Representativeness of Samples Enrolled in Alzheimer's Disease Research Centers

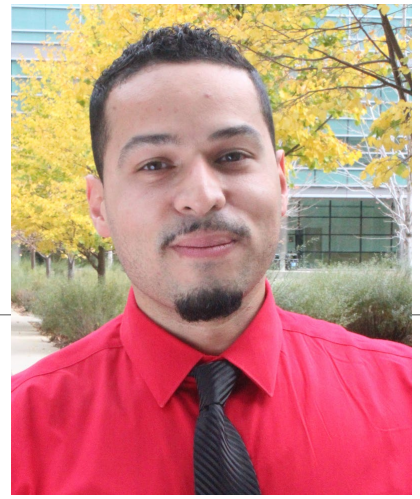
MIGUEL ARCE RENTERÍA, PHD

ASSISTANT PROFESSOR OF NEUROPSYCHOLOGY

COLUMBIA UNIVERSITY MEDICAL CENTER

Taylor M. Mobley

Nicole D. Evangelista



Luis D. Medina

Kacie D. Deters

Joshua T. Fox-Fuller

Lex R. Minto

Justina Avila-Rieger

Brianne M. Bettcher

ADRD & Multi-Site Collaborations

By 2050, it is anticipated that 12 million people in the United States will have Alzheimer's disease and related dementias (ADRD).

Many public-private partnerships have been created

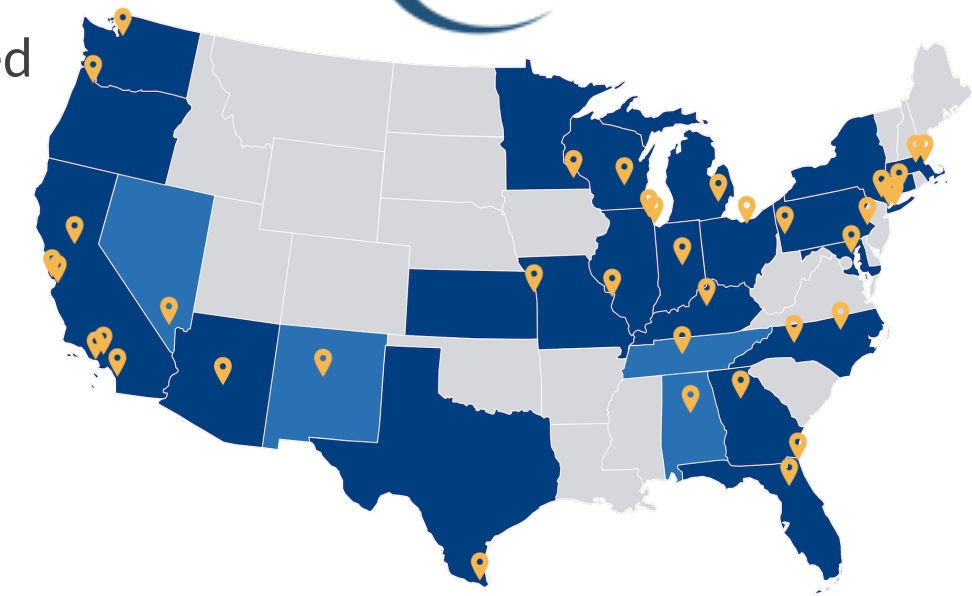
- Multi-site collaborations and data repositories

GAAIN
ALZHEIMER'S ASSOCIATION

ADNI
ALZHEIMER'S DISEASE NEUROIMAGING INITIATIVE

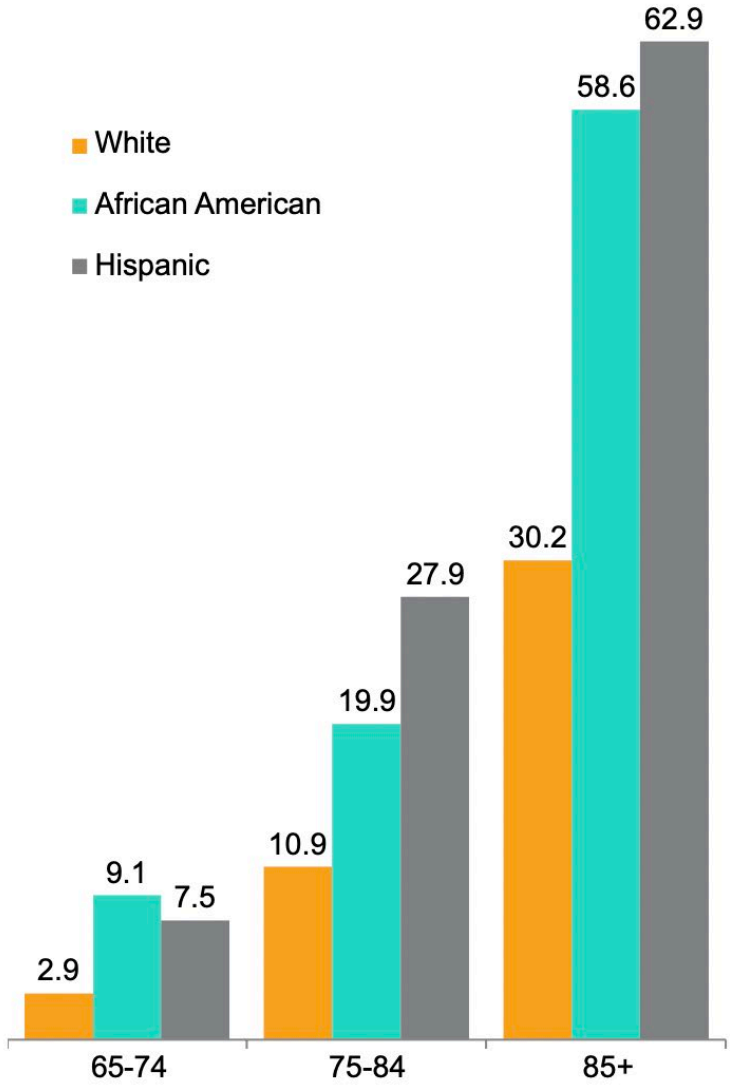
NCRAD

NACC

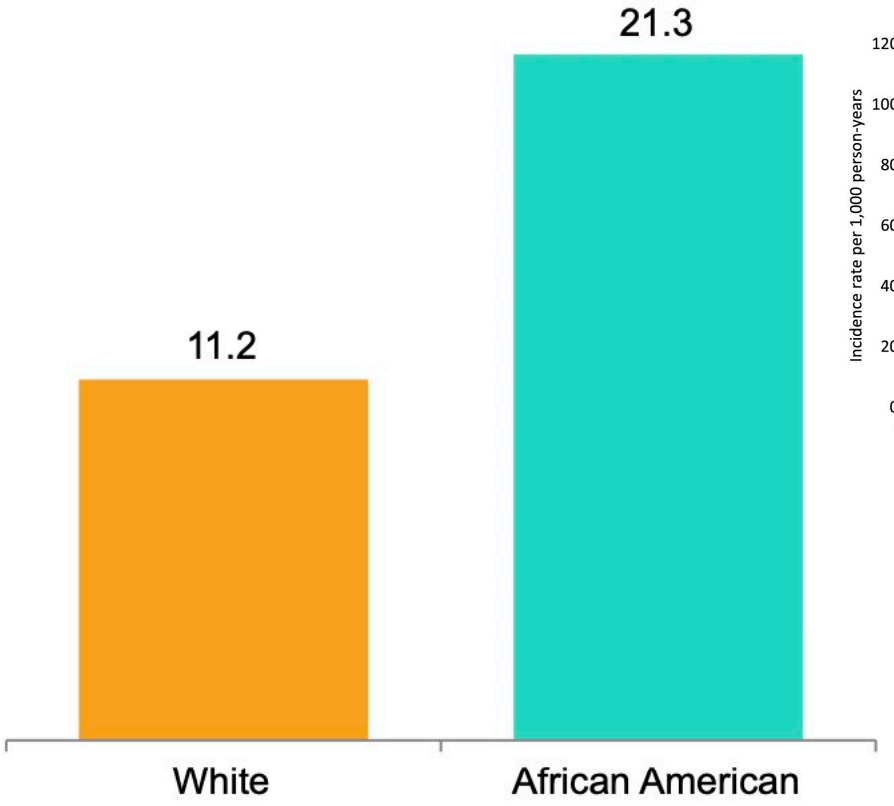


Racial and ethnic disparities in ADRD

Proportion of People Aged 65 and Older with Alzheimer's and Other Dementias
Washington Heights-Inwood Columbia Aging Project



Proportion of Americans Aged 71 and Older with Alzheimer's and Other Dementias
Aging, Demographics, And Memory Study (ADAMS)



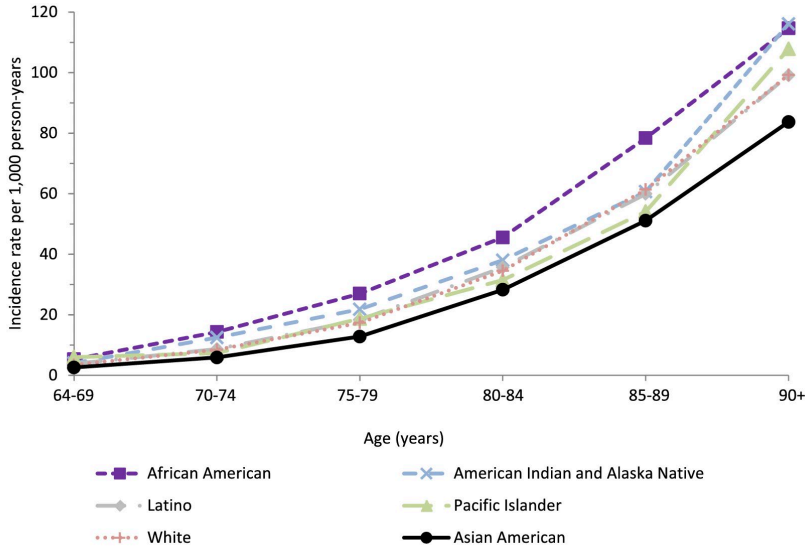


Fig. 2. Dementia incidence rates per 1000 person-years by age and race-ethnicity, 2000–2013.

(Mayeda, ER., et al, 2016)

Figures from Alzheimer's Impact Movement – Alzheimer's Association 2020

The National Alzheimer's Coordinating Center's (NACC) Uniform Data Set

DOI: 10.1002/alz.12509

FEATURED ARTICLE

Alzheimer's & Dementia®
THE JOURNAL OF THE ALZHEIMER'S ASSOCIATION

Black and White individuals differ in dementia prevalence, risk factors, and symptomatic presentation

Jack C. Lennon[1] | Stephen L. Aita[2] | Victor A. Del Bene[3] | Tasha Rhoads[4] | Zachary J. Resch[4] | Janelle M. Eloi[2] | Keenan A. Walker[5]

Featured Article

Neuropathologic differences by race from the National Alzheimer's Coordinating Center

Neill R. Graff-Radford[a,*], Lilah M. Besser[b,c], Julia E. Crook[d], Walter A. Kukull[b,c], Dennis W. Dickson[e]

Assessment of Racial Disparities in Biomarkers for Alzheimer Disease

John C. Morris, MD[1,2]; Suzanne E. Schindler, MD, PhD[1,2]; Lena M. McCue, PhD[2,3]; et a

2018 National Institute on Aging—Alzheimer's Association (NIA-AA) Research Framework

NIA-AA Research Framework: Toward a biological definition of Alzheimer's disease

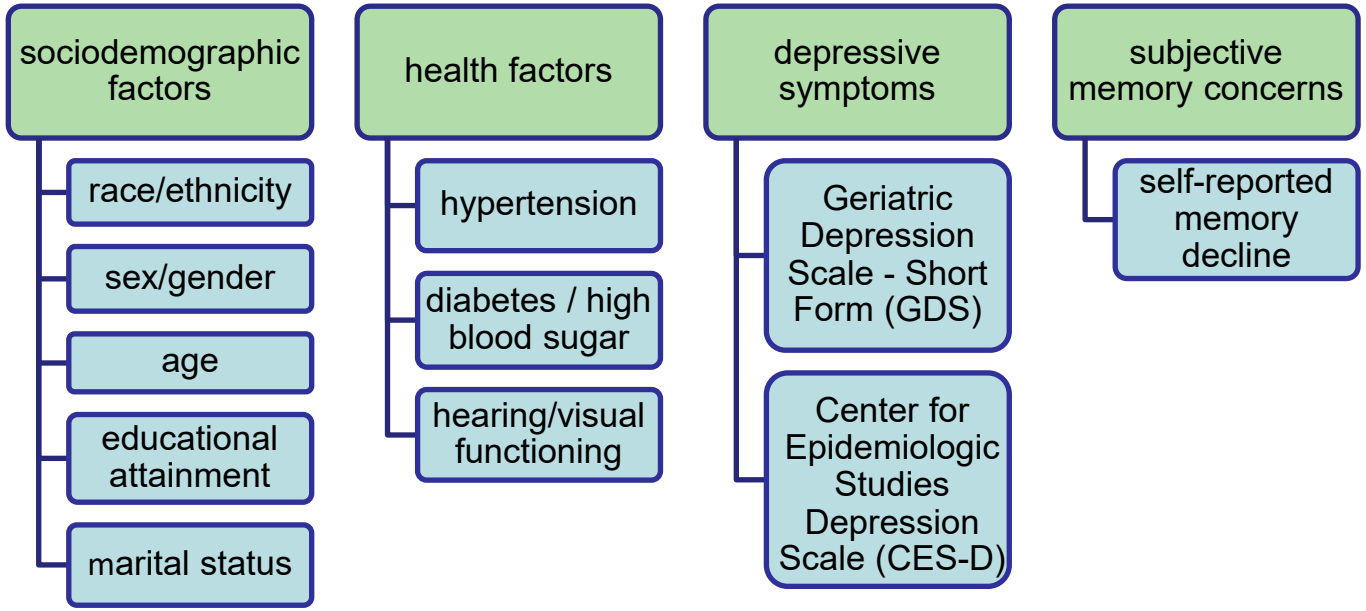
To clarify how racial and ethnic disparities impact aging and ADRD and the magnitude of these effects on incidence and progression, we must better understand how large, multi-site study samples reflect the U.S. population.

Current Study

Overall aim:

- Examine selection factors across racial and ethnic groups included in National Alzheimer's Coordinating Center data (NACC) compared to the general U.S. population using data from the Health and Retirement Study (HRS).

- NACC participants' baseline visit, aged 60+ years
- HRS 2010 wave participants aged 60+ years, sample weighted up to the 2010 US population



Analysis

Means and frequencies calculated to describe each sample.

Standardized mean differences calculated and stratified race and ethnicity to assess differences between samples.

Standardized mean differences greater than +/- 0.25 were considered strong selection factors into NACC.

Sample Characteristics

	NACC	HRS
	(N=36,639)	(N=52,071,840)
Age, years (mean [SD])	74.2 (8.0)	71.5 (8.8)
Female (%)	56.7	53.4
Race/Ethnicity (%)		
Latinx	8.5	7.7
non-Latinx White	77.9	82.6
non-Latinx Black	13.7	9.7
Married/living as married (%)	64.2	61.2
Education, years (mean [SD])	14.5 (2.9)	12.8 (3.1)
Hypertension/high blood pressure (%)	53.2	61.7
Diabetes/high blood sugar (%)	13.6	22.2
Elevated depressive symptoms (%)	3.6	12.7
Poor subjective cognition (%)	57.7	28.4
Self-reported vision difficulty (%)	6.0	6.2
Self-reported hearing difficulty (%)	11.9	6.1

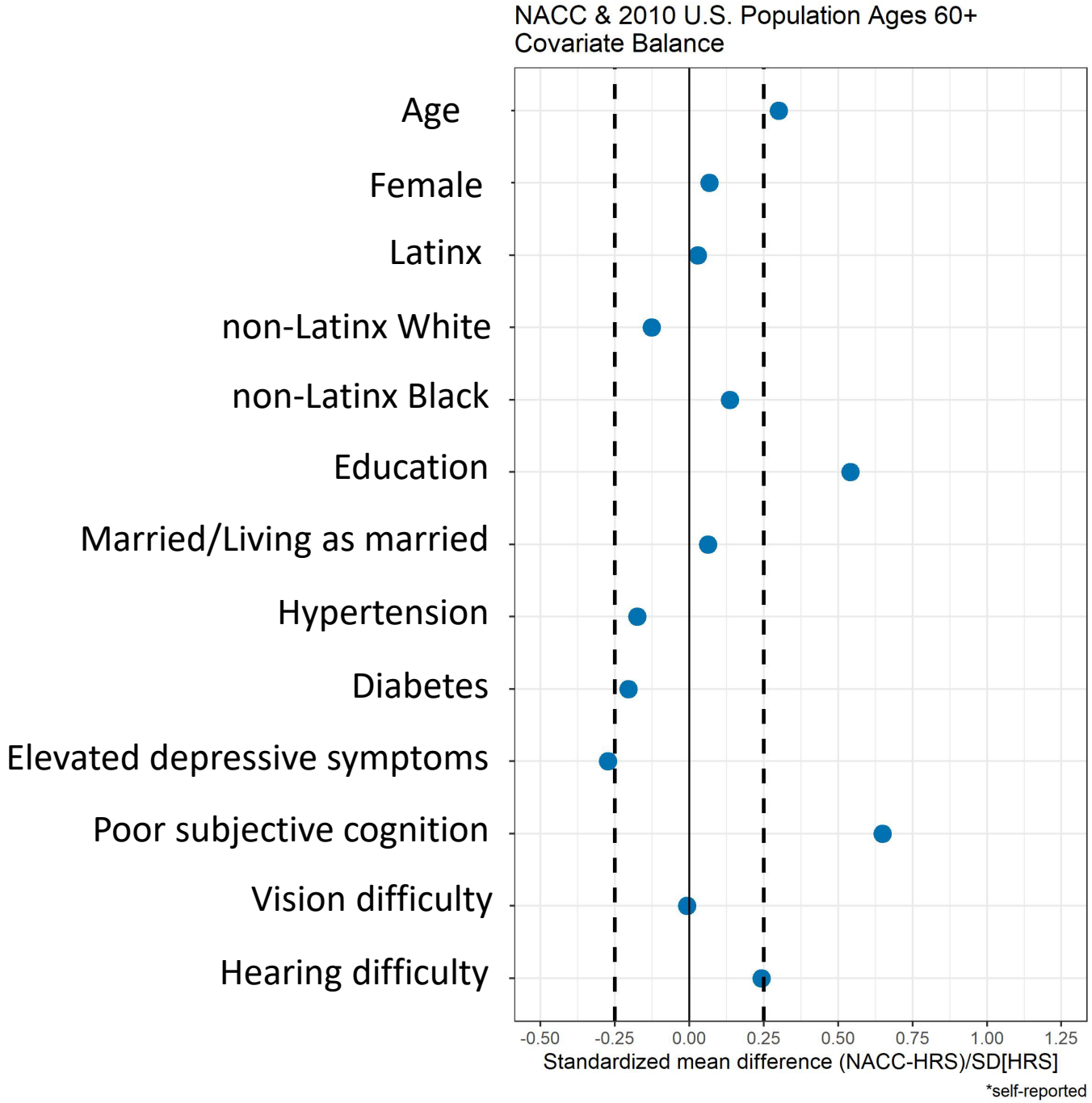
Note: Characteristics are averaged across 20 multiply imputed samples. HRS percentages are shown weighted to be representative of the 2010 adult US population aged 60+

Overall covariate balance (standardized mean differences)

Between:

National Alzheimer's Coordinating Center (NACC)

The Health and Retirement Study (HRS)

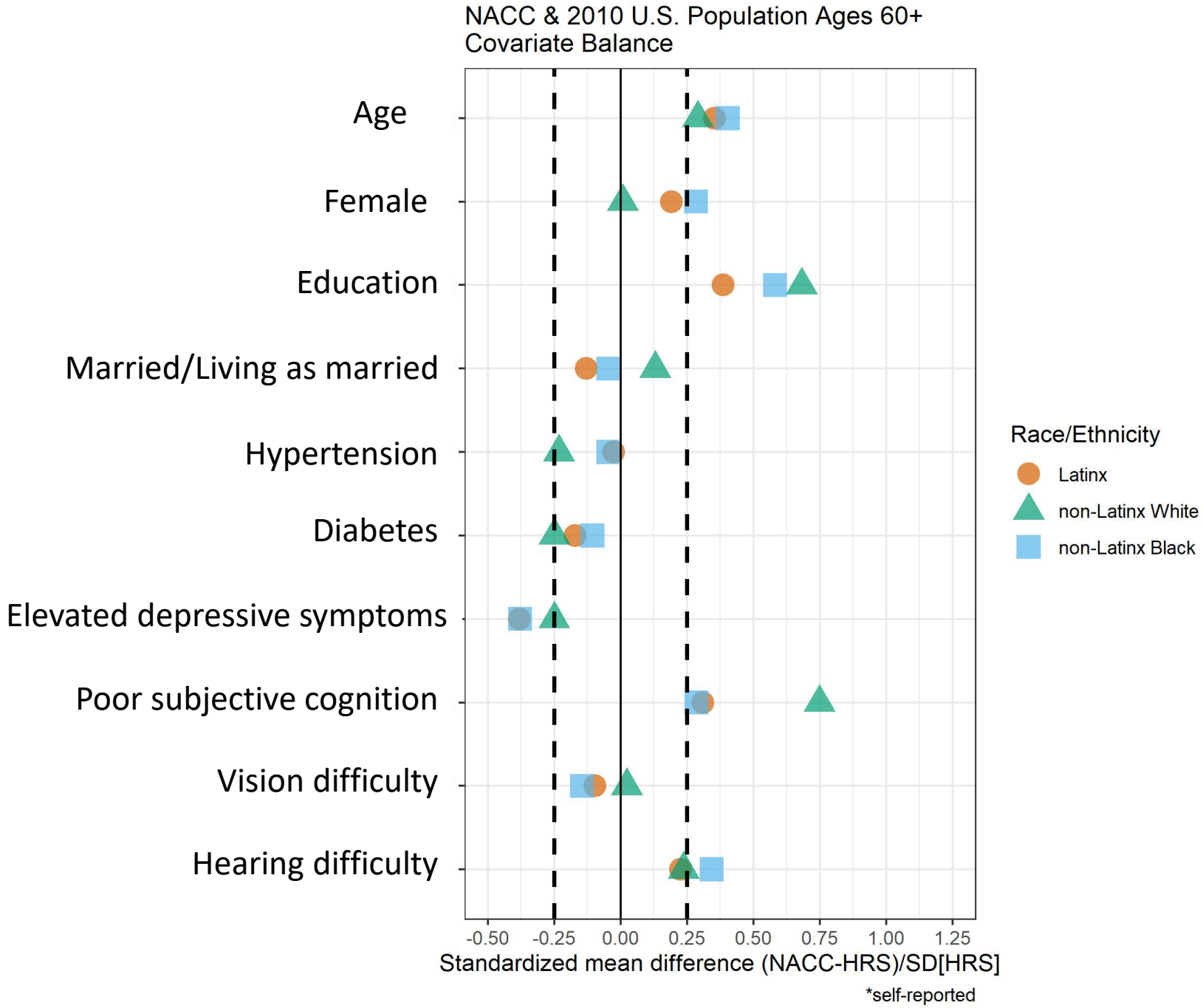


Covariate balance (standardized mean differences) By race and ethnicity

Between:

National Alzheimer's Coordinating Center (NACC)

The Health and Retirement Study (HRS)



Conclusions

Overall, our study suggests that that NACC participants are not representative of the U.S. population across key sociodemographic and health factors.

NACC participants were typically:

- older and more likely to have higher educational attainment, reported worse subjective cognition as well as greater hearing difficulties, but
- less likely to report depressive symptoms and cardiovascular risk factors compared to the U.S. older adult population.

These selection factors differed across racial and ethnic groups.

What now?

Our findings demonstrate the need to increase efforts for inclusive recruitment strategies to ensure adequate representation across and within racial and ethnic groups.

Dedicated funding to increase diversity and representativeness in ADRCs may also be helpful.

The NACC UDS is designed as a case series, but typically analyzed as a cohort sample.

- Each site is permitted to use different enrollment criteria that fit with their individual ADRC aims, goals, and budget.
- Efforts could be directed towards creating a unified inclusion/exclusion criteria across sites.

Future studies should assess the degree to which these factors may bias current findings and conceptualizations of ADRD clinical and biological outcomes.

Acknowledgements

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