# Understanding Sleep Inertia: A Qualitative Study of the Patient Experience With Idiopathic Hypersomnia

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### Introduction

- Sleep inertia, which is characterized by difficulty awakening with repeated returns to sleep, irritability, automatic behavior, and confusion, is a common feature of idiopathic hypersomnia<sup>1-4</sup>
- There is a need to better understand the experience of sleep inertia from the perspective of patients with idiopathic hypersomnia to improve identification and measurement of sleep inertia and monitor treatment response

# **Objective**

 To generate insights into how people with idiopathic hypersomnia describe and experience sleep inertia

#### Methods

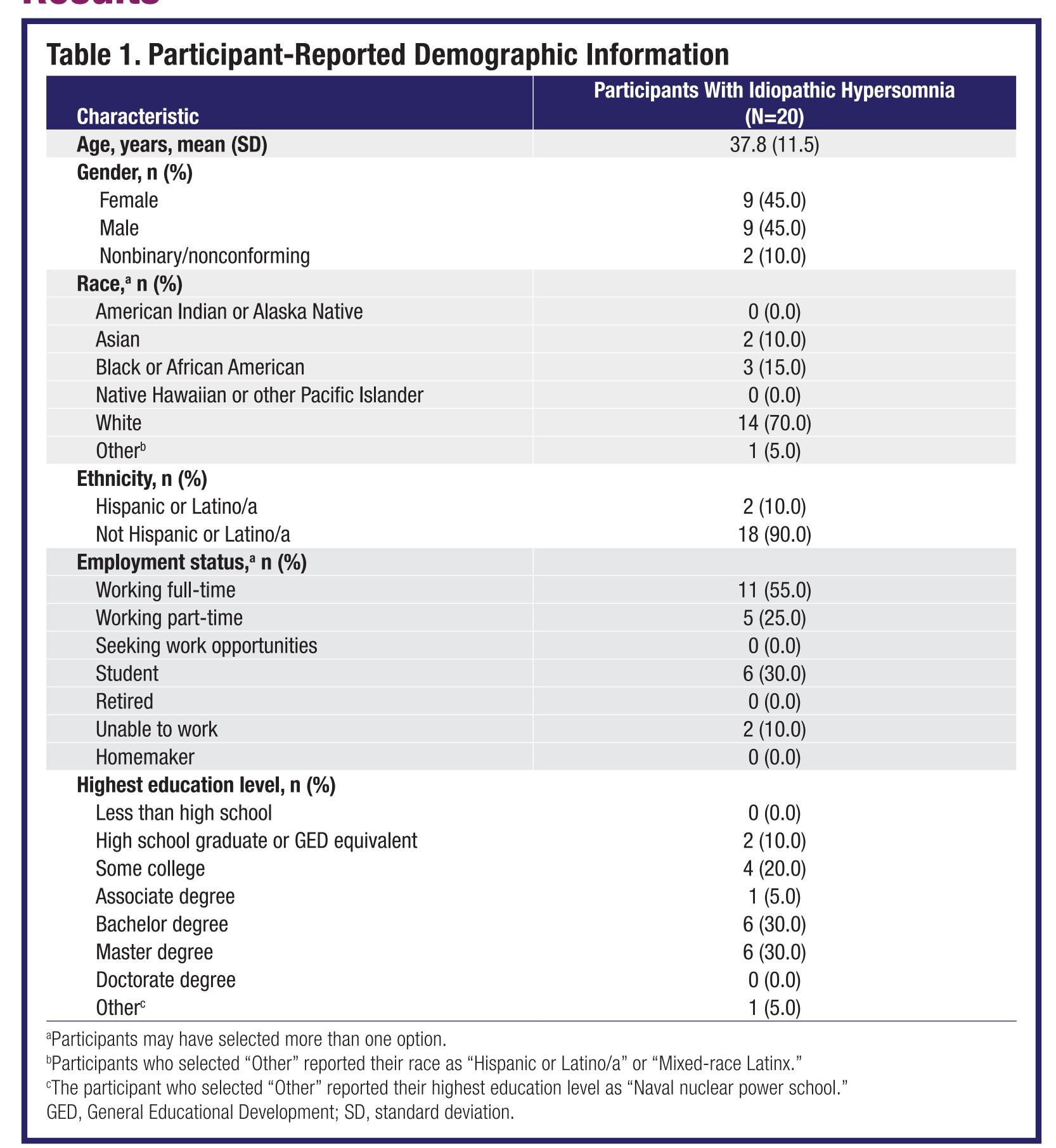
- Concept elicitation interviews were conducted with 20 adults with idiopathic hypersomnia
- These interviews were designed to explore the patient experience of living with idiopathic hypersomnia and included open-ended and probing questions to elicit descriptions of symptoms and impacts associated with idiopathic hypersomnia, including sleep inertia
- Key requirements for interview inclusion: age 18–64 years at time of screening, confirmed idiopathic hypersomnia diagnosis, current excessive daytime sleepiness (EDS) experience, US residence, fluency in English, and consent to the interview process
- Participants were excluded if they had a diagnosis of another medical condition or medication associated with EDS; untreated or inadequately treated sleep-disordered breathing or periodic limb movement disorder resulting in daytime sleepiness (sleep apnea permitted if adequately treated); average total sleep time of <7 hours/night over the preceding 6 months; or an occupation that required nighttime or variable shift work
- During interviews, participants were asked to provide severity ratings (0–10) for all past/current symptoms and bothersomeness ratings (0–10) for all current symptoms and impacts
- Participants were also asked to report their 3 worst and 3 most bothersome symptoms
- Interview data were coded and analyzed using MAXQDA (qualitative software)
   Frequency of report and bothersomeness ratings were used to evaluate salience (reported by ≥50% of participants; average bothersomeness rating ≥5)
- Sleep inertia data were analyzed quantitatively (eg, frequency of report; severity and bothersomeness ratings) and qualitatively (eg, patient descriptors of sleep inertia experience), where appropriate

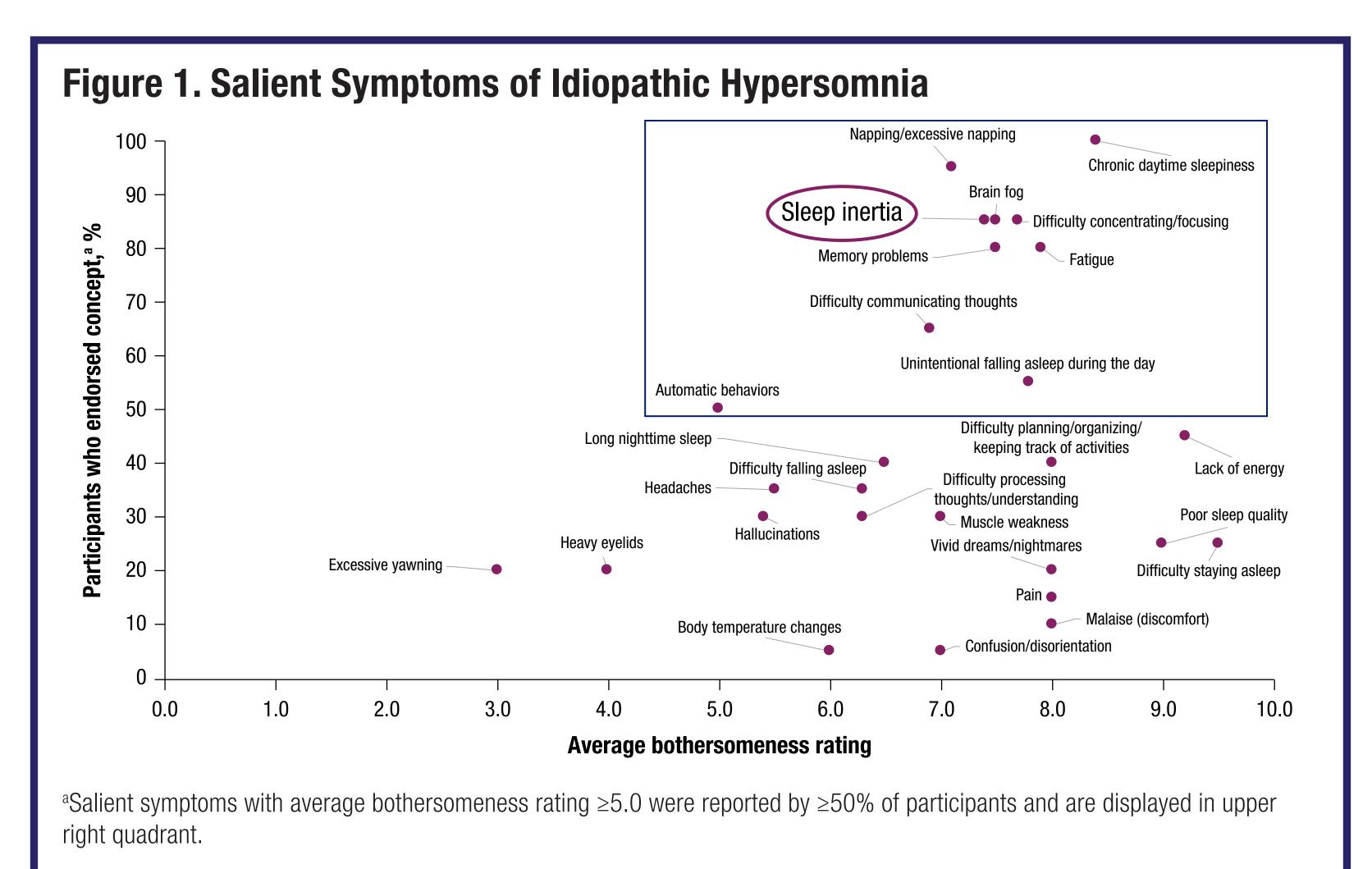
**References: 1.** American Academy of Sleep Medicine. *International Classification of Sleep Disorders — Third Edition, Text Revision*. Darien, IL: American Academy of Sleep Medicine; 2023. **2.** Stevens J, et al. *Nat Sci Sleep*. 2023;15:593-606. **3.** Trotti LM. *Sleep Med Rev.* 2017;35:76-84. **4.** Arnulf I, et al. *Sleep Med Rev.* 2023;69:101766.

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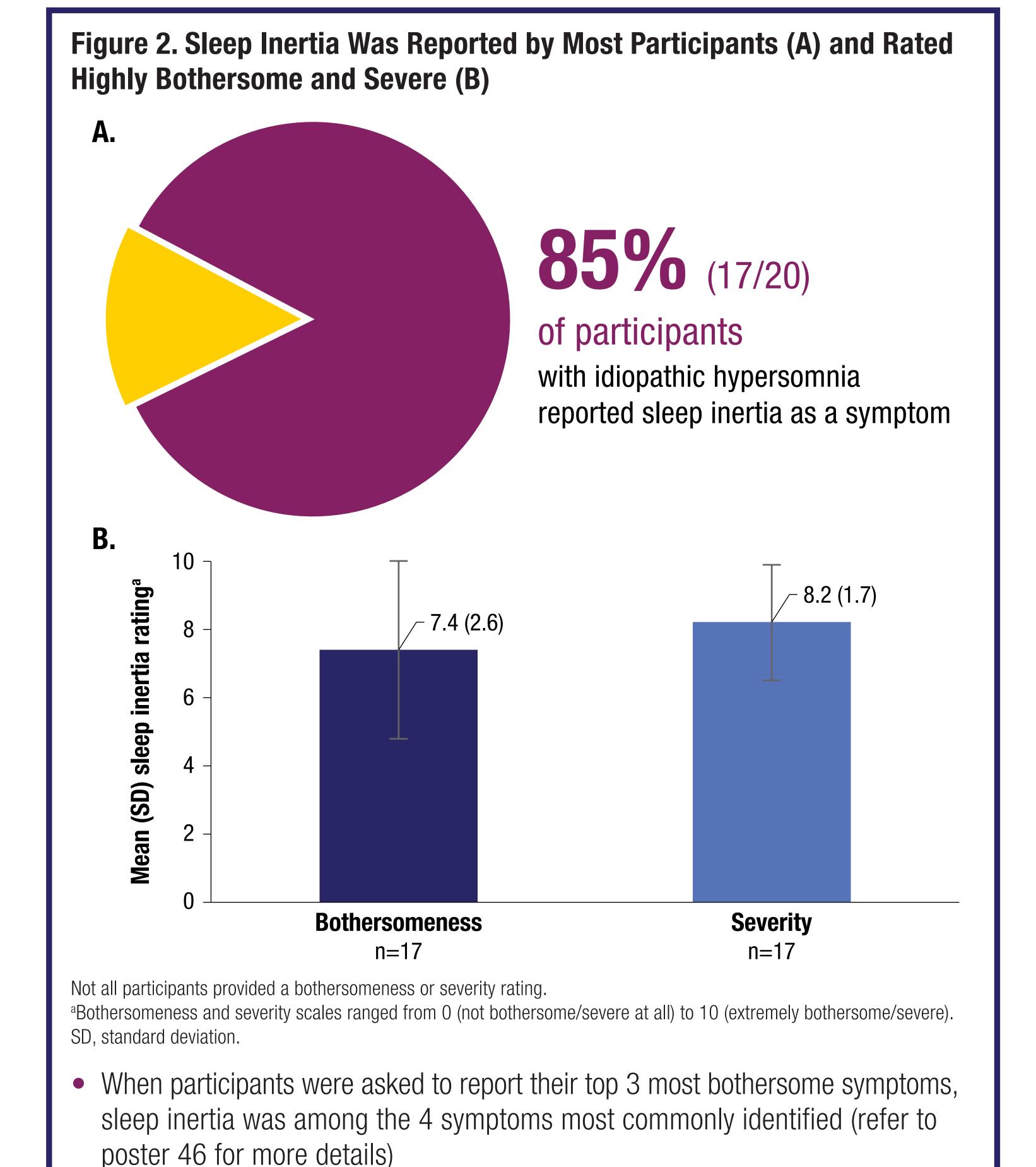
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#### Results

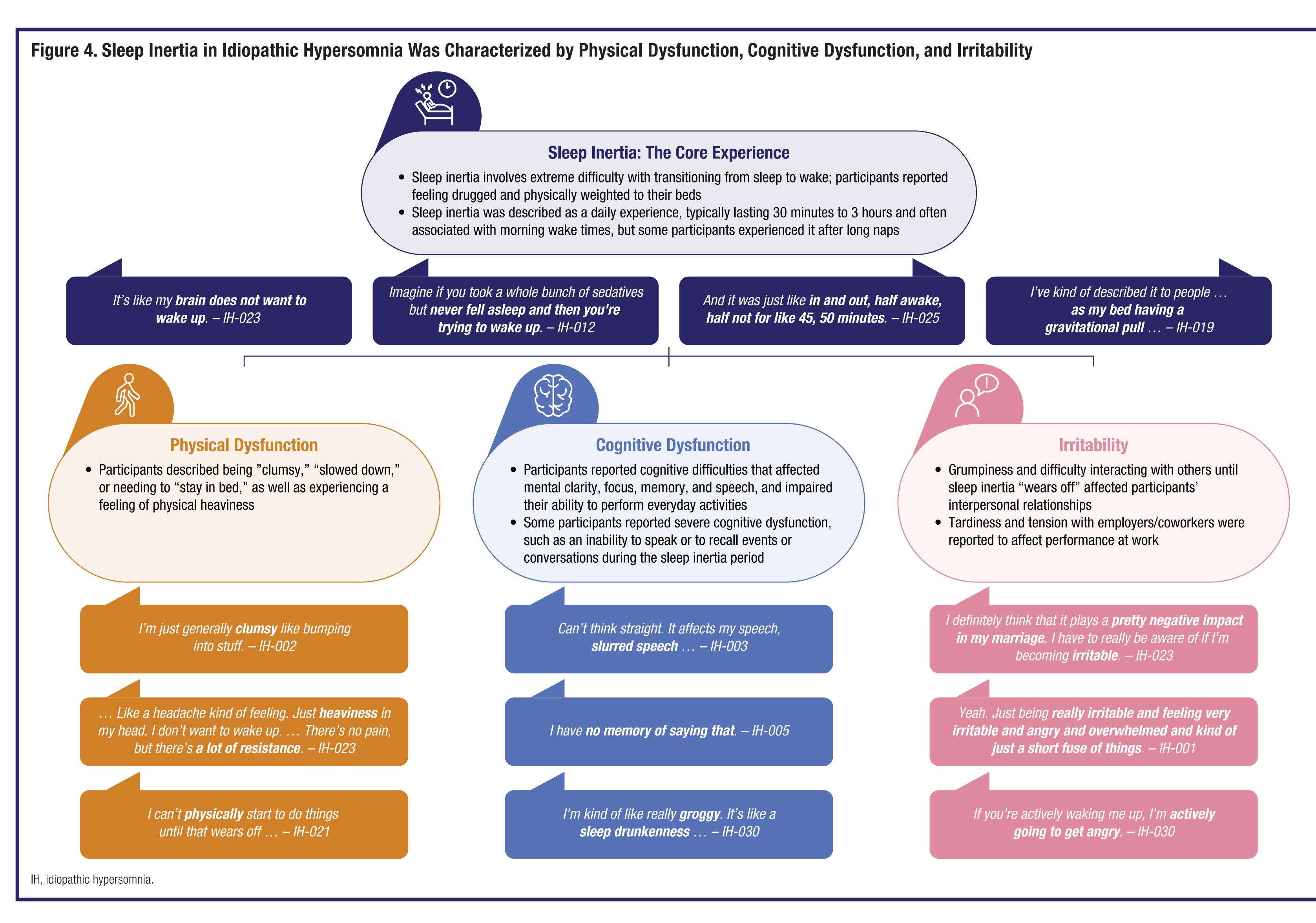




 Of the 31 symptoms reported by participants with idiopathic hypersomnia, sleep inertia was among the 10 symptoms identified as salient to the patient experience (refer to poster 46 for more details)







## Conclusions

- Exploration of the patient experience with sleep inertia provided insight into this common and important symptom of idiopathic hypersomnia:
   85% of participants reported experiencing sleep inertia, and bothersomeness and severity ratings were high
  - Participants described sleep inertia as extreme difficulty emerging from sleep, which was accompanied by cognitive and physical dysfunction, including grogginess, confusion, difficulty focusing and speaking, and clumsiness; irritability was also described with sleep inertia
- Sleep inertia significantly impacted participants' quality of life and day-to-day function, including daily activities, work productivity, and mood
- Data were extracted from interviews that focused on the overall idiopathic hypersomnia experience. As it is possible that interviews that focused specifically on sleep inertia may have elicited additional information, these results may not reflect the full patient experience with sleep inertia
- These patient-centric findings demonstrate the pervasiveness, complexity, and impact of sleep inertia in idiopathic hypersomnia and support increased awareness of and probing for sleep inertia in clinical practice

