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## Diversity and Disparities in Dementia Diagnosis and Care A Challenge for All of Us

Claudia H. Kawas, MD; María M. Corrada, ScM, ScD; Rachel A. Whitmer, PhD

**Health disparities** are one of the most important public health challenges in the United States. Disparities and inequities in rates and treatment of disease stem from a complex web of environmental, sociocultural, behavioral, and biological factors that accumulate over a lifetime to produce population-level differences.<sup>1</sup> As evidenced by the COVID-19 pandemic, health disparities result in markedly different rates of disease, complications of disease, and access to care and treatment. In the US, Alzheimer disease and related dementias are conditions with profound health disparities, disproportionately affecting many racial/ethnic groups. An identified goal of the 2012 federally mandated National Plan to Address Alzheimer Disease was to redress disparities in Alzheimer disease and dementia. Delineating barriers and trajectories of care, particularly among those with health insurance, is an important step for furthering our understanding of disparities in dementia.

In this issue of *JAMA Neurology*, Tsoy and colleagues<sup>2</sup> examine the associations between race/ethnicity and timeliness of dementia diagnosis and comprehensiveness of diagnostic evaluation in a Medicare population. The study included 10 472 California Medicare fee-for-service beneficiaries who were continuously enrolled from January 1, 2013, to December 31, 2015, and received a diagnosis of mild cognitive impairment (MCI) or dementia in the first 6 months of 2015. Timeliness of diagnosis was operationalized as first receiving a diagnosis of MCI rather than dementia. The investigators found that individuals who identified as Asian (odds ratio [OR], 0.46; 95% CI, 0.38-0.56), Black (OR, 0.73; 95% CI, 0.56-0.94), or Hispanic (OR, 0.62; 95% CI, 0.52-0.72) were less likely to receive a timely diagnosis of MCI vs dementia compared with White beneficiaries. Asian beneficiaries were also less likely to receive key elements of a diagnostic evaluation (specialty referral, laboratory assays, and neuroimaging) compared with White beneficiaries (incidence rate ratio, 0.81; 95% CI, 0.74-0.87). In addition, greater neighborhood disadvantage, older age, and greater comorbidity burden were each independently associated with later diagnosis. Although not surprising, these results underscore the pressing need in the United States to address ethnic and racial health care disparities, particularly among elderly individuals, the fastest growing segment of the population and the leading consumers of health care.

Use of a Medicare database has advantages and disadvantages. The large sample size, diversity of participants, complete capture of medical encounters, and diagnosed comorbidities strengthen the robustness of the study and minimize several biases associated with volunteer research cohorts. In

addition, this approach allows the study of disparities when all participants have access to health care and insurance, thereby minimizing the effects of these factors that greatly contribute to disparities but do not explain the whole picture. On the other hand, a Medicare database does not capture the richness of data that may be collected in other types of studies, nor does it delineate the causes of the observed disparities. For example, timeliness of diagnosis, as defined in this study,<sup>2</sup> may possibly reflect clinician and health care system biases or poor performance of screening instruments in these populations, but it is also likely to be related to cultural differences in what is normal aging or the appropriate time to present to the health care system with memory problems.

Ethnoracial disparities in health care are well known and greatly contribute to public health outcomes. Barriers to health care come from many sources, including inadequate health insurance, poor language proficiency, limited transportation, and lack of specialty clinics in disadvantaged communities.<sup>3</sup> Although most adults in the United States older than 65 years, and all of the individuals in the study by Tsoy et al,<sup>2</sup> have access to health insurance through Medicare, poorer understanding of these services diminishes access.<sup>4</sup> In the investigation by Tsoy et al,<sup>2</sup> individuals 65 years or older who identified as racial/ethnic minorities were significantly underrepresented in the California Medicare fee-for-service database (<26% compared with state estimates for the study period (40%).<sup>5</sup>

Even among those with insurance, prior studies have indeed shown disparities in dementia care and treatment. For example, studies of Medicare beneficiaries have found that non-Hispanic White individuals are more likely to receive antidementia medications compared with other ethnoracial groups, with differences persisting even after accounting for socioeconomic factors, health care access and utilization, and comorbidities.<sup>6,7</sup> Although identifying disparities in dementia treatment is important, delineating other aspects of care are also necessary. Novel in the work by Tsoy et al<sup>2</sup> is the focus on time to diagnosis and comprehensiveness of evaluation, which has not been done before, to our knowledge.

Difficult to capture in a Medicare database are cultural factors, including differences in perceptions about what is normal aging and issues of trust between different racial/ethnic groups and the medical establishment. Additionally, the diagnosis of cognitive loss in diverse populations may be complicated by racial and ethnic biases inherent in cognitive screening tools widely used by clinicians and researchers. Perhaps more surprising than the observed disparities in the study by Tsoy et al<sup>2</sup> is the observation that despite having Medicare insurance, less than half of all beneficiaries received any recom-



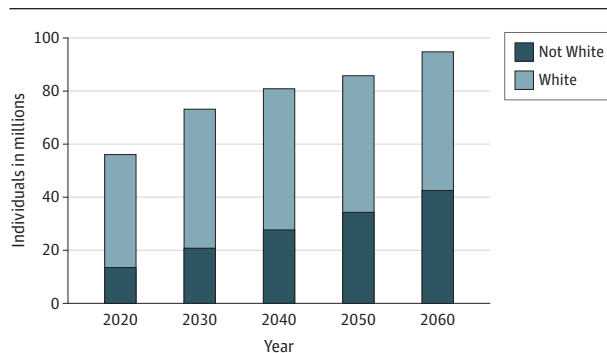
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mended workup, including neuroimaging, laboratory blood assays, and specialty referrals, for their diagnoses of MCI or dementia. The absence of workup was particularly true for those who were older and had multiple comorbidities, groups that may be more likely to benefit from completion of these studies. Physician education and outreach will be an essential component to address these issues and to improve health care delivery to the most vulnerable populations.

In the US, the population of individuals 65 years and older is projected to grow from 56 million in 2020 to almost 95 million by 2060 (Figure).<sup>8</sup> This rapid growth will more than double the number of individuals with a dementia diagnosis, projected to be almost 14 million by 2060.<sup>9</sup> Consequently, Alzheimer disease and other dementias are expected to become a public health crisis as health care systems will be challenged to meet the societal, medical, and economic demands of an aging population. As the elderly population grows, it will also become more racially and ethnically diverse. Census projections estimate the percentage of individuals 65 years and older who are Hispanic or not White will grow from 24% in 2020 to 45% by 2060 (Figure).<sup>8</sup> Given the racial and ethnic diversification of the older population in the US and the higher burden of dementia in some ethnoracial groups, understanding the determinants of dementia as well as barriers to diagnosis in racially and ethnically diverse individuals is ever more crucial.

Current evidence suggests the incidence and prevalence of dementia may be considerably higher in African American individuals and American Indian/Alaskan Native individuals, lower in Asian individuals, and intermediary for non-Hispanic White individuals. Studies in Latino individuals suggest that there is heterogeneity in rates of dementia, with studies on the West Coast showing rates similar to non-Hispanic White individuals and studies on the East Coast showing higher rates.<sup>10</sup> However, dementia research in diverse populations is still in its infancy, particularly for studies that encompass numerous racial/ethnic groups and have information on life-course risk factors. Given the anticipated ethnic and racial diversification in elderly populations, it is imperative for researchers to enroll cohorts that reflect the elderly population of tomorrow.<sup>11-13</sup> Ethnoracial differences in biological risk factors, such as genetics (ie, frequency of apolipoprotein e4 allele) and cardiovascular

Figure. Increasing Number and Diversity of the Population 65 Years and Older in the US From 2020 to 2060



Numbers extracted from US Census Bureau.<sup>8</sup>

disease, may help to partially explain disparities in the incidence and prevalence of Alzheimer disease and other types of dementia and provide an important opportunity to understand biological processes. Environmental and societal differences such as quantity and quality of education, treatment of risk factors, exposure to toxins, physical activity, health behaviors, psychosocial stress, socioeconomic state, and health care access also can explain differences in Alzheimer disease and dementia rates. A better understanding of these factors and of how their interactions differ across groups may allow clinicians to more effectively diagnose and treat dementia in patients of all racial and ethnic groups.<sup>14</sup>

A major challenge to our understanding of dementia care is the absence of diversity in study populations engaged in research. Most of what we know today about risk and protective factors for dementia, treatment effects, and biomarkers related to cognitive impairment is derived from highly educated, urban dwelling, non-Hispanic White individuals. Recruiting diverse populations into research requires directed resources to cultivate trust and engage with different communities. Importantly, physicians must be made aware of the disproportionate effect of dementia in underrepresented and diverse communities and fully recognize the biases of the medical establishment in the diagnosis and care of these underserved individuals.<sup>15</sup> It is a challenge we all must address.

#### ARTICLE INFORMATION

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## Bariatric Surgery in Patients With Idiopathic Intracranial Hypertension—The Silver Bullet?

Deborah I. Friedman, MD, MPH

**Weight loss** is a mainstay of therapy for obese patients with idiopathic intracranial hypertension (IIH). Barbara Newborg,<sup>1</sup> an internist, performed the first study of a low-calorie rice-based diet among 9 patients in 1974. This diet generated rapid



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weight loss and resolution of symptoms; however, visual parameters were not assessed. Subsequent case series from neuro-ophthalmologic practices indicated that a reduction of approximately 6% of body weight with or without concomitant medical therapy was associated with a reduction in papilledema and improvements in visual parameters.<sup>2,3</sup> The Idiopathic Intracranial Hypertension Treatment Trial (IIHTT), the first randomized placebo-controlled clinical trial for this condition, enrolled newly diagnosed patients with mild visual field loss to assess the effect of acetazolamide therapy compared with placebo.<sup>4</sup> All participants had access to weight loss coaches from the New York Nutrition and Obesity Research Center via telephone. The acetazolamide group experienced statistically significant improvements in visual field assessments, papilledema grade, and quality-of-life measures compared with the placebo group. Moreover, they lost more weight.

Successful and sustained weight loss among patients with IIH is more difficult to achieve in clinical practice than in a clinical trial. Organized weight loss programs offer the advantages of camaraderie, motivation, and ongoing supervision. However, these programs are often not feasible for patients with IIH, who are often so impaired by headaches and visual symptoms that they are unable to work or participate in fee-based dietary programs or exercise plans. In the US, IIH disproportionately affects Black women with low income, creat-

ing socioeconomic disparities that further limit access to individualized dietary programs.<sup>5</sup> Furthermore, although sodium and calorie restriction are recommended, the ideal approach to successful weight loss is uncertain.

In this issue of *JAMA Neurology*, Mollan and colleagues<sup>6</sup> report the findings of a randomized clinical trial comparing bariatric surgery with a community weight management intervention for the treatment of patients with IIH. They enrolled 66 women meeting the criteria for diagnosis of definite IIH who had tried unsuccessfully to achieve adequate, clinically beneficial weight loss for at least 6 months. The extent of visual loss for eligibility was not prespecified, but the cohort was composed of participants with mild visual loss (mean Humphrey perimetric mean deviation in the worse eye of  $<4$  dB and mean Frisén papilledema grade of 2) and a body mass index (calculated as weight in kilograms divided by height in meters squared) of 35 or greater. Participants were randomized to receive bariatric surgery as determined by their surgeon's discretion or 1 year of paid participation in a community weight management program (Weight Watchers). Randomization was stratified according to whether participants were receiving acetazolamide therapy at baseline.

There were 6 protocol deviations regarding adherence to the treatment assignment and 2 withdrawals in the community weight management group. Despite a delay in surgery of 2 to 10 months (median, 4.4 months; range, 2.2-10.3 months) after the treatment assignment, participants in the surgery arm had a significantly greater decrease in lumbar puncture opening pressure from baseline to 12 months after surgery (mean [SD], 34.8 [5.8] cm CSF at baseline and 26.4 [8.7] cm CSF at 12 months; adjusted mean [SE] difference,  $-8.7$  [1.3] cm CSF; 95%