



Association of Social Determinants of Health with Rare Cancer Burden in the United States: A MEPS-Based Analysis

Harshit Dixit¹, Navneet Kumar¹, Jatinder Kumar¹, Coby Martin², Sabrina Gaiazov³, and Ankur Goyal¹

¹Atria India Pvt. Ltd, DLF Cybercity, Gurugram India; ²Atria Inc., Toronto, ON, Canada; ³Atria Inc., 300 Connell Drive, Berkeley Heights, NJ, US

INTRODUCTION

- Rare cancers, although individually uncommon but collectively account for a substantial share of cancer-related morbidity and health care burden in the United States. Patients diagnosed with rare cancers often face delayed diagnoses, limited treatment options, and fragmented care pathways compared with common cancers.^{1,2}
- Social determinants of health (SDoH), including economic stability, access to care, and health behaviors, are key drivers of cancer disparities. However, most evidence linking SDoH to cancer outcomes is derived from studies of common cancers, with limited evidence specific to rare cancers.³
- Evidence on the role of SDoH in shaping rare cancer burden at a national level remains limited. Addressing this gap is clinically and policy relevant, as identifying key social and economic factors may inform more targeted, equitable approaches to screening, care delivery, and resource allocation.

OBJECTIVE

To evaluate SDoH characteristics among individuals with rare cancers compared with those with common (non-rare) cancer in the United States, and to assess their association with rare cancer burden using nationally representative Medical Expenditure Panel Survey (MEPS) data (2018–2022).

METHODS

Data Source

A cross-sectional analysis was conducted using pooled data from the MEPS Full Year Consolidated Files spanning 2018 through 2022. MEPS is a nationally representative survey of the US civilian non-institutionalized population, administered by the Agency for Healthcare Research and Quality.⁴ Pooling five survey years yielded a weighted sample covering 1,646,572,515 US patient-years (137,545 person-year observations from 73,004 unique respondents).

Rare Cancer Identification

Rare cancer status was ascertained using the MEPS CAOTHER variable, which captures diagnoses of cancer types appearing in fewer than 20 observations in a given survey year or classified as clinically rare by the National Institutes of Health. Of the total weighted patient-years, 1.59% (26,105,886) had a rare cancer diagnosis.

Social Determinants of Health

SDoH variables were operationalized using selected domains from an established framework: economic stability, education, health care access and quality, social and community context, and neighborhood and built environment.⁵

Economic stability was assessed through employment status and income level. Education was captured using highest educational attainment. Health care access and quality were assessed using insurance coverage type, medication and prescription affordability, and presence of a usual source of care. Social and community context included marital status, race, ethnicity, US birth status, language spoken at home, and census region. Neighborhood and built environment was captured through smoking status and physical activity level.

Age and sex were treated as separate sociodemographic covariates. All SDoH measures were derived from standardized MEPS variables and categorized according to predefined reference groups.

Statistical Analysis

Multivariable logistic regression was used to assess associations between SDoH variables and rare cancer burden. All analyses incorporated MEPS complex survey design parameters.

Rare Cancer Types Captured in MEPS, Grouped by Body System

Digestive / GI

- Esophagus
- Stomach
- Rectum
- Liver
- Gallbladder
- Pancreas
- Mouth

Head, Neck & Respiratory

- Brain
- Larynx
- Throat
- Thyroid

Reproductive & Urinary

- Ovary
- Testis
- Kidney

Blood & Bone

- Leukemia
- Bone

The listed cancers were classified as clinically rare.

Baseline Characteristics of the Study Population

- Mean age was 58.58 years among individuals with rare cancer compared with 65.78 years among those without rare cancer. Males comprised 45.10% of the rare cancer group versus 43.80% among those without rare cancer.
- A higher proportion of adults with rare cancer spoke a language other than English at home (11.80% vs 7.50%). Adults with rare cancer were less likely to have a usual source of care (80.50% vs 85.00%) and more likely to report inability to afford medications (5.60% vs 3.50%), suggesting gaps in healthcare access within this group.

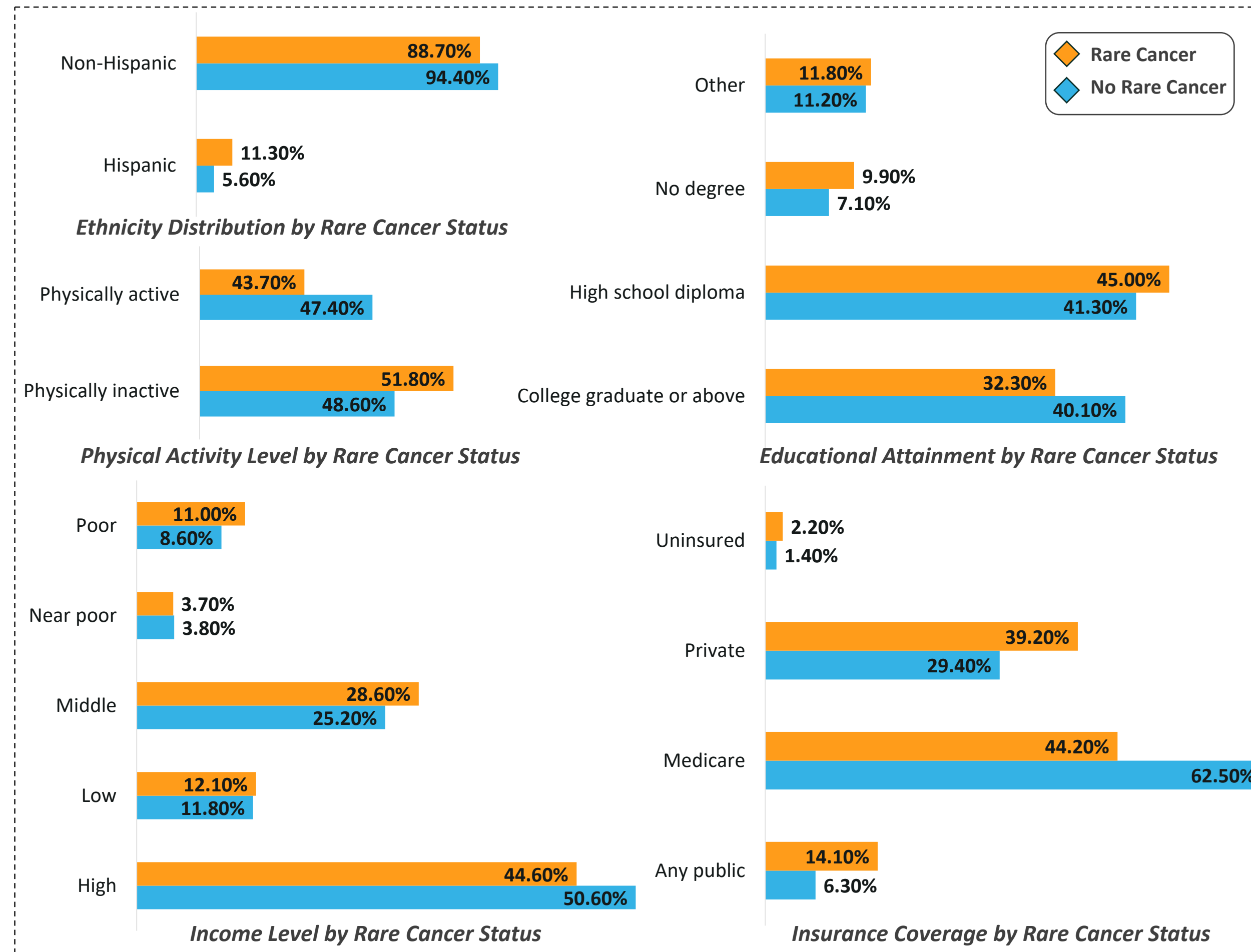


Table 1. Demographic, behavioral, and social characteristics by rare cancer status

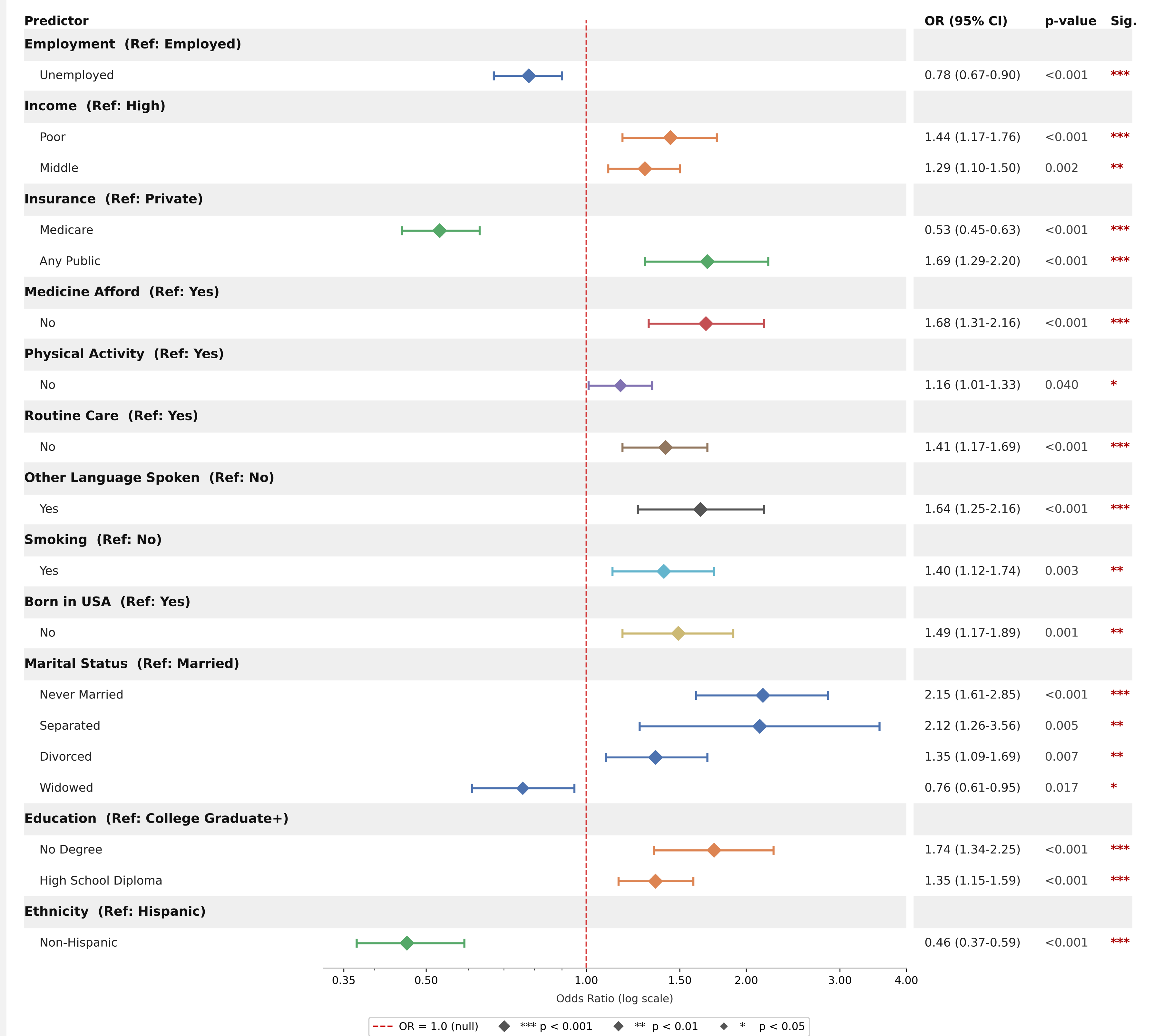
Variable	Category	No Rare Cancer	Rare Cancer
Smoking	Yes	9.80%	13.10%
	No	86.40%	82.30%
Race	Asian	1.90%	2.80%
	Black	6.20%	8.80%
	Other	1.90%	2.50%
	White	89.90%	85.90%
	Employment	Employed	40.10%
Marital Status	Unemployed	58.60%	52.60%
	Divorced	14.50%	17.80%
	Married	59.40%	53.70%
	Never married	7.20%	13.90%
	Separated	1.30%	2.50%
	Widowed	17.60%	12.10%

Note: Inapplicable and missing response categories are excluded from all figures and tables. Proportions may not sum to 100%.

Key Findings from Regression Analysis

- Economic Stability Domain:** Compared with high income, poor-income (OR = 1.44) and middle-income (OR = 1.29) individuals had higher odds of rare cancer, while unemployed individuals had lower odds than those employed individuals (OR = 0.78).
- Education Domain:** Individuals without a degree (OR = 1.74) and those with a high school diploma (OR = 1.35) had higher odds of rare cancer compared with college graduates or above.
- Social & Community Context Domain:** Compared with married individuals, never-married (OR = 2.15) and separated (OR = 2.12) individuals had ~2-fold higher odds of rare cancer. Non-US-born (OR = 1.49) vs US-born and non-English speakers (OR = 1.64) vs English speakers also had higher odds, while non-Hispanic individuals had lower odds vs Hispanic (OR = 0.46).
- Neighborhood & Built Environment Domain:** Smoking (OR = 1.40), compared with non-smoking, and physical inactivity (OR = 1.16), compared with active individuals, were associated with higher odds of rare cancer.
- Healthcare Access & Quality Domain:** Public insurance (OR = 1.69) was associated with higher odds than private insurance, while Medicare showed lower odds (OR = 0.53); inability to afford medications (OR = 1.68) and lack of routine care (OR = 1.41) were also associated with higher odds

Forest Plot: Association of SDoH with Rare Cancer



Survey-weighted logistic regression examining associations between SDoH and rare cancer diagnosis (CAOTHER) using pooled MEPS data (2018–2022). Each point represents the odds ratio for the listed category relative to its reference group; horizontal lines indicate 95% confidence intervals. All predictors shown are statistically significant (p < 0.05).

CONCLUSIONS

- Across economic and education domains, poor income and lower educational attainment were associated with higher odds of rare cancer, while unemployment showed lower odds relative to employment.
- Within social and community factors, non-married individuals, non-US-born individuals, and those speaking a language other than English at home had higher odds of rare cancer, whereas non-Hispanic individuals had lower odds compared with Hispanic individuals.
- Behavioral factors, including smoking and physical inactivity, were also linked to higher odds of rare cancer.
- From a health care access perspective, public insurance, inability to afford medications, and lack of routine care were associated with higher odds, while Medicare coverage was associated with lower odds.
- Overall, these findings demonstrate that multiple dimensions of social determinants of health are associated with rare cancer status, highlighting the presence of disparities across populations.
- The cross-sectional design limits causal interpretation, and potential misclassification and residual confounding may influence these findings. Further analyses comparing rare and non-rare cancer populations will help contextualize these disparities and inform targeted interventions.

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DISCLOSURES

NK, HD, JK, and AG are employees of Atria India Pvt. Ltd., Gurugram, India. SG is an employee of Atria Inc., USA. CM is an employee of Atria Inc., Canada. All authors declare no conflicts of interest related to this research.

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