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

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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, and 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)[3,5]
- Narcolepsy has been associated with negative impacts on patients' lives (eg, education, employment), which may result in socioeconomic burden[5-7]
  - Further, narcolepsy may be associated with increased healthcare resource use and direct medical costs[8,9]

OBJECTIVE

- To compare the economic burden in adults with narcolepsy versus adults without narcolepsy

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

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

STUDY OUTCOMES

- Self-reported daytime sleepiness was assessed on the Epworth Sleepiness Scale (ESS)
- Healthcare resource use (HCRU) in past 6 months, including traditional healthcare provider (HCP) visits (eg, neurologist, psychiatrist, psychologist/therapist, and pulmonologist visits), emergency room (ER) visits, and hospitalizations
  - Direct costs were calculated by annualizing HCP visits, ER visits, and hospitalizations and multiplying these by their respective unit costs from the 2021 Medical Expenditure Panel Survey data by the US Department of Health and Human Services Agency for Healthcare Research and Quality
  - Direct medical costs were inflated to 2023 medical care costs using data from the US Bureau of Labor Statistics retrieved from the Federal Reserve Bank of St. Louis
- Work productivity was measured using the Work Productivity and Activity Impairment questionnaire
  - Indirect costs due to loss of work productivity were calculated for each employed respondent using 2023 age-, sex-, and race-adjusted wage estimates from the US Bureau of Labor Statistics

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 = 578 in the narcolepsy and control cohorts, respectively, were included in the study
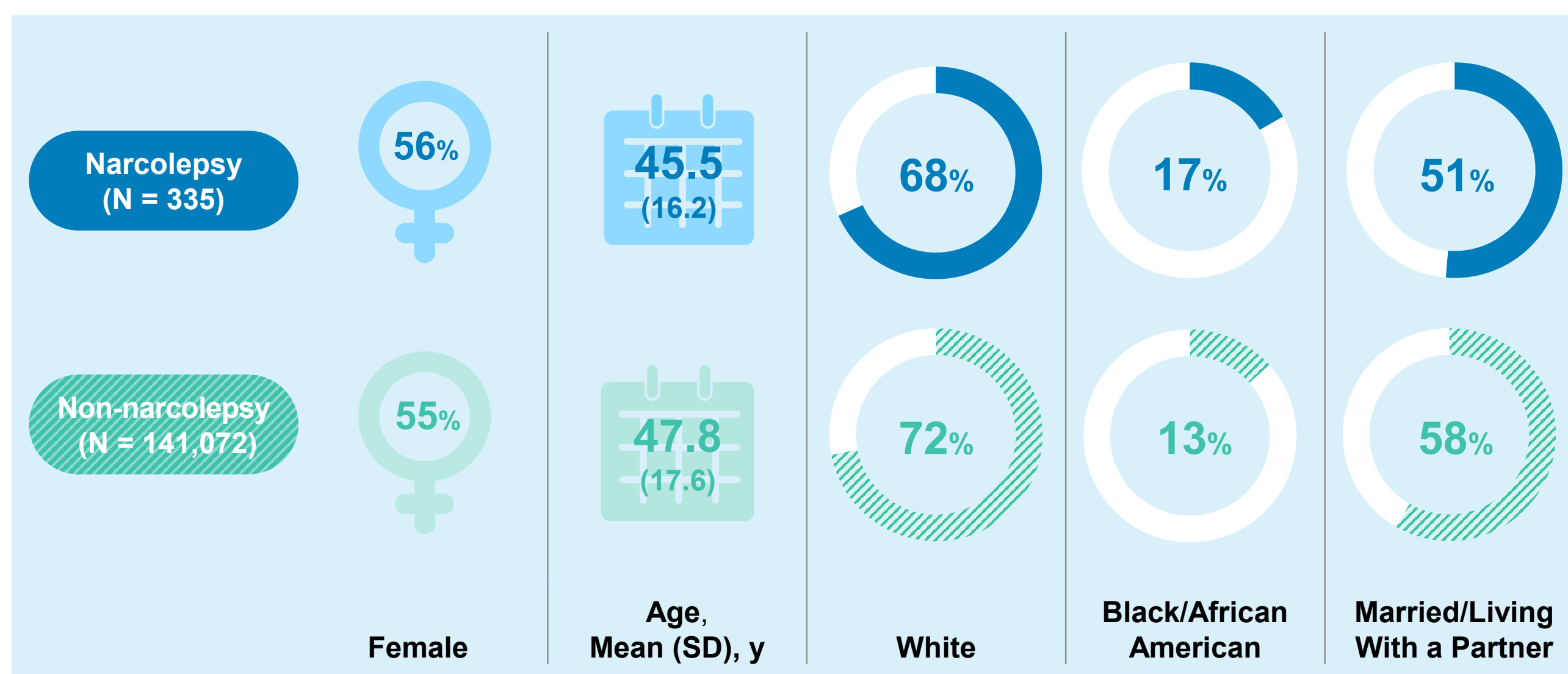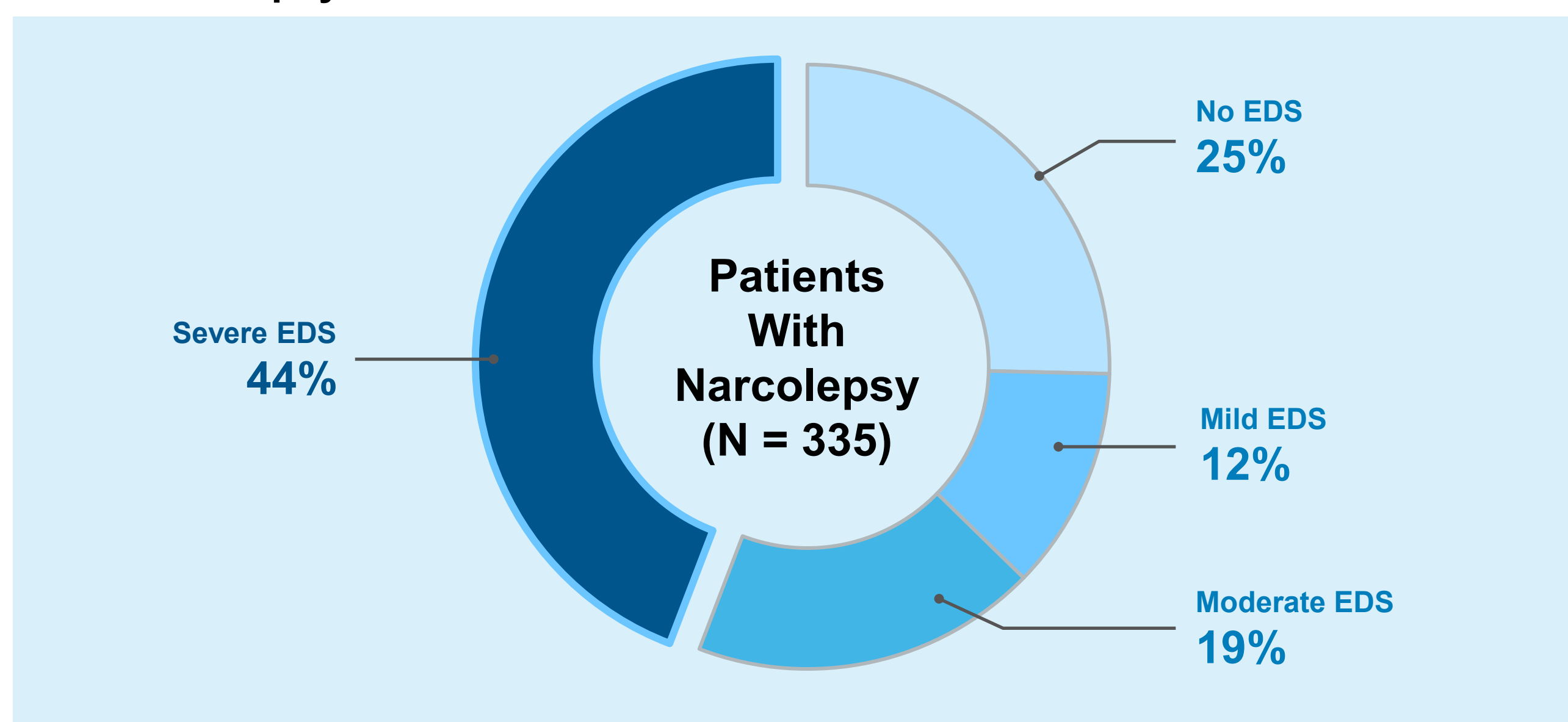
FIGURE 1: Baseline Characteristics

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

Patients With Narcolepsy (N = 335)
- No EDS 25%
- Mild EDS 12%
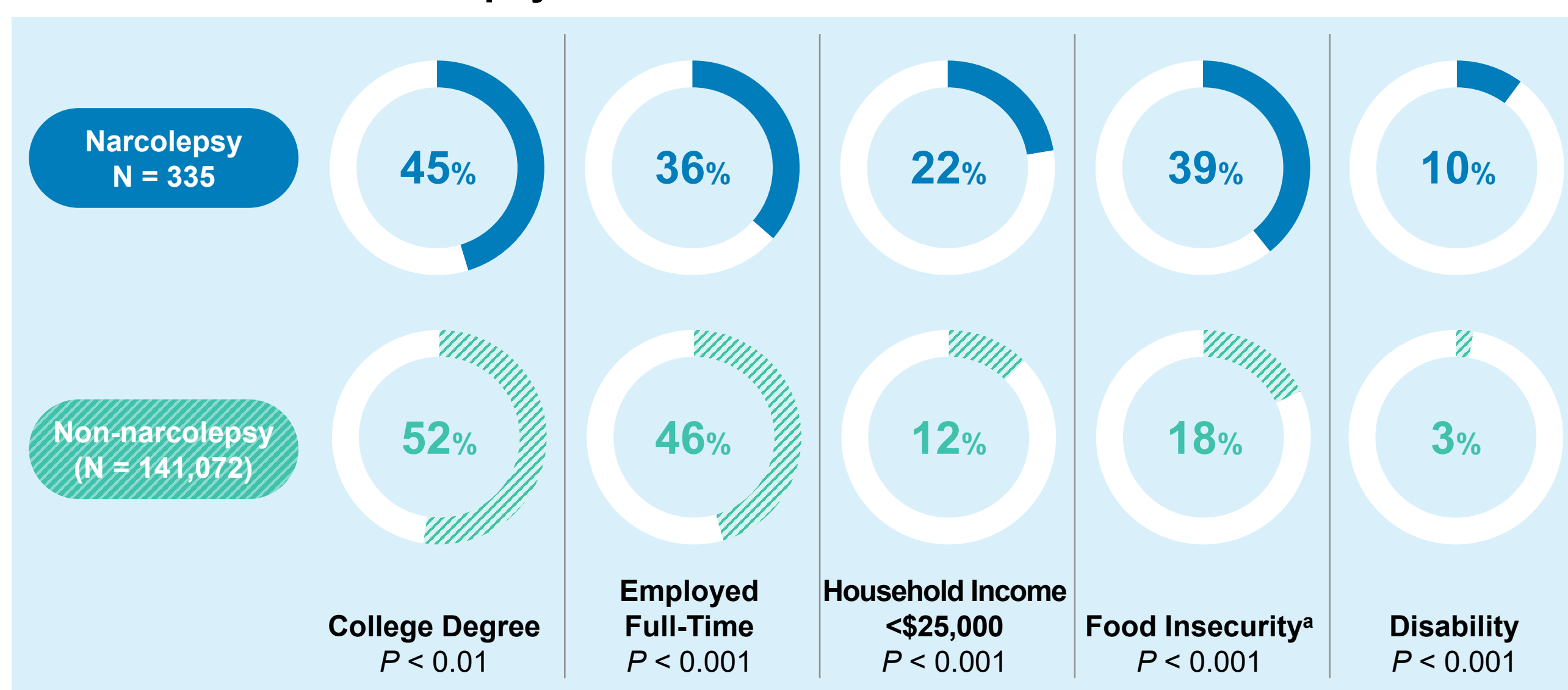- Moderate EDS 19%
- Severe EDS 44%

[a]ESS composite score range: no EDS = 0-10; mild EDS = 11-12; moderate EDS = 13-15; severe EDS = 16-24. EDS = excessive daytime sleepiness; ESS = Epworth Sleepiness Scale.

EDUCATION AND EMPLOYMENT IN PATIENTS WITH NARCOLEPSY

- Before matching, patients with narcolepsy versus without narcolepsy were significantly less likely to have a college degree, be employed full-time, and more likely to be on disability (Figure 3)
- Compared with the unmatched non-narcolepsy cohort, the narcolepsy cohort was nearly twice as likely to have a household income of less than $25,000 and more than twice as likely to report food insecurity (Figure 3)

FIGURE 3: Education and Employment Status in Patients With Narcolepsy Versus Unmatched Non-narcolepsy Patients

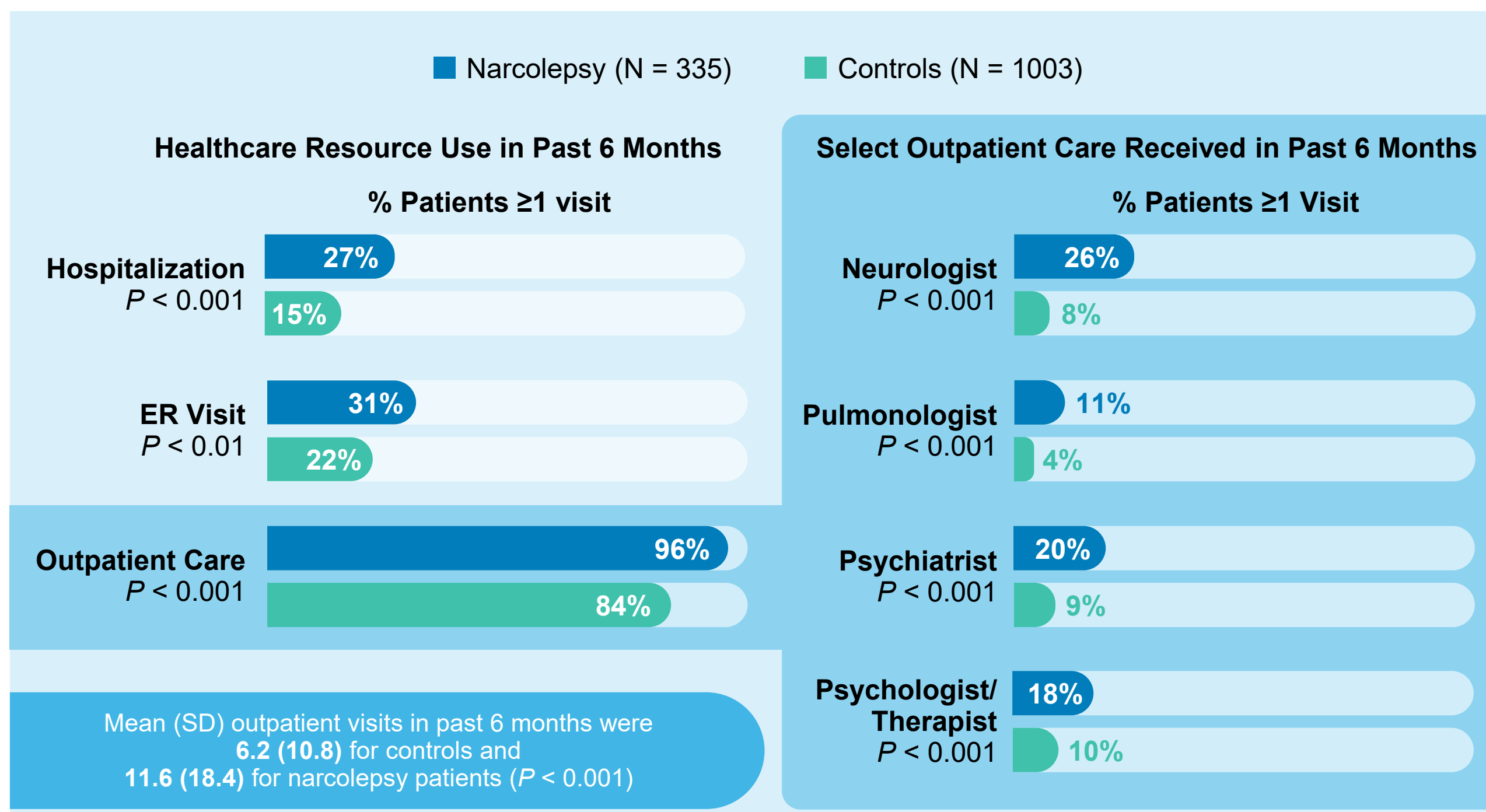|	College Degree P < 0.01	Employed Full-Time P < 0.001	Household Income <$25,000 P < 0.001	Food Insecurity[a] P < 0.001	Disability P < 0.001
Narcolepsy N = 335	45%	36%	22%	39%	10%
Non-narcolepsy (N = 141,072)	52%	46%	12%	18%	3%

[a]2023 respondents only were asked whether they were "worried food would run out before getting money to buy more" or whether "the food bought didn't last and I/we didn't have money to get more within the past 12 months." Individuals who responded "yes" to either question were categorized as experiencing food insecurity. Sample sizes for food insecurity question include N = 181 in the narcolepsy and N = 73,857 in the non-narcolepsy cohort.

HEALTHCARE UTILIZATION AND ASSOCIATED COSTS IN PATIENTS WITH NARCOLEPSY

- Patients with narcolepsy were more likely to have acute care events and more outpatient visits (including visits to neurologists, pulmonologists, psychiatrists, and psychologists/therapists), compared with controls in the past 6 months (Figure 4)
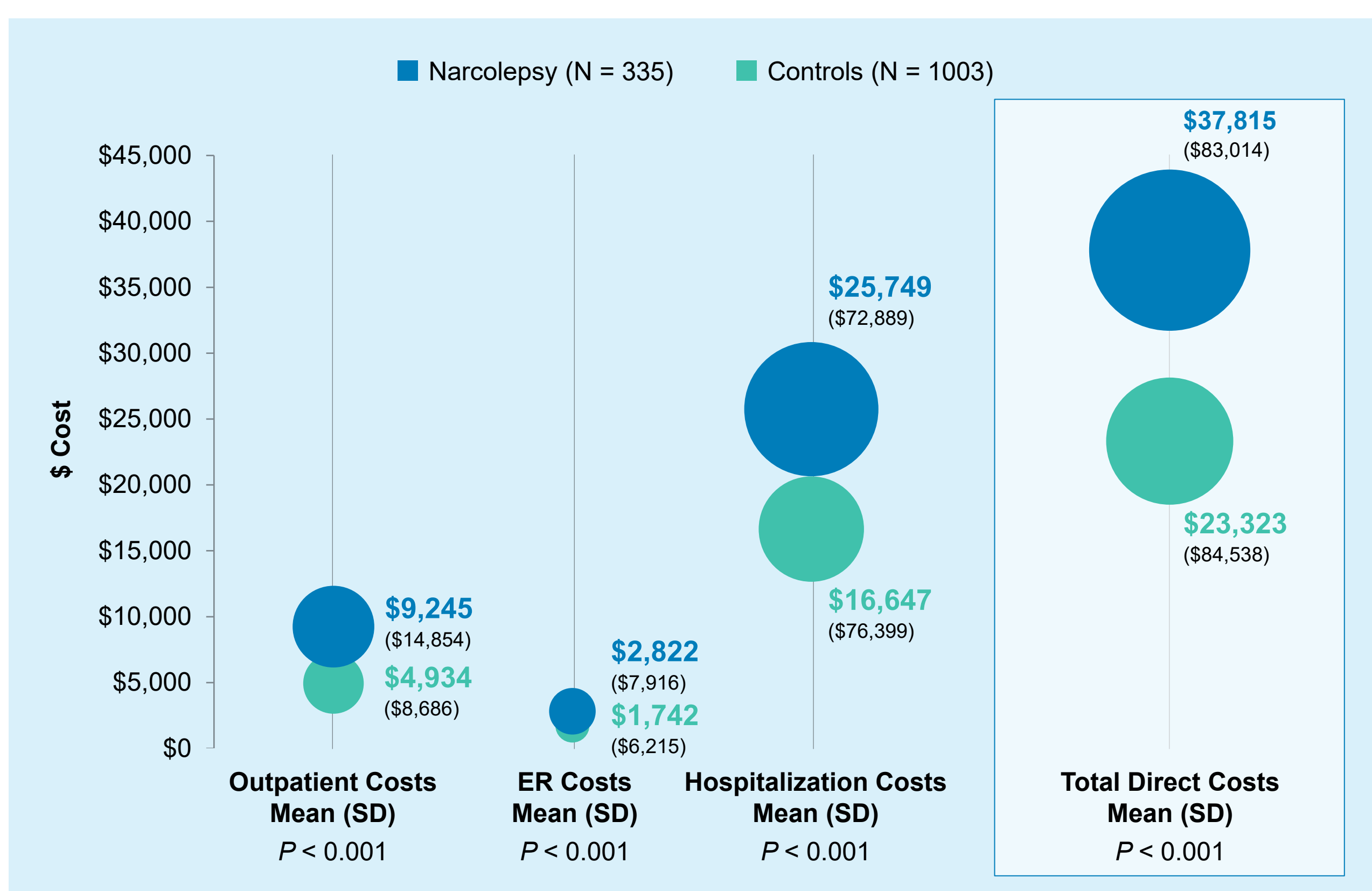
FIGURE 4: Healthcare Utilization in Patients With Narcolepsy Versus Matched Controls[a]

Narcolepsy (N = 335) ■ Controls (N = 1003) ■

Healthcare Resource Use in Past 6 Months
% Patients ≥1 visit
- Hospitalization P < 0.001: 27% / 15%
- ER Visit P < 0.01: 31% / 22%
- Outpatient Care P < 0.001: 96% / 84%

Mean (SD) outpatient visits in past 6 months were 6.2 (10.8) for controls and 11.6 (18.4) for narcolepsy patients (P < 0.001)

Select Outpatient Care Received in Past 6 Months
% Patients ≥1 Visit
- Neurologist P < 0.001: 26% / 8%
- Pulmonologist P < 0.001: 11% / 4%
- Psychiatrist P < 0.001: 20% / 9%
- Psychologist/Therapist P < 0.001: 18% / 10%

[a]Two respondents in the control group were removed from HCRU and direct costs analyses due to outliers. Data were visually inspected for outliers across all HCRU outcomes (hospitalizations, ER visits, and HCP visits), and 2 outliers from the control group were removed from HCRU analyses due to scores that were >15 SDs above the mean for ≥1 HCRU outcome. ER = emergency room; HCP = healthcare provider; HCRU = healthcare resource use.

- Patients with narcolepsy had an additional mean (SD) of $14,492 per-person-per-year annual direct medical costs, compared with controls ($37,815 [$83,014] vs $23,323 [$84,538]; P < 0.001) (Figure 5)
  - Higher annualized direct medical costs in the narcolepsy group versus controls included costs of HCP visits, ER visits, and hospitalizations (all P < 0.001)

FIGURE 5: Annual Direct Medical Costs in Patients With Narcolepsy Versus Matched Controls[a,b]

Narcolepsy (N = 335) ■ Controls (N = 1003) ■

	Outpatient Costs Mean (SD) P < 0.001	ER Costs Mean (SD) P < 0.001	Hospitalization Costs Mean (SD) P < 0.001	Total Direct Costs Mean (SD) P < 0.001
Narcolepsy	$9,245 ($14,854)	$2,822 ($7,916)	$25,749 ($72,889)	$37,815 ($83,014)
Controls	$4,934 ($8,686)	$1,742 ($6,215)	$16,647 ($76,399)	$23,323 ($84,538)

[a]Annual direct medical costs do not include pharmacy costs and thus may provide an underestimate of all medical costs. [b]Two respondents were removed from direct costs analyses from the controls group due to outliers. Data were visually inspected for outliers across all HCRU outcomes (hospitalizations, ER visits, and HCP visits), and 2 outliers from the control group were removed from HCRU analyses due to scores that were >15 SDs above the mean for ≥1 HCRU outcome. Size of the circles in the graph corresponds to the amount of direct medical costs. ER = emergency room; HCP = healthcare provider; HCRU = healthcare resource use.

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, including 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
- External data sources, including the US Bureau of Labor Statistics and the Medical Expenditure Panel Survey Cost outcomes, were used to estimate cost outcomes
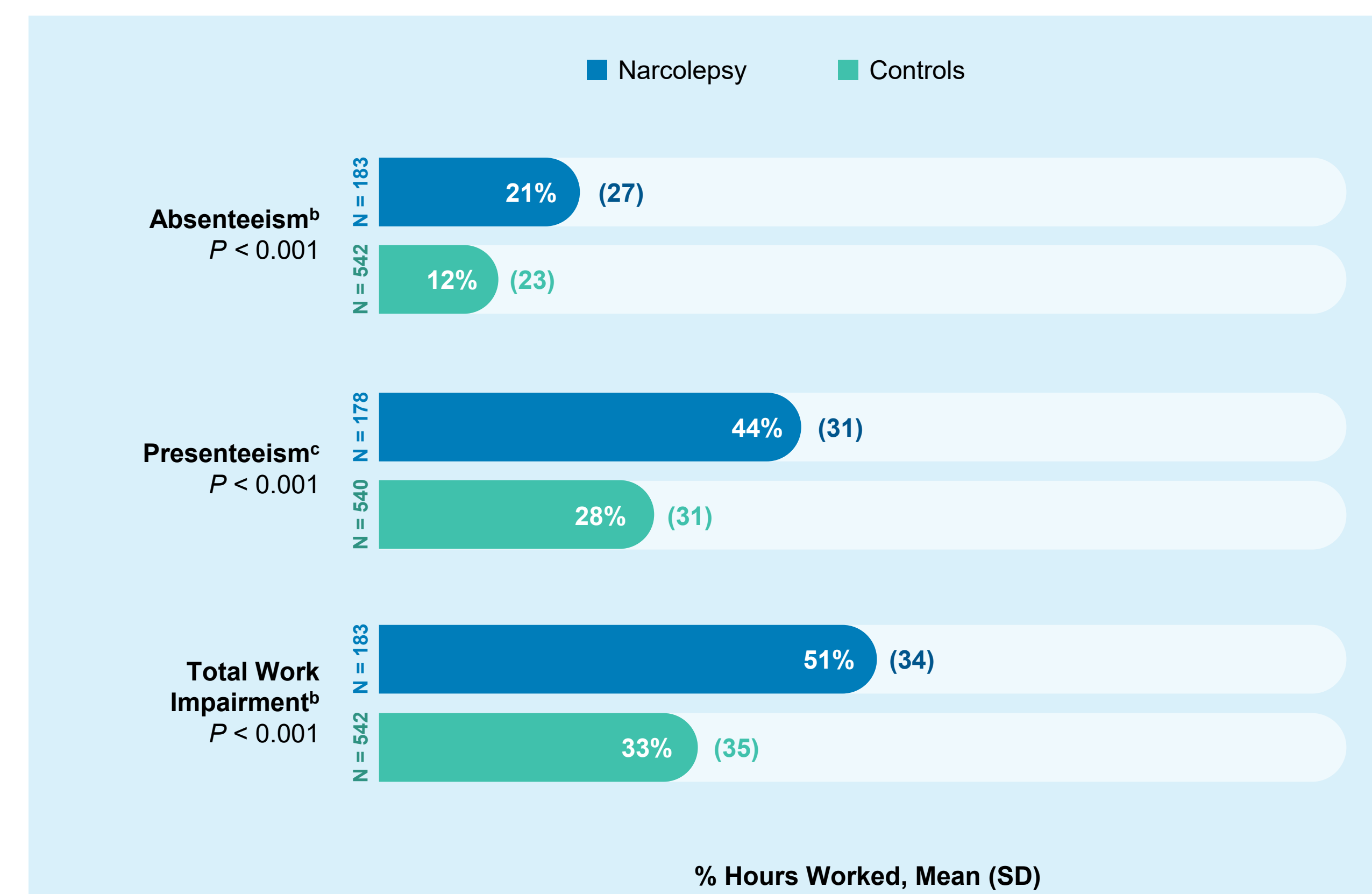
INDIRECT COSTS ASSOCIATED WITH NARCOLEPSY
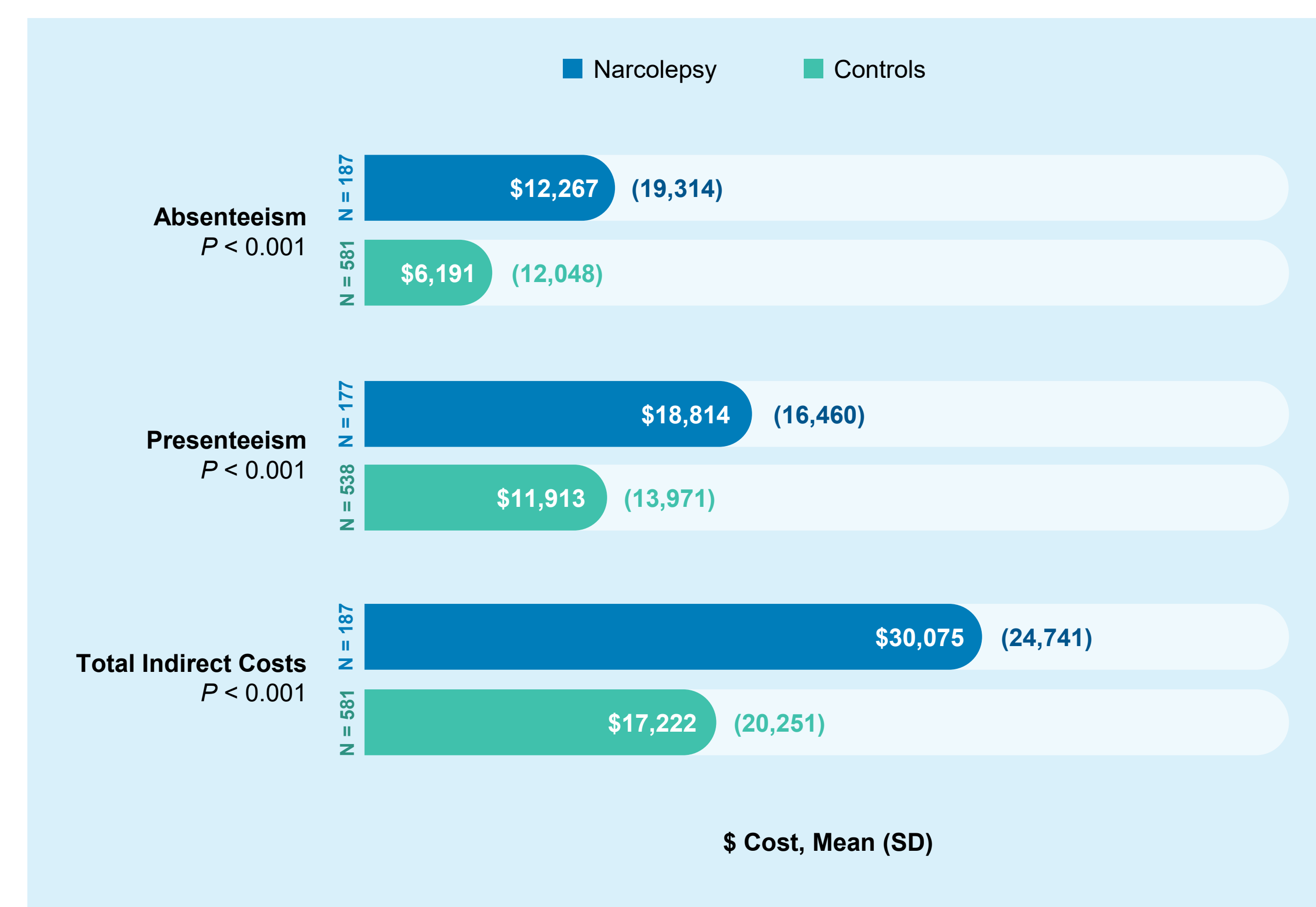
- Patients with narcolepsy reported greater impairment of work productivity relative to controls (Figure 6)
- Estimated mean (SD) annual indirect costs were higher by an additional $12,852 among those with narcolepsy compared with controls ($30,075 [$24,741] vs $17,222 [$20,251] P < 0.001)
  - Patients with narcolepsy had higher mean costs associated with absenteeism and presenteeism compared with controls (Figure 7)

FIGURE 6: Work Productivity Impairment in Patients With Narcolepsy Versus Controls[a]

Narcolepsy ■ Controls ■

	Narcolepsy	Controls
Absenteeism[b] P < 0.001 (N = 183 / N = 542)	21% (27)	12% (23)
Presenteeism[c] P < 0.001 (N = 178 / N = 540)	44% (31)	28% (31)
Total Work Impairment[b] P < 0.001 (N = 183 / N = 542)	51% (34)	33% (35)

% Hours Worked, Mean (SD)

[a]Only respondents who reported being full-time, part-time, or self-employed provided data for absenteeism, presenteeism, and overall work impairment. [b]Absenteeism and overall work productivity impairment was not calculated for those who worked 0 hours and missed 0 hours in the last 7 days. [c]Presenteeism was only asked among those who worked >0 hours in the last 7 days.

FIGURE 7: Annual Indirect Costs in Employed Patients With Narcolepsy Versus Controls[a]

Narcolepsy ■ Controls ■

	Narcolepsy	Controls
Absenteeism P < 0.001 (N = 187 / N = 581)	$12,267 (19,314)	$6,191 (12,048)
Presenteeism P < 0.001 (N = 177 / N = 538)	$18,814 (16,460)	$11,913 (13,971)
Total Indirect Costs P < 0.001 (N = 187 / N = 581)	$30,075 (24,741)	$17,222 (20,251)

$ Cost, Mean (SD)

[a]Indirect costs were calculated for each respondent using 2023 estimated age-, sex-, and race-adjusted wages provided by the US Bureau of Labor Statistics. Respondents with 0 hours missed and 0 hours worked were excluded from the absenteeism calculation[10] but retained in the indirect cost calculation with a value of $0.00. Respondents with total reported time (worked, missed, or vacation) that exceeded 112 hours in a week were flagged as invalid and excluded from the presenteeism cost calculation.

CONCLUSIONS

- Narcolepsy is associated with a substantial socioeconomic burden for patients, healthcare systems, and employers
- Individuals with narcolepsy have lower socioeconomic status, require more acute and outpatient care, and experience greater work impairment compared with those without narcolepsy, resulting in higher direct medical and indirect costs
- To mitigate these effects, further research is needed to assess how psychosocial supports and treatments may improve healthcare utilization and overall financial burden among people living with narcolepsy

References
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