533

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

Anan Zhou, MPH[1]; Katarina Irwin, MS[2]; Sarah C. Markt, ScD, MPH[3]; Jon Michael Stroh[2]; Jiayuan Wang[2]; Martin Zagari, MD[2]; Caroleen Drachenberg, PhD, MSPH[3]; Silky Beaty, PharmD, MSPH[3]; Jessica K. Alexander, PhD[3]; Marisa Whalen, PharmD[3]; Junko Saber, MBA[2]; Barbara Hutchinson, MD, PhD[4]

[1]Genesis Research Group, Hoboken, NJ, USA; [2]Innopiphany, LLC, Irvine, CA, USA; [3]Jazz Pharmaceuticals, Palo Alto, CA, USA; [4]Chesapeake Cardiac Care, Bowie, MD, USA

Introduction

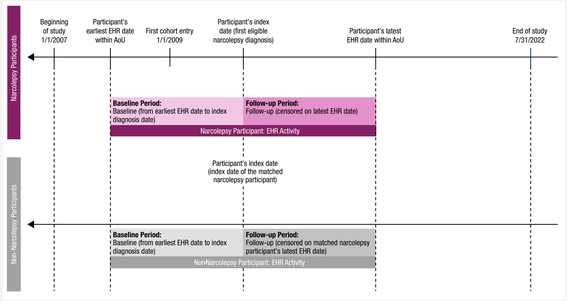
- Although the clinical comorbidity burden of narcolepsy, a central disorder of hypersomnolence characterized by excessive daytime sleepiness, is well documented,[1] the impact of social determinants of health (SDoH) on this population remains poorly understood
- The National Institutes of Health (NIH) launched the *All of Us* Research Program as a nationwide initiative to create a database reflecting the increasingly diverse US population[2]
  - 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

Figure 1. Study Design



AoU, *All Of Us*; EHR, electronic health record.

- 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,[3,4] loneliness,[5] perceived stress,[6] social support,[7] social cohesion,[8] medical discrimination,[9] and food insecurity[10] were evaluated in participants that completed the additional SDoH survey
  - SDoH scales were constructed based on Tesfaye et al[11]
- 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

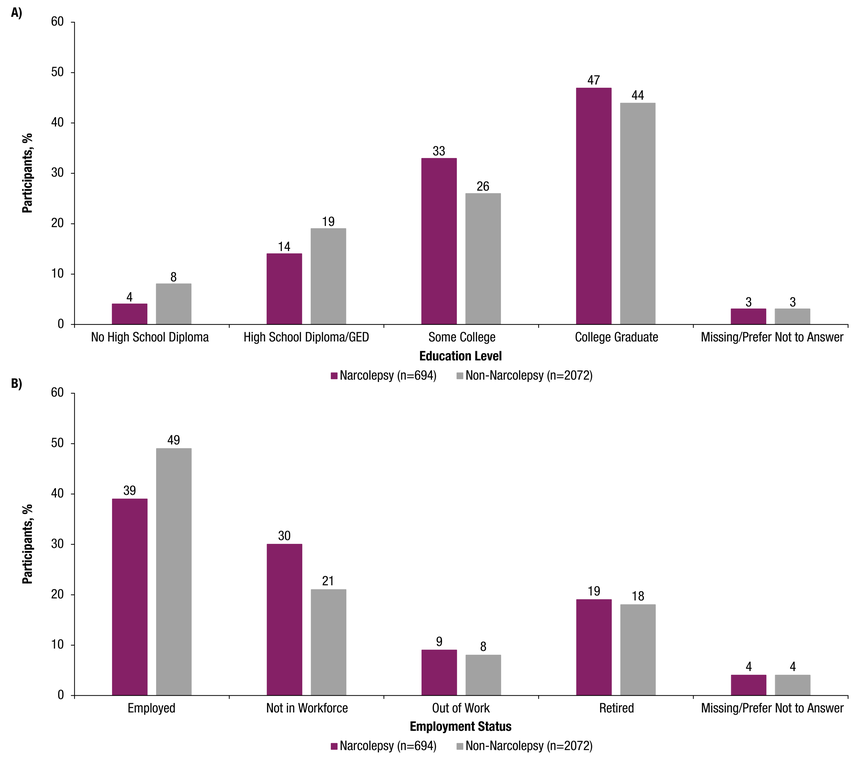
Table 1. Demographic Characteristics for Participants With Narcolepsy and Matched Participants Without Narcolepsy[a]

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,[b] mean (SD)	2.7 (3.0)	2.1 (2.6)

[a]Values for proportions have been rounded to the nearest integer. [b]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

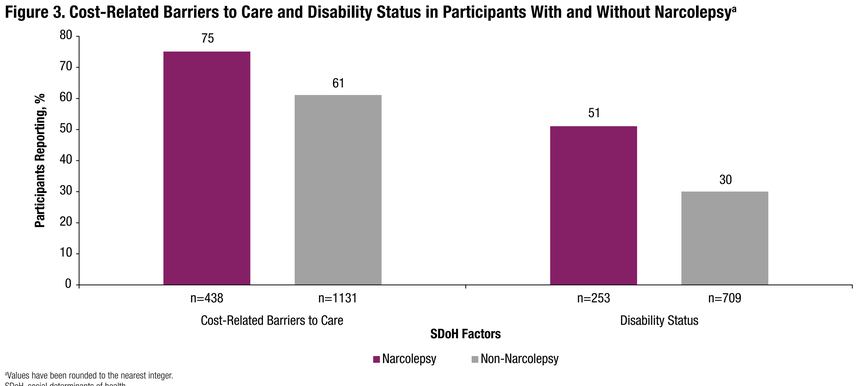
Figure 2. Self-reported (A) Education and (B) Employment in Participants With and Without Narcolepsy[a]



[a]Values have been rounded to the nearest integer.
GED, General Education Development.

- Participants with narcolepsy reported higher education levels than participants without narcolepsy (at least some college education: narcolepsy: 80.0%; non-narcolepsy: 69.7%)
- A larger proportion of narcolepsy versus non-narcolepsy participants were out of work/the workforce (38.5% vs 29.2%, respectively)

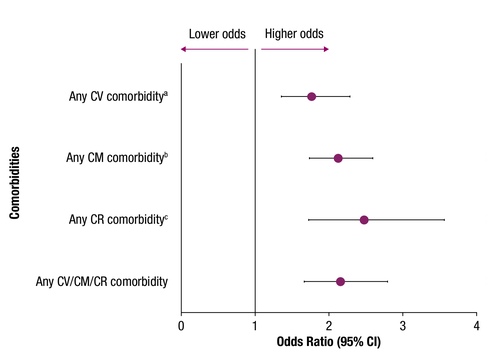
Figure 3. Cost-Related Barriers to Care and Disability Status in Participants With and Without Narcolepsy[a]



[a]Values have been rounded to the nearest integer.
SDoH, social determinants of health.

- Cost-related barriers to care (75.1% vs 61.4%) and disability (50.6% vs 30.3%) were reported more frequently by participants with narcolepsy versus without narcolepsy

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

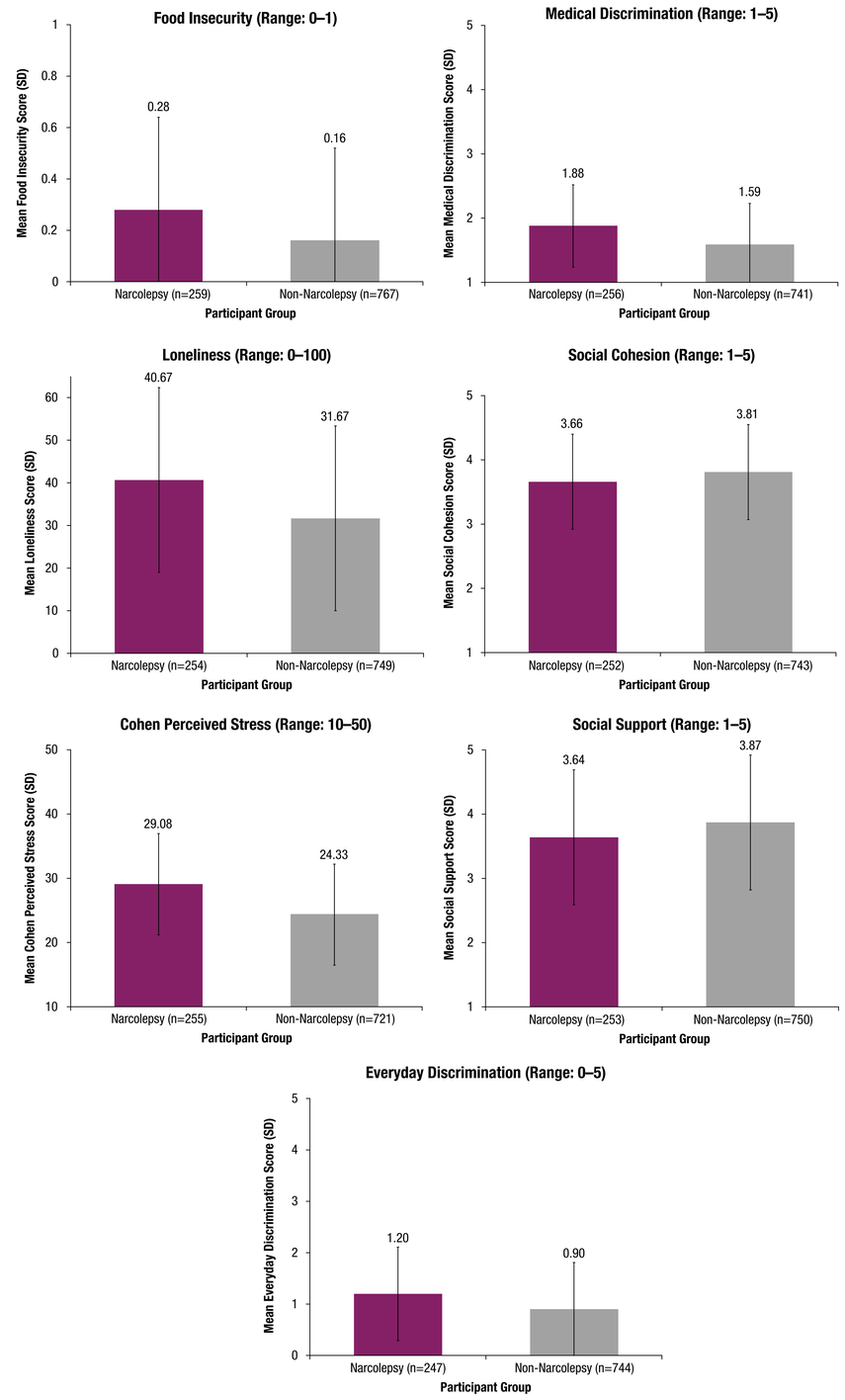


	OR (95% CI)	Prevalence Among Participants With Narcolepsy (n=694)	Prevalence Among Participants Without Narcolepsy (n=2072)
Any CV comorbidity[a]	1.76 (1.35, 2.28)	50.4%	37.6%
Any CM comorbidity[b]	2.12 (1.73, 2.59)	52.0%	38.2%
Any CR comorbidity[c]	2.47 (1.72, 3.56)	9.5%	4.5%
Any CV/CM/CR comorbidity	2.15 (1.66, 2.79)	64.8%	49.8%

[a]CV comorbidities were angina pectoris, atrial fibrillation, heart failure, myocardial infarction, cardiac arrest, coronary arteriosclerosis, hypertension, and stroke. [b]CM comorbidities were hyperlipidemia, type 2 diabetes mellitus, obesity, and metabolic encephalopathy. [c]CR comorbidities were chronic kidney disease and hypertensive renal disease.
CI, confidence interval; CM, cardiometabolic; CR, cardiorenal; CV, cardiovascular; EHR, electronic health record; OR, odds ratio.

- Participants with narcolepsy versus without narcolepsy had a higher prevalence of hypertension (48.7% vs 36.3%), heart failure (7.4% vs 2.8%), and obesity (32.1% vs 19.9%)
- Participants with narcolepsy also had higher odds (OR [95% CI]) of having a CV (1.76 [1.35, 2.28]), CM (2.12 [1.73–2.59]), or CR (2.47 [1.72–3.56]) comorbidity, and at least 1 CV/CM/CR comorbidity (2.15 [1.66, 2.79]) during the baseline period, compared with participants without narcolepsy

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



SD, standard deviation; SDoH, social determinants of health.

- Among respondents who completed the additional SDoH survey (narcolepsy: n=259; non-narcolepsy: n=768), participants with narcolepsy reported higher levels of food insecurity, loneliness, perceived stress, and everyday and medical discrimination, as well as lower levels of social support and cohesion

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

References: 1. American Academy of Sleep Medicine. *International Classification of Sleep Disorders – Third Edition*, Text Revision. Darien, IL: American Academy of Sleep Medicine; 2023. **2.** Denny JC, et al. *N Engl J Med*. 2019;381:668-76. **3.** Williams DR. *Ann Epidemiol*. 1997;7:322-33. **4.** Williams DR, et al. Everyday Discrimination Scale. 2025. Available at: https://scholar.harvard.edu/davidrwilliams/node/32397. **5.** Hays RD, DiMatteo MR. *J Pers Assess*. 1987;51:69-81. **6.** Cohen S, et al. *J Health Soc Behav*. 1983;24:385-96. **7.** Moser A, et al. *J Clin Epidemiol*. 2012;65:1107-16. **8.** Mujahid MS, et al. *Am J Epidemiol*. 2007;165:858-67. **9.** Peek ME, et al. *Ethn Dis*. 2011;21:502-9. **10.** Hager ER, et al. *Pediatrics*. 2010;126:e26-32. **11.** Tesfaye S, et al. *Scientific Reports*. 2024;14:8815.

Support and Acknowledgments: This study was supported by Jazz Pharmaceuticals. We gratefully acknowledge *All of Us* participants for their contributions, without whom this research would not have been possible. We also thank the National Institutes of Health's *All of Us* Research Program for making available the participant data examined in this study. Under the direction of the authors, Peloton Advantage, LLC (an OPEN Health company), employees, Aeja Jackson, PhD, MS, and Eleanor Bush, MA, provided medical writing support and an editor provided editorial support, which were funded by Jazz Pharmaceuticals.

Disclosures: A Zhou is a full-time employee of Genesis Research Group and has received consulting fees from Jazz Pharmaceuticals, plc. **K Irwin, JM Stroh, J Wang, M Zagari,** and **J Saber** are employees of Innopiphany, LLC, which has received consulting fees from Jazz Pharmaceuticals, plc. **SC Markt, C Drachenberg, S Beaty, JK Alexander,** and **M Whalen** are full-time employees of Jazz Pharmaceuticals who, in the course of this employment, have received stock options exercisable for, and other stock awards of, ordinary shares of Jazz Pharmaceuticals, plc. **B Hutchinson** is a consultant to Jazz Pharmaceuticals, plc.

Scan this code to access this poster online.
This code is not for promotional purposes.

Presented at SLEEP 2025, the 39th Annual Meeting of the Associated Professional Sleep Societies, LLC (APSS); June 8–11, 2025; Seattle, WA, USA