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Journal

Alzheimers & Dementia: The Journal of the Alzheimers Association, 19(4)

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Publication Date

2023-04-01

DOI

10.1002/alz.12755

Peer reviewed



HHS Public Access

Author manuscript

Alzheimers Dement. Author manuscript; available in PMC 2024 April 01.

Published in final edited form as:

Alzheimers Dement. 2023 April ; 19(4): 1274–1280. doi:10.1002/alz.12755.

To Donate, or not to Donate, that is the Question: Latino Insights into Brain Donation

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STRUCTURED ABSTRACT

INTRODUCTION: Latinos are underrepresented in brain autopsy research on Alzheimer’s disease and related dementias (ADRD). The study’s purpose is to identify Latino’s attitudes about brain donation (BD) to inform methods by which researchers can increase autopsy consent.

METHODS: Forty Latinos (Mean age: 59.4 years) completed a semi-structured interview and were presented with educational information about BD. Participants completed a questionnaire assessing their understanding of BD and willingness to donate their brain for research.

RESULTS: Among participants, there was near unanimous support for BD to study ADRD after hearing educational information. However, prior to the information presented, participants reported a lack of knowledge about BD and demonstrated a possibility that misunderstandings about BD may affect participation.

DISCUSSION: While nearly all study participants agree that donating is beneficial for research and that of future generations, the lack of BD information must be addressed to help support positive attitudes and willingness for participation.

Keywords

Latinos/Hispanic; Brain donation; Autopsy; Qualitative analyses; Alzheimer’s Disease

Background

Latinos are the largest ethnic/racial group in the US (18.5% of the population), and are 1.5 times more likely to develop Alzheimer’s disease (AD) than Whites¹⁻³. However,

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Declaration of interest

The authors have nothing to disclose.

Disclaimer

Views on this paper do not necessarily reflect the NIH/NIA.

current data across approximately 30 NIA-funded Alzheimer's Disease Centers (ADRC) across the US, shows that only 3.7% of neuropathology data is from Latinos, compared to 91% from Whites⁴. Brain donation (BD) is key to dementia research and understanding Latinos' beliefs can provide important information for culturally-relevant approaches to increase awareness and BD. Neuropathological confirmation of amyloid- β plaques, tau neurofibrillary tangles and brain pathologies (e.g., vascular disease, Lewy bodies) from brain autopsy is still the "gold standard" for a definitive diagnosis of dementia etiologies and for biomarker validation studies⁵⁻⁸. Despite the number of initiatives to increase underserved populations representation, this number remains low in BD research. The lack of minoritized populations enrollment in brain autopsy reduces the opportunities to explore the unique neuropathological characteristics of brain function in these groups. Of all the dementia neuropathology studies to-date, only three studies include autopsy data from Latinos⁹⁻¹¹, with small sample sizes. One of these studies reported that Latinos diagnosed with dementia were more likely to have cerebrovascular disease and mixed pathologies than Whites.⁹ Based on these three studies to date, unknown Latino heritages severely limits meaningfulness to specific Latino groups and creates a major barrier to knowledge on dementia etiologies among diverse Latinos⁹⁻¹¹. As such, the need for diverse Latinos to participate in research that involves BD is critical and highlights an important scientific gap for our continued understanding of ADRD. This work, although small, addresses ADRD summits/AD milestones.

Only a handful of studies have explored organ donation among Latinos¹²⁻¹⁴, and even fewer focus on Latino's attitudes and challenges to BD¹⁵⁻¹⁸. In prior research, Latino study participants expressed concern about a lack of follow-through by family members regarding their BD wishes after they signed the Uniform Anatomical Gift Act for research¹⁷. In Montoya and colleagues¹⁸, Latinos described sociocultural barriers and lack of knowledge about the BD process as influential factors to not support BD. Boise and colleagues¹⁵ found that age, Latino ethnicity, understanding of how the brain is used by researchers, and what subjects need to do to ensure that their brain will be donated to be significant positive predictors to donate.

Underserved populations are less likely to participate in research, due to unawareness of research opportunities, language of study or mistrust for researchers. The 2013-2019 Health Disparities Priority summit recommends that researchers efforts are increased to invite diverse populations to participate in autopsy research via culturally-relevant and community-based practices. Additionally, as outlined in the Belmont Report³⁷, researchers have a responsibility to ensure three core principles: 1) beneficence, 2) justice, and 3) respect for all populations, specifically vulnerable and underserved populations. Insights into Latino's attitudes and barriers are necessary to inform research and raise trust for collaboration with underserved communities. As such, this study is a step towards a larger target and objectives needed to expand the field. In this study, we describe community responses to BD that can inform other studies for inviting Latinos to participate in BD research.

Method

Participants

Data were collected between July and October 2020 via phone calls as part of the *Perceptions and Attitudes of Aging-Related Research in Older Latinos (PASION)* study. Participants included 40 healthy community-dwelling adults who self-identified as Latino, were 50-years of age or older and spoke Spanish and/or English. Individuals who were unable to provide consent to participate, did not let us record the interview, were unable to communicate in Spanish and/or English or did not pass the Assessment to Consent Form were excluded from the study (Figure 1). Participants were recruited via social media, flyers, convenience, and “snowball” referral sampling. The UC San Diego Institutional Review Board reviewed and approved this study.

Procedures and Materials

By phone, trained bilingual (Spanish/English) and bicultural staff explained the study’s purpose, screened individuals, and, upon enrollment, administered questionnaires to assess demographic characteristics, acculturation and participant knowledge of aging-related research including questions related to AD (Appendix A). Qualitative data was collected during a one-hour semi-structured phone interview with the principal investigator in the participant’s preferred language. Following the phone interview, participants completed the same aging-related research knowledge questionnaire administered prior to the interview. All interview data were uploaded to a secure server, were digitally recorded, then transcribed, and checked for accuracy by the PI. Transcriptions were de-identified for privacy. No transcripts were translated as the PI and coders were bilingual.

Aging-related research knowledge questionnaire: Participants were asked six multiple choice questions regarding knowledge of research related to AD. Items were developed by the author (AMP) for the purposes of this study (Appendix A).

Psychological Acculturation Scale (PAS)³⁸: The PAS is a 10-item questionnaire assessing an individual’s feelings and opinions to American and Latino cultures. Participants were instructed to respond to each item using a 9-point Likert-type scale, ranging from 1 (only Latinos) to 9 (only Americans). Composite scores were calculated by averaging the 10-items, with lower scores indicating lower levels of acculturation.

Qualitative Interviews and Analysis

A predetermined list of broad, research-driven questions developed by the investigative team were used to guide interviews with participants (Appendix B). Additional questions were asked to further prompt discussion. Transcripts were uploaded to a qualitative analysis program ATLAS.ti Cloud (ATLAS.ti 9, Mac) and analyzed using the method of “Coding Consensus, Cooccurrence, and Comparison”¹⁹, and rooted in grounded theory [GT] (i.e., theory generated from data and illustrated using characteristic examples²⁰). Qualitative data was examined as follows: (1) All data were reviewed by the PI to develop a general understanding of content as it related to the study’s specific aims. During this step, the PI and three other coders used a sample of four transcripts to highlight initial impressions of

the text and define specific codes in order to reach a consensus for the development of a codebook (Appendix C) that was to be used for the rest of the transcripts²¹. (2) The coders independently coded the rest of the interviews. When appropriate, segments of text ranging from a phrase to several paragraphs were assigned multiple codes²². (3) Once all responses were coded, the PI and one of the coders used frequency analysis (the number of times an event/code occurs) to identify an initial list of themes, to visualize how these codes were associated with each other.

Results

Participant characteristics

Participants included 40 community-dwelling Latinos living in the US (Mean age: 59.4, *SD* = 7.35). Most participants were female (67.5%) had an average of 12.55 (*SD* = 3.21) years of education and preferred language was Spanish (92.5%). Most participants were born in México (85%) and had low levels of acculturation (Mean: 2.98. *SD* = 2.03; Table 1.)

Qualitative findings

Our qualitative analyses revealed four themes: Lack of knowledge, misconceptions, altruistic motivation, and beliefs and traditions that influence openness toward BD. The themes are discussed in more detail below, with illustrative quotes from participants included in Tables 2–5 (See Appendix D for original quotes in Spanish.) Recommendations from participants to increase willingness to participate and learn more about BD for research is also summarized in Table 6.

Theme 1: Lack of knowledge about BD—Prior to the interview, participants answered a multiple-choice question on BD, with 58% (*n*=22) responding correctly to knowing what BD is. However, during the phone-interview many participants were unfamiliar with the concept of BD (92%). Answering questions about the topic was difficult as the majority had no prior knowledge on this topic and found themselves wanting more information to decide (even if hypothetical) to donate their brain for research. Most participants were aware of organ (e.g., eyes, kidneys) donation (94%) as compared to BD (5%). While some participants assumed donated brains would be used for research purposes (5%), envisioning themselves as a brain donor was perceived as a more difficult task. See table 2 (supplementary file) for illustrative quotes.

Theme 2: Misconceptions about BD—Participants that had some knowledge of BD for research expressed the misconception that because they were listed as an organ donor on their driver's license, that also included the brain (52%). Additionally, the use of the term “organ donation” (for transplants) and “BD” (for research) was used interchangeably by some participants. See table 3 (supplementary file) for illustrative quotes.

Theme 3: Altruistic motivation for BD—After discussing the benefits and value of BD, many participants expressed having a better understanding and a more positive attitude towards the idea of BD, especially among participants who expressed altruistic and empathic beliefs (72%). Some participants expressed a higher willingness to donate knowing it

could help researchers find a cure for AD from which their family, future generations and humanity could benefit (57%). See table 4 (supplementary file) for illustrative quotes.

Theme 4: Beliefs and traditions influence openness towards BD—When considering BD, participants discussed cultural and religious beliefs. Many participants asserted that religion, culture, and familial traditions were likely barriers to BD for other Latinos but not themselves (65%). Participants explained that other Latinos may not want to donate their brain due to beliefs about death and what is considered body integrity after death. These beliefs included comments about following God’s word (47%), continuing their parents’ tradition and religious beliefs of what is considered a proper burial (53%). See table 5 (supplementary file) for illustrative quotes.

Participant Recommendations

Participants were especially interested in practical messages, suggesting shorter messages (in length), easy and more digestible words, and avoiding jargon or “unnecessary” medical information. Participants were more interested in learning about BD if these messages included images/videos of the autopsy process without being too graphic or detailed. Additionally, participant suggested expanding existing state organ donation programs to include accurate BD information and a convenient avenue for engaging them in brain autopsy research. Besides increasing general BD knowledge, some participants mentioned that knowing they “will be dead already” was a strong piece of information and motivator to donate as they would have “nothing to lose” post-mortem. See Table 6 for a list of recommendations provided by participants.

Discussion

In this study, we identified four themes: 1) Lack of knowledge 2) Misconceptions, 3) Altruistic motivation, and 4) Beliefs and traditions that influence openness towards BD. In addition, participants provided recommendations to increase Latino willingness to participate in BD research. Although some of these themes are related to those in previous studies, which often focus on other racial/ethnic groups, our findings represent new information regarding Latinos. In this Latino sample, participants discussed both positive attitudes (Themes 3), barriers (Themes 1, 2 and 3) and recommendations to increase willingness towards BD.

Lack of knowledge and misconceptions about BD

Lack of knowledge was identified as a major barrier; this absence of information extends to Latinos’ misconceptions and inaccurate beliefs about BD and its process. Participants with some organ donation knowledge believed that because they are organ donors on their driver’s license or identification card, that it includes the brain when in reality this is a separate process. This highlights a confusion between organ donation for transplants and BD for research purposes. This confusion can be due to how similar BD sounds to organ donations, and thus the misconception that the brain, as an organ, is part of the driver’s license or identification card organ donation registry or the Donate Life California Program²³. The acquisition of BD consent in the US varies from state to state, with some

research centers or brain banks accepting both healthy brains and brains affected by diseases of people already being part of longitudinal research studies or interested in donating their brain after death^{24,25}. However, as demonstrated in our results, the process and information about becoming a brain donor is unknown and confusing to many Latinos.

The lack of knowledge, confusion and misconceptions participants expressed about BD have great implications for research moving forward. For example, some participants suggested incorporating information about BD as part of the already in existence organ donation registry for driver's license or identification card applicants. The suggestion to add BD as an option to organ donation programs already in place has the potential of impacting policy at a national level. However, both organ donation and BD are very different and require different logistics which could take years to merge (depending on state laws). Before we can approach Latinos about participating in studies that include BD, participants and their families need the knowledge and information to decide to consent or not. Thus, actionable steps for researchers and clinicians include increasing and developing culturally-appropriate information about different aspects of ADRD and BD, as suggested by participants.

When opening the discussion, many participants assumed donated brains would be used for research purposes, but for some, thinking of the autopsy process and death was a “creepy” concept. The scarcity of information and educational material about BD in this community reflects the lack of knowledge, and it highlights a need to make BD a more normalized topic, such as blood donation which was viewed by our participants as ordinary.

Boise et al.¹⁶ found that among Latinos, understanding how researchers use brain tissue and what they need to do to ensure brain donation were significant positive predictors of BD. Similar to our study, increasing information on BD (e.g., specific steps, potential benefits) can subsequently increase a person's basic knowledge to make an informed decision and potentially influence their willingness to donate (or not). Similarly, Montoya and colleagues described that lack of knowledge and information was a barrier for the family's willingness to support BD of their loved one¹⁸. These findings further suggest the need for educational information targeting not only the donor, but their families as well, as is supported by Glover and colleagues' findings indicting a lack of family follow-through as a barrier to successively completing brain autopsies¹⁷. Family involvement in this process is an important component in donor decision-making, enrollment and a completed brain autopsy^{26,27}.

Different theories and models have been proposed to predict behavioral intention to donate^{28–30}. Studies incorporating a person's attitudes, normative beliefs, values, and knowledge reveal that exposure to educational messages about organ donation³¹ and family discussions determine an individual's decision to donate^{26,27,32}. Based on our findings and participant suggestions, purposeful and culturally-tailored educational material could aid in increasing knowledge of BD and cultivate trust in research.

Altruistic motivation for BD

Latinos in this study shared several positive attitudes toward BD—although some of these emerged when some background was presented to them—again highlighting the need for

increasing knowledge to allow Latinos to make informed decisions. Similar to other studies with racial/ethnic minorities, altruism was a motivator to increase willingness to donate one's brain^{17,18,33,34}. Beliefs that donating their brain could help scientists find a cure to AD/DRD, and that BD would benefit their community, family, and future generations was a powerful motivator for BD^{15,16,18}. In observation, altruism or good intention towards BD is one thing but the actual action of consenting will be a challenge to future research. Not everyone responds to altruistic messages about BD, and altruism, unlike knowledge, is a core value that is difficult to develop. Nevertheless, in order to reach individuals who already value altruism (e.g., many of our participants), BD awareness campaigns should include altruistic messages and/or partner with organizations or religious groups.

Beliefs and traditions that influence openness towards BD

There are also religious and spiritual beliefs that have been shown to be barriers to donation in Latinos and other populations^{15,18}. One concern among Latinos is whether brain removal would interfere with the soul's journey in the afterlife or the necessity to remain whole¹⁵. Similarly, our participant's beliefs about BD were rooted in cultural, religious and family traditions. However, it is important to note that for many study participants, the cultural and religious factors reported as barriers to donation were their perception of other Latinos, not their personal beliefs. This might be due to the fact our participants were younger (mean age 59-years) than previous studies¹⁵⁻¹⁸ and therefore may hold less traditional values than their parents which served as a point of reference when discussing "other Latinos" beliefs. This finding is different from that of Boise and colleagues¹⁶ which included older age as a positive predictor to donating which could be due to selection bias effects of participants already engaged in their study. Similar to other studies among Black Americans, the perception of death and what is considered body integrity after death, was seen as an impediment to donating^{15,33}. Participants perceived that those with stronger religious beliefs would not consider BD due to perceptions of "Gods will." As such, engaging and consulting religious leaders on BD might be another opportunity for reaching Latinos.

As seen in this study, Latinos intergenerational attitudes toward BD may vary. Such familial involvement or *familismo* (i.e., prioritizing family) is important for decision-making^{15-18,35}. Thus, optimal BD education may involve adult children and loved ones, including matters of proper burial and end of life wishes (e.g., donation). As noted above, prior research highlighted the importance of family follow-through to carry out the donor's wishes among participants already enrolled in BD with their loved ones expressed support¹⁹. Further, their findings emphasize the need for continuous engagement with the family and not simply providing them information (e.g., a flyer, session) once with the expectation that the family remember the donor's wishes (and donation steps) upon death. Studies that include BD could include campaigns and outreach events not only for the participant but their families to keep them engaged and make them feel valued.

Recommendations from participants

Participants shared their recommendations to the research community independently and when explicitly asked. The lack of awareness about BD, provides actionable targets for affecting individual, familial and policy change to improve Latino BD. Participants

expressed a desire for increased accessible BD information available to individuals and families from trusted sources. For example, we found that religious figures, children (outreach through schools) and educational information at doctors' offices may be key trusted resources to share information on what is considered a new topic to most Latinos. Additionally, participants mentioned being more receptive if messages were seen/communicated during a convenient time to them; for example, while waiting to see their medical providers or at home while watching television (e.g., commercials). The convenience piece of learning this topic on their own, could offer a less pressured approach to formulating their own ideas of what it is most likely a new and intimidating topic.

Limitations and Future Directions

The current study has several limitations. First, the sample size was small, and the majority of participants were from México, thus researchers should use caution when generalizing our results to other Latino groups. Future research should divide participants according to their religion, educational background, age, and gender, to compare the results based on these groups. Although we recognize the need for larger sample size to make greater generalizations the results presented from this pilot study are a necessary first step towards larger targets and objectives in the field. Statistical significance, and larger sample sizes, require a starting point and must build off a framework informed by the way group members think and approach knowing more about BD and making complex decisions such as whether to donate or not their brain for research.

Moreover, our participants had low levels of acculturation despite living in the US for an average of 25-years. Thus, some of the information shared by the participants may be less applicable to those with higher acculturation and English-speakers. Notably, due to the COVID-19 pandemic, interviews were conducted one-on-one and over the phone, preventing behavior and body language from being observed by the interviewer. However, phone interviews offered anonymity that might have increased participant candor. Due to the audio recording method used, some of the audio was difficult to transcribe resulting in lost data. However, data loss was minimal.

As recommended by the 2022 ADRD summit recommendations and priorities, two of their goals are to prioritize biomarker studies of ethnic/racial persons with a special focus on increasing BD and to provide outreach and education to underrepresented groups, including studies on barriers to autopsy, importance of BD, as well as support and resources necessary to ensure studies consenting participants to BD studies are successful. Additionally, to increase autopsies on subjects from diverse backgrounds representative of the diversity of the US, including minority groups (e.g., Latinos). The support of policies and funding for human and material resources are critical. For example, 1) having sufficient personnel directly involved in recruiting and testing Latino participants, 2) having culturally-appropriate BD information for participants and 3) having a network flow between medical institutions/brain banks and funeral homes. Future research should interview staff from different ADRCs serving Latinos and discuss limitations and barriers to BD research. Findings from this small pilot study, lay the groundwork for our long-term goal of leveraging the Study of Latinos-Investigation of Neurocognitive Aging (SOL-INCA),

to enroll diverse Latinos for invasive procedures. SOL-INCA being the largest, and most representative/diverse longitudinal study of Latinos to date could greatly enhance and inform the recommendations to advance AD/ADRD research.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

Acknowledgment

We want to thank undergraduate students Ericka Garcia and Susana Murillo for helping with coding the transcripts. We also want to thank the participants who generously donated their time to participate in this study.

Funding

This work was supported by the National Institutes of Health (NIH)/National Institutes of Aging (NIA): P30AG059299; R01AG048642; UL1TR001442

BIBLIOGRAPHY

1. Dilworth-Anderson P, Hendrie HC, Manly JJ, Khachaturian AS, Fazio S. Diagnosis and assessment of Alzheimer's disease in diverse populations. Wiley Online Library; 2008.
2. Steenland K, Goldstein FC, Levey A, Wharton W. A meta-analysis of Alzheimer's disease incidence and prevalence comparing African-Americans and Caucasians. *Journal of Alzheimer's Disease* 2016;50(1):71–76.
3. Hispanic Heritage Month 2020 US Census Bureau. Accessed May 27, 2021. <https://www.census.gov/newsroom/facts-for-features/2020/hispanic-heritage-month.html>
4. National Alzheimer's Coordinating Center Uniform Data Set (UDS) Demographic and Diagnoses. Accessed March 2021. <https://naccdata.org/requesting-data/data-summary/uds>
5. Blennow K, de Leon MJ, Zetterberg H. Alzheimer's disease. *Lancet* (London, England) 2006;368(9533):387–403. [PubMed: 16876668]
6. Ikonomic MD, Klunk WE, Abrahamson EE, et al. Post-mortem correlates of in vivo PiB-PET amyloid imaging in a typical case of Alzheimer's disease. *Brain* 2008;131(6):1630–1645. [PubMed: 18339640]
7. Jack CR Jr, Knopman DS, Jagust WJ, et al. Tracking pathophysiological processes in Alzheimer's disease: an updated hypothetical model of dynamic biomarkers. *The Lancet Neurology* 2013;12(2):207–216. [PubMed: 23332364]
8. Rodriguez JL, Karikari TK, Suárez-Calvet M, et al. Plasma p-tau181 accurately predicts Alzheimer's disease pathology at least 8 years prior to post-mortem and improves the clinical characterisation of cognitive decline. *Acta Neuropathologica* 2020;140(3):267–278. [PubMed: 32720099]
9. Filshtein TJ, Dugger BN, Jin L-W, et al. Neuropathological Diagnoses of Demented Hispanic, Black, and Non-Hispanic White Decedents Seen at an Alzheimer's Disease Center. *J Alzheimers Dis* 2019;68(1):145–158. doi:10.3233/JAD-180992 [PubMed: 30775996]
10. Soria JA, Huisa BN, Edland SD, et al. Clinical-neuropathological correlations of Alzheimer's disease and related dementias in Latino volunteers. *Journal of Alzheimer's Disease* 2018;66(4):1539–1548.
11. Weissberger GH, Gollan TH, Bondi MW, et al. Neuropsychological deficit profiles, vascular risk factors, and neuropathological findings in Hispanic older adults with autopsy-confirmed Alzheimer's disease. *Journal of Alzheimer's Disease* 2019;67(1):291–302.
12. Alolod G, Gardiner H, Agu C, et al. A Culturally Targeted eLearning Module on Organ Donation (Promotoras de Donación): Design and Development. *Journal of medical Internet research* 2020;22(1):e15793–e15793. doi:10.2196/15793 [PubMed: 31929102]

13. Alvaro EM, Jones SP, Robles ASM, Siegel J. Hispanic organ donation: impact of a Spanish-language organ donation campaign. *Journal of the National Medical Association* 2006;98(1):28. [PubMed: 16532975]
14. Frates J, Bohrer GG. Hispanic perceptions of organ donation. *Progress in Transplantation* 2002;12(3):169–175. [PubMed: 12371041]
15. Boise L, Hinton L, Rosen HJ, Ruhl M. Will my soul go to heaven if they take my brain? Beliefs and worries about brain donation among four ethnic groups. *The Gerontologist* 2017;57(4):719–734. doi:doi:10.1093/geront/gnv683 [PubMed: 26935242]
16. Boise L, Hinton L, Rosen HJ, et al. Willingness to be a brain donor: a survey of research volunteers from four racial/ethnic groups. *Alzheimer disease and associated disorders* 2017;31(2):135. doi:10.1097/WAD.000000000000174 [PubMed: 27779492]
17. Glover CM, Shah RC, Bennett DA, Wilson RS, Barnes LL. Perceived Impediments to Completed Brain Autopsies Among Diverse Older Adults Who Have Signed a Uniform Anatomical Gift Act for Brain Donation for Clinical Research. *Ethnicity & Disease* 2020;30(Suppl):709–718. [PubMed: 33250618]
18. Montoya Y, Balbim GM, Glover CM, Marquez DX. “My Parent’s Body Is Sacred”: Perspectives From Adult Latino Children About Brain Donation for Alzheimer Disease Research. *Alzheimer Disease & Associated Disorders* 2021;35(1):88–90. [PubMed: 32218066]
19. Willms DG, Best JA, Taylor DW, et al. A systematic approach for using qualitative methods in primary prevention research. *Medical Anthropology Quarterly* 1990;4(4):391–409.
20. Glaser BG, Strauss AL. *Discovery of grounded theory: Strategies for qualitative research* Routledge; 2017.
21. Miles MB, Huberman AM. *Qualitative data analysis: An expanded sourcebook* sage; 1994.
22. Corbin J, Strauss A. *Basics of qualitative research: Techniques and procedures for developing grounded theory* Sage publications; 2014.
23. Donate Life California October 2, 2021. Accessed October 2, 2021. <https://donatelifecalifornia.org/>
24. Alzheimer’s Disease Research Centers. webpage. National Institute on Aging. 2021. Updated September 09, 2021. Accessed October 2, 2021. <https://www.nia.nih.gov/health/alzheimers-disease-research-centers#top>
25. Brain Donor Project 2021. Accessed October 2, 2021. <https://braindonorproject.org/>
26. Jeffres LW, Carroll JA, Rubenking BE, Amschlinger J. Communication as a predictor of willingness to donate one’s organs: An addition to the theory of reasoned action. *Progress in Transplantation* 2008;18(4):257–262. [PubMed: 19186578]
27. Smith SW, Kopfman JE, Lindsey LLM, Yoo J, Morrison K. Encouraging family discussion on the decision to donate organs: The role of the willingness to communicate scale. *Health communication* 2004;16(3):333–346. [PubMed: 15265754]
28. Fishbein M, Ajzen I. Belief, attitude, intention, and behavior: An introduction to theory and research. *Philosophy and Rhetoric* 1977;10(2)
29. Morgan S, Miller J. Communicating about gifts of life: The effect of knowledge, attitudes, and altruism on behavior and behavioral intentions regarding organ donation. *Journal of Applied Communication Research* 2002;30(2):163–178.
30. Morgan S, Miller J, Arasaratnam L. Signing cards, saving lives: An evaluation of the worksite organ donation promotion project. *Communication Monographs* 2002;69(3):253–273.
31. Weber K, Martin MM, Corrigan M, 160 MoC. Real donors, real consent: Testing the theory of reasoned action on organ donor consent. *Journal of Applied Social Psychology* 2007;37(10):2435–2450.
32. Oz MC, Kherani AR, Rowe A, et al. How to improve organ donation: results of the ISHLT/FACT poll. *The Journal of Heart and Lung Transplantation* 2003;22(4):389–410. [PubMed: 12681417]
33. Darnell KR, McGuire C, Danner DD. African American participation in Alzheimer’s disease research that includes brain donation. *American Journal of Alzheimer’s Disease & Other Dementias* 2011;26(6):469–476.
34. Schnieders T, Danner DD, McGuire C, Reynolds F, Abner E. Incentives and barriers to research participation and brain donation among African Americans. *American Journal of Alzheimer’s Disease & Other Dementias* 2013;28(5):485–490.

35. Ruiz ME, Ransford HE. Latino elders reframing familismo: Implications for health and caregiving support. *Journal of Cultural Diversity* 2012;19(2):50. [PubMed: 22924203]
36. Salsman JM, Butt Z, Pilkonis PA, et al. Emotion assessment using the NIH Toolbox. *Neurology* Mar 12 2013;80(11 Suppl 3):S76–86. doi:10.1212/WNL.0b013e3182872e11 [PubMed: 23479549]
37. United States. National Commission for the Protection of Human Subjects of Biomedical, Behavioral Research. The Belmont report: ethical principles and guidelines for the protection of human subjects of research Department of Health, Education, and Welfare, National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research; 1978.
38. Tropp LR, Erkut S, Coll CG, Alarcon O, García HAV. Psychological acculturation: Development of a new measure for Puerto Ricans on the US mainland. *Educational and psychological measurement* 1999;59(2):351–367 [PubMed: 21415932]

RESEARCH IN CONTEXT

Systematic Review:

Latinos are a large and understudied group within dementia brain and brain autopsy research. In this study, we interviewed community-dwelling Latinos who provided their insights and recommendations regarding the prospect of participating in brain donation research for ADRDs.

Interpretation:

Findings reveal willingness from this group to participate in brain donation research and recommendations for culturally-competent outreach and research strategies to include Latinos in autopsy consent for brain donation research.

Future directions:

Given new information from this study and the need for increased brain donation among Latinos in dementia research, we offer actionable recommendations for change and implementation.

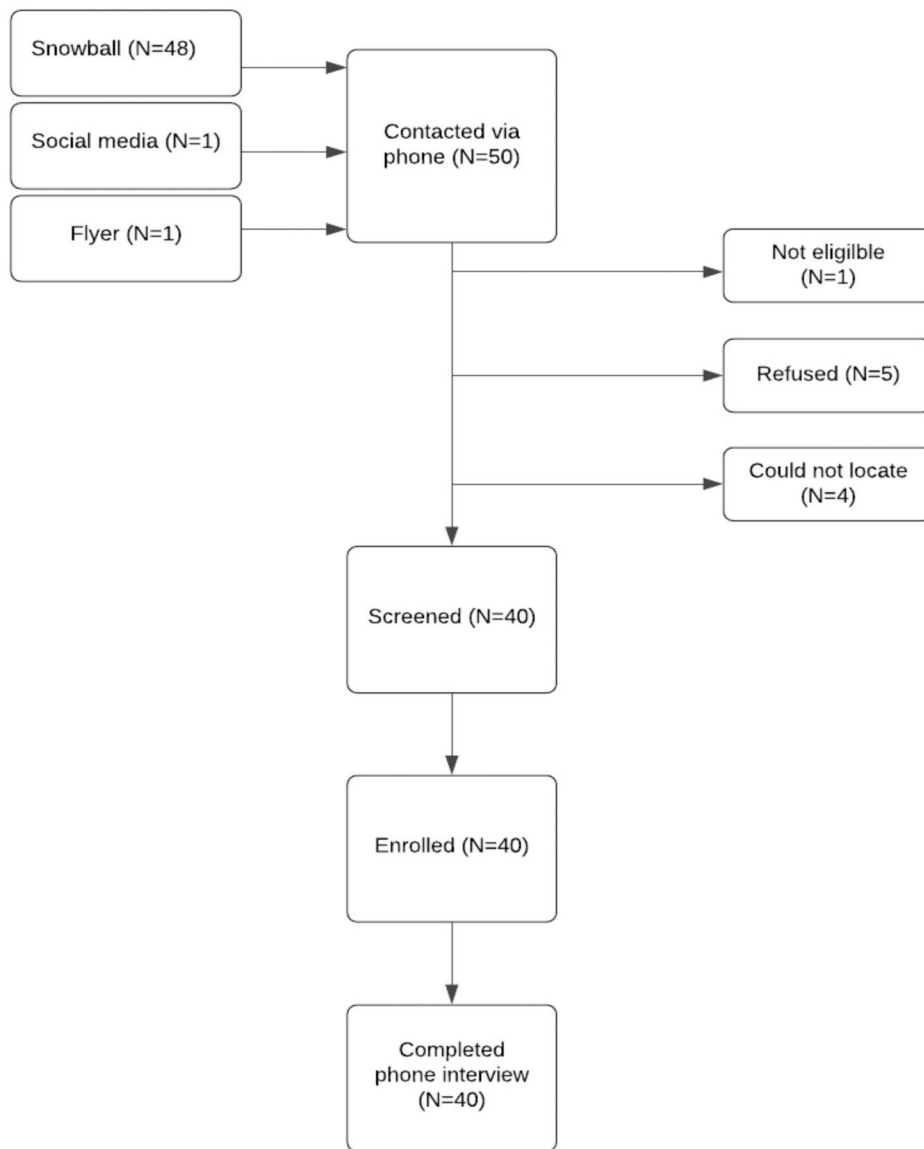


Figure 1.

Flow chart of participant recruitment.

Note: Flow chart depicts recruitment and enrollment of participants interviewed for the study

Table 1.

Participant characteristics

	Mean (SD)/ Count (%)
Demographics	N=40
Age	59.4 (7.35)
Gender (women)	27 (67.5%)
Total years of education	12.55 (3.21)
Country of birth	
Mexico	34 (85%)
US	4 (10%)
Other Latin American country	2 (5%)
Preferred language (Spanish)	37 (93%)
Years living in the U.S.	25.07 (11.77)
Household income	
Less than 10,000	2 (5%)
10,000 to 19,999	4 (10%)
20,000 to 34,999	7 (18%)
35,000 to 49,999	7 (18%)
50,000 to 74,999	9 (23%)
75,000 to 99,000	1 (3%)
100, 000 to 149,999	3 (8%)
150,000 or more	6 (15%)
Marital status	
Married or living in marriage-like relationship	28 (70%)
Separated	2 (5%)
Divorced	6 (15%)
Widowed	2 (5%)
Never married	2 (5%)
Culturally relevant factors	
Acculturation level*	2.98 (2.03)

* Using the PAS

Table 2.

Selected participant quotes for theme 1

Theme 1: Lack of knowledge about brain donation	
<p>“No, I have not thought about brain donation. I don’t know if I even knew [what] that was-- I’ve heard of it, but it doesn’t stand out in my- when I think about donating organs, I don’t think about the brain, I think of the heart, the lungs, the kidneys. I’ve heard of eyes but I’ve never really-- It goes deep down into science fiction movie status.”</p> <p>Subject 13, female, age 66</p>	
<p>“It is just that I don’t know, can a person while alive donate their brain? Well, if they will donate it is because they know they will die, right? But can they take it out and put it back? I don’t know.”</p> <p>Subject 34, female, age 80</p>	
<p>“What you are telling me right now about brain donation, I did not know [...]. I know that brains are studied and all, but donations, no. That is what should be talked about, what donations are for. We all know about blood donation, and we don’t do it. I know that here are there, and we don’t do it.”</p> <p>Subject 35, female, age 60</p>	
<p>“Not exactly. A friend of my mother died, and her body was donated to [a] university here. I don’t know exactly what the direct purpose was, what it was for.”</p> <p>Subject 2, female, age 61</p>	
<p>“I imagine that when the person dies, it is not that they take out the whole brain, but that a sample or a part of the brain is extracted and that is how research is done.”</p> <p>Subject 28, male, age 65</p>	

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Table 3.

Selected participant quotes for theme 2

Theme 2: Misconceptions about brain donation	
<p>“The truth is that I do not know why I feel that—you know how you get your license, and they tell you if you want to be a donor or not, if you accept to be a donor—you are donating all your body to science. Firstly, if there is someone that needs some part of your body, some organ or something like that, they will take it away, you already signed so I am imaging that the brain is part of the organs that they can extract.”</p> <p>Subject 23, male, age 51</p>	
<p>“No, never, actually, I didn’t know [...]. I think that the person who wants to donate their brain, would have to be in a vegetative state, ready to be disconnected from the machine. That would be the only way that the person could donate their brain.”</p> <p>Subject 31, female, age 58</p>	
<p>“[...] you know that when you are going to get a license, [they ask] if you want to donate organs, of course, everything must be in life, but right now [talking about the brain], just like for the moment, I don’t know, I would have to think about it very well, [...]”</p> <p>Subject 16, female, age 81</p>	
<p>“[I heard] the other day about brain transference. I heard that but [not sure if its true]. I didn’t give it any more thought.”</p> <p>Subject 13, female, age 66</p>	
<p>“Of course, I’m a donor [talking about driver license]. If they are going to use my whole body to help diseases, [they can also use] the brain, all the parts of my body are fine.”</p> <p>Subject 11, female, age 50</p>	

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Table 4.

Selected participant quotes for theme 3

Theme 2: Altruistic motivation for brain donation
<p>"Any little grain of salt we can contribute ourselves so that the future is better for other people is alright. It is a donation that one gives so that other people get better, not necessarily ourselves, because you will no longer feel anything, but other people might be helped with that."</p> <p>Subject 20, female, age 63</p>
<p>"No, I think that people, in actuality, we are more conscientious to be organ donors, to serve others if we can. If some part of my body can work, even better. Even better to donate it to another person. I think that people, little by little, become organ donors. I think, in my way of looking at things, that you live more conscientiously, more conscious about the future of others. Another person who does not have to be a family member, right?"</p> <p>Subject 19, male, age 59</p>
<p>"I think that it is a responsibility of each human being to put in the hands of scientists, of science, their brain, I think that it is a responsibility, since it's a characteristic of humankind to practice empathy."</p> <p>Subject 1, male, age 69</p>
<p>"I put myself in the place, in the function, to let it be known how one can help, you understand? In one way or another, let's suppose that one can help, but more than anything knowing about the illness and how, even if now, in five years, in ten years, this illness could no longer be, you understand? The illness needs to be known about, we know the consequences, but also in the studies people in the Latino community can contribute and we are more closed off."</p> <p>Subject 35, female, age 60</p>
<p>"It will not give me any benefit, I will have already died; but the direct or indirect future generations and the more people we do this I think that the sooner and more reliably there could be a treatment for future generation, and I think that is good."</p> <p>Subject 4, male, age 61</p>

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Table 5.

Selected participant quotes for theme 4

Theme 3: Beliefs and traditions influence openness towards brain donation	
<p>“Because almost all people with who we communicate at my age and at around 63, it is the culture, that is very important [...]. Because we can be very educated and read a lot of books, but beliefs are stronger than anything and the beliefs, that is the culture, that I hear people say, “oh no, I would not do it because my God would punish me, and I could not do that.”</p> <p>Subject 26, female, age 63</p>	Author Manuscript
<p>“Because Latinos we come from very little schooling, our culture is very close-minded [...]. Even some of us who finish school, we have some very engrained beliefs, and these are difficult to control, but the majority of Hispanics – depending on where they come from – it’s more work for us to realize that, because we were not taught that since childhood. Even though it can help others, we don’t see it, it doesn’t transcend into our thoughts that it could really help, how will I help if they will tear me all apart? It has to do a lot with our religion, our way of thinking, what will happen in the future. We don’t think that we can really do something later.”</p> <p>Subject 38, male, age 60</p>	Author Manuscript
<p>“A lot of people, really, we are ignorant sometimes. We were inculcated since childhood that we die and have to be buried. As Hispanics who come from, are afraid that the body is burnt, we have to be buried because that is what God said. I think that it makes it more difficult to donate their body, because they think it is like my mom says “why?” because God wants the body altogether, how will you be one hand here, and the other over there? No. making older people understand is impossible. Not like one sees and understands, we think differently. With our own culture it is very difficult that we donate part of our body.”</p> <p>Subject 32, female, age 50</p>	Author Manuscript
<p>“I think sometimes it’s a religious belief, “Oh, no, it’s a sin to cremate someone. You have to bury them”, and I don’t necessarily believe in that. I won’t need my body anymore. I’m going to get a new body, a heavenly body, so I’m not worried about that, but I think a lot of it would be cultural and spiritual, having to do with religious traditions, just lack of understanding or lack of education, where there’s people that don’t even want to talk about things like that. not for me, because for me, the religious aspect is me and God, spiritually, how we connect spiritually, the relationship that I have with him, and it has nothing to do with my body or what I do with it after I die. What they do with it after I die, if it can bring good, I think that’s wonderful.”</p> <p>Subject 13, female, age 66</p>	Author Manuscript
<p>“I am Christian, and I think that leads me to think that I should participate in the betterment of humanity.”</p> <p>Subject 1, male, age 69</p>	Author Manuscript

Table 6.

List of participant recommendations for recruitment of Latinos in brain donation research

Participant Recommendations	
<ul style="list-style-type: none"> • Content of information <ul style="list-style-type: none"> - Simple graphics - Easy to digest/read - Emphasize altruism - Emphasize the benefits • Type/method of information <ul style="list-style-type: none"> - Short videos online - Flyers or pamphlets - Television commercials - Radio - Yearly campaigns (e.g., brain donation month) to create conscience of ADRDs among Latinos - Workshops/presentations • Location of information <ul style="list-style-type: none"> - Outreach through schools (e.g., aimed at college students) - Flyers shared in waiting rooms and doctors' offices - Community centers where Latinos already congregate • Who should this information be directed to: <ul style="list-style-type: none"> - Primarily families coping with individuals with ADRD - Older Latinos - Children and college students (i.e., to create conscience of these issues at an early age) • Who should share the information: <ul style="list-style-type: none"> - Information coming from trusted sources (e.g., older children, doctor, pastor/priest) - Latino researchers that speak and identify with the targeted population 	

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