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The HEARD Study:

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

Crystal M. Glover, Ph.D.

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Rush Alzheimer's Disease Center

Today's Talk

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- Discuss health disparities in aging and Alzheimer's disease (AD)
- The importance of brain donation in achieving health equity
- The role of mixed-methods research
- The HEARD Study: Background and Preliminary Findings
- Next Steps
- Questions and Thoughts

Health Disparities

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- Disparities: Imbalance

- Health disparities: Largely preventable differences in the burden of disease, injury, violence, or opportunities to achieve optimal health experienced by socially disadvantaged groups

- Not an anomaly but the state of health and healthcare

Health Disparities in Aging

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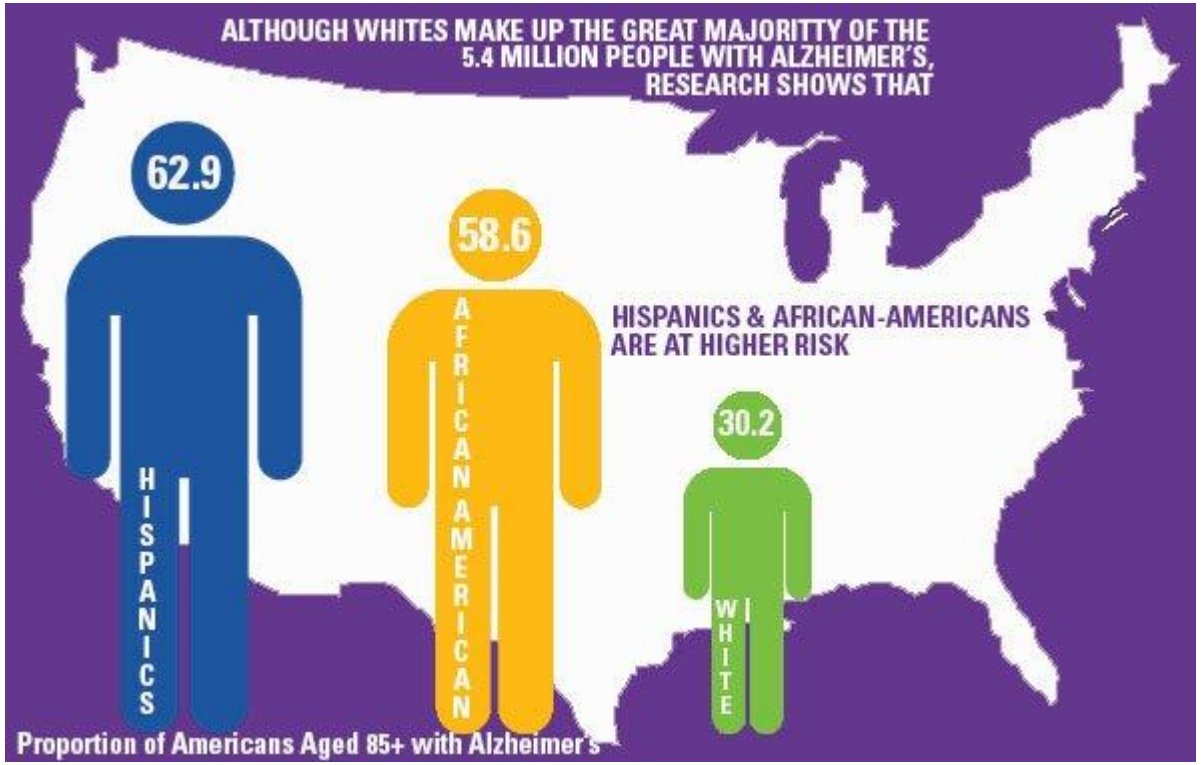

Health Equity in AD and Aging

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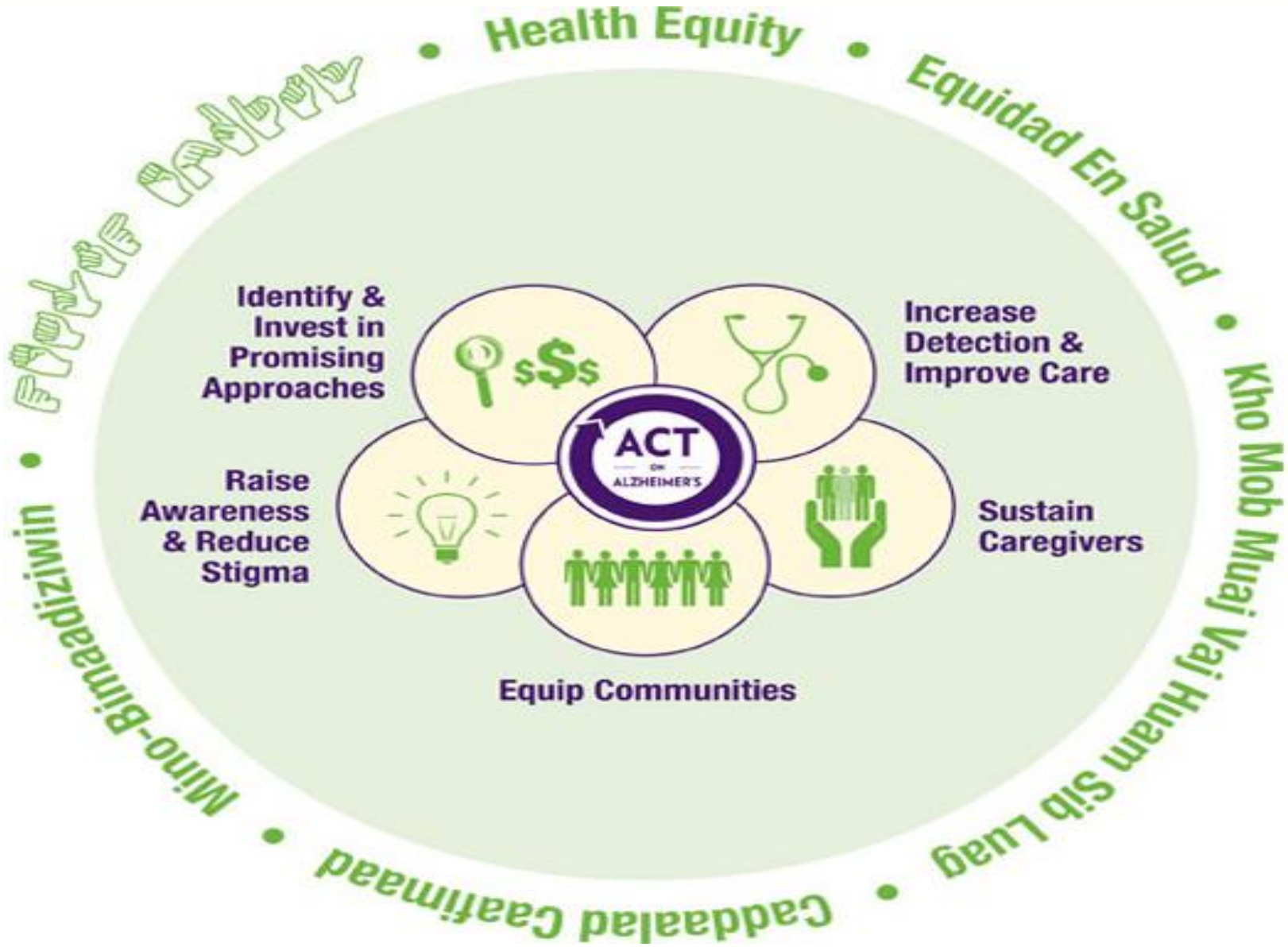

Considering Brain Donation

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- With brain donation, we can:
  - ➢ Learn more about AD in a multitude of diverse populations
  - ➢ Improve existing treatments for AD
  - ➢ Discover how to better prevent AD
  - ➢ Develop a cure….

- Currently, only a post-mortem autopsy of the brain can positively indicate that a person had AD or any other dementia

Challenges Related to Brain Donation

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- Low minority participation in brain donation – despite persistent efforts
- Of older minorities who consent, lower rates of completed brain autopsies exist
- Sensitive topics – process of and information gained from brain donation
- Sensitive topics – process of brain autopsy and effect on interment

Issue

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Limited availability of brain tissue from persons who belonged to underrepresented and understudied populations

Consequences

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A Lack of:

- Inclusion in research and brain donation
- Understanding of AD within diverse communities
- Identification of issues and their potential 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

Why Mixed-Methods Research

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Integration of 2 Components Into 1 Study: Quantitative and Qualitative

- Sensitive, nuanced concepts where quantitative methods alone cannot adequately capture the appropriate information
- Centrality of diverse participant perspectives or “lived” experiences
- A “real world view” of concepts
- Development of culturally competent instruments, educational materials, and intervention strategies

The HEARD Study

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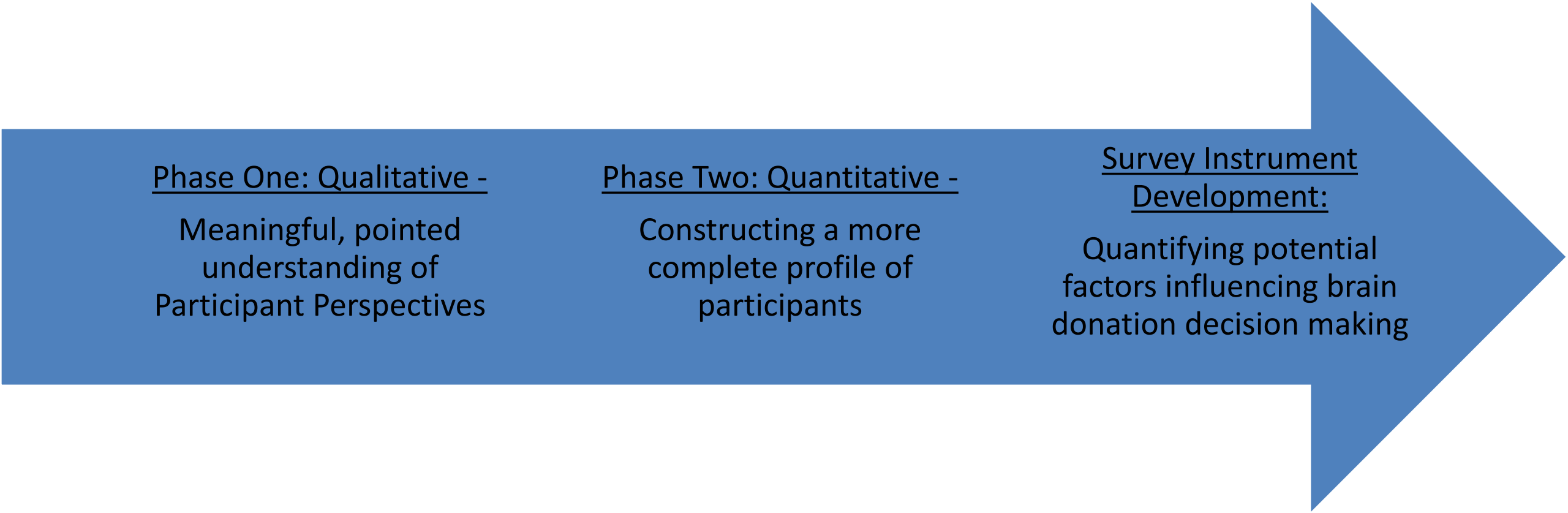
HEARD: Health Equity through Aging Research and Discussion

Two-Phase Sequential Mixed-Methods Research Design



Glover et al. (Under Review)

The HEARD Study

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Purpose

To identify specific factors that either serve as barriers to or facilitators of brain donation among older minorities using a mixed-methods research design

The HEARD Study: Phase One - Qualitative

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Phase One-A: Identify barriers to brain donation

- Who: Participants who declined brain donation or are unsure about brain donation

- Why: Understanding why participants, overall and by minority group, decline brain donation can enrich and tailor research efforts

The HEARD Study: Phase One - Qualitative

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Phase One-B: Identify facilitators of brain donation

- Who: Participants who agreed to brain donation
- Why: Understanding why minority participants agreed to brain donation can inform how to design and implement tailored research efforts
- Identify specific factors that may impede completed brain autopsies among older minorities who have agreed to brain donation

The HEARD Study: Phase Two - Quantitative

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Phase Two: Examine distinguishing factors

- Who:
  - —Between brain donation decision groups
  - —Within groups - brain donation decision AND minority group
- What: Variables representing a Biopsychosocial-Spiritual Approach to Aging
- How: Statistical analyses using existing RADC cohort data
- Why: Develop more complete profiles of participants who agreed and declined

The HEARD Study: Merging

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Develop a survey instrument regarding brain donation

- What: Addressing both barriers and facilitators to brain donation
  - —Directly stemming from focus group data
  - —Directly stemming from statistical analyses
  - —Questions operationalize qualitative themes and significant quantitative variables
- Who: Distribute survey instrument to a subsample of RADC participants
- Why: Examine participant responses
  - — Examine the quality of the survey instrument
  - — Refine
  - — Disseminate across all RADC cohorts where brain donation is optional

Phase One: Qualitative Focus Groups

Phase One: Participants

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- 60 years of age or older
- Free of dementia
- Self-identified as African American, Latinx, or White of lower income
    - —Self-reported income ≤150% of the 2018 Federal Poverty Level or a yearly income of ≤$19,999
- Agreed to or declined brain donation
- English proficiency – written and verbal

Phase One: Recruitment

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- Two simultaneous strategies

- Strategy 1: Identify eligible persons based on study criteria who belong to 1 of 4 existing RADC cohort studies

- Strategy 2: Presentations and flyers at community-based sites where existing cohort study participants and affiliated persons frequent

Phase One: Focus Group Guides

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- Two Separate Guides
  - —One for participants who agreed to brain donation
  - —One for participants who declined brain donation

- Questions Represent 7 Content Areas
  - —Knowledge of AD
  - —Perceptions of research
  - —Perceptions and knowledge of brain donation
  - —Brain donation decision
  - —Altruism and thinking of the future
  - —Religious beliefs
  - —Closing

Phase One: Focus Group Design

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- 3 (Minority Group: African American, Latinx, Older White of Lower Income) x 2 (Brain Donation Decision: Consented or Declined) Design
- Hence, at least 6 separate focus groups
- One-time, semi-structured
- Qualitative sampling algorithm – 5-8 participants per cell
- Unit of analysis is the focus group
- Focus groups audio-recorded and transcribed

Phase One: Analyses

Four Phases

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- Phase One:
  - —Inductive Grounded Theory Approach with Open Coding
  - —Stratify by brain donation status – consented or declined
- Phase Two: Facilitators
  - —Inductive Grounded Theory Approach with Constant Comparative Coding
  - —Stratify by minority group status
- Phase Three: Barriers
  - —Inductive Grounded Theory Approach with Constant Comparative Coding
  - —Stratify by minority group status
- Phase Four: A Focus on Minority Group Status
  - —Inductive Grounded Theory Approach with Open Coding
  - —Stratify by brain donation status – consented or declined

Phase One: Recruitment Funnel

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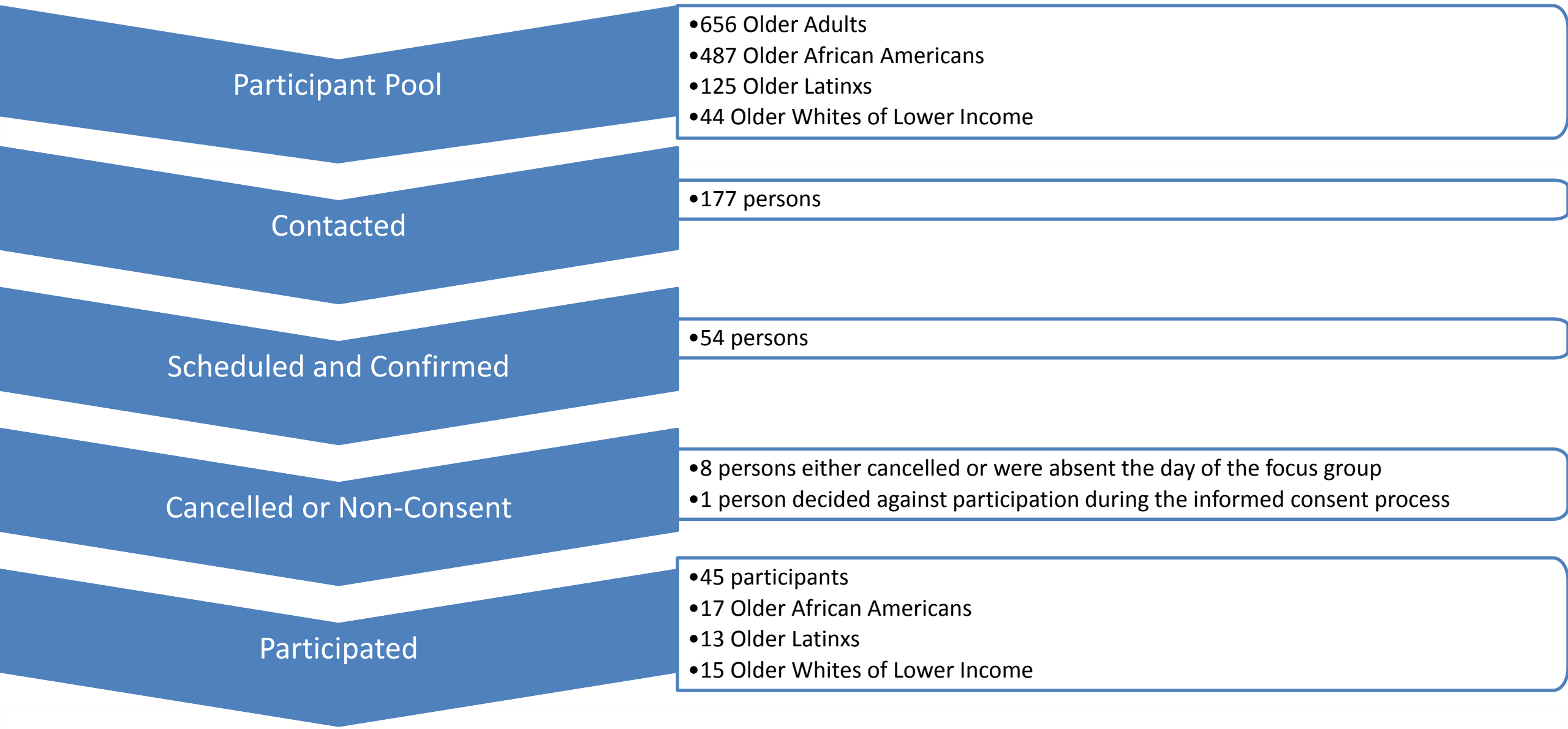

Phase One: Participant Demographic Characteristics

	Barriers/ No to Brain Donation (n)	Facilitators/ Yes to Brain Donation (n)	Women (%)	Income (Median)	Age (Mean)	Years of Education (Mean)	Divorced (%)
Older African Americans	9	8	94%	$50,000 - $74,999	77 years	17 years	44%
Older Latinxs	7	6	92%	$20,000 - $24,999	73 years	14 years	54%
Older Whites of Lower Income	7	8	87%	$15,000 - $19,999	76 years	16 years	55%
Total Sample (N=45)	23	22	91%	$30,000- $34,999	76 years	16 years	51%

Phase One: Themes for Facilitators of Brain Donation

Theme	Subtheme	Representative Quote
Family and the Future	• Altruism and giving back • Brain donation benefits family • Participant discordant from family regarding brain donation • Distinct focus on the future	….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.
Activity and the Acquisition of Knowledge	• Active: civic, cognitive, social, religious, research • Importance of education: overall health and AD • Curious • Social networks/open transmission of knowledge	So, you know, I just enjoyed learning, so- being a retired teacher, I always love education.
The Role of Research and Brain Donation	• Trust/belief in research and brain donation to help self and serve community • Familiarity with research • Pride in research participation • Act of commitment to AD solutions through brain donation	You need research, and you cannot find the answer without research.
Elements of Decision Making for End of Life	• Why not/Can't take it with you • Ownership of old age • Preparation in relation to the future • Spiritual beliefs not hindering brain donation	It can benefit others, and for me, that is the spirituality. **Glover et al. (In Preparation)**

Phase One: Impediments to Brain Autopsy Completion

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Issue	Most Affected Population	Ways to Address
Uncertainty Surrounding the Processes of Brain Donation and Brain Autopsy	Whites of Lower Income	• Continued engagement - brain donation • Continued education - brain donation/autopsy • Printed materials - brain donation/autopsy • Potential simulation of brain autopsy
Lack of Family Buy-In	African Americans, Latinxs	• Family as participant • Family engagement - loved one's research participation • Family education - role of research and brain donation in AD • Family education – the process of brain autopsy

Next Steps: Completion of The HEARD Study

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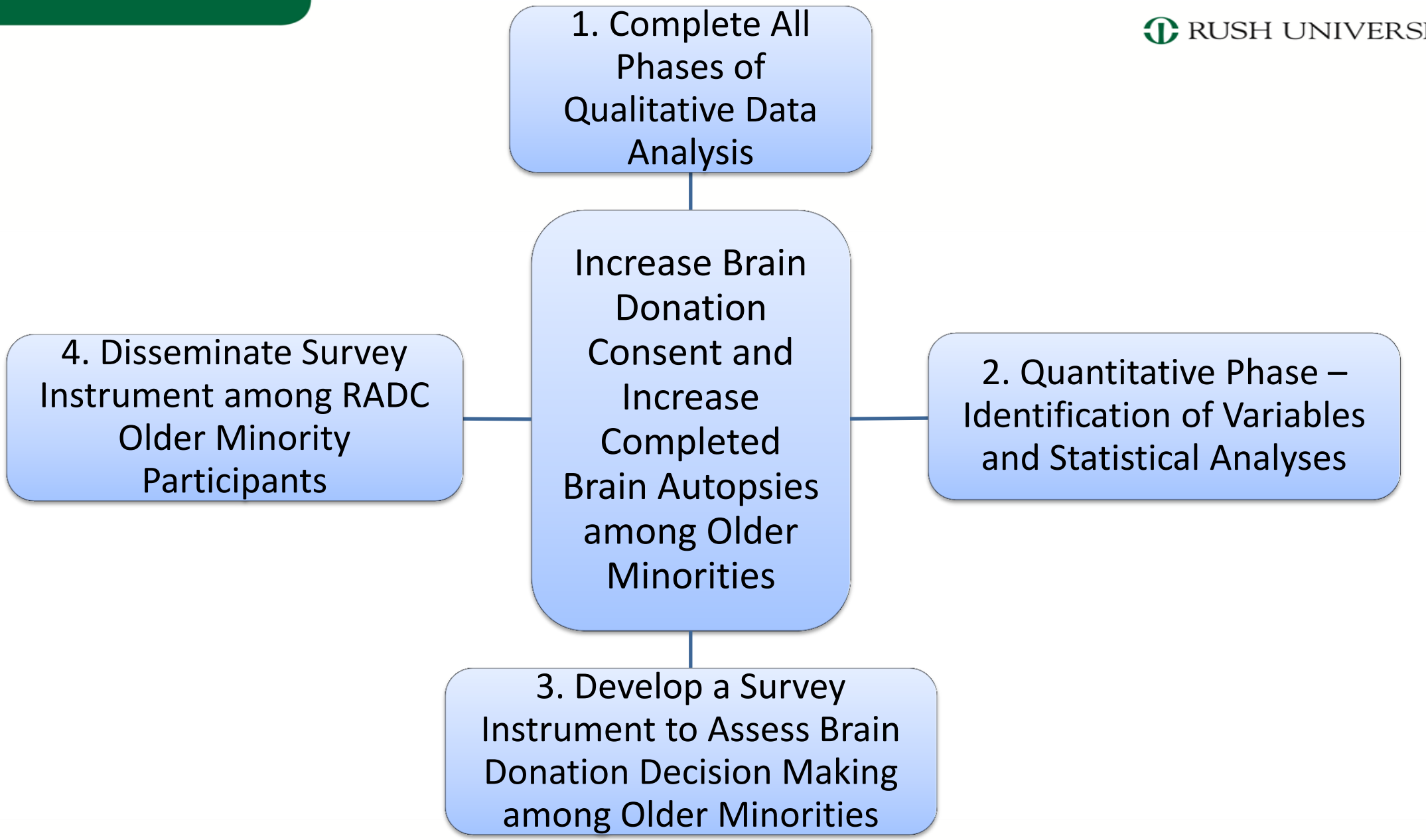

Other Potential Next Steps

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Thank You….Questions and Comments (Now and Later)

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All HEARD Study Participants

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- Lisa L. Barnes, Ph.D.
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