

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

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## Introduction

- Idiopathic hypersomnia is a debilitating central disorder of hypersomnolence characterized by excessive daytime sleepiness, severe sleep inertia, and prolonged nighttime sleep<sup>1</sup>
- Although a limited number of studies have shown that idiopathic hypersomnia negatively impacts quality of life (QoL) and functioning,<sup>2-5</sup> 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

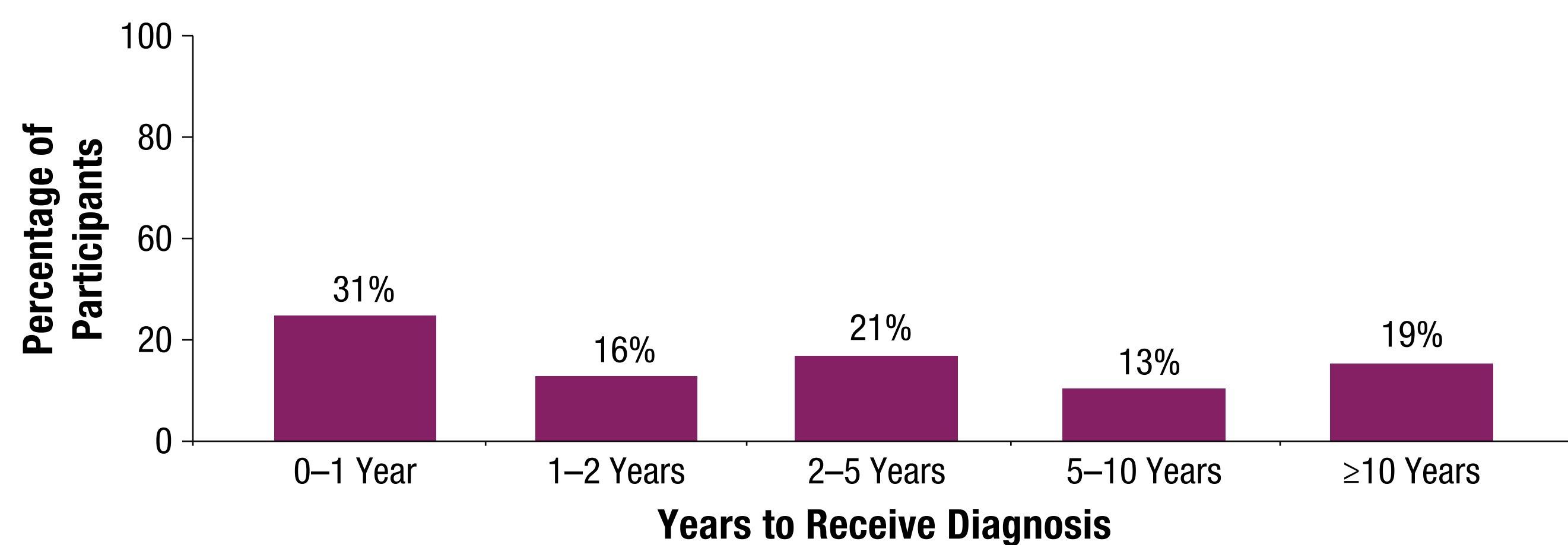
**Table 1. Participant Demographics**

	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)

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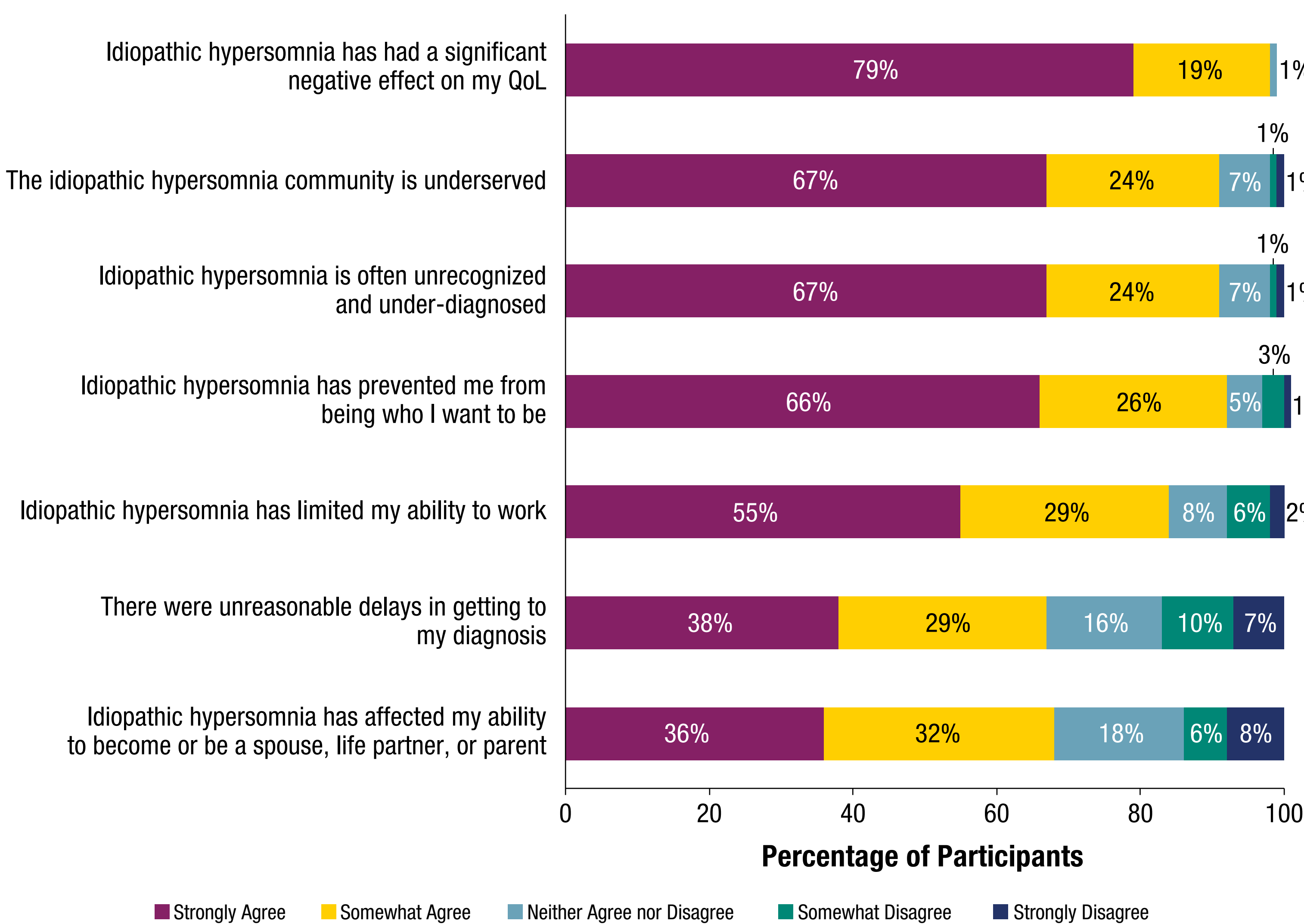
**Figure 1. Many Participants Reported Waiting Several Years to Receive Their Idiopathic Hypersomnia Diagnosis**



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?

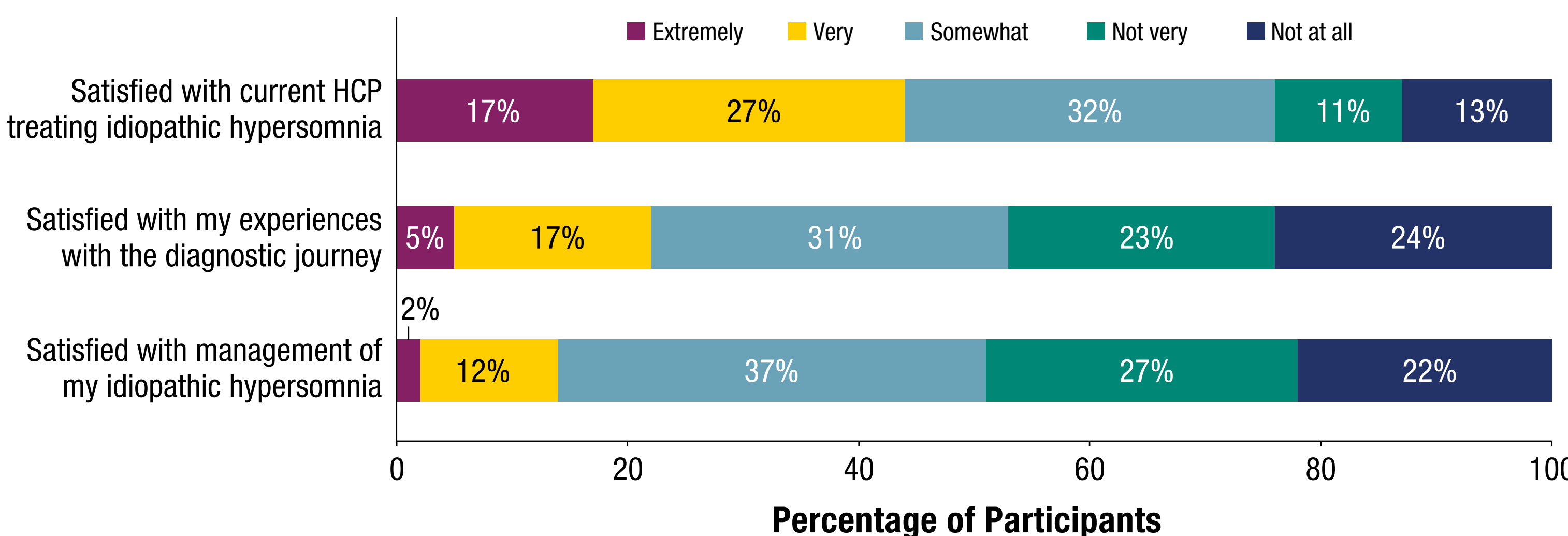
- In a companion survey of physicians (see poster number 156), few physicians reported an average time to diagnosis for patients with idiopathic hypersomnia of ≥5 years
- Many participants (61%) reported being misdiagnosed prior to their idiopathic hypersomnia diagnosis
- Diagnoses of depression/anxiety, 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 3. The Majority of Participants Reported That Idiopathic Hypersomnia Had a Significant Impact on Their QoL**



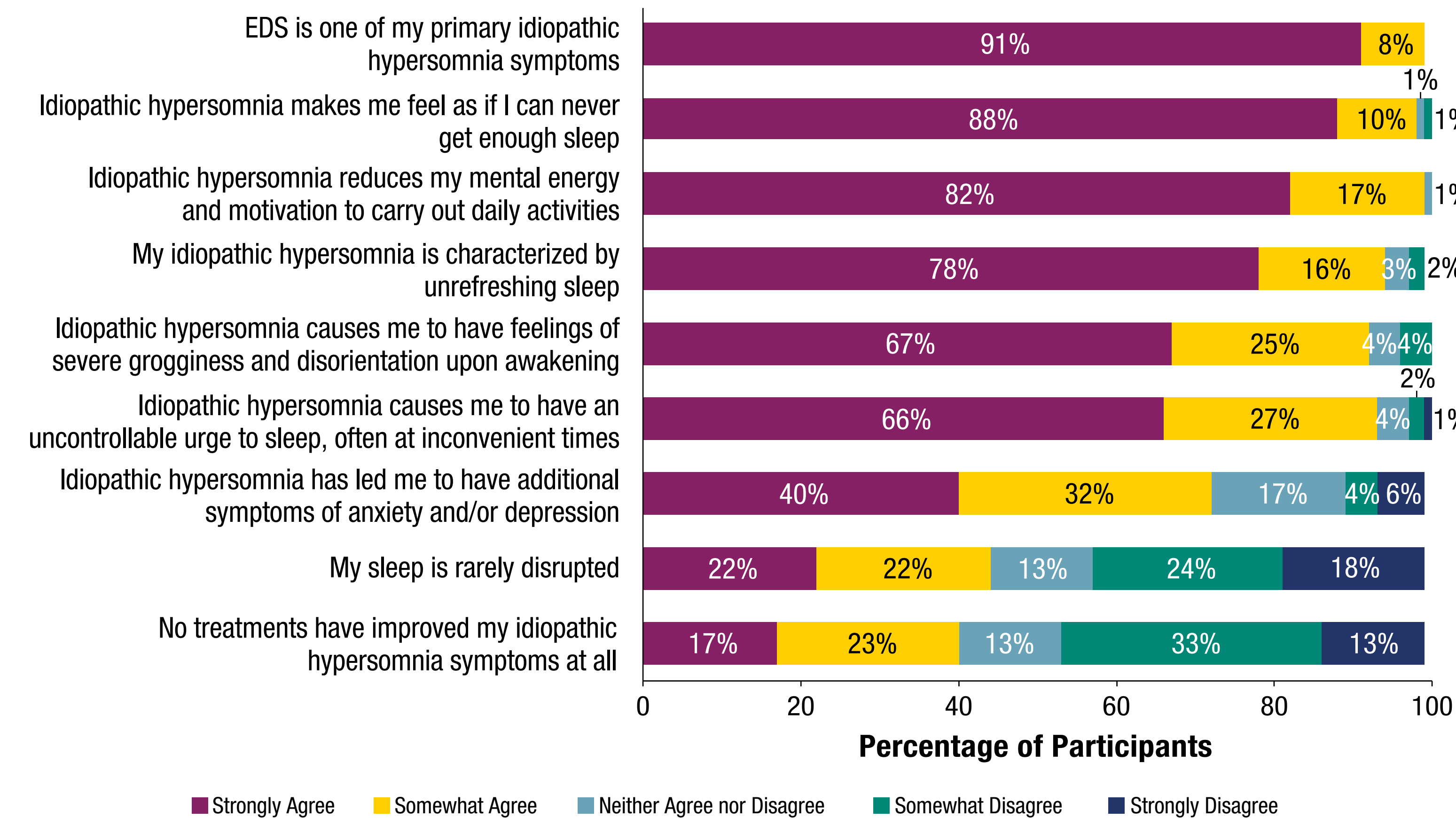
Question: What is your level of agreement with the following statements?  
QoL, quality of life.

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



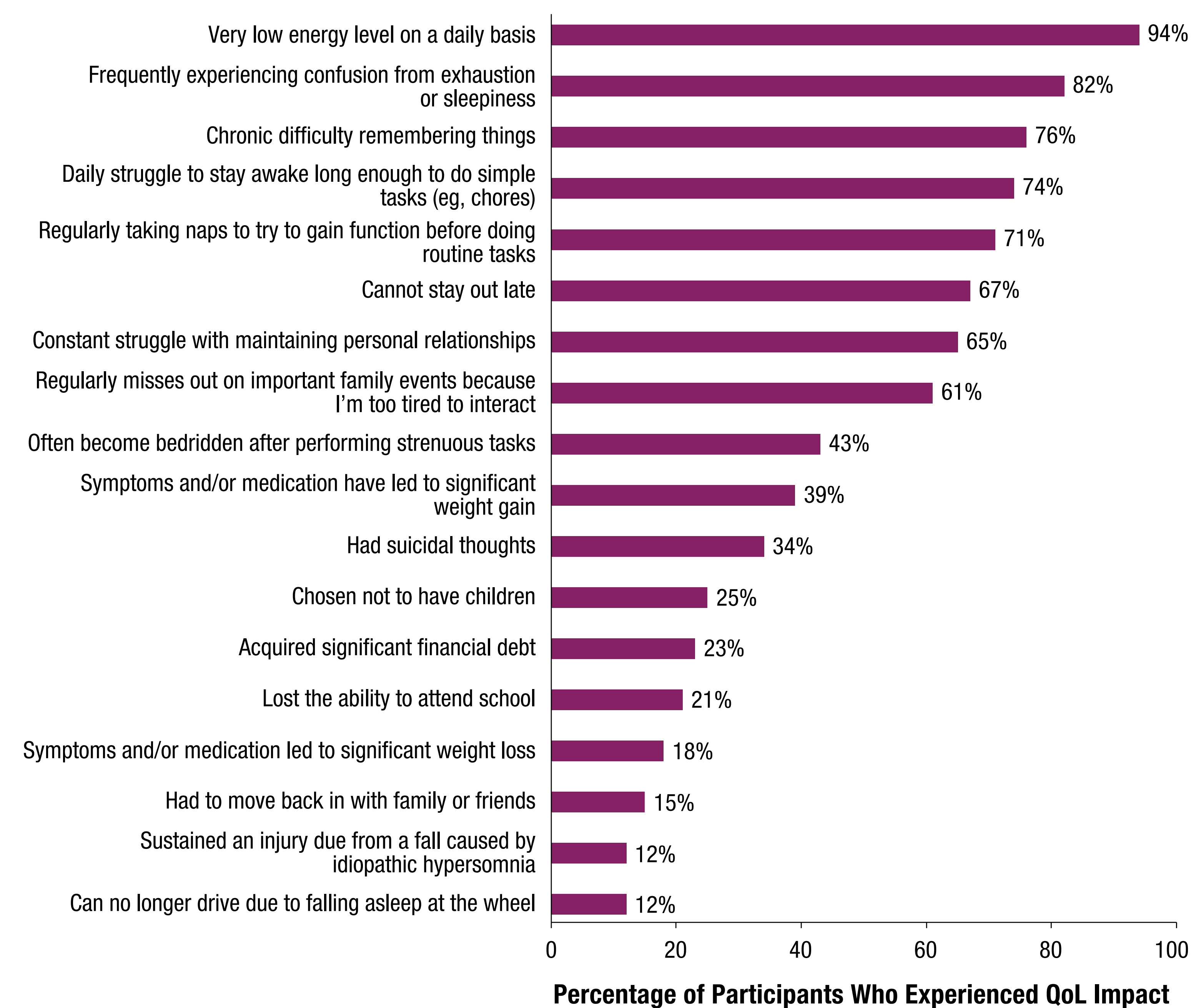
Question: In general, when it comes to my idiopathic hypersomnia, I feel...  
HCP, healthcare provider.

**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 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.

## 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

**References:** **1.** American Academy of Sleep Medicine. *International Classification of Sleep Disorders*. 3rd ed. Darien, IL: American Academy of Sleep Medicine; 2014. **2.** Ozaki A, et al. *J Clin Sleep Med*. 2008;4:572-8. **3.** Dauvilliers Y, et al. *J Neurol Neurosurg Psychiatry*. 2009;90:636-41. **4.** Pizza F, et al. *PLoS One*. 2015;10:e0129386. **5.** Thorpy MJ, et al. Presented at: Annual Meeting of the American Neurological Association; October 17-19, 2021. **Support and Acknowledgments:** This study was supported by Jazz Pharmaceuticals. Under the direction of the authors, Shivani Vaidya, PharmD of Peloton Advantage, LLC, an OPEN Health company, provided medical writing and editorial support for this poster, which was funded by Jazz Pharmaceuticals. **Disclosures:** **M Whalen**, **T Steininger**, and **N Dronamraju** are full-time employees of Jazz Pharmaceuticals who, in the course of this employment, have received stock options exercisable for, and other stock awards of, ordinary shares of Jazz Pharmaceuticals, plc. **B Roy** and **D Enson** have no financial conflicts of interest to disclose.



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