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Willingness to be a brain donor: A survey of research volunteers from four racial/ethnic groups

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Abstract

Introduction—Racial and ethnic groups are under-represented among research subjects who assent to brain donation in Alzheimer's disease research studies. There has been little research on this important topic. While there are some studies that have investigated the barriers to brain

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donation among African American study volunteers, there is no known research on the factors that influence whether or not Asians or Latinos are willing to donate their brains for research.

Methods—African American, Caucasian, Asian, and Latino research volunteers were surveyed at fifteen Alzheimer's Disease Centers to identify predictors of willingness to assent to brain donation.

Results—Positive predictors included older age, Latino ethnicity, understanding of how the brain is used by researchers, and understanding of what participants need to do to ensure that their brain will be donated. Negative predictors included African/African American race, belief that the body should remain whole at burial, and concern that researchers might not be respectful of the body during autopsy.

Discussion—The predictive factors identified in this study may be useful for researchers seeking to increase participation of diverse ethnic groups in brain donation.

Keywords

brain; Alzheimer's; research; autopsy; subjects; ethnicity

1. Introduction

Postmortem study of the human brain is a critical component of longitudinal research on neurodegenerative conditions such as Alzheimer's disease and other dementias. For patients and research subjects who have been followed over an extended period while living, brain autopsy provides valuable data for studying underlying causes of dementia, for establishing and verifying prevalence estimates of clinically diagnosed disease, and for uncovering risk factors or associations with disease states.[1] Despite its importance, only a portion of the brains of study volunteers in Alzheimer's disease research programs come to autopsy when subjects die. Data from the National Alzheimer's Coordinating Center (NACC), the repository for data for NIH-funded Alzheimer's Research Centers, showed that for the 4552 recorded deaths among the 32 research centers that participated in the Uniform Data System (UDS) of the NACC between September 2005 and June 2013, only 62.8% percent had autopsies completed.[2] The proportion of autopsies for non-white subjects has been even lower[3], thus reducing the opportunities to study the unique neuropathological aspects of brain function among ethnic groups.

Since the 1990's, researchers have investigated factors associated with brain donation for volunteers in Alzheimer's disease research programs. Other studies, mostly involving African Americans have identified concerns about the effects of brain removal on the physical appearance of the body[4,5], religious beliefs[5,6], attitudes of family members[4,6], and the lack of understanding about the rationale for brain autopsy[4,6] as barriers to assenting to brain donation. While no prior studies have examined attitudes among Hispanic or Asian Americans towards brain donation, studies of attitudes towards research in general suggest that culturally-shaped values and beliefs may influence willingness to participate in Alzheimer's research or to be a brain donor. For example, in one study Chinese Americans expressed concerns that participating in research might be harmful for a cognitively impaired person.[7] It has also been reported that in Chinese culture, it is believed that when a

person dies, one's body should remain whole, presumably creating a barrier to brain donation.[8] Studies have also found that Asians and Latinos often hold family-centered values ("familismo") around medical decision-making.[9–11] The dispersal of decision-making among multiple family members may hinder a study volunteer's consideration about donating his or her brain.

The aim of this study is to identify predictors of willingness to assent to brain donation for research volunteers from four racial/ethnic groups, African American, Caucasian, Asian, and Latino. The survey was carried out in fifteen NIA-funded Alzheimer's Disease Centers (ADCs). We hypothesized from our prior qualitative research[12] and from a review of the literature that factors in four domains would predict a research subject's willingness to assent to brain donation. These factors include the subject's personal characteristics; religious beliefs and practices; family attitudes and support for brain donation; and experience, knowledge and concerns of study volunteers about participating in research.

2. Methods

2.1. Sample

The sample for this study included non-demented research volunteers in one or more studies at fifteen NIH-funded Alzheimer's Disease Centers (ADCs). Only subjects participating in studies that did not require assent to brain donation as a condition of participation were surveyed. Participants were recruited by each collaborating center without regard to whether they had or had not signed assent to serve as a brain donor. A variety of recruitment methods were used in order to capture the greatest number of respondents. These included having the volunteer complete the survey in writing as part of their regular research assessment visit, mailing the survey to eligible research volunteers with phone follow-up as needed, and completing the survey through face-to-face interviews. By design, minorities were oversampled. The recruitment and implementation process was approved by the OHSU Institutional Review Board and the Institutional Review Board at the institution where subjects were recruited.

2.2 Survey development

The survey developed for this study includes questions on a range of factors developed through a multi-step process by co-investigators and research staff of four collaborating Alzheimer's Disease Centers. It was designed to address the themes and concerns identified from focus groups conducted with African American, Chinese, Latino and White donor and non-donor research subjects and their family members from these centers to explore their beliefs and attitudes about brain donation.[12] The themes identified in the focus groups included: family participation in decision making and their support for brain donation; religious practice, beliefs, and funeral arrangements; and factors related to study volunteers' experience, knowledge and concerns about participating in research and brain donation.

Factors related to family included the family member research subjects would most likely discuss brain donation with and whether that person was supportive, whether family members would have difficulty carrying out their wishes for brain donation (if they agreed to

brain donation), whether the respondent believes donating one's brain is mostly an individual or family decision. Religious characteristics included primary religious affiliation, frequency of attendance at religious services, and the extent to which religion influenced the respondent's thinking about brain donation. To measure respondents' religiosity, they were asked to locate themselves on a continuum from 1, "strongly agree", to 7, "strongly disagree" (reverse coded for analysis) on the following statement, "I consider myself to be a religious person." The same response options were used to rate their spirituality. Questions were also asked about beliefs and plans related to funeral arrangements, including whether the respondent had made arrangements for burial or cremation; whether they expected to have an open or closed casket, a memorial service only, or no service at all; and if they were concerned that a brain autopsy might affect the appearance of their body.

Respondents' experience, knowledge and concerns about participating in Alzheimer's disease research were assessed using a series of questions that asked whether the respondent was concerned that researchers would not be respectful of their body, the extent to which they or their family members trust medical researchers, whether it would be helpful to have a clerical representative come to the center to discuss brain donation, and whether having more information about brain donation would be helpful for making a decision about brain donation. To assess understanding about the rationale for and process of brain donation, respondents were asked five questions ("yes" or "no") of whether or not they understood "… how study of the brain is important for research on Alzheimer's", "…what researchers do with the brain", "…how the researchers will remove the brain", "…what one needs to do ahead of time to make sure the brain is donated after a person dies" and "…the difference between brain donation for research and donation of other organs for patients in need."

The survey also gathered data on personal characteristics including age, gender, preferred language (English, Spanish, Chinese or other), country of birth, living arrangement, household finances ("have enough financial resources to do the things we want to do", "mostly have enough financial resources to do the things we want to do" and "barely have enough money to take care of our needs") and race/ethnicity (Latino, Hispanic; Chinese or other Asian; African or African American; Non-Hispanic White). An additional data collection form was created to collect information from the center's data base where the respondent was a research subject. These data included years of education, cognitive status (normal, mild cognitive impairment (MCI), or other non-dementia condition affecting cognition), Clinical Dementia Rating[13] score (0 or 0.5), and whether the subject had signed assent to brain donation.

The dependent variable used for analysis was the following question asked in the survey: "Whether or not you have been asked, how likely are you to donate your brain for research when you die." Respondents were asked to pick one of five options: "Definitely not likely to donate my brain", "Probably will not donate my brain", "possibly will donate my brain," "probably will donate my brain", and "definitely will or already have agreed to donate my brain."

The survey questions were written, reviewed, and refined by the study co-investigators and their research assistants and associates. The survey draft was reviewed by an expert in

multicultural survey development (C. Nicolaidis, MD, January & March 2012) who advised the team on the organization, response options, and wording of survey questions to improve their appropriateness for persons from diverse ethnic groups. The survey was then pretested with four research subjects (two African American and two white), two Latino research assistants, and a Chinese research assistant. The survey was then refined to ensure language appropriateness and clarity, and the number of questions was reduced to minimize the time required for completion.

After the survey was finalized in English, it was translated into Mandarin Chinese and Spanish with consultation from C. Nicolaidis (March 2012) on best practices for translation. The Chinese version of the survey was translated by a professional translator who worked in a community service organization serving Chinese immigrants and back-translated to identify semantic discrepancies between the translated and the original English versions. Discrepancies were then reconciled. The Spanish version of the survey was translated by a native Spanish speaker from a professional translation service. Education level and cultural origin were expected to be varied for this group, so the translator used language that would be suited to a broad audience. Back translation was provided by a second professional translator at the same translation service. Discrepancies between the English survey and the back translated version were reviewed and reconciled by a Spanish instructor at the university of this study's principal investigator. The survey was also reviewed by bilingual research staff of the collaborating center for language appropriateness for the population from which the Latino study subjects was drawn.

2.3. Analysis

Descriptive data (means and standard deviations and frequencies) are provided for personal characteristics. Chi-square and t-tests were used to compare those likely to donate their brain with those not likely to donate. To define "willingness to donate one's brain", a dichotomized dependent variable defined donors (scored 1) as those who checked that they "definitely will or already have agreed to donate my brain" or "probably will donate my brain" and non-donors (scored 0) as those who responded that they "possibly will donate my brain", "probably will not donate my brain", and "definitely will not donate my brain." The factors considered in bivariate analysis are grouped into four categories: a) personal characteristics, b) family communication, agreement and support, c) religion, funeral arrangements, and beliefs related to handling of the body at death, and d) experience with research including length of study participation, preferences for discussing brain donation with researchers or staff, and knowledge and concerns about brain donation. Most of the independent variables were dichotomized into binary variables. Student's t-tests or Wilcoxon Rank Sum Test were used as appropriate to compare ordinal and continuous variables with multiple response options.

Significant variables in the bivariate analysis were then used in logistic regression to evaluate five models for predicting willingness to donate one's brain for research: Model 1) baseline personal characteristics including ethnic group measured as dichotomous variables with white as the reference, Model 2) baseline variables plus variables representing religious factors, Model 3) baseline variables plus factors related to family involvement in decision-

making about brain donation, and Model 4) baseline variables plus factors related to the respondents' experience in, attitudes, and understanding about brain donation. The final model included baseline variables and those that were significant in Models 2 through 4. All models showed adequate fit using Hosmer & Lemeshow goodness-of-fit test statistic. Analyses were performed using SAS software 9.3®.

3. Results

Data from 479 respondents were included in the analysis. Of these, 185 were non-Hispanic whites, 169 were African Americans, 50 were Asian (all but two were Chinese), and 61 were Hispanic. Thirty-one (51%) of the Hispanic respondents completed the survey in Spanish and 16 (32%) of the Asian participants completed the survey in Chinese. Other personal characteristics are reported in Table 1. Most of the survey respondents were likely brain donors: 49% reported that they definitely would donate their brains for research when they die or already had agreed to do so. An additional 14% reported that they "probably will" donate their brain bringing the "donor" group to 63%. Thirty-seven percent were classified as non-donors. This group included 19% of the sample who reported that they "possibly will" donate their brain, 10% reported that they "probably will not", and the remainder, 8%, reported that they definitely were not likely to donate their brain.

3.1. Comparison of donors and non-donors

Table 2 reports the bivariate analyses comparing donors and non-donors. Most of the factors analyzed were significantly different for donors and non-donors. Of particular note are the differences among the four ethnic groups, especially with respect to white and African/African American in their receptivity to brain donation. Religious affiliation and factors related to funeral plans were also highly significant. The family's involvement in and supportiveness of brain donation were also strongly significant as were respondents' understanding about and concerns related to the research purpose and process of brain donation.

3.2. Multivariate analyses

Variables included in the logistic regression models (Table 3) were selected from among significant variables in the bivariate analyses that best represented the model-specific domains. The baseline model, including racial/ethnic group, is reported in Model 1. Older age was a significant predictor of willingness to donate. Being African or African American (compared with being white), Asian, and living alone were negative predictors of willingness to donate. In Model 2, we fit the baseline model and religion variables. Significant variables included plans for cremation, which was a positive predictor of willingness to donate one's brain, and belief that the body should remain whole, which was a negative predictor. Of the family-related variables considered in Model 3, discussing brain donation with a spouse was not significant but having a supportive confidant regardless of the relationship was a strong predictor of willingness to donate one's brain. Also, belief that brain donation is a personal rather than a family decision was a predictor of willingness to donate one's brain. Of the research-related variables om Model 4, a significant negative factor was concern that researchers would not be respectful. Significant positive factors were

reported understanding of what researchers will do with the brain and what to do ahead of time to make sure the brain is donated after they die. A desire to have more information about brain donation was not a predictor of willingness to donate.

We entered into the final model all baseline variables, including race/ethnicity, and those variables in each of the four additional hypothesized domains that were significant predictors in the prior models. As with all prior models, African American ethnicity was a significant negative predictor of willingness to donate one's brain. Although not significant in the four prior models, Latino ethnicity was a positive predictor of willingness to donate in the final model. Older age remained a significant predictor. In the religion domain, the only significant variable was the belief that the body should remain whole which was a negative predictor. For the family related variables, having a supportive confidant was a strong predictor of willingness to donate. Concern that researchers will not be respectful was a strong negative predictor of willingness to donate while understanding about what researchers will do with the brain and what the subject needs to do ahead of time were positive predictors of willingness to donate one's brain.

4. Discussion

This study fills a critical gap in understanding of factors that influence research subjects from diverse ethnic groups to assent to brain donation. Our findings support our hypotheses that factors from four domains predict willingness to be a brain donor. However, while many of the factors investigated were significantly associated with willingness to donate one's brain in the bivariate analysis, when entered into multivariate logistic regression, the number of factors that remained significant was reduced. In the final model, significant positive predictors were age, Latino ethnicity, understanding of how the brain is used by researchers and what subjects need to do to ensure that their brain will be donated. The relationship between older age and willingness to donate one's brain may be due to the association of age with the length of time respondents had participated in research. This is suggested by the non-significance of age in Model 4 which included years followed, allowing for shared variance between these two variables. An alternative interpretation is that older respondents may have had the opportunity for greater reflection about the ending of their lives, may be more comfortable considering the ultimate disposition of their bodies, and/or may be more decisive about and open to brain donation. The first interpretation (along with the correlation of age and length of duration as a study volunteer) is supported by Schnieders et al.[14] who found that longer term enrollment as a study volunteers was associated with greater likelihood of agreeing to brain donation. The reason behind the significance of Latino ethnicity as a predictor of willingness to donate one's brain is unclear, especially since this relationship was not significant in the baseline model or the subsequent domain-specific models. One possible explanation is suggested by a study of Hispanics and African Americans living in Los Angeles, which found that health and healthcare information were important motivators for research participation for Hispanics.[15] Whether the Centers in this study offered unique education and/or informational programs for their Hispanic research volunteers in ways that gained their openness to brain donation is unclear but worthy of further exploration. Information and education about the essential role of brain autopsy in

longitudinal Alzheimer's research may well support the goal of increasing the number of brain donors especially for Latinos but for other ethnic groups as well.

Negative predictors were African/African American ethnicity, belief that the body should remain whole, and concern that researchers might not be respectful of the body when performing autopsy. Of particular note is the significance of African/African American ethnicity as a predictor of unwillingness to donate one's brain in all five regression models. This finding is consistent with prior research that has found that African Americans often express high degrees of mistrust in researchers[6,16,17] and are acutely aware of the unethical treatment afforded members of their race in past research.[18] In contrast to our findings for African/African Americans, we found an unstable relationship between Asian ethnicity and willingness to donate one's brain. Although being Asian was associated with being a non-donor in the baseline logistic regression (Model 1), this relationship was not sustained when variables in the hypothesized domains were included in the models nor in the final model. This suggests that factors related to religious beliefs, family dynamics, and research knowledge and concerns moderate the relationship between being Asian and willingness to be a brain donor. This moderating effect may be related to our findings in prior qualitative research in which we found that Chinese research volunteers and their family members often expressed the desire for the body to remain whole after one dies and the high value the Chinese participants placed on family decision-making around brain donation.[14] In contrast to our findings with respect to Asian ethnicity, we found that Hispanic ethnicity was only associated with willingness to be a brain donor in the final model and this association was positive. Further research is needed to more fully explicate the factors that influence the receptivity of these and other ethnic groups to brain donation.

Our findings provide clues to strategies for increasing brain donation of enrolled or potential study volunteers. While some factors, such as the belief that one's body remain whole may not be feasible and/or ethically appropriate to attempt to modify, other factors such as uncomfortable attitudes of close family members and concerns that researchers might not be respectful may be amenable to change through education and other communications. Providing opportunities to learn about the research being conducted and to meet researchers in informal settings may be valuable strategies for improving autopsy rates.

There are several important limitations to this study. First, the respondents represented subjects already participating in clinical Alzheimer's disease research; thus the results cannot be generalized to the larger community of potential research volunteers. Second, respondents in this study were not drawn from a random sample. Bias may have been introduced in several ways: first, recruitment processes of subjects varied with some centers inviting completion of the survey when they came into the clinic for a regularly scheduled study visit and others mailing the surveys to eligible research volunteers; second, we asked some centers to recruit only from specific ethnic groups in order to increase the number of respondents from these groups; third, eligibility criteria for studies within centers varied, introducing further potential for bias. Thus, it was not possible to determine a response rate for survey respondents. Additionally, willingness to complete the survey may have been biased towards subjects who held more or less positive views on brain donation. Despite its limitations, this study offers valuable insights into the factors that influence research

volunteers to agree or not to agree to brain donation particularly among Asian, Latino and Caucasian subjects for which there has been little prior research. Further exploration will increase our understanding of how these factors differentially influence study volunteers and may yield ideas for more effective approaches to working with dementia research volunteers from diverse racial and ethnic groups.

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Table 1

Demographic and clinical characteristics of survey participants (n=479). Data from continuous variables is presented as mean ± standard deviation and data from categorical variables is presented as number (%).

Variable	Mean ± SD or Number (%)
Age (yrs)	74.7 ± 8.8
Female	323 (69%)
Education (yrs)	15.2 ± 3.6
Race/Ethnicity (n=465)	
Non-Hispanic white	185 (40%)
African American	169 (36%)
Latino, Hispanic	61 (13%)
Chinese, Asian[a]	50 (11%)
Duration of follow-up (yrs.)	6.2 ± 5.1
Cognitively Impaired (MCI)	134 (29%)
Living Alone	173 (37%)
Religious affiliation (n=464)	
Christian - Catholic	92 (20%)
Christian - Protestant	221 (48%)
Christian - Unknown	42 (6%)
Jewish	29 (7%)
Other Religion	7 (2%)
No Affiliation	73 (16%)
Household finances: Have enough resources to do the things we want to do	231 (50%)

[a]All but two Asian respondents were Chinese

Table 2

Likelihood to donate brain according to participant characteristics and survey responses. Continuous variables are compared using t-tests and categorical variables using chi-square tests.

	Not likely to donate brain (n=178)	Likely to donate brain (n=301)	p-value
Variables	**Mean ± SD or Number (%)**	**Mean (SD) or Number (%)**	
Participant characteristics			
Age, yrs (Range: 48 – 99)	73.3 ± 8.9	75.5 ± 8.6	<0.01**
Female	129 (75%)	194 (66%)	0.047*
Education (yrs)	15.0 ± 3.4	15.3 ± 3.7	0.37
Living Alone	78 (45%)	95 (32%)	<0.01**
Household finances (Enough resources)	76 (45%)	155 (53%)	0.08
Cognitive impairment	53 (30%)	81 (28%)	0.59
Race/ethnicity			
White	41 (24%)	144 (49%)	<0.0001***
Black	96 (55%)	73 (25%)	
Hispanic	14 (8%)	47 (16%)	
Asian	22 (13%)	28 (10%)	
Family			
Most likely to discuss with spouse	53 (30%)	153 (51%)	<0.0001***
Most likely to discuss with child	86 (48%)	117 (39%)	0.04*
Person most likely to talk to is supportive of decision	45 (30%)	213 (75%)	<0.0001***
Donation is mostly a personal decision vs. family decision	132 (76%)	262 (88%)	<0.001**
Family will not have difficulty carrying out your wishes after death	44 (34%)	224 (77%)	<0.0001***
Family members trusts medical researchers	65 (38%)	150 (52%)	<0.01**
Religion			
Religious affiliation			
Christian- Catholic	22 (13%)	70 (24%)	<0.0001***
Christian - Protestant	115 (66%)	148 (51%)	
Jewish	14 (8%)	15 (5%)	
Other Religion	6 (3%)	1 (<1%)	
No Affiliation	16 (9%)	57 (20%)	
Church attendance at least weekly	91 (58%)	116 (49%)	0.09
Religiosity (Scale 1 – 7)	5.3 ± 2.1	4.3 ± 2.5	<0.0001***
Spirituality (Scale 1 – 7)	5.7 ± 1.9	5.3 ± 2.1	0.04*
Arranged for cremation vs. not	32 (19%)	103 (36%)	<0.001**
Body should remain whole	58 (33%)	18 (6%)	<0.0001***
Plans for open casket vs. none	62 (35%)	49 (16%)	<0.0001***

	Not likely to donate brain (n=178)	Likely to donate brain (n=301)	p-value
Variables	**Mean ± SD or Number (%)**	**Mean (SD) or Number (%)**	
Research experience, knowledge & concerns			
Duration of follow-up, yrs	5.1 ± 4.3	6.9 ± 5.4	<0.0001***
Asked by staff to donate brain	105 (63%)	254 (87%)	<0.0001***
Heard a presentation on brain donation	28 (16%)	83 (29%)	<0.01**
Primary reason for research participation is to help future generations	95 (55%)	210 (70%)	<0.01**
Prefer a researcher/doctor ask me about donating vs. an RA	97 (85%)	192 (83%)	0.70
It makes a difference who asks me about donating	49 (30%)	54 (21%)	0.03*
Do you understand…			
..how study of brain is important for research on AD?	145 (88%)	273 (93%)	0.14
..what researchers will do with brain?	50 (31%)	143 (55%)	<0.0001***
..how researchers will remove brain?	37 (22%)	98 (35%)	<0.01**
..what one needs to do ahead of time?	57 (35%)	185 (65%)	<0.0001***
..difference between brain donation for research and donation of other organs for patients in need?	66 (42%)	191 (68%)	<0.0001***
More info would be helpful	84 (49%)	93 (32%)	<0.001**
Inviting clergy go talk about brain donation would be helpful	21 (12%)	32 (11%)	0.71
Concern about body's appearance after autopsy	42 (25%)	16 (5%)	<0.0001***
Concern researchers will not be respectful	70 (41%)	41 (14%)	<0.0001***
Trust medical researchers	125 (71%)	259 (88%)	<0.0001***

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Table 3

Multivariate logistic regression models relating predictors to willingness to donate brain. Results are presented as odds ratios (OR) and 95% confidence intervals (CI).

Variables	Model 1 Demographics only OR (95% CI)	Model 2 Demographics + Religion OR (95% CI)	Model 3 Demographics + Family OR (95% CI)	Model 4 Demographics + Research knowledge & concerns OR (95% CI)	Model 5 Demographics + significant covariates OR (95% CI)
Demographics					
Age, yrs	**1.03 (1.01 – 1.06)**	**1.06 (1.02 – 1.10)**	**1.03 (1.00 – 1.07)**	1.03 (0.99 – 1.07)	**1.06 (1.02 – 1.11)**
Female vs. Male	0.98 (0.61 – 1.59)	0.87 (0.44 – 1.74)	0.66 (0.35 – 1.25)	0.70 (0.38 – 1.30)	0.50 (0.23 – 1.06)
Living alone vs. not alone	**0.62 (0.40 – 0.98)**	**0.53 (0.29 – 0.99)**	0.80 (0.41 – 1.56)	**0.56 (0.31 – 0.98)**	0.51 (0.25 – 1.04)
Race/ethnicity					
White	reference	reference	reference	reference	Reference
Black	**0.25 (0.15 – 0.40)**	**0.28 (0.14 – 0.56)**	**0.34 (0.18 – 0.62)**	**0.41 (0.21 – 0.80)**	**0.41 (0.19 – 0.85)**
Hispanic	0.96 (0.48 – 1.94)	1.01 (0.36 – 2.84)	1.87 (0.73 – 4.83)	1.73 (0.75 – 4.01)	**3.38 (1.12 – 10.21)**
Asian	**0.39 (0.20 – 0.77)**	0.68 (0.25 – 1.82)	0.60 (0.26 – 1.40)	0.85 (0.34 – 2.09)	0.77 (0.29 – 2.05)
Religion					
Catholic Religion vs. other	--	1.68 (0.73 – 3.91)	--	--	--
Arranged for cremation vs. not	--	**2.32 (1.13 – 4.73)**	--	--	1.53 (0.73 – 3.21)
Body should remain whole	--	**0.12 (0.06 – 0.27)**	--	--	**0.24 (0.10 – 0.60)**
Plans for open casket vs. none	--	1.06 (0.54 – 2.07)	--	--	--
Religiosity	--	0.91 (0.80 – 1.03)	--	--	--
Family					

Variables	Model 1 Demographics only OR (95% CI)	Model 2 Demographics + Religion OR (95% CI)	Model 3 Demographics + Family OR (95% CI)	Model 4 Demographics + Research knowledge & concerns OR (95% CI)	Model 5 Demographics + significant covariates OR (95% CI)
Most likely to discuss with spouse vs. not	--	--	1.23 (0.60 – 2.52)	--	--
Supportive person vs. no	--	--	**6.60 (3.83 – 11.35)**	--	**5.70 (3.00 – 10.85)**
Donation is mostly a personal decision vs. family decision	--	--	**1.90 (1.04 – 3.50)**	--	1.05 (0.48 – 2.26)
Family trusts medical researchers vs. no	--	--	0.91 (0.53 – 1.56)	--	--
Research knowledge & concerns					
Years followed at ADC	--	--	--	1.04 (0.98 – 1.11)	--
Primary reason for participating in research:					
To help future generations	--	--	--	1.68 (0.99 – 2.85)	--
Concern about body's appearance	--	--	--	0.48 (0.20 – 1.13)	--
Concern researchers will not be respectful	--	--	--	**0.36 (0.19 – 0.70)**	**0.27 (0.14 – 0.54)**
Trust medical researchers	--	--	--	1.52 (0.79 – 2.92)	--
Understand what researchers will do with brain	--	--	--	**2.01 (1.12 – 3.62)**	**2.20 (1.14 – 4.24)**

Variables	Model 1 Demographics only OR (95% CI)	Model 2 Demographics + Religion OR (95% CI)	Model 3 Demographics + Family OR (95% CI)	Model 4 Demographics + Research knowledge & concerns OR (95% CI)	Model 5 Demographics + significant covariates OR (95% CI)
Understand what to do ahead of time	--	--	--	**2.22 (1.25 – 3.96)**	**2.19 (1.13 – 4.24)**
More info would be helpful	--	--	--	0.94 (0.55 – 1.62)	--