THE NGAGEDD MODEL:

RESEARCH EFFORTS WITH LATINO COMMUNITIES, BEFORE AND DURING COVID-19

Crystal M. Glover, Ph.D.
Keynote Address
ADC/ADRC ORE Core Meeting
Fall 2020
Acknowledgments

- NIA and All ORE Core Teams
- Dr. Allison Lindauer
- Alzheimer’s Association
- The Rush ADC and Dr. David A. Bennett, Director
  - Dr. Lisa L. Barnes, Leader of the Clinical Core
  - Dr. Raj C. Shah, Past Leader of the ORE Core

Dr. David X. Marquez, Leader of the Latino Core at the Rush ADC

The Rush ADC ORE Core and Latino Core Teams

All Caregivers and Community Members Engaged In Research
Overall Goal of the Rush ADC ORE CORE

To **cultivate inclusive** and **engaged participation** of **diverse persons underrepresented and understudied in research** on the etiology, pathogenesis, diagnosis, treatment, and prevention of **ADRD**.
Demographics: A Focus on Latino Communities

- Currently, largest ethnic minority group in the U.S. - 18% and rising

- From 2017 to 2050, the number of older Latinos is expected to increase from 4.2 to 15.9 million

- 33 subgroups – Largest being Mexican, Puerto Rican, and Cuban

- Varying in culture and related practices, race, language, and immigration status

- Illinois ranks 7th in the U.S. for the number of older Latinos, mostly in Chicagoland
ADRD: A Focus on Latino Communities

Number of Latinos in U.S. with AD is projected to increase by 832% by 2060

(Wu, Vega, Resendez, Jin, & Scholar, 2016)
Findings from ADRD studies with older non-Latino Whites may not apply

Older Latinos face potentially distinctive:

- Risk factors for ADRD such as structural assimilation
- Resilience factors like familial relationships and religiosity
- Requires a minority health/health equity lens

To identify potential causes and related risk reduction strategies specific to older Latinos in relation to ADRD

Marquez, Glover, Lamar, et al., 2020
The NGAGEDD Model

Network
Give First
Advocate for Research
Give Back
Evaluate
Design
Develop

Outer circle represents community activities, middle circle represents participant input on research, and inner circle represents individual study activities.

NGAGEDD Efforts: A Focus on Latinos

- Diverse demographic and professional team-based approach
- Cultural competence, as implicit and explicit biases can rear their heads
  - Learning and appreciating the lived experiences of participants
  - Learning and understanding historical knowledge regarding diverse Latino communities
- Shared/common values (e.g., Familismo, Personalismo, and Fatalismo)
## NGAGEDD Activities

<table>
<thead>
<tr>
<th>Event or Activity (N=794)</th>
<th># Participants</th>
<th>Ethnicity Latino</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Network</td>
<td>8,561</td>
<td>2,911 (34%)</td>
</tr>
<tr>
<td>2. Give First</td>
<td>10,713</td>
<td>4,607 (43%)</td>
</tr>
<tr>
<td>3. Advocate for Research</td>
<td>5,844</td>
<td>2,194 (36%)</td>
</tr>
<tr>
<td>4. Give Back</td>
<td>7,766</td>
<td>699 (9%)</td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td><strong>32,884</strong></td>
<td><strong>10,194 (31%)</strong></td>
</tr>
</tbody>
</table>

## Research Participation

<table>
<thead>
<tr>
<th>Activity</th>
<th># Participants</th>
<th># Latino</th>
</tr>
</thead>
<tbody>
<tr>
<td>Signed into Rush Memory Clinic Data and Specimen Repository</td>
<td>33</td>
<td>2 (6%)</td>
</tr>
<tr>
<td>Enrolled in Rush ADC and NIH-Supported Studies</td>
<td>561</td>
<td>40 (7%)</td>
</tr>
</tbody>
</table>
Shared/common values are important, but other factors also impact Latinos.

- Focused on participant perspectives to better understand individuals.
  - Background including their lives in the U.S. and/or immigration experiences.
  - Current resilience and coping mechanisms, and challenges and barriers.
  - The role of research and related experiences.
Brain Donation: A Focus on Latino Communities

- Low Latino participation in brain donation – despite persistent efforts
- Of older Latinos who agreed, lower rates of completed brain autopsies
- Limited availability of brain tissue from older Latinos
- Severely limits our understanding of ADRD
Brain Donation Across 5 Rush ADC Cohort Studies

Latinos

N=444 Consented to Study

N=175 Not Agreed to Brain Donation
N=267 Agreed to Brain Donation

N=201 Alive

N=66 Deceased

N=18 (27%) Missed Brain Autopsy
N=48 (73%) Completed Brain Autopsy
## Barriers and Facilitators of Agreeing to Brain Donation Among Older Latinos

<table>
<thead>
<tr>
<th>The Role of Family</th>
<th>Barriers Among Older Latinos Who Have Not Agreed to Brain Donation</th>
<th>Facilitators Among Older Latinos Who Have Agreed to Brain Donation</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Lack of family buy-in, in general</td>
<td>Altruism and giving back</td>
</tr>
<tr>
<td></td>
<td>Culture and family blended and overlapped</td>
<td>Brain donation benefits family</td>
</tr>
<tr>
<td></td>
<td>Male-centered approval in brain donation decision making</td>
<td>Avoidance of sadness of AD</td>
</tr>
<tr>
<td>Perceived Impediment</td>
<td>Most Affected Population</td>
<td>Representative Quote</td>
</tr>
<tr>
<td>------------------------------</td>
<td>--------------------------</td>
<td>----------------------------------------------------------------------------------------------------------</td>
</tr>
</tbody>
</table>
| Lack of Family Follow-Through| Latinos                  | “And so the children have to know that because my son said—one of my sons said, ‘I’m glad you’re telling me this. And I’m glad it’s written down because I would’ve fought hard not to have any of this done.’” | ❑ Family as participant  
❑ Family engagement - loved one’s research participation  
❑ Family education - role of research/brain donation  
❑ Family education - process of brain autopsy |

Glover, Shah, et al., In Press
Perspectives of Adult Children of Older Latinos Regarding Brain Donation for ADRD Research

- 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, (2020)
Strategies to Address Brain Donation: A Focus on Latinos

- Provide a packet to each participant who has agreed to brain donation
  - And their family members

- Ask for funeral home information at home visits

- Send informational letters to funeral homes regarding Rush ADC study participant

- Discuss brain donation with those who are not opposed but have not agreed

- Developing strategies based on previous qualitative research

Marquez, Glover, Lamar, et al., 2020
Next Steps in ORE and Other Research Activities With Latino Communities

- Continue quarterly “Cafecitos” as retention events

- Continue addressing intertwined needs for bicultural and/or race/ethnicity-matched staff
  - Especially those who are bilingual in English and Spanish

- Continue community-based efforts

- ORE efforts with older Latino men, specifically

- ORE efforts with diverse Latinos
A Partial Pivot: Research As Service

CDC Has Information For Older Adults at Higher Risk

8 out of 10 COVID-19 deaths reported in the U.S. have been in adults 65 years old and older. Visit CDC.gov/coronavirus for steps to reduce your risk of getting sick.

cdc.gov/coronavirus

COVID-19 CASES, HOSPITALIZATION, AND DEATH BY RACE/ETHNICITY

<table>
<thead>
<tr>
<th>FACTORS THAT INCREASE COMMUNITY SPREAD AND INDIVIDUAL RISK</th>
<th>American Indian or Alaska Native, Non-Hispanic persons</th>
<th>Asian, Non-Hispanic persons</th>
<th>Black or African American, Non-Hispanic persons</th>
<th>Hispanic or Latino persons</th>
</tr>
</thead>
<tbody>
<tr>
<td>CROWDED SITUATIONS</td>
<td>2.8x higher</td>
<td>1.1x higher</td>
<td>2.6x higher</td>
<td>2.8x higher</td>
</tr>
<tr>
<td>CLOSE / PHYSICAL CONTACT</td>
<td>5.3x higher</td>
<td>1.3x higher</td>
<td>4.7x higher</td>
<td>4.6x higher</td>
</tr>
<tr>
<td>ENCLOSED SPACE</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>DURATION OF EXPOSURE</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>CASES*</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>HOSPITALIZATION*</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>DEATH*</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Race and ethnicity are risk markers for other underlying conditions that impact health — including socioeconomic status, access to health care, and increased exposure to the virus due to occupation (e.g., frontline, essential, and critical infrastructure workers).
A Partial Pivot: Research As Service (COVID-19)

- Provided informational letters – Spanish and English

- A series of Townhalls addressing COVID-19 and Latino communities – Spanish and English

- Hosted a webinar on the proper use of PPE – Spanish and English

- PPE drives and distribution, especially focused on Latino and other diverse communities

- Laundromat Health and Wellness Fairs
  - Partnered with local laundromats owned by Latinos and other persons of color
  - Provided informational materials, PPE, and resources for laundering
  - Focused on communities of color, especially essential workers
Curbside Cafecitos – First One Next Month!

Virtual Memory Café/ Café de los Recuerdos

Almorzando Juntos – Caminando Juntos AARP Caregiving Conference

Brain Activity Journal – Spanish

Stressbusters for Caregivers - Spanish
In Closing…

**Inequality**
Unequal access to opportunities

**Equality?**
Evenly distributed tools and assistance

**Equity**
Custom tools that identify and address inequality

**Justice**
Fixing the system to offer equal access to both tools and opportunities
Thank You....Questions and Comments