Improving access to dementia diagnosis and treatment in communities and special populations

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I have no financial relationships to disclose in relation to this presentation.

We bear the responsibility to improve dementia care



Brain health equity

• The fair distribution of brain health determinants, outcomes, and resources within and between segments of the population, regardless of social standing.



Health Disparities



- **Preventable** differences in health, health care, and disease burden between populations
 - Higher burden of illness, injury, disability, and/or mortality
- Occur across a broad range of marginalized identities
 - Race/ethnicity; socioeconomic status; gender; age; disability; sexual orientation; gender identity; geographic location, etc.
 - Intersectionality is critical
- Arise from a complex and interrelated set of historic societal and economic factors



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^E June 13, 2017; 88 (24) **ARTICLE**

Racial disparities in neurologic health care access and utilization in the United States

Altaf Saadi, David U. Himmelstein, Steffie Woolhandler, Nicte I. Mejia

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Altaf Saadi, MD

- Brain diseases disproportionately affect Black, Latinx, Asian, Native American, LGBTQ+, those in lower socioeconomic groups, individuals living in underserved geographies, and other marginalized populations in the United States.
- These are the same US populations that often experience lack of basic access to healthcare, neurological care, and other types of health disparities
 - Stroke
 - TBI
 - Dementias
 - Migraine
- Black and Latinx people are up to 40% less likely than White people to see a neurologist
 - More likely to be treated in the emergency department with prolonged hospital stays
 - Increased morbidity
 - Increased mortality
- Disparities occur not only within incidence & prevalence rates but along the entire care continuum

National Institute on Minority Health and Health Disparities Research Framework

		Levels of Influence*					
_		Individual	Interpersonal	Community	Societal		
ence	Biological	Biological Vulnerability and Mechanisms	Caregiver–Child Interaction Family Microbiome	Community Illness Exposure Herd Immunity	Sanitation Immunization Pathogen Exposure		
	Behavioral	Health Behaviors Coping Strategies	Family Functioning School/Work Functioning	Community Functioning	Policies and Laws		
mains of Influer (Over the Lifecourse)	Physical/Built Environment	Personal Environment	Household Environment School/Work Environment	Community Environment Community Resources	Societal Structure		
Domains of Influence (Over the Lifecourse)	Sociocultural Environment	Sociodemographics Limited English Cultural Identity Response to Discrimination	Social Networks Family/Peer Norms Interpersonal Discrimination	Community Norms Local Structural Discrimination	Social Norms Societal Structural Discrimination		
	Health Care System	Insurance Coverage Health Literacy Treatment Preferences	Patient–Clinician Relationship Medical Decision-Making	Availability of Services Safety Net Services	Quality of Care Health Care Policies		
Health Outcomes		A Individual Health	Family/ Organizational Health	合 Community 合合 Health	Health		

National Institute on Minority Health and Health Disparities, 2018

*Health Disparity Populations: Race/Ethnicity, Low SES, Rural, Sexual and Gender Minority

Other Fundamental Characteristics: Sex and Gender, Disability, Geographic Region

Context: Mapped dementia diagnostic disparities

- Higher incidence, prevalence, burden, & mortality
- Manifested across the full range of disease course
- Diagnostic disparities
 - Location: Emergency rooms vs specialty clinics
 - Timing: Initial diagnosis more often at moderate stage
 - Nature: Less accurate
- Disparities have not shown much decline over the past two decades

Barriers to dementia diagnosis and care

- Systemic
 - Inadequate health insurance
- Institutional
 - Lack of specialty clinics
 - Staff w/limited language capacity
- Interpersonal/Individual
 - Dementia literacy
 - Transportation

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National Institute on Minority Health and Health Disparities Research Framework

National Institute on Minority Health and Health Disparities, 2018 'Health Disparity Populations: Race/Ethnicity, Low SES, Rural, Sexual and Gender Minority Other Fundamental Characteristics: Sex and Gender, Dissolity, Geographic Region

Dilworth-Anderson, et al. (2008); Social, Behavioral and Diversity Research Workgroup of the Alzheimer's Association. Diagnosis and assessment of Alzheimer's disease in diverse populations. Alzheimer's Dement,4(4):305-309

Improving access: Intervention for research

- Intentional methodologic design to expand the science
 - Clinical Research:
 - Recruitment
 - Tiered recruitment prioritizing special populations at first tier
 - Less restrictive exclusion criteria
 - Build in psychoeducation: videos, social media, mobilize community navigators
 - Data collection supports: home visits; budget for sensory/ergonomic needs
 - Scheduling flexibility for participant best time of day
 - Leverage technologies
 - Machine learning
 - Regular progress and experience/feedback checks
 - Transparency re: limitations/challenges in science communications

Improving access: Interventions for practice

- Setting
 - Shift to primary care
 - Community clinics
- Routine dementia screenings
- Care partner engagement/education
- Mobile memory clinics
- Targeted ADRD awareness campaigns in primary care clinics
 - Impacts on MCC care



Improving access: Knowledge Gaps

- Sustainability of interventions
- Telehealth & dementia disparities
- Mixed methods approaches to identify stakeholder perception of health condition hierarchy
 - Physicians
 - Medical staff
 - Family members
- Measured benefits in MCC management for early ADRD screening
- Improvement in end of life care/planning
- Healthcare cost savings
- Caregiver experience



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Thank you!