


Incentives and Barriers to Research Participation and Brain Donation Among African Americans

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Abstract

Successful African American recruitment for aging research requires sensitivity to factors that influence participation. In this work, a structured face-to-face educational interview was used to recruit African Americans for a longitudinal aging study and to collect information about attitudes related to research. The interview was designed to build trust and respect for research and to educate participants about the need for minority participants. Of the 91 African Americans aged 65 and older who completed interviews, 65 (71%) agreed to participate in the longitudinal study and approximately half agreed to brain donation. Those who enrolled and consented to brain donation were more likely to consider benefit to themselves or direct family unit as the main motivator for participation ($P < .01$). The study also found a significant increase in agreement to brain donation across enrollment periods ($P = .0005$).

Keywords

African American, research, participation, barriers, incentives, brain donation

Introduction

The African American community has historically been unreceptive to research. Reasons for this lack of participation involve forms of mistrust due to a history of past abuse and perceived present injustices in research and health care delivery.¹⁻⁵ The Tuskegee study, for example, has been shown to have significant negative effects on the participation of African Americans in research projects.⁶ Conversely, studies also suggest that a sense of mistrust does not necessarily result in refusal to participate.^{7,8} Research has shown that some participants report a desire to overcome mistrust as an incentive for study enrollment, while others have found that knowledge of Tuskegee increased willingness to participate by both African Americans and caucasians.^{3,9} Such findings suggest that previous exposure, knowledge, and desire to alleviate mistrust could enhance the recruitment of African Americans.^{9,10} Other barriers to research and organ donation include participant feelings of being utilized as a guinea pig, institutional racism, fear of potential side effects and risk, and lack of knowledge about research processes such as informed consent and possible benefits of research.^{1,3,6,11-13} These issues have been raised by many independent researchers and continue to influence research participation.

Research has found that including knowledge of how medical research can benefit the individual participant could improve research participation.^{1,3,6,7,11,12} Other incentives include education about advances in treatment and cures that occur because of research, provision of information about research and organ

donation in a clear, understandable, and culturally sensitive way, inclusion of African Americans in the research process as study personnel, and emphasis on altruism and how participation can help other African Americans.^{3,5,12,14}

Alzheimer's disease (AD) continues to affect the African American population in greater numbers than their caucasian counterparts. Research has shown that prevalence rates in the African American community are 14% to 500% higher than in other groups.¹⁵ This higher prevalence may be partly explained by the increased risk of the African American population for disorders including hypertension, diabetes mellitus, and stroke.¹⁵ Tissue studied through brain donation has been useful in investigating differences between healthy aging and dementia and in identifying potential genetic differences between races.

On the individual level, although clinical researchers' ability to identify AD is high, 80% to 90%,¹⁶ it is important to investigate the clinical assessments and brain tissue because a definitive diagnosis of AD can only be made at autopsy.¹⁷

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Recent research has shown that significant cerebrospinal fluid biomarker measurements can facilitate diagnosis of AD in living individuals. However, these data are still preliminary and are not widely used in diagnosis.¹⁸ Research suggests that African Americans are often not aware of the differences between normal and abnormal brain aging and believe that memory loss is a normal part of the aging process.¹⁹ Therefore, they may delay diagnosis and treatment even though current dementia medications work best early in the disease. Without adequate engagement of African Americans in research and education, this problem will likely continue.

Open dialog coupled with education about research safeguards and the importance of research could develop trust, increase understanding of AD, and build community engagement related to research. It is important to include information on current safety measures to ensure that participants are informed of potential risks and benefits and, when possible, to include the family in these discussions as they are responsible for end-of-life wishes.^{1,14} The educational recruitment interview developed for this study is based on what we have learned from the literature and from our educational outreach in the local African American community.

The purpose of this study is to identify barriers and incentives related to AD research and brain donation for African Americans in our community. We hypothesize that individuals will be more likely to participate in research if they understand the health benefits of the research for themselves and their family. We also hypothesize that there will be an increase in willingness to consent to brain donation across enrollment periods due to increased education.

Methods

Participants

Participants were 91 older African Americans, recruited from a database of registered voters. Voters aged 65 and older are from the county where the center is located. Those included in the database responded to a letter asking for participants for the studies of aging. Positive responses were obtained from approximately 13% of those contacted. For this study, we selected individuals who identified themselves as African American, approximately 7% of those who responded. Telephone contact was made by trained interviewers to determine interest in the study and to schedule an interview time. Participants were not paid for their participation. Interviewers followed a scripted discussion for each telephone contact. All research activities were approved by the University of Kentucky Institutional Review Board, and written informed consent was obtained from the participants.

Procedures

Two trained interviewers, at least 1 of whom was African American, completed the semistructured in-home interview with the study participants. Interviews took 30 to 60 minutes, depending on how much the participant wanted to share and

were conducted during 2 time periods—2006 to 2007 and 2010 to 2011, when appropriate trained staff were available. No interviews were conducted in 2008 and 2009 due to staff limitations. For each scheduled session, 1 interviewer conducted the interview, while the other took notes. In 2006 to 2007, both the interviewer and the note taker were African American. In 2010 to 2011, the interviewer was caucasian and the note taker was African American. After arriving at the home the study was described, and written informed consent was obtained. The first part of the interview provides background information about the Center on Aging, the AD center, and the ongoing efforts of scientists at the center toward finding a cure for AD and providing support to families coping with the disease. Next, the participants were asked about their personal experience with health and medical procedures, their feelings about research, their interest in participating in annual memory and cognitive testing, and their willingness to donate their brain after death. Finally, if interested in participating, medical history information was collected to confirm study eligibility.

Research Participation Questions. Questions in this section asked about general thoughts and feelings about research. Participants were asked what research meant to them, including any benefits or barriers, if they or a family member had participated in research, if they were currently interested in participating in research and why, and if there was anything about a particular study that would either increase or decrease their willingness to participate. Participant responses were followed by a request for more detail. After interviews were completed, all qualitative responses were classified. For example, reasons for participating (incentives) and not participating (barriers) were coded separately. After initial coding, all categories were reviewed by a second coder and, if necessary, discussed and arbitrated to determine appropriate classification.

Healthy Aging Research Study and Related Research Questions. The interviewer explained that the current group of healthy aging volunteers being followed at the center includes only a small number of African Americans. The importance of studying older healthy African Americans was explained, and the participants were asked whether this research was of interest to them. For those who answered “no” or “don’t know,” an explanation for declining was requested and the interview was ended.

For those individuals who expressed an interest in participation, the research was described as a program dedicated to the study of healthy older persons for comparison to patients with memory and thinking problems. Interviewers explained that involvement in this research required annual evaluations of memory and cognitive performance. If participants were willing to be followed, inclusion criteria were reviewed. Inclusion criteria include the availability of an informant or family member to provide information. Brain donation is not a requirement for participation and was brought up only if the interviewer felt that the participant would be comfortable with this topic. Participants were ineligible to participate if they had medical illnesses or injuries that could affect cognition or if

Table 1. Barriers to Participation.

Barrier	Frequency (%)
Among those who were asked and gave reasons (n = 43 of 91).	
Categories are not mutually exclusive	
Invasive/health risk	23 (53.5)
Transportation	7 (16.3)
Confidentiality	6 (14.0)
Time commitment	7 (16.3)
Mistrust	5 (11.6)
Lack of diversity	3 (7.0)
Barriers to research participation among those who enrolled (n = 31 of 43). Categories are not mutually exclusive	
Invasive/health risk	17 (54.8)
Transportation	6 (19.4)
Confidentiality	3 (9.7)
Time commitment	5 (16.1)
Mistrust	5 (16.1)
Lack of diversity	2 (6.5)

they had a history of substance abuse. After the inclusion and exclusion criteria were reviewed, participants were thanked for their time; those who wished to participate and met criteria were told that they would be contacted in the next few weeks to schedule their initial testing and neurological examination.

Open responses for incentives and barriers were recorded and then matched based on the topic in order to create a list of reported incentives and barriers that are shown in Table 1. Some responses included more than 1 topic and were recorded as separate answers.

Autopsy and Brain Donation Questions. As part of the inclusion criteria, autopsy and brain tissue donation were discussed if the interviewer considered the participant to be comfortable with the sensitivity of this topic. Observed level of rapport, verbalized attitudes and beliefs, nonverbal responses during the interview, and overall openness to research influenced whether or not participants were asked about autopsy and brain tissue donation. Individuals were also left with a brochure on brain donation in order to have materials to review and discuss with the family.

Individuals in this study are involved in our longitudinal study on Alzheimer's disease. Each year these participants are asked at their clinic visit to review their decision on brain donation.

Statistical Analyses

Group comparisons were conducted with *t* tests for means and chi-square tests for proportions. Fisher's exact test was used when sample size assumptions for the chi-square test were not met. Trends over time were assessed with the Cochran-Armitage test for linear trend. Statistical significance was set at .05.

Results

A total of 91 participants completed recruitment interviews. Of the 91 who were interviewed, 71.4% agreed to enroll into the

Table 2. Demographics.

Demographic Detail	Enrolled (n = 65) ^a	Not Enrolled (n = 26)
Age (mean ± SD)	73.0 ± 4.9	74.9 ± 6.6
Education (mean ± SD)	14.7 ± 2.9	13.6 ± 3.4
Sex (% female)	73.9	76.9
Reported family history of dementia ^b (%)	34.5	43.7

Abbreviation: SD, standard deviation.

^a Four participants were not asked about brain donation.

^b First- or second-degree relative.

longitudinal research cohort as a normal control or as a patient with memory loss, if neuropsychological testing identified problems with memory and thinking—12.1% declined participation beyond the initial interview, 7.7% did not meet inclusion criteria, and were excluded from the study, while 8.8% agreed to enroll but were not scheduled because some individuals changed their minds, became too busy, or had medical issues that took precedence.

General demographic information of study participants is provided in Table 2. Characteristics of the 65 participants who enrolled in research when compared to the 26 who did not enroll are shown separately. No statistically significant differences were observed for age ($t = 1.37$, $df = 31.1$, and $P = .17$), education ($t = 1.55$, $df = 89$, and $P = .71$), sex (chi-square [χ^2] = 0.09, $df = 1$, and $P = .76$), or family history of dementia ($\chi^2 = 0.53$, $df = 1$, and $P = .47$) between the 2 groups. However, those who agreed were a little younger (73.0 years of age compared to 74.9) with slightly more education (14.7 years compared to 13.6). Both the groups consisted of more women than men (73.9% for those who agreed compared to 76.9% who did not). Finally, slightly more of those who did not enroll indicated that they had a first- or second-degree relative with AD (43.7% vs 34.5%).

Table 3 presents reasons for participation provided by those who gave a response to this item (n = 47). Note that some participants gave more than 1 response. Benefit to self or family was the most frequent response (53%). Other major motivations for participation included benefit to others (21.3%) and personal interest (21.3%). Responses of those who enrolled in the research (n = 34) were examined separately; responses were similar except that benefit to self and family was much higher for those who enrolled than for those who did not enroll (84% vs 16%).

Table 1 shows barriers to participation identified by those who provided a response (n = 43). Invasiveness or health risk was the most frequent response (53%). Problems with transportation (16.3%), excessive time commitment (16.3%), concerns about confidentiality (14.0%), and issues of mistrust (11.6%) were also noted as barriers. Again, responses and frequencies were similar for the participants who enrolled (n = 31) in comparison to those who did not enroll (n = 12).

As shown in Table 4, approximately half (49%) of those who enrolled in this research agreed to brain donation. Those who enrolled and consented to brain donation were more likely

Table 3. Reasons for Participation.

Motivation	Frequency (%)
Reasons given for interest in research participation among those who were asked and gave reasons (n = 47 of 91). Categories are not mutually exclusive	
Benefit to self or family	25 (53.2)
Benefit to others	10 (21.3)
Personal interest	10 (21.3)
Increase scientific knowledge	6 (12.8)
Money	4 (8.5)
Diversity	3 (6.4)
Positive staff interaction	1 (2.1)
Something to do	1 (2.1)
Free services	1 (2.1)
Reasons given for interest in research participation among those who enrolled (n = 34 of 47). Categories are not mutually exclusive	
Benefit to self or family	21 (61.8)
Benefit to others	7 (20.6)
Personal interest	8 (23.5)
Increase scientific knowledge	5 (14.7)
Money	2 (5.9)
Diversity	1 (2.9)
Positive staff interaction	0 (0.0)
Something to do	1 (2.9)
Free services	1 (2.9)

Table 5. Consent to Brain Donation by Interview Year: Proportion of Interviewees Agreeing to Brain Donation Has Increased Across Time Periods ($P = .0005$).

Interview Year	Autopsy Consent		Total (No.)
	No, No. (%)	Yes, No. (%)	
2006	10 (76.92)	3 (23.08)	13
2007	8 (72.73)	3 (27.27)	11
2010	10 (58.82)	7 (41.18)	17
2011	3 (15.00)	17 (85.00)	20
Total	31	30	61

to consider benefit to themselves or family members as the main motivator for participation ($P < .01$). No significant relationship was found between barriers and agreement to participate. Interestingly, 65% of those who mentioned perceived invasiveness of the research procedure as a barrier consented to brain donation. There were participants who over time dropped from our study. Reasons for withdrawing from the study were failing health and excess time commitment. A staff change after the first recruitment period may have also contributed to a number of withdrawals.

The proportion of participants agreeing to brain donation increased across enrollment periods (Cochran-Armitage $Z = 3.48$, $P = .0005$; see Table 5).

Discussion

Recruiting African Americans for research participation remains a challenge. However, the development and use of a

Table 4. Consent to Brain Donation.

	Ever Enrolled (n = 61)	Active (n = 38)
Autopsy consent = yes	30/61	24/38
Benefit to others	5/24	5/20
Benefit to self/family	18/24 ^a	15/20 ^a
Autopsy consent = no	31/61	14/38
Benefit to others	1/13	1/9
Benefit to self/family	2/13	2/9

^a $P < .01$.

structured, educational, and in-home interview has allowed our center to recruit healthy older African Americans into a longitudinal study of brain aging. The success of our recruitment effort has been impressive, with 65 (71%) of the 91 participants interviewed enrolled either as a normal control or as a patient with memory loss. This recruitment success has resulted in a longitudinal research cohort that reflects the percentage of African Americans who live in the community—approximately 13.5% of the local community is African American, the largest minority in the state, and approximately 15% of our research cohort is African American. However, it should be noted that the group of African Americans in this study had already expressed a general interest in research by responding to a mailing from our center, so they were likely more responsive to the educational message the interview provided than a general older population of African Americans.

For this study, emphasis was placed on examining potential differences in incentives and barriers that might lead to a better understanding of those who agree to participate in research and brain donation. One of our major findings was that those who enrolled and consented to brain donation were more likely to consider benefit to themselves or family as the main motivator for participation ($P < .01$). This finding confirms our hypothesis that education specifically about personal research benefits would increase the likelihood of participation and more specifically brain donation. Bonner et al²⁰ reported similar findings on their study of autopsy recruitment for African Americans. Bonner et al also highlighted the importance of cultural sensitivity, family involvement, and open discussions regarding past research abuse.²⁰ Similarly, Lambe et al³ found the main incentive for brain donation was the possibility of family benefit, specifically in those families with a history of AD. Although this study did not find those who had a reported family history of AD more likely to enroll in research or to agree to brain donation, the larger number of African Americans who reported no family history likely influenced our findings. Additionally, our structured interview did not place a major emphasis on the genetic components of AD. We should expand this information in future interviews so that this topic is more completely addressed.

Another study finding was a significant increase in enrollment and brain donation across enrollment periods. Lambe et al³ suggest that it is important to have a culturally diverse group involved in research, so that participants can identify with someone who looks like them and thus be more open in the discussion of sensitive topics. For this study, we included

at least 1 African American in all recruitment interviews. As mentioned earlier, over the period of the study, 2 different interview teams were used. Although both teams received similar training, 1 explanation for the greater enrollment in research and agreement to brain donation over the study period is the effectiveness of the research teams. Perhaps participants responded better to the racially mixed recruitment team used in 2010 to 2011, or this team was better able to establish and maintain rapport with the participants. Another explanation is that our center's reputation was building in the local community, and because African Americans were agreeing to participate, they were spreading the word in their social networks about the importance of AD research. Also, during both the recruitment periods, our center maintained a strong presence in the African American community by participating in health fairs, offering conferences targeting African Americans, and presenting on AD and brain health at churches and senior groups. Likely, our success was a combination of these factors.

Although we found no significant differences between those who enrolled and those who did not enroll, striking trends related to research barriers were observed. Among those who said they would not participate if the project involved a procedure that was too invasive, a great number consented to brain donation. Negative feelings about brain donation could have been changed by the information provided as part of the interview. Many participants were surprised to find out that brain donation would not affect planned funeral arrangements or the ability to have an open casket. A discussion of realistic expectations related to brain donation could have made volunteers more receptive to this research.

Other barriers to research participation mentioned by participants included transportation, time involved to participate, and mistrust. Providing transportation services whenever possible and limiting the time involvement of participants are relatively easy issues to address with study design. However, mistrust can remain an issue even with the use of educational protocols such as the one used in this study. We received comments such as "I think of Tuskegee. If something was not above board or if someone had ulterior motives, I would not participate," and "I would want to know what the study is all about." Both the participants who made these comments agreed to participate, reinforcing the success of the approach we used. Open and honest communication through this interview may have increased participants' comfort with research.

Through strategies such as the recruitment interview used in this work, potential participants can be informed about the importance of research, benefits of research participation, and may begin to understand the necessity of specific study practices. Kennedy et al¹² found that leaving written materials with potential participants facilitated the recruitment process. This was another strategy used in this study. Written materials about brain donation were left at the home so that participants could review this information and discuss it with their family. Contact information was also provided in case the participant or the families had questions.

This study allowed our center to develop a research cohort of African Americans who agreed to annual neurological

evaluations with many also agreeing to brain donation. However, study limitations should also be considered. First, our high rates of agreement to participate in research and brain donation were influenced by a sample of participants who had already expressed an interest in finding out more about research. Our rates of agreement would likely have been much lower had we not had this pool of participants available to us. Next, using 2 different interview teams, necessary because of staff and financial issues, may have also affected our findings even though both the teams received the same training. Finally, because the majority of our participants were women, our results may not be generalizable to African American men. Further research should continue to emphasize the importance of education in the recruitment and retention of target populations and measuring how specific education efforts affect program outcomes.

In summary, recruiting African Americans for research participation continues to be a challenge. Fear of the unknown ("I know I need to know, but I'm afraid to know."), confusion ("Why do I need to know something for which you have no cure."), and religious zeal ("God will take care of me!") highlight some of the issues expressed by the participants in this study. Unfortunately, these obstacles are ones that recruiters often cannot overcome. Yet, patience and education as exemplified by the semi-structured education interview in this work and a continued positive presence in the target community can facilitate recruitment.

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References

1. Corbie-Smith G, Thomas SB, Williams MV, Moody-Ayers S. Attitudes and beliefs of African Americans toward participation in medical research. *J Gen Intern Med.* 1999;14(9):537-546.
2. Corbie-Smith G, Thomas SB, George St. DM. Distrust, race and research. *Arch of Int Med.* 2002;162(21):2458-2463.
3. Lambe S, Cantwell N, Islam F, Horvath K, Jefferson AL. Perceptions, knowledge, incentives, and barriers of brain donation among African American elders enrolled in an Alzheimer's research program. *Gerontologist.* 2011;51(1):28-38.
4. Friemuth VS, Quinn SC, Thomas SB, Cole G, Zook E, Duncan T. African American's views on research and the Tuskegee Syphilis study. *Soc Sci Med.* 2001;52(5):797-808.
5. Minniefield WJ, Yang J, Multi P. Differences in attitudes toward organ donation among African Americans and whites in the United States. *J Nat Med Assoc.* 2001;93(10):372-379.

6. Shavers VL, Lynch C, Burmeister L. Factors that influence African Americans' willingness to participate in medical research studies. *Cancer*. 2001;91(suppl 1):233-236.
7. Gadegbeku CA, Stillman PK, Huffman MD, Jackson JS, Kusek JW, Jamerson KA. Factors associated with enrollment of African Americans into a clinical trial: results from the African American study of kidney disease and hypertension. *Contemp Clin Trials*. 2008;29(6):837-842.
8. Brown DR, Topcu M. Willingness to participate in clinical treatment research among older African Americans and Whites. *Gerontologist*. 2003;43(1):62-72.
9. Durant RW, Legedza AT, Marcantonio ER, Freeman MB, Landon BE. Willingness to participate in clinical trials among African Americans and whites previously exposed to clinical research. *J Cult Divers*. 2011;18(1):8-19.
10. Darnell K, McGuire C, Danner D. African American participation in Alzheimer's disease research that includes brain donation. *Am J Alzheimers Dis Other Demen*. 2011;26(6):469-476.
11. Calderon JL, Baker RS, Fabrega H, Conde JG, Hays RD, Fleming E. An ethno-medical perspective on research participation: a qualitative pilot study. *MedGenMed*. 2006;8(2):23-39.
12. Kennedy B, Burnett M. Clinical research trials: factors that influence and hinder participation. *J Cult Divers*. 2007;14(3):141-147.
13. Jefferson AL, Lambe S, Cook E, Pimontel M, Palmisano J, Chaisson C. Factors associated with African American and White elders' participation in a brain donation program. *Alzheimers Dis Assoc Disord*. 2011;25(1):11-16.
14. Marcantonio ER, Aneja J, Jones RN, Alsop DC, Fong TG, Crosby GJ. Maximizing clinical research participation in vulnerable older persons: identification of barriers and motivators. *J Am Geriatr Soc*. 2008;56(8):1522-1527.
15. Froehlich TE, Bogardus ST, Jr, Inouye SK. Dementia and race: are there differences between African-Americans and Caucasians? *J Am Geriatr Soc*. 2001;49(4):477-484.
16. Blacker D, Albert MS, Bassett SS, Go RC, Harrell LE, Folstein MF. Reliability and validity of NINCDS-ADRDA criteria for Alzheimer's disease. The National Institute of Mental Health Genetics Initiative. *Arch Neurol*. 1994;51(12):1198-1204.
17. Beach TG, Monsell SE, Phillips LE, Kukull W. Accuracy of the clinical diagnosis of Alzheimer disease at National Institute on Aging Alzheimer Disease Centers. *J Neuropathol Exp Neurol*. 2012;71(4):266-273.
18. Tabaraud F, Leman JP, Milor AM, Roussie JM, Barriere G, Tartary M. Alzheimer's CSF biomarkers in routine clinical setting. *Acta Neurol Scand*. 2011;125(6):416-423.
19. Connell CM, Roberts JS, McLaughlin SJ, Akinleye D. Racial differences in knowledge and beliefs about Alzheimer's disease. *Alzheimer Dis Assoc Disord*. 2009;23(2):110-116.
20. Bonner GJ, Darkwa OK, Gorelick PB. Autopsy recruitment program for African Americans. *Alzheimer Dis Assoc Disord*. 2000;14(4):202-208.