



Published in final edited form as:

Alzheimer Dis Assoc Disord. 2010 ; 24(0): S19–S23. doi:10.1097/WAD.0b013e3181f12432.

Challenges and Opportunities: Recruitment and Retention of African Americans for Alzheimer's disease Research: Lessons Learned

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Abstract

For more than three decades, recruitment and retention of African Americans for research in Alzheimer's disease have been regarded as difficult undertakings with poor results. The typical explanation for failure to respond to research participation options is widespread mistrust of research and the biomedical community. Mistrust is a reasonable response given the historical reality of malfeasance, victimization, and mistreatment over the course of the research participation history of African Americans. The challenges are real but there are opportunities for successful recruitment and retention of African Americans for research including research on Alzheimer's disease. Participation, however, comes with specific terms and considerations. Two of the most prominent criteria for research recruitment and retention are the transparency and accountability of the investigator which may determine how he or she proceeds from the start of the process throughout the steps of recruitment, retention and subsequent follow-up with the community.

Keywords

Alzheimer's; Recruitment; Retention; Minorities; Mistrust; Guidelines

Introduction

Despite the importance of an early diagnosis and the increased prevalence of Alzheimer's disease in African Americans, this group is among those considered least likely to participate in biomedical research. Recruiting and retaining sufficient numbers of African Americans for Alzheimer's research has been a continuing quandary for investigators. In the past, recruitment and retention were seen as difficult, expensive efforts with minimal return on investment. (1-2).

However, *less likely to participate* (past and/or present state) does not equate *to less willing to participate* (present and/or future state). Re-examining the effectiveness of past and current approaches to reach minorities is crucial to increasing and maintaining sufficient enrollment in research as competition increases for minority participants (3). The stakes are

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even higher with federal research funding mandates. Epstein refers to this rising concern as *the Science of Recruitmentology and the Politics of Trust* in his book, *Inclusion: The Politics of Difference in Medical Research*.

This paper will review what we know about current research participation and what we know about how to increase future participation. We will review consensus about the challenges still facing research investigators; how to reach minority individuals using pragmatic strategies for enrolling and retaining persons in studies; and discuss why the mindset and behaviors of the investigator and research staff may be the most important criterion for the success of recruitment and retention.

There are many complex issues associated with minority recruitment. Lavizzo-Mourey, R. and Knickman, JR (4) among others agree that there is no single, simple solution, perhaps because there is no single, simple cause for non-participation. Reasons for participating or not participating in research, for example, are closely aligned to the reasons for using or not using community resources. Limited access or poor service has been a perennial response from many minorities when seeking community resources. Reasons in the past and now may be as straightforward as poor access to transportation, time demands, cost—financial, physical or psychological, distance from point of residence, limited information about the research project, or perceptions of its value for the person with Alzheimer's disease. An unrelated incident or something minor may become the deciding factor: low physical energy, language problems, viewing the research project as inappropriate or incongruent because of religious beliefs, or simply the need to prioritize competing demands. An Atlanta physician comments: “If a patient's most urgent problem is finding Depends for her incontinent 91-year-old father, she's not interested in listening to you talk about a research project even when it may seem like an excellent option for her. If you are able to solve her problem by recommending a resource that could help her, she may then be willing to listen to you about your research project.”

Challenges in Reaching African Americans for Research Participation

The most universally reported barrier to recruitment in the minority community is distrust of research and the medical infrastructure of hospitals, universities, and clinics. The flagship incident consistently reported in the literature as the reason for such widespread distrust is the 1932-1972 Study of the Untreated Syphilis in the Negro Male (more commonly known as the Tuskegee Study) involving 399 African American males in the late stages of the disease and the subsequent deaths and or disabilities of not only the men but also some of their wives and children. The decision to continue the study even after an effective treatment for syphilis was available spanned a period of forty years. This is perhaps one of the most egregious abuses of research power and should never be minimized or forgotten. It is seen by many as *the* reason for black mistrust. This has a limiting effect and tends to place emphasis and energy on the wrong target—the individual being recruited.

Lost in this conversation is the fact that there have been numerous abuses in research before the Tuskegee incident, a few of which continue to the present. Research was not always designed or conducted in the best interest of the participants thereby creating a wary attitude toward research by many minority groups even today (5). These abuses have included minorities, women, children and vulnerable cognitively impaired older persons. Alzheimer's families, regardless of ethnic or socioeconomic factors, want reassurance that the research will be conducted with care and reasonable protection for the individual. Beginning with the Nuremberg Code and subsequent federal legislation, there have been comprehensive safeguards in place protecting the safety and well-being of individuals, particularly those who have less capacity to protect themselves. Nonetheless, there have been disturbing

incidents to circumvent the legal protections resulting in less confidence that these protections are automatic or universal. (6) The Willowbrook Study from 1963-1966, for example, involved “mentally defective persons” in a study the natural history of infectious hepatitis from 1946 to 1965.

The common perception that the black community alone has been unfairly abused by researchers or the medical establishment prevents African Americans from moving from a place of victim (sense of being alone) to a place of advocate (sense of being part of a group and thus empowered) for participating in Alzheimer's disease research. African Americans would benefit on many levels by findings derived from research in general and specific to them.

Language matters. The language we use bears scrutiny in planning and conducting recruitment and retention of African Americans and other minorities for Alzheimer's research. It matters in tone and content when delivering the research investigators' message in person-to-person contacts; it matters in brochures, articles, newsletters, consent protocols and training materials. This is a technical issue affected by color, font, and syntax worthy of expert consultation on how to do it well.

Language also matters in a more fundamental way. When an individual or group is labeled “hard to reach” the conclusion and expectation is that the group has failed to respond in a certain way and the goal becomes one of getting them to behave in a way to fit a specified plan or activity. When the language is changed to “hard to sell,” the expectation immediately suggests that the investigator must change his or her behavior; that the idea or research proposal must be written, packaged, or presented in a way that is, in the participant's opinion, appealing, appropriate, or of value to the individual or dependent family member (7). It should then follow if the investigator is having difficulty, the approach may be faulty.

Language may also matter when addressing individuals. African Americans of that heritage prefer or accept by default that label; others prefer the term black or black American. The research investigator must be sensitive to these differences and ask because some individuals have strong opinions about their minority group label. For example, one rural older North Carolinian resented the reference to himself as African American. He responded “I am not from Africa!”. Others may resent the label “black” because of many negative, sometimes painful associations with not only the term but “being” black.

The overall participation rate of adults in research on average is low—about one in twenty. It is useful to note the relatively comparable black participation rate relative to the general white population from similar socioeconomic strata. Socioeconomic and educational factors are likely far more important than race or ethnicity. In a review of twenty published research studies that reported consent rates by race or ethnicity, Wendler et al. (16) “found very small differences in the willingness of minorities, most of whom were African Americans and Hispanics in the U.S., to participate in health research compared to non-Hispanic whites” (p. 0201). These 20 studies represented the research consent decisions of 70,000 individuals.

When families' lives are chaotic because of financial strain, they operate on a daily needs basis for the basic necessities of life: food, medicine, shelter, child or elder care. Research participation is a luxury even when individuals are paid to participate.

Toward transparency and accountability

Language may be most limiting with the use of “mistrust” as a label to explain the widespread reluctance of the African American community to participate in research. When

the language is changed, and *mistrust* is replaced with *transparency* or *accountability* as an expectation on the part of the black community from the investigator or research institution, the responsibility for action or change lies not with the community but with the investigator and research organization. This requires a whole new set of activities to engage the community.

Moreover, what is described as mistrust, the general reluctance or apprehension to believe that what is offered is beneficial, not harmful, is a historical response to years of failed promises, or deliberate deeds to defraud minorities by mainstream society, with little or no redress or hope of remedy from even the highest authority of government. Mistrust must be viewed as a larger entity than fear of research. Race/ethnicity, class, and health are inextricably bound and together they determine in a major way the life chances, beliefs and attitudes of individuals in succeeding generations. There are elder black World War II veterans who were excluded from the GI Bill with its immediate benefits of housing, educational subsidies, and help with finding jobs. The GI Bill established a white middle class with continuing social benefits traced back to that original legislation. George McGovern commented that had it not been for the GI Bill, he would not have a Ph.D. from Northwestern University in Evanston, Illinois, would not have served in the Senate, and would not have won the Democratic nomination for President of the United States.

In parallel, there are black communities, some of which have remained poor and have become dumping grounds for the nation's waste and pollutants suspected of causing health problems such as asthma (8). These are extreme examples. This is important because it is the basis of residual memories of institutional neglect that influence one's decision about research participation. Old grievances around ethnic or racial concerns can be easily triggered by such memories. Texan Rep. Betty Brown created a minor stir with an insensitive remark suggesting Chinese Americans change their name to something easier for other Americans to use. These kinds of incidents bring with them "residual memories" of social and/or political histories when the specific group in question occupied a place of social or political constraints sanctioned by law or customs. (a greater vulnerability to exploitation without equal protection of the law).

Incentives for Inclusion

In 1994, the National Institutes of Health increased incentives with its mandated guidelines addressing the disparities in prevalence rates, risk factors, and health outcomes among different ethnic groups as a prerequisite for funding research proposals. *The white male model* as norm in biomedical research was being challenged to also include women, children, and minorities heretofore left out. The argument stated that it was no longer justified to extrapolate findings using *the white male model* for other individuals including children or vulnerable older adults who clearly could be harmed by the practice.

In Alzheimer's specifically, there were increasing questions about differences in etiology, manifestation of symptoms, behaviors, treatment and thus a need for research looking at subgroup populations, age, gender, race and ethnicity. Welsh and others stated that from a scientific viewpoint alone, it was important to study diverse groups to understand the biological mechanisms of the disease (2). Research also offers the opportunity to learn from minority populations those aspects of care behaviors and responses that may be useful across ethnic groups (9).

Perhaps the most compelling reason is one of ethics: African Americans are at a higher risk for Alzheimer's, vascular dementia, and risk factors associated with dementia and they stand to benefit from participating in research on a number of levels.

Welsh et al. note: “Altruistic intentions may not be sufficient to motivate participation in the face of limited social constraints and limited economic resources. Education aimed at correcting misconceptions, flexibility in protocols, and financial incentives may be necessary to ensure an appropriate number of enrolled subjects for scientific analysis.”

“I would be very reluctant to give anybody a blank check with respect to experimenting with my body, my life, and my health. It is my arm and I decide what to do with it. I am not just holding it out for anybody. I think that most of the people who are in control of research don't look like me, and I don't have confidence in how they perceive my value and my worth.” This individual works as Health and Outreach Minister at his church. As such he can influence the decisions of persons in that church.

This attitude may represent a lack of familiarity and information about Alzheimer's disease research in general. Experience too often has been what some derisively refer to as “drive-by research.” “They come and get what they want and we never hear from them again.” The community sees research as “something they do to you, not something they do with you or for you.” This, unfortunately, leaves a negative attitude about the next person who comes looking for participants. It does not help investigators who are “under pressure not only to come up with bodies but to come up with the right ones.” Epstein (3).

It is helpful to remind the community of the long term investment and potential return for both present and future generations. Investigators found this a powerful motive in encouraging poor black women in five North Carolina counties involved in breast cancer research with a slogan, “do it for your sisters, do it for your daughters” (10).

Methodology

The Bryan ADRC AACOP: African American Community Outreach Program

The Bryan ADRC ACCOP began in 1995 as an initiative to increase public awareness of Alzheimer's disease and related memory disorders specifically within the North Carolina African American community. North Carolina consists of 100 counties; these counties have been strategically divided into nine geographical regions served presently by twenty-one ACCOP members known as Statewide Visitors. They know the attitudes, beliefs, and needs in the black community regarding Alzheimer's disease. They understand and appreciate the reluctance and disinterest in participating in research. Having received training, educational materials, and up-to-date information about the disease, including how this relates specifically to African Americans, the statewide visitors are able to share this information through various channels with their communities, churches, social groups, and individual personal contacts.

The statewide visitors work in partnership with the Bryan Alzheimer's Disease Research Center, critiquing our literature and programs, bringing us questions and concerns from the community and, more specifically, questions from families and professionals caring for persons with dementia. Despite their prerequisite credentials as known and respected individuals within the community, the statewide visitors themselves were discouraged by initial slow increases in research participation from their communities. However, this cadre of Statewide Visitors steadily made progress as a trusted link between the community and the research center. This suggests a complex, varying formula for reaching and retaining African Americans for research.

The philosophy and guiding principles below are the basis of the ACCOP model:

1. Form community research partnerships with community representatives and community-based organizations that are mutually beneficial. Value and respect are

what the Statewide Visitors bring to the table. They have information and insights not available to the Bryan ADRC from any other source.

2. Provide forums, retreats, and meetings offering a two-way learning process. There are opportunities for input from ACCOP members to report or request materials and speakers in response to questions or concerns from their local communities. Faculty from the Bryan Alzheimer's Disease Research Center constantly shares relevant research findings, the state of Alzheimer's care, and current educational materials with the statewide visitors. The statewide visitors select, adapt or suggest modifications for their communities. There is sensitivity in providing materials geared to a spectrum of interests and abilities. For example, it is known that 90 million American adults are illiterate, a stunning statistic with major implications for health disparities generally and, in particular, when the ability to read supersedes all other measures, including race, class, gender, region, and income in influencing health outcomes. The most basic instruction in understanding and following medical directions may be lost to the person who can not read, even minimally. (11)
3. Provide social events as an important activity for exchange of ideas and trust building opportunities. One of the most meaningful activities that happened by chance at a dinner preceding an ACCOP meeting involved a Nigerian social work intern mentored by two members of the Bryan ADRC Education Core faculty. She replaced a guest speaker who had an emergency and without even ten minutes for preparation, she spoke eloquently about her country, her tribe and customs, many of which hit a familiar chord with the Statewide Visitors. They were delighted to know the source and connection for behavior, beliefs, and ideas now part of their own African American culture. This magical evening set the tone for the next day's meeting and exchange and underscored the meaning of family, community and responsibility to others in the group. It was a serendipitous opportunity no one had planned or foreseen.
4. ACCOP is quasi-research participatory in approach. It makes suggestions regarding how to reach or interest the community in Alzheimer's research. The group has had, for example, a "brainstorming session" on how to craft brochures that are effective recruitment tools, and suggest research questions that are of immediate interest and relevance to their communities.
5. Individual Statewide Visitors with personal experience have "told their stories" on local, state, and national levels, written regular newsletter columns for the ACCOP VOICE newsletter, and participated in training families, nurses, medical students and residents in person and in the media. They express an urgent need to use their talents and experience to validate the investment in their partnership with Duke and the Bryan ADRC.
6. The Statewide visitors teach investigators how they, their families, and members of their community would like to be treated. There is great diversity in African American communities. There is great diversity in individual families; one family may have an education range from little or no formal education to someone with a doctorate, members living in poor housing to middle, upper middle or high income lifestyles. This results in very different behaviors and expectations. Increasingly, an individual family may be composed of persons with different ethnic or racially defined traits. Additionally, the definition of family may include persons not related by blood or marriage, yet individuals have all the expectations, rights, and responsibilities of persons who legally fit the definition of family. Sometimes defined by sociologists as "fictive kin", this individual, singly or sharing the role

with one or more persons, with whom the investigator must accept as responder for the research participant. Group ethnicity has been and continues to be a moving feast. The axiom one size fits all has not and does not apply.

Changes in Bryan ADRC African-American Outreach Strategies—The Bryan ADRC Education Core faculty learned over time to be more strategic in selecting church, civic and state events for staffed displays or booths. Sites and events are selected because of proximity of participants to the Bryan ADRC, potential for emerging partnerships with the organizations and priorities of the sponsoring organizations. Some sponsoring organizations are primarily interested in disease-specific information and services best provided by the Alzheimer's Association and some health fairs attract primarily African Americans.

The Bryan ADRC staff learned that exposure and initial expression of interest at a health fair booth never insures actual research enrollments. There are now more personally tailored, prompt and systematic tracking procedures in place to respond to potential interests, eligibility and options for research participation.

The Bryan ADRC education staff learned to be accountable for overcoming obvious transportation barriers to research participation. One established community partner church has members who are unable to drive almost three hours each way to the Bryan ADRC. Now, after group health fairs and screenings, trained clinical teams from the Bryan ADRC schedule in-home initial assessments in a specific community over a several-day stay in that community. Prospective participants are offered the opportunity to visit the Bryan ADRC, meet with the clinical team at a local community site like their church or have the clinical team meet with them in their own homes, and they invariably choose the privacy of a home visit. Some individuals preferred the home setting because they didn't own a car or have other access to transportation. This preference for home visits has been confirmed by research teams citing similar reasons (12-14).

The key to successful dissemination of this model has been the transparency, sensitivity and accountability of the field team members. Research participants tell others in their community of their positive experience with the clinical team on their home turf, which encourages their peers to participate in the next annual screening and follow-up in-home visits. The Bryan ADRC AACOP community research participation model is an example of a collaborative relationship designed to facilitate mutually beneficial participation in research.

Results

In 2005, the Bryan ADRC set a minimal goal for African American representation in research studies of twenty-five percent. The Bryan ADRC is located in Durham County and that goal is representative of Durham's African-American population. Since 2005, African American participation in Bryan ADRC studies has grown from nine percent to twenty-two percent. Even more impressive, the Bryan ADRC research retention rate for follow-up visits is 81%, and there are no differences in retention between African Americans and other groups. The program is considered successful, not just in terms of the number of participants enrolled in research, but even more in successfully forged community partnerships. Transparency and accountability of the research investigators and the entire team are important ingredients in the partnership with ACCOP members. The relationships are collegial and respectful, each group aware of the importance of the other in forming the partnership.

The Bryan ADRC Community Research Partnership Model: Basic Principles

1. The community works with researchers to identify problem issues.
2. The research team involves the community as a full partner and collaborator in the research.
3. The community is a partner with the researcher, and individuals enrolled in studies are regarded as participants and not subjects.
4. The researchers and community work together to help build community capacity.
5. The researchers and community share control and dissemination of research findings.

One ACCOP member, Reverend Dr. James Brown of Jacksonville, NC has been recognized locally and nationally for a unique community research partnership with the potential to serve his community while informing his community about Alzheimer's research important to African Americans. In 2008, he delivered a platform presentation at ICAD (International Conference on Alzheimer's Disease) in Chicago with Henry Edmonds, Coordinator of AACOP and a key member of the Bryan ADRC Education Core. Reverend Brown, as an AACOP statewide visitor, is actively involved in participatory research. He is involved in the design and testing of studies involving community participants. He is co-authoring a paper about the Jacksonville community research partnership model and his role as a full partner. The specific community research partnerships address requests from AACOP members for larger roles that may be helpful to the Bryan ADRC in the shared goal of inclusive community participation in research. This is an example that has been successfully sustained in one community and is now a prototype for other communities.

AACOP statewide visitors furthered their community awareness aims with their three-year active participation in a statewide Candlelight Reflections event on the first Thursday evening during November's Alzheimer's and Family Caregiver Months. This annual event on the same date and time in over 70 local churches and community sites throughout NC recognizes persons living with, deceased or affected by Alzheimer's and related disorders and their families. For AACOP statewide visitors, many of whom take the lead of planning and participating on the program, this is an opportunity to recognize families in their communities who may report feeling alone in their journey to care for the person who has Alzheimer's disease. This activity seems to be important to their overall statewide visitor experience; Statewide Visitors want to be more than "sources of information" but to take action that validates and honors the experience of Alzheimer's families in their communities. The statewide visitors generally select a church setting, include music, personal testimonies and prayers acknowledging individuals and families living and deceased.

The Bryan ADRC AACOP program is about a sustained investment of time and resources by investigators and community members to meet the needs of both the science of Alzheimer's disease and the needs, values and preferences of African American communities. The key to its success may indeed reside in transparency and accountability over time.

Addressing the Conventional Notion That African Americans Are Slow to Participate in Research

In conclusion, in outreach to minorities, "care must be taken in deciding when to view the person as an individual and when to view him or her as a member of a group." (15). Individuals' socio-political history may not be necessarily served well because he or she is categorized and assumed to share sufficient personal, social, or cultural characteristics to be

subject to some common description or methods of professional intervention. The answers to addressing disparities in Alzheimer's research participation may well focus on the transparency, accountability and behavior of the investigators in relation to the expectations of diverse research participants.

Acknowledgments

This paper was supported by the Joseph and Kathleen Bryan Alzheimer's Disease Research Center grant #P30 AG028377 from the National Institute on Aging

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