

Deconstructing Race, Ethnicity, and Culture for ADRD Research

Jennifer J. Manly, PhD
Columbia University
jjm71@cumc.columbia.edu



#DementiaCareSummit

Collaborators

Maria Glymour	Laura Zahodne
Adam Brickman	Sze Liu
Christopher Weiss	Yaakov Stern
Karen Siedlecki	Richard Mayeux
Wei-Ming Watson	Nicole Schupf

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Overview

- Evidence for dementia disparities
- Challenges and opportunities for research on diversity in dementia care & services
 - Selection bias
 - Multiple domains and levels of analysis
 - Lifecourse approach
- Research recommendations

Evidence of Disparities Kaiser Permanente Northern California Mayeda et al., 2016

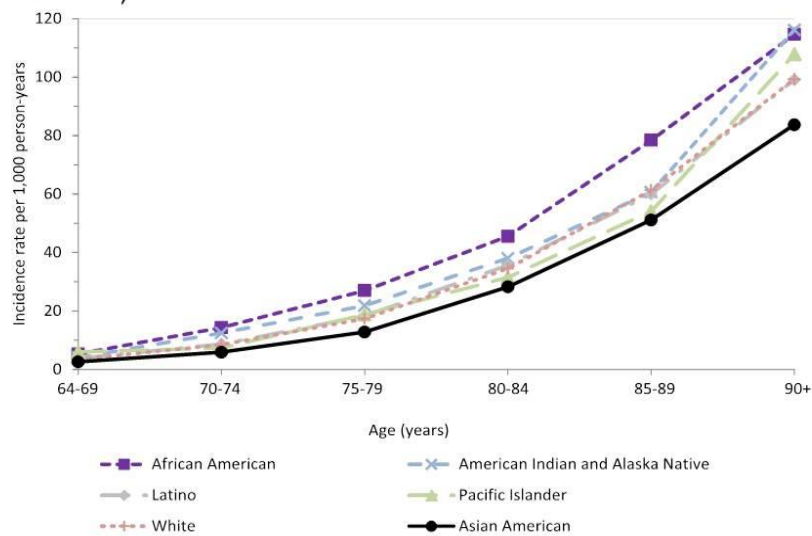
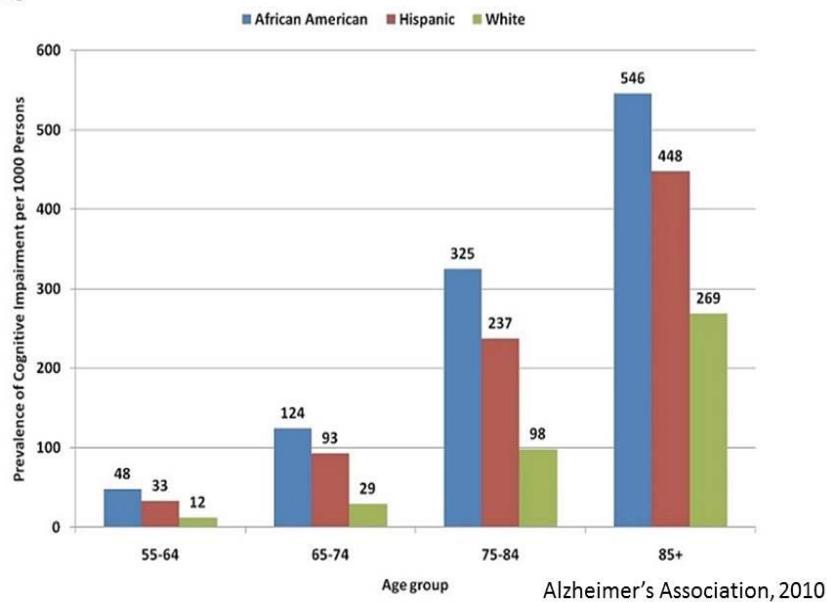


Fig. 2. Dementia incidence rates per 1000 person-years by age and race-ethnicity, 2000–2013.

Evidence of Disparities

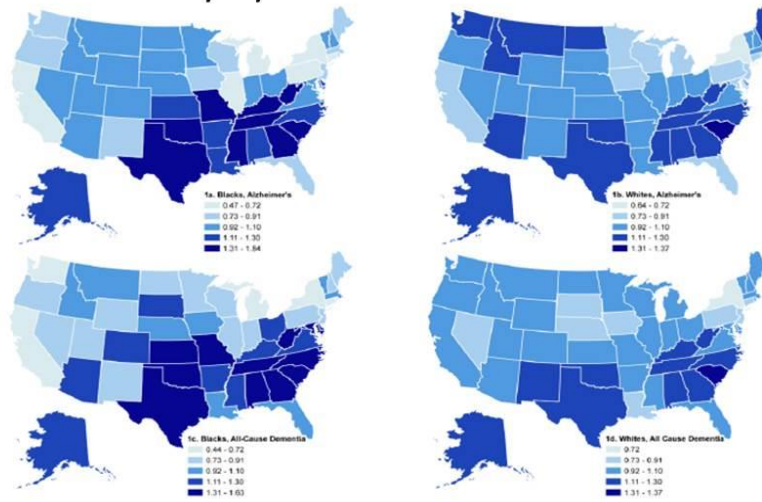
Prevalence of Cognitive Impairment by Age and Race/Ethnicity HRS 2006



Societal Burden of Disparities

- Disparities populations are less likely to receive a diagnosis of dementia
- Disparities populations are typically diagnosed in later stages of the disease
 - Average per-person Medicare payments are 45 percent higher for African Americans with a dementia diagnosis and 37 percent higher for Hispanics compared with whites who have dementia.
 - Higher prevalence of neuropsychiatric symptoms among African Americans and Hispanics (Sink et al., 2004)
- Blacks and Whites born in the stroke belt states are at higher risk of dementia mortality than those born in other states, even if they moved out of stroke belt (Glymour et al., 2011)

Alzheimer's Disease and All-cause Dementia Mortality by Race and Place of Birth



Odds ratios for Alzheimer's or all-cause dementia-related mortality in 2000, by race and state of birth, compared to the national average, based on empirical Bayes (shrinkage) random effect estimates from logistic models, US born blacks and whites ages 65–89.

Glymour et al., *Alzheimer Dis Assoc Disord* 2011

Incident cognitive impairment in the US



Figure 2. State-specific map of incident cognitive impairment (n = 23,298). Map depicts dichotomously split ranked odds of state-specific incident cognitive impairment, adjusted for age, race, sex, education level, and time between first and last cognitive assessments. In the median split of the distribution of ORs, lightly shaded states (rank 1) had lower ranked odds of incident impairment. Darkly shaded states (rank 2) had higher odds. Unshaded states had insufficient data for inclusion (states with < 100 eligible participants*). The Stroke Belt states are outlined.

*Arizona, Delaware, Idaho, Kansas, Maine, Montana, Nebraska, Nevada, New Hampshire, New Mexico, North Dakota, Oregon, Rhode Island, South Dakota, Utah, Vermont, West Virginia, and Wyoming

Wadley et al., 2011

Selection Bias

- Differences in recruitment across racial/ethnic groups may lead to non-generalizable results
 - Ethnic minority participants may not be broadly representative of the community
 - Consider how barriers to participation may influence sample characteristics and bias results
- Racial and ethnic minorities are less likely to present to Memory Disorders Clinics, are less likely to receive a formal diagnosis of AD than non-Hispanic Whites
 - Minorities who present to clinics are more likely to have neuropsychiatric symptoms than Whites

Mistrust of research and stigma causes selection bias

- Lack of cultural and linguistic competency in health care system
 - Scheduling
 - Practitioner
 - Billing
- Impact of historical medical abuses including use of IQ tests to support racist policies
- Little evidence of benefits of medical research for underserved communities
 - Intractable disparities
- Ongoing experiences of discrimination in the medical setting
- Lack of access to information

Adapted from Scharff et al., 2010

Stigma, Fear & Shame

- Stigma - “attribute that is deeply discrediting” and causes us to change our view of the person from “a whole and usual person to a tainted and discounted one” (Goffman, 1963)
- Stigma associated with dementia causes discomfort and embarrassment, which can lead to:
 - Delay in diagnosis and care
 - Poor interactions with medical care providers
 - Increased burden on caregivers
 - Social isolation
 - Lack of participation in clinical research

Equal community partnerships

- Community-based participatory research
 - Create a trusting relationship
 - Share concerns and determine community priorities
 - Define questions
 - Identify important constructs
 - Choose or create measures
 - Decide on all procedures, weighing costs and benefits
 - Monitor participant burden
 - Communication of results
 - Plan next steps, maintaining relationships
- Maintain a community advisory board
- Consider word-of-mouth

Representative recruitment method

- Convenience samples, volunteers, and clinic-based samples rarely lead to representative samples
- Random Digit Dialing
- Representative school-based
- Medicare or regional health plan
- Voter registration lists
- Door-to-door

Financial resources are needed to come to the clinic/hospital

- Travel time
- Transportation costs
- Parking
- Food
- Physical limitations make travel to the clinic more difficult
 - Frailty
 - Wheelchairs
 - Visual impairment

Neuropsychological testing in the Dominican Republic



Photo credit: Adam M. Brickman, PhD

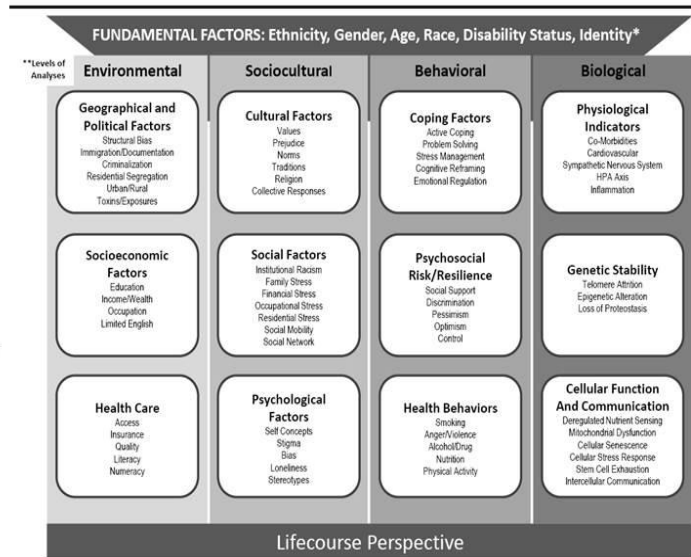
Existing and emerging technologies improve access, ecological validity, and sensitivity to change

- Telephone assessment including IVR
- Internet Assessment
 - Web-based measures
 - Skype or other software using webcams
- Mailed tablet
- Cell Phone burst measures (e.g., Sliwinski et al.)
- Digital Capture/Unobtrusive Assessment (e.g., Kaye et al.)
 - Wearables
 - Home-Based

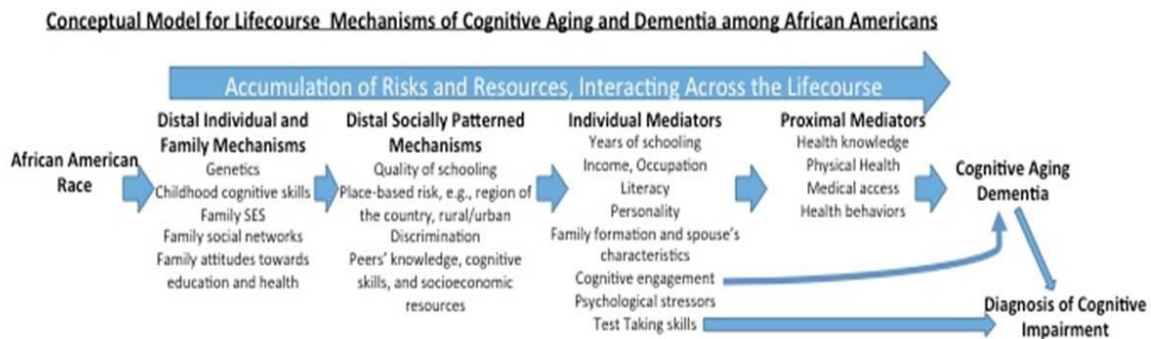
NIA Disparities Research Framework

Hill et al., 2015

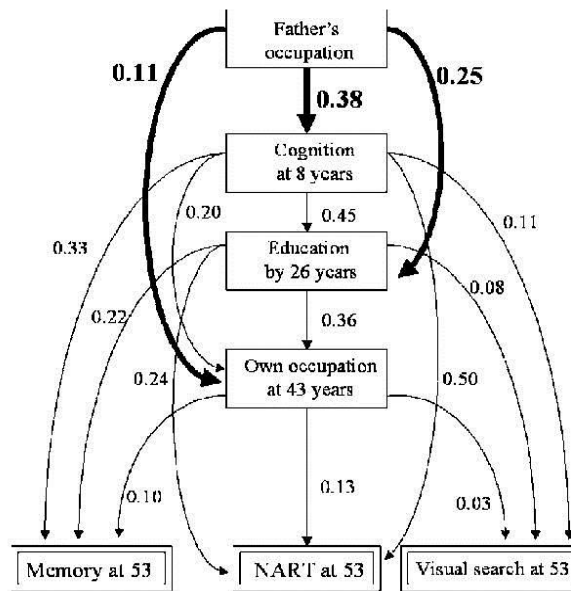
- Multiple levels of analysis and domains of influence
- Environment can become biologically embedded in the body
 - Stress response pathways (McEwen and Stellar, 1993)
 - Allostatic load (Geronimus, Hicken, Keene, & Bound, 2006)
 - Neuronal development, and epigenetic mechanisms (Waterland & Michels, 2007)
- Not easy to separate out biological effects from behavioral responses that might alleviate or exacerbate the effects of early conditions



Life Course influences



Life Course influences



Richards et al., 2003
JCEN

MRC National Survey
= socially stratified
birth cohort, all births
within one week in
March 1946, followed
until age 53

Research Recommendations

- Specify and support community-based participatory research
- Large, representative cohorts of people with dementia and their caregivers
 - Leverage studies of middle age and older adults with diverse cohorts for caregiving research
 - Clinic-based recruitment is less suitable for research on disparities or for research including diverse participants
- Increase understanding of stigma associated with dementia/cognitive impairment across cultures
- Home visits and use of existing and emerging technology to increase access to assessment and interventions

Research Recommendations

- Longitudinal studies
 - Baseline prior to development of dementia (midlife or prior)
 - Repeat assessment
 - Emphasize importance of trajectory data
- Reveal risk and resilience factors by considering intersecting domains and levels of influence
 - Domains
 - Biological
 - Psychosocial
 - Behavioral
 - Built environment/neighborhood
 - Sociocultural environment
 - Healthcare system and access to healthcare
 - Levels
 - Individual
 - Interpersonal
 - Community
 - Societal

Research Recommendations

- Conduct studies designed to elucidate causal mechanisms
- Lifecourse perspective
 - Follow up into mid-life and later life needed for school, twin, and birth cohorts
 - Investigate potential critical periods for intervention
 - Evaluate natural experiments using instrumental variables
- Embed dementia care & services research within planned interventions
 - Increased income
 - Neighborhood and household interventions
 - Healthcare policy changes