

# Ethnic and racial disparities in dementia



**Jaime Perales Puchalt, PhD, MPH**  
**Director, Latino Brain Health Lab KU ADRC**

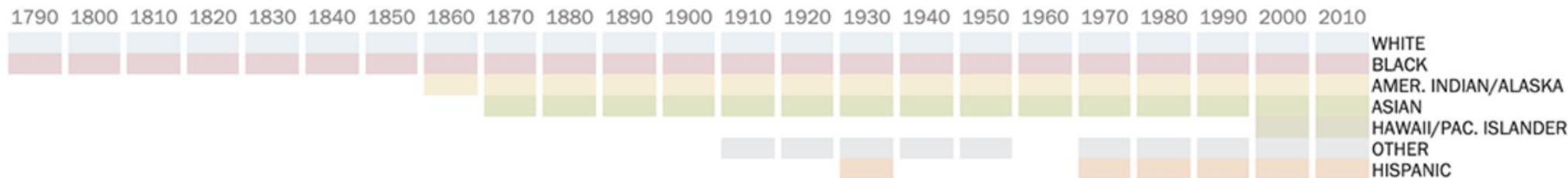
# Index

1. Racial and ethnic groups
2. Impact of Alzheimer's and other dementias
3. Determinants of health
4. Dementia disparities
5. Our work addressing dementia caregiving disparities

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# Racial and ethnic groups

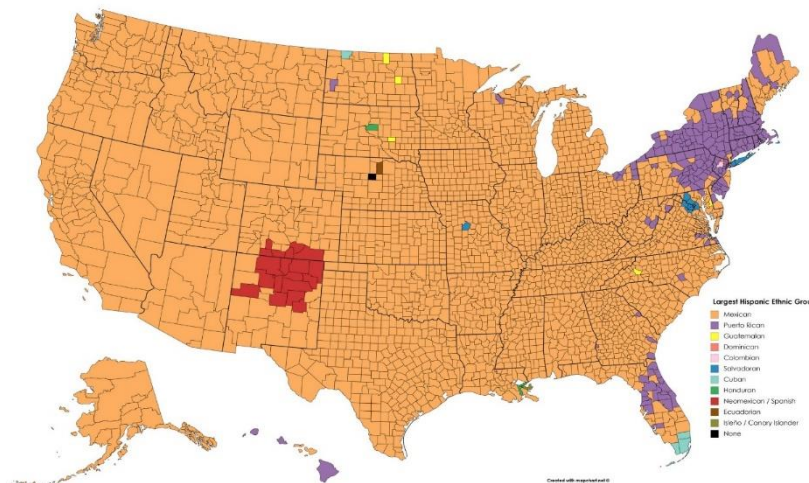


- **Definition**

- Not biological but social
- Context-dependent
- Used as a tool for oppression
- Census categories are commonly used

# Example: Who are Hispanics/Latinos?

- **Census:** (self-identify as) a person of Cuban, Mexican, Puerto Rican, South or Central American, or other Spanish culture or origin regardless of race.

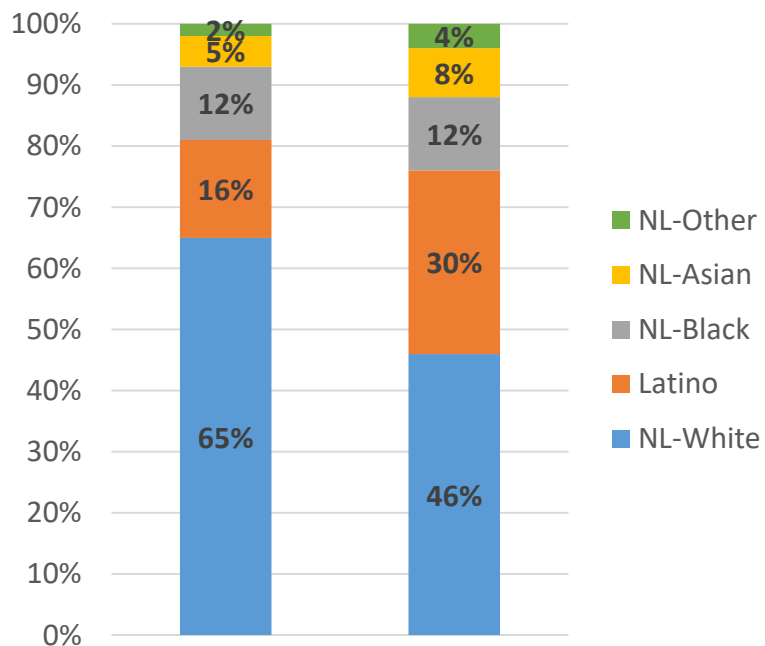






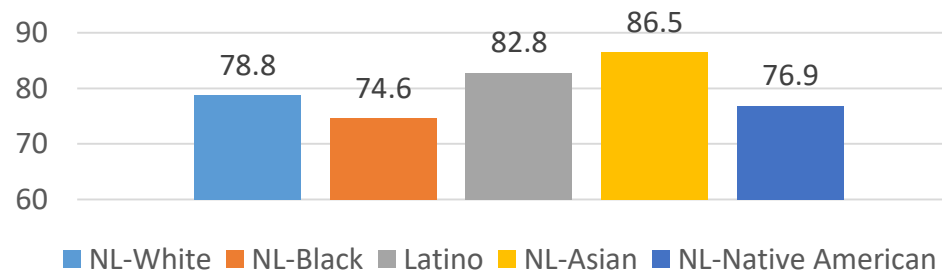
# Demographics of different groups

## US population 2010 vs 2050



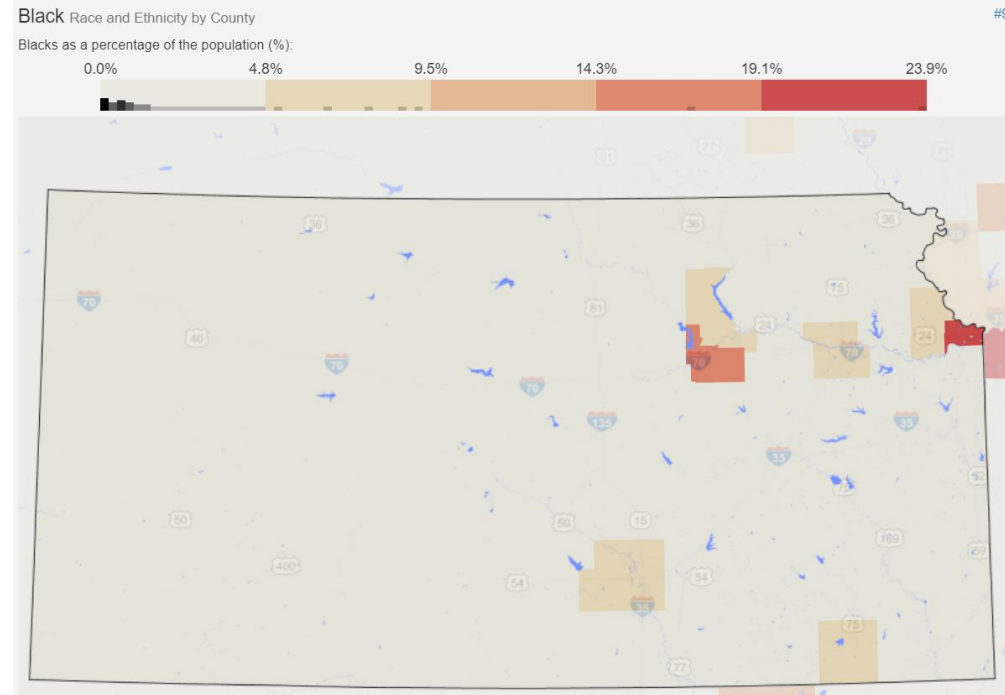
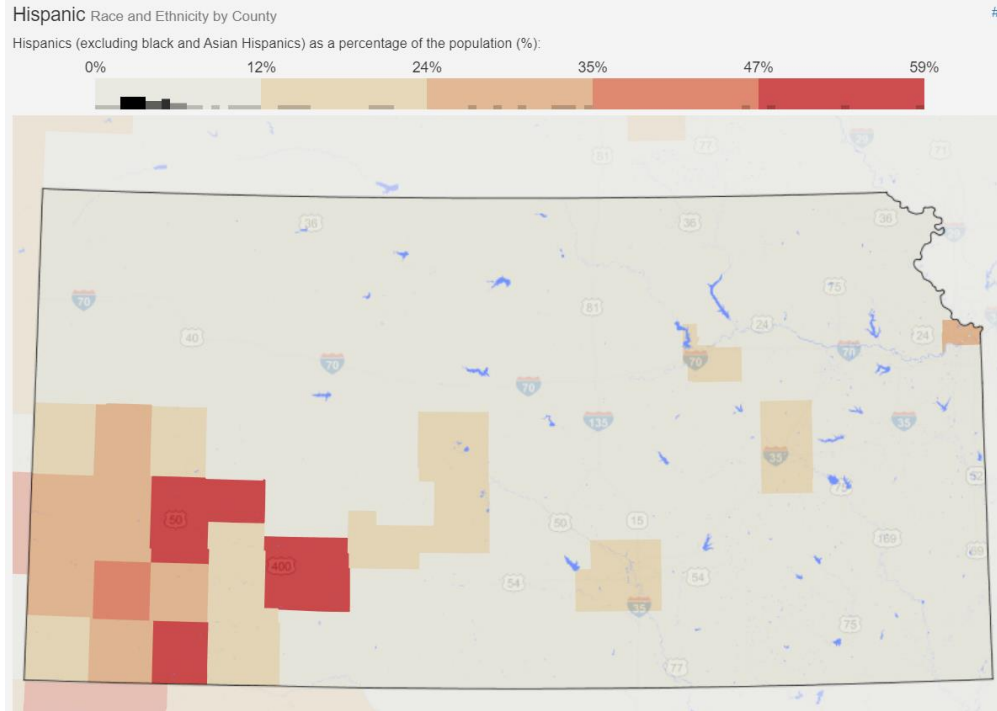
Pew, 2019

## Life Expectancy



65+ population increase projections 2015-2030	
Latino	123%
NL-White	43%
NL-Black	81%
NL-Native American	82%
NL-Asian	90%

# Distribution by county



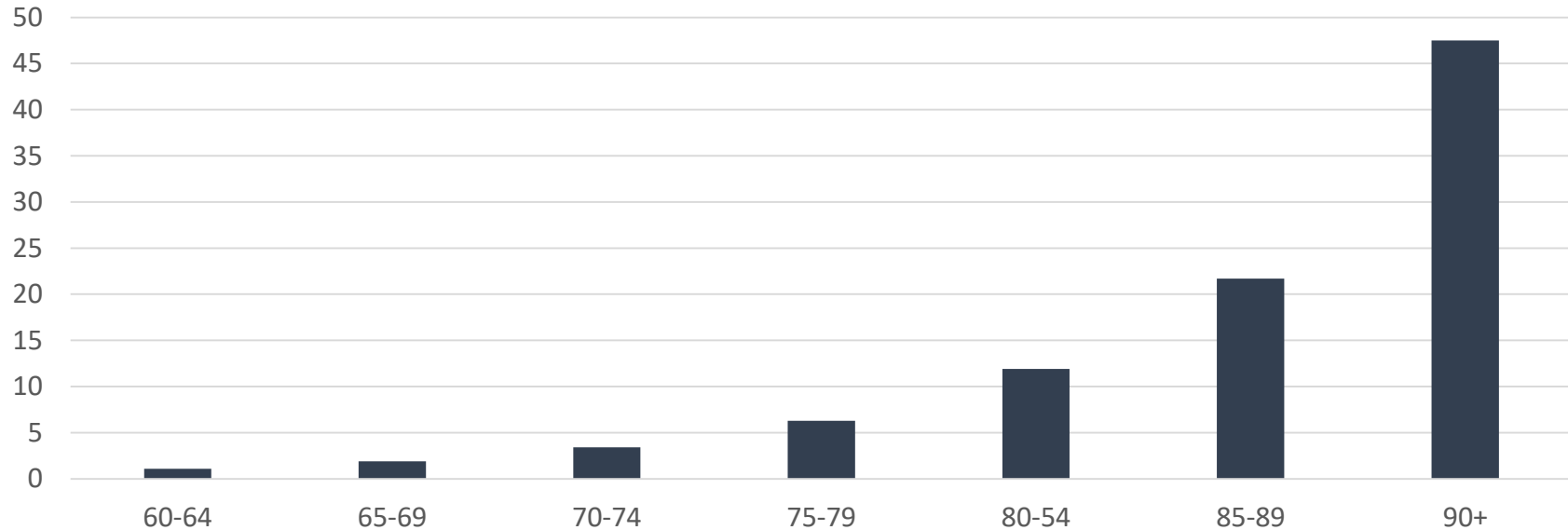


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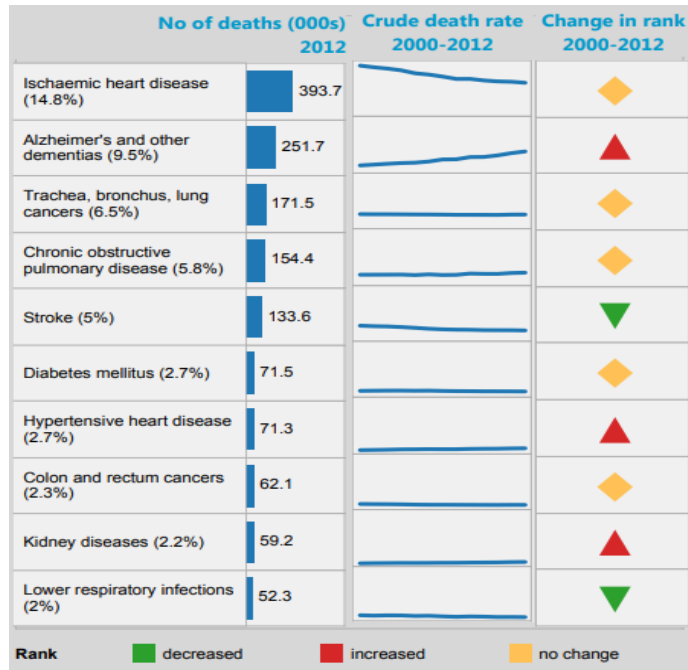
# Dementia has a devastating impact

## Dementia prevalence (%) in the USA by age



# Dementia has a devastating impact on people with dementia

## Causes of death in the USA



12<sup>th</sup> cause of disability in 2010

Compared to older adults without dementia:

- + Chronic conditions
- + Polypharmacy use
- + Hospitalizations

# Dementia has a devastating impact on care partners

## Physical

Compared to non-care partners:

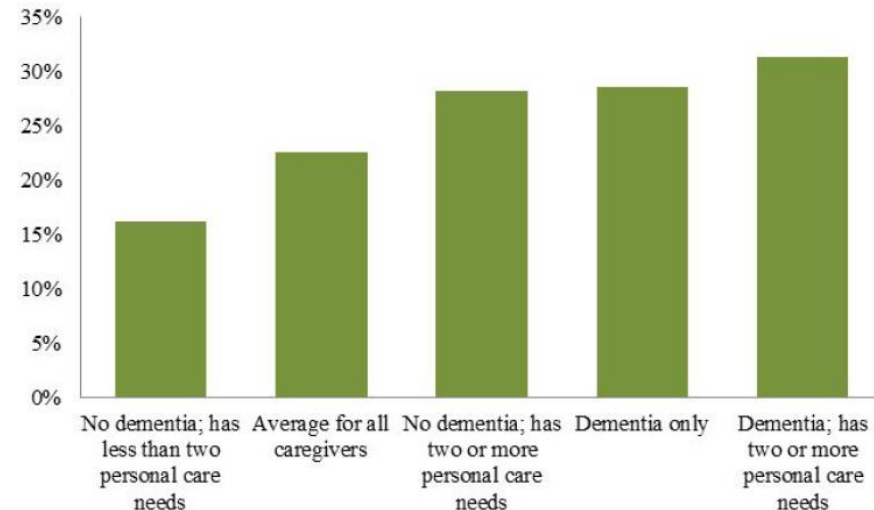
- + 23% stress hormones
- - 15% antibody responses
- + 10% physical symptoms
- + 12% medication use

## Psychological

Caregiver type	Dementia	Stroke	Non
Depression	30-40%	19%	5-17%
Anxiety	44%	31%	-

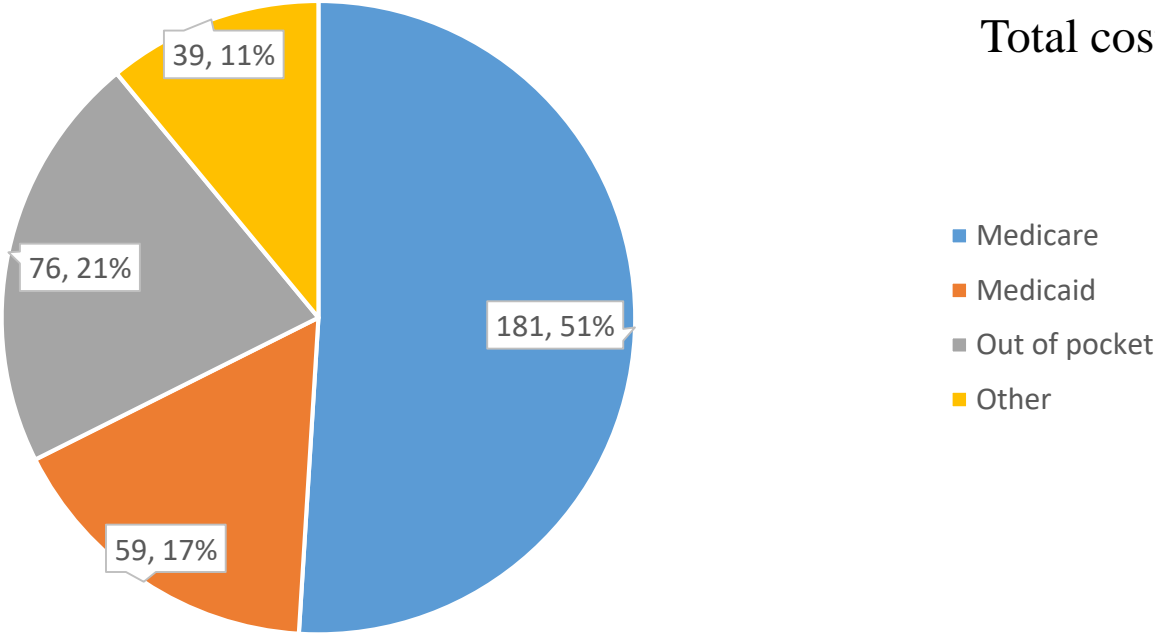
## Financial

Percentage of care partners reporting financial difficulties



# Dementia has a devastating impact on the society

Costs of Care by Payment Source for Americans Age 65 and Older with Dementia, 2021



Total cost: \$355 Billion

World Health Organization, 2013; Hurd, 2013; Alzheimer's Association, 2019 and 2021

# Dementia is not the end

- **There is no cure for most, but...**
- **Treatment** can stabilize and delay outcomes
  - Memory and thinking
  - Activities of daily living
  - Depression, worry, agitation
  - Impact on caregiver



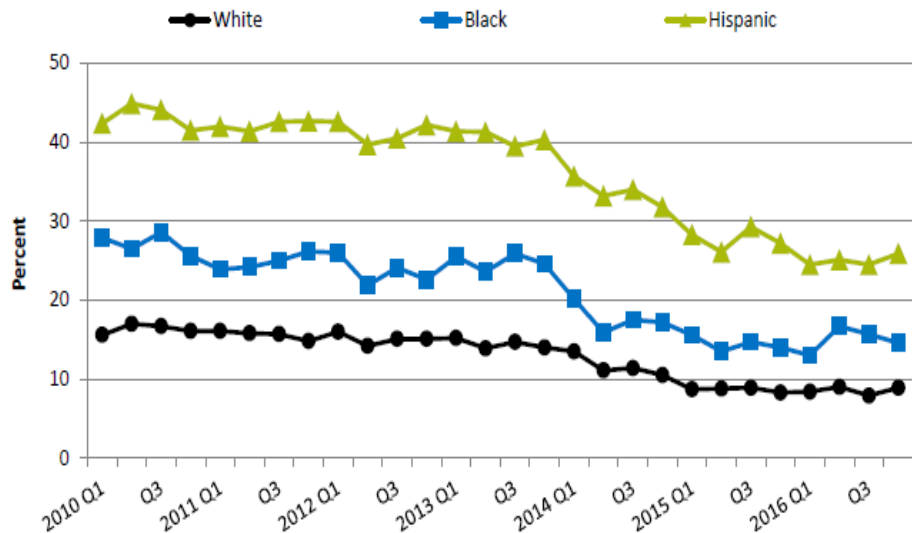


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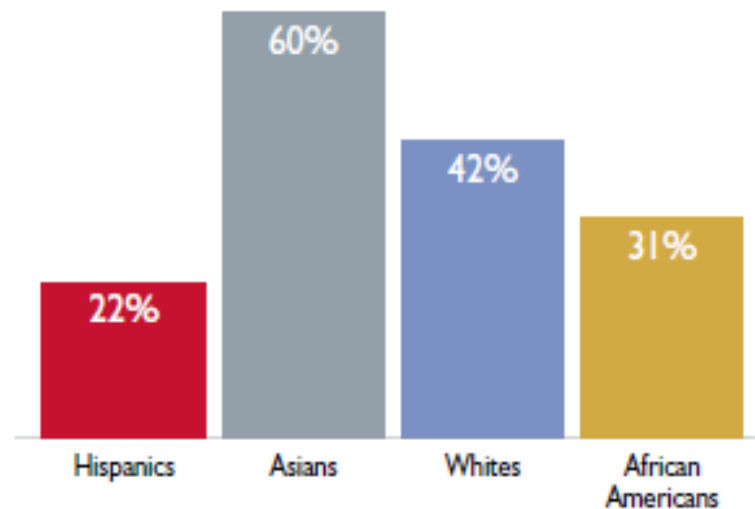
# Insurance status and education

Figure 13. Improving: Adults ages 18-64 who were uninsured at the time of interview, by race/ethnicity, 2010-2016



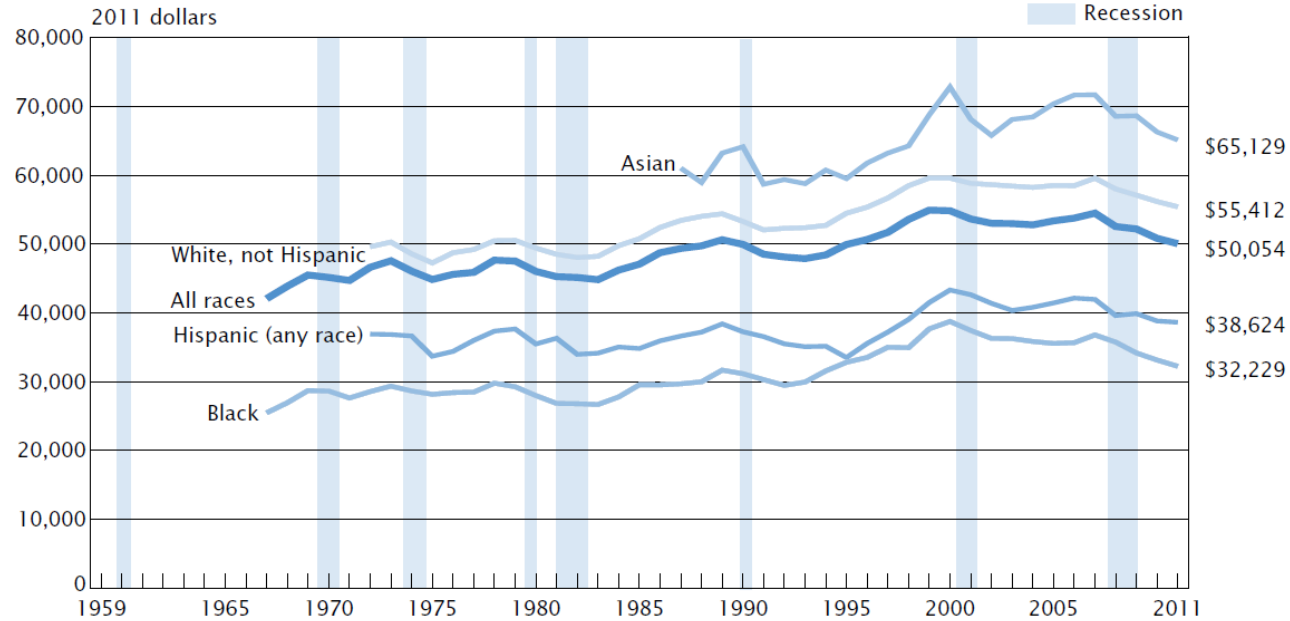
U.S. Census Bureau, 2013; Gallagher-Thompson, D., et al. (2003)

Percent of Adults Who Have Earned an Associate Degree or Higher – 2013



# Income

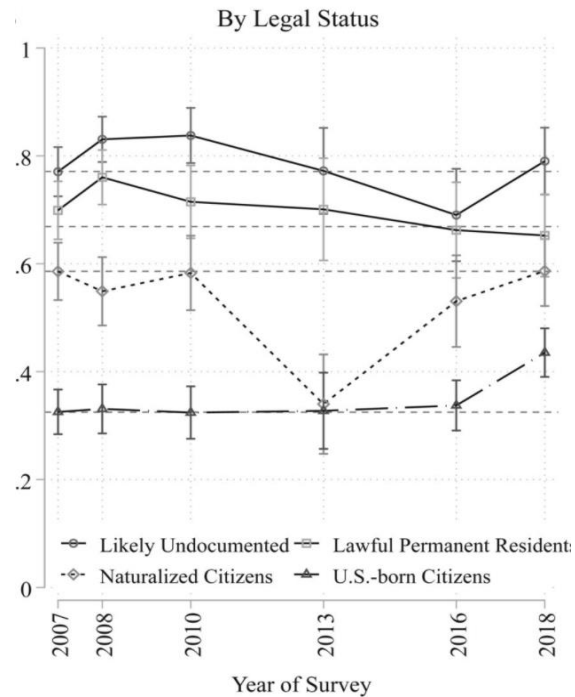
Real Median Household Income by Race and Hispanic Origin: 1967 to 2011



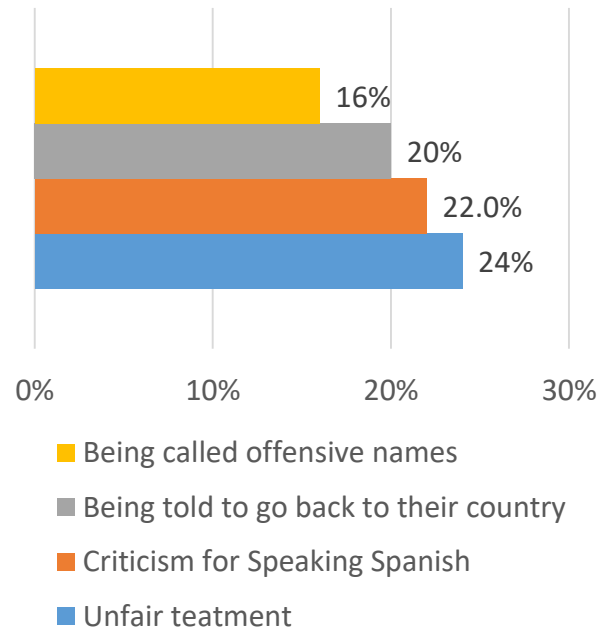
U.S. Census Bureau, 2013; Gallagher-Thompson, D., et al. (2003)

# Discrimination

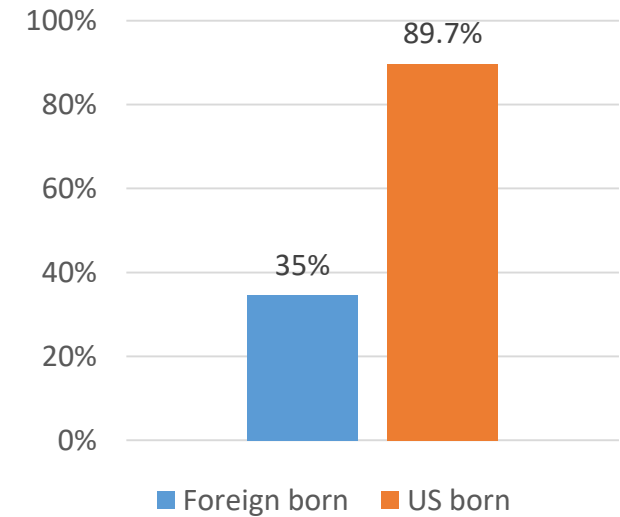
## Deportation fear



## Latinos who report



## Latinos who report speaking English very well



# Cultural factors

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## Shared cultural elements among Hispanics/Latinos

Familismo	Collectivistic orientation. i.e. discussing mental disorders with outsiders may affect the image of the family.
Personalismo	Importance of warm interactions. i.e. interactions with institutions and providers are perceived as cold and business-like.
Machismo	Strong sense of roles stereotypically masculine. Dementia might be a sign of weakness for men.
Fatalismo	Subjugating events to destiny. More likely to believe problems are inherent to fate.

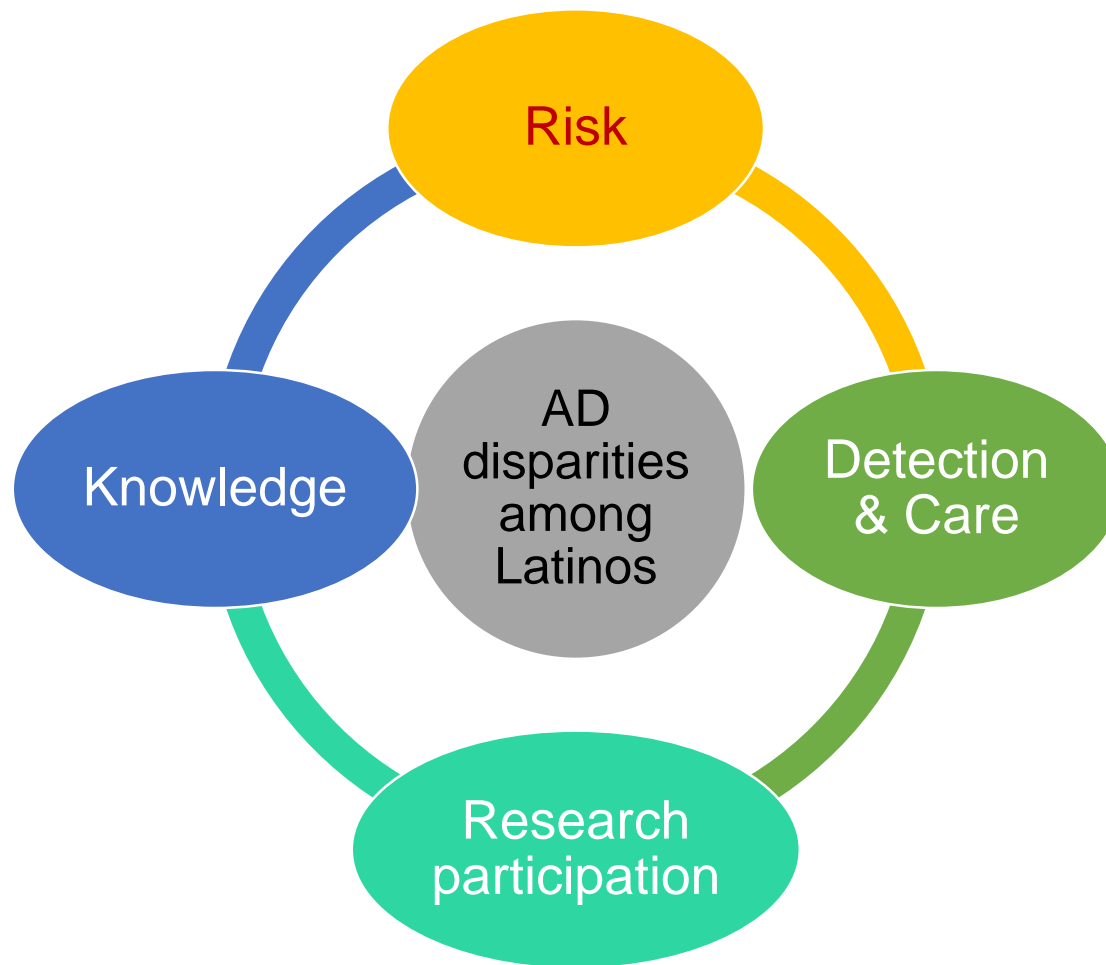
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U.S. Census Bureau, 2013; Gallagher-Thompson, D., et al. (2003)

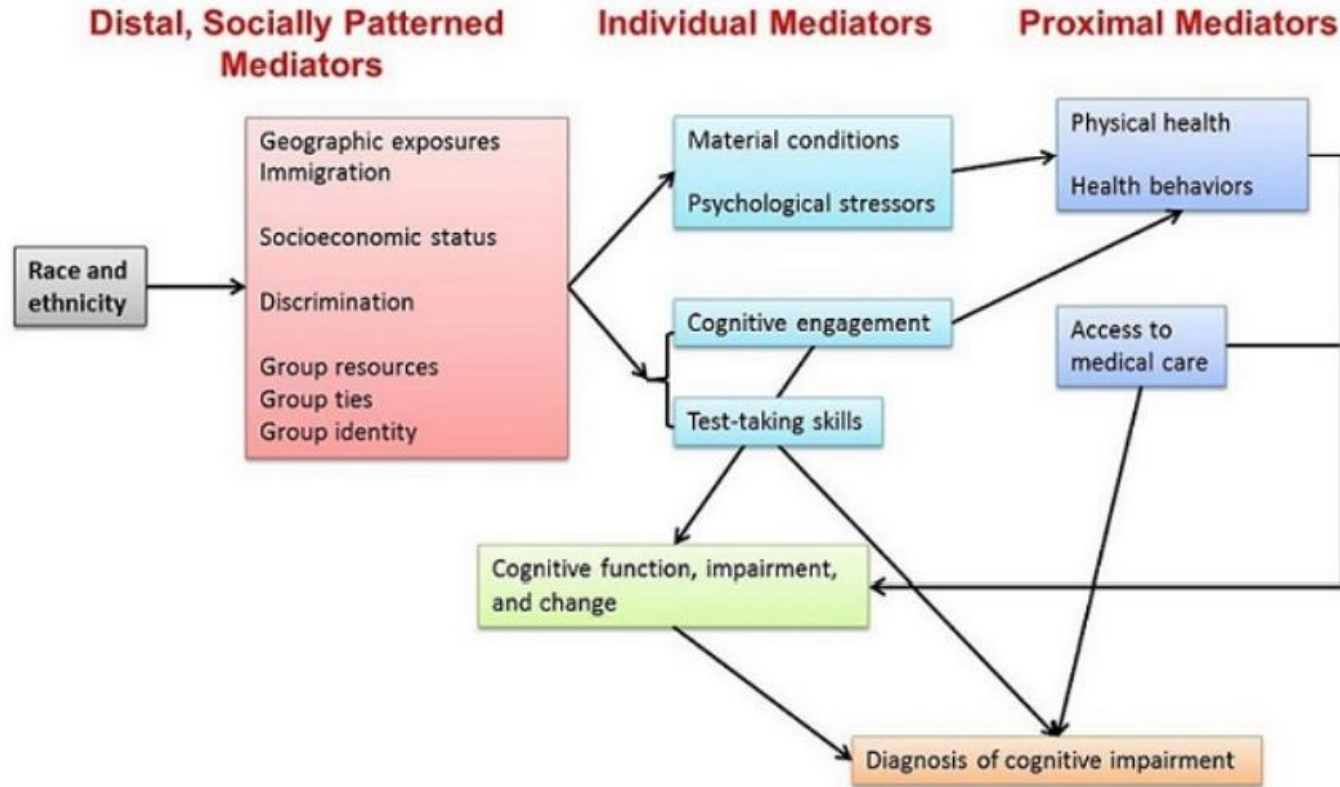
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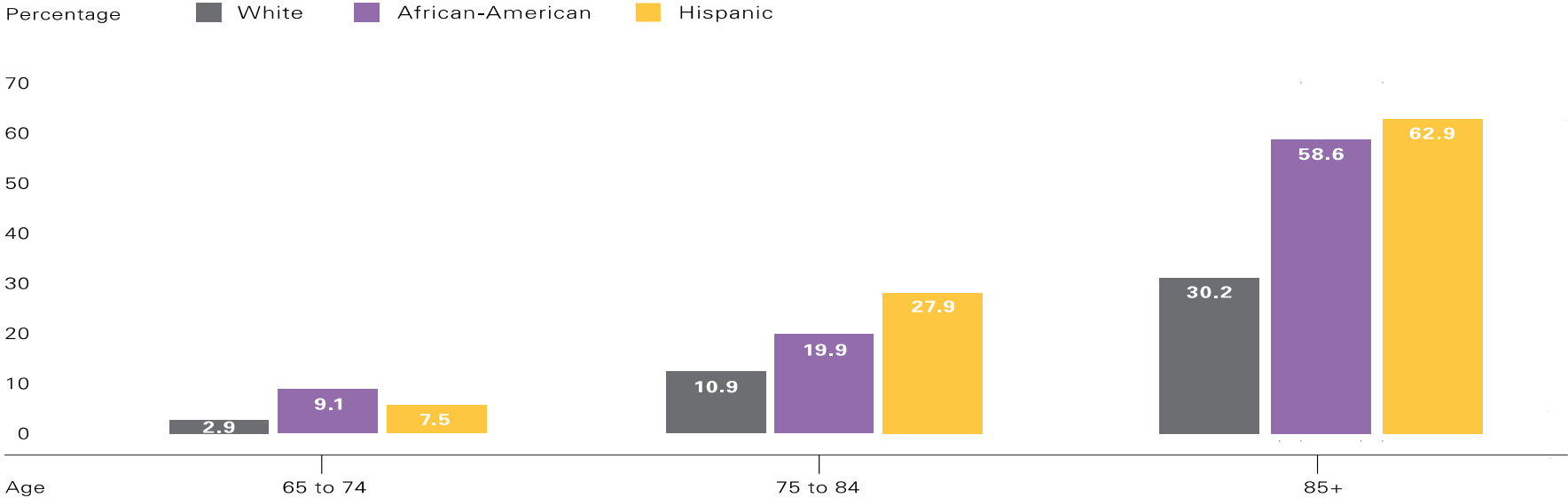




# Potential mechanisms

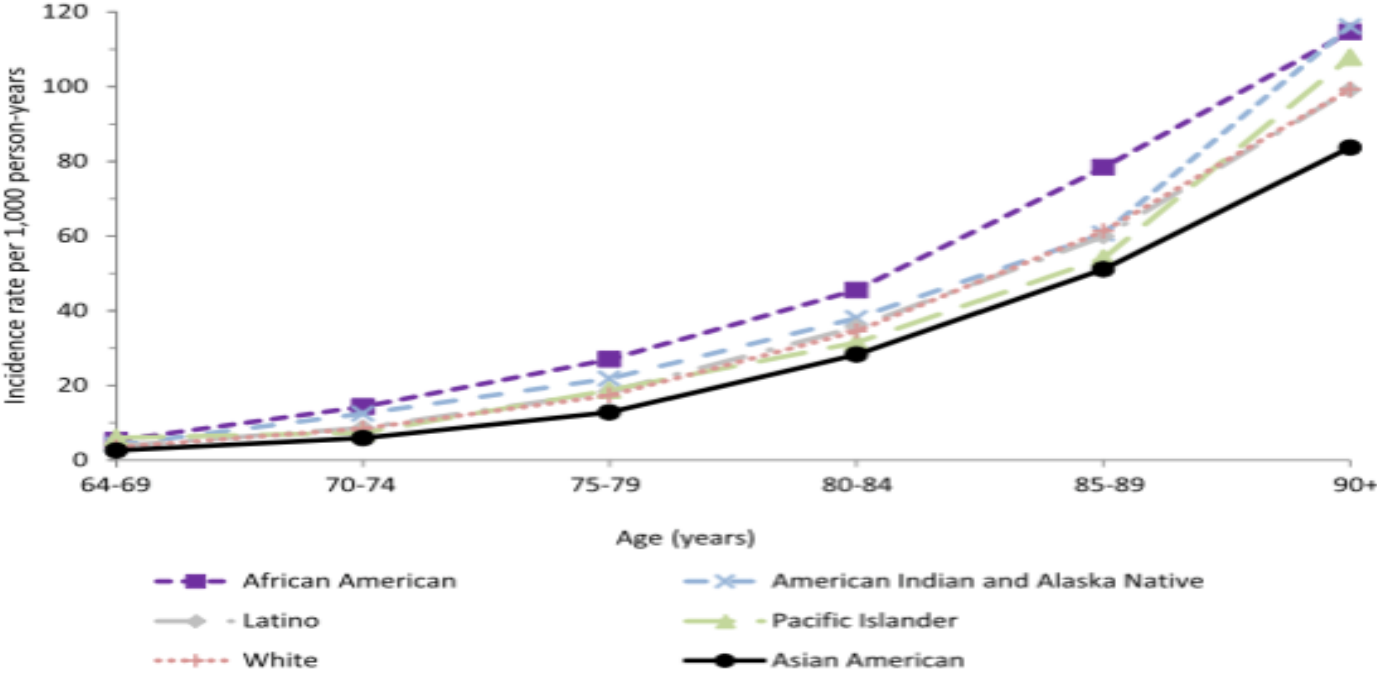


# Prevalence of dementia in New York



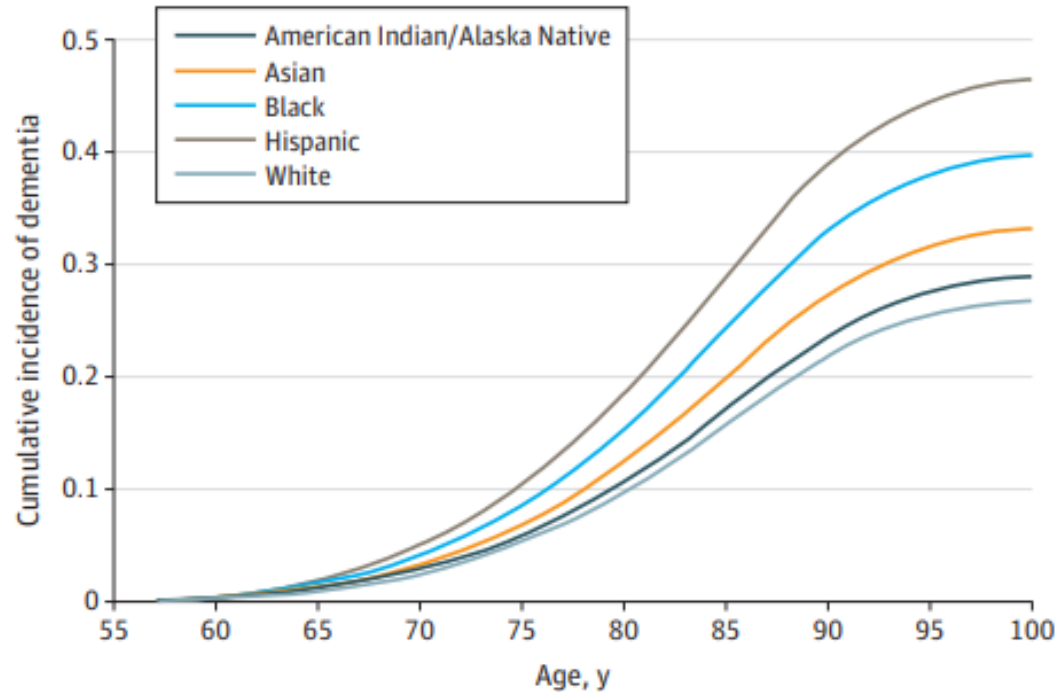
Gurland, 1999

# Incidence of dementia in California



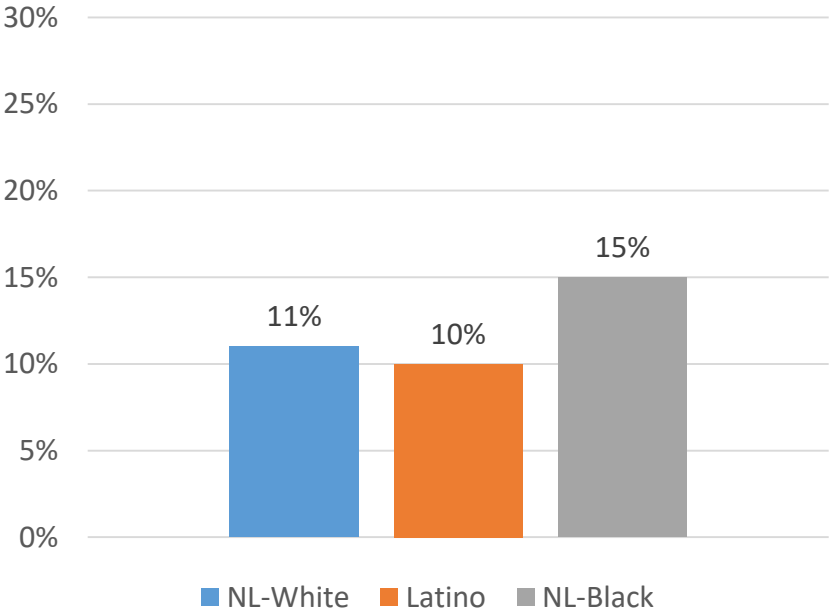
Mayeda, 2016

# Incidence of dementia among US veterans

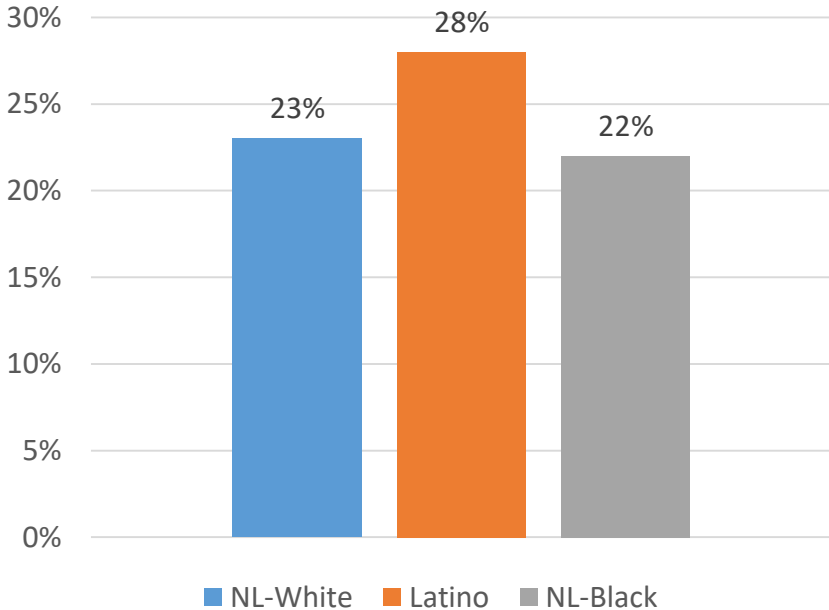


# Prevalence of dementia and MCI in the US population

Dementia



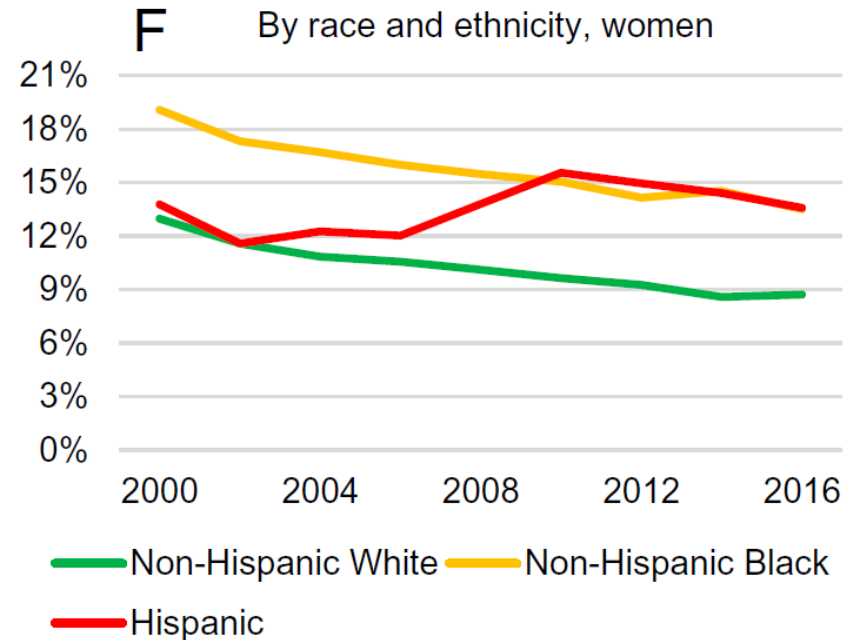
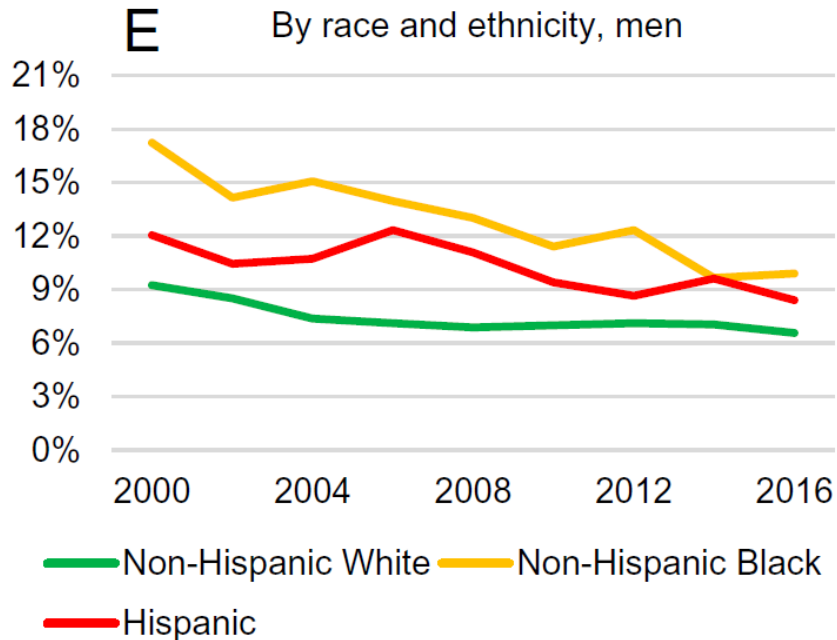
MCI



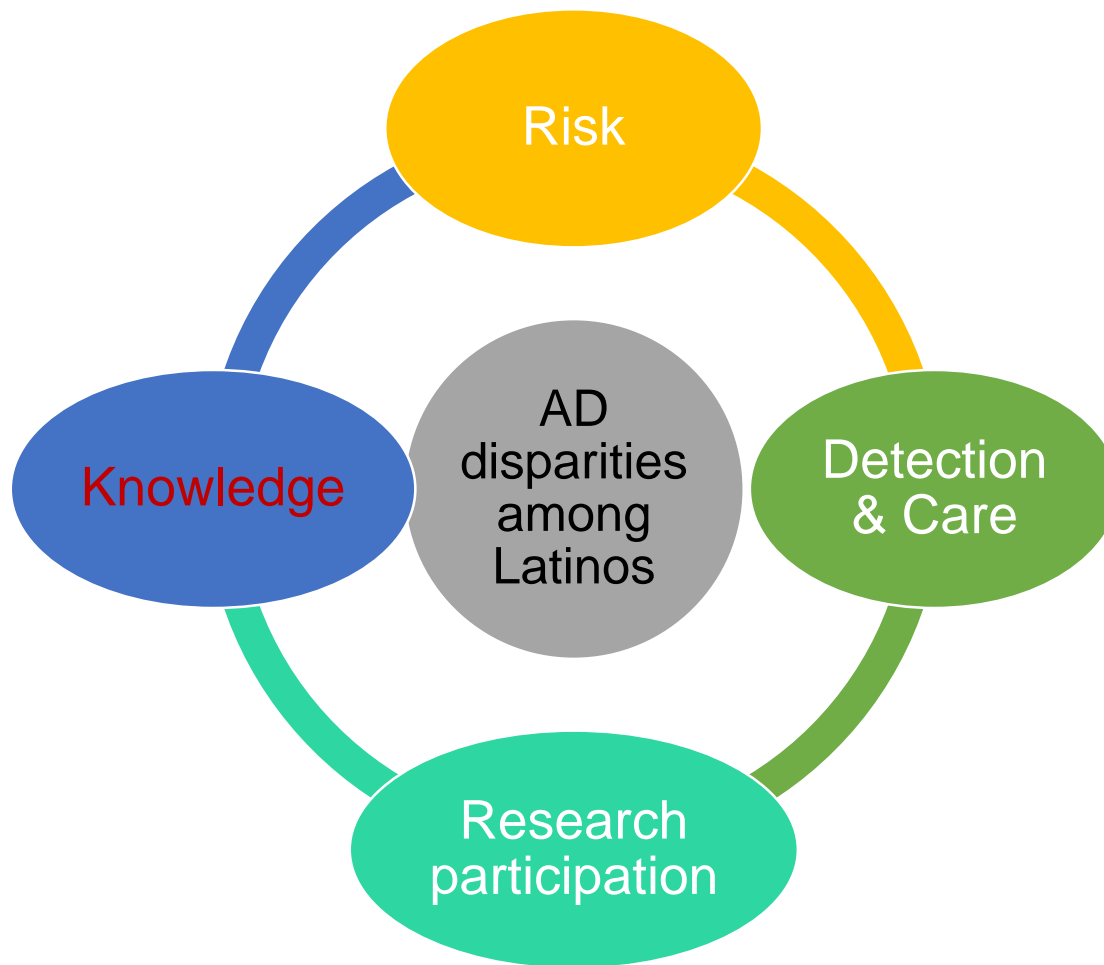
Manly, 2022



# Trends in prevalence of dementia in the US population

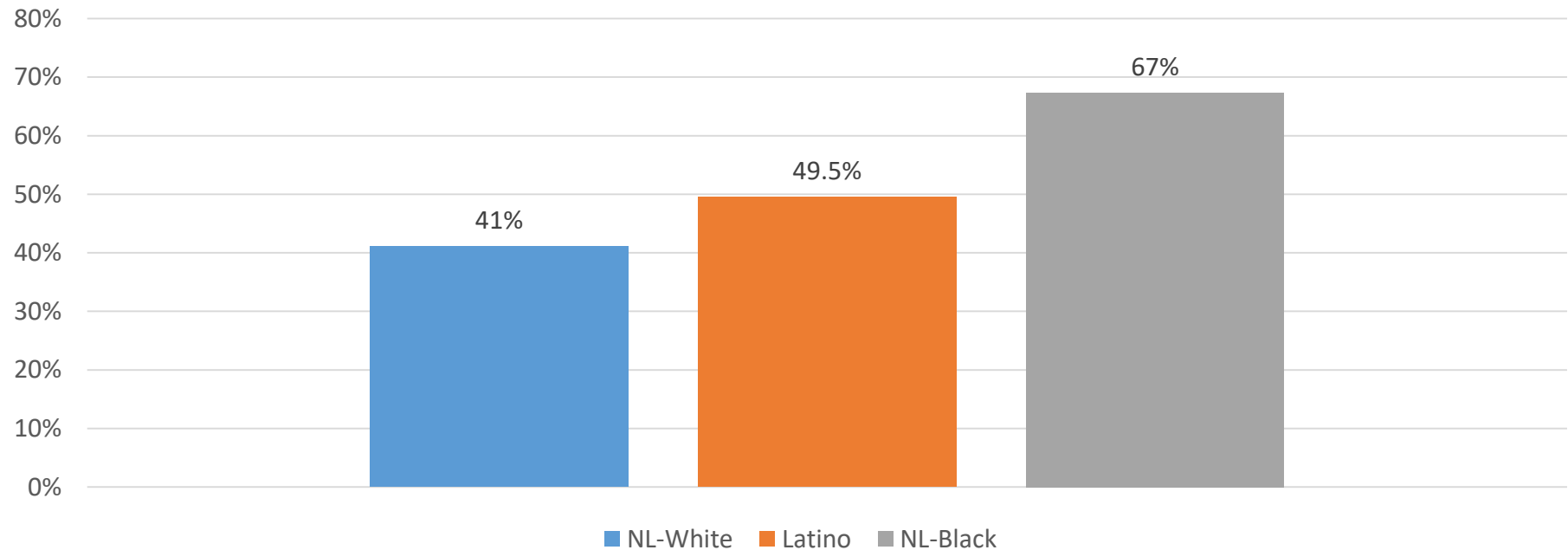


Hudomiet, 2022

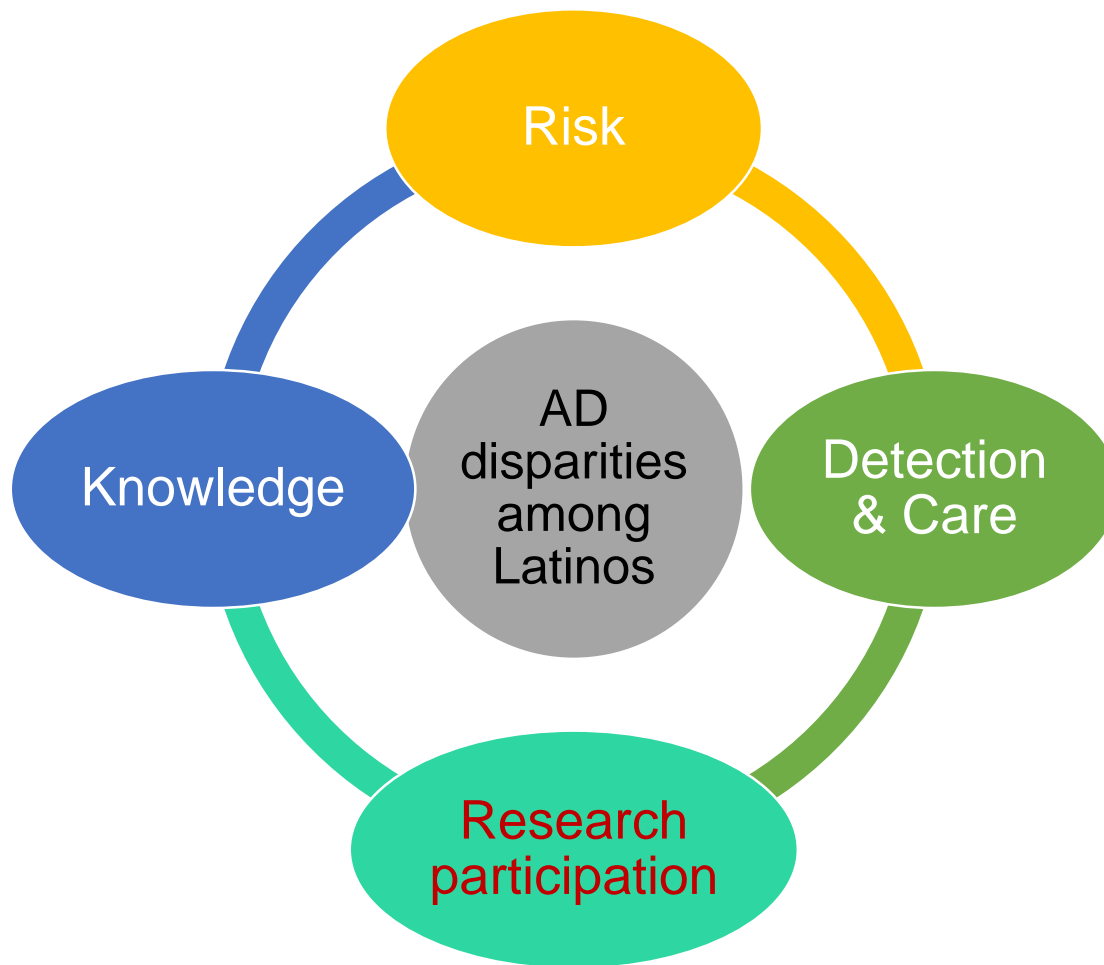


# Levels of dementia knowledge

Alzheimer's is normal memory loss as we get older

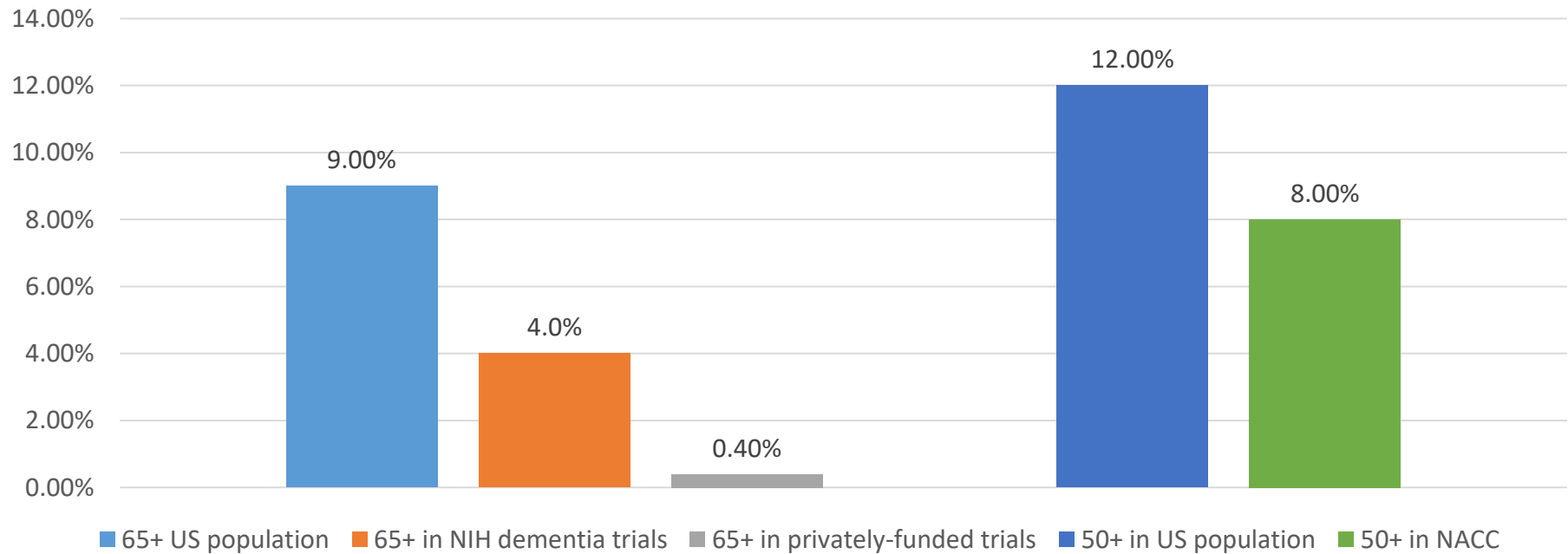


Connell, 2007



# Underrepresentation dementia research

Percentage of Latinos in...



US Census, 2016; Faison, 2007; NACC, 2018

# Consequences of underrepresentation

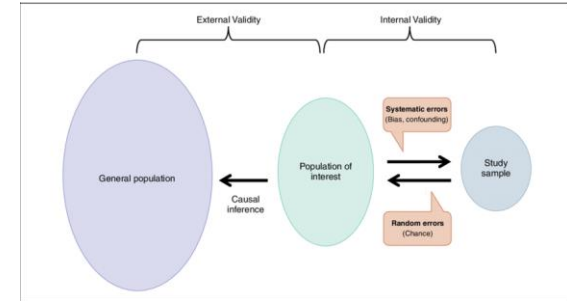


Rights



Findings for all

Jackson, 2020; Mayeda, 2018; Ramamoorthy, 2015; Jackson, 2016

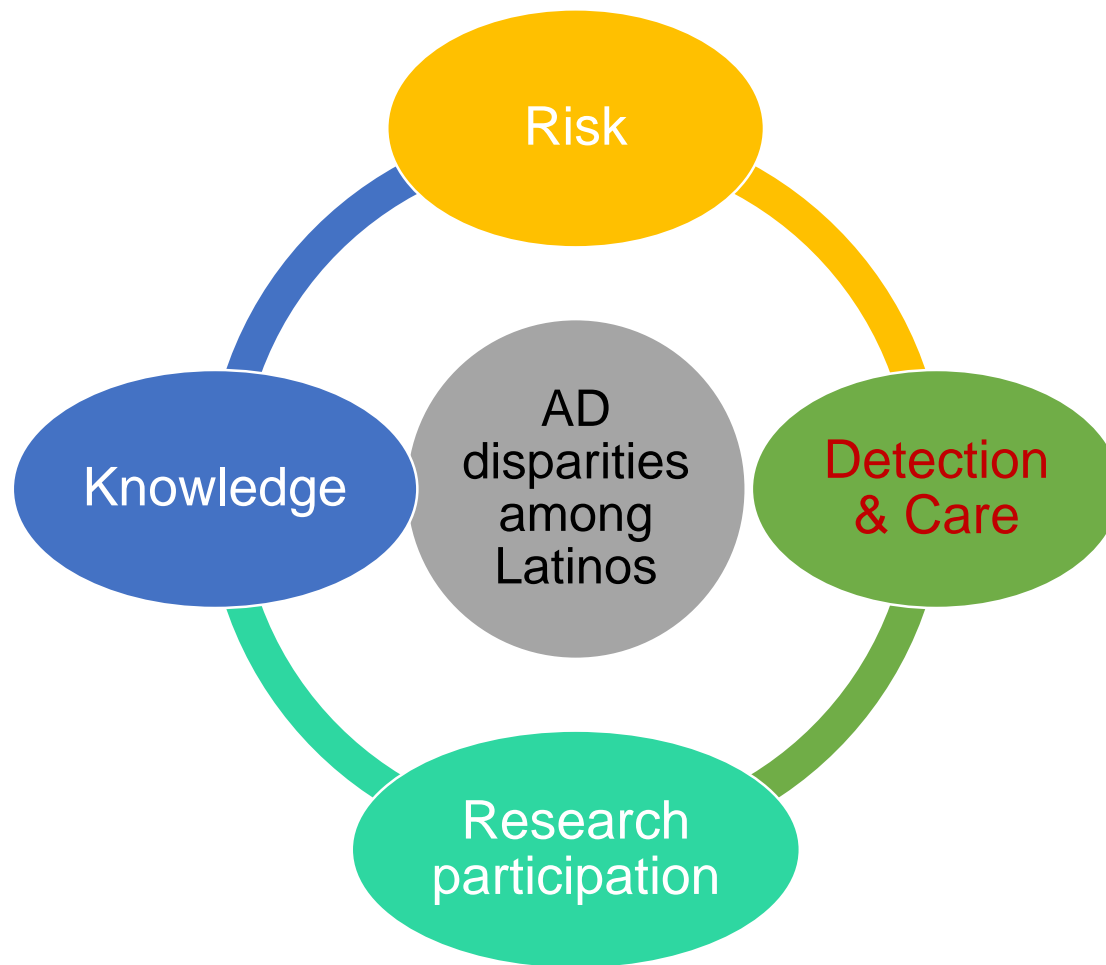


Validity

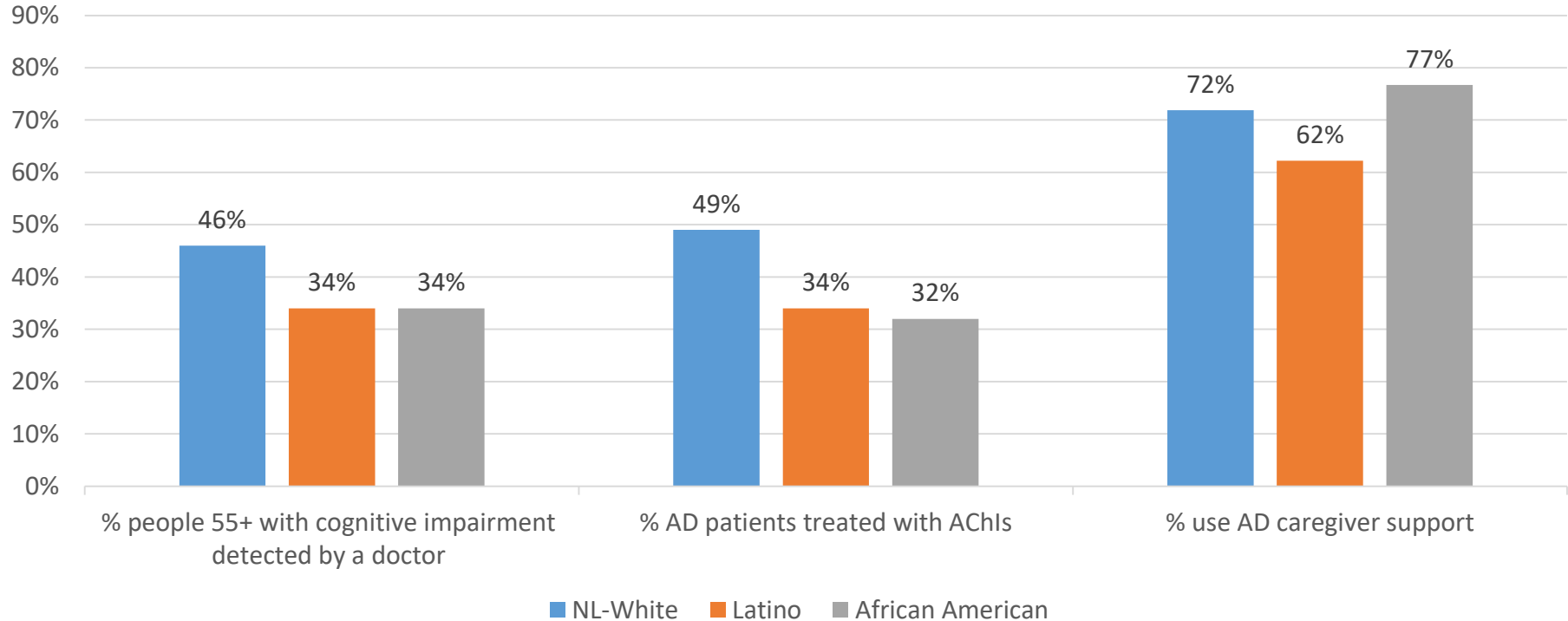


Widening gap





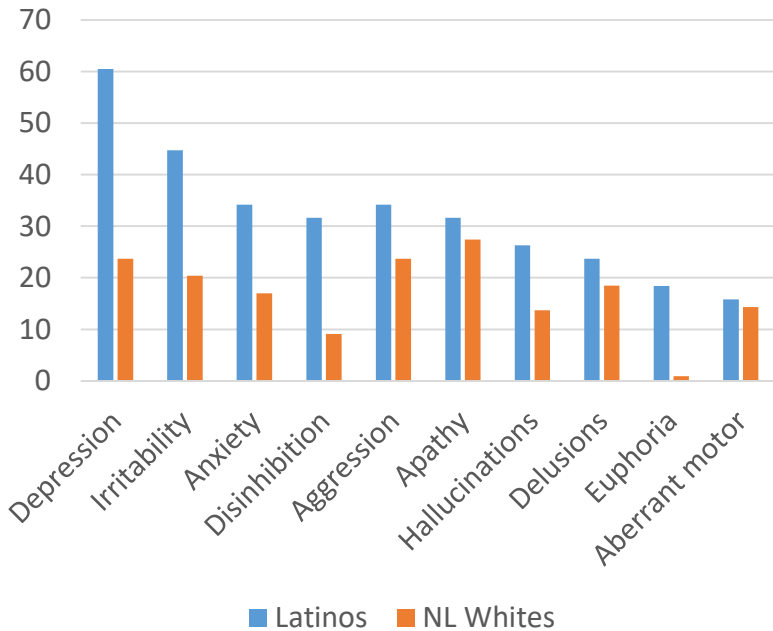
# Underdiagnosis and undertreatment



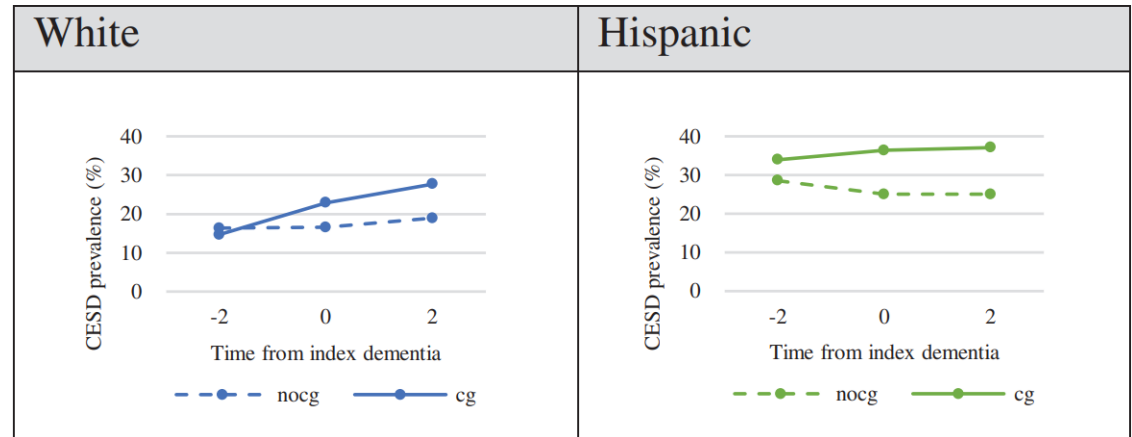
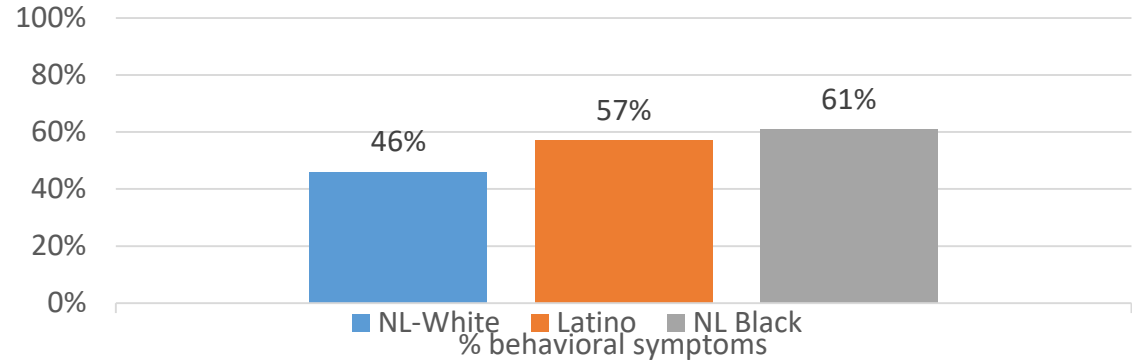
Lin, 2020; Mehta, 2005; Scharlach, 2008

# Poor behavioral health of care recipients and caregivers

Prevalence of Neuropsychiatric symptoms among PLWD (%)



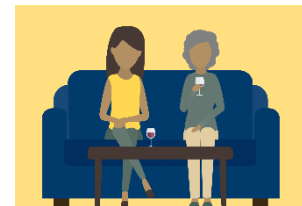
Hinton, 2003; Lyketsos, 2000; Chen, 2020



# Index

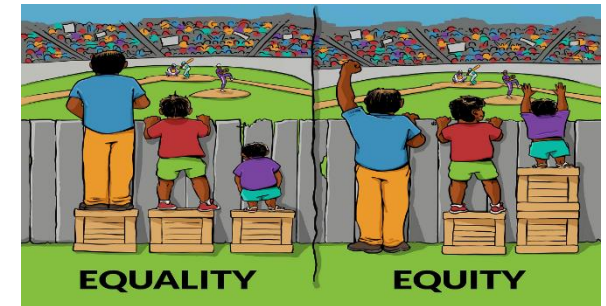
1. Racial and ethnic groups
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  1. CuidaTEXT

# Our team



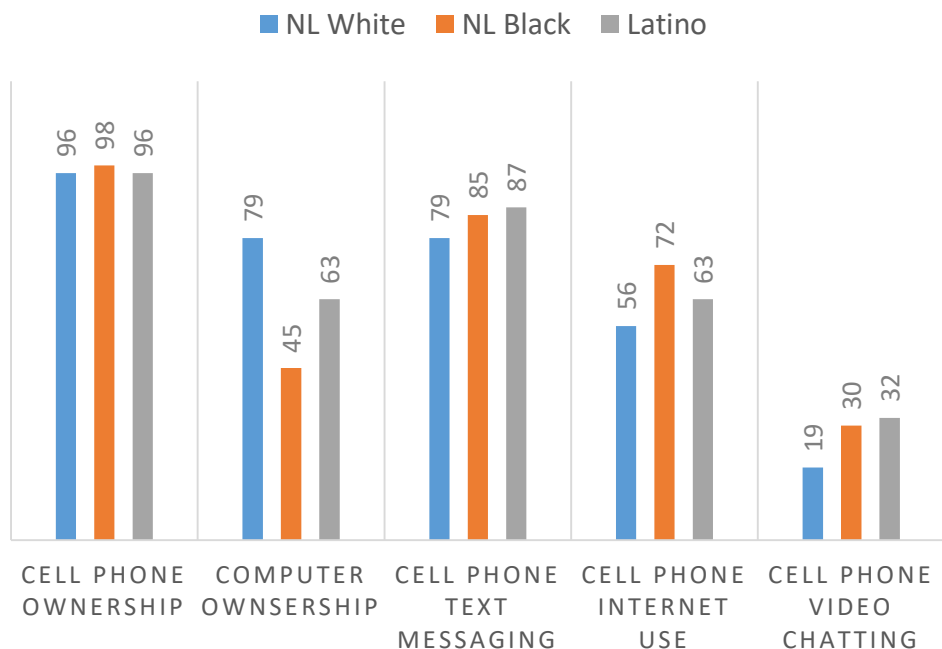
# Why focus on Latino people with dementia and their caregivers

- Very few interventions have been designed/tested among Latinos
  - Low generalizability
  - Potentially widens disparities
- Latinos experience barriers to care/caregiving giving interventions
  - Time constraints
  - Unreliable transportation
  - High cost vs income level
  - Language and cultural barriers



# Text messaging may be the solution

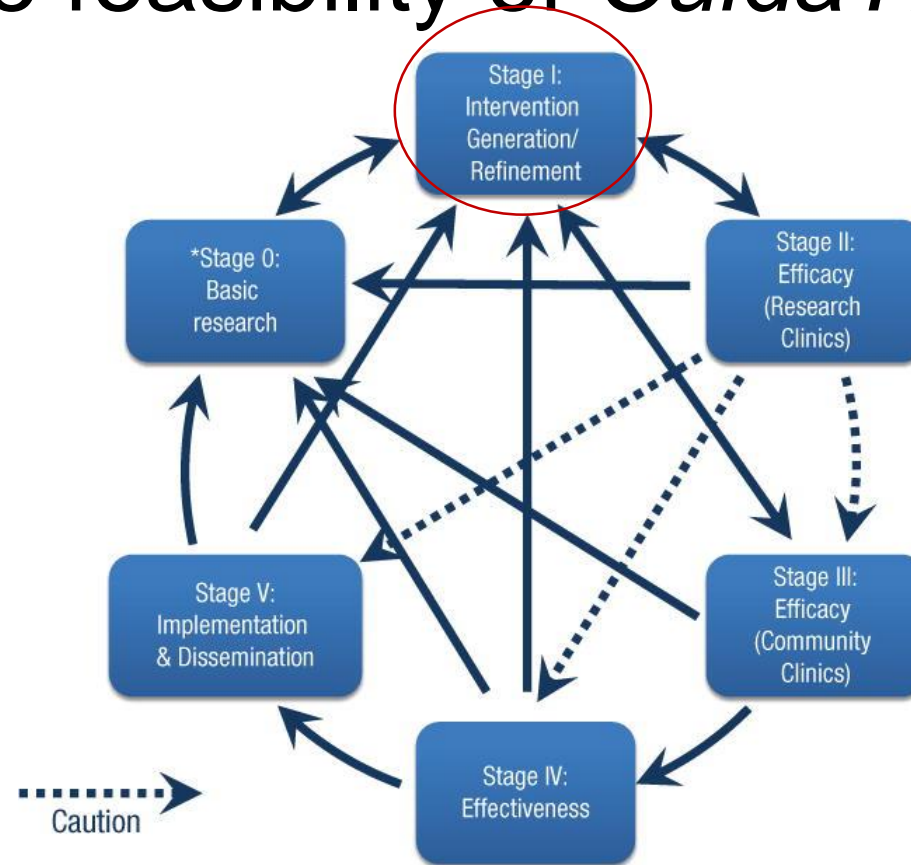
PEW, 2013 AND 2015 (%)



Potential for:

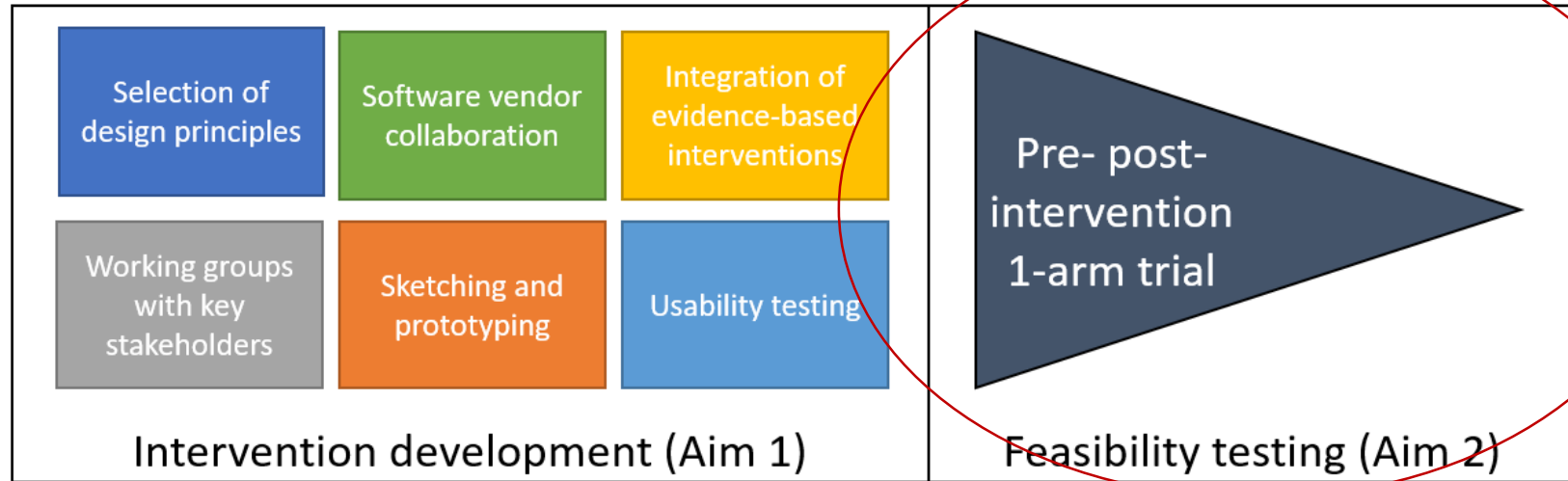
- Fidelity
- Effective
- Anywhere and anytime
- Low cost
- Personalized
- Private
- Highly engaging for Latinos

# Testing the feasibility of *CuidaTEXT*





# Testing the feasibility of *CuidaTEXT*



# CuidaTEXT, the intervention

Daily automatic text messages (1-3/day)



Keyword-driven text messages (upon request)



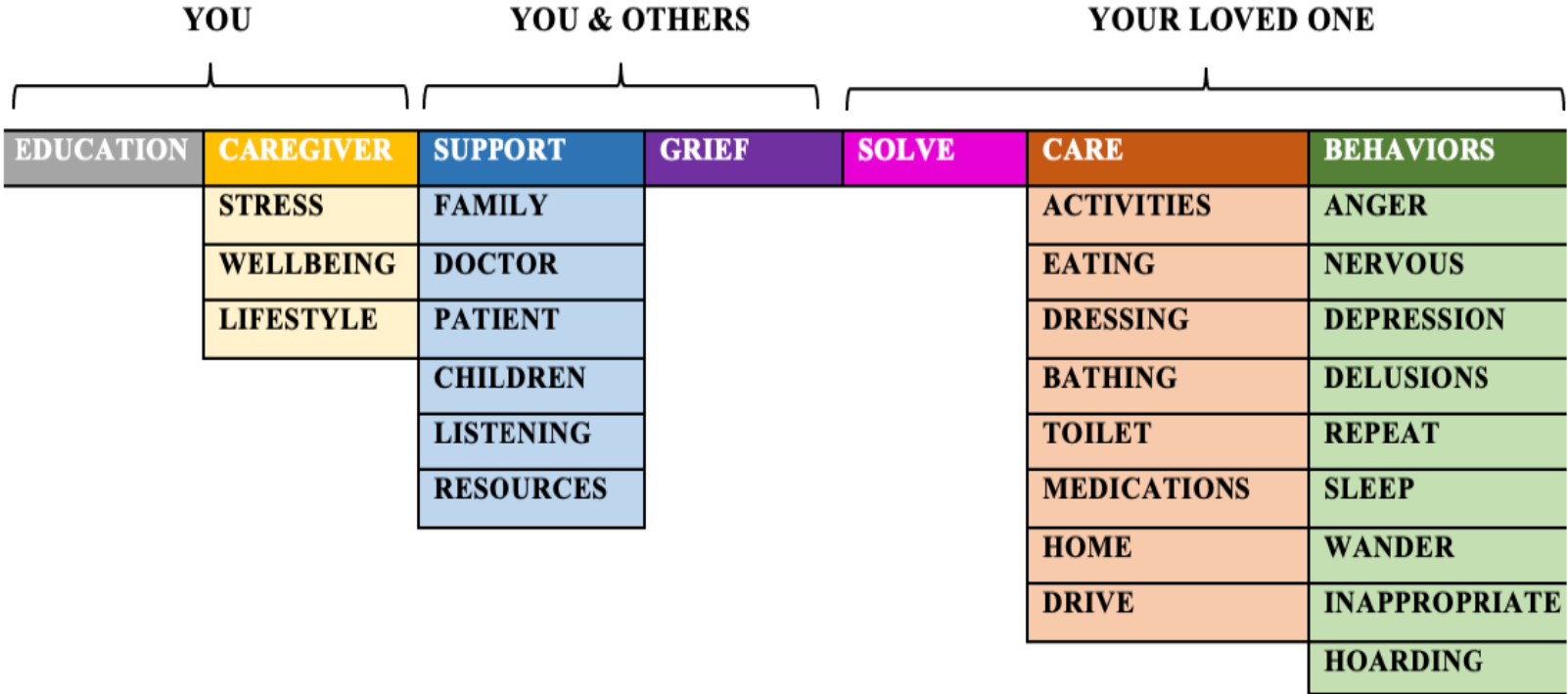
Live chat text messages (upon request)



CuidaTEXT booklet (at the time of enrollment)



# CuidaTEXT, the intervention



Pearlin, 1990; Perales-Puchalt, 2021

# Testing

**Study design:** one-arm pre- & post intervention trial; convenience sampling

**Intervention:**

- Six-month bilingual culturally-tailored SMS-based
- Two-way communication

**Participants**

- Spanish/English speaking Latinos
- Provide in-person caregiving to relative with dementia

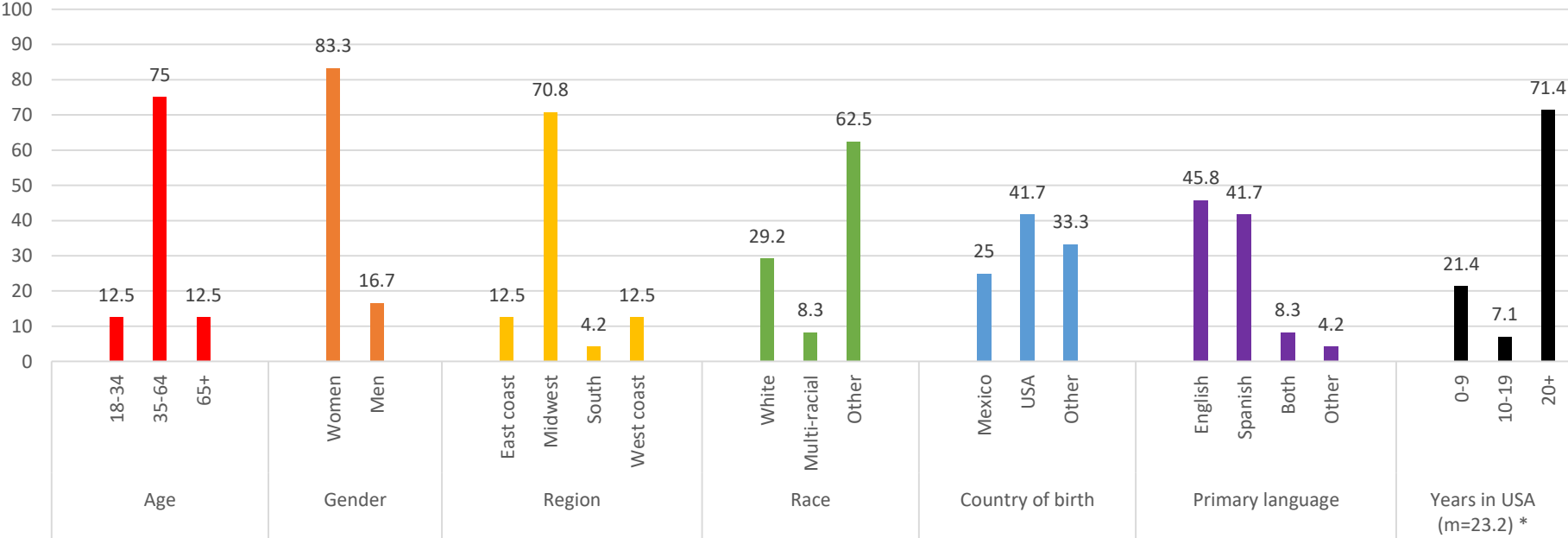
**Outcomes** (metrics, or pre- & post-intervention survey)

- Feasibility, acceptability, preliminary efficacy



# Caregiver baseline characteristics

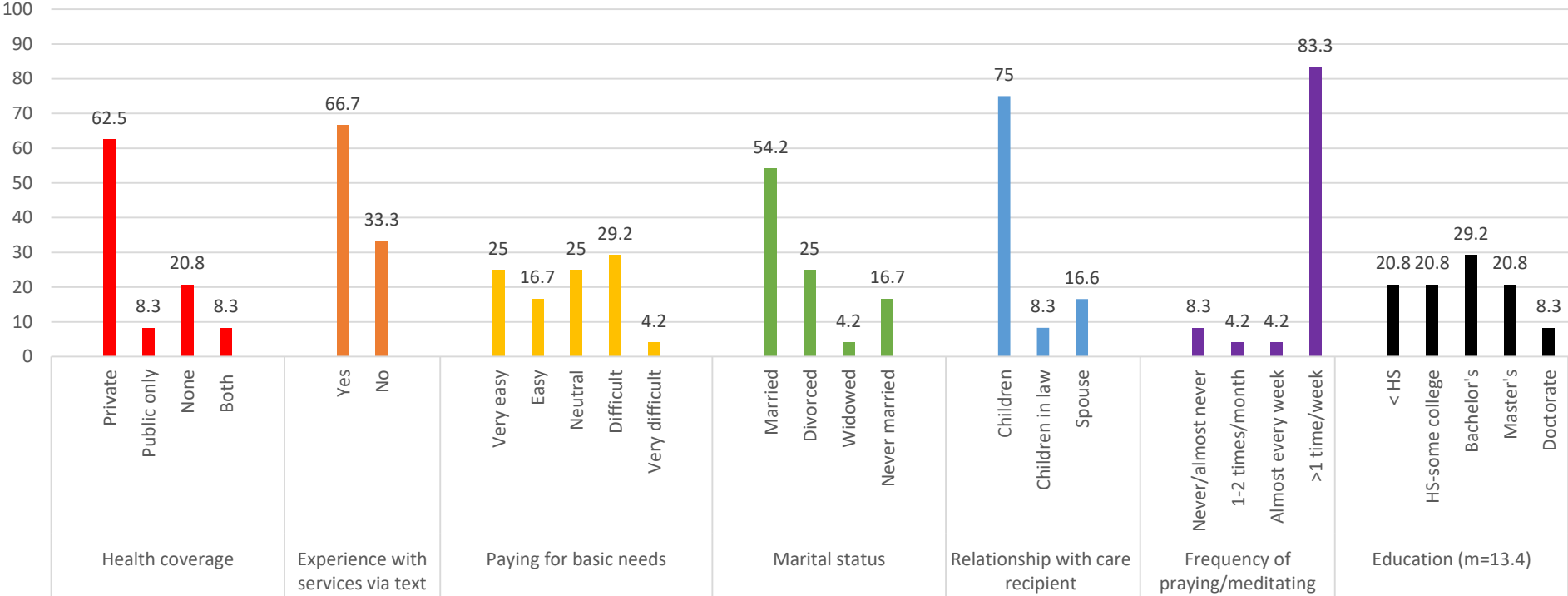
(%; n=24)



\* n=14

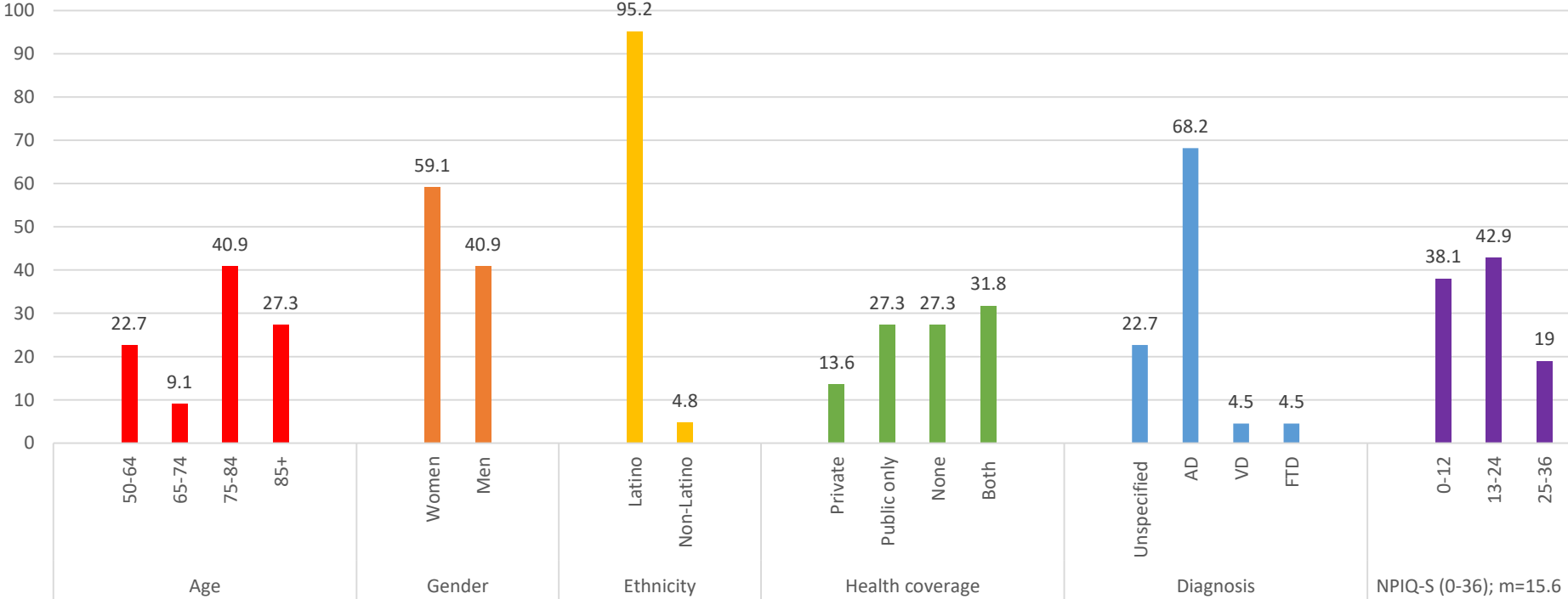
# Caregiver baseline characteristics

(%; n=24)



# Care recipient baseline characteristics

(%; n=21)



# Feasibility and acceptability

**Study enrollment:** 20 days

**Retention rate:** 88%, n=21

**Assessment rate of secondary outcomes:** 83%, n=20

**Technical issues:** 10%, n=2

- Sometimes no internet to see videos
- Broken phone=lost history



[kualzheimer.org](http://kualzheimer.org)



# Feasibility and acceptability

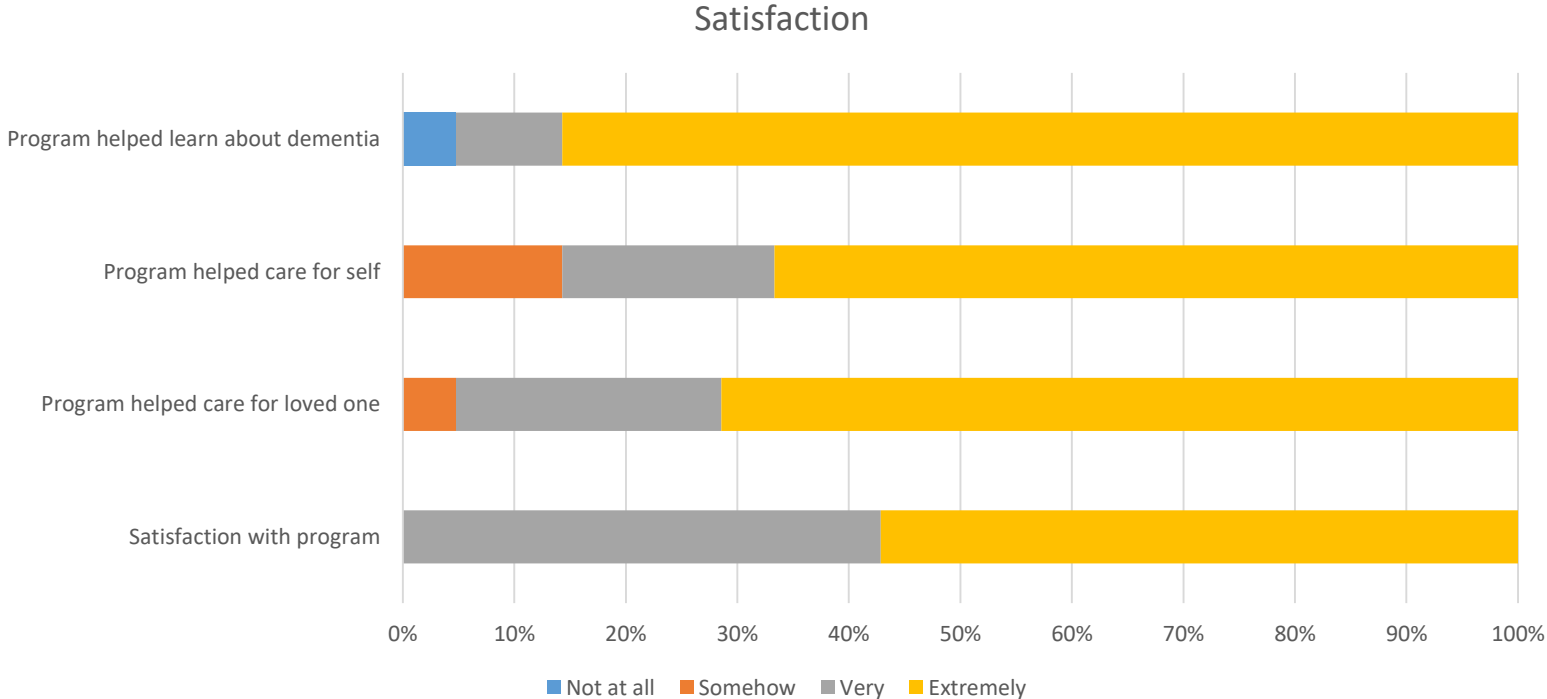
## Intervention engagement:

- Texted STOP to discontinue: 0%
- Average texts per participant: 77
- Sent at least one message: 92%, n=22
- Read most message thoroughly: 86%, n=18

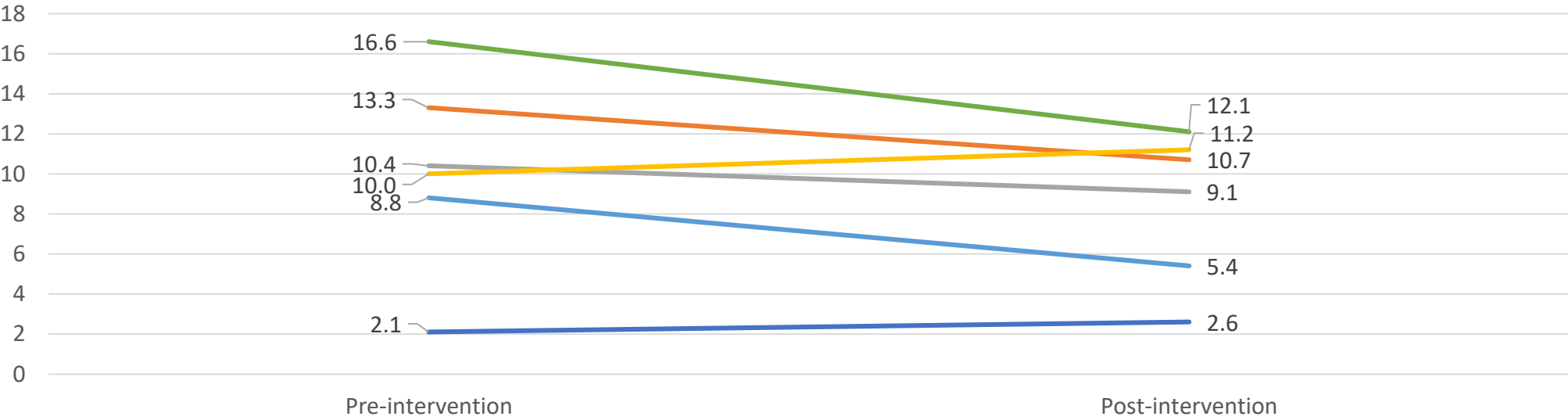


[kualzheimer.org](http://kualzheimer.org)

# Feasibility and acceptability



# Preliminary efficacy



— Depression (CESD10; 0-30); p=0.008  
 — Burden (ZBI6; 0-24); p=0.179  
 — Competence (PCS; 0-4); p<0.001

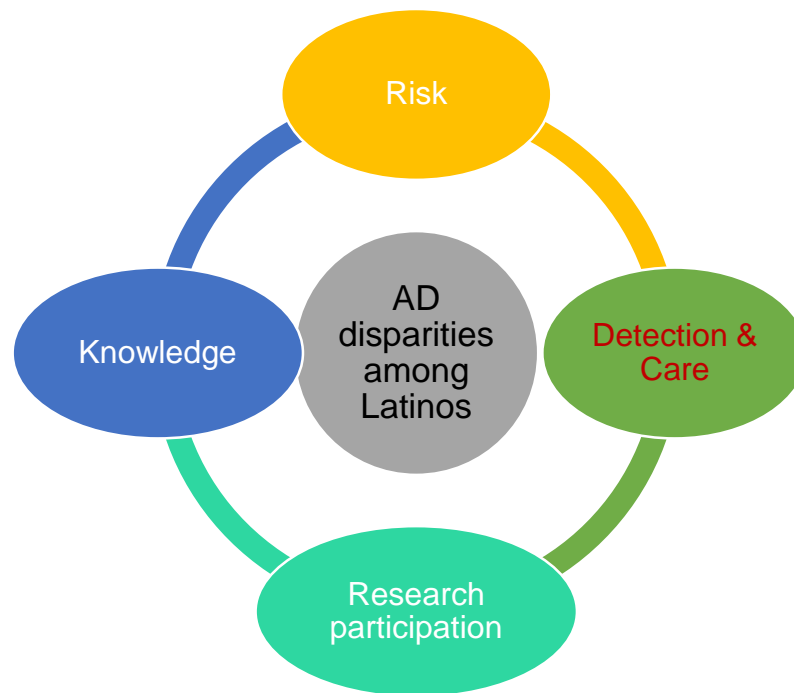
— Strain (CSI; 0-26); p=0.003  
 — Knowledge (EEDS; 0-14); p=0.005  
 — Neuropsychiatric symptom severity (NPIQ-S); p=0.01

# Discussion

- CuidaTEXT design feasible
- CuidaTEXT intervention has high acceptability
- Next step: Proceed with an efficacy study




# Other projects



# Alianza Latina

- Continue training Primary Care Providers
- Enrolling Latino families in care support
  - Texts + phone calls
  - Nationwide
    - n=100
- If interested, call 913-588-3716



*Do YOU have  
a loved one with  
memory issues?*

RECEIVE SUPPORT ON YOUR PHONE.

**CONSIDER THE ALIANZA LATINA STUDY**

Alianza Latina is a study to support caregivers of Latinos with dementia through personalized phone calls and text messages at NO COST.

**WHAT TO EXPECT:**

- / Improve your skills in taking care of yourself and your loved ones
- / Learn about dementia and related resources
- / Get tips and strategies to relax, get active, and make your home safer
- / Chat with a coach live via text and receive phone calls to help you find care support for your loved one (home delivery meals options, medical appointments, etc.)
- / The study lasts for six months

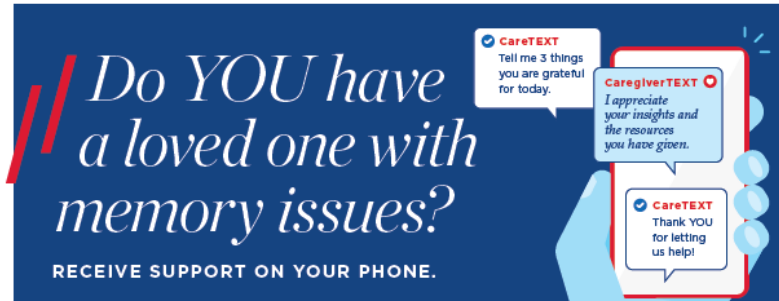
**THIS STUDY IS FOR THOSE WHO:**

- / Take care of a loved one with memory problems (Alzheimer's or other dementias)
- / Are 18 years old or older
- / Have an active cellphone to receive text messages
- / Speak English or Spanish
- / The person with memory issues is Hispanic or Latino and live anywhere in the U.S. including Puerto Rico

*Take advantage of this unique study.*

# CareTEXT

- Service
- Adapted CuidaTEXT to other groups
- Enrolling family caregivers in caregiver support
  - Texts only
  - In 5 Missouri counties
    - n=150
- If interested, call 913-588-1851



*Do YOU have a loved one with memory issues?*

RECEIVE SUPPORT ON YOUR PHONE.

**CareTEXT**  
Tell me 3 things you are grateful for today.

**CaregiverTEXT**  
I appreciate your insights and the resources you have given.

**CareTEXT**  
Thank YOU for letting us help!

## CONSIDER THE CareTEXT PROGRAM

CareTEXT is a program to support caregivers of people with dementia through text messages at NO COST.

### WHAT TO EXPECT:

- / Improve your skills in taking care of yourself and your loved ones
- / Learn about dementia and related resources
- / Get tips and strategies to relax, get active, and make your home safer
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### THIS PROGRAM IS FOR THOSE WHO:

- / Take care of a loved one with memory problems (Alzheimer's or other dementias)
- / Are 18 years old or older
- / Have an active cellphone to receive text messages
- / Speak English or Spanish
- / The person with memory issues lives in Cass, Clay, Jackson, Platte or Ray counties in Missouri

*Take advantage of this unique opportunity.*



CALL 913.588.1851  
EMAIL [cbaker10@kumc.edu](mailto:cbaker10@kumc.edu) OR  
VISIT [bit.ly/careTEXT](http://bit.ly/careTEXT)

[kualzheimer.org](http://kualzheimer.org)

# Moltes gràcies!

## Acknowledgements:

- Our funders (NIH, ACL, Prime Health, MARC, KUMC Frontiers)
- Current and previous participants
- Advisory board members
- Research team
- Current and previous mentors
- Community partners
- Recruitment sources

