Title:
Strategies for the Recruitment and Retention of Racial/Ethnic Minorities in Alzheimer Disease and Dementia Clinical Research

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This is a pre-print of an article published in *Current Alzheimer Research* before peer-review. The final authenticated version is available online at: https://doi.org/10.2174/1567205016666190321161901

ABSTRACT

Background

Racial/ethnic minorities have the highest risk for Alzheimer disease and dementia, but remain underrepresented in clinical research studies.

Objective

To synthesize the current evidence on strategies to recruit and retain racial/ethnic minorities in Alzheimer disease and dementia clinical research.

Method

We conducted a systematic review by searching CINAHL, EMBASE, MEDLINE, PsycINFO, and Scopus. We included studies that met four criteria: (1) included a racial/ethnic minority group (African American, Latino, Asian, American Indian or Alaska Native, and Native Hawaiian or Other Pacific Islander); (2) implemented a recruitment or retention strategy for Alzheimer disease or dementia clinical research; (3) conducted within the U.S.; and (4) published in a peer-reviewed journal.

Results

Of the 19 included studies, 14 (73.7%) implemented recruitment strategies and 5 (26.3%) implemented both recruitment and retention strategies. Fifteen studies (78.9%) focused on African Americans, two (10.6%) on both African Americans and Latinos, and two (10.5%) on Asians. All articles were rated weak in study quality. Four major themes were identified for recruitment strategies: community outreach (94.7%), advertisement (57.9%), collaboration with health care providers (42.1%), and referral (21.1%). Three major themes were identified for retention strategies: follow-up communication (15.8%), maintain community relationship (15.8%), and convenience (10.5%).

Conclusion

Our findings highlight several promising recruitment and retention strategies investigators should prioritize when allocating limited resources, however, additional well-designed studies are needed. By recruiting and retaining more racial/ethnic minorities in Alzheimer disease and dementia research, investigators may better understand the heterogeneity of disease progression among marginalized groups. PROSPERO registration #CRD42018081979.

Keywords: Alzheimer disease, Dementia, Ethnicity, Minority, Race, Recruitment, Retention, Systematic review.

1. INTRODUCTION

Although Alzheimer disease is prevalent across all U.S. sociodemographic groups, incidence rates for Alzheimer disease are notably higher among racial/ethnic minorities. One prior study compared dementia risk across all major U.S. Census racial/ethnic groups and found that incidence rates for dementia were highest among minorities, particularly African Americans (hazard ratio [HR]=1.7) and American Indians (HR=1.3), compared to Whites (HR=1.2) [1]. Similarly, a recent systematic review comparing racial/ethnic differences in dementia risk found that the annual average incidence rates for dementia were higher among Hispanics (3.6%), African Americans (2.6%), and Asian Americans (2%) compared to Non-Hispanic Whites (1.6%) [2].

Diversity of participants engaged in clinical research on Alzheimer disease and dementia has recently garnered considerable attention. The National Institutes of Health (NIH) defines clinical research as the study of "people, either through direct interaction or through the collection and analysis of blood, tissues, or other samples" [3]. In the context of Alzheimer disease and dementia, clinical research typically includes the collection of samples through blood, neuroimaging, lumbar puncture, or brain donation. Prior research, however, indicates that racial/ethnic minorities including African Americans, Hispanics, and Asian Americans are less likely to enroll in Alzheimer disease clinical research [4, 5]. Reported barriers hindering participation of African Americans in Alzheimer disease and dementia research include mistrust of researchers, fear of adverse effects from medications and procedures, and inconvenience due to location and time [6, 7]. Barriers for Hispanics include constraints due to finances, linguistics, transportation, and immigration status [8]. Barriers to Alzheimer disease research participation for Asian Americans include poor health, no spare time, lack of transportation, and lack of family support [9].

A recent literature review was conducted to identify gaps in available methods to improve the recruitment of participants in Alzheimer disease research [10]. This review indicated that few studies have identified effective strategies to increase minority participation in Alzheimer research. This gap is noteworthy, given that the National Institutes of Health Revitalization Act of 1993 established guidelines to enforce the inclusion of minorities in federally-funded clinical research [11], and the National Institute on Aging approved a new initiative in January 2018 urging additional research aimed at developing and evaluating innovative recruitment and retention methods to enhance diversity among study participants engaged in Alzheimer disease research [12]. Increasing the diversity of participants in Alzheimer research is critical in order to better understand and reduce the disproportionate burden of Alzheimer disease among racial/ethnic minorities.

The aim of this systematic review was to identify strategies for the recruitment and retention of racial/ethnic minorities in Alzheimer disease and dementia clinical research. To the best of our knowledge, this is the first systematic review that has examined strategies to increase Alzheimer disease and dementia research participation among minority populations. In addition, this is the first review of any type that has examined retention strategies for Alzheimer disease and dementia research. Our systematic review sought to answer three research questions: 1) What are the knowledge gaps in the literature on racial/ethnic minority recruitment and retention in clinical research studies on Alzheimer disease and dementia?, 2) What is the quality of evidence on strategies to recruit and retain racial/ethnic minorities in clinical research studies on Alzheimer disease and dementia?, and 3) What are the strategies for recruiting and retaining racial/ethnic minorities in clinical research studies on Alzheimer disease and dementia?

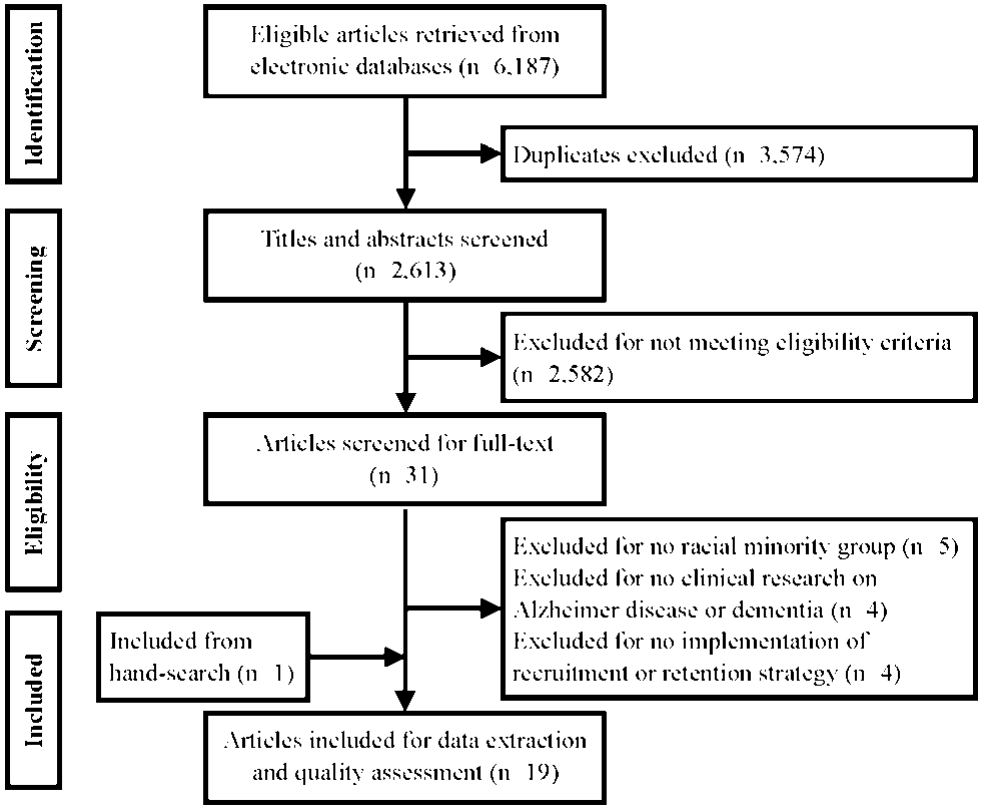
2. METHOD

We conducted a systematic review adhering to the guidelines recommended by the Cochrane Handbook [13]. In addition, we followed the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines for reporting results of the screening process [14]. Before conducting the review, this study was registered on PROSPERO (#CRD42018081979). To be eligible for this review, studies needed to target at least one racial/ethnic minority group, implement a recruitment or retention strategy in Alzheimer disease or dementia clinical research, conduct the study within the U.S., and had to be published in English through a peer-reviewed journal. Eligible racial/ethnic minority groups in this study were based on the NIH guidelines for the inclusion of minorities in clinical research [11]: African American, Hispanic or Latino, Asian, American Indian or Alaska Native, and Native Hawaiian or Other Pacific Islander.

Before implementing the search, we consulted with a library information scientist to develop the search strategy and finalize electronic databases included in this review. The general search terms included: (minority OR african american OR black OR hispanic OR latino OR asian OR american indian OR alaska native OR native american OR

native hawaiian OR pacific islander) AND (alzheimer OR dementia) AND (recruit OR enroll OR participate OR retention OR retain OR remain). The search terms were modified for each of the five electronic databases searched in December 2017 for this review: CINAHL, EMBASE, MEDLINE via EBSCO, PsycINFO, and Scopus. The full search strategy can be retrieved in Appendix A. In addition, hand-searching was implemented by reviewing bibliographies and citations of included papers using the Scopus electronic database. References were imported into EndNote 8 (Clarivate Analytics, Philadelphia, PA) and screened using Rayyan [15] between December 2017 and January 2018. Duplicates were identified and excluded by matching authors, publication year, title, journal, and volume. Full details for included and excluded studies are provided in Fig. **1**.

Fig. (1). PRISMA flow diagram.



Our data extraction instrument was adapted from the data extraction item checklist in the Cochrane Handbook [13]. Study quality of the included studies was also assessed using the Effective Public Health Practice Project (EPHPP) Quality Assessment Tool (QAT) for Quantitative Studies, which has the advantage of assessing study quality for both experimental and non-experimental study designs. The QAT was used to assess each study through seven domains: selection bias, study design, confounders, blinding, data collection methods, withdrawals and drop-outs, and intervention integrity. All seven domains and the global rating for each paper were rated as weak, moderate, or strong based on criteria listed in the QAT. The QAT has been tested to have sufficient content and construct validity, and acceptable levels of test-retest reliability (Kappa=0.74) and inter-rater reliability (Kappa=0.61) [16]. During title and abstract screening, full-text screening, data extraction, and quality assessment, each article was independently assessed by at least two reviewers and conflicts were discussed and resolved through arbitration from a third reviewer.

3. RESULTS

Among the 2,613 unique studies identified, 2,582 were excluded during title/abstract screening, 13 were excluded during full-text screening, and 18 were deemed eligible. One additional study was included through hand-searching bibliographies and citations of the 18 eligible articles. Consequently, the final sample included 19 articles for data extraction and quality assessment (Fig. **1**).

3.1. Characteristics of Included Studies

Of the 19 included studies, 14 (73.7%) focused strictly on recruitment strategies and 5 (26.3%) examined both recruitment and retention strategies (Table **1**) [17-33]. Fifteen studies (78.9%) focused on African Americans only, two studies (10.5%) on both African Americans and Latinos, and the remaining two (10.5%) on Asian Americans only. Most studies adopted a one-group pre-post design (n=10, 52.6%) or a one-group post-test only design (n=7, 36.8%). Notably, there were no randomized clinical trials among the included studies. The majority of the studies (n=15, 78.9%) were conducted in an urban setting. Sixteen studies (84.2%) involved research focusing on Alzheimer disease, whereas three (15.8%) did not mention specific dementia subtypes of interest. Seven studies (36.8%) requested a blood sample, six studies (31.6%) requested a brain donation, four studies (21.1%) requested neuroimaging procedures (e.g. MRI, PET, CT scan), and one study (5.3%) requested a lumbar puncture. Approximately half of all included studies reported length of the recruitment intervention (n=10, 52.6%), participants' age (n=11, 61.1%), sex (n=10, 52.6%), and dementia severity (n=10, 52.6%). The mean participant age ranged from 64 to 77 years and the percent of female participants ranged from 65% to 76%.

Table 1. Characteristics of included studies.

Study	Study Purpose (Study Design)	Study Setting (Recruitment Duration)	Racial/Ethnic Group: Sample Size*	Sample Age (Percent Female)	Dementia Subtypes (Reported Severity)	Procedures Requested
Bachman *et al.*, 2009 [17]	Recruitment (1 group, posttest only)	NR (NR)	AA: 96	Age range: <64 to 85+ (73.9%)	AD, MCI, non-dementia (Normal cognition - moderate dementia)	NR
Ballard *et al.*, 1993 [18]	Recruitment (1 group, pre-post)	NR (2 years)	AA: baseline = 60; follow up = 150; Latino: NR	NR (NR)	AD (Mild - moderate dementia)	Brain donation, unspecified neuroimaging
Ballard *et al.*, 2010 [19]	Recruitment & Retention (1 group, pre-post)	Urban (NR)	AA: NR	NR (NR)	AD (NR)	NR
Barnes *et al.*, 2012 [20]	Recruitment & Retention (1 group, posttest only)	Urban (6 years)	AA: 366	65+ (71.9%)	AD, MCI, VD, PD, unspecified dementia (Normal cognition)	Blood sample, brain donation, neurological exam
Bonner *et al.*, 2000 [21]	Recruitment & Retention (1 group, pre-post)	Urban (2.5 years)	AA: baseline = 133; follow up = 52	Mean age: Female = 75; male = 74 (65%)	AD, VD (NR)	Brain donation
Chao *et al.*, 2011 [9]	Recruitment (1 group, posttest only)	Urban (NR)	Asian: 125	Mean age: outreach clinics = 64; community health fair = 75.4 (Outreach clinics = 27.3 %; community health fair = 63.8 %)	AD, FD, LBD, MCI, mixed dementia, VD, other (Normal, MCI, dementia)	Blood sample, MRI, neurological exam, other
Christensen *et al.*, 2015 [22]	Recruitment (Cross-sectional)	Urban (NR)	AA: 167	NR (NR)	AD (NR)	Blood sample
Darnell *et al.*, 2011 [23]	Recruitment (1 group, posttest only)	Urban (NR)	AA: 46	Mean age: 74 (73.9%)	AD (Normal cognition)	Blood sample, brain donation, other
Ford, 1996 [24]	Recruitment (1 group, pre-post)	Urban (1 year)	AA: NR	NR (NR)	AD (NR)	Other
Fritsch *et al.*, 2006 [25]	Recruitment (1 group, pre-post)	Urban (NR)	AA: NR	NR (NR)	AD (NR)	NR

Gauthier & Clarke, 1999 [26]	Recruitment & Retention (NR)	Urban (NR)	AA: NR	NR (NR)	AD (NR)	NR
Hinton *et al*., 2010 [27]	Recruitment (1 group, pre-post)	Suburb (5 years)	AA: baseline: = 33; follow up = 151; Latino: baseline = 23; follow up = 127	Mean age: AA = 73; Latino = 71 (AA = 69%; Latino = 68%)	MCI, unspecified dementia (Normal, MCI, dementia)	MRI, CT scan, other
Jefferson *et al*., 2013 [28]	Recruitment (1 group, pre-post)	Urban (NR)	AA: 52	Mean age: 75 (76%)	NR (Normal, MCI, dementia)	Brain donation
Li *et al*., 2016 [29]	Recruitment (1 group, posttest only)	Urban (1 year)	Asian: 98	Mean age: 73.9 (65.3%)	NR (Normal, MCI, dementia)	Blood sample, other
Picot *et al*., 1996 [30]	Recruitment & Retention (1 group, pre-post)	Urban (3 years)	AA: 30	Mean age: 77 (75%)	AD (NR)	NR
Romero *et al*., 2014 [31]	Recruitment (1 group, posttest only)	Urban (3 years)	AA: 146	55+ (NR)	AD (Normal cognition)	Blood sample, other
Schnieders *et al*., 2013 [6]	Recruitment (1 group, posttest only)	NR (NR)	AA: 65	Mean age: 73 (73.9%)	AD (NR)	Brain donation, other
Souder & Terry, 2009 [32]	Recruitment (1 group, pre-post)	Urban (5 years)	AA: 135	NR (NR)	AD (NR)	Other
Williams *et al*., 2011 [33]	Recruitment (1 group, pre-post)	Urban (4 years)	AA: 29	NR (NR)	AD (Normal cognition to mild dementia)	Blood sample, MRI, PET scan, lumbar puncture, other

* Number enrolled, recruited, or participated in the study

Abbreviations: AA, African American; AD, Alzheimer disease; CT, computed tomography; FD, frontotemporal dementia; LBD, Lewy Body disease; MCI, mild cognitive impairment; MRI, magnetic resonance imaging; NR, not reported; PD, Parkinson's disease; PET, positron emission tomography; VD, vascular dementia.

3.2. Quality Assessment

A summary of the quality assessment ratings for all included studies is presented in Table **2** and detailed quality assessment ratings for each included study are available in Appendix B. The overall methodological rating of included studies was weak (n=19, 100%). A majority of studies (n=14, 73.7%) were rated weak in the assessment for selection bias due to lack of information on the percent of participants who agreed to participate in the research study (n=12, 63.2%). For the assessment of study design, most studies (n=10, 52.6%) were rated moderate for adopting a cohort analytic design, but lacked randomization. For the assessment of confounders, all studies (n=19, 100%) were rated weak due to a lack of reporting for potential group differences and control of confounders. For the assessment of blinding, most studies (n=10, 52.6%) were rated moderate due to adequate blinding of the research question from the subjects (n=10, 52.6%), but the outcome assessor may have been aware of the intervention for recruitment or retention (n=10, 52.6%). For assessment of data collection methods, the majority of studies (n=18, 94.7%) were rated weak for not reporting information on validity and reliability of the data collection instruments used. For assessment of drop-outs, most studies (n=7, 36.8%) were rated weak due to lack of reporting drop-out or completion rates. For assessment of intervention integrity, most studies did not report the percentage of participants who received the intervention (n=13, 68.4%), did not measure the consistency of the recruitment or retention strategies (n=15, 79.0%), and some participants may have been exposed to multiple recruitment or retention strategies that were implemented simultaneously (n=11, 57.9%).

Table 2. Quality assessment of included studies.

Characteristic		Number of Studies (%)*
A. Selection Bias		
Representative sample	Very likely	2 (10.5)
	Somewhat likely	10 (52.6)
	Not likely	2 (10.5)
	Can't tell	5 (26.3)
Percentage of participants agreed to participate	80%-100%	0 (0)
	60-79%	2 (10.5)
	<60%	5 (26.3)
	Can't tell	12 (63.2)
Rating	Weak	14 (73.7)
	Moderate	5 (26.3)
	Strong	0 (0)
B. Study Design		
Randomization		0 (0)
Nonrandom assignment	One group (pre + posttest)	10 (52.6)
	One group (posttest only)	7 (36.8)
Other	Cross-sectional	1 (5.3)
Can't tell		1 (5.3)
Rating	Weak	9 (47.4)
	Moderate	10 (52.6)
	Strong	0 (0)
C. Confounders		
Differences between group prior to intervention compared	Yes	1 (5.3)
	No	1 (5.3)
	Can't tell	17 (89.5)
Percentage of confounders that were controlled	80%-100%	0 (0)
	60%-79%	0 (0)
	<60%	1 (5.3)
	Not applicable	18 (94.7)
Rating	Weak	19 (100)
	Moderate	0 (0)
	Strong	0 (0)
D. Blinding		

	Outcome assessor awareness of intervention	Yes	10 (52.6)
		No	1 (5.3)
		Can't tell	8 (42.1)
	Subject aware of research question	Yes	0 (0)
		No	10 (52.6)
		Can't tell	9 (47.4)
	Rating	Weak	8 (42.1)
		Moderate	10 (52.6)
		Strong	1 (5.3)
E.	**Data Collection Methods**		
	Instrument validity	Yes	1 (5.3)
		No	1 (5.3)
		Can't tell	17 (89.5)
	Instrument reliability	Yes	1 (5.3)
		No	1 (5.3)
		Can't tell	17 (89.5)
	Rating	Weak	18 (94.7)
		Moderate	0 (0)
		Strong	1 (5.3)
F.	**Withdrawals and Drop-outs**		
	Withdrawal and drop-out reported	Yes	4 (21.1)
		No	2 (10.5)
		Can't tell	4 (21.1)
		Not applicable	9 (47.4)
	Completion rate	80-100%	4 (21.1)
		60-79%	1 (5.3)
		Less than 60%	2 (10.5)
		Can't tell	5 (26.3)
		Not applicable	7 (36.8)
	Rating	Weak	7 (36.8)
		Moderate	1 (5.3)
		Strong	4 (21.1)
		Not applicable	7 (36.8)
G.	**Intervention Integrity**		
	Percentage of participants received the allocated intervention	80-100%	5 (26.3)
		60-79%	1 (5.3)
		Less than 60%	0 (0)
		Can't tell	13 (68.4)
	Consistency of the intervention measured	Yes	0 (0)
		No	15 (79.0)
		Can't tell	4 (21.1)
	Contamination	Yes	11 (57.9)
		No	1 (5.3)
		Can't tell	7 (36.8)
Global Rating			
		Weak	19 (100)
		Moderate	0 (0)
		Strong	0 (0)

* Out of 19 included studies

3.3. Common Recruitment Strategies in All Racial/Ethnic Groups

Across all racial/ethnic minority groups, recruitment strategies for Alzheimer disease and dementia clinical research were divided into four major themes: community outreach (94.7%), advertisement (57.9%), collaboration with health care providers (42.1%), and referral (21.1%) (Table **3**). Community outreach activities typically included community presentations (57.9%) through health fairs and meetings with local organizations. Other community outreach activities included educational programming and materials (52.6%), engagement with community leaders and organizations (42.1%), and direct contact (42.1%) such as through interviews and home visits. The second theme, advertisements, included marketing for research volunteers through mass media such as a newspaper (31.6%), television (26.3%), and radio (21.1%). The third theme, collaboration with health care providers, typically involved establishing relationships with local clinics or physicians to recruit potential participants. The fourth theme, referral, typically included referrals that originated from current participants (10.5%) or from friends and family (5.3%). Other recruitment strategies included benefits such as transportation assistance (10.5%) or a volunteer stipend (5.3%).

Out of 19 included studies, 17 (89.5%) evaluated recruitment strategies, however, through different methods due to variations in the study design. Among the ten studies utilizing a pre-post design, the outcome was reported as the change in the proportion of racial/ethnic minorities enrolled before and after a strategy was implemented. For example, these studies reported the number of racial/ethnic minorities enrolled in the volunteer registry at baseline in addition to the number enrolled at a follow-up point after implementing a recruitment strategy. In contrast, among the seven studies utilizing a post-test only design, the outcome was reported as the proportion of racial/ethnic minority participants who were enrolled out of the entire target sample after a strategy was implemented. For example, these studies only reported the number of racial/ethnic minorities who were enrolled after implementing a single or multiple recruitment strategies.

Within the community outreach theme, there was a median increase of racial/ethnic minority participants by 13.5% (range: 3.0%-19.9%) for pre-post study designs, and a median participation rate of 44.3% (range: 5.6%-87.0%) for post-test only study designs. Among studies using a pre-post study design, one community outreach subtheme that was particularly effective was community presentations through a live theater play, resulting in a 19.9% increase from baseline [25]. Among studies using a post-test only design, a community outreach subtheme that was particularly effective was direct contact through recruitment interviews, resulting in a recruitment rate of 87.0% in one study [23] and 71.4% in another study [6]. Within the advertisement theme, there was a 11.0% median increase (range: 3.0%-18.0%) for pre-post studies and a 32.1% median participation rate (range: 5.6%-43.4%) for post-test only studies. Within the collaboration with health care providers theme, there was a 7.9% median increase (range: 3%-14%) for pre-post studies and a 34.5% median participation rate (range: 17.6%-43.4%) for post-test only studies. Within the referral theme, there was a 15.4% median increase (range: 13.0%-17.7%) for pre-post studies, and a 34.5% participation rate in one post-test only study.

Among studies that compared recruitment rates across multiple strategies, collaboration with health care providers was typically most effective and advertisements were the least effective recruitment strategy. For instance, Picot *et al*. examined the effectiveness of multiple strategies for recruiting African Americans in Cleveland for Alzheimer disease research [30]. This study achieved the highest recruitment rates through collaboration with health care providers (66%) compared to other strategies such as community outreach through partnerships with local organizations (9%), advertisements on television (3%), and referrals from research staff (3%) or family and friends (0%). Similarly, Chao *et al*. evaluated various recruitment strategies to increase the enrollment of Chinese older adults in San Francisco for Alzheimer disease research [9]. This study gained the most participants through collaboration with health care providers (18.4%) compared to other strategies such as referrals from current research participants (17.6%) or staff (5.6%), community outreach through community presentations at health fairs (8.8%), and advertisements through flyers (6.4%) or newspapers (1.6%).

3.4. Distinct Recruitment Strategies by Racial/Ethnic Group

Several studies utilized distinct recruitment strategies targeting Latino [19, 27] and Asian American populations [9, 29]. In particular, all of these studies utilized strategies within the community outreach and advertisement themes. Within the community outreach theme, some recruitment strategies were tailored for their respective populations such as establishing a bilingual outreach team [9, 18] and distributing educational materials written in Spanish [18]. Within the advertisement theme, recruitment strategies were aimed at distributing advertisements through flyers and

newspapers written in Spanish or Chinese [9, 18, 27], and marketing through mass media on television and radio in Spanish or Chinese [9, 18].

3.5. Common Retention Strategies in All Racial/Ethnic Groups

Out of the 19 included studies, 5 (21.0%) reported strategies for retaining participants. Across all racial/ethnic groups, retention strategies for Alzheimer disease and dementia clinical research were divided into three major themes: follow-up communication (15.8%), maintain community relationship (15.8%), and convenience (10.5%) (Table **3**). Follow-up communication typically included mailing reminders (10.5%). Various strategies were used to maintain relationships with the community, such as hiring a community outreach worker (10.5%) and hosting regular recognition events for volunteers (5.3%). For the third theme, convenience, numerous strategies were used such as providing clear instructions for future brain donation (10.5%) and conducting the annual assessments within the participant's home (5.3%).

Four out of the five studies that examined retention strategies provided evaluation results. Multiple retention strategies were implemented simultaneously in each study and an overall retention rate was reported, with a median retention rate of 80.5% (range: 27.2%-90.5%). Although we were unable to isolate the effectiveness of each retention theme, studies with the highest retention rates shared common retention strategies such as follow-up communication through mail such as holiday cards and appointment reminders [20, 30], and maintain community relationships through partnerships with local programs [19] and hosting annual participant recognition events [30].

3.6. Distinct Retention Strategies by Racial/Ethnic Group

In the existing literature, all retention strategies have only targeted African American populations. As a result, there are currently no distinct themes in retention strategies by racial/ethnic group.

Table 3. Recruitment and retention strategies for racial/ethnic minorities in Alzheimer disease and dementia clinical research.

	Number of Studies*	(%)	African American	Latino	Asian
Recruitment Strategy					
Community Outreach	18	(94.7)	16	2	2
Community presentations	11	(57.9)	10	2	1
Health fair	8	(36.8)	7	1	1
Local organization	3	(15.8)	2	1	1
Live theater play	2	(10.5)	2	0	0
Participant meeting	1	(5.3)	1	0	0
Unspecified	2	(10.5)	2	0	0
Education	10	(52.6)	8	1	2
Program	8	(42.1)	7	1	1
Materials	6	(31.6)	5	0	1
Community leaders and organizations	8	(42.1)	7	1	1
Diverse outreach staff	5	(26.3)	4	1	1
Partnership and collaborations	5	(21.1)	5	0	0
Unspecified	1	(5.3)	1	0	0
Direct contact	8	(42.1)	8	1	0
Recruitment interview	4	(21.1)	4	1	0
Home visit	3	(15.8)	3	1	0
Phone call	2	(10.5)	2	0	0
Clinic waiting rooms	1	(5.3)	1	0	0
Unspecified	2	(10.5)	2	0	0
Advertisement	11	(57.9)	9	2	2
Newspaper/newsletter	6	(31.6)	4	0	2
Television	5	(26.3)	4	1	1
Radio	4	(21.1)	4	1	1
Flyer	4	(21.1)	2	2	1

Brochure/pamphlet/book	3	(15.8)	2	0	1
Website	2	(10.5)	2	0	0
Video	1	(5.3)	1	0	0
Mail	1	(5.3)	1	0	0
Referral cards	1	(5.3)	1	0	0
Unspecified	1	(5.3)	1	0	0
Collaboration with Health Care Providers	8	(42.1)	7	0	1
Referral	4	(21.1)	4	1	0
From current participants	2	(10.5)	2	1	0
From another study	1	(5.3)	1	0	0
From friends/family	1	(5.3)	1	0	0
Other	4	(21.1)	4	1	0
Benefits	2	(10.5)	2	1	0
Transportation assistance	2	(10.5)	2	1	0
Stipend and pay for services	1	(5.3)	1	1	0
Offer useful medications	1	(5.3)	1	0	0
Request brain donation at each visit	1	(5.3)	1	0	0
Create waitlist	1	(5.3)	1	0	0
Make brain donation optional	1	(5.3)	1	0	0
Search medical records	1	(5.3)	1	0	0
Retention Strategy					
Follow-up Communication	3	(15.8)	3	0	0
Mail	2	(10.5)	2	0	0
Disseminate research findings	1	(5.3)	1	0	0
Contact funeral home for brain	1	(5.3)	1	0	0
Give families postmortem evaluation of brain	1	(5.3)	1	0	0
Unspecified	2	(10.5)	2	0	0
Maintain Community Relationship	3	(15.8)	3	0	0
Community outreach worker	2	(10.5)	2	0	0

Learn about community's history	1	(5.3)	1	0	0
Partner with local programs	1	(5.3)	1	0	0
Hold recognition events	1	(5.3)	1	0	0
Convenience	2	(10.5)	2	0	0
Provide instructions for brain donation	2	(10.5)	2	0	0
Conduct assessment in home	1	(5.3)	1	0	0
Assure no burden for brain donation	1	(5.3)	1	0	0
Other	2	(10.5)	2	0	0
Assign same data collector	1	(5.3)	1	0	0
Encouragement from current participants	1	(5.3)	1	0	0

* Out of 19 included studies

4. DISCUSSION

This systematic review revealed major themes in recruiting and retaining racial/ethnic minorities in Alzheimer disease and dementia clinical research. In this section, we respond to our research questions by commenting on the gaps in knowledge, quality of the evidence, and effectiveness of recruitment and retention strategies. We conclude with recommendations and implications for future research and practice.

4.1. Gaps in Knowledge

Consistent with prior research that have examined racial/ethnic differences in Alzheimer disease [2], most of the available research on recruitment and retention in Alzheimer disease and dementia research is specific to African Americans (Table **1**). Even though two studies implemented strategies recruiting Asian Americans, only Chinese Americans were targeted in both studies. Further, no studies exclusively targeted recruitment for other major U.S. racial/ethnic groups such as Latinos, American Indians, Alaska Natives, Native Hawaiians, and other Pacific Islanders, despite the fact that Latinos and American Indians have among the highest incidence rates for Alzheimer disease and dementia across all racial/ethnic groups [1, 2].

Our review of retention strategies in the current literature also identified three major gaps. First, there was generally limited research for racial/ethnic minority retention compared to recruitment. This finding is particularly noteworthy given that the initial recruitment of participants may not necessarily equate to long-term research participation, which is essential for investigators to track disease progression over time. Second, among the retention studies that reported procedures or samples they requested from participants, most focused on brain donation compared to the collection of other biomarkers through neuroimaging, lumbar puncture, and blood sample. Third, there were no retention strategies discussed for Latinos, Asian Americans, and American Indians.

4.2. Quality of Evidence

A recent literature review concluded there is a lack of controlled comparisons for the large variety of recruitment strategies, especially in the evaluation of cost-effectiveness, among available methods to improve the recruitment of participants in Alzheimer disease research [10]. This gap was supported in our findings, which indicated that less than half of all included studies formally evaluated the effectiveness of a strategy by examining changes in recruitment or retention rates before and after a strategy was implemented. Likewise, no study has used a randomized clinical trial study design to recruit or retain racial/ethnic minorities in Alzheimer disease or dementia clinical research. Such a design would be valuable as it would increase the validity of the evidence. A prior review found weak methodological rigor in recruitment interventions for health research, particularly a lack of randomization, a control group, and formal statistical analyses to compare strategies [34]. Similarly, our findings also suggested a major need to address selection bias, lack of control for confounders, and limited reporting of data collection methods.

4.3. Effectiveness of Recruitment and Retention Strategies

A previous review discussed four major strategies for recruiting vulnerable populations (e.g. racial/ethnic minority and low socioeconomic status) in health research studies: social marketing, community outreach, health system, and referrals [34]. In comparison, our review identified similar themes with advertising, community outreach, collaboration with health care providers, and referrals. Although the previous review found social marketing (82%) and community outreach (80%) were most frequently adopted for recruitment in health research [34], our review found that community outreach (94.7%) was more commonly used than advertisements (57.9%) in Alzheimer disease and dementia research. Higher frequencies of community outreach in our review may be attributed to the more invasive and time-consuming procedures common in Alzheimer disease and dementia research, such as lumber puncture and neuroimaging. Many authors utilizing a community outreach approach frequently reported these actions were strategically implemented to establish a relationship with the community [20, 24, 26, 31, 32], and increase trust [20, 21, 24, 26].

The review of recruitment interventions in health research also indicated that social marketing, health system, and referrals were most effective, while community outreach was least effective [34]. In contrast, our review found that community outreach and collaboration with health care providers were typically the most effective strategies. In particular, the highest recruitment rates were reported in studies that utilized community outreach through direct contact with participants, however, the range of recruitment rates was wider within the community outreach theme compared to the other recruitment themes. Although all included studies implemented multiple retention strategies

simultaneously, our review also found that follow-up communication and maintaining community relationships were both common retention strategies across studies with the highest retention rates.

4.4. Future Research and Practice

Our review offers four recommendations for future research and practice. First, investigators should consider implementing recruitment and retention strategies that are evidence-based. In particular, recruitment strategies incorporating elements of community outreach and collaboration with health care providers may hold promise for increasing participation of racial/ethnic minorities. In addition, retention strategies that incorporate elements of follow-up communication and maintaining community relationships may hold promise for retaining engagement of racial/ethnic minorities. Adopting evidence-based strategies would allow investigators to use limited resources more effectively within their research and practice. Second, we recommend future research increase study quality by adopting more rigorous study designs, such as a randomized control trial, and expand methodological reporting by detailing study sample characteristics and data collection procedures. Although adopting randomized control trials may not be feasible given the difficulty of accessing racial/ethnic minority populations [10], investigators may also consider minimizing selection bias by developing multi-center trials in which each participating research center is randomly assigned a different recruitment or retention strategy to implement and evaluate. Third, studies implementing multiple strategies simultaneously should evaluate each strategy separately, or at least consider requesting participants to state the primary strategies that contributed to their recruitment or retention. Finally, this review indicated there are limited or no studies that have focused on Latino and American Indian populations. It is imperative that future research consider methods to recruit and retain these two populations given their elevated risk for Alzheimer disease compared to other racial/ethnic groups [1, 2].

4.5. Strengths and Limitations

To the best of our knowledge, this is the first review that has synthesized strategies for recruitment and retention of racial/ethnic minorities in Alzheimer disease and dementia clinical research. There is prior research that has reviewed recruitment strategies for vulnerable populations in general health research [34], but our study is unique in that we included all racial/ethnic minority groups identified by the NIH and we synthesized strategies for retention applied to Alzheimer disease and dementia research specifically. Despite these strengths, we were unable to conduct a meta-analysis to assess the effectiveness of recruitment and retention strategies in the literature given the wide variety of strategies that were dissimilar and the diverse methods for evaluation due to study design. Second, one of our inclusion criteria was that a study must implement a recruitment or retention strategy. Some studies, however, did not intentionally test a recruitment or retention strategy as the primary aim. Nonetheless, we allowed these studies to be included considering the main objective of this review was to synthesize all published strategies on recruiting and retaining racial/ethnic minorities, and these studies frequently reported changes in minority recruitment and retention as an outcome measure. Finally, major racial/ethnic groups, such as Latinos and Asian Americans, contain multiple subgroups (e.g. Mexican, Puerto Rican, Chinese, and Japanese). As a result, recruitment and retention strategies that have worked for one subgroup may not be as effective for other subgroups given intra-group variations in beliefs, knowledge, barriers, and facilitators to participating in clinical research.

CONCLUSION

Racial/ethnic minorities have the highest risk for Alzheimer disease and dementia, however, there is limited consensus on what risk factors or pathways contribute to these health disparities [35]. To address this gap, recruitment and retention of racial/ethnic minorities in Alzheimer disease and dementia research is essential for investigators to better understand the heterogeneity of disease progression among marginalized groups. Our findings highlight the need for researchers to shift towards recruitment and retention strategies that are evidence-based, which would improve effective use of limited resources. Additional well-designed studies are also needed to strengthen quality of the overall evidence. Further research is particularly needed in recruitment strategies for racial/ethnic groups outside of African American populations, and retention strategies for racial/ethnic minorities in Alzheimer disease and dementia clinical research.

CONSENT FOR PUBLICATION

Not applicable.

CONFLICT OF INTEREST

The authors declare no conflict of interest, financial or otherwise.

ACKNOWLEGEMENTS

We would like to express our gratitude to Susan Fowler, director of the Brown School Library at Washington University in St. Louis, for her input in revising and finalizing our search strategy in this review. We would also like to thank John Morris, Susy Stark, and Andrea Denny from the Knight Alzheimer Disease Research Center at Washington University in St. Louis for their comments in earlier drafts of this manuscript.

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APPENDIX A. Detailed search strategy.

CINAHL
(minorit* OR "african american*" OR black* OR hispanic* OR latino* OR asian* OR "american indian*" OR "alaska native*" OR "native american*" OR "native hawaiian*" OR "pacific islander*") AND (alzheimer* OR dementia*) AND (recruit* OR enroll* OR participa* OR retention OR retain* OR remain*)

EMBASE
((minorit* OR 'african american*' OR black* OR hispanic* OR latino* OR asian* OR 'american indian*' OR 'alaska native*' OR 'native american*' OR 'native hawaiian*' OR 'pacific islander*') AND (alzheimer* OR dementia*) AND (recruit* OR enroll* OR participa* OR retention OR retain* OR remain*)):ti,ab,kw

MEDLINE via EBSCO
(minorit* OR "african american*" OR black* OR hispanic* OR latino* OR asian* OR "american indian*" OR "alaska native*" OR "native american*" OR "native hawaiian*" OR "pacific islander*") AND (alzheimer* OR dementia*) AND (recruit* OR enroll* OR participa* OR retention OR retain* OR remain*)

PsycINFO
(minorit* OR "african american*" OR black* OR hispanic* OR latino* OR asian* OR "american indian*" OR "alaska native*" OR "native american*" OR "native hawaiian*" OR "pacific islander*") AND (alzheimer* OR dementia*) AND (recruit* OR enroll* OR participa* OR retention OR retain* OR remain*)

Scopus
TITLE-ABS-KEY((minorit* OR "african american*" OR black* OR hispanic* OR latino* OR asian* OR "american indian*" OR "alaska native*" OR "native american*" OR "native hawaiian*" OR "pacific islander*") AND (alzheimer* OR dementia*) AND (recruit* OR enroll* OR participa* OR retention OR retain* OR remain*))

APPENDIX B. Detailed quality assessment of included studies.

Study	Selection Bias			Study Design			Confounder			Blinding			Data Collection Methods			Withdrawals and Drop-outs			Intervention Integrity			Global Rating
	Representative sample	% of participants agreed to participate	Rating	Randomization	Study design*	Rating	Differences between group compared	% of confounders controlled	Rating	Outcome assessor aware of intervention	Subject aware of the research question	Rating	Instrument validity	Instrument reliability	Rating	Withdrawals and drop-outs reported	Rate of completion	Rating	% of participants who received intervention	Consistency of the intervention	Contamination	
Bachman *et al*., 2009	SL	<60	W	N	1	W	CT	NA	W	Y	N	M	CT	CT	W	NA	NA	NA	80-100	N	CT	W
Ballard *et al*., 1993	SL	CT	W	N	2	M	CT	NA	W	Y	N	M	CT	CT	W	NA	NA	NA	CT	N	Y	W
Ballard *et al*., 2010	SL	CT	M	N	2	M	CT	NA	W	Y	CT	W	CT	CT	W	N	80-100	S	CT	N	Y	W
Barnes *et al*., 2012	SL	<60	W	N	1	W	CT	NA	W	Y	N	M	CT	CT	W	Y	80-100	S	80-100	N	Y	W
Bonner *et al*., 2000	CT	<60	W	N	2	M	CT	NA	W	Y	N	M	Y	Y	S	N	<60	W	CT	N	Y	W
Chao *et al*., 2011	SL	60-79	M	N	1	W	CT	NA	W	CT	N	M	CT	CT	W	Y	80-100	S	CT	N	Y	W
Christensen *et al*., 2015	VL	CT	M	N	3	W	Y	<60	W	CT	N	M	CT	CT	W	NA	NA	NA	80-100	N	Y	W
Picot *et al*., 1996	CT	CT	W	N	2	M	CT	NA	W	Y	N	M	CT	CT	W	Y	80-100	S	CT	N	Y	W
Darnell *et al*., 2011	SL	<60	W	N	1	W	CT	NA	W	Y	N	M	N	N	W	NA	NA	NA	80-100	N	N	W
Ford, 1996	NL	CT	W	N	2	M	CT	NA	W	N	N	S	CT	CT	W	NA	NA	NA	CT	N	Y	W
Fritsch *et al*., 2006	NL	CT	W	N	2	M	CT	NA	W	Y	CT	M	CT	CT	W	NA	NA	NA	CT	CT	Y	W
Gauthier & Clarke, 1999	CT	CT	W	N	CT	W	CT	NA	W	CT	CT	W	CT	CT	W	NA	NA	NA	CT	CT	CT	W
Hinton *et al*., 2010	SL	CT	W	N	2	M	CT	NA	W	CT	CT	W	CT	CT	W	CT	CT	W	CT	CT	CT	W
Jefferson *et al*., 2013	SL	60-79	M	N	2	M	N	NA	W	CT	CT	W	CT	CT	W	NA	<60	W	60-79	N	CT	W
Li *et al*., 2016	SL	CT	W	N	1	W	CT	NA	W	CT	CT	W	CT	CT	W	NA	CT	W	CT	N	CT	W
Romero *et al*., 2014	SL	CT	M	N	1	W	CT	NA	W	CT	N	M	CT	CT	W	CT	CT	W	CT	CT	Y	W
Schnieders *et al*., 2013	VL	<60	W	N	1	W	CT	NA	W	Y	CT	W	CT	CT	W	Y	60-79	M	80-100	N	CT	W
Souder & Terry, 2009	CT	CT	W	N	2	M	CT	NA	W	Y	CT	W	CT	CT	W	CT	CT	W	CT	N	CT	W
Williams *et al*., 2011	CT	CT	W	N	2	M	CT	NA	W	CT	CT	W	CT	CT	W	CT	CT	W	CT	N	Y	W

* (1) = one group, posttest only, (2) = cohort (one group, pre + post), (3) = cross-sectional

Abbreviations: CT, Can't tell; M, moderate; N, no; NA, not applicable; S, Strong; W, Weak; Yes, Y; SL, Somewhat likely; VL, Very likely; NL, Not likely.