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Nighttime Symptom Prevalence and 24-Hour Symptom Burden in Patients With Narcolepsy: Findings From the Adelphi Real World Narcolepsy Disease Specific Programme™

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Objective

- To assess the prevalence of specific nighttime sleep complaints and describe their association with daytime symptoms, work productivity, and quality of life in individuals with narcolepsy

Conclusions

- This real-world, multistakeholder study found that patients with evaluated nighttime sleep complaints (shallow nighttime sleep, frequent nighttime awakenings, and/or early awakenings) were numerically more likely than those without these complaints to experience daytime symptoms such as brain fog, inattention, poor memory, and moderate or severe excessive daytime sleepiness
- Patients experiencing ≥1 evaluated nighttime sleep complaint also reported numerically greater work impairment and numerically lower health-related quality of life than those without these complaints, suggesting a higher overall disease burden across the day among those experiencing nighttime sleep complaints
- Since no statistical comparisons were conducted, findings are descriptive and cannot be interpreted causally; in addition, reports of nighttime sleep complaints were provided by patients' healthcare providers rather than by the patients themselves
- These findings highlight the 24-hour burden of narcolepsy; further research into the impact of nighttime sleep complaints and relationship with daytime burden is required to optimize treatment and management of patients with narcolepsy

References: **1.** Kornum BR, et al. *Nat Rev Dis Primers.* 2017;3:16100. **2.** Ortiz LE, et al. *CNS Drugs.* 2025;39(Suppl 1):23-36. **3.** Anderson P, et al. *Curr Med Res Opin.* 2023;39(12):1707-1715. **4.** Babineaux SM, et al. *BMJ Open.* 2016;6(8):e010352. **5.** Higgins V, et al. *Diabetes Metab Syndr Obes.* 2016;9:371-380. **6.** Rabin R, de Charro F. *Ann Med.* 2001;33(5):337-343. **7.** Reilly MC, et al. *Pharmacoeconomics.* 1993;4(5):353-365.

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Introduction

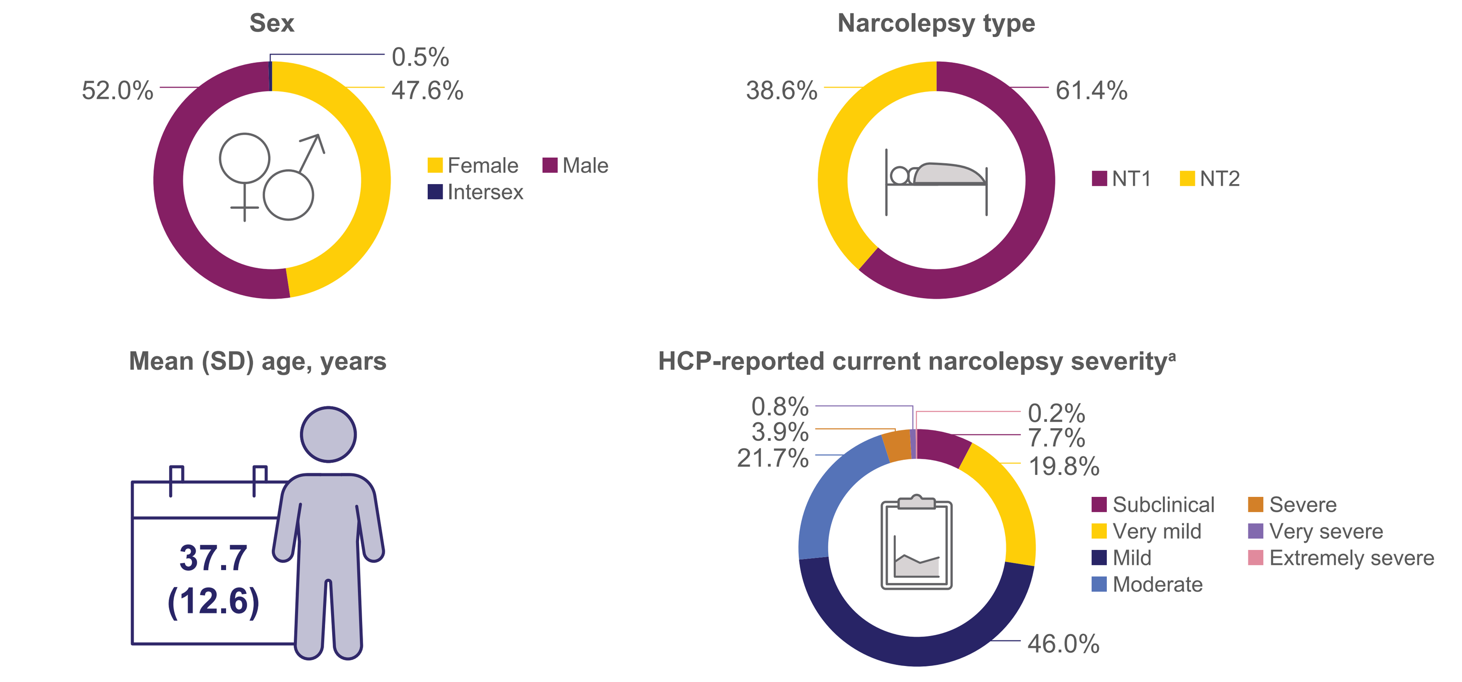
- Narcolepsy is a chronic neurological sleep disorder characterized by symptoms including excessive daytime sleepiness (EDS), disrupted nighttime sleep, sleep paralysis, hypnagogic/hypnopompic hallucinations, and cataplexy (narcolepsy type 1 only); these symptoms can substantially impair daily functioning and quality of life[1]
- A recent US patient survey highlighted the substantial burden of narcolepsy, with most patients reporting that narcolepsy had an extremely severe or very severe impact on their daily lives[2]
- However, the relationship between nighttime sleep complaints and daytime symptom burden remains poorly understood

Methods

- Data were drawn from the Adelphi Real World Narcolepsy Disease Specific Programme™ (DSP), a real-world, cross-sectional survey of patients and their treating physicians in the United States from August 2025 to March 2026
 - The DSP methodology has been previously described, validated, and shown to be representative and consistent over time[3-5]
- The healthcare provider (HCP) survey was completed by primary care physicians, neurologists, psychiatrists, and pulmonologists
 - HCPs provided data on patient demographics, clinical characteristics, current Epworth Sleepiness Scale (ESS) scores (normal daytime sleepiness, 6–10; mild EDS, 11–12; moderate EDS, 13–15; severe EDS, 16–24), and current daytime symptoms and nighttime sleep complaints
 - Evaluated nighttime sleep complaints comprised shallow nighttime sleep, frequent nighttime awakenings, and early morning awakenings
- Patients completed the Work Productivity and Activity Impairment–Specific Health Problem (WPAI-SHP) and EuroQol Visual Analogue Scale (EQ-VAS; score range: 0–100, where 0 = the worst health imaginable and 100 = the best health imaginable) questionnaires,[3,4] along with de novo questions about the impact of narcolepsy on quality of life
- Findings are descriptive; numerical differences are reported for the study sample, stratified by evaluated nighttime sleep complaints as reported by HCPs

Results

Figure 1. HCP-Reported Patient Demographic and Clinical Characteristics (N=637)

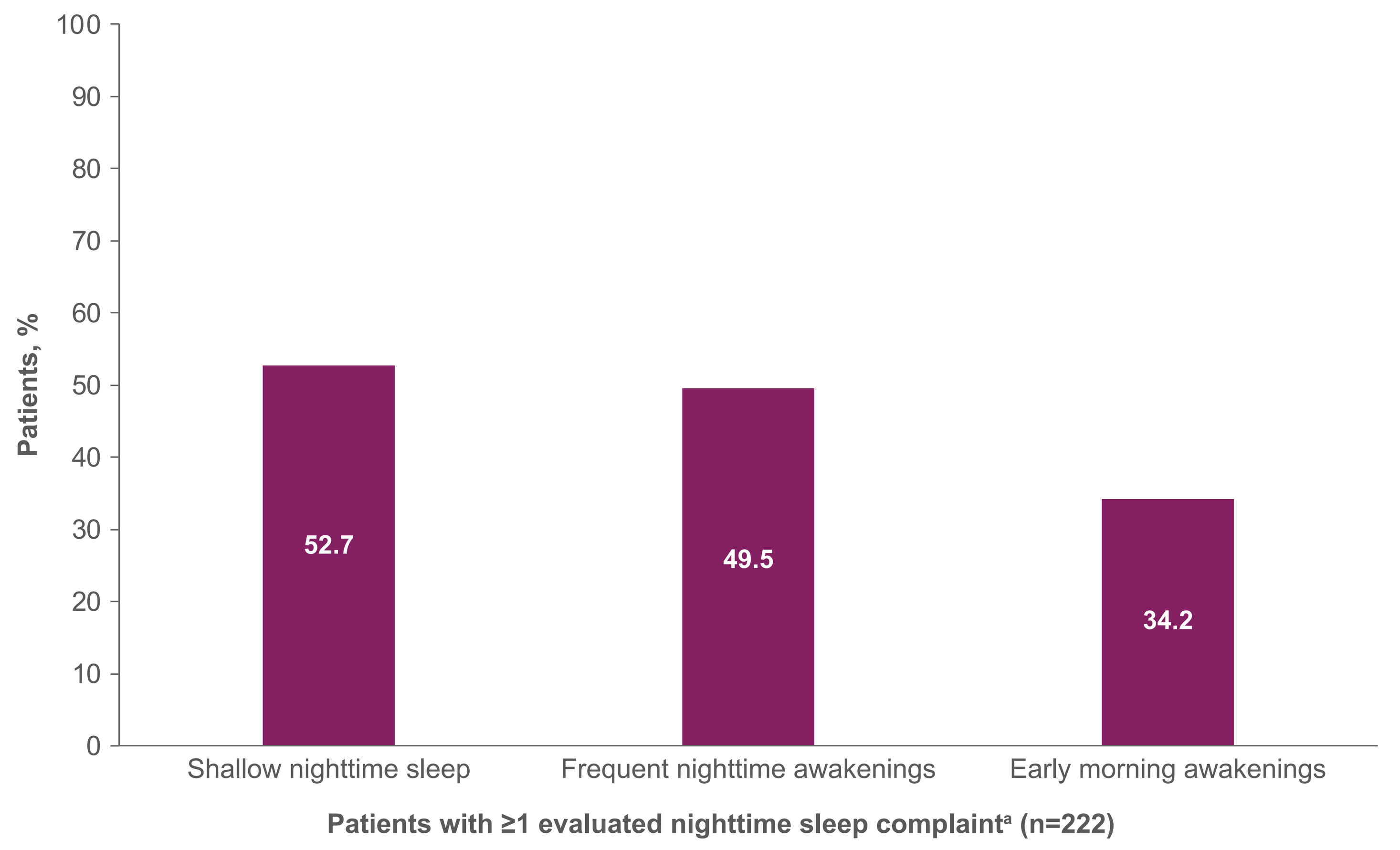


Sex
52.0%
0.5%
47.6%
Female
Male
Intersex
Narcolepsy type
38.6%
61.4%
NT1
NT2
Mean (SD) age, years
37.7 (12.6)
HCP-reported current narcolepsy severity[a]
0.8%
3.9%
21.7%
0.2%
7.7%
19.8%
46.0%
Subclinical
Very mild
Mild
Moderate
Severe
Very severe
Extremely severe

[a]De novo question.
HCP, healthcare provider; NT1, narcolepsy type 1; NT2, narcolepsy type 2; SD, standard deviation.

- HCP-recorded data were available for 637 patients
- The mean (SD) patient age was 37.7 (12.6) years, 47.6% were female, and 61.4% had narcolepsy type 1
- Mild narcolepsy severity was reported by HCPs for 46.0% of patients

Figure 2. HCP-Reported Prevalence of Shallow Nighttime Sleep, Frequent Nighttime Awakenings, and/or Early Morning Awakenings, Among Those With ≥1 Evaluated Nighttime Sleep Complaint

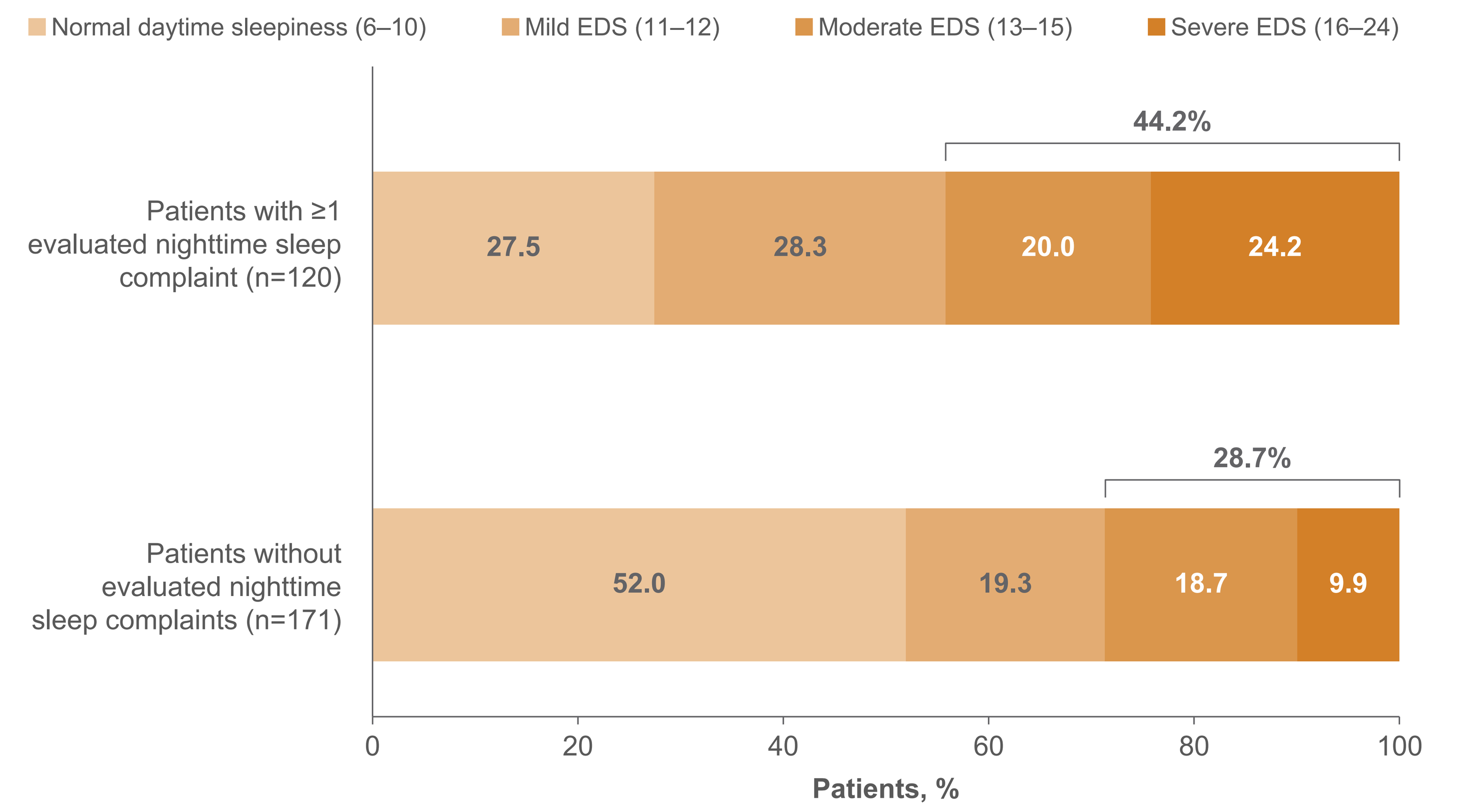


Patients, %
100
90
80
70
60
50
40
30
20
10
0
52.7
49.5
34.2
Shallow nighttime sleep
Frequent nighttime awakenings
Early morning awakenings
Patients with ≥1 evaluated nighttime sleep complaint[a] (n=222)

[a]Evaluated nighttime sleep complaints comprised frequent nighttime awakenings, shallow nighttime sleep, and early morning awakenings, as reported by HCPs.
HCP, healthcare provider.

- Of the 637 patients, HCPs reported that 222 patients (34.9%) had ≥1 evaluated nighttime sleep complaint at the time of data collection; 64.7% of these patients were reported to experience nighttime sleep complaints several nights per week or more frequently
- Of the 3 nighttime sleep complaints evaluated, shallow sleep was the most frequently recorded (52.7%, n=117), followed by frequent nighttime awakenings (49.5%, n=110) and early morning awakenings (34.2%, n=76)

Figure 3. Patients With vs Without ≥1 Evaluated Nighttime Sleep Complaint Were Numerically More Likely to Also Have Moderate or Severe EDS (HCP-Reported Data; n=291)[a]

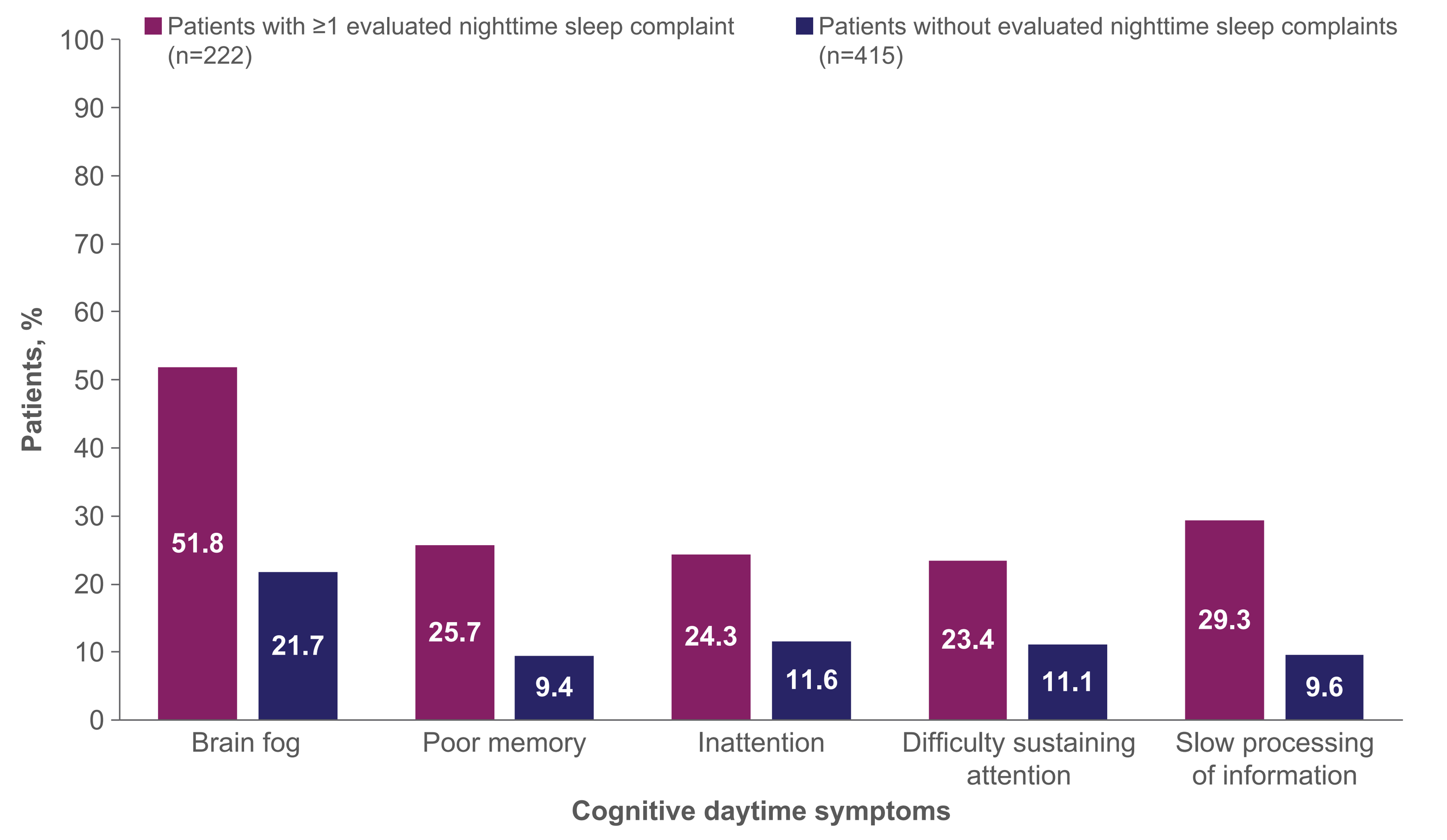


Normal daytime sleepiness (6–10)
Mild EDS (11–12)
Moderate EDS (13–15)
Severe EDS (16–24)
Patients with ≥1 evaluated nighttime sleep complaint (n=120)
27.5
28.3
20.0
24.2
44.2%
Patients without evaluated nighttime sleep complaints (n=171)
52.0
19.3
18.7
9.9
28.7%
0
20
40
60
80
100
Patients, %

[a]EDS as defined by HCP-reported ESS score; ESS scores were not available for all patients. A further 38 patients had ESS scores of 0 to 5, indicating lower normal daytime sleepiness; data not shown. Evaluated nighttime sleep complaints comprised frequent nighttime awakenings, shallow nighttime sleep, and early morning awakenings, as reported by HCPs. Proportions have been rounded.
EDS, excessive daytime sleepiness; ESS, Epworth Sleepiness Scale; HCP, healthcare provider.

- Numerically higher proportions of patients with vs without ≥1 evaluated nighttime sleep complaint had ESS scores indicating moderate or severe EDS (44.2% vs 28.7%)

Figure 4. Patients With vs Without ≥1 Evaluated Nighttime Sleep Complaint[a] Were Numerically More Likely to Have Cognitive Daytime Symptoms Recorded (HCP-Reported Data; n=637)

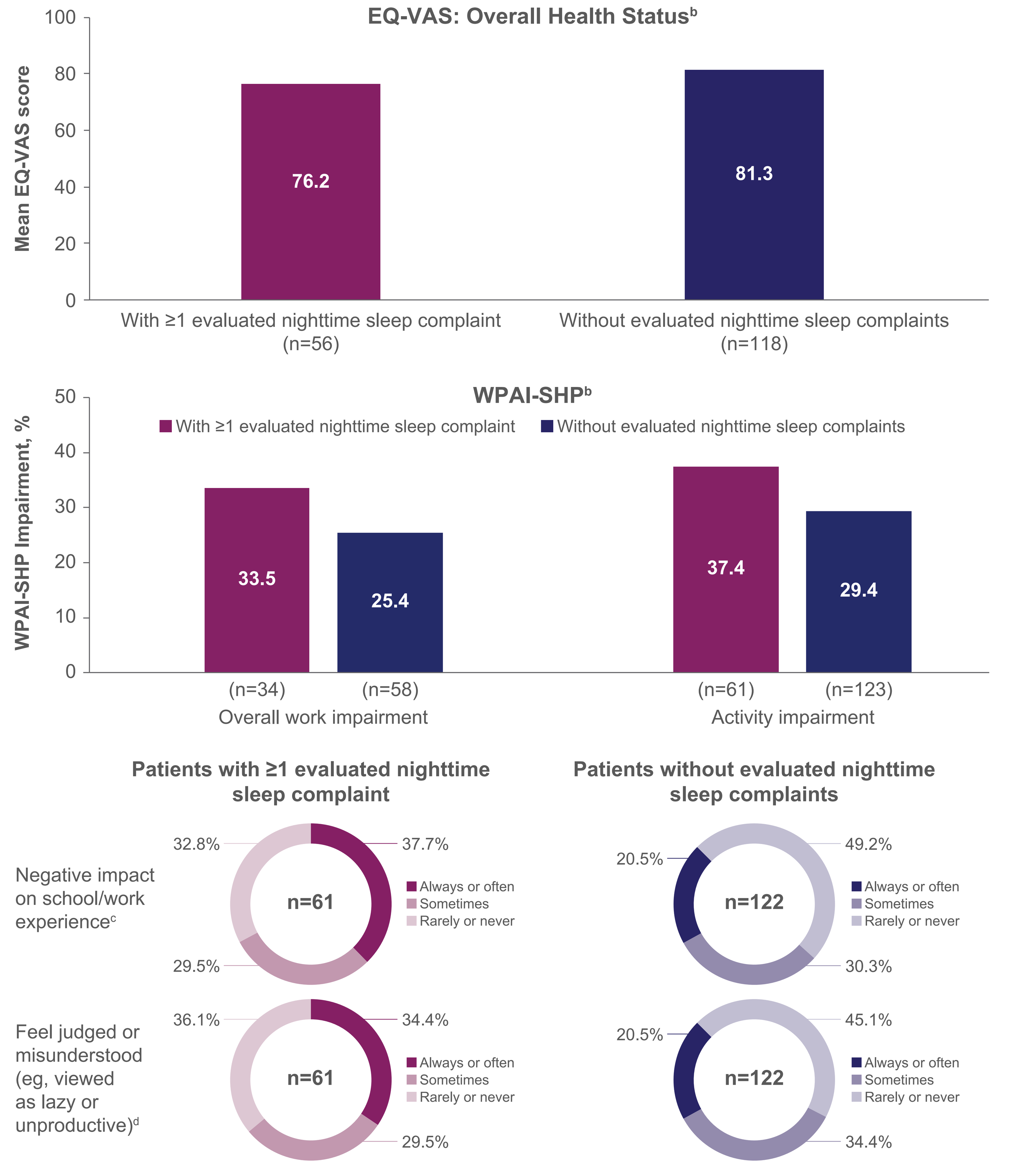


Patients with ≥1 evaluated nighttime sleep complaint (n=222)
Patients without evaluated nighttime sleep complaints (n=415)
Patients, %
100
90
80
70
60
50
40
30
20
10
0
51.8
21.7
25.7
9.4
24.3
11.6
23.4
11.1
29.3
9.6
Brain fog
Poor memory
Inattention
Difficulty sustaining attention
Slow processing of information
Cognitive daytime symptoms

[a]Evaluated nighttime sleep complaints comprised frequent nighttime awakenings, shallow nighttime sleep, and early morning awakenings, as reported by HCPs.
HCP, healthcare provider.

- Numerically greater proportions of patients with vs without ≥1 evaluated nighttime sleep complaint also had cognitive daytime symptoms recorded, including brain fog, poor memory, and inattention

Figure 5. Patients With vs Without ≥1 Evaluated Nighttime Sleep Complaint[a] Reported Numerically Lower Health Status and Greater Work Impairment (Patient Survey; n=184)



EQ-VAS: Overall Health Status[b]
Mean EQ-VAS score
100
80
60
40
20
0
76.2
81.3
With ≥1 evaluated nighttime sleep complaint (n=56)
Without evaluated nighttime sleep complaints (n=118)
WPAI-SHP[b]
With ≥1 evaluated nighttime sleep complaint
Without evaluated nighttime sleep complaints
WPAI-SHP Impairment, %
50
40
30
20
10
0
33.5
25.4
37.4
29.4
(n=34)
(n=58)
Overall work impairment
(n=61)
(n=123)
Activity impairment
Patients with ≥1 evaluated nighttime sleep complaint
Patients without evaluated nighttime sleep complaints
Negative impact on school/work experience[c]
32.8%
37.7%
29.5%
n=61
Always or often
Sometimes
Rarely or never
20.5%
49.2%
30.3%
n=122
Always or often
Sometimes
Rarely or never
Feel judged or misunderstood (eg, viewed as lazy or unproductive)[d]
36.1%
34.4%
29.5%
n=61
Always or often
Sometimes
Rarely or never
20.5%
45.1%
34.4%
n=122
Always or often
Sometimes
Rarely or never

[a]Evaluated nighttime sleep complaints comprised frequent nighttime awakenings, shallow nighttime sleep, and early morning awakenings, as reported by HCPs. [b]Higher EQ-VAS scores indicate better health-related quality of life; lower WPAI-SHP scores indicate less impairment. No minimal important difference has been established for the EQ-VAS or WPAI-SHP in narcolepsy. [c]Patients were asked, "How often do you feel that your narcolepsy negatively impacts your school/work experience?" [d]Patients were asked, "How often do you feel judged or misunderstood by others due to your narcolepsy (eg, being viewed as lazy or unproductive)?"
EQ-VAS, EuroQol Visual Analog Scale; WPAI-SHP, Work Productivity and Activity Impairment–Specific Health Problem.

- Patient-reported data were available for 184 patients, of whom 61 (33.2%) experienced ≥1 evaluated nighttime sleep complaint (as reported by HCPs)
- Numerically lower EQ-VAS scores were reported among patients with vs without ≥1 evaluated nighttime sleep complaint (76.2 vs 81.3), indicating lower health-related quality of life
- Patients with vs without ≥1 evaluated nighttime sleep complaint reported numerically greater overall work impairment (33.5% vs 25.4%) and activity impairment (37.4% vs 29.4%) via the WPAI-SHP
- Patients with vs without ≥1 evaluated nighttime sleep complaint were numerically more likely to report "always" or "often" experiencing a negative impact of narcolepsy on work or school (37.7% vs 20.5%), as well as feeling judged or misunderstood (34.4% vs 20.5%) due to narcolepsy