

Title: Aiming to improve representation of African-Americans in dementia research: Community-based outreach and engagement

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Methodological Question Being Answered: How can we improve representation of racial minorities in dementia research/clinical trials?

Abstract:

Aims: It has been reported that African-Americans (AAs) have a higher risk for late-onset Alzheimer's disease (AD) than white Americans.¹ In a recent analysis pooling 18 studies from the Alzheimer's Disease Cooperative Study (ADCS) and the Alzheimer's Disease Neuroimaging Initiative (ADNI), a cohort of 5,164 individuals, compared comorbidities and clinical trial dropouts by race,² AA had higher prevalence of cardiovascular disorders and a higher rate of study dropouts compared with whites but lower rates of other disorders. However, only 7% of AD, 4% of MCI, and 11% of normal participants in this large ACDS/ADNI sample were AA. Additionally, since AA are 60% more likely to drop out of a trial (or miss a final study visit), increased effort to optimize study retention is needed.

Community partnerships address health disparities, and may help to develop and sustain care approaches that positively impact community elders.^{3,4} Informed by principles of community based participatory research (CBPR), these partnerships can bring together researchers and

communities for mutual learning and education.⁵ This pilot funded by two academic clinical trial teams convened a minority advisory board (MAB) tasked with using CBPR approaches to target dementia stigma in AA communities, raise support awareness and improve AA representation in research.

Methods: MAB goals included 1.) Use of snowball sampling to assemble a membership composed of clinician-researchers, community organizers and families with lived dementia experience; 2) Co-development and delivery of community programs that engage AA and address dementia stigma; 3) Collection of data on perceived community needs with respect to how the MAB and affiliated research centers might best serve their interests and concerns.

Results: MAB meetings were held monthly for a year-long period, with conferencing available for those not able to make in-person sessions. Lived-experience members were the most productive source of other lived-experience membership referrals. Meetings were held in a central location accessible to public bus-lines with a small compensation for time/travel. Two interactive presentations were held in March and April of 2018. Presentations provided 1.) a concise summary of AD/dementia including issues specific to AA 2.) a focus on stigma & managing stigma, 3.) family and community resources and 4.) information on the experience of research participation. A key feature was an interactive panel including clinical and lived-experience experts, former research participants and community support agency staff. Pre/Post program survey evaluations of 37 attendees, mean age 65.47 (SD 11.18), 75.7% African-American, found 97.3% agreed or strongly agreed the program was useful. Respondents generally increased their intention to use services and supports and suggested receptivity to research participation. MAB members with research participation experience offered their experience as someone who has 'been there'. Attendees received new information on types of studies that might be available including observational/surveillance projects and requested information on where the studies/research is being done and how to be involved.

Conclusions: Data from racial and ethnic minorities can provide unique insights on dementia initiation, course and outcomes. Preliminary experience suggests that a CBPR approach to research participation may help address the gap in representation.

References:

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³ Grill JD, Galvin JE. Facilitating Alzheimer disease research recruitment. *Alzheimer disease and associated disorders*. 2014;28(1):1-8. Epub 2013/12/11. doi: 10.1097/WAD.000000000000016. PubMed PMID: 24322484; PMCID: 3945167.

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⁵ VanDevanter N, Kwon S, Sim SC, Chun K, Trinh-Shevrin C. Evaluation of community-academic partnership functioning: center for the elimination of hepatitis B health disparities. *Progress in community health partnerships : research, education, and action*. 2011;5(3):223-33. Epub 2011/11/15. doi: 10.1353/cpr.2011.0032. PubMed PMID: 22080771; PMCID: 3646378.