long period of time, while Hispanics used a lot of care for a short period of time. Moreover, in this study, respite staff working with Blacks and Hispanics found a strong sense of self-sufficiency and general distrust of government services.



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 groups, and there was conflicting evidence on hospice usage. Artificial nutrition and other life-sustaining treatments (such as ICU care and mechanical ventilation) were more frequently used, and decisions to withhold treatment less common, in African Americans and Asians (Connolly et al., 2012).

## Use of Medications

Multiple studies have shown that Whites are generally more likely to be taking acetylcholinesterase inhibitors (AChEIs) and other dementia medications than are non-Whites. A meta-analysis and literature review by Cooper and colleagues (2010) that pooled the results of three studies found that African Americans were 30% less likely to be prescribed AChEIs than Whites, whereas Hispanics had a similar likelihood of prescriptions as Whites. Three other studies of the use of medications by race/ethnicity that were not included in the above meta-analysis also found that African Americans

were less likely to use dementia medications (Gruber-Baldini et al., 2007; Hernandez et al., 2010; McClendon et al., 2009). One analysis of data using the 2000-2002 Medicare Current Beneficiary Survey found the opposite: community-dwelling African American and Hispanic Medicare beneficiaries were more likely to be prescribed Aricept than were Whites (Perryman et al., 2009). In an analysis of four state Medicaid populations, Gilligan and colleagues found significant disparities in medication (AChEIs and memantine) use between Hispanics and non-Hispanic Whites (in favor of Hispanics) in Florida, between non-Hispanic Blacks and Hispanics (in favor of Hispanics) in California and Florida, between non-Hispanic Blacks and non-Hispanic others (in favor of non-Hispanic others) in California and New York, and between Hispanics and non-Hispanic others (in favor of non-Hispanic others) in California and New York (Gilligan et al., 2012).

## Health Care Expenditures

Published literature on disparities in health and long-term services and supports expenditures is very sparse. Only two peer-reviewed studies were found, one of which used data from the early 1990s, and one used Medicaid data from 2004. In the first, Blacks with vascular dementia in Tennessee had higher total expenditures than did Whites with the same diagnosis (\$17,359 vs. \$12,904) (Husaini et al., 2003). In the second study, Blacks had significantly higher expenditures than Whites, Hispanics, and those of other racial/ethnic backgrounds, and Hispanics and Whites had significantly higher expenditures than others (Gilligan et al., 2013).

	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.



In a study funded by the Alzheimer's Association, total Medicare costs were substantially (45% and 37%) higher for older African Americans and Hispanics diagnosed with Alzheimer's disease 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.

## Caregiving

In a 2010 survey conducted on behalf of the Alzheimer's Association, 70% of caregivers were White, 15% were African American, 12% were Hispanic, 1% were Asian American, and 2% were from other ethnic groups (Alzheimer's Association, 2012). Compared to caregivers of other races, African American and Hispanic caregivers were more likely to be single/never married, and more likely to have incomes 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.

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). The concept of the "primary caregiver" may not be equally applicable in all cultures; therefore, interventions that are aimed at the family, rather than just the primary caregiver, may be more culturally appropriate for these cultures (Janevic & Connell, 2001). Korean and Korean American caregivers are less likely to be spouses and more likely to be another family member (Janevic & Connell, 2001). The tradition in cultures with Confucian values is for the daughter-in-law of the eldest son to provide care.

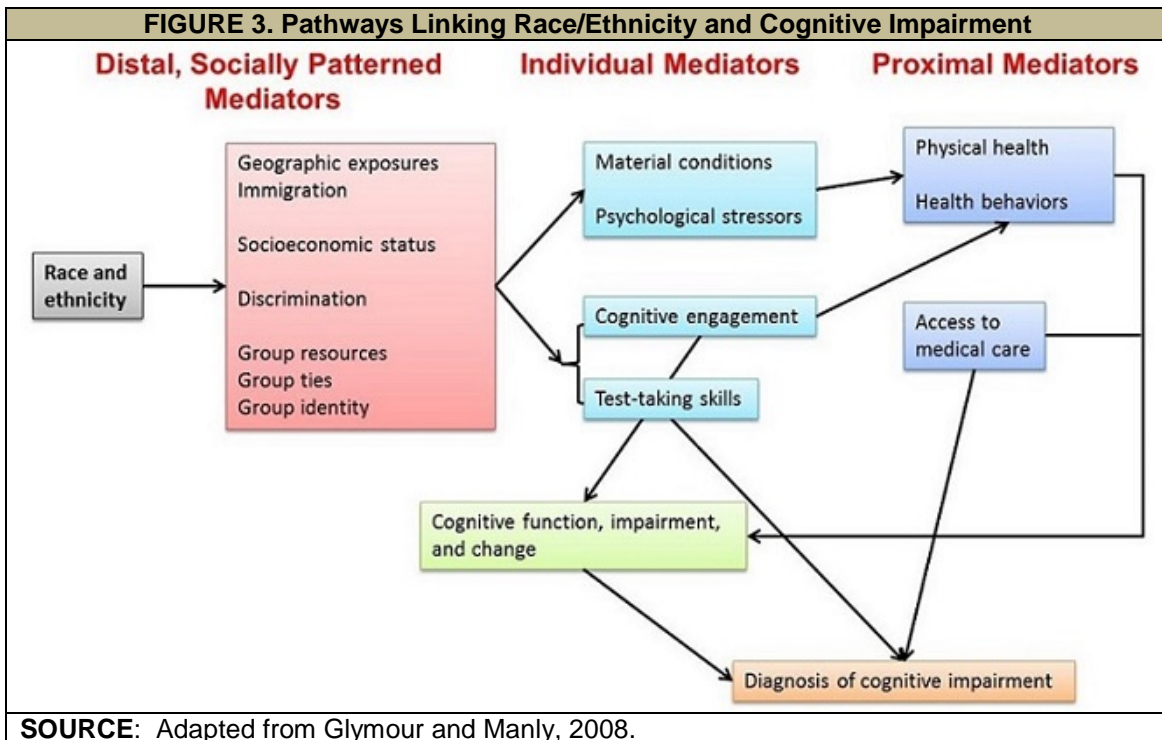
Compared with non-Hispanic Whites, Mexican American caregivers of persons with dementia report greater distress, poorer self-rated health, more somatic complaints, and increased levels of sensitivity to patient problem behaviors (Harwood & Ownby, 2000). Similarly, depression is more common in Hispanic family caregivers than in Whites (Janevic & Connell, 2001).

Some studies of caregiving interventions for people with dementia suggest that African Americans find some aspects of caregiving less stressful than Whites and get more emotional benefit from the experience (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). The fact that caregiving is more expected in some cultures may be protective against stress. Baseline differences between groups in psychological distress may account for differences in the impact of Alzheimer's disease on caregivers (Janevic & Connell, 2001).



## POSSIBLE REASONS FOR RACIAL AND ETHNIC DISPARITIES

Possible reasons for racial and ethnic disparities include factors related to measurement of Alzheimer's disease, genetics, cardiovascular and cerebrovascular disease, socioeconomic factors, cultural differences, and racial and ethnic discrimination. A range of pathways have been suggested that link race and ethnicity with cognitive impairment, some of which have implications for disparities (**Figure 3**) (Glymour & Manley, 2008). In this section, we describe the evidence underlying selected factors, mediators, and pathways associated with disparities in this population.



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

The historically higher prevalence rates for community-dwelling African Americans than for Whites may be partially attributable to the measurement of disease prevalence and incidence. For example, historically, lower institutionalization rates among African Americans in the past left more people with dementia in the community, whereas comparable Whites 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, and cultural biases in reporting of cognitive impairment are likely to substantially affect prevalence estimates. The number of years of education may not be equivalent between racial/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 control for differences in educational quality (Glymour & Manley, 2008).

Cognitive testing instruments--including the most widely used instrument, the MMSE--perform differently among individuals of different educational levels and racial/ethnic groups (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, greater variability in scores for African Americans on standard cognitive tests makes it difficult to establish cutpoints for abnormal results (Froehlich et al., 2001).

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). In addition, many community physicians are reluctant to diagnose Alzheimer's disease for reasons such as 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, and belief that there is no treatment. Anecdotally, this reluctance is more prevalent in minority communities (National Institute on Aging, 2010). Moreover, there is 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 changes in cognition differently (Rovner et al., 2012).

The 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. Moreover, some diagnostic instruments contain items that may carry substantial cultural implications that vary by group. For example, a hangman's noose, one of the items on the Boston Naming Test, may have very different implications for elderly African American and White respondents (Jett, 2006).

## Genetics

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

diseases. The E4 variant is the most important known genetic risk factor for Alzheimer's disease.

In a recent review and meta-analysis, E4 has been shown to be associated with about 65%-75% of cases of sporadic (not genetically inherited) Alzheimer's disease and up to 20% of all dementias (Crean et al., 2011). The meta-analysis found that 39% of Alzheimer's disease patients from Asian countries carried the E4 allele; 43% of patients from Southern Europe and the Mediterranean; 54% from Central Europe; 59% from North America; and 64% from Northern Europe.

Having one or two alleles, or forms, of the APOE gene is a major predictor of Alzheimer's disease in Whites but a weak or inconsistent predictor in African Americans and Hispanics (Crean et al., 2011). In an earlier meta-analysis, the prevalence of E4 among those with Alzheimer's disease was highest in Whites (37%), followed by African Americans (32%), Japanese (28%), and Hispanics (19%) (Farrer et al., 1997). Two genetic studies have found that the E4/E4 genotype is more likely to be associated with dementia in African Americans than in Whites (Green et al., 2002; Maestre et al., 1995), but a third found that one or more E4 alleles was not associated with increased risk in African Americans or Hispanics, but was in Whites (Maestre et al., 1995). The E2/E4 and E3/E4 genotypes have been shown to be associated with an increased risk of Alzheimer's in Whites, but not African Americans, in one study (Green et al., 2002). However, an earlier study found an increased risk associated with the E2/E3 genotype among African Americans, but not Whites (Maestre et al., 1995).

## **Cardiovascular and Cerebrovascular Disease**

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 & Manley, 2008). Although there is no definitive evidence linking cardiovascular disease and Alzheimer's disease, studies have found associations between cognitive impairment and cardiovascular disease (Purnell et al., 2009).

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

Vascular dementia accounts for a larger proportion of cases of related 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% (Noble et al., 2012).

A few studies suggest that differences in Alzheimer's disease prevalence cannot be attributed to differences in underlying cardiovascular disease rates. In one study, Black Alzheimer's disease patients had higher crude rates of hypertension than did Whites, but differences in other rates of cardiovascular disease (heart disease, stroke, diabetes) were not significantly different between the groups (Hargrave et al., 1998). In another study, although the cumulative incidence rate of Alzheimer's disease 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).

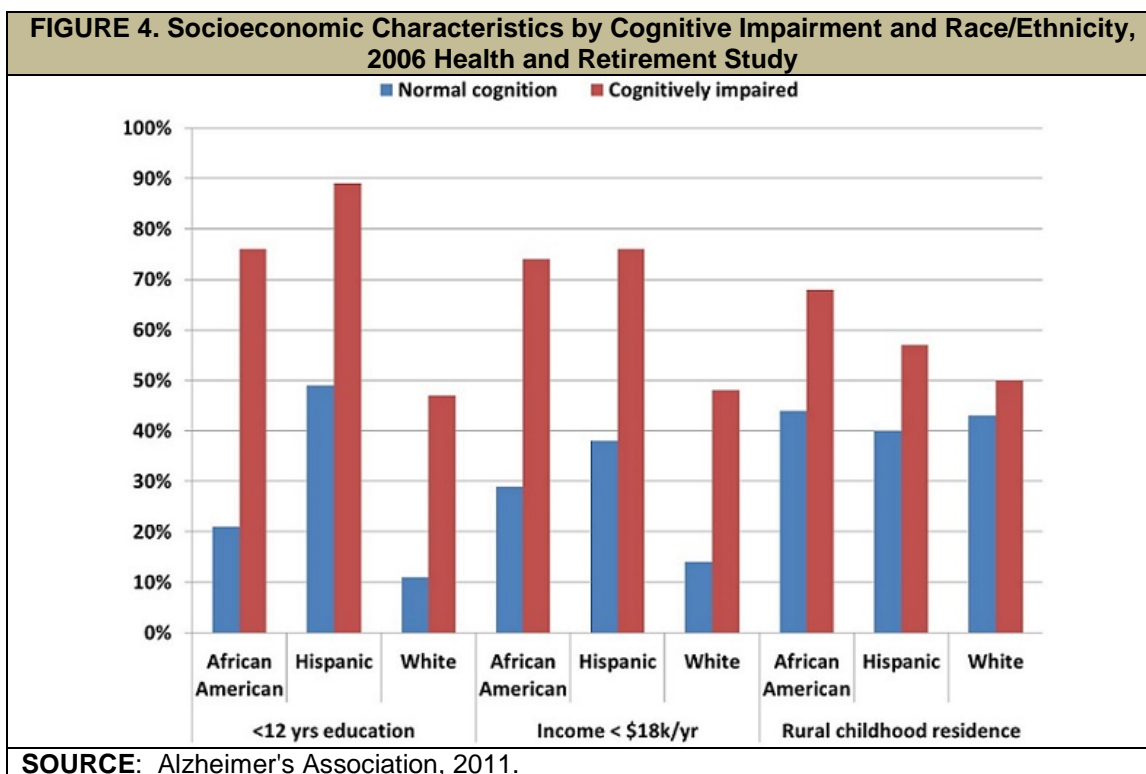
## **Socioeconomic Factors**

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 & Manley, 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 & Manley, 2008).

Geronimus et al. (2006) attributed many racial and ethnic disparities in health to "weathering," the accumulated consequences of 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 influences health both through stress and material deprivation, and through toxic work conditions (Glymour & Manley, 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 & Manley, 2008). If the effect of education on cognitive aging is primarily through material advantages, then credentials may be more important than quality. But if education's effect is because of cognitive skills or engagement, then school quality is 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 & Manley, 2008).

Additional evidence for the link between cognitive impairment and low income, less education, and having lived in a rural area comes from the 2006 Health and Retirement Study. All of these socioeconomic characteristics are more common among people with cognitive impairment, as shown in **Figure 4** (Alzheimer's Association, 2011). For example, 89% of Hispanics over age 55 with cognitive impairment possess less than 12 years of education, compared to 49% of those with normal cognition.



## Cultural Differences

Culture has been defined as a group's values, beliefs, traditions, symbols, language, and social organization (Harwood & Ownby, 2000). The United States 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 United States culture emphasizes full disclosure by providers, 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 influences on African Americans that may affect disparities in treatment or access to medical care include the legacy of slavery and Jim Crow laws, the Tuskegee syphilis study, the interaction of religion with health care, 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). Some African Americans have strong religious beliefs, including the belief that illness can be cured or is controlled by God. Strong spirituality has been correlated with lower medication adherence and later stage cancer diagnosis (Eiser & Ellis, 2010). Similarly, some elderly African Americans and other non-White patients are more likely to use traditional or herbal medicines instead of, prior to, or alongside allopathic medicines.

Many individuals and cultures perceive dementia-related symptoms as a natural part of aging (Ayalon & Arean, 2004; Eiser & Ellis, 2010; Gelman, 2010; Gray et al., 2009; Jett, 2006). For example, one study 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% agreed, compared to 55% of Hispanics and 33% of Chinese (Gray et al., 2009). An earlier study used different wording and found very different results: "Alzheimer's disease is a normal process of aging, like graying of hair or wrinkles." In that study, 66% of Whites, 50% of African Americans, 24% of Latinos, and 17% of Asians agreed with the statement (Ayalon & Arean, 2004).

Numerous cultural differences around caregiving for patients with Alzheimer's disease 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 to 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). In a review of the literature, seven studies found evidence of worse mental health among Hispanic caregivers compared to Whites, whereas among African American caregivers, 11 studies found evidence of better mental health compared to Whites (Napoles et al., 2010). African American caregivers of people with Alzheimer's disease also appear to have more social support than White caregivers.

Research focused on Asian American caregivers is more limited, but there is evidence of a strong sense of filial responsibility in those communities (Napoles et al., 2010). Confucian cultures have a tradition of first-born sons and their wives being responsible for elder care (Janevic & Connell, 2001); people from these cultures may also be less likely to seek outside help in dealing with their family member and be less affected by the stress of caregiving.

## **Racial and Ethnic Discrimination**

Although discrimination by providers 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 Alzheimer's disease. Indeed, there appear to be few empirical studies 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 group or the other and did not see either group 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 to report being looked down upon or treated with disrespect than Whites. Specifically, adjusting for sex, language, income, insurance coverage, and education, 20% of Asians, 19% of Hispanics, and 14% of Blacks reporting being treated disrespectfully or looked down upon by their provider compared to 9% of Whites.

Although not specifically about Alzheimer's disease, the Institute of Medicine's (IOM's) *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care* (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. Provider lack of empathy and limited contact with people of other races/ethnicities were identified as potential factors. The IOM report also cites the theory that the pressures of the health care environment can lead to providers stereotyping patients as a cognitive shortcut, which reduces the amount of time they need to spend with patients. The common tendency to see the patient-provider 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.

## INTERVENTIONS TO REDUCE RACIAL AND ETHNIC DISPARITIES

Although there is extensive evidence documenting disparities among different racial and ethnic groups with Alzheimer's disease, there are few studies evaluating interventions to address disparities in this population. Almost all interventions designed to explicitly address racial and ethnic disparities focus on cultural competency on the part of the health care provider and/or health system. Interventions not specific to the Alzheimer's disease 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 et al., 2003).

A culturally competent health care environment includes the following characteristics (Anderson et al., 2003): a culturally diverse staff that reflects the communities served; bilingual staff or interpreters for the clients' languages; culture-specific and language-specific training for providers; and signs and materials in the clients' languages that 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 2000 (Office of Minority Health, 2001). This policy mandates certain activities (e.g., competent language assistance services and signage/materials in different languages) and encourages others (such as culturally competent care and staff diversity). The 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 are debating 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 Alzheimer's disease, 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, three studies found that cultural competence training of health professionals improved 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).

The goal of the Administration for Community Living-funded Alzheimer's Disease Supportive Services Program (previously called the Alzheimer's Disease Demonstration Grants to States program) is to provide or expand support services for traditionally underserved or hard-to-serve Alzheimer's patients and their caregivers, especially minorities and rural residents. The Illinois intervention 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 providers to screen for dementia.

A recent comprehensive review of interventions focused on Alzheimer's disease and related disorders caregivers found 18 studies, of which 11 considered cultural factors in their design; eight of those 11 studies were from the REACH initiative (Napoles et al., 2010). Cultural tailoring in these studies addressed familism (i.e., the primacy of the family over individual interests), 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 providers (Daker-White et al., 2002; Means, 2002). Where service providers match clients with staff according to ethnicity and language, patient outcomes may be improved (Braun & Browne, 1998). Similarly, when staff receive training in cultural awareness and sensitivity and cognitive testing is language-appropriate, this may help address some disparities (Daker-White et al., 2002).

Caregiver interventions may be more effective if delivered by staff who are not only bilingual but also 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). One of REACH's strengths is the tailoring of the intervention materials individual caregivers, and the bilingual/bicultural staff.

## **Outreach to Minority Communities**

Another approach to addressing disparities involves targeting programs and outreach to minority populations. For example, the Alzheimer's Disease Demonstration Grants to States program provided demonstration grants to Florida, Kentucky, and the District of Columbia, that focused on African Americans (Wiener & Mitchell, 2007). For example, in the District of Columbia, the intervention focused on educational efforts conducted within church communities. They 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 ethnic or 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 one of the 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. Strategies that have met success include improved patient coordination, increasing the personal attention patients receive, home visits, and support groups (National Institute on Aging, 2010).

## CONCLUSIONS

This paper reviews the research literature on ethnic and racial disparities as it relates to Alzheimer's disease. The literature shows consistent and adverse disparities among Blacks and Hispanics compared to non-Hispanic Whites in the prevalence and incidence of Alzheimer's disease, 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 include possible genetic differences, prevalence of other diseases that may increase the risk of Alzheimer's disease, higher rates of poverty, and lower levels of education. In addition, differences in the use of services 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 Alzheimer's disease, with almost no studies available that evaluate possible interventions.

In seeking to alleviate these disparities, one of the important points made in the IOM's *Unequal Treatment* report is that matching needs to services is a more important goal than trying to provide equal amounts of services to different groups (Smedley et al., 2003). Both undertreatment and overtreatment can be a problem, and it would be undesirable to insist on all patients being equally overtreated. Instead, the goal should be the right care, delivered to the right patient, at the right time, in the right setting (Fowler et al., 2011).

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# REVIEW OF ALZHEIMER'S AND RELATED DEMENTIA RESEARCH

## Reports Available

Care Coordination for People with Alzheimer's Disease and Related Dementias: Literature Review

Executive Summary <http://aspe.hhs.gov/daltcp/reports/2013/AlzCCes.shtml>  
HTML <http://aspe.hhs.gov/daltcp/reports/2013/AlzCC.shtml>  
PDF <http://aspe.hhs.gov/daltcp/reports/2013/AlzCC.pdf>

Racial and Ethnic Disparities in Alzheimer's Disease: A Literature Review

HTML <http://aspe.hhs.gov/daltcp/reports/2014/RacEthDis.cfm>  
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FAX: 202-401-7733  
Email: [webmaster.DALTCP@hhs.gov](mailto:webmaster.DALTCP@hhs.gov)

NOTE: All requests must be in writing.

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