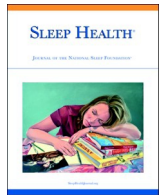




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## The impact of idiopathic hypersomnia on the social lives of young adults

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## ABSTRACT

**Objectives:** People with idiopathic hypersomnia report significant impairment in their lives due to idiopathic hypersomnia symptoms, and this likely includes an impact on social relationship health. This study investigated the effects of idiopathic hypersomnia on social relationships (friends, romantic, and sexual) during the key developmental period of young adulthood.

**Methods:** Young adults (N = 106; 18–39 years) with idiopathic hypersomnia were recruited through national hypersomnia patient organizations. Participants completed an online survey assessing the impact of symptoms on overall social functioning, as well as assessing friendships, romantic relationships, and sexual relationships.

**Results:** Nearly all participants (98%) reported that idiopathic hypersomnia made their social life more challenging. Over half (56%) felt they had too few close friends. While 69% were currently in a romantic relationship, the majority (92%) reported that idiopathic hypersomnia made it more challenging to enter a romantic relationship, with 89% stating that it impacted their sex life. Symptoms with the greatest perceived impact on social relationships were excessive sleepiness, brain fog, and long sleep. Most participants expressed that they would like their clinicians to ask about their social lives.

**Conclusions:** Idiopathic hypersomnia substantially impacts the social lives of young adults, including friendships, romantic partnerships, and sex lives. Despite the importance of social relationships, clinicians seldom address this topic during clinic visits. When considering whole person health for people with idiopathic hypersomnia, clinical care would benefit from more attention to social health.

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## Introduction

Idiopathic hypersomnia (IH) is a rare neurologic sleep disorder, with an estimated 10.3 cases per 100,000 adults.<sup>1</sup> Though it is clinically heterogeneous, the primary symptom is excessive daytime sleepiness, with lapses into sleep or drowsiness, despite ample or prolonged nighttime sleep.<sup>2,3</sup> In addition, people with IH often report long periods of nocturnal sleep (12–14 hours or more), unrefreshing and often lengthy daytime naps, severe morning sleep inertia (difficulty waking from sleep), and cognitive clouding or “brain fog.”<sup>3</sup>

The impact of IH on daily life can be pervasive, with a symptom burden that is associated with significant decrements in overall quality of life.<sup>4,5</sup> Given the constellation of symptoms for patients with IH, there is the potential for significant impact of their sleep disorder on social relationship health. People with narcolepsy describe a “limited bandwidth” to engage in social relationships due to both the symptoms of the sleep disorder and side effects of treatments,<sup>6</sup> and report that the disorder seems to define their social lives and directly impact their mood.<sup>7</sup> In addition, people with IH and narcolepsy experience relationship breakups due to excessive daytime sleepiness.<sup>5</sup> This is a crucial topic for further study as social relationships play a fundamental role in physical and psychological health outcomes, such as depression, cardiovascular disease, and even mortality.<sup>8,9</sup>

To our knowledge, the effects of IH on social relationships in young adults have not been previously investigated. This problem is

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especially salient for young adults (aged 18–39 years), who are in a crucial developmental phase where they often forge lifelong connections with spouses/partners and friends.<sup>10</sup> We assessed the impact of IH on social relationship health among young adults and the extent of their communication with clinicians about this critical issue. In addition, this study investigated demographic and disease-specific factors that may impact social functioning.

## Participants and methods

### Study design

Individuals with IH were recruited through national nonprofit patient organizations via emails to their members. Organizations that contacted their members were: the Hypersomnia Foundation, Narcolepsy Network, Wake Up Narcolepsy, and Project Sleep. Study procedures were approved by the Institutional Review Board of Beth Israel Deaconess Medical Center.

### Participants

Individuals were eligible to participate in the study if they: (1) self-reported an IH diagnosis from a medical provider; (2) were between 18–39 years old; (3) lived in the United States; and (4) were fluent in English. Participants were excluded if they did not complete all survey-related questions. To encourage participants to answer sensitive questions more openly, we used anonymous online survey procedures.<sup>11</sup> All participants completed the survey in November 2021.

### Procedure

The anonymous online questionnaire was administered through Research Electronic Data Capture (REDCap) tools hosted at Beth Israel Deaconess Medical Center. REDCap is a secure, web-based software platform designed to support data capture for research studies.<sup>12,13</sup> When participants clicked the link for the survey, they completed a series of screening questions to ensure eligibility. If eligible, participants then reviewed a prospective agreement indicating that they were agreeing to participate in the study if they continued with the survey. At the end of the survey, participants were asked to choose a nonprofit patient organization that would receive a \$25 donation per completed questionnaire. Due to the potentially sensitive nature of some of the study questions, we did not collect patient identifying information.<sup>11</sup> Responses were reviewed for duplicates.

### Measures

The survey was developed through an iterative process by a group of relevant stakeholders: two sleep physicians with expertise in IH, a sleep psychologist with expertise in central disorders of hypersomnolence, and a health psychologist with expertise in coping with chronic health conditions. In addition, three young adult patients with IH reviewed the survey and provided feedback. A list of the survey questions related to IH and social functioning are provided in [Supplementary Materials](#) – Appendix A.

### IH symptoms and medical history

Participants were asked about their IH history (age of symptom onset, age of diagnosis, and symptoms), medical and psychiatric comorbidities, and management of their IH disorder. Participants were asked about whether they ever have experienced the following symptoms (with a brief description of the symptom), in addition to which symptoms they experienced in the past week: *excessive*

*daytime sleepiness, sleep attacks, disrupted nighttime sleep, brain fog, sleep inertia, long sleep duration, and sleep drunkenness.*

### Social/romantic relationships

We adapted several items from the National Longitudinal Study of Adolescent and Adult Health (AddHealth) study, a national cohort study, including: current friendship information, history of romantic relationships, and current relationship status.<sup>14</sup>

### IH and social/romantic relationships

The survey included questions on the impact of IH on social relationship health. Themes included general impact of symptoms on social life and impact on romantic relationships, including contribution to past break ups and specific symptoms impacting relationships. Participants were asked about the impact specific symptoms had on their social lives using a visual analog scale (0 = Not at all; 50 = Somewhat; 100 = A lot).

### UCLA Loneliness Scale

The UCLA Loneliness scale is a 3-item questionnaire designed to assess loneliness.<sup>15,16</sup> The current scale utilized the original scale's 4-item Likert scale (1 = never, 2 = hardly ever, 3 = sometimes, 4 = often). For scoring, item responses were collapsed to the 3-item response (1 = never or hardly ever, 2 = sometimes, 3 = often) and a total scale score was computed by summing the three items. A score of 6 indicates "lonely."

### Communication with clinicians regarding IH

Participants were asked whether the medical clinicians who treat their IH have asked about their social and sex life, as well as whether they would like their clinicians to ask these questions.

### Open-ended responses

Participants were asked several open-ended questions throughout the survey. Questions included: (1) *Please explain how IH has impacted your social life;* (2) *What strategies do you use to maintain your social and romantic life without IH (including strategies related to alcohol use, dating culture, etc.);* (3) *We know that IH can have an impact on multiple aspects of your personal life including social and sexual functioning as well as other domains. What information have we not asked about that you think is important for us to know?*

### Data analysis

We conducted descriptive analyses, including frequencies, means, and standard deviations for most variables of interest. We used hierarchical multiple linear regressions to examine factors which may predict perceived loneliness (UCLA Loneliness Scale) and participant's perception of the level of impact excessive daytime sleepiness had on their social life. Factors included in the regressions included: demographic factors, including age (Emerging Adult [ $<29$ ] and Adult [ $>29$ ]),<sup>17</sup> relationship status (single/dating or cohabitating/engaged/married), and parental status (had children or not), followed by IH diagnosis timing factors (time between symptom onset and diagnosis and time since diagnosis). To account for non-normally distributed variables, bootstrapping was utilized with 2000 iterations at a 95% confidence interval utilizing bias-corrected and accelerated bootstrap. Analyses were conducted using SPSS 28.0.1.0.<sup>18</sup>

## Results

### Demographics and IH characteristics

Of the 137 individuals who viewed the survey landing page, 106 completed the survey ([Table 1](#)). The average age of participants was 29.6 years (SD = 5.2; range = 18–39), with the majority female

**Table 1**  
Demographics

Demographics	Total (N = 106)
Age (mean; SD)	29.6 (5.2)
Gender (n, %)	
Female	96 (92)
Male	7 (7)
Other (transgender/nonbinary)	3 (3)
Race (n, %)	
White	95 (90)
Other	12 (11)
Black	3 (3)
Hispanic	2 (2)
Employment (n, %)	
Working full-time	62 (59)
Working part-time	23 (22)
Student	21 (20)
Other – unemployed	18 (17)
<b>Disease characteristics</b>	
Age at symptom onset (mean, SD)	16.8 (7)
Age at diagnosis (mean, SD)	25.9 (5)
Years between symptom onset and diagnosis (mean, SD)	9.1 (7)
IH-specific medication use (n, %)	
No medications	7 (7)
1+ medications	99 (93)
2+ medications	61 (58)
3+ medications	1 (1)
Symptoms well controlled	
Strongly disagree	22 (21)
Disagree	44 (42)
Neutral	19 (18)
Agree	20 (19)
Strongly agree	1 (1)
<b>Comorbidities</b>	
Anxiety	73 (69)
Depression	71 (67)
Migraines	29 (27)
PTSD	18 (17)
Narcolepsy	17 (16)
Obesity	13 (12)
Hypertension	7 (7)
Postural orthostatic tachycardia syndrome	7 (7)
Ehlers-Danlos syndrome	7 (7)
Chronic fatigue syndrome	5 (5)
None	5 (5)
Substance abuse	1 (1)
Multiple comorbidities	
Anxiety + depression	56 (53)
Depression + PTSD	14 (13)
Anxiety + PTSD	14 (13)
Anxiety + depression + PTSD	11 (10)

Abbreviations: IH, idiopathic hypersomnia; PTSD, post-traumatic stress disorder.

(91%) and identifying as White (90%). Most participants were employed at least part-time (80%). The average age at diagnosis was 25.9 years (SD = 5.4; range = 13-39) with an average of 9.1 years (SD = 6.7; range = 0-32) between symptom onset and diagnosis. At the time of survey completion, participants were an average of 3.7 years postdiagnosis (SD = 3.6; range = 0-20). Almost all participants were taking at least one medication to manage their IH (93%). The most common symptoms that participants ever experienced were excessive daytime sleepiness (99%), brain fog (96%), and sleep inertia (96%; Table 2). Less common symptoms included sleep attacks (67%) and disrupted nighttime sleep (62%). Few participants felt that their symptoms were well controlled (20%). Most

**Table 2**  
IH symptoms experienced

Symptom	Total (N = 106)			
	Ever		Last week	
	N	%	N	%
Excessive daytime sleepiness	105	99	95	90
Brain fog	102	96	82	77
Sleep inertia	102	96	83	78
Long sleep duration	98	93	67	63
Sleep drunkenness	97	92	77	73
Sleep attacks	71	67	40	38
Disrupted nighttime sleep	66	62	42	40

Abbreviation: IH, idiopathic hypersomnia.

experienced several symptoms in the past week, including excessive daytime sleepiness (90%), sleep inertia (78%), brain fog (77%), sleep drunkenness (73%), and long sleep duration (63%).

### Mental health

Over two thirds of participants indicated they had also been diagnosed with or treated for anxiety (69%) or depression (67%) by a medical professional, with few reporting they had not been diagnosed or treated for either comorbidity (5%).

### Exemplar quote

“I don’t know if my IH is a cause of my depression, or if IH is a side effect of my depression. One seems to feed into the other quite often.”

### Impact of IH on social life

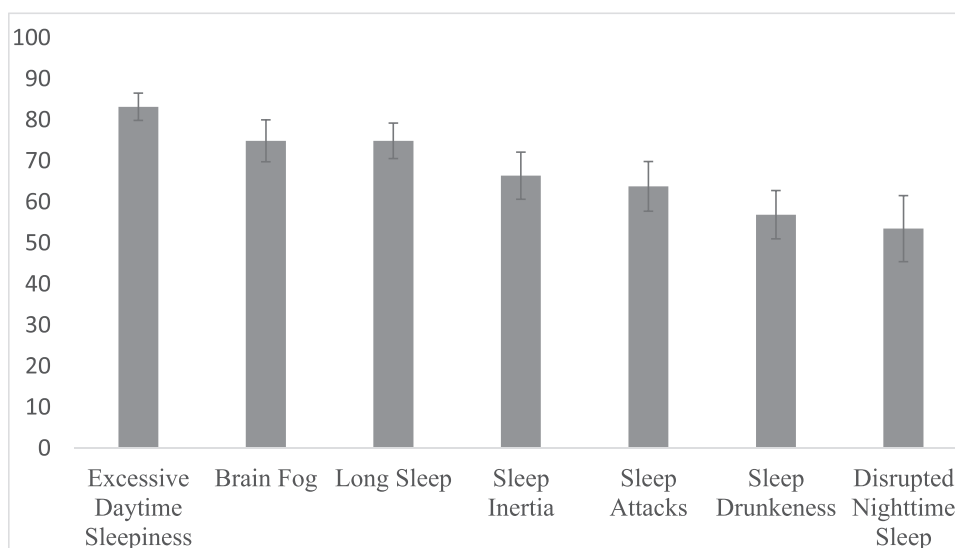
Nearly all (98%) participants indicated that IH made their social lives harder. The symptoms perceived to have the greatest impact on their social lives using the visual analog scale were excessive sleepiness (M = 83.2; SD = 17.3, range = 27-100), brain fog (M = 74.9; SD = 25.8; range = 0-100), and long sleep duration (M = 74.9; SD = 21.4, range = 7-100; Fig. 1).

### Friendships and romantic relationships

Over half (56%) of participants indicated that they had too few close friends, with a mere 1% reporting that they had too many friends. In our sample, 89% of participants had been in a romantic relationship at some point, with 69% indicating that they were currently in a romantic relationship (Table 3). Of those not currently in a relationship, 72% reported that they were looking for a relationship. The overwhelming majority (92%) of participants reported that IH made it more challenging to enter a romantic relationship. IH symptoms had contributed to a past breakup in 37% of participants who had been in at least one romantic relationship, and 89% of participants reported that IH symptoms impacted their sex lives. Further, 84% of individuals reported that sleep inertia specifically had at least somewhat of an impact on their romantic relationships.

### Exemplar quote

“To be frank, there isn’t time for a social life when you are sleeping 12–18 h a day.”



**Fig. 1.** Mean perceived impact of specific IH symptoms on social life. Mean reported score based on visual analog scale (range 0-100) of the impact of specific symptoms on social functioning, with 95% confidence interval. IH, idiopathic hypersomnia

**Table 3**  
Romantic relationships

	N	%
Disease impact on entering a relationship (friendship or romantic)		
Makes it a lot harder	54	51
Makes it somewhat harder	44	42
Has no impact	7	7
Makes it somewhat easier	0	0
Makes it a lot easier	1	1
Ever in a relationship		
Yes	94	89
No	12	11
Currently in a relationship		
Total (n = 93)		
Yes	64	69
No	29	31
Current relationship status		
Total (n = 64)		
Married	25	39
Cohabiting/living together (> 1 mo)	20	31
Engaged to be married	9	14
Currently dating	10	16
Childbearing/pregnancy	0	0
If not in a relationship, are you...		
Total (n = 29)		
Not looking	17	59
Looking	21	72
Friends with benefits	3	10
Hooking up	3	10
Other	6	21
Symptoms contribute to break up		
Total (n = 93)		
No	59	63
Yes	34	37
Symptoms impact sex life		
Total (n = 93)		
Yes	84	89
No	10	11
To what extent does sleep inertia (difficulty waking up in the morning) impact your relationship?		
Total (n = 64)		
Not at all	1	1
Very little	9	14
Somewhat	24	38
Quite a bit	18	28
Very much	12	19
Don't know	0	0

“My husband has to be my caregiver about my IH. He has to wake me up every day; weekdays and weekends.”

#### Loneliness

With an average UCLA Loneliness Scale total score of 7.0 (SD = 1.8, range 3-9), the average participant in our study exceeded the scale's cutoff score of 6 for “lonely” (80.0%). Additionally, 37% of individuals reported they lacked companionship, 47% reported that they often felt left out, and 57% reported they felt isolated from others. The regression model predicting perceived loneliness using a model including demographic and specific IH diagnosis variables (time from symptom onset to diagnosis and time since diagnosis) was not significant (Table 4).

#### Exemplar quote

“Losing friendships, feeling isolated and too tired to do the things I want to do has caused [significant] depression. Most people are unaware of the overall feeling of sadness I experience due to this debilitating disease.”

#### Communication with clinicians about social relationships

Only 34% of participants reported that the primary clinician treating their IH had ever asked about how IH impacted their social life, and only 9% reported that their clinician had ever asked about how IH impacted their sex life. Though these topics were often not discussed, the majority (70%) of participants wanted their clinician to ask about their social lives, with only 4% not wanting clinicians to ask. Regarding sex lives, 34% wanted their clinician to ask, whereas 24% expressed that they did not want their clinician to ask.

#### Exemplar quote

“Also, social interactions with doctors can be expanded on. In the five minutes we get with our ‘check ups’ with neurologists, most of the questions that get asked are superficial at best.”

“Often miss social outings or am late; do not respond to texts/calls in a normal time frame; brain fog makes socializing difficult at times.”

“Sometimes when I go I feel like a zombie and I have to try really hard to have fun when all I want to do is go home and sleep.”

**Table 4**  
Regression model predicting UCLA Loneliness Score

	B	SE B	$\beta$	p	Lower confidence	Upper confidence
<i>Step 1</i>						
Constant	9.999	0.255		<.001	9.483	10.522
Age >29	0.033	0.502	0.008	.954	- 0.915	0.886
Married*	- 1.326	0.590	- 0.266	.025	- 2.509	- 0.131
With children	0.670	0.607	0.122	.277	- 0.443	1.940
<i>Step 2</i>						
Constant	10.055	0.430		<.001	9.204	10.953
Age >29	0.041	0.533	0.010	.944	- 0.951	0.916
Married*	- 1.314	0.582	- 0.264	.026	- 2.513	- 0.145
With children	0.731	0.609	0.133	.224	- 0.371	1.938
Time between symptom onset and diagnosis	0.010	0.032	0.031	.761	- 0.048	0.072
Time since diagnosis	- 0.044	0.065	- 0.074	.492	- 0.185	0.089

Note: Adjusted  $R^2 = 0.038$  for step 1;  $\Delta R^2 = 0.008$  for step 2 ( $ps > .05$ ).

\* $p < .05$

**Table 5**  
Regression model predicting perceived impact of excessive daytime sleepiness social life

	B	SE B	$\beta$	p	Lower confidence	Upper confidence
<i>Step 1</i>						
Constant	82.771	2.699		<.001	77.136	88.267
Age >29	5.859	3.676	0.170	.112	- 1.957	13.489
Significant relationship	- 6.004	3.261	- 0.174	.069	- 12.244	- 0.017
With children	4.464	4.451	0.100	.297	- 4.195	12.893
<i>Step 2</i>						
Constant	84.038	3.570		<.001	77.262	90.456
Age >29	6.053	3.640	0.175	.101	- 1.438	13.743
Significant relationship*	- 6.531	3.175	- 0.190	.048	- 12.662	- 0.476
With children	6.060	4.643	0.136	.185	- 2.833	15.120
Time between symptom onset and diagnosis	0.239	0.262	- 0.093	.370	- 0.257	0.825
Time since diagnosis	- 0.958	0.547	- 0.200	.083	- 2.154	0.071

Note:  $N = 105$ . Perceived impact of excessive daytime sleepiness on social life was measured using a visual analog scale (0-100).  $R^2 = 0.032$  for step 1;  $\Delta R^2 = 0.058$  for step 2 ( $p < .05$  for step 1,  $p < .05$  for step 2).

\* $p < .05$

“You ask about whether my MD asked me about social/sex life ... my professional life, academic life, and mental health were also never inquired about, all of which I would really liked her to have asked me.”

#### Factors associated with perceived symptom impact on social life

Regressions predicting participants perception of the extent excessive daytime sleepiness negatively impacted social life were significant when including both demographic and IH timing factors (time from symptom onset to diagnosis and time since diagnosis). Having a significant romantic relationship was a protective factor, decreasing the reported perceived impact of excessive daytime sleepiness on social life (Table 5).

#### Exemplar quote

“It really impacts parenthood. Kids have so many obligations that are rigid and not able to be adjusted because you didn’t sleep last night and are going to have trouble driving safely in the morning, etc.”

## Discussion

IH is likely to present challenges for young adults in their ability to develop and maintain key social relationships due to their daytime sleepiness and being awake less during the day than their peers. Our data demonstrate just how substantial of an impact IH has on the friendships, romantic partnerships, and sex lives of young

adults. There is also significant level of loneliness and high comorbidity of mental health diagnoses in this group. Despite the importance of social relationships, young adults with IH report that their clinicians seldom address this topic during clinic visits. When considering whole person health for a young adult with IH, it is clear that social health is a key need that is often overlooked in current clinical care models.

Many participants felt that their time and energy are finite resources, and many noted in their open-ended responses that they tended to prioritize romantic pursuits over other social relationships. Rates of marriage were similar to, or even higher, than those seen in nationally representative samples of typical developing young adults.<sup>19</sup> This pattern of prioritizing romantic relationships is similar to that seen in young adults with narcolepsy,<sup>6</sup> who also find themselves in a position where they feel compelled to purposefully plan how to allocate their energy. Importantly, romantic partners also may provide day-to-day support, such as helping the partner with IH wake up or sharing daily household tasks. Living with a significant other or being married was associated with a reduced perceived impact of excessive daytime sleepiness and sleep inertia on social functioning. Participants with a live-in partner or spouse reported less impact of symptoms on their social life and less loneliness compared to participants who were just dating or did not currently have a partner. A live-in relationship may not alter the severity of IH, but having a supportive partner in the home may buffer against the perceived impact IH symptoms have on their social lives.

In contrast to rates of romantic relationships, respondents indicated that they felt like they had too few friends. Though there was not a direct comparison with people with narcolepsy for this study, these findings are consistent with patterns seen among young adults

with narcolepsy,<sup>6</sup> and may partially explain the high levels of loneliness reported by participants in our sample. Most participants met the cut-off score to be considered in the lonely group (80%), which is much higher than that seen in both primary care populations (20%)<sup>20</sup> and other populations with chronic illnesses, including spinal cord injuries (25%).<sup>21</sup> A diverse relationship network is essential for young adults as each type of relationship serves different roles.<sup>22</sup>

We also observed high rates of mental health comorbidities in our sample, which may be related to impact on social life. Approximately two-thirds of participants indicated that they had been diagnosed with an anxiety or depressive disorder at some point in their life. Though depression is common among patients with chronic medical conditions,<sup>23</sup> rates may be especially high in people with IH. For example, one study reported that almost half (47%) of participants with IH had current symptoms of depression.<sup>24</sup> Most likely, IH exacerbates depression, and depression worsens the impact of IH on an individual's day-to-day life. Similarly, rates of anxiety in our sample were approximately double that seen in other chronic illness populations, such as cystic fibrosis.<sup>25</sup> Anxiety may make it more challenging for individuals to initiate social interactions and impair ability to be present and engaged during social interactions with friends or romantic or sexual partners. Anxiety and depression can also contribute to feelings of fatigue and tiredness worsening IH symptoms and complicating diagnosis.

The majority of participants in our study indicated that their treating clinicians did not ask about the impact of their sleep disorder on their social life, even though most expressed wanting their clinicians to raise these important questions.<sup>6</sup> These findings, in addition to previous work and recommendations suggesting that people with chronic conditions would welcome conversation about the impact of health symptoms on their social well-being,<sup>7,26,27</sup> highlight the importance of clinicians inquiring about social and romantic lives when providing care for young adults with IH. One important consideration in this context relates to the patient's IH medications. As individuals with IH may generally lean toward preference for evenings and more likely to experience circadian phase delay,<sup>28</sup> medication regimens are often scheduled to promote wakefulness during the work or school day. Though this may help for school or work, it may not consider time spent with friends or family, which often occurs in the evening. Discussion and shared decision-making between physicians and people with IH on how medications could be timed or dosed to support social and family life or on behavioral strategies for navigating symptoms could promote improved social relationships. In addition, physicians should be prepared to direct people with IH to appropriate resources to support navigating social challenges if necessary (e.g., counseling for management and coping with a chronic illness, coping with marital/relationship difficulties, parenting resources).

This study provides a more nuanced view of the impact of IH on social lives for young adults, but we acknowledge some limitations. First, participants were recruited from patient-oriented hypersomnia organizations, which may bias who participated. Participants were primarily White, employed, and female, which may limit the generalizability of findings. Notably, similar participant demographics have been seen in prior studies, specifically when utilizing patient registries.<sup>6,29</sup> Though there were similar demographics in the current study, there were higher rates of mood disorders than in other chronic illness populations in addition to several participants indicating a diagnosis of narcolepsy. It is unclear whether participants currently were undergoing treatment for these disorders as questions focused on whether participants ever were diagnosed with comorbidities, but many participants indicated that IH impacted their mental health and their mental health issues may worsen IH symptoms. The high rates of comorbid mood disorders aligns with prior studies showing elevated rates of depression in

patients with IH.<sup>24,30,31</sup> However, one challenge is that symptoms of IH and depression may overlap, and a thorough clinical evaluation is needed to ensure accurate diagnoses.<sup>30</sup>

In addition, the study design intentionally focused on young adults up to the age of 39, as this is a period of life when developing relationships is especially important. The impact of IH on social life may change as life demands and social/relationship expectations change, so these findings should not be generalized to other age groups. Additionally, there are significant chronotype changes that occur during this age range<sup>32,33</sup> which were not assessed and may mediate the impact of IH symptoms on social functioning. The current study was also administered in November 2021, a time when feelings of social isolation and isolation were generally high due to the COVID-19 pandemic.<sup>34</sup> This may have impacted reports of loneliness and should be taken into consideration when interpreting findings.

Finally, anonymity was a crucial element of the study due to the sensitive nature of the subject material which also required the diagnosis of IH to be based on participant self-report of a physician diagnosis without confirmation of IH diagnosis via medical diagnosis. Further, it limited the ability to ensure that participants only completed the survey once. Participants were not compensated directly but as a donation to specific organizations to minimize incentive to complete multiple times and surveys were checked for duplicate entries.

Though the current study provides information from a specific subset of the IH population, it will be important to increase recruiting efforts from IH clinics across the country to better understand the impact for a broad range of patients. In the future, researchers should consider conducting longitudinal assessments of social relationship health among patients with IH. IH symptoms may change over time and this may be associated with age-related changes in sleep physiology, including chronotype.<sup>35</sup> Thus, the impact of IH on social relationships may change as well. As we better understand the mechanisms that underlie IH symptoms and the changes in these symptoms over time, it will also be important to understand the role of romantic relationships and parental status and whether these continue to be factors associated with the overall impact of IH on social lives. In addition, it will be important to understand differences in the impact of symptoms on social lives compared to patient populations for individuals with other chronic conditions, or during a period outside of the COVID-19 pandemic when young adults faced more social challenges. Further, the mechanism by which sleepiness contributes to mental health symptoms has not been well established.<sup>36</sup> The relationship between IH and depression and/or anxiety may be bidirectional<sup>30</sup> whereby IH symptoms may exacerbate mental health concerns which may exacerbate IH symptoms or worsen sleep difficulties (daytime sleepiness, disrupted sleep, long sleep). Individuals with IH want their providers to ask about their social lives, though it may be an area that providers feel under resourced. In addition to increasing available behavioral health interventions for patients, it may also be helpful to develop quality improvement project interventions aimed at increasing provider awareness of local and national behavioral health resources for those with IH. Given the significant impact of IH on social and romantic lives in addition to the negative relationship that IH symptoms have on patient mental health, it is important that sleep clinicians conduct thorough evaluations and have appropriate referral systems in place to provide adequate psychosocial support for individuals with IH.

#### Author contributions

**Ryan Davidson:** Conceptualization, Methodology, Formal analysis, Data curation, Writing – original draft & review and editing.  
**Margaret Blattner:** Conceptualization, Methodology, Writing –

original draft & review and editing. **Thomas Scammell:** Conceptualization, Methodology, Writing – original draft & review and editing, Project administration, Funding acquisition. **Eric Zhou:** Conceptualization, Methodology, Writing – original draft & review and editing, Project administration, Funding acquisition.

### Data availability

The data underlying this article will be shared on reasonable request to the corresponding author.

### Declaration of conflicts of interest

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### Appendix A. Supporting information

Supplementary data associated with this article can be found in the online version at [doi:10.1016/j.sleh.2024.10.006](https://doi.org/10.1016/j.sleh.2024.10.006).

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