

A Mini-Review of Strategies for Recruiting Older African Americans to Alzheimer's Disease Research

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Darlingtona Esiaka, PhD¹ , Christina C. Yarborough, MS¹, Bernadette A. Fausto, PhD¹, and Mark A. Gluck, PhD¹

Abstract

African Americans experience higher incidence and prevalence of Alzheimer's disease (AD). Yet, they continue to be underrepresented in AD research, limiting the ability to generalize findings to the increasingly diverse US population. To reduce AD disparities, targeted efforts are needed to increase the representation of African Americans in AD research. This mini review identified evidence-based strategies that increased research participation among older African Americans. Four recruitment strategies emerged from eight published peer-reviewed studies that directly evaluated the effectiveness of strategies aimed at increasing the number of African American participants in Alzheimer's research. The strategies include community outreach and education, face-to-face discussions, remote access, and referral and partnership with local organizations. Across different locations, these strategies increased the number of African Americans enrolled into AD research, the number of people that signed up to donate their brains for AD research upon death, and the knowledge and perception of AD in the communities. Targeted efforts are effective in increasing AD research participation among older African Americans, especially when combined with approaches that emphasize transparency and mutual trust and involve the community as stakeholders in the research process.

Keywords

dementia, alzheimer's, black, clinical trials, recruitment, and aging

Introduction

African Americans are twice as likely to be impacted by Alzheimer's disease (AD) compared to their white American counterparts.¹ It is projected that the number of African Americans, aged 65 and older, affected by AD will double by 2030.² Despite the higher incidence and prevalence of AD among African Americans, this group continues to be underrepresented in AD research, especially in clinical trials. Although African American adults make up approximately 9% of the older adult population in the United States, they constitute less than 5% of research subjects in clinical trials of therapeutic agents for AD.^{3,4} The majority of AD research in the US is done primarily with highly educated, white participants, limiting the ability to generalize findings to the broader demographics of the US population.⁵

The most cited barriers to African American participation in AD research are mistrust of the scientific community, fear of exploitation, and unfamiliarity with research.^{6–8} These concerns may be exacerbated by

literacy and language barriers, transportation costs, lengthy appointments, lack of cultural competency among researchers, and high turnover of research staff. While previous research has focused mostly on identifying barriers to research participation among older African Americans, relatively few studies focus on effective strategies to enhance participation of this underrepresented subgroup.

¹Aging and Brain Health Alliance, Center for Molecular and Behavioral Neuroscience, Rutgers University–Newark, Newark, NJ, USA

Corresponding Authors:

Darlingtona Esiaka, Aging and Brain Health Alliance, Center for Molecular & Behavioral Neuroscience, Rutgers University–Newark, 197 University Ave, Suite 209, Newark, NJ 07102, USA.
Email: de255@rwjms.rutgers.edu

Mark A. Gluck, Aging and Brain Health Alliance, Center for Molecular & Behavioral Neuroscience, Rutgers University–Newark, 197 University Ave, Suite 209, Newark, NJ 07102, USA.

Email: gluck@rutgers.edu

This mini review aimed to identify evidence-based recruitment strategies that have been shown to increase participation among older African Americans in AD research.

Method

Studies were identified by searching the PubMed database. The search strategy is described in Table 1. Only the studies that met the following criteria were included in the current mini-review (Figure 1): (1) evaluated the effectiveness of recruitment strategies aimed at increasing the number of African American participants in Alzheimer’s or aging studies; (2) included either a control and intervention group, pretest-posttest design, or retrospective cohort analyses to assess the effectiveness of the recruitment strategy; (3) conducted in the US; (4) published in English; and (5) published in a peer-reviewed journal.

Article titles and abstracts were reviewed individually by a single reviewer (C. Y.). The full-text articles were located and reviewed for studies that appeared to meet inclusion criteria. A discrepancy in articles deemed eligible, such as articles that merely described recruitment strategies in the research study, was solved by consent from one of the senior authors (B. A. F). To be inclusive, there were no exclusion criteria based on publication date. The final studies included in the results were published between 1993 and 2018. All studies were conducted in the United States.

We identified eight published peer-reviewed studies that evaluated the effectiveness of recruitment strategies aimed at increasing the number of African American participants in AD research. The studies included six with a pretest-posttest design and two with retrospective cohort analyses to assess the effectiveness of recruitment strategies.

Table 1. Search strategy.

Database	Search Strategies
PubMed	#1 Recruit*[ti] OR Outreach*[ti] OR Engag*[ti] OR Enroll*[ti] OR Retention*[ti] OR Inclusion*[ti] OR Strateg*[ti] OR Participat*[ti]
	#2 African-American*[ti] OR African American*[ti] OR Black*[ti] OR “African Americans”[Mesh]
	#3 Aging*[ti] OR Alzheimer*[ti] OR Dementia*[ti] OR Elderly*[ti] OR Older*[ti] OR Senior*[ti] OR “Dementia”[Mesh]
	#4 (#1 AND #2 AND #3)
	#5 (#1 AND #2 AND #3) filters: English

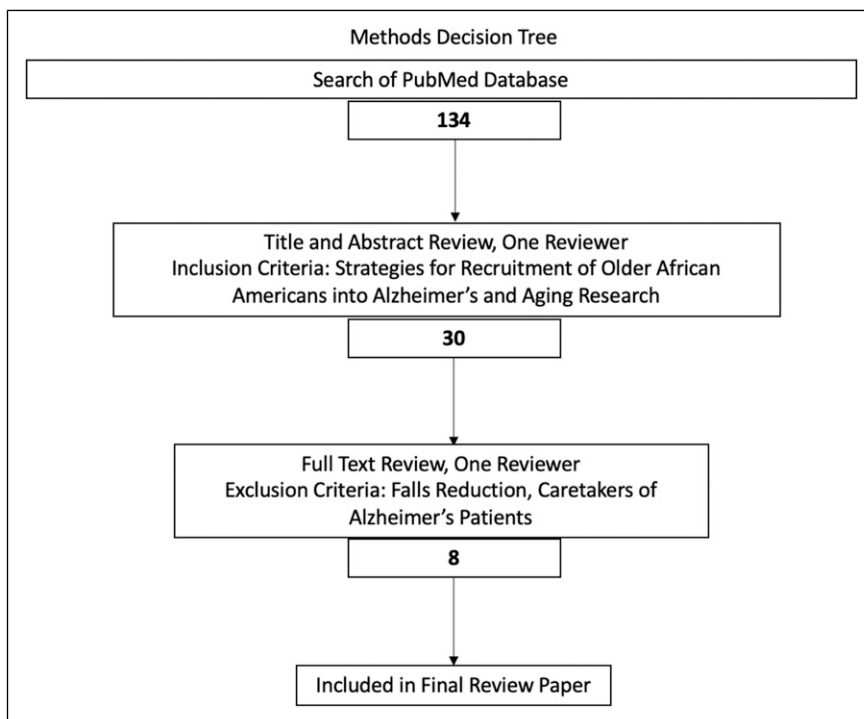


Figure 1. Methods decision tree.

Table 2. Summary of recruitment interventions and outcome measures for included studies (k = 8).

Author (Year)	Study type	Objective	Description of recruitment strategy	Results
Ballard (1993)	Pre-post test	To increase recruitment of black patients participating in CERAD Alzheimer's study	<p>Community outreach and education (1) Creation of a CERAD Minority enrollment committee to review the barriers to minority recruitment</p> <p>(2) Inviting clinical sites specifically concerned with the demented black elderly to join the Consortium</p> <p>(3) outreach efforts to increase the number of black participants which included presentations at local churches and nursing homes, radio and television announcements about dementia, referrals from nearby medical clinics, forming strong links with black physicians who primarily served black patients, working with the local Alzheimer's Association, availability of sliding scale payments, and the utilization of educational brochures written at a 6th grade reading level.</p>	Between September 1989 and September 1991, the number of black participants with AD enrolled in the CERAD increased from 60 cases and 12 controls (9.9% and 2.9%) in September 1989 to 150 cases and 28 controls (17.7% and 6.1%) in September 1991.
Chadiha (2011)	Retrospective cohort study	To increase recruitment of older African Americans in research volunteer registry	<p>Community outreach and education (1) Adoption of a logic model, for clarifying how community outreach health education activities supported development of a research volunteer registry of older urban African Americans, which included a community outreach partnership between older residents and academic researchers of the Healthier black Elders Center facilitate recruitment of older urban African Americans consumer health education learning series, monthly CAB meetings, an annual health reception, and a semi-annual newsletter.</p>	<p>Paralleling the 7 years in which an annual health reception was held, enrollees in a research volunteer registry increased from 102 to 1273 enrollees.</p> <p>The percentage change in participation was 82% for 2004, 53% for 2005, 15% for 2006, 143% for 2007, 14% for 2008, and 40% for 2009. In the 2009 registry, among participants aged 60 years or older, 99.7% were African Americans, 92.5% were women (92.5%)</p>

(continued)

Table 2. (continued)

Author (Year)	Study type	Objective	Description of recruitment strategy	Results
Coleman (1997)	Pre-post test	To examine the effectiveness of recruitment strategies used to recruit African American older adults for a senior center-based health promotion trial with a 6-month exercise component.	Phone Bank A \$50 incentive for completing a 6-month assessment with the option to donate to senior center; having individual members of the board of directors individually phoning senior center members to invite them to participate in the study; and the implementation of a phonathon, where six members of the senior center board of directors and two study staff worked together at a bank of telephones and were available to answer individual questions (vs traditional approaches)	Phonathons involving five or six senior center board members in two half-day sessions yielded 40 participants or 33 % of all participants. Strategies categorized as printed media yielded 39 participants or 33% of all participants. Strategies categorized as word-of-mouth yielded 31 participants or 26% of all participants. Remaining approaches accounted for an additional 10 participants or 8% of all participants. Participants recruited through telephone contact were statistically significantly more likely to be African American ($p < .001$).
Danner (2011)	Pre-post test	To determine African American interest in Alzheimer's disease (AD) research and to recruit African Americans as normal controls in current AD studies with the goal of eventually gaining consent for brain donation upon death	Face-to-face Discussions After confirming interest in participation via telephone contact, interviewers conducted in-home interviews that included questions related to personal experience with health and medical procedures, feelings about research, interest in participating in annual memory and cognitive screenings, and willingness to donate brain tissue to AD research. If the interviewees were willing to participate in the study, they were asked questions on the following topics: Health and experience medical procedures, research participation history, healthy aging initiatives, and autopsy and brain donation.	A total of 46 participants completed the initial interview. Motives for participation includes "to help others" (30.8%; $n = 12$); "to increase scientific knowledge" (7.7%; $n = 3$); and "participation incentives" such as compensation for free medical care (5.1%; $n = 2$). Of the 46 initially contacted to be interviewed, six did not agree to be followed annually. At the time of publication, 40 healthy African American participants were being followed and tested annually, of which 13 participants have consented to brain tissue donation, making the current donation consent rate 31.7%. Two deaths have occurred, with one autopsy completed, yielding a 50% autopsy completion rate with this group.
Ford (1996)	Pre-post test	To increase awareness of AD among African Americans with the opening of the Hill house at the AOC (Alzheimer outreach Center).	Community outreach and Education A three-step approach included the following: (1) developing trust and credibility in the community by showing a consistent interest in community projects and events; (2) increasing the visibility of the ADRC and AOC by participating in community health fairs, church activities and implementing a Community Advisory board; and (3) creating an environment and education that reflected and appealed to the African American and underserved communities with a diverse research staff and educational videos that reflected the experiences of local families coping with AD.	The number of nonwhite patients participating in the studies at the ADRC was 2% prior to implementation of the intervention. During the first-year of the community outreach effort, that percentage increased to 16%.

(continued)

Table 2. (continued)

Author (Year)	Study type	Objective	Description of recruitment strategy	Results
Graham (2017)	Retrospective cohort study	Analysis of recruitment data to identify the most effective strategies for enrolling older black participants in clinical trials.	Other Data used in these analyses were obtained from 3266 potential volunteers, ages 50 or older, who completed a Mini-Mental state Exam as part of recruitment and screening for various clinical studies on Alzheimer's disease. Researchers retrospectively collected data from 3266 senior residents aged 50 and older at 16 different recruitment sites including medical clinics, church events, health fairs, senior housing and assisted living facilities, and senior wellness centers; additional recruitment methods included direct mailing, newspaper advertisements, hospital and community-based flyers, and craigslist	Of the total 3266 candidates screened, 2830 black volunteers were identified for further analysis. Overall, more women than men (73.8% vs 26.2%) participated in recruitment activities. However, a significantly higher proportion of men than women were engaged through family (3.86% vs 1.30%, $p = .0004$) and referral sources (5.89% vs 2.59%, $p = .0005$). Compared to other sources for recruitment, researchers encountered a higher proportion of volunteers at health fairs (42.95%), and through advertisements (14.97%). In the sample, years of education and age did not appear to influence the likelihood of an encounter, screening, and potential participation. The findings indicate black men and women in the sample were predominantly recruited from health fairs and through advertisements tailored to their health needs and interests. Conversely, the research team mostly engaged black men through family referrals and persons known to them, indicating a need for trust in their decision to engage study personnel and/or participate in clinical trials.
Jefferson (2013)	Pre-post test	(1) implement an informational protocol for African Americans elders and their loved ones about the benefits of clinical research and brain donation program participation in AD, and (2) quantitatively assess changes in knowledge, attitudes, and trust.	Face-to-face Discussions Registry participants completed a pre- and post-group survey assessing brain donation knowledge, factors influencing brain donation, attitudes about medical research, and trust in medical researchers. All participants who elected to enroll in the discussion group participated in four procedures: (1) completion of a pre-group discussion survey, (2) participation in the group discussion, (3) completion of a follow-up telephone interview post-group discussion and (4) completion of a post-group discussion survey. Group discussions focused on four main areas including human rights violations within the black community; health issues within African American communities; symptoms, treatment, and prevention of AD; and relevance of AD research within African American communities.	There were no significant changes in mean scores between the pre- and post-group surveys. However, post-group outcomes revealed that 69% of participants shared details from the protocol with loved ones, 27% expressed an interest in joining Center-sponsored studies, and 10% indicated an interest in changing their brain donation status. The informational protocol implemented in this study is an effective method to encourage family discussions about brain donation and increase interest in other AD research

(continued)

Table 2. (continued)

Author (Year)	Study type	Objective	Description of recruitment strategy	Results
Williams (2010)	Pre-post test	To enhance minority recruitment to optimize enrollment of African American participants with normal cognition and mild dementia of the Alzheimer type in longitudinal Alzheimer's disease research Center studies	<p>Community outreach and Education</p> <p>The satellite developed a comprehensive outreach and recruitment plan that identifies and addresses barriers to research participation. The satellite conducts community outreach and recruitment programs and training for health care providers.</p> <p>Specifically, their model included three components: (1) formative research which examines the needs and wants of potential participants prior to implementing programs, (2) pretest research which is used to test strategy elements prior to being used in the field, and (3) monitoring and evaluation research which is used to examine the status of projects so that they can be refined to optimize efficiency and effectiveness.</p> <p>Additional components of the intervention included a training program entitled the urban clinician partners program (UCPP) that was offered to health care professionals who care for African American patients; brief presentations about AD presented to the clergy during their administrative meetings, and radio interviews regarding the relevance of AD research participation.</p>	<p>Enrollment of cognitively healthy and mildly demented African Americans for participation in all ADRC studies increased following implementation of the recruitment plan.</p> <p>In the first 6 months following the implementation of the revised recruitment plan, 19 African American participants enrolled in ADRC studies. In 2007, 29 African American participants enrolled in ADRC studies and a total of 3451 African Americans attended outreach and recruitment activities.</p> <p>Additionally, the number of African American participants in ADRC supported activities increased (95% of African American participants contribute blood for genotyping, 52% of eligible African Americans participate in structural MRI, and 43% participate in PIB PET studies).</p>

Results

Below, we organize our findings by recruitment strategy (see Table 2): “Community Outreach and Education” included 4 studies,^{6,9–11} “Face-to-face Discussions” included 2 studies,^{12,13} “Remote Access” included 1 study,¹⁴ and the “Referral and Partnership with Local Organizations” category included 1 study.¹⁵

Community Outreach and Education

Community outreach and education was the most recurring theme for recruitment interventions evaluated in the papers that we identified.^{6,9–11} The first study evaluated an intervention that aimed to recruit clinical sites with a special interest in AD among older Black Americans as contributors to a larger database.⁹ The second study evaluated a community outreach partnership between older residents and academic researchers to increase the recruitment of older urban African Americans for a research volunteer registry.¹⁰ The third study evaluated a satellite program that was established to increase the awareness of AD among African Americans and historically medically underserved communities.¹¹ Finally, the fourth study evaluated a comprehensive outreach and recruitment plan that sought to identify and address barriers to research participation.⁶ Below, we summarize the major aspects of the interventions that made them successful.

Across the four studies, community outreach interventions were reported to be effective at increasing the participation of older African Americans in AD research. The interventions utilized strategies that created continued and long-lasting community partnerships between academic researchers and older Black community members. For example, the Consortium to Establish a Registry for Alzheimer’s Disease (CERAD) worked with clinical sites to form a CERAD Minority Enrollment Committee—tasked with reviewing the barriers to and strategies for enhancing minority recruitment. The efforts of CERAD included presentations at local churches and nursing homes; radio and television announcements about dementia; referrals from nearby medical clinics; forming strong links with Black physicians who primarily served Black patients; working with the local Alzheimer’s Association; availability of sliding scale payments based on an individual’s income for medical services rendered as part of the research study; and the utilization of educational brochures written at a 6th-grade reading level.⁹

Targeting areas with a large percentage of African Americans (e.g., Lexington, KY; St. Louis, MO; and Boston, MA) and utilizing a social marketing business approach as a primary recruitment approach also emerged as effective recruitment strategies. For example, the Washington University Alzheimer’s Disease Research Center’s (ADRC) social marketing approach included three components: (1) formative research to examine the needs and wants of potential

participants prior to implementing programs; (2) pretest research to test strategy elements prior to being used in the field; and (3) the monitoring and evaluation of research to examine the status of projects so that they can be refined to optimize efficiency and effectiveness.⁶

Common across all four recruitment interventions were training of partners and stakeholders who are community members and/or who provide essential services to the community, such as pastors, counselors, health center workers, mayors, peer educators, and leaders. To exemplify, the ADRC had a training program entitled the Urban Clinician Partners Program (UCPP) that was offered to health care professionals in the St. Louis, Missouri, area who care for African American patients, brief presentations about AD presented to the clergy during their administrative meetings, and radio interviews regarding the relevance of AD research participation.

Finally, despite the differences in community outreach efforts, the studies show that the following approaches were effective to reach African Americans and increase their enrollment in AD research: (1) developing trust and credibility in the community by showing a consistent long-term interest in community projects and events; (2) participating in community health fairs, church activities and implementing a Community Advisory Board; and (3) creating an environment that reflected and appealed to African American communities with a diverse research staff and educational videos that reflected the experiences of local families coping with AD.

Face-to-Face Discussions

Face-to-face discussions emerged as an effective strategy for increasing enrollment of African Americans into AD research.^{12,13} This strategy involved structured, in-depth at-home interviews with older African Americans. On the one hand, this strategy helped the researchers to explore the life experiences, feelings about scientific/medical research, current health behaviors such as annual cognitive screening, and willingness to participate in scientific/medical research studies among older African Americans. On the other hand, face-to-face discussions provided participants with the opportunity to receive detailed clarification about research procedures in an intimate, familiar setting. Darnell and colleagues (2011) reported that the University of Kentucky Sanders-Brown Center on Aging successfully utilized this strategy to gain consent for brain donation upon death.¹²

Another face-to-face strategy, using a group setting, assessed attitudes towards medical research and brain donation. Using this strategy, the researchers gained an in-depth understanding of the (1) current perceptions of the historic healthcare-related ethical and rights violations on African Americans; (2) health issues within African American communities as identified by the communities and not the researchers; (3) knowledge of symptoms, treatment, and

prevention of AD; and (4) relevance of AD research within African American communities.¹³ This technique allowed the researchers to develop a better understanding of the barriers and facilitators to brain donation for research purposes.

Remote Access

Remote access leverages technological innovations combined with convenience and accessibility. One study implemented a “phonathon” where six members of the senior center board of directors and two study staff members worked together at a bank of telephones to recruit participants and were available to answer individual questions from potential research participants about the research study.¹⁴ The effectiveness of this intervention was compared to previous traditional approaches to recruitment. Phone conversations effectively reached a higher number of active and mobile older African Americans within a short time and eliminated challenges related to travel to research sites/laboratories.

Referral and Partnership with Local Organizations

Personal referrals proved effective in attracting African Americans to AD studies. Graham and colleagues (2018) showed that older African Americans might be more likely to participate in research when the recommendation originates from familiar and trusted individuals such as community leaders, pastors, and local physicians.¹⁵ Also, partnership with different local organizations that served as recruitment sites such as medical clinics, churches, community health centers, senior housing and assisted living facilities, and senior wellness centers was an effective intervention strategy to increase AD research participation among older African Americans.¹⁵ The strategy allowed researchers to engage with older African American participants within trusted and familiar spaces.¹⁵

Discussion

Long-standing community outreach and education are consistently found to be the most effective means to increase AD research participation among older African Americans. A longer period of exposure to research information and more frequent contact with research staff will likely increase familiarity with the proposed study, encourage more enthusiastic participation, and maintain engagement.⁹ By reassuring participants that they will be provided with adequate protection and given full transparency of the study purposes and protocols, researchers will be better positioned to attract and retain older African Americans to AD research studies.

Other observational and case-study papers on this topic did not meet eligibility criteria but offer additional support for the effectiveness of tailored recruitment strategies in African American communities. The observational and case-study papers identified facilitators and barriers to African American

participation in research and noted that orchestrating community partnerships and facilitating a two-way learning process are key strategies to improve research participation.^{16,17} Rexroth et al. (2010) suggested that researchers address economic factors that may hinder research participation by providing transportation or reimbursement for transportation, having convenient hours to accommodate the participants’ schedules, and conducting the research study in a familiar place such as their home or a local community center.¹⁸ A study by Ballard et al. (2010) identified that the research staff’s transparency and cultural sensitivity were facilitators of research participation.⁷ The study also concluded that both the researchers and community members participate in disseminating research findings.⁷

Consistent with the findings of this review, some studies have identified that building long-term relationships and formalizing community involvement are keys to increasing AD research participation among older African Americans. For example, Gluck and colleagues found that older African American participants in the Newark area were recruited to research primarily from long-standing partnerships with local churches and senior centers and from public and subsidized housing sites.¹⁹ They also reported that the creation of a community advisory board that reflects the breadth of the older African American communities in the area helped guide research activities and provided a bridge to community needs and interests.¹⁹ Similarly, Mitchell and colleagues (2020) reported that the formation of a community advisory board, which oversees research recruitment of fellow minority older adults and supports community health programming, has led to successful recruitment and retention of older African Americans in metro Detroit to research studies over the past 20 years.²⁰

Another important factor to consider while conducting research among older African Americans is the power differentials that exist between researchers and participants. Reed et al. (2003) argued for incorporating recruitment strategies that increase autonomy in an environment where community members may feel pressure to participate.²¹ This can be accomplished by providing complete and accurate communication about research and maintaining a consistent presence in the community,²¹ and by ensuring that information is presented in a clear, understandable format that conveys how these studies can potentially benefit the African American community.^{21,22} While gaining the trust of older African American participants may be difficult, researchers who have committed themselves to the local community have shown notable successes in recruitment. Having minority researchers, including race-concordant study staff, has also been shown to be helpful.²³

Future Directions

The current mini-review provided evidence that tailored strategies are needed to increase the recruitment and retention

of African Americans to longitudinal and interventional research—a vital step toward improving our ability to generalize research findings to the diverse US population and reducing AD disparities. Older Americans are becoming increasingly diverse, and additional efforts are needed in recruitment science to create and maintain consistent methods for recruiting and retaining diverse older Americans for Alzheimer's disease and aging research.²⁴ Second, because probable AD is often diagnosed through procedures that may be viewed as invasive or carrying some risk (e.g., PET and lumbar punctures), future research is needed to understand better appropriate educational and motivation techniques geared to improve participation by older African Americans in these procedures.²⁵ Finally, across all aging and AD research programs, there is a notable lack of African American men who participate relative to higher levels of participation by African American women. Because of the importance of examining sex as a biological variable to influence AD risk and progression, identifying validated methods for increasing participation by African American men is critical.

Implications for Expanding African American Participation in Future Alzheimer's Studies

Recruiting and retaining sufficient numbers of African Americans for Alzheimer's research remains an essential public health task because, through research, we can better understand the risk and protective factors for AD. In turn, knowledge of these factors has the potential to inform future interventions to reduce AD disease burden within the African American community. Currently, the absence of older African Americans in AD research limits the ability to generalize research findings to this population, further perpetuating AD disparities. A better understanding of the prevalence of AD in African Americans will be informative as we discover treatments and potential cures for AD suitable for diverse older adults.

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ORCID iD

Darlingtona Esiaka  <https://orcid.org/0000-0001-9214-5677>

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