Sociocultural Aspects and Determinants of Care for Alzheimer's Disease and Related Dementias (ADRD) among Minority Ethnic Populations

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EPIDEMIOLOGY OF ADRD AMONG MINORITY ETHNIC POPULATIONS

Although ADRD impacts all populations, it occurs at different rates, and has different consequences in different demographic groups (Arvanitakis, Shah, and Bennett 2019; Babulal et al. 2019; Gurland et al. 1999; Matthews et al. 2019; Plassman et al. 2011). While recent estimates in the U.S. note a decade of decline in dementia prevalence from 11.6 percent in 2000 to 8.8 percent in 2012, these favorable trends have not been equally experienced across all population groups (Langa et al. 2017). Although these downward trends in dementia prevalence may appear paradoxical given concurrent increases in diabetes and obesity rates over the last few decades, improvements in achieving treatment targets may have led to reductions in vascular and metabolic disease exacerbations, such as lower incidence of stroke, lower-extremity amputations, and myocardial infarction events, and generated lower dementia "spillover" effects (Langa et al. 2017). The myriad mechanisms and temporal relationships between morbidity risk factors and cognitive change preceding dementia onset are not clear, nor is it evident that improvements in chronic disease treatment and favorable dementia trends have equally benefitted older adults from underrepresented racial and ethnic backgrounds. Efforts to better understand population trends and the factors that influence dementia onset and progression remain critical priorities because of the vast clinical and policy implications involved in caring for persons with dementia.

Examinations of national data have long indicated higher prevalence, earlier onset, and greater severity at initial presentation among various minority ethnic groups in the United States (Matthews et al. 2019). Black Americans have consistently shown higher age-specific ADRD prevalence and incidence when compared to non-Hispanic white Americans. Further, differences in dementia subtype prevalence have been identified among minority ethnic older adults, with higher rates of vascular dementia among black Americans. In addition, black adults are often diagnosed later in the course of ADRD than white adults, and experience greater cognitive decline throughout the course of their disease (Dodge et al. 2014; Vásquez et al. 2016). This increased prevalence and more advanced stage at initial presentation for minority ethnic populations connotes important and fundamental challenges to providing equitable access to ADRD care for the most vulnerable segments of the U.S. population.

Assessment of ADRD levels among Hispanic Americans is somewhat mixed. While older studies find that overall, non-Hispanic whites exhibit lower prevalence and incidence of dementia relative to black and Hispanic older adults (Gurland et al. 1999), more recent investigations of trends across multiple racial and ethnic groups indicate that dementia incidence is highest among African Americans, American Indian or Alaska Natives, intermediate among Hispanic, Pacific Islander and white Americans, and lowest among Asian Americans (Mayeda et al. 2016). These differences may be attributable to large variances within American Indian or Alaska Natives (there are currently 573 federally recognized tribes) (US Department of Health and Human Services n.d.), as well as Hispanic ethnic categories, which are quite heterogeneous. Dementia risk differs widely among Hispanic subgroups, with higher risk found among Hispanics of Caribbean descent but not among those of Mexican descent. Evidence from the Hispanic Community Health Study/Study on Latinos (HCHS/SOL) provides support for this variation and finds that dementia risk is highest among older adults of Dominican and Puerto Rican origin compared to persons of Mexican origin. In addition, differences that may be attributable to nativity (i.e., between foreign-born and U.S.-born Hispanic persons) have not been fully disentangled, yet they have important implications for appropriate and acceptable ADRD care models with attention to ethnic, cultural, and linguistic considerations (Moon et al. 2019; Zsembik and Peek 2001). Despite a growing interest to clarify relationships between racial and ethnic correlates with ADRD, large gaps remain in the scientific understanding of ADRD presentation among minority ethnic populations (Yaffe et al. 2009).

The greater burden of ADRD and more severe cognitive impairments among minority ethnic populations mean it is especially important to connect minority ethnic adults and their caregivers to appropriate neurocognitive assessment and if indicated, to treatments and care services. The UK National Institute for Health and Clinical Excellence (NICE) ADRD advises clinicians to be "mindful of the need to secure equality of access to treatment for patients from different ethnic groups" (Cooper et al. 2010). Ensuring equity of access to services is not sufficient; further steps are needed to ensure equity of implementation of treatments and support programs to improve care. Once a diagnosis of ADRD has been made, non-minority and minority ethnic adults alike use community social services, demonstrating similar demand for these services across minority ethnic and socioeconomic groups (Cooper et al. 2010). This suggests that improved community engagement efforts are needed to facilitate access to social care for minority ethnic people with ADRD who remain disconnected from ADRD support services.

ADDRESSING PATIENT-CENTERED ADRD CARE AMONG MINORITY ETHNIC POPULATIONS

Research undertaken thus far has yet to demonstrate a definitive or unitary causal pathophysiologic pathway, clinically effective treatments, or preventive strategies (Arvanitakis et al. 2019; Langa et al. 2017). Instead, the accumulated evidence points toward multiple and complex pathways and pathologies, highlighting the need to better model the relationship between ADRD, its comorbidities, and sociocultural factors that exacerbate the effects of ADRD on disproportionately burdened segments of the U.S. population, such as minority ethnic groups

(Cooper et al. 2010; Mayeda et al. 2016). Older adults with ADRD rarely have isolated cognitive deficits, particularly at advanced ages (Quiñones et al. 2018; Wei et al. 2019). Therefore, it is essential to perform a geriatric assessment with clear goals of care ascertained for persons with ADRD, provided from a whole-person patient-centered perspective.

Adults with multiple chronic conditions exposed to multiple medications (polypharmacy) may experience greater cognitive decline. Moreover, persons with ADRD and additional chronic conditions have more rapid progression of cognitive decline and worse outcomes than peers with fewer conditions (Sperling et al. 2011; Wei et al. 2019). While the research on minority ethnic accumulation of multiple chronic diseases alongside ADRD is nascent, minority ethnic groups have, on average, earlier onset and greater accumulation of multiple, co-existing chronic diseases (Quiñones et al. 2019) and may not have health care providers who speak the necessary languages, especially for AI/AN, and Asian adults (Morhardt, Pereyra, and Iris 2010). This points toward greater chronic disease management burden for minority ethnic older adults, with detrimental effects on functional and cognitive health. Thus, it is imperative not to separate and treat one condition in isolation of or assume the absence of additional health conditions and limitations (Doyle and Rubinstein 2014; Fabbri et al. 2015; Quiñones et al. 2018).

Polypharmacy, which is highly-prevalent among people with multiple chronic conditions and among those with ADRD (Nørgaard et al. 2017; Parsons 2017), represents an incremental challenge for the care of patients with ADRD. Polypharmacy and inappropriate (over- and under-prescribing) medication use are more prevalent among people with ADRD compared with their peers without ADRD, and has a dose-dependent association with serious adverse consequences such as unplanned emergency department and hospitalization use and death (Mueller et al. 2018). There is limited research on the prevalence, drivers, and consequences of racial/ethnic disparities in polypharmacy (either appropriate or inappropriate) among patients with ADRD. However, it is quite clear that polypharmacy is unequally distributed across population subgroups, with low-income and low-education minority groups showing a higher prevalence of polypharmacy (Assari and Bazargan 2019). Given that complex drug regimens often indicate missed treatment opportunities (observed in either over- or under-prescribing patterns) (Lau et al. 2010; Molist Brunet et al. 2014) and complicate the interpretation of disease symptomatology and evaluation of disease progression, it is imperative to keep in mind interconnections between polypharmacy and multimorbidity among vulnerable minority ethnic persons with ADRD. Polypharmacy introduces considerations of cultural and language concordance and communication compatibilities among clinicians and pharmacists serving minority ethnic communities, particularly those with sub-optimal health literacy and limited English proficiency.

This further highlights a pressing need for an accessible language-appropriate, person-centered approach to ADRD care that is holistic and personalized, and requires more sophisticated research and program design strategies than are typically applied (Alzheimer's Association 2016). ADRD can undermine a person's capacity for adequate self-management and place substantial burden on their caregivers. Individuals with ADRD have difficulty in keeping medical appointments, following behavioral recommendations, and refilling and taking medications on schedule (Plassman 2008), and rely on caregivers to provide assistance to complete these tasks as cognitive performance degrades. Some tasks, such as diabetes self-management, involve complex reasoning and planning, which may prove too difficult even for those with mild cognitive impairment who do not have reliable formal or informal caregiver support (Gure et al. 2010).

Barriers to the effective management of chronic conditions for minority ethnic populations with ADRD are understudied and likely vary substantially by socioeconomic status, health literacy, access to providers with expertise in managing ADRD, and competing demands from dominant individual conditions (Bayliss et al. 2003; Shaw et al. 2009, 2012). Suboptimal management of chronic conditions diminishes health, wellbeing, and functioning, and has profound negative consequences on the health care system, such as through costly and avoidable hospitalizations and the need for more aggressive medical treatments. Costs for potentially modifiable health conditions are considerably higher for patients with than without ADRD (Kerr et al. 2007) and health care utilization may increase after a diagnosis of ADRD (Deb et al. 2017; Lin et al. 2016; Schaefer et al. 2019). Health care systems are aware of the need to identify ways to adapt clinical interventions for those with cognitive impairments, but a key challenge remains that the task of chronic disease management typically falls to informal caregivers, a role for which they may not be trained or prepared for and which may exacerbate their own stress levels and degrade their health status.

The current disorganized patchwork of referral and fragmented pathways to diagnosis and care needs to be redirected and remediated to facilitate early access for racial and ethnic minorities (Hinton, Franz, and Friend 2004). By all indications, intensive efforts are still needed to connect minority ethnic families—and black families in particular—with timely ADRD diagnoses that enable families to understand the illness, consider patient safety, and make long-term plans that are culturally sensitive and community aligned (Clark et al. 2005).

Cultural beliefs and norms

ADRD cannot be understood in a physiological framework alone, because it is embedded in the cultural contexts and perceptions of health that derive from cultural values. Recognition and response to illness are largely determined by prior assumptions regarding social norms and informed by the conceptual processes in the theoretical models discussed below. Illness representations and recognition are largely governed by social norms, beliefs, and values (Calia, Johnson, and Cristea 2019; Dilworth-Anderson and Gibson 2002). Cultural values shape illness representations and self-perceptions of illness, health seeking, and ultimately, connection to services and supports (Dilworth-Anderson and Gibson 2002). Culturally specific norms, values, and beliefs shape definitions and recognition of ADRD, and inform the varying roles, responsibilities, duties that minority ethnic populations subscribe to. Different ethnic groups may have specific beliefs and expectations about familial roles in the involvement and care of relatives with ADRD. For example, not all the American Indian or Alaska Natives tribes have a word or concept for dementia. Cross-cultural differences in ADRD recognition and health seeking behavior are largely driven by self-assessed susceptibility, severity of symptoms experienced, and one's own evaluation of the expected benefits relative to the barriers of ADRD assessment. These differences in response to and recognition of ADRD symptoms undoubtedly lead to delays in seeking care.

SOCIOCULTURAL CHARACTERISTICS AFFECTING DECISIONS TO SEEK CARE

Several conceptual models are particularly relevant to understanding minority ethnic inequities in ADRD care and outcomes. Various frameworks concerning health care seeking, health inequality, and the cumulative complexity involved in managing chronic disease burden among older minority ethnic populations each inform ADRD outcomes. "Cumulative Inequality" (Ferraro and Shippee 2009) places social structures, not individual choices and actions, as central to generating inequality in health outcomes. Here, individual trajectories of health are shaped by life-long accumulation of risks and available resources—such as educational attainment, cognitive reserve, and compensatory skills—and result in inequitable health outcomes. In consideration of how persons with ADRD navigate health care systems and networks of specialists and services, the Cumulative Complexity Model (Leppin, Montori, and Gionfriddo 2015; Shippee et al. 2012; Spencer-Bonilla et al. 2017) frames how the process of seeking care and connecting to services generates a non-trivial amount of work related to managing complex chronic health conditions. The decision-making process of how and when individuals seek out care is carefully detailed in the Sociocultural Health Belief Model (Sayegh and Knight 2013). This framework addresses differences in dementia care-seeking behavior that are predicated on individual characteristics such as cultural attitudes and beliefs. Health seeking behaviors for ADRD are seen as driven by an internal assessment of one's susceptibility to ADRD, the severity of symptoms experienced, and the perceived benefits relative to experienced barriers of accessing ADRD services**.** This model views the cultural collection of beliefs, values, and customs—for which ethnicity may be serving as a proxy—as the driving set of factors eliciting ethnic-group differences in dementia-related outcomes.

These conceptual elements inform the heuristic model presented in **FIGURE 1-1**. Here, sociodemographic factors of persons with ADRD and their caregivers converge to influence decisions to seek assessment and care for ADRD, as well as conceptualize the interactions between ADRD and additional chronic disease burdens on the capacity and wherewithal to navigate, manage, and coordinate the full spectrum of chronic care needs. For example, personal characteristics, such as acculturative status and subscription to family centered values (e.g., filial piety or familism), directly affect cultural beliefs and knowledge about dementia, which in turn affects the decision-making process involved in taking action: weighing one's own perceptions of susceptibility to and severity of dementia, barriers to care, and the perceived threat associated with not seeking care. Delays in seeking assessment and connection to care services, in addition to having multiple chronic conditions, may result in persons with ADRD and additional morbidities to experience increased severity of symptoms. Similarly, increased burden of chronic conditions may also necessitate seeing a greater number of specialists, being prescribed greater numbers of medications, adhering to multiple treatment regimens, and engaging in a broader range of self-management activities. Increased severity and more numerous self-management activities inevitably increase the workload for persons with ADRD and their caregivers.

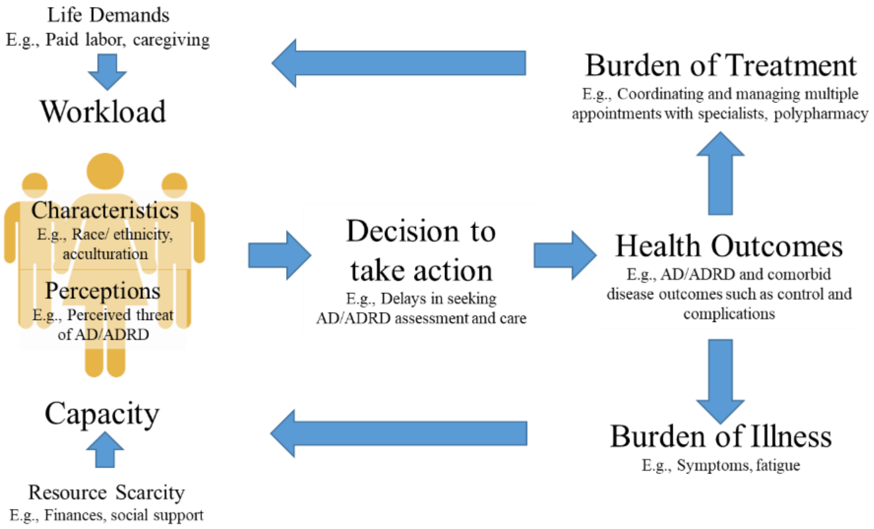

FIGURE 1-1 Sociocultural Cumulative Complexity Model Affecting AD/ADRD and Co-Occurring Disease Care
Note: This framework is adapted from the Cumulative Complexity and Sociocultural Health Belief Models.

The diagnosis and treatment of ADRD poses specific challenges for minority ethnic groups (Dilworth-Anderson et al. 2008). Many minority ethnic populations have limited physician and health care system contact, and as a result, lack of access to assessment and diagnosis is widespread in minority ethnic communities (Dunlop et al. 2002). Yet, a timely diagnosis is critically important and beneficial for persons with ADRD and their caregivers. However, trust is not always present, and some American Indian or Alaska Natives believe that ADRD assessment will disrupt community life by imposing non-Native or culturally insensitive evaluations or treatments due to a lack of respect for their traditional medicine (Griffin-Pierce et al. 2008).

There are important benefits to caregivers in understanding ADRD, keeping the patient safe, and planning for the future (Clark et al. 2005). There is also an important case for identifying the condition in its earlier stages: maximizing the participation of the person with ADRD in the planning process provides an important opportunity to voice and incorporate their wishes and preferences and address fears and concerns. In addition, pharmacological and non-pharmacological therapies and interventions to delay the progression of the disease are more likely to be effective if begun earlier in the course of illness (Hinton et al. 2004; Prince, Bryce, and Ferri 2011). The primary goal of obtaining a timely and correct dementia diagnosis, particularly among minority ethnic populations, is to reduce patient and family member burden, and improve the quality of life for the patient as long as possible (Sayegh and Knight 2013).

There are multiple reasons to identify the disease early and to engage in a population-based approach to address ADRD care in a broad and preventive context. Efforts to better and more widely disseminate information about risk and protective factors, particularly among populations that present with higher and more severe ADRD, are warranted (Alladi and Hachinski 2018). This would involve more effective efforts to reach and connect minority ethnic adults and caregivers into important discoveries, including a better understanding of risk factors and protective factors of ADRD development (Reuben, Gupta, and Skootsky 2019). For example, connecting persons with ADRD to advanced care planning and palliative care services involves important steps of eliciting patient values and preferences, initiating and continuing discussions goals of care, evaluating health care decisions, identifying health care surrogates, completing and registering advanced health care directives (such as living wills, medical directives, and durable powers of attorney for health care), as well as engaging in financial planning and household/estate planning. These tasks are critical early in the ADRD disease process. Because minority ethnic persons with ADRD may have delays in assessment and care, engagement in these critical activities is inevitably also delayed.

Several studies highlight important racial/ethnic differences in both initiation and discontinuation of antidementia medications (Cooper et al. 2010; Poon et al. 2009; Thorpe et al. 2016; Zuckerman et al. 2008). Although not perfectly congruent in their findings, possibly due to period effects, these studies suggest lower rates of initiation and higher rates of discontinuation of such treatments among minority ethnic groups. Specifically, the rates of initiation of antidementia medication appeared to be similar or higher among Hispanic compared with white individuals, although Hispanics also discontinued the medications at a higher rate. In addition, the rates of initiation were found to be lower and the rates of discontinuation higher among black adults compared with whites. These studies also note that the observed racial/ethnic disparities in the use of pharmacological dementia treatments are neither cost-related nor attributable to differences in demographic, economic, or health status characteristics, or the availability or use of health care services (Thorpe et al. 2016; Zuckerman et al. 2008). Differential knowledge, attitudes, and beliefs about dementia (Connell, Roberts, et al. 2009; Connell, Scott Roberts, et al. 2009) and antidementia medication between racial and ethnic groups and provider and health care system factors may contribute to disparities in initiation and discontinuation. Although minorities with good access to care and few financial barriers may be willing to try antidementia medications when presented this option, their less medicalized view of dementia may contribute to lower adherence to these medications, especially if they experience side effects or perceive lack of effectiveness.

Lack of effective provider education and communication about these issues, lack of cultural competency of providers, and lower trust in providers by minorities may also contribute. In addition, differences in medication use might arise from differences in psychosocial environment (e.g., neighborhood effects or immediate peer group effects) or discrimination experienced by members of minority groups, both of which are important determinants of the mental health of non-Hispanic black Americans (Williams and Earl 2007). This brief summary suggests that differences in the uptake of pharmacological and non-pharmacological treatments are driven by socially constructed perceptions of illness, differences in acceptability and tolerability of treatments, differential knowledge, attitudes, and beliefs about dementia and known or exploratory therapies which vary by race and ethnicity. In addition, provider and health care system factors may substantially contribute to disparities in use of currently available therapeutic options (Sayegh and Knight 2013; The ICTUS Group et al. 2014).

Drivers and barriers of health care seeking behavior

Fundamental concepts of access—affordability, accessibility, availability, acceptability, and accommodation—underlie drivers and barriers to seeking assessment and care for ADRD and have special application to minority ethnic populations (McLaughlin and Wyszewianski 2002). For example, while affordability concerns may be mitigated by Medicare and Medicaid coverage for eligible and dually eligible individuals, these insurance programs may not cover the full range of needed services, leaving persons with ADRD and their caregivers with substantial out of pocket costs. This is particularly true as the disease progresses and needed levels of support and care increase (Deb et al. 2017). Considerations for accessible, available, and acceptable specialists and specialized services offered in neighborhoods by a workforce of providers with accommodating schedules and who engender trust from minority ethnic populations also constitute important barriers to care.

Minority ethnic groups report several barriers to assessment and diagnosis that prevent connection to ADRD care and services, the most cited of which include unfamiliarity with symptoms, misrecognition of symptoms as part of the normal aging process, as well as stigma and fear associated with an ADRD diagnosis (Ayalon and Areán 2004; Calia et al. 2019; Connell, Scott Roberts, and McLaughlin 2007; Gelman 2010; Hinton et al. 2004). Unfamiliarity with symptoms and lack of knowledge represent substantial barriers to understanding and recognizing the illness. While the information campaigns by the Alzheimer's Association have been cast widely and comprehensively, it is noteworthy that these messages may not be as effectively transmitted across all affected populations and require further effort for translation into linguistically and culturally appropriate messaging. If persons at risk and their families are armed with more knowledge about the disease and perceive more options for care within health care systems and within their communities, they will likely choose to be more proactive and seek out services. Normalization of early symptoms as a routine and inevitable process of aging is another barrier that results in inaction in the face of ADRD symptoms and directly contributes to delays in seeking care. If persons and their families do not perceive that symptoms are atypical and problematic or normalize these early signs of a problem, then they will not seek consultation or help. Across multiple studies, black, Hispanic, American Indian and Alaska Native adults are significantly more likely to believe that ADRD is a normal part of aging, but other minority ethnic groups are also susceptible to normalizing early ADRD symptoms (Ayalon and Areán 2004; Connell et al. 2007; Gelman 2010; Griffin-Pierce et al. 2008).

Stigma and fear associated with receiving a diagnosis also represents a significant barrier to seeking care (Werner, Goldstein, and Heinik 2011). However, research on stigma and stigmatizing attitudes toward ADRD in U.S. minorities is very limited (Herrmann et al. 2018). Available evidence suggests that stigma burden is higher among some racial/ethnic minority groups, and that people with dementia and their families may feel shame and embarrassment in their communities. On the positive side, some cultural groups have more family support for elders generally, including for those with ADRD. On the negative side, there is ample distrust of formal medical institutions and medical research in many minority ethnic communities, stemming from a reprehensible and unethical history of offenses against minority ethnic research subjects. As a result, ethnic minorities often prove especially reluctant to engage with medical research or to participate in screenings, assessments, and cutting edge ADRD trials (Gaugler, McCarron, and Mitchell 2019; Simonds et al. 2014). In turn, vast programs of ADRD research suffer from having low representation of minority ethnic participation. Black men in particular are notable in this regard because they are suspicious of clinics and the motivations of clinicians and researchers (Dilworth-Anderson et al. 2008). There is a justified fear, shaped from historical precedent, that the medical research enterprise and clinicians themselves are not always good faith representatives with a minority ethnic patient’s best interests at the forefront. In addition, a long history of systemic exclusion from care and discrimination fuels much of the distrust in medical trials and programs, including ADRD clinical trials. Even though various minority ethnic groups face greater burden from ADRD, they are considerably less likely to participate in clinical research (Coakley et al. 2012). Various studies report that few minority ethnic persons with ADRD enroll in clinical trials, and many publications from trials did not even report racial or ethnic group status (Canevelli et al. 2019). This means that findings from most research may not apply to the population subgroups most severely affected by ADRD.

PROMISING AREAS FOR FUTURE WORK

We propose that the next wave of research and clinical interventions in ADRD must, at every level, account for not only the "whole person," but also the "whole community" such that all segments of the U.S. population are represented and included. Working toward these goals requires attentiveness to the following six issues.

Need for construct validity in ADRD assessment

There remains a critical need to understand the mechanisms by which age, social, behavioral, and medical factors contribute to racial and ethnic differences in cognitive decline, ADRD onset, and the course of ADRD. However, before these mechanisms can be specified, ADRD assessment tools need to be validated for minority ethnic populations, with attentiveness to nativity, language, cultural orientation, education, and literacy considerations. There may be detection biases with cognitive assessment tools that are not calibrated for linguistic or cultural anchors and may thus be culturally inappropriate. For instance, researchers have found that optimal cutoffs for detecting ADRD differ by racial/ethnic status (Milani et al. 2018). Failing to consider racial/ethnic status in the design and conduct of research, and to involve sufficient numbers of minority ethnic participants, will limit the applicability of results. Current testing may unduly penalize on these characteristics and potentially bias the tests to the dominant culture.

Lower participation of black Americans in research makes it difficult to assess, validate and calibrate assessments (Dilworth-Anderson et al. 2008; Mayeda et al. 2016). Ensuring consistency of diagnostic criteria is an important challenge for the field of ADRD research given concerns that even very comprehensive neuropsychological batteries are sensitive to educational and cultural differences (Mayeda et al. 2016). Work remains to address a need for developing a gold standard for assessing or harmonizing diverse assessments of ADRD in all populations. ADRD expresses itself in heterogeneous ways, especially in the early stages. Therefore, better and more consistent markers of early disease that are appropriate to multiple cultural and linguistic differences is needed (Dilworth-Anderson et al. 2008).

Need for greater granularity

Greater attentiveness is also needed to better define specific aspects of minority ethnic groups to understand drivers of ADRD care. This involves greater representation from a wider range of ethnic minority groups in ADRD research. For example, American Indian or Alaska Native, and Asian groups are vastly underrepresented in research studies because of small numbers of recruited participants and lack of engagement with these communities. Greater efforts are needed to provide a more complete picture of cognitive health for groups that have been excluded and are underrepresented in ADRD research.

Relying on race or ethnicity as markers or proxies for groups that represent a large amount of heterogeneity within their classifications also constitutes a significant issue (Hargrave et al. 2000). Here, assessing potential “subgroup” differences is indicated: there is likely substantial heterogeneity within tribal, “Hispanic” or “Asian” classifications, as well as by other important considerations such as nativity status and linguistic differences. Race and ethnicity should be broken down into more precise indicators and differentiated from differences in region, language, years of education, quality of education, literacy, acculturation, wealth, and disease-associated genes and biomarkers. These factors may prove more telling than racial or ethnic differences alone or at the very least, provide specificity of the mechanisms that operate on cognitive decline (Dilworth-Anderson et al. 2008; Mayeda et al. 2016). Likewise, attention to differences in dialect and more granular cultural aspects should be addressed. For example, intraethnic diversity in Chinese dialects spoken between persons with ADRD and their providers and resulting communication difficulties may be obscured by seemingly concordant “Asian” or even “Chinese” designations (Hinton et al. 2004).

Minority ethnic populations are frequently geographically clustered and residentially segregated in many metropolitan areas (White, Haas, & Williams, 2012; Williams & Collins, 2001). Future research about ADRD burden in local areas—by varying levels of specificity such as by state, rural/urban, and zip code or census tract levels—is needed to identify communities that will potentially bear disproportionate burdens of ADRD. The prevalence and burden of ADRD in one area may be driven by sociodemographic factors or health conditions that differ across geographic areas. Understanding the reasons why ADRD varies by place is critical to the development of formal and informal services that are responsive to local contexts (Matthews et al. 2019).

Need for greater diversification of the workforce

A vital area for expansion in the next decade is training, staffing, recruiting, and retaining a diverse workforce to service a diverse population (Browne et al. 2017). Recruitment of a diverse workforce and workforce training initiatives may be effective routes to minimize and avoid discrimination and marginalization of minority ethnic persons with ADRD in interactions among those who provide ADRD services. There is a great need to train and continue to develop a dementia-capable workforce to support the unique care needs of persons with ADRD, as well as a diverse set of cultural norms and practices that may exist among minority ethnic persons with ADRD (Borson et al. 2016; Super, Ahuja, and Proff 2019; Surr et al. 2017). This lack of a diverse ADRD workforce may be particularly salient for minority ethnic persons with ADRD who do not have family members residing nearby, those whose family members and informal care networks have constraints that preclude more active participation in care and care decision making, and those without any family or caregiver support. The expectation is that greater training and inclusivity in the workforce may translate to better provision of care through culturally responsive care models, and increased communication and connection to minority ethnic groups with similar cultural norms, practices, and linguistic dialects (Borson et al. 2016). Creating and sustaining a dementia-capable workforce that delivers good quality and culturally sensitive care is critical given the wide array of older persons with ADRD from various ethnic, cultural, and linguistic backgrounds.

In addition, this is a need to diversify the ADRD research workforce. Scientific teams are often not trained to partner and work with underrepresented ADRD communities. As a result, it may take substantial effort and resources to build the trust necessary to conduct research and supplement an inadequate evidence base around ADRD innovations applicable to minority ethnic populations. Improving the pipeline of researchers from diverse backgrounds to join ADRD teams may facilitate connections to underserved communities (Babulal et al. 2019).

Need for best practices for outreach

An additional area of focus should be the identification of best practices and best methods for outreach to so-called “hard to reach” populations to communicate accurate information and debunk misconceptions. We need to distinguish the best mechanisms and transmission of information for racial/ethnic populations. Despite national dissemination efforts and growing efforts to “maintain your brain” by engaging in productive activities, such as keeping mentally and physically fit, the general public is not aware of prevention practices to reduce risk of ADRD

(Connell et al. 2007). Related to this need for wider awareness of best practices for brain health is the importance of battling the ill-conceived fatalism that “nothing can be done” for persons living with ADRD by providing outreach education and information to improve agency, awareness, and control. Conducting more effective outreach in minority ethnic communities will also increase awareness that ADRD is not part of normal aging, and should be incorporated in messaging alongside educational outreach about all risk-reduction strategies—pharmacological, behavioral, as well as social approaches to help manage the disease and improve quality of life (Connell et al. 2007).

Importantly, directly addressing ADRD related stigma, distrust, and fear of exclusion among ethnic minority communities is further necessary given the predicted increase in minority group population growth in the United States. As such, evidence-based stigma-reduction approaches specifically for Hispanic and black Americans are greatly needed. Effective communication efforts to reduce stigma should target the population broadly, as well as targeted to groups that may have higher levels of misconceptions about ADRD.

Need for integration of cultural and social information about diverse groups

The unmet needs of patients with ADRD may be largely non-medical and related to patient and caregiver characteristics. In order to address the needs of persons with ADRD, their families, and their caregivers, it is vital to build the understanding of how ADRD impacts different groups. Although the development of culturally appropriate caregiving and brain health promotion interventions (Croff et al. 2019; Richardson et al. 2019) have begun, many more are needed. Continuing to engage in participatory ways is needed and involves soliciting input, as well as partnering with and maintaining involvement from diverse groups about priorities for

ADRD research and interventions. These efforts move beyond recruiting and retaining more racial/ethnic minorities to investigator-designed trials and serve to reinforce these efforts.

There are ample opportunities to leverage ADRD research and test which programs (or elements thereof) work and under which circumstances they work (Browne et al. 2017; Dilworth-Anderson and Gibson 2002). For example, this includes incorporating culturally relevant strategies in the American Indian or Alaska Native communities such as: familial and collective caregiving, cultural ethos of respect of elders, strong reciprocal relationships with elders, and the importance of elders as cultural memory and language stewards (Browne et al. 2017). There is a need to develop and test innovative models of support that coordinate the provision of health care together with a wide range of community-based supports and services (e.g., care facilities, respite care, meal programs, transportation services) to improve the quality of life for persons with ADRD and their caregivers. Additionally, we need to develop and test interventions that more effectively improve health maintenance and chronic disease management in diverse groups of ADRD patients.

Need for more data and work devoted to other populations experiencing disparities

In order to identify and overcome potential barriers to ADRD assessment, treatment, and connection to services, more information needs to be gathered about disability status, rural residence, sexual identity/sexual orientation, socioeconomic status, as well as housing insecurity or populations with high psychosocial risks and mental illness (Duran and Pérez-Stable 2019). Despite the focus on racial and ethnic minority groups, health disparity populations are broader in scope and include underserved rural residents, lower socioeconomic status groups, as well as sexual and gender minorities. Each of these minority groups confront challenges of discrimination, social disadvantage, and differential access to care and resources. For example, the sexual and gender minority community has unique needs: many do not have biological families or children, and their social networks may be dwindling earlier in life due to HIV mortality (Fredriksen-Goldsen et al. 2018). As a result, sexual and gender minorities are at increased risk of social isolation. Experienced stigma in this community is substantial with many care providers, programs, and care institutions erecting barriers to access to care. In addition, legal protections for sexual and gender minorities living with ADRD and their partners/spouses are not universally observed, recognized, or respected across geographic communities, states, and regions (Peel, Taylor, and Harding 2016). As a result, sexual and gender minorities exhibiting ADRD symptoms and their partners may be hesitant to seek out services or support (Alzheimer's Association and SAGE Advocacy and Services for LGBT Elders 2018; Fredriksen-Goldsen et al. 2018). Similarly, persons with ADRD and their caregivers residing in rural areas may experience the same barriers, such as difficulty finding appropriate care providers, services, and supports nearby that may contribute to higher levels of caregiving strain (Stewart et al. 2016). For example, it is possible that rural populations may also engage in "normalization" of symptoms or lack the knowledge and awareness to recognize ADRD symptoms (Weden et al. 2018). However, little work has been done to discover the unique needs and barriers to care for these populations and specific knowledge of important factors and the mechanisms by which these operate are largely unknown and need to be clarified.

Groups that experience health disparities may have similar or overlapping barriers to ADRD care, but there are likely nuances in how these barriers operate and the relative importance of specific barriers tied to the specific circumstances and context of these groups. Barriers, issues, concerns, and preferences need to be carefully detailed, vetted, considered, and evaluated to ensure care is acceptable and available to these disparate groups. To this end, sophisticated and thoughtful approaches are needed to identify the most relevant factors for interventions that consider specific group circumstances, needs, and preferences and have meaningful and sustained impacts on quality of life.

It has become almost *pro forma* in all recommendations to plea for more support for research, in particular implementation and dissemination to these underserved Americans. However, careful attention to various issues and mindful intention is necessary to establish and maintain research in underserved communities. These efforts are dependent on building community trust, establishing community engagement, conducting effective recruitment outreach, and having sufficient material and structural support to facilitate continued participation and cohort retention. Funding agencies serious about inclusivity and generalizability of their supported research need to be cognizant of the intensive levels of resources needed—both in terms of money and time—to conduct research in communities that have been historically disenfranchised from the ADRD research enterprise. Better and more effective outreach, ensuring equitable access to high quality care, and enabling research to investigate important mechanisms and therapeutic effectiveness for disenfranchised populations is vital. Currently the costs in informal care giving, health care utilization, functional status, social isolation, and community integrity incurred by these communities and their members is typically unknown and inadequately captured in health economic surveys.

SUMMARY

While there may be promising pharmacological therapies for some forms of ADRDs, the social and personal costs of ADRD will not diminish until such treatments are fully developed, broadly disseminated, and widely accessible. This does not detract from the importance of the early diagnosis of dementia, which can afford persons with ADRD and their families and caregivers a timely initiation of social and support services and critical access to management of common comorbidities. Addressing reasons for delays in diagnosis and connection to these critical services among minority ethnic populations remains an important challenge.

Successful strategies in caring for ADRD on individual and population levels will depend not only on treatments developed through basic and clinical sciences, but also on more refined and culturally grounded models of care for ADRD, and recognition of its broad effects on health and society. Close attention needs to be paid to include populations disproportionately affected by ADRD whose needs are not well addressed by current pharmacological and non-pharmacological management strategies. Acknowledging barriers to care for minority ethnic populations and improving efforts to reach these groups is only a first step. In order to make progress, thoughtful design of programs and sufficient allocation of resources is needed to eliminate barriers experienced by some of the most vulnerable members of our society living with and caring for persons with ADRD.

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