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A cultural approach to dementia — insights from US Latino and other minoritized groups

Clara Vila-Castelar¹, Joshua T. Fox-Fuller^{1,2}, Edmarie Guzmán-Vélez¹, Dorothee Schoemaker¹, Yakeel T. Quiroz^{1,3,†}

¹Department of Psychiatry, Massachusetts General Hospital, Harvard Medical School, Boston, MA, USA.

²Department of Psychological and Brain Sciences, Boston University, Boston, MA, USA.

³Department of Neurology, Massachusetts General Hospital, Harvard Medical School, Boston, MA, USA.

Abstract

Alzheimer disease and related dementias (ADRD) present considerable challenges to health-care and medical systems worldwide, especially in low-income and middle-income countries. In this Perspective, we leverage our experience and expertise with older Latino groups to review and discuss the need to integrate cultural factors into dementia research and care. We examine the importance of considering the effects of cultural factors on clinical presentation and diagnosis, dementia risk factors, dementia research and recruitment, and caregiving practices, with a focus on minoritized groups in the USA. We highlight critical gaps in the literature to stimulate future research aimed at improving ADRD prevention and early detection of ADRD and developing novel treatments and interventions across ethnoracially diverse populations. In addition, we briefly discuss some of our own initiatives to promote research and clinical care among Latino populations living in the USA.

Introduction

Alzheimer disease (AD) and related dementias (ADRD) are predicted to become one of the greatest challenges facing health-care and medical systems worldwide¹, especially in low-income and middle-income countries, where the number of older people is predicted to increase by 185% by 2050². The demographics in countries such as the USA are also rapidly changing with the expansion of populations traditionally considered as minority ethnic and racial groups. Hispanic/Latino/a/e, – hereby referred as Latino individuals – generally include persons of Cuban, Mexican, Puerto Rican, South or Central American, or other Spanish culture or origin regardless of race, and are the fastest growing subpopulation among aged individuals in the USA³. Latino and Asian populations are expected to surpass the Black population as the largest minority groups in the U.S in the coming decades.

[†] yquiroz@mgh.harvard.edu .

The authors contributed equally to all aspects of the article.

Ethnic and racial disparities in dementia research have been documented⁴. In the USA, older Black and Latino individuals are more likely than older white individuals to have ADRD⁵, but also have an increased risk of missed or delayed diagnosis^{6,7}, a disproportionately high rate of misdiagnosis of cognitive disorders⁸ and a reduced likelihood of being informed of their dementia status by their doctor⁹. These factors all impede access to timely and effective early interventions and recommendations, resulting in worse outcomes for the patient, caregiver and family^{10,11}.

Culture — a set of traditions, beliefs, values and living styles shared by a group of individuals — is a key component of a person's life; it is integrated into people's behaviours and passed through generations¹³. Culture consists of factors such as language, religion and spiritual beliefs, gender roles, geographical location or country of origin, education, upbringing and migration history. Culture also has a crucial roles in health behaviours, perception of illness and even the aetiology of dementia, all of which can contribute to delays in diagnosis and treatment¹⁴ as well as influencing the risk of and resilience to AD.

The cultural, racial and ethnic diversity in the USA and worldwide creates an urgent need to promote cultural competence and awareness by increasing multicultural education and training among clinicians and researchers in the field of ADRD⁴. Culture should be considered when conducting clinical evaluations to diagnose cognitive impairment or dementia, and should also inform the design of clinical and research studies, not only to increase research engagement of diverse individuals who are more representative of the larger population but also to enable equitable clinical research and care that is relevant to diverse communities. The goal of this Perspective is to highlight key considerations of multicultural research and clinical practices in the field of ADRD, with particular attention to the challenges and opportunities of working with ethnically and racially diverse populations. Specifically, we focus on the role of cultural factors in clinical evaluations, dementia risk, research and study recruitment and caregiving experiences in the Latino population living in the USA.

Clinical evaluation

Culture has an important role in the expression and manifestation of symptoms (for example, anxiety, depression or cognitive concerns), as well as reporting of symptoms, perceptions of their causes, coping mechanisms and help-seeking behaviours. Therefore, it is important to conduct a comprehensive clinical evaluation, including assessment of behavioural and psychiatric symptoms, that integrates relevant cultural factors within a biopsychosocial framework (BOX 1)^{15,16}. For instance, individuals often believe that ageing is associated with cognitive decline and might view AD symptoms such as memory loss as part of 'normal ageing'. Cognitive or behavioural changes can sometimes be dismissed, or people might be reluctant to report mood symptoms or seek an evaluation to assess memory concerns. In some Latino cultures, AD might be viewed as a punishment from God, witchcraft ('brujeria'), or a sign of mental illness or going crazy ('volverse loco'), all of which carry additional sociocultural stigma for the individual and their family¹⁷, which can also lead to delays in seeking treatment¹⁷.

Neuropsychological assessment is important for detecting, diagnosing and monitoring cognitive change over time, as well as for guiding treatment and recommendations. However, most neuropsychological tests were originally developed in western, English-speaking, non-Latino White populations. Performance on these tests can be affected by a range of interacting cultural factors, including macrosocietal structures (for example, economics, sociopolitical history, government structures and educational systems) and individual characteristics, such as cultural values, race, ethnicity, racial socialization, socioeconomic status, language, educational attainment, literacy and immigration history^{18–20}. In the USA, several sets of guidelines and standards have been developed to improve the cultural competence and awareness of clinicians when working with linguistically and culturally diverse individuals^{15,16,21}, including the National Standards for Culturally and Linguistically Appropriate Services (CLAS) from the Office of Minority Health of the US Department of Health and Human Services, as well as specific considerations for the assessment of culturally diverse individuals^{22,23}. Similarly, the ECLECTIC framework²⁴ has been proposed to guide neuropsychological assessment by integrating an individual's relevant cultural factors that affect test performance, such as education and literacy, culture and acculturation, language, economics, communication style, testing situation, how intelligence is defined and migration history.

The opportunity to learn, defined by the American Psychological Association as “the extent to which individuals have had exposure to instruction or knowledge that affords them the opportunity to learn the content and skills targeted by the test²²”, is influenced by both duration and quality of education. Literacy skills and education affect neuropsychological test performance, as they shape both cognitive processes and test-taking abilities²⁵, which might, in turn, have an impact on test fairness, for example, via content bias, testing context, test response, accessibility and/or validity²². In addition, low education levels have been identified as a risk factor for dementia^{1,26}. Although efforts have been made to develop neuropsychological tests and normative data to assess individuals from diverse ethnic and racial groups with high rates of illiteracy and/or low levels of formal education (see review), including the Rowland Universal Dementia Assessment Scale²⁷, NEUROPSI²⁸ and the Figure Memory Test²⁹, additional tools and normative data are needed to better characterize cognitive functioning in these individuals³⁰.

Culture also influences performance on neuropsychological tests³¹, as these tests generally measure learned abilities that are influenced by an individual's lived experiences and learning opportunities. Moreover, neuropsychological evaluations rely on procedures and values that are inherently culture-dependent, such as the examinee–examiner relationship, the use of stereotyped language in standardized testing instructions and familiarity with the testing materials, which can influence various aspects of the testing approach, including speed, strategy and task engagement.

Acculturation — that is, the process of assimilation to another culture — is another factor that has been shown to affect neuropsychological test performance³². The level of acculturation can be ascertained during the clinical interview by gathering information regarding age at the time of immigration, exposure to culture, and cultural identity, behaviour, language and values, and can also be assessed more formally through validated

questionnaires, such as the Abbreviated Multidimensional Acculturation Scale³³, the Short Acculturation Scale for Hispanics³⁴ or the Asian American Multidimensional Scale³⁵).

Taking all of these factors into account, careful selection of cognitive measures is paramount to ensure the construct validity of instruments within a culture or population. In addition, the reference population to which an individual's performance on cognitive testing will be compared, termed the normative data, must be from an appropriate culturally representative sample. To this end, a growing number of initiatives in cross-cultural neuropsychology are being established^{27,36–38}, including work to develop culturally appropriate measures for Spanish-speaking individuals, such as the Brain Health Assessment^{39,40} and the Latin American Spanish version of the Face–Name Associative Memory Exam (LAS-FNAME)⁴¹, and to obtain normative data from several Spanish-speaking countries, including Colombia⁴², Ecuador⁴³, the USA²⁹, Mexico⁴⁴, the US–Mexico border region⁸ and Spain⁴⁵. Similarly, the US National Alzheimer's Coordinating Center has worked on translating and adapting the Uniform Data Set 3 (UDS3), which is used in the standardized annual evaluations conducted at the National Institute on Aging (NIA)-funded Alzheimer's Disease Research Centers (ADRCs) across the USA⁴⁶, for use in diverse Spanish-speaking Latino populations, and efforts are underway to include social determinants of health measures. Despite recent strides, however, tools and normative data to assess culturally and linguistically diverse individuals continue to be scarce, and culturally tailored interventions are lacking. Further research is needed to examine cognitive ageing and ADRD risk factors in diverse, minoritized and underrepresented individuals in the USA.

Cultural diversity is also linked to linguistic diversity. Thousands of languages are spoken worldwide, and in the latest US census, 22% of residents reported speaking a language other than English at home⁴⁷. Neuropsychological evaluation of bilingual and multilingual individuals poses key challenges,^{21,48} a lack of competency and training among clinicians, and limited tools and normative data to assess these individuals. Despite the availability of tests such as the Multi-Lingual Naming Test (MINT)⁴⁹, the Bilingual Verbal Abilities Test⁵⁰ and the Receptive and Expressive One-Word Picture Vocabulary Tests — Bilingual Edition⁵¹, patients often experience delayed diagnosis or misdiagnosis¹¹. Research into bilingualism and multilingualism offers unique opportunities to explore mechanisms of resilience and reserve in ADRD^{52–55} and to examine the impact of linguistic factors on cognitive presentations and trajectories^{11,56}.

Neuropsychological evaluations should preferably be conducted in the patient's primary language by a clinician who is proficient in that language. However, in the USA, few neuropsychologists have the necessary proficiency in non-English languages and competency in cultural neuropsychology²¹. If an appropriate referral is not available, interpreters can be used to conduct the evaluation⁵⁷; though, clinicians would still require comprehensive training and expertise in cultural neuropsychology to understand the cultural factors that may influence neuropsychological performance^{23,48,58}. Language and culture influence communication and interpersonal style (for example, interactions between various social roles, self-disclosure, and establishing rapport and trust), as well as non-verbal communication (for example, eye contact, expressions, gestures and interpersonal distance),

all of which are integral aspects of behavioural observations during a neuropsychological evaluation.

Cultural factors, together with sociodemographic and linguistic factors, are important when assessing functional abilities to determine a clinical diagnosis. This process requires careful review of an individual's development, educational and occupational history within a cultural context. Alongside presenting concerns, evaluation of functional abilities is important to avoid bias in the assessment process. For example, individuals who perform below average on cognitive tests might be independent in performing activities of daily living, whereas individuals with high cognitive reserve might report subtle difficulties managing activities of daily living while continuing to perform above average on cognitive tests.

One of the main goals of clinical evaluation and neuropsychological assessment is to provide recommendations regarding issues such as driving, supervision, compensatory strategies, referrals to specialty services (for example, neurology, psychiatry or psychology), speech and language therapy, cognitive rehabilitation and educational resources⁵⁹. However, marked disparities exist in the use and availability of neuropsychological services, as well as specialty services such as neurology, psychiatry, speech and language therapy and cognitive rehabilitation, among minoritized groups owing to systemic, cultural and language barriers. These barriers include racism and discrimination, as well as inequalities with regard to health-care access, financial and time resources, language proficiency, and access to linguistically and culturally congruent providers¹¹. Moreover, minoritized groups experience marked disparities in access to culturally relevant and appropriate recommendations.

Dementia risk factors

The aforementioned racial and ethnic disparities in dementia prevalence raise the possibility that, in addition to differences in genetic predisposition⁶⁰, disparities in sociocultural factors place individuals from certain groups at an increased risk of dementia. Lifestyle habits and genetic risk are reported to be independently associated with the risk of dementia and cardiovascular disease (CVD), and a healthy lifestyle might substantially decrease dementia risk regardless of genetic risk (BOX 2)^{61–63}. The few published studies that have addressed differences in risk factors in culturally diverse groups consistently suggest that a plethora of sociocultural factors could account for disparities in dementia prevalence between groups. Fortunately, many of these sociocultural risk factors are modifiable and, thus, represent a promising avenue for creating public policy and interventions that can help decrease dementia risk across racially and ethnically diverse groups.

CVD, which encompasses coronary artery disease and stroke, as well as obesity, hypertension, diabetes, tobacco use and hypercholesterolaemia, is one of the most notable risk factors for dementia⁶⁴. These conditions are highly prevalent in the USA, particularly among Black, South Asian and Latino individuals^{5,65,66}. Within the US Latino population, differences in CVD risk factors have been reported among individuals from different backgrounds⁶⁵. Specifically, Puerto Rican individuals have significantly higher rates of CVD risk factors than people from Mexican, Cuban, Dominican, Central American and South

American backgrounds⁶⁵. Studies have also shown that South Asian individuals have the highest CVD-associated mortality rates in the USA^{67,68}. In addition, within the US Latino population, CVD and related risk factors were found to be more prevalent among US-born individuals who had low education levels, low socioeconomic status and/or high levels of acculturation than among individuals who were foreign-born or first-generation immigrants, had lived in the USA for less than 10 years and/or for whom Spanish was the preferred language^{65,69}. In fact, greater acculturation has been associated with worse health outcomes and behaviours detrimental to health, including greater substance use and less nutritious diets in some groups, particularly those experiencing financial hardships^{69–71}.

Poor diets and sedentary lifestyles also contribute to cognitive decline and dementia risk, as they increase inflammation levels, AD pathology burden and CVD risk^{72–76}. Consequently, individuals from cultures and environments that promote diets low in saturated fat and high in plant-based products, and that foster physical activity, might have greater protection against dementia^{77,78}. Individuals from various ethnic and racial groups who report leading sedentary lifestyles have identified multiple barriers to engaging in physical activity. These barriers include the perception that exercise is expensive and unimportant, which is also highly associated with lower socioeconomic status, low literacy, depression, insufficient time, and limited access to recreational centres, sidewalks, parks or other facilities^{79,80}. Thus, policies that aim to improve the infrastructure of cities, access to affordable fitness facilities and healthy foods, and cultural values surrounding diet and physical activity could substantially help individuals to lead healthier lives. A 2020 Lancet Commission report identified additional factors that contribute to dementia risk, including excessive alcohol use, untreated depression, limited social contact, hearing loss, traumatic brain injury, air pollution, smoking and poor sleep, some of which are more prevalent in low-income populations¹. By contrast, factors have been identified that protect against dementia, including attaining a high level of education, engaging in stimulating cognitive activities, and bilingualism or multilingualism. As such, countries that provide free and quality access to education and learning and encourage the use of two or more languages might help to confer protection against dementia^{81–83}.

Taken together, the evidence suggests that multiple modifiable sociocultural factors influence dementia risk (BOX 2). Consideration of cultural values and countries' and individuals' economic resources, and implementation of public health policies could potentially contribute to reducing the incidence of dementia worldwide. The differences in risk factors and perceptions of health between ethnically and racially diverse groups also highlight the need to tailor interventions to an individual's cultural background.

Dementia research

Racial and ethnic disparities in recruitment and participation in AD trials are a persistent problem^{84,85}. Raman and colleagues⁸⁶ examined data from the Anti-amyloid Treatment in Asymptomatic Alzheimer's Disease (A4) trial, a study of an anti-amyloid- β monoclonal antibody, and reported racial and ethnic differences in recruitment sources, demographic and clinical characteristics, and reasons for exclusions, all of which have important implications for research and therapeutic development in AD^{87,88}. Dementia research studies require

careful consideration of cultural factors that are important to the participants and of potential barriers with recruitment and retention that could arise owing to cultural differences. A qualitative study of Chinese–American dementia caregivers revealed that barriers to participating in research included cultural stigmatization of a dementia diagnosis and the perception that research studies are invasive and offer little to no direct benefit to the participant or their community⁸⁹. Among Black individuals in the USA mistrust towards research institutions persists owing to racist, unethical and involuntary research practices in studies as recent as the 20th century⁹⁰. In the Latino population, lower levels of formal education, inequitable health-care access and perceptions about the brain and ageing are some of the common barriers to recruitment for research studies^{91,92}.

To improve recruitment and retention, investigators must culturally diversify their research teams to reflect the communities that they intend to serve. More ethnically and racially diverse research teams can better understand and be better equipped to partner with communities in addressing the systemic barriers that affect recruitment of culturally diverse research participants. In addition, they can actively serve as liaisons between these communities and ongoing research studies through community partnerships, such as tabling events and speaking engagements at community centers (for example, churches or community fairs). Community events can provide excellent opportunities to disseminate information regarding brain health, cognitive decline and dementia, gauge attitudes and identify barriers to participating in research, and even offer brief assessments of memory concerns⁹³, which can ultimately facilitate recruitment in dementia research. Offering culturally and linguistically appropriate memory screenings at community centres in diverse neighbourhoods, and advertising these events through varied sources and in multiple languages, can help mitigate disparities in study recruitment and participation. Interpretation of data from studies of diverse groups also needs to be done in a culturally competent fashion⁹⁰.

Given that dementia affects not only the person with the condition but also their family and community, culture impinges on dementia research in many ways. One aspect of cultural identity that is often forgotten when designing a study recruitment protocol is the patient's geographical history, that is, where they were born and raised and have lived for most of their life. A person's culture reflects not only their customs but also the broader community in which they were raised, so it is important to consider potential geographical links to dementia risk. For example, research has shown that exposure to air pollution is related to an increased incidence of dementia⁹⁴, elevated levels of neurodegenerative disease biomarkers in people with cognitive impairment⁹⁵, and accelerated rates of cognitive decline, such as in memory encoding⁹⁶. In the USA, Black and Latino individuals are more likely than white individuals to live in neighbourhoods with elevated levels of air pollution^{97,98}. However, some communities in which White individuals tend to predominate, such as the coal mining communities of West Virginia, also have increased levels of dementia mortality⁹⁹. The Area Deprivation Index (ADI)¹⁰⁰ is a validated, neighbourhood-level composite index that captures data from 17 social determinants of health and can be used as a useful proxy to examine neighbourhood disadvantage in ADRD research studies.

Several US organizations have provided guidance on the recruitment of more diverse samples¹⁰¹. The NIA, for example, has published recommendations for increasing enrolment and retention of culturally diverse research participants¹⁰², including the Alzheimer's & Dementia Outreach, Recruitment & Engagement (ADORE)¹⁰³ resources. Similarly, the NIH actively encourages researchers to collect information on the enrolment of racially diverse participants¹⁰⁴, and the Institute on Methods and Protocols for Advancement of Clinical Trials in ADRD (IMPACT-AD) has developed a course to help increase diversity among ADRD clinical trialists¹⁰⁵. In addition, groups such as the Alzheimer's Clinical Trial Consortium¹⁰⁶ are providing training and cross-institutional support for the recruitment of diverse individuals in clinical trials.

Researchers should be aiming to create meaningful, appropriate partnerships with community organizations and leaders such that they are viewed not solely as people working on abstract scientific questions but rather as individuals who can provide direct benefits to the community, for example, through speaking engagements to promote healthy aging and sharing findings and new study goals in plain language (BOX 3). The experience of our group and collaborators working with Latino populations in Boston (MA, USA) and surrounding areas indicates that creating and nurturing these community partnerships requires considerable investment on the part of the research team and identification of key community partners (for example, community activists, clergy or politicians) to reach communities that have been historically marginalized and excluded from research. Building these partnerships takes intentional efforts and dedicated time to liaise with communities and understand their needs, which in turn can be used to shape culturally informed research studies. In addition, community engagement could allow greater transparency when reporting research findings, thereby providing a valuable service to participants by conveying clinically relevant information.

Dementia caregiving

Evidence highlights the presence of cultural, ethnic and racial differences in the physical and mental health of dementia caregivers. For instance, in the USA, Black and Latino caregivers tend to report greater adverse physical health outcomes than non-Latino white caregivers^{107,108}. Across studies^{108,109}, Black caregivers report better psychological well-being when compared with non-Latino white caregivers, whereas Latino and Asian American caregivers tend to experience higher levels of emotional stress and depression. As emphasized in a 1997 paper by Aranda and Knight¹¹⁰, multiple factors underlie discrepancies in caregiver outcomes across cultural, ethnic and racial groups (BOX 4).

In the USA, ethnic and racial minoritized groups, including indigenous groups, engage in more caregiving hours than non-minoritized groups¹¹¹ but make less frequent use of formal services^{112–114}. This disparity in service use has been linked to several factors, including unavailability of health insurance; limited knowledge or understanding of dementia; language or other communication barriers; limited knowledge by health professionals on cultural differences in the expression of mental illness; and mistrust of Western medicine^{114,115}. Compounding this issue, Latino and Black caregivers report lower household incomes, on average, than non-Latino White or Asian American caregivers and

devote a greater proportion of their income to caregiving activities, leading to a greater overall financial burden¹⁰⁷. Caregivers from diverse cultural, ethnic and racial groups might, therefore, lack resources and face substantial obstacles to accessing adequate health-care services.

Multiple sociocultural factors influence perceptions and attitudes toward caregiving, including faith, cultural norms, beliefs and values (for example, sense of obligation or devotion toward family members, often referred to as ‘familism’) and perceptions of the ageing process^{116,117}. Compared with non-Latino White and Asian American caregivers, Latino and Black caregivers more often report that caregiving provides them with a sense of purpose. Black and Latino individuals also report more positive caregiving experiences¹¹⁸ and stronger cultural motivations (for example, sense of duty, expectations and values) for providing care¹¹⁹. These positive conceptualizations of the caregiving experience might act as a buffer to reduce adverse emotional impacts^{114,119}. However, other forms of sociocultural conceptualization seem to be detrimental. For instance, sociocultural stigma and social embarrassment associated with a diagnosis of dementia or patients’ behavioural disturbances are important stressors that increase the risk of adverse emotional outcomes^{120,121}. Thus, sociocultural values and expectations could both enhance and impair the emotional well-being of dementia caregivers.

The scarcity of culturally specific research and interventions in the field of dementia caregiving is an important factor to consider when interpreting differences in caregiver outcomes across cultural groups¹²². Interventions that integrate specific sociocultural characteristics could be more effective in terms of outcomes, satisfaction, adherence and costs than interventions that do not take these characteristics into account¹²³. Although caregivers share many common stressors, culture must be recognized as an important component in any efforts to explore differences in caregiver well-being or in the implementation of interventions^{124,125}. Initiatives are being introduced to address this issue, including Resources for Enhancing Alzheimer’s Caregiver Health II (REACH II) — a multicomponent, evidence-based programme that offers specialized educational and counselling services to culturally diverse caregivers of people with dementia^{126,127} in the USA, including Non-Latino white, Black and Latino as well as American Indian and Alaska Native communities¹²⁸. Despite such efforts, however, an estimated two-thirds of published intervention studies in the field fail to stratify results by racial or ethnic groups¹¹², highlighting the limited attention to racial and ethnic differences and cultural factors. As discussed in greater detail in the next section, the lack of representation of diverse cultural groups in dementia research, including dementia caregiving, is an important limitation to current knowledge and clinical practices¹²².

To develop effective interventions, an urgent need exists to characterize factors that influence the physical and emotional well-being of dementia caregivers. Importantly, research into dementia caregiving should recognize the intersectionality and evolving nature of sociocultural factors, health-care systems and dementia care needs in relation to caregiver outcomes¹²⁴. For example, caregiver individuals who self-identify as lesbian, gay, bisexual, transgender and/or queer (LGBTQ) might face additional challenges that result in greater caregiver strain¹²⁹. Therefore, future research studies must apply culturally

relevant theoretical models and adapted measurements and recruit diverse and inclusive samples, recognizing the presence of culturally distinct subgroups within larger ethnic and racial groups. This effort is crucial to appropriately address the needs of the culturally and ethnically diverse caregiving populations of patients with dementia and inform the development of effective interventions.

New initiatives

Our group in the Multicultural Alzheimer's Prevention Program at Massachusetts General Hospital (MGH) in Boston (MA, USA) has developed several initiatives and programmes to diversify research into ADRD. With the support of the NIA, we recently launched the Boston Latino Aging Study (BLAST). The goal of this study is to investigate the impact of various AD risk factors on cognition, brain function and molecular markers of AD pathology in older Latino individuals living in Boston and the surrounding areas. As part of the study, participants will undergo comprehensive cognitive assessments and biomarker testing. In addition, dementia risk factors, including physical inactivity, low social contact, sleep disturbances, depression, stress and obesity, will be assessed. This study will allow us to better characterize psychosocial factors, lived experiences and social determinants of health in this population. Of note, we carefully selected cognitive measures that have been validated in Latino individuals as culturally appropriate means to evaluate cognitive functioning in this population. Moreover, to ensure that the cohort is representative of the community and to maximize the generalizability of the findings, individuals will not be excluded on the basis of psychiatric or medical conditions (for example, depression or hypertension) that are well controlled.

We also recently launched the Multicultural Assessment and Research Center (MARC) at MGH to offer culturally and linguistically appropriate neuropsychological services, including clinical evaluations and cognitive training, to a diverse range of adults, including monolingual and bilingual Spanish speakers and individuals who speak neither English nor Spanish. This centre aims to integrate clinical and research work and to advance cultural neuropsychology research and training, for example, by developing novel measures and normative data. Importantly, the administrative staff, clinical leadership and staff neuropsychologists at MARC are multicultural and multilingual and have received specialized training in multicultural neuropsychology. A major objective of the centre, beyond facilitating access to high-quality clinical services, is to provide training opportunities in multicultural neuropsychology for individuals at different training stages, so as to enhance diversity in the field of ADRD.

MARC's goals also include expansion of patient access to research and clinical studies by using novel tools, such as remote cognitive assessment. Our remote cognitive assessment work includes understanding the psychometric properties of existing cognitive measures administered with the patient in their own home¹³⁰, as well as ongoing work focusing on the development and norming of several new digital cognitive measures that individuals will be able to self-administer on personal electronic devices¹³¹. Careful consideration of culture is central to this line of work, and we are currently assessing the cultural utility and validity of the new digital measures in English, Spanish and Korean speakers. We aim to make these

remotely administered cognitive tests available on a variety of electronic devices, including computers, smartphones and tablets, to facilitate use in individuals with varying levels of technological literacy and familiarity. Having a range of methods to remotely administer cognitive tests should enable researchers to provide equitable access to these tests.

Conclusions and future directions

In this article, we have argued that cultural factors — together with socioenvironmental factors — should be integrated into dementia research. Research from the USA shows that older Black and Latino individuals are disproportionately more likely to have ADRD than older non-Latino white individuals. However, most ADRD studies conducted in this region have not included a good representation of diverse participants, thereby limiting our knowledge of normal ageing, cognitive decline and AD biomarkers among diverse and/or minoritized groups. Therefore, an urgent need exists to promote recruitment and retention of diverse individuals in ADRD research.

Beyond recruitment strategies to engage diverse individuals in ADRD research, cultural factors also need to be integrated into the design and implementation of clinical studies. For instance, common inclusion and exclusion criteria, such as basic literacy skills and exclusion of participants with major medical, neurological and/or psychiatric conditions, limit the generalizability of the results, as findings from a highly selected research sample might not be representative of the general population. Language barriers to study participation also need to be addressed: although approximately 22% of US residents report speaking a language other than English at home, most studies conducted in the USA require proficiency in English to participate.

Cognitive performance is commonly a major variable of interest or outcome measure in ADRD research, and culture influences performance on neuropsychological tests⁸. Most neuropsychological tests were originally developed in western, English-speaking, non-Latino white populations, which might affect recruitment and measurement of cognition in diverse populations. Furthermore, we need to explore how sociocultural and environmental factors, along with social determinants of health and lived experiences, such as racism, discrimination, acculturation, bilingualism, immigration history and social support, influence dementia risk and progression. In addition, recruitment, support and retention of diverse research teams and leaders is paramount to establishing partnerships with communities and provides the foundation for diversifying research in ADRD.

In conclusion, the goal of this Perspective was to highlight the need to integrate cultural factors in dementia research. We reviewed the importance of considering the effects of cultural factors on clinical presentation and diagnosis, dementia risk factors and caregiving practices in diverse populations in the USA. We highlighted crucial gaps in the literature to prompt future research that advances the field towards improving prevention, early detection and development of novel treatments and interventions in diverse populations. In addition, we hope that the discussion of some of our own research and clinical initiatives will guide other investigators who wish to expand their research or clinical work to more diverse populations.

Competing interests

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Box 1 |**Clinical evaluation: key points and recommendations**

- Cultural factors need to be considered in clinical evaluations to diagnose cognitive impairment or dementia, as well as to inform the design of clinical and research studies in Alzheimer disease and related dementias (ADRD).
- Clinicians should follow proposed cultural guidelines, standards and clinical frameworks, such as ECLECTIC.
- Cultural factors, including cultural values and identity, race, ethnicity, socioeconomic status, language, educational attainment, occupational history and immigration history, should be integrated into clinical evaluations.
- Consideration of cultural and linguistic factors, including acculturation, education, literacy and bilingualism, can facilitate selection of cognitive measures and norms, assessment of functional abilities, and clinical case conceptualization and diagnosis.
- Following the evaluation, culturally relevant and appropriate recommendations should be provided.
- Research examining the impact of sociocultural and linguistic factors on cognitive presentations and trajectories is required to guide clinical evaluation and help to mitigate health disparities in the field of ADRD.

Box 2 |**Risk factors: key points and recommendations**

- Healthy lifestyle factors can decrease dementia risk independently of genetic risk.
- Cardiovascular disease, smoking, sedentary lifestyles, poor diet, low socioeconomic status and greater levels of acculturation are associated with an increased risk of dementia in the USA.
- Multiple risk factors, including cardiovascular disease and financial hardship, are particularly prevalent among ethnic and racial minority groups in the USA.
- Exercise, a healthy diet, engaging in stimulating cognitive activities, and bilingualism or multilingualism can all help to mitigate dementia risk.
- Culturally informed interventions and public health policies that promote healthy lifestyles (for example, greater physical activity and healthier diets) represent a promising avenue to substantially reduce dementia risk.

Box 3 |**Dementia research: key points and recommendations**

- Racial and ethnic disparities in recruitment and participation in research and clinical trials creates concerns about the generalizability of research findings, and limits research advances and development of clinical treatments and interventions in Alzheimer disease and related dementias (ADRD).
- Increasing cultural diversity in ADRD research requires intention and dedication by researchers to recruit and retain culturally diverse participants, research teams and leaders.
- Partnerships between researchers with trusted community hubs and leaders (for example, churches, community fairs and cultural events) can promote recruitment and research engagement of historically marginalized and excluded communities.
- Anecdotally, the experience of our research group and others suggests that building meaningful partnerships with diverse communities not only bolsters recruitment efforts but also informs the design of research studies that are meaningful to participants and communities.
- Formal guidance for increasing enrolment and retention of culturally diverse research participants is available, such as the Alzheimer's & Dementia Outreach, Recruitment & Engagement (ADORE) resources curated by the National Institute on Aging.

Box 4 |**Caregiving: key points and recommendations**

- Cultural, racial and ethnic differences in the health and emotional outcomes of dementia caregivers have been reported.
- Multiple sociocultural factors, including faith, cultural norms, beliefs and values, influence perceptions and attitudes toward caregiving.
- Caregivers from diverse cultural, ethnic and racial groups might have limited resources and face substantial obstacles accessing adequate health-care services.
- A need exists to develop culturally specific research and effective interventions to appropriately address the needs of the culturally and ethnically diverse caregiving populations for patients with dementia.