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“My Parent’s Body is Sacred”: Perspectives from Adult Latino Children about Brain Donation for Alzheimer’s Disease Research

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INTRODUCTION

Older Latinos are at higher risk of developing Alzheimer’s disease and related dementias (ADRD) compared to older non-Latino Whites.[1–2] The examination of brain tissue is a critical pathway to advancing our understanding of the ADRD disparities found in the growing and diverse older adult population. ADRD studies examining the autopsied brains of diverse older adults with dementia diagnosis point to differences in the types of dementia affecting Latinos compared to non-Latino Whites.[3] However, brain tissue from older Latinos remains scarce. Between June 2005 and May 2016, Latino participants comprised 8% of all participants - 2,557 of 33,762 - across the 30+ Alzheimer’s Disease Centers in the United States, with neuropathological data existing for only 160 deceased older Latinos.[4] Documented barriers to brain donation among Latinos include cultural and religious beliefs, distrust of the medical system, concerns about brain removal, and awareness and experiences of discrimination in the United States.[5,6] Previous research also points to the important and complex role of family members in brain donation among older Latinos adults.[6] Understanding family perspectives can provide insight into how researchers and others may facilitate participation in brain donation among older Latinos. The purpose of this study was to examine the attitudes and beliefs about brain donation among adult children of older Latinos.

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Conflicts of Interest
The authors declare no conflicts of interest.

METHODS

Participants took part in one of three semi-structured focus group discussions (two women-only groups and one men-only group) led by two trained sex-matched moderators. Focus group participants belonged to a larger qualitative study focused on assessing the resonance of public health messages about dementia. Inclusion criteria for both studies included: a) being 18 years of age or older, b) self-identification as Latino/a, c) having a living parental-figure, including a parent, step parent, or parent-in-law, aged 65 years or older, and d) proficiency in English – verbal and written. Participants were recruited within a large urban city in the Midwest. Sample focus group questions included: “Can you tell me what you know or have heard about organ donation for medical research?” and “How would you feel if your parents enrolled in a research study that asks for organ donation?” All procedures were approved by the Institutional Review Board at BLINDED FOR REVIEW.

Focus groups were audio-recorded, transcribed, and analyzed using an inductive Grounded Theory Approach with Open Coding.[7] To ensure inter-rater agreement, each transcript was analyzed by two trained members of the research team. Analyses consisted of five steps: 1) researchers independently read each transcript to familiarize themselves with content, 2) researchers independently identified key passages in the transcripts, 3) researchers independently assigned codes to key passages then compared and discussed their codes, 4) together researchers created subthemes by grouping and labeling related codes, and 5) subthemes were grouped into overarching themes. At each step, researchers discussed findings and reached consensus. All data analyses were first performed by hand, followed by utilization of Atlas.ti version 7.1.

RESULTS

Participants (N=15) consisted of 11 females and 4 males with a mean age of 39.9 years (SD=9.8). All participants were born in the United States with most (n=11) parental-figures being immigrants. Most participants (66.7%) possessed a college degree, worked full-time (80%), and had an annual income >$25,000 (86.7%).

Analyses revealed three overarching themes: a) the impact of social and cultural contexts on perceptions about brain donation, b) knowledge and information about the brain donation process, and c) recommendations for engaging older Latinos and their families in brain donation and ADRD research. (See Table 1).

First, participants indicated that social and cultural context may serve as both barriers and facilitators to consenting to brain donation among their parental-figures. Parental-figures’ cultural and religious beliefs about dying served as prominent barriers to brain donation. Here, participants anticipated that parental-figures would view brain donation as an impediment to traditional cultural beliefs of being “buried properly” or “buried whole.” Participants noted that talking about brain donation with older loved ones was linked to conversations about death and difficult end-of-life decisions such as interment - rarely initiated topics among participant families. Discussions about death and related issues were particularly complex for participants with immigrant parental-figures.

Family involvement in the decision making process was both a barrier and a facilitator. Participants spoke about supporting their parent's decision with some caution. For example, participants anticipated questioning their parents' decision to donate their brain and whether it was the correct decision. Other participants spoke about encouraging their parental-figure to consider brain donation. Some participants reported being willing to donate their brains, but simultaneously indicated strong reservations about their parents' brain donation participation. Additionally, participants identified altruism as facilitative factor. They spoke about altruism in two main ways – their parental figures having an altruistic personality and their willingness for brain donation as a benefit to their immediate families and the broader Latino community.

Second, participants expressed confusion about brain donation for research and how it differs from organ donation in general (e.g., transplants). Participants often discussed brain and organ donation interchangeably. Participants also expressed a lack of information regarding the purpose and consenting process of brain donation. This lack of information led to misconceptions and mistrust about the process of brain donation with pervasive concerns of mistreatment and disrespect. Family involvement remained pivotal as participants spoke about the expectation of being part of their parental-figures decision making process for brain donation. With their support being dependent on whether their parental-figure had a clear understanding of the process.

Lastly, participants noted the importance of three factors in facilitating older Latino participation in brain donation and ADRD research: a) increasing education about the process of brain donation, b) highlighting benefits of brain donation to families and future Latino generations, and c) making ADRD research relatable by using a family-centered approach. Participants also indicated a desire to know about potential vital health and genetic information that could stem from parental-figures' brain autopsies.

DISCUSSION

The critical role of family members in increasing rates of brain donation[4–6] and medical research[8] participation among older Latinos has been previously documented. This study adds to existent literature regarding cultural norms and beliefs serving as barriers to consenting to brain donation among older Latinos[4–6]; however, previously documented barriers may also serve as facilitators. Study participants expressed a desire to be included in all stages of ADRD research and brain donation decision making process. Even if participants did not agree with their parental-figure's decision, many were willing to support brain donation if they were included in the process. Furthermore, altruistic beliefs can be leveraged to increase brain donation willingness, and eventually, participation rates.

Overall, recommendations to engage older Latinos in ADRD research and related brain donation efforts include: 1) increasing education about ADRD and the role of research; 2) being inclusive of the family in the decision making process; and 3) highlighting the benefits to immediate family members and the greater Latino community. Education materials about brain donation should include symptoms and disease trajectories of ADRD, prior ADRD research findings, and information about the purpose of brain autopsies with both healthy individuals and individuals with a dementia diagnosis. These recommendations are consistent with a systematic review of health research participation, in general, which cited Latinos' willingness to participate in health research for altruistic reasons embedded in cultural and community priorities.[9]

Limitations to the current study include a small sample size and the heterogeneity of the Latino population. Overall, employing a family-centered approach to brain donation and framing it as being directly beneficial to Latino families may facilitate increased ADRD research and brain donation participation among older Latinos.

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Table 1.

Themes and Illustrative Quotes

Overarching themes	**Illustrative quotes**
1. Social and Cultural Context and Their Impact on Participant Perceptions about Brain Donation	“*My mom would be [say] no. She’d be like I want to go complete. She’s very traditional*” (Female participant)
	“I think that my dad would be open to it. Yes, he’s kind of a cheerful guy I guess. He would be like well, I’m already dead and so do whatever you want and like if they want to study it, that’s fine. That’s not going to serve me any purpose. It wouldn’t be a big deal.” (Female participant)
	“*If they decide in their life that they want to do it [donate their brain], I would support it. I’m not going to overrule them.”* (Male participant)
2. Knowledge and Information about the Brain Donation Process	*“When you think about research, it’s just like why are you taking my stuff [brain]? I think that they think about it more like that, without really thinking about like oh, you know, because we don’t know much about this [Alzheimer’s disease] and so we’re trying to learn about it.”* (Female participant)
	“Well, she [my mom, has] talked about organ donation. She signed her driver’s license...but she’s never mentioned like for science, you know?” (Female participant)
	“No one ever talks to them about research and how things are advancing. I think that when you’re talking about organ donation, they really think like I’m going to save someone else’s life.” (Female participant)
3. Participant recommendations for engaging Latino older adults and their families in brain donation and ADRD research	*“I would need to know what are some outcomes of the research that they’ve done so far, so that I can know that my parent’s brain will continue helping out with the research project.”* (Male participant)
	“Researchers should highlight the family.... I don’t think that people really think about that. I think that they picture your body being passed around at like different areas and nobody knows where the body is at...”(Female participant)