

Acknowledging Disparities in Dementia Care for Increasingly Diverse Ethnoracial Patient Populations

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Alzheimer disease and related dementias are a global health concern, affecting nearly 47 million people worldwide. Alzheimer disease and related dementias were among the top 10 causes of death worldwide in 2015 and are expected to increase by 10 million cases annually.¹ Despite the ethnic diversity of the US, there are considerable gaps in the literature regarding dementia and how it is diagnosed and treated among many ethnic and racial groups.

In 2012, President Barack Obama signed a declaration with the intention of decreasing ethnoracial disparities in Alzheimer disease research and treatment by increasing clinical care, research, and services targeted to racial and ethnic minorities.² Despite that declaration, in the US there are gaps in access to care for the geriatric population in general. The American Geriatrics Society estimates that the US has fewer than half the needed number of practicing geriatricians. In 2016, there was 1 geriatrician for every 1,924 Americans aged ≥ 65 years.³ Furthermore, health care providers (HCPs) are often not of the same ethnicity or adequately trained to assess and build relationships with ethnically and racially diverse populations.² Given the projected growth in the numbers of individuals worldwide with dementia, we have a responsibility to continue to develop strategies to provide more inclusive care.

By 2060, minority populations aged ≥ 65 years are expected to represent 45% of the US population, up from 22% in 2014.⁴ The growth of racial and ethnic minority groups are expected to exceed the growth of the non-Hispanic white population in the next few decades. By 2060, it is estimated that the US population will increase by 75% for non-Hispanic whites, 172% for African Americans, 270% for Asian and Pacific Islanders, 274% for American Indian and

Alaska Natives, and 391% for Hispanics.⁴

A growing body of evidence suggests that Alzheimer disease and related dementias may disproportionately afflict minority groups in the US, which will become quite significant in the years ahead. The Alzheimer's Association estimates that the prevalence of Alzheimer disease and other dementias among those aged > 65 years, is about twice the rate in African Americans and about 1.5 times the rate in Hispanics when compared with non-Hispanic whites.⁵ While increases in the incidence of Alzheimer disease and related dementias in non-Hispanic whites is expected to plateau around 2050, its incidence in ethnic and racial minority groups will continue to grow, especially among Hispanics.⁴ This stark realization provides additional compelling reasons for the US to develop preventative interventions or treatment options that may help delay the onset of the disease and to improve the quality of life of those with the disease or caregiving for those afflicted with it. Culturally competent care of these individuals is paramount.

DIAGNOSIS

Early and accurate diagnosis of individuals with dementia confers many benefits, including early treatment; clinical trial participation; management of comorbid conditions; training, education, and support for patients and families; and legal, financial, and end of life care planning.³ Beyond the logistical concerns (such as HCP shortages), one of the challenges of assessing minority groups is finding staff who are culturally competent or speak the language necessary to accurately communicate and interact with these subgroups. Hispanics and African Americans often receive delayed or inadequate health care services or are diagnosed in an emergency department

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or other nontraditional setting.⁵

Even those individuals seeking or receiving care in primary care settings are not always forthcoming about their cognitive status. Only 56% of respondents in a recent survey of patients who had experienced subjective cognitive decline reported that they had discussed it with their HCP.⁴ This reticence is thought to be influenced by multiple factors, including distrust of the medical establishment, religious or spiritual beliefs, cultural or

family beliefs and expectations about geriatric care, and lack of understanding about normal aging vs cognitive disorders. Furthermore, the sensitivity and specificity of current diagnostic tests for dementia have been questioned for nonwhite populations given the clinical presentation of dementia can vary across ethnorracial groups.⁵

As Luria noted, cognitive assessment tools developed and validated for use with one culture frequently results in experimental failures and are not valid for use with other cultural groups.¹ Cognitive testing results are influenced by educational and cultural factors, and this is one of the challenges in correctly diagnosing those of differing ethnorracial backgrounds. Individuals in racial and ethnic minorities may have limited formal education and/or high illiteracy rates and/or cultural nuances to problem solving, thinking, and memory that may not be reflected in current assessment tools.¹

There is hope that testing bias could be altered or eliminated using neuroimaging or biomarkers. However, the Alzheimer's Disease Neuroimaging Initiative study of patients in the US and Canada included < 5% African American or Hispanic participants in its total sample. Few studies have systematically examined ethnorracial differences in amyloid positron emission tomography, and

none have been published to date in ethnorracially diverse groups that assess the more recently developed tau imaging agents.¹

DIVERSITY AMONG CAREGIVERS

The research community must make greater efforts to improve recruitment of more diverse populations into clinical trials. Recent efforts by the National Institute on Aging in conjunction with the Alzheimer's Association include developing a national strategy for clinical research recruitment and retention with an emphasis on local and diverse populations. This strategy should include various training modules, webinars, and similar educational opportunities for researchers and clinical HCPs, including HCPs from diverse ethnorracial backgrounds, to implement culturally appropriate research methodologies across these diverse groups. It is important that these educational materials be disseminated to caregivers in a way they can comprehend, as the impact on caregivers of those with Alzheimer disease and related dementias is considerable.

The US currently has 7 unpaid caregivers for every adult in the high-risk group of patients aged ≥ 65 years, but this will decline to a ratio of 4:1 by 2030.⁴ More than two-thirds of caregivers are non-Hispanic white, while 10% are African American, 8% are Hispanic, and 5% are Asian.³ About 34% of caregivers are themselves aged ≥ 65 years and are at risk for declines in their own health given the time and financial requirements of caring for someone else.³ In 2017, the 16.1 million family and other unpaid caregivers of people with dementia provided an estimated 18.4 billion hours of unpaid care, often resulting in considerable financial strain for these individuals. More than half of the caregivers report providing ≥ 21 hours of care per week; and 42% reported providing an average of 9 hours of care per day for people with dementia.

Caregivers report increased stress, sleep deprivation, depression and anxiety, and uncertainty in their ability to provide quality care to the individual with Alzheimer or a related dementia.³ The disproportionate prevalence of Alzheimer disease and other dementias in racially and ethnically diverse populations could further magnify already existing socioeconomic

and other disparities and potentially lead to worsening of health outcomes in these groups.⁴ Given that minority populations tend to cluster geographically, community partnerships with local churches, senior centers, community centers, and other nontraditional settings may offer better opportunities for connecting with caregivers.

CONCLUSIONS

The growth and increasing diversity of the US older adult population in the coming decades require us as HCPs, researchers, and educators to dedicate more resources to ethnoracially diverse populations. There are still a great many unknowns about Alzheimer disease and dementia, most especially among nonwhites. Research, clinical care, and education must focus on outreach to marginalized groups so we may better be able to diagnose and treat the fastest growing older adult populations in the US. A complex combination of educational, cultural, social, and environmental factors likely contribute to delayed diagnosis and care of these groups, as well as lack of access to medical care, research venues, and trust issues between minority groups and the medical establishment.

We all have an obligation to acknowledge these disparities and elicit the support of our colleagues and workplaces to raise awareness and dedicate necessary resources to this growing concern.

Author disclosures

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Disclaimer

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