The Health Equity through Aging Research and Discussion (HEARD) Study:

A Mixed-Methods Approach to Barriers and Facilitators of Brain Donation Among Diverse Older Adults

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Rush Alzheimer’s Disease Center
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Acknowledgements

The Diversity of Community Members Engaged in Research
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Tarisha Washington, M.S. – ORE & MMR

Nothing To Disclose

National Institute on Aging (NIA)
Alzheimer’s Association
Challenges Related to Brain Donation

- Acceptable assessments of Alzheimer’s disease (AD) now include PET brain scan
- Diagnosis of Alzheimer’s disease and related dementias (ADRD) still require brain autopsy
- Low participation rates among older Black and Latino adults – despite persistent efforts
- Of older Black and Latino adults who consent, lower rates of completed brain autopsies
- Sensitive topics – process of and information gained from brain donation
- Sensitive topics – process of brain autopsy and effect on interment
Consequences

Limited availability of brain tissue from persons who belonged to under-included and understudied populations

- Understanding of ADRD within diverse communities
- Identification of issues and their potential treatments and solutions
- Applicability/generalizability of research findings to diverse populations
  - Drug and other pharmaceutical discoveries and their safety and efficacy
  - Preventive methods
  - Educational materials and outreach efforts
- Perceptions and lived experiences

Severely limited understanding of ADRD within Black and Latino communities
SOCIAL COGNITION

General Definition

The study of how people process and utilize information in social situations

“Social cognition is the study of how people make sense of other people and themselves.” (Fiske & Taylor, 1984)
The HEARD Study

Two-Phase Sequential Mixed-Methods Research Design

Data from the first phase inform the second phase to create a pipeline

Phase One: Qualitative
Meaningful, pointed understandings of diverse participant perspectives

Phase Two: Quantitative
Constructing more complete profiles of diverse participants

Survey Instrument Development
Quantifying potential factors influencing perspectives and decision making among a larger sample of diverse participants

Glover, Shah, Bennett, Wilson, & Barnes, 2020 (A)
<table>
<thead>
<tr>
<th></th>
<th>Barriers/ No to Brain Donation (n)</th>
<th>Facilitators/ Yes to Brain Donation (n)</th>
<th>Women (%)</th>
<th>Income (Median)</th>
<th>Age (Mean)</th>
<th>Years of Education (Mean)</th>
<th>Divorced (%)</th>
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</thead>
<tbody>
<tr>
<td>Older Black Adults</td>
<td>9</td>
<td>8</td>
<td>94%</td>
<td>$50,000 - $74,999</td>
<td>77 years</td>
<td>17 years</td>
<td>44%</td>
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<td>Older Latinos</td>
<td>7</td>
<td>6</td>
<td>92%</td>
<td>$20,000 - $24,999</td>
<td>73 years</td>
<td>14 years</td>
<td>54%</td>
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<td>Older Whites with Lower Income</td>
<td>7</td>
<td>8</td>
<td>87%</td>
<td>$15,000 - $19,999</td>
<td>76 years</td>
<td>16 years</td>
<td>55%</td>
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<td>Total Sample (N = 45)</td>
<td>23</td>
<td>22</td>
<td>91%</td>
<td>$30,000 - $34,999</td>
<td>76 years</td>
<td>16 years</td>
<td>51%</td>
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<tr>
<td>Theme</td>
<td>Subtheme</td>
<td>Representative Quote</td>
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<td>Family and the Future</td>
<td>Altruism and giving back</td>
<td>“...that's the one reason why I decided to donate my brain is because it may not save me, but it may save somebody's grandchild.”</td>
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<td></td>
<td>Brain donation benefits family</td>
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<td></td>
<td>Participant discordant from family re: brain donation</td>
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<td></td>
<td>Distinct focus on the future</td>
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<td>Activity and the Acquisition of Knowledge</td>
<td>Active: civic, cognitive, social, religious, research</td>
<td>“So, you know, I just enjoyed learning, so-being a retired teacher, I always love education.”</td>
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<td>Importance of education: overall health and AD</td>
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<td>Curious</td>
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<td>Social networks/open transmission of knowledge</td>
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<td>The Role of Research and Brain Donation</td>
<td>Trust/belief in research and brain donation to help self and serve community</td>
<td>“You need research, and you cannot find the answer without research.”</td>
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<td>Familiarity with research</td>
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<td>Pride in research participation</td>
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<td>Commitment to AD solutions through brain donation</td>
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<td>Elements of Decision Making for End of Life</td>
<td>Why not/Can’t take it with you</td>
<td>“It can benefit others, and for me, that is the spirituality.”</td>
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<td>Ownership of old age</td>
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<td>Preparation in relation to the future</td>
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<td>Spiritual beliefs not hindering brain donation</td>
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<td>Issue</td>
<td>Most Affected Group</td>
<td>Strategies to Address</td>
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<td>Uncertainty Surrounding the Processes of Brain Donation and Brain Autopsy</td>
<td>Older Whites with Lower Income</td>
<td>- Continued engagement - brain donation</td>
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<td>- Continued education - brain donation/autopsy</td>
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<td>- Printed materials - brain donation/autopsy</td>
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<td>- Potential simulation of brain autopsy</td>
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<td>Lack of Family Buy-In</td>
<td>Older Black Adults</td>
<td>- Family as participant</td>
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<td>- Family engagement - loved one’s research participation</td>
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<td>- Family education - role of research and brain donation in AD</td>
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<td>Lack of Family Follow-Through</td>
<td>Older Latinos</td>
<td>- Family education – the process of brain autopsy</td>
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Glover, Shah, Bennett, Wilson, & Barnes, 2020 (B)
Perspectives from Adult Latino Children About Brain Donation

Social and cultural context impacting BD perceptions
- Cultural beliefs
- Preparing for death
- Generational differences
- Decision making
- Altruism

Knowledge and information about the BD process
- Lack of knowledge or information
- General organ donation or BD?

Recommendations for engaging older Latinos and their families
- Increasing education about process of BD
- Raise awareness of benefits of BD
- Make it relatable with a family-centered approach

Montoya, Balbim, Glover, & Marquez, (2021)
Strategies to Address Brain Donation Consent and Completion

- Provide a brain donation packet to each participant who agrees to organ donation and their family members.
- Ask for funeral home information at home visits.
- Send letters to funeral homes informing them that a RADC study participant has signed the Uniform Anatomical Gift Act.
- Discuss brain donation with those who are not opposed but have not agreed.
- Increase diversity in methodological approaches to understand and leverage diverse participant perspectives.
- Develop strategies based on previous qualitative work.
- Co-design and co-strategize research questions, research conduct, addressing research-related challenges, and setting research agendas and priorities.

Marquez, Glover, Lamar, et al., 2020
Phase Two: Expanding Qualitative with Quantitative

Qualitative Theme
- Activity and the Acquisition of Knowledge

Qualitative Subtheme
- Active: Civic, cognitive, social, religious, research

Quantitative Measures
- Late Life Cognitive Activity
- Late Life Social Activity
Next Steps: Completion of The HEARD Study

1. Completed All Phases of Qualitative Data Analysis

Increase Brain Donation Consent and Completed Brain Autopsies among Older Black and Latino Adults

2. Complete Quantitative Phase – Identification of Variables and Statistical Analyses

3. Develop a Survey Instrument to Assess Brain Donation Decision Making among Older Black and Latino Adults

4. Disseminate Survey Instrument among Older Black and Latino RADC Participants
I Welcome Questions and Comments

RADC Research Resource Sharing Hub

Your vision

Our data

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