

2024 Fall ADRC Meeting - Theme: Biomarkers of Co-Occurring Pathologies
Wednesday, October 16, 2024

Special Session on Brain Donation
Hosted by ORE and Neuropathology Cores

Speakers and Panelists: Nancy Cherico, PhD, Tish Hevel, Katherine Brandt, MM
Arline Faustin, MD, and Darby Morhardt, PhD

Moderator: Crystal M Glover, PhD
ORE Core Leader: Rush Alzheimer's Disease Center

Session Overview

- ❑ The Focus of This Session and Why

- ❑ Welcoming Each Speaker
 - Introduce Themselves
 - Discuss Their Relationship to Brain Donation
 - Set Forth Takeaways from Their Perspective

- ❑ Panel Discussion

- ❑ Adjournment

Session Purpose

- ❑ Brain Donation as:
 - “The Gold Standard” - Remains critical for definitive dementia diagnosis and understanding disease trajectories
 - “...The Ultimate Marker of Retention.” – Dr. Dorothy Farrar Edwards
- ❑ Low rates of brain donation consent and subsequent autopsy completion among diverse older adults – despite consistent efforts
 - Severely limits our understanding of aging and ADRD
- ❑ Inform our brain donation approaches from diverse perspectives and methods

The HEARD Study

HEARD: Health Equity through Aging Research and Discussion

Purpose: To identify barriers, facilitators, and person-centered/-informed strategies regarding brain donation among diverse older adults

Two-Phase Sequential Mixed-Methods Research Design

Phase One: Qualitative (Focus Groups)

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

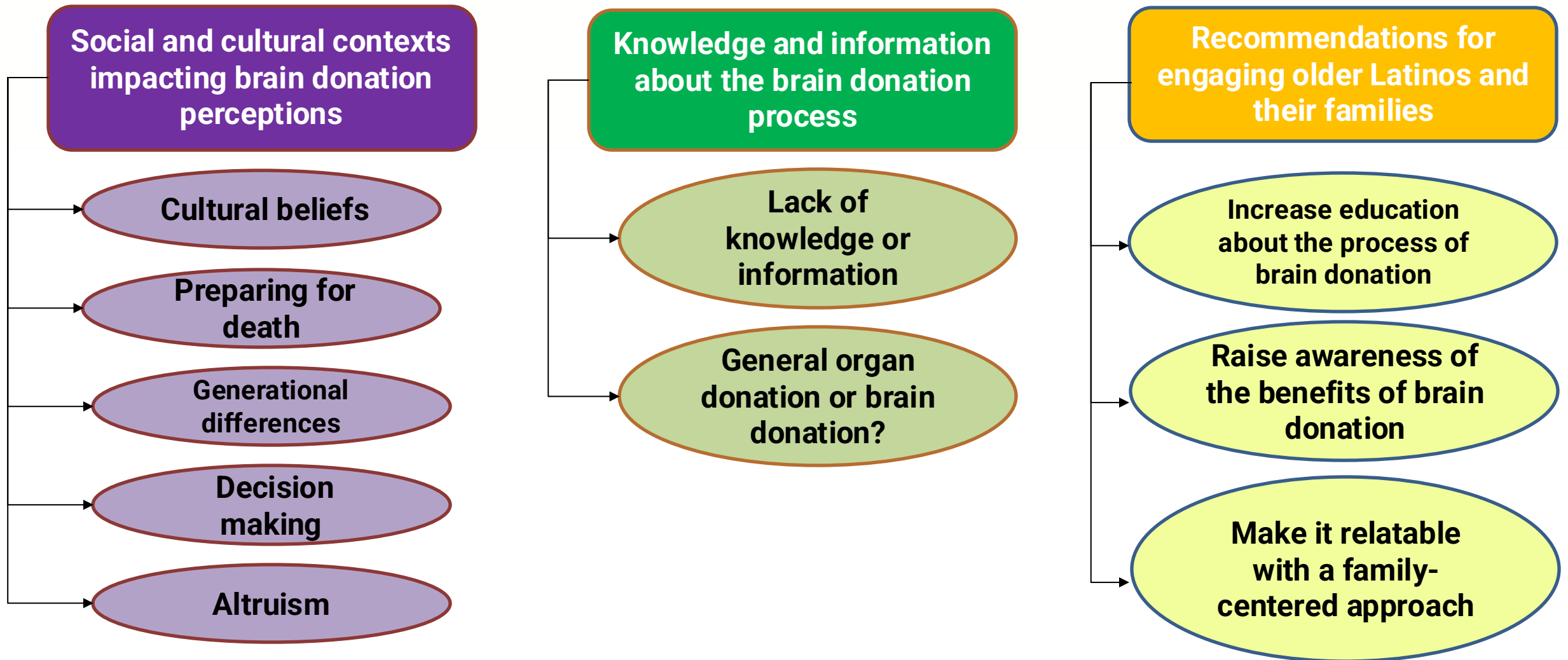
Phase One: Facilitators of Brain Donation Consent

Theme	Subthemes	Representative Quote	Divergent Elements
<p>Family and the Future</p>	<ul style="list-style-type: none"> ▪ Altruism and giving back ▪ Brain donation benefits family ▪ Participant discordant from family regarding brain donation ▪ Distinct focus on the future 	<p>“...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.”</p>	<p><u>Older Black Adults</u> Give back to family and the Black community – an obligation Define themselves by their roles in their families</p>
			<p><u>Older Latinos</u> A strong focus on their culture Avoidance of sadness of ADRD</p>
			<p><u>Older Whites with Lower Income</u> Give back to society, at large</p>

Phase One: Perceived Impediments to Brain Autopsy Completion

Issue	Most Affected Group	Strategies to Address
<p>Uncertainty Surrounding the Processes of Brain Donation and Brain Autopsy</p>	<p>Older Whites with Lower Income</p>	<ul style="list-style-type: none"> ▪ Continued engagement - brain donation ▪ Continued education - brain donation/autopsy ▪ Printed materials - brain donation/autopsy ▪ Potential simulation of brain autopsy
<p>Lack of Family Buy-In</p>	<p>Older Black Adults</p>	<ul style="list-style-type: none"> ▪ Family as participant ▪ Family engagement - loved one's research participation ▪ Family education - role of research and brain donation in ADRD
<p>Lack of Family Follow-Through</p>	<p>Older Latinos</p>	<ul style="list-style-type: none"> ▪ Family education - the process of brain autopsy

Perspectives of Adult Children of Older Latinos on Brain Donation



Strategies to Address Brain Donation Consent and Autopsy Completion

To facilitate brain autopsy completion, we have incorporated the following procedures, all with participant permission:

- ❑ For each participant who signs the Uniform Anatomical Gift Act (AGA) for organ donation (i.e., agrees to organ donation) and their family member(s), we (in part):
 - Provide a packet that includes informational flyers, refrigerator magnets, a list of frequently asked questions, and the lead investigator's business card with his telephone number for contact at anytime and to share with family members
 - Provide information to family members regarding the participant's RADDC cohort study involvement, organ donation wishes, and our telephone number to call upon death
 - Speak with family members to, in part, emphasize their important role of informing us when the participant passes away

Phase Two: Preliminary Quantitative Findings

- ❑ Minority Aging Research Study (MARS) ONLY (N = 812 as of 10/2023)
- ❑ Agreed to Brain Donation (AGA Signed, Consented; n= 423)
- ❑ Declined Brain Donation (AGA Not Signed, Not Consented; n= 389)

Factors Associated With Brain Donation Consent (AGA Signed)

(-) John Henryism Active Coping

(+) Global Cognition

(+) Care provision for others/Caregiving

(+) Healthcare and Financial Decision Making

Phase Two: Preliminary Quantitative Findings

- Latino Core (LATC) ONLY (N = 248 as of 10/2023)
- Agreed to Brain Donation (AGA Signed, Consented; n= 80)
- Declined Brain Donation (AGA Not Signed, Not Consented; n= 168)

Factors Associated With Brain Donation Consent (AGA Signed)	
(-) Neuroticism	(+) Late Life Cognitive Activity
(-) Familism	(+) Acculturation
(-) Vascular Risk Burden	(+) English-language proficiency
	(+) English-language use

Takeaway Messages

- ❑ The Central Role of Family and Community: “Family As Participant”

- ❑ Diversity In:
 - Expertise

 - Methodologies, Methods, and Engagement/Educational Approaches

 - Populations

- ❑ ADRCs as Resources

All Hands On Deck!