

The Clinical and Humanistic Burden of Narcolepsy: Matched Analysis of US National Health and Wellness Survey Data

Kiran P. Maski,¹ Michael J. Doane,² M. Janelle Cambron-Mellott,³ Shakiba Eslamimehr,³ Adam Jauregui,³ Wilbur P. Williams, III²

¹Department of Neurology, Boston Children's Hospital, Boston, MA, USA; ²Alkermes, Inc., Waltham, MA, USA; ³Oracle Life Sciences, Austin, TX, USA

Poster No: 323

INTRODUCTION

- Narcolepsy is a rare, chronic neurologic disorder that affects the brain's ability to regulate sleep–wake cycles, resulting in excessive daytime sleepiness (EDS)^{1,2}
- Narcolepsy type 1 (NT1) and narcolepsy type 2 (NT2) are characterized by EDS (including sleep attacks), sleep inertia, sleep paralysis, and/or hallucinations^{3,4}
 - In addition, NT1 features cataplexy, which is a sudden, spontaneous, and temporary loss of muscle control triggered by strong emotional stimuli (eg, fear, anger, laughter, or stress)³
- Narcolepsy may be associated with substantial clinical and humanistic burden, and more research is needed to understand the broad impacts of this condition⁵⁻⁷

OBJECTIVE

- To compare clinical and humanistic outcomes in adults with narcolepsy versus adults without narcolepsy

RESULTS

PATIENT DEMOGRAPHICS AND DISPOSITION

- Among patients with narcolepsy (N = 335), 56% were female, mean age was 45.5 years, and 68% were White (Figure 1)
 - Mean (SD) ESS score for the narcolepsy group was 14.3 (5.9) and just under half (44%) had severe EDS (Figure 2)
- Among respondents without narcolepsy (N = 141,072), 55% were female, mean age was 47.8 years, and 72% were White (Figure 1)
- After 1:3 propensity score matching, 1340 eligible participants were retained for study analyses; N = 335 in the narcolepsy population and N = 1005 in the matched general population (controls)
 - For select outcomes assessed in the 2023 survey only, N = 181 and N = 542 in the narcolepsy and controls cohorts, respectively, were included in the study

FIGURE 1: Baseline Characteristics

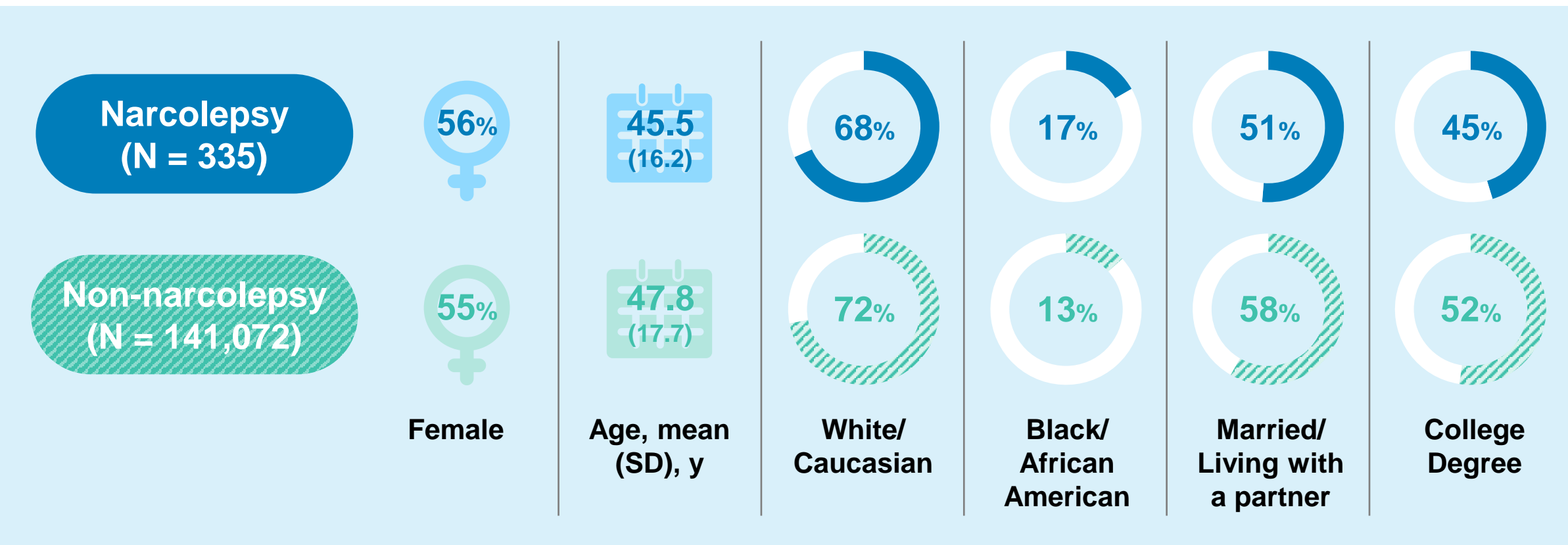
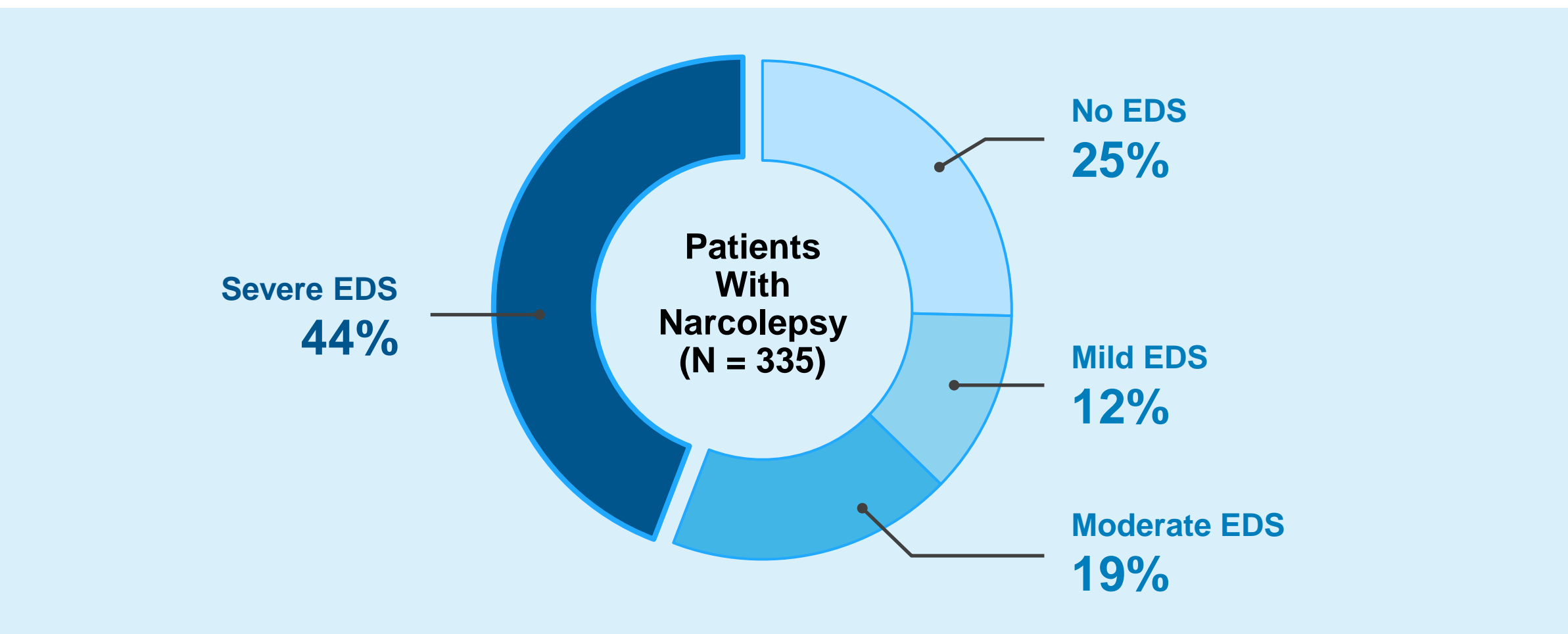


FIGURE 2: Severity Categories of Epworth Sleepiness Scale Scores in Patients With Narcolepsy^a

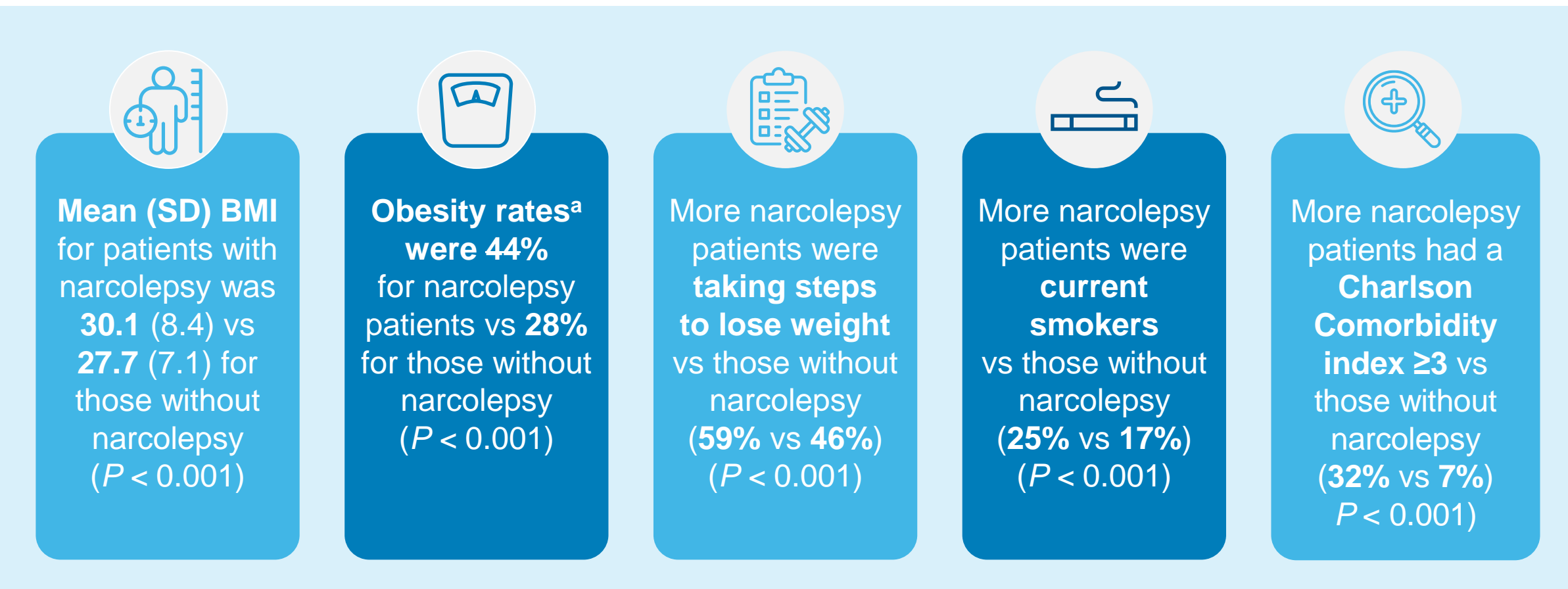


^aEpworth Sleepiness Scale composite score ranges: No EDS = 0-10; mild EDS = 11-12; moderate EDS = 13-15; severe EDS = 16-24. EDS = excessive daytime sleepiness.

CLINICAL BURDEN OF NARCOLEPSY

- Before matching, the narcolepsy cohort had higher mean body mass index, was more likely to have obesity, and be current smokers versus those without narcolepsy (Figure 3)

FIGURE 3: Weight-Related Data and Smoking Rates Among Patients With Narcolepsy vs Those Without



^aObesity was defined as having BMI > 30. BMI = body mass index.

References

- Ruoff C, Rye D. *Curr Med Res Opin*. 2016;32(10):1611-1622. 2. NINDS. Narcolepsy Fact Sheet. https://www.ninds.nih.gov/narcolepsy-fact-sheet#3201_1 (accessed May 20, 2025). 3. Dauvilliers Y. *Nat Rev Neurol*. 2014;10(7):386-95. 4. Trotti LM. *Sleep Med Rev*. 2017;35:76-84. 5. Ohayon MM. *Sleep Med*. 2013;14(6):488-492. 6. Maski K, et al. *J Clin Med Sleep*. 2017;13(3):419-425. 7. Ingravallo F, et al. *Sleep Med*. 2012;13(10):1293-1300.

METHODS

STUDY DESIGN

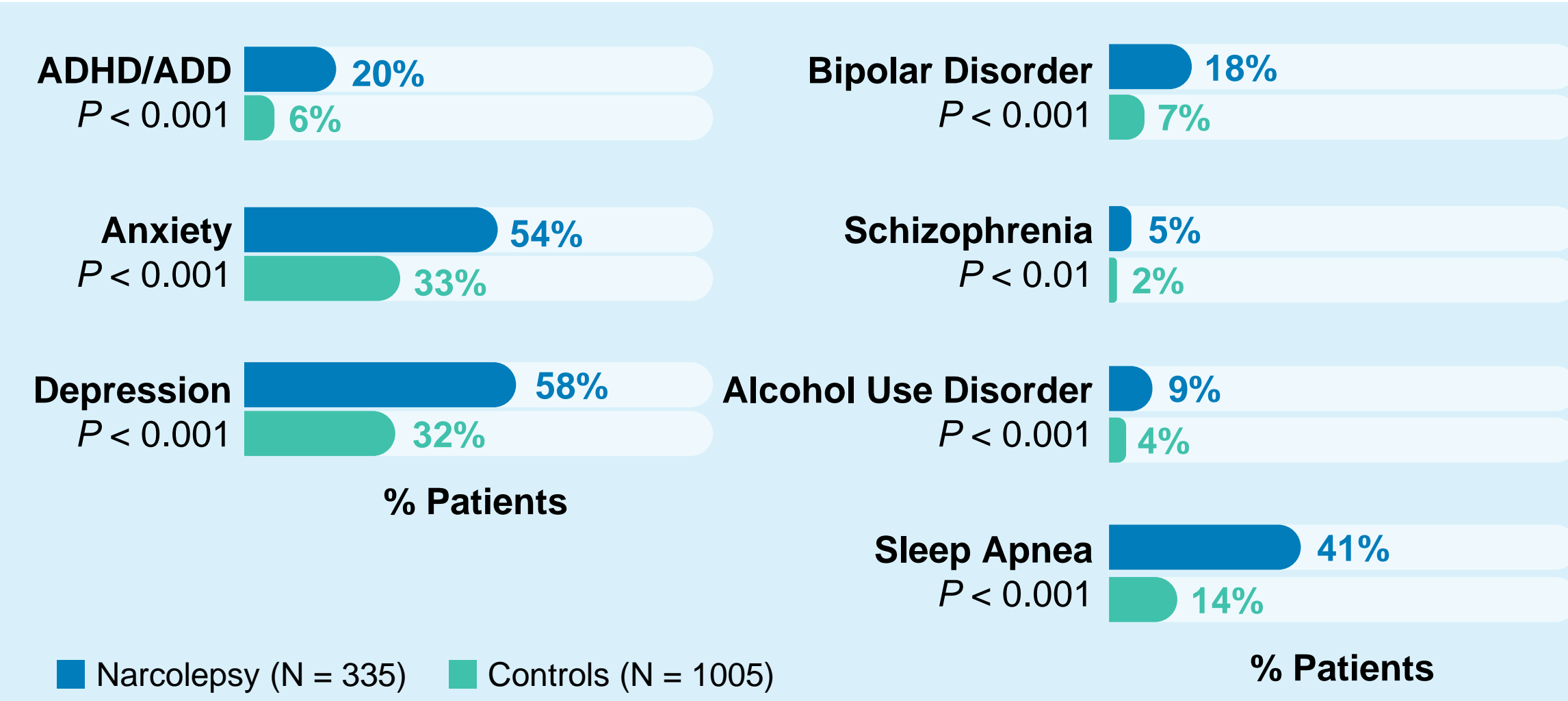
- Retrospective, cross-sectional analysis of responses to the 2021 and 2023 US National Health and Wellness Survey (NHWS)
 - The NHWS is a self-administered, online survey conducted yearly among a representative sample of US adults (based on age, sex, and race)
- If a respondent completed both years of the NHWS, the 2023 survey was used

STUDY POPULATION

Adults With Narcolepsy (N = 335)	Adults Without Narcolepsy (N = 141,072)
Participants (aged ≥18 years) with self-reported physician-diagnosed narcolepsy and reported narcolepsy symptoms in the past 12 months	Participants (aged ≥18 years) without physician-diagnosed narcolepsy and without narcolepsy symptoms in the past 12 months

- Patients with narcolepsy were more likely to experience select comorbidities compared with controls (Figure 4)

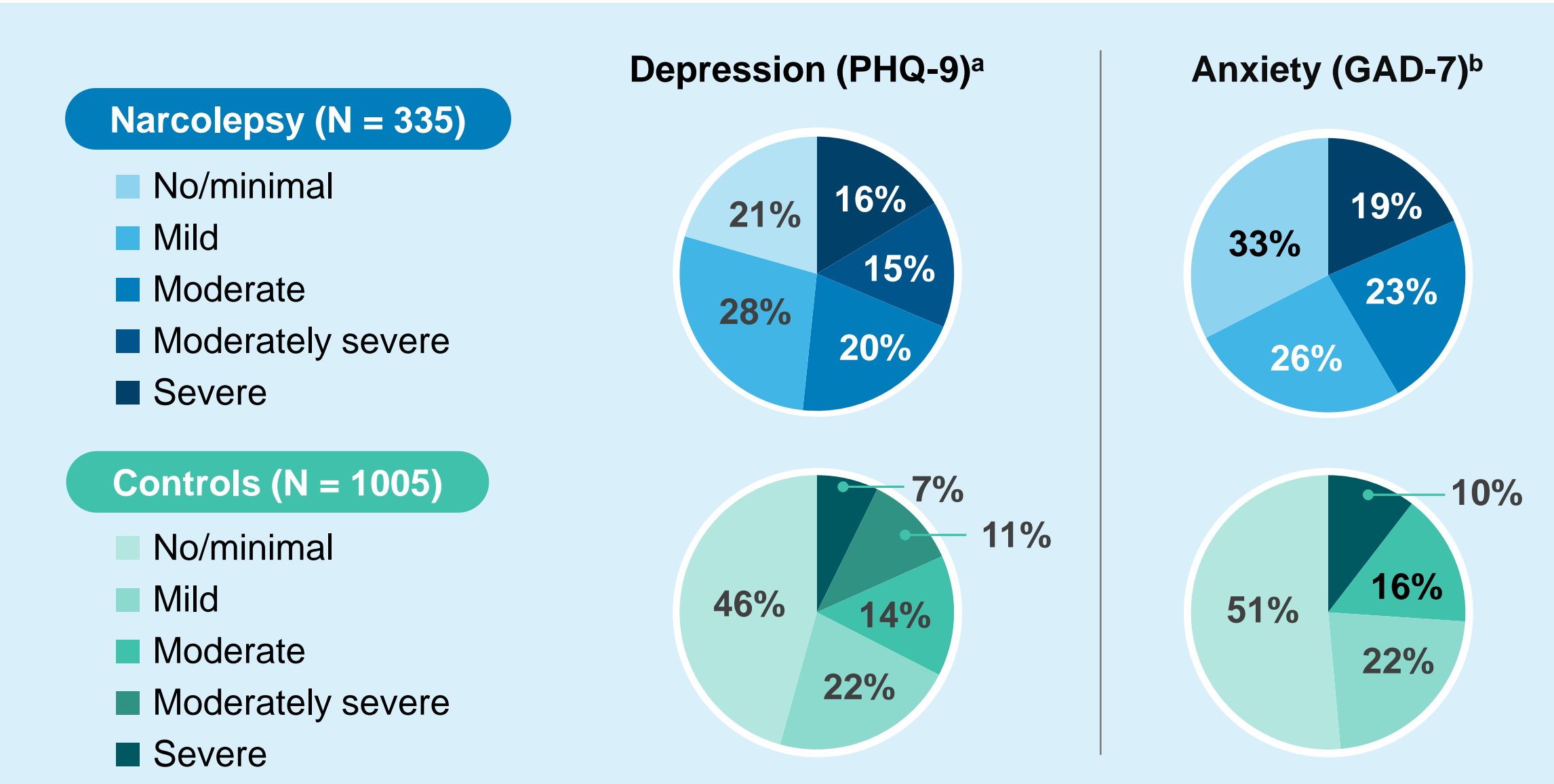
FIGURE 4: Prevalence of Select Comorbidities in Patients With Narcolepsy vs Controls



ADHD/ADD = attention-deficit hyperactive disorder/attention-deficit disorder.

- Patients with narcolepsy also experienced more severe symptoms of depression and anxiety compared with controls
 - After matching, patients with narcolepsy versus controls had significantly greater symptoms of depression (mean [SD] PHQ-9 scores: 11.2 [7.6] vs 7.4 [7.0]; $P < 0.001$) and anxiety (mean [SD] GAD-7 scores: 8.5 [6.2] vs 5.9 [5.9]; $P < 0.001$)
 - Compared with controls, a significantly higher proportion of patients with narcolepsy had moderate-to-severe depression levels according to PHQ-9 scores and moderate-to-severe anxiety levels according to GAD-7 scores ($P < 0.001$ for both) (Figure 5)

FIGURE 5: Severity of Depression and Anxiety Based on PHQ-9 and GAD-7 Scores, Respectively, in Patients With Narcolepsy



Due to rounding of individual percentages to the nearest whole number, the combined total may not equal 100%.
^aIn PHQ-9, a higher score indicates more severe depression (range, 0-27). Scores of 5, 10, 15, and 20 represent cutoffs for mild, moderate, moderately severe, and severe depression, respectively. ^bIn GAD-7, a higher score indicates more severe general anxiety disorder (range, 0-21). Scores of 5, 10, and 15 represent cutoffs for mild, moderate, and severe anxiety, respectively.
GAD-7 = General Anxiety Disorder–7 items; PHQ-9 = Patient Health Questionnaire–9 items.

STUDY LIMITATIONS

- Self-reported data cannot be independently verified and may be associated with:
 - Recall bias for measures requiring recollection over extended periods
 - Selection bias due to excluding individuals with well-controlled narcolepsy who did not report experiencing symptoms in the past 12 months
- Data may not be representative of narcolepsy patients in general, or of subpopulations such as those with limited online access, elderly and institutionalized individuals, and those with severe comorbidities or disabilities
- The cross-sectional design limits the ability to establish causality
- Propensity score matching may not account for all variables that impact outcomes

Acknowledgments

The study was supported by Alkermes, Inc. Medical writing support was provided by Aparna Rao, PhD, at Envision Pharma Group, and was funded by Alkermes, Inc. This poster was developed in accordance with Good Publication Practice (GPP4) guidelines. Authors had full control of the content and made the final decision on all aspects of this poster.

Disclosures

KPM has received grant funding from Jazz Pharmaceuticals and Harmony Biosciences, and has consulted for Alkermes, Avadel, Harmony Biosciences, Jazz Pharmaceuticals, Synchronicity Pharma, Takeda, Taysha Gene Therapies, and Zevra Pharmaceuticals. She has served as a co-principal investigator for Takeda, and as the Data Safety and Monitoring Board chair for Idris. She has received royalties from Uptodate, Inc. **MJD** and **WPP** are employees and stockholders of Alkermes, Inc. **MJC-M, SE**, and **AJ** are/were employees of Oracle Life Sciences, who received funding from Alkermes, Inc. to conduct this study.

STUDY OUTCOMES

- Self-reported daytime sleepiness was assessed on the Epworth Sleepiness Scale (ESS). Clinical outcomes included body mass index, obesity rates, presence of select comorbidities, and the presence of depression and anxiety symptoms using the Patient Health Questionnaire–9 items (PHQ-9) and the General Anxiety Disorder–7 items (GAD-7) scales
- Humanistic outcomes were assessed by evaluating health-related quality of life (HRQoL) using the RAND 36-Item Short Form Survey Instrument (RAND-36) for 2023 data, health status using the EQ-5D-5L, resilience using the Brief Resilience Scale, and perceived social support using the 8-item modified Medical Outcomes Study Social Support Survey

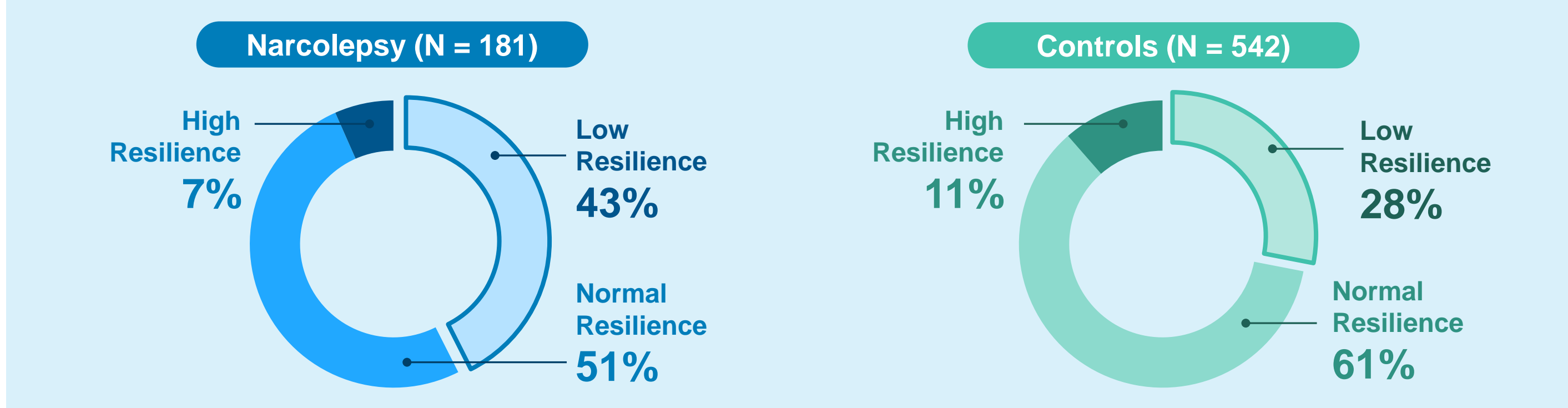
STATISTICAL ANALYSIS

- Unadjusted bivariate analyses compared narcolepsy and general population cohorts on sociodemographics, health characteristics, and outcomes using chi-square tests (for categorical variables) and t tests (for continuous variables)
- Propensity score matching (1:3) balanced sociodemographic and health characteristics between adults with narcolepsy and those without (**control group**), with matched bivariate analyses performed to examine adjusted differences in outcomes

HUMANISTIC BURDEN OF NARCOLEPSY

- More respondents with narcolepsy reported low resiliency scale scores compared with controls (43% vs 28%; $P < 0.001$) (Figure 6)

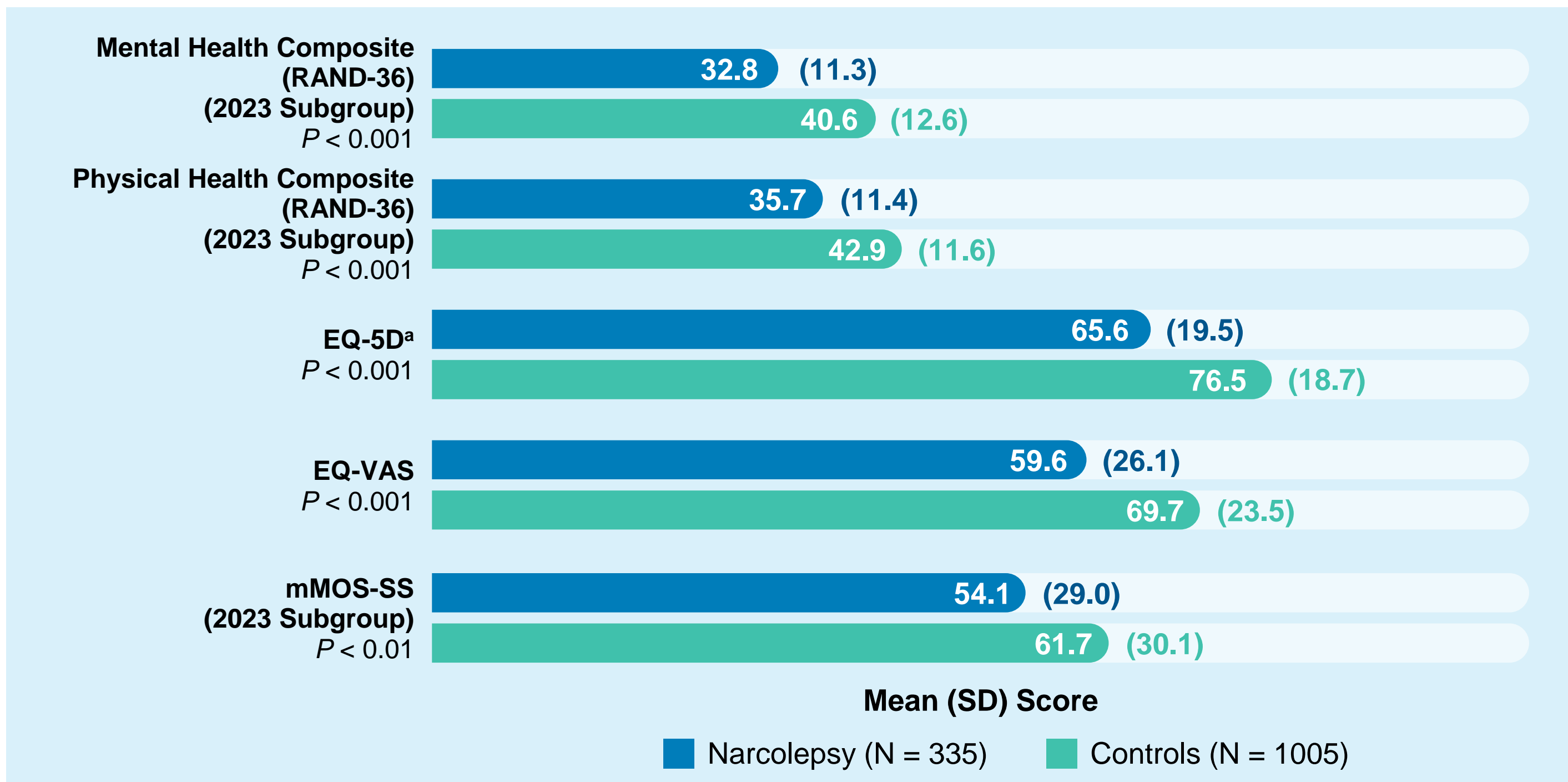
FIGURE 6: Brief Resiliency Scale Scores^{a,b} of Patients With Narcolepsy vs Controls (2023 Subgroup)



Due to rounding of individual percentages to the nearest whole number, the combined total may not equal 100%.
^aBrief Resiliency Scale (range 0-5); a higher score indicates greater resilience. Scores of 1.00-2.99 are indicative of low resilience, 3.00-4.30 of normal resilience, and 4.31-5.00 of high resilience.
^bResiliency is only being reported from 2023 US National Health and Wellness Survey respondents.

- Respondents with narcolepsy also perceived lower levels of social support compared with controls (Figure 7)
 - Lower mean [SD] instrumental support subscale scores (51.4 [30.9] vs 60.2 [32.6]; $P < 0.001$) and lower mean [SD] emotional support subscale scores (56.7 [31.3] vs 63.1 [30.8]; $P < 0.05$) were observed in patients with narcolepsy compared with controls
- Compared with controls, the narcolepsy cohort scored lower on HRQoL measures, including mean mental health and physical health composite scores on the RAND-36 (Figure 7)
- The narcolepsy cohort also reported a greater impairment in daily activities compared with controls on the Work Productivity and Activity Impairment questionnaire (51% vs 34%; $P < 0.001$)

FIGURE 7: HRQoL and Social Support in Patients With Narcolepsy vs Controls



Mental Health Score, Physical Health Score, and social support is only being reported from 2023 US National Health and Wellness Survey respondents for the narcolepsy (N = 181) and controls (N = 542) cohorts.
^aEQ-5D was converted to be out of 100 points for ease of presentation.
EQ-5D = EuroQoL 5-dimensions; EQ-VAS = EuroQoL 5-visual analog scale; HRQoL = health-related quality of life; mMOS-SS = 8-item modified Medical Outcomes Study Social Support Survey; RAND-36 = 36-item Short Form Survey Instrument.

CONCLUSIONS

- Narcolepsy is associated with a substantial burden of illness, with deleterious consequences for patients' mental and physical health, social support, and daily activities
- Individuals with narcolepsy are at increased risk of developing comorbid psychiatric conditions, experiencing severe depressive and anxiety symptoms, and exhibiting reduced resilience and social support, compared with the general population. Moreover, they report significantly impaired HRQoL
- To mitigate these effects, a comprehensive management approach for narcolepsy is essential, incorporating both pharmacologic and non-pharmacologic interventions that prioritize mental health support and promote overall well-being



Scan QR code to download poster