Access, accuracy, and equity in dementia diagnosis

35th Annual Southern California Alzheimer's Disease Research Conference

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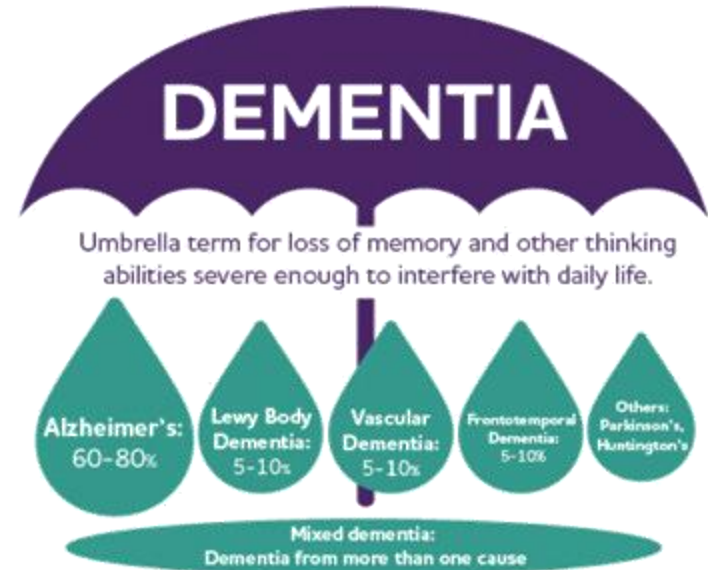Global Brain Health Institute

Disclosures

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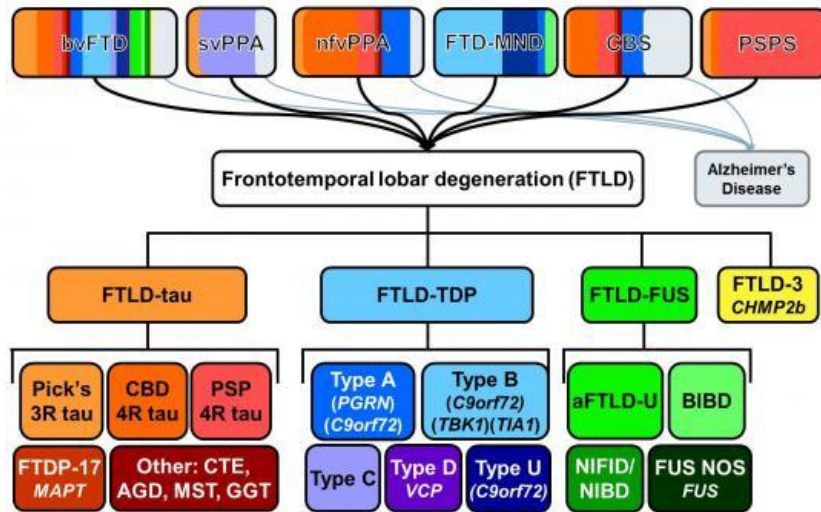
Outline

- What is the current state of ADRD diagnosis?

- What do ADRD diagnostic disparities mean for patients, families, and societies?

- What factors drive ADRD diagnostic disparities?

- What can be done to reduce disparities in ADRD diagnosis and to facilitate equity in ADRD research and care?

Dementia as a Clinical Syndrome

- Dementia is **not a disease** and has many causes.

- Dementia **symptoms differ** depending on the underlying cause.
  - E.g., early behavioral changes are more likely in dementia due to FTLD than AD.

DEMENTIA

Umbrella term for loss of memory and other thinking abilities severe enough to interfere with daily life.

Alzheimer's: 60-80%

Lewy Body Dementia: 5-10%

Vascular Dementia: 5-10%

Frontotemporal Dementia: 5-10%

Others: Parkinson's, Huntington's

Mixed dementia: Dementia from more than one cause

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Dementia as a Clinical Syndrome

Slide courtesy W.W. Seeley, UCSF

Different "types" of dementia are

- caused by different **diseases** (or comorbid multiple diseases)

- characterized by different **care and treatment needs**

- associated with different **expenditure patterns** and **mortality rates**

Chen 2019 Alzheimers Dement, Liang 2021 Lancet Healthy Longev

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Dementia Diagnosis

- Diagnostic procedures typically include, but are not limited to
  - Clinical history and evaluation of concerns
  - Physical or neurological exam
  - Neuropsychological testing
  - Laboratory testing
  - Neuroimaging
  - Biomarker testing

Why Timely Diagnosis Matter

Timely diagnosis allows to

- identify **etiological causes**,

- inform and coordinate **care**,

- enable **planning** for the future,

- address **safety issues**,

- connect **families and caregivers** with interventions,

- identify candidates for **clinical trials and novel treatments**.
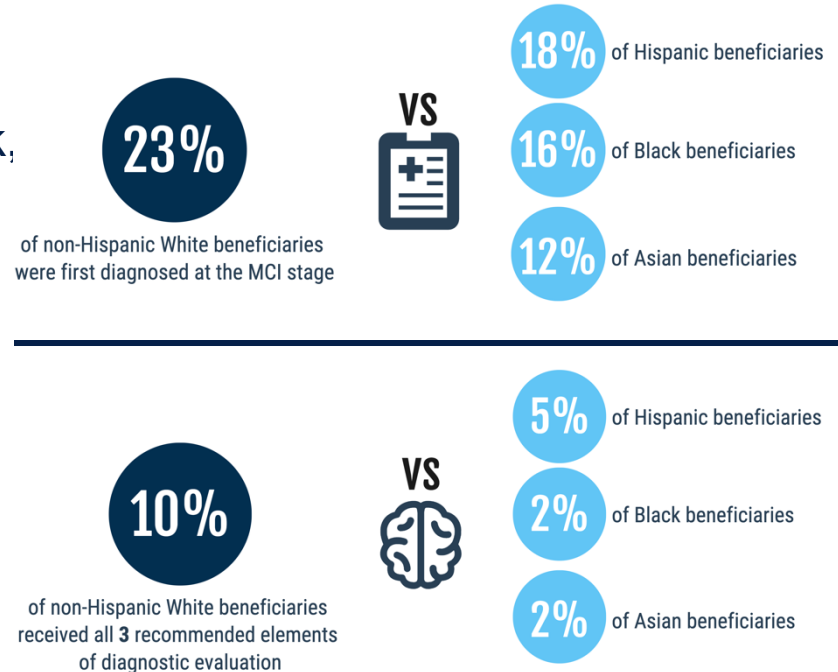
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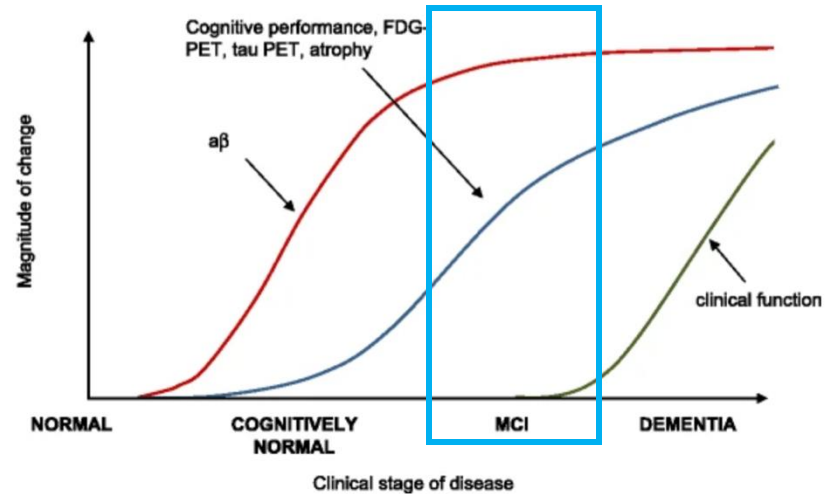
Disparities in Dementia Diagnosis

- Dementia is massively **underdiagnosed**, especially in its earlier stages and non-specialty settings.

    - Patients who had not received a dementia diagnosis accounted for **50-66% of all cases** of dementia in the primary care samples.

- **Underdiagnosis** is more common among those who

    - Identified as Non-Hispanic Black or Hispanic

    - Had lower educational attainment (less than high school)

    - Had below-median wealth

    - Had limited English proficiency

    - Did not have a partner, caregiver, or informant

Boustani 2003 Ann Intern Med, Qian 2021 J Gerontol A Biol Sci Med Sci, Amjad 2018 J Gen Intern Med, Lang 2017 BMJ Open, Franco 2020 J Immigr Minor Health
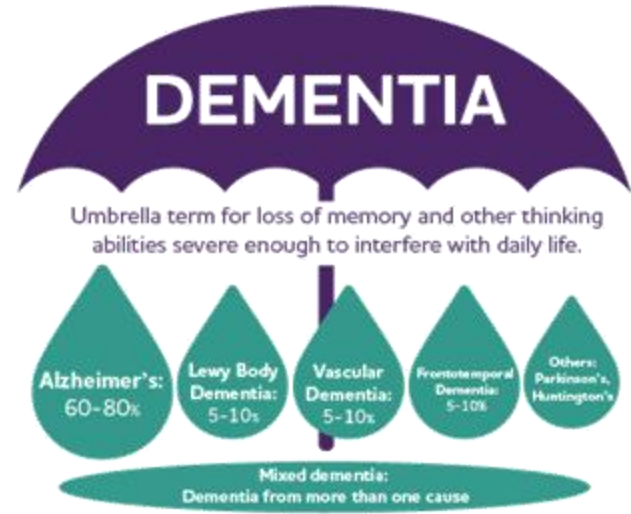
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Disparities in Dementia Diagnosis

- **Late diagnosis** is more common among individuals who

  - identified as Asian, non-Hispanic Black, and Hispanic

  - were older at the time of the diagnosis

  - had a greater comorbidity burden

- **Less comprehensive** diagnostic care is more common among

  - Asian and Hispanic older adults

23% of non-Hispanic White beneficiaries were first diagnosed at the MCI stage

VS

18% of Hispanic beneficiaries
16% of Black beneficiaries
12% of Asian beneficiaries

10% of non-Hispanic White beneficiaries received all **3** recommended elements of diagnostic evaluation

VS

5% of Hispanic beneficiaries
2% of Black beneficiaries
2% of Asian beneficiaries

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Disparities in Dementia Diagnosis

- Ongoing analysis of 898,041 Medicare FFS beneficiaries with diagnoses of dementia:

- Non-Hispanic White

  - **80%** of all-cause dementia
  - **81%** of AD dementia
  - **85%** of Lewy body / Parkinson's disease dementia
  - **87%** of progressive supranuclear palsy / corticobasal syndrome
  - **92%** of frontotemporal dementia

Why Diagnostic Disparities Matter

Patients and Families

Delayed diagnosis

Misdiagnosis

Fewer specialist referrals

Dementia healthcare trajectory

Initial assessment, diagnosis, and referral

Ongoing treatment and support

Less likely to receive & more likely to discontinue anti-dementia meds

Increased antipsychotic use

Increased hospitalization and emergency room utilization

Later stages, end-of-life care

Reside in long-term care facilities with lower quality of care

Less advanced care planning

More aggressive and costly care

Lower utilization of hospice care

FDA NEWS RELEASE

FDA Converts Novel Alzheimer's Disease Treatment to Traditional Approval

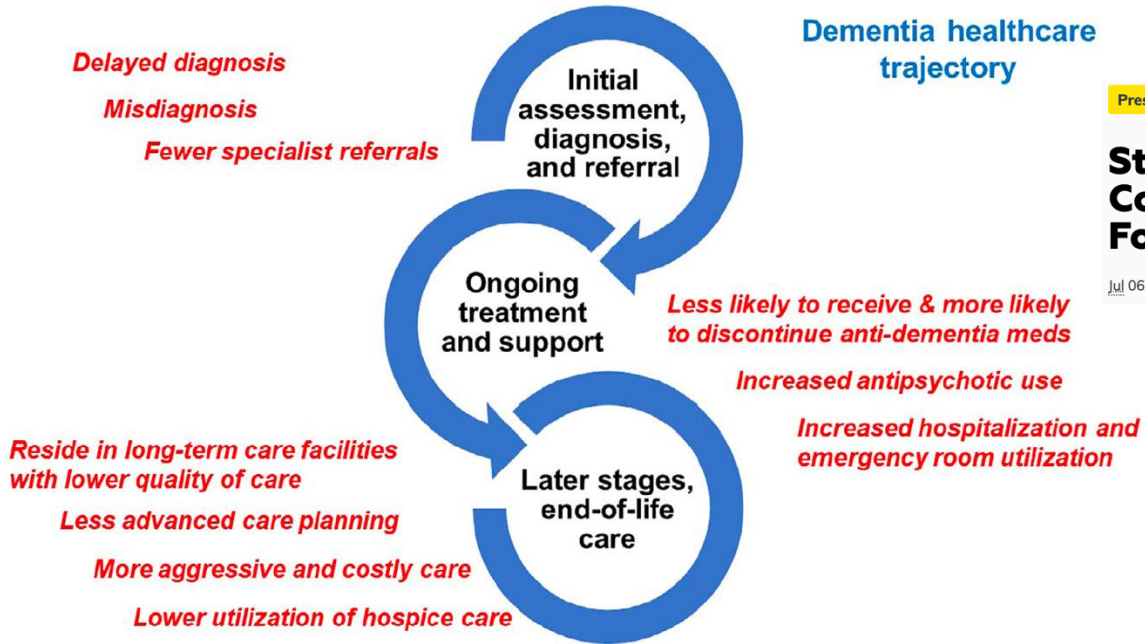*Action Follows Confirmatory Trial to Verify Clinical Benefit*

Press release

Statement: Broader Medicare Coverage of Leqembi Available Following FDA Traditional Approval
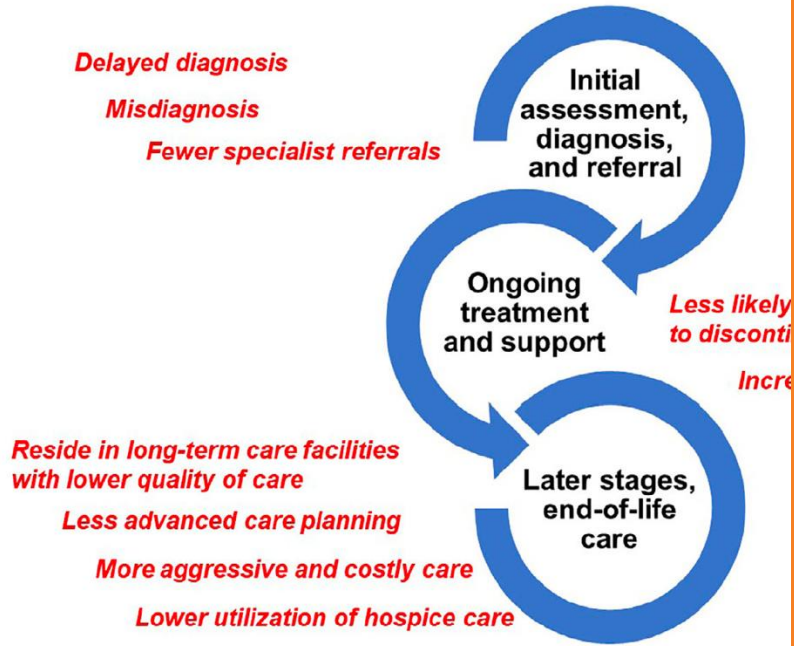
Jul 06, 2023 | Coverage, Medicare Part D

1) be enrolled in Medicare,
2) be diagnosed with **mild cognitive impairment or mild AD dementia**, with documented evidence of Aβ plaque on the brain,
3) have a physician participating in a qualifying registry.

Hinton 2024 Alzheimers Dement, Tsoy 2021 World Alzheimer Report, US FDA 2023, Centers for Medicare & Medicaid Services 2023

Why Diagnostic Disparities Matter

Patients and Families

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Later stages, end-of-life care

*"Well, it was, I would say, good. Not good, but it was something that at least we finally found out what it was because before we were not sure what the problem was. Now, **we know how we have to deal with it**."* (Hispanic, M)

*"Had I not had that diagnosis…That would be a disaster. So at least I know, based on that diagnosis, **what road I was going down**."* (African American, F)

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Why Diagnostic Disparities Matter
Research Community

- Late or missed diagnoses likely underlie **underrepresentation and exclusion** of diverse older adults in clinical trials, epidemiological, and observational studies.

- This pervasive pattern may in turn lead to **biased** results and conclusions, which then influence future science.
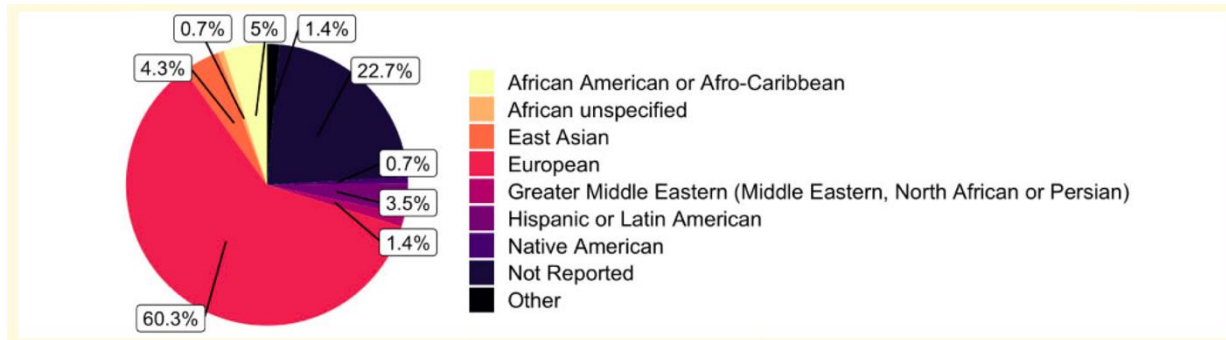

Figure 4 Broad ancestry represented in the 76 Alzheimer's disease GWAS that are part of the NHGRI-EBI GWAS catalogue.

Why Diagnostic Disparities Matter
Economy and Society

- Older Americans who experience diagnostic disparities often belong to communities that are at greatest risk of dementia.

  - Are Non-Hispanic Black

  - Are Hispanic

  - Have high comorbidity

  - Are socioeconomically disadvantaged

  - **Prevalence** is 2x in Black and 1.5x in Hispanic Americans.

  - **Incidence** is highest in Black and Hispanic Americans.

  - **Age, low education, and high cardiovascular burden** each increase dementia risk.

US Census Bureau 2017, Chen 2018 Alzheimers Dement (N Y), Mayeda 2016 Alzheimers Dement, Mathews 2019 Alzheimers Dement

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Why Diagnostic Disparities Matter

Economy and Society

- If 88% of individuals are diagnosed in the MCI phase, $7 trillion could be saved in healthcare costs

  - a smaller spike in costs immediately before and after diagnosis

  - lower medical and long-term care costs in those with diagnosed and managed MCI and dementia

- These potential benefits **would not be realized** unless diagnostic disparities are addressed.

Projected Total Medical Savings (in Trillions of 2017 Dollars, Present Value of Future Savings[A23]) Under the Partial Early Diagnosis Scenario Compared with the Current Status Quo, by Category of Expenditures[A24]

Total savings: $7.0 Trillion (T)

Medicare $3.3 T, 47%

Medicaid $2.3 T, 32%

Other* $1.4 T, 20%
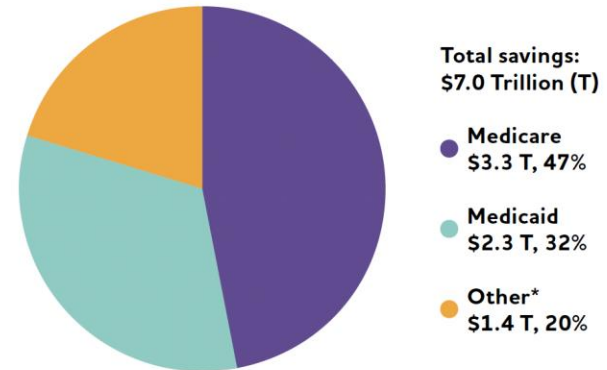
*The "Other" category includes all savings outside of Medicare and Medicaid, such as out-of-pocket expenses and private insurance.
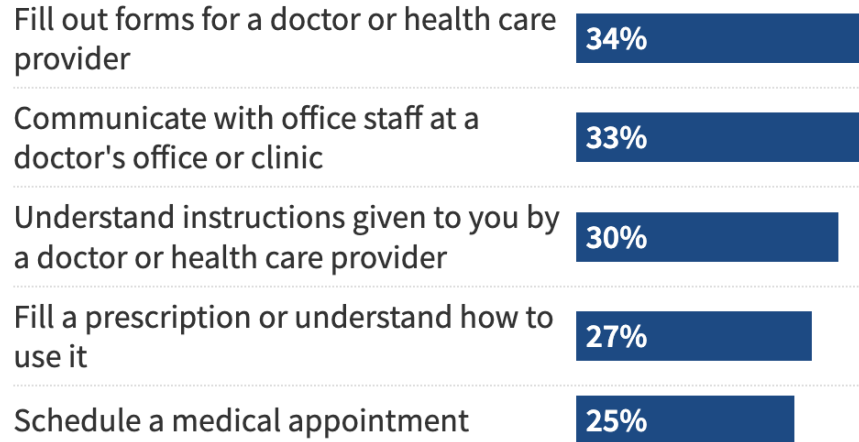
Drivers of Diagnostic Disparities

- Mechanisms underlying diagnostic disparities are **complex, multifactorial, and not well understood**.

- Research to date has identified at least two broadly defined categories of disparity drivers:

  - Patient-level factors

  - System-level factors

Drivers of Diagnostic Disparities

Patient-level Factors

- **Language and communication** barriers

  - 48% of US adults with limited English proficiency encountered language barriers in the last three years

Fill out forms for a doctor or health care provider	34%
Communicate with office staff at a doctor's office or clinic	33%
Understand instructions given to you by a doctor or health care provider	30%
Fill a prescription or understand how to use it	27%
Schedule a medical appointment	25%

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Drivers of Diagnostic Disparities

Patient-level Factors

- **Health and healthcare literacy** factors

  - Low **awareness** of dementia

    - More than half of Asian (56%), Black (55%), Hispanic (57%), and Native (53%) Americans believe that significant loss of memory or cognitive abilities is "a normal part of aging."

  - **Limited trust** in healthcare systems and services

    - Substantial number of Black (66%), Hispanic (29%), Native (40%), and Asian (34%) Americans believe it is harder for them to get excellent care for dementia because of their race or ethnicity.

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Drivers of Diagnostic Disparities

Patient-level Factors

- Cultural and familial **perceptions** of dementia and ageing and **stigma** of mental illness

  - These are complex phenomena that are deeply rooted in historical and cultural environments and differ within and across diverse communities

  - "Loss of dignity," changing perception of the "elder" in family systems, "being burdensome" to one's family or the healthcare system, "an inability to contribute to society", etc.
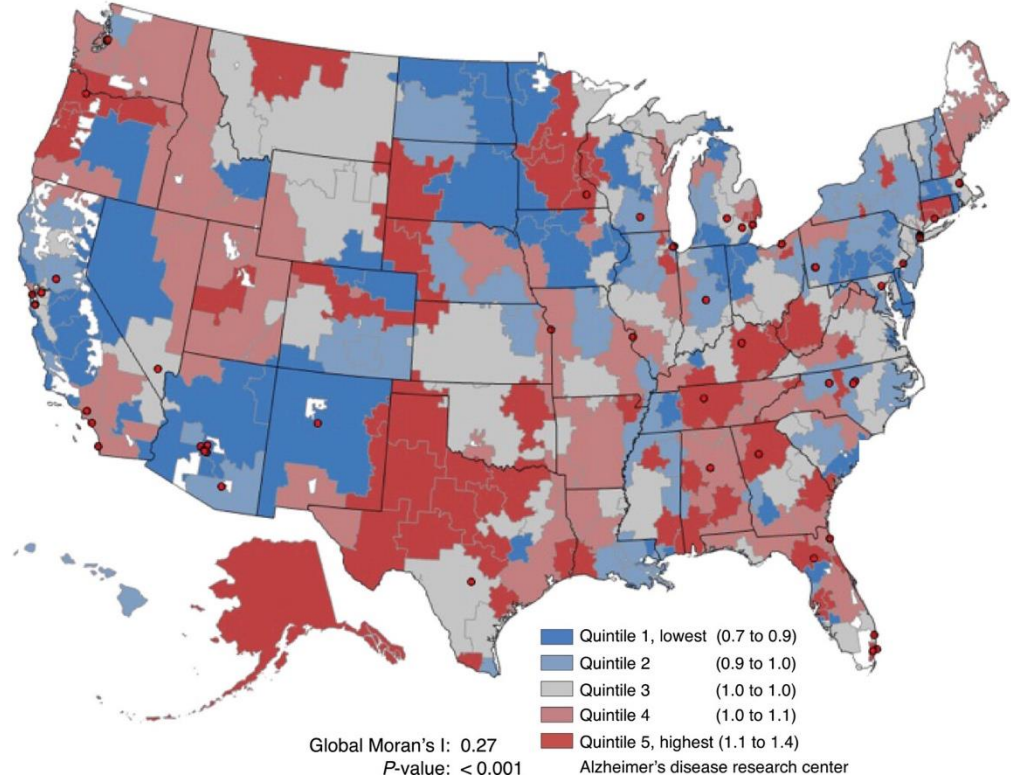
Let's Talk About Race

- Race is a **social construct** with little to no biological basis.

- Genetic factors do not account for the large differences in prevalence and incidence among racial groups.
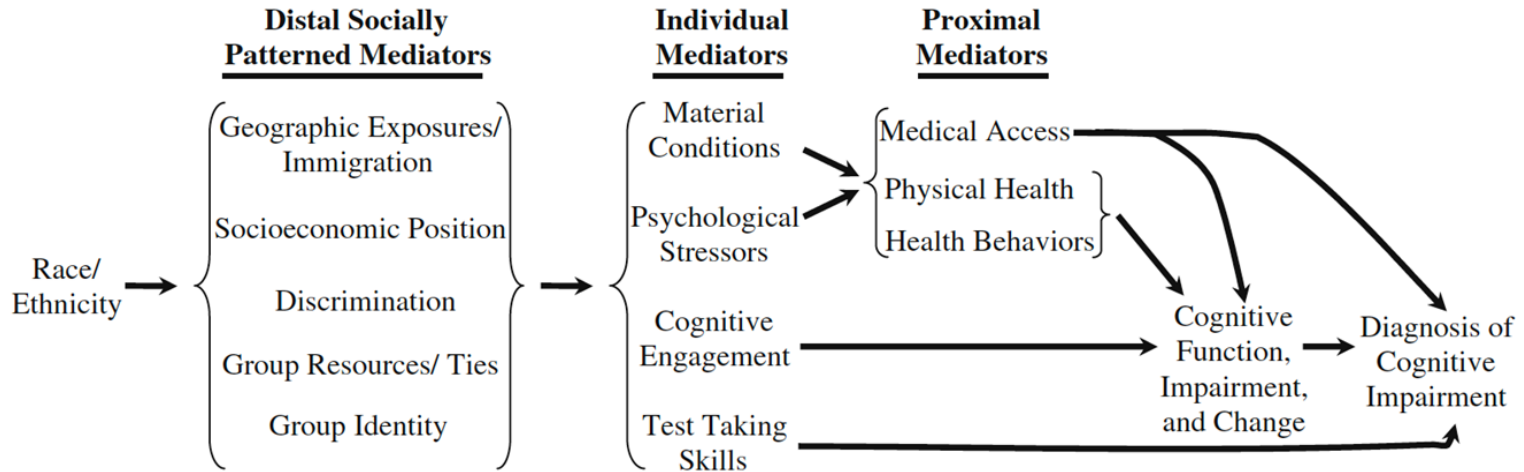
Drivers of Diagnostic Disparities

System-level Factors

- Lack of **culturally appropriate** services and tools

  - E.g., biases in cognitive assessment results

- Shortage of **dementia specialists** particularly in low resource areas

Global Moran's I: 0.27
P-value: < 0.001

Quintile 1, lowest (0.7 to 0.9)
Quintile 2 (0.9 to 1.0)
Quintile 3 (1.0 to 1.0)
Quintile 4 (1.0 to 1.1)
Quintile 5, highest (1.1 to 1.4)
Alzheimer's disease research center

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Drivers of Diagnostic Disparities

System-level Factors

- Inadequate **training of general healthcare professionals** in the recognition of dementia

  - 21% of PCPs were highly confident that they correctly recognized when a patient had an NCD and 13% were highly confident in making a specific NCD diagnosis

- **Bias in referral practices** to specialists

  - African Americans were less likely to be seen in specialty memory clinics and have PET neuroimaging

- **Time- and cost-related barriers** to access quality care

Facilitating Equity in Dementia Diagnosis: A Multi-Pronged Approach

Facilitating Equity in Dementia Diagnosis

- **Communities**:
  - Culturally tailored campaigns to **increase public knowledge** of brain health/dementia
    - E.g., new biomarkers
  - Culture- and location-informed campaigns to **facilitate healthcare navigation**
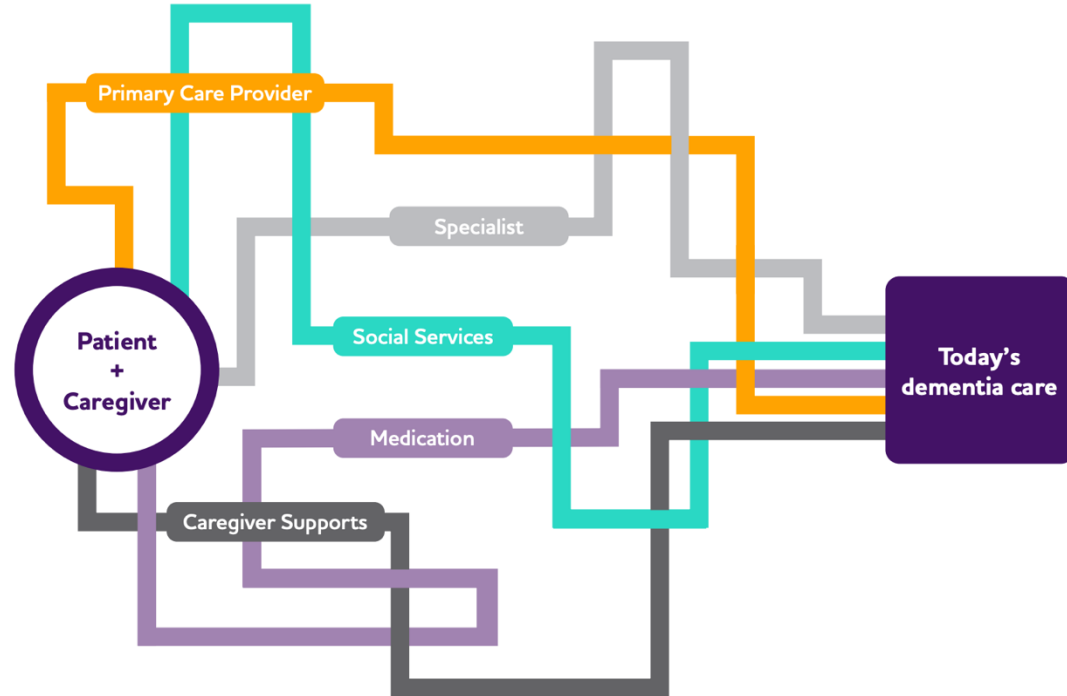
Facilitating Equity in Dementia Diagnosis

- **Healthcare systems**:

  - Increasing the **diversity** of the general practitioner and dementia specialty healthcare **workforce**

  - Better **education and training** for general practitioners on dementia recognition and culturally informed care

  - **Outreach by dementia specialist** providers to facilitate referral of underserved patient groups

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Facilitating Equity in Dementia Diagnosis

- **Policymakers:**

  - Providing **adequate reimbursement and time** for providers to diagnose and manage dementia

  - Improving **access to effective dementia care models** that provide critical support for individuals, carers, and general practitioners following diagnosis.

    - Guiding an Improved Dementia Experience (GUIDE) Model

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Conclusions

- There are substantial and persistent disparities in the **availability, timeliness, and accuracy** of dementia diagnosis.

- These inequities have **detrimental impacts** on patients, families, and societies and hinder scientific discoveries.

- Collaborative efforts among **researchers, clinicians, community partners, and policymakers** are essential to achieve equity in dementia diagnosis.
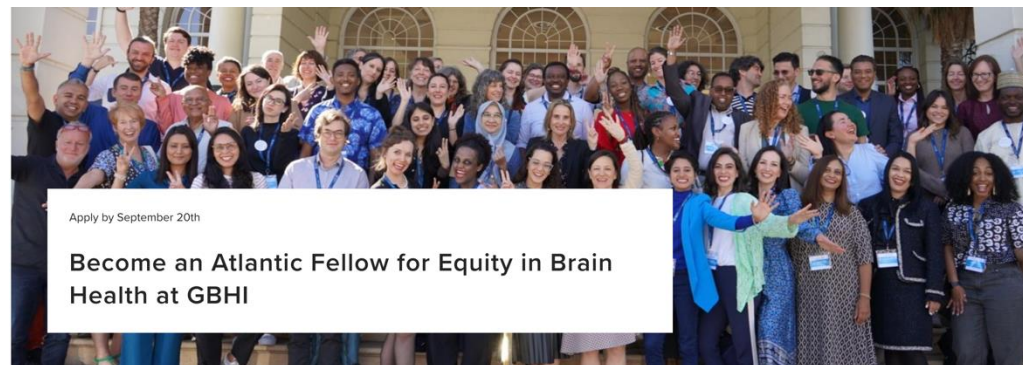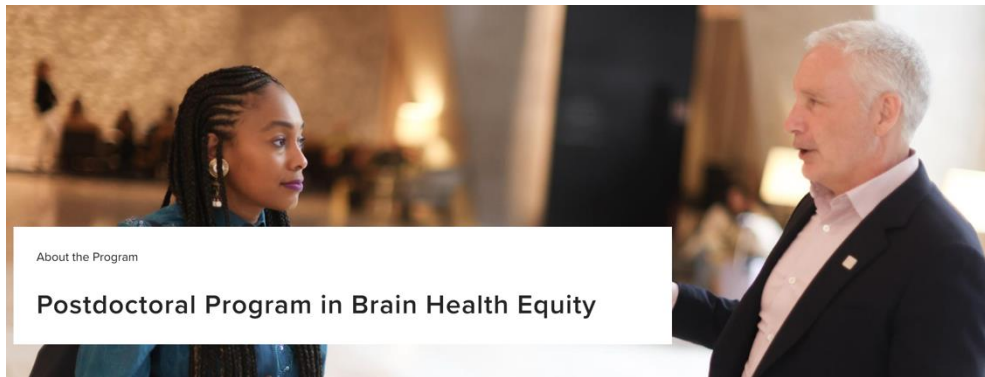
Thank you!

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…and many others!

About the Program

Postdoctoral Program in Brain Health Equity

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