

# The Impact of Idiopathic Hypersomnia on Social and Romantic Relationships of Young Adults

Ryan D. Davidson, PhD<sup>1,2</sup>, Margaret S. Blattner, MD, PhD<sup>2,3</sup>, Thomas E. Scammell, MD<sup>1-3</sup>, & Eric S. Zhou, PhD<sup>1-4</sup>

<sup>1</sup>Boston Children's Hospital, Boston, MA; <sup>2</sup>Harvard Medical School, Boston, MA, <sup>3</sup>Beth Israel Deaconess Medical Center, Boston, MA <sup>4</sup>Dana-Farber Cancer Institute, Boston MA; <sup>5</sup>

## Introduction

- Idiopathic hypersomnia (IH) is a rare and debilitating neurologic disorder
- IH is characterized by daytime sleepiness, and many IH patients have very long sleep times and problematic sleep inertia.
- Patients with IH report that it affects many aspects of their daily lives, but the impact on their social lives has not been studied.

### Current Study

**Exploratory study investigating the impact of IH on social, romantic, and sexual relationships in young adults with IH.**

**Investigated whether people with IH disclosed their diagnosis to peers and social concerns to health care providers.**

## Methods

### Participants

- 106 young adults (M = 29.6 years; SD = 5.2; 18-39) with a self-reported diagnosis of IH from the United States who were fluent in English completed the survey.
- Participants recruited from patient organizations: Hypersomnia Foundation, Project Sleep, Narcolepsy Network, Wake Up Narcolepsy
- Primarily white (90%), employed (80%), and female (90%).

### Procedure

- Survey developed by relevant stakeholders through iterative process and included open-ended questions.

## Results

### Impact of IH on Social Functioning

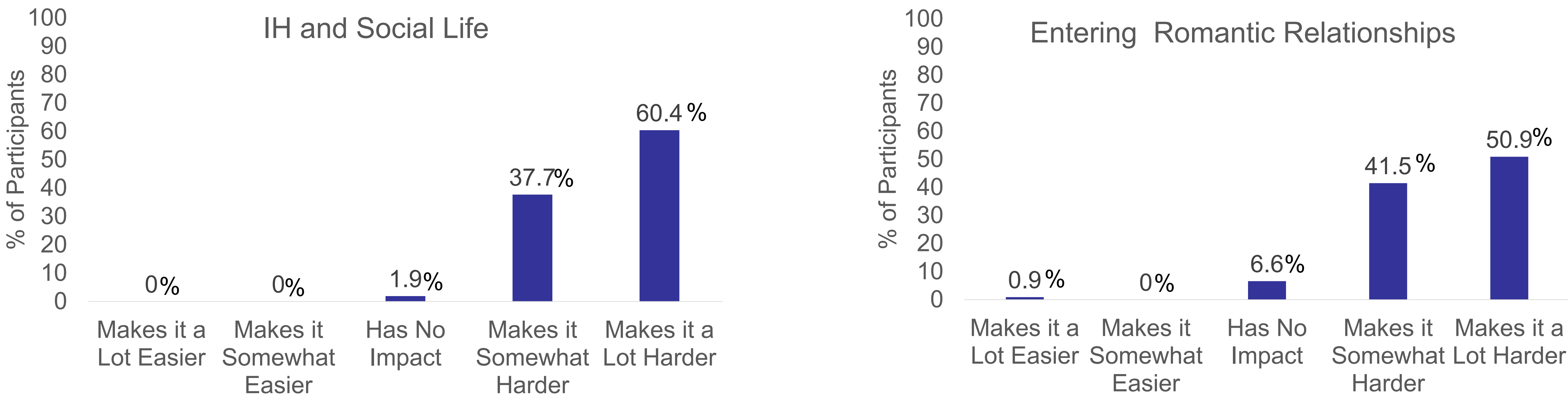


Figure 1 & 2. No participants indicated that IH made social lives easier and only 1 reported IH made entering new romantic relationships easier.

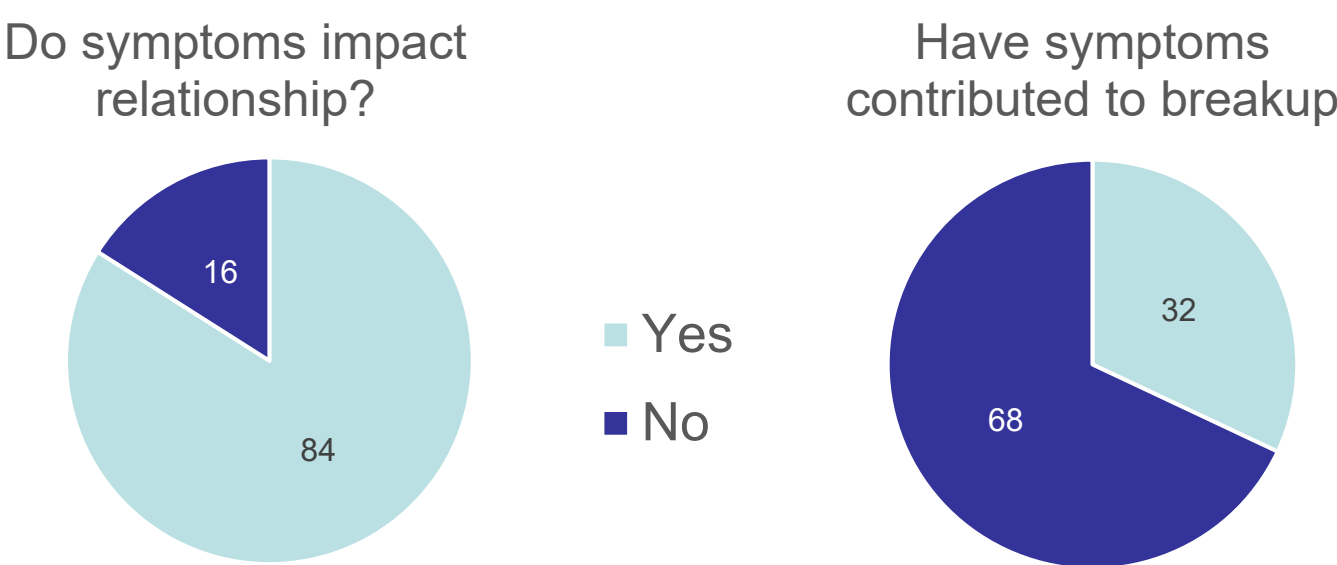
*"I have a hard time staying awake for evening/nighttime dates"*  
*"Dating is difficult because [IH] limits social opportunities (no drinking, no staying out late)"*  
*"To be frank, there isn't time for a social life when you are sleeping 12-18 hours a day"*

### Impact of IH on Romantic Relationships Current Relationship Status (Table 1)

	Current Study		AddHealth (Sorgi, 2016)
	Yes	%	%
Ever in a relationship	94	88.7	-
	No	12	1.9*
Currently in a relationship	Total (n = 93)		
	Yes	64	68.8
	No	29	31.2
Current relationship status	Total (n = 64)		
	Married	25	39.1
	Cohabiting/living together (>1 month)	20	31.3
	Engaged to be married	9	14.1
	Currently dating	10	15.6
	Childbearing/pregnancy	0	0

Note: \*p<.001

### Symptom Impact on Relationships



*"I forget things a lot so my partner thinks I am not listening to them"*

*"It has been very hard on my marriage since I can't spend as much time as I want with my husband..."*

### Perceived Social Support

Based on the MSPSS, perceived social support from significant others was significantly higher than both perceived social support from friends (p <.001) and from family (p<.001).

*"I've lost a lot of friends because I can't keep up"*

### Impact of IH on Sexual Functioning

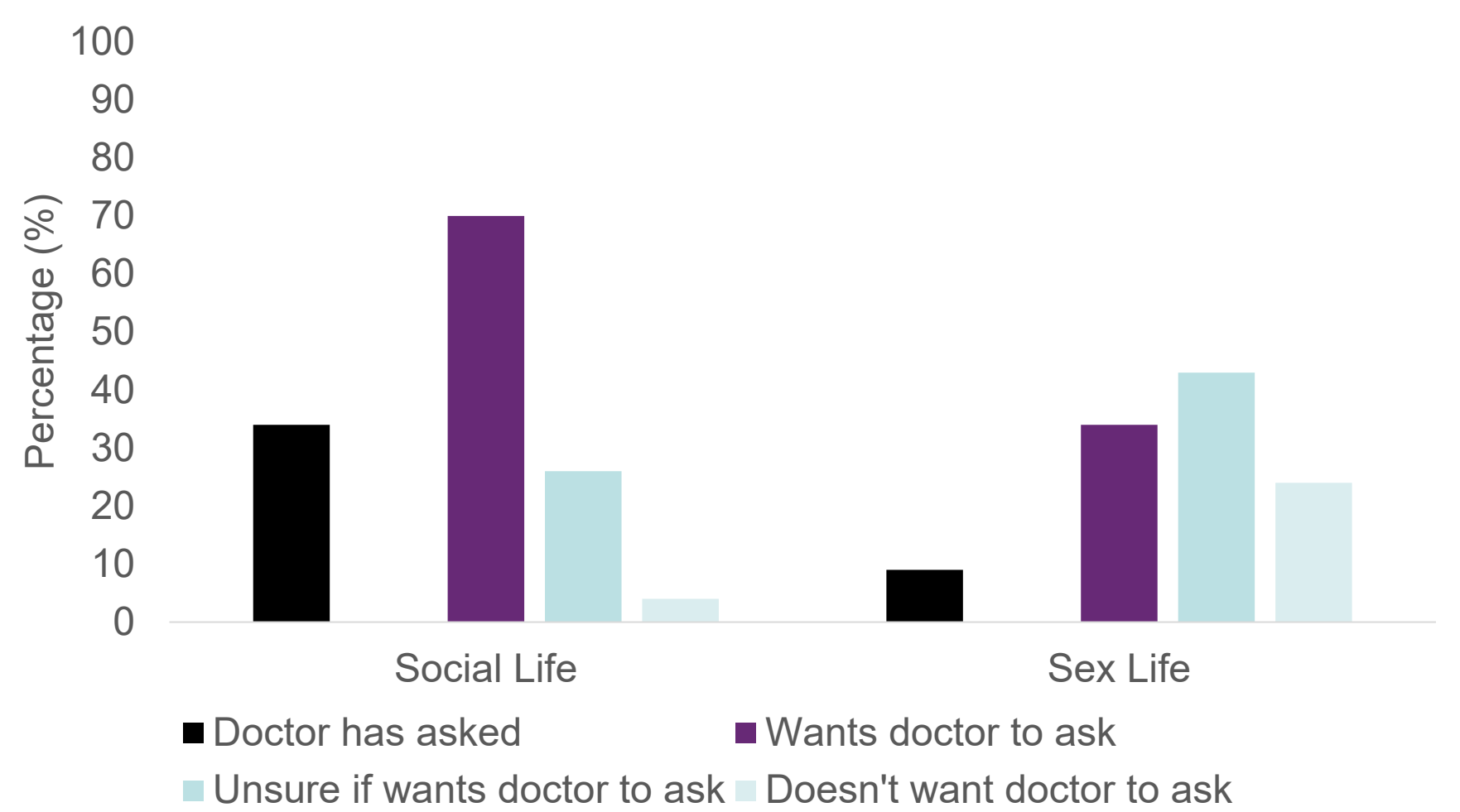
#### IH Impact on Sexual Activity



*"Too tired to engage in sexual activities or to feel aroused. ...I want to sleep if I am in bed ..."*

Most of participants indicated that IH impacted their sex life (89%) and had lower rates of engaging in sexual activities than national samples (~90% in nationally represented samples compared to ~70% in current study).

### Disclosure of Impact with Providers (Table 3)



## Discussion

### Conclusion 1

- Young adults with IH report that IH substantially impacts their lives, making their social and romantic relations harder.

### Conclusion 2

- IH impacts sexual relationships, with most participants indicating symptoms impacting sex life (ex: feeling too sleepy for sex).

### Conclusion 3

- Many participants were interested in discussing their social and sexual relationships with medical providers, however, only a small proportion of providers inquire.

### Limitations

- This study included primarily female, high functioning individuals (mostly employed), with self-reported IH. Surveys were completed during the COVID-19 pandemic.

### Future Directions

- Effective treatment of IH in young adults should include evaluation of social relationships and further support to minimize the impact on relationship health.

*"I think it is important for others who are actively around someone with IH, that they understand it isn't a choice to feel the way we do. I WANT to be able to do x, y, z, like normal people do, I want to be able to enjoy every single moment of a romantic encounter with the one I love."*

## Support

This project was supported by funding from Jazz Pharmaceuticals.