DEMENTIA
Care Aware
Early detection. Better care.

Dementia and the African American Population

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Introduction

Speaker

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Speaker

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Relevant Financial Disclosures
Tanisha Hill-Jarrett, PhD

Cogstate – consultant

Housekeeping

We will leave 10-15 minutes at the end of this session for Q&A. Throughout the webinar, you can put your questions into the Q&A/chat functions, and some may be answered in real time.

We will share instructions for claiming Continuing Education (CE) credit at the end of this webinar and via email within 48 hours.

You will receive the recording of this webinar via email within 48 hours

You can also access the webinar slides and recording from the Dementia Care Aware website and YouTube channel.

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Dementia Care Aware Program Offerings

Warmline:

1-800-933-1789

A provider support and consultation service that connects primary care teams with Dementia Care Aware experts

Trainings:

- Online Trainings e.g., Cognitive Health Assessment training
- Monthly Webinars
- Podcasts

Interactive Case Conferences:

- UCLA and UCI ECHO (Extension for Community Healthcare Outcome) conferences

Practice change support:

- UCLA Alzheimer's and Dementia Care Program
- Alzheimer's Association Health Systems

DEMENTIA Care Aware   DHCS   DementiaCareAware.org   DCA@ucsf.edu

Our Training

Welcome!

Welcome to the Dementia Care Aware (DCA) learning management system. This site provides access to the training modules for the DCA program. When you registered, you were automatically enrolled in the "*The Cognitive Health Assessment: The Basics*" course. Select Start in the "The Cognitive Health Assessment: The Basics" block below to begin.

Screening for Dementia: The Cognitive Health Assessment (CHA)

Goal: Screen patients older than age 65 annually (who don't have a pre-existing diagnosis of dementia)

Part 1

Take a Brief Patient History

Part 2

Use Screening Tools

Part 3

Document Care Partner Information

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Sign Up for Upcoming Live CHA Trainings

- Dementia Care Aware offers the CHA training as **a free 1-hour live session** multiple times each month.

- Led by Dementia Care Aware partners at the Alzheimer's Association and UC, Irvine.

- Open for anyone who is interested.

- Eligible participants can claim **1 free CE/CME/MOC credi**t.

Objectives

Review disparities in Alzheimer's disease and dementia that impact African Americans

Identify how social determinants of health drive disparities and are key to correcting disparities

Review practical use of the DCA Cognitive Health Assessment to improve dementia care and help reduce disparities

A Definition of Health Disparities

Health disparities

Higher burden of illness, injury, disability or mortality experienced by one group relative to another

Healthcare disparities

Differences between groups in health coverage, access to/use of care, and quality of care

Health inequities – systematic differences in the health of groups and communities occupying unequal positions in society that are avoidable
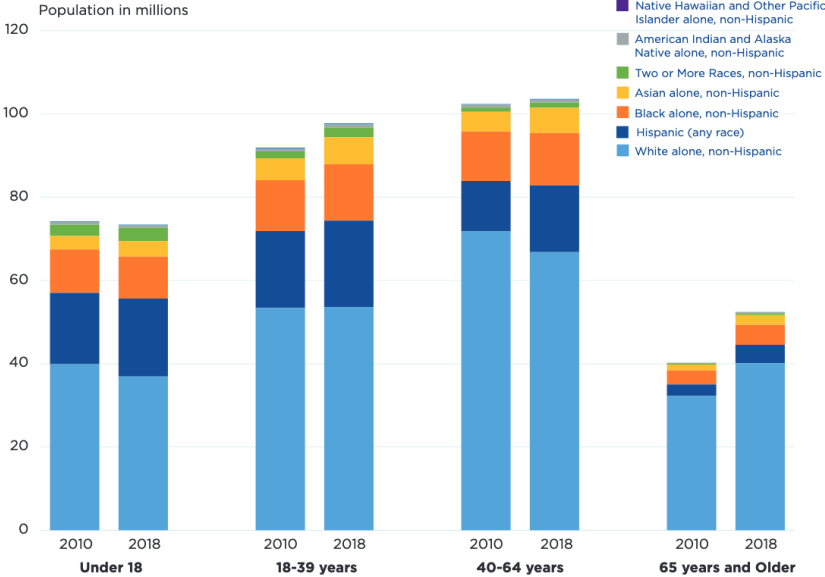
ADRD Incidence and Prevalence

Projected Number of People Age 65 and Older (Total and by Age) in the U.S. Population with Alzheimer's Dementia, 2020 to 2060

Millions of people   ■ Ages 65-74   ■ Ages 75-84   ■ Ages 85+
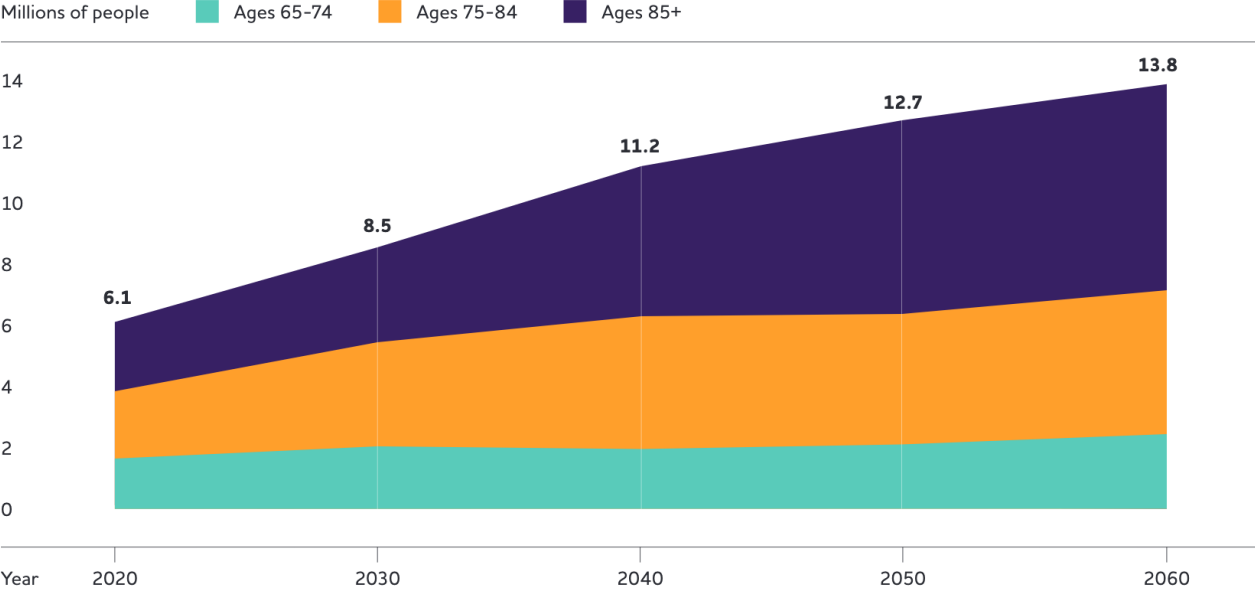
Rajan, Alz & Dementia, 2016

A More Diverse Nation
Distribution of Race and Hispanic Origin by Age Groups

Population in millions

Legend:
- ■ Native Hawaiian and Other Pacific Islander alone, non-Hispanic
- ■ American Indian and Alaska Native alone, non-Hispanic
- ■ Two or More Races, non-Hispanic
- ■ Asian alone, non-Hispanic
- ■ Black alone, non-Hispanic
- ■ Hispanic (any race)
- ■ White alone, non-Hispanic

Credit: US Census Bureau

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Disparities in Prevalence of Alzheimer's Disease and Dementia

Clinical Alzheimer's dementia is more than 2x as common among African American and 1.5x as common among Latino individuals

Black and Latino individuals have the highest incidence of clinical Alzheimer's Disease

There are no signs of progress in reduction of these disparities

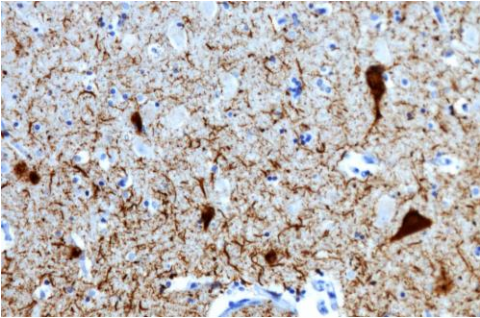- The magnitude of these disparities in dementia risk persisted across 2000-2016
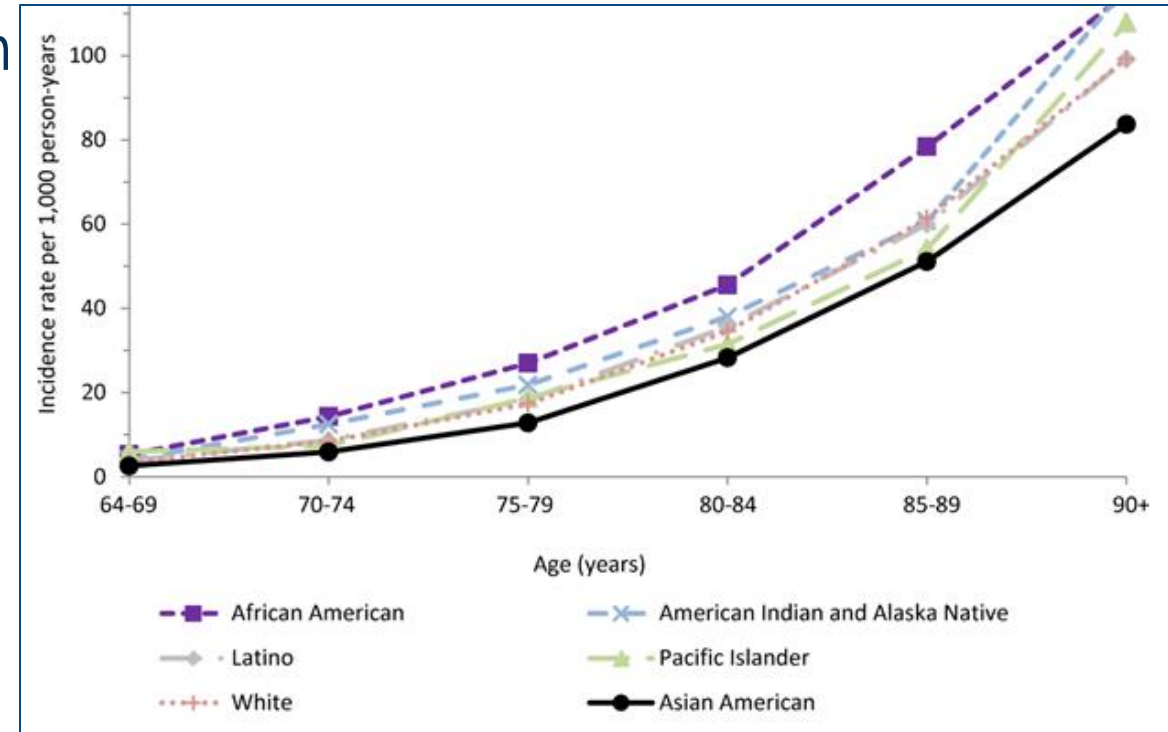
Mayeda, Alz & Dementia, 2016

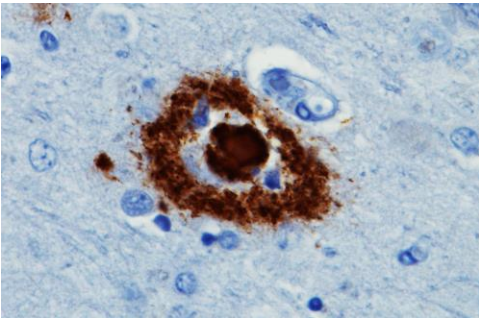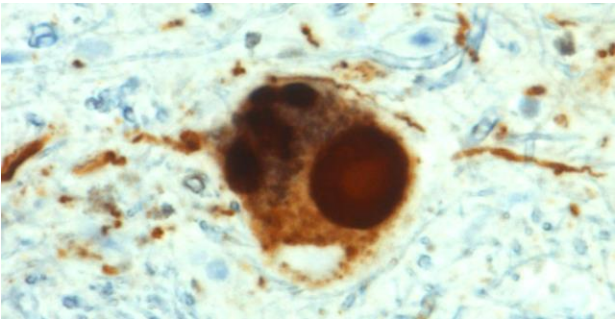# Pathologies and Dementia: Is it all Alzheimer's?
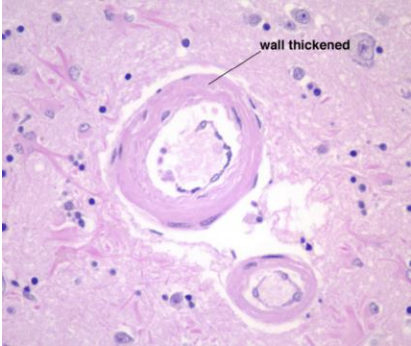

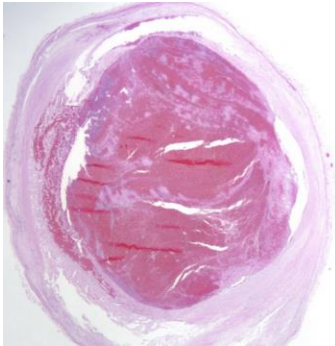Alzheimer's disease

Tangles

Plaques

Lewy Bodies

Arteriolosclerosis
wall thickened

Thrombus

Hemorrhage
Credit S. Spina, R.Seldman

Cerebrovascular Pathology May Disproportionately Contribute to Dementia Among Certain Groups

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Pathologies and Dementia: Is it all Alzheimer's? **IDEAS** study
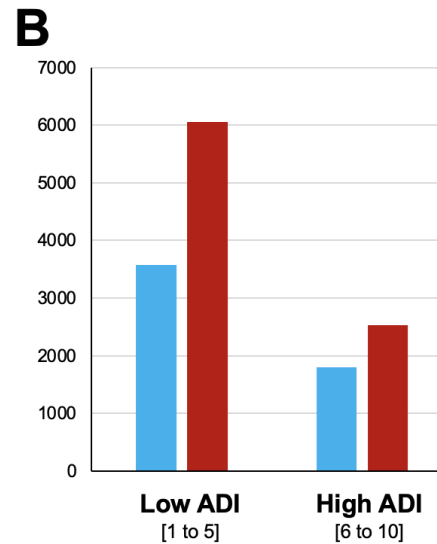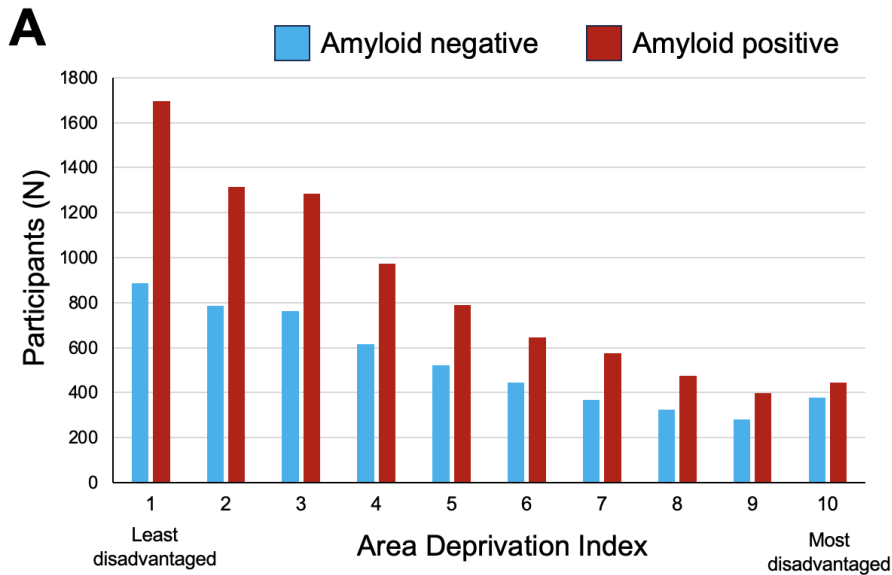
Table 1. Participant Demographic Characteristics

Variable	Race and ethnicity, No. (%)				
	Total	Asian	Black	Hispanic	White
No.	17 107	321	635	829	15 322
Age, median (range), y	75 (65-105)	76 (65-93)	75 (65-95)	76 (65-96)	75 (65-105)
Sex					
Female	8769 (51.3)	171 (53.3)	399 (62.8)	515 (62.1)	7684 (50.2)
Male	8338 (48.7)	150 (46.7)	236 (37.2)	314 (37.9)	7638 (49.8)
Education					
<High school	1160 (6.8)	41 (12.8)	110 (17.3)	316 (38.1)	693 (4.5)
History of hypertension					
No	8386 (49.0)	171 (53.3)	203 (32.0)	380 (45.8)	7632 (49.8)
Yes	8721 (51.0)	150 (46.7)	432 (68.0)	449 (54.2)	7690 (50.2)
History of diabetes					
No	14 352 (83.9)	241 (75.1)	458 (72.1)	608 (73.3)	13 045 (85.1)
Yes	2755 (16.1)	80 (24.9)	177 (27.9)	221 (26.7)	2277 (14.9)
Family history of dementia					
No	12 907 (75.4)	279 (86.9)	531 (83.6)	682 (82.3)	11 415 (74.5)
Yes	4200 (24.6)	42 (13.1)	104 (16.4)	147 (17.7)	3907 (25.5)
Impairment level					
MCI	10 400 (60.8)	169 (52.6)	305 (48.0)	370 (44.6)	9556 (62.4)
Dementia	6707 (39.2)	152 (47.4)	330 (52.0)	459 (55.4)	5766 (37.6)

Table 3. Multivariable Logistic Regression Model Adjusting for All Matching Variables (N = 17 107)

Variable	OR (95% CI)	P value[a]
Intercept	0.09 (0.06-0.14)	
Age (10 y)	1.36 (1.30-1.44)	<.001
Sex		
Female	1.20 (1.12-1.28)	<.001
Male	1 [Reference]	NA
Race and ethnicity		
Asian	0.47 (0.37-0.59)	<.001
Black	0.71 (0.60-0.84)	<.001
Hispanic	0.68 (0.59-0.79)	<.001
White	1 [Reference]	NA

Wilkins, JAMA, 2022

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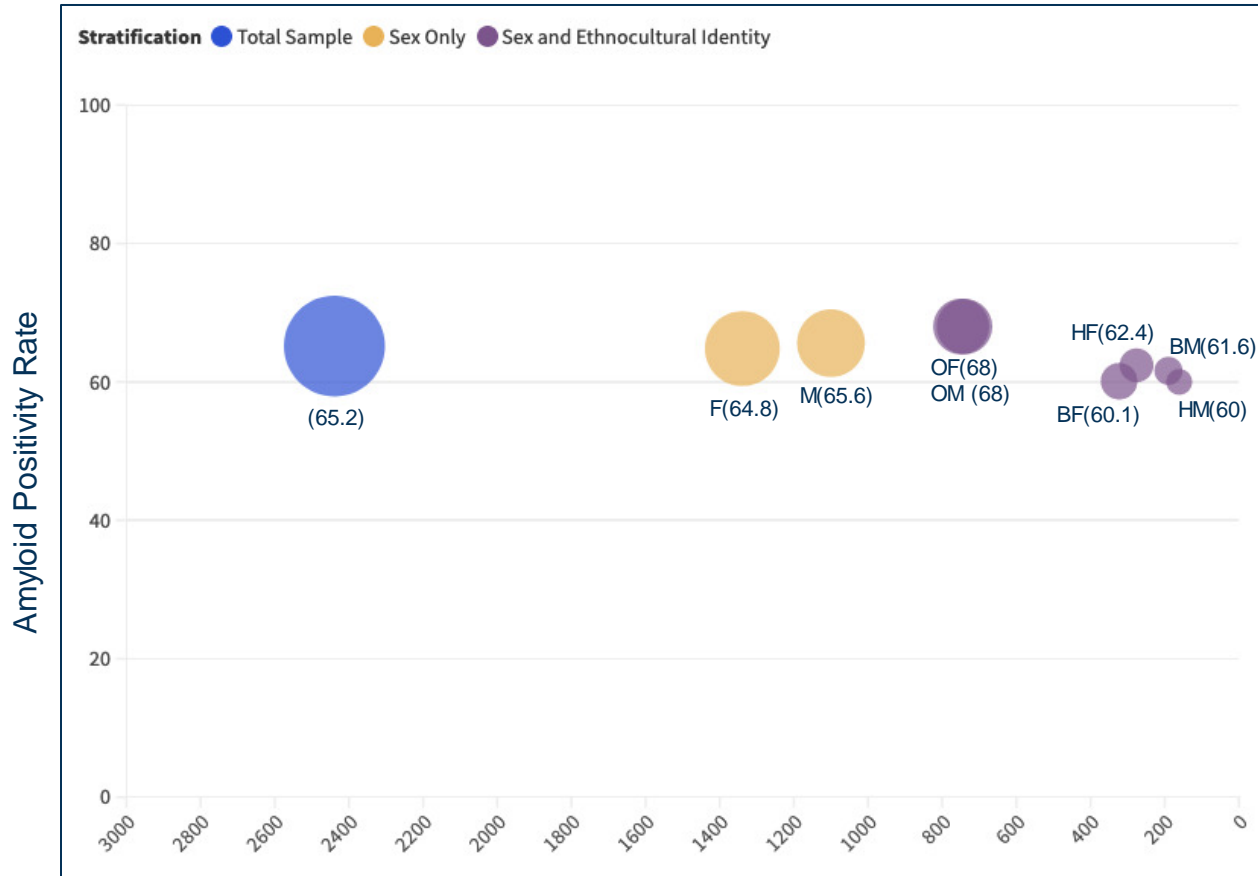# Pathologies and Dementia: Is it all Alzheimer's? **IDEAS** study

A

Participants (N) vs Area Deprivation Index

Legend: Amyloid negative (blue), Amyloid positive (red)

Area Deprivation Index: 1 (Least disadvantaged) to 10 (Most disadvantaged)

B

Low ADI [1 to 5], High ADI [6 to 10]

Variable	aOR (95% CI)	p-value
Area Deprivation index (ADI)		
Least disadvantaged - 1	Ref	
2	0.87 (0.76, 1.00)	0.051
3	0.89 (0.77, 1.04)	0.150
4	0.82 (0.71, 0.95)	0.008
5	0.80 (0.69, 0.92)	0.002
6	0.77 (0.65, 0.91)	0.002
7	0.80 (0.67, 0.95)	0.013
8	0.77 (0.63, 0.93)	0.007
9	0.75 (0.61, 0.91)	0.004
Most disadvantaged - 10	0.61 (0.51, 0.73)	<.001

Windon, Unpublished

Greater Neighborhood Disadvantage Associated with NON-Alzheimer's Pathology in Mild Cognitive Impairment & Dementia

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Pathologies and Dementia: Is it all Alzheimer's? **New IDEAS** Study

Stratification ● Total Sample ● Sex Only ● Sex and Ethnocultural Identity

Amyloid Positivity Rate (y-axis) vs Number of Individuals (x-axis)

- (65.2)
- F(64.8)
- M(65.6)
- OF(68) / OM (68)
- HF(62.4)
- BM(61.6)
- BF(60.1)
- HM(60)

KEY: F – Female, M – Male, OF – Other Female, OM – Other Male, BF – Black Female, HF – Hispanic Female, BM – Black Male, HM – Hispanic Male

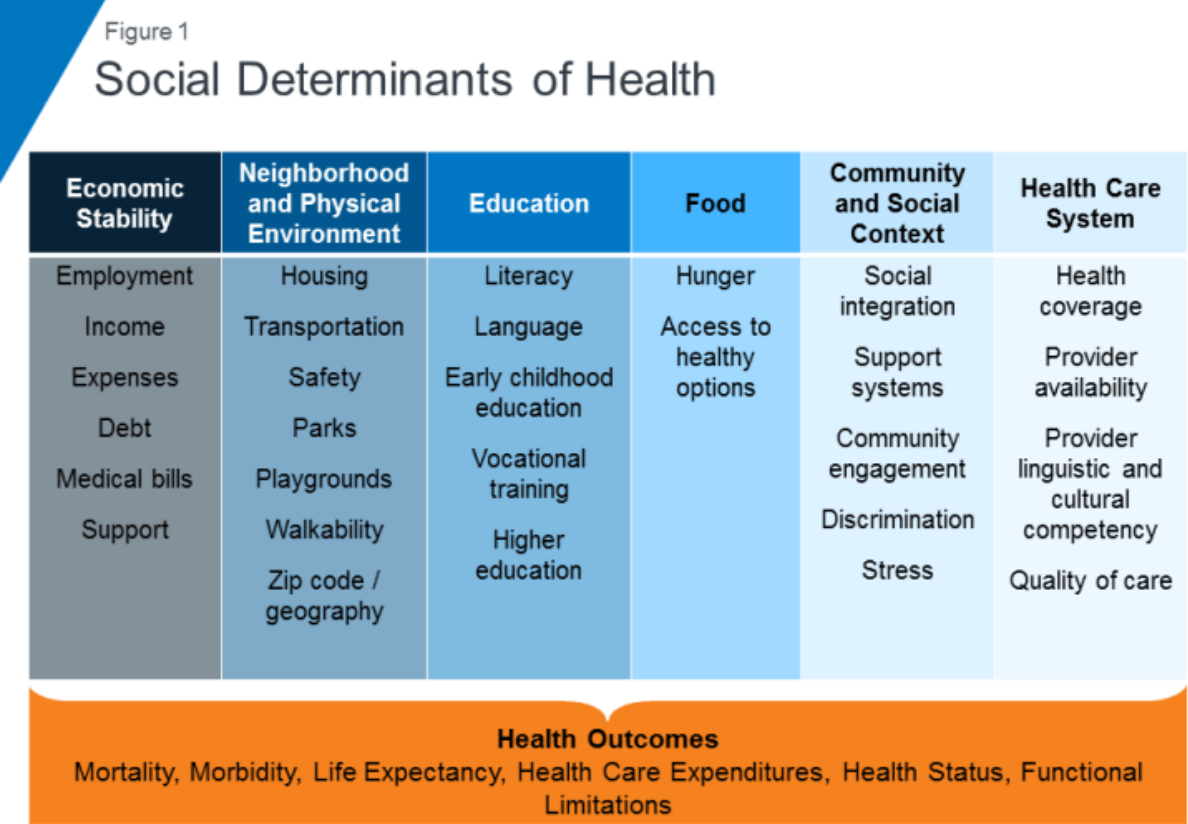| Variable	Total	Race and Ethnicity, N		
		Black	Hispanic	Neither Black nor Hispanic
No. of Scans	3744	845	710	2189
Positive Scan				
Female	1339	323	276	740
Male	1100	190	161	749
Negative Scan				
Female	728	214	166	348
Male	576	118	107	351

Windon, Unpublished

Social determinants of brain health

Social determinants of health: non-biological factors that influence health outcomes (Word Health Organization).

Things that make up our communities – the places where we live, work, learn and play.

Addressing these are key to reducing health disparities.

Figure 1

Social Determinants of Health

Economic Stability	Neighborhood and Physical Environment	Education	Food	Community and Social Context	Health Care System
Employment	Housing	Literacy	Hunger	Social integration	Health coverage
Income	Transportation	Language	Access to healthy options	Support systems	Provider availability
Expenses	Safety	Early childhood education		Community engagement	Provider linguistic and cultural competency
Debt	Parks	Vocational training		Discrimination	
Medical bills	Playgrounds			Stress	Quality of care
Support	Walkability	Higher education			
	Zip code / geography				

Health Outcomes
Mortality, Morbidity, Life Expectancy, Health Care Expenditures, Health Status, Functional Limitations

KFF
HENRY J KAISER FAMILY FOUNDATION

Source: Henry J Kaiser Family Foundation

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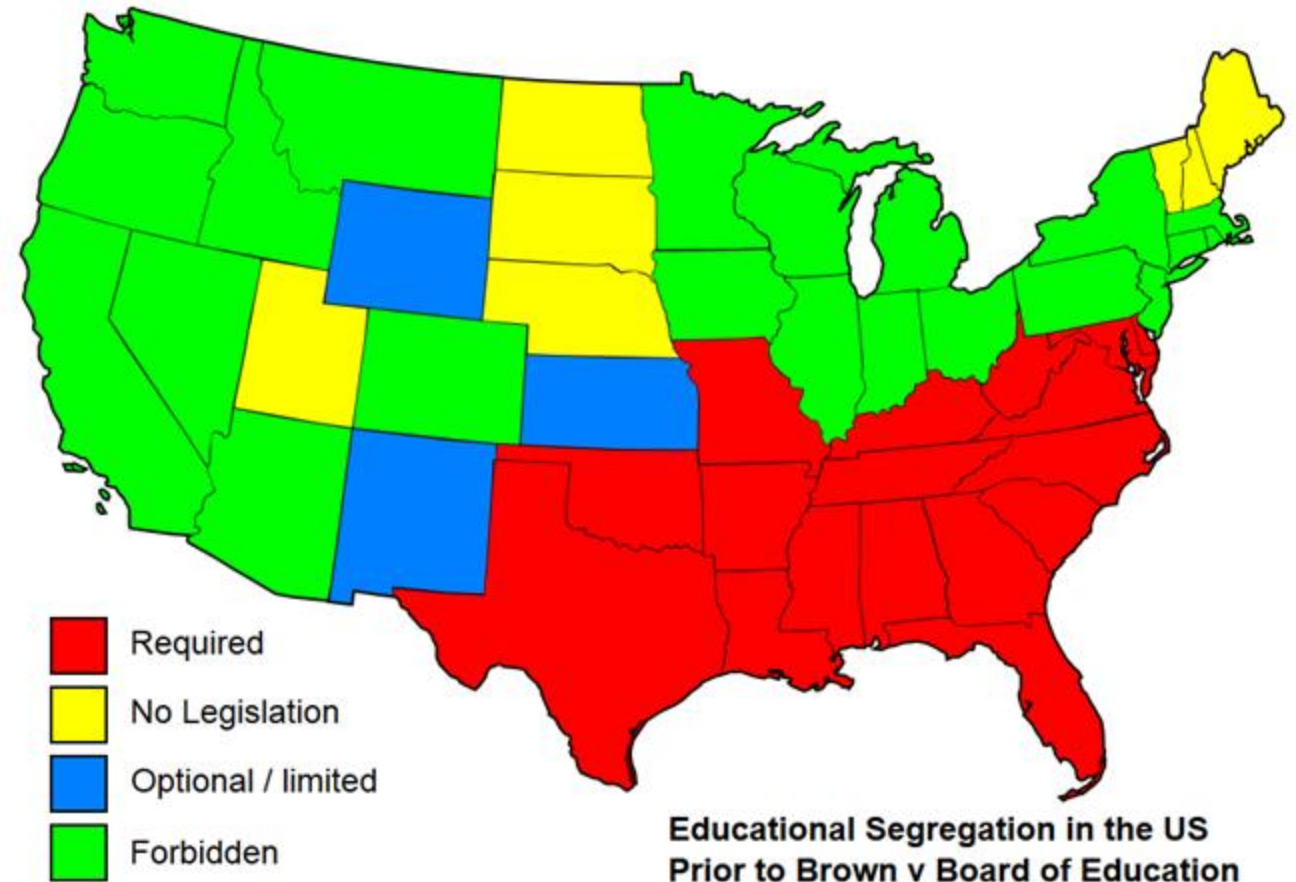# Structural & social determinants of brain health

Understanding the influence of structural factors is critical!
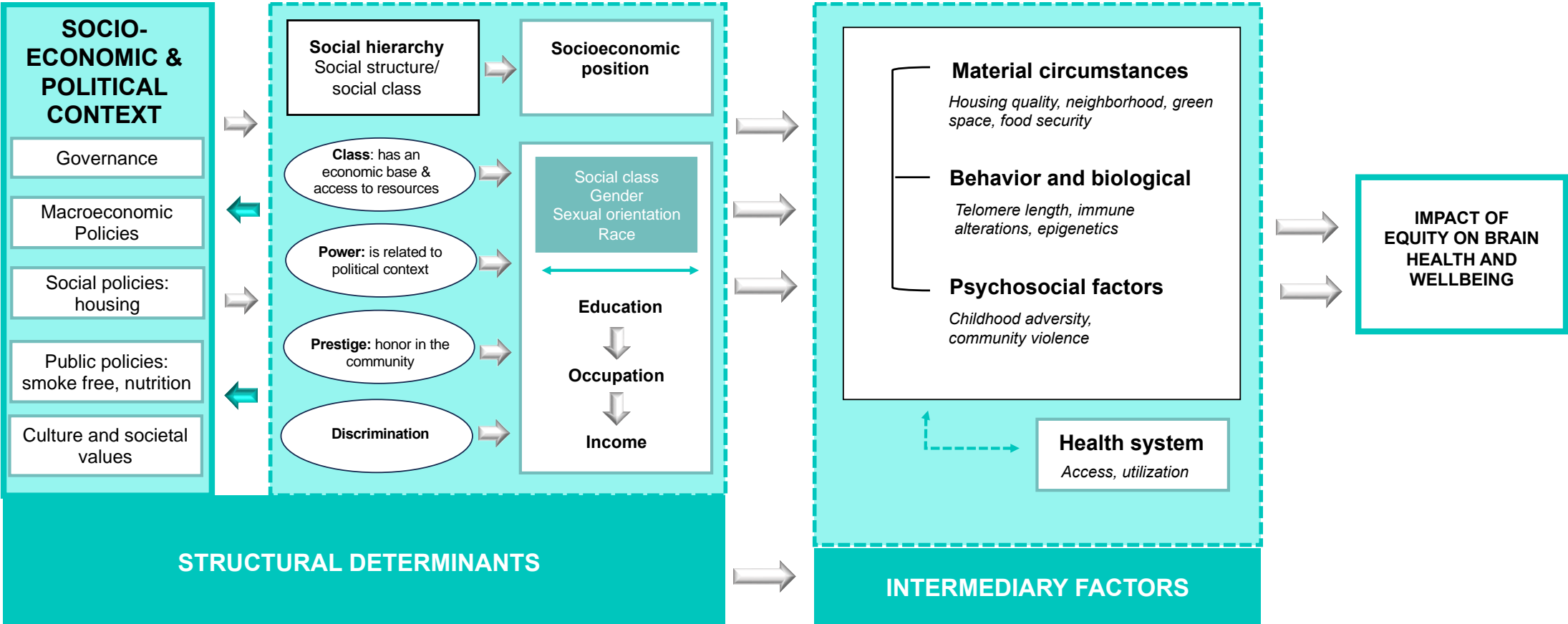
Adapted from Prof John McMurty & Sullivan et al., 2020

An Example: Education Inequity and Cognitive Health

Understanding the relationship between education and cognition within older African American adults is especially complex given historical structural inequities in the U.S. education system.

Required
No Legislation
Optional / limited
Forbidden

Educational Segregation in the US Prior to Brown v Board of Education

An Example: Education Inequity and Cognitive Health

Formal education is thought to provide protection against the deleterious effects of brain pathology on cognitive outcome and dementia conversion (Meng & D'Arcy, 2012; Stern, 2009; Stern et al., 1994; Stern, Albert, Tang, &Tsai, 1999).

- **Cognitive reserve**
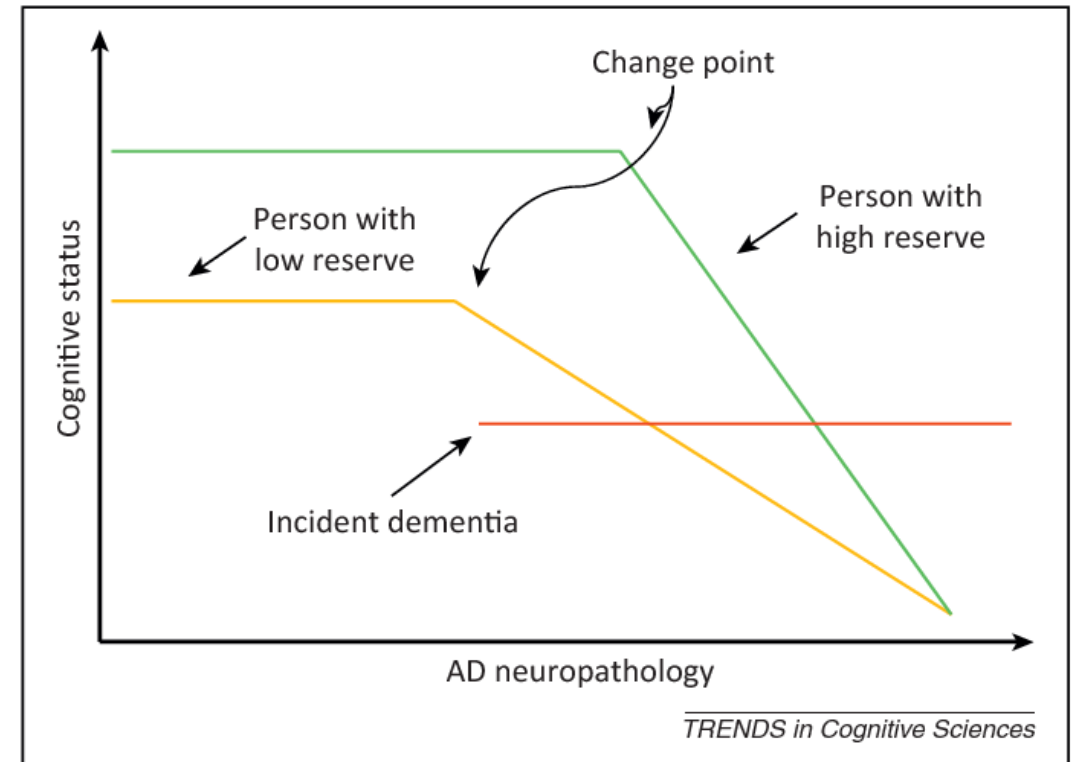
Figure 1. Representation of how CR may mediate between AD pathology and its clinical expression based on epidemiological and imaging studies. The x-axis represents AD pathology, slowly increasing over time. The y-axis represents cognitive function. We assume that AD pathology increases over time at the same rate in two individuals with high and low reserve. The amount of pathology

Barulli & Stern, 2013

An Example: Education Inequity and Cognitive Health

Structural racism and changes in education policy (e.g., U.S. Supreme Court ruling in 1954 *Brown v. Board of Education)*, may explain some of the late life racial disparities in rates of cognitive impairment.

- Quality of education > years of education
- Education quality has been shown to explain a portion of late-life disparities in cognitive functioning (Fyffe et al., 2011; Sisco et al., 2013)

Alley, Suthers, & Crimmins, 2007; Cagney & Lauderdale, 2002; Carvalho et al., 2014; Manly et al., 1998; Manly & Jacobs 2001; Whitfield, 2002; Zhang, Hayward, & Yu, 2016

Education differentially contributes to cognitive reserve in African Americans
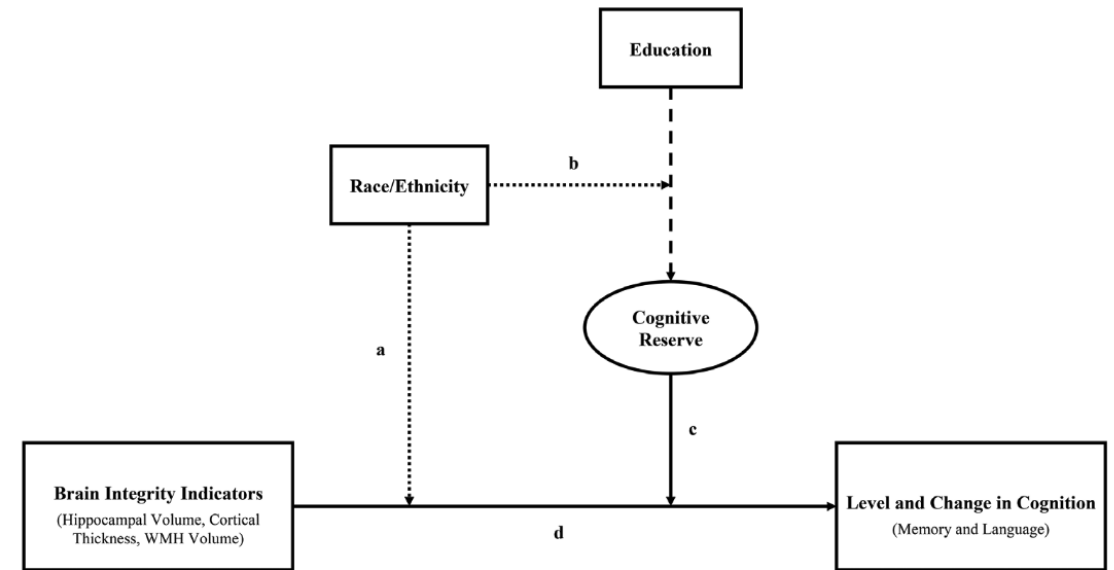

FIGURE 1   Schematic representation of conceptual framework

Higher educational attainment attenuated the detrimental impact of WMH burden on memory (β = −0.03; 99% CI: −0.071, −0.002) and language decline (β = −0.024; 99% CI:− 0.044, −0.004), as well as the impact of cortical thinning on level of language performance for White participants but not for Black or Latino participants.

Structural & social determinants of brain health
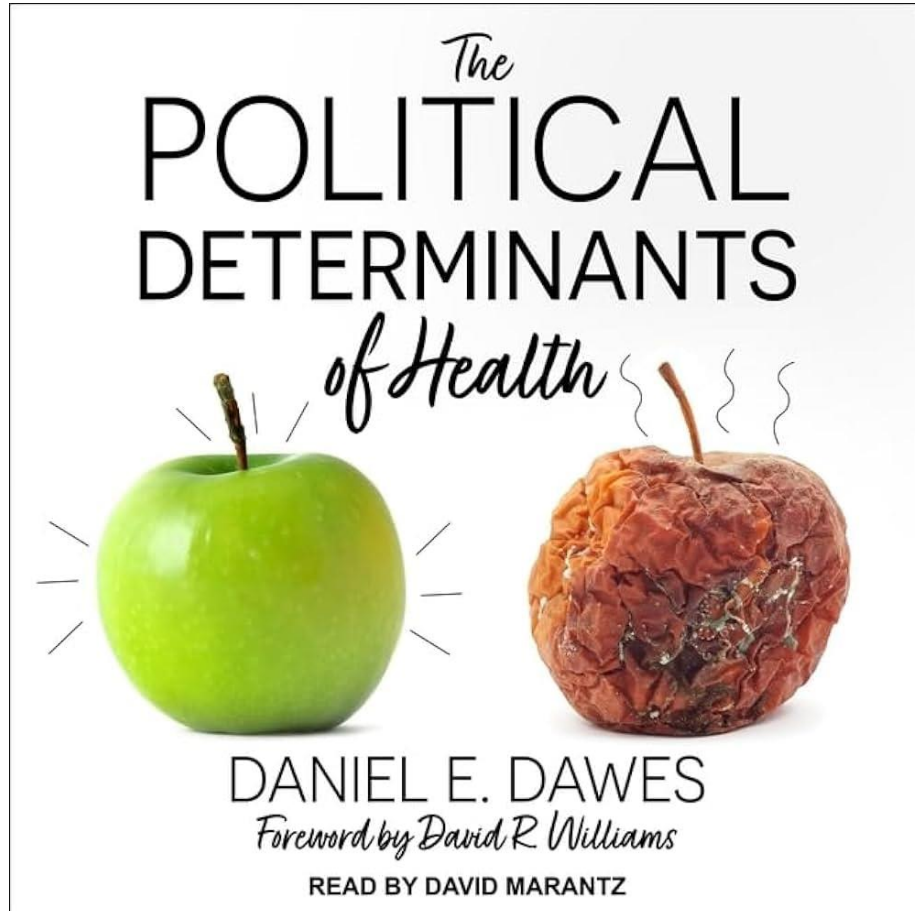
Alzheimer's & Dementia®
THE JOURNAL OF THE ALZHEIMER'S ASSOCIATION

REVIEW ARTICLE

The structural and social determinants of Alzheimer's disease related dementias

Paris B. Adkins-Jackson[1] | Kristen M. George[2] | Lilah M. Besser[3] | Jinshil Hyun[4] | Melissa Lamar[5] | Tanisha G. Hill-Jarrett[6] | Omonigho M. Bubu[7] | Jason D. Flatt[8] | Patricia C. Heyn[9] | Ethan C. Cicero[10] | A. Zarina Kraal[11] | Preeti Pushpalata Zanwar[12,13] | Rachel Peterson[14] | Boeun Kim[15] | Robert W. Turner II[16] | Jaya Viswanathan[17] | Erin R. Kulick[18] | Megan Zuelsdorff[19] | Shana D. Stites[20] | Miguel Arce Rentería[21] | Elena Tsoy[22] | Dominika Seblova[23] | Ted K.S. Ng[24,25] | Jennifer J. Manly[26] | Ganesh Babulal[27,28,29,30]

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What goes into health?

Socioeconomic Factors

Education Job Status Family Support Income

Physical Environment

Housing

Health Behaviors

Tobacco Use Diet & Exercise Alcohol Use Sexual Activity

Health Care

Access & Quality of Care

40%
10%
30%
20 %

50% of health can be traced back to zip code.

20% of health is related to health care access and environment
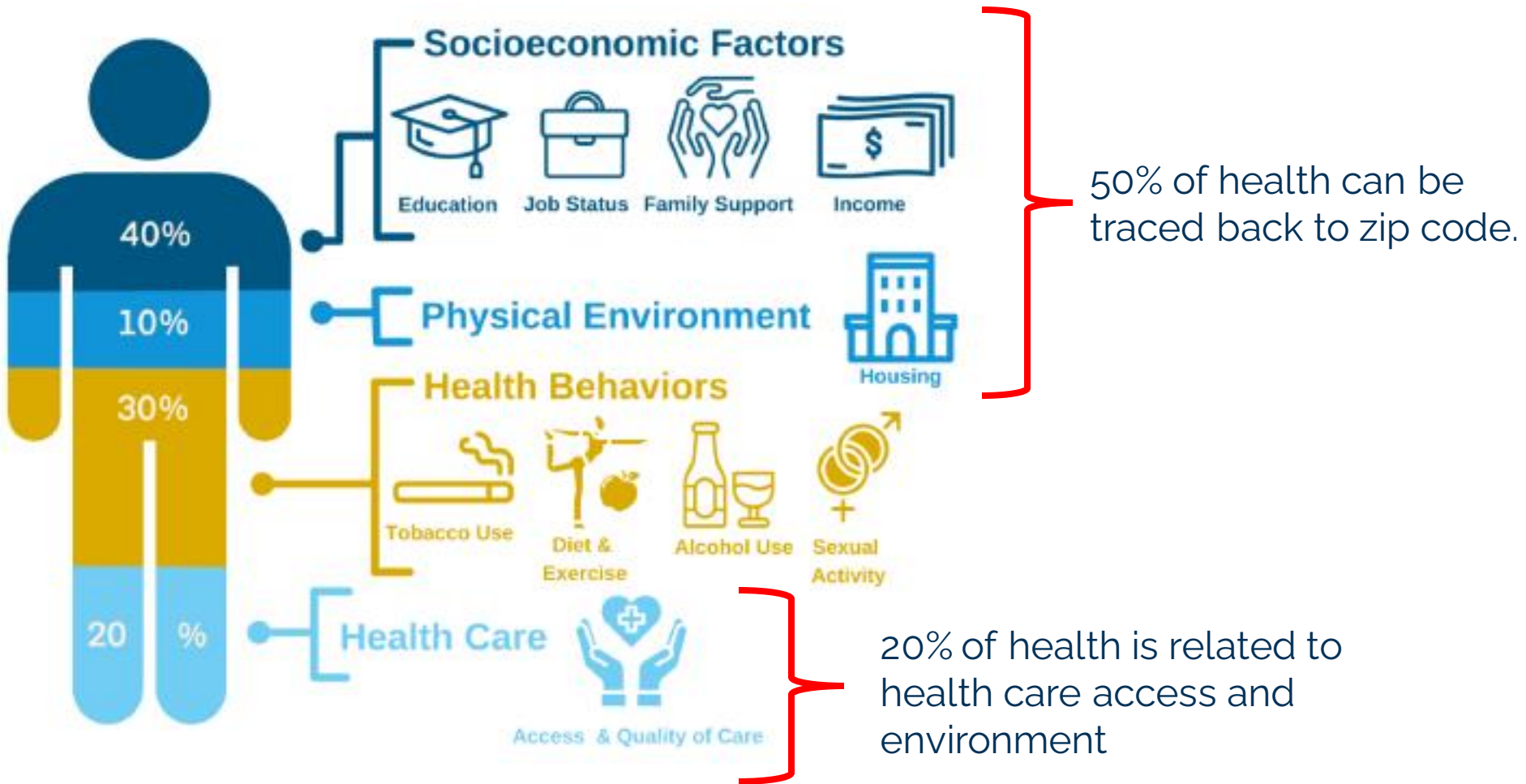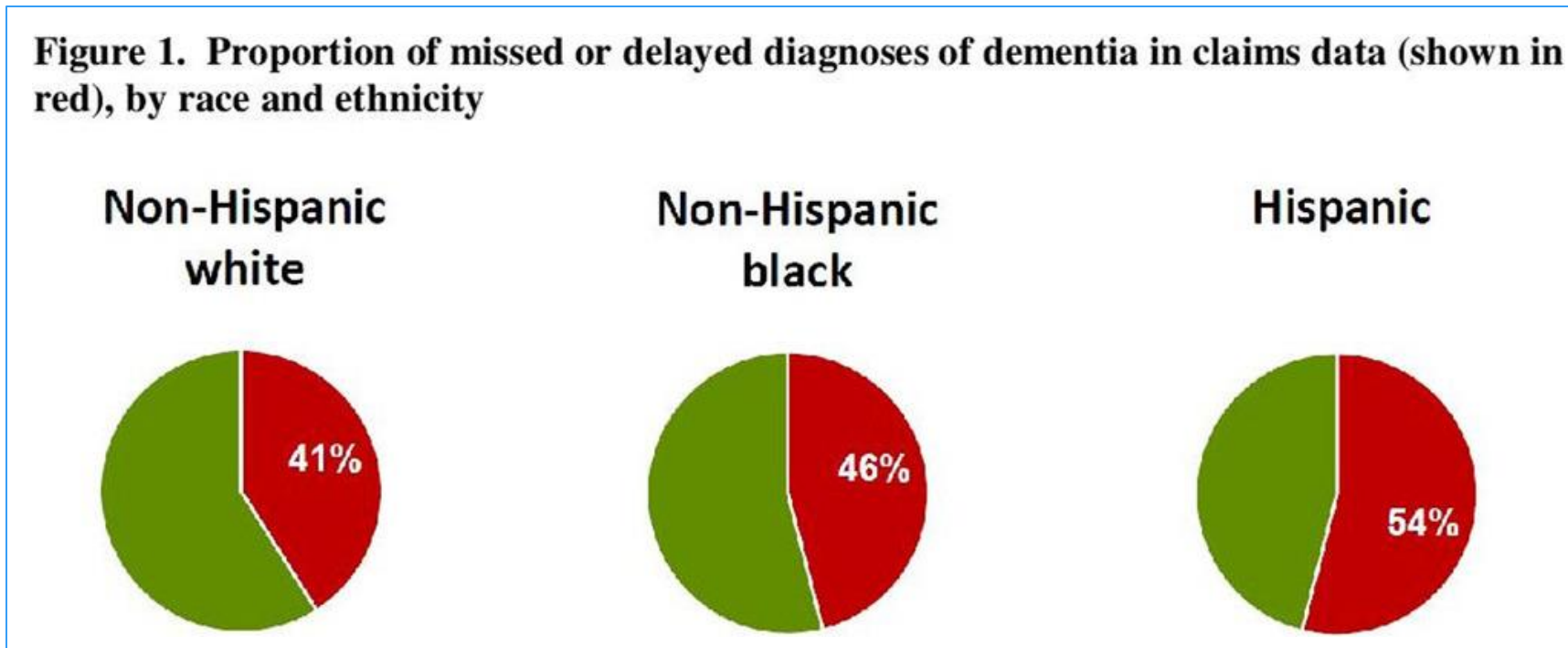
Dementia diagnosis disparities by race and ethnicity

While Black Americans are about two times more likely than White Americans to have Alzheimer's and other dementias, they are only 34% more likely to have a diagnosis. (Alz Association, 2020)

Also tend to present with more advanced symptoms at later stages of disease. (Alz Association, 2020)

Figure 1. Proportion of missed or delayed diagnoses of dementia in claims data (shown in red), by race and ethnicity

Non-Hispanic white — 41%

Non-Hispanic black — 46%

Hispanic — 54%

Lin et al., (2020). Alzheimer's & Dementia

Discrimination in Healthcare Settings

Two national surveys conducted by Alzheimer's Association

The percentage of people experiencing discrimination in dementia healthcare:

- 50% of Black Americans
- 42% of Native Americans
- 34% of Asian Americans
- 33% of Hispanic Americans

Alzheimer's Association. 2023 Alzheimer's Disease Facts and Figures. Alzheimers Dement 2023;19(4).

Discrimination in Healthcare Settings

20% of Black Americans say that they **have no barriers to excellent health care and support for Alzheimer's or other dementias.**

48% of Black Americans report being confident they can access **culturally competent care**.

53% of Black Americans **believe that a cure for Alzheimer's will be distributed fairly**, without regard to race, color or ethnicity.

42% of Black caregivers say they have faced discrimination when navigating health care settings for their care recipient, with the top concern being that providers or staff do not listen to what they are saying because of their race, color or ethnicity.

Alzheimer's Association. 2021 Alzheimer's Disease Facts and Figures. Alzheimers Dement 2021;17(3), Special Report: Race, Ethnicity and Alzheimer's in America

Experiences of discrimination and interest in AD testing

Hill-Jarrett et al., 2024, *Neurology*

Rapid developments in AD biomarker research suggest predictive testing may become widely available.

To ensure equal access to AD predictive testing, it is important to understand factors that impact testing interest.

Discrimination may influence attitudes toward AD testing, particularly among racially and ethnically minoritized populations

- Structural racism in healthcare systems

Experiences of discrimination and interest in AD testing

Hill-Jarrett et al., 2024, *Neurology*

Participants

- *N* = 1,499 older adults in Health & Retirement Study (HRS)
- 2010 and 2012 biennial waves
- Age 51 and older

Measures

- **Exposures:** Williams Discrimination Scale (1997)
    - Everyday discrimination
    - Lifetime discrimination
- **Outcome:** Willing to receive AD predictive test?

Moderator:
Race/ethnicity
- Non-Hispanic, Black/African American
- Hispanic/Latinx/Mexican American/Chicanx
- Non-Hispanic
- Non-Hispanic, White/Caucasian

Controlled for:

- Age, sex, education, income, marital status, number of living children, home ownership, retired, self-report of Medicaid enrollment, urbanicity of residence, US region of residence, born in US (vs. not).

Everyday Discrimination

(Williams, Jackson, & Anderson, 1997)

In your day-to-day life, how often do any of the following things happen to you?

1. You are treated with less courtesy than other people are.
2. You receive poorer service than other people at restaurants or stores.
3. People act as if they think you are not smart.
4. People act as if they are afraid of you.
5. You are threatened or harassed.
6. You receive poorer service or treatment than other people from doctors or hospitals

Response Options:
(5) Almost everyday
(4) At least once a week
(3) A few times a month
(2) A few times a year
(1) Less than once a year
(0) Never

Total score range: 0 - 30

*Created a binary variable

Reasons: Ancestry or national origin, sex, race, age, religion, weight, physical disability, physical appearance, sexual orientation, financial status, other

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Lifetime discrimination

(Williams, Jackson, & Anderson, 1997)

For each of the following events, please indicate whether the event occurred at any point in your life:

1. You were unfairly dismissed from a job
2. Not been hired for a job
3. Unfairly denied a promotion
4. Unfairly prevented from moving into a neighborhood because the landlord or a realtor refused to see or you a house or apartment
5. Unfairly denied a bank loan
6. Unfairly stopped, searched, question, physically threated or abused by the police
7. Unfairly denied health care or treatment

Response Options:
(0) No (1) Yes

Total score range: 0-7

*Created a binary variable

Outcome

Alzheimer's disease test interest:

"If you could receive a test from your doctor, free of charge, that would definitely determine whether or not you would develop Alzheimer's disease [*sometime within the next five years/sometime in the future*], would you want to be tested?"

(*yes = 1 /no = 0*)

Results

80.3% of respondents expressed interest in testing

Sample Characteristics (Mean, SD)	Interest in Future AD Testing		Total (*n* = 1499)
	No (*n* = 296)	Yes (*n* = 1203)	
Age	69.7 (10.7)	65.8 (9.88)	66.6 (10.2)
Sex (#, % male)	121 (40.9%)	518 (43.1%)	639 (42.6%)
Race (#, %)			
Non-Latinx, white	222 (75.0%)	763 (63.4%)	985 (65.7%)
Non-Latinx, Black/African American	44 (14.9%)	234 (19.5%)	278 (18.5%)
Hispanic/Latinx/Mexican American/Chicanx	23 (7.8%)	163 (13.5%)	186 (12.4%)
Non-Latinx, other	7 (2.4%)	43 (3.6%)	50 (3.3%)
Education (#, % high school graduate or higher)	226 (76.4%)	932 (77.4%)	1158 (77.3%)
Marital Status (#, %)			
Married/partnered	184 (62.2%)	765 (63.6%)	949 (63.3%)
Separated/divorced	30 (10.1%)	175 (14.5%)	205 (13.7%)
Widowed	67 (22.6%)	206 (17.1%)	273 (18.2%)
Never married	15 (5.1%)	57 (4.7%)	72 (4.8%)
Income (corrected for household size)	46,558 (69,866)	42,959 (51,539)	43,670 (55,496)
Everyday Discrimination in at least one domain (n, % yes)	115 (48.9%)	532 (56.2%)	647 (54.7%)
Lifetime Discrimination in at least one domain (*n*, % yes)	43 (18.5%)	239 (25.5%)	282 (24.1%)

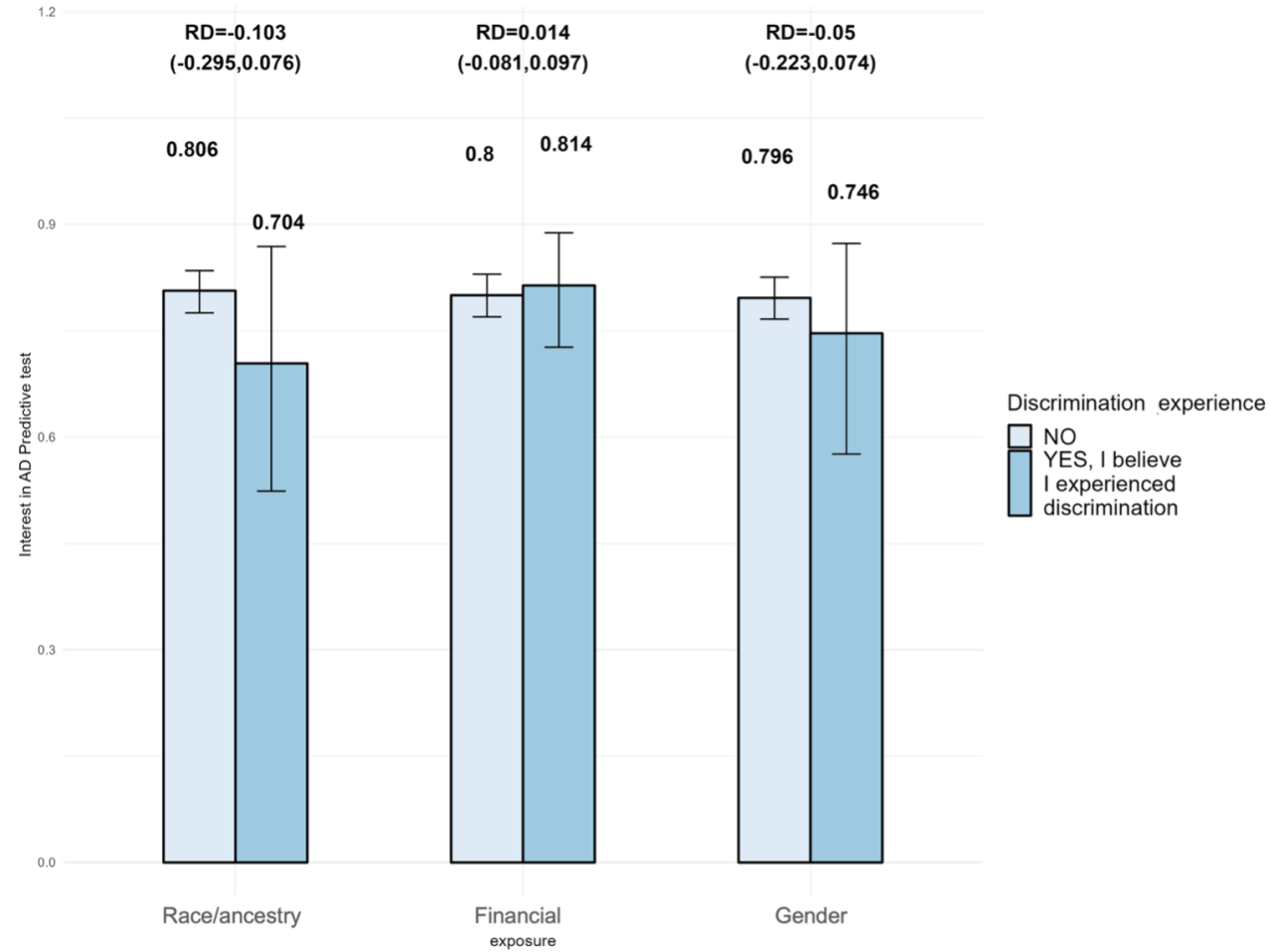DEMENTIA Care Aware

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Results

Probability of wanting an AD predictive test by experiences of discrimination in at least one domain
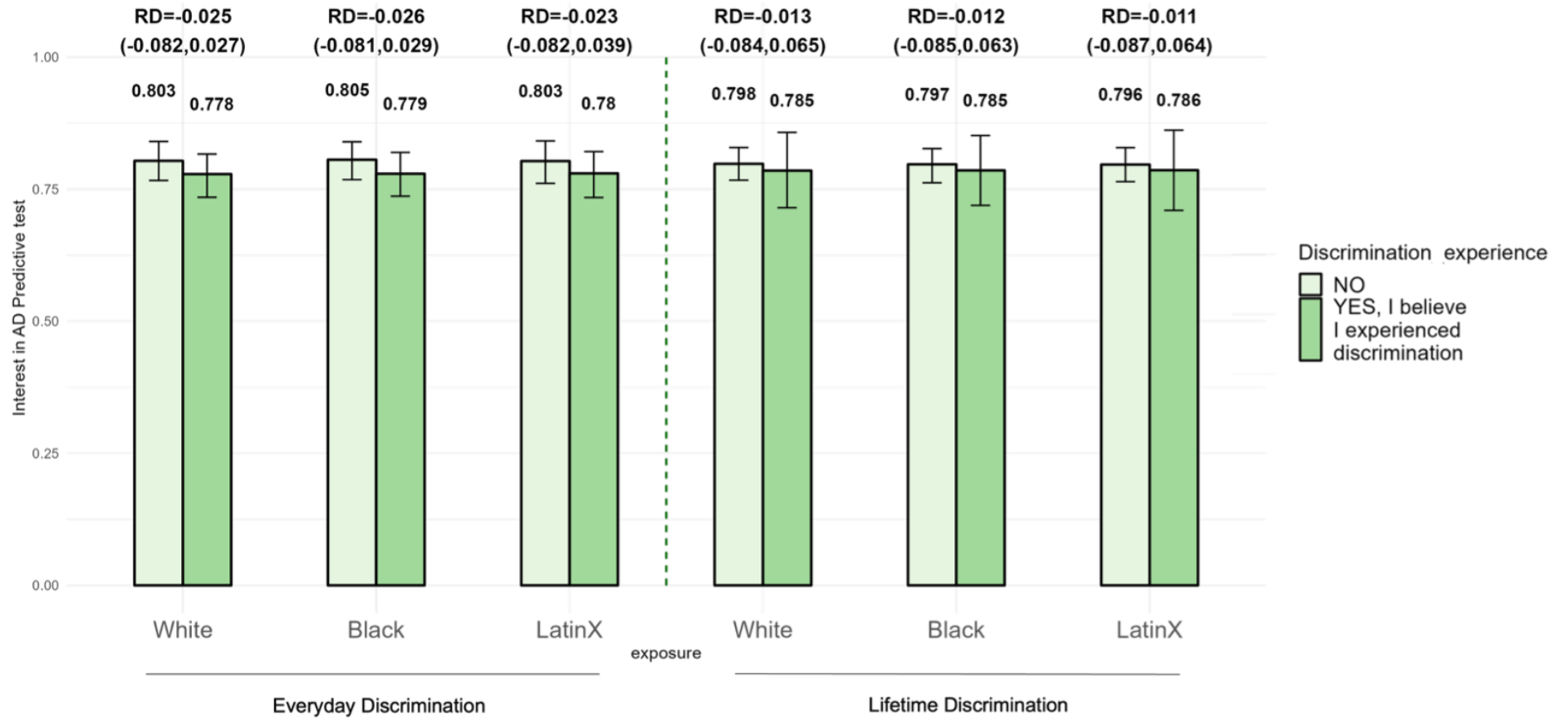
RD = Risk difference

Results

Probability of wanting an AD predictive test by reason for experiencing everyday discrimination

RD = Risk difference

Summary & Implications

Most respondents (~80%) indicated interest in receiving a test for AD

Despite historical and contemporary experiences of discrimination, Black and Latinx respondents expressed interest in AD testing.

- No association

Black and Latinx individuals remain underrepresented in AD research, including research on AD testing.

- If this pattern continues when testing is available in routine clinical settings, results implicate structural and systemic barriers rather than individual preferences.

Next steps: Interest in providing biomarker samples (saliva, blood)

Developing and Accessing Better Therapies in the Future

Therapies in the Pipeline Target Amyloid, Tau, Vasculature, Inflammation, and many other targets

Diverse delivery methods for therapies will increase access and improve compliance

Early and accurate diagnosis will remain the first and most important step in consideration of therapies

Cummings, Alz & Dem, 2023

Practical Tips: Improving Diagnosis and Outcomes

Part 1

Take a Brief Patient History

Take a very brief cognitive health history of the patient. This history can be:

- The response to an annual screening question (e.g., Have you or friends/family noted changes in your mental abilities?) OR

- The observation of a sign of cognitive decline by someone (e.g., a care partner reports that the patient has difficulty remembering medication changes)

Part 2

Use Screening Tools

Assess the patient directly for both cognitive and functional decline using screening tools. If the patient screens negative, use cognitive and functional screening tools with the patient's care partner, if available. Refer to the next table for a list of recommended tools.

Part 3

Document Care Partner Information

Identify a care partner and document the partner's contact information in the patient's record. Ideally, this is a health care agent who has legal authority to make decisions on behalf of the patient. Even if a patient's cognitive and functional screenings are negative, ask about the patient's support system. If the patient can't identify someone, then document this instead.
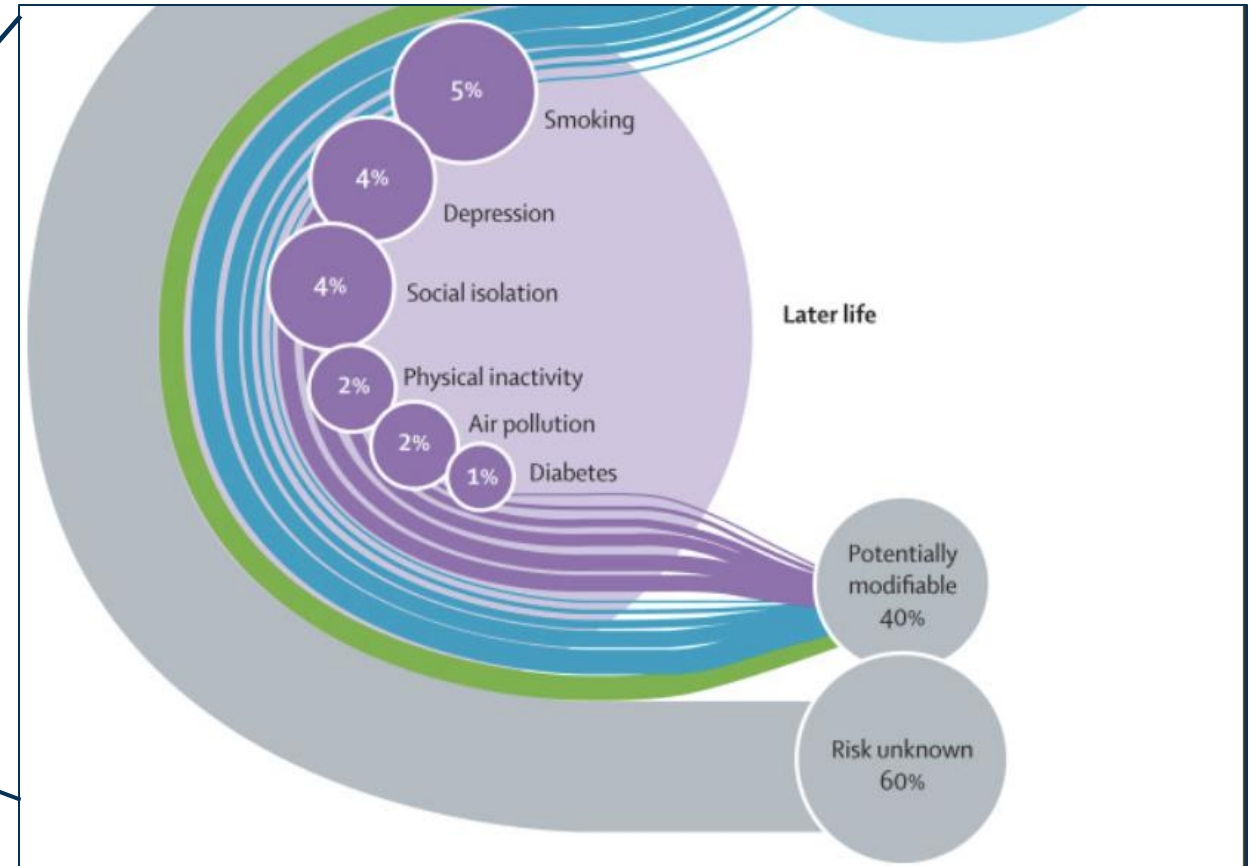
Livingston,, Lancet, 2020

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DCA Cognitive Health Assessment: After a Positive Screen
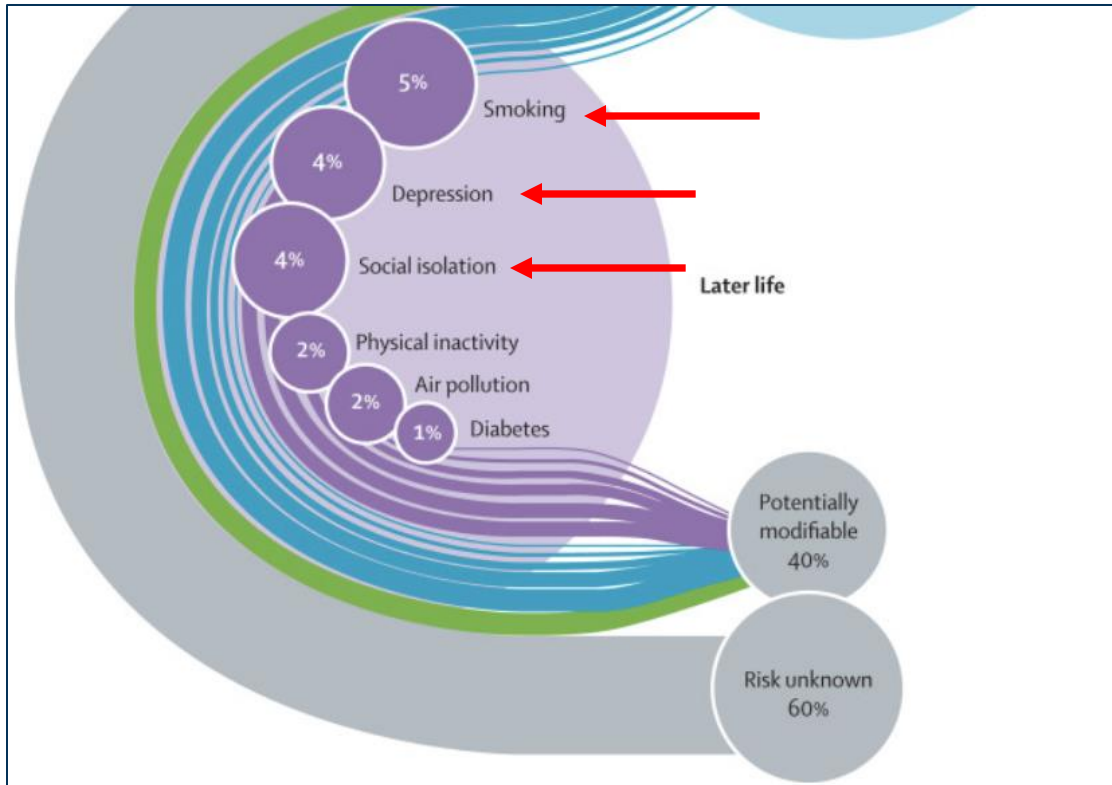
Livingston,, Lancet, 2020

Cognition

If the CHA comes back positive:

- Screen for depression and substance use

- Evaluate for other diseases with cognitive symptoms (e.g., HIV, syphilis, thyroid disorders, obstructive sleep apnea, vitamin B12 deficiency)

- Order labs and head imaging if less than 12 months of symptoms (CBC, electrolytes, BUN/Cr, fasting glucose)

- A more detailed cognitive symptom history is also recommended to identify whether referral to a specialist is warranted.

Function

Based on the results of the functional assessment, consider connecting patients to services based on their needs, such as:

In-Home Supportive Services to obtain a caregiver

Money management services

Meal delivery services

Legal services for access to benefits through Medi-Cal and other programs

Support System

Document the roles and contact information for the patient's support system:

- The care partner for the CHA screen

- Support persons or additional care partners

- Health care agent(s) or durable power of attorneys

Connect the patient's support system to needed services such as legal services for advance care planning.

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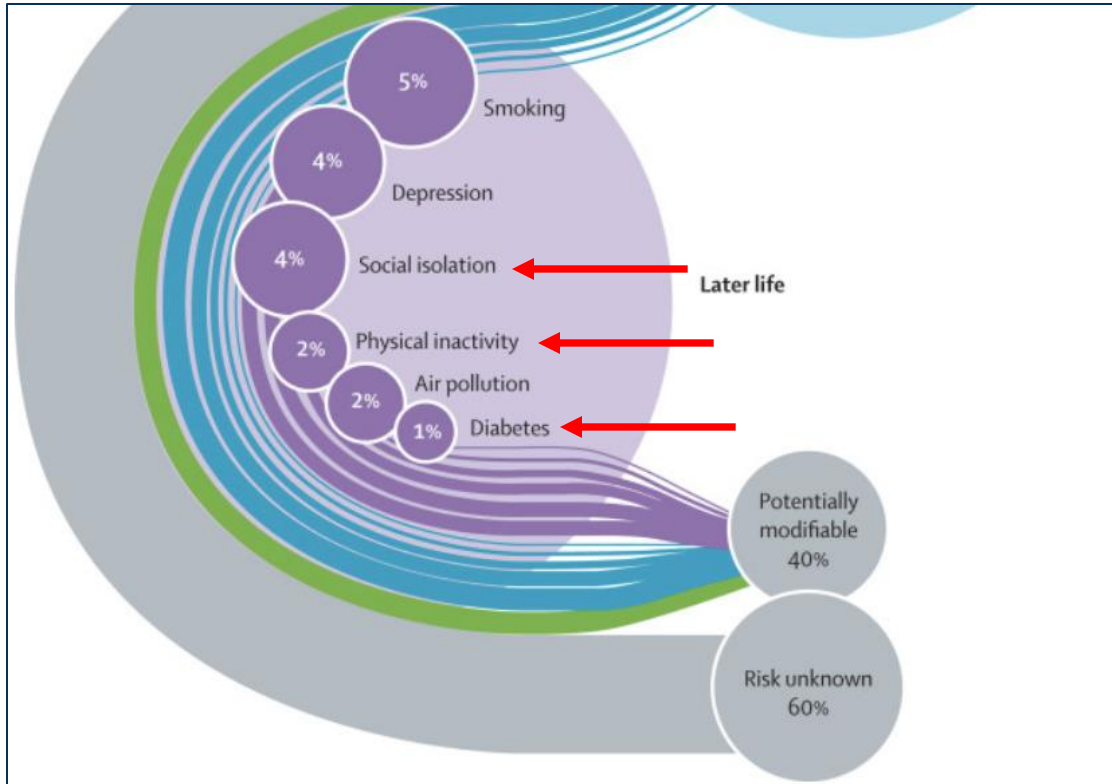
Livingston,, Lancet, 2020

Start a Brain Health Plan

You can start a brain health plan to maximize brain function in all older adults, but it will especially benefit those with cognitive or functional decline. You can also start the plan before any diagnosis of mild cognitive impairment or dementia is made. A brain health plan consists of the following:

- Make sure vision and hearing assessments are up to date and, if impairments are present, correct them accordingly.

- Review medications for cognitive side effects and reduce as many of these as you can in dose or frequency, and preferably stop them.

- Encourage social and physical activity.

- Continue to address blood pressure and diabetes management goals.

Thank You!

Have more questions? Get answers through our Warmline @ **1-800-933-1789** or our support page!

Here are some examples!

What do I prioritize if my patient tests positive for cognitive impairment?

What medications should I avoid if my patient has cognitive complaints?

What cognitive assessment should I use for a Spanish speaking patient experiencing homelessness?

Open your phone camera and scan the QR code to submit questions:

Or visit: www.dementiacareaware.org

DEMENTIA Care Aware

UCSF University of California San Francisco

UCI Division of Geriatric Medicine and Gerontology

UC San Diego School of Medicine

UCLA Health

UCSF–UC Law

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