Published in final edited form as:

Am J Alzheimers Dis Other Dement. 2013 August ; 28(5): 485–490. doi:10.1177/1533317513488922.

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

Tyler Schnieders, M.S., Deborah Danner, Ph.D., Caitlin McGuire, B.A., Flores Reynolds, M.A., and Erin Abner, MPH

Sanders-Brown Center on Aging, University of Kentucky

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 ($P < 0.01$). The study also found a significant increase in agreement to brain donation across enrollment periods ($P = 0.0005$).

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 a 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 an 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% – 500% higher than for 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, even though clinical researchers' ability to identify Alzheimer's disease is high, 80 – 90%¹⁶, it is important to investigate clinical assessments and brain tissue because a definitive diagnosis of AD can only be made at autopsy.¹⁷ Recent research has shown that significant CSF biomarker measurements can facilitate diagnosis for 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 dialogue coupled with education about research safeguards and the importance of research could develop trust, increase understanding of Alzheimer's disease 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 Alzheimer's disease 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 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 participants.

Procedures

Two trained interviewers, at least one of whom was African American, completed the semi-structured in-home interview with study participants. Interviews took 30 to 60 minutes, depending on how much the participant wanted to share, and were conducted during two time periods – 2006–2007 and 2010–2011, when appropriate trained staff were available. No interviews were conducted in 2008 and 2009 due to staff limitations. For each scheduled session, one interviewer conducted the interview while the other took notes. In 2006–2007, both the interviewer and note taker were African American. In 2010–2011, the interviewer was Caucasian and the note taker 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 Alzheimer's Disease Center, and the on-going efforts of scientists at the Center toward finding a cure for Alzheimer's disease and providing support to families coping with the disease. Next, 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 participants were asked if 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 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 topic in order to create a list of reported incentives and barriers that are shown in Table 3. Some responses included more than one 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. Individuals were also left with a brochure on brain donation in order to have materials to review and discuss with family. Individuals enrolled and followed in our longitudinal cohort were asked each year to re-consent to brain donation (if they agreed) or if they would like to consent if they were not asked at the recruitment interview or said no at the annual assessment.

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 years with complete data (2006–2011). Statistical significance was set at 0.05.

Results

A total of 91 participants completed recruitment interviews. Of the 91 who were interviewed, 71.4% agreed to enroll into the 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 as some individuals changed their minds, became too busy or had medical issues that took precedence.

General demographic information for study participants is provided in Table 1. Characteristics of the 65 participants who enrolled in research as compared to the 26 who did not enroll are shown separately. No statistically significant differences were observed for age ($t=1.37$, $df=31.1$, $P=0.17$), education ($t=1.55$, $df=89$, $P=0.71$), sex ($\chi^2=0.09$, $df=1$, $P=0.76$), or family history of dementia ($\chi^2=0.53$, $df=1$, $P=0.47$) between the two 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 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 2 presents reasons for participation provided by those who gave a response to this item ($n=47$). Note that some participants gave more than one 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 (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 3 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 to consider benefit to themselves or family members as the main motivator for participation ($P < 0.01$). 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 also have contributed to number of withdrawals.

Finally, the proportion of participants agreeing to brain donation increased across enrollment periods (Cochran-Armitage $Z=3.48$, $P=0.0005$). See Table 5.

Discussion

Recruiting African Americans for research participation remains a challenge. However, the development and use of a structured, educational, 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 of the 91 participants interviewed (71%) enrolled either as a normal control or 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 ($P < 0.01$). 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 al, 2000, reported similar findings on their study of autopsy recruitment for African Americans. Bonner also highlighted the importance of cultural sensitivity, family involvement, and open discussions regarding past research abuse.²⁰ Similarly, Lambe et al. (2011) found the main incentive for brain donation was the possibility of family benefit, specifically in those families with a history of AD. Even though 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 Alzheimer's disease. 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 al. 2011 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 one African American in all recruitment interviews. As mentioned earlier, over the period of the study, two different interview teams were used. Even though both teams received similar training, one 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 2010–2011 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 as African Americans were agreeing to participate, they were spreading the word in their social networks about the importance of AD research. Also, during both 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, the 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 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 al, 2007, 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 also was provided in case the participant or family had questions.

This study allowed our Center to develop a research cohort of African Americans who agree 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 using 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 two different interview teams, necessary because of staff and financial issues, may have also affected our findings even though both 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 targeted populations and measuring how specific education efforts effect 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 structured education interview in this work and a continued positive presence in the target community can facilitate recruitment.

Bibliography

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. [PubMed: 10491242]
2. Corbie-Smith G, Thomas SB, StGeorge DM. Distrust, race and research. *Arch of Int Med.* 2002; 162:2458–2463. [PubMed: 12437405]
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. [PubMed: 20679141]
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. [PubMed: 11218181]
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; 93:372–379.
6. Shavers VL, Lynch C, Burmeister L. Factors that influence African Americans’ willingness to participate in medical research studies. *Cancer.* 2001; 91(S1):233–236. [PubMed: 11148585]
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; 29:837–842. [PubMed: 18639652]
8. Brown DR, Topcu M. Willingness to participate in clinical treatment research among older African Americans and Whites. *The Gerontologist.* 2003; 43(1):62–72. [PubMed: 12604747]
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 Div.* 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 Alz Dis Other Deme.* 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. *Medscape Gen Med.* 2006; 8(2):23–39.
12. Kennedy B, Burnett M. Clinical research trials: Factors that influence and hinder participation. *J Cult Div.* 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. *Alz Dis Assoc Dis.* 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; 56:1522–1527. [PubMed: 18662204]
15. Froehlich TE, Bogardus ST Jr, Inouye SK. Dementia and race: Are there differences between African-Americans and Caucasians. *J Am Geriatr Soc.* 2001; 49:477–484. [PubMed: 11347796]
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; 51:1198–1204.

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. [PubMed: 22437338]
18. Tabaraud F, Leman JP, Milor AM, Roussie JM, Barriere G, Tartary M. Alzheimer CSF biomarkers in routine clinical setting. *Acta Neurol Scand*. 2011; 125:416–423. [PubMed: 21954973]
19. Connell CM, Roberts JS, McLaughlin SJ, Akinleye D. Racial differences in knowledge and beliefs about Alzheimer's disease. *Alz Dis Assoc Dis*. 2009; 23(2):110–116.
20. Bonner GJ, Darkwa OK, Gorelick PB. Autopsy recruitment program for African Americans. *Alz Dis Assoc Dis*. 2000; 14:202–208.

Table 1

Demographics

Demographic Detail	Enrolled (n=65) [*]	Not Enrolled (n=26)
Age, (mean $\pm$ SD)	73.0 $\pm$ 4.9	74.9 $\pm$ 6.6
Education, (mean $\pm$ SD)	14.7 $\pm$ 2.9	13.6 $\pm$ 3.4
Sex (% female)	73.9	76.9
Reported Family history of dementia ^{**} (%)	34.5	43.7

^{*} 4 participants were not asked about brain donation.

^{**} 1st or 2nd degree relative

Table 2**Reasons for Participation**

1. Reasons given for interest in research participation among those who were asked and gave reasons (n = 47 out of 91). Categories are not mutually exclusive.

Motivation	Frequency (%)
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)

2. Reasons given for interest in research participation among those who enrolled (n = 34 out of 47). Categories are not mutually exclusive.

Motivation	Frequency (%)
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 3**Barriers to Participation****1. Among those who were asked and gave reasons (n = 43 out of 91). Categories are not mutually exclusive.**

Barrier	Frequency (%)
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)

2. Barriers to research participation among those who enrolled (n = 31 out of 43). Categories are not mutually exclusive.

Barrier	Frequency (%)
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)

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 *	15/20 *
Autopsy Consent = No	31/61	14/38
Benefit to others	1/13	1/9
Benefit to self/family	2/13	2/9

*
P < 0.01

Table 5

Consent to brain donation by interview year

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

Proportion of interviewees agreeing to brain donation has increased across time periods($P=0.0005$).