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Ethnic Differences in Willingness to Assent to Brain Donation

Principal investigator
Linda Boise, PhD, MPH, Oregon Health & Science University

Collaborating centers
University of California, Davis; University of California, San Francisco; Boston University

Project description
Across the NIH-funded Alzheimer's Disease Centers, the challenge of recruiting and retaining research subjects from diverse ethnic communities leads to under-representation of ethnic minorities in research studies. Even greater difficulties arise when the research protocol requires consent to brain autopsy. In this proposed project, we will study the factors that influence whether or not research subjects from four population groups agree to donate their brain when they die. Our specific aims are (1) examine the knowledge, attitudes, and beliefs of research subjects and family members (or significant others) from four ethnic groups (African American, Latino, Chinese and non-Hispanic Whites) about brain donation for research, and (2) identify the effect of ethnicity and other factors on willingness to assent to brain donation for research. This two-year study will be carried out in two phases. First, using qualitative methods (focus groups), we will explore the attitudes and beliefs of older adults from four ethnic groups about brain autopsy. Second, we will implement a questionnaire based on results of the focus groups to investigate the factors that influence whether or not research subjects are likely to consent to brain autopsy. The self-report questionnaire will include demographic variables (age, ethnic group, gender, education, acculturation), variables identified from the focus groups (for example, religious beliefs, attitudes towards/beliefs about the body, experience with research, involvement of family members in decisions, and knowledge of Alzheimer’s disease) and other factors (e.g., ADC site). The questionnaire will be administered in English, Spanish, and Chinese. We will use logistic regression to determine whether there are differences in the proportion of willingness to consent to autopsy for the different ethnic groups, and for each ethnic group analyzed separately to identify the factors associated with willingness to consent for autopsy. This study will fill a critical gap in our knowledge about a key aspect of Alzheimer's disease research and will inform the development of culturally specific community outreach and educational materials to increase understanding and receptivity to participate in Alzheimer's disease research programs, including assent to brain autopsy.

Contact information
For further information regarding this study, please contact:
Linda Boise PhD
Oregon Health & Science University
Aging & Alzheimer Disease Ctr CR131
3181 SW Sam Jackson Park Rd
Portland OR 97239-3098
503-494-6370
http://www.ohsu.edu/research/alzheimers