



# Diverse Populations, Health Disparities and Dementia

2013 NIH/ACL Alzheimer's Webinar Series

July 24, 2013



# Welcome

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## Webinar Series Purpose

- Improve coordination of federal resources available to assist people with Alzheimer's disease or other dementias and their family caregivers
- Encouraging awareness of research participation opportunities

# National Alzheimer's Plan Goals

1. Prevent and Effectively Treat Alzheimer's Disease by 2025
2. Optimize Care Quality and Efficiency
3. Expand Supports for People with Alzheimer's Disease and Their Families
4. Enhance Public Awareness and Engagement
5. Track Progress and Drive Improvement

See the Plan & Progress: <http://aspe.hhs.gov/daltcp/napa/>

# Accomplishments and Current Work

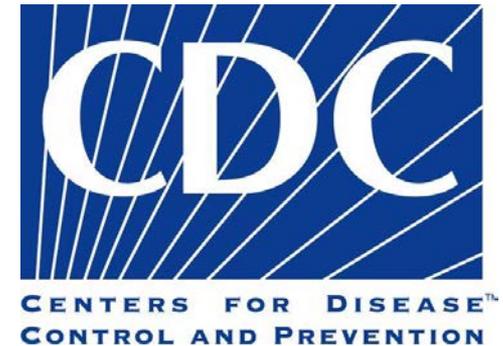
- Health disparities session of the Alzheimer's Disease-Related Dementias meeting held May 1-2, 2013 on the NIH campus in service of NAPA (See Session 5):  
<https://meetings.ninds.nih.gov/index.cfm?event=agenda&ID=4077>
- Convened a Specific Populations Task Force focused on 3 subgroups: (1) individuals with younger onset dementia, (2) racial/ethnic minorities, and (3) individuals with intellectual disabilities such as Down Syndrome.
  - Report from the Task Force on Specific Populations published in June 2013: <http://aspe.hhs.gov/daltcp/reports/2013/AlzSpPop.pdf>
  - Includes stakeholder recommendations

# Webinar Series Calendar

- **Webinar #4:** *Younger Onset Dementia*: Tuesday, August 20, 1:30-3pm ET
- **Webinar #5:** *Advanced Stage Dementia & Palliative Care*: Tuesday, September 24, 1:30-3pm ET
- Archives will be available at:  
[http://www.aoa.gov/AoARoot/AoA\\_Programs/HPW/Alz\\_Grants/index.aspx](http://www.aoa.gov/AoARoot/AoA_Programs/HPW/Alz_Grants/index.aspx) (under Resources & Useful Links)

# Recruiting Older Adults into Research (ROAR)

Aims at engaging older adults, including those of diverse ethnic and racial backgrounds, to volunteer for participation in clinical research.



Thereby helping accelerate scientific discovery.

Delaying dementia by 5 years would reduce projected Medicare dementia costs by nearly 50%\*.



Source: R.A. Sperling et al. / Alzheimer's & Dementia (2011) 1–13

# **Diverse Populations, Health Disparities and Dementia**

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# Disclosure Information

## **Financial Disclosure:**

None

## **Grant Support:**

P30 AG 10161

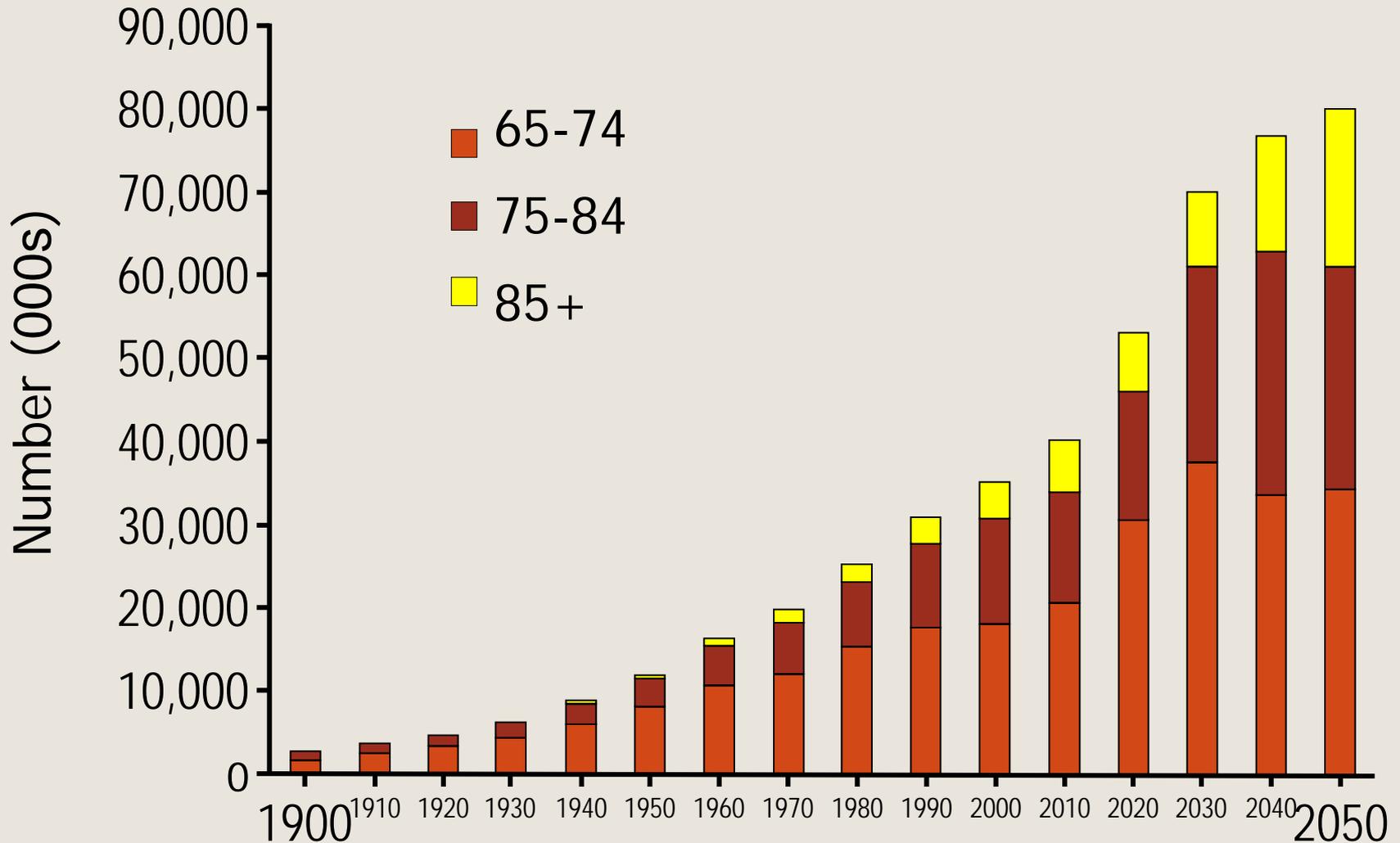
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# Objectives

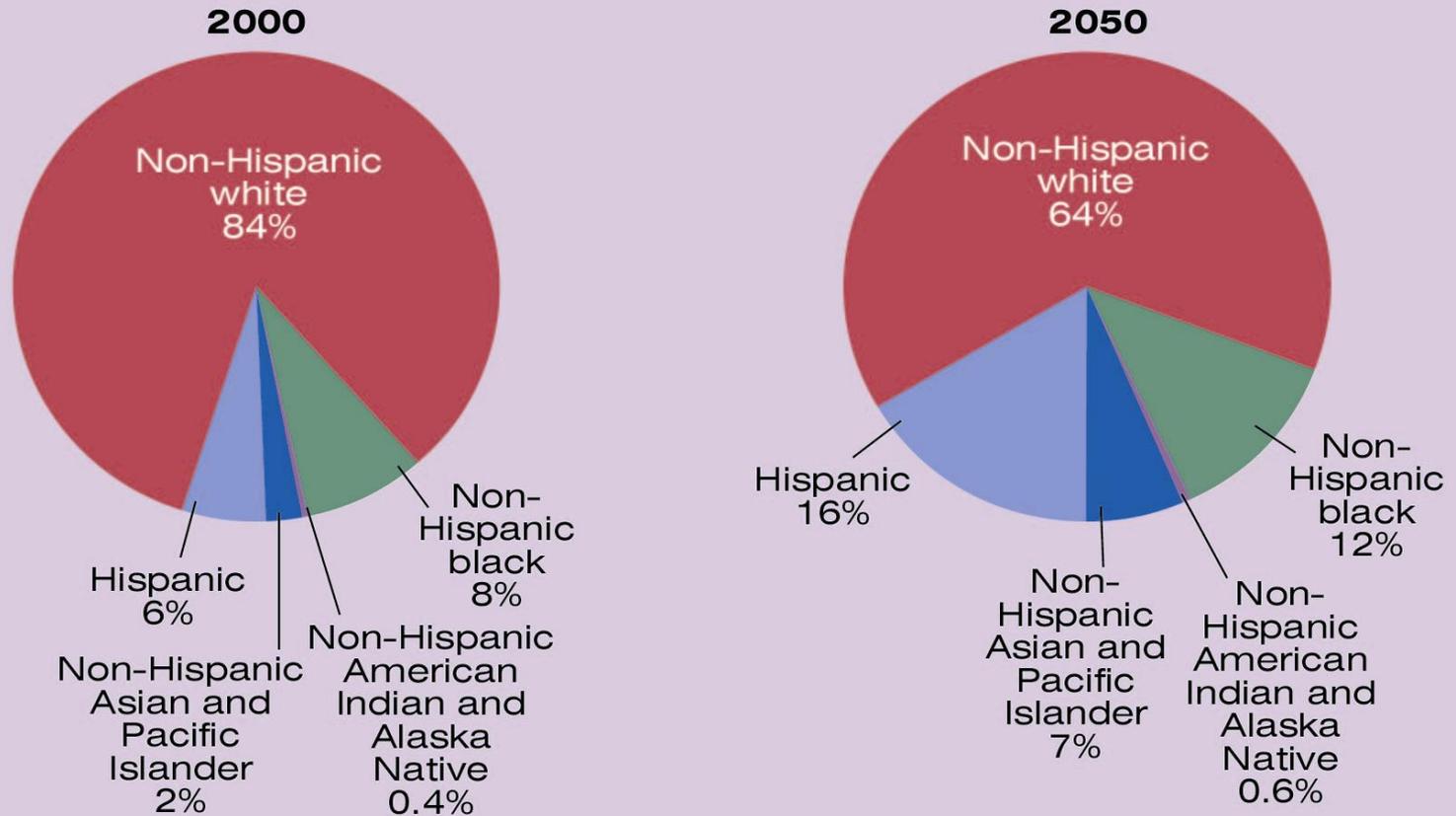
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- 2) Highlight latest research trends on the course of dementia in diverse populations
- 3) Discuss the opportunities and challenges when conducting studies in these populations
- 4) Highlight some possible solutions to overcoming these challenges

# Number of Persons Over Age 65 in US



# Distribution of Older Adults by Race and Ethnicity

**Projected distribution of the population age 65 and older, by race and Hispanic origin, 2000 and 2050**

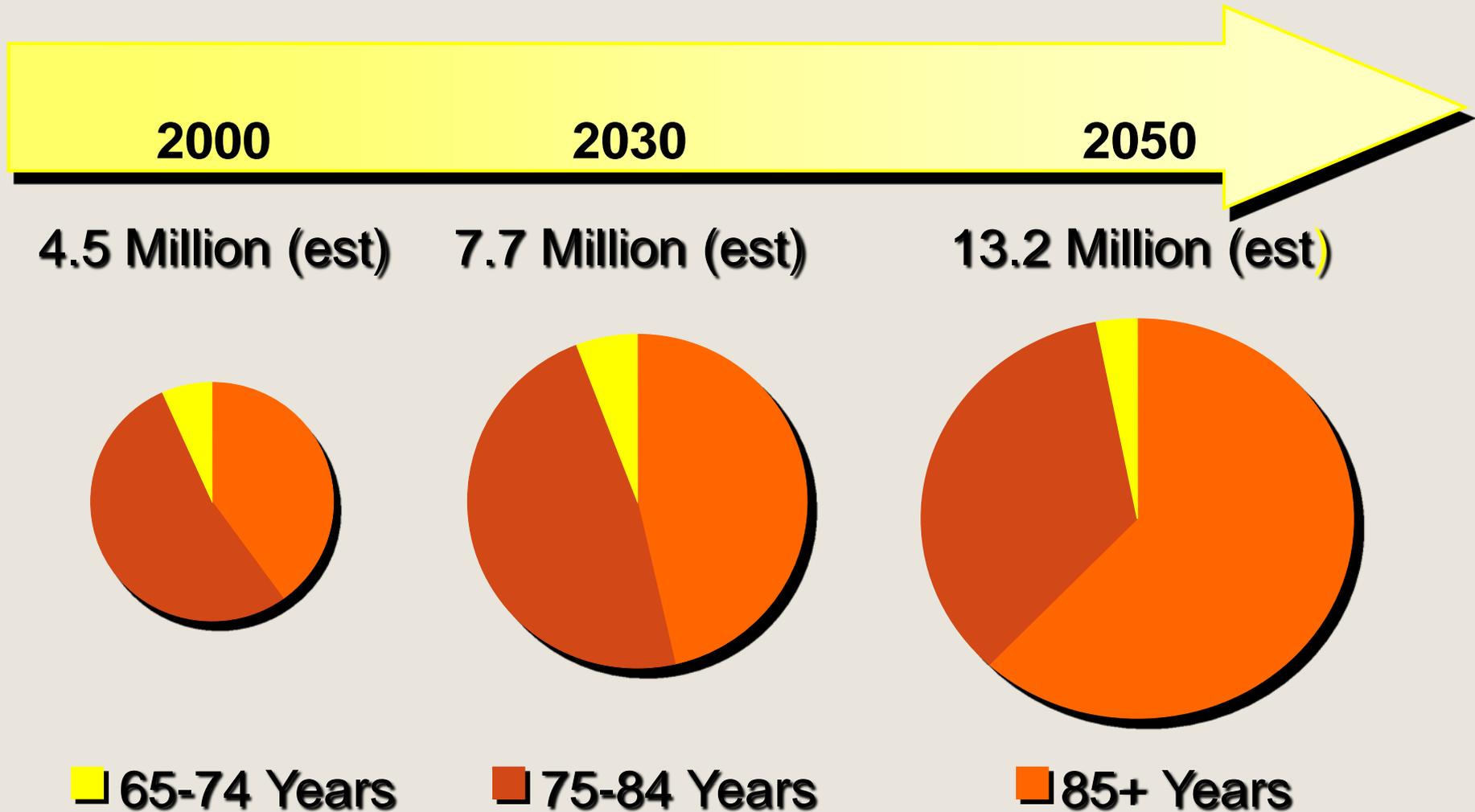


Note: Data are middle-series projections of the population. Hispanics may be of any race.

Reference Population: These data refer to the resident population.

Source: U.S. Census Bureau, Population Projections.

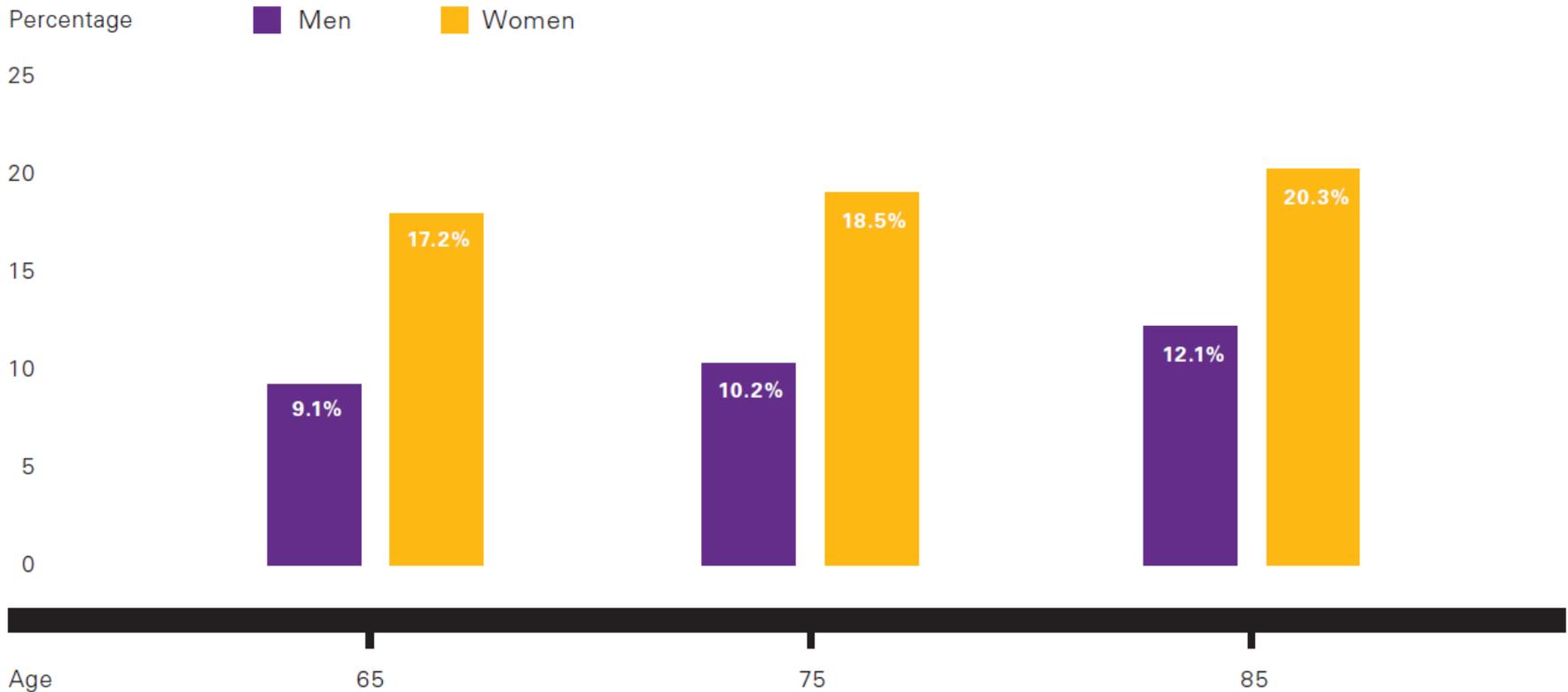
# Forecast of Alzheimer's Disease Prevalence in the U.S.



Source: Hebert LE, et al. *Arch Neurol.* 2003;60:1119-1122

# Lifetime Risk for AD

**figure 2:** Framingham Estimated Lifetime Risks for Alzheimer's by Age and Sex



Created from data from Seshadri et al. <sup>(71)</sup>

# Objectives

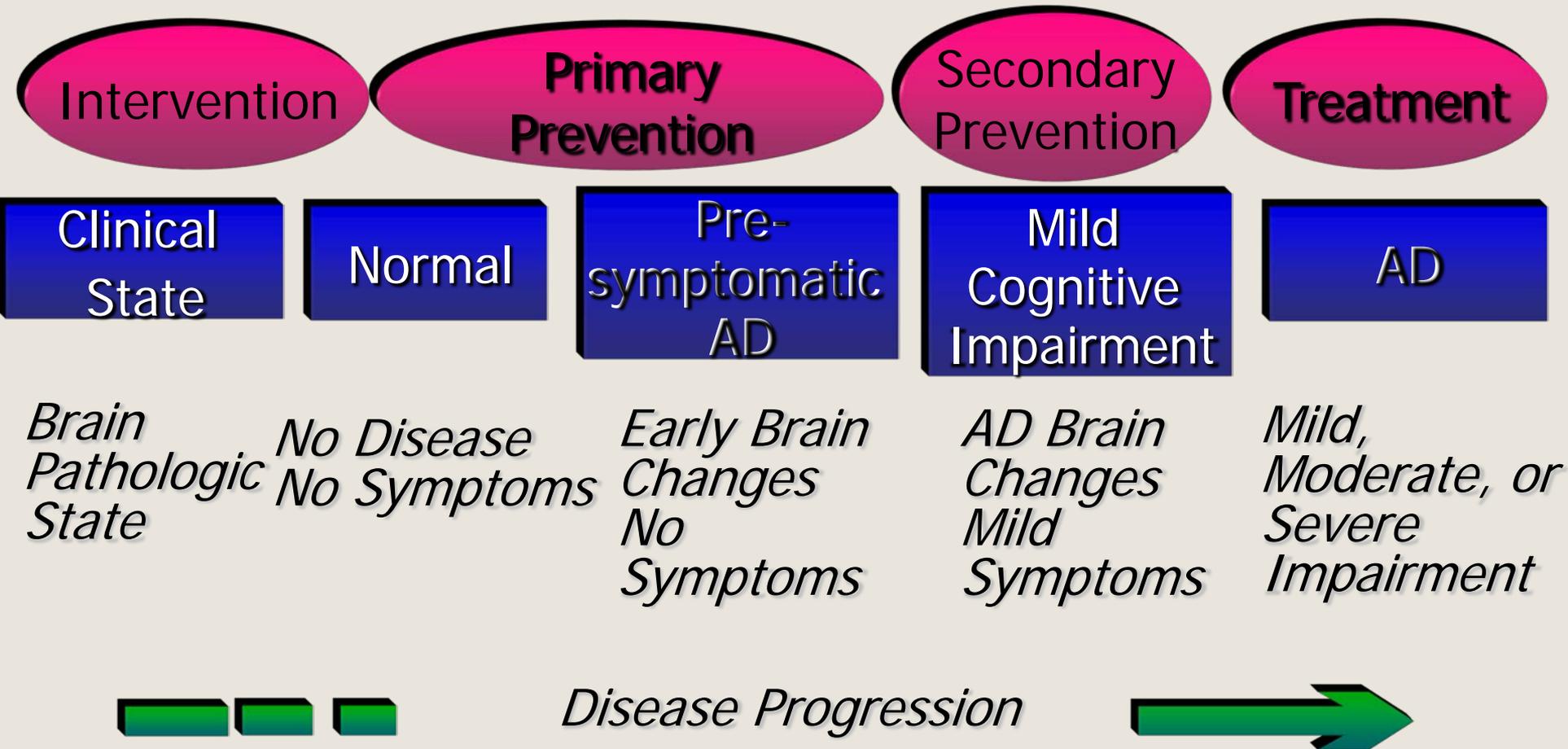
- 1) Overview of the aging population and dementia rates in racial/ethnically diverse populations
- 2) **Highlight latest research trends that have an impact studying the course of dementia in diverse populations**
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# New Diagnostic Criteria and Guidelines for Alzheimer's Disease

Four main goals:

- To better define the natural history of Alzheimer's disease from asymptomatic stages to dementia
- To relate the clinical symptoms, to the underlying pathophysiology
- To use present knowledge to better diagnose the disease
- To *define a research agenda* that will help to extend our knowledge to better reach these goals

# Alzheimer's Disease: Course, Prevention, Treatment Strategies



# Clinical Definition of Dementia – Past

- Key principles
  - Patient has experienced a decline from some previous higher level of functioning
  - The dementia “significantly interferes with work or usual social activities”
- Transparent vs blurred issues for families and physicians
  - Co-morbid conditions – impact of them?
  - Marital and child-parent relationships – differing views on cognitive concerns

# Clinical definition of Dementia – Present

## Clinical Criteria for Dementia:

- Dementia is diagnosed when there are cognitive or behavioral symptoms that:
  - Interfere with the ability to function independently at work or at usual activities
  - Represent a decline from prior levels of functioning and performing
  - The cognitive or behavioral impairment involves a minimum of two of the following domains:
    - Memory, executive functioning, visuospatial, language, personality/behavior

# AD Diagnostic Criteria - Past

Dementia established by clinical examination;  
confirmed by cognitive screening tests

Deficits in two or more areas of cognition

Progressive worsening of *memory* and other cognitive  
functions

No disturbance of consciousness

Onset between 40 and 90, most often after 65

Absence of systemic disorders or other brain disease  
that could account for the deficits and progression

# AD Dementia - Present

Probable AD:

- Meets criteria for dementia, and in addition, has the following characteristics:
  - A. Symptoms have a gradual onset over months to years, not sudden over hours or days;
  - B. Clear-cut history of worsening of cognition by report or observation;
  - C. The initial and most prominent cognitive deficits are evident on history and examination.

***\*\*\*Probability can be enhanced by factors including a documented longitudinal decline and positive evidence from biomarkers, or they may be an AD mutation carrier***

# AD Dementia - Present

Possible AD:

Atypical course: Cognitive deficits for AD dementia, but has a sudden onset or lacks objective cognitive documentation of progressive decline.

Etiologically mixed presentation: Meets all core clinical criteria but has *evidence of \*a) concomitant cerebrovascular disease; or b. features of Dementia with Lewy bodies (other than the dementia); or \*c) evidence for another neurological disease or a non-neurological medical comorbidity or medication use that could have a substantial effect on cognition.*

- *Potentially problematic for assessing AD in minority populations*

# Mild cognitive impairment – Past

MCI is an intermediate zone ( i.e. gray zone) between cognitively normal elderly and those with dementia

Impairment in at least 1 cognitive domain (usually recent memory) but functioning independently in daily affairs

Utilized neuropsychological cut off scores

# MCI – Core Clinical Criteria - Present

Different from original criteria for MCI:

Concern about a *change in cognition* from prior level (patient, an informant, or a skilled clinician).

Impairment in 1 or more cognitive domains: Performance should be lower than would be expected from the patient's age and education. Memory impairment is clearly the most common but other domains may be impaired, may be impairments in more than 1 domain.

MS Albert et al. <http://dx.doi.org/10.1016/j.jalz.2011.03.008>

# MCI –Clinical Criteria

Preservation of independence in functional abilities with minimal aids and assistance; may have mild problems with complex tasks such as paying bills, preparing meals, or shopping, etc.

Not demented - cognitive changes should be sufficiently mild that there is no evidence of impairment in social or occupational function.

*\*MCI diagnosis in minority populations based on these criteria may remain low in clinical settings- “cultural” perspectives on performance level*

# Pre-Clinical AD

Operational **research** criteria for the study of preclinical AD

These criteria developed to advance the *scientific understanding* of the preclinical stages of AD and a foundation for the evaluation of preclinical AD treatments.

RA Sperling et al. <http://dx.doi.org/10.1016/j.jalz.2011.03.003>

# Challenges for the Physician – Patient

# Understanding of memory abilities in the aging process

- Myth: “Forgetfulness” is an inevitable consequence of aging
- Typical aging per se does not lessen memory - - - disease does
- Everyday forgetfulness occurs in most individuals
  - Easy to overlook genuine memory lapses in dementia
  - Result: MCI as an “issue” is overlooked in many minority communities

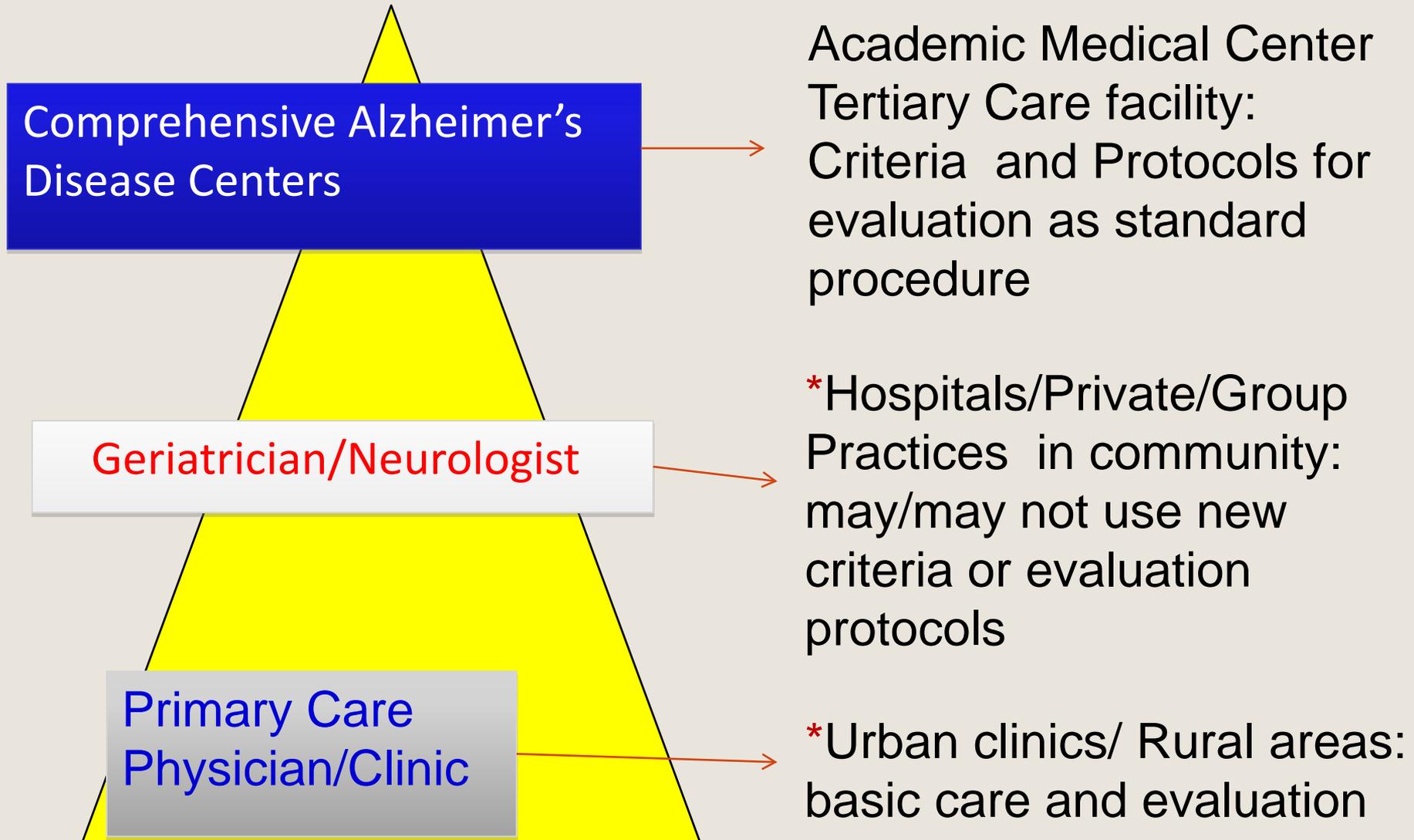
# Words used to describe AD from the “field”

“No one dies from having AD”

“No way to stop the disease when it starts so why go through trouble of getting treated with memory medicine?”

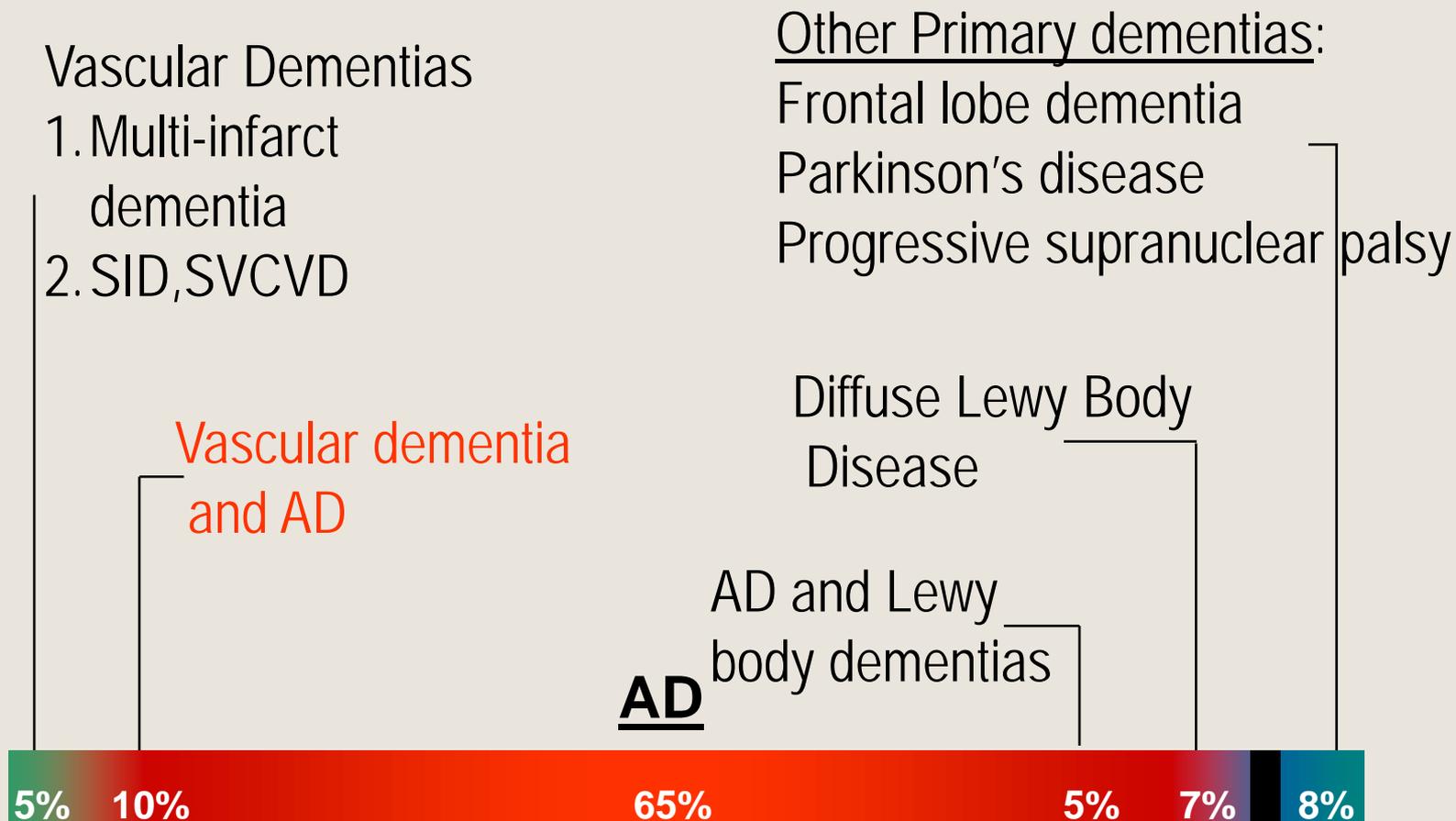
“It is not AD, the trouble thinking is because of “strokes” and “stress””

# Obtaining Care for Dementia /AD



\*Many Minorities are seen in these settings here

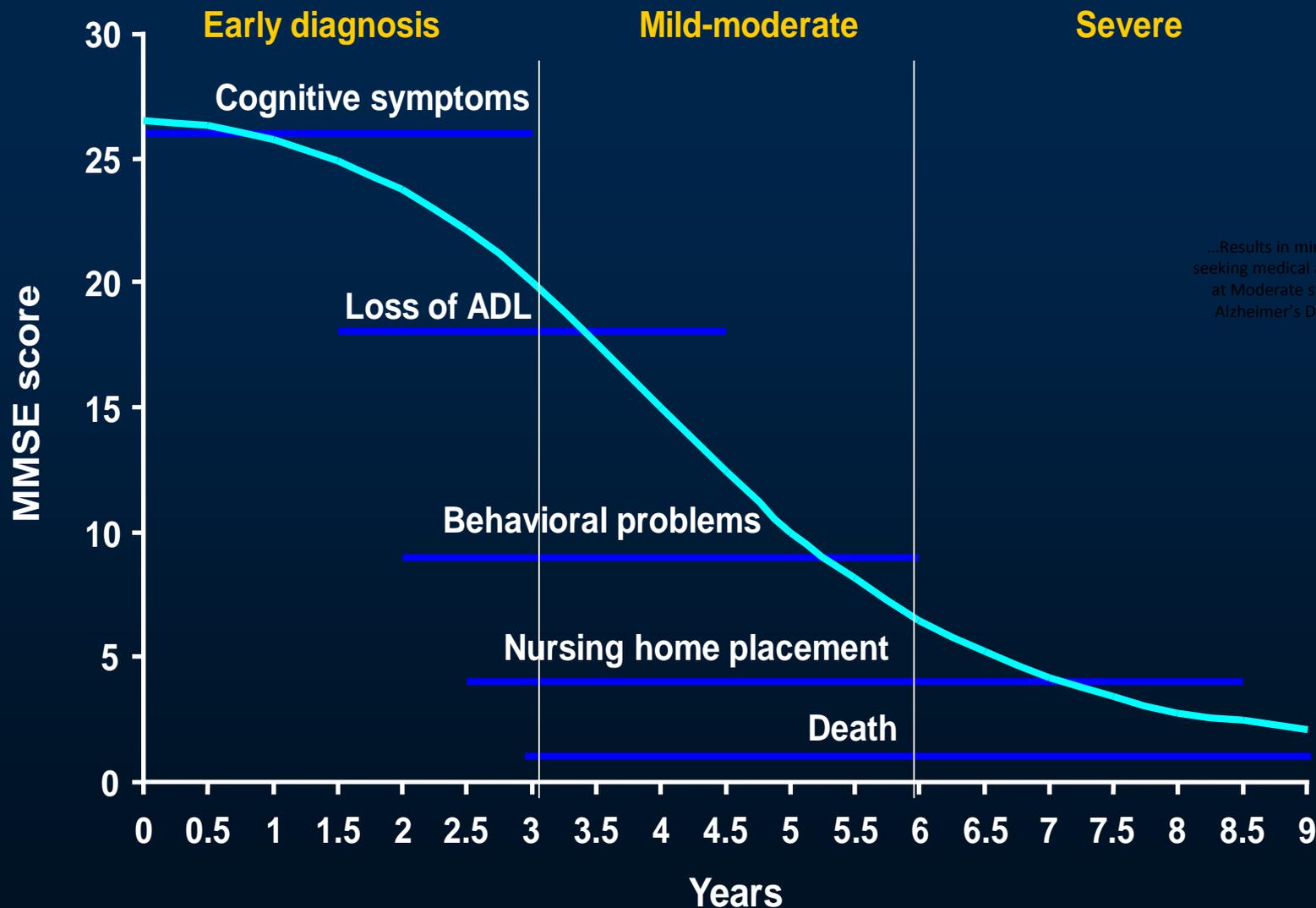
# DIAGNOSING ISSUES - CLINICAL GOAL IS STILL TO RULE IN OR OUT DEMENTIA ...NOT TO DIAGNOSE MCI



Small GW, et al. *JAMA*. 1997;278:1363-1371.

American Psychiatric Association. *Am J Psychiatry*. 1997;154(suppl):1-39.; Morris JC. *Clin Geriatr Med*. 1994;10:257-276.

# .....Results in minorities seeking medical attention at Moderate stage of Alzheimer's Disease



...Results in minorities seeking medical attention at Moderate state of Alzheimer's Disease



# Objectives

- 1) Overview of the aging population and dementia rates in diverse populations
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# Beyond age, risk factors for dementia include:

**Smoking**

**Coronary artery disease**

**Diabetes mellitus**

**High dietary**

**Saturated fat and  
cholesterol**

**Hypertension**

**\* Serum cholesterol**

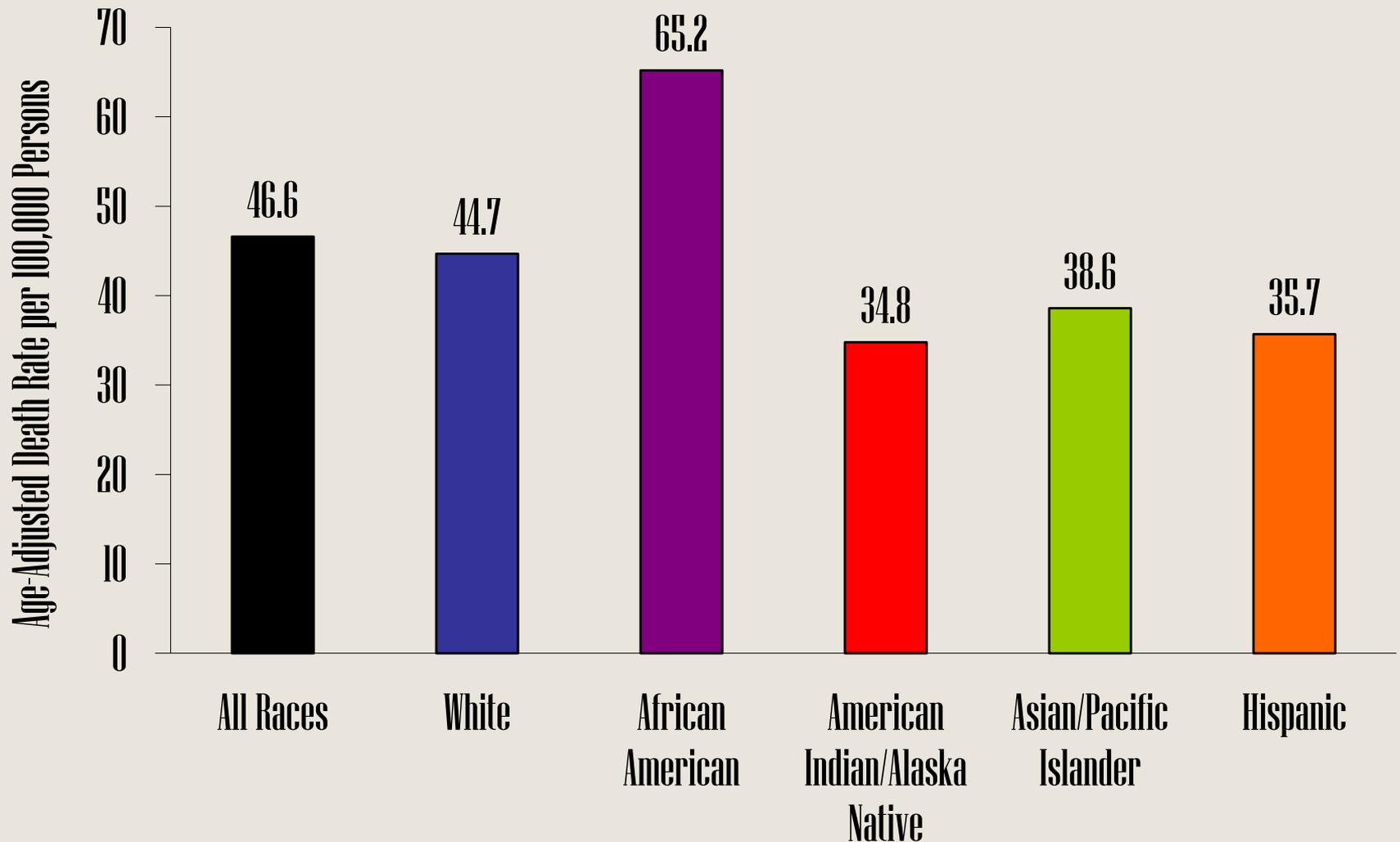
\*These CVD conditions are seen very frequently in minority populations, and thus only cardiovascular disease (stroke) issues discussed by physicians with patients and vice versa – no discussions on signs/symptoms of MCI or early AD

# Other CVD risk factors that are implicated in dementia

- Excessive Alcohol consumption
- Overweight/obesity
- Poor sleep hygiene and depression
- Poor physical fitness
- Dietary habits
- \* **These risk factors are related to serious co-morbid medical conditions or potential death leaving little time for physicians to focus treatment plans for cognitive issues**

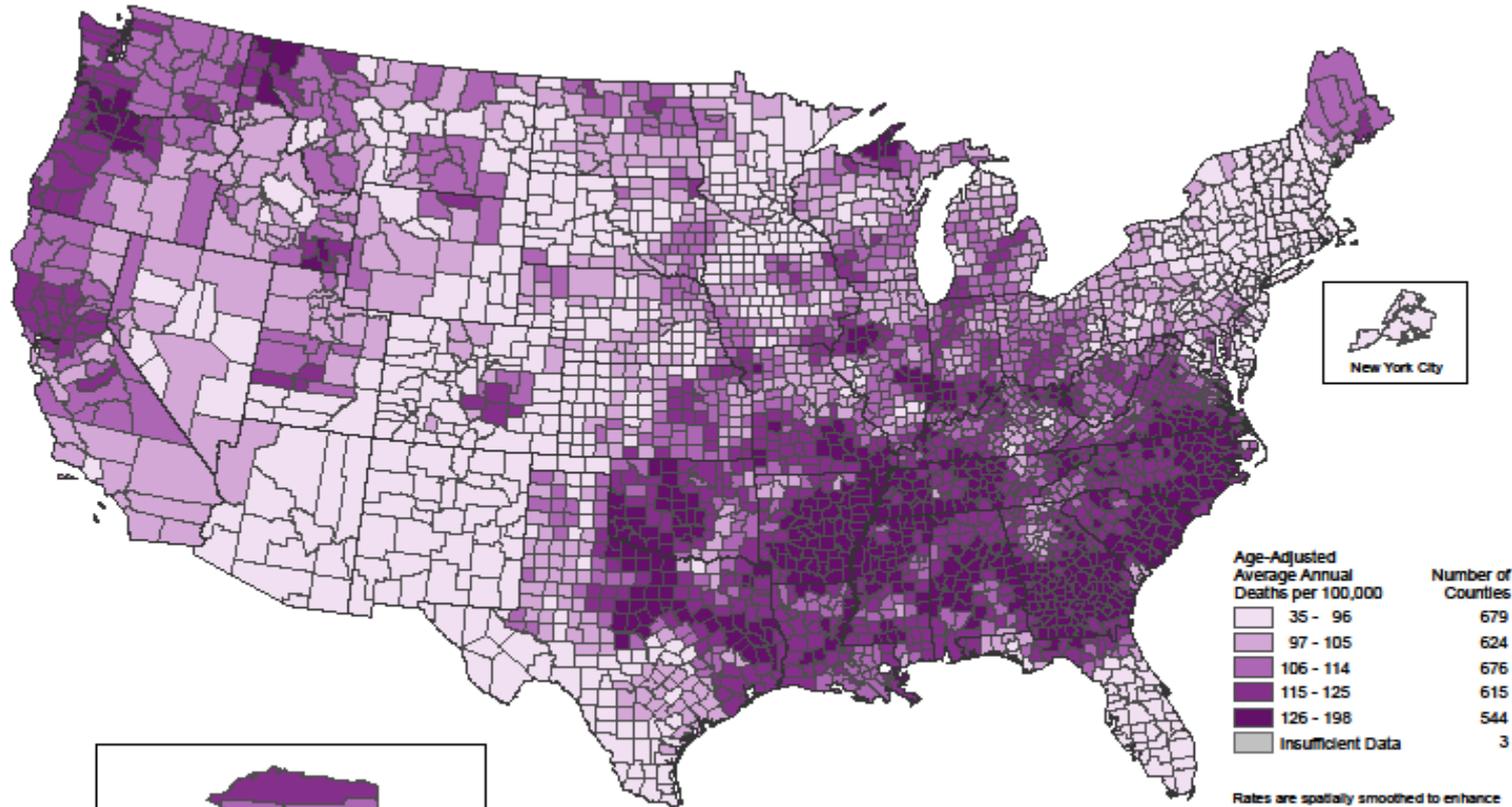
# Stroke Age-Adjusted Death Rates per 100,000 Persons by Race & Hispanic Origin: U.S.

2008



# Stroke Mortality in the U.S.

**Stroke Death Rates, 2000-2006  
Adults Ages 35+, by County**

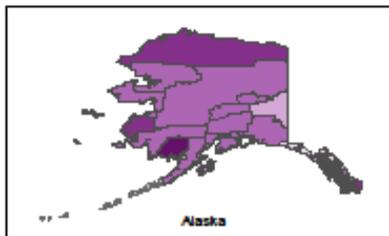


Age-Adjusted Average Annual Deaths per 100,000	Number of Counties
35 - 96	679
97 - 105	624
106 - 114	676
115 - 125	615
126 - 198	544
Insufficient Data	3

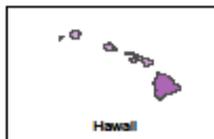
Rates are spatially smoothed to enhance the stability of rates in counties with small populations.

ICD-10 codes for stroke: I60-I69

Data Source: National Vital Statistics System and the U.S. Census Bureau



Alaska



Hawaii



# Triad of factors implicated in dementia/AD

Age, Sex, Race, Customs,  
Occupation, Genetic profile,  
Marital status, Family background,  
Co-morbid medical conditions,  
immune status.

The patient/participant

Affected by the  
environment

Affected by an  
Various agents

Housing, Neighborhood,  
Social contacts, Psychosocial  
factors,  
Air, Water pollution

Biologic (bacteria, viruses),  
Chemical (alcohol, smoke),  
Physical (trauma),  
Nutritional (lack)

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Demographics

Culture

Healthcare Cost Increases

Unequal Access

Language

Race and Ethnicity

Health Care Quality

# Causes of *Health Disparities* in diverse Communities can affect dementia care or future study participation

## **Socioeconomic differences**

Health services access

Medication compliance

Patient-Doctor specific barriers

Lack of communication between Patient/Doctor

Medication-specific barriers

***Lack of trust***

## **Education and behavior**

Minorities have decreased awareness of signs and symptoms of many health conditions, including dementia, stroke and heart disease (MI)

# Types of barriers that lead to mistrust

## Barriers to *awareness*

Lack of education about treatments/  
trials

Lack of dissemination of study  
opportunities to  
patients/providers

Lack of knowledge about the origins  
of the disease process pertinent  
to the trial

## Barriers to *opportunity*

Cost

Functional status- disabilities

Study's duration and visit structure

Time commitment

## Barriers to *opportunity*

Lack of or inadequate health  
insurance

Lack of transportation

Provider attitude

## Barriers to *acceptance*

Perceived harms of clinical  
trial participation

Mistrust of research,  
researchers, and the  
medical system

Fear

Family considerations

# Ethnic Groups and Distrust

Distrust exists among *all* ethnic groups

For African Americans there is the history of racial discrimination and exploitation : US Public Health Service Syphilis Study at Tuskegee or the Henrietta Lacks story

African Americans more likely to believe

- doctors would ask them to participate in harmful research or expose them to unnecessary risks
- doctors would not explain research or would treat them as part of an experiment without their consent

Corbie-Smith et al, *Archives of Internal Medicine*, Nov 2002

# Strategies to manage Community mistrust in Medicine and Research

Showing genuine respect and interest in participant's culture

*Must be* in the community setting performing talks/outreach

You need to know the neighborhood and the news affecting people from the "hood"

Developing relationships first

Discussing topics relevant to the community and their health concerns

Watch the use of phrases with negative connotations

Be careful with words such as "research or trial"- use "study"

Be careful when stating the study is a "Government funded trial"- may not be looked upon favorably for many ethnic groups

# Strategies to manage Community mistrust in Medicine and Research - the Importance of Health Literacy

Literacy is the *strongest predictor* of health status – stronger than age, income, employment status, education level

Literacy is much more than being able to read, it is the ability to really *understand* the information presented about health, and *ACT* on that information

Impacts the clinical care and study consent process, impacts following up with visits and treatments

It impacts EVERYTHING!

# Strategies to manage community mistrust in medicine and research - the Importance of Health Literacy

Estimated that half of the US population cannot understand and use information provided by their clinicians, thereby:

Increasing the risk of:

Misunderstanding instructions

Errors

Poor Outcomes

Increasing the risk of missed appointments

Non-compliance of medical and study regimens

# Strategies to Manage community mistrust in medicine and research – the importance of Clear and Concise Communication

Illustrating concepts by drawing pictures

Using the “teach back” and “show me” techniques to illustrate comprehension

Ask the participant to repeat back what you have said

Using plain language, “living room talk”

*Understand the words used in the community -*

“Disease” is replaced by “Condition”

“Hypertension “ is replaced by “ High blood pressure”

“Diabetes” is replaced by “sugar” or “suga”

# Special Issues - Education about Clinical Trials

Educating the public about clinical trials and different types of trials is lacking

Confusion exists about “what is a trial?” and how they normally “run” – how is it different from medical care?

Is a *clinical trial* the same thing as a *research study*?

Are there differences with government versus industry sponsored trials?

Confusion as to “who” participates in trials – healthy vs. non-healthy, white vs. non-white

Varying opinions of the “why” to participation

# Cultural Competency

A set of behavior, attitude and policies that are embedded in systems, or are utilized by health professionals that can work in cross-cultural situations and diverse environments

Requires a *reality based examination* of stereotypes with each ethnic group regarding health and *attitudes* toward health and disease

# Components of becoming “Culturally Competent”

Value diversity and awareness in relation to the person  
(i.e. patient)

Self-awareness in relation to the entire health professional  
team (MD, NP, RN, SC, RA)

Being aware and conscious of differences *and* the  
dynamics that result when cultures interact

Knowledge of the person's (i.e. patient) culture - *living and  
social environment*

Adapting and transforming learned skills to fill the needs  
of the person (i.e. patient)

# Components of becoming “Culturally Competent” and application to recruitment for clinical trials

Before consenting occurs, think about how the following relates to the patient/family:

What is the baseline knowledge regarding health issues or the disease process?

Do you know the health literacy level for the person (i.e. patient), caregiver or family members?

Does the person (i.e. patient) know what it means to participate in a “research study”?

What has the person **heard** about “research” as it relates to minorities

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# Possible Solutions to Overcome Challenges – Rush Experience

*Lunch and Learn's* were developed by to discuss relevant health care topics under the heading of “Healthy Aging”

Effectively – teaching Health Literacy

Format is roundtable discussion or Power Point with few slides

Vitally important to discuss “health” and how to “keep and maintain health” *before* discussing disease process

Delivered by Principal Investigator or MD with ample time for Q/A

# Possible Solutions to Overcome Challenges – Rush Experience

*Home visits* ensure that members of the field team:

- (1) become knowledgeable of cultural values and norms for patient/participant and family
- (2) witness possible family dynamics and impact of this
- (3) learn about social issues within the community and participant's life

Initially performed for all observational studies at Rush

Extended to clinical trials with all non technology/procedural aspects ( i.e. LP) of trial done in the home

RN, RA and phlebotomist take all materials to home and enter data on laptops or paper forms

MD then visits participant to conduct the visit, brings any pertinent information regarding health/wellness information , blood results and discuss results

Highly successful in recruitment/retention – once initial baseline has occurred and sample size for trial increased, coordinated visits by zip code or neighborhoods to increase efficiency

# Possible Solutions to Overcome Challenges – Rush Experience

What do Home Visits do for study recruitment and retention?

(1) They *address the barriers* in the knowledge transformation process

(2) They *guide study staff and researchers* through a systematic process of communicating findings that will be relevant to:

- ongoing research about mechanisms and interventions;

- clinical and community provider practice in real world settings;

- patient and caregiver decision-making and health behaviors in every day life; and

- related health care policies

(3) They can help *accelerate knowledge transfer* to the participant and family

They require a lot of work but they *WORK!*

# Final Comments

Changing demographics of the country

Minorities are the majority, aging in place

Disparities in healthcare are increasing

Co-morbid medical conditions taking prominent role in health concerns

Quality of life issues for patients, their caregivers and family

Constellation of psychological, social, depression, neighborhood, financial concerns

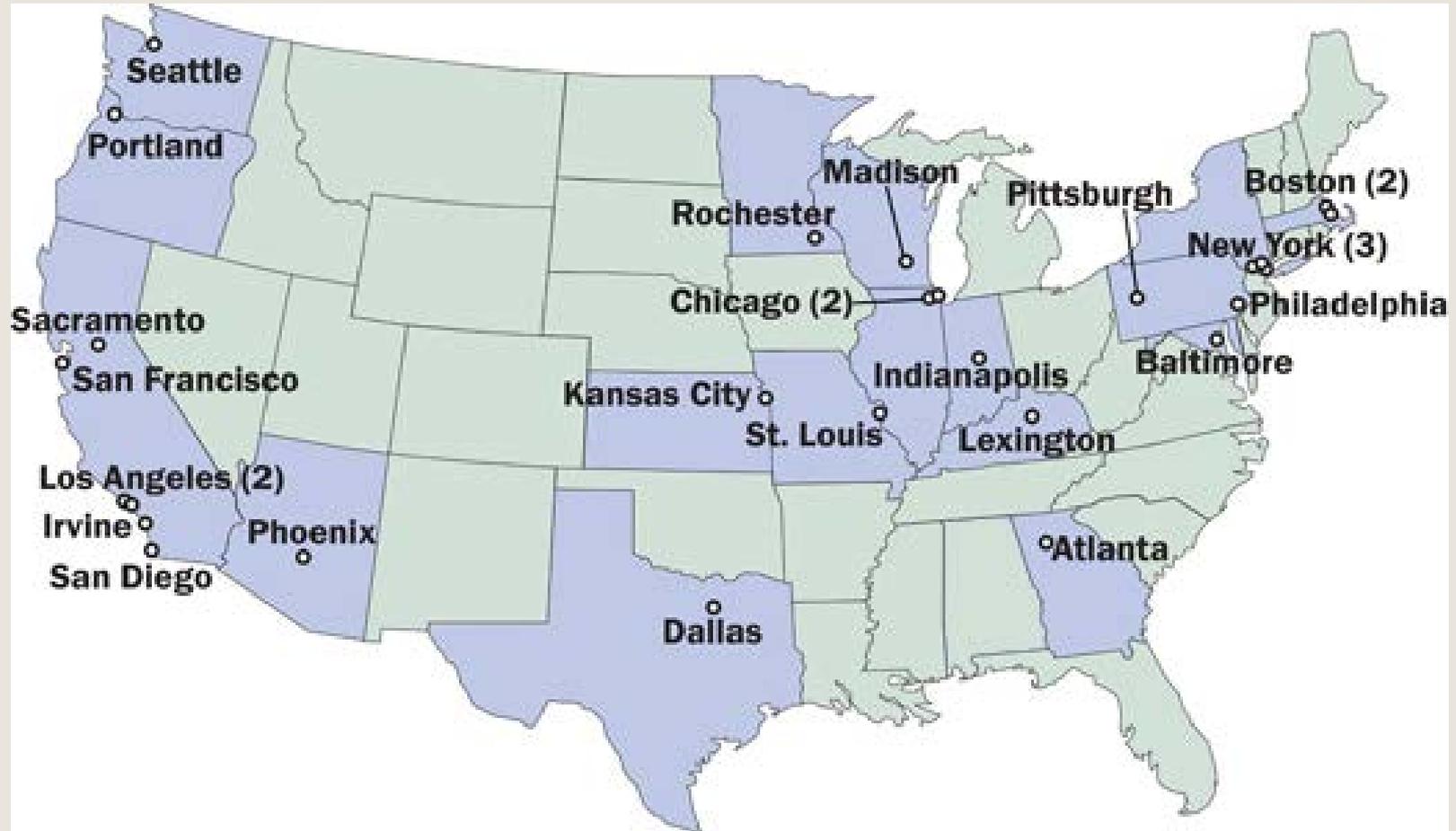
Multiple factors influence seeking care or participating in research

Effective strategies need to be multidimensional and address community concerns and expectations

## Suggested Reading List and Resources

- \*Skloot, R. (2010). *The Immortal Life of Henrietta Lacks*. Crown Random House
- Curry, L., and Jackson, J. (2003). The Science of Including Older Ethnic and Racial Group Participants in Health Related Research. *Gerontologist*, 43(1):15-17.
- Freimuth, V. (2001). African American's Views on Research and the Tuskegee Syphilis Study. *Social Science and Medicine*, 52:797-808.
- Kane, M. (2002). Ethno Culturally Sensitive Practice and Alzheimer's Disease. *American Journal of Alzheimer's Disease*, 15(2):80-84.
- Levkoff, S., and Sanchez, H. (2003). Lessons Learned About Minority Recruitment and Retention from the Centers on Minority Aging and Health Promotion. *Gerontologist*, 43(1):18-26.

# Map of NIA Funded Alzheimer's Disease Centers



# NIA funded Alzheimer's Disease Centers Focus Areas (note: list not exhaustive)

- Underrepresented Groups
  - English as a Second Language (Northwestern)
  - Rural (Oregon, Wash U; telemedicine - UTSW)
  - Oldest Old (UC Irvine)
  - African American (e.g., Rush, Kentucky, Wash U)
  - Asian (UCSF)
  - Hispanic (e.g., UC Davis, Penn, Columbia)
  - Native American (Arizona, UTSW)
- Specific Populations
  - Down Syndrome (Columbia, UC Irvine, Kentucky)
  - Dominantly Inherited Alzheimer's Disease (DIAN study run by Wash U)
  - FTLD (UCSF, Indiana, Mayo, Northwestern)



# **Alzheimer's Disease in diverse populations: African Americans**

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Lisa Barnes, PH.D.

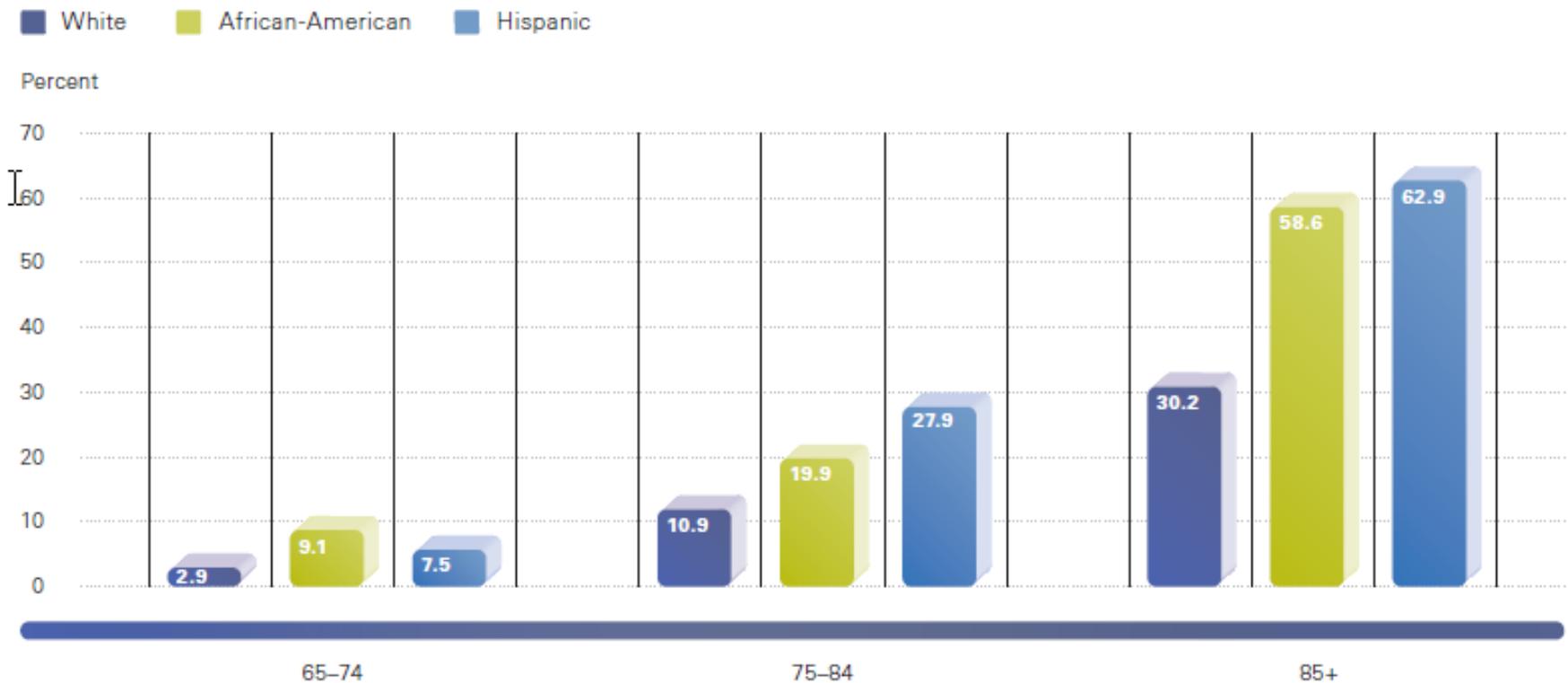
Professor of Neurological Sciences  
and Behavioral Sciences

Rush University Medical Center

Chicago, IL

# African Americans are about twice as likely to have AD

Figure 13: Proportion of People Aged 65 and Older with Alzheimer's Disease and Other Dementias, by Race/Ethnicity, Washington Heights-Inwood Columbia Aging Project, 2006, N=2,162



Created from data from Gurland et al.<sup>27)</sup>

# Challenges to an accurate diagnosis

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## □ Structural

- SES (years of education, income)
- Educational quality (e.g., literacy)

## □ Cultural

- Stigma
- Privacy
- Less knowledge & lower recognition of symptoms
- Under-utilization of healthcare services

## □ Medical

- Higher comorbidities (e.g., diabetes, hypertension)
-

# Cognitive Test Performance

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- Perform more poorly, on average, than non-Hispanic white elders
  - Differences exist after controlling for:
    - years of education
    - occupation
    - income
  - Cognitive function tests influenced by many factors making performance/impairment difficult to interpret
-

# Factors that may play a role

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- Genetics?
  - Medical comorbidities?
  - SES?
  - Cultural factors?
-

# Genetics

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- Several risk factor genes
    - APOE- $\epsilon$ 4 most well established
    - Others: SORL1; CLU; CR1; PICALM; TREM2
  - Although  $\epsilon$ 4 allele more common in African Americans, its link to AD has been inconsistent
  - Recent report by Reitz et al. 2013 (JAMA)
    - Confirmed APOE- $\epsilon$ 4 is associated with AD
    - ABCA7 gene increased risk ~1.8-fold
-

# Medical Comorbidities

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- Vascular health conditions and risk factors prevalent in African Americans
    - Diabetes
      - Age-adjusted percentage of person >18yrs with diabetes: 12.9% Blacks; 7.6% Whites
    - Hypertension
      - Tend to get earlier in life, more severe, more complications
    - Stroke
      - More common & more deadly; age-adjusted incidence is 2x as high
  - All factors suspected to play a role in AD
-

# Socioeconomic Status (SES)

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- Years of education
  - Income
  - Occupation
    - Older minorities, on average, have lower levels of education and other indicators of socioeconomic status
    - All 3 indicators have been associated with risk of AD
-

# Cultural Factors

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- Educational quality
    - Literacy
    - School location
    - School Expenditures
  - Early-life residence (rural, south)
  - Perceived discrimination
  - Less knowledge about symptoms
    - Less likely to receive AD medications
    - Come to attention to healthcare at later stages
-

# What is the Impact ?

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- ❑ Potentially increase rates of misdiagnosis of AD
  - ❑ Clinical trials of treatments may be less informative
  - ❑ Currently available treatments/ interventions may be less effective
-

# What do we need to do?

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- Identify risk factors for AD
    - Vascular, psychosocial, cultural
  - Determine biologic pathways linking risk factors to disease
    - Autopsy studies
    - Biomarkers (blood; neuroimaging)
  - Develop strategies to prevent AD
-

## Need studies that include:

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- Large numbers of African Americans *without* dementia
  - Annual testing with detailed assessment of risk factors
  - Donation of blood for genetic testing
  - Biomarkers that will allow us to measure changes in the brain
-

# Our Philosophy at Rush

*“In the heart of the community, ever seeking to win the community’s heart”*

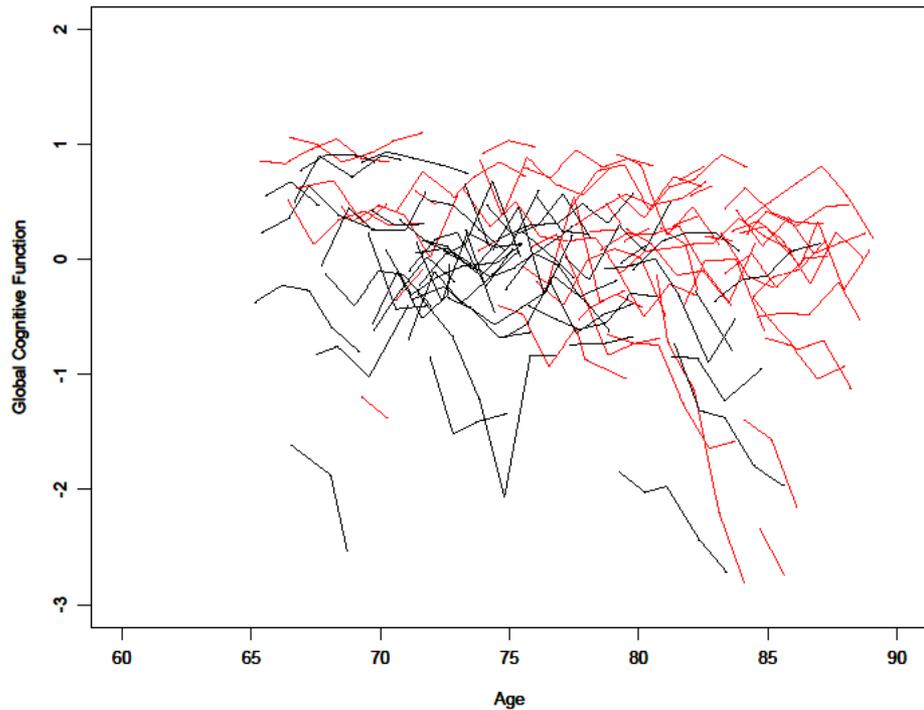


# Rush Cohort studies that focus on older African Americans

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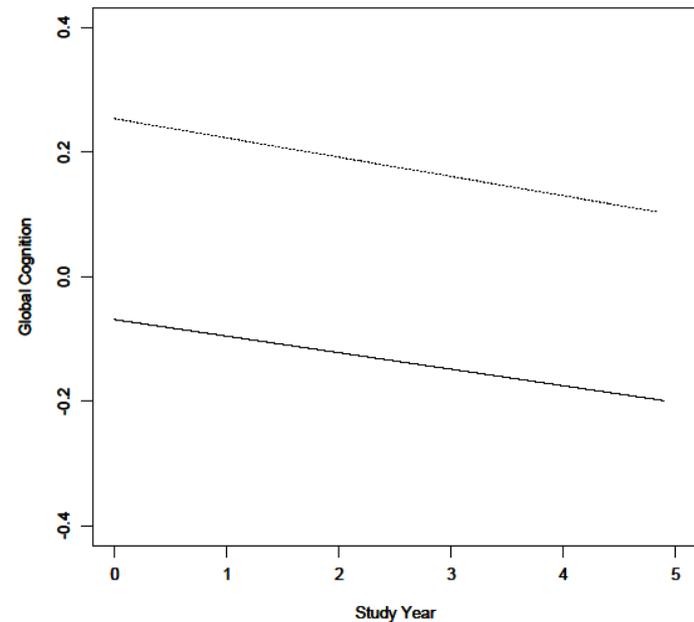
- ❑ Minority Aging Research Study & Rush Clinical Core
  - >800 African Americans, 65 years and older
  - no known dementia at time of enrollment
- ❑ Annual in-home cognitive testing, risk factor assessment, blood draw, & neurological exam
- ❑ Both studies offer organ donation as optional components
  - Over 50 autopsies in demented & non-demented to date

# Wide individual differences in where people start and how fast they decline



Red – Whites  
Black - Blacks

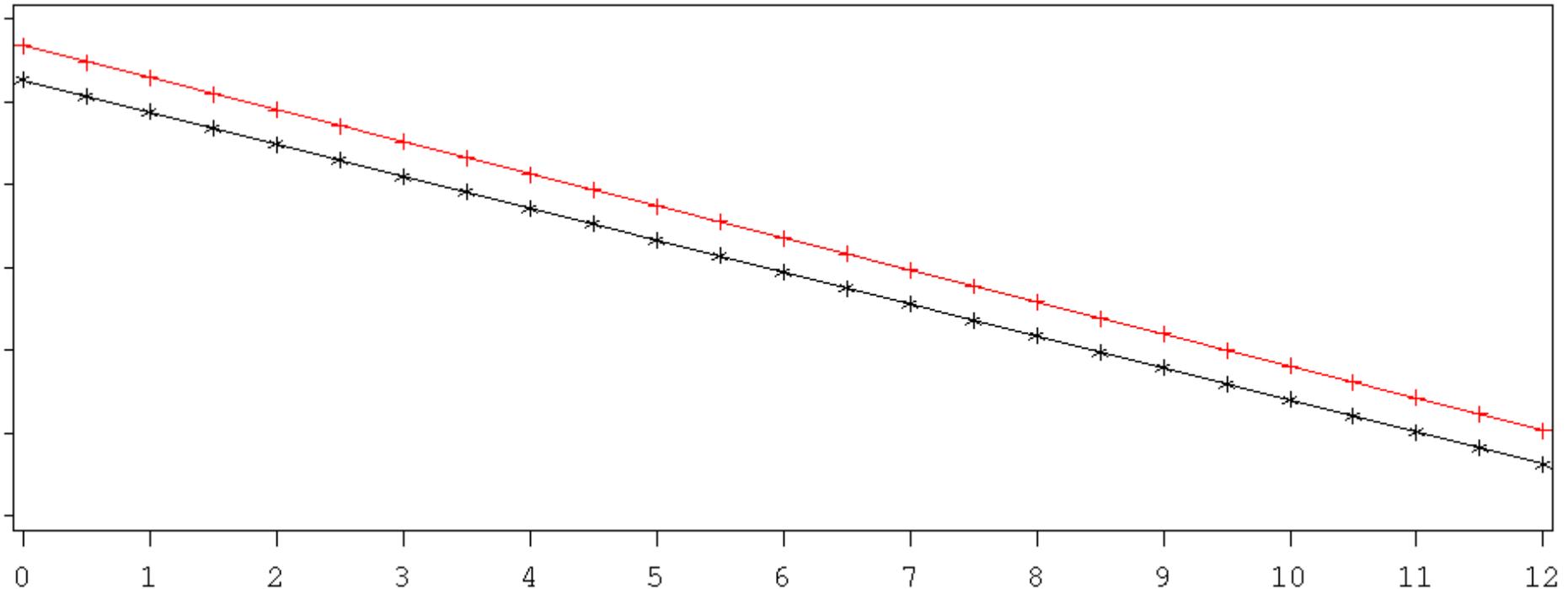
No differences between  
Blacks and Whites in rate  
of decline over time



Top line– Whites  
Bottom line - Blacks

# CHAP - Global Cognitive Test Performance For Blacks and Whites

4432 subjects followed up to 12 yrs with 4 data collection cycles (13,908 observations)



---

Slide courtesy of Denis Evans, MD

# Some risk factors appear to operate the same in African Americans as in Whites

---

## **Decrease Risk**

- Cognitive activity
- Social networks
- Vitamin E
- Fish
- Life space
- Purpose in life

## **Increase Risk**

- Smoking
- Depressive symptoms

Data come from published studies from CHAP, MAP, and MARS cohorts

---

# But other risk factors appear to operate differently

---

## Decrease Risk

- Social Engagement
- Alcohol use
- Early life adversity

## Increase Risk

- Apoe  $\epsilon$ 4 allele
- Distress Proneness
- Neighborhood social disorder

Data come from published studies from CHAP, MAP, and MARS cohorts

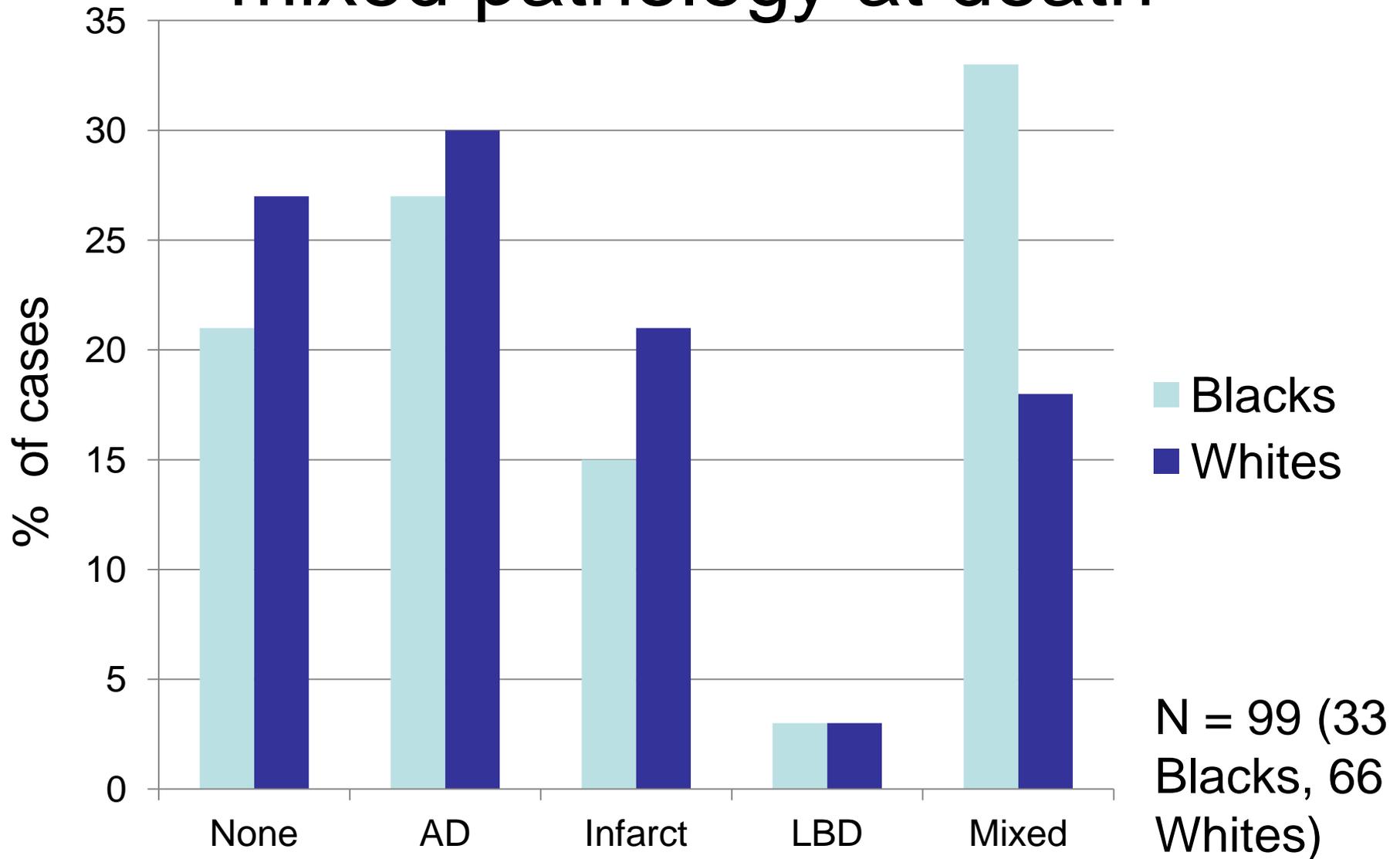
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# Clinical characteristics of those who have come to autopsy

	African Americans (n=33)	Whites (n=66)
Mean age at death	80.7 (8.8)	83.7 (5.6)
Female, %	82	82
Education	14.3 (3.9)	14.8 (3.6)
Mean MMSE at death	21.2 (9.3)	23.8 (8.0)

All persons non-demented at study entry; unpublished data (Rush cohorts)

# African Americans more likely to have mixed pathology at death



# Summary

---

- African Americans more likely to have cognitive impairment/AD
- Because of challenges associated with interpreting test performance in minority populations, future research needs to consider
  - Longitudinal studies of persons without dementia
  - Identify risk factors
- Help understand the complex ways in which risk factors interact with biological pathways to influence clinical disease in this population



COLUMBIA UNIVERSITY

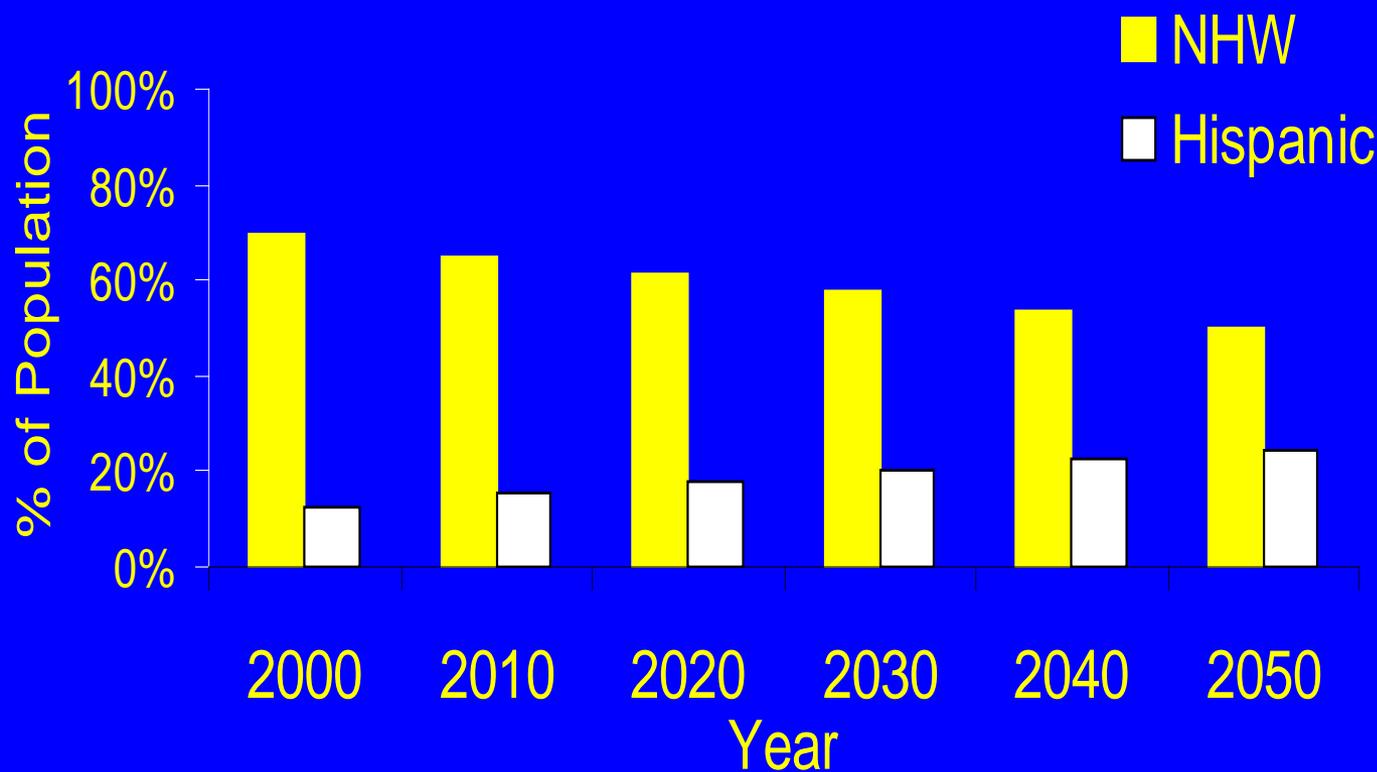
*College of Physicians  
and Surgeons*

# Hispanic/Latino Perspectives

**José A. Luchsinger, MD**

**Center on Aging and Health Disparities  
Northern Manhattan Center of Excellence  
on Minority Health and Health Disparities  
Columbia University Medical Center**

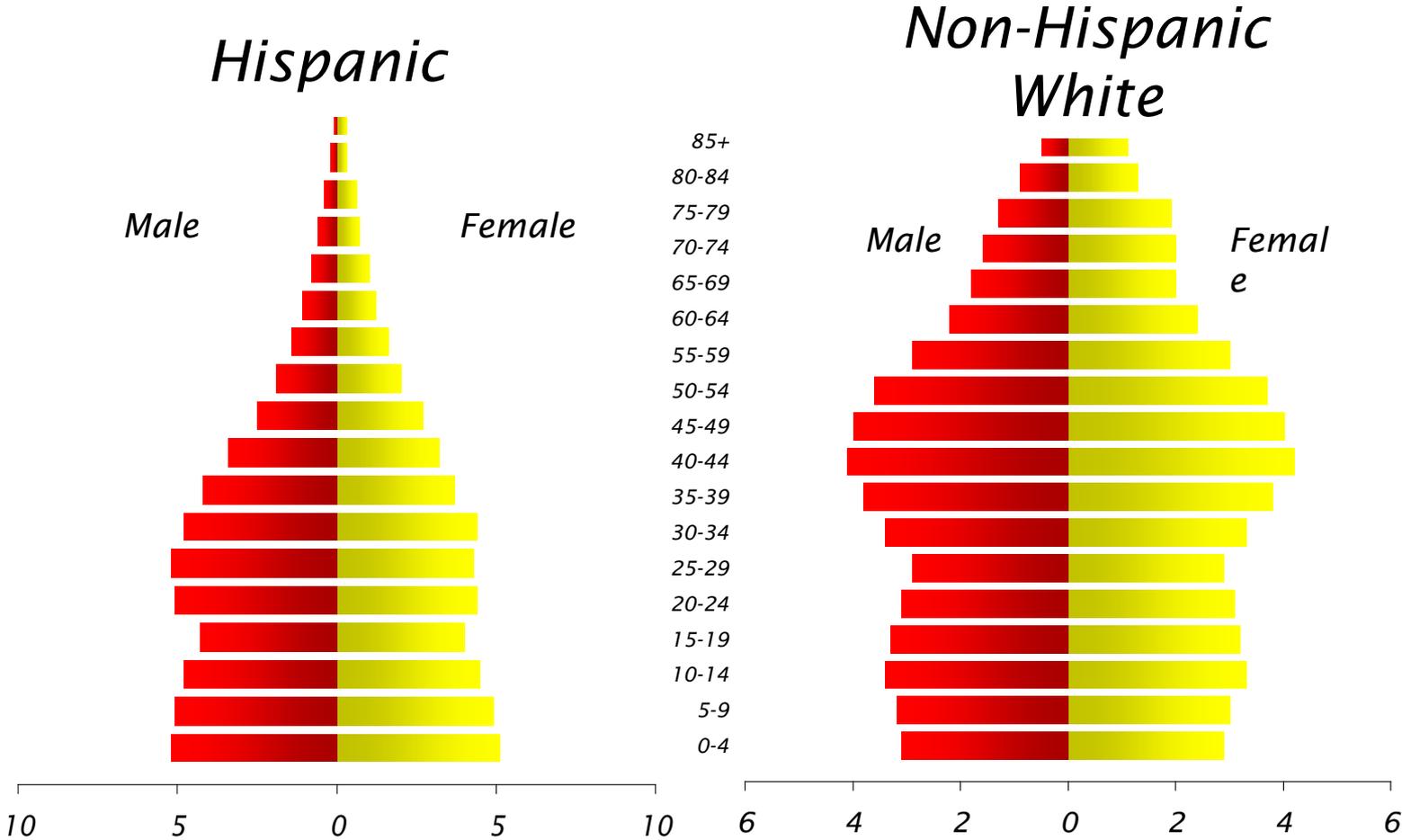
## Population Projection



Source: U.S. Census Bureau,  
Population Division, Interim State  
Population Projections, 2005.

	<b>2000</b>	<b>2050</b>
NHW	195,729	210,283
Hispanic	35,622	102,560
<b>Total</b>	<b>282,125</b>	<b>419,854</b>

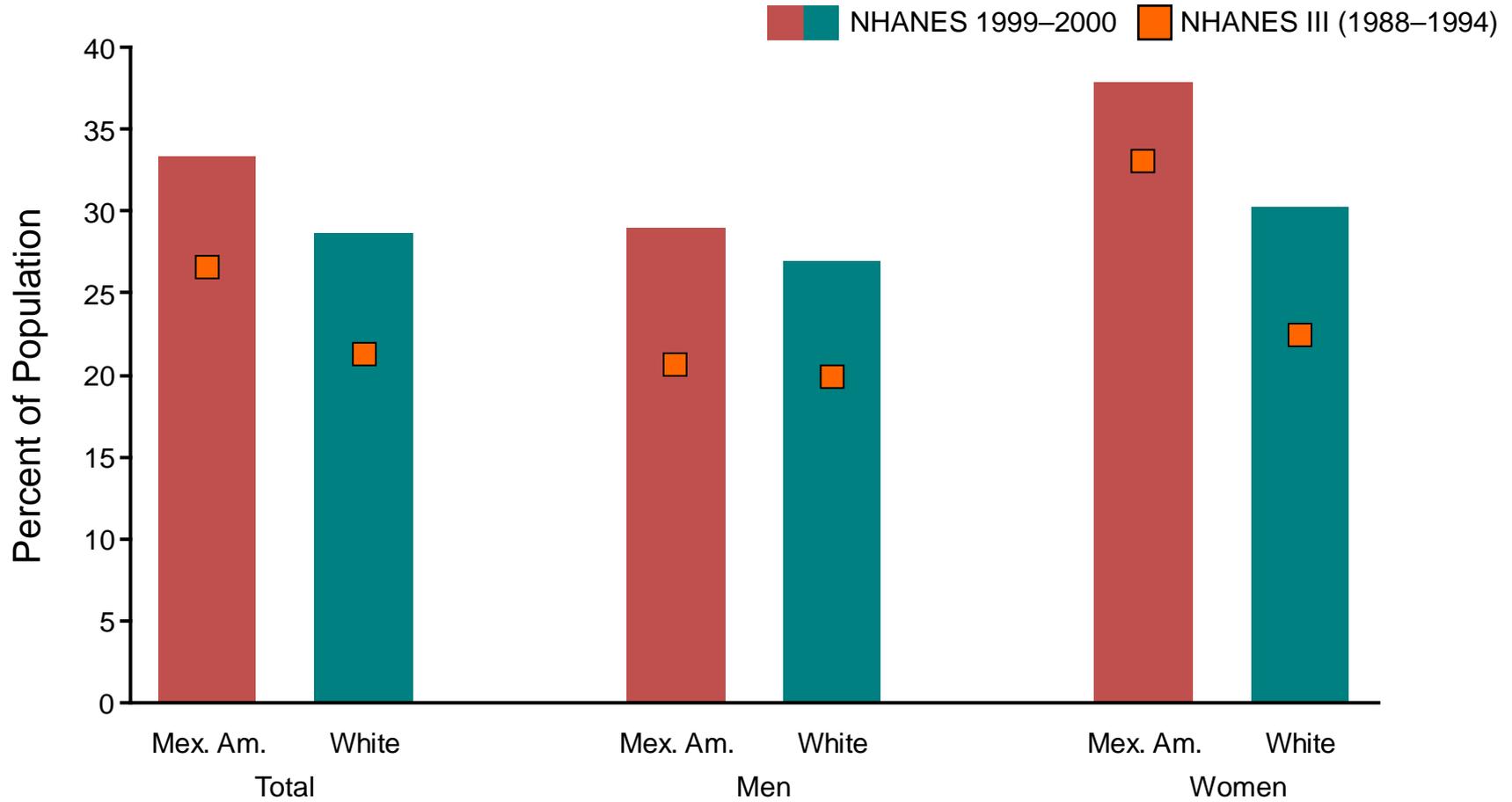
# Age Distribution by Sex and Hispanic Origin: 2002



Source: Current Population Survey, March 2002, PGP-5

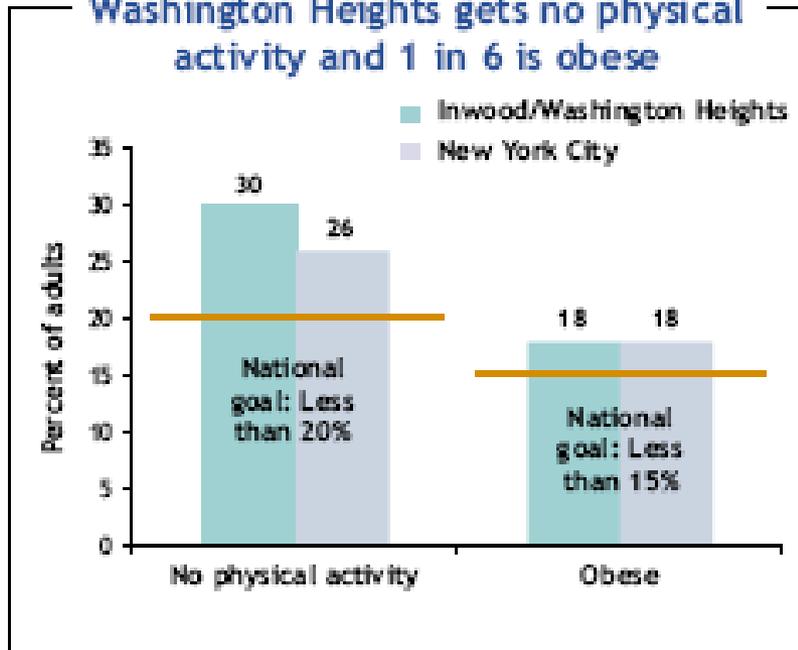
Note: Each bar represents the percent of the Hispanic (non-Hispanic White) population who were within the specified age group and of the specified sex.

# Prevalence of Obesity by Ethnicity/Race and Gender

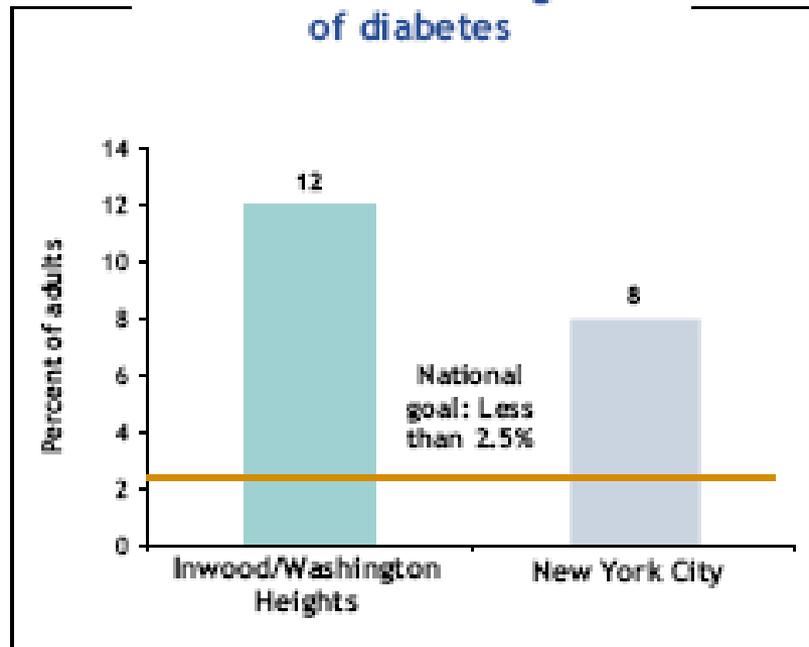


# Local Data

Nearly 1 in 3 adults in Inwood and Washington Heights gets no physical activity and 1 in 6 is obese

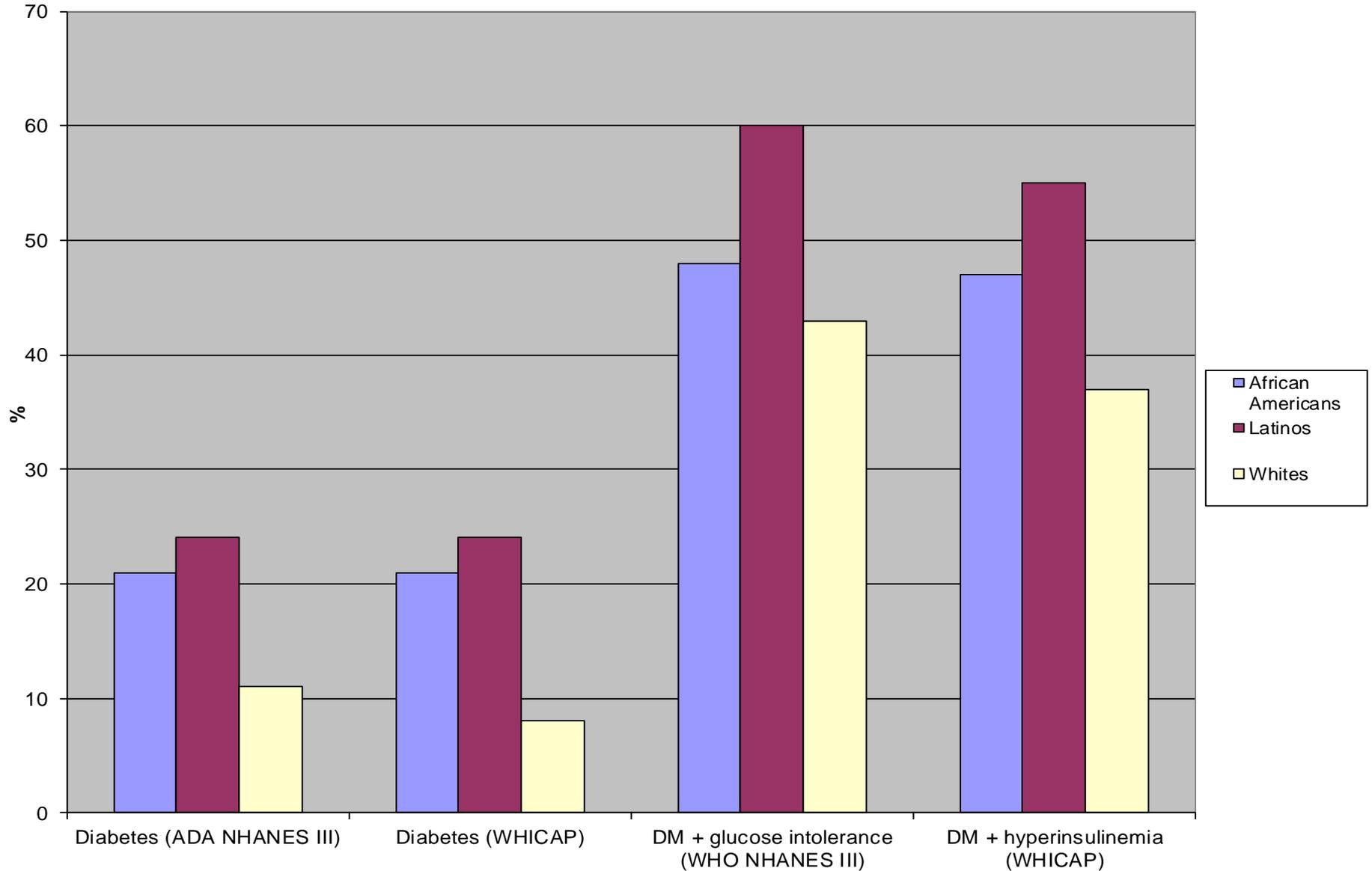


... which leads to high rates of diabetes

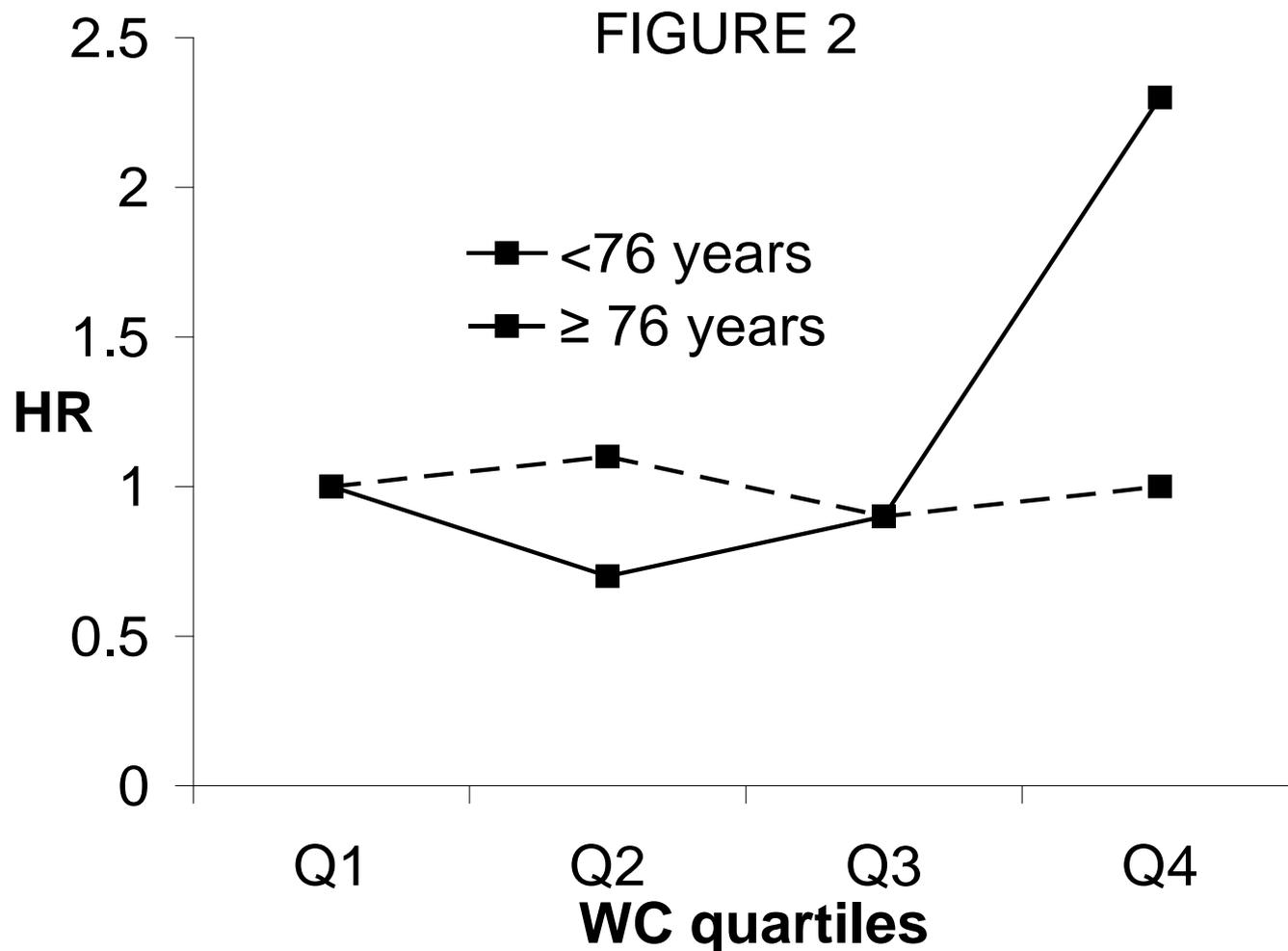


- The CDC recommends that adults get either moderate exercise for at least 30 minutes, 5 or more times per week, or vigorous exercise for at least 20 minutes, 3 or more times per week.
- Obesity is BMI — being over 30. “Overweight” is BMI over 25.

# Diabetes Rates



# Waist Circumference (WC) and Dementia Hazard Ratio (HR)



# Hyperinsulinemia, diabetes and dementia

	<b>HR (95% CI)</b>	<b>p value</b>
<b>AD (137)</b>	2.1 (1.5,3.1)	0.0001
<b>All dementia (149 )</b>	1.9 (1.3,2.7)	0.0007

# Cognitive Impairment Disparities

- 39% of cases of AD in Northern Manhattan could be explained by hyperinsulinemia and diabetes
- Diabetes ethnic disparities may account for 18% of disparities in cognitive impairment

# Prevention and Cure of Dementia

Currently, firm conclusions cannot be drawn about the association of any modifiable risk factor with cognitive decline or Alzheimer's disease. Highly reliable consensus-based diagnostic criteria for cognitive decline, mild cognitive impairment, and Alzheimer's disease are lacking, and available criteria have not been uniformly applied. Evidence is insufficient to support the use of pharmaceutical agents or dietary supplements to prevent cognitive decline or Alzheimer's disease.

[http://consensus.nih.gov/2010/docs/alz/ALZ\\_Final\\_Statement.pdf](http://consensus.nih.gov/2010/docs/alz/ALZ_Final_Statement.pdf)



# Hispanics have a higher burden of dementia caregiving

- Higher dementia prevalence
- Particular attitudes about caregiving
  - Familism
  - Less likely to delegate care

# More evidence is needed on caregiver interventions in Hispanics

- Paucity of data in Hispanics from the most common caregiver interventions (REACH, NYUCI)
- Psychosocial stressors and lack of resources particularly high in Hispanics

# Ongoing caregiver projects in Hispanics

- Northern Manhattan Caregiver Intervention Project (NOCIP; NCT01306695; P60 MD000206-8S1: PI: Luchsinger)
  - RCT of NYUCI vs. case management (n=139)
- New York City Hispanic dementia caregiver Research Program (NHiRP; 1R01NR014430-01)
  - Long term follow-up of NOCIP
  - New Registry
  - Development of new interventions

# Pending projects

- Northern Manhattan Hispanic Caregiver intervention Effectiveness Study (NHiCE; submitted to PCORI)
  - RCT of NYUCI vs. REACH
- Northern Manhattan Dementia Daycare Assessment Project (NDAP; in preparation for PCORI)
  - Comparison of daycare program vs. homecare

# Conclusions

- Hispanics have a higher prevalence of dementia than NHW.
- The burden of dementia caregiving on Hispanics seems disproportionately high.
- More research is needed on the risk factors, prevention, treatment of dementia in Hispanics, including supporting caregivers.

# DEMENTIA IN ASIAN AND PACIFIC ISLANDER AMERICAN ELDERS

*Gwen Yeo, PhD, AGSF*

Stanford Geriatric Education Center

Partially supported by the Bureau of Health  
Professions, HRSA

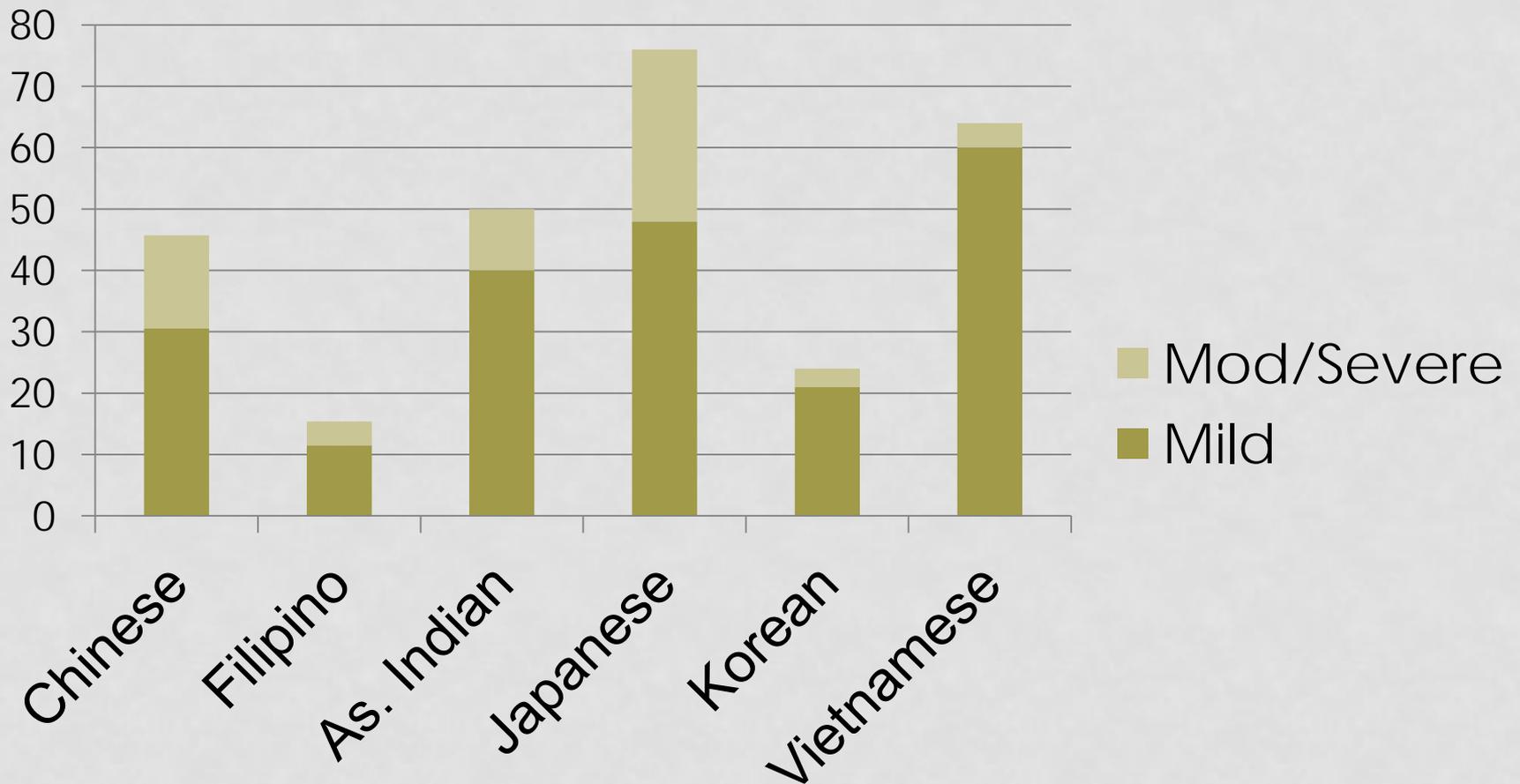
# TOPICS

- Older populations among Asian and Pacific Islander Americans (API)
- Limitations of the data
- What we do know about:
  - Prevalence of dementia among the API populations
  - Perceptions of dementia
  - Assessment/management issues
  - Caregiving and help seeking patterns

# “DECONSTRUCTING” ASIAN

- Importance of “unlumping” all Asian and PI elders
- Recognizing variability between and **within** ethnic populations
- Recognizing unique cohort experiences of elders from different ethnic groups

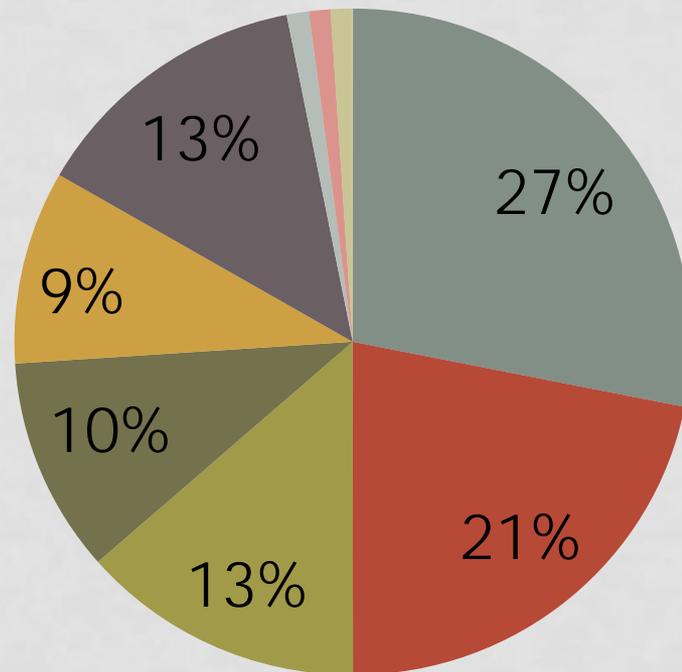
# PERCENT OF OLDER ASIAN AMERICANS WITH DEPRESSION IN NEW YORK CITY STUDY



Mui et al. 2006

# WHO ARE THE ASIAN AMERICAN ELDERS?

**Asian Elders 65+ in U.S., 2010**  
**N=1,376,471**



- Chinese
- Filipino
- Japanese
- Korean
- Vietnamese
- Asian Indian
- Cambodian
- Laotian
- Hmong

# FOLLOWERS OF CHILDREN

Invisible Immigrants, Old and Left With □ Nobody to Talk To □



Indian men, members of the 100 Years Living Club, gathering at a shopping center plaza in Fremont, Calif., to discuss the news from home and the issues of the day.

Patricia Brown/Jim Wilson/The New York Times, August 30, 2009

# NATIVE HAWAIIAN & OTHER PACIFIC ISLANDER AMERICAN ELDERS (NHOPI)

- Combined with Asian in census until 2000 although culturally and physically distinct
- Still frequently lumped with Asian in analyses because of their small numbers
- Total NHOPI 65+ in 2010 = 31,213

Largest ethnic populations:

Native Hawaiian	14,105
Samoaan	4,724
Guamanian or Chamorro	4,198

***WHAT WE KNOW ABOUT THE  
PREVALENCE OF DEMENTIA  
AMONG AMERICAN ELDERS  
FROM ASIAN AND PACIFIC  
ISLANDER BACKGROUNDS***

# ***AVAILABLE LITERATURE ON DEMENTIA IN U.S.***

<b>Population</b>	<b>Prevalence</b>	<b>Perception</b>	<b>Care-giving</b>	<b>Assessment</b>
Chinese		XX	XX	X
Filipino			X	
Japanese	XX		X	
Asian Indian			X	
Korean		XX	XX	
Vietnamese		XX	XX	
Hmong		XX	X	
Guamanian	XX			

# JAPANESE AMERICAN PREVALENCE STUDIES

- Hawaii studies of Japanese American men 71+ found 5.4% with Alzheimer's and 4.2% with Vascular Dementia

White et al, 1996

- In Seattle study of Japanese American men and women 65+ there were 4.5% with Alzheimer's and 1.9% with Vascular Dementia

Graves et al, 1996



**No Known Studies of Prevalence  
of Dementia in Other Asian  
American Elders**

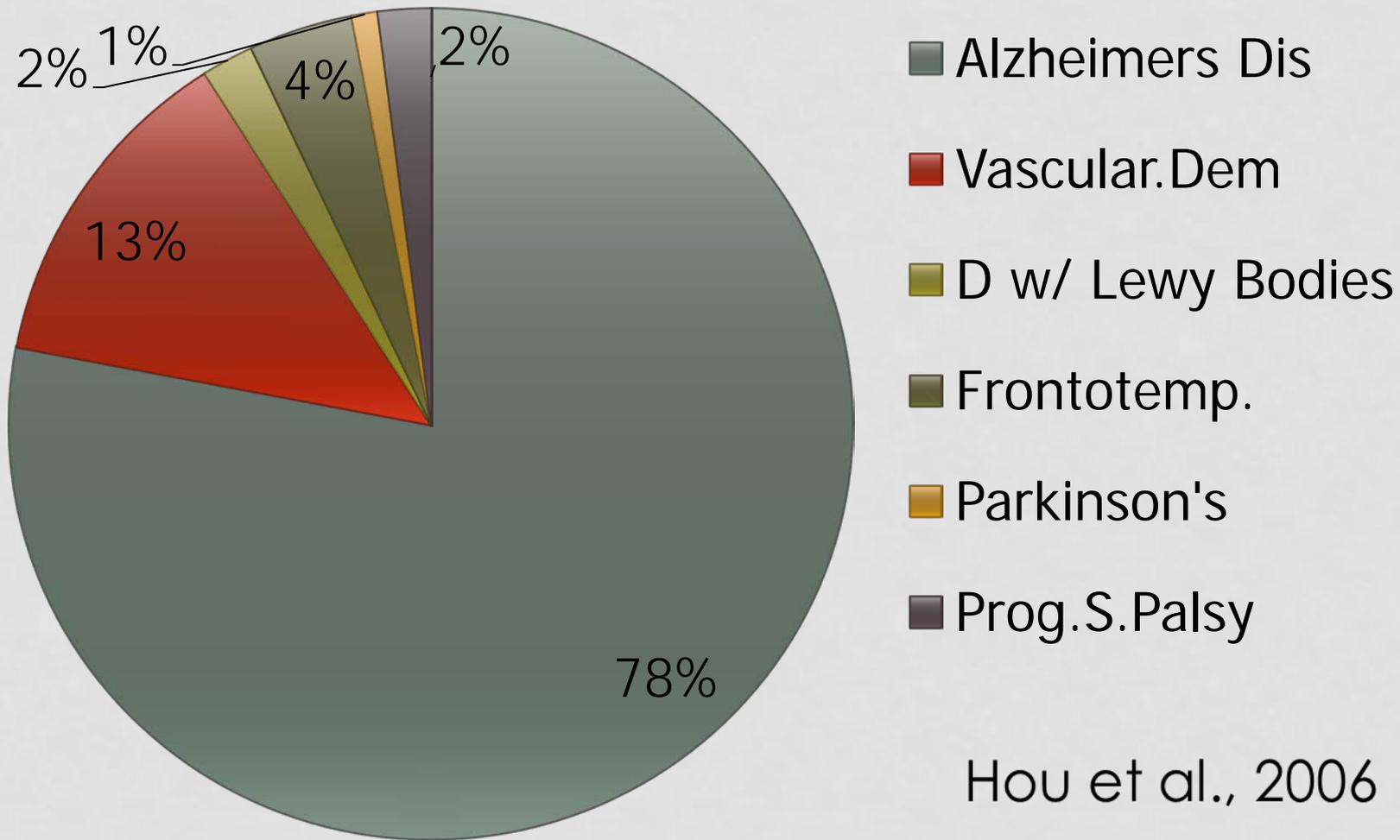
## *DEMENTIA PREVALENCE STUDIES IN ASIAN COUNTRIES\**

<b>Countries (# of studies)</b>	<b>% with Dementia</b>	<b>% with Alzheimer's</b>	<b>% with Vascular</b>
Japan (8)	0.03-33.2	0.009-16.0	0.015-9.8
Korea (4)	5.2-9.0	3.9-4.2	0.9-2.4
India (4)	0.09-9.0	0.3-1.6	0.09-1.1
China (3)	2.7-2.9	1.6-2.1	0.8
Hong Kong (1)	19.4	14.3	4.3
Singapore (1)	1.6	0.9	0.7
Thailand (1)	2.4	1.6	0.3
Sri Lanka (1)	4.0	2.8	0.6

\*published 2000-2010, as reported by Catindig et al, 2012

# TYPES OF DEMENTIA IN API

FROM 10 CALIFORNIA ADDTCS 1992-2002  
(N=425)



Hou et al., 2006

# DEMENTIA IN GUAM'S CHAMORRO ELDERS

- After WWII, high prevalence of ALS and Parkinsonian Dementia Complex (PDC)
- In last 50 years: ALS diminished, less so for PDC; unique late life dementia emerged without parkinsonism, without plaques, but with tangles, labeled Guam dementia (GD) (in ~9% of 65+)
- Search for environmental factors focused on flour made from Cycad seeds (*fadang*)
- Still debated in the literature, but strong evidence that Chamorro elders who handled or consumed cycad seeds or flour in young adulthood are at higher risk for GD & PDC.

Borenstein, 2007; Fillenbaum, 2007

# OTHER UNIQUE RISK FACTORS FOR DEMENTIA IN SPECIFIC API POPULATIONS

- Very high rates of obesity and diabetes among Native Hawaiian and Other Pacific Islanders
- PTSD among Southeast Asian elders (e.g., Cambodian, Hmong, Vietnamese)
- Very low educational level among Hmong (42% have NO formal education) (Gerdner et al., 2007)
- Lower risk among Japanese American elders who lived in Japan and have traditional life style (Graves et al., 1999)
- Some evidence that curcumin widely used in Asian Indian cooking may be protective (Periyakoil, 2006)

# PERCEPTIONS OF DEMENTIA

# CHINESE AMERICAN PERCEPTIONS

Descriptions from review of 18 studies among Chinese American caregivers by Sun and colleagues (2012):

- Fate, wrongdoing, result of worrying too much, craziness
- Early stage frequently attributed to normal aging
  - return to a child-like state deemed natural
- Advanced stages, the main concern is stigma
  - a mental illness that evokes “craziness” or as a contagion that causes feelings of shame or loss of face.

Liu et al. used the term “tribal stigma” to describe the extension of humiliating feelings to the entire family.

# KOREAN AMERICAN CONCEPTIONS

- Stigma very strong

- Major attributions:

Not keeping mind active enough

Inactivity due to living alone/isolation

Problems with brain chemistry

Stress

Introverted or passive personality

Unresolved personal/family conflicts, hardships, or issues that cannot be shared with others (*han*)

Changes from immigration to the U.S.

Head injury

Lee, Diwan, & Yeo, 2010

# VIETNAMESE AMERICAN CONCEPTIONS

- Normal part of aging
- Physiological factors: brain shrinkage, overeating, stroke, blood pressure/clogged arteries, heredity, medication
- Psychosocial factors: worrying or thinking too much, loneliness & isolation, difficult life events, out of balance (e.g. too “hot”), difficulty adjusting to U.S., loss of respect from younger generation
- Spiritual factors, or fate: possession by spirit, karma

Yeo, Tran, Hikoyeda, & Hinton, 2001

# HMONG AMERICAN CONCEPTIONS

- No word for dementia, closest term is translated as chronic confusion
- Normal part of aging; like an old tree that is hollow
- “Too many things on their mind, they forget things”
- Not enough blood when you get old; brain does not get a lot of blood
- Emotional stress causes memory loss
- A person’s souls/spirits are captured and taken away
- May be treated by a traditional healing ceremony performed by a shaman

# ADDITIONAL CONCEPTIONS FROM HAWAIIAN FOCUS GROUPS

Filipino: Normal part of aging, going back to childhood

Native Hawaiian: Normal part of aging

Braun et al., 1998

# ASSESSMENT

# *BARRIERS TO ASSESSMENT*

- Beliefs that cognitive loss and dementia are a normal part of aging so nothing can be done, are found in all of the API American populations that have been studied
- Stigma of dementia is very common; affects the entire family.
- As a consequence, in the populations that have been reported, presentation of dementia to health care providers tends to be in later stages of the disease (e.g., 53% of Japanese American men with dementia whose family recognized memory problems did not receive a medical evaluation. (Ross et al., 1997)

# CHALLENGES OF ASSESSMENT

- With the exception of Japanese and Filipino elders, 29% to 86% of 65+ in the various Asian American populations speak little or no English.
- Linguistic differences (e.g., lack of terms in some languages, idioms that are difficult to translate and make no sense in other languages)
- Lack of, and differences in education (e.g. lack of familiarity with a pencil); low literacy
- Lack of culturally fair evaluation tools

# CROSS-CULTURAL ASSESSMENT INSTRUMENTS

- \* CASI (Cognitive Assessment Screening Instrument) Teng, Hasegawa, Homma et al. *Int. Psychogeriatr* 6 (1) 45-58. 1994.
- \* CCNB (Cross-Cultural Neuropsychological Test Battery) Dick, Teng, Kempler, et al. In Ferraro (Ed.) *Minority and Cross-cultural Aspects of Neuropsychological Assessment*. Lisse: Swets & Zeitlinger, 2002.

# CAREGIVING

# FAMILY BASED CARE

- Most of the members of the Asian American populations that have been studied expect that elders will be cared for by family members. As a result, in most of the ethnic groups, especially those most recently immigrated, use of formal long term care programs is very minimal.
- When families are very stressed with care for an elder with dementia and their only option is nursing home placement, there is frequently an extreme sense of guilt.

# DEMENTIA CAREGIVING AMONG CHINESE AMERICANS

- Heavily influenced by cultural values of family harmony and filial piety, conferring a strong obligation on adult children to care for parents
- Stigma of dementia reduces social support, increases stress, and reduces help seeking
- Mixed evidence on the effect of filial piety on caregiver well-being
- Frustration with the low level of culturally and linguistically competent information and services
- Reticence to participate in research

# RESOURCES

# DVD AND WORKBOOK FOR CHINESE AMERICAN CAREGIVERS OF ELDERERS WITH DEMENTIA

Based on extensive research on effects of CBT-based psychoeducational approach to help dementia caregivers increase coping skills, including work with Chinese Americans

This set provides culturally appropriate skill training in how to manage common situations that create stress in family caregivers. A narrator describes in Mandarin (or English) the enactments portrayed in the video and encourages the caregiver to learn more about the techniques being taught by completing the exercises in their workbook. This set is available at cost (\$25) from Stanford Geriatric Education Center.

By Dolores Gallagher-Thompson et al.

# *ETHNICITY & THE DEMENTIAS, 2<sup>ND</sup> ED.*

Royalties support Stanford Geriatric Education Center

Prevalence of Dementia

Assessment in Asians

Working with Families

Asian Indian Americans

Chinese American

Filipino American

Hmong American

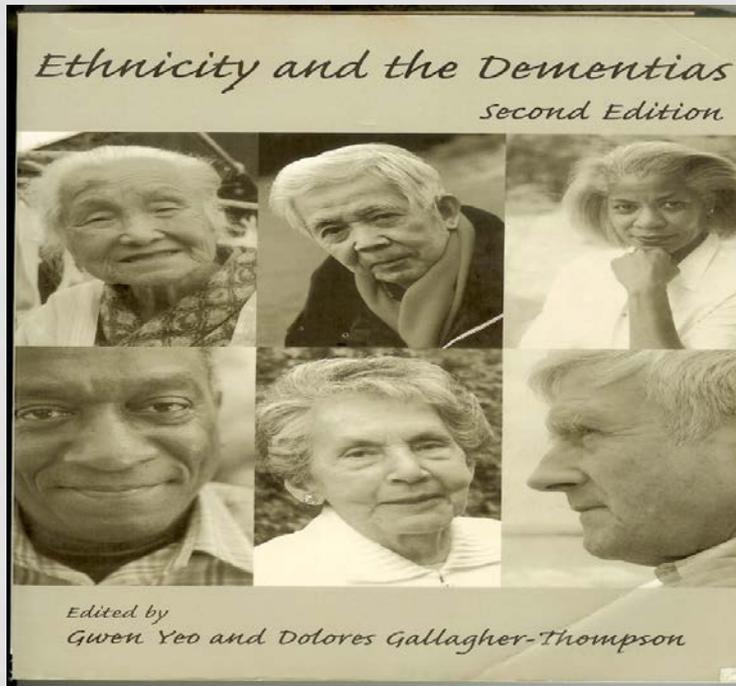
Japanese American

Korean American

Vietnamese American

\*\*\*\*\*

Yeo & Gallagher-Thompson. *Ethnicity & the Dementias*, 2<sup>nd</sup> Ed. Routledge/Taylor & Francis, 2006



# STANFORD GEC WEBINAR SERIES

## *ETHNICITY & THE DEMENTIAS*

- Recorded one-hour webinars available for viewing at no cost.
- Includes webinars on Assessment and Caregiving among the following Asian American populations:

Chinese American

Japanese American

Korean American

Hmong American

Filipino American

Vietnamese American

**[http://sgec.stanford.edu/video/2009-2010\\_Webinars.html](http://sgec.stanford.edu/video/2009-2010_Webinars.html)**

# ALZHEIMER'S ASSOCIATION RESOURCES

- Diverse Communities and Alzheimer's Website

**<http://www.alz.org/diversity/>**

- Asian resources include dementia-related topics in several languages, including warning signs, Alzheimer's basics and an interactive brain tour.
- [Chinese Website](#)
- [Japanese Website](#)
- [Korean Website](#)
- [Vietnamese Website](#)

# FOR MORE INFORMATION

- Stanford Geriatric Education Center Website

**<http://sgec.stanford.edu/>**

- Gwen Yeo, PhD

**[gwenyeo@stanford.edu](mailto:gwenyeo@stanford.edu)**

# *American Indian and Alaska Native Perspectives on Dementia*



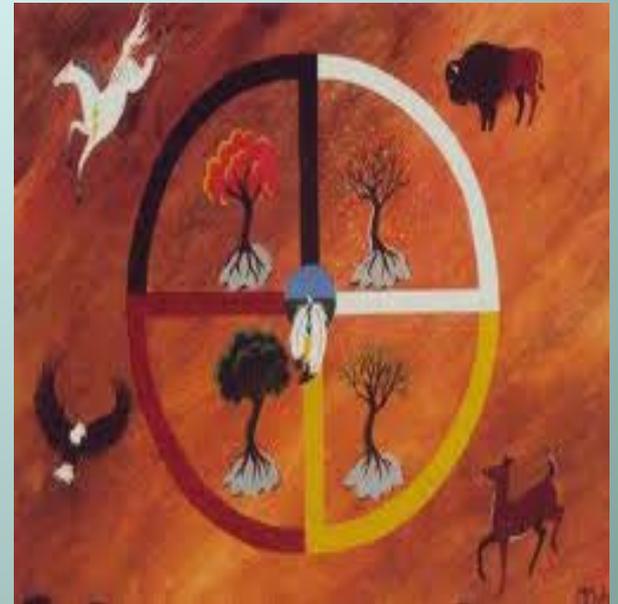
**Lori L. Jervis, Ph.D.**  
**University of  
Oklahoma**  
**Department of  
Anthropology and  
Center for Applied  
Social Research**

# *Goals of Presentation*

- 1) Provide brief overview of what is known about American Indian/Alaska Natives (AI/ANs) and dementia.**
- 2) Discuss prevalence, cognitive assessment, dementia caregiving and services, and future directions.**

# *State of the Literature*

- The research-based literature on dementing disorders in American Indians and Alaska Natives is quite limited.
  - Alaska Natives even more so
- Little is known about the epidemiology, etiology, or phenomenology of dementia in this population.



# *Prevalence*

- Prevalence in AI/ANs unknown.
- A study using data from Canadian provincial administrative health databases found more dementia in Alberta First Nations (Jacklin, Walker, and Shawande, 2013).
  - First Nations = 7.5 per 1,000
  - Non-First Nations = 5.6 per 1,000
- Among First Nations, Dementia disproportionately affected younger age groups and males ( $p=0.017$ ).

# *Prevalence*

- **91 Cree Indians 65 years and older were compared to 67 non-Indians (Hendrie et al. 1993).**
- **Two groups had similar prevalences of probable dementia (4.2%).**
  - Methodological issues...
- **Subtypes varied.**
  - Cree: more vascular/alcohol-related dementia
  - Non-Natives: more AD

# *Dementia Etiologies*

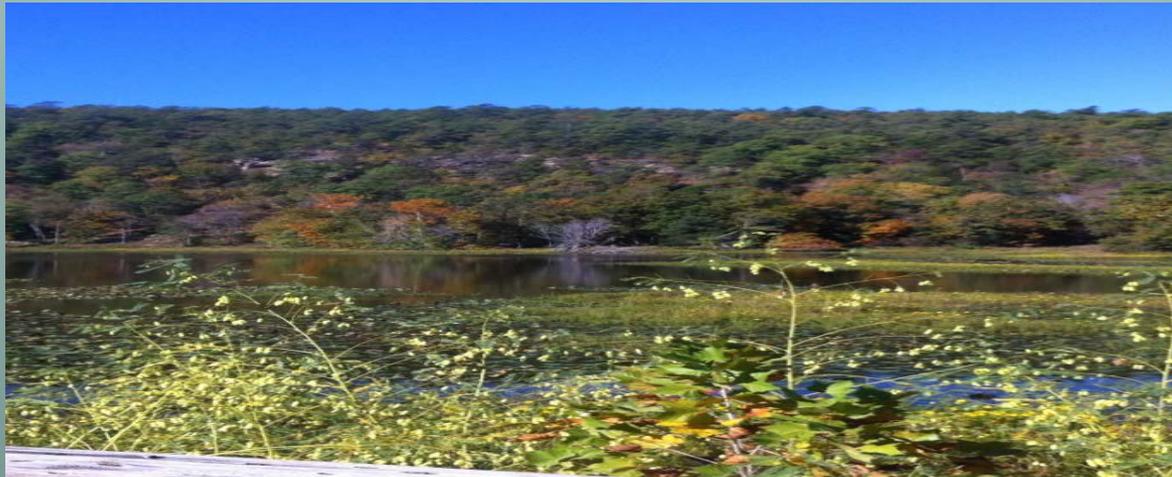
- **Similarly, in a Navajo Nation nursing home, dementia other than AD was the most common diagnosis, whereas AD was quite rare (Mercer, 1994).**
  - **Non-AD = 48% of women and 50% of men**
- **In a northern plains tribal nursing home, 42% were diagnosed with a non-AD dementia; 22% had dementias with other etiologies (Jervis and Manson, 2007).**

## *Genetic Contributors and AD Course*

- **A few non-epidemiological studies of genetic contributors to and clinical course of AD among AIs from SE culture area have been conducted.**
- **One such study found that the degree of genetic Cherokee ancestry was associated with a lower frequency of AD (Rosenberg et al., 1996).**

# *Genetic Contributors and AD Course*

- **Studies with Choctaws have found:**
  - Apolipoprotein E4 allele frequencies and tau H2 haplotypes were lower than whites (Henderson et al., 2002).
  - AD disease course was not associated with blood quantum; less Apo E4 frequency = potentially less AD (Weiner et al., 2003).



# *Summary*

- Prevalence unknown, but possibility that Natives have higher frequencies of dementia.
- Most of this is probably not AD.
- How can this be?



# *Summary*

- **Shorter life expectancies:**
  - 4.1 years lower than the general population (Indian Health Services, 2013)
  - AD is strongly associated with advancing age, meaning shorter life spans would most likely limit the number of AD cases
- **Genetic factors:**
  - But acculturation and “lifestyle” can be hard to separate out from genetic variables
  - Do people with different “blood quantum” live different lives, experience different risk and protective factors?

# *Risk Factors*

- **AI/ANs have high prevalences of several conditions that increase risk for poor cognitive functioning and/or dementia:**
  - Alcohol abuse/addiction
  - Diabetes
  - Overweight/obesity
  - Cardiovascular disease
  - Traumatic brain injury
- **Disproportionately poor (28.4% compared to 12.4% of the U.S. general population) (US Census Bureau, 2002).**



# *Cognitive Assessment*

- **Much written about bias in cognitive assessment for ethnic minorities and need for culturally relevant tests.**
- **Challenges:**
  - **566 federally recognized American Indian tribes and Alaska Native villages and over 64 state-recognized tribes (Bureau of Indian Affairs, 2013)**
  - **Tribes (and individual tribal members) have different degrees of acculturation**
  - **Geographical variation (e.g., region and rural/urban location)**

# *Cognitive Assessment*

- **Several studies found existing assessments/norms to be applicable for AIs (Ferarro et al., 1996; Ferarro et al., 2002; Morris, 1988; Whyte et al., 2005).**
  - **Some of these tribes had relatively high levels of acculturation**
- **A study of 140 Northern Plains AIs ages 60-89 found that nearly 11% were assessed as cognitively impaired using the MMSE, as were 27% to 81% using the DRS-2 (Jervis et al., 2007).**
  - **The tests and set of norms *mattered***

# *Cognitive Assessment*

- **Predictors of better performance on the MMSE (using multivariate regression) were:**
  - **Younger age, more education, not receiving Supplemental Security Income (SSI), and frequent receipt of needed health care (Jervis et. al, 2010)**
- **Better performance on the DRS-2 was predicted by:**
  - **More education, boarding school attendance, not receiving SSI, and frequent receipt of needed health care**

# *Dementia Caregiving and Services*

- **The existing dementia caregiving literature focuses on burden in the SW culture area (John et al., 1996; John et al. 2001).**
  - **Guilt predominated**
- **Pueblo caregivers highlighted respect accorded to tribal elders, contrasted with infantilization and resentment they believed to be common among white caregivers (Hennessy and John, 1995).**

# *Dementia Caregiving and Services*

- **The extended family is often the primary—and sometimes the sole provider of care—to older Natives in rural and reservation settings (LaFromboise, 1988; Hennessy and John, 1995).**
- **The predominance of family caregiving has been attributed both to cultural emphases on familial interdependence and dire necessity (Hennessy and John, 1996; Jervis and Manson, 1999).**

# Indian Health Service

- **The Indian Health Service provides very little long-term care, and local, culturally appropriate residential care facilities are in short supply (Rousseau, 1995; Jervis and Manson, 1999; Baldrige, 2001).**
- **A national survey of program officials found a wide disparity between perceived need and actual availability of nearly all long-term and supportive services in AI rural and reservation communities (Jervis et al., 2002).**

## *“Ideal vs. Real”*

- **Service use among AI/ANs with dementia and their caregivers would ideally comprise a continuum of care:**
  - (i.e., home health care, day care programs, respite care, traditional healing, residential care facilities, and IHS medical facilities.
- **In reality, many of these services are not available on reservations/rural areas; those that do exist are typically delivered with no central mechanism for coordination.**

# *Access to Alzheimer's Disease Centers*

- **Of the 13 cities with the largest number of AI/ANs (US Census Bureau, 2012), 6 have NIA-funded Alzheimer's Disease Centers and 7 do not.**
  - **Centers with Native American focus (Arizona, UTSW)**
- **Opportunities exist for involvement in clinical trials in some cities, but clearly more are needed.**



# *Future Directions*

- **Prevalence: Still undetermined.**
- **Culturally relevant cognitive assessment: Linked to ability to conduct prevalence studies and provide adequate health care.**
- **Dementia caregiving and services:**
  - What does care look like formally or informally?
  - Some Natives may not seek help due to normalizing dementia symptoms.
- **Research/Clinical Trials:**
  - How many AI/ANs actually have access to these?
  - How many don't even know they exist or how to access them?

# Diverse Populations, Health Disparities & Dementia: LGBT Community

Jed A. Levine, Executive Vice President,  
Director of Programs & Services  
Alzheimer's Association, New York City Chapter

July 24, 2013

# Older Gay Men & Lesbians

## Background – Terminology

- Generational issues
- Criminalized
- Marginalized
- “Coming Out”
- Fear of job loss, status and family rejection
- Stonewall Generation
- 1973 APA decision
- HIV/AIDS

# Recent Major Milestones

- Don't Ask Don't Tell 1992
- States legalize same-sex marriage 2004
  - Massachusetts first state to legalize “gay” marriage
- Don't Ask Don't Tell abolished 2011
- DOMA repealed – 2013

# LGBT Groups

- Why?
- How?
- With whom?
- When?



# Special Needs

- Caring in non-traditional relationships
- Not unusual to be caring for two or more individuals. R's mother and partner are in same nursing home.
- More discussion/disclosure of co-morbidities of alcoholism, over-eating, depression
- Need to talk about intimacy without fear of being judged

# Special Needs of LGBT Caregivers

- Some reported feeling misunderstood in groups for straight spouses.
- De-valued “Your relationship is different from my caring for my wife”
- Fear/discomfort of coming out in a straight group
- Need to be authentic and genuine in the group, not hide a part of themselves.

# Influence of HIV/AIDS Experience

- Trauma re-awakened from AIDS epidemic
- Often 1<sup>st</sup> caregiving experience was for friends with AIDS
- Re-awakened fear of getting seriously ill or dying

# Why a Special Group for LGBT Caregivers?

- Gay partner or spouse treated differently from other in-law children.
- Safe place to share caregiving concerns without the exhausting burden of hiding their sexual orientation.
- “There is already an existing bond”

# Group Member Concerns Specific to LGBT Group

- Fears about who is going to care for them if they don't have a partner or children. (MetLife Study)
- Insensitive family members who assume that the gay adult child will do the caregiving, (they don't have a traditional family to care for).
- Family/staff not recognizing the validity of their relationships
- Homophobia or fear of homophobia in nursing homes, adult day care, or home care provider settings.

# LGBT Concerns Expressed in Group

- Affects relationships with boyfriend/girlfriend/partner/spouse
- Not being acknowledged as the caregiver – in non-traditional caregiving relationships
- Communal caregiving; groups of friends who provide care for another. Seems more common in the LGBT community. - ASA – Aging Today July-August 2013, “Friendship a pillar of survival for LGBT elders,” Robert Espinoza

# Collaboration with



- Partners since 1995
- Professionals from the community approached us about the need.
- SAGE was a logical partner.
- Co-leadership: male and female when possible
- AA-NYC and SAGE recruit members
- Co-market the group
- AA-NYC provides SG leader training
- We recruit, screen, train and supervise group leaders

# LGBT Group with SAGE

- Groups have grown – now three active groups, two for current caregivers and one bereavement group.
- Meet weekly
- Group membership steady and consistent.
- Many of the members of the groups have been attending for 3 – 5 years.

# Group Member Concerns

- Varied and similar to other SG's in NYC.
- Acceptance of the disease
- Difficulty accessing services
- Dealing with feelings of helplessness, anger, guilt, sadness, frustration, confusion, and exhaustion
- Mourning the person they once knew.
- When is it “too much”?
- How do I find time for my life?

# Health and Human Services Policies and Procedures

- LGBT friendly care
- Forms and paper work
- Defining family
- Visitor policy
- Formal non-discrimination policy

# Advancing Care

### Gay and Gray: Welcoming LGBT Elders in Long Term Care

As long as there have been nursing homes, there have been residents living in them who were lesbian, gay, bi-sexual or transgender (LGBT). This may surprise some, because it is a common assumption that it is possible to identify LGBT individuals by appearances, experiences, or external characteristics. However, nothing could be further from the truth: LGBT elders do not all look the same way or adopt the same mannerisms or ways of dressing. Indeed, they may have past life experiences—such as being previously married or having children or grandchildren—that conflict with common assumptions about LGBT people.

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The unhappy reality is that people in nursing homes who are lesbian, gay, bi-sexual, or transgender have almost always been reluctant and even afraid to be identified as such, from fear of how staff, other residents and family members would respond to them. Surveys indicate that four out of five LGBT elders say they don't trust the health-care system, and in 2010 the federal government noted in its Healthy People 2010 campaign that LGBT people face specific and magnified health vulnerabilities. These vulnerabilities range from LGBT elders avoiding health care providers because of their worries about how they'll be treated, to the damaging physical and mental health effects of being stigmatized and/or the focus of prejudice and discrimination, which create a hostile and stressful environment. There are approximately 1.5-2 million LGBT Americans over 65, and they have the same needs for long-term care services as other elders. However, in order to be sure we are providing them with the same quality of care that we provide to others, it is essential that we take steps to ensure that they feel genuinely welcome, and while in our care, free from fear or discrimination. Here are some suggestions from the *National Resource Center on LGBT Aging*:

- **Presume you have LGBT residents.**
- **Do not assume you can identify an LGBT person.**
- **Do remember a client's sexual orientation and gender are only two aspects of a person's overall identity and life experience.** In addition to sexual orientation and gender identity, each resident brings with them their racial, ethnic, and cultural heritage, as well as their unique individual history.
- **Do ask your residents about their sexual orientations and gender identities in a safe and confidential manner.** Remember that while it is important to ask about sexual orientation and gender identity along with all of the other key components of care, LGBT people have significant histories of discrimination and stigma, which make them far less willing to disclose these parts of their identities. Ask the questions as you would any other factual question, but do not force anyone to answer. If a resident looks uncomfortable, anxious, or refuses to answer, move on to the next question.
- **Do not assume that treating everyone the same, regardless of sexual orientation or gender identity, is effective or will make LGBT elders feel safe or welcomed.** More often than not, treating everyone the same translates to treating everyone as heterosexual, and glosses over challenges LGBT elders may have faced, including discrimination, physical and emotional stress, and violence.

#### First Impressions: What does welcome look like?

Including same-sex couples in marketing materials sends a positive message. In addition, prominently post your

# Research

- Growing body of research on LGBT aging
- National Gay and Lesbian Task Force Policy Institute – Study on Caregiving in the LGBT community.
  - “Caregiving among older lesbian, gay, bisexual and transgender New Yorkers”, Cantor, Brennan and Shippy, 2004
- National Resource Center on LGBT Aging

# Research cont'd.

- Dementia specific concerns – little or no research
- AAIC 2013 – no research papers presented on LGBT and AD issues.

# Resources

## National Resource Center on LGBT Aging

<http://www.lgbtagingcenter.org/>

## The National Gay and Lesbian Task Force

<http://www.taskforce.org>

**MetLife Mature Market Institute.  
*Still Out, Still Aging: The MetLife  
Study of Lesbian, Gay, Bisexual,  
and Transgender Baby Boomers.*  
March 2010**



### **lgbt caregiver concerns**

Many lesbian, gay, bisexual and transgender (LGBT) people have experienced difficult and alienating relationships with family, friends, employers and service providers. Some have felt the need to move away from their families of origin, to stay in the closet or to distance themselves from discriminating and prejudiced situations. Yet, LGBT people are more likely to become caregivers for a partner, friend or biological family member. While caregiving can be rewarding, it can also be isolating. This brochure will help you navigate community resources and options for support.



The Alzheimer's Association welcomes, and is supportive of, all persons regardless of age, race, gender identity, class, ethnicity, sexual orientation, language, physical ability or religion.

While LGBT-specific services may not be available everywhere, the Alzheimer's Association is here to help you find the right care and support options.

# Resources

- SAGE
  - <http://www.sageusa.org>
- LGBT Aging Project
  - <http://www.lgbtagingproject.org>
- Family Caregiver Alliance
  - Online LGBT Caregiver Support Group
    - <http://www.Caregiver.org>

**When Alzheimer's disease touches your life turn to us.**

**Nationwide 24-hour Helpline**

**Whether you need information or just want to talk, call  
us. **1.800.272.3900****

**<http://www.alz.org>**

**Our award-winning Web site is a rich resource of  
evidence-based content**



## Questions?

Registration for Webinar #4 Now Open:

<http://goo.gl/k3ThK>

Registration for Webinar #5 Now Open:

<http://goo.gl/w03Or1>

Slides, audio and transcript for 2013 webinar series will be available under Resources and Useful Links at:

[http://www.aoa.gov/AoARoot/AoA\\_Programs/HP\\_W/Alz\\_Grants/index.aspx](http://www.aoa.gov/AoARoot/AoA_Programs/HP_W/Alz_Grants/index.aspx)