CAREGIVING FOR INDIVIDUALS WITH DEMENTIA: RACIAL AND ETHNIC DIFFERENCES IN CAREGIVER HEALTH OUTCOMES

MOHAMMADREZA MOSLEHIKHAH, CONNOR SOTELO, PRABHU CHAITANYA MOLABANTI, AKHIL THANGALLAPELLI

Department of Health & Clinical Outcomes Research
Saint Louis University, St. Louis, Missouri

Background

- In 2024, nearly 7 million Americans are living with Alzheimer's disease, affecting over 10.9% of the population aged 65 and older[1]. By 2050, the number of people affected by this disease in the US is expected to grow to nearly 13 million[1].
  - The impact of dementia extends beyond those affected, deeply influencing primary caregivers. These caregivers assist with daily activities, from basic self-care to complex tasks like financial management and community involvement [2].
- Caregiving for individuals with dementia is linked to significant emotional and physical stress. Research shows that caregiver health is crucial for their own sustainability and quality of life[3].
  - Previous care models for dementia patients focus more with biopsychosocial principles of the patient and caregiver, but often do not consider the family system and existing social relationships as factors or determinants[4].
- Existing literature on the health of dementia caregivers often overlooks the role of racial and ethnic minority identity.

Goals of study

- To predict the differences in emotional, physical, and social health outcomes of caregivers based on their self-described race/ethnicity.
- To identify the differential factors that contribute to care-partner health compared to those who self-identify as non-hispanic white.

Methods

I. Data Source and Sampling

- National Survey of Older Americans Act Participants (NSOAAP) - Conducted by Administration on Aging (AoA) Administration for Community Living (ACL)
  - Caregivers datasets from 2021–2022
- Cross-sectional survey data collected from caregivers of individuals with dementia.
  - Cohort was defined as being a care partner to a care recipient with diagnosed case of dementia. Selection of caregivers with available race/ethnicity data.

II. Measures and Outcomes

- Outcomes: Physical, Emotional, Social health
- Exposure variable: Self described race/ethnicity
- Health related survey response covariates selected from the NSOAAP dataset.

III. Data Preparation

- Combined 2021/2022 data; removed missing/duplicate data
  - Variable substitution for inconsistently recorded variables
  - Missingness correlation analysis on outcome variables
- Feature engineering and variable composition

IV. Feature Understanding via Exploratory Data Analysis (EDA)

- Variable examination and descriptive analysis
  - Distribution analysis for outcome variables and covariates
  - Creation of outcome variable scaling
- Outcome distribution + covariate correlation
  - Covariate and outcome distribution analysis stratified by race/ethnicity
- Covariate-outcome analysis with chi-squared test

V. Regression Modeling Analysis

- Setup models with re-encoded variables
- Applied ordered logistic regression on health outcomes.
  - Train/test split for model predictions and evaluation
  - Used BFGS optimizer
  - Physical, emotional, and social health stratified by race/ethnicity
- Explored how covariates influenced the health outcomes within each group.

Table 1 Categorical and Continuous Variable Descriptive Statistics

Categorical Variables

Variable	Category	Count	Percentage
RACE_ETHNICITY4CAT	Non-Hispanic White	1140	71.79%
	Non-Hispanic Black	247	15.55%
	Hispanic	128	8.06%
	Other	73	4.60%
CGFAMILY	3	642	40.43%
	4	312	19.65%
	2	247	15.55%
	1	200	12.59%
	5	187	11.78%
CGSOCIAL	3	492	30.98%
	5	476	29.97%
	4	301	18.95%
	1	172	10.83%
	2	147	9.26%
CGFINCLI	2	1243	78.27%
	1	345	21.73%
RGENDER	2	956	60.20%
	1	632	39.80%
CGGENDER	2	1161	73.11%
	1	427	26.89%
DEINAB	2	1505	94.77%
	1	83	5.23%
MSA2	1	765	48.17%
	2	474	29.85%
	0	349	21.98%
CGREL_RECODED	Daughter	544	34.26%
	Wife	472	29.72%
	Husband	255	16.06%
	Other	173	10.89%
	Son	144	9.07%
CGNHBTR	1	1119	70.47%
	1	469	29.53%
CGBASIS	1	1355	85.33%
	2	233	14.67%
Lonely	Lonely	1011	63.66%
	Not Lonely	577	36.34%
MARITAL_STATUS	1	1409	88.73%
	2	179	11.27%
CAREMP	2	1210	76.20%
	1	378	23.80%
CGHEALTH	3	721	45.40%
	4	537	33.82%
	2	149	9.38%
	5	106	6.68%
	1	75	4.72%
SIUCLA1	1	577	36.34%
	2	530	33.38%
	3	481	30.29%
SIUCLA2	2	641	40.37%
	1	588	37.03%
	3	359	22.61%
SIUCLA3	3	556	35.01%
	2	482	30.35%
	4	391	24.62%
	1	159	10.01%
CGFEELC	3	583	36.71%
	2	395	24.87%
	1	372	23.43%
	4	165	10.39%
	5	73	4.60%
CGFEELA	3	609	38.35%
	2	417	26.26%
	4	387	24.37%
	5	117	7.37%
	1	58	3.65%
CGFEELB	3	609	38.35%
	4	384	24.18%
	2	379	23.87%
	5	164	10.33%
	1	52	3.27%
CGPAGE	7	649	40.87%
	6	610	38.41%
	5	285	17.95%
	4	44	2.77%
CGCRHL	2	164	10.33%
	1	49	3.09%
	5	551	34.70%
	4	478	30.10%
	3	346	21.79%
AGEC	5	562	35.39%
	6	357	22.48%
	3	344	21.66%
	4	235	14.80%
	7	80	5.04%
DEEDUC	3	573	36.08%
	2	332	20.91%
	5	322	20.28%
	4	285	17.95%
	1	76	4.79%
CGPORT	5	1019	64.17%
	4	293	18.45%
	3	150	9.45%
	2	88	5.54%
	1	38	2.39%
CGINSTY	4	632	39.80%
	5	400	25.19%
	3	358	22.54%
	2	121	7.62%
	1	77	4.85%
CGSATISA	3	776	48.87%
	2	702	44.21%
	1	110	6.93%
CGJOY	1	506	31.86%
	3	504	31.74%
	2	348	21.91%
	4	149	9.38%
	5	81	5.10%
CGACOMP	3	507	31.93%
	1	500	31.49%
	2	401	25.25%
	4	116	7.30%
	5	64	4.03%
CGRAPREC	1	640	40.30%
	3	403	25.38%
	2	318	20.03%
	4	133	8.38%
	5	94	5.92%
CGDUTY	1	1022	64.36%
	2	414	26.07%
	3	128	8.06%
	4	14	0.88%
	5	10	0.63%

Continuous Variables

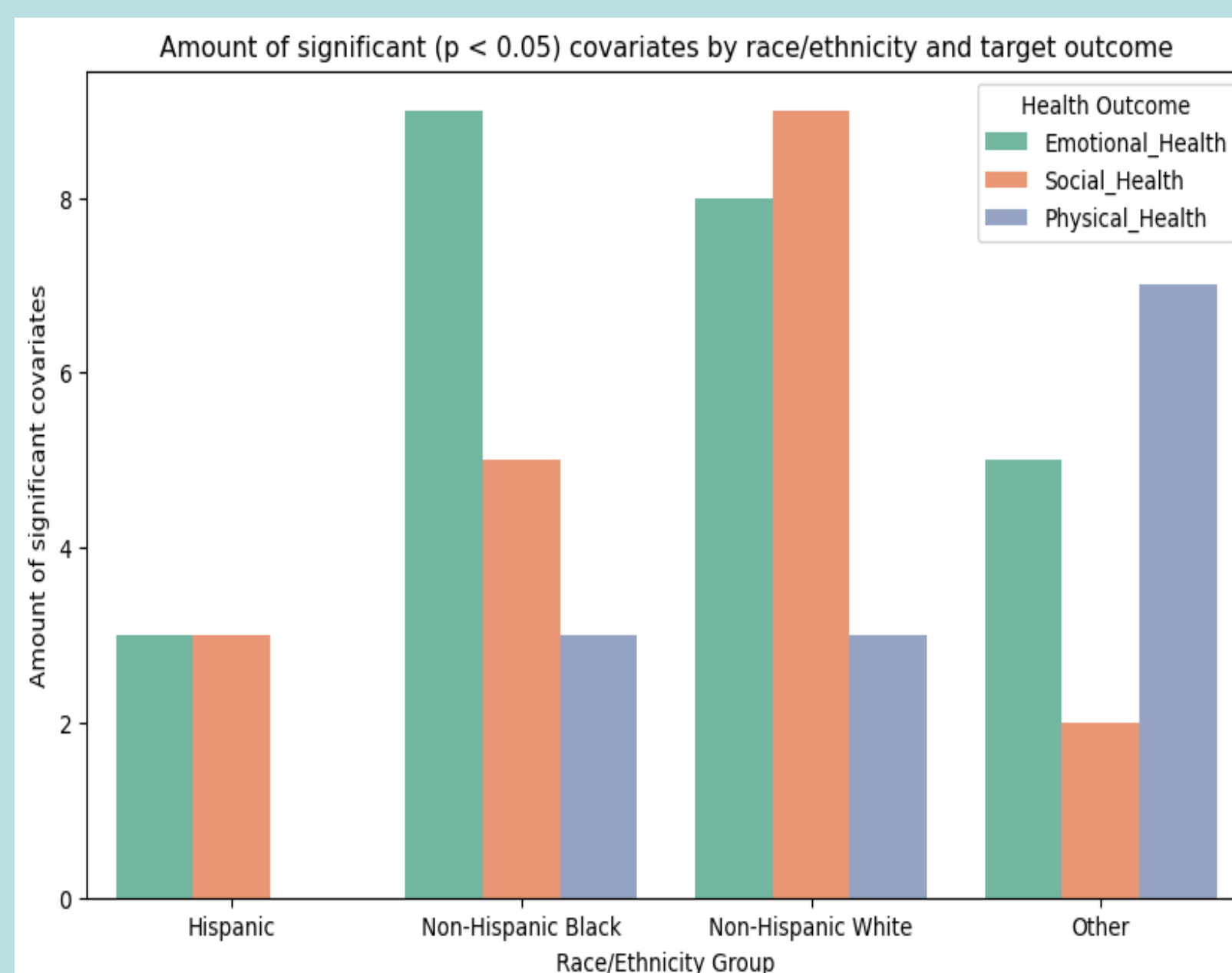| Variable	Count	Mean	Std Dev	Min	25%	Median	75%	Max
UCLA_Total	1588	6.54	2.17	3	5	7	8	10
Social_Health_Score	1588	8.14	2.32	3	7	8	10	12
Emotional_Health_Score	1588	8.68	2.5	3	7	9	10	15

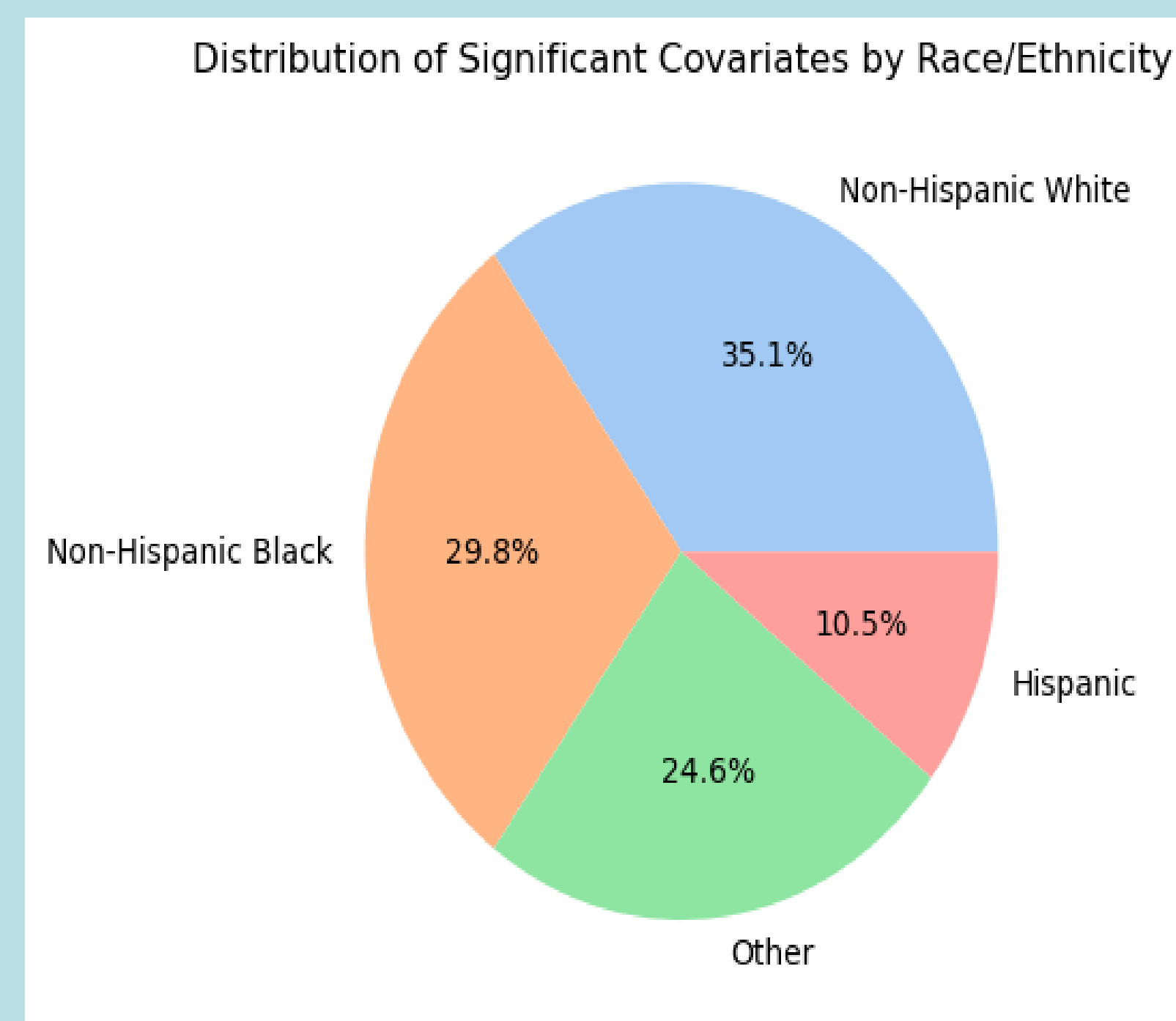Figure 1. Count of Significant Covariates by Race/Ethnicity

Figure 2. Distribution of Significant Covariates by Race/Ethnicity

Results

- An ordered logistic regression study revealed unique predictors impacting the three health outcomes among the 4 categories of race/ethnicity. Several covariate predictors never showed any significance like caregiver gender or caregiver joy.
- Positive association = GREEN, Negative association = RED

Health_Outcome	Race/Ethnicity	Covariate
Social_Health	Hispanic	Intensity of Care
		Care recipient age group
		Located in MSA Non-City Center
	Non-Hispanic Black	Not responsible for 24-hr care
		Care recipient perceived health
		Did not quit job for caregiving
		Caregiver satisfaction
		Household income above $20k
		Caregiver age group
	Non-Hispanic White	Sense of accomplishment
		Not responsible for 24-hr care
		Care recipient perceived health
		Did not quit job for caregiving
		Intensity of Care
		Proportion of care
		Caregiver satisfaction
	Other	Caregiver education level
		Care recipient perceived health
		Proportion of care

Health_Outcome	Race/Ethnicity	Covariate
Physical_Health	Non-Hispanic Black	Care recipient perceived health
		Sense of fulfilling duty
		Care recipient age group
	Non-Hispanic White	Care recipient perceived health
		Sense of fulfilling duty
		Caregiver satisfaction
	Other	Caregiver age group
		Not responsible for 24-hr care
		Disagrees with recipient better off in assisted living
		Care recipient age group
		Proportion of care
		Caregiver satisfaction
		Household income above $20k

Health_Outcome	Race/Ethnicity	Covariate
Emotional_Health	Hispanic	Caregiver age group
		Sense of appreciation
		Household income above $20k
	Non-Hispanic Black	Not providing 24-hour care
		Did not quit job for caregiving
		Intensity of Care
		Proportion of care
		Caregiver satisfaction
		Sense of appreciation
		Caregiver education level
		Located in MSA City-Center
		Located in MSA Non-City Center
	Non-Hispanic White	Caregiver age group
		Sense of accomplishment
		Not responsible for 24-hr care
		Care recipient perceived health
		Intensity of Care
		Caregiver relation as Husband
		Caregiver relation as Wife
		Caregiver satisfaction
	Other	Care recipient perceived health
		Disagrees with recipient better off in assisted living
		Proportion of care
		Household income above $20k
		Not married

Conclusion

The examination of social, mental, and physical health consequences reveals varying impacts on different racial/ethnic groups, ranked by the number of significant predictors for each group. Non-Hispanic Whites are the most afflicted, but compared to them it seems that non-Hispanic Blacks are comparable from the remaining race/ethnic groups. This study highlights significant disparities in the health outcomes of caregivers of individuals with dementia based on their race and ethnicity, emphasizing the critical need for culturally sensitive interventions. Strictly by numbers, from significant factors across all evaluations conducted, we count 32 influentially related factors for non-Hispanic Black caregivers, 41 for non-Hispanic White caregivers, 15 for Hispanic, and 14 for other non-Hispanic other caregivers totaling 102 observations of significant covariate influencers. Compared to non-Hispanic caregivers, non-Hispanic Black caregivers may be the most affected by dementia caregiving disparities.

References: [1]Alzheimer's disease facts and figures. Alzheimer's Disease and Dementia. (2024). https://www.alz.org/alzheimers-dementia/facts-figures., [2]Lin, C. Y., Shih, P. Y., & Ku, L. E. (2019). Activities of daily living function and neuropsychiatric symptoms of people with dementia and caregiver burden: The mediating role of caregiving hours. Archives of gerontology and geriatrics, 81, 25–30. https://doi.org/10.1016/j.archger.2018.11.009 ., [3]Schulz, R., & Sherwood, P. R. (2008). Physical and mental health effects of family caregiving. The American journal of nursing, 108(9 Suppl), 23–27. https://doi.org/10.1097/01.NAJ.0000336406.45248.4c, [4]Podgorski CA, Anderson SD, Parmar J. A Biopsychosocial-Ecological Framework for Family-Framed Dementia Care. Frontiers in psychiatry. 2021;12:744806. doi:10.3389/fpsyt.2021.744806,