

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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Deaths and Autopsies (NACC data, 2011)



Ethnic group	No. Centers N = 29	# deaths	# Autopsies	Percent autopsy
Caucasian	29	2611	1505	57%
African American	26	279	56	20%
Asian	16	26	10	38%
Latino*	17	101	73	72%

* Based on primary language

Study Aims



Aim 1. Examine the knowledge, attitudes, beliefs and experiences regarding donating one's brain of research subjects and their family members from 4 ethnic groups

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

- a. Identify the effect 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**

Aim 1: Focus groups



Conducted 17 focus groups with 97 research subjects from four Centers (OHSU, Boston U, UC Davis, UCSF)

Themes identified from focus groups

- Family
- Body – (e.g., cremation, what happens at death)
- Research or researchers
- Religion/spiritual
- Culture/ethnicity/traditions - one's culture or others' culture
- Personal choice
- Trust/mistrust in research and health care providers
- Attributes of the person (e.g., age, health status, education)
- Information needs
- Feelings about death
- Value of research for subject

Aim 2: Survey Caucasian, African American, Latino, and Chinese research subjects about brain donation



Dependent variable: Whether or not the subject is willing to agree to brain donation (or already has)

Predictors:

- Reasons subjects participate in research
- Influence of family on decisions about brain donation
- Concepts about the body at death (e.g., cremation, keeping the body whole)
- Religion/spiritual beliefs and practices
- Culture & traditions surrounding death and organ donation
- Trust/mistrust of researchers and the health system
- Attributes of the person (e.g., age, health status, education)
- Understandings about brain donation and need for information

Aim 2: Survey Caucasian, African American, Latino, and Chinese research subjects



- Survey to be developed from focus group results (Fall 2012)
- Pilot testing and refinement (October-December 2012)
- Recruit ADCs (Education Cores) to participate in survey distribution
- Translate surveys to Spanish and Chinese
- Distribute surveys: 160 X four ethnic groups=640 (White, African American, Latino, Chinese) (December 2012)
- Receive surveys (January – April, 2013)
- Data entry and analysis (April – May 2013)
- Report preparation (June 2013)

Preliminary Data from NACC on Subjects: Number of Centers (includes Normal, MCI, or Impaired /not MCI)



Ethnic group	Number of Centers
White subjects	27
African American subjects	26
Chinese subjects*	10
Latino subjects*	23

*Based on primary language

Participating in survey dissemination



**15/27 Centers have responded positively
(so far)**

<u>Preferred method of dissemination</u>	<u>Preferred or acceptable</u>	
1. Distribute at regular study visits	7	3
2. Mail survey	3	5
3. On-line	--	5
4. Distribute at event	--	4

Sample from 15 Centers (from NACC 9/2012)



Target sample size: 160 respondents/ethnic group

	<u># S's in 15 ADCs</u>	<u>Proportion needed</u>
Caucasion	3078	.05
African American	827	.20
Latino/Hispanic	212	.75
Chinese*	50	1.00

*** based on language**

Next steps



- ❑ **LUNCH MEETING TOMORROW NOON FOR PARTICIPATING CENTERS**
- ❑ **SURVEY TO BE FINALIZED (OCT-NOV)**
- ❑ **BEGIN DISSEMINATION (DEC-JAN)**
- ❑ **COMPLETE DISSEMINATION (APRIL, 2013)**
- ❑ **DATA ENTRY (APRIL-MAY)**
- ❑ **ANALYSIS AND REPORT PREPARATION (JUNE)**

Surveys to be distributed through ADC's in 2012



You can still join us in disseminating the survey to your subjects. If interested, please talk with me here or contact me at:

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