

REVIEW ARTICLE

Including ethnic minorities in dementia research: Recommendations from a scoping review

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Abstract

Introduction: Ethnicity influences dementia etiology, prognosis, and treatment, while culture shapes help-seeking and care. Despite increasing population diversity in high-income settlement countries, ethnic minorities remain underrepresented in dementia research. We investigated approaches to enhance the recruitment, and consistent collection and analysis of variables relevant to, ethnic minorities in dementia studies to make recommendations for consistent practice in dementia research.

Methods: We did a scoping review, searching Embase, PsycINFO, Medline, CENTRAL, and CINAHL between January 1, 2010 and January 7, 2020. Dementia clinical and cohort studies that actively recruited ethnic minorities in high-income countries were

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included. A steering group of experts developed criteria through which high-quality studies were identified.

Results: Sixty-six articles were retrieved (51 observational; 15 experimental). Use of interpreters and translators ($n = 17$) was the most common method to facilitate participant recruitment. Race and ethnicity ($n = 59$) were the most common variables collected, followed by information on native language ($n = 14$), country of birth ($n = 9$), and length of time in country of settlement ($n = 8$). Thirty-three studies translated or used a culturally validated instrument. Twenty-three articles conducted subgroup analyses based on ethnicity. Six high-quality studies facilitated inclusion through community engagement, collected information on multiple aspects of ethnic diversity, and adjusted/substratified to analyze the impact of ethnicity on dementia.

Discussion: We make recommendations for consistent recruitment, collection, and reporting of variables relating to ethnic and cultural diversity in dementia research.

KEYWORDS

dementia, ethnic minorities, research, underserved

1 | BACKGROUND

It is now well established that in most high-income countries (HIC; e.g., the United States, UK, and Australia) ethnic-minority communities have different dementia etiologies, prognosis, and treatment;¹ patterns of help-seeking;^{2,3} care practices;⁴ and experiences of marginalization and systemic racism.^{5,6} Collectively, these factors contribute to ethnic disparities in dementia.

With increasing population diversity and longevity due to migration, advances in public health, and social and economic development, ethnic minorities must have equitable access to health and care across the life course. This includes not only benefiting from the latest advances in dementia research^{7,8} but also ensuring that such scientific advances are derived from the inclusion of diverse communities in research.

Unfortunately, dementia research remains largely void of diversity.^{1,9} A systematic review of 96 randomized controlled trials (RCTs) to improve cognition related to dementia (total of 37,278 participants) found only 39 trials (39.4%) reported ethnicity and only 11.4% (95% confidence interval [CI], 7.5–15.9%) of all participants were non-White.¹⁰ Underrepresentation of ethnic minorities in research means that clinical and policy decisions are likely to be based on data that reflect the needs of only some groups and not others. The problem has been widely recognized by dementia researchers¹ and is also endemic to medical research.¹¹

In this article, we refer to ethnic, cultural, and linguistic diversity and have avoided the use of the word “race” in our own analysis. Ethnicity and race are polemic concepts, difficult to define, and often used interchangeably. However, the terms are distinctive; ethnicity refers to a sense of personhood or shared descent based on national origin, cultural background (including language), and/or religious beliefs.¹² Definitions of ethnicity locate it as self-identified, identified by others, and associating specific behaviors with a particular ethnic group. Importantly, ethnicity is not static, but a dialectical concept evolving in relation to migration, kinship patterns, and other social and cultural trends.

All humans have an ethnicity, although those who belong to a majority ethnic group may not see themselves as being “ethnic.”¹²

Race, on the other hand, is a classification, a signifier, and a synonym.¹³ As a classification, biological ideas of race, dominant from the early 19th century, were the basis on which human populations were divided into subcategories mainly based on visible physical characteristics.¹⁴ This concept is widely discredited as the biological basis of race is much more dynamic than such classifications posit. By contrast, race as a signifier refers to the social practices on the basis of physical markings and (falsely) imputed behaviors directed at particular groups, and is closely related to the third concept of race as a synonym for the intersections among identity, history, trauma, and structural racism.¹³ Put more simply, “race as biology is fiction, racism as a social problem is real.”¹⁵ For this reason, race continues to be considered important in understanding health disparities research as a sociopolitical rather than biological category.¹⁶

Recognizing the different logics underpinning ethnicity and race, some scholars advocate treating them as distinct categories;¹⁷ others do not.¹⁸ Consequently, there is conflation of the two categories in many studies. Therefore, in this scoping review we treat these categories as distinct in our analyses but not when it comes to reporting on studies that treat them similarly. Such an approach has precedent (for example Torres' work¹⁷).

To promote the consistent collection of data on ethnic and cultural diversity in dementia, researchers have identified the need for evidence-based strategies to enhance recruitment of ethnic minorities as well as the need for more robust reporting mechanisms for the collection and analysis of data relevant to ethnicity and culture.^{1,19} Part of the challenge that dementia researchers and policy makers face is difficulty in knowing which variables to include to address issues of ethnic,

cultural, and linguistic diversity. For while governments may set standards for the collection of a minimum set of variables that capture ethnic diversity (e.g., country of birth, language spoken at home, English proficiency), the ethnic diversity of minority populations in HICs as it relates to dementia risk and treatment is a complex issue. This complexity can be captured through a number of variables that can impact health individually, and/or in concert with each other, and/or at the intersection of other cognate factors such as socioeconomic status, segregation, and discrimination.¹¹ There is no single variable for ethnicity in settlement countries; rather, variables are multiple and intersecting.

Furthermore, there is inconsistency in the collection of information relating to ethnic differences, and studies have shown that the collection of information related to ethnicity and culture is often incomplete.²⁰ Analyses of health disparities are also hampered by inconsistent measurement of related variables, making comparison across studies difficult.¹¹ While a multi-dimensional approach to capturing ethnic diversity is recommended, it is also acknowledged that what counts as relevant may differ based on context.²¹

Concerned with the underrepresentation of ethnic minorities in high-income countries of settlement and the associated contextual issues in conducting such research, this scoping review responds to some of these challenges. Our objectives are 3-fold: First, to investigate approaches to enhance the recruitment of, and consistent collection and analysis of variables relevant to, ethnic minorities in dementia clinical and cohort studies in HIC. Second, to identify high-quality studies in this area. Finally, to make recommendations for consistent practice in dementia research based on the evidence.

2 | METHODS

2.1 | Design

Given the exploratory and broad nature of our aims, a scoping review methodology was selected. Systematic reviews are useful for answering well-defined research questions with a narrow, specialized scope, but are less relevant when little is known about a topic and thus a broader search and scoping of literature is initially required.^{22,23}

We applied the PCC (population, concept, and context) mnemonic to guide development of our research questions and review title, described in the Joanna Briggs Institute's Manual for Evidence Synthesis.²⁴ Munn et al.²⁵ note that while the PICO (population, intervention, comparator, outcomes) mnemonic for question development is the most well known and widely used, reviewers often force their reviews into this format, which is designed specifically to cater to the information needs of systematic reviews of interventions. As this was a scoping review, and one taking in a broad range of study types and designs, the PCC format was assessed as the most suitable as the "concept" under review can accommodate this range.

The protocol (unpublished) operationalized the PCC as follows: population—ethnic minorities with dementia, ethnic minorities without dementia, caregivers of people from ethnic minorities with demen-

RESEARCH IN CONTEXT

- 1. Systematic Review:** With migration and ageing, high-income countries have increasingly older ethnically diverse populations, many of whom will experience dementia. Despite the relevance of ethnicity and culture to multiple aspects of dementia, ethnic minorities remain underrepresented in dementia research. This means information about ethnic and cultural diversity that would enable understanding of dementia in different communities are not consistently collected and reported.
- 2. Interpretation:** The review synthesises evidence from the published academic literature to make recommendations for dementia research. In doing so, clear standards are offered around the recruitment, collection, and reporting of variables relating to ethnic diversity to support greater representation of minorities in dementia research.
- 3. Future Directions:** These recommendations can enhance consistent practice and greater inclusion of minorities in dementia research. Recommendations may also have salience for medical research and may strengthen the evidence-base on reducing ethnic disparities in health-care.

tia; concept—recruitment, collection, and reporting of variables relating to ethnic and cultural diversity in trial and cohort dementia studies covering risk, prevention, prevalence, incidence, treatment, and/or care; context—minority racial/ethnic/cultural/linguistic status in HIC.

2.2 | Search strategy and selection criteria

Embase, PsycINFO, Medline, CENTRAL, and CINAHL were searched using terms such as "ethni*," "race," "minorit*," "migrant," "culture" AND "Alzheimer's," "Parkinson's," "neurocognitive disorder" AND "RCT," "cohort," "case control," "longitudinal" (full search strategy is in Appendix A in supporting information).

Inclusion criteria were: a priori intention to recruit ethnic minorities into the study; conducted in countries defined as HIC by the World Bank (2020); published January 1, 2010 to January 7, 2020; and trial or cohort study design. We only included studies on dementia risk if the mean age of participants was 65+ and incident dementia or mild cognitive impairment (MCI) was the primary outcome. Studies were excluded if they did not meet these criteria and/or focused on outcomes such as: instrumentality (e.g., validation or translation of diagnostic tools, etc.); knowledge, attitudes, and perceptions unless linked to dementia outcomes; caregivers, where not relevant to the care of ethnic minority people with dementia; risk or prevention studies where the sample mean age is below 65 and dementia or cognitive impairment is not the primary outcome (must meet both criteria); studies not

about dementia or where dementia is incidental (e.g., one among many chronic conditions reported on).

2.3 | Data analysis

Two authors (SC and JS) screened the abstracts in Covidence, then independently screened all the full texts. Discrepancies were resolved by a third reviewer (BB). As there is no gold standard for reporting on ethnicity in medical research, the team developed via consensus 19 data points drawing on our collective disciplinary expertise in dementia, psychology, public health, epidemiology, health and data policy, healthy equity, ethnic disparities, and consumer experience as well as our experience in research institutes, advocacy groups, policy and funding bodies, data agencies, and ethnic minority communities (anonymous is a consumer from an ethnic minority).

Six authors (SC, JS, SE, AT, AM, and FC) extracted data on these 19 points: country; setting (e.g., urban/rural); study design; dementia study type; aims; population; sample size; mean age; sex ratio; recruitment source; techniques used to facilitate recruitment and participation of ethnic minority participants; techniques used to enhance retention; ethnicity-related variables collected; measures of diversity created; culture-specific tools used; analyses performed on ethnic and cultural-related variables; type of data analyzed (e.g., categorical/continuous); corrections, adjustments, and subgroup analyses conducted; and whether there was triangulation of measures of ethnicity and culture. These data points were derived via consensus, drawing on the team's knowledge of how variables on ethnicity are operationalized in government-funded statistics agencies (e.g., the Australian Bureau of Statistics), medical, and gerontology literatures.^{17,26,27}

Though quality assessment is not a requirement for scoping reviews,²⁴ we also developed the following proxy indicators of good practice in conducting research with ethnic minorities: whether researchers described the strategies they used to recruit, support, and retain participants in their research; triangulation for ethnic and cultural diversity through the collection of more than one variable capturing this diversity; using assessment tools that were adapted or designed specifically for ethnic minorities; and investigating diversity through subgroup analyses, corrections, or adjustments. Similar to the data extraction points, these quality indicators were derived via consensus, drawing on the team's wider knowledge of recommendations for more granular reporting on ethnicity in medical research.^{7,28,29} We acknowledge that these are rough, untested proxy indicators that do not take into consideration the broad sweep of study types included in this review and that may have missed other factors contributing to dementia risk, diagnosis, treatment, and care in ethnic minorities. Nevertheless, these indicators provide a starting point and studies meeting all these criteria were further analyzed as examples of good practice.

3 | RESULTS

There were 66 eligible articles (see Figure 1) of which 20 comprised results from 8 large studies. These included six from the Washington

Heights–Inwood Columbia Aging Project (WHICAP),^{30–35} three from the Sacramento Area Latino Study on Aging (SALSA),^{36–38} and two from the Honolulu–Asia Aging Study (HAAS).^{39,40} There was one article from the Resources for Enhancing Alzheimer's Caregiver Health (REACH) study,⁴¹ and two from REACH II.^{42,43} There were two articles each from a study of biomarkers for Alzheimer's disease (AD) in African-Americans,^{44,45} a caregiver intervention among Hispanic Americans,^{46,47} and a genetics study on Caribbean Hispanics with a family history of AD.^{48,49} Where articles are from the same studies, we treated them as individual entities to capture the reporting and analytic practices that were article specific. We indicate where we refer to practices (e.g., recruitment) that relate to studies as a whole.

The majority of articles came from studies that were conducted in the United States ($n = 57$), including three multicenter studies based on research conducted in the United States, Puerto Rico, and the Dominican Republic (see Appendix B in supporting information). Included in the prioritized articles were five based in Australia, two in the UK, and one each in the Netherlands and Singapore. The majority of articles were from observational studies, while 16 described studies with experimental designs, including 13 RCTs and three non-randomized intervention studies. While RCTs are considered the highest quality of evidence for medical interventions, as our questions in this review were methodological rather than clinical, we have not given precedence to evidence from RCTs. Nevertheless, we note that 10 of the 13 RCTs included were caregiver interventions and the 3 remaining studies were interventions for help-seeking,⁵⁰ MCI,⁵¹ and an RCT looking at how knowledge of race affects diagnosis.⁵² Five articles were about culturally tailored interventions including, for example, the development of a "fotonovela" picture book illustrating coping strategies, promoting help-seeking, and stress management for Latino caregivers.⁵³ Others tested general interventions with multi-ethnic groups.

The topics in dementia covered by these 66 articles included 24 on risk and prevention, 22 on care, 10 on dementia prevalence and incidence, 5 on treatment and management, 3 on prognosis, and 2 on diagnosis. Sixteen articles dealt with people with or without dementia, and 22 were concerned with family caregivers, including caregiving dyads. Six articles were based on studies that included participants with and without cognitive impairment, one with and without memory problems, while 14 drew samples from a general population of older adults. Five genetic studies included people with a family history of dementia, while two studies covered deceased individuals with a dementia diagnosis at time of death.

Of the 57 articles based on studies conducted in the United States: 22 focused on African-Americans; 21 on Hispanics or Latinos including the three SALSA articles; 8 on a multi-ethnic population (three of which were from the WHICAP study), 4 each on Mexican Americans and Caribbean Hispanics, 2 articles each that focused on Chinese Americans and Japanese Americans (both from HAAS), and 1 on Puerto Ricans and Spanish-English bilinguals. The Australian studies included three on multi-ethnic minority groups,^{54–56} Spanish and Chinese speakers,⁵⁷ and Greek and Italian Australians.⁵⁸ The two UK studies looked at Black African, Black Caribbean, and Black British people,⁵⁰ and people with Indian and Pakistani backgrounds.⁵⁹ The

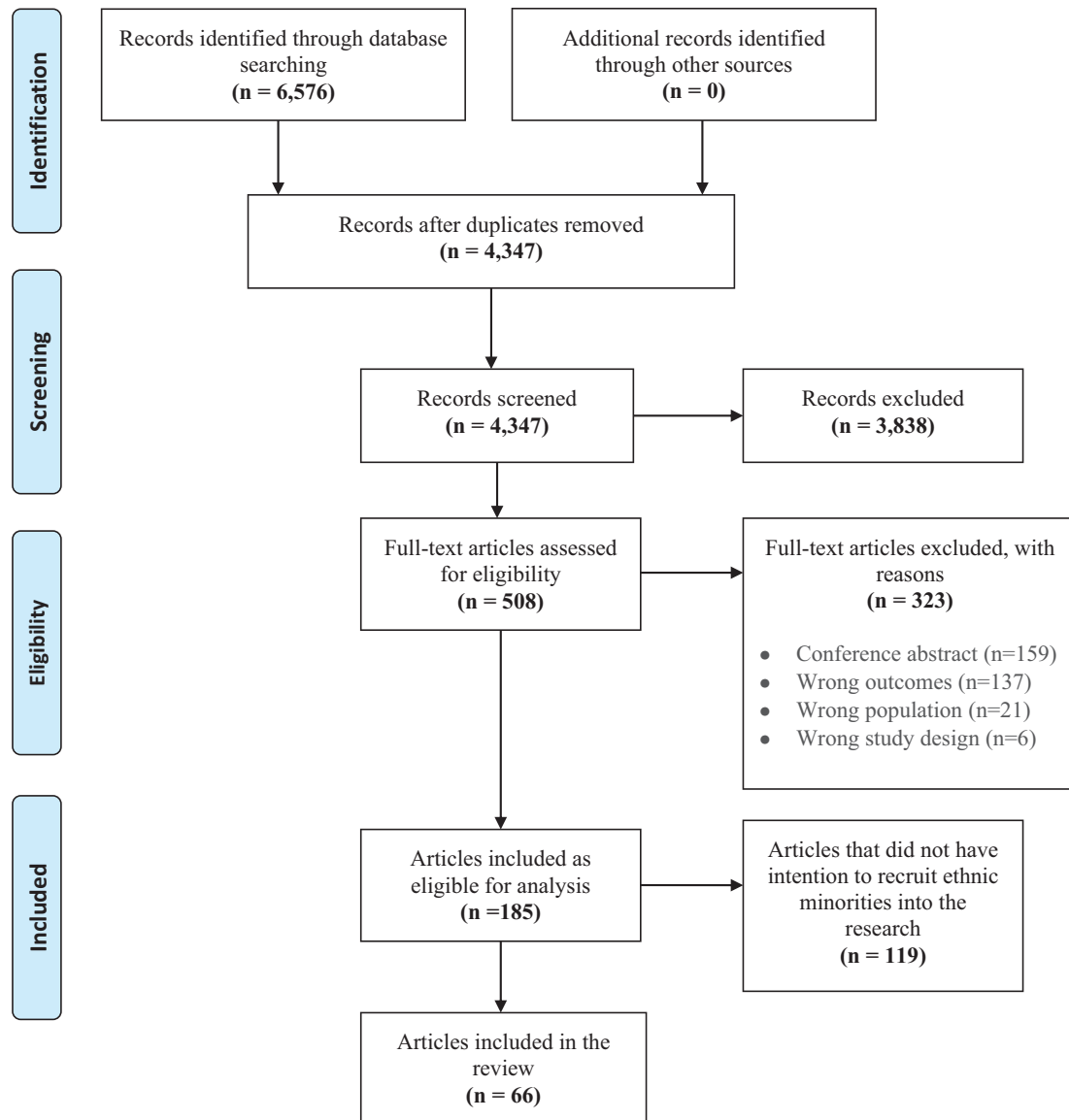


FIGURE 1 Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) flowchart showing inclusion process

study from Singapore, which has a majority ethnic Chinese population, focused on the ethnic minority groups from Malaysia and India,⁶⁰ while the Netherlands study looked at overseas-born people of Turkish, Surinamese, and Moroccan backgrounds.⁶¹

3.1 | Strategies to recruitment and retain participants

Thirty-seven articles reported on strategies to recruit and support racial and ethnic minorities' participation in their research (see Table 1). Using interpreters and translating study materials was the most common technique used ($n = 17$), with two articles from the WHICAP study.^{34,35} This included the translation of study materials into the participants' preferred languages, advertising through flyers in English and the target population's language, and provid-

ing the option for interventions to be delivered in participants' preferred language.^{34–36,38,41,42,53,55,56,58,61–67} Thirteen articles reported the use of bilingual and bicultural workers, including employing bilingual research assistants, having participants assessed by a physician who spoke their language, and making use of race-concordant community health workers^{38,51,53,54,57,58,61,64,68–72} (see Table 1).

Researchers commonly gave community presentations to facilitate recruitment with six articles reporting having adopted this strategy.^{41,64,68,73–75} Five articles reported on providing flexible modes of participation,^{38,61,68,69,74} while four provided monetary compensation.^{50,76–78} Four articles described community-based outreach methods including word of mouth, attendance at health fairs, and community surveys.^{72,79–81} Two articles reported on flexible approaches to information gathering such as triangulating through consultation with family members and clinical staff to address problems in documentation for ethnic-minority patients.^{56,72}

TABLE 1 Recruitment, collection, and reporting of variables relating to ethnic and cultural diversity

Author	Recruitment source	Techniques for recruitment and participation	Variables collected	Ethnic minority specific tools used	Subgroup analyses or corrections/adjustments for years in country, language proficiency, or visa type
Barral et al. (2015)	Clinics (including memory clinics), community organizations	Advertising in ethnic media	Race and ethnicity (participants all Caribbean Hispanic)	Woodcock-Johnson Spanish psycho-educational battery; PSEUDOMARKER for analyzing more complex family structures in multigenerational Caribbean Hispanic families	No
Brown et al. (2014)	Hospitals	Interpreting and translation	Language (first/preferred)	English version of MMSE translated by interpreters	Subgroup analysis (English and CALD)
Chao et al. (2014)	Memory clinics in Chinatown, community organizations	Verbal vs. written	Race and ethnicity, English proficiency	Chinese version of the Cognitive Abilities Screening Instrument (CASI C-2.0)	Subgroup analysis (Chinese and White Americans)
Cucciare et al. (2010)	Service professionals, media outlets, and informal sources	Interpreting and translation	Race and ethnicity (participants all Hispanic/Latino)	Tools were translated into Spanish	No
Czaja et al. (2013)	Memory clinics, community organizations, social service agencies, churches	Giving community presentations, flexible/convenient options for participation, employing bilingual workers	Race and ethnicity	Tools were translated into Spanish	Subgroup analysis (Hispanic and Black)
Easom et al. (2020)	Community organizations, churches	Interpreting and translation, use of simplified language	Race and ethnicity	Not specified	Subgroup analysis (Hispanic and non-Hispanic White)
Feliciano-Astacio et al. (2017)	Dementia specialists, aged care facilities; community events; community organizations	Giving community presentations	Race and ethnicity (participants all Puerto Ricans)	Not specified	Unclear
Filstein et al. (2019)	Alzheimer's Disease Center—Brain donation program cohort	Employing bilingual workers; flexible/convenient options for participation	Race and ethnicity, other ancestry (genetic ancestry)	Tools administered in Spanish if needed	Subgroup analysis (Black, Hispanic, and non-Hispanic White)
Fitten et al. (2014)	Medical centers with high CALD caseload, community organizations	Giving community presentations; employing bilingual workers; interpreting and translation	Race and ethnicity, language, other ancestry (ancestry and surname), country of birth	Validated Spanish-language MMSE, neuropsychological battery normed and standardized for Hispanics in Southern California	Subgroup analysis (Hispanic and non-Hispanic White)
Gallagher-Thompson et al. (2015)	Not described	Interpreting and translation; employing bilingual workers	Country of birth, years in country; race and ethnicity (participants all Hispanic/Latino)	Not applicable	Corrections/adjustments (years in country)

(Continues)

TABLE 1 (Continued)

Author	Recruitment source	Techniques for recruitment and participation	Variables collected	Ethnic minority specific tools used	Subgroup analyses or corrections/adjustments for years in country, language proficiency, or visa type
Gardner et al. (2019)	Not described	Not described	Race and ethnicity, other ancestry (genetic ancestry)	Not applicable	Subgroup analysis (Black, non-Hispanic Whites)
Gelber et al. (2012)	From the HHP	Not described	Race and ethnicity (participants all Japanese American)	Not specified	No
Giebel et al. (2016)	Seniors center, day centers	Not described	Race and ethnicity, language (first), country of birth, years in country, age at migration, religion	Versions of scales in Urdu and Gujarati	No
Gollan et al. (2017)	Research center	Interpreting and translation	Language (dominant language, % use of English), English proficiency, years in country	Not applicable	No
Golub et al. (2017)	WHICAP— Medicare beneficiaries	Not described	Race and ethnicity	Not specified	No
Gonyea et al. (2016)	Community, bilingual agencies	Interpreting and translation; culturally appropriate content	Language (primary, spoken at home), other ancestry (cultural roots), childhood country; race and ethnicity (participants all Hispanic/Latino)	Spanish version of the Neuropsychiatric Inventory–Severity Scale (NPI-S), Spanish version of the Neuropsychiatric Inventory–Distress (NPI-D), Spanish version of the Center for Epidemiological Studies Depression Scale (CES-D), Spanish version of the Revised Scale for Caregiving Self-Efficacy (RSCSE), Spanish version of the State Anxiety Inventory State (STAI-S)	No
Gonzalez et al. (2014)	Not described	Not described	Race and ethnicity	Not specified	No
Gottesman et al. (2016)	From Atherosclerosis Risk in Communities (ARIC) study	Not described	Race and ethnicity	No	Subgroup analysis (Black and White)

(Continues)

TABLE 1 (Continued)

Author	Recruitment source	Techniques for recruitment and participation	Variables collected	Ethnic minority specific tools used	Subgroup analyses or corrections/adjustments for years in country, language proficiency, or visa type
Graham-Phillips et al. (2016)	Not described	Interpreting and translation	Race and ethnicity	Not specified	No
Higuchi et al. (2015)	From HHP	Not described	Race and ethnicity (participants all Japanese American)	Not specified	No
Holland et al. (2011)	Media advertisements, mailings/contact with relevant agencies.	Employing bilingual workers	Race and ethnicity	Not specified	No
Howell et al. (2017)	Not described	Not described	Race and ethnicity	Not specified	Subgroup analysis (Black, White)
Kajiyama et al. (2018)	Community	Monetary compensation	Race and ethnicity (participants all Hispanic/Latino)	Not specified	No
Kamara et al. (2018)	Not described	Not described	Race and ethnicity	Not applicable	No
Kaufman et al. (2010)	Community	Monetary compensation	Race and ethnicity	Not specified	No
Kaup et al. (2019)	Community	Not described	Race and ethnicity	Not specified	Subgroup analysis (Black and White)
Lee et al. (2010)	Not described	Not described	Race and ethnicity	All assessments provided in English and Spanish	No
Lee et al. (2012)	Not described	Not described	Race and ethnicity	Not specified	No
Leone et al. (2014)	local ethnic media, community, aged care networks	Employing bilingual workers; advertising in ethnic media; culturally appropriate content	Language, country of birth, years in country	Unclear whether the DASS-21 was administered in language but assumed that it was given its availability in numerous languages	Subgroup analysis (Chinese and Spanish)
Levy-Storms et al. (2017)	High minority case load outpatient memory clinic	Employing bilingual workers	Race and ethnicity, language	Not specified	No
Livney et al. (2011)	High minority case load primary care practice	Community-based outreach	Race and ethnicity	MMSE and DSRs available in either English or Spanish as preferred by participant. Unclear whether this applied to the GDS also	Subgroup analysis (Latinos and Blacks)
Luchsinger et al. (2012)	Memory clinics, hospitals, ambulatory care network linked to hospital, senior centers, community	Not described	Race and ethnicity (participants all Hispanic)	Not specified	No

(Continues)

TABLE 1 (Continued)

Author	Recruitment source	Techniques for recruitment and participation	Variables collected	Ethnic minority specific tools used	Subgroup analyses or corrections/adjustments for years in country, language proficiency, or visa type
Luchsinger et al. (2015)	Not described	Not described	Language (interviewed in); race and ethnicity (participants all Hispanic/Latino)	Not specified	No
Melrose et al. (2015)	Not described	Community-based outreach	Race and ethnicity, language	Spanish and English Neuropsychological Assessment Scales (SENAS)	No
Merritt et al. (2013)	Senior centers, caregiver registries	Monetary compensation	Race and ethnicity (participants all Black)	Not specified	No
Meyer et al. (2014)	From the SALSA	Interpreting and translation	Language (interviewed in—as measure of acculturation); race and ethnicity (participants all Hispanic/Latino)	Center for Epidemiological Studies Depression scale (CESD) which has been used with Latino populations. Survey conducted in Spanish or English	No
Miller et al. (2015)	Not described	Community-based outreach	Race and ethnicity	Spanish and English Neuropsychological Assessment Scales	Subgroup analysis (White, Black, Hispanic)
Moss et al. (2018)	Via Program of All-Inclusive Care for the Elderly (PACE)	Not described	Race and ethnicity (participants all Black)	Not specified	No
Mungas et al. (2010)	Memory clinics, community	Community-based outreach; employing bilingual workers; triangulation of information gathering	Race and ethnicity	Unclear	Subgroup analysis (Black, Hispanic, and White)
Nervi et al. (2011)	Memory clinics with high minority case loads	Not specified	Race and ethnicity (participants all Caribbean Hispanic)	Not specified	No
Noble et al. (2017)	WHICAP—Medicare beneficiaries	Not described	Race and ethnicity	Not specified	Subgroup analysis (non-Hispanic White, Hispanic, Black)
Noble et al. (2012)	WHICAP—Medicare beneficiaries	Not described	Race and ethnicity	Not specified	No

(Continues)

TABLE 1 (Continued)

Author	Recruitment source	Techniques for recruitment and participation	Variables collected	Ethnic minority specific tools used	Subgroup analyses or corrections/adjustments for years in country, language proficiency, or visa type
O'Bryant, Johnson, Balidin et al. (2013)	Community, community organizations, seniors' organizations	Giving community presentations; flexible/convenient options for participation	Race and ethnicity	Not specified	Subgroup analysis (Mexican American and non-Hispanic White)
Ornstein et al. (2018)	WHICAP—Medicare beneficiaries	Not described	Race and ethnicity	Not specified	No
Parlevliet et al. (2016)	General practitioners in suburbs with large immigrant populations	Interpreting and translation; employing bilingual workers; flexible/convenient options for participation	Race and ethnicity	Culture-fair Cross-Cultural Dementia (CCD) test, validated with population of interest; test in relevant languages; IQCODE-sf used to screen for and diagnose dementia in illiterate populations	Subgroup analysis (native Dutch, Turkish, Surinamese, Moroccan)
Rabinowitz et al. (2010)	Community organizations, seniors' organizations, diagnostic centers, Alzheimer's Association chapters, day care programs, caregiver centers	Giving community presentations; interpreting and translation	Race and ethnicity	Not specified	No
Rajabli et al. (2018)	AA from: John P. Hussman Institute for Human Genomics (IHG) at the University of Miami Miller School of Medicine (Miami, FL), North Carolina A&T State University (Greensboro, NC), Case Western Reserve University (Cleveland, OH), and the Alzheimer's Disease Genetic Consortium, PR from Puerto Rico Alzheimer Disease and Related Disorders Initiative study.	Not described	Race and ethnicity	Not specified	No

(Continues)

TABLE 1 (Continued)

Author	Recruitment source	Techniques for recruitment and participation	Variables collected	Ethnic minority specific tools used	Subgroup analyses or corrections/adjustments for years in country, language proficiency, or visa type
Ravenscroft et al. (2016)	Clinics, the Mayo Clinic Florida brain bank and the Florida Presentile Alzheimer's Disease Subjects registry	Not described	Race and ethnicity (participants all Hispanic)	Not applicable	No
Roche et al. (2018)	General practitioners in suburbs with high density of residents from Black backgrounds	Monetary compensation	Race and ethnicity, country of birth, years in country	APEND—Attitudes of People from Ethnic Minorities to Help-Seeking for Dementia16 TPB questionnaire	Subgroup analysis (Black British, Black African, Black Caribbean, Asian Caribbean)
Rote et al. (2017)	Not described	Interpreting and translation	Country of birth; race and ethnicity (participants all Mexican American)	Not specified	Subgroup analysis (Mexico-born and US-born Mexican Americans)
Rovner et al. (2018)	Senior centers, senior housing sites, churches, primary care clinics	Employing bilingual workers	Race and ethnicity (participants all Black)	Tests with race/ethnicity-adjusted norms	no
Runci et al. (2012)	Aged care facilities	Employing bilingual workers; interpreting and translation	Race and ethnicity, years in country, English proficiency	Greek or Italian versions of the MMSE	Corrections/adjustments (proficiency in language of country of settlement)
Shih et al. (2018)	From the SALSA	Not described	Country of birth, language (primary); race and ethnicity (participants all Hispanic/Latino)	Spanish English Verbal Learning Test	No
Tang et al. (2019)	From the Population Study of Chinese Elderly	Not described	Years in country, age at migration, migration reason: (participants all Chinese American)	Not specified	No
Teresi et al. (2012)	Geriatric Ambulatory Practice (GAP)	Not described	Race and ethnicity, religion	Unclear	Subgroup analysis (non-Hispanic White, Hispanic, Black)

(Continues)

TABLE 1 (Continued)

Author	Recruitment source	Techniques for recruitment and participation	Variables collected	Ethnic minority specific tools used	Subgroup analyses or corrections/adjustments for years in country, language proficiency, or visa type
Tinklenberg et al. (2015)	Alzheimer's Disease Centers, universities	Not described	Race and ethnicity	MMSE in different languages	Subgroup analysis (Latinos, Asian Americans, Blacks, and other)
Turner et al. (2017)	Churches, community organizations, clinics, senior-subsidized housing facilities	Giving community presentations	Race and ethnicity (participants all Black)	Not specified	No
Vaingankar et al. (2016)	Not described	Not described	Race and ethnicity	Not specified	Subgroup analysis (Chinese, Malay, Indian, other)
Vardarajan et al. (2015)	Not described	Not described	Race and ethnicity	Not specified	No
Vardarajan et al. (2017)	Part of the AD sequencing project (ADSP)	Not described	Race and ethnicity (participants all Caribbean Hispanic)	Not specified	No
Wand et al. (2013)	Hospitals	Interpreting and translation; triangulation of information gathering	Language (language group, need for and use of interpreters)	Rowland Universal Dementia Assessment Scale (if English was not first language)	No
Wharton et al. (2019)	Not described	Not described	Race and ethnicity	Not specified	No
Xiao et al. (2016)	Community organizations	Employing bilingual workers; researcher culture training	Country of birth, language (spoken at home), other ancestry (cultural background)	Not specified	No
Zahodne et al. (2014)	WHICAP—Medicare beneficiaries	Interpreting and translation	Race and ethnicity, language (bilingualism), English proficiency, years in country, age at migration	Battery of tests were translated into Spanish and back translated for accuracy.	Corrections/adjustments in country
Zeki Al Hazzouri et al. (2013)	From the SALSA	Employing bilingual workers; interpreting and translation; flexible/convenient options for participation	Race and ethnicity (participants all Mexican American)	Not specified	No
Zhu et al. (2019)	WHICAP—Medicare beneficiaries	Interpreting and translation	Race and ethnicity	Unclear	Subgroup analysis (Black and Hispanic)

Abbreviations: CALD, culturally and linguistically diverse; DASS-21, Depression Anxiety Stress Scale-21 items; DSRS, Dementia Severity Rating Scale; GDS, Geriatric Depression Scale; HHP, Honolulu Heart Program; IQCODE-sf, Informant Questionnaire on Cognitive Decline in the Elderly, short form; MMSE, Mini-Mental State Examination; SALSA, Sacramento Area Latino Study on Aging; TPB, Theory of Planned Behavior questionnaire; WHICAP, Washington Heights—Inwood Columbia Aging Project.

Other techniques included providing options for study questionnaires to be filled out in writing or verbally to cater to participants who were not literate,⁸² making use of simplified language in study materials,⁶³ and providing training in cultural sensitivity for researchers working on such projects.⁵⁴ Researchers commonly recruited through specialist clinics with high ethnic-minority patient caseloads such as memory clinics in Chinatown⁸² or primary care clinics in predominantly ethnic-minority neighborhoods.⁵⁰ Other common sources of recruitment were community organizations and places of worship.

Only one article reported on retention.⁷⁶ Kajiyama et al.⁷⁶ reported 6 of a total of 25 participants dropping out of an intervention study trialing an online “Webnovela” due to lack of time and other personal issues. The researchers provided flexibility within the study protocol for participants to choose time and frequency of engagement. Rabinowitz et al.⁴¹ described the REACH study and cite an earlier REACH article covering retention of participants. Some intervention sites in the REACH study reported feeling as though they should provide some kind of service (unspecified) to participants to ensure continued participation in the project.⁸³

3.2 | Ethnic and cultural variables collected

Information on race and ethnicity was the most common variable related to ethnic and cultural diversity that studies collected ($n = 59$, 89%). Items we coded as “race and ethnicity” included those that used either or both of these terms or combinations of them such as “ethno-racial group,”⁷⁹ as well as studies that focused on one ethnic group such as Hispanics or Japanese Americans. Five studies were coded as having collected information on “other ancestry.” These included genetic ancestry,⁶⁹ haplotype ancestry,⁸⁴ ancestry and surname,⁶⁴ as well as country of family’s cultural roots.⁶⁶

It was less common for studies to collect information on country of birth ($n = 9$), and time lived in country of settlement ($n = 8$). Fourteen articles (21%) reported on some aspects of participants’ language, including language spoken at home,⁶⁶ first or preferred language,⁵⁵ bilingualism,³⁴ age at which use of Spanish and English began,⁶⁵ need for interpreters for participation in study,⁵⁶ and the language in which study interviews were conducted.^{36,46}

One-third of the articles ($n = 22$) collected more than one variable, triangulating for cultural and linguistic diversity. Nine studies triangulated with one other variable, six with two other variables, and six with three or more other variables (see Table 1). For example, a study from the Netherlands compared prevalence of dementia and cognitive impairment between native Dutch and immigrants, defining participant cultural background or ethnicity according to country of birth rather than other indicators of ancestry.⁶¹ Data in this study were analyzed by ethnic group (i.e., native Dutch, Moroccan-Arabic, Moroccan-Berber, Turkish, Surinamese-Creole, and Surinamese-Hindustani). In another study, Tang et al.⁸⁵ examined the incidence and prevalence of cognitive impairment among Chinese Americans, and explored the role of immigration factors. The researchers collected information on reasons for

immigration (e.g., whether involuntary, in search of better life, or for reunification with family), amount of time participants had lived in the United States, age at which they had migrated. Acculturation was measured using a 12-item questionnaire that covered preferred language, type of media accessed, and preferences for ethnicity of people they interact with. These were used as factors in logistic regression.

3.3 | Analysis of ethnic and cultural data

Twenty-two articles (33%) used assessment tools that were tailored to ethnic minorities, including versions in participants’ language and measures with ethnic-adjusted norms. Ethno-specific tools used included the Woodcock–Johnson Spanish psycho-educational battery and PSEUDOMARKER software for analyzing more complex family structures in multigenerational Caribbean Hispanic families;⁸⁶ Attitudes of People from Ethnic Minorities to Help-Seeking for Dementia (APEND);⁵⁰ and the Rowland Universal Dementia Assessment Scale (RUDAS), which was used if English was not the participant’s first language.⁵⁶

In 23 articles, the authors carried out some kind of subgroup analysis. Two articles controlled for years lived in country,^{34,53} and one for proficiency in language of the country of settlement.⁵⁸ Reporting on religious affiliation was relatively uncommon, with only two articles doing so,^{52,59} while three other articles were from studies that investigated the role of religion in coping.^{41,43,78}

3.4 | High quality studies

Six articles met all of the quality assessment criteria (see Table 2).^{34,50,58,64,69,82} Four were US studies and one each was from the UK and Australia. To facilitate the participation of ethnic minorities, researchers in these studies used tools developed or adapted for the groups of interest. For example, researchers used validated translated versions of instruments,^{50,64,82,87} or translated and back-translated relevant test batteries for their participants.³⁴

The participation of ethnic minority groups was also enhanced through recruitment from clinics with high caseloads of groups of interest,^{50,64,82} places of worship and community organizations,⁶⁴ and direct presentations to communities by the research team.⁶⁴ Employment of bilingual staff in the research team strengthened recruitment⁶⁴ and assessment.⁶⁹ Other methods to facilitate ethnic minorities’ participation were providing flexible options for participation,⁸² for example, by providing options for written and verbal assessment to cater to differences in literacy,⁸² and providing monetary compensation for participation.⁵⁰

Cultural and linguistic diversity were triangulated using multiple variables, and researchers controlled and adjusted for these to investigate differences in dementia among ethnic minorities. Data on ethnicity combined with data on age of migration,³⁴ country of origin,^{34,50} years lived in settlement country,^{34,50,58} native language,^{34,58} proficiency in the settlement country language,^{58,82} age,^{64,69,82} sex,^{64,69,82}

TABLE 2 Indicators of best practice

Author	Ethnic minority-specific tools used	Triangulation of methods (more than one measure of ethnic minority status: e.g., country of birth, language, visa, etc.)	Techniques to enhance recruitment, participation, retention of ethnic minorities	Subgroup analysis or correction/adjustment for years in country, language proficiency, or visa type
Barral et al. (2015)	Y		Y	
Brown et al. (2014)	Y		Y	Y
Chao et al. (2014)	Y	Y	Y	Y
Cucciare et al. (2010)	Y		Y	
Czaja et al. (2013)	Y		Y	Y
Easom et al. (2020)			Y	Y
Feliciano-Astacio et al. (2017)			Y	
Filshtein et al. (2019)	Y	Y	Y	Y
Fitten et al. (2014)	Y	Y	Y	Y
Gallagher-Thompson et al. (2015)		Y	Y	Y
Gardner et al. (2019)		Y		Y
Gelber et al. (2012)				
Giebel et al. (2016)	Y	Y		
Gollan et al. (2017)		Y	Y	
Golub et al. (2017)				
Gonyea et al. (2016)	Y	Y	Y	
Gonzalez et al. (2014)				
Gottesman et al. (2016)				Y
Graham-Phillips et al. (2016)			Y	
Higuchi et al. (2015)				
Holland et al. (2011)			Y	
Howell et al. (2017)				Y
Kajiyama et al. (2018)			Y	
Kamara et al. (2018)				
Kaufman et al. (2010)			Y	
Kaup et al. (2019)				Y
Lee et al. (2010)	Y			
Lee et al. (2012)				
Leone et al. (2014)		Y	Y	Y
Levy-Storms et al. (2017)		Y	Y	
Livney et al. (2011)	Y		Y	Y
Luchsinger et al. (2012)				
Luchsinger et al. (2015)		Y		
Melrose et al. (2015)	Y	Y	Y	
Merritt et al. (2013)			Y	
Meyer et al. (2014)	Y	Y	Y	
Miller et al. (2015)	Y		Y	Y
Moss et al. (2018)				
Mungas et al. (2010)			Y	Y
Nervi et al. (2011)				

(Continues)

TABLE 2 (Continued)

Author	Ethnic minority-specific tools used	Triangulation of methods (more than one measure of ethnic minority status: e.g., country of birth, language, visa, etc.)	Techniques to enhance recruitment, participation, retention of ethnic minorities	Subgroup analysis or correction/adjustment for years in country, language proficiency, or visa type
Noble et al. (2017)				Y
Noble et al. (2012)				
O'Bryant, Johnson, Balldin et al. (2013)			Y	Y
Ornstein et al. (2018)				
Parlevliet et al. (2016) A47	Y		Y	Y
Rabinowitz et al. (2010)			Y	
Rajabli et al. (2018)				
Ravenscroft et al. (2016)				
Roche et al. (2018)	Y	Y	Y	Y
Rote et al. (2017)		Y	Y	Y
Rovner et al. (2018)	Y		Y	
Runci et al. (2012)	Y	Y	Y	Y
Shih et al. (2018)	Y	Y		
Tang et al. (2019)		Y		
Teresi et al. (2012)		Y		Y
Tinklenberg et al. (2015)	Y			Y
Turner et al. (2017)			Y	
Vaingankar et al. (2016)				Y
Vardarajan et al. (2015)				
Vardarajan et al. (2017)				
Wand et al. (2013)	Y	Y	Y	
Wharton et al. (2019)				
Xiao et al. (2016)		Y	Y	
Zahodne et al. (2014)	Y	Y	Y	Y
Zeki Al Hazzouri et al. (2013)			Y	
Zhu et al. (2019)			Y	Y

education,^{64,69,82} employment,⁵⁰ and religion.⁵⁰ For example, comparing age of dementia diagnosis in Hispanic bilinguals and monolinguals, Zahodne et al.³⁴ collected information on age of migration, country of origin, and years in the United States, using these as covariates in their analysis. Similarly, Runci et al.⁵⁸ in their study of Greek and Italian Australians with dementia in residential aged care, controlled for ethnicity, years lived in Australia, native tongue, and English proficiency. The collection of information beyond race and ethnicity allowed the researchers to be attuned to the multiple and intersecting variables that are relevant to dementia, ethnicity, and culture. For example, Chao et al.⁸² were able to demonstrate the role of socioeconomic status in dementia risk, treatment, and care among ethnic minority groups. By recruiting sufficient numbers of participants from different groups that supported subgroup analyses, these studies made contributions to understanding differences in dementia etiology between groups.⁶⁹

4 | DISCUSSION

4.1 | Key findings

Excluding ethnic minorities from research based on language, race, ethnicity, or culture fails to live up to the principle of justice, a core guiding principle in medical research ethics.⁸⁸ Addressing barriers to participation is a key component of greater inclusion in dementia research. By investigating approaches to enhance the recruitment of, and consistent collection and analysis of variables relevant to, ethnic minorities in dementia clinical and cohort studies, our objectives were to identify common strategies and high-quality studies in this area (Objectives 1 and 2).

Our key findings indicate that the most common techniques identified to facilitate recruitment and participation were the use of interpreters and the translation of study materials, followed by the

employment of bilingual and bicultural researchers. One-third of the articles reported on the use of translated versions of assessment tools or the use of measures with ethnic-adjusted norms. In the studies identified as high quality, ethnic minority participants were most often recruited via community-based approaches typically comprising gaining support for recruitment from service providers working with ethnic minority communities,^{50,64,69,82} and engaging in community outreach through community organizations and institutions.⁶⁴ These findings reinforce that partnership with communities is an important component of dementia research involving ethnic minority communities.⁸⁹ As underscored in several systematic reviews,^{90–95} such partnerships enhance recruitment and retention in RCTs and cohort studies by invoking feelings of altruism among participants and hope for positive clinical outcomes, give access to best treatment options, enhance community connectedness and peer support, and build trust in doctor–patient relationships. However, as also pointed out in Gilmore-Bykovskiy et al.'s¹⁹ review of recruitment and retention in dementia research, the strong focus on recruiting through primary care and community settings means that there is a paucity of evidence on what might work in acute care settings such as hospitals and emergency departments. This is a missed opportunity, especially in those HICs in which many ethnic minority communities overwhelmingly seek basic and primary care needs through such settings.¹⁹

Additionally, employment of researchers or clinical staff who spoke the participants' primary language^{38,51,53,54,57,58,61,64,68–72} or translation of study materials⁵⁸ were key ways in which researchers made participation in dementia research accessible to ethnically diverse people. The researchers used in-language versions of the relevant tools^{58,64,82} and where these were not available, translated and back-translated the tools themselves.³⁴ To further enable participation of ethnic minority participants in their studies, researchers provided flexible modes of participation that took into account different levels of literacy.⁸²

The most common variables collected in order were race and ethnicity, native language, country of birth, and length of time in country of settlement. Only one study collected information on reason for migration, and this was related to the specific study aims.⁸⁵ In the reported analyses, years of education was the most common variable controlled for. Only one study⁵⁸ adjusted for English proficiency, which related to the study aims.

Finally, studies that triangulated cultural and linguistic diversity through multiple variables beyond race and ethnicity often provided more nuanced analyses around diversity. This allowed greater appreciation of how variables such as socioeconomic status can have an impact on dementia prevention, treatment, and care.⁸² By recruiting sufficient numbers to support subgroup analyses,⁶⁹ researchers were also able to make valuable contributions toward understanding differences in etiology between groups.¹

4.2 | Recommendations

Our third objective in this review was to collate findings to make recommendations for consistent practices that will enhance the inclu-

siveness of dementia research (Objective 3). These recommendations (Table 3), categorized as “essential” and as “highly recommended,” are intended to be relevant to all dementia research for which the inclusion of ethnic minorities is appropriate and possible.

Our recommendations, though derived from the dementia research, have broader applicability to medical research. By systematically synthesizing the evidence we have a better understanding of *what has worked* and can build on this knowledge. Sound science requires continuous evaluation and assessment to determine a rigorous evidence base and the feasibility and transferability of an initiative. Too often researchers note the underrepresentation of ethnic minorities in dementia studies and medical research, but fail to offer practical ways to overcome known barriers. Our recommendations address this gap. In developing recommendations to address systemic inequities both within and outside medical research, our findings show that there is no “magic bullet” or “secret formula” for how to better include underrepresented ethnic minorities in dementia research and indeed more broadly in medical research. Rather, it is an ongoing process, necessitating an approach that recognizes diverse life experiences, involves authentic collaboration, and solicits the participation of all stakeholders in the research.⁹⁶ New methodological approaches may emerge—for example, co-design and co-production—but ultimately, understanding local context, especially in marginalized communities, and how power and conflict affect the health of the most vulnerable is critical.

4.3 | Limitations

There are limitations in the articles on which our recommendations are based. The included articles are overwhelmingly from the United States. As the issues surrounding dementia in ethnic minorities may be specific to historical and social contexts, context-specific reviews may be of value. Another major limitation of the included articles was the paucity in the reporting of retention and recruitment rates, which limits our ability to comment on the effectiveness of the strategies used by these studies to include ethnic minorities in their research.

The broad scope of this review, encompassing a range of topics and study designs in dementia research, is an essential first step to synthesizing the evidence of how ethnic and cultural diversity is treated in clinical and cohort studies of dementia. This broad scope inevitably requires sacrificing precision in some areas. First, in identifying high-quality studies, we have used indicators that are applicable to most, but not all, study designs. For example, the need for techniques to recruit ethnic minorities may not be relevant to genetic studies drawing samples from brain banks. Future research could investigate these questions by focusing on specific study designs. Second, it is possible that our search excluded otherwise relevant studies that referred to specific ethno-cultural groups in HIC, but that did not use other terms related to ethnic minorities. Third, by also confining our search to HIC, we might have also missed out on other approaches applied in low- and middle-income countries to include ethnic minorities in dementia research. Fourth, in covering recruitment, collection, and reporting simultaneously, our methodological decisions may have

TABLE 3 Recommendations to increase representation of ethnic minorities in dementia research

	Essential	Highly Recommended
Recruitment, participation, and retention	<p>Use interpreters or bilingual/bicultural workers.</p> <p>Translate study materials into participants' preferred language, using accredited translators where possible.</p> <p>Work in partnership with communities (e.g., through the use of community-based outreach methods) to build trust, raise awareness of, and engage communities in, dementia research.</p> <p>Use culture-appropriate tools (e.g., The Rowland Universal Dementia Assessment Scale [RUDAS]; The Zarit Burden Interview [ZBI]) and materials that take into consideration differences in levels of education and health literacy.</p>	<p>Design research that, where relevant, ensures recruitment of sufficient participants in various groups to enable subgroup analyses.</p> <p>Consistent reporting on recruitment and retention rates specific to ethnic minorities in dementia studies.</p>
Collection and reporting of data	<p>Use accredited interpreters and/or bicultural/bilingual workers in the collection of data. Collect information on:</p> <ul style="list-style-type: none"> • Ancestry • Languages (first, preferred or languages spoken at home) and • Country of birth • Length of time in country of settlement^a • Conditions of migration (e.g., visa type)^b 	<p>Use validated, culturally adapted instruments where possible. Where these are not available, researchers should consider undertaking the translation of these instruments as it enhances the scientific contribution of their research.</p> <p>Collect information on religious or spiritual affiliation.^c</p>
Analysis		<p>Provide greater detail in descriptive statistics of sample characteristics and comment on whether the sample reflects the target population.</p> <p>Recognize the diversity within ethnic minority populations (e.g., cultural differences in meaning of dementia and stigma). Where possible, use between-subgroup analysis, rather than comparisons only between minorities (combined) and the mainstream population.</p> <p>Adjust for relevant covariates such as years lived in country of settlement, ancestry, and proficiency in language of country of which is often correlated with race and ethnicity.⁴⁹</p>

^aTriangulating information on time in country and country of birth will capture important within-community differences (e.g., recent arrivals versus established communities; first versus second generation).

^bPre- and post-migration experiences differ among migrants (e.g., economic migrants compared to asylum seekers and refugees). Collecting information on conditions of migration will contribute to how these differences influence dementia risk and help-seeking.

^cWe recommend the collection of this information as religious affiliation and spirituality can be an important aspect of the diversity of ethnic minority populations, and is known to play a role in well-being after a diagnosis of dementia,⁵⁰ how dementia is understood, and in whether help is sought.⁵¹

reduced our ability to deal comprehensively with all these areas. In particular, our restriction of the review to articles published from 2010 onward excluded information about recruitment and retention from some of the longitudinal studies in which this information might have been published before the search period. We have provided information about the studies in the review, and readers may wish to refer to earlier publications from these studies (especially WHICAP, SALSA, HAAS, REACH, and REACH II) for greater detail about techniques to enhance recruitment, participation, and retention. Finally, the review excluded evidence from gray literature, including government reports using large datasets.

5 | NEXT STEPS

The COVID-19 pandemic has disproportionately impacted many ethnic minorities across the world as existing inequalities associated with

ethnicity, race, sex, and poverty have intersected to further marginalize already vulnerable groups. Medical research has a crucial part to play as part of a wider global response to secure health justice for all. An important part of this response is strengthening current research guidelines to offer recommendations to researchers on how to plan and report on a minimum set of variables related to ethnic diversity, for example, extensions to existing research guidelines such as the Standard Protocol Items: Recommendations for Interventional Trials (SPIRIT) and Consolidated Standards of Reporting Trials (CONSORT) statements. The international consensus underpinning the development of these guidelines and their reach and imprimatur from funders, scholars, ethics and governance authorities, and publishers, can be transformative of how we do medical research. Such guidelines offer a standard way for authors to prepare reports of trials, facilitate complete and transparent reporting, and critical appraisal and interpretation, which collectively will contribute to more transparent reporting of studies that include variables relevant to ethnicity.

Widespread uptake of such guidance will also make it easier for decision makers (e.g., policy makers, evidence synthesizers, and guideline producers) to find and use evidence to reduce ethnic disparities in health.

6 | CONCLUSION

This scoping review offers recommendations for more consistent recruitment, collection, and reporting on variables of ethnic and cultural diversity in dementia research. Such recommendations can improve the overall rigor of dementia research. More robust science in turn can improve the well-being of ethnic minorities living with dementia and their carers, help policy makers and program designers reduce health and care inequities, and ensure that ethnic minorities are able to share in the benefits brought about by advances in dementia science.

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CONFLICTS OF INTEREST

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SUPPORTING INFORMATION

Additional supporting information may be found in the online version of the article at the publisher's website.

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