

Equity and Cultural Adaptation in Dementia Caregiving I

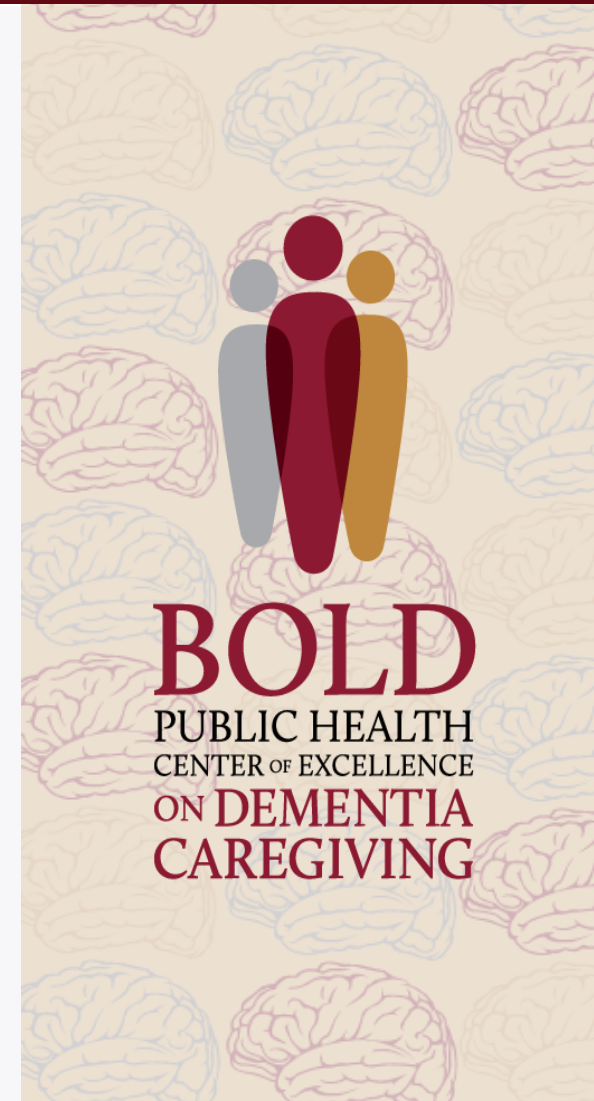
It's a Family Affair: Caregiving in African American/Black Communities

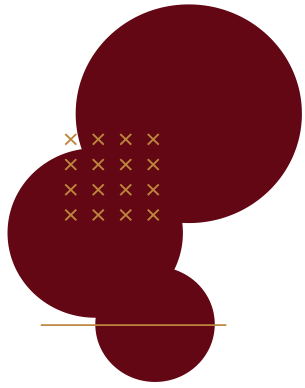
Kalisha Bonds Johnson, PhD, RN, PMHNP-BC

Assistant Professor, Tenure Track

Nurse Practitioner

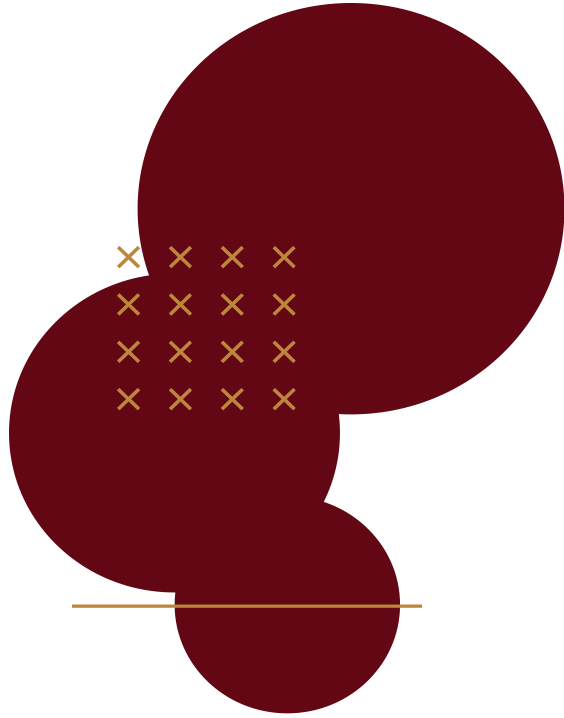
Emory University





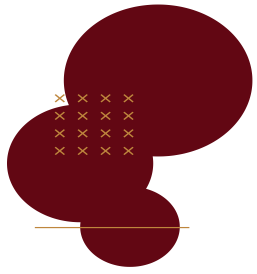
Session Outline

- 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

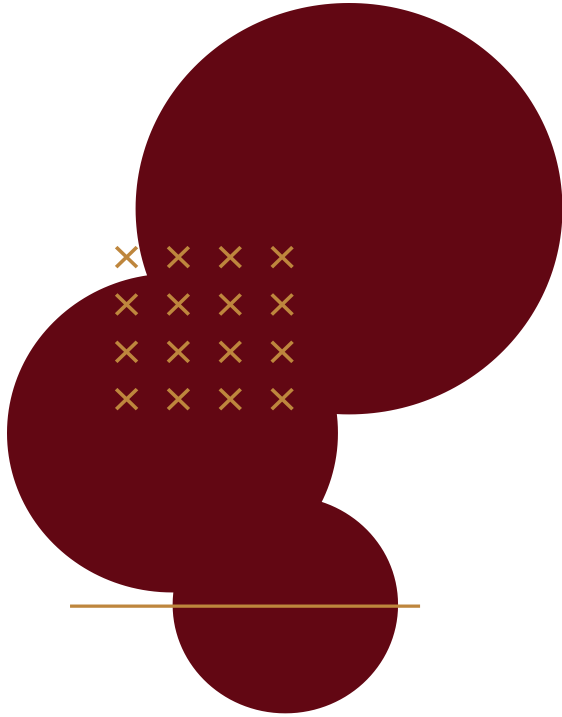
- Time

- Community partnerships

K23 Grant Proposal

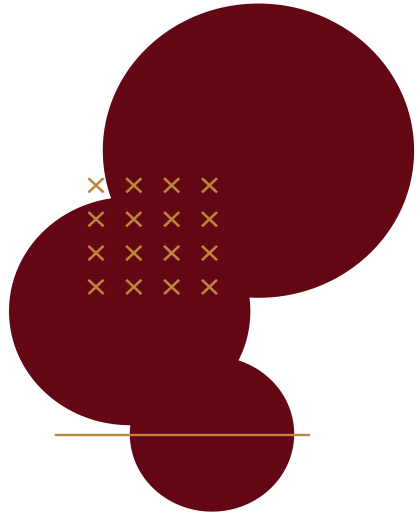
Designing a Culturally Tailored Formal Care Decision-Making Intervention for African American Dementia Dyads and Families

- 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

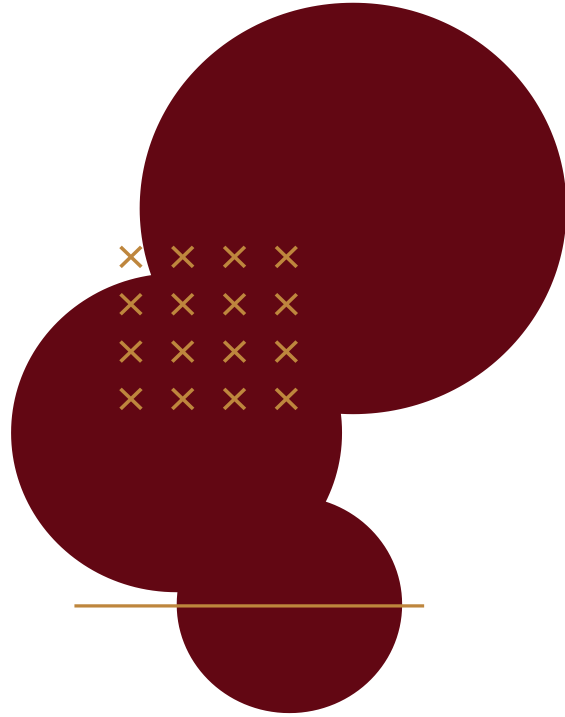
- Partnering with researchers or research-intensive institutions

Role in cultural adaptation of interventions

- From inception to dissemination

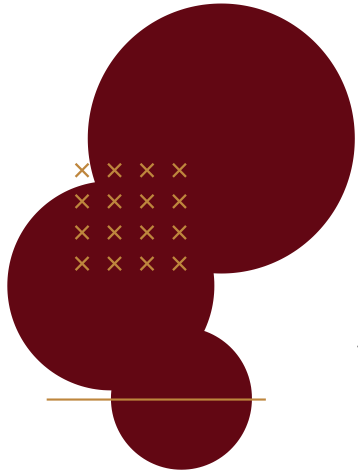
Policy recommendations

- Practice change about identifying caregivers



Why should public health agencies be aware of this work?





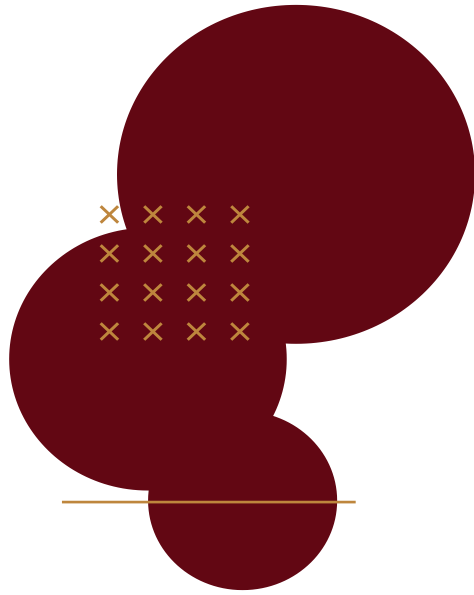
Awareness of this work

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

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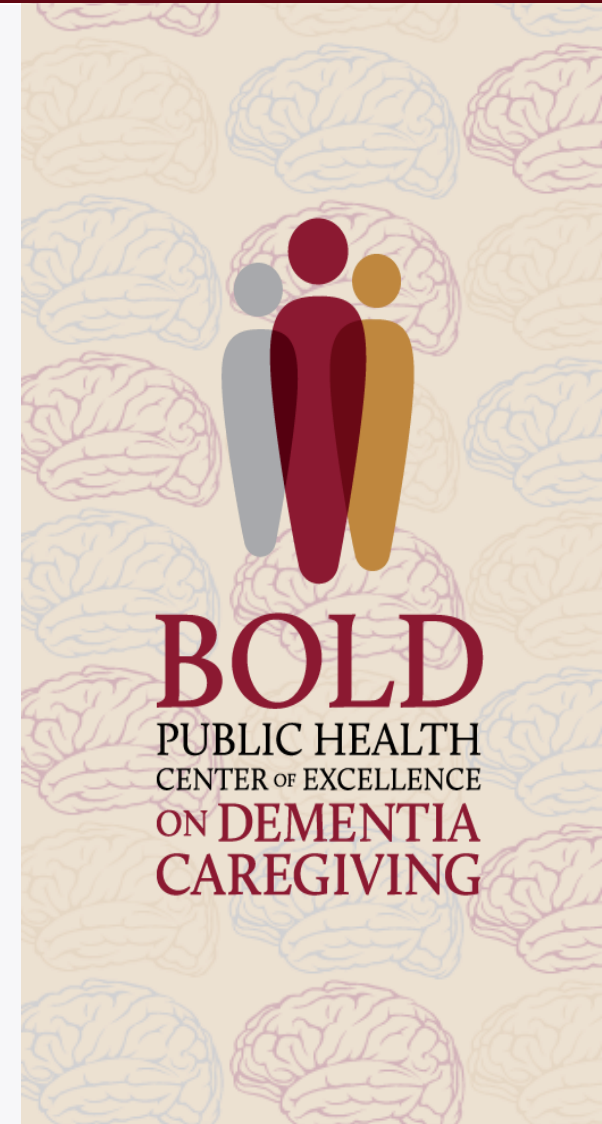
Cuidando Entre Nos: Caregiving in Hispanic/Latin American Communities

Luis D. Medina, PhD

Assistant Professor, Tenure Track

Neuropsychologist

University of Houston



The CARMA Team @ UH

(est. 2018)



LDMedina2@uh.edu



Collaborative on
Aging
Research and
Multicultural
Assessment

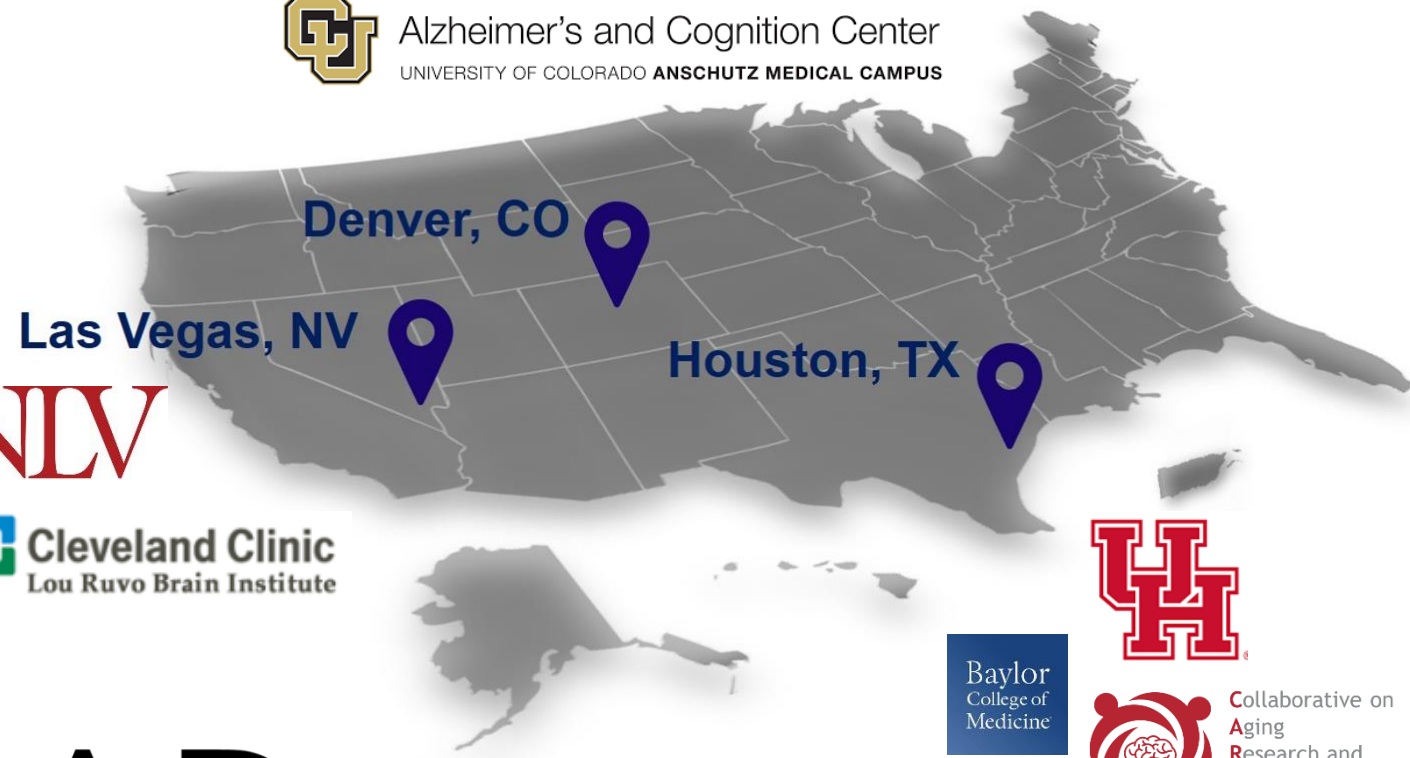
Colaboradores

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





 Alzheimer's and Cognition Center
UNIVERSITY OF COLORADO ANSCHUTZ MEDICAL CAMPUS



 Cleveland Clinic
Lou Ruvo Brain Institute

Baylor
College of
Medicine



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Assessment



 **CHAR**
Network
www.echarnetwork.com

Long-term goal:

- to address effective recruitment of Hispanics/Latinos into aging and Alzheimer's disease research

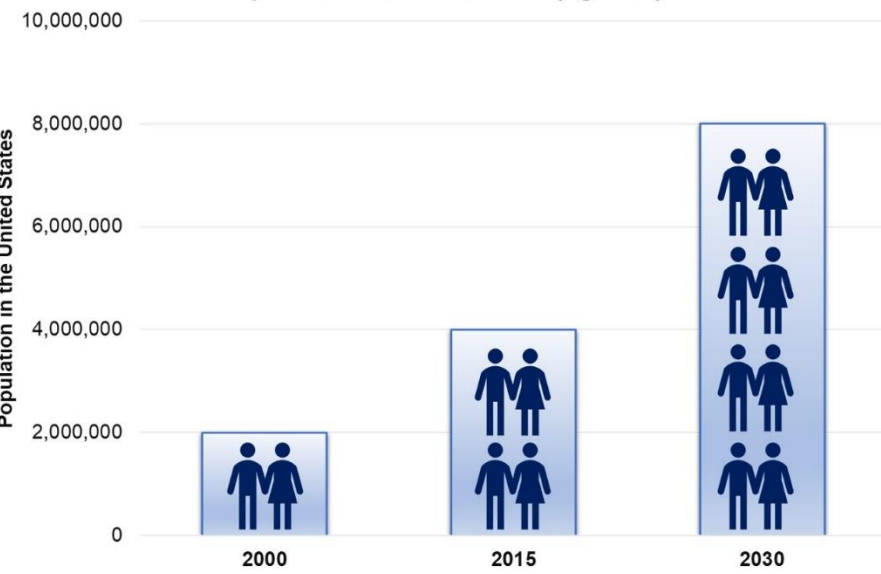
Aims:

- 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)





Hispanic/Latino Older Adults (Age 65+)



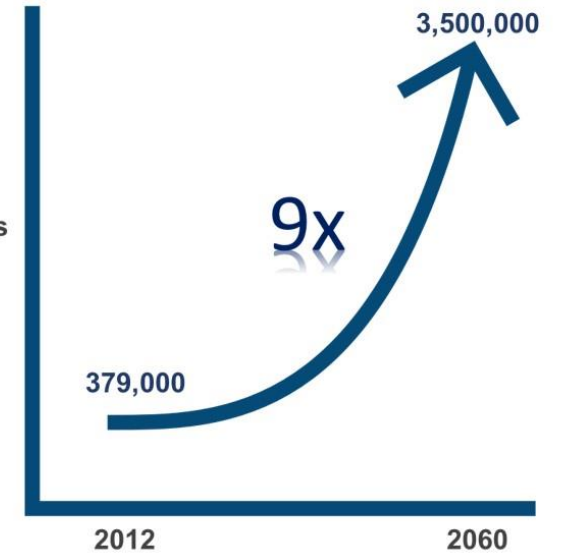
Non-Hispanic
White



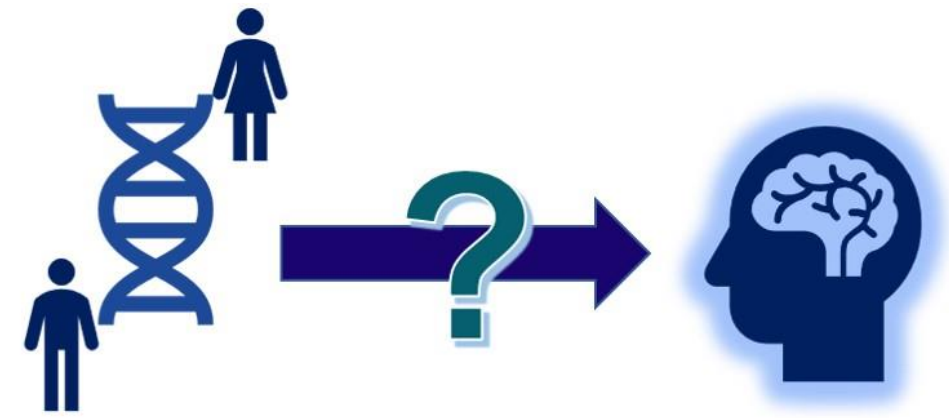
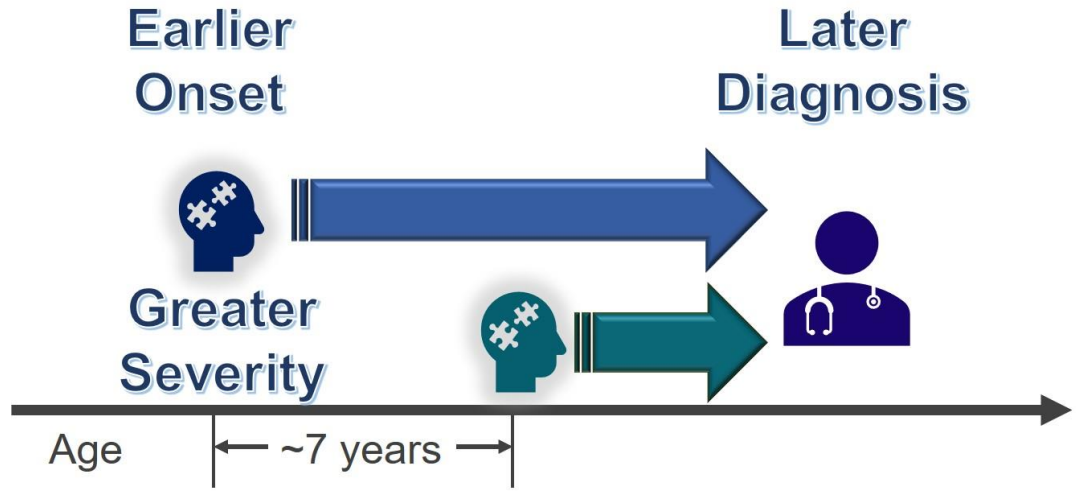
Hispanic/
Latino

1.5x Risk

Hispanics/Latinos
with ADRD
Diagnosis



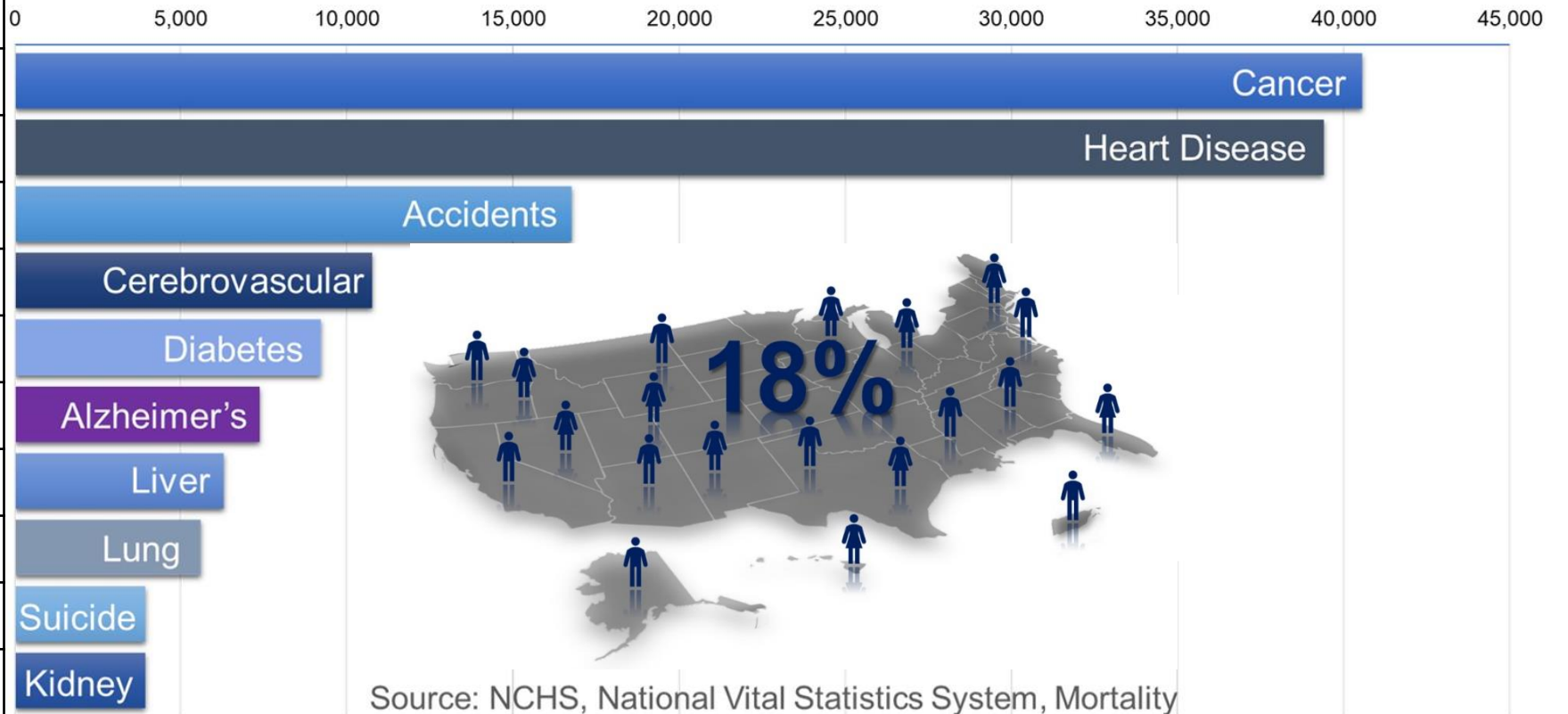
Hispanic/Latino Paradox of AD



NIH RCDC 2018 Report

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

**United States 2017:
Leading Causes of Death in Hispanics/Latinos**

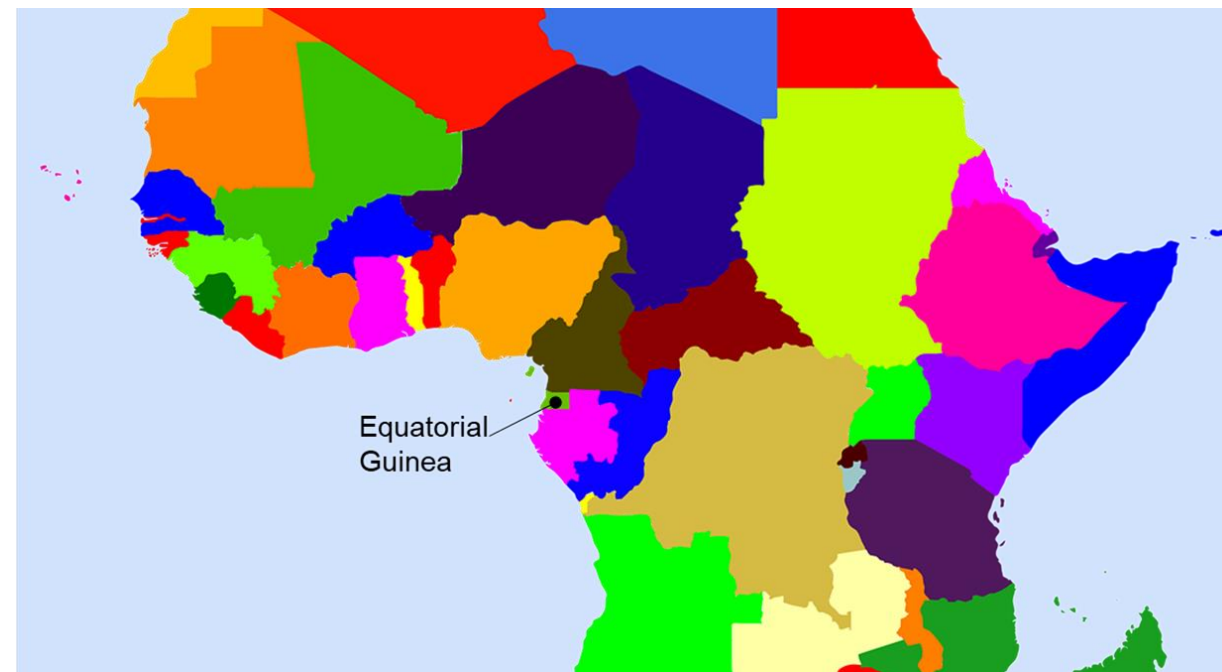


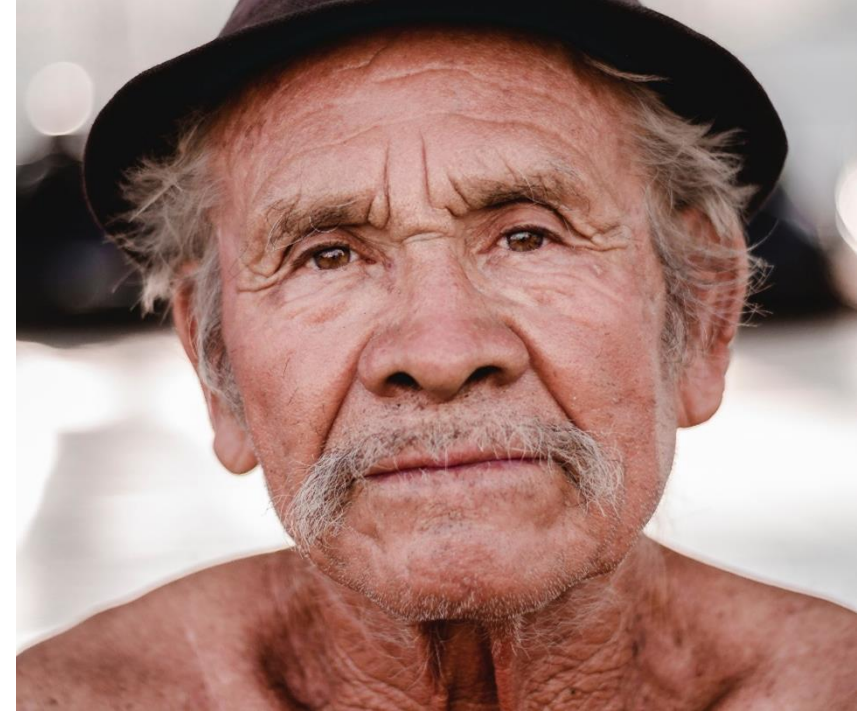
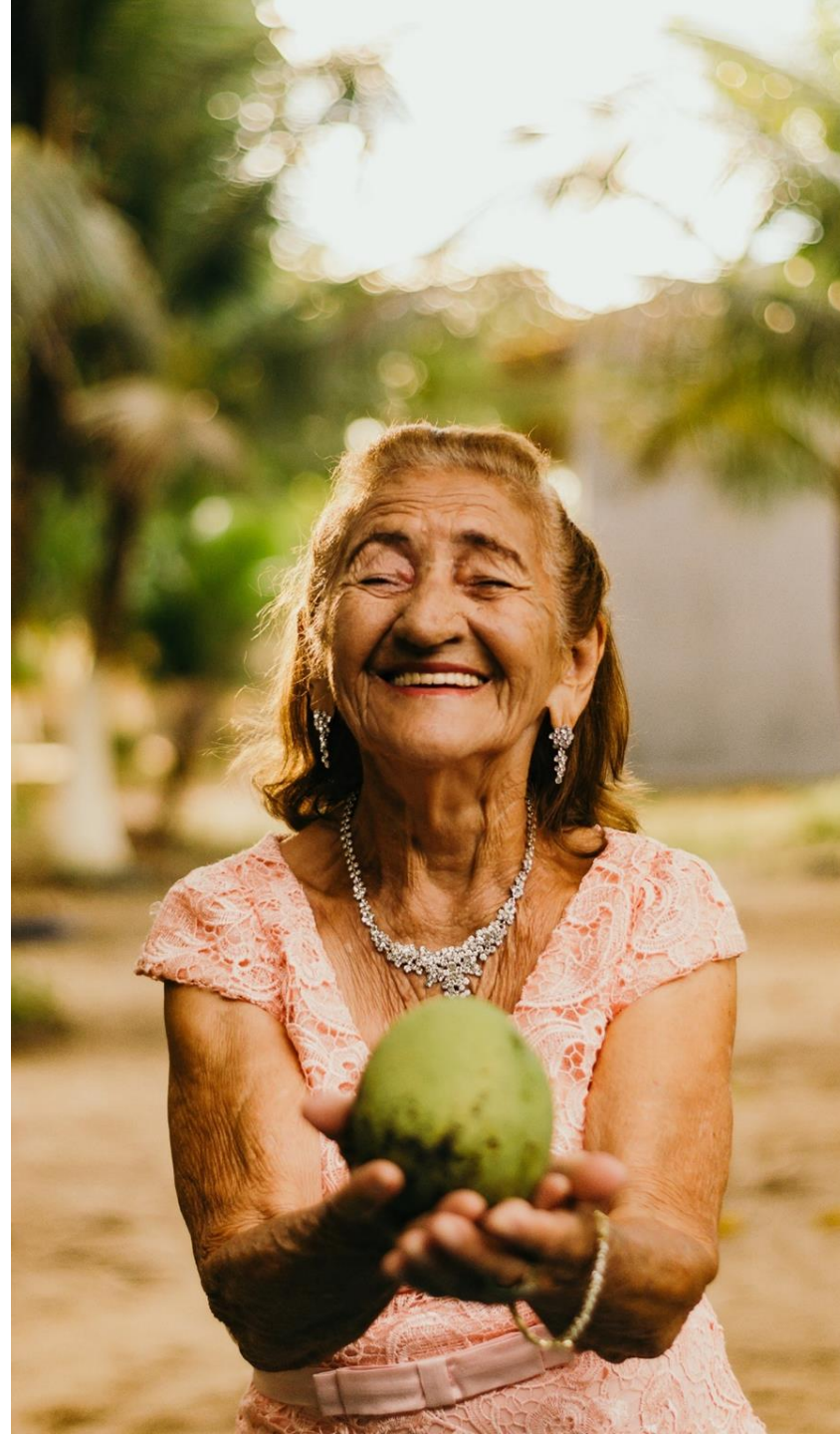
*Represents RCDC Category "Emergency Care"

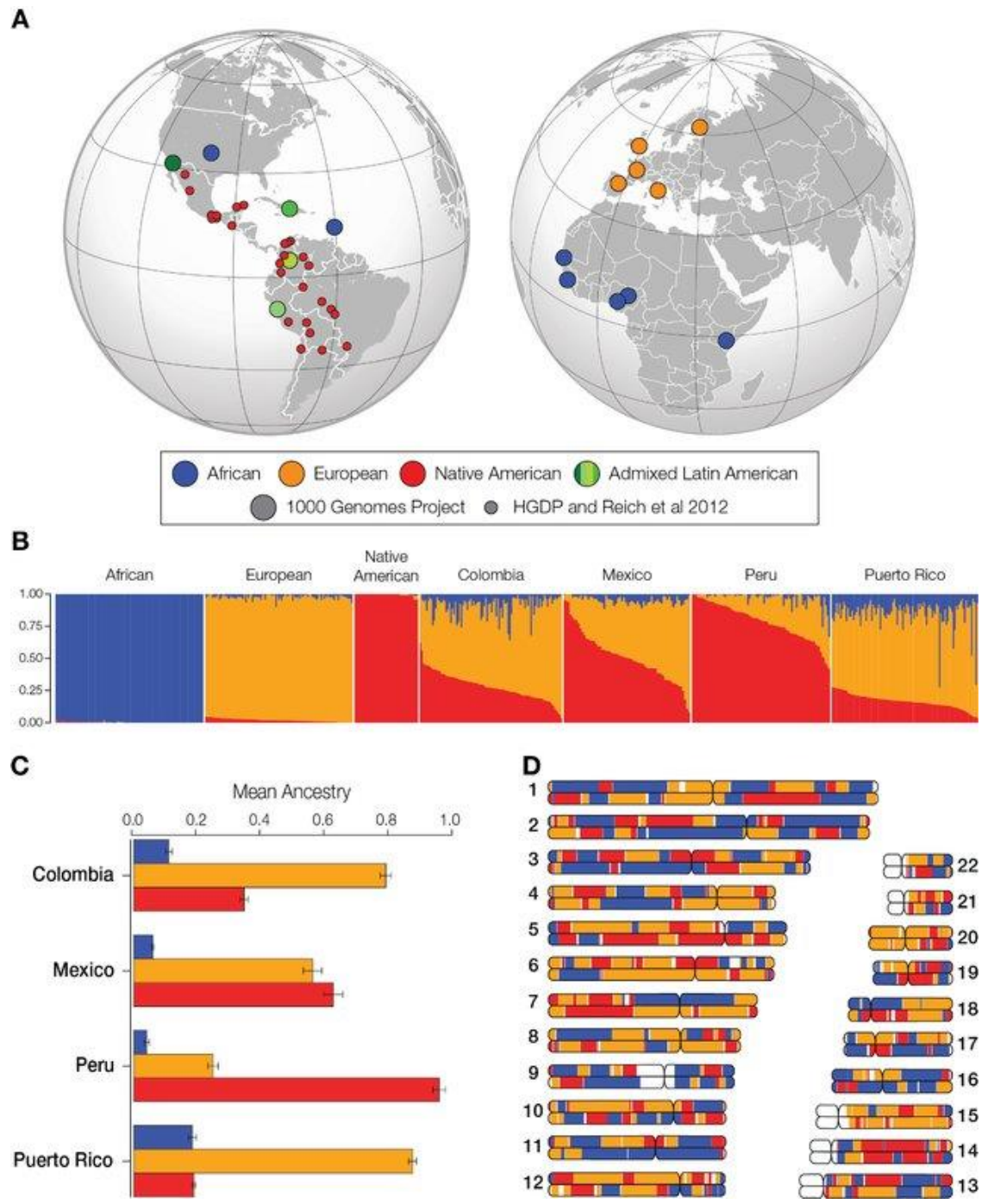
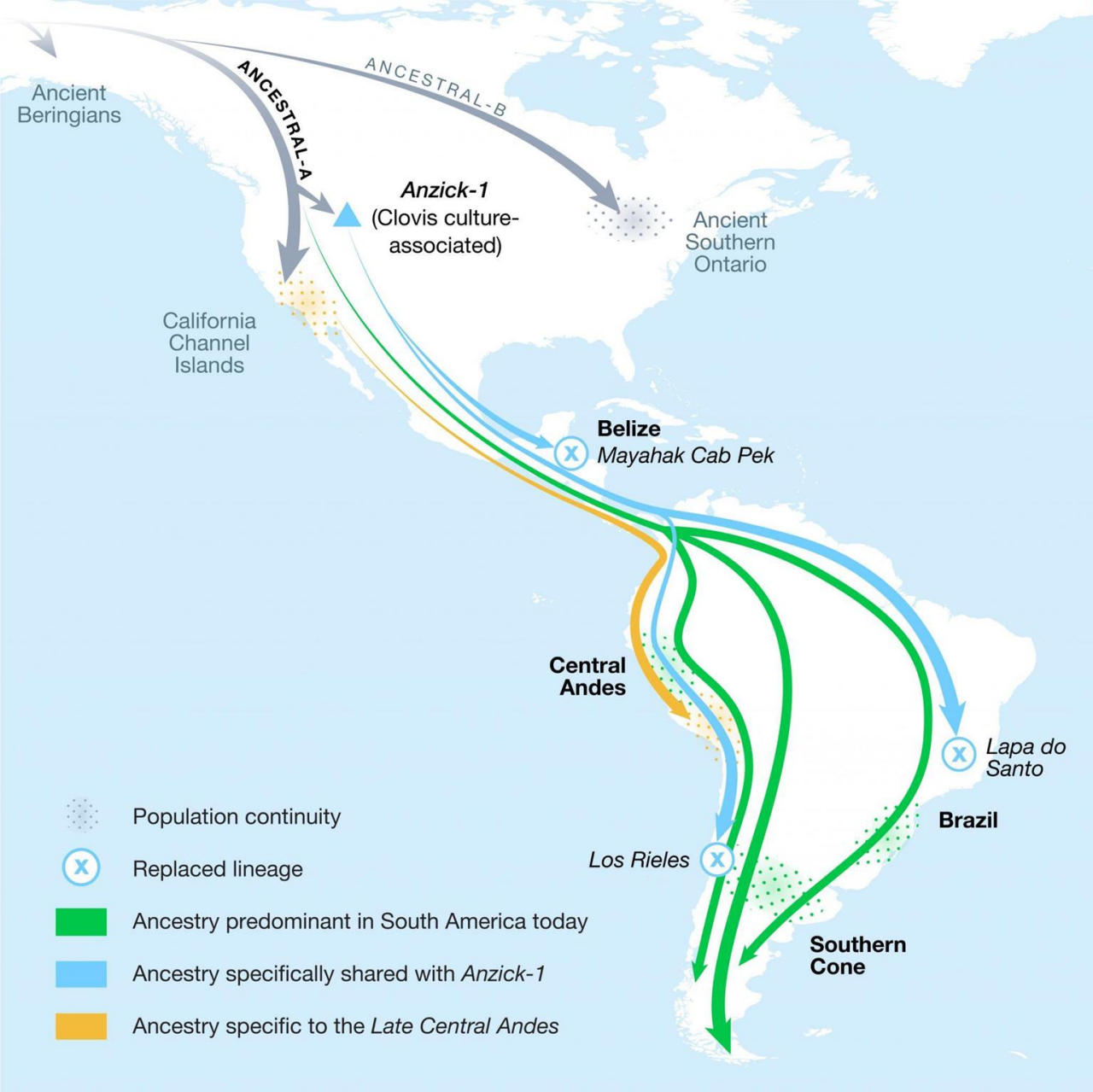
Representation vs Transparency

	Age		Education		Gender		Race/ Ethnicity		Acculturation		Language		SES	
	2004	2019	2004	2019	2004	2019	2004	2019	2004	2019	2004	2019	2004	2019
ACN	97.3	98.7	82.3	83.1	82.3	93.9	35.0	44.1	0.0	0.0	10.2	15.4	11.1	3.6
JCEN	99.0	100	77.1	77.9	92.3	98.1	20.0	31.7	0.0	0.0	12.0	20.7	8.5	9.1
JINS	97.5	100	72.9	76.7	87.9	96.7	22.9	37.1	0.4	0.0	15.7	17.1	10.4	12.5
NEU	95.7	100	74.5	74.7	84.9	97.0	10.8	23.2	0.0	0.9	13.8	22.3	8.0	12.9
TCN	98.1	99.3	85.6	91.4	90.9	98.6	24.5	56.1	0.0	2.2	6.3	27.3	7.7	6.5
Total	97.6	99.6	77.7	80.8	88.0	89.6	21.5	38.4	0.1	0.6	12.0	20.6	9.0	8.9

O'Bryant et al. (2004); Medina et al. (2021)

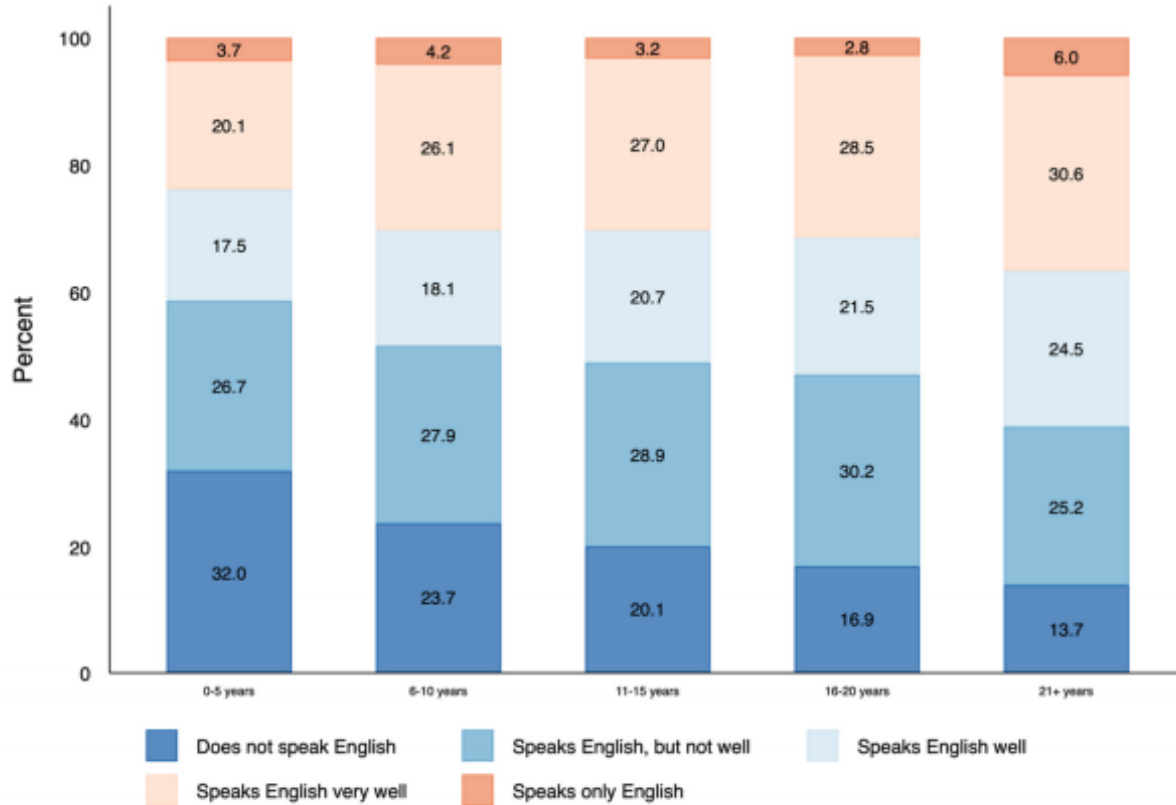






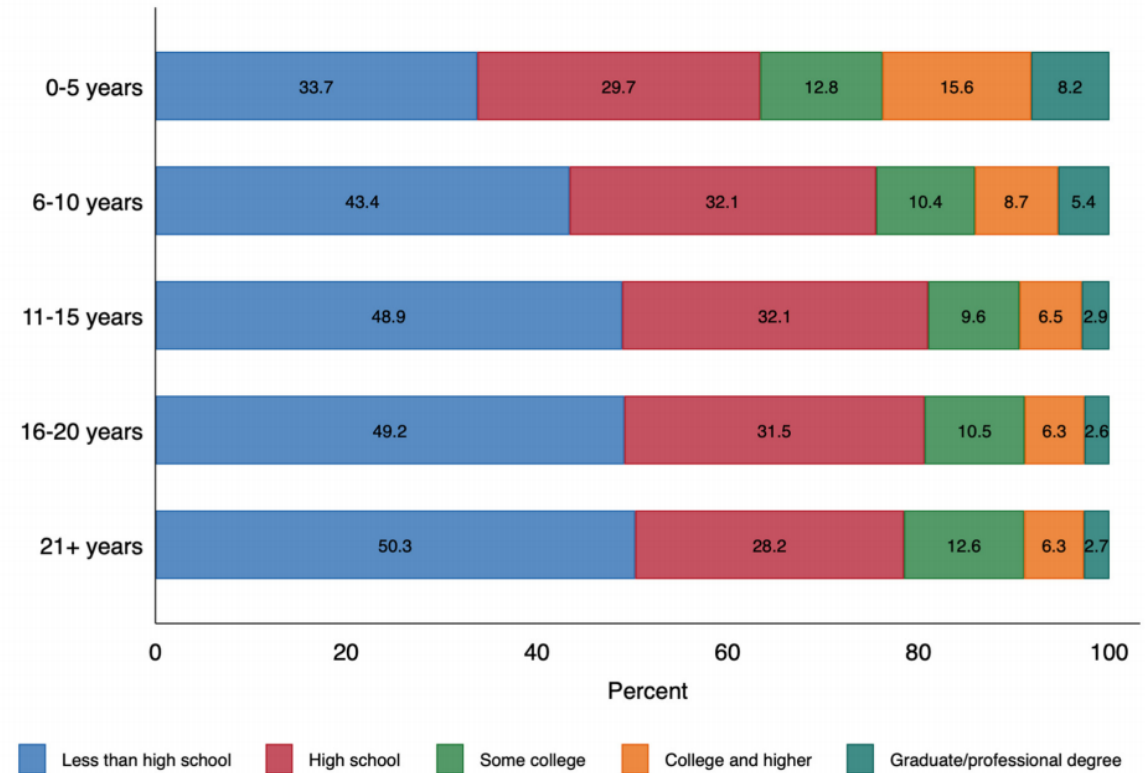
No One-Size-Fits-All

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



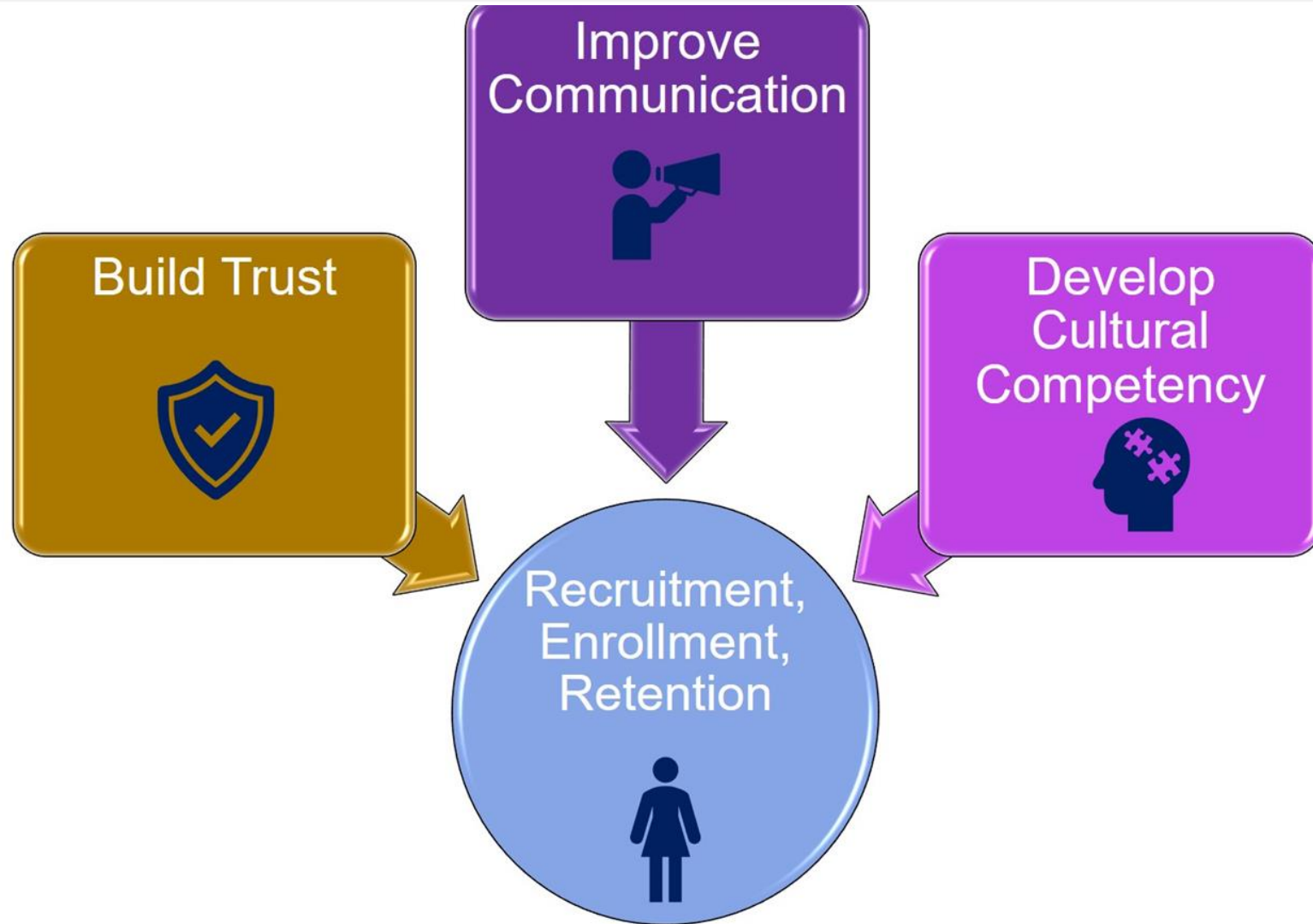
Source: US Census Bureau, American Community Survey, 2013-2017, IPUMS-USA

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



Source: US Census Bureau, American Community Survey, 2013-2017, IPUMS-USA

“ 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

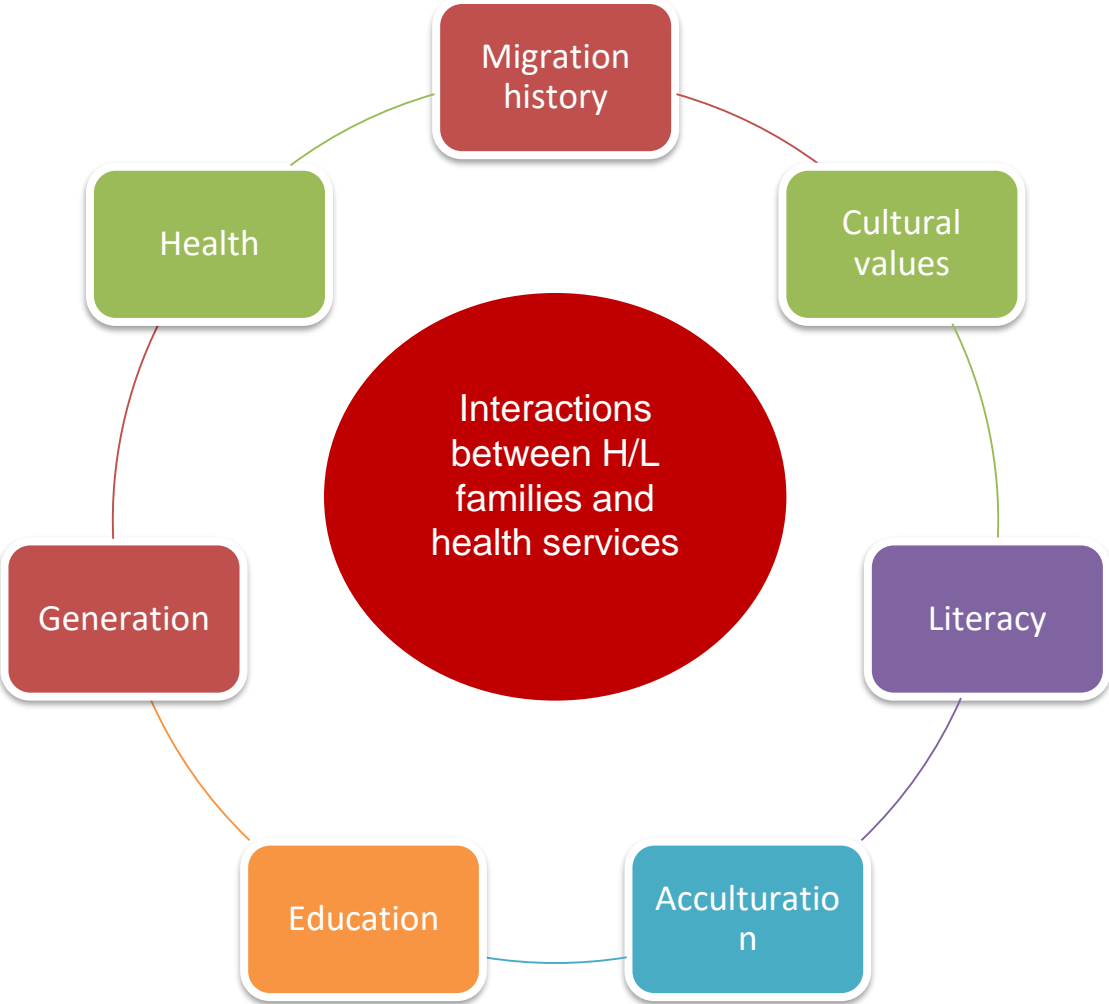
Communication of Health Topics

- 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



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



Community Health Workers

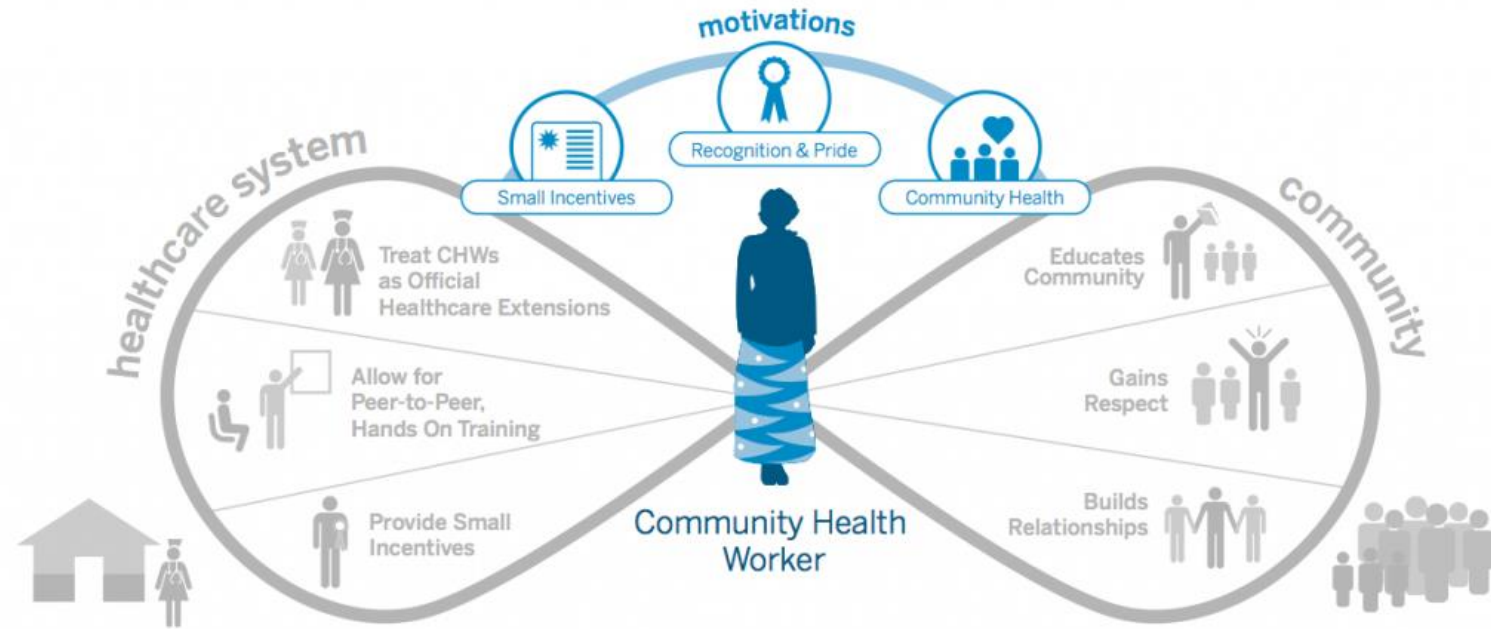


A day in the life of a community health worker

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.

- PROMOTORA DE SALUD
- COMMUNITY HEALTH REPRESENTATIVE
- OUTREACH WORKER
- HEALTH COACH
- PATIENT NAVIGATOR
- PEER COUNSELOR
- HEALTH ADVISOR



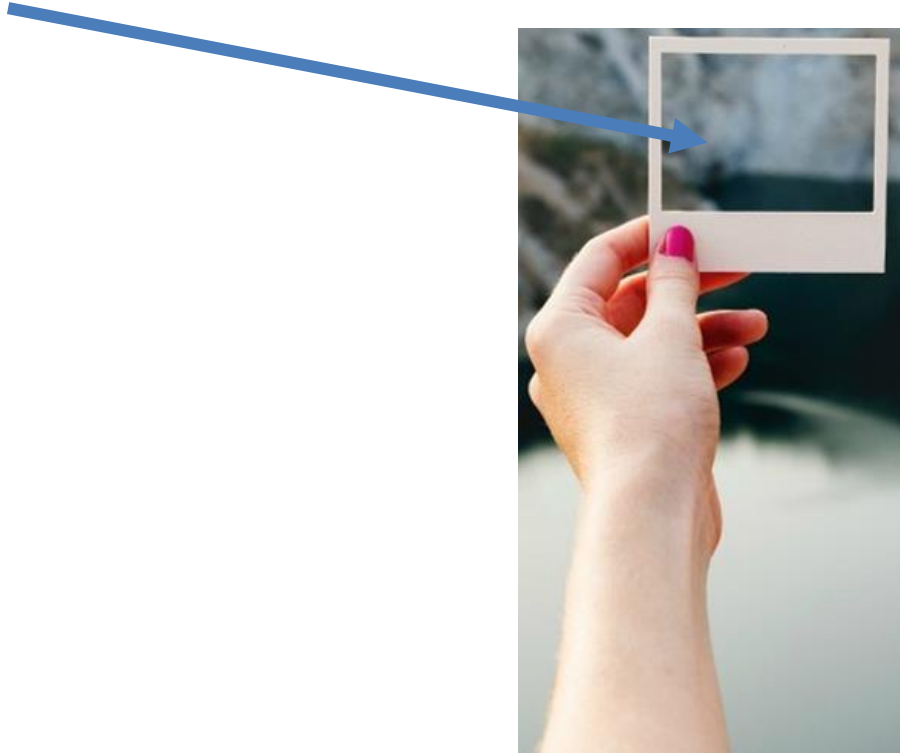
But what, exactly, does Carmen do?

What does this mean for the health of H/L adults with dementia and their loved ones?

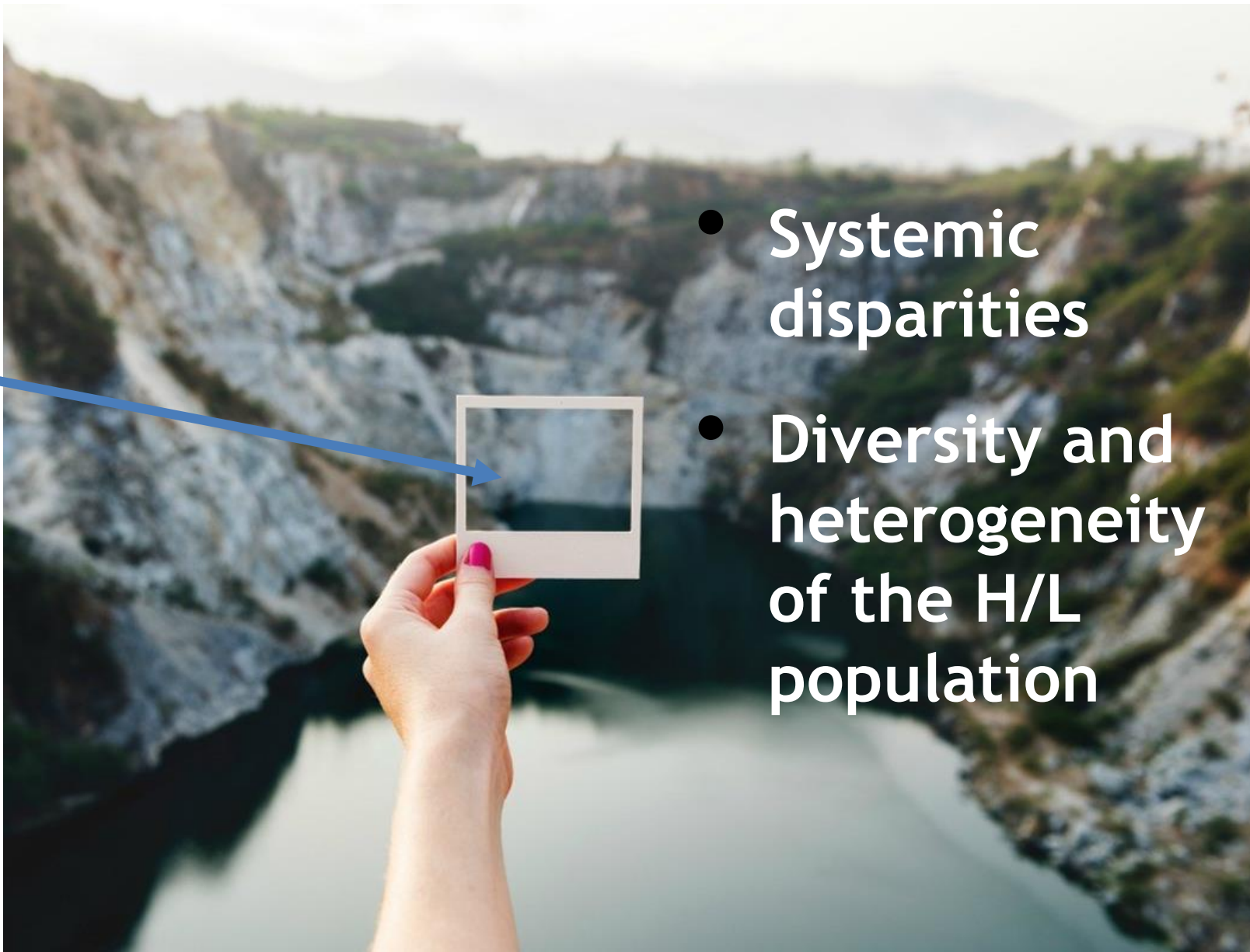
- **Family takes priority:** Family financial security > individual well-being
- **Duty towards parents:** Adult children closely involved in the needs of older family members
- **Diligence equals affection:** Caregiving is not described as "burden," but rather as "doing right" by family
- **"Yes, doctor":** 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

LDMedina2@uh.edu

713.743.9318

<http://www.uh.edu/CLASS/CARMA>

[@CARMA_lab_UH](https://twitter.com/CARMA_lab_UH)

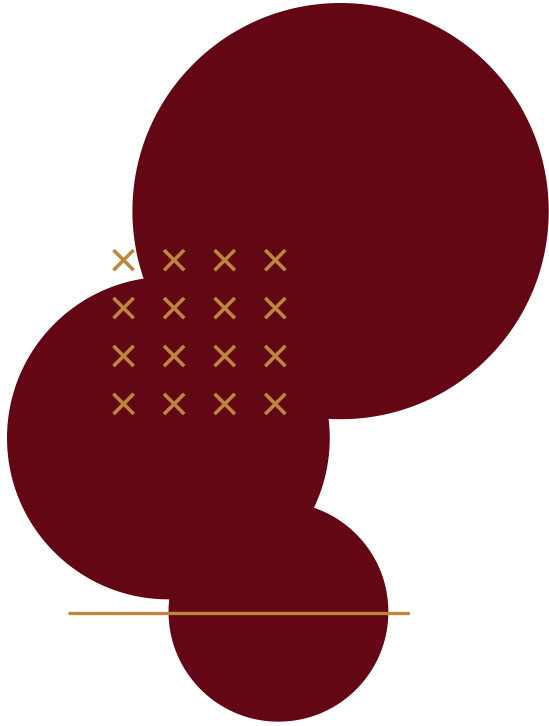


BOLD
PUBLIC HEALTH
CENTER OF EXCELLENCE
ON DEMENTIA
CAREGIVING

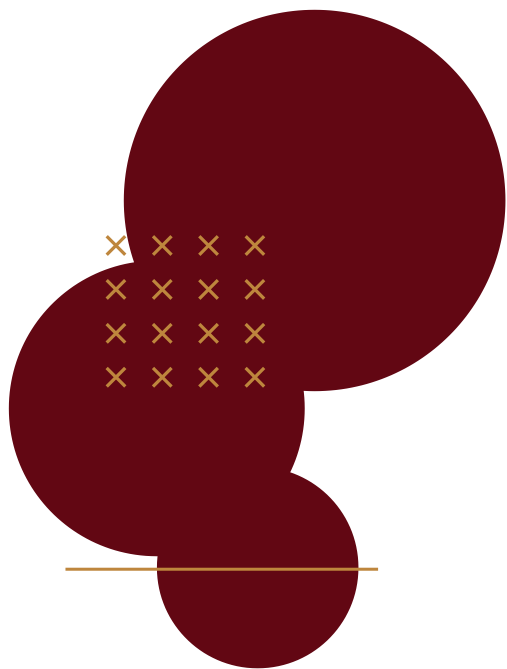


Collaborative on
Aging
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“ *Echar*, a Spanish verb with several definitions, is fitting given our goals “to cast or throw” a wide net for recruitment, “to put” infrastructure in place, “to lay” out a plan for better health communication, and “to oust” health disparities.



What are the similarities & differences between these communities?



Similarities in both communities

Heterogeneity in both communities

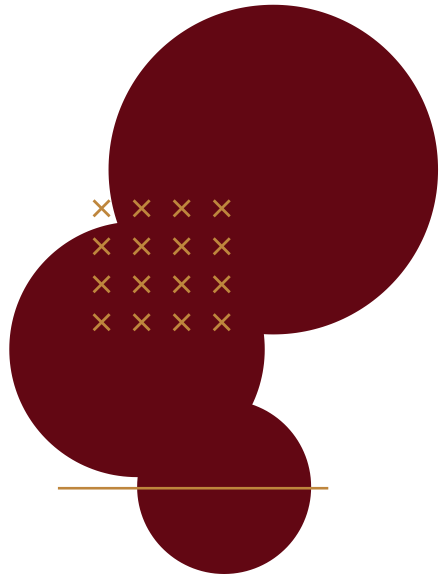
- Importance of asking for individual preference

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.)