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Introduction

- Narcolepsy is a rare, lifelong, neurological disorder characterized by excessive sleepiness and the inability to regulate sleep-wake cycles normally.1
- Symptoms typically begin during childhood or adolescence, although diagnosis may not occur until years later.
- In the pediatric population, narcolepsy has been associated with significant economic burden, including increased health care utilization and costs along with an increased comorbidity burden.²

Objective

• To study health care utilization and costs in the year before and up to 2 years after diagnosis in children and adolescents newly diagnosed with narcolepsy

Methods

- Retrospective cohort study that identified newly diagnosed US narcolepsy patients <18 years of age with ≥ 2 narcolepsy diagnosis claims during 2012 to 2014, using data from the Truven Health Analytics MarketScan[®] Commercial Claims and Encounters database
- Patients were followed for ≥ 1 year before diagnosis and ≥ 2 years after diagnosis following the index date (narcolepsy diagnosis date).
- Patients were identified with a qualifying Multiple Sleep Latency Test (MSLT) that met the following requirements:
- Had a nondiagnostic narcolepsy claim, which was defined as a claim for evaluation and management services with a confirmatory diagnosis of narcolepsy and no claim for diagnostic services containing a potentially probable, questionable, or rule-out diagnosis, within the 6 months after MSLT
- Was continuously enrolled during the disease-free washout period of 1 year to 60 days prior to MSLT
- Did not have a claim for sodium oxybate any time prior to MSLT
- Did not have a non-MSLT narcolepsy claim during the disease-free washout period

Figure 1. Newly Diagnosed Patient Identification



MSLT, Multiple Sleep Latency Test.

- Comorbidities, health care utilization, and annual costs were compared in the year before, 1 year after, and 2 years after diagnosis for those who had ≥ 2 years of follow-up data after diagnosis.
- Health care utilization was assessed by the mean number of inpatient hospitalizations, hospital days, outpatient visits, and diagnostic tests.
- Use of narcolepsy-related medications (narcolepsy treatment and other related medications) was also assessed as a measure of health care utilization and costs.
- The Agency for Healthcare Research and Quality (AHRQ) Clinical Classifications Software (CCS) "body system" classification was used to measure the number of comorbid conditions, excluding narcoleps
- Descriptive statistics, including means and standard deviations for continuous data and relative frequencies and percentages for categorical data, were reported yearly and indexed to the narcolepsy diagnosis date.
- Appropriate statistical tests (eg, t test or Wilcoxon test for means and Chi-square or Fisher's exact test for proportions) based on distributional assumptions were performed.
- The *P* values presented are nominal, and no adjustments for multiplicity or multiple comparisons were made.

References: 1. Thorpy MJ, Krieger AC. Sleep Med. 2014;15(5):502-507. 2. Reiss Reddy S, et al. Sleep. 2018;41(suppl 1):A301-A302. 3. Maski K, Herous T. Curr Sleep Medicine Rep. 2016;2(1):31-37. **Support:** This study was supported by Jazz Pharmaceuticals.

Health Care Cost and Utilization Before and After Diagnosis in Pediatric Patients With Newly Diagnosed Narcolepsy: A Claims-based Analysis

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Results

Table 1. Cohort Characteristics				
	Children and adolescents with newly diagnosed narcolepsy (N = 121)			
Age, n (%)				
≤6 years	1 (0.8)			
7-11 years	26 (21.5)			
12-17 years	94 (77.7)			
Female, n (%)	52 (43.0)			
Geographic region, n (%)				
Northeast	25 (20.7)			
Midwest	29 (24.0)			
South	52 (43.0)			
West	15 (12.4)			
 121 pediatric patients with newly diagnosed narcolepsy were identified. 				

Figure 2. Frequency of Claims (or Visits) Related to Comorbid Conditions of **Interest Decreased in the Years Following Diagnosis**^a



Y, Year; ADHD, attention-deficit/hyperactivity disorder

^aThe figure shows conditions with diagnostic codes in \geq 10% of narcolepsy patients. Conditions were selected based on clinical experience and previous association with narcolepsy from the literature.³

- The number of body systems affected by acute and chronic comorbid conditions in newly diagnosed pediatric patients with narcolepsy, as measured by the AHRQ CCS "body system" classification, decreased from 6.1 to 5.4 per patient from baseline to Year (Y) 1 and from 5.4 to 4.7 per patient from Y1 to Y2 (all differences from baseline and from Y1 to Y2, nominal P < 0.001; data not shown).
- Obstructive sleep apnea, upper respiratory tract infections, other sleep disorders, insomnia, epilepsy/seizures, and sleep-related movement disorders decreased both from baseline to Y1 and from baseline to Y2 (all nominal P < 0.05).
- The frequencies of attention-deficit/hyperactivity disorder, depression, epilepsy/seizures, insomnia, obstructive sleep apnea, other sleep disorders, sleep-related movement disorders, and injuries (trauma or burns) also decreased from Y1 to Y2 (all nominal P < 0.05).

Disclosures: SRR, MSB, and RT are employees of Partnership for Health Analytic Research, LLC, which received funding from Jazz Pharmaceuticals, plc; KFV and JP are full-time employees of Jazz Pharmaceuticals, who, in the course of this employment, and other stock awards of, ordinary shares of Jazz Pharmaceuticals, plc; KFV and JP are full-time employees of Jazz Pharmaceuticals, who, in the course of this employment, and other stock awards of, ordinary shares of Jazz Pharmaceuticals, plc; KFV and JP are full-time employees of Jazz Pharmaceuticals, who, in the course of this employment, and other stock awards of, ordinary shares of Jazz Pharmaceuticals, plc; KFV and JP are full-time employees of Jazz Pharmaceuticals, who, in the course of this employment, and the course of this employees of Jazz Pharmaceuticals, who, in the course of this employees of Jazz P

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Y. Year: ADHD, attention-deficit/hyperactivity disord

, selective serotonin reuptake inhibitors, serotonin-norepinephrine reuptake inhibitors, and tricyclic agents. Other medication inhibitors, other anxiety medications, anticonvulsants, nonstimulant ADHD medications, and antipsychotics ^bAll differences from baseline and from Y1 and Y2, nominal P < 0.001.

• At baseline, Y1, and Y2, 48.8%, 90.1%, and 75.2% of patients used narcolepsy-related medications, respectively (all differences, nominal P < 0.001; data not shown).

Table 2. Mean Annual Medical Care Costs per Pediatric Patient Declined While **Pharmacy Costs Increased in the Years Following Diagnosis**^a

	Baseline (N = 121), \$	Y1 (N = 121), \$	Y2 (N = 121), \$
Inpatient hospitalizations cost	1,903	1,644	470*,†
Outpatient services cost	11,241	6,815*	5,249*
Total medical services cost	13,144	8,460*	5,718 *,†
Narcolepsy-related Rx cost	941	7,376*	9,172* ^{,†}
Other Rx cost	750	1,180	883
Total pharmacy cost	1,691	8,556*	10,055*
Total health care cost	14,834	17,015	15,773

Y. Year: Rx. prescription

^aTotal health care costs and cost by type of service were estimated as a per-patient annual average. All costs were reported as means with standard deviations, and inflation was adjusted to 2015 USD *Nominal P < 0.05 versus baseline. [†]Nominal *P* < 0.05 versus Y1

- Total medical care costs (excluding pharmacy costs) accounted for about 90% of total health care costs at baseline and decreased in the years following diagnosis.
- Pharmacy costs increased from baseline to Y1 and Y2, while total costs remained relatively stable over time due to decreases in medical costs.

CONCLUSIONS

- Health care utilization and costs were substantial in the year leading up to a narcolepsy diagnosis in pediatric patients.
- After a diagnosis of narcolepsy, there was a decrease, on average, in health care utilization, medical care costs, and claims related to comorbid conditions.
- Total health care costs stayed relatively stable 2 years following diagnosis, which is attributable to a decline in medical service costs from baseline to 1 and 2 years following diagnosis, coupled with an increase in pharmacy costs over this period.

