

BACKGROUND

Idiopathic hypersomnia (IH) is a neurologic condition characterized by chronic excessive daytime sleepiness despite normal sleep duration in which sleepiness is unexplained by other sleep disorders, behaviors, or other identifiable causes.

Population-based prevalence estimates of IH are unavailable, though a recent analysis* of a US insured population found ~1/10,000 persons (~0.01%) were diagnosed with IH. However, as with many other sleep disorders, the prevalence of IH is likely to be substantially underestimated using only diagnosed cases.

Here we estimate “probable IH” prevalence in the Wisconsin Sleep Cohort (WSC), a non-clinical population-based cohort of middle-to-older-aged adults. A large subset of the WSC has been assessed for many objective and subjective sleep and sleepiness characteristics that allow for the evaluation of “probable IH” – IH established by multiple research tools but generally without specific IH diagnostic assessment by a sleep medicine specialist.

*Acquavella et al., Prevalence of narcolepsy and other sleep disorders and frequency of diagnostic tests from 2013-2016 in insured patients actively seeking care. *J Clin Sleep Med.* 2020;16(8):1255-1263.

METHODS

Sample: The WSC was established in the late 1980s from a working non-clinical population and, over the ensuing decades, has been examined for the natural history of sleep behaviors and common sleep disorders from mid-to-later adulthood. A subset of WSC participants (N=792, 48% female, age range=40-78 years), provided sufficient information for the establishment or exclusion of “probable idiopathic hypersomnia.”

Data Collection:

- Overnight in-laboratory polysomnography (PSG)
- Clinical Multiple Sleep Latency Tests (MSLT)
- Epworth Sleepiness Scale (ESS)
- One-week sleep diaries
- Questionnaires regarding sleep problems and habits as well as a broad range of medical, health and sociodemographic information.
- Chart review by sleep medicine specialist (D.T.P.)

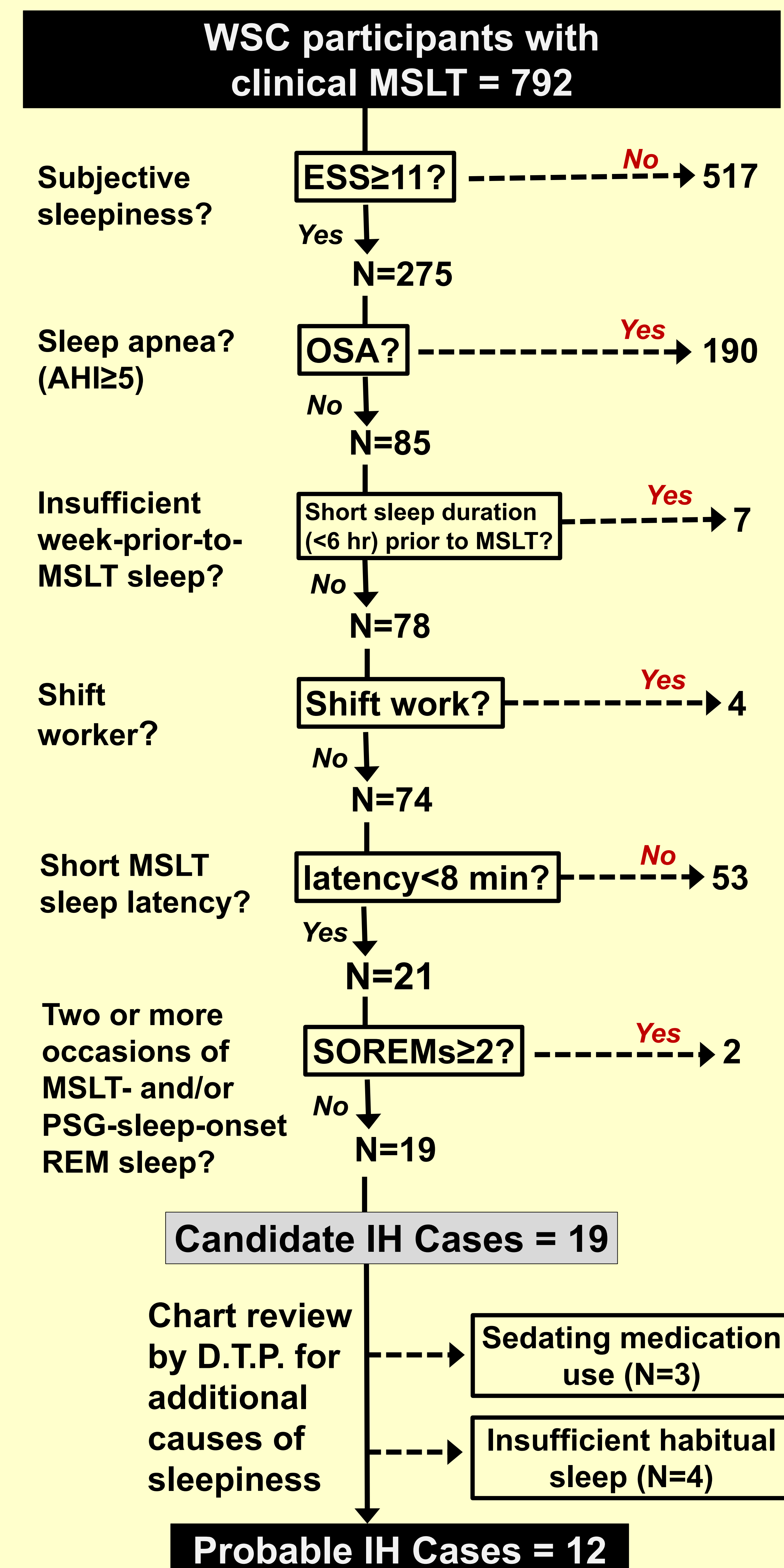
Classification of probable idiopathic hypersomnia: See the “Idiopathic Hypersomnia (“probable IH”) Case Identification Flowchart” in Results for a depiction of the process by which probable IH cases were identified.

RESULTS

Sample Characteristics

	WSC MSLT Sample (N=792)	Idiopathic hypersomnia sub-sample (N=12)
Female gender, N (%)	383 (48%)	7 (58%)
Age, mean (SD)	59 (8) yr.	57 (8) yr.
BMI, mean (SD)	32 (7) kg/m ²	30 (6) kg/m ²
ESS Score>10, N (%)	275 (35%)	12 (100%)
Feelings of excessive daytime sleepiness, often-always, N (%)	144 (18%)	7 (58%)
MSLT sleep latency, mean (SD)	12 (5) min.	6 (2) min.
Daily average sleep duration from 1-week diary including naps, mean (SD)	7.9 (1.0) hr.	8.1 (0.9) hr.
AHI category, N (%)		
0-<5 events/hr	308 (39%)	12 (100%)
5-<15 events/hr	224 (28%)	0%
15+ events/hr	260 (33%)	0%
PSG sleep efficiency, mean (SD)	81% (10%)	82% (15%)
PSG sleep latency, mean (SD)	12 (14) min.	4 (2) min.
Sedative use, N (%)	74 (9%)	0%
Antidepressant use, N (%)	186 (23%)	5 (42%)

Idiopathic Hypersomnia (“probable IH”) Case Identification Flowchart



Thus, prevalence of “probable IH” in the WSC = $\frac{12}{792} = 1.5\%$ (95%CI=0.7% to 2.4%)

CONCLUSION

Idiopathic hypersomnia (IH) is likely underdiagnosed, perhaps greatly so. We found a prevalence of probable IH approximately 100-fold higher than has been estimated using diagnosed cases. However, there are reasons why our findings may either somewhat overestimate (e.g., missed alternative causes of sleepiness that might be identified in diagnostic interviews) or underestimate (e.g., exclusion of IH due to the presence of OSA that might be masking underlying IH) “true” idiopathic hypersomnia prevalence.

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