

## Short Communication

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# Attitudes and Perceptions about Brain Donation Among African Americans: Implications for Recruitment into Alzheimer's Disease Research

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**Abstract.** The objective of this study was to investigate attitudes toward brain donation and perceptions of medical research that influence brain donation among African Americans. Cross-sectional surveys were administered to African American community members ( $n = 227$ ). Findings indicate that only 27% of respondents were willing to donate their brain. As medical mistrust was not found to be a significant barrier to research participation, there may be opportunity to increase brain donation by providing information about Alzheimer's disease and brain donation to potential donors and their families so that informed decisions about participating in research can be made.

**Keywords:** Alzheimer's disease, Black or African American, brain donation, dementia, medical mistrust, recruitment, research participation

## INTRODUCTION

Brain autopsy after death remains a rich source of data for examining Alzheimer's disease and related dementias (ADRD). Examination of the brain

postmortem is considered the definitive source of diagnosis for most brain disorders [1, 2]. However, while African Americans (AAs) are twice as likely to develop Alzheimer's disease (AD) as compared to their non-Hispanic White counterparts [3–5], they remain largely underrepresented as brain donors. According to the National Alzheimer's Coordinating Center, less than 4% of brain donations for research are from AAs [6].

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Prior research has explored barriers and facilitators to brain donation. For instance, among AA, White, Asian, and Latino research volunteers, Boise and colleagues [7] found positive predictors of willingness to donate one's brain included Latino ethnicity, older age, and both an understanding of how the brain is used in research and what needs to be done to ensure brain donation after death. Negative predictors of willingness to donate one's brain included Black race, believing one's body should remain whole at burial, and concern that researchers might not treat the body respectfully during autopsy. Notably, this study sample consisted of research volunteers engaged with NIH-funded Alzheimer's Disease Research Centers (ADRCs), thus, these findings regarding brain donation may not generalize to the broader population, especially to those people of color who may be hesitant to consider research participation due to historical mistreatment in medical research [8]. Respondents at ADRCs would have likely overcome any number of social and cultural barriers of mistrust and distrust to actively participate in AD research. Thus, such research findings about willingness to participate in brain donation may not be generalizable to those not engaged in AD research. However, findings from Deep-Soboslay et al. (2019) suggest that AAs are willing to consent to brain donation of a loved one at relatively high rates when approached after the donor has died even without prior engagement in research [9].

A systematic review of literature regarding reasons that people donate their brains distilled four "universal factors" that affect decisions about brain donation: 1) contextual knowledge (health literacy), 2) conceptual understandings (personal motivation), 3) importance of family/friends (follow-through on deceased person's wish for brain donation), and 4) personal experience, time and process (quality and timeliness of the request for brain donation) [10]. The authors conclude that addressing these "universal factors" may increase brain donations when addressed sensitively with potential brain donors and their families.

Mistrust in medical research among AAs has been well-documented as a barrier to participation in medical research [11]. Qualitative information collected from focus groups of older AAs has shown that the legacy of human rights violations against AAs is a barrier to research and brain donation participation [8]. Beyond historical atrocities, mistreatment of AAs in society and in healthcare today foments persistent underrepresentation of AAs in research, contributing

to overrepresentation of disparities in AAs—which exacerbates a lack of trust in medical research [12]. Understanding the role of mistrust as a barrier to AA brain donation and AD research participation and by actively working to provide trustworthy experiences and build authentic relationships, researchers may be able to increase the engagement of AAs in these endeavors. The objective of the current study is to collect preliminary data on attitudes of AA individuals toward brain donation, as well as examine family influences and trust in medical research that may hinder or facilitate brain donation, as an initial step in the development of a brain donation awareness and education program for AAs.

## MATERIALS AND METHODS

A 74-item cross-sectional survey was developed to collect preliminary data about attitudes and beliefs regarding medical research and brain donation among AAs. Validated demographic and survey items used included the Perceived Threat Scale [13], Alzheimer's Disease Knowledge Scale [14], Research Attitudes Questionnaire [15], and a survey designed to assess predictors of brain donation willingness [7]. The survey was administered via REDCap® (Research Electronic Data Capture) and paper formats at sites in four U.S. states, Florida (University of Miami), New York (Columbia University), North Carolina (Wake Forest University School of Medicine), and Ohio (Case Western Reserve University); a research consortium investigating genetic risk for AD in relation to ancestry. Surveys were collected during community outreach events in each state from November 2021 to September 2022. Across sites survey respondents were not directly known to the study staff. Respondents who completed the survey were provided a \$25 gift card. The survey procedures complied with guidelines on human experimentation and were approved by the Institutional Review Board at each site. Descriptive analyses of data on demographics, AD knowledge, and trust in medical research were conducted using SAS® software version 9.4. Respondents in this analysis were restricted to individuals who reported being Black or AA ( $n = 227$ ).

## RESULTS

In the overall sample, approximately three-quarters of the respondents were female and the median year of birth was 1970 (minimum: 1936, max-

Table 1  
Sociodemographic summary of participants

Characteristics	Likelihood of donating brain after death <i>n</i> (%)		
	Not likely <i>n</i> = 73 <i>n</i> (%)	Somewhat/Very likely <i>n</i> = 61 <i>n</i> (%)	Unsure/Prefer not to answer <i>n</i> = 93 <i>n</i> (%)
Gender*			
Male	20 (27)	16 (27)	19 (20)
Female	53 (73)	44 (73)	74 (80)
Year born (M,SD)*	1972 (18)	1973 (18)	1970 (18)
Years of education (M,SD)*	13 (2)	13 (4)	14 (3)
Relationship Status			
Married/Living with partner	12 (16)	11 (18)	31 (33)
Widowed	5 (7)	6 (10)	3 (5)
Divorced/Separated	14 (19)	14 (23)	19 (20)
Never Married	33 (45)	22 (36)	26 (28)
Unknown	9 (12)	8 (13)	12 (13)
Employment Status			
Employed	37 (51)	31 (51)	50 (54)
Retired	21 (29)	16 (26)	24 (26)
Other	15 (21)	14 (23)	19 (20)
Religion			
Christian	52 (74)	40 (66)	67 (76)
Catholic	2 (3)	3 (5)	5 (6)
Protestant	2 (3)	3 (5)	5 (6)
Judaism	0 (0)	1 (2)	0 (0)
Muslim	2 (3)	0 (0)	0 (0)
Prefer not to answer	12 (17)	14 (23)	11 (13)
How concerned are you about developing Alzheimer's disease in your lifetime? <sup>†</sup>			
Very/Somewhat concerned	39 (53)	48 (79)	54 (58)
Not Concerned/Unsure/Prefer not to answer	34 (47)	13 (21)	39 (42)

\*Gender, missing 1; year born, missing 6; years of education, missing 7. <sup>†</sup> $p < 0.05$ . A chi square test was conducted for each demographic variable and likelihood of donating brain after death, excluding religion.

imum: 2003). On average, respondents had at least a high school diploma. See Table 1 for additional descriptive information stratified by respondents' willingness to donate their brain.

Among our respondents, 27% reported being very likely or somewhat likely to donate their brain to research after death vs. 32% who reported being not likely. Among respondents who were somewhat or very likely to donate their brain 79% were concerned about developing AD in their lifetime. By comparison, among participants who were not likely to donate their brain 53% were concerned about developing AD in their lifetime.

In contrast to the low percentage of respondents who expressed a willingness to donate their brain for research, 77% of participants indicated that they had positive attitudes towards medical research and there were no significant differences in relation to likelihood of brain donation (Table 2). Similarly, 73% of participants indicated that they trusted medical researchers regardless of willingness for brain donation.

Overall, few respondents had been asked to donate their brain (11%) or a loved one's brain (6%). There were no significant differences between likelihood of brain donation groups in terms of brain donation knowledge, including knowing how a research team removes a brain, how researchers use brains for research, what must be done in advance to make sure a brain is donated after death, the difference between brain donation and donation of other organs. However, a significantly greater proportion of respondents who were somewhat or very likely to donate their brains to research (69%) reported knowing that the study of the brain is important for research on AD and other problems in thinking compared to respondents who were not likely to donate their brain (48%) or unsure or preferred not to answer (60%) about their likelihood to donate their brain to research.

Religious or spiritual beliefs did not have a significant influence on respondents' willingness to donate their brain. However, the role of family played a significant role in the likelihood of brain donation. Many respondents were unsure or preferred not to

Table 2  
Participants' trust in medical research

Characteristics	Likelihood of donating brain after death <i>n</i> (%)		
	Not likely	Somewhat/Very likely	Unsure/Prefer not to answer
I have a positive view about medical research			
False	14 (19)	10 (16)	8 (9)
True	53 (73)	49 (80)	73 (78)
Prefer Not to Answer	6 (8)	2 (3)	12 (13)
Medical researchers are motivated by personal gain			
False	33 (45)	32 (52)	40 (43)
True	27 (37)	23 (38)	33 (35)
Prefer Not to Answer	13 (18)	6 (10)	20 (22)
Medical researchers can be trusted to protect the interests of participants			
False	13 (18)	10 (16)	12 (13)
True	47 (64)	41 (67)	57 (61)
Prefer Not to Answer	13 (18)	10 (16)	24 (26)
We all have a responsibility to help others by volunteering for medical research			
False	16 (22)	11 (18)	15 (16)
True	47 (64)	50 (82)	68 (73)
Prefer Not to Answer	10 (14)	0 (0)	10 (11)
In general, my family trusts medical researchers			
False	26 (36)	14 (23)	23 (25)
True	36 (49)	42 (69)	54 (58)
Prefer Not to Answer	11 (15)	5 (8)	16 (17)
Modern science does more harm than good			
False	38 (52)	35 (57)	50 (54)
True	24 (33)	21 (34)	24 (26)
Prefer Not to Answer	11 (15)	5 (8)	19 (20)
Society needs to devote more resources for medical research			
False	8 (11)	6 (10)	5 (5)
True	61 (84)	52 (85)	75 (81)
Prefer Not to Answer	4 (5)	3 (5)	13 (14)
Medical research needs to be closely regulated to prevent harm to participants			
False	6 (8)	9 (15)	9 (10)
True	63 (86)	51 (84)	74 (80)
Prefer Not to Answer	4 (5)	1 (2)	10 (11)
If I volunteer for medical research, I know my personal information will be kept private and confidential			
False	13 (18)	9 (15)	16 (17)
True	52 (71)	48 (79)	62 (67)
Prefer Not to Answer	8 (11)	4 (7)	15 (16)
Medical research will find cures for many major diseases during my lifetime			
False	11 (15)	6 (10)	8 (9)
True	54 (74)	51 (84)	71 (76)
Prefer Not to Answer	8 (11)	4 (7)	14 (15)
In general, I trust medical researchers			
False	11 (15)	8 (13)	12 (13)
True	50 (68)	50 (82)	65 (70)
Prefer Not to Answer	12 (16)	3 (5)	16 (17)
Too much emphasis on medical research and scientific progress is likely to harm research volunteers			
False	34 (47)	40 (66)	52 (56)
True	27 (37)	14 (23)	24 (26)
Prefer Not to Answer	12 (16)	7 (11)	17 (18)

Table 3  
Participants' Perceptions and Knowledge about Brain Donation for Research

Brain Donation Knowledge	Likelihood of donating brain after death <i>n</i> (%)		
	Not likely	Somewhat/Very likely	Unsure/Prefer not to answer
You have been asked to donate your brain for research after you die*	11 (15)	9 (15)	4 (4)
You have been asked to donate the brain of a loved one for research after they die	6 (8)	4 (7)	4 (4)
You have heard a presentation on brain donation by a researcher	7 (10)	13 (21)	9 (10)
You know how a research team removes a brain	9 (12)	8 (13)	4 (4)
You know how researchers use a brain for research	13 (18)	9 (15)	8 (9)
You know the study of the brain is important for research on Alzheimer's disease and other problems in thinking*	35 (48)	42 (69)	56 (60)
You know what a person must do ahead of time to make sure their brain is donated after they die.	11 (15)	8 (13)	9 (10)
You know the difference between brain donation for research and donation of other organs for patients in need.	24 (33)	17 (28)	21 (23)
<b>Religion</b>			
Your religious or spiritual beliefs influence your thinking about brain donation	14 (19)	12 (20)	11 (12)
You would find it helpful if you heard a clergy or other religious leader talk about brain donation	24 (33)	24 (39)	24 (26)
<b>Role of Family</b>			
After my death, if I agree to brain donation, my family members will have difficulty carrying out my wishes*			
No	23 (32)	21 (34)	16 (17)
Yes	24 (33)	14 (23)	19 (20)
Unsure/No answer	26(36)	26 (43)	58 (62)
The decision to donate one's brain is mostly an individual decision			
No	8 (11)	6 (10)	8 (9)
Yes	55 (75)	47 (77)	59 (63)
Unsure/No answer	10 (14)	8 (13)	26 (28)
The decision to donate one's brain is a mostly a family decision			
No	46 (63)	29 (48)	48 (52)
Yes	14 (19)	18 (30)	16 (17)
Unsure/No answer	13 (18)	14 (23)	29 (31)
My family can openly discuss issues surrounding death*			
No	22 (30)	8 (13)	17 (18)
Yes	38 (52)	38 (62)	44 (47)
Unsure/No answer	13 (18)	15 (25)	32 (34)
Members of my family would be better able to discuss brain donation if they had more information*			
No	17 (23)	7 (11)	8 (9)
Yes	37 (51)	39 (64)	48 (52)
Unsure/No answer	19 (26)	15 (25)	37 (40)

\*Chi-square test,  $p < 0.05$ .

report if their family would have any difficulties carrying out their wishes if they agreed to donate their brain after death, with the largest proportion being

among respondents who were unsure or did not provide a response about their willingness to donate their brain (62%). Further, most respondents felt that fam-

ily could better discuss brain donation if they had more information. Those who were somewhat or very likely to donate their brain had a significantly greater proportion of respondents that reported that additional information was necessary for their family to better discuss brain donation.

## DISCUSSION

We assessed attitudes toward brain donation and perceptions of medical research that may impede or influence brain donation among a community sample of AAs. An important finding is that AAs concerned about developing AD in their lifetime were more likely to donate their brain to research after death. Equally important, most respondents had not been asked to donate their brain to research, so even if concerned about AD they had not been afforded the opportunity for brain donation.

Interestingly, in this sample of AA individuals, survey results did not indicate high mistrust in research nor the researchers. Contrary to previous studies among AAs [12, 16], respondents reported high levels of trust in research and researchers and endorsed beliefs that research is important in the treatment of disease, including AD. One possible reason for these results could be that the collaborators in this study invested in community outreach for some time prior to the survey distribution. It may be that early investments and visibility in these communities may have led to trust of the study staff with community members, resulting in the high trust in medical research ratings seen in this sample. However, survey respondents across sites were not previously participating in research at the site nor known to the study staff. This may suggest that, for the current sample, that medical mistrust may not be a prevalent viewpoint to overcome. Despite the belief that research is important, only a small percentage of the respondents reported a willingness for brain donation for themselves or a loved one. Additional findings show that neither respondents nor their family members appear to have sufficient information about brain donation or AD, which would likely cause decision-making about brain donation or participation in AD research to be challenging. Awareness of brain donation research procedures and processes should be focused on the whole family. Including families in the consenting process will be pivotal in increasing agreement to brain donation. Increased health literacy in AD research and brain donation procedures may

facilitate engagement of AAs to participate in such research and may be fruitful areas for educational intervention.

One advantage of the current investigation relative to prior studies is that the respondents were recruited from the community, not current AD or brain donation research studies. Thus, insights from the current study may assist in strategizing engagement approaches for individuals who are not participating in brain donation nor AD research. We believe that this study serves as a first step in understanding how to engage AAs in brain donation programs. The juxtaposition of the relatively low level of knowledge about AD and brain donation as compared to the high levels of trust and hope in research and science to cure disease that the respondents endorsed may point to a significant opportunity for engagement with AAs with regard to brain donation.

The authors note some limitations of the current study. An important issue to be addressed in subsequent work is that only approximately a quarter of the sample reported being male. Customized efforts to engage AA males in research on AD and brain donation are needed, perhaps provided in locations where men are already gathered, such as barbershops or faith-based institutions. Further, AAs were recruited using a convenience sampling approach; therefore the results of this study may not be generalizable to all AAs. Another limitation is that this preliminary investigation did not include a comparison sample. However, our results are consistent with prior work of Akinyemi and colleagues [17] indicating that in a research naïve sample of sub-Saharan Africans, approximately 27% of participants endorsed a willingness for brain donation. Notably, this finding did not vary based on age, the same as was found in the current study.

Taken together, these data/findings suggest multiple opportunities to change willingness to participate in brain donation among AAs. Though respondents have little information nor knowledge about brain donation, they do believe that brain donation and research are important, and they trust in science and researchers to cure diseases. Further, most respondents have not been approached about brain donation. Thus, a focus on providing brain donation literacy coupled with making the opportunity available may lead to increased brain donations in AA individuals, particularly for those endorsing being unsure or preferred not to answer who may be open to brain donation compared to those unlikely to donate. Findings from this study will be used to inform themes for

focus groups to understand what would be needed in the development of an effective, culturally relevant, community-informed health literacy program focused on enhanced engagement of AAs in AD research and brain donation.

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## CONFLICT OF INTEREST

The authors have no conflict of interest to report.

## DATA AVAILABILITY

The data are not publicly available.

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