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PERSPECTIVE

Promoting diverse perspectives: Addressing health disparities related to Alzheimer's and all dementias

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Abstract

Dementia research lacks appropriate representation of diverse groups who often face substantial adversity and greater risk of dementia. Current research participants are primarily well-resourced, non-Hispanic White, cisgender adults who live close to academic medical centers where much of the research is based. Consequently, the field faces a knowledge gap about Alzheimer's-related risk factors in those other groups. The Alzheimer's Association hosted a virtual conference on June 14–16, 2021, supported in part by the National Institute on Aging (R13 AG072859-01), focused on health disparities. The conference was held entirely online and consisted of 2 days of core programming and a day of focused meetings centered on American Indian and Alaska Natives and on LGBTQIA+ populations. Over 1300 registrants attended discussions focused on the structural and systemic inequities experienced across diverse groups, as well as ways to investigate and address these inequities.

KEYWORDS
disparities, diversity, LGBTQIA+, racial/ethnic minorities, sexual and gender minorities

1 | INTRODUCTION

Despite research advances in Alzheimer's disease and related dementias (ADRD) over the past three decades, their generalizability has been called into question due to low representation of those from minoritized backgrounds in studies. Diverse life experiences bring with them different risks and protective factors for disease. To capture how living conditions over the life course can affect a person's health and well-being, the Social Determinants of Health (SDoH) framework was developed. This includes consideration of a person's economic characteristics, education, health care, built environment, and community and how these factors change over the lifetime. Understanding how these variables affect different groups and their risk or protection from diseases, including ADRD, is essential.[1]

Health disparities refer to avoidable, higher burdens of illness, disability, or mortality in one group relative to another, whereas disparities in health care mean that groups differ in terms of access to optimal diagnostics and care.[2,3] These disparities are linked to the SDoH-related milieus of different groups. Ideally, the benefits of science and health care would be equally available and accessible for all people, regardless of gender, gender identity, race, ethnicity, geography, sexual orientation, or socioeconomic status. Yet this ideal remains unrealized. In a recent special report from the Alzheimer's Association ("Race, Ethnicity, and Alzheimer's in America"),[4] surveys found that Blacks, Hispanics, Asian Americans, and Native Americans experienced multiple barriers to ADRD treatment and care, and substantial numbers reflected a lack of trust in medical research and the scientists conducting ADRD research.

Efforts to study and reduce health disparities are under way and must always be sensitive to the experiences and viewpoints of different groups based on lived experience. For example, researchers need to find ways that refer to subgroups in ways that are both descriptive and respectful. The nomenclature target is moveable, however; no terms will be accepted by all, and these will likely fall out of favor eventually. Agreeing on some guidelines can help standardize the nomenclature used by scientists and in some cases may even sharpen the question addressed in a study. No matter the question relevant to health disparities, advising the community and identifying affirming terms is an essential first step. References with adjectives are often preferred (eg, Black participants instead of Blacks), and situational descriptors offer precision (eg, instead of saying "disadvantaged," specify how the group is disadvantaged, as in people from a neighborhood who lack material advantage).[5] A number of resources and style guides have been developed to provide guidance on the use of terminology and lexicon in research. One such example, the Alzheimer's Association Inclusive Language Guide, which was developed with input and critical feedback from the broader ADRD scientific community, experts in health disparities and aging, and ADRD patient and advocacy organizations, emphasizes the considerable variability in global, regional, and local contexts that necessitates flexibility in nomenclature and communication style.[6]

To highlight these health disparities and to identify strategies for overcoming them in the field, the Alzheimer's Association, supported in part by the National Institute on Aging (NIA) (R13 AG072859-01), convened a 3-day conference in June 2021. Due to the COVID-19 pandemic, the meeting was virtual, yet it featured over 1300 registrants and a multidisciplinary array of speakers, as well as a day of strategic focus meetings organized around American Indian and Alaska Native (AIAN) populations and Lesbian, Gay, Bisexual, Transgender, Queer, Intersex, Asexual, and additional identities (LGBTQIA+) populations.

The resulting conversations from the meeting highlighted the need for more inclusive participation and heterogeneous representation in

dementia research, to better understand the risk (defined as an individual's vulnerability to disease or illness), resilience (defined as an individual's ability to maintain optimal functioning), and protective factors (factors that contribute to an individual's overall resilience) operating among these diverse populations, as well as to obtain the relevant safety and efficacy data in treatment trials. A frequent touchstone was the NIA's Health Disparities Research Framework, which outlines research domains important for understanding health disparities related to aging.[3] These are categorized as environmental, sociocultural, behavioral, and biological determinants that impact health and well-being throughout a person's life course.

2 | STATE OF HEALTH DISPARITIES RESEARCH AND OPPORTUNITIES FOR ALZHEIMER'S AND ALL DEMENTIAS

In the opening plenary, Jennifer Manly, PhD, of Columbia University put forward that the recent US Food and Drug Administration (FDA) accelerated approval of aducanumab (Aduhelm) offers an emblematic example of how clinical trial study designs and recruitment and inclusion strategies fall short when considerations for SDoH and health disparities are not implemented.[7] Aducanumab is the first FDA-approved therapy since 2003 that is aimed at targeting an underlying biological hallmark of Alzheimer's disease (AD), amyloid beta plaques, with the goal of treatment being to change disease progression. This treatment received approval, but not without controversy, as only one Phase 3 clinical trial showed significant reduction in cognitive and functional decline for participants on the therapy.[8]

Diverse groups have historically been underrepresented in clinical trials. This trend persists in contemporary clinical trial data, and researchers must increase efforts to collect more information regarding the safety and effectiveness of this treatment in the broader population. The Phase 3 trials for aducanumab is just one example of this trend, with less than 1% of participants identifying as Black and less than 5% identifying as Hispanic.[8] The price tag for a treatment course of aducanumab – initially estimated at $56,000 and recently reduced to $28,200 – further adds to health inequities by imposing significant financial barriers to access for this new treatment. To make such findings more widely applicable, research must proactively create inclusive and representative participant pools, starting in the earliest stages of study conception, so the results can be more generalizable to all groups and populations that are most at risk for ADRD.

Even prior to treatment, disparities are at work. For example, the proportion of people with a delayed diagnosis of dementia is higher in Hispanic and non-Hispanic Black people compared to non-Hispanic White people.[9] As new treatments become available, this will likely have an impact on their ability to access them. Early life variables can substantially shape ADRD risk, such as less education being linked to lower executive function,[10] and geographic place of US birth being linked to lower baseline cognitive scores among those born in the US South.[11]

3 | STRUCTURAL ACCOUNTABILITIES TO REDUCE DISPARITIES IN ALZHEIMER'S AND ALL DEMENTIAS

A panel discussed societal structures, including research and medical institutions, funding agencies, and governmental bodies that are set up in such a way that they are not equally accessible to all. Identifying structural barriers is necessary in order to find the leverage points where action can be taken to reduce health disparities.[12]

Panelists argued that governmental bodies, through legislation and funding initiatives, should set priorities for addressing ADRD disparities. The panel highlighted other loci for change such as the research enterprise and the food industry. Research studies need to be realigned with the realities of health care practice by making clinical trials inclusive and by investing in infrastructure to attract, and create opportunities for, researchers and healthcare workers that reflect the diversity of the communities they work in. Granting institutions, too, need to recognize and fund community outreach components of research done in diverse communities in the United States, just as they do when the research is done in foreign countries.[13]

4 | ENVIRONMENTAL AND SOCIOCULTURAL DETERMINANTS OF DISPARITIES IN ALZHEIMER'S AND ALL DEMENTIAS

Socioeconomic and environmental factors that influence ADRD risk are often overlooked yet reflect deep-seated societal inequities and drive health-related behaviors. Quantifying these factors can be achieved through community input on innovative approaches to understanding environmental and social correlates of disparities. For example, an association between social activity and slower cognitive decline was not initially found among African American study participants until additional activities deemed important to the community, such as shopping with friends, were included in the social activity measure.[14] Further quantification can also be achieved using geo-precise multidomain indices of socioeconomic disadvantage, toxic exposures, the built environment, and other exposome measures.

Socioeconomic and environmental factors have detectable effects relevant to brain health. The Neighborhood Atlas (https://www.neighborhoodatlas.medicine.wisc.edu) is a free data democratization tool that compiles different datasets to calculate a neighborhood-level multidomain index of socioeconomic disadvantage called the area deprivation index (ADI). This tool has helped reveal associations between living in a disadvantaged neighborhood and cognitive decline and cortical thinning[15] as well as AD neuropathology.[16] These factors can have lasting effects; for example, living in racially segregated neighborhoods as young adults has been associated with worse processing speed and smaller brain volumes in midlife among African American adults.[17,18] Among women, any time spent in the paid workforce has been associated with slower memory declines.[19]

5 | BEHAVIORAL DETERMINANTS OF DISPARITIES IN ALZHEIMER'S AND ALL DEMENTIAS

Many studies have tracked how individual behaviors, such as exercise, influence dementia risk. [20] Yet, life course circumstances may exert considerable influence on how readily a person may make a lifestyle change. People who live in an unsafe neighborhood or for whom gym memberships are expensive may be less able to access and engage in these health-promoting behaviors. Actions that promote healthier contexts for all will require institutional commitments to allocate resources for this level of change. National dementia plans can also encourage changes that promote healthier environments, with a focus on strategic choices that can have cascading effects on multiple health-related behaviors.[21]

Education is a contextual factor that can powerfully shape a person's ADRD risk. In Latin America, dementia seems to arise earlier, and this may have to do with low education levels and poor control of cardiovascular risk factors.[22] A number of studies have documented the link between education, cognitive reserve, and dementia risk.[23,24] Studying this association in detail requires tools that can capture cognition in ways that rely less on literacy and that are validated in different populations.

Access to and engagement in health-promoting behaviors may also explain cognitive resilience. Some people with signs of AD-related brain pathology do not develop cognitive impairment; do lifestyle factors somehow mitigate the clinical manifestation of this pathology? Answers may arise from longitudinal studies, such as the Study of Healthy Aging in African Americans (STAR) (https://rachelwhitmer.ucdavis.edu/star), that capture a comprehensive range of information about health, behavior, birthplace, quality of education, and other factors and therefore may detect salient risk and protective factors.

Panelists noted the importance of gaining a community's trust when looking for participants in a research project or public health campaign. This may begin with outreach to respected people in the community to seed the formation of a community advisory board. This provides a space for researchers and healthcare workers to understand the community's concerns and interests. This style of relationship building with a community contrasts with past approaches when researchers "dropped in" on a community when they needed something, then left. Forming this kind of relationship with a community takes time and is fundamental to the integrity and success of these projects.[25,26]

6 | BIOLOGICAL DETERMINANTS OF DISPARITIES IN ALZHEIMER'S AND ALL DEMENTIAS

Biological factors that contribute to dementia risk may be sensitive to or contribute to health disparities related to aging. Keynote speaker Richard Morimoto, PhD, of Northwestern University described how aging affects many cellular functions,[27] including the quality control systems that govern protein manufacture. There are a series of molecules and signaling steps, called proteostasis, that direct how proteins fold into the correct shape and detect and destroy any that have misfolded. With age, however, the proteostasis efficiency declines, and this may help explain why proteins like amyloid-beta become toxic in AD. Potential targets that might restore proteostasis have been identified in the human brain.[28] Also, finding ways to mimic the mild cellular stress that prevents protein damage and promotes cellular longevity could help reduce dementia risk.[29]

The biology underlying ADRD has been the greatest focus of federally funded research to date, but insight from epidemiological, clinical neuropathological, or even biomarker studies has largely come from non-Hispanic White participants living in high-income countries. Recent work has challenged the generalizability of findings from studies, including national, lacking participant diversity. There are known genetic risk factors or disease-related mutations that are overrepresented in certain populations, but social determinants of health can also result in measurable biological changes (eg, exposome). For example, it has now been demonstrated in at least four cohorts that Black adults have lower levels of cerebrospinal fluid biomarkers related to tau than non-Hispanic White adults regardless of cognitive status.[30–32] It is not always straightforward to distinguish between ancestry-related risks and SDoH-related biological outcomes, and causal inferences can be difficult to validate.

Genetic characterization remains the most established approach in characterizing biological diversity in ADRD research. The full range of human genetic variation is still coming to light as more global populations have their genomes sequenced, yet ancestry can be global at the genomic level or local at the risk gene level. Because genomic traits reflect ancestral migration and cultural patterns, care must be taken not to confuse disparate findings in genetic risks with intrinsic biological differences. Genetic admixture and political determinants of health (including policies related to slavery and segregation) also means that genetic ancestry cannot be used as a proxy for the social aspects of race. In a study looking at both race and genetic ancestry information, self-identified non-Hispanic Black people showed lower brain levels of amyloid beta protein compared to non-Hispanic White people. When researchers further evaluated this by the proportion of African genetic ancestry contained within participant genomes, a lower percentage of African ancestry correlated with higher amyloid.[33] Another study highlights the presence of observable differences between estimates based on ancestry and race, despite the seemingly high degree of concordance between genetic ancestry and self-reported race.[34]

7 | MULTILEVEL DETERMINANTS OF DISPARITIES IN ALZHEIMER'S AND ALL DEMENTIAS WITH A FOCUS ON METHODS AND ANALYTICAL APPROACHES

When studying the origins of health disparities, looking at a single factor in isolation is a building block for understanding the fuller picture. Importantly, associations with dementia risk may not apply to everybody, which makes it essential to study diverse and well-characterized

cohorts, who ideally reside in the same neighborhood. This panel discussed opportunities in existing cohorts, such as the Washington Heights/Inwood Columbia Aging Project (WHICAP), to address some of these questions. This multiethnic cohort of over 6000 people living in the same neighborhoods in New York City have been followed for several years. This project helped reveal that white matter hyperintensities that commonly appear in the brain with age and that are correlated with memory and language decline are sensitive to education for some, but not all: years of schooling seemed to protect against white matter hyperintensities – but only in White people, not in Caribbean, Hispanics, or Black people.[35]

The Rush Alzheimer's Disease Clinical Core, a community-based prospective cohort based in the Chicago area, revealed similar profiles of AD-related brain pathology among cognitively unimpaired subgroups of Black, Hispanic, and White participants, whereas different pictures of pathology were seen among participants recruited from a memory clinic.[36] This indicates that groups recruited by different methods are not comparable and that careful attention to recruitment and retention methods is integral to a study's success.

8 | RESEARCH AND TRAINING OPPORTUNITIES

Diversifying the research workforce can propel understanding of health disparities, and a number of institutes involved in dementia research have programs to encourage this through support of health equity researchers in the early stages of their careers. The National Institute on Aging (NIA) has established a network of AD Resource Centers for Minority Aging Research (AD-RCMAR) around the United States. These centers mentor scientists from underrepresented groups and encourage researchers to take up questions related to health disparities and AD. The centers have supported researchers from diverse backgrounds, and since 2018 over 75% of these have been non-White. The RCMAR at Washington State University is notable for its focus on Native American communities (https://ireach.wsu.edu/nad-rcmar/). Approximately 50% of the mentors are AIAN or Native Hawaiian/Pacific Islanders (NHPI). Junior faculty and faculty new to the field receive intensive mentoring for careers in AD research among the priority populations. This involves funding, grant writing workshops, meetings with mentors and all mentors and mentees, and pilot studies.

The National Institute of Minority Health and Health Disparities also provides a granting mechanism (Clinical Research Education and Career Development [CRECD]) that helps potential researchers build the skills needed for clinical research. Since 2002, it has enrolled over 200 people in this program, over 90% of scholars were from underrepresented groups. Of the programs to enhance diversity at the National Institute of General Medical Sciences, the new Maximizing Opportunities for Scientific and Academic Independent Careers (MOSAIC) (https://www.nigms.nih.gov/training/careerdev/Pages/MOSAIC.aspx) program offers up to 5 years of research funding to help young researchers transition to running their own research programs. Participation in the program comes with mentorship, as well as contact with other grantees. Studies find that attentive mentorship can help retain people in science careers and give them a sense of belonging.[37]

9 | STRATEGIC FOCUS MEETINGS

9.1 | AIAN populations and health disparities

The AIAN population is diverse, with 574 federally recognized tribes across the United States. On average, AIANs have a lower income and higher poverty level than their White counterparts and more often experience chronic health conditions such as diabetes. Information on the incidence and prevalence of mild cognitive impairment (MCI) and ADRD in the AIAN population is insufficient; however, the increased life expectancy seen in recent decades has almost certainly increased ADRD in the population.[38] The AIAN population aged 65 and older will increase fivefold by 2050. While welcome news for tribal communities, the huge increase in the number of older AIANs may severely test the core cultural values of caring for elders.[39] The conceptualization of dementia may differ from the majority culture, and labeling elders with a diagnosis of dementia may be seen as disrespectful and inappropriate. A lack of awareness of ADRD also means that recognition and management of memory problems can be delayed, negatively impacting the possibility to intervene.[40]

Many AIAN people have ADRD-related risk factors, such as hypertension, diabetes, and obesity. Whether stress is an upstream driver of these chronic health conditions among the AIAN population warrants further study. The role of genetic factors in ADRD is unclear among the AIAN population. The genetic risk variant apolipoprotein E (APOE)-e4 does not appear to be associated with brain markers of ADRD risk.[41] Research suggests that vascular health of the brain may exert a greater influence on ADRD risk than APOE ε4 or that genetic risk is somehow offset by yet unknown protective factors and resilience.

Though many AIAN community members endorse the need to participate in ADRD research, the research community will need to tailor cognitive evaluations to AIAN culture and experiences.[42] Future studies will need to examine the operating characteristics of these tests in the AIAN elder population to understand whether these findings reflect the beginnings of cognitive decline or are an artifact of testing. Expertise for engaging with AIAN communities was also shared by a speaker involved in the National Heart Lung and Blood Institute's Strong Heart study (https://www.nhlbi.nih.gov/science/strong-heart-study-shs), which is geared toward understanding the high rates of heart disease among AIAN people. This identified recruitment as crucial in that it needs strategic and committed attention, investment, and consistent engagement. Talented community members need to be identified to build trust and to effectively work with this population.

9.2 | LGBTQIA+ population and health disparities

The LGBTQIA+ population is composed of subgroups of communities that are diverse in sexual orientation and gender identity. The health

disparities faced by LGBTQIA+ people are coming to light, and these may well shape their aging trajectory. However, not all health disparities are uniformly experienced by all LGBTQIA+ subgroups, and many subgroups remain underrepresented in health-related research. Some studies point to higher rates of poor health in the LGBTQIA+ population, including heart disease, diabetes, and depression, which may be caused or further exacerbated by the stress surrounding their experiences of oppression, stigma, and discrimination.[43] These experiences contribute to social inequities and may also leave LGBTQIA+ people socially isolated – LGBTQIA+ people are more likely to experience barriers to healthcare, more likely to experience poverty and economic insecurities, less likely to have a relationship with their family of origin, less likely to have children, and more likely to live alone than non-LGBTQIA+ people.[44] Whether their experiences with oppression and discrimination along with social isolation put them at risk for ADRD or if their social networks and community connections put them on a path of resilience remains unclear.[44,45]

Despite the burden of ADRD-related risk factors experienced by some in the LGBTQIA+ population, the field lacks a comprehensive picture of how cognition changes with aging in this group. A new study finds a higher prevalence of subjective cognitive decline or self-reported memory problems among LGBTQIA+ adults over 44 years old than in non-LGBTQIA+ adults.[46] This and other studies lack objective measurements of cognition, which will be necessary to understand the risk and resilience factors for ADRD in this population. This also highlights the importance of increasing participation of older adults who identify as LGBTQIA+ in ADRD research studies, particularly LGBTQIA+ adults who are also members of other marginalized groups and those underrepresented in ADRD research.

A full characterization of aging in the LGBTQIA+ population is also essential for developing interventions to mitigate risk factors. For example, data from the ongoing "Aging with Pride" longitudinal study has developed a new Innovations in Dementia Empowerment and Action (IDEA) intervention, which comprises a 6-week cognitive behavioral program focused on exercise, communication, and problem-solving skills.[47] It seeks to improve the quality of life for people with dementia and their caregivers, by both reducing stress and delaying institutionalization (https://ageidea.org). Other studies, such as one examining the long-term effects of living with HIV, including cognitive outcomes, may also have insights on aging in some of the subgroups represented within the LGBTQIA+ community.[48]

The field is also focused on supporting caregivers as they navigate the complicated effects of cognitive decline among their family and friends. Comprehensive surveys of caregivers of LGBTQIA+ individuals with dementia will help understand their needs, and training programs can be developed to help caregivers navigate senior service programs and long-term care settings.[49]

10 | SUMMARY

ADRD is the primary cause of disability and dependency worldwide, but it does not affect all populations equally. Research designed to understand, prevent, and ameliorate health disparities of any kind, including those relating to dementia, should be a public health priority. In the United States, African American, AIAN, Hispanic, and Latino populations are disproportionately at risk for developing dementia, and much less is known about dementia risk among LGBTQIA+ populations. As such it is critical that researchers, study sponsors, and regulatory agencies seek to better engage these populations in dementia research. Doing so requires new approaches to research funding, innovative recruitment methodologies, diverse research workforces, and accountability throughout the review process.

The Alzheimer's Association conference Promoting Diverse Perspectives: Addressing Health Disparities Related to Alzheimer's and All Dementia provided a platform for diffusion of learnings from successful and failed attempts at promoting equity in research on AD and all other dementias. While this meeting provided an opportunity to conduct an in-depth review and discussion on health disparities specific to AIAN and LGBTQIA+ communities, the Alzheimer's Association plans to highlight disparities impacting other marginalized communities in future meetings. The Alzheimer's Association, supported in part by the NIA ([R13 AG072859-01), plans to reconvened this conference in 2022.

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CONFLICT OF INTEREST STATEMENT

Maria Carrillo, Carl Hill, Percy Griffin, and Stephen Hall are full-time employees of the Alzheimer's Association. Gladys Maestre is an employee of the University of Texas Rio Grande Valley School of Medicine and, in the last 36 months, reports grants or contracts from the National Institutes of Health (NIH) (5P30AG059305, 1R13AG071167, 1P30AG066546, 1DP1AG069870, 1R13AG066391), consulting fees from the University of Texas Health Houston School of Public Health, serving on the Data Safety Monitoring Board or Advisory Board for Appremed, and holding a leadership or fiduciary role for Fundaconciencia, Inc. William Hu is an employee of Rutgers University and, in the last 36 months, reports grants or contracts from NIA, Rutgers University, TMCity Foundation, and Fujirebio Diagnostics, consulting fees from Fujirebio Diagnostics, Apellis Pharmaceuticals, Biogen, and Roche, and payment for expert testimony from Stern Edlin. William has patents pending on CSF-based prognosis of very mild AD and spinal muscular atrophy. Jason Flatt is an employee of the University of Nevada Las Vegas School of Public Health and, in the last 36 months, reports

grants or contracts from the NIA and the Michael J. Fox Foundation. Ganesh Babulal is an employee of the Washington University School of Medicine and, in the last 36 months, reports grants of contracts from the NIA (R01AG074302, R01AG068183, R01AG067428) and BrightFocus (A2021142S, SG-22-968620-ARCHES). Ganesh serves on the Data Safety Monitoring Board for SEABIRD and holds a leadership or fiduciary role for the Alzheimer's Association International Society to Advance Alzheimer's Research and Treatment Diversity and Disparities Professional Interest Area. Roland Thorpe is an employee of Johns Hopkins University. J. Neil Henderson is an employee of the University of Minnesota Medical School and, in the last 36 months, reports grants or contracts from the State of Washington Aging and LTC Services and Wallin Foundation for Alzheimer's Research, consulting fees from the State of Washington, and honoraria from the Great Lakes Inter-Tribal Council. 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SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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