

Patient Perspective on Idiopathic Hypersomnia: Impact on Quality of Life and Satisfaction With the Diagnostic Process and Management

SLEEP 2022, the 36th Annual Meeting of the Associated Professional Sleep Societies (APSS)
June 4-8, 2022 • Charlotte, NC

Marisa Whalen, PharmD¹; Bailey Roy, BA²; Teresa Steininger, PhD³; Nalina Dronamraju, PhD¹; Daniel Enson, MBA⁴

¹Jazz Pharmaceuticals, Philadelphia, PA, USA; ²GCI Health, New York, NY, USA; ³Jazz Pharmaceuticals, Palo Alto, CA, USA; ⁴Toluna, Inc., Norwalk, CT, USA

Introduction

- Idiopathic hypersomnia is a debilitating central disorder of hypersomnolence characterized by excessive daytime sleepiness, severe sleep inertia, and prolonged nighttime sleep¹
- Although a limited number of studies have shown that idiopathic hypersomnia negatively impacts quality of life (QoL) and functioning,²⁻⁵ patient satisfaction with the diagnostic process and disease management has not been well established

Objectives

- The primary objectives were to measure the impact of idiopathic hypersomnia on patient QoL and gauge patient satisfaction with their physician and the diagnostic process for idiopathic hypersomnia

Methods

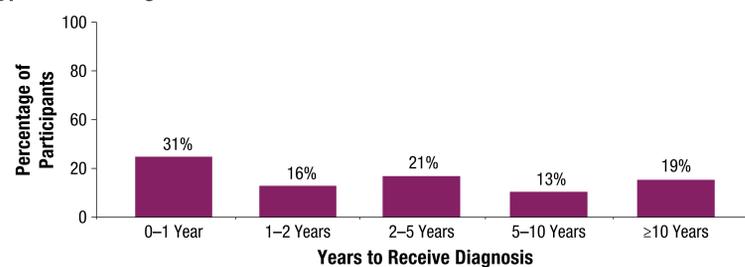
- United States residents with idiopathic hypersomnia completed an online survey (Toluna Inc., Norwalk, CT) between June 10 and July 2, 2021 assessing the symptoms, impact, diagnosis, and management of idiopathic hypersomnia
- Eligible patients were required to live in the United States and to have received a formal diagnosis of idiopathic hypersomnia from their healthcare provider
- Descriptive statistics were used to summarize all data

Results

Table 1. Participant Demographics

	Total (N=290)
Gender, n (%)	
Female	256 (88)
Male	27 (9)
Nonbinary	5 (2)
Prefer not to answer	2 (1)
Age (years), n (%)	
18-24	45 (16)
25-34	89 (31)
35-44	81 (28)
≥45	75 (26)
White/Caucasian, %	255 (88)
Highest education completed, n (%)	
4-year degree or higher	173 (60)
No 4-year degree	113 (39)
Prefer not to answer	4 (1)
Employment, n (%)	
Full-time/Part-time	182 (63)
Other	108 (37)

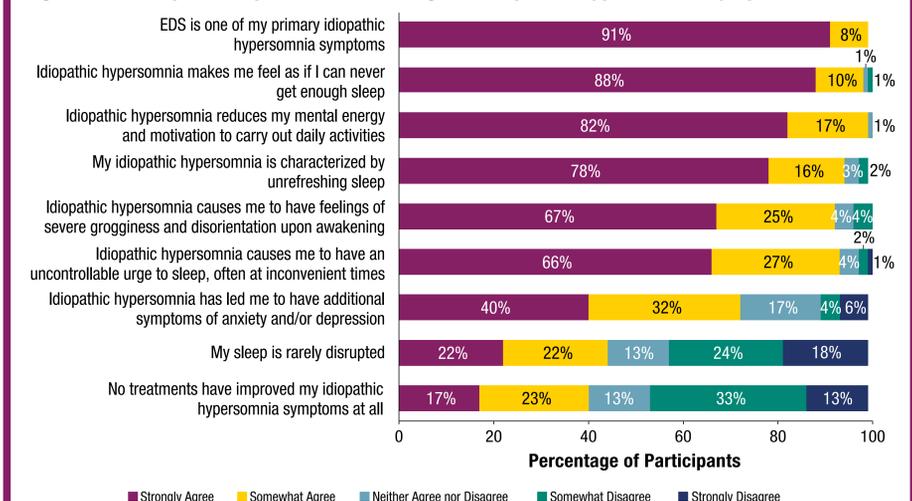
Figure 1. Many Participants Reported Waiting Several Years to Receive Their Idiopathic Hypersomnia Diagnosis



Question: How long did it take you to receive your idiopathic hypersomnia diagnosis after you first visited a physician to discuss your idiopathic hypersomnia symptoms?

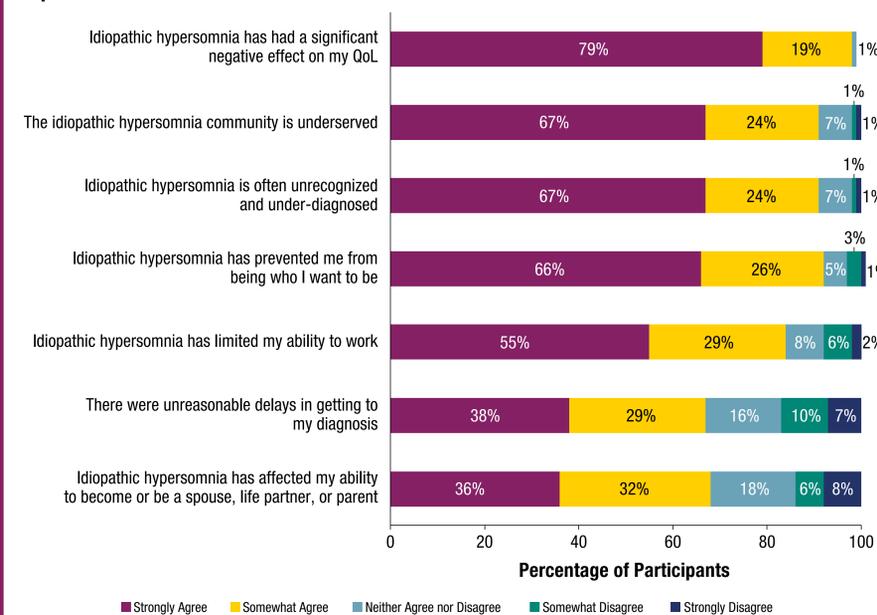
- In a companion survey of physicians (see poster number 156), few physicians reported an average time to diagnosis for patients with idiopathic hypersomnia of ≥5 years
- Many participants (61%) reported being misdiagnosed prior to their idiopathic hypersomnia diagnosis
- Diagnoses of depression/anxiety, sleep apnea, or narcolepsy type 2 were reported by 72%, 25%, and 10% of respondents, respectively
 - These diagnoses were later changed to idiopathic hypersomnia in 26%, 30%, and 57% of those participants diagnosed with other disorders, respectively; the remaining patients were left with dual diagnoses

Figure 2. Participants Reported a Wide Range of Idiopathic Hypersomnia Symptoms



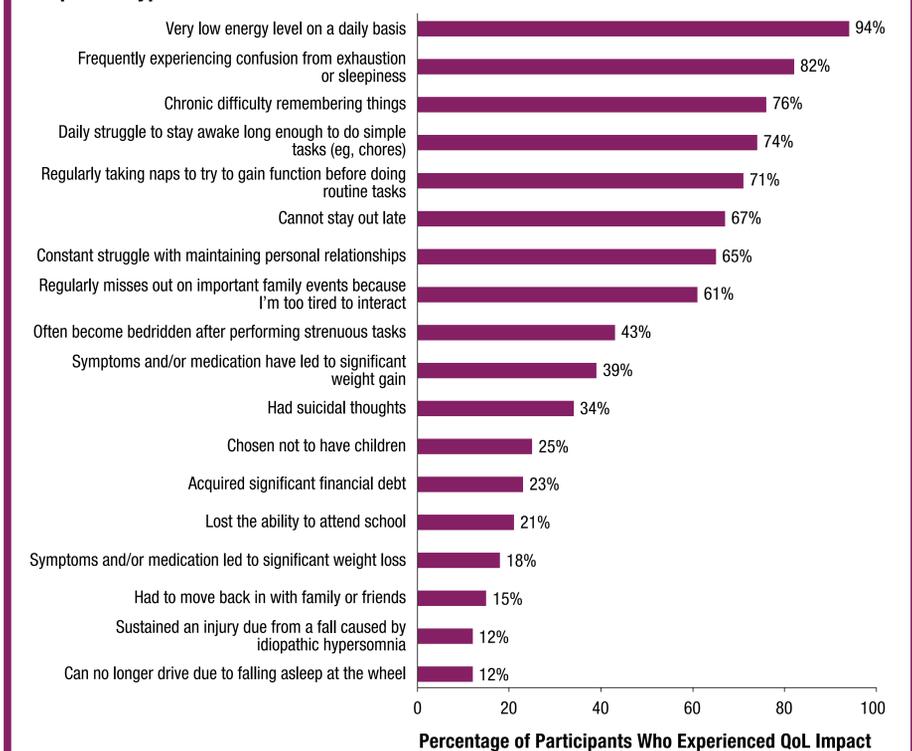
Question: What is your level of agreement with the following statements? EDS, excessive daytime sleepiness.

Figure 3. The Majority of Participants Reported That Idiopathic Hypersomnia Had a Significant Impact on Their QoL



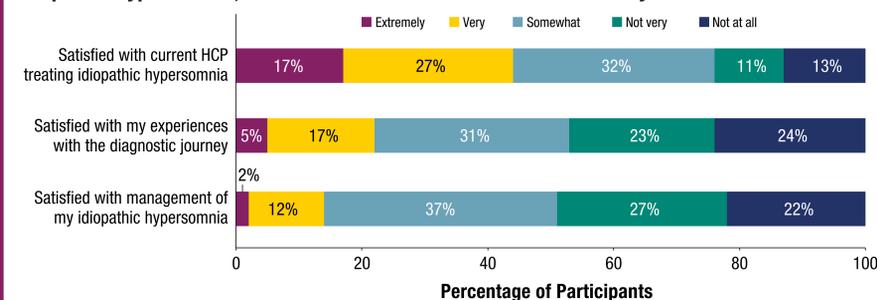
Question: What is your level of agreement with the following statements? QoL, quality of life.

Figure 4. Participants Highly Endorsed Multiple Specific QoL Impacts Related to Their Idiopathic Hypersomnia



Question: Which of the following, if any, have you experienced because of idiopathic hypersomnia? QoL, quality of life.

Figure 5. Nearly Half of Participants Reported Dissatisfaction With the Management of Their Idiopathic Hypersomnia, but Were More Satisfied With Their Own Physician



Question: In general, when it comes to my idiopathic hypersomnia, I feel... HCP, healthcare provider.

Conclusions

- These findings indicate that patients with idiopathic hypersomnia experience a profound negative impact on QoL
- Most participants waited ≥2 years, and most received a misdiagnosis, prior to being diagnosed with idiopathic hypersomnia
- Many participants reported dissatisfaction with their diagnostic journey and management

