

# Social Determinants of Health and Clinical Burden in Narcolepsy: A Retrospective Cohort Analysis

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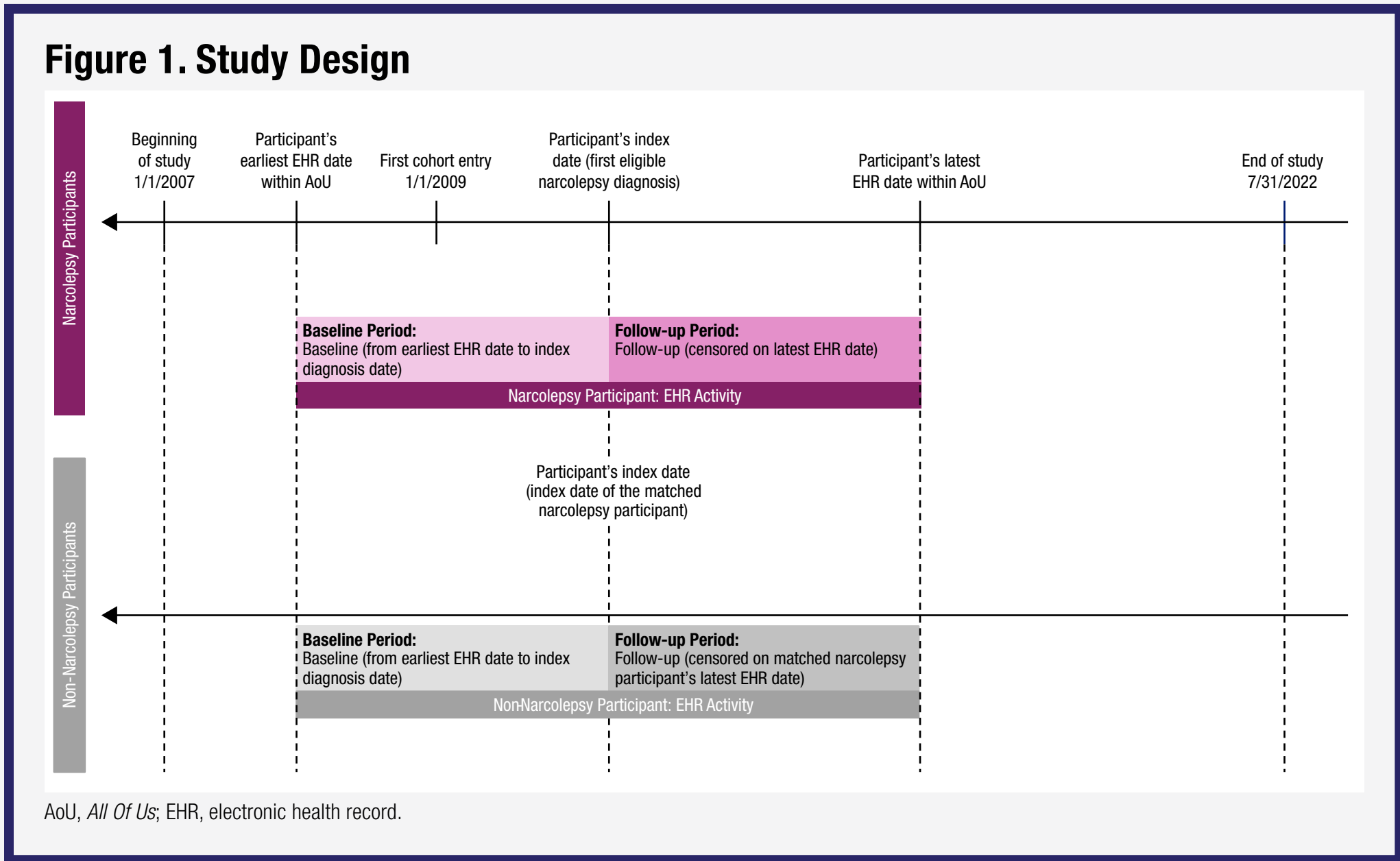
## Introduction

- Although the clinical comorbidity burden of narcolepsy, a central disorder of hypersomnolence characterized by excessive daytime sleepiness, is well documented,<sup>1</sup> the impact of social determinants of health (SDoH) on this population remains poorly understood
- The National Institutes of Health (NIH) launched the *All of Us* Research Program as a nationwide initiative to create a database reflecting the increasingly diverse US population<sup>2</sup>
  - The *All of Us* Database is a comprehensive resource that includes deidentified data from electronic health records (EHRs) and participant surveys, including information on demographics, overall health, lifestyle, and a specific survey assessing SDoH factors

## Objective

- To describe demographic and clinical characteristics of individuals with narcolepsy, focusing on SDoH and health disparities

## Methods



- A retrospective, observational study was conducted using EHR and survey data from the *All of Us* Research Program (1/1/2007–7/31/2022)
- Individuals with narcolepsy were required to have 1 Systematized Nomenclature of Medicine (SNOMED) code for narcolepsy (1/1/2009–1/31/2022); index was defined as the earliest diagnosis date
- Participants without narcolepsy were selected using risk set sampling and matched 3:1 to those with narcolepsy on age and year at main survey completion, sex, year and month of earliest EHR encounter, available time in the EHR, and SDoH survey completion status
- SDoH factors, including education level, employment status, disability status, and healthcare access, were obtained from core surveys (The Basics, Overall Health, and Lifestyle)
  - Additionally, measures of everyday discrimination,<sup>3,4</sup> loneliness,<sup>5</sup> perceived stress,<sup>6</sup> social support,<sup>7</sup> social cohesion,<sup>8</sup> medical discrimination,<sup>9</sup> and food insecurity<sup>10</sup> were evaluated in participants that completed the additional SDoH survey
  - SDoH scales were constructed based on Testaye et al<sup>11</sup>
- Clinical comorbidities were identified using SNOMED codes from EHR data during the baseline period
  - Cardiovascular (CV) comorbidities were angina pectoris, atrial fibrillation, heart failure, myocardial infarction, cardiac arrest, coronary arteriosclerosis, hypertension, and stroke
  - Cardiometabolic (CM) comorbidities were hyperlipidemia, type 2 diabetes mellitus, obesity, and metabolic encephalopathy
  - Cardiorenal (CR) comorbidities were chronic kidney disease and hypertensive renal disease
- Descriptive statistics were used to summarize participant demographics, SDoH factors, and clinical comorbidities
- Multivariable logistic regression analyses, adjusted for age at diagnosis, sex, time in EHR, race/ethnicity, education, income, employment status, health insurance, and disability status, were conducted to estimate odds ratios (ORs) and 95% confidence intervals (CIs) for having a CV, CM, or CR comorbidity, overall and separately

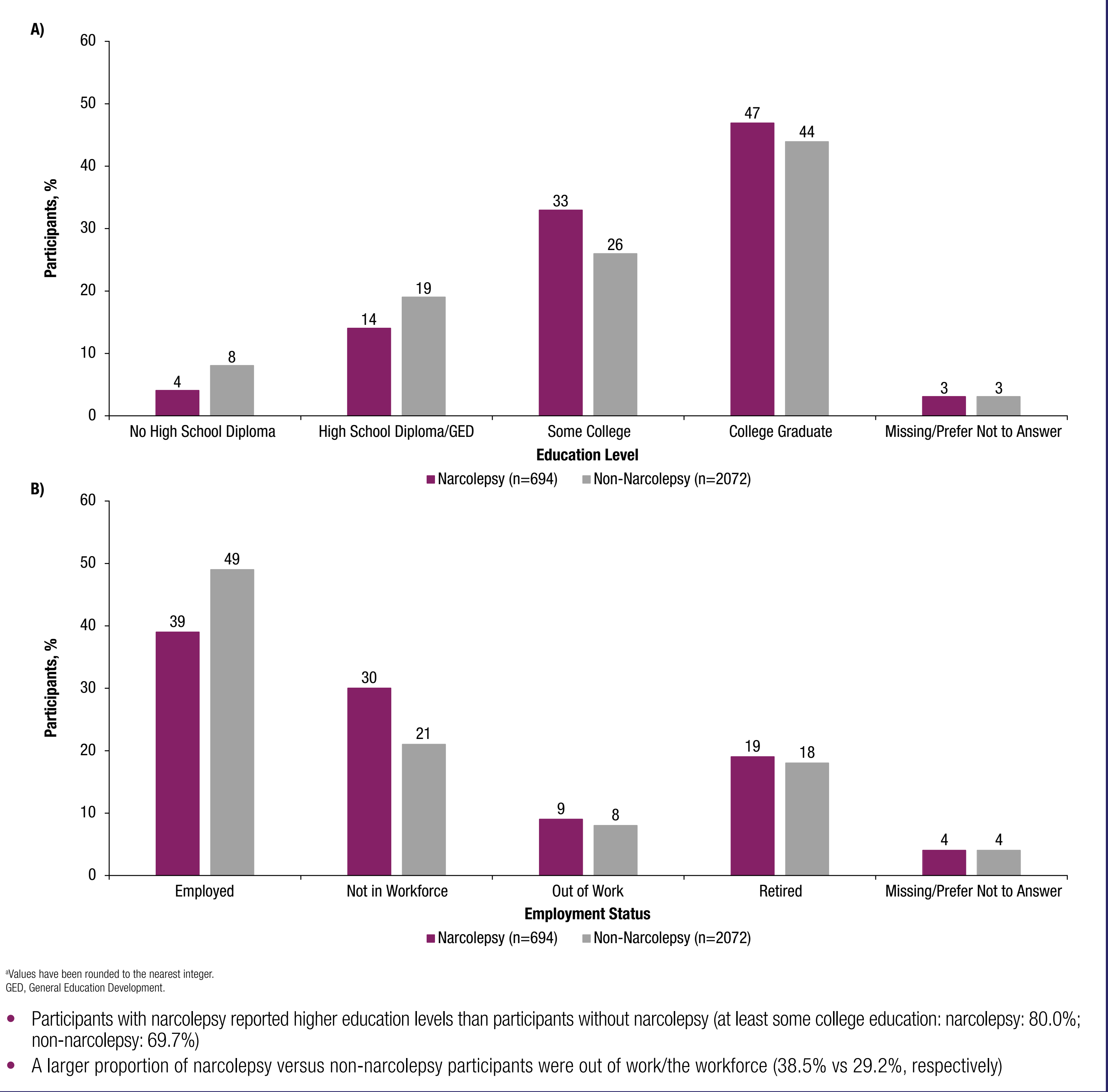
## Results

Table 1. Demographic Characteristics for Participants With Narcolepsy and Matched Participants Without Narcolepsy <sup>a</sup>		
Characteristic	Narcolepsy (N=694)	Non-Narcolepsy (N=2072)
Age at time of core survey completion, mean (SD), years	48.0 (16.8)	49.2 (16.4)
Age at diagnosis (index), mean (SD), years	45.5 (16.3)	46.7 (16.0)
Sex, n (%)		
Female	496 (71)	1449 (70)
Race/ethnicity, n (%)		
Non-Hispanic Asian/NHPI	22 (3)	47 (2)
Non-Hispanic Black	82 (12)	383 (18)
Hispanic	58 (8)	391 (19)
Non-Hispanic White	466 (67)	1115 (54)
Other	36 (5)	77 (4)
Missing/prefer not to answer	30 (4)	59 (3)
Insurance type, n (%)		
Private	260 (37)	872 (42)
Medicare	226 (33)	480 (23)
Medicaid	126 (18)	435 (21)
Other	54 (8)	122 (6)
Missing/prefer not to answer	27 (4)	152 (7)
Income, USD, n (%)		
<25,000	190 (27)	479 (23)
25,000–49,999	134 (19)	354 (17)
50,000–99,999	138 (20)	387 (19)
≥100,000	118 (17)	444 (21)
Missing/prefer not to answer	114 (16)	408 (20)
Charlson Comorbidity Index, <sup>b</sup> mean (SD)	2.7 (3.0)	2.1 (2.6)

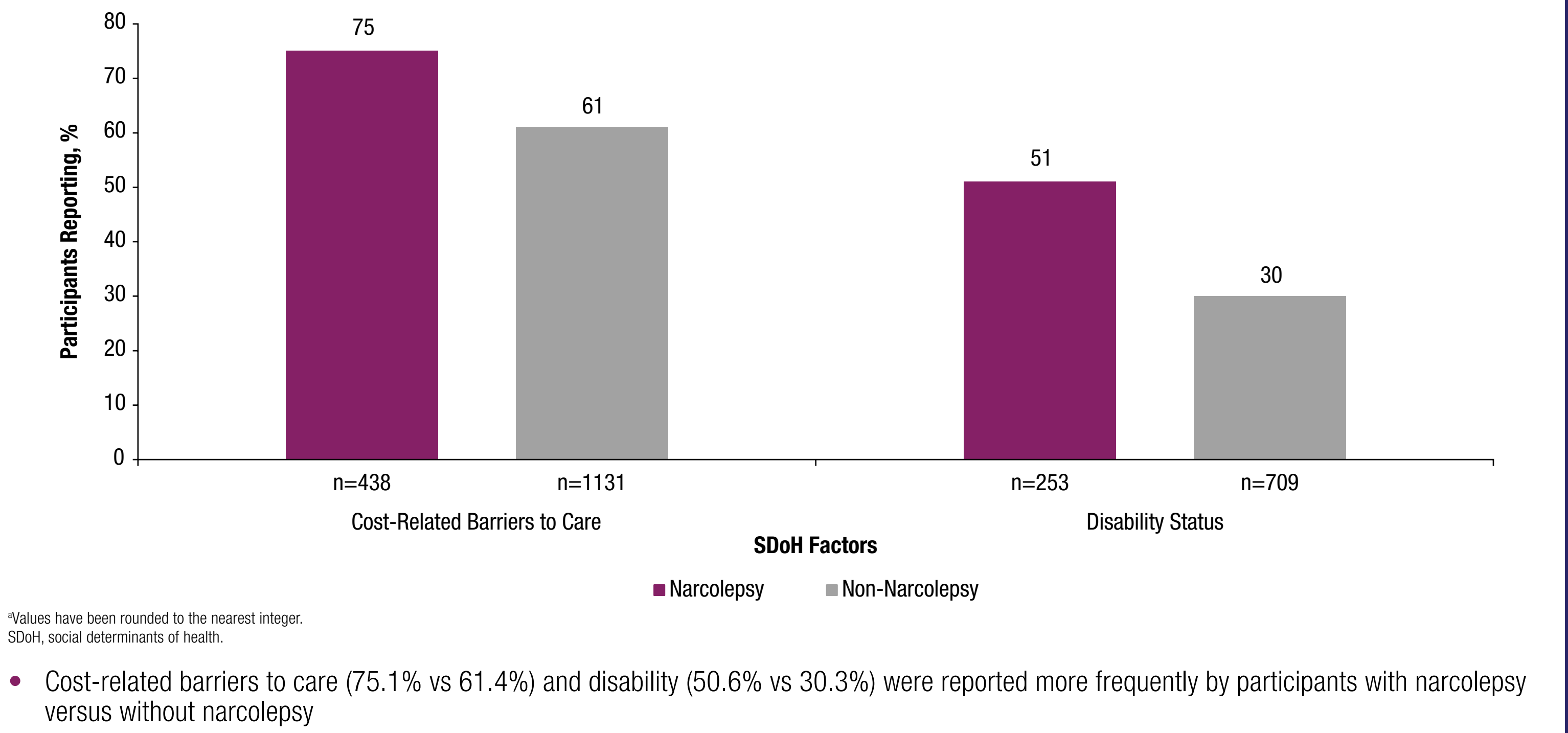
<sup>a</sup>Values for proportions have been rounded to the nearest integer. <sup>b</sup>Charlson Comorbidity Index (CCI) ranges from 0 to 33, with scores of 0 indicating no comorbidity, 1–2 mild, 3–4 moderate, and 5+ severe comorbidity burden associated with increased mortality risk. NHPI, Native Hawaiian or Pacific Islander; SD, standard deviation; USD, United States dollar.

- In total, 2766 participants (narcolepsy: n=694; non-narcolepsy: n=2072) were identified, with a mean age of 49.0 years; 70.3% were female; 57.2% were non-Hispanic White; and 20.3% were covered by Medicaid

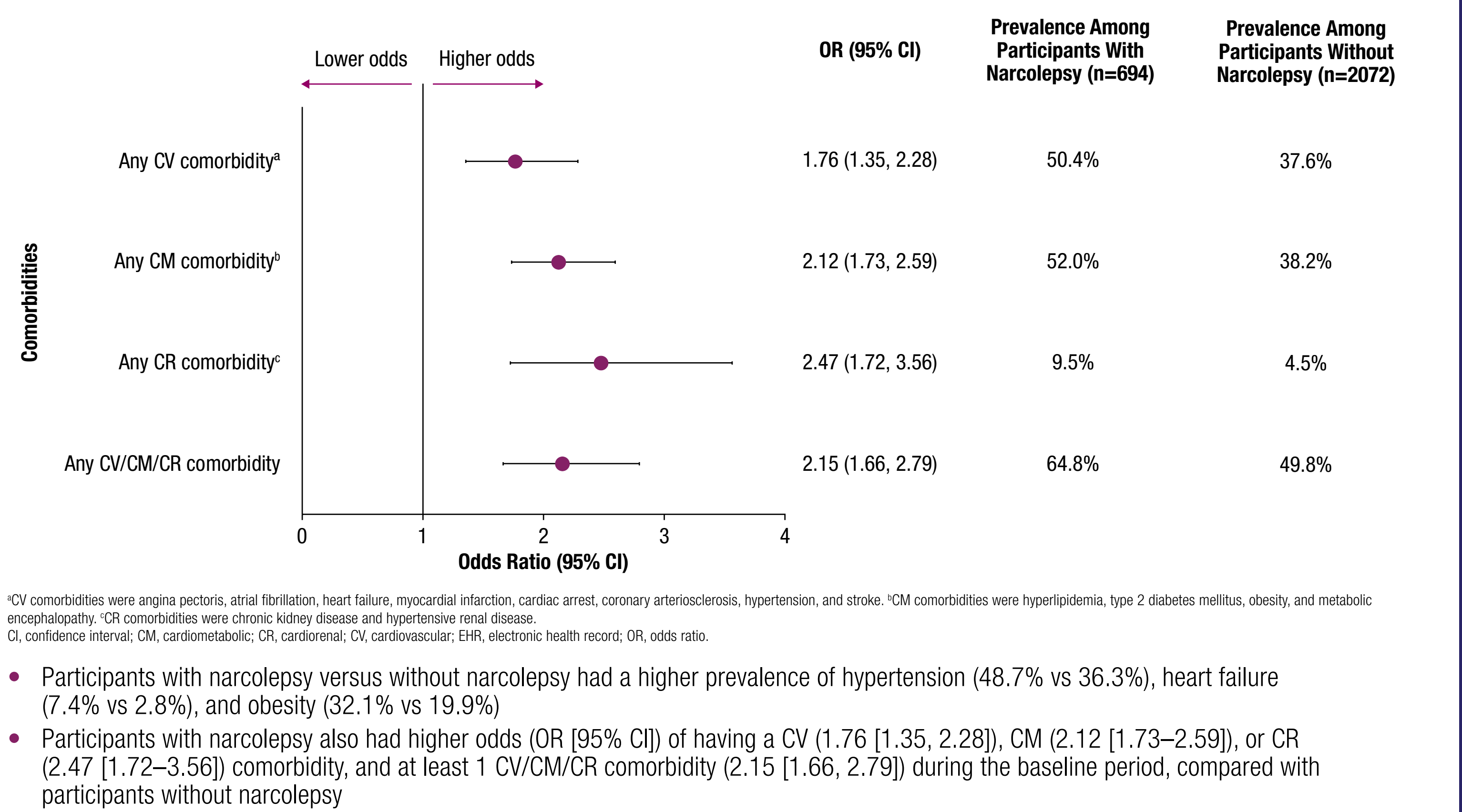
**Figure 2. Self-reported (A) Education and (B) Employment in Participants With and Without Narcolepsy<sup>a</sup>**



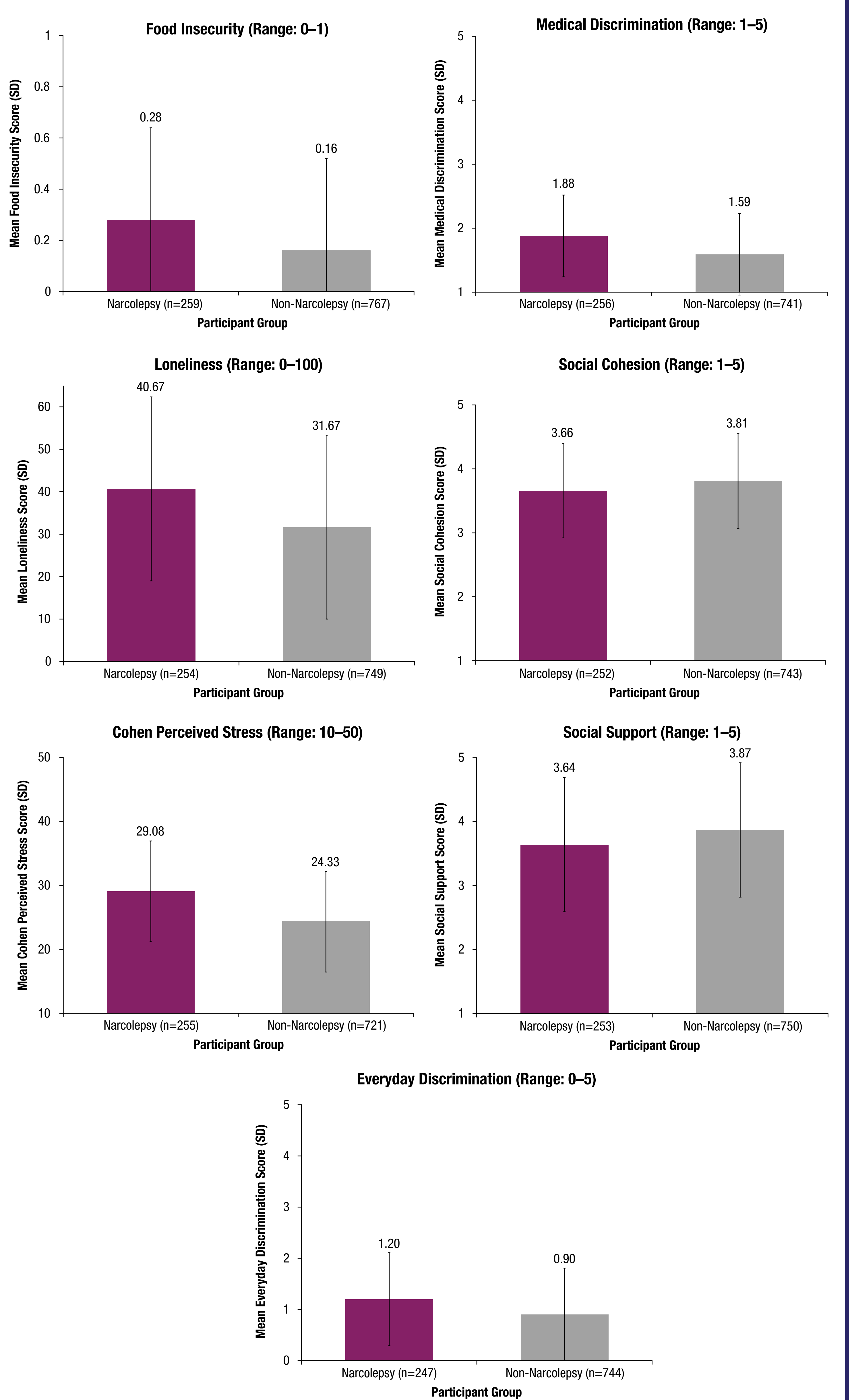
**Figure 3. Cost-Related Barriers to Care and Disability Status in Participants With and Without Narcolepsy<sup>a</sup>**



**Figure 5. Association Between Narcolepsy and Odds of Prevalent Cardiovascular, Cardiometabolic, or Cardiorenal Comorbidities**



**Figure 4. SDoH Factor Scores in Participants With and Without Narcolepsy Who Completed the SDoH Survey**



## Conclusions

- Narcolepsy is associated with social and clinical challenges, including employment barriers, SDoH-related disparities, and higher burden of comorbidities
- Limitations of the study include a small sample size, particularly for analyses that required completion of the additional SDoH survey
- Comprehensive and timely narcolepsy management strategies are warranted to address whole-person health, including comorbidities and social factors that may influence access to care and health outcomes



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