

The Economic Burden of Idiopathic Hypersomnia in the United States: Analysis of the National Health and Wellness Survey

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Introduction

- Idiopathic hypersomnia is a central disorder of hypersomnolence characterized by excessive daytime sleepiness, sleep inertia, long and unrefreshing naps, and cognitive impairment, with a prevalence of 37.0 diagnosed cases per 100,000 persons as of 2021¹⁻³
- Previous analyses of administrative claims databases found that individuals with idiopathic hypersomnia had high healthcare resource utilization (HCRU) and medical costs^{4,5}
- US National Health and Wellness Survey (NHWS) data offer the opportunity to obtain respondent-reported insights into the economic burden associated with idiopathic hypersomnia in US adults⁶

Objective

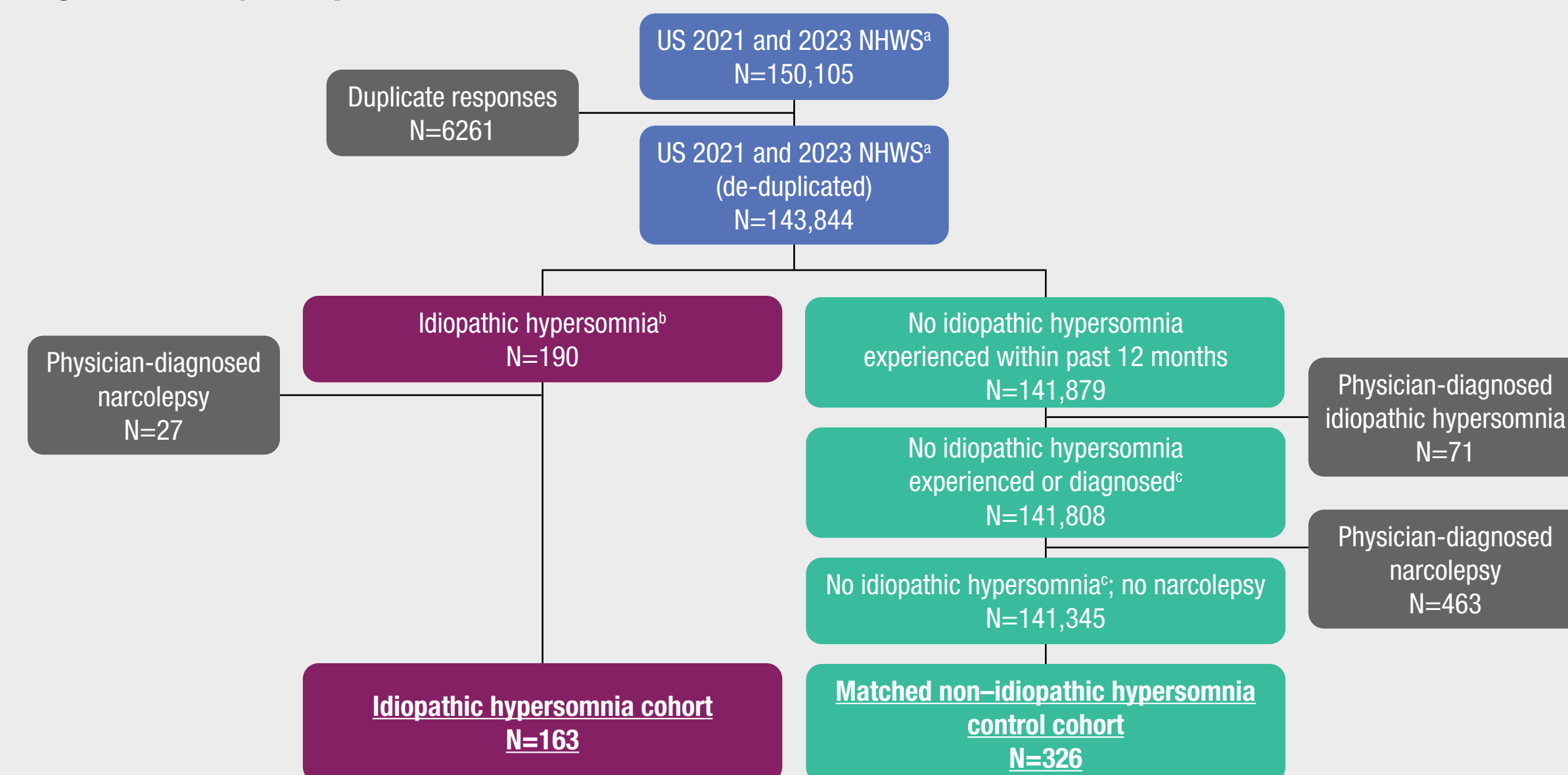
- This study aimed to quantify the HCRU and medical costs associated with idiopathic hypersomnia in a geographically diverse US sample of community-dwelling adults with idiopathic hypersomnia and matched non-idiopathic hypersomnia controls

Methods

- This retrospective analysis used de-duplicated data from the 2021 and 2023 US NHWS, a cross-sectional, self-administered, internet-based survey designed to reflect health in a representative sample of the US general adult population
- Eligible participants were adults (≥18 years of age) residing in the United States; participants were excluded from this analysis if they self-reported a physician diagnosis of narcolepsy
- Propensity score matching (1:2) was conducted to minimize differences in baseline demographic and health characteristics between adults with idiopathic hypersomnia and matched non-idiopathic hypersomnia controls
 - The covariates used for matching were survey year, sex, age, race, marital status, education, annual household income, insurance type, smoking status, and days exercising vigorously for ≥20 minutes within the past month
- Frequencies and percentages were reported for categorical variables; means and standard deviations were reported for continuous variables (means adjusted based on propensity score matching)
- Bivariate analyses examined differences in HCRU, Work Productivity and Activity Impairment (WPAI) scores,⁷ and annualized direct and indirect costs between adults with idiopathic hypersomnia and matched non-idiopathic hypersomnia controls
 - Direct costs were calculated from HCRU data and Medical Expenditure Panel Survey data⁸
 - Indirect costs were calculated for each respondent through use of estimated age- and sex-adjusted wages provided by the US Bureau of Labor Statistics. The latest wage data available were from 2021; for 2023 NHWS, data were inflated to 2023 costs⁹

Results

Figure 1. Study Sample



NHWS was reviewed by Pearl Institutional Review Board (Indianapolis, IN) and granted exemption status. *Participants experienced idiopathic hypersomnia within past 12 months and reported a physician diagnosis of idiopathic hypersomnia. *Participants did not experience idiopathic hypersomnia within past 12 months or report a physician diagnosis of idiopathic hypersomnia. NHWS, National Health and Wellness Survey.

- Analyses included 163 adults with idiopathic hypersomnia and 326 matched non-idiopathic hypersomnia controls

Table 1. Sociodemographic and Health Characteristics: Adults With Idiopathic Hypersomnia Compared With Matched Non-Idiopathic Hypersomnia Controls

	Idiopathic Hypersomnia Cohort (N=163)	Matched Non-Idiopathic Hypersomnia Control Cohort (N=326)	P
Age, years, mean (SD)	38.4 (13.7)	39.6 (14.7)	0.405
Female, n (%)	105 (64.4)	215 (66.0)	0.737
Race, n (%)			
White	130 (79.8)	263 (80.7)	
Black/African American	19 (11.7)	32 (9.8)	0.925
Asian	3 (1.8)	7 (2.1)	
Other race or origin/multi-race	11 (6.7)	24 (7.4)	
Hispanic ethnicity, n (%)	23 (14.1)	51 (15.6)	0.655
Married/living with partner, n (%)	78 (47.9)	162 (49.7)	0.701
University or higher degree, n (%)	71 (43.6)	136 (41.7)	0.698
Employment status, n (%)			
Employed*	108 (66.3)	204 (62.6)	
Retired	11 (6.7)	29 (8.9)	0.053
Long- or short-term disability	14 (8.6)	10 (3.1)	
Unemployed	17 (10.4)	36 (11.0)	
Annual household income, n (%)			
<\$50,000	68 (41.7)	135 (41.4)	0.976
\$50,000 to <\$100,000	49 (30.1)	96 (29.4)	
\$100,000+	40 (24.5)	83 (25.5)	
Insurance type, n (%)			
Commercial	80 (49.1)	163 (50.0)	
Medicaid	37 (22.7)	67 (20.6)	0.083
Medicare	22 (13.5)	44 (13.5)	
VA/CHAMPUS, TRICARE, or not sure	10 (6.1)	24 (7.4)	
Uninsured	14 (8.6)	28 (8.6)	
Smoking status, n (%)			
Current smoker	45 (27.6)	89 (27.3)	0.997
Former smoker	37 (22.7)	74 (22.7)	
Never smoker	81 (49.7)	163 (50.0)	
Days exercised vigorously for ≥20 minutes within past month, mean (SD)	7.0 (8.5)	7.6 (9.1)	0.465

*Full-time employment, part-time employment, or self-employment. SD, standard deviation.

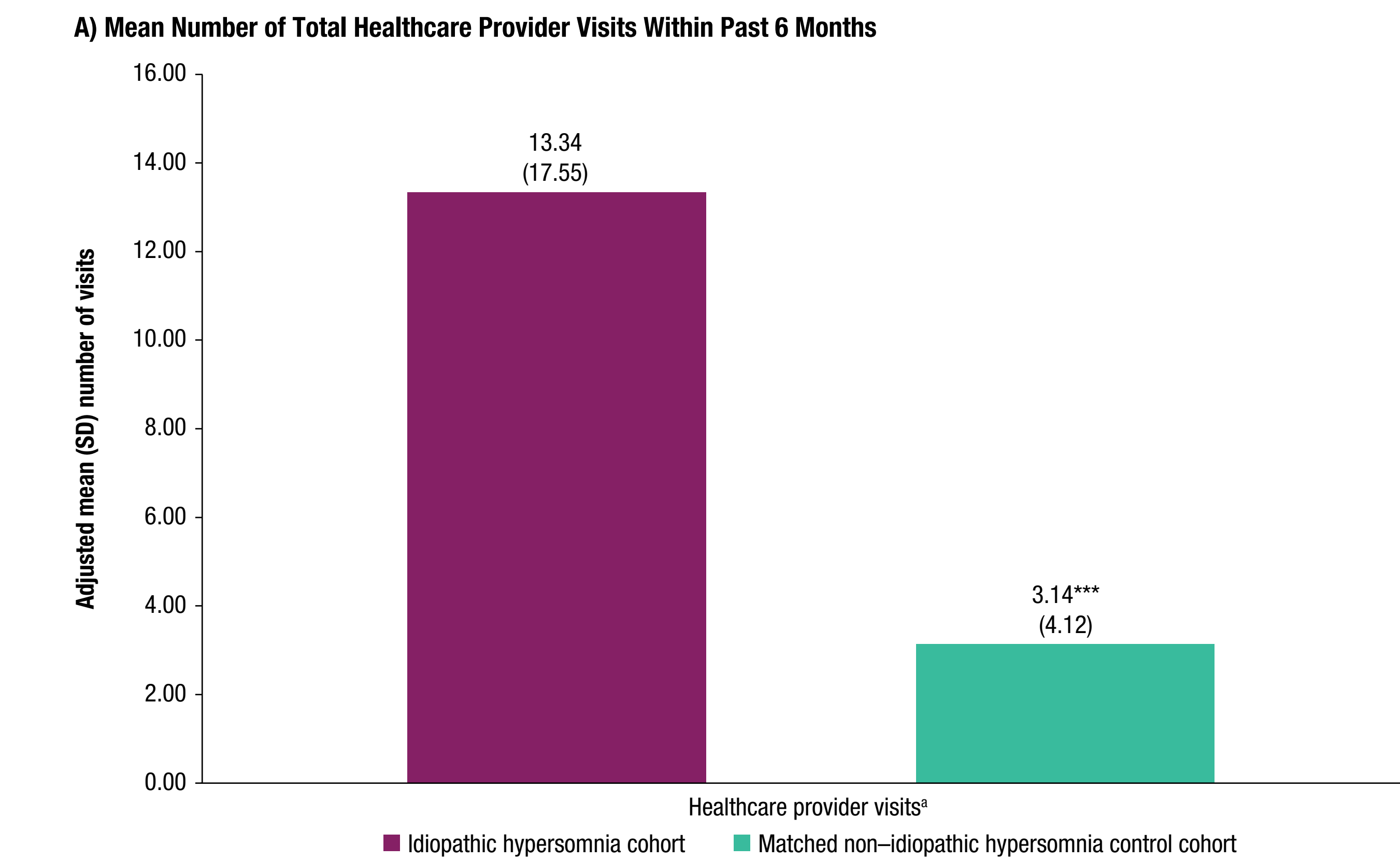
- After matching, no differences in the selected matched variables were observed between the two cohorts

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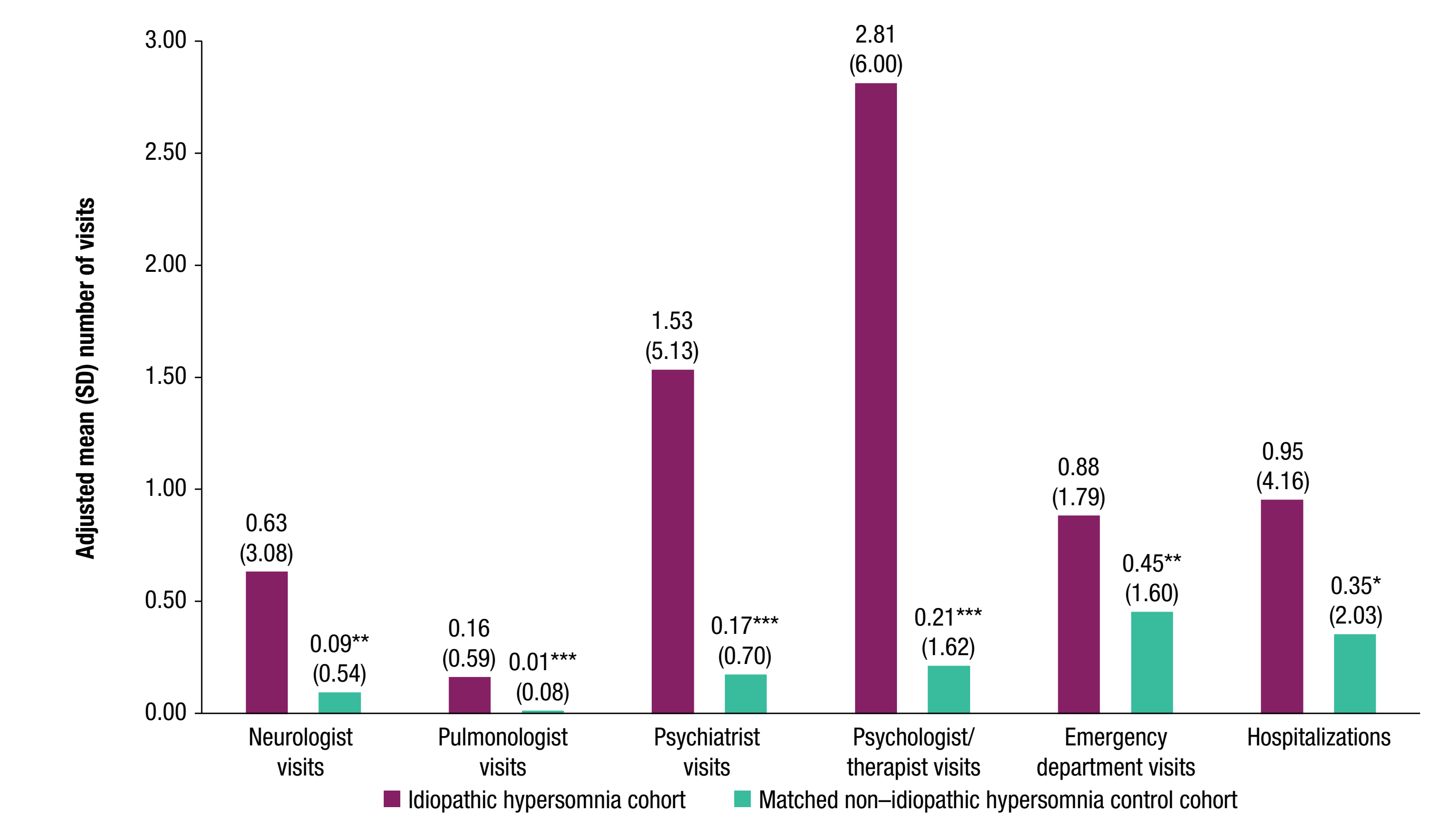
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Figure 2. Healthcare Resource Utilization Within Past 6 Months Was Higher Among Adults With Idiopathic Hypersomnia Than Among Matched Non-Idiopathic Hypersomnia Controls



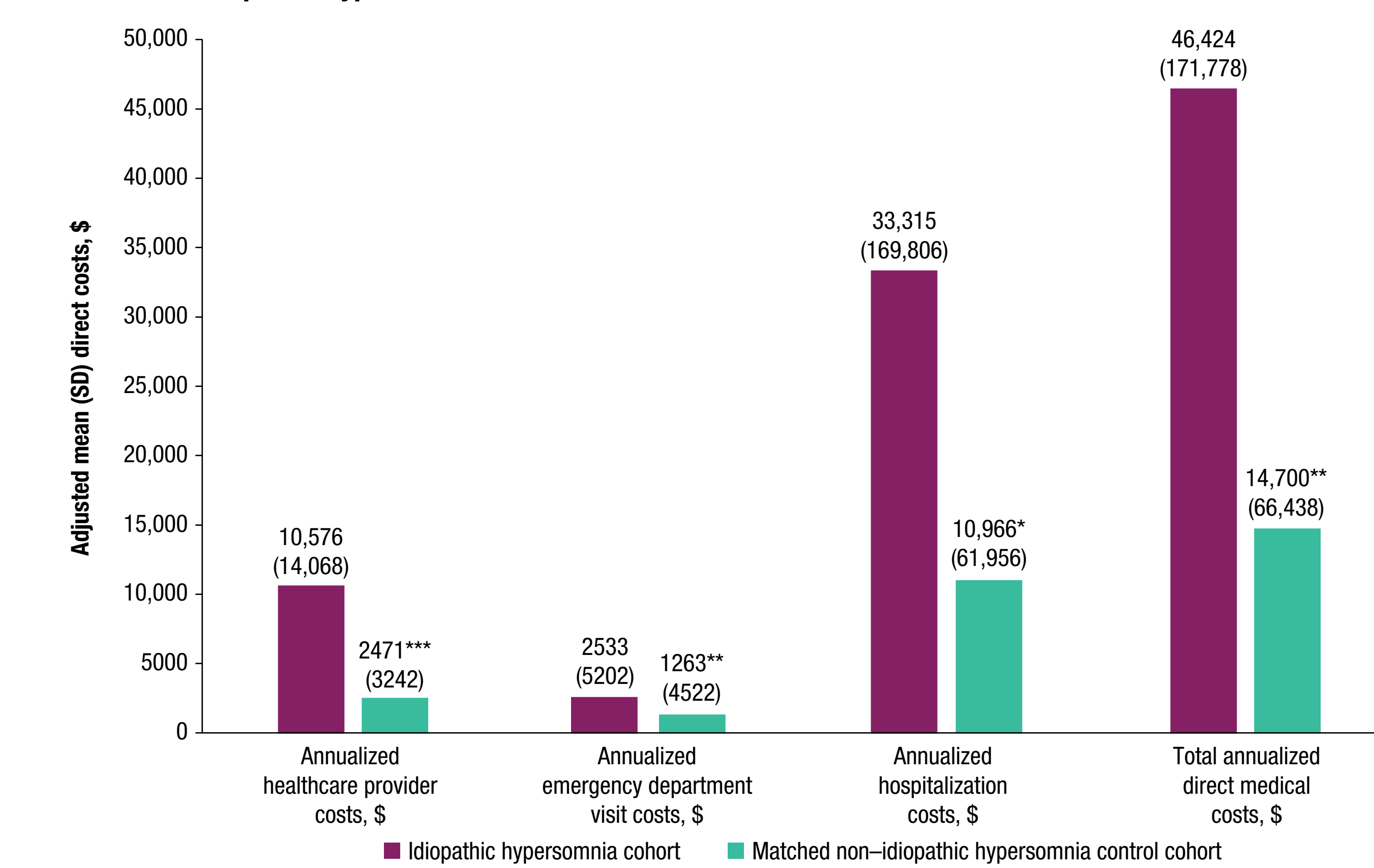
B) Mean Number of Healthcare Provider Visits by Specialist, ED Visits, and Hospitalizations Within Past 6 Months



***P<0.001. **P<0.01. *P<0.05. P values are reported for comparisons between the idiopathic hypersomnia and matched control cohorts. *Includes visits to general practitioner/family practitioner, internist, allergist, cardiologist, dentist, dermatologist, diabetologist, endocrinologist, gastroenterologist, geriatrician, gynecologist, hepatologist, infectious disease specialist/infectiologist, nephrologist, neurologist, nurse practitioner/physician assistant, obstetrician, oncologist, ophthalmologist, orthopedist, otolaryngologist, plastic surgeon, podiatrist, psychiatrist, psychologist/therapist, pulmonologist, respiratory therapist, rheumatologist, urologist, other medical specialist. SD, standard deviation.

- Compared with matched non-idiopathic hypersomnia controls, adults with idiopathic hypersomnia reported higher HCRU within the past 6 months, including more total healthcare provider visits; more neurologist, pulmonologist, psychiatrist, and psychologist/therapist visits; more emergency department visits; and more hospitalizations

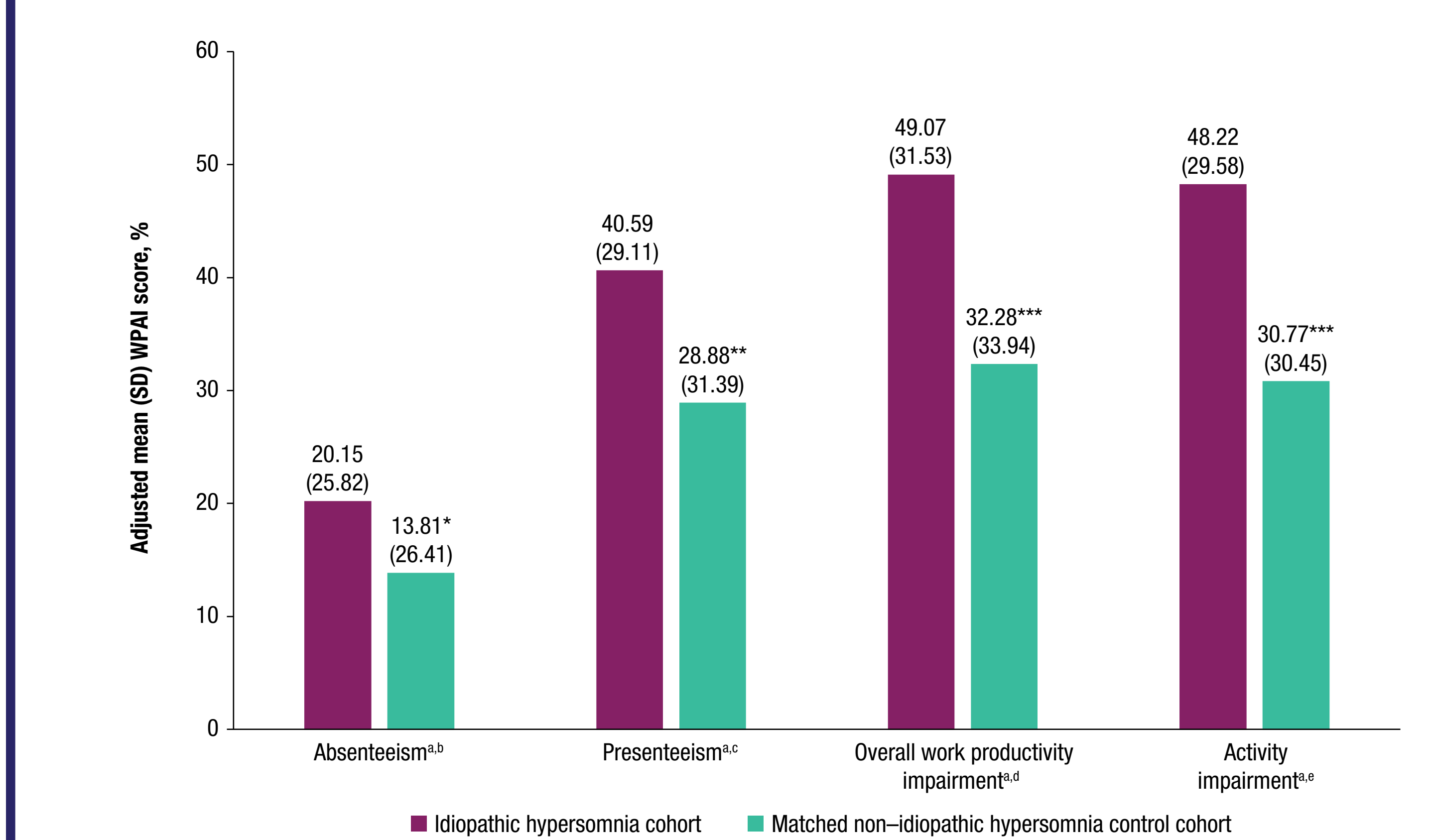
Figure 3. Annualized Direct Medical Costs Were Higher Among Adults With Idiopathic Hypersomnia Than Among Matched Non-Idiopathic Hypersomnia Controls



***P<0.001. **P<0.01. *P<0.05. P values are reported for comparisons between the idiopathic hypersomnia and matched control cohorts. SD, standard deviation.

- Total annualized direct medical costs (inclusive of healthcare provider visits, emergency department visits, and hospitalizations) were higher among adults with idiopathic hypersomnia than among matched non-idiopathic hypersomnia controls: \$46,424 and \$14,700, respectively (P=0.004)

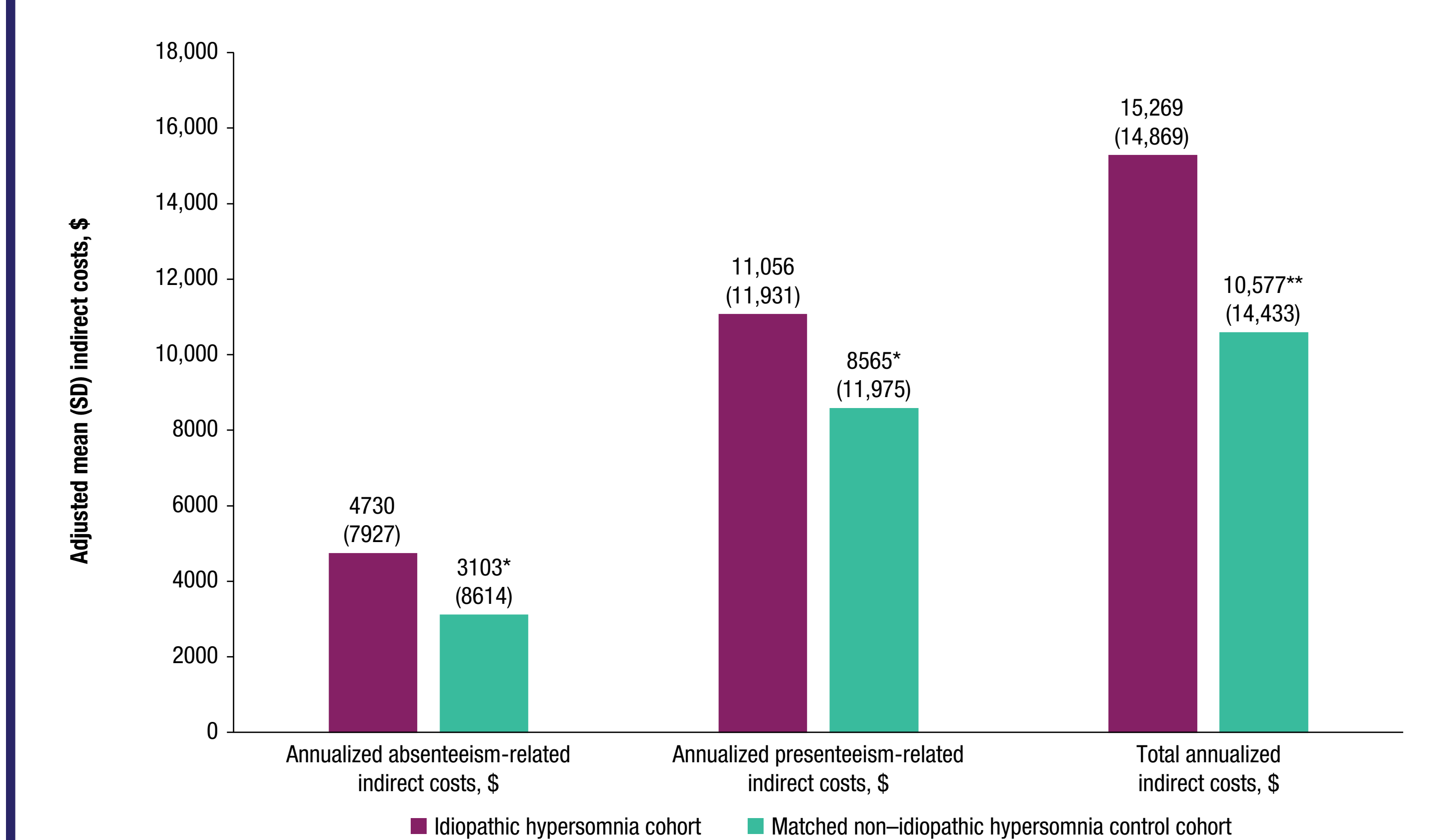
Figure 4. Work Productivity and Activity Impairment (WPAI) Scores Were Higher Among Adults With Idiopathic Hypersomnia Than Among Matched Non-Idiopathic Hypersomnia Controls



***P<0.001. **P<0.01. *P<0.05. P values are reported for comparisons between the idiopathic hypersomnia and matched control cohorts. ^aScores range from 0 to 100; higher scores indicate more impairment. ^bAbsenteeism not calculated for individuals who worked >0 hours within past 7 days; presenteeism inquired about only among individuals who worked >0 hours within past 7 days. ^cAbsenteeism defined as percentage of work time missed because of health issue within past 7 days and calculated for 103 of 163 adults with idiopathic hypersomnia and 186 of 326 matched non-idiopathic hypersomnia controls with data for this outcome. ^dPresenteeism defined as percentage of impairment at work because of health issue within past 7 days and calculated for 102 of 163 adults with idiopathic hypersomnia and 178 of 326 matched non-idiopathic hypersomnia controls with data for this outcome. ^eOverall work productivity impairment defined as overall impairment estimate combining absenteeism and presenteeism and calculated for 102 of 163 adults with idiopathic hypersomnia and 178 of 326 matched non-idiopathic hypersomnia controls with data for this outcome. ^fActivity impairment defined as percentage of impairment in daily activities because of health issue within past 7 days and calculated for 163 of 163 adults with idiopathic hypersomnia and 326 of 326 matched non-idiopathic hypersomnia controls with data for this outcome. SD, standard deviation; WPAI, Work Productivity and Activity Impairment.

- Compared with matched non-idiopathic hypersomnia controls, adults with idiopathic hypersomnia had greater absenteeism, presenteeism, overall work productivity impairment, and activity impairment

Figure 5. Annualized Indirect Costs Attributable to Work Activity Impairment Were Higher Among Adults With Idiopathic Hypersomnia Than Among Matched Non-Idiopathic Hypersomnia Controls



**P<0.01. *P<0.05. P values are reported for comparisons between the idiopathic hypersomnia and matched control cohorts. ^aAnnualized absenteeism-related indirect costs and total annualized indirect costs calculated for individuals with valid response to number of hours missed (idiopathic hypersomnia, 107; non-idiopathic hypersomnia control, 204); annualized presenteeism-related indirect costs calculated for individuals with valid response to both number of hours worked and work productivity affected (idiopathic hypersomnia, 102; non-idiopathic hypersomnia control, 178). SD, standard deviation.

- Mean total annualized indirect costs were higher among adults with idiopathic hypersomnia than among matched non-idiopathic hypersomnia controls: \$15,269 and \$10,577, respectively (P=0.007)

Conclusions

- This study, which builds on prior work with administrative claims data,^{4,5} highlights the significant HCRU and medical cost burden among people with idiopathic hypersomnia in the United States compared with matched non-idiopathic hypersomnia controls
- Higher direct medical costs and greater work productivity and activity impairment contribute to the considerable economic burden among people with idiopathic hypersomnia
- The limitations of this study may include reliance on self-reported data, which can be subject to recall bias; inability to infer causation from cross-sectional data; and underrepresentation of individuals who lack internet access or are uncomfortable using the internet
- This study highlights the need to assess specific aspects of care, treatment, and comorbidities that contribute to the HCRU and cost burden associated with idiopathic hypersomnia



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