

# Ethnic Differences Among Research Subjects in Willingness to Assent to Brain Donation



**A NATIONAL ALZHEIMER'S  
COORDINATING CENTER  
NACC  
COLLABORATIVE PROJECT  
GRANT # U01 AG016976.**

# Investigator Team



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# Alzheimer's Disease Centers participating in survey dissemination



- Emory University
- Johns Hopkins
- NorthWestern
- Rush
- Univ of Kentucky
- Mayo/Jacksonville
- Univ of Mass/Harvard
- Pittsburgh
- UC Irvine
- UCLA
- UC San Diego
- USC
- Washington Univ
- OHSU
- UC Davis
- UCSF

# Deaths and Autopsies (NACC data, to June 2014)



<b>Ethnic group</b>	<b>No. Centers N = 28</b>	<b># deaths</b>	<b># Autopsies</b>	<b>Percent autopsy</b>
Caucasian	28	4488	2704	60%
African American	25	489	118	24%
Asian	19	182	28	15%
Hispanic	24	234	110	47%

# Two phases for this study



Phase 1. Focus groups with research subjects and family members from 4 ethnic groups: African American, Chinese, Hispanic, White

**Phase 2. Survey subjects in Alzheimer's disease research programs to:**

- a. Identify the effects of ethnicity and other factors on subjects' willingness to assent to brain donation**
- b. For each of the 4 groups analyzed separately, identify predictors of willingness to assent to brain donation

# Phase 2: Survey



Target: 160 subjects from each ethnic group –African American, Caucasian, Chinese, Hispanic

Inclusion criteria:

- Research subjects with normal cognition or MCI
- Studies subject participates in does not require brain donation

Survey recruitment targets for Centers based on number of subjects with normal cognition or MCI from each of the four ethnic groups

For some centers, only subjects from a specific ethnic groups were recruited.

# Data Collection



**Most data from subject self-report in survey**

**Data collected from Center:**

**Number of years followed at Center**

**Years of Education**

**Cognitive Status (Normal, MCI, Other)**

**CDR (0, 0.5)**

**Signed consent to brain donation (yes/no)**

# Variables grouped for analysis



**Dependent variable:**

Willing (or already has agreed to donate) /  
not-willing to agree to brain donation

**Predictors:**

- Demographics, including ethnicity
- Religion/spiritual beliefs and practices, including concepts about the body at death (e.g., cremation, keeping the body whole)
- Family involvement in decision and attitudes
- Experience, knowledge and concerns about research



## Final Sample (n=479)



African American	169 (35%)
Caucasian	185 (39%)
Chinese	50 (10%)
Latino, Hispanic	61 (13%)
<u>Ethnicity unknown</u>	<u>14 ( 3%)</u>
	479 (100%)

Sample with ethnic group identified: 465

63% willing to donate brain for research

# Sample Characteristics



<b>Variable</b>	<b>Total</b>
<b>N</b>	479
<b>Age (yrs) (48-99)</b>	74.7 ± 8.8
<b>Gender (% Women)</b>	323 (69%)
<b>Education (yrs)</b>	15.2 ± 3.6
<b>Duration of follow-up (yrs)</b>	6.2 ± 5.1
<b>Cognitive Impairment (%)</b>	134 (29%)
<b>Living Arrangement (% Alone)</b>	173 (37%)
<b>Religious affiliation (n=422)</b>	
<b>Christian - Catholic</b>	92 (22%)
<b>Christian - Protestant</b>	221 (52%)
<b>Jewish</b>	29 (7%)
<b>Other Religion</b>	7 (2%)
<b>No Affiliation</b>	73 (17%)
<b>Household finances: Enough resources</b>	231 (50%)

# Likely/not likely to donate: Personal Characteristics



Variable	Not Likely to Donate Brain	Likely to Donate Brain	p-value
<b>N</b>	178 (37%)	301 (63%)	
<b>Age (yrs) (48-99)</b>	73.3 ± 8.9	75.5 ± 8.6	<0.01**
<b>Gender (% Women)</b>	129 (75%)	194 (66%)	0.047*
<b>Education (# years)</b>	15.0 ± 3.4	15.3 ± 3.7	0.37
<b>Living Arrangement (% Alone)</b>	78 (45%)	95 (32%)	<0.01**
<b>Household finances (Enough resources)</b>	76 (45%)	155 (53%)	0.08
<b>Cognitive Impairment (%)</b>	53 (30%)	81 (28%)	0.59
<b>Race/Ethnicity</b>			
<b>Non-Hispanic white</b>	41 (24%)	144 (49%)	<0.0001***
<b>African American</b>	96 (55%)	73 (25%)	
<b>Latino, Hispanic</b>	14 (8%)	47 (16%)	
<b>Chinese, Asian</b>	22 (13%)	28 (10%)	

# Likely/Not Likely to Donate: Religion



Variable	Not likely to donate	Likely to donate	P-value
<b>Religious affiliation (n=422)</b>			
Christian - Catholic	22 (15%)	70 (26%)	<0.0001***
Christian - Protestant	92 (61%)	129 (47%)	
Jewish	14 (9%)	15 (6%)	
Other Religion	6 (4%)	1 (<1%)	
No Affiliation	16 (11%)	57 (21%)	
Church attendance- Weekly or greater	58%	49%	0.09
I consider myself to be a religious person. 1=Strongly Agree, 7= Strongly Disagree	2.9 ± 2.0	3.8 ± 2.3	<0.0001***
I consider myself to be a spiritual person. 1=Strongly Agree, 7= Strongly Disagree	2.5 ± 1.8	2.9 ± 2.0	0.09
Believes body should remain whole	24%	9%	<0.0001***
Have arranged for cremation	18%	36%	<0.001**
Plans for open casket (yes)	35%	16%	<0.0001***

# Likely/Not Likely to Donate: Family

Variable	Not Likely to Donate Brain	Likely to Donate Brain	p-value
N	178	301	
Do you believe brain donation is mostly...			
A personal decision	76%	88%	<0.001**
A family decision	24%	12%	
Most likely to discuss with Spouse	30%	51%	<0.0001***
Most likely to discuss with Child	48%	39%	0.04*
Person most likely to talk to is supportive (n=432)	30%	75%	<0.0001***
After your death do you think your family will have difficulty carrying out your wishes?			
No	34%	77%	<0.0001***
Yes	27%	6%	
I am not sure	39%	17%	
Family members trust medical researchers	38%	52%	<0.01**

# Likely/Not Likely to Donate: Research Experience



Variable	Not Likely to Donate my Brain	Likely to Donate my Brain	p-value
Duration of follow-up (# years)	5.1 ± 4.3	6.9 ± 5.4	<0.0001***
Asked by staff to donate brain?			
Yes	63%	87%	<0.0001***
No	27%	8%	
Not sure	11%	5%	
Have heard a presentation on brain donation	16%	29%	<0.01**
Primary reason for participation: to help future generations	55%	70%	<.01**
I would prefer a researcher or doctor to ask me about donating instead of RA.	85%	83%	0.70
It does make a difference who asks me.	30%	21%	0.03*

# Likely/not likely to donate: Research Knowledge and Concerns

Variable	Not Likely to Donate my Brain	Likely to Donate my Brain	p-value
Do you understand...			
.. how study of brain is important for research on AD?	88%	93%	0.14
..what researchers will do with brain?	31%	55%	<0.0001***
..how researchers will remove brain?	22%	35%	<0.01**
..what one needs to do ahead of time?	35%	65%	<0.0001***
..difference between brain donation for research and donation of other organs for patients in need?	42%	68%	<0.0001***
More information would be helpful.	49%	32%	<0.001**
Inviting clergy to talk about brain donation would be helpful	12%	11%	0.71
Concerned that researchers will not be respectful	41%	14%	<0.0001***
Trust medical researchers	71%	88%	<0.0001***
Concerned that autopsy might affect body appearance	25%	5%	<0.0001***

# Multivariate analysis



Logistic regression using Maximum Likelihood Estimates

- 1) Demographics, including ethnicity
- 2) Family variables controlling for demographics & ethnicity
- 3) Religion controlling for demographics & ethnicity
- 4) Research experience, knowledge & concerns controlling for demographics
- 5) Demographics, ethnicity, and significant variables from family, religion and research experience, knowledge & concerns



# Model #1: Demographics only



## Analysis of Maximum Likelihood Estimates

Parameter	DF	Estimate	Standard Error	Wald Chi-Square	Pr > ChiSq	Exp(Est)
Intercept	1	-0.9889	1.0393	0.9053	0.3414	0.372
Age	1	0.0324	0.0128	6.4569	0.0111	1.033
Gender	1	-0.0194	0.2467	0.0062	0.9374	0.981
Live alone	1	-0.4750	0.2310	4.2281	0.0398	0.622
Black	1	-1.4056	0.2551	30.3649	<.0001	0.245
Hispanic	1	-0.0385	0.3580	0.0116	0.9144	0.962
Asian	1	-0.9477	0.3512	7.2817	0.0070	0.388

# Model #2: Demographics + Religion



## Analysis of Maximum Likelihood Estimates

Parameter	DF	Estimate	Standard Error	Wald Chi-Square	Pr > ChiSq	Exp(Est)
<b>Intercept</b>	1	-2.1243	1.3805	2.3677	0.1239	0.120
<b>Age</b>	1	0.0576	0.0180	10.2894	0.0013	1.059
<b>Gender</b>	1	-0.1352	0.3521	0.1474	0.7010	0.874
<b>Lives alone</b>	1	-0.6289	0.3172	3.9306	0.0474	0.533
<b>Black</b>	1	-1.2810	0.3594	12.7064	0.0004	0.278
<b>Hispanic</b>	1	0.00460	0.5294	0.0001	0.9931	1.005
<b>Asian</b>	1	-0.3900	0.5045	0.5976	0.4395	0.677
<b>Catholic</b>	1	0.5214	0.4292	1.4757	0.2244	1.684
<b>Cremation</b>	1	0.8397	0.3645	5.3074	0.0212	2.316
<b>Open casket</b>	1	0.0602	0.3413	0.0311	0.8600	1.062
<b>Whole body</b>	1	-2.1066	0.4059	26.9297	<.0001	0.122
<b>Religious Person</b>	1	-0.0978	0.0659	2.2019	0.1378	0.907

# Model #3: Demographics + Family



## Analysis of Maximum Likelihood Estimates

Parameter	DF	Estimate	Standard Error	Wald Chi-Square	Pr > ChiSq	Exp(Est)
<b>Intercept</b>	1	-2.1164	1.4512	2.1270	0.1447	0.120
<b>Age</b>	1	0.0321	0.0158	4.1269	0.0422	1.033
<b>Gender</b>	1	-0.4139	0.3236	1.6357	0.2009	0.661
<b>Alone</b>	1	-0.2292	0.3441	0.4436	0.5054	0.795
<b>Black</b>	1	-1.0938	0.3154	12.0300	0.0005	0.335
<b>Hispanic</b>	1	0.6275	0.4830	1.6879	0.1939	1.873
<b>Asian</b>	1	-0.5101	0.4336	1.3844	0.2394	0.600
<b>Discuss with spouse</b>	1	0.2077	0.3663	0.3215	0.5707	1.231
<b>Confidant is supportive</b>	1	1.8864	0.2770	46.3930	<.0001	6.595
<b>Personal decision vs. family</b>	1	0.6436	0.3108	4.2881	0.0384	1.903
<b>Family trusts researchers</b>	1	-0.0975	0.2772	0.1238	0.7249	0.907

# Model #4: Demographics + Research Knowledge & concerns

## Analysis of Maximum Likelihood Estimates

Parameter	DF	Estimate	Standard Error	Wald Chi-Square	Pr > ChiSq	Exp(Est)
Intercept	1	-1.6530	1.4560	1.2888	0.2563	0.191
Age	1	0.0287	0.0180	2.5281	0.1118	1.029
Gender	1	-0.3560	0.3138	1.2865	0.2567	0.700
Live alone	1	-0.5897	0.2918	4.0829	0.0433	0.555
Black	1	-0.8833	0.3392	6.7800	0.0092	0.413
Hispanic	1	0.5474	0.4297	1.6226	0.2027	1.729
Asian	1	-0.1671	0.4608	0.1315	0.7169	0.846
Years Followed	1	0.0395	0.0313	1.5915	0.2071	1.040
Vol to Help Future Gen's	1	0.5200	0.2698	3.7144	0.0539	1.682
Concern about appearance	1	-0.7397	0.4415	2.8070	0.0939	0.477
Concern researchers not respectful	1	-1.0179	0.3404	8.9439	0.0028	0.361
Trust Researchers	1	0.4155	0.3342	1.5458	0.2138	1.515
Understand purpose of brain research	1	0.6988	0.3000	5.4254	0.0198	2.011
Understand what to do ahead of time	1	0.7984	0.2954	7.3070	0.0069	2.222
Would like more info	1	-0.0624	0.2771	0.0507	0.8219	0.940

# Demographics plus significant covariates



## Analysis of Maximum Likelihood Estimates

Parameter	DF	Estimate	Standard Error	Wald Chi-Square	Pr > ChiSq	Exp(Est)
<b>Intercept</b>	1	-3.3436	1.6591	4.0615	0.0439	0.035
<b>Age</b>	1	0.0596	0.0205	8.4882	0.0036	1.061
<b>Gender</b>	1	-0.7015	0.3854	3.3137	0.0687	0.496
<b>Live s alone</b>	1	-0.6672	0.3624	3.3891	0.0656	0.513
<b>Black</b>	1	-0.8995	0.3776	5.6745	0.0172	0.407
<b>Hispanic</b>	1	1.2191	0.5634	4.6812	0.0305	3.384
<b>Asian</b>	1	-0.2669	0.5029	0.2816	0.5956	0.766
<b>Cremation</b>	1	0.4281	0.3764	1.2937	0.2554	1.534
<b>Believes body should remain whole</b>	1	-1.4149	0.4586	9.5188	0.0020	0.243
<b>Confidante is supportive</b>	1	1.7408	0.3282	28.1275	<.0001	5.702
<b>Personal decision</b>	1	0.0436	0.3936	0.0123	0.9118	1.045
<b>Concern respect</b>	1	-1.3109	0.3502	14.0121	0.0002	0.270
<b>Understand brain research</b>	1	0.7860	0.3359	5.4752	0.0193	2.195
<b>Understand preparation</b>	1	0.7818	0.3382	5.3441	0.0208	2.185

# Next Steps



## **Presentations:**

**Gerontological Society of America (GSA) – November, 2014**

## **Manuscripts:**

**Full Sample**

**Separate analyses by ethnic group**

## **Intervention?**

**OHSU**

**Collaborative project?**

# African Americans vs. Whites (Demographics)



<b>Variable</b>	<b>African American</b>	<b>White</b>	<b>p-value</b>
<b>N</b>	<b>169</b>	<b>185</b>	
<b>Age (yrs)</b>	<b>74.5 ± 8.1</b>	<b>75.6 ± 9.1</b>	<b>0.24</b>
<b>Gender (% Women)</b>	<b>86%</b>	<b>56%</b>	<b>&lt;0.0001</b>
<b>Education (yrs)</b>	<b>14.8 ± 3.1</b>	<b>16.2 ± 2.4</b>	<b>&lt;0.0001</b>
<b>Years of follow-up (yrs)</b>	<b>5.2 ± 3.8</b>	<b>7.5 ± 6.0</b>	<b>&lt;0.01</b>
<b>Cognitive Status (% MCI)</b>	<b>27%</b>	<b>29%</b>	<b>0.71</b>
<b>Percent Alone</b>	<b>55%</b>	<b>27%</b>	<b>&lt;0.0001</b>
<b>Religious affiliation</b>			
<b>Christian</b>	<b>89%</b>	<b>62%</b>	<b>&lt;0.0001</b>
<b>Jewish</b>	<b>0%</b>	<b>14%</b>	
<b>Other</b>	<b>10%</b>	<b>2%</b>	
<b>None</b>	<b>1%</b>	<b>22%</b>	
<b>Likely to donate brain</b>	<b>43%</b>	<b>78%</b>	<b>&lt;0.0001</b>

# African Americans vs. Whites (Family)



Variable	African American	White	p-value
<b>N</b>	169	185	
<b>Q4. Most likely to discuss with Spouse</b>	26%	64%	<0.0001
<b>Q4. Most likely to discuss with Child</b>	58%	29%	<0.0001
<b>Q5. Person above is supportive of brain donation</b>	48%	75%	<0.0001
<b>Q8. After your death do you think your family will have difficulty carrying out your wishes?</b>			
No	42%	74%	<0.0001
Yes	23%	3%	
I am not sure	24%	15%	
Does not apply, I do not have family members	1%	3%	
Does not apply, I will not donate	10%	5%	
<b>Q10. Brain donation is mostly a personal decision (vs. family decision)</b>	78%	88%	<0.01



# African Americans vs. Whites (Religion)



Variable	African American	White	P-value
<b>Q12. Church attendance <math>\geq</math> Weekly</b>	69%	32%	<0.0001
<b>Q15a. I consider myself to be a religious person. 1=Strongly Agree, 7= Strongly Disagree</b>	2.8 $\pm$ 2.1	3.9 $\pm$ 2.2	<0.0001
<b>Q15b. I consider myself to be a spiritual person. 1=Strongly Agree, 7= Strongly Disagree</b>	2.0 $\pm$ 1.7	3.3 $\pm$ 2.2	<0.0001
<b>Q16. Believes body should remain whole at cremation/burial.</b>	24%	9%	<0.0001
<b>Arrangements for body after death</b>			
Cremation	18%	36%	<0.001
Burial	30%	16%	
I have not made arrangements	52%	48%	
<b>Q20. Concerned that autopsy might affect body appearance</b>	17%	6%	<0.01

# African Americans vs. Whites (Knowledge and Trust)



Variable	African American	White	P-value
<b>Q21. Concerned that researchers will not be respectful</b>	28%	16%	0.011
<b>Q22. Trust medical researchers</b>	67%	91%	<0.0001
<b>Q23. Family members trust medical researchers</b>	37%	57%	<0.001
<b>Q32. Household finances are enough</b>	38%	63%	<0.0001
<b>Q34. What do you understand about brain donation for research? Sum of five questions, Higher score is less understood.</b>	7.6 ± 1.7	6.9 ± 1.5	<0.001
<b>Q36. More information would be helpful.</b>	44%	26%	<0.001
<b>Q39. I would prefer a researcher or doctor to ask me about donating instead of RA.</b>	86%	85%	0.80
<b>Q40. It does make a difference who asks me.</b>	33%	17%	<0.01

# Multivariate analysis: Adjusting for Ethnicity



Multivariate model of likelihood of willing to donate brain (adjusted for race)

N=342 observations used; 220 likely to donate

Covariates	Estimate	Standard Error	Wald Chi-Square	p-value	Odds Ratio	95% Confidence Intervals	
Intercept	-1.0705	1.6633	0.4142	0.5199			
Family vs personal decision	-0.4114	0.3877	1.1259	0.2886	0.663	0.31	1.417
Whole body vs no/not sure	-1.2182	0.4472	7.4216	0.0064	0.296	0.123	0.711
Supportive person to discuss with vs not	1.7968	0.3124	33.0891	<.0001	6.03	3.269	11.123
Religiosity (Higher=less religious)	0.0806	0.0804	1.0032	0.3165	1.084	0.926	1.269
Concern researchers will not be respectful of body vs none	-1.3914	0.3446	16.3074	<.0001	0.249	0.127	0.489
Black (referent=White)	-0.8463	0.397	4.5455	0.033	0.429	0.197	0.934
Hispanic	0.2856	0.5991	0.2272	0.6336	1.331	0.411	4.305
Asian	0.1036	0.5281	0.0385	0.8445	1.109	0.394	3.122
Age	0.0348	0.0198	3.1009	0.0782	1.035	0.996	1.076
Female vs male	-0.6854	0.3647	3.5322	0.0602	0.504	0.247	1.03
Years Followed at ADC	0.0607	0.0358	2.8767	0.0899	1.063	0.991	1.14
Catholic (referent=Protestant)	1.0542	0.3862	7.4503	0.0063	3.287	1.297	8.328
No Religion	0.136	0.4114	0.1092	0.741	1.312	0.421	4.091
Other Religion	-1.0543	0.4378	5.8004	0.016	0.399	0.119	1.334