

Ethnic Differences in Willingness to Assent to Brain Donation

An Education Core collaborative study
(2010 – 2012)

Funded by the National Alzheimer's Coordinating
Center (NACC)

Collaborators

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Why this study?

- Ethnic groups are under-represented in Alzheimer's disease studies, even fewer for neuropathological data
- Some knowledge about African Americans, little on Latinos or Asians
- Obtaining consent for brain donation from research subjects from diverse ethnic groups has been problematic
 - A small number of brains from minorities have been obtained
 - Few subjects agree to donation
 - Many have not been asked or, if asked, say they will think about it

Aims

- To gain understanding of the attitudes, beliefs of African Americans, Chinese, Latino, and Caucasian research subjects and their family members about donating one's brain for research
- Through a survey, to investigate the differences among these four ethnic groups in:
 - Willingness to donate their brain for research
 - Factors that influence their willingness towards donating their brain for research
 - Experiences in being asked

Focus Groups

Population group	Research Subjects who have consented to brain autopsy	Family members of subjects who have consented to brain autopsy	Research Subjects who have not consented to brain autopsy	Family members of subjects who have not consented to brain autopsy
African American	Boston University	Boston University	OHSU Layton Center	OHSU Layton Center
Latino	UC Davis (Spanish)	UC Davis (Spanish)	UC Davis (Spanish)	UC Davis (Spanish)
Chinese	UCSF (English)	UCSF (English?)	UCSF (Chinese?)	UCSF (Chinese?)
Caucasian	OHSU Layton Center	OHSU Layton Center	Boston University	Boston University

Domains of interest

- **“Studies have shown that people from some ethnic groups may be less likely to participate in a brain donation program. What do you think accounts for these lower levels of participation?”**
- **Religious or spiritual beliefs or practices**
- **Feelings about the body and how the body is treated when someone dies**
- **Feelings about participating in research in general**
- **How people feel about hospitals or research centers**
- **Experiences they or other people in your community have had with health care providers or researchers**
- **Experiences in being asked to donate one’s brain**
- **Differences between research subjects and their family members in attitudes**
- **“What might make brain donation more appealing to you, your family, and your community?”**

Timeline

Year 1 (July 2010 – June 2011)

- Develop focus group recruitment plan and interview guide; obtain IRB approval
- Conduct focus groups
- Translate and transcribe audiotapes
- Analyze focus group data: themes (attitudes, beliefs) and experiences
- Develop and pre-test survey instrument

Timeline

Year 2 (July 2011 – June 2012)

- Disseminate survey (N=640 - 160/ethnic group)
- Data entry and analysis
- Report and manuscript preparation
- Present results to ADC directors

Will you help us disseminate the survey?



Thank you

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