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An Intervention to Enhance Alzheimer's Disease Clinical Research Participation among Older African Americans

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Abstract

Background—Alzheimer's disease (AD) rates are higher among African Americans than in other racial or ethnic groups. However, Black elders participate in research at lower rates than Whites.

Objective—The present study aimed to: (1) implement an informational protocol for African Americans elders and their loved ones about the benefits of clinical research and brain donation program participation in AD, and (2) quantitatively assess changes in knowledge, attitudes, and trust.

Methods—Participants included 52 African American participants from the Boston University Alzheimer's Disease Center research registry (74 ± 8 years, 83% female) and 11 loved ones. Registry participants completed a pre- and post-group survey assessing brain donation knowledge, factors influencing brain donation, attitudes about medical research, and trust in medical researchers.

Results—There were no significant changes in mean scores between the pre- and post-group surveys. However, post-group outcomes revealed that 69% of participants shared details from the protocol with loved ones, 27% expressed an interest in joining Center-sponsored studies, and 10% indicated an interest in changing their brain donation status.

Conclusion—The informational protocol implemented in this study is an effective method to encourage family discussions about brain donation and increase interest in other AD research

studies. Longitudinal follow-up is necessary to assess the long-term implications of these groups on participation in a brain donation program.

Keywords

Black populations; brain autopsy; cognitive impairment; research enthusiasm

INTRODUCTION

Alzheimer's disease (AD) is a major public health issue, especially among the African American community where AD rates are higher than in other racial and ethnic groups [1, 2]. It is speculated that such a disparity in AD prevalence is due to racial disparities in environmental risk factors, such as diabetes mellitus [3] and hypertension [4]. While AD is a major public health issue for the African American community, Black elders participate in research at lower rates than White elders [5, 6]. In light of the expected doubling of AD prevalence over the next two decades [2], engaging African American elders in research to advance prevention and treatment efforts is a critical component in minimizing the public health implications of AD and its impact on the African American community.

In an effort to increase African American participation in AD research, including brain donation programs, the provision of key information about the burden of AD to Black communities may be useful. Previous research indicates that, compared to their White counterparts, African American adults demonstrate less awareness about AD, report fewer sources of information, view AD as less of a threat, have less concern about its personal consequences [7, 8], and believe that a cure will be found within their lifetime [9]. In contrast, African Americans are more likely than Whites to be aware of ways to prevent or delay the onset of AD [9]. Given these findings, AD educational efforts for African Americans might be most effective if focused on increasing AD knowledge about early symptoms and providing accurate information about current treatment options.

Relatedly, educational efforts should target the critical importance of brain donation research in diagnosing AD and developing therapeutic targets. Black elders participate in brain donation programs at lower rates than their White peers [10, 11], and there are a number of barriers to donation that have been reported for the African American community. Bonner et al. found family disagreement about donation, concern over funeral arrangements, and inadequate information about the donation process as barriers [10]. Our work also suggests that misconceptions about brain donation procedures exist, and racial mistrust may deter individuals from consenting to brain donation [12]. Health literacy, or the degree to which one is able to gather, process, and understand relevant medical information to make an appropriate health-related decision, may also play a role in donation assent. We previously reported that African American elders with an intent to donate had higher mean reading scores than their peers who declined donation [11], and reading ability has been linked to health literacy [13]. Consistent with our findings, Darnell, McGuire, and Danner reported that knowledge about complex medical procedures is associated with donation assent [14].

Education programs specifically focused on minorities may improve donation rates [15] and increase interpersonal communication about donation with loved ones to increase donation assent [16]. Focusing on improving medical research attitudes, increasing knowledge about brain donation, reducing mistrust, and including family members in donor decisions may affect donation success rates.

Established in 1996, the Boston University Alzheimer's Disease Center (BU ADC) is one of approximately 30 ADCs funded by the National Institute on Aging (NIA). A primary goal of the BU ADC is to assess barriers and incentives to research participation, particularly for the brain donation program. Recent efforts have focused on understanding brain donation program participation barriers among the African American community served by the BU ADC [11, 12]. To advance these efforts, this study had two aims. The first aim was to provide standardized information via an informational protocol to African American elders and their loved ones about the personal and societal benefits of participating in research and brain donation programs associated with the BU ADC. Based on our prior research, we hypothesized that there would be misperceptions about donation prior to group participation that would at least be partially resolved following participation. The second aim was to quantitatively assess changes in attitudes toward medical research before and after participation in the group discussion. Based on our prior work [11, 12] and that of the broader literature [15, 17, 18], our hypothesis was that participants would have a more favorable attitude toward research after participating in the group discussion as compared to pre-discussion assessments. Finally, as a function of resolving misperceptions about donation and enhancing attitudes toward clinical research, we hypothesized that participants would express an increased interest in brain donation program participation following group participation.

METHODS

Study participants

The BU ADC registry, which has been described in detail elsewhere [19, 20], includes a cohort of older adults representing the cognitive aging spectrum (i.e., cognitively normal, mild cognitive impairment, and dementia) who participate in annual evaluations to promote research on the early detection, prevention, and treatment of AD and related disorders. An annual visit includes neuropsychological testing, a medical history interview, and a neurological examination. Each participant's study partner is interviewed about the participant's daily functioning and cognitive abilities. Brain donation is an optional commitment for all African American registry participants. Each participant is approached during a one-on-one conversation with a research team member during their first visit and asked if they would be interested in donating their brain for research. Written information about the donation process is provided to the participant. Regardless of donation status, each participant is approached about brain donation at their subsequent annual visit to assess for any changes in donation decisions and to re-document assent when appropriate.

At the time that recruitment efforts were launched for the African American discussion groups (November 2009), there were $n = 394$ active participants in the BU ADC registry, including $n = 84$ African American elders and $n = 307$ White elders. For the purposes of this

study, all active African American registry participants regardless of clinical diagnosis ($n = 84$) were contacted by telephone and invited to participate in a two hour discussion group on AD and research within the African American community held on the Boston University Medical Campus or in the local community. Participants were asked to identify and invite a family member or a close friend whom they trusted with their healthcare information and decision making to join them for the group discussion. Participants who were unable to bring a family member or close friend were still eligible to participate. Participants and their loved ones were offered transportation, lunch or dinner, and a \$25 gift card.

Procedures

For participants who enrolled in the discussion group, the protocol included four procedures: (1) completion of a pre-group discussion survey, (2) participation in the group discussion, (3) completion of a follow-up telephone interview post-group discussion, and (4) completion of a post-group discussion survey. Details of each procedure are described below. The study protocol was approved by the local Institutional Review Board, and participants provided informed consent prior to participation.

Survey measures

The pre- and post-group discussion surveys assessed changes in knowledge of and attitudes toward research and brain donation before and after participation in the group discussion. The pre-group discussion survey was distributed via postal mail prior to the group discussion, and participants were asked to complete the survey materials and bring the packet with them to the discussion group meeting. A second survey packet, including a post-group survey and a self-addressed, stamped envelope, was distributed via postal mail to the participants a minimum of 10 days after group discussion participation. To increase response rates, study staff contacted participants by phone to remind them to complete and return the post-group survey. The following survey tools were included in both survey packets:

1. *Brain Donation Knowledge Survey*: This tool includes 11 true/false questions to assess participants' knowledge of brain donation procedures (e.g., "If one consents to brain donation, then that means they will donate their entire brain") and personal benefits (e.g., "Brain autopsy is the only way to determine with certainty that an individual had Alzheimer's disease"). Scores range from 0 to 11, with higher scores reflecting more accurate knowledge.
2. *Factors Influencing Brain Donation* [21]: Using a forced-choice paradigm (i.e., yes/no), this measure assesses 16 factors that may influence an individual's decision to donate their brain for research. Examples include having a religious leader advocate for brain donation, being able to contribute to research, and having family members agree with the decision to donate one's brain. Scores range from 0 to 16, and a higher score indicates that a participant has a greater number of factors influencing their decision to participate in research.
3. *Attitudes about Medical Research Scale* [22]: This scale measures participants' attitudes about medical research. Participants rate each of 11 items using a Likert scale ranging from one ("strongly disagree") to five ("strongly agree"). Examples

include: “*I have a positive view about medical research in general*” and “*Participating in medical research is generally safe.*” Scores range from 11 to 55, with a higher score indicating a more positive attitude toward medical research.

4. *Trust in Medical Researchers Scale* [23]: This tool assesses African Americans’ trust in medical researchers. Participants rate each of 12 statements using a Likert scale ranging from one (“strongly disagree”) to five (“strongly agree”). Examples include: “*Health researchers act different towards minority subjects than White subjects*” and “*In general, health researchers care more about doing their research than about participants’ health needs.*” Scores range from 12 to 60, with a higher score indicating greater mistrust for medical researchers.

Group discussion protocol development

In our prior work on barriers and incentives to brain donation among African American older adults [12], participants reported that group-based discussions about brain donation that include family members are critical to increasing donation knowledge and facilitating donor decisions. In 2009, we held two focus groups with a subset of African American registry participants ($n = 11$ with one loved one attending) to develop and refine the discussion content for the informational intervention in the present study. The final informational intervention, as described below, includes information on risk factors, symptoms, and prevention of AD.

Group discussion protocol implementation and content

The discussion protocol was designed to provide participants with opportunities to learn about AD and related research by building rapport between BU ADC staff and registry participants, creating dialogue among participants, and facilitating discussion between participants and their loved ones. Because focus group participants called for greater racial diversity among staff, the groups were facilitated by one of two individuals of color (i.e., an African American woman or a Pakistani woman). At the time of the group discussions, each facilitator worked as Education Core staff and was involved in Center outreach initiatives.

To build rapport, the facilitator began discussions by describing her role at the BU ADC and connection to the project (e.g., being a public health student who is committed to reducing health disparities among racial/ethnic minority populations). The discussion facilitator followed a structured discussion guide that included four areas of focus:

1. *Human Rights Violations*: The historical significance of medical research in Black communities was reviewed, with a focus on acknowledging human rights violations in research against African American communities. The facilitator emphasized how such violations led to the creation and reform of ethical guidelines and review boards intended to protect all human subjects.
2. *Health Issues within African American Communities*: Participants were queried about health issues that disproportionately affect Black communities (e.g., diabetes, dietary salt sensitivity). This section emphasized that research can contribute to advanced treatments for these diseases, and that some major health issues in the African American community increase risk of AD.

3. *Symptoms, Treatment, and Prevention of AD:* The facilitator asked the participants to share their knowledge about AD symptoms, prevention, and treatment options. In addition, participants were encouraged to ask the facilitator questions about AD.
4. *Relevance of AD Research to African American Communities:* Participants were asked to share reasons for joining the BU ADC research program and how they thought their participation contributed to research both generally and to African American communities specifically. A major component of this section was providing information about procedures related to brain donation, and participants were given information on the personal (e.g., definitive diagnosis) and societal benefits (i.e., advancements in AD diagnosis and treatment) for brain donation. Any incorrect information presented by group members was corrected by the group facilitator.

Follow-up telephone interviews

Approximately of one week after the discussion group, the group facilitator called each registry participant to conduct a semi-structured telephone interview that lasted up to 15 minutes. Participants were asked about their experience in the group discussion, if they had acquired any new information, if they had any questions regarding the group content, what information they found to be most valuable, and whether they shared any discussion details with family members or friends.

Statistical analysis

Prior to analyses, prorated scores were calculated for the Attitudes about Medical Research Scale, Trust in Medical Researchers Scale, and Willingness to Participate in Medical Research scale to account for any missing responses [11, 19]. Missing answers were assigned a prorated average that equaled the mean value obtained across the other responses within that particular scale. Next, descriptive statistics and frequencies were generated for all registry participants ($n = 394$) broken down by race, for the African American participants who participated in the discussion groups ($n = 52$), for the subset of discussion group participants who completed the post-discussion telephone interviews ($n = 37$), for the subset who completed the pre- and post-discussion survey packet ($n = 30$), and for the non-discussion group participants ($n = 32$). Wilcoxon tests were used to compare distributions for continuous variables, and Pearson chi-square tests were used to compare frequency distribution of categorical variables, including gender and brain donation status. Secondary analyses were run using an ANOVA test to compare mean survey responses between brain donation sub-groups (e.g., brain donors versus non-donors). All quantitative analyses were performed using SPSS 16.0 (Chicago, IL) and R 2.12.1 (<http://www.r-project.org>). Significance was set *a priori* at $p < 0.05$.

RESULTS

Registry characteristics by race

Comparisons between White and African American registry participants reveals differences for age ($F = 8.1, p = 0.005$), gender ($\chi^2 = 15.0, p < 0.001$), education ($F = 19.0, p < 0.001$),

WRAT-3 Reading subtest ($F = 39, p < 0.001$), time in registry ($F = 6.6, p = 0.01$), and brain donation status ($\chi^2 = 23, p < 0.001$). No differences emerged between the two groups for MMSE ($F = 2.1, p = 0.15$). See Table 1 for details.

Sample Characteristics

A total of 52 African American participants enrolled into 12 discussion groups held between January and December 2010 with 11 family or friends enrolling. One participant, who was not a brain donor, died during the study follow-up period. Table 2 reports sample characteristics for all participants enrolled in the discussion groups, including the subset who completed the telephone interviews ($n = 37$), the subset who completed both the pre- and post-discussion survey packet ($n = 30$), and the participants who did not enroll in the discussion groups ($n = 32$). There were no differences between the participants who enrolled in the discussion group and those participants who did not enroll with respect to age ($F = 0.71, p = 0.4$), gender ($\chi^2 = 3.2, p = 0.08$), education attainment ($F = 1.6, p = 0.21$), MMSE total score ($F = 2.4, p = 0.13$), WRAT-3 Reading total score ($F = 0.17, p = 0.68$), and brain donation ($\chi^2 = 1.9, p = 0.38$). However, there was a significant difference between groups for years in the registry ($F = 6, p = 0.016$), such that discussion group participants had been enrolled in the registry longer than non-participants. See Table 2 for details.

Post-discussion telephone interview outcomes

Of the 52 discussion group participants, 14 (or 27%) expressed an interest in research opportunities sponsored by the BU ADC. Of the 41 discussion group participants who were not brain donors, 4 (or 10%) expressed an interest in changing their donation status following the group discussion. To put this number into context, only one individual who did not participate in the discussion groups expressed an interest in changing their donation status from “no” to “will consider” over the follow-up period. Furthermore, one individual who did not enroll in the discussion groups whose brain donation status was “will consider” changed his/her mind over the follow-up period to “no.” No discussion group participants changed their minds about donation or went from “will consider” to “no.” Of the 35 participants interviewed by telephone post-discussion, 24 individuals (69%) reported sharing the discussion group content about brain donation with their family or friends.

When queried for the most useful part of the discussion, 15 (40%) of participants endorsed brain donation information was most useful. Eleven (30%) respondents stated hearing about the importance of research and current research advances impacting African American health was most important. Five (15%) participants reported learning more information about the research opportunities at the BU ADC was most useful. Last, 6 (15%) reported discussion of historical impact on African American research engagement to be the most useful information. These details along with excerpts from the phone interviews are presented in Table 3.

Pre- and post-discussion survey comparisons

Descriptives for pre- and post-discussion responses for the survey measures are provided in Table 4. For the entire sample, there was no pre- versus post-discussion group difference for any of the survey measures, including Brain Donation Knowledge ($t = -1.3, p = 0.21$),

Factors Influencing Brain Donation ($t = 0.7, p = 0.48$), Attitudes About Medical Research Scale ($t = 0.4, p = 0.66$), or the Trust in Medical Researchers Scale ($t = -1.4, p = 0.18$).

When baseline (pre-discussion) survey responses were examined by brain donation group (“yes,” “will consider,” and “no”), we observed a between-group difference for the Brain Donation Knowledge Scale ($F = 5.5, p = 0.01$) and a borderline difference for Factors Influencing Brain Donation ($F = 3.3, p = 0.06$). *Post-hoc* comparisons revealed significant differences between the brain donors and non-donors for both measures, such that brain donors had higher Brain Donation Knowledge scores ($p = 0.01$) and higher Factors Influencing Brain Donation scores ($p = 0.049$) as compared to non-donors (see Table 5 for details).

Among the non-brain donors, pre- and post-discussion survey responses revealed an increase in Brain Donation Knowledge post-discussion ($t = -2.4, p = 0.05$). Among the “will consider” group, pre-and post-discussion survey responses revealed an increase in the Attitudes About Medical Research Scale post-discussion ($t = -2.6, p = 0.05$). No additional significant pre- versus post-discussion survey changes were observed for any other measures (all p -values > 0.08). See Table 5 for details.

DISCUSSION

This study implemented a one-time, informational protocol as a feasible method to provide African American older adults with general information about AD, AD among the African American community, and the importance of increasing African American participation in AD research, including brain donation. Our primary findings suggested that there were no changes pre- versus post-group participation in surveys assessing brain donation knowledge, factors influencing brain donation, attitudes towards research, or trust in medical researchers. However, there was evidence that the informational protocol promoted family discussion about AD and related research and increased interest in participating in research studies at the BU ADC. In addition, the protocol may have helped to facilitate the decision-making process around donation, as some participants expressed an interest in changing their donation status. Despite limited findings in our survey measures, the current study reflects some preliminary promise that a discussion group format can enhance positive dialogue, interest, and enthusiasm on a sensitive topic, such as brain donation.

The lack of global findings in brain donation knowledge, factors influencing brain donation, attitudes toward research, or trust in medical researchers was unexpected. However, given that some differences emerged when pre- and post-group responses were assessed by brain donation status (i.e., “yes,” “no,” “will consider”), it is possible that informational interventions with a focus on brain donation will be more effective if they differ in content based on willingness to assent to brain donation. Future research on this topic is warranted.

Among non-donors, knowledge about brain donation and factors affecting donor decisions increased. Although these findings should be interpreted with caution, non-donors may decline participation because they need to know more information about donation (e.g., details such as an open casket funeral is feasible following donation and donation is the only

definitive way to diagnose AD). In addition, non-donors may benefit from support around the brain donation deliberation process, including determining factors that can inform their donor decisions. Participants who are considering donation demonstrated an increased positivity in attitudes toward medical researchers, suggesting that informational interventions with this group should include content about research ethics and clinical application of research findings.

The finding that (post-group) a majority of participants spoke with family members about the informational intervention is important because family members participate in activities related to AD diagnosis and treatment [24, 25] as well as AD research. Given the importance of involving family members, we initially aimed to include participants' loved ones to directly provide them with information about AD and related research. Although we offered transportation, food, and modest compensation for participation (i.e., a \$25 gift card), few family members (i.e., ~20% of our sample) attended the informational protocol. While we did not formally assess reasons for limited family attendance, the burden of inviting loved ones to attend was placed on the participants. Many participants reported that either their loved ones did not live locally or they lived locally but had limited time to participate. It is also possible that family members have less interest in learning about AD relative to other common diseases of aging (e.g., hypertension), or they might avoid information about health issues that could cause emotional distress. Future efforts should formally assess barriers and incentives to family participation and identify better methods to increase family involvement (e.g., conducting informational sessions in participants' homes).

The high proportion of participants who spoke with their families about the informational protocol content may have important implications for choices about brain donation, which involve a complex [15, 26–28] versus yes-no decision-making process. Based on the transtheoretical model and stages of change developed by Prochaska and DiClemente [29], donor decisions involve various steps that include pre-contemplation (no intention to donate), contemplation (considering donation), preparation (knowledge seeking about donation), action (agreeing to donate), and maintenance (maintaining an intent to donate for more than 6 months) [15, 26–29]. Discussing donation with family members may indicate that an individual is moving along the decision-making process, which is critical, as donation rates are higher among individuals who have discussed decisions with family members [30].

Similar to other research groups [15], our intention was to create low-pressure discussions focused more on providing information about donation than on “marketing” donation, which is a potentially sensitive topic among African American communities [11, 12]. Prior work implementing and evaluating clinical organ donation interventions have similarly found that donor decisions do not immediately change post-intervention. For example, Arriola and colleagues [31] evaluated an informational intervention targeted at increasing readiness for organ and tissue donation among African American adults and found that after one year, participants in the informational intervention group were 1.6 times more likely than those participants in the control group to discuss donation with their loved ones. However, there was no significant difference between groups on written intent to donate organs. Given that donation decisions may not change immediately after an informational intervention, future

research on brain donation among African American older adults should more formally assess readiness for brain donation and target interventions accordingly.

Our inclusion of participants with a diversity of perspectives on donation (i.e., yes, will consider, and no) in a single group discussion warrants some comment because it might have the potential to contradict the goals of our groups. While we did not conduct a discourse analysis of participant dialogue, our detailed review of group discussion transcripts did not yield any concerning negative comments about donation. Furthermore, following the groups, not one of our donors changed their mind about their donation commitment and none of our will consider participants changed their mind to no. Collectively, this information suggests inclusion of diverse perspectives on donation (specifically including non-donor participants) did not negatively impact our outcomes or contradict our goals. The current study only reflects preliminary findings that a discussion group format provides a venue for discussing a sensitive topic like brain donation. Future research, including discourse analysis, is warranted to better understand how different opinions or views might affect contemplation, preparation, or maintenance of behavior change.

The present study had a number of strengths. First, to our knowledge, this study is among the first informational interventions on AD research and brain donation designed and evaluated for use with older African American adults. Second, the one-time meeting format implemented for our group discussion offers a feasible and replicable method to encourage discussions about AD among families, which may be an important step in increasing AD knowledge and research participation, as well as supporting the brain donation decision-making process. Third, the protocol increased interest in other BU ADC activities, which is important in light of the Center's goal to include registry participants (particularly African American elders) in multiple studies. Inclusion of diverse staff in research efforts has been previously shown to play an important role in clinical research participation among minorities [32–34], so the increased interest in research activities among group participants might be related to our minority staff acting as discussion group leaders. Next, our protocol design and implementation was based on a combination of relevant literature and our African American registry participants' input. Last, we selected participants from our research registry, which provides important continuity in rapport and long-term follow-up with continued opportunities to facilitate discussion and provide additional information on AD and brain donation participation.

Despite numerous strengths, several limitations should also be considered, including the possibility of insufficient power to detect effects in some of our survey tools as well as the inherent limitations that come with survey research, such as respondent bias. In addition, it is possible that the survey tools were insufficiently robust. Future research should include open-ended survey questions to gain greater knowledge about the constructs of interest and shape follow-up conversations or interviews to better assess contemplation of and preparation for behavior change (i.e., donation assent). Future efforts should also include multiple intervention time points to determine if repeated contact with African American participants increases research participation and attitudes toward medical research, particularly brain donation. Efforts should focus on understanding reasons for limited family

member participation (as seen in our study), increasing family member participation in educational efforts, and assessing family members' knowledge about AD and attitudes about medical research. Consistent with other cognitive aging research [35], our sample was predominantly female, which may limit the generalizability of our findings. Finally, long-term contact with and follow-up of this cohort is critical to assess changes in brain donation status and increased participation in clinical research studies.

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Table 1

Clinical characteristics for registry participants by race

Characteristics, units	White participants	African American participants
Sample size, n	307	84
Age, years **	78 ± 8	75 ± 8
Gender, % female ***	52	76
Education, years ***	16 ± 3	14 ± 3
MMSE, total score	26 ± 6	27 ± 4
WRAT-3 Reading, total score ***	50 ± 5	46 ± 7
Time in Registry, years *	5 ± 3	5 ± 2
Brain Donation Status ***		
Yes%	75	47
No%	7	18
Will Consider %	19	35

Values are denoted as percentages or mean ± SD; MMSE, Mini-Mental State Examination; WRAT-3, Wide Range Achievement Test, 3rd Edition

* $p < 0.05$ significant difference between groups;

** $p < 0.01$ significant difference between groups;

*** $p < 0.001$ significant difference between groups.

Table 2

Clinical characteristics for African American participants and non-participants

Characteristics, units	Discussion group participants	Completed phone interviews	Survey responders	Non-participants
Sample size, n	52	37	30	32
Age, years	74 ± 8	74 ± 7	75 ± 8	76 ± 9
Gender, % female	83	76	73	66
Education, years	15 ± 3	15 ± 3	15 ± 3	14 ± 3
MMSE, total score	28 ± 2	27 ± 3	28 ± 2	26 ± 5
WRAT-3 Reading, total score	46 ± 7	46 ± 7	46 ± 8	46 ± 6
Time in Registry, years	5 ± 2	5 ± 2	5 ± 2	4 ± 3*
Brain Donation Status				
Yes%	52	59	50	41
No%	19	14	20	16
Will Consider %	29	27	30	44

Values are denoted as percentages or mean ± SD; MMSE, Mini-Mental State Examination; WRAT-3, Wide Range Achievement Test, 3rd Edition; Wilcoxon tests were used to compare means for continuous variables, and Pearson chi-square tests were used to compare frequency distribution of categorical variables, including gender and brain donation status;

* $p < 0.05$ significant difference from discussion group participants.

Table 3

Follow-up telephone interview discussion points

Most useful part of discussion group	Endorsement (%)	Excerpt
Historical Impact on Research Engagement	15	“Yes. It brought up issues and concern. It put things into perspective about past issues with African Americans, and make a case with family and friends about getting involved.”
Importance of Research & Impact on African American Health	30	“It impacted me very much. Until recently I was interested in how to recognize AD and learn more about what is was, but after my mother I got more interested in research. It’s important to get involved. It makes you think about [research].”
BU ADC Research Opportunities	15	“... there are so many opportunities to hook in to. I don’t know where to get started. They were helpful. I didn’t know there was so much here.”
Brain Donation Information	40	“I kind of liked the brain study program part because what I’m trying to do now is talk about this with my family, but they don’t want to keep talking to me about this. But right now I think it’s wonderful if someone can do that. It’s helpful to know that your body would not be exposed and that everything would be ok, you could still have the ceremony as normal.”

Examples are from unique participants from different discussion groups; Items are organized in order of how topics appeared in the discussion group protocol.

Table 4

Pre- and post-discussion survey outcomes

	Pre- discussion <i>n</i> = 30	Post- discussion <i>n</i> = 30
Brain Donation Knowledge	8.3 ± 1.9	8.7 ± 1.5
Factors Influencing Brain Donation Scale	7.9 ± 5.1	7.3 ± 5.0
Attitudes about Medical Research Scale	38.0 ± 4.6	37.6 ± 3.2
Trust in Medical Researchers Scale	33.6 ± 6.4	35.0 ± 4.6

Table 5

Pre- and post-discussion survey outcomes by brain donation group

	"Yes" brain donation n = 16		"Will consider" brain donation n = 7		"No" brain donation n = 7	
	Pre- discussion	Post- discussion	Pre- discussion	Post- discussion	Pre- discussion	Post- discussion
Brain Donation Knowledge Scale	9.2 ± 1.8 [‡]	9.1 ± 1.4	8.0 ± 1.5	8.0 ± 1.3	6.8 ± 1.4 ^{‡*}	8.2 ± 1.8 [*]
Factors Influencing Brain Donation Scale	9.5 ± 4.1 [‡]	8.0 ± 3.5	9.2 ± 5.5	10.0 ± 6.7	4.5 ± 5.4 [‡]	3.8 ± 3.9
Attitudes about Medical Research Scale	39.5 ± 3.6	38.3 ± 2.5	35.0 ± 6.7 [^]	36.7 ± 5.7 [^]	37.3 ± 3.5	37.1 ± 1.1
Trust in Medical Researchers Scale	34.0 ± 5.3	36.9 ± 4.5	31.4 ± 9.8	33.0 ± 5.2	37.8 ± 4.5	33.2 ± 2.6

[‡] significantly different at $p < 0.05$;[‡] significantly different at $p < 0.05$;^{*} significantly different at $p < 0.05$;[^] significantly different at $p < 0.05$.