

SLEEP 2018, the 32nd Annual Meeting of the Associated Professional Sleep Societies (APSS); June 2-6, 2018 • Baltimore, MD

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Introduction

- Narcolepsy is a rare, lifelong, neurological disorder characterized by excessive sleepiness and the inability to regulate sleep-wake cycles normally¹
- Symptoms typically begin during childhood or adolescence, although diagnosis may not occur until years later¹

Objectives

- To compare comorbid conditions and annual health care utilization and costs in children with and without narcolepsy
- To understand the impact of pediatric narcolepsy from a health plan perspective

Methods

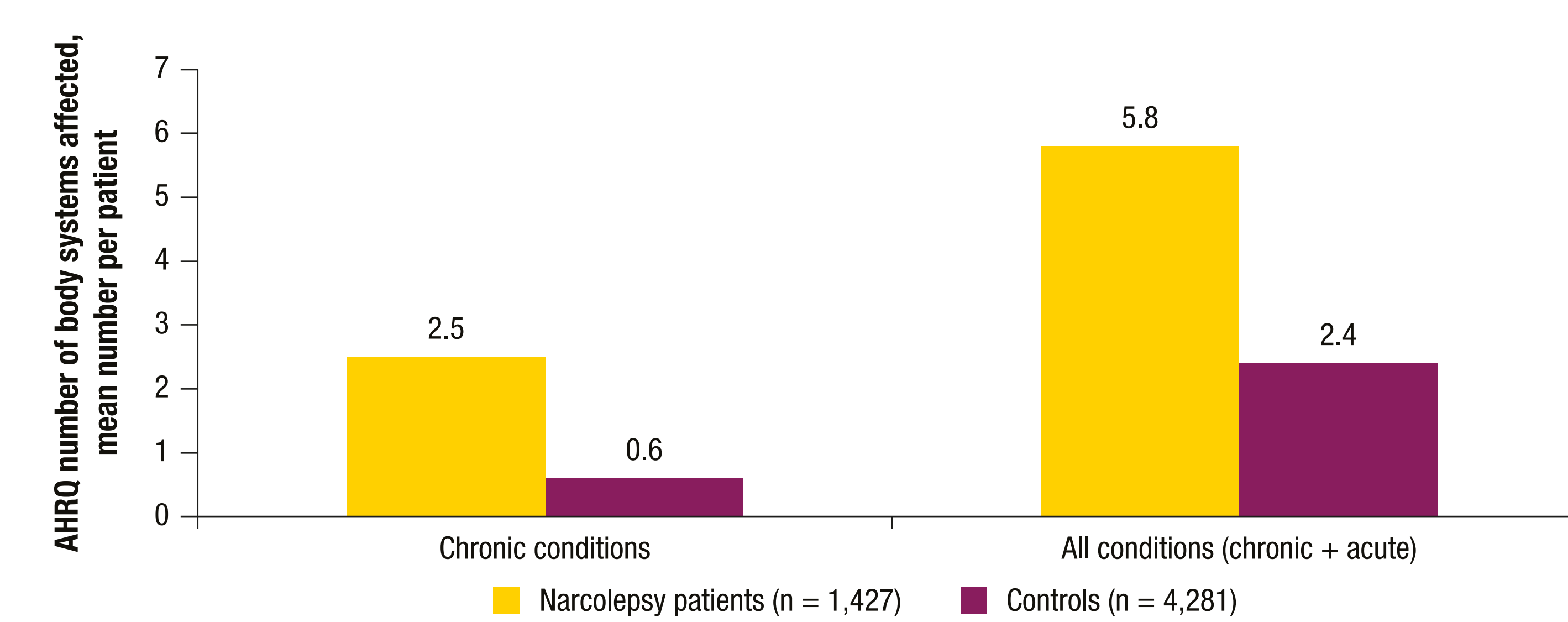
- Retrospective, cross-sectional, case-control study
- Identified US narcolepsy patients ≤18 years of age with ≥1 inpatient (IP) or ≥2 outpatient (OP) claims for narcolepsy using data from the Truven MarketScan[®] Commercial Claims and Encounters database
 - Five yearly prevalent cohorts of patients were identified (2011-2015), and these cohorts were combined into one 5-year prevalent cohort for the analysis
 - For prevalent patients appearing in multiple calendar years, 1 year per patient was randomly selected to create a prevalent cohort of unique patients with narcolepsy
- Identified patients were matched 1:3 to control patients without narcolepsy by age, sex, region, insurance type, and calendar year. The control group served as a reference to describe health care experience for a typical child without narcolepsy
- Comorbid conditions, health care utilization, and costs (allowed medical and pharmacy charges) were measured on a calendar-year basis
 - Health care utilization was assessed by the mean number of IP admissions, emergency room visits, OP visits, diagnostic tests, and narcolepsy-related medication
- The Agency for Healthcare Research and Quality's Clinical Classifications Software "body system" classification was used to measure the number of comorbid conditions (range: 0-18)

Results

Table 1. Cohort Characteristics

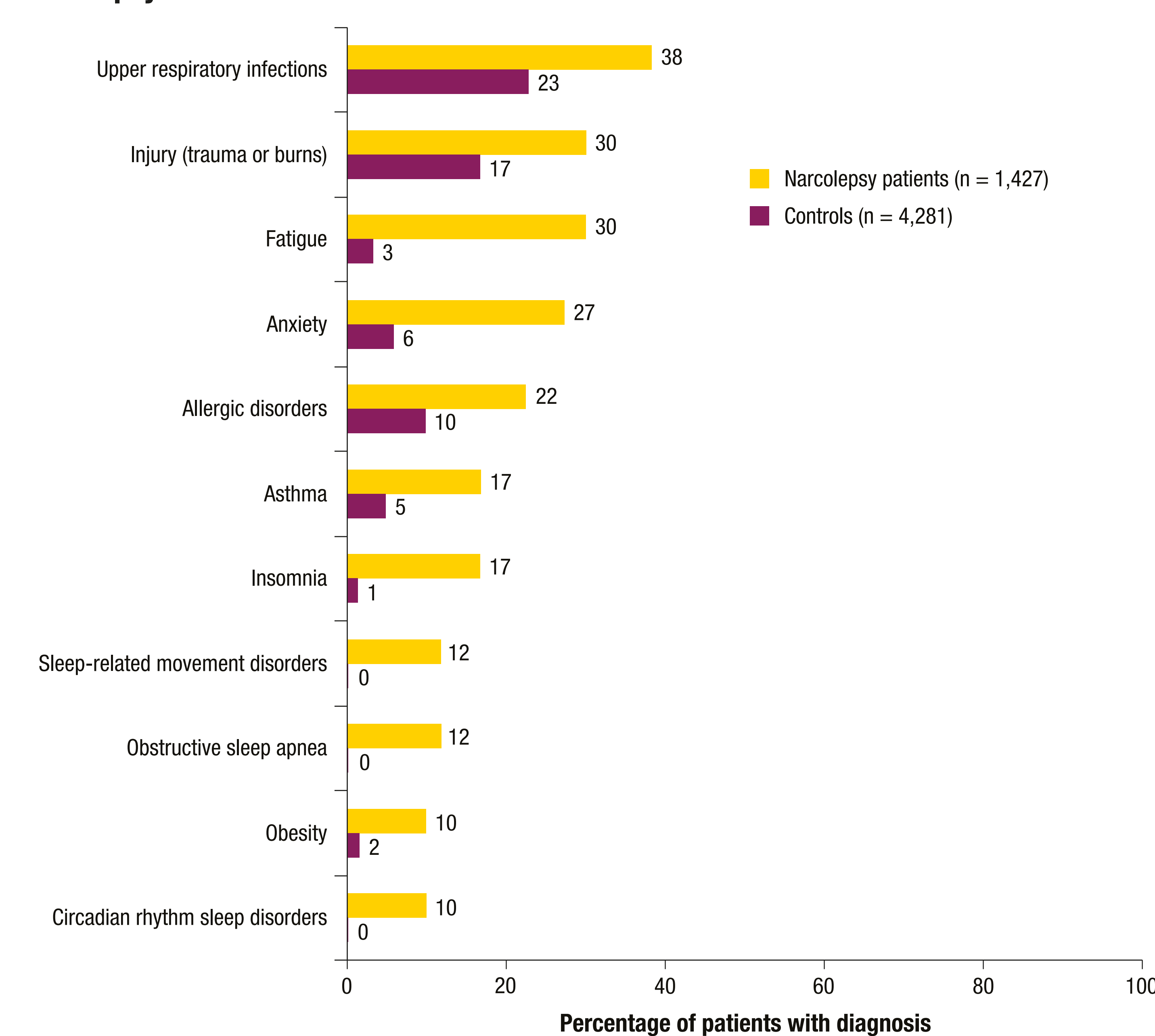
	Narcolepsy (n = 1,427)	Controls (n = 4,281)
Age, n (%)		
≤6 years	38 (2.7)	114 (2.7)
7-11 years	213 (14.9)	639 (14.9)
12-17 years	1,176 (82.4)	3,528 (82.4)
Female, n (%)	687 (48.1)	2,061 (48.1)
Geographic region, n (%)		
Northeast	246 (17.2)	738 (17.2)
Midwest	327 (22.9)	981 (22.9)
South	691 (48.4)	2,073 (48.4)
West	163 (11.4)	489 (11.4)
Type I narcolepsy (ie, cataplexy)	515 (36.0)	—

Figure 1. Pediatric Patients With Narcolepsy Experience More Chronic and Acute Health Conditions Versus Controls^{a,b}



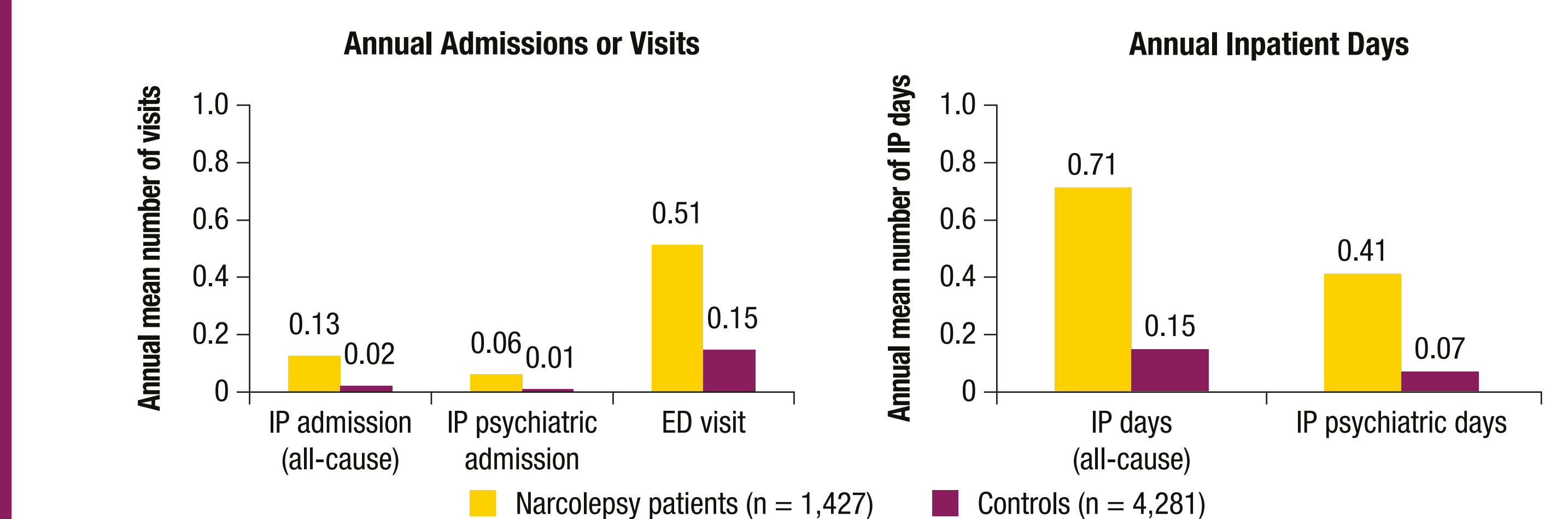
AHRQ, Agency for Healthcare Research and Quality.
^aNumber of body systems affected was based on the Clinical Classifications Software, provided by the AHRQ Healthcare Cost and Utilization Project, and was also based on diagnosis codes and a hierarchical classification system (range of 0-18 different body systems). The proportion of patients with an affected body system was statistically significantly different between cases and controls for 16 of the 18 body systems studied. The 2 that were not statistically significant (complications of pregnancy, childbirth and the puerperium; and certain conditions originating in the perinatal period) had very small numbers of patients.
^bDifferences between narcolepsy and comparison groups were significant at 95% confidence levels ($P < 0.001$).

Figure 2. Higher Percentage of Comorbid Diagnoses of Interest in Pediatric Patients With Narcolepsy Versus Controls^{a,b}



^aThe figure shows conditions with diagnostic codes in ≥10% of narcolepsy patients. Conditions were selected based on clinical experience and previous association with narcolepsy from the literature.
^bAll differences $P < 0.001$.

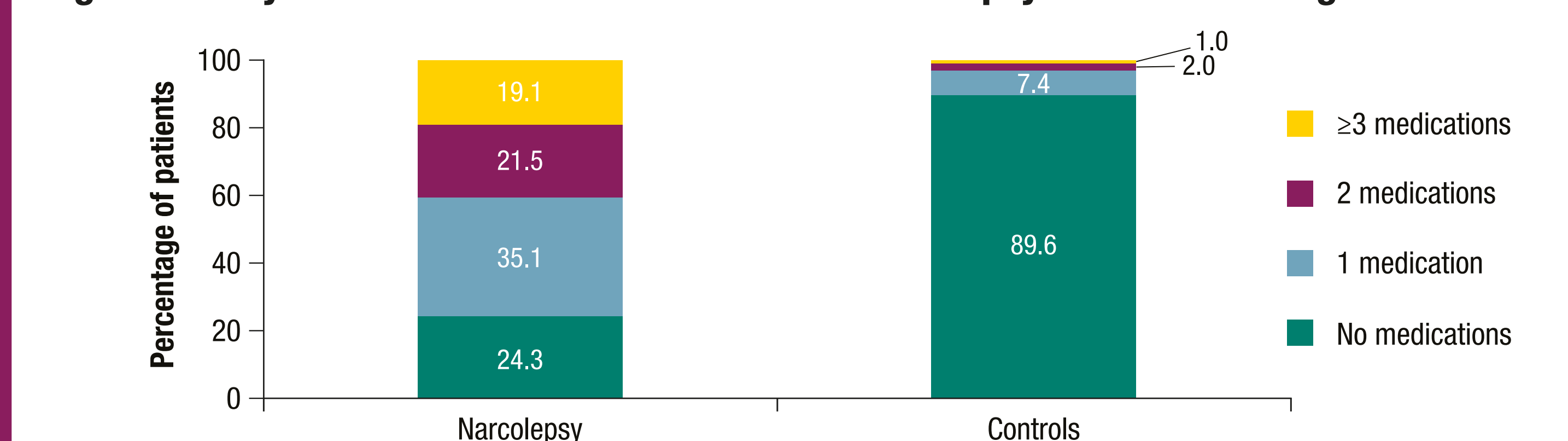
Figure 3. Pediatric Patients With Narcolepsy Use Inpatient and Emergency Care at Higher Rates Versus Controls^a



IP, inpatient; ED, emergency department.
^aAll differences $P < 0.001$.

- In addition to increased IP admissions, there were also higher annual mean numbers of OP visits and electroencephalography and brain computed tomography/magnetic resonance imaging tests performed in patients with narcolepsy compared with controls ($P < 0.001$ for all comparisons); the greater use of these tests in patients with narcolepsy is a substantial contributor to the economic burden of narcolepsy

Figure 4. Forty Percent of Pediatric Patients With Narcolepsy Take ≥2 Neurological Medications^a



^aMedications included medication used to treat narcolepsy symptoms (sleepiness and cataplexy): modafinil, armodafinil, sodium oxybate, methamphetamine/amphetamines, methylphenidate, selective serotonin reuptake inhibitors, serotonin-norepinephrine reuptake inhibitors, tricyclic antidepressants. Other medications that act on the brain and are used to treat potentially related conditions in children or misdiagnosed narcolepsy symptoms were also examined: monoamine oxidase inhibitors, other anti-anxiety medications, anticonvulsants, nonstimulant attention-deficit/hyperactivity disorder medications, and antipsychotics. Medication use was defined by having ≥1 claim for any of the specified medications during the calendar year.

Table 2. Pediatric Patients With Narcolepsy Have Higher Mean Annual Medical Costs (in US Dollars) Per Patient Versus Controls^{a,b}

	Narcolepsy (n = 1,427), \$	Controls (n = 4,281), \$
IP admissions	1,899	557
ED visit (without admission)	440	116
OP physician visit	1,139	259
Other OP	3,666	825
Total medical care services	10,140	1,956
OP pharmacy	5,656	493
Narcolepsy and related Rx	4,481	130
Other Rx	1,175	364
Total costs (medical + drug)	15,797	2,449

IP, inpatient; ED, emergency department; OP, outpatient; Rx, prescription.

^aAll differences, $P < 0.001$.

^bTotal health care costs and cost by type of service were estimated as a per-patient annual average. All costs were reported as means, and inflation was adjusted to 2015 US dollars.

- Medical care costs in patients with narcolepsy accounted for 64% of their total health care costs; medical care costs for narcolepsy patients were \$8,184 higher (5.2 times) than that of controls, and total costs (medical + drug) for narcolepsy patients were \$13,348 higher (6.45 times) than that of controls

Conclusions

- In a commercially insured population of pediatric patients seeking care for narcolepsy, a narcolepsy diagnosis was associated with a significantly greater comorbidity burden, as well as higher health care utilization and costs, than in children without a narcolepsy diagnosis
- 64% of total costs were associated with medical care (excluding drug costs) for pediatric patients with narcolepsy
- A limitation of the study is that claims studies only capture diagnoses that are recorded for billing purposes and may not fully capture all relevant diagnoses
- The burden of narcolepsy on children and adolescents should be further examined in future studies in order to be better understood

