

Demographics and Comorbidities of Patients With Narcolepsy: A Propensity Score–Matched Cohort Study

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INTRODUCTION

- Narcolepsy is a rare, chronic sleep disorder that affects approximately 30-40 per 100,000 people in the United States and 50 per 100,000 people in the European Union¹⁻³
- Symptoms of narcolepsy include excessive daytime sleepiness, disturbed nighttime sleep, sleep paralysis, and hypnagogic/hypnopompic hallucinations; people with narcolepsy type 1 also experience cataplexy⁴
- These symptoms often lead to negative impacts on quality of life, impaired ability to function at work or school, and difficulty maintaining social relationships⁵⁻⁷
- In a previous analysis of electronic health record (EHR) data from Mayo Clinic, sleep, mood, and pain disorders were significantly increased in the narcolepsy cohort compared with a matched nonnarcolepsy cohort⁸
- A key goal of the current work is to build upon prior research from Mayo Clinic by incorporating a more racially diverse patient population, thereby enhancing generalizability and inclusivity of findings

OBJECTIVE

- To describe the demographic characteristics and the medical and psychiatric comorbidities of patients with narcolepsy using EHR data from Duke Health

METHODS

STUDY DESIGN

- A retrospective, EHR-based search identified first-time patients at Duke Health between January 1, 2012, and March 31, 2024
- Data were included from patients who had the following:
 - ≥1 narcolepsy-specific *International Classification of Diseases, 9th Revision* (ICD-9 [347.*]) or *10th Revision* (ICD-10 [G47.4*]) code AND
 - ≥1 disease-supportive statement in clinical notes, identified using a natural language processing algorithm
- A control cohort of randomly sampled patients from Duke Health was propensity matched for birth year, age at first institutional encounter, sex, race, number of diagnosis code instances, and mortality
 - Ethnicity was not available for matching

DATA ANALYSIS

- Common comorbidities detected by ICD codes were compared and ranked between cohorts by odds ratio (OR)
- Statistical significance was determined using a chi-squared test
- P* values were corrected for multiple comparisons using Bonferroni correction to control for a 5% false discovery rate

RESULTS

PATIENT DEMOGRAPHICS

- Of the 2,617,188 patients within the EHR database, 1659 patients with narcolepsy were identified
- Median age at first presentation to Duke Health was 31 years (**Table 1**)

TABLE: Patient Demographics

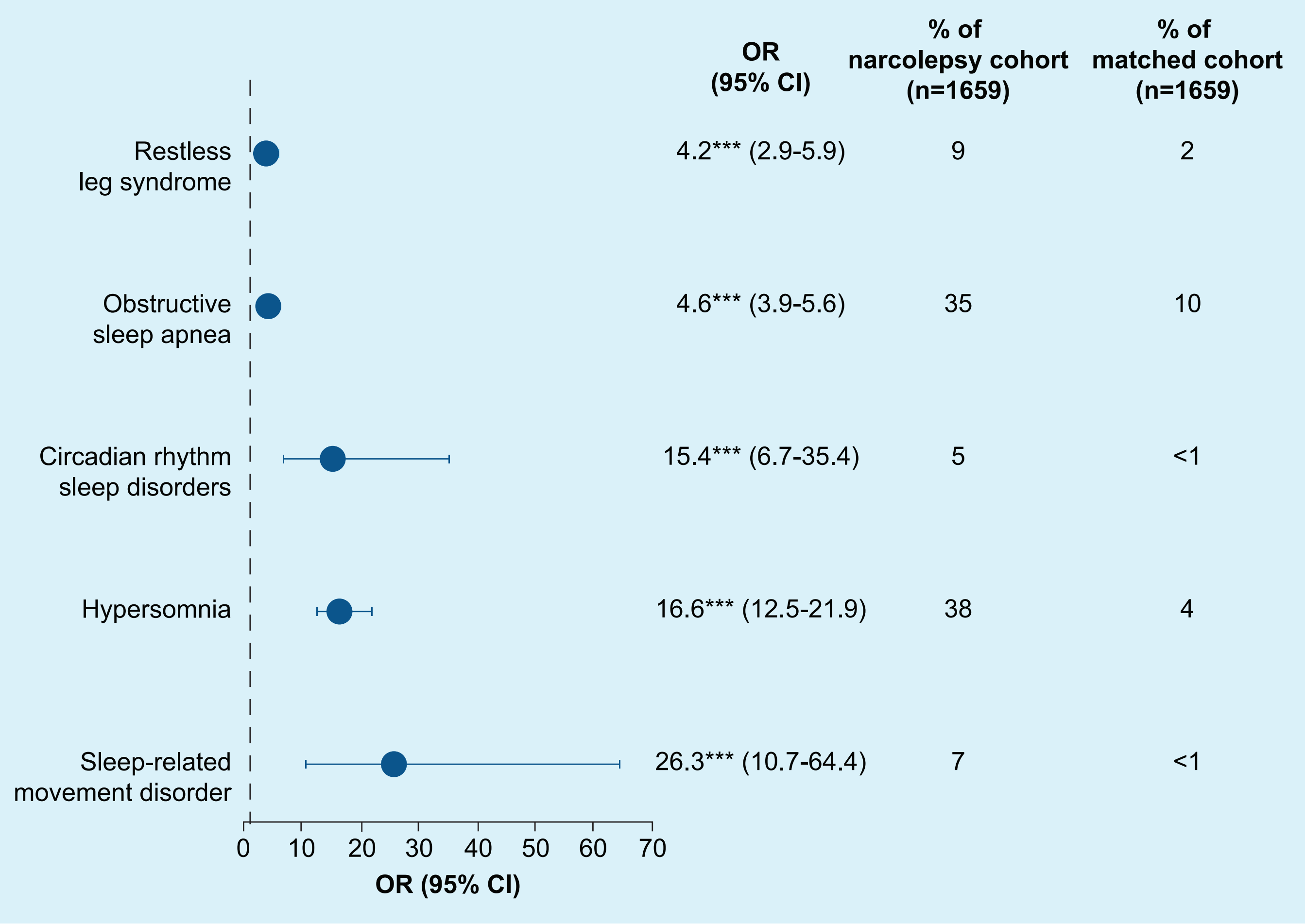
Characteristic	Narcolepsy cohort (n=1659)	Propensity-matched cohort (n=1659)
Age at first encounter, median (IQR), y	31 (21, 43)	31 (21, 43.5)
Birth year, median (IQR), y	1977 (1962, 1989)	1977 (1961, 1989)
Sex, n (%)		
Female	1142 (69)	1142 (69)
Male	517 (31)	517 (31)
Race, n (%)		
Black	371 (22)	371 (22)
White	1146 (69)	1145 (69)
Other ^a	142 (9)	143 (9)
Number of diagnosis code instances, median (IQR)	103 (35, 261)	102 (12, 243)
Mortality, n (%)	109 (7)	109 (7)

^aIncludes Asian or Asian American, Native American or Pacific Islander, mixed race, and unknown.

COMORBIDITIES

- Of the top 23 comorbidities ranked by OR that occurred significantly more frequently among the narcolepsy cohort compared with the control cohort, 15 were sleep, psychiatric or mood, and pain disorders
 - 5 sleep disorders occurred significantly more frequently in the narcolepsy cohort compared with the control cohort (all *P*<0.0001; **Figure 1**)
 - Hypersomnia and sleep-related movement disorder had the greatest ORs (16.6 and 26.3, respectively)

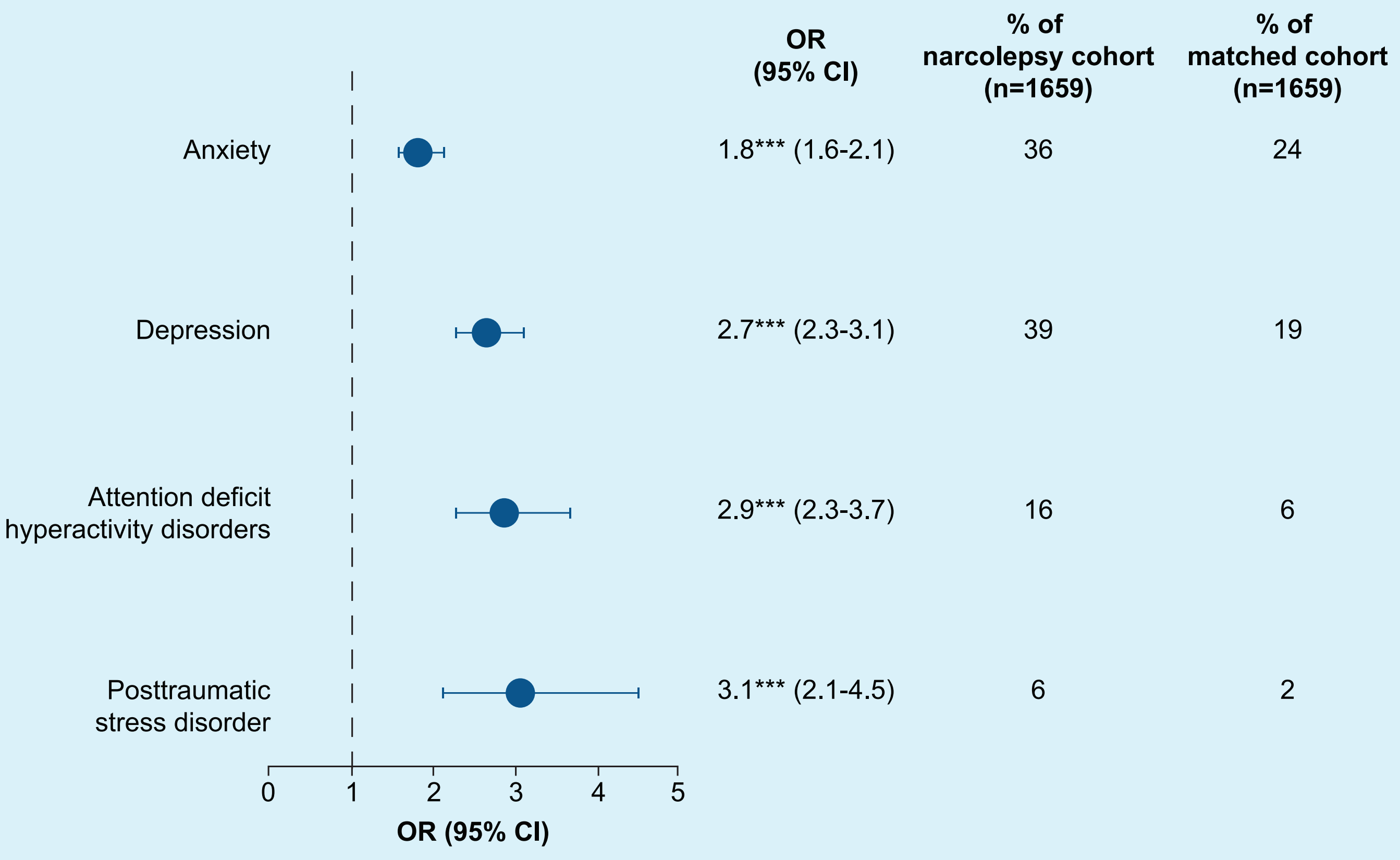
FIGURE 1: Sleep Disorders Comorbid With Narcolepsy



****P*<0.0001.

- 4 psychiatric or mood disorders occurred significantly more frequently in the narcolepsy cohort compared with the control cohort (all *P*<0.0001; **Figure 2**)
 - Attention deficit hyperactivity disorder and posttraumatic stress disorder had the highest ORs (2.9 and 3.1, respectively)

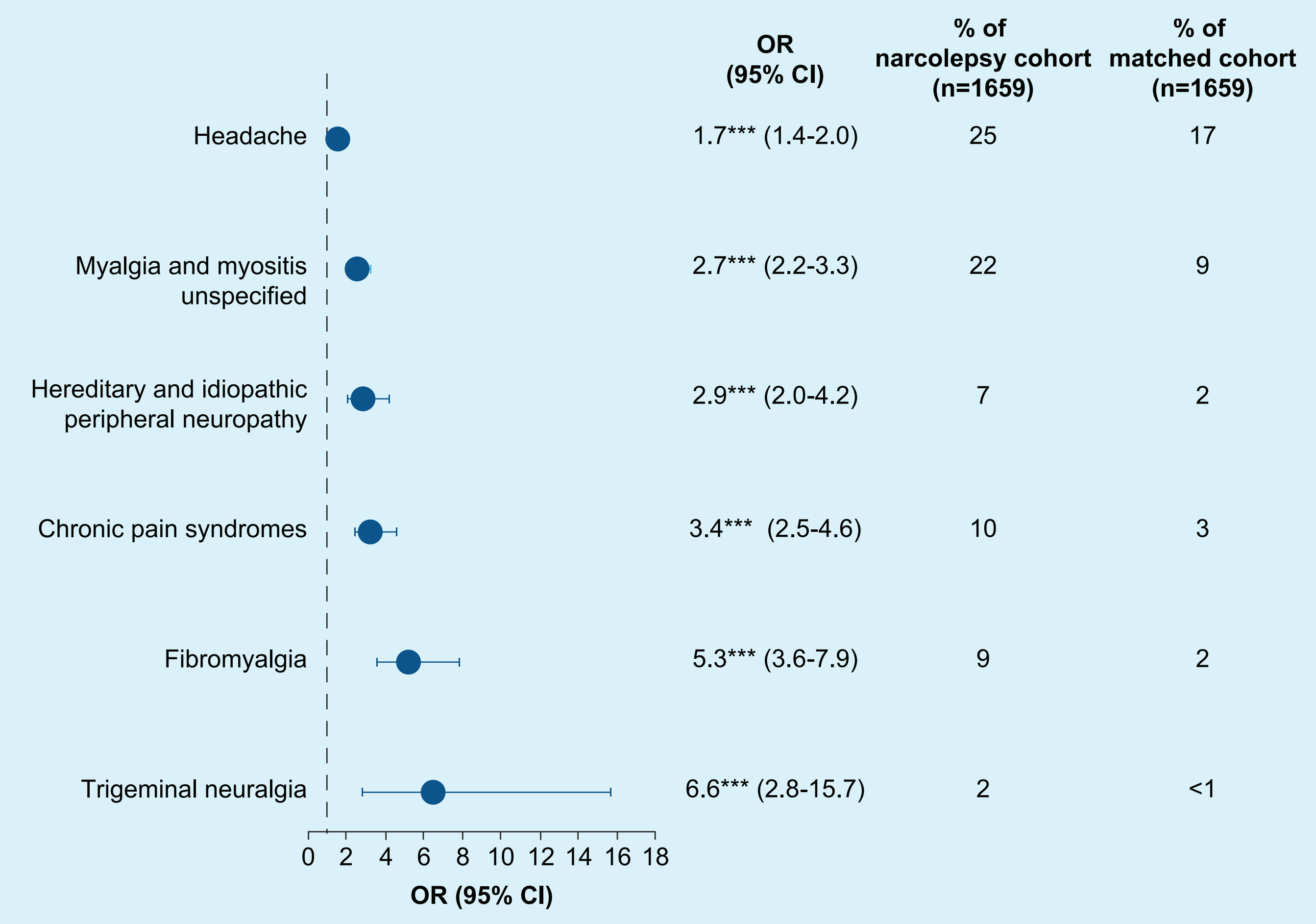
FIGURE 2: Psychiatric or Mood Disorders Comorbid With Narcolepsy



****P*<0.0001.

- 6 separate pain disorders occurred significantly more frequently in the narcolepsy cohort compared with the control cohort (all *P*<0.001; **Figure 3**)
 - Fibromyalgia and trigeminal neuralgia had the greatest ORs (5.3 and 6.6, respectively)

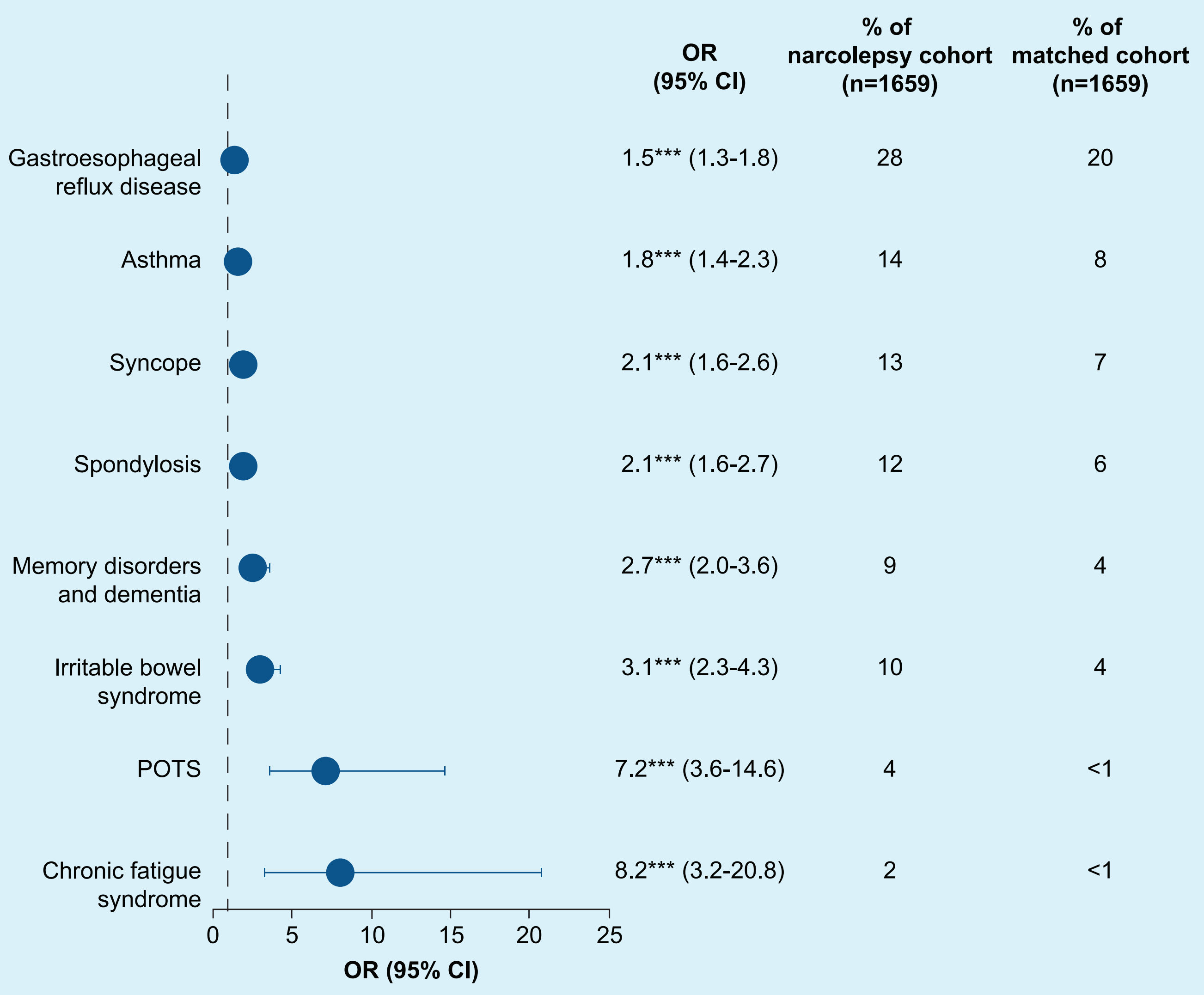
FIGURE 3: Pain Disorders Comorbid With Narcolepsy



****P*<0.0001.

- Other comorbidities that occurred significantly more frequently in the narcolepsy cohort compared with the control cohort (all *P*<0.0001) included chronic fatigue syndrome and postural orthostatic tachycardia syndrome (POTS; **Figure 4**)

FIGURE 4: Additional Disorders Comorbid With Narcolepsy



****P*<0.0001.

POTS, postural orthostatic tachycardia syndrome.

STUDY LIMITATIONS

- As this analysis used the number of diagnosis code instances for propensity matching, the control cohort may have relatively higher rates of comorbidities and thus not be representative of the general population without narcolepsy

CONCLUSIONS

- The findings from this analysis of EHR data corroborate and expand upon those of a prior EHR study,⁸ with significantly increased frequency of comorbid sleep, psychiatric or mood, and pain disorders in patients with narcolepsy compared with matched controls
- Compared with the prior EHR study from Mayo Clinic,⁸ POTS and chronic fatigue syndrome were newly identified among the most frequent comorbidities associated with narcolepsy
- These real-world data identifying the most frequent comorbidities in a narcolepsy cohort may be important to consider when evaluating potential therapies

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DISCLOSURES

MS has served on advisory boards for Jazz Pharmaceuticals. **MCL** has no disclosures to report. **AS** was an employee of nference. **JG** was an employee of Avadel Pharmaceuticals and is a consultant to Alkermes, Inc.

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