

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



**A NATIONAL ALZHEIMER'S  
COORDINATING CENTER  
NACC  
COLLABORATIVE PROJECT**

**GRANT # U01 AG016976.**

# Participating ADCs



- **Oregon Health & Science University**  
Linda Boise, PhD, MPH, principal investigator
- **Boston University Medical Center**  
Angela Jefferson, PhD, co-investigator
- **University of California, Davis**  
Ladson Hinton, MD, co-investigator
- **University of California, San Francisco**  
Howard Rosen, MD, co-investigator

# Study Aims



**Aim 1. Examine the knowledge, attitudes, beliefs and experiences of research subjects and their family members from 4 ethnic groups about brain donation for research**

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

- A. Identify the effect of ethnicity or other factors on willingness to assent to brain donation**
- B. For each of the 4 groups analyzed separately, identify predictors of willingness to assent to brain donation**

# Number of Participants in Seventeen Focus Groups



	<b>Subjects who have consented to autopsy</b>	<b>Family members of consenting subjects</b>	<b>Subjects who have not consented to autopsy</b>	<b>Family members of non-consenting subjects</b>
<b>Caucasian</b>	<b>9</b>	<b>7</b>	<b>6</b>	<b>2</b>
<b>African American</b>	<b>8</b>	<b>7</b>	<b>7</b>	<b>4</b>
<b>Latino</b>	<b>6</b>	<b>6</b>	<b>5</b>	<b>4</b>
<b>Chinese</b>	<b>2</b>	<b>3</b>	<b>13</b>	<b>4</b>

2 groups conducted in Spanish; 2 groups in Cantonese;  
1 in Mandarin

Some focus groups were not clearly consenting or non-consenting

# Coding and analysis for focus groups



- **Audiotapes transcribed (and translated)**
- **Coding frame developed**
- **Transcripts coded by two researchers or research assistants**
- **Coding reviewed by PI**
- **Reconciliation of coding differences**
- **Codes entered into NVIVO qualitative analysis software**
- **Analysis team to analyze factors that influence willingness to agree to autopsy or that inhibit willingness**

# Comments that reflect attitudes about brain donation (positive or negative)



- “No downsides”
- Family
- Body – (e.g., cremation, what happens at death)
- Research or researchers
- Culture/ethnicity - one’s culture or others’ culture
- Personal choice
- Trust – trust issues not related to research or medical care
- Religion/spiritual /”tradition”
- Health system, medical care, doctors
- Attributes of the person (e.g., age, health status)
- Information needs
- Feelings about death
- Value for research subject

# Some examples: Coded as religion



*“What do you think would happen to the soul if you donate your brain, and your soul is a part of your brain – or is the brain?” (family member)*

*“Religion-wise, I believe that the body is just a structure, that it’s not the essence of the individual and so I don’t see that as something an autopsy, biopsy, whatever, denigrating any of that and, so that all supports . . . how I could make that decision. I have on my driver’s license to donate organs if something should unforeseen happen to me. My husband on the other hand can’t quite make that decision, even though he has even more training, but he believes . . . that the body has to stay whole...” (family member)*

*“Many churches now have the alternative of memorial services, most people in our church, the United Methodists, have memorial services rather than the funerals. I’ve gone to very few funerals...”*

# Coded as “Research”



- *“But the point is: how do you rally the communities around the idea of donation of brains for research? Because there’s that fear out there; a lot of different reasons, fear – our history, for one thing. People still remember the Tuskegee situation...”*
- *“I think the only thing that will change the tide of how people think is not so much – I mean, I know the research, the physicians and the scientists, you know, you guys are dealing with the science, but to those of us on the other side, emotion drives a lot of what we do and how we feel.”*



## Coded as “Personal Choice”



Interviewer: *“So it is possible that a family member will say, ‘I don’t care what my mother wanted. You’re telling me that she said she wanted that done. I don’t think I can give my consent for that.’ ”*

Participant: *“If you have a family where there’s dissension on that the family members that are supporting the wishes that have been documented, and if [the research center] decides to not go through with it, that they are actually setting themselves up for some liability, because you could actually have the family members that are in support of that sue that those wishes were not followed. Especially if there’s good documentation. I’d be curious about that.”*

## 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 (January 2012)
- ADCs (Education Cores) to participate in survey distribution (beginning January 2012)
- Distribute surveys: 160 X four ethnic groups=640 (White, African American, Latino, Chinese) (February - March 2012)
- Data entry and analysis (April – May 2012)
- Report preparation (June 2012)

# Preliminary Data on Subjects: Number of Centers

(includes Normal, MCI, or Impaired /not MCI)



<b>Ethnic group</b>	<b>Number of Centers</b>
White subjects	29
African American subjects	29
Asian subjects*	25
Latino subjects**	21

\* All Asian, not only Chinese

\*\*Based on primary language

# Deaths and Autopsies



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

\* Based on primary language

# Surveys to be distributed through ADC's in 2012



*Please join us in conducting the survey!*

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