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## Factors Associated With African-American and White Elders' Participation in a Brain Donation Program

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### Abstract

This study examined factors associated with brain donation program participation among African-American and White elders. By postal mail, participants were recruited from an Alzheimer's research registry (all of whom had been invited to participate in the Center's brain donation program) and asked to complete surveys assessing brain donation knowledge, trust in healthcare systems, and religiousness. African-American respondents completed a cultural mistrust inventory. Demographic, brain donation status, and literacy data (as assessed by the Wide Range Achievement Test-3 Reading subtest) were compiled from the respondents' most recent registry visit. The survey response rate was 60% (n=184 White and n=49 Black respondents). Logistic regression, comparing religiousness, trust in healthcare institutions, and educational attainment, identified a single predictor (ie, religiousness) in the prediction of donation status among White respondents ( $P=0.008$ ), whereas no predictors were observed for donation status among the Black respondents. Using all African-American donors and nondonors from the registry (n=68), comparisons revealed Wide Range Achievement Test-3 Reading score differences for African-American donors ( $46.8\pm 5.9$ ) and nondonors ( $42.8\pm 8.4$ ,  $P=0.02$ ). Results suggest that increased religiousness is related to White elders' decisions not to donate, whereas lower reading ability might be related to African-American participants' decisions not to donate.

### Keywords

African-American; brain donation; cultural mistrust; religiousness; research participation

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Alzheimer's disease (AD) is a major public health issue that affects Black individuals at higher rates than Whites,<sup>1</sup> and AD prevalence is expected to double among African-Americans age 65 years and over by 2030.<sup>2</sup> It is not well known why African-Americans are at increased risk for AD, but genetic and environmental factors have been purported.<sup>3,4</sup> Additional research focused on the clinical and neuropathological phenotype of AD in Black versus White elders is needed to determine if such racial disparities in AD are secondary to unique neuropathological profiles or neuropathological mechanisms. Unfortunately, African-Americans participate in brain donation research programs at lower rates than their White peers, and factors associated with African-American participation in brain donation programs are not well known.<sup>5</sup>

Barriers to clinical organ donation participation among African-Americans may provide important clues for factors associated with brain donation research program participation. Such barriers include general societal mistrust,<sup>6</sup> mistrust in healthcare institutions and physicians,<sup>6-9</sup> cultural mistrust,<sup>10,11</sup> lack of awareness about donation needs and benefits,<sup>12-14</sup> and religious beliefs.<sup>15</sup> To address an important knowledge gap regarding brain donation research program participation among Black elders, this study aimed to (1) compare Black and White elders on willingness to participate in a research-focused brain donation program, (2) compare Black and White elders' knowledge about brain donation procedures, (3) describe reasons African-American and White elders attribute to their brain donation program decision, and (4) relate trust in healthcare institutions, religiousness, and years of formal education to brain donation program participation among Black and White elders. As a secondary aim, we explore whether cultural mistrust or quality of education<sup>16-18</sup> among Black elders related to brain donation program participation.

## METHODS

### Study Participants

Participants were recruited from the Boston University Alzheimer's Disease Core Center (ADCC) research registry. The registry, which has been described in more detail elsewhere,<sup>19,20</sup> is a longitudinal research program that follows older adults annually with a medical history intake, informant interview, neurological examination, neuropsychological assessment, and consensus team diagnosis for cognitive status (eg, mild cognitive impairment,<sup>21,22</sup> AD23). Participants are then eligible for recruitment into ADCC-approved clinical research studies, including a brain donation program.

For the purposes of this study, all active Boston University ADCC registry participants were contacted via postal mail with a survey packet (n=464). Each survey packet was assigned a random identification number to preserve confidentiality in responses, and these packets were distributed with a cover letter from the ADCC Director explaining the survey goals, a consent statement, the survey materials described below, and a self-addressed stamped return envelope. To increase response rates, appointment reminder phone calls for annual registry visits were used to encourage interested participants to complete the survey before their visit. Registry participants were also queried about the receipt and completion of their survey during their annual study visit. To increase participation rates among African-Americans, personal phone calls were made to all African-American registry participants who did not return their survey within 30 days. The response rate was 60% with 280 final respondents. For this study, participants were excluded if they self-identified as something other than White or Black/African-American (n=2) and if someone other than the registry participant completed the surveys on behalf of the participant (eg, a spouse or care partner, n=45). These exclusions resulted in 233 participants for this study. The local Institutional Review Board approved the research before data collection.

### Measures

The survey mailing included several self-report instruments as described below:

1. The Registry Participation Satisfaction Survey covered basic demographic information and aspects of registry study participation, including motivation for research and brain donation participation, registry participation experience, and knowledge about brain donation program goals and procedures. All participants were asked to complete this survey.
2. The Intrinsic Religiousness Motivation Survey consisted of the 10-item Intrinsic Religious Motivation Scale<sup>24</sup> (eg, "Nothing is as important to me as serving God

as best I know how”) plus 3 questions from the Brief Multidimensional Measure of Religiosity/Spirituality<sup>25</sup> (eg, “To what extent do you consider yourself a religious person?”). Scores ranged from 11 (low levels of religiosity) to 55 (high levels of religiosity). All participants were asked to complete this survey.

3. The Healthcare System Distrust Scale<sup>26</sup> included 10-items measuring attitudes toward the healthcare system, including competence, confidentiality, honesty, and fidelity, as well as beliefs about healthcare system practices (eg, doing blood tests) and healthcare system motives (eg, holding costs down). Scores ranged from 10 (low levels of trust) to 50 (high levels of trust). All participants were asked to complete this survey.
4. The Cultural Mistrust Inventory<sup>27</sup> was administered to African-American participants only. The 48-item measure assesses the extent to which Blacks mistrust Whites. For this study, 26 questions from only 2 domains were included: (1) the Interpersonal Relations dimension (consisting of 14 questions with scores ranging from 0 to 126) was used to assess the way in which Black elders view their interpersonal relations with Whites, which might affect their willingness to participate in research that is lead primarily by White researchers and (2) the Politics/Law dimension (consisting of 12 questions with scores ranging from 0 to 108) was selected to assess the extent to which Black elders trust political and legal systems that are responsible for the establishment of ethical guidelines for research, which might affect their participation in a brain donation program. Higher scores indicated higher levels of cultural mistrust.

In addition to the survey mailing, variables collected from the annual registry visit were included in analyses, such as education level, brain donation status, length of time in the registry, and most recent performance on the Wide Range Achievement Test-3 (WRAT-3) Reading subtest,<sup>28</sup> a measure of reading achievement that has been associated with educational attainment<sup>29</sup> and education quality.<sup>16–18</sup>

## Data Analyses

Before analyses, prorated scores were calculated for each survey measure to account for missing responses while preserving the overall estimate of religiosity, healthcare system distrust, and cultural mistrust.<sup>30</sup> Specifically, missing items were assigned a prorated value that equaled the mean value across the remaining responses within that specific survey. Descriptive statistics were generated to compare demographic and clinical characteristics, including age, sex, education, length of time in registry (years), and brain donation status, first between survey respondents (n=280) and nonrespondents (n=184) and next between White (n=184) and African-American (n=49) respondents on the basis of exclusion criteria. Between-group (White, African-American) comparisons for individual items assessing brain donation knowledge were made using  $\chi^2$  analyses. Descriptive statistics were calculated to summarize reasons for donation decisions for donors and nondonors between the 2 racial groups. Next, using only respondents who were documented as donors or nondonors (ie, excluding the “will consider” participants, n=38), predictor variables assessing healthcare trust, religiosity, and education attainment were related to brain donation status (yes, no) via stepwise logistic regression, first for the White respondents and next for the African-American respondents. The logistic regression procedure was selected to balance predictive capability with model parsimony and to account for possible multicollinearity of the predictor variables. Finally, limiting the sample to the African-American survey respondents, post-hoc analyses related brain donation status (yes n=24, no n=14) to age, sex, education, WRAT-3 Reading subtest score, Cultural Mistrust Inventory—Interpersonal Relations dimension, Cultural Mistrust Inventory—Politics/Law dimension, length of time in registry, personal familiarity with AD, and items assessing brain donation knowledge. To

enhance power, post-hoc analyses were then expanded to include all active African-American registry participants who were donors ( $n=40$ ) or nondonors ( $n=28$ ), and between-group comparisons on the basis of brain donation status (yes, no) were made for age, sex, education, and WRAT-3 Reading subtest score.

## RESULTS

### Sample Characteristics

Survey respondents ( $n=280$ ) and nonrespondents ( $n=184$ ) were comparable for age ( $t=-0.2$ ,  $P=0.86$ ), race ( $\chi^2=2.4$ ,  $P=0.30$ ), and sex ( $\chi^2=1.0$ ,  $P=0.33$ ). However, respondents were significantly different from nonrespondents for years of education ( $t=4.5$ ,  $P=0.0001$ ), length of time in registry ( $t=6.6$ ,  $P=0.0001$ ), and brain donation status ( $\chi^2=8.0$ ,  $P=0.02$ ). Table 1 for between-group differences. When the sample was restricted to survey respondents on the basis of inclusion criteria for this study ( $n=226$ ), group differences emerged between the White and African-American participants for age ( $t=3.1$ ,  $P=0.002$ ), sex ( $\chi^2=9.1$ ,  $P=0.003$ ), education ( $t=2.5$ ,  $P=0.01$ ), number of years in the registry ( $t=3.3$ ,  $P=0.001$ ), and brain donation status ( $\chi^2=14.3$ ,  $P=0.001$ ). Table 2 for between-group differences.

### Between-group Comparisons for Brain Donation Knowledge

The 2 groups significantly differed in their responses to 2 questions about brain donation goals and procedures. Specifically, the African-American participants were more likely to believe that “most religions do not support brain donation” ( $\chi^2=6.1$ ,  $P=0.02$ ) and they were less likely to think that “to donate your brain to research, your memory abilities and everyday functioning must be evaluated before death” ( $\chi^2=6.0$ ,  $P=0.02$ ). Table 3 for frequency details.

### Respondent Reasons for Brain Donation Decision

Among brain donors, the most common reason attributed to donation status was to help researchers find a cure for AD, regardless of race (White respondents=95%, African-American respondents=91%); however, helping researchers enhance in-vivo diagnosis of AD was also rated highly (White respondents=80%, African-American respondents=86%). Again, regardless of race, the most common reason attributed to donation status among nondonors was that brain donation is too intrusive (White respondents=63%, African-American respondents=55%). Table 4 for frequency details.

### Brain Donation Status Predictors

Among the White respondents, stepwise logistic regression using both forward and backward stepwise procedures, using a likelihood ratio criterion for variable addition/deletion, selected a model with the Intrinsic Religiousness Motivation Survey Total Score as the single significant predictor for brain donation status among the White respondents ( $\beta=-0.08$ ,  $P=0.008$ ). That is, higher levels of intrinsic religiousness were associated with being a nondonor. Using similar procedures, no single significant predictor was identified for brain donation status among the African-American respondents.

### Comparisons Across African-American Brain Donation Status

Limiting the sample to the African-American survey respondents, post-hoc analyses comparing donors and nondonors revealed no differences for age ( $t=-1.20$ ,  $P=0.24$ ), sex ( $\chi^2=2.58$ ,  $P=0.11$ ), education ( $t=1.07$ ,  $P=0.29$ ), WRAT-3 Reading subtest score ( $t=-0.33$ ,  $P=0.74$ ), length of time in registry ( $t=-0.61$ ,  $P=0.55$ ), Cultural Mistrust Inventory Interpersonal Relations dimension ( $t=0.4$ ,  $P=0.97$ ), Cultural Mistrust Inventory Politics/Law dimension ( $t=-0.65$ ,  $P=0.52$ ), Intrinsic Religiousness Motivation ( $t=0.94$ ,  $P=-0.36$ ),

Healthcare System Distrust ( $t=-0.24$ ,  $P=0.82$ ), and personal familiarity with AD ( $\chi^2=0.10$ ,  $P=0.74$ ). Similarly, no significant between-group differences emerged for the brain donation knowledge questions (all  $P$  values  $>0.19$ ). Table 5 for descriptive statistics for each group.

Because of the null findings and concerns about insufficient power, post-hoc comparisons were made using the entire African-American registry cohort (ie, survey responders and nonresponders) but limiting the analyses to donors ( $n=40$ ) and nondonors ( $n=28$ ). Between-group comparisons revealed no differences for age ( $t=1.34$ ,  $P=0.19$ ), sex ( $\chi^2=1.7$ ,  $P=0.20$ ), education ( $t=-0.08$ ,  $P=0.94$ ), or length of time in registry ( $t=0.91$ ,  $P=0.37$ ). However, the 2 groups did differ on WRAT-3 Reading subtest scores ( $t=2.32$ ,  $P=0.02$ ), such that the donors had higher reading scores ( $46.8\pm 5.9$ ) than the nondonors ( $42.8\pm 8.4$ ). Table 6 for descriptive statistics for each group.

## DISCUSSION

This study aimed to better understand factors associated with brain donation program participation among African-American and White elders. Consistent with other published rates of commitment among autopsy-focused recruitment programs,<sup>31</sup> a disparity was observed for brain donation commitment between the 2 groups. Specifically, 75% of White elders in our research registry have consented to brain donation whereas  $<50\%$  of African-American elders have consented.

Regarding brain donation knowledge, African-American elders were more likely than their White peers to incorrectly respond that a memory evaluation was not necessary before brain donation and that most religions do not support brain donation. Such differences suggest that donation programs may benefit by providing prospective enrollees with more specific requirements for program participation (eg, to be part of the ADCC donation program, an annual evaluation is necessary to characterize memory and thinking abilities) and by clarifying conflicts between organ harvesting and most religious belief systems about organ donation (for a review on religion and autopsy, see Souder and Trojanowski<sup>32</sup>). In fact, prior research has shown that organ donation agreement is more likely when individuals believe that their religious leader will support their donation decision.<sup>33</sup> Therefore, integration of clergy in brain donation educational programs may be beneficial for bridging this gap.

Among nondonor respondents, both White and African-American participants selected intrusiveness as the primary reason accounting for their brain donation decision. However, consistent with prior work reporting the benefits of autopsy,<sup>34,35</sup> both White and African-American donors reported that helping researchers find a cure and helping researchers improve in-vivo diagnosis of AD were important factors in their decision to donate. Brain donation commitment rates may be improved by emphasizing the unique information gained from brain autopsy, including clinicopathological data for enhancing the in-vivo AD diagnosis as well as critical neuropathological data for identifying disease processes, both of which would not be possible through other research methods.

When implementing logistic regression to better understand how religiousness, trust in healthcare institutions, and education level related to donation status, religiousness was the only significant predictor of brain donation status among the White respondents, such that higher levels of intrinsic religiousness were associated with not being a brain donor. This observation is consistent with some of the organ donation literature,<sup>8,35,36</sup> as religiousness is associated with a decision not to donate one's organs,<sup>36</sup> and religious views may influence autopsy decisions among elders.<sup>35</sup> In addition, prior research has suggested that Whites, but



not African-Americans, refer to religiousness as a reason for opposing organ donation.<sup>8</sup> Replication in larger samples is needed to confirm our finding.

Though prior research has reported that African-Americans cite issues around mistrust of healthcare institutions for opposing organ donation,<sup>8</sup> this study found no significant predictor (including religiousness, trust in healthcare institutions, or education) for brain donation status among the African-American respondents. The null finding may be due insufficient power (ie, too few African-American survey respondents), use of measures that lacked sensitivity in assessing factors associated with lower donation rates (eg, cultural mistrust), or a priori selection of predictors that inadequately captured reasons for donation status (eg, focusing on education or religiousness).

In the absence of any significant predictors associated with donation status among the African-American respondents, post-hoc analyses were conducted for the African-American respondents to explore possible differences between donors and nondonors. Again, these analyses yielded limited information, as the 2 groups did not differ on demographic variables (ie, age, sex, education level), reading ability (as assessed by the WRAT-3 Reading test), dimensions of cultural mistrust, personal familiarity with AD, length of time in the research registry, or brain donation knowledge. Because of power concerns within this small subset of respondents, these comparisons were repeated for a slightly larger sample (ie, all active African-American participants in the registry) combining information available from the survey (ie, age, education, sex) and from the most recent registry visit (ie, WRAT-3 Reading test). With the larger sample, post-hoc comparisons revealed that African-American nondonors had significantly lower WRAT-3 Reading test scores than donors. The WRAT-3 Reading test is a measure of reading ability that is associated with education quality.<sup>16–18</sup> It has been related to health literacy<sup>37</sup> or the degree to which one is able to gather, process, and understand relevant health information to make an appropriate health-related decision. Though replication is needed, this preliminary finding suggests that among African-American elders, lower levels of reading ability and education quality may impact understanding the complexities of brain donation and its contribution to research on the prevention, diagnosis, and treatment of AD.

This study is among the first to examine factors associated with brain donation<sup>5</sup> and emphasizes factors related to racial disparities in a brain donation research program in which individuals are making donation decisions for themselves (versus for a loved one with dementia). Overall, the current findings extend prior research in several ways. First, this study provides some insight on the religiousness/research participation literature by examining racial diversity and demonstrating that religiousness is relevant to White elders' decisions to participate in brain donation programs but perhaps less relevant to African-American elders' decisions. Second, we have identified that reading ability (or education quality) may be related to African-American participants' decisions not to donate their brain, an important factor when developing and implementing brain donation programs and materials. Finally, based on self-report, we have demonstrated that nondonors, regardless of race, attribute their decision to the invasiveness of donation, whereas donors, regardless of race, attribute their decision to the desire to help researchers find a cure and improve the clinical diagnosis of AD.

This study has a number of strengths, including the strong survey response rate (ie, 60%), the comprehensive survey measures that were theoretically selected a priori for comparison to brain donation status, and the combination of quantitative and qualitative data collected. However, a number of limitations should be considered when interpreting the results, including insufficient power to detect possible effects, particularly among African-American respondents, as well as limitations inherent to survey research. Specifically, the self-

reporting nature of data collection might have limited information obtained (compared with individual administration) and certain survey questions may have presented some conceptual ambiguity, making them difficult for participants to understand and respond appropriately. We also cannot assume that the survey nonrespondents and respondents were similar, which was supported by our descriptive comparisons suggesting that the respondents were more educated, had participated in the registry longer, and were more likely to be brain donors than the nonrespondents. Finally, the respondents may reflect those who felt predominantly positive or negative about the research registry and were therefore motivated to respond, particularly in light of the fact that the respondents had been evaluated in the research registry an average of 4 or more times, which may have limited the generalizability of the results.

Future directions include qualitative studies of brain donation program participation among African-Americans, as many factors associated with organ donation or clinical research participation (eg, cultural mistrust, mistrust in healthcare institutions) may be more sensitively assessed through qualitative interviews.<sup>35</sup> Future studies should also develop a more comprehensive brain donation knowledge test that extends beyond the basic procedural elements of brain donation to include potential benefits of donation and other factors related to donation. Finally, additional work is needed to create and evaluate interventions aimed at increasing brain donation participation, particularly among African-American older adults.

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**TABLE 1**

## Sample Characteristics by Responder Status

	Survey Responders, n=280	Survey Nonresponders, n=184	P
Age (y)	75.8±8.5	75.9±8.2	0.86
Sex, % female	60	55	0.33
Race, % White	80	74	0.30
Education (y)	15.9±3.1	14.6±3.0	0.00001
Length in registry (y)	4.9±1.8	3.7±2.0	0.00001
Brain donation status, % yes	69	56	0.02

**TABLE 2**

## Respondent Characteristics by Race

	White, n=184	African-American, n=49	P
Age (y)	76.2±7.8	72.2±8.7	0.02
Sex, % female	56	80	0.003
Education (y)	16.4±3.1	15.2±2.7	0.01
Length in registry (y)	5.2±1.8	4.3±1.4	0.001
Brain donation status, % yes	75	49	0.001

**TABLE 3**

## Between-group Brain Donation Knowledge Items

	White, n=184	African-American, n=49	P
Open casket funeral is possible (true)	95	89	0.16
Religions do not support brain donation (false)	93	79	0.03
Brain donation requires memory problems (false)	96	91	0.27
Family pays for the diagnosis (false)	100	98	0.21
You cannot change your mind about brain donation (false)	99	96	0.11
Brain donation requires evaluation before death (true)	90	77	0.02

Values reflect % correct in responding to knowledge item; accuracy of responses is based on the ADCC brain donation program policy (eg, brain donation at the ADCC does require evaluation before death).

ADCC indicates Alzheimer's Disease Core Center.

**TABLE 4****Reasons for Brain Donation Decision by Race**

	White, n=138	African-American, n=24
Reasons for agreeing to donate one's brain...		
To help researchers find a cure for AD	95	91
To help researchers diagnose AD before death	80	86
I would like my family to know whether I definitely had AD or a related disorder	47	48
Reasons for not agreeing to donate one's brain...		
I have not been asked to donate my brain	6	18
Brain donation is too intrusive	63	55
I do not know what brain donation requires	13	18
I do not have memory problems	25	18

Frequency data exclude participants with "will consider" brain donation status, including n=27 White and n=11 African-American participants; response categories were prefixed and respondents were asked to check all that applied.

AD indicates Alzheimer disease.

TABLE 5

## African-American Donor Versus Nondonor Comparisons

	African-American Donors, n=24	African-American Nondonors, n=14	P
Age (y)	73.5±8.2	70.1±8.3	0.24
Sex, % female	71	93	0.11
Education (y)	14.8±1.9	15.8±3.8	0.29
WRAT-3 Reading subtest, total	48.3±5.1	47.7±5.4	0.74
Length of time in registry (y)	4.6±1.5	4.3±1.3	0.55
Personal familiarity with Alzheimer disease, % yes	63	57	0.74
Intrinsic Religiousness Motivation Survey, total	35.7±10.7	38.9±7.2	0.36
Healthcare System Distrust, total	32.7±5.0	32.3±5.2	0.82
Cultural Mistrust Survey-Politics/Law Dimension, total*	58.3±13.8	54.9±15.5	0.66
Cultural Mistrust Survey-Interpersonal Relations Dimension, total*	84.1±10.8	84.2±13.9	0.97
Open casket funeral is possible, % correct	83	93	0.38
Religions support brain donation, % correct	75	78	0.87
Brain donation requires memory problems, % correct	86	93	0.55
Family pays for the diagnosis, % correct	100	100	—
You cannot change your mind about brain donation, % correct	100	93	0.19
Brain donation requires evaluation before death, % correct	78	79	0.98

\* Nine fewer participants completed the Cultural Mistrust Survey, so analyses were conducted using 17 donors and 12 nondonors.

WRAT indicates Wide Range Achievement Test.



**TABLE 6**

## African-American Donor Versus Nondonor Comparisons For the Entire Registry

	African-American Donors, n=40	African-American Nondonors, n=28	<i>P</i>
Age (y)	73.8±8.1	71.2±7.6	0.19
Sex, % female	73	86	0.20
Education (y)	13.8±2.5	13.9±3.4	0.94
WRAT-3 Reading subtest, total	46.8±5.9	42.8±8.4	0.02
Length of time in registry (y)	4.2±1.6	3.9±1.6	0.37

WRAT indicates Wide Range Achievement Test.