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Barriers and Facilitators of African American Participation in Alzheimer's Disease Biomarker Research

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Abstract

African Americans experience a greater risk of Alzheimer's disease (AD), but are underrepresented in AD research. Our study examined barriers and facilitators of AD research participation among African Americans. Investigators conducted 11 focus groups with African American participants (n=70) who discussed barriers and facilitators to AD research participation including lumbar puncture (LP) studies. The moderator and co-moderator independently reviewed transcripts, identified themes, and coded transcripts for analysis. Participants were predominately female (73%) with a mean age of 52y (range 21–86y). Concerns and attitudes were consistent across education, socioeconomic status, and gender. Mistrust was a fundamental reason for nonparticipation. Additional barriers included insufficient information dissemination in the African American community, inconvenience, and reputation of the researcher and research institution. Barriers to participation in AD biomarker studies were fear of the unknown and adverse effects. Altruism and relevance of research projects to the individual, family members, or the African American community facilitate participation. Increased participation results from relationships with the community that extend beyond immediate research interests, dissemination of research findings, and emphasis on relevance of proposed studies. Pervasive barriers impede African American participation in AD research but can be overcome through a sustained presence in the community.

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Keywords

African Americans; Alzheimer disease; research; barriers; facilitators; biological markers

INTRODUCTION

African Americans experience higher incidence and prevalence of Alzheimer's disease (AD)^{1–6} but remain underrepresented in AD research.^{7–9} Inequities in research participation mirror disparities in health and healthcare utilization. African Americans have less knowledge of this disorder,¹⁰ tend to have a greater delay to presentation for evaluation,¹¹ and are less likely to receive treatment for dementia.^{12,13}

In 1994, the Consortium to Establish a Registry for Alzheimer Disease (CERAD) conducted a survey of nine member organizations to ascertain barriers to recruitment and retention of African American participants.¹⁴ Several primary factors were identified: mistrust, lack of education and information about AD and AD research, financial difficulties for minority elders and their families that rendered participation burdensome, and cultural differences such as a more diffuse network of caregivers. The extent to which the study staff and the research project were culturally responsive also influenced participation. The potential role of healthcare providers who serve the African American community was discussed. The authors explained that providers could serve as study advocates and a source of referrals.¹⁴

Studies consistently indicate that mistrust is a key factor in AD research participation for African Americans.^{8,9,15} Data from studies of trust and mistrust in the healthcare setting indicate that complexities of mistrust need to be examined systematically in order to define fully how mistrust influences health outcomes.¹⁶ Aspects of mistrust that influence research participation include mistrust of the research infrastructure, the impact of past events, and perceptions of the skills, experience, and abilities of the researchers.¹⁴ However, few studies defined whether participants report mistrust of the researcher, the research infrastructure, or both.

Goals to increase African American research participation may be impeded by lack of empiric evidence to direct investigators in the development, initiation, completion, and assessment of recruitment and retention methods.¹⁷ Factors influencing participation in AD research are not understood fully. Even less is known regarding African Americans' perceptions of barriers and facilitators of AD biomarker research. Our study examines barriers and facilitators to AD research in general and specifically AD biomarker research participation among African Americans.

METHODS

Participants

A convenience sample of community-dwelling African American adults ($n = 70$) was recruited to participate in one of 11 focus groups. An intended objective was to create focus groups that were homogenous based on at least one of three variables: previous or current participation in research, gender, and age (18–35, 35–55, and 55 years and older). Groups were formulated to reflect a spectrum of socioeconomic status and education categories. These variables were selected to define the groups as they were considered to have the greatest influence on attitudes regarding research participation.

Participants in four of the focus groups previously participated in research. Most were recruited from studies conducted at the Washington University Alzheimer's Disease Research Center

(ADRC). Participants in one focus group were recruited by a research team member. The remaining groups consisted of participants who responded to advertisements in a local African American newspaper, flyers distributed at a health center, or through community contacts. The Washington University Human Research Protection Office approved all procedures. Informed consent was obtained from participants after the study was described in complete detail.

Interview

Each focus group interview lasted 90 minutes. All interviews were audio-recorded and transcribed. A moderator, co-moderator, and ADRC investigator attended all focus groups. Interviews were conducted in community settings, such as the Urban League, with the exception of one focus group that was conducted at the ADRC. Each participant received a \$25 stipend to a local grocery store.

The study investigators designed the focus group interview, and the moderator revised the questions to render them more conversational. As a result of this process, a focus group interview guide was developed and provided the content and format for the interviews. In order to facilitate maximum participation, the flow of questions followed a conventional focus group format with introductory, key, ending, and summary questions.¹⁸ Questions were formulated to achieve the goal of examining three main topics: 1) barriers to participation in research, 2) facilitators of research participation, and 3) recommendations for increasing participation among African Americans. Each main question was followed by probes or clarification questions for the three main topics. For example, participants were asked to enumerate the reasons for participating in AD research. Subsequently, each reason was explored in depth. In addition, the moderator and co-moderator asked participants about specific topics when not mentioned by participants, e.g., whether a research recruiter must be the participant's healthcare provider or African American, or focus group participants' attitudes and beliefs about more invasive studies and clinical treatment trials.

Data collection

Each focus group lasted 90 minutes and was recorded. Audio-taped recordings were transcribed by a professional transcriptionist. All participants were encouraged to answer the questions posed by the moderator. If the participants did not respond, the moderator asked them directly for responses. The moderator and co-moderator completed a debriefing following each focus group.

Data analysis

Grounded theory is a systematic qualitative research methodology that employs an inductive approach to data collection. This theory defined data collection and analysis methodology used in our study. Grounded theory functions in a manner that is distinctly different from methods conventionally used in quantitative research. There is no preconceived theoretical framework that drives data collection. Rather, theory evolves from systematic data collection and observation of the reciprocal relationships among categories of information.¹⁹ Thus, there were no theories about barriers to research participation that influenced data collection at the inception of the study. Consequently, the study provides an exhaustive review of barriers and facilitators to research participation, rather than generalities.²⁰

The initial stage of analysis involved examining the transcripts. Focus group transcripts were reviewed independently by the moderator and co-moderator using a whole-text analysis, open-coding method²¹ to determine themes related to barriers and facilitators of research participation. The moderator and co-moderator reviewed their notes and developed a description of themes and observations of group tone and process for each focus group. These themes served as the basis for developing the codes for data analysis. The code list was reviewed

and compared with the focus group interview guide, and pertinent items included in the interview guide that were not initially identified as themes were subsequently added as codes.

The next step of analysis was focused coding²² using codes generated in the first stage. We established inter-rater reliability between the moderator and co-moderator by independently coding a transcript, reviewing the coding, and achieving consensus on discrepancies. This process was repeated until no inconsistencies were identified, which was accomplished after four transcripts were reviewed. Subsequently, the remaining transcripts were coded independently, and all were reviewed by a senior team member. Codes were entered into N6 (QSR International, Melbourne, Australia) qualitative data analysis software. Data were organized by codes and analyzed.

RESULTS

A total of 70 African American participants attended one of 11 focus groups. The sample was 73% female and had a mean age of 52 years with an age range of 21 to 86 years. Three focus groups had a mean age greater than 65 years. Table 1 shows the demographic characteristics of the sample. As a convenience sample was used for this study, it was not possible to create homogenous groups as initially planned. However, some focus groups were homogenous on specific variables, e.g., previous participation in research, age, education, gender, and income. The range of demographic characteristics is representative of the African American population in the metropolitan St. Louis area.

General perceptions of research participation

Focus group participants were asked numerous questions regarding their beliefs about the importance of research for themselves and their community. Participants expressed the belief that research is important in order to study and cure disease, for drug discovery, to develop new techniques, and to improve health. Several focus group participants explained that individuals who volunteer for research may benefit directly from research participation. One participant explained that research is relevant, *“because research benefits us. We’re the ones that benefit from research, but we don’t know that yet.”* The assertions that research is pertinent and important were tempered by extensive concerns about participating in studies. Participants explained that adverse perceptions of the concept of experimentation are due to the long-standing history of unethical research studies involving African Americans participants. Participants in every group used the term “guinea pig.” Many equated the term specifically with the use of African Americans to test medications or procedures.

Barriers to research participation

A general question followed by a series of follow-up questions was used to assess barriers to research participation. Five barrier themes were identified: mistrust, access to information, fear of the unknown or adverse effects, inconvenience, and reputation of both the researcher and the research institution. Mistrust was the fundamental barrier to nonparticipation. The conspicuous influence of mistrust was apparent in the focus group attendees’ comments regarding other barrier themes.

Mistrust—Mistrust of researchers, the healthcare system, and healthcare providers was consistent across socioeconomic status, age, and gender. Participants appreciated that medical research often occurs within the healthcare system, and that the infrastructure of clinical care and medical research overlap. Consequently, adverse perceptions that stem from mistrust of clinical care and the healthcare infrastructure extend to medical research. Focus group participants explained that pervasive mistrust of the healthcare system and research is due to historical events such as the Tuskegee Syphilis Study. *“As far as I can remember growing up,*

I was always told about the Tuskegee experiments,” a participant explained. Another reported that knowledge of the Tuskegee Syphilis Study remains prominent in the thoughts of many African Americans. A participant explains, *“that [Tuskegee Syphilis Study] is on a lot of people’s minds. I know it is on my mind.”* Focus group attendees discussed the persistent impact of the Tuskegee Syphilis Study on perceptions of research and healthcare, and it was emblematic of the factors that caused lasting mistrust of biomedical research. Past experiences of unethical research impact the willingness to participate in current studies. Potential participants remain *“suspicious... because of things that have happened in the past.”* Focus group participants also conveyed mistrust of the integrity of current research studies.

Access to information—Participants emphasized the importance of access to adequate information about research studies. A participant summarized the issue:

Well, you’ve got a certain amount of people that require information, a lot of information. They consider themselves to be well-informed. And so they won’t participate if they’re not informed. If they’re well-informed, they might consent to participate.

Participants believed misinformation or lack of information has caused African Americans to enroll in studies without thoroughly understanding the implications of participation. Some participants explained that they did not receive complete information regarding the risks and benefits of research or that investigators intentionally provided misinformation. They contended that researchers intentionally targeted vulnerable populations, such as homeless people, prisoners, children, impoverished individuals, and the elderly, to conduct research because researchers believed that these individuals were less likely to question researchers. They also expressed concern that financial remuneration served as an incentive to attract vulnerable groups to research studies. Focus group attendees emphasized skepticism of adequate protection of personal information obtained through research.

Participants explained that researchers do not communicate well with the African American community. They contended that information provided regarding studies and the results of research was limited and presented in a manner that was neither professional nor understandable. Participants described situations in which they had been invited to participate in research but refused because they felt they were rushed and not permitted to inquire about the study. In addition to behavior perceived as disrespectful, a researcher’s lack of enthusiasm served as a deterrent to participation. Inadequate dissemination of pertinent research results was another concern discussed. The focus group attendees explained that the need for a researcher to develop a rapport with an individual participant was integral to recruitment success. They asserted that the entire research organization needed to have a relationship with the community as well.

There’s never ... or rarely I’ll say ... I’ve never seen anybody ... I assume you have them somewhere ... the situation where they develop enough rapport with a community organization or something where this community organization has had time to question what they’re doing and to get all their questions answered, not just over a week or a day, but over some time, and then they take ... invest enough interest in it themselves so that they’re supporting this and they’re promoting it just as much as this researcher.

Fear of the unknown or adverse effects—Participants reported that fear of the unknown and fear of adverse effects of medications or procedures were barriers to research participation. Many suggested that they were quite comfortable with survey or focus group studies but were less likely to consider participation in more invasive studies. They indicated that they might

be willing to volunteer for studies that included phlebotomy or imaging, but were very reluctant to enroll in research that involved more invasive procedures such as lumbar puncture (LP).

We think in terms of guinea pigs, medical research and like that. Also I think patients worry about what you are going to do... I think it depends on whether it's invasive or non-invasive. I think because non-invasive is easy, just talking or something, but being given any kind of medication or being stuck could be dangerous.

Many had heard stories concerning adverse outcomes of LP. Reports of these outcomes were passed down from generation to generation. A number of misperceptions concerning LP were conveyed, e.g. pain during the procedure, risk of paralysis, and the use of inexperienced or unqualified researchers to perform the procedure. Some participants acknowledged that their perceptions might not be totally justified, but they would place greater weight on what they had heard from friends and family than information from investigators or health professionals.

I think a lot of it has to do with your experience, because I've only known one person that had a spinal tap and that one person had a hard time. So I would be leery of something that has to do with a spinal tap. Although there are probably thousands done every day and nobody is the worse for wear.

Participants also differentiated between procedures that were medically necessary and those done for research purposes: *"If I had to do that because my doctor ordered it, I probably would do it. But if it was for research, really, to answer honestly, I don't know if I would do it."*

Inconvenience—Participants explained that two primary issues related to convenience impeded research participation: location and time. Many stated that they would be reluctant to participate in studies that were located far from home. *"Distance always makes a difference to me,"* a participant explained. Time-consuming studies that interfered with daily life were not desirable. *"I don't want my life interrupted for that [research participation],"* one focus group attendee commented. Studies with multiple visits over the course of months or years also were seen as an excessive time burden. Inadequate transportation and lack of caregiving alternatives during study participation were additional barriers. A participant explained:

Myself, I don't have a car, and I manage to get around pretty good on the buses... I have done studies where they actually send a cab to get you and pick you up where you want... They brought us home, so I didn't have to worry about it. I didn't have to worry about getting home, and I know most places don't do that.

Reputation of Researchers and Research Institutions—Participants described the reputation of researchers and research institutions as an additional barrier to research participation. Many participants were concerned that researchers may not receive adequate training to conduct research appropriately. They indicated that researchers must have both credibility and experience. A participant explained that a research clinician should be *"a real doctor with some real credentials. I want to see a diploma and everything. And how many years he has been doing it."* Focus group participants explained that credibility can be determined by word-of-mouth or a "sense" that they acquire from interactions with the researcher. Research institutions that are unfamiliar or seemingly lack permanence in the local community cause considerable concern regarding credibility.

Facilitators of research participation

Participants responded to general and follow-up questions about factors that would motivate research participation. Four major themes emerged: relevance of research, altruism, a desire to learn more about the disease and ways that it may impact the individual's health, and positive reputation of the research institution. The focus group participants explained that they would be more likely to participate in studies that are relevant or helpful to them and emphasized the

importance of the applicability of research to individuals, others, or their community. Participants would be more likely to enroll in studies that address problems that are prevalent in the African American community. Altruism had considerable impact on willingness to participate in research. Participants described both moral duty and pragmatic beliefs about participating in research. One explained, *“Nothing will change until at least one person starts.”* Focus groups attendees explained that an additional advantage of research participation is the opportunity to learn more about their health conditions and risks for diseases. The reputation of the research institution and investigators influences the decision to participate. *“I think the reputation of the institution or the group, the specific person doing the spinal tap... I would want the institution to be the one that I felt had a good reputation,”* a participant explained.

Suggestions for increasing African American participation in research

The fundamental action that researchers can take is to cultivate relationships with the African American community. This can be accomplished by providing complete, consistent, and accurate communication about research and maintaining a constant presence in the community. The research team should convey their interest and concern about the community. Information about research projects should be presented in a clear, understandable format. Researchers should convey the relevance of research findings and indicate how studies can potentially benefit the African American community. A participant advised:

get your doctors who are so unapproachable, you get them out in the community, start dealing with the people, start talking to the people in the programs, in the city, telling them about what they're trying to do. Not just one or two [times] but several ...

Participants described the types and appropriate uses of a number of dissemination venues and strategies. Their recommendations include: health centers, polling places, Urban League block meetings, ward meetings, neighborhood association meetings, schools, malls, theaters, pharmacies, and churches. The importance of developing relationships with African American churches was emphasized. Ministers can be important community partners and advocates for research participation as an endorsement from one's pastor can have considerable influence:

Some ministers have a lot of influence over congregations. I know from being raised in a Baptist church. I know how that goes... Especially when you are older... Some people call their minister before they call their doctor.

Participants discussed the importance of the media for increasing awareness of research opportunities. Newspapers, radio, and television were recommended as potential modes of recruitment and community education. The small group format used for the focus groups was recommended as an optimal format for recruitment. Focus group participants explained that small recruitment sessions permit discussions and interactions with the research team. Potential participants are able to obtain information about research studies, discuss concerns about participation, and correct myths and misperceptions. In addition, the small group sessions would build trust, and attendees would tell friends and family about research studies. The focus group attendees explained that endorsements from current study participants can have considerable influence on others in the community.

DICSUSSION

An examination of research perceptions among African Americans who participated in a series of focus groups demonstrated that they believe in the importance of medical research, the need for research participation, and the benefits of research for society and future generations. Despite altruism and appreciation of the importance of research, barriers to research participation are pervasive and persistent. Mistrust, a fundamental factor in nonparticipation,

is due to the impact of historical events and current experiences. Mistrust of the healthcare infrastructure mirrors mistrust of the research environment and researchers. Focus group participants asserted that if researchers have knowledge of injustices in treatment in clinical settings in their communities but do nothing to rectify the situation, then they have a level of complicity with the process.

Trust and mistrust can be conceptualized as multidimensional, consisting of two principal domains: technical competence and values.¹⁶ The values domain may include numerous values, e.g. fiduciary responsibility, fidelity, honesty, respect, caring, reliability, and confidentiality.¹⁶ Focus groups participants conveyed that their mistrust of research stems from both domains. Perceptions of technical competence were a barrier due to concern that researchers may be inexperienced or inadequately trained. Additionally, participants reported unease that investigators are not fully honest, respectful, and compassionate.

A group of investigators recently validated an instrument developed specifically to assess mistrust of biomedical researchers.²³ The instrument may be used by investigators who intend to recruit diverse samples for studies. By examining mistrust among potential participants, investigators could develop recruitment methodology to address mistrust and improve perceptions of the trustworthiness of the research group.

The focus group attendees described mistrust as the primary barrier to participation in research. Several other barriers were characterized: concern about adverse effects and fear of the unknown, insufficient information, inconvenience, and reputation of the researcher and the research institution. Mistrust inextricably impacts these additional barriers. Refusal to participate may be multifactorial due to the aggregate of numerous barriers.

These barriers to research participation are not insurmountable. The focus group participants describe facilitators and offer solutions to increase the participation of African Americans in AD research. Investigators must establish and sustain involvement and dialogue in the African American community to define the goals of research studies and disseminate the results of completed projects. A growing body of evidence demonstrates the impact of sustained involvement in the African American community on recruitment outcomes.^{8,9,15,24,25} The Washington University ADRC developed an African American Outreach Satellite in 1993 to extend the expertise of the ADRC to minority and underserved elderly in the St. Louis area. The Satellite's role has evolved as research goals changed, and the current objective of the Satellite is to facilitate recruitment and retention of African American participants for the ADRC's studies. More than 15 years of sustained involvement in the African American community and successful partnerships with key community collaborators resulted in success in African American recruitment. This study provides evidence for the rationale for the Satellite's recruitment methodology, and the results have helped to inform outreach activities to further augment success in minority recruitment.

As AD research becomes increasingly involved and invasive, a systematic, scientific approach to African American outreach and recruitment is essential to achieving goals for recruitment and retention of a diverse cohort of participants. Participants expressed concern about participation in invasive research studies due to inadequate access to information and misperceptions regarding procedures such as lumbar puncture. Increasing awareness of the relevance of studies, the safety of procedures, and developing a dialogue in the African American community can lead to success in recruitment and retention of diverse participant samples for Alzheimer's disease biomarker research.

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Table 1

Demographic Characteristics of Focus Group Participants

Variable	Mean \pm SD	Range
Age (yrs)	52.37 \pm 15.03	21 – 86
	N (%)	
Gender		
Female	51 (73)	
Male	19 (27)	
Education		
< High School	6 (9)	
High School	10 (14)	
Some college	24 (34)	
Bachelors degree or greater	30 (43)	
Annual Income		
<\$10,000	19 (28)	
\$10,000 – \$-20000	16 (24)	
\$21,000 –\$40,000	13 (19)	
> \$40,000	20 (29)	
Previously Participated in Research		
Yes	30 (43)	
No	40 (57)	