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Changing Faces of Cognitive Impairment in the U.S.: Detection Strategies for Underserved Communities

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Between 2015 and 2050, the U.S. population aged 65 years and older will nearly double in size, from 48 million to 88 million and with it, the number of older American adults with cognitive impairment will surge, challenging a healthcare system that is ill-equipped to meet their related health and social needs. More than five million people in the U.S. have Alzheimer's disease, the best known and most frequent form of cognitive impairment.¹ By 2050, this number may rise to more than 13 million people. Projecting current costs and standards of care forward, annual Medicare costs related to cognitive impairment inclusive of Alzheimer's disease will exceed one trillion dollars.²

Despite its frequency, healthcare providers currently diagnose or recognize less than half of cognitively impaired individuals, resulting in fewer opportunities for appropriate treatment and management, worse health outcomes, and escalating healthcare and psychosocial costs.³ Earlier detection of cognitive impairment has several advantages. It enables providers to identify underlying conditions that may impair cognition and improve diagnostic assessment and treatment recommendations. It also supports patient-centered care, enabling patients at risk for dementia to establish their treatment preferences when such discussions can still be accomplished. Early detection enables proactive implementation of strategies that minimize safety concerns and improve linkages for psychosocial support and community services. Moreover, detecting cognitive impairment creates the opportunity for professionals to meaningfully connect with families who often feel isolated, stigmatized, and lost, having no understanding of where to turn for help. Such caregiver connections are critical to achieving therapeutic relationships, which become even more important under such stressful circumstances. Undiagnosed cognitive impairment, on the other hand, often creates a cascade of problems, such as poor adherence with chronic disease management, onset of preventable illness, accidents and injuries at home and at work, job loss without disability support, elder abuse, and family stress and discord.

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Racial and ethnic minorities and communities with low income or education are among the most vulnerable in terms of burden, delayed diagnosis, and poor management of cognitive impairment. These disparities can be further magnified by poor access to healthcare services and limited cultural competency among providers regarding beliefs, symptom presentation, and perceptions about cognitive impairment, all of which can lead to excessive delays of care until later stages of disease.⁴ Minority communities have among the fastest growing older adult populations, with the greatest increases being among Asian and Hispanic Americans—largely immigrant populations with varying levels of limited English proficiency.⁵ Reducing disparities in cognitive impairment requires use of culturally appropriate detection strategies that account for the language and social needs of the diverse communities represented in the U.S. population.

Surprisingly, despite persistent poor detection, a number of brief, evidence-based screening tools exist and are readily available for healthcare providers. Some of the more commonly used tools have been validated in multiple languages and have been widely recommended for use in the Medicare Annual Wellness Visit, which requires a brief cognitive assessment as one of a number of components. Although use of the Annual Wellness Visit has increased since its introduction and a public awareness campaign regarding cognitive impairment has become increasingly prominent, as few as 27.5% of eligible Medicare beneficiaries currently utilize this benefit,⁶ with lower utilization among socially disadvantaged groups.⁷

Then why are detection rates so poor? On the clinical front lines, most providers under diagnose cognitive impairment because of time constraints, limited training, and inexperience with screening tools.³ Cognitive impairment detection may be delayed as a result of a focus on chronic comorbid conditions and related symptoms that are common among older adults. Because of the time required to care for patients with complex and multiple chronic conditions, providers may not recognize initial signs of cognitive impairment in the context of treating other clinical priorities that may appear more immediate and pressing.⁸ There are also substantial cultural barriers. Family members may be reluctant to consent to diagnostic testing, as information and materials generally lack clear, culturally sensitive explanations of the symptoms associated with cognitive impairment, dementia, and Alzheimer's disease. Often, in part because of social stigma and poor understanding of cognitive impairment symptoms, family members attribute signs of cognitive impairment to other causes, such as depression, interpersonal issues, or normal aging. Finally, there are cultural nuances across diverse communities that influence how aging and cognitive impairment is understood and supported.

Although innovative, low-cost and acceptable approaches exist to improve cognitive impairment detection across all older adult populations, culturally tailored cognitive detection paradigms are urgently needed for racial and ethnic minority communities. Collaborative care delivery models centered in primary care settings should be considered, given the need for evaluation and continuity for those who are detected. One viable approach worth testing is the use of community health workers (CHW).

By definition, CHWs are paraprofessionals who perform frontline outreach engagement to communities with which they share cultural and linguistic congruence and range from lay

health workers to community health advocates to peer health professionals. Although experience with dementia has been limited in the U.S., previous work has demonstrated that CHWs can be trained as frontline detectors for dementia in resource-poor Korean American communities⁹ and culturally and linguistically diverse communities of Australia.¹⁰ In the authors' own experience, CHWs have been effective in both community and clinical settings for preventing and managing diabetes, hypertension, hepatitis B, and cancer among low-income, limited English proficient Asian American communities in New York City. There is also a well-established literature on the role of peers and CHWs in substance abuse and mental health programs, conditions that are often highly stigmatizing and require trusted sources to facilitate access and retention in care.¹¹ Building on cultural and social congruence with their clients, CHWs provide key social support and effective interpersonal communication strategies to facilitate healthful behavior change.¹² These strategies have been particularly effective in reaching culturally and socioeconomically diverse patient populations and helping to shift social norms and attitudes and increase education and understanding about stigmatized conditions. In the authors' work, they have observed how CHWs can support community capacity-building and provide place-based solutions in neighborhoods with gaps in formal resources. CHWs are uniquely positioned to improve health outcomes among immigrant and minority communities because of their valued interpersonal attributes, serving as a bridge to health and non-health resources, and often addressing social barriers to care.¹²

The authors envision that CHWs could potentially play a key role in helping clinical teams develop a more grounded, patient-centered understanding of barriers and facilitators to cognitive impairment detection by providing experiential-based insight that arises from culturally congruent relationships. Through their linking function, CHWs may be able to alert providers as to which of their patients are cognitively impaired and facilitate timely and appropriate care for early cognitive impairment detection. They may help to educate, activate, and navigate families to appropriate services and resources. For limited English proficient families, patient navigation via a CHW approach may be vital in removing the language and other cultural barriers to seeking care. The authors believe that testing this approach to increase detection of cognitive impairment while bridging inequities most pronounced in lower socioeconomic communities is a strategy whose time has arrived.

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