



# Racial Barriers May Hamper Diagnosis, Care of Patients With Alzheimer Disease

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CHICAGO—Alzheimer disease (AD) may present something of a double whammy to black Americans. Evidence suggests that elderly African Americans may be more likely than white people to receive a misdiagnosis because of racial bias inherent in at least some of the available screening tools, and even those who are given correct diagnoses face barriers that discourage them and their caregivers from obtaining needed services.

“Barriers exist to early detection of Alzheimer’s disease and acquisition of services for African Americans,” said geriatrician Vicki T. Lampley-Dallas, MD, MPH, of the University of Oklahoma Health Sciences Center in Oklahoma City, speaking here at the 10th National Alzheimer’s Disease Education Conference. Based on her analysis of published studies, she said that “African Americans stand a greater chance of being misdiagnosed and mistreated by the very people who are supposed to help them, including physicians, nursing homes, and community service providers.”

Experts agree that early recognition of AD has become increasingly impor-

tant for several reasons. Currently available drugs are useful only in the early stages of the disease, and new agents being developed are considered far more likely to arrest or slow disease progression than to reverse damage that has already occurred. Other interventions, such as adult day care programs that help support caregivers and stimulate patients, also are aimed at those with early disease.

## BIAS IN SCREENING TESTS?

Neuropsychological tests used to screen for AD often fail to detect early dementia, so pursuing the lengthy investigation that may lead to early diagnosis often depends on investigating red flags raised by the patient, a family member, or an astute primary care physician, Lampley-Dallas pointed out. The limitations of screening tests may be compounded by racial bias in some standard neuropsychological tests, such as the Mini-Mental Status Examination (MMSE), that too often result in misdiagnosis of black patients, she added.

Some researchers have found that these brief screening tests result in a disproportionate number of false-positive results in blacks, incorrectly classifying as many as 42% of black

Americans without dementia as being demented vs 6% of whites. And while some studies have found that such racial bias is eliminated when education and socioeconomic conditions are taken into account, others have found it persists even after controlling for these elements.

This situation suggests that other, unknown factors are involved, resulting in higher false-positive rates of cognitive impairment in African Americans compared with whites, noted Lampley-Dallas.

Whatever the reason, misdiagnosis can be traumatic for the patient and family, can lead to unnecessary and costly testing and inappropriate treatment, and may further undermine an already tenuous sense of trust that many blacks have in the health care system.

“The literature does seem to suggest diagnostic disparities across populations with respect to Alzheimer’s disease and that blacks tend to be overdiagnosed, particularly when the MMSE is part of the screening process,” agreed Jennie Ward Robinson, PhD, director of Medical and Scientific Affairs at the Alzheimer’s Association. “But it’s not clear where the bias lies.”

According to Lampley-Dallas, more intensive screening tools, such as the Cambridge Cognitive Examination (Br J Psychiatry. 1986;149:698-709), which takes 20 minutes to administer compared with the 10 minutes needed for the MMSE, may be more successful in detecting early dementia and have the potential to be less biased in their application. In the CamCog, as this “mini-neuropsychological test” is called, values range from 0 to 106 rather than 0 to 30, as in the MMSE, thus allowing for the detection of smaller differences in cognitive abilities.

The Alzheimer Association’s Robinson said she was unfamiliar with the CamCog, which was developed in Great Britain, but that she is interested in learning more about the examination and its application—particularly about whether it is useful in minority groups—because better evaluation tools are needed that are culturally sensitive and



can account for cultural, ethnic, and racial differences among individuals. “We really need to have more tests and to have more African Americans and other minorities included in large-scale population studies that will tease out small nuances and will allow us to get accurate prevalence figures,” she said.

Given the limitations of current screening tools, physicians “should consider culture and experiential differences, along with age and education, when administering these tests to any minority groups,” said Lampley-Dallas. “The good news is that there’s a lot of interest in this area and studies are being planned.”

#### **UNANSWERED QUESTIONS**

Getting a better handle on how AD plays out in different populations is more than an academic question. There’s a pressing need to determine whether there are differences in disease risk, incidence, and prevalence among various racial and ethnic groups, according to the National Institute on Aging’s Progress Report on Alzheimer’s Disease, 2000. For one thing, the proportion of older nonwhites in the US population is growing rapidly and is expected to rise from 16% to 34% between now and 2050.

In addition, differences in prevalence among racial and ethnic groups

could help researchers zero in on the roles particular genetic and environmental factors play in the development of AD. Although some studies have found evidence that the overall risk of developing the disorder is higher among African Americans and Hispanic Americans than whites, others have turned up conflicting results.

“Clearly, further careful investigation is needed to examine the role that ethnic and racial differences may play in determining the risk of [AD], and studies now ongoing should begin to provide the answers,” the report notes.

#### **OTHER BARRIERS**

In addition to screening tests that too often misdiagnose black patients, such factors as caregivers’ perception of covert racism or cultural insensitivity by some health care professionals and support staff has kept patients and family members from seeking needed services, explained Lampley-Dallas.

For example, participants in two focus group sessions involving 13 black caregivers of people with AD said they were insulted by automatic assumptions that they would not be able to pay for services. “This may not be so much racism as cultural ignorance or insensitivity, so cultural sensitivity training may help change this,” said Lampley-Dallas.

Some focus group participants also noted that many blacks care for a loved one through the extended family, and because they consider it a private matter, they are reluctant to share their “business” with others, particularly in an integrated setting. This reticence, and the lack of local support groups for caregivers within many minority communities, tends to reinforce the isolation of blacks caring for family members with AD.

Lampley-Dallas noted that the Alzheimer’s Association of Oklahoma is taking steps to address this situation by developing support groups in minority communities. The Oklahoma chapter also has formed a multicultural committee to ensure inclusion of multicultural issues in all new and existing programs.

In other areas of the country—Detroit, St Louis, and Los Angeles, for ample—Alzheimer’s Association chapters have developed outreach efforts and are finding creative ways to address the lack of resources targeting minorities in the community and to include minorities in research efforts, said Robinson. “There is really a need for recruitment, retention, and inclusion in general of minorities in population-based studies that get at not only detection but also diagnosis and clinical trials,” said Robinson, “This is an urgent matter.” •