Oxybate Treatment Experience and Preferences of People With Idiopathic Hypersomnia

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INTRODUCTION

- Idiopathic hypersomnia (IH) is a central disorder of hypersomnolence characterized by excessive daytime sleepiness (EDS), unrefreshing sleep, and sleep inertia[1]
- The only US Food and Drug Administration (FDA)–approved treatment for IH is immediate-release (IR) calcium, magnesium, potassium, and sodium (mixed-salt) oxybates[2]
  - IR mixed-salt oxybates can be administered as a twice- or once-nightly regimen for the treatment of IH (at a maximum dose of 6 g if once-nightly), although it is often administered as a twice-nightly regimen[3-6]
  - Patients may find this twice-nightly regimen challenging, as it requires the patient to take a dose at bedtime and a second dose 2.5-4 hours later[2]
- Extended-release sodium oxybate (ER-SXB) is a once-nightly dose currently approved by the FDA for the treatment of cataplexy or EDS in patients 7 years of age and older with narcolepsy[7-8]
  - ER-SXB is not approved by the FDA for the treatment of patients with IH[8]
- Patient-reported survey data may offer candid insight into patients' experiences with IR oxybates and their treatment preferences

OBJECTIVE

- To characterize IR oxybate treatment experiences and preferences of people with IH using survey data

METHODS

- A 33-item online survey was fielded in 2 phases to respondents recruited from:
  - Facebook and Reddit (January 23, 2025, to March 19, 2025)
  - Rare Patient Voice members and patients who were provided the survey link by their clinician (July 28, 2025, to August 5, 2025)
- Eligible participants self reported that they were ≥18 years of age, were residing in the United States, had clinician-diagnosed IH, and were currently/previously receiving an IR oxybate
- The survey received ethics committee approval
- Participants were compensated for completing the survey

RESULTS

RESPONDENTS

- A total of 50 respondents completed the survey (**Table**)
- The majority of respondents were female (96%) and were currently taking or previously took IR mixed-salt oxybates as treatment for IH (88%)

TABLE: Respondent Characteristics

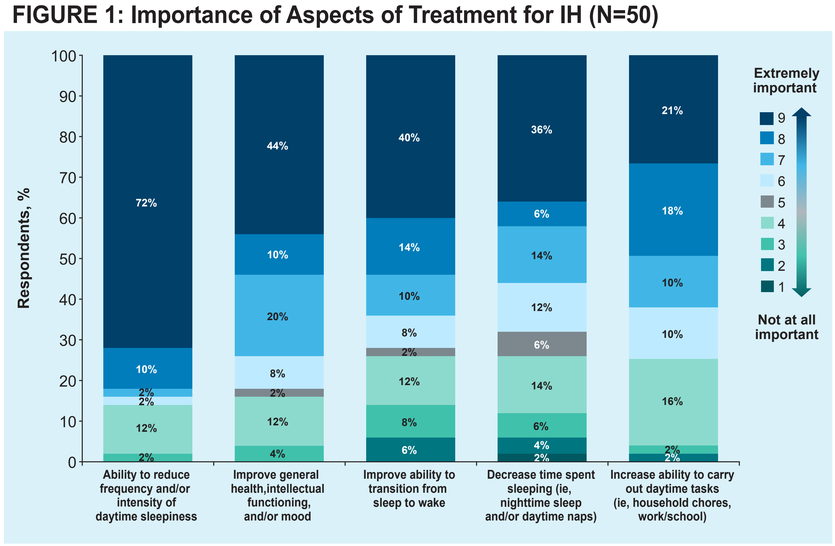
Characteristic	Respondents (N=50)
Age range, y	19-66
Sex, n (%)	
Female	48 (96)
Male	2 (4)
Time from symptom onset to diagnosis, y	
Mean (range)	13 (<1-37)
Median	10
Medications, n (%)	
Current or previous IR mixed-salt oxybate use	42 (84)
Current or previous IR SXB use	12 (24)
Previous use of both IR mixed-salt oxybates and IR SXB	2 (4)

IR, immediate release; SXB, sodium oxybate.

IH TREATMENT ASPECTS

- >50% of respondents rated the ability of a medication to reduce the frequency and/or intensity of EDS (84%; n=42); improve general health, functioning, and/or mood (74%; n=37); improve the transition from sleep to wake (64%; n=32); and decrease time spent sleeping (56%; n=28) as ≥7 on a 9-point scale (1=not important; 9=extremely important; **Figure 1**)
  - Nearly half of respondents (49%; n=24) rated the importance of a medication in increasing their ability to carry out daytime tasks as ≥7 on a 9-point scale (**Figure 1**)

FIGURE 1: Importance of Aspects of Treatment for IH (N=50)

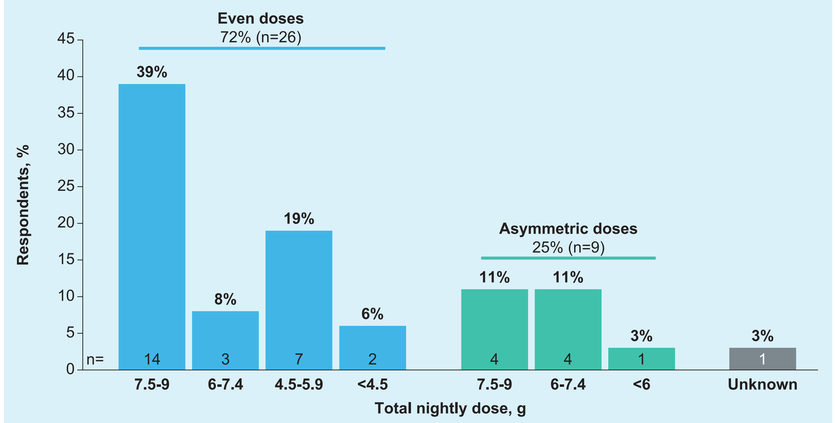


Q. When you were deciding whether to initiate an oxybate to treat your IH, how important were each of the following aspects of an IH treatment/therapy in making that decision? Select 1 response for each aspect of therapy on a scale of 1-9, where 1=not at all important and 9=extremely important.
IH, idiopathic hypersomnia.

IR OXYBATE REGIMENS

- IR oxybates were prescribed as a twice-nightly regimen for 72% (n=36) of respondents and as a single dose for 12% (n=6) of respondents
  - 16% (n=8) of respondents were prescribed both single-dose and twice-nightly regimens at some point
- Of respondents who took twice-nightly doses, 72% (26/36) took equal first and second nightly doses (**Figure 2**)
  - Among the 25% (9/36) of respondents who took asymmetric doses, 56% (5/9) took a higher first nightly dose than second nightly dose

FIGURE 2: IR Oxybate Twice-Nightly Dosing Regimens (n=36[a])

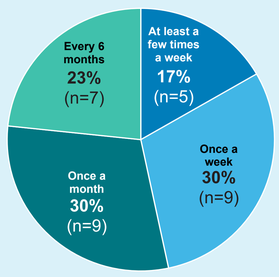


Q. You have been prescribed to take an IR oxybate twice nightly. Can you please tell us the amount of each dose you take?
IR, immediate release.
[a]The subgroup of participants who responded that they were taking an IR oxybate twice nightly.

MISSED AND MISTIMED IR OXYBATE DOSES

- The majority (60%; 30/50) of respondents reported accidentally missing their second IR oxybate dose; of these, nearly half (47%; 14/30) missed ≥1 dose per week (**Figure 3**)
  - Consequences of missed doses were extreme sleepiness, brain fog, migraines, and functional impairment

FIGURE 3: Frequency and Consequences of Missed Second IR Oxybate Doses (n=30)

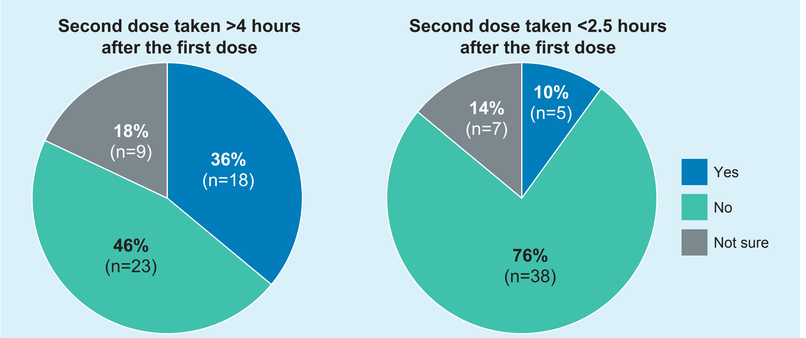


Missed dose frequency	Respondent comments on consequences of missed doses
At least a few times a week	*"Increased daytime sleepiness; irritability; decreased cognitive function"* *"I feel worse the next day ... I am irritable and discouraged."*
Once a week	*"I feel a lot more tired, like I hardly slept the night before."* *"My brain feels pretty foggy and I struggle to get through the day."*
Once a month	*"Inability to wake to alarm clock, or sound on alarm clock was turned off."* *"I often end up with a migraine if I miss a dose accidentally. And I am more fatigued, grumpy, and struggle to function."*
Every 6 months	*"I wake up too early, unable to get back to sleep. I am then extremely tired and struggle to function the next day."* *"I have excessive daytime sleepiness."*

Q. During the time you have been on IR oxybate therapy, have you accidentally missed your second dose? Describe any impact or issues you have experienced due to accidentally missing your second dose.
IR, immediate release.

- Mistimed secondly nightly IR oxybate doses were reported: 36% (n=18) of respondents had taken their second dose >4 hours and 10% (n=5) had taken their second dose <2.5 hours after the first dose (**Figure 4**)

FIGURE 4: Frequency of Mistimed Second IR Oxybate Doses (N=50)



Q. During the time you have been on IR oxybate therapy, have you taken your second dose (A) >4 hours or (B) <2.5 hours after your first dose?
IR, immediate release.

- Respondents reported injuries (ie, falling) after waking to take the second IR oxybate dose (18%; n=9) and challenges preparing IR oxybate doses (18%; n=9)
- More than two-thirds of respondents (68%; n=34) agreed or strongly agreed that a single, premeasured, extended-release bedtime dose of sodium oxybate would be safer/more convenient than current treatment options

STUDY LIMITATIONS

- Respondents were predominately female and self-selected to those with access to technology and who could speak English, which potentially skews the sample and may not be representative of the broader IH population
- Respondents were currently/previously receiving an IR oxybate and may be more likely to prefer a once-nightly treatment option compared with patients who have never taken an IR oxybate, potentially introducing selection bias
- These self-reported data were collected via an unvalidated questionnaire, which may impact the reliability of the results

CONCLUSIONS

- These survey data from people with IH who had taken IR oxybates identified important considerations for IH treatment, including the desire for improvements in daytime symptoms, sleep-wake transitions, and sleep time
- IR oxybates were prescribed as a twice-nightly, even-dose regimen for the majority of people with IH
- Missed or mistimed second doses of IR oxybates were prevalent among people with IH, and some patients reported overnight or next-day consequences due to missed or mistimed second doses
- Two out of 3 people with IH reported a preference for a single bedtime dose

ACKNOWLEDGMENTS

Medical writing support was provided by Taylor Johnson, PharmD, from Citrus Health Group, Inc. (Chicago, IL) and was funded by Avadel Pharmaceuticals (Chesterfield, MO).

FUNDING

This study was funded by Avadel Pharmaceuticals (Chesterfield, MO). *Avadel Pharmaceuticals Limited (formerly Avadel Pharmaceuticals plc) is an affiliate of Alkermes plc.

DISCLOSURES

JCC has received research funding from Avadel Pharmaceuticals, Inspire Medical Systems, and Sommetrics and has served as a consultant and/or on advisory boards for Avadel Pharmaceuticals, Fisher & Paykel Healthcare, Inspire Medical Systems, Resmed, and Zoll Medical. **AMM** has served as an investigator, consultant, speaker, and/or on advisory boards for Alkermes, Inc., Apnimed, Avadel Pharmaceuticals, Axsome Therapeutics, Eisai, Harmony Biosciences, Jazz Pharmaceuticals, Lilly, Noble Pharmaceuticals, Novartis, and Takeda Pharmaceutical Co.; has received grant funding from Coverys Community Healthcare Foundation, Geisinger Health Plan, Harmony Biosciences, Jazz Pharmaceuticals, the National Institutes of Health, ResMed Foundation, and UCB Pharmaceuticals; is the Chief Executive Officer of DAMM Good Sleep, LLC; and serves as an advisor for FloraWorks, Neura Health, and OpenEvidence. **MJT** has served as a consultant or on advisory boards for Alkermes, Inc., Avadel Pharmaceuticals, Axsome Therapeutics, Balance Therapeutics, Centessa Pharmaceuticals, Eisai, Harmony Biosciences, Jazz Pharmaceuticals, NLS Pharmaceutics, Suven Life Sciences Ltd., and Takeda Pharmaceutical Co. **BCC** is a member of the speakers' bureaus of Eisai, Harmony Biosciences, Jazz Pharmaceuticals, and Merck & Co. He has served as an advisor for and has received consulting fees and honoraria from Avadel Pharmaceuticals. **SI** is affiliated with a hospital that has received funding for research from Avadel Pharmaceuticals and has received research grant funding from Centessa Pharmaceuticals, Harmony Biosciences, Jazz Pharmaceuticals, and the National Institutes of Health. **MP** is an owner of and owns stock options in TREND Community. Clients of TREND Community are pharmaceutical and biotechnology companies including, but not limited to, Horizon Therapeutics, Chiesi Global Rare Disease, Novartis, Harmony Biosciences, and Avadel Pharmaceuticals. **AC** is an employee of and owns stock options in TREND Community. Clients of TREND Community are pharmaceutical biotechnology companies including, but not limited to, Amgen, Harmony Biosciences, Acadia, Soleno Therapeutics, and Avadel Pharmaceuticals. **LD** is an employee of and owns stock options in TREND Community. Clients of TREND Community are pharmaceutical and biotechnology companies including, but not limited to, Horizon Therapeutics, Chiesi Global Rare Disease, Novartis, Harmony Biosciences, and Avadel Pharmaceuticals. **JB** is an employee of Alkermes, Inc. **JG** was an employee of Avadel Pharmaceuticals and is a consultant to Alkermes, Inc.

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Presentation Type: Oral presentation

Category Topic: Clinical Sleep Science and Practice

Category Subtopic: Hypersomnia – Treatment

Title Character/Word Count (limit 150 characters, including spaces/75 words): 82/10

Word Count (limit 350, including Introduction, Methods, Results, Conclusion, and Support sections, not including headings): 350

Introduction: Treatment options for idiopathic hypersomnia (IH) are limited. Oxybate treatment experiences and preferences of people with IH were characterized using survey data.

Methods: Surveys were fielded in 2 phases to respondents recruited from Facebook and Reddit (1/23/2025-3/19/2025) and from Rare Patient Voice members and patients who were provided the link by their clinician (7/28/2025-8/5/2025). Respondents were required to live in the US, be aged ≥18 years, report clinician-diagnosed IH, and be currently/previously receiving an oxybate.

Results: Fifty respondents (female, 96%; age range, 19-66 years) completed the survey. Mean and median time from symptom onset to diagnosis was 10 and 13 years, respectively (range, <1-37 years). When considering IH treatment, ability to reduce frequency/intensity of excessive daytime sleepiness; improve general health, intellectual functioning, and/or mood; and improve the transition from sleep to wake were rated ≥7 on a 9-point scale (1=not important; 9=extremely important) by 84%, 74%, and 64% of respondents, respectively. Immediate-release (IR) calcium/magnesium/potassium/sodium oxybates was the most common current/previous oxybate taken (84%), followed by IR sodium oxybate (24%); 4% of respondents had previously taken both. IR oxybates were most often prescribed as a twice-nightly regimen (72%); 12% of respondents were prescribed a single IR oxybate dose; 16% were prescribed both single and twice-nightly regimens at some point. Of respondents taking twice-nightly doses, 72% took equal first and second doses (total nightly dose: <4.5 g, 6%; 4.5-5.9 g, 19%; 6-7.4 g, 8%; 7.5-9 g, 39%), 25% took asymmetric doses, and 1 did not recall their dose. Of 30 respondents (60%) who accidentally missed their second oxybate dose, 47% missed ≥1 dose/week. Consequences of missed doses were extreme sleepiness, brain fog, migraines, and functional impairment. Respondents reported mistimed doses: 36% took their second dose >4 hours and 10% took their second dose <2.5 hours after the first dose. More than two-thirds of respondents agreed or

strongly agreed that a single, premeasured, extended-release bedtime dose of sodium oxybate would be safer/more convenient than current treatment options.

Conclusion: These survey data from people with IH identified delayed diagnoses, challenges with IR oxybates, and a desire for extended-release, once-nightly sodium oxybate.

Support: Avadel Pharmaceuticals

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Meeting Information

SLEEP 2026

June 14-17, 2026

Baltimore, MD