Equity and Cultural Adaptation in Dementia Caregiving I

It’s a Family Affair: Caregiving in African American/Black Communities

Kalisha Bonds Johnson, PhD, RN, PMHNP-BC
Assistant Professor, Tenure Track
Nurse Practitioner
Emory University
Session Outline

- Presentation by Dr. Bonds Johnson
- Presentation by Dr. Medina
- Shared Slides
- Audience Questions
Where do we stand with culturally adapting dementia caregiving interventions for African American/Black dementia caregivers?
Culturally adapting dementia caregiving interventions

Lessons learned
  Previous research
  Lived experiences
Successes
  Developing interventions
  Testing interventions
Still needed
  Time
  Community partnerships
Designing a Culturally Tailored Formal Care Decision-Making Intervention for African American Dementia Dyads and Families

• Disproportionate burden of caregiving for persons living with Alzheimer’s disease and related dementias
• Health care is essential
• Structured approach focused on contextual factors that influence formal care decision-making process
What are the implications for practice for public health agencies to better support African American/Black caregivers?
Implications for practice for public health agencies

Opportunities to increase access
- Partnering with researchers or research-intensive institutions

Role in cultural adaptation of interventions
- From inception to dissemination

Policy recommendations
- Practice change about identifying caregivers
Why should public health agencies be aware of this work?
Awareness of this work

African American/Blacks are at greater risk for developing dementia

- More caregivers
- More need for resources

Caregivers “look” different in African American/Black communities

- Predominantly adult daughters or nonspouse caregivers
- Not a monolithic group of individuals
How can public health agencies elevate this work within African American/Black communities?
How to elevate this work

Recognizing your reputation
• Gatekeeper in the community

Awareness of the research/researchers
• Word of mouth

Establishing and sustaining partnerships
• “Real” community engagement
Thank You!

@DrBondsJohnson & @DECIDE_Lab
kbonds@emory.edu

NIA K23 [K23 AG073516] (2021-2026)
Kenneth Hepburn, PhD, FGSA
Karen Lyons, PhD, FGSA
Wizdom Powell, PhD, MPH, MS, BA
Equity and Cultural Adaptation in Dementia Caregiving I

*Cuidando Entre Nos: Caregiving in Hispanic/Latin American Communities*

Luis D. Medina, PhD
Assistant Professor, Tenure Track
Neuropsychologist
University of Houston
The CARMA Team @ UH
(est. 2018)

LDMedina2@uh.edu

Colaboradores

University of Colorado School of Medicine
Baylor College of Medicine
Rice University
University of Southern California
University of Northern Texas
Massachusetts General Hospital
University of California San Diego
**Long-term goal:**
- to address effective recruitment of Hispanics/Latinos into aging and Alzheimer's disease research

**Aims:**
- inspire & recruit community members (stakeholders) to become part of the recruitment infrastructure
- develop community-relevant awareness, education, and recruitment materials (products)
- support research infrastructure & facilitate inclusive enrollment in aging research (pilot grants)

"There are a lot of people in the community who want to help and who are curious. All you have to do is ask."  
Ned Norman, High Plains Research Network Community Advisory Council member
Hispanic/Latino Paradox of AD

1.5x Risk

Earlier Onset
Greater Severity
Later Diagnosis

Age ~7 years
NIH RCDC 2018 Report

<table>
<thead>
<tr>
<th>Total</th>
<th>Median</th>
<th>% H/L</th>
</tr>
</thead>
<tbody>
<tr>
<td>2,660,047</td>
<td>6%</td>
<td></td>
</tr>
<tr>
<td>1,209,266</td>
<td>6%</td>
<td></td>
</tr>
<tr>
<td>822,859*</td>
<td>10%</td>
<td></td>
</tr>
<tr>
<td>165,533</td>
<td>6%</td>
<td></td>
</tr>
<tr>
<td>294,562</td>
<td>10%</td>
<td></td>
</tr>
<tr>
<td>203,113</td>
<td>5%</td>
<td></td>
</tr>
<tr>
<td>236,517</td>
<td>14%</td>
<td></td>
</tr>
<tr>
<td>486,706</td>
<td>6%</td>
<td></td>
</tr>
<tr>
<td>52,256</td>
<td>11%</td>
<td></td>
</tr>
<tr>
<td>171,644</td>
<td>6%</td>
<td></td>
</tr>
</tbody>
</table>

*Represents RCDC Category “Emergency Care”
### Representation vs Transparency

<table>
<thead>
<tr>
<th></th>
<th>Age</th>
<th>Education</th>
<th>Gender</th>
<th>Race/Ethnicity</th>
<th>Acculturation</th>
<th>Language</th>
<th>SES</th>
</tr>
</thead>
<tbody>
<tr>
<td>ACN</td>
<td>97.3</td>
<td>98.7</td>
<td>82.3</td>
<td>83.1</td>
<td>82.3</td>
<td>93.9</td>
<td>35.0</td>
</tr>
<tr>
<td>JCEP</td>
<td>99.0</td>
<td>100</td>
<td>77.1</td>
<td>77.9</td>
<td>92.3</td>
<td>98.1</td>
<td>20.0</td>
</tr>
<tr>
<td>JINS</td>
<td>97.5</td>
<td>100</td>
<td>72.9</td>
<td>76.7</td>
<td>87.9</td>
<td>96.7</td>
<td>22.9</td>
</tr>
<tr>
<td>NEU</td>
<td>95.7</td>
<td>100</td>
<td>74.5</td>
<td>74.7</td>
<td>84.9</td>
<td>97.0</td>
<td>10.8</td>
</tr>
<tr>
<td>TCN</td>
<td>98.1</td>
<td>99.3</td>
<td>85.6</td>
<td>91.4</td>
<td>90.9</td>
<td>98.6</td>
<td>24.5</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>97.6</strong></td>
<td><strong>99.6</strong></td>
<td><strong>77.7</strong></td>
<td><strong>80.8</strong></td>
<td><strong>88.0</strong></td>
<td><strong>89.6</strong></td>
<td><strong>21.5</strong></td>
</tr>
</tbody>
</table>

O’Bryant et al. (2004); Medina et al. (2021)
No One-Size-Fits-All

Figure 5: English Proficiency Among Foreign-Born Latinx - 2017

Figure 7: Educational Attainment of Foreign-Born Latino Adults by Length of Residence in the U.S. - 2017

The Public Health Opportunities and Challenges of Dementia Caregiving
National Conference June 14-15 2022
“Building trust, improving communication, and developing cultural competency are vital steps for inclusion. Including diverse voices from the community at each of these steps is vital for equity.
Culturally Responsive Language

- **Actively and consciously** considering beliefs, phrases, and customs that may be specific to H/Ls.
- Communication depends on target group.
  - Heritage Groups (e.g., Mexican, Cuban, Puerto Rican)
  - Socioeconomic Status (SES)
  - Age
  - Education
  - Health Literacy
Health literacy:  
The ability to *find, understand,* and *use* information to make health related decisions (NIH).

DEMENTIA ≠ DEMENCIA  
CAREGIVER ≠ CUIDADOR
Boot Camp Translation

• Process based on principals of community engagement (CE) and community-based participatory research (CBPR)
• Aims to “translate” medical jargon into community-relevant language
  • Disseminate these meaningful messages to the community
• Not a series of focus groups
• Not a training program for community health liaisons

• Main questions BCT seeks to answer:
  • What are the key messages (about this health topic) for my community?
  • Who in my community needs to hear these messages?
  • How do we best get these message to my community?

ACADEMIC RESEARCH PARTNERS BRING EXPERTISE TO THE GROUP IN:
• facilitation
• coordination
• administrative support
• research methods
• medical knowledge

COMMUNITY MEMBERS BRING EXPERTISE TO THE GROUP IN:
• authentic, real-life experiences and knowledge about the community and culture to create locally meaningful outcomes
• essential brainstorm interpreting and idea generating
• creativity and outside-the-box thinking
Communication of Health Topics

- Ensure H/Ls exemplified both IN the materials and HOW the materials are presented.
- Pictures should reflect the community (physical features and culturally) and ones with people who are in closer proximity are more desirable.
- Shorter messages that are both easier and quicker to read.

What is good for your heart, is good for your brain!
Culture, Health Care, and Trust

Interactions between H/L families and health services

- Migration history
- Cultural values
- Generation
- Literacy
- Education
- Acculturatio n

The Public Health Opportunities and Challenges of Dementia Caregiving
National Conference June 14-15 2022
Intergenerational Information Transfer (IGI)

Transfer of information to each subsequent generation.

"Brokering": family members acting as linguistic and cultural intermediaries for their families with limited English proficiency and/or health literacy.

The Public Health Opportunities and Challenges of Dementia Caregiving
National Conference June 14-15 2022
Community Health Workers

A day in the life of a community health worker

Meet Carmen, a community health worker at a local nonprofit. Community health workers like Carmen go by many different titles and work for organizations like clinics, hospitals, and insurance companies.

But what, exactly, does Carmen do?
What does this mean for the health of H/L adults with dementia and their loved ones?

- **Family takes priority**: Family financial security > individual well-being
- **Duty towards parents**: Adult children closely involved in the needs of older family members
- **Diligence equals affection**: Caregiving is not described as "burden," but rather as "doing right" by family
- **"Yes, doctor"**: Health providers are highly respected and rarely questioned
- **There is no "I"**: The well-being of one strongly influences the well-being of the others
- **When in doubt, the best equipped speaks for the rest**: When a family member is unable to engage with the world as needed, whomever can step in must do so
Cultural needs of H/L caregivers & families
Cultural needs of H/L caregivers & families

• Systemic disparities

• Diversity and heterogeneity of the H/L population
¡Muchas Gracias!

Luis D. Medina, PhD

Echar, a Spanish verb with several definitions, is fitting given our goals "to cast or throw" a wide net for recruitment, "to put" infrastructure in place, "to lay" out a plan for better health communication, and "to oust" health disparities.
What are the similarities & differences between these communities?
Similarities in both communities

- Heterogeneity in both communities
- Importance of asking for individual preference
- Role and value of family in supporting older adults
- Older daughter
- Desire for racial/ethnic concordance of providers
- Cultural adaptations often do not center communities
Differences in both communities

Distrust is influenced by different factors

- African American caregivers rooted in long-standing mistreatments
- Hispanic/Latin American (immigration, language, insurance, etc.)