

African-Americans and Alzheimer's Disease: The Silent Epidemic



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Introduction

The Alzheimer's Association has identified an emerging public health crisis among African-Americans — the Silent Epidemic of Alzheimer's Disease. This report brings together for the first time an accumulating body of evidence about the scope and nature of Alzheimer's disease in African-Americans. Each study is important on its own, but only when put together does the magnitude of the crisis become clear.

Among the findings from research highlighted in this report :

- Alzheimer's disease is more prevalent among African-Americans than among whites — with estimates ranging from 14% to almost 100% higher;
- There is a greater familial risk of Alzheimer's in African-Americans; and
- Genetic and environmental factors may work differently to cause Alzheimer's disease in African-Americans.

Scientists are at a vital juncture in research. Advances in genetics and imaging, combined with our increased understanding of the mechanisms of Alzheimer's, provide immense opportunities to examine the disease in African-Americans in ways that would not have been possible even five years ago. Without additional investment in Alzheimer's research targeted to all populations, but especially to African-Americans, there is a danger that research will be stopped in its tracks.

The Promise of Vascular Research

One of the most promising areas of research where additional funding is needed is the growing body of evidence that vascular disease may be a key

mechanism in triggering the manifestation of Alzheimer's disease. Data from longitudinal studies suggest that high cholesterol and high blood pressure may be significant risk factors for Alzheimer's. The implications of these discoveries are enormous for African-Americans, among whom vascular disease and its risk factors are disproportionately present. Effective therapies for primary and secondary prevention of vascular disease already exist – including cholesterol-lowering drugs (statins) and anti-hypertensive medications. Now, observational studies indicate that these drugs may also protect against cognitive impairment and Alzheimer's disease. This is a line of scientific inquiry that must be pursued as aggressively as possible.

The epidemic of Alzheimer's will continue to spread over the next 30 years, as the number of African-Americans entering the age of risk more than doubles to 6.9 million. There is no time to waste.

Call To Action

This report lays out a plan of action that will require an unprecedented mobilization of public and private resources on three fronts:

First, to accelerate the research to understand Alzheimer's in African-Americans and to develop effective methods to manage and prevent disease.

Second, to increase awareness of Alzheimer's among African-Americans, to expand their participation in research and to get services and treatments to those who are affected by the disease.

Third, to develop and expand affordable, culturally appropriate services, including assessment, diagnosis, and care.

What the Research Shows

African-Americans Are Hard Hit by Alzheimer's Disease

- Age-specific prevalence of dementia has been found to be 14% to 100% higher in African-Americans. (While the rates vary among studies, three out of four report these higher prevalence rates.)
- The cumulative risk of dementia among first-degree relatives of African-Americans who have Alzheimer's disease is 43.7%.

The prevalence, incidence, and cumulative risk of Alzheimer's disease appears to be much higher in African-Americans than in non-Hispanic whites.

- For spouses (who share environmental but not genetic backgrounds), the cumulative risk was 18.4%. These findings of familial risk, reported in January 2002, are based on family histories of the largest number of African-American families ever studied for Alzheimer's disease.

The Number of African-Americans Entering Age of Risk is Growing Rapidly

- Age is a key risk factor for Alzheimer's disease in all racial and ethnic groups. Over 10% of all persons over 65, and nearly half of those over 85 have Alzheimer's disease.
- The number of African-Americans age 65 and over will more than double by 2030, from 2.7 million in 1995 to 6.9 million by 2030
- The number of African-Americans age 85 and over is growing almost as rapidly, from 277,000 in 1995 to 638,000 in 2030 and will increase more than five-fold between 1995 and 2050, when it will reach 1.6 million.

Genetic and environmental risk factors for Alzheimer's disease seem different in African-Americans

- Genetic risk factors seem different in African-Americans and white Americans. APOE genotype alone does not explain the increased frequency of Alzheimer's disease in older African-Americans.

Vascular disease may be a particularly powerful factor in the prevalence of Alzheimer's among African-Americans.

- Data from a large-scale longitudinal study indicate that persons with a history of either high blood pressure or high cholesterol levels are twice as likely to get Alzheimer's disease. Those with both risk factors are four times as likely to become demented.
- Sixty-five percent of African-American Medicare beneficiaries have hypertension, compared to 51% of white beneficiaries. They are also at higher risk of stroke. (Data from the Current Medicare Beneficiary Survey)
- African-Americans have a 60% higher risk of type 2 diabetes — a condition that contributes directly to vascular disease.
- African-Americans have a higher rate of vascular dementia than white Americans.

Screening and assessment tools and clinical trials are not designed to address the unique presentation of Alzheimer's disease in African-Americans

- Ethnic and cultural bias in current screening and assessment tools is well documented. As a result,



African-Americans who are evaluated have a much higher rate of false-positive results. At the same time, there is substantial evidence of underreporting of dementia among African-Americans.

- African-Americans tend to be diagnosed at a later stage of Alzheimer's disease — limiting the effectiveness of treatments that depend upon early intervention.
- African-Americans are seriously underrepresented in current clinical trials of potential treatments for Alzheimer's disease, particularly in trials conducted by drug companies. This has occurred even though evidence of genetic differences and response to drugs varies significantly by race and ethnicity.

A Plan of Action

As the largest private funder of Alzheimer research, the Alzheimer's Association has invested nearly \$120 million to find answers to this disease. We are providing research grants to encourage new African-American investigators and research on African-Americans at a number of institutions and are particularly proud of our early investment in some of the most important research described in this report, including the longitudinal study of African-Americans and Nigerians at Indiana University. In 2002, a primary focus of the research funded by the Association will be vascular disease and dementia. We have also formed a Diversity Work Group of leading researchers working on Alzheimer's disease in diverse cultures to help us identify priorities for future research.

The Association values its collaborations with the National Institute on Aging and we are gratified to see the results of our work together. As a result of a workshop on Race and Cultural Effects on Measurement of Cognition, which we cosponsored in late 2001, the NIA is launching an important

initiative that will address racial and cultural effects on cognitive function and measurement.

While we accelerate the search for answers, we have to do more to help and support those who are dealing with the disease right now. Alzheimer's disease is underreported in African-Americans, and diagnosis often occurs at a much later stage of the disease. That has huge consequences. People aren't getting the help they need, and families struggle on their own at great personal, emotional and financial cost. Many miss the opportunity for the treatments that now exist, which are most effective in the early stages of the disease.

The Association is working to improve care and support for people with Alzheimer's disease. Through our chapters, we have stepped up our outreach to African-American communities and are developing specific tools for outreach, education and services. Through a collaboration with the Administration on Aging, we are developing model programs that are finding new ways to reach underserved communities.

We call on Congress to join us in this campaign against Alzheimer's disease, through the following specific actions:

- Appropriate an additional \$200 million in fiscal year 2003 for Alzheimer research across the National Institutes of Health, and reiterate the goal of \$1 billion in total funding by fiscal year 2004.
- Establish and fund a program through the Centers for Disease Control to expand

community outreach efforts, to translate research results to public health practice, and to develop a system to report accurately the incidence and prevalence of Alzheimer's disease.

- Reauthorize the Alzheimer state matching grant program at the Administration on Aging and convert it from a demonstration to a 50-state program designed to expand and reach underserved communities dealing with Alzheimer's disease.

Summaries of Recently Published Research

Risk of Dementia among White and African-American Relatives of Patients With Alzheimer's Disease

R. Green et al.

First-degree relatives of African-Americans with AD have a higher cumulative risk of dementia than do those of whites with AD. However, in this study, the additional risk of dementia conferred by being a first-degree relative, by being female, or by the probability of having an APOE $\epsilon 4$ allele appeared similar in African-American and white families. These data provide estimates of dementia risk that can be used to offer counseling to family members of patients with AD. *JAMA* 2002;287:329-336

Dementia and Race: Are There Differences Between African-Americans and Caucasians?

T. Froehlich et al.

This study provides an overview of racial differences in etiology and prevalence of dementia. Preliminary findings indicate that the clinical and molecular etiologies of dementia differ among races. African-Americans have a higher prevalence of vascular dementia and a lower prevalence of Parkinsonian dementia than do Caucasians. The genetic etiologies of Alzheimer's-type dementia appear to differ between

African-Americans and Caucasians. The variations in dementia etiologies and in cognitive testing accuracy between races suggests the urgent need to develop racially appropriate cognitive assessment methods and to develop preventive and treatment etiologies differently according to racial background of individual patients. *J Am Geriatr Soc* 49:477-484, 2001

Incidence of Dementia and Alzheimer Disease in Two Communities: Yoruba Residing in Ibadan, Nigeria and African-Americans Residing in Indianapolis, Indiana

H. Hendrie et al.

The age-standardized annual incidence rates were significantly lower among Yoruba than among African-Americans for dementia. This is the first report of incidence rate differences for dementia and AD in studies of two populations from nonindustrialized and industrialized countries using identical methods and the same group of investigators in both sites. Further explorations of these population differences may identify potentially modifiable environmental or genetic factors to account for site differences in dementia and AD. *JAMA*. 2001;285:739-747



Racial and Ethnic Differences Among Medicare Beneficiaries

L. Murray

Sixty-five percent of African-American beneficiaries had hypertension, a much higher rate than for Caucasian beneficiaries (51 percent) and Hispanic beneficiaries (56 percent). The difference is even larger when looking at the aged population only. African-American and Hispanic beneficiaries also had higher rates of diabetes than Caucasian beneficiaries. *Health Care Financing Review*/Summer 2000/Volume 21, number 4, 117-127

Serum cholesterol, APOE genotype, and the rise of Alzheimer's disease: A population-based study of African-Americans

R.M.Evans et al.

A significant interaction among total serum cholesterol (TC), APOE genotype, and AD risk was found in a population-based study of elderly African-

Americans. Increasing TC was associated with increased AD risk in the group with no e4 alleles, whereas TC was not associated with increased AD risk in the group with one or more e4 alleles. Further study of the relationship between cholesterol and APOE genotype is needed to confirm this association, but the results suggest that cholesterol may be a potentially modifiable environmental risk factor for AD. *Neurology* 54:240-242 (2000)

The APOE-e4 Allele and the Risk of Alzheimer Disease Among African-Americans, Whites, and Hispanics

M-X Tang et al

The presence of an APOE-e4 allele is a determinant of AD risk in whites, but African-Americans and Hispanics have an increased frequency of AD regardless of their APOE genotype. These results suggest that other genes or risk factors may contribute to the increased risk of AD in African-Americans and Hispanics. *JAMA*.1998;279:751-755

