

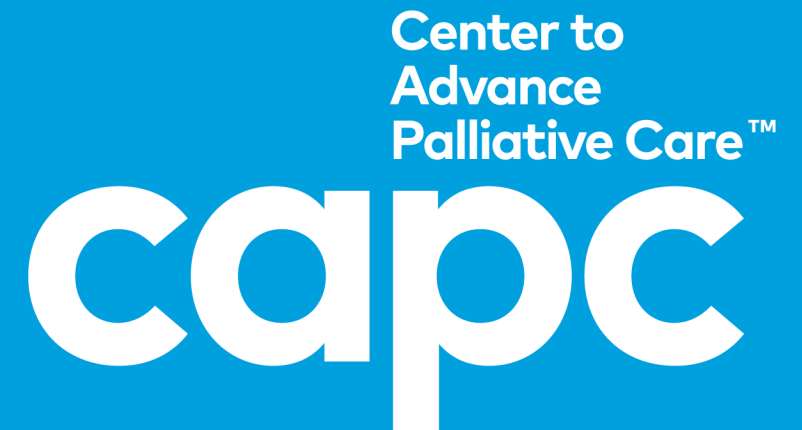
# Understanding Disparities in Dementia Care for Hispanic/Latino Communities

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CaringKind –The Heart of Alzheimer's Caregiving



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# Learning Objectives

1. Understand the broad diversity of the Hispanic/Latino community and its relation to healthcare.
2. Recognize the unique challenges and disparities faced by Hispanic/Latino individuals with dementia and their caregivers.
3. Identify practical strategies to address the diverse needs of the Hispanic/Latino community affected by dementia.

# Who we are and our why: Leah

- Caregiver from the age of 10
- First generation Hispanic-American
- Second-generation Guatemalan – Salvadoran immigrant
- Clinical experience in Pediatric ICU in Miami
  - Introduction to palliative care



# Who we are and our why: Dante

- First-generation Latino American from Peru
- Caregiver to my father, who lived with dementia
- 25 years of experience in geriatric social work
  - ❖ Introduced to palliative care in 1997 at Mt. Sinai
  - ❖ 18 years of inpatient and outpatient hospital social work
  - ❖ Witness health disparities firsthand

# Diversity within the Hispanic/Latino Community

# Hispanic/Latino Diversity

Latino	Hispanic
Individuals not only from Spanish-speaking Latin America	Individuals from Spanish-speaking countries (including Spain)
Latino, Latina, Latine, and Latinx may be used based on personal preference	

To note, Hispanic is the most commonly used term among Hispanic/Latino U.S. adults.

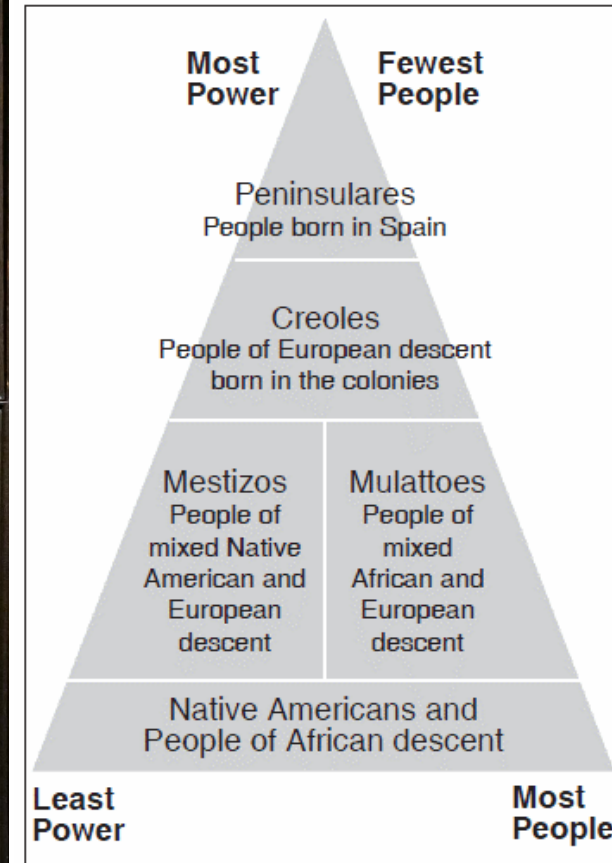
# Hispanic/Latino Diversity

Terms and Background: Race, Ethnicity, and Nationality

- People who share a common ancestry from a particular region of the world
- Phenotypical features
- Street Race: how others perceive you
- How US groups race:
  - American Indian or Alaska Native, Asian, Black or African American, Native Hawaiian or Other Pacific Islander, White



# Racial Caste Structure of Latin American



# Hispanic/Latino Diversity

Terms and Background: Race, **Ethnicity**, and Nationality

- Belonging to a group of people who share a common culture (beliefs, values, etc.)
- Cultural categorization

# Hispanic/Latino Diversity

Terms and Background: Race, Ethnicity, and **Nationality**

- Connection to a country
- 20 countries: North, Central, and South America, Caribbean
- e.g., Dominican, Mexican, etc.

# Hispanic/Latino Diversity

## Language

- One third of Mexican immigrants in New York City (NYC) speak an Indigenous language (e.g., Mixteco)
- Proportion of bilingual Latinos (English, Spanish) is decreasing
- Bilingualism varies by generational status
- Hispanic/Latino languages include: Brazilian Portuguese, English, 560 Indigenous languages, and Spanish

# Important Notes

Never use the word “illegal”, its offensive

- Dehumanized
- Causes unnecessary traumatization
- Legality is socially constructed

Better to use: undocumented, unauthorized, non-citizen

# Reasons for Immigrating

## Historical Context

- War
- Authoritarian governments
- Violence

## Present Day: Asylum

- Gang violence
- Drug, weapon, human trafficking
- Government corruption
- Structural racism/discrimination



# Social Determinants of Health and the Hispanic/Latino Community



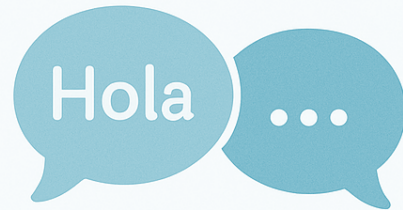
## Economic

Estimated 25% live in poverty



## Barriers to Health Care

High rates of uninsured



## Cultural and Linguistic

About 60% of older Hispanic/Latino adults are not fluent in English



## Immigration and Discrimination

Fear of seeking care

# Dementia in the Hispanic/Latino Community



# Dementia



**Group of diseases  
of cognitive  
impairment**



**Terminal Diagnosis**



**Complex  
management of  
symptoms**



**Unique  
presentation and  
progression**

# Dementia Risk and Subcultural Differences Example

Cardiovascular Disease



Cuban, Puerto Rican, Central American Communities

Overweight Prevalence



Mexican Communities

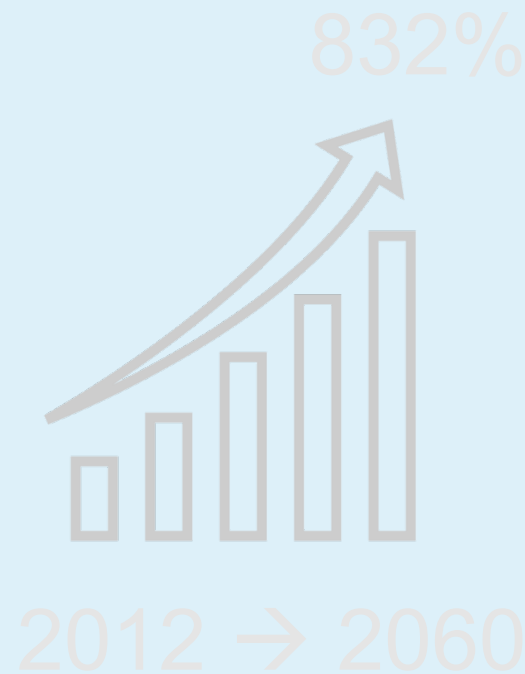
Dementia Prevalence



Caribbean-origin Communities

# Dementia Disparities in the Hispanic/Latino Community

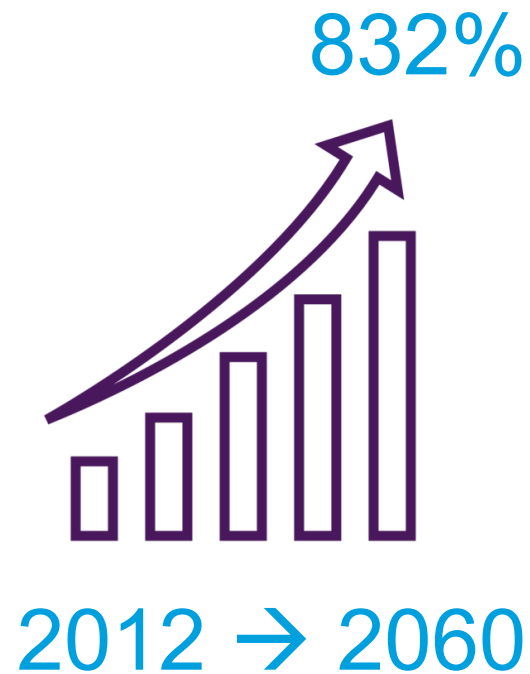
1.5x more likely  
than non-  
Hispanic/Latino  
white older  
adults



Delayed  
Diagnosis

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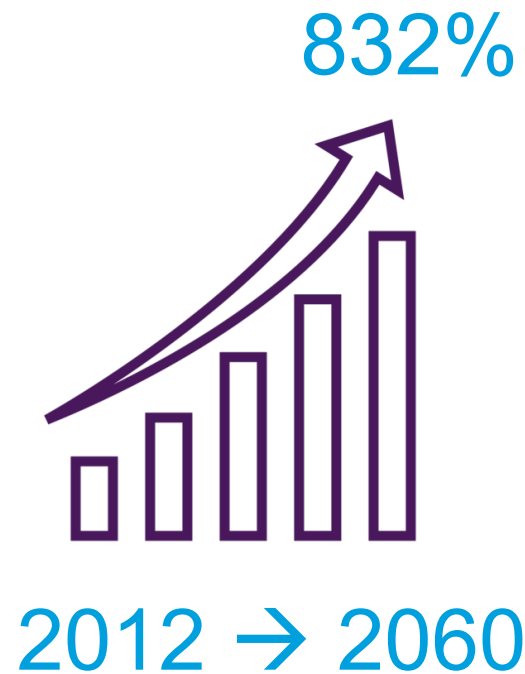
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# Dementia Disparities in the Hispanic/Latino Community

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# Hispanic/Latino Family Caregivers at a Glance



1.8 million  
family caregivers



More intensive  
caregiving situations

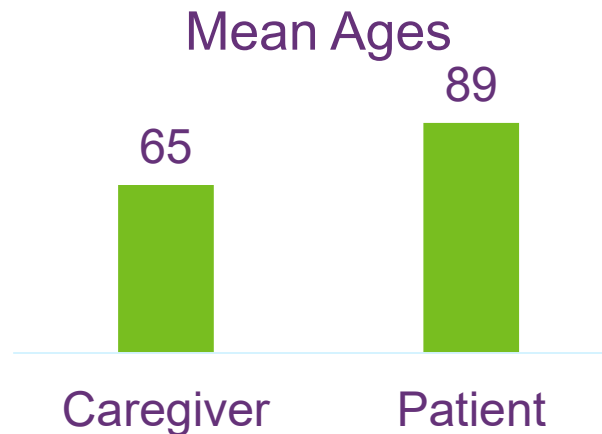


More hours per  
week caregiving  
and more likely to  
live with patient



Underutilization  
of hospice and  
palliative  
services

# Working Towards Health Equity Through Culture Centered Palliative Care for Hispanic/Latino Persons with Dementia



- Navigating health care
- Understanding of palliative care
- Values and beliefs in caregiving

**Participants did not know what palliative care is.**

“It’s very hard. I think dementia is such a horrible, horrible thing to have. Because it drains not only the – the patient with dementia, it drains the family member with dementia...Everything is affected....It’s like a domino effect. It affects everybody.”

- 56 year old daughter caring for 89 year old mother



# Hesitancy to problematize changes in function

*“Well, let me tell you. For me, my dad doesn’t have dementia. To me, my dad is a normal person. Yes, sometimes when I see that he doesn’t recognize me, then it does affect me. But I treat him normally.”*

# Tension that describes dementia symptoms, but don't acknowledge difficulty behind them

*"I wouldn't call it a burden, you know. People who call it a burden is someone who doesn't want the job"*

*"You know I mean like when it comes to their personal hygiene...sometimes it's def a struggle. But you know, we get around it...we just do things and we don't even think about it it being a problem ...we really don't...don't think that way."*

# Hispanic/Latino Cultural Values



- **Familismo:** Deep commitment to family—caregiving seen as a responsibility and honor
- **Respeto:** Respect for elders, authority, and traditional roles
- **Personalismo:** A preference for warm, personal relationships with healthcare providers, where trust is built over time
- **Spiritualidad:** Faith, prayer, and religious beliefs often play a major role in coping and care decision-making
- **Colectivismo** Emphasis on the well-being of the family over individual needs

# Dementia-Specific Challenges



- ✓ Cultural stigma and misinformation
- ✓ Delayed diagnosis due to denial or lack of awareness
- ✓ Care burden placed on family with little support
- ✓ Limited culturally tailored dementia services

# Case Vignette 1 – Late-Stage Dementia

## Mrs. R

- **Age:** 77-year-old woman originally from P.R. with advanced AD for about 10 years and actively receiving palliative care at home
- **Speaks:** Only Spanish
- **Lives:** With her daughter, son-in-law, and grandchildren
- **Symptoms:** Bedbound, agitation when bathing and dressing, spits out meds
- **Daughter:** Struggles with understanding PallCare and burden

# Cultural Challenges

- Language & Communication
- Perception of Palliative Care
- Religious Beliefs
- Family Decision-Making



# Mrs. R Outcomes

- Assigning a bilingual team
- Reframing palliative care as “comfort-focused”
- Coordinating visits with a Spanish-speaking chaplain
- Providing culturally sensitive educational and support



# Case Vignette 2 – Early-Stage Dementia (Mr. G)

- **Age:** 63 years old, originally from Mexico and recently dx with early-stage AD.
- **Speaks:** Spanish, some English
- **Lives:** with his wife, daughter, son, and grandchildren
- **Symptoms:** short-term memory loss, word finding, and anxiety
- **Family:** hesitant to engage in advance care planning and accept help from others



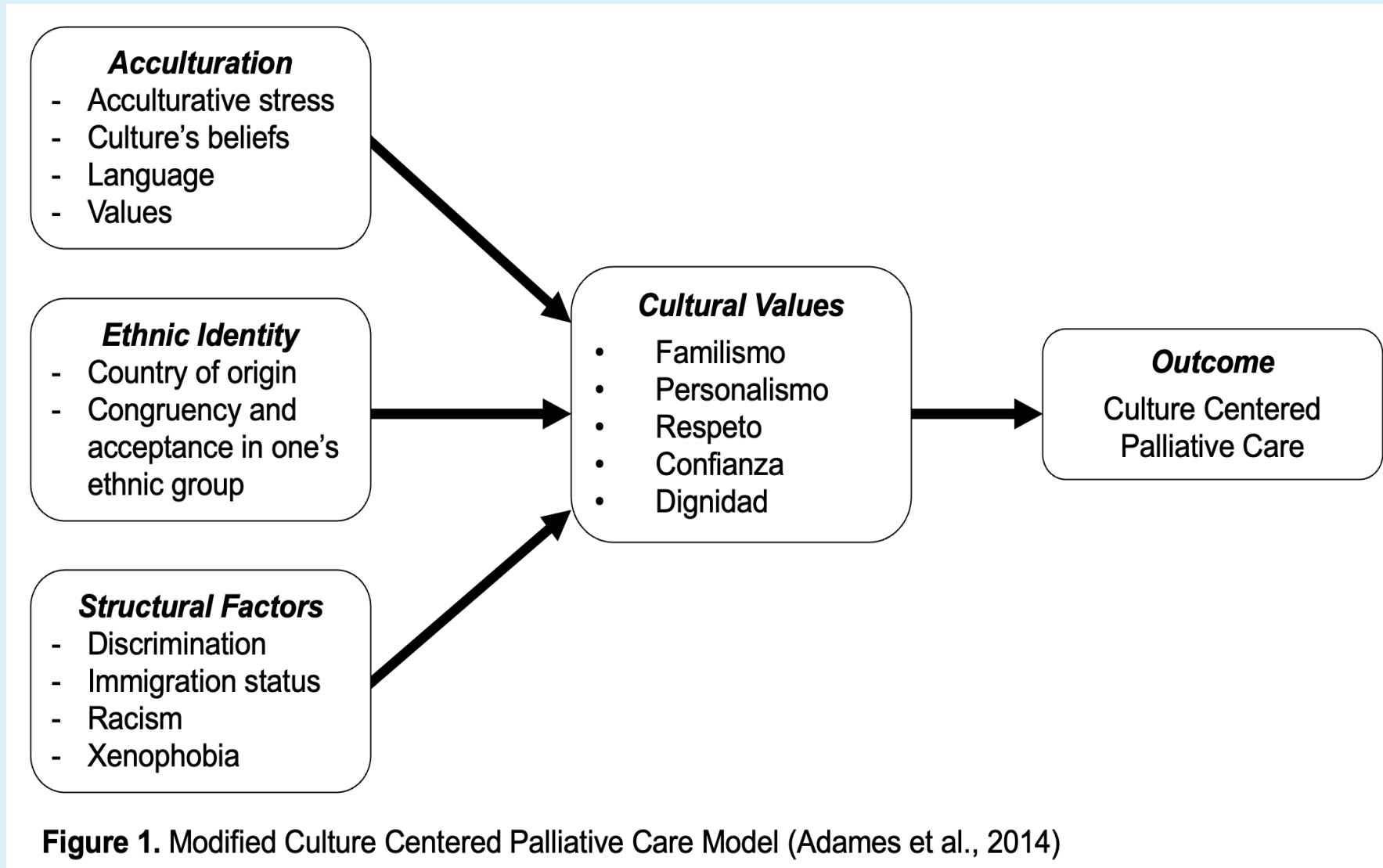
# Cultural Challenges

- Language Nuances
- Perception of Palliative Care
- Fatalism and Beliefs About Illness
- Collective Decision-Making
- Respect for Authority Figures

# Mr. G Outcome

- Utilize bilingual providers and interpreter services as needed
- Describing palliative care as “*cuidado para vivir mejor*”
- Education material and support in Spanish
  - Support groups
  - Parish priest

# Practical Strategies to Address the Diverse Needs of the Hispanic/Latino Dementia Community



# What Does “Culturally Centered” Mean?

“Care that addresses the patient’s and family’s needs and goals with an emphasis on cultural indicators, such as the influence of cultural beliefs and practices on patients’ and families’ perspectives.”

- Understand that **culture shapes**:
  - Identity, language, preferences, needs
  - Views on aging, caregiving, and illness
  - Use of formal health systems vs. family care
- Do not make assumptions of who the person is and their care preferences

# Culturally Centered Examples in Practice



- Build trust and listen
- Explore communication preferences
- Validate family's love and desire to help
- Recognizing that family members may not see caregiving as “burdensome” or “stressful”
- Understand the strong family networks, faith, and respect for elders

# Best Practices for Providers

- Build trust over time
- Avoid jargon: use “comfort care” vs. “palliative” or “hospice”
- Ask open-ended questions about values and fears
- Frame hospice as care “para estar cómodo en casa” (to be comfortable at home)
- Explain disease progression in culturally sensitive terms

# Conclusion

- Need to acknowledge rich diversity to address disparities in dementia care
- Integrate cultural centeredness in practice
- Create inclusive, accessible, person-centered care truly supports families navigating the challenges throughout their dementia journey





# Resources for Hispanic/Latino Families

- CaringKind –The Heart of Alzheimer's Caregiving
- Alzheimer's Association
- National Hispanic Council on Aging (NHCOA)
- NYC Dept. for the Aging (DFTA)
- Faith-based and community-based groups/ organizations

# References

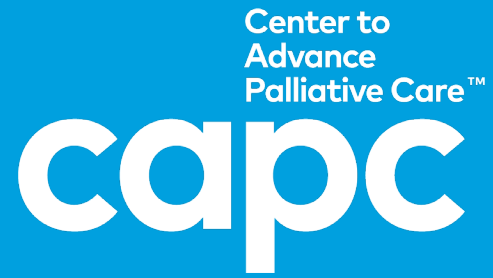
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# Questions

