Nighttime Symptom Experience and Treatment Challenges: Perspectives From People With Narcolepsy

Luis E. Ortiz, MD[1]; Maggie Lavender, MSN, RN, FNP-C[2,3]; Anne Marie Morse, DO[4]; Beth Schneider, BA[5]; Matthew Horsnell, BS[6]; Dan Liss[7]; Shawn Kuczenski[8]; Jennifer Gudeman, PharmD[9,a]

[1]Johns Hopkins Medical Institutions, Johns Hopkins All Children's Hospital, St. Petersburg, FL; [2]Comprehensive Sleep Medicine Associates, Houston, TX; [3]Sleep Medicine Advanced Practice Providers (SMAPP) President and Founder, East Hanover, NJ; [4]Geisinger Commonwealth School of Medicine, Geisinger Medical Center, Janet Weis Children's Hospital, Danville, PA; [5]Swoop, New York, NY; [6]Patient author, Erin, TN; [7]Patient author, New Oxford, PA; [8]Patient author, Perryville, AR; [9]Avadel Pharmaceuticals, Chesterfield, MO; [a]At the time of the study

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INTRODUCTION

- Narcolepsy is a rare, chronic sleep disorder characterized by daytime and nighttime symptoms, including excessive daytime sleepiness (EDS), disturbed or disrupted nocturnal sleep, and rapid eye movement (REM)–related phenomena such as sleep-related hallucinations, sleep paralysis, and cataplexy in persons with narcolepsy type 1 (NT1)[1,2]
- Symptoms of narcolepsy can be burdensome and negatively affect quality of life for people with narcolepsy (PWN)[3]
- Sodium oxybate has a strong recommendation from the American Academy of Sleep Medicine for the treatment of EDS, cataplexy, and disease severity associated with narcolepsy[4]
  - Immediate-release sodium oxybate and calcium/magnesium/potassium/sodium (mixed-salt) oxybates require twice-nightly dosing, with the second dose administered 2.5-4 hours after the first dose[5,6]
  - Extended-release, once-nightly sodium oxybate (ER-OXB) is administered once at bedtime[7]
- As narcolepsy is fundamentally a 24-hour disorder, it is important to assess the perspectives of PWN regarding their experience with both daytime and nighttime symptoms and their treatment options to ensure adequate management of all symptoms

OBJECTIVE

- To identify and describe common symptoms and daytime and nighttime challenges of PWN and gain insights among those experienced with ER-OXB and oxybate-naive PWN

METHODS

- MyNarcolepsyTeam is an online social network where >12,000 members can share their experiences, challenges, journeys, and questions related to narcolepsy in their own words[3,8]
- This study used a 2-pronged approach in which MyNarcolepsyTeam members from the US participated in 1) an online survey and/or 2) in-depth online focus group discussions
- Participants were required to indicate whether they had NT1, had narcolepsy type 2 (NT2), or were unsure of their narcolepsy type

ONLINE SURVEY

- In September 2022, PWN were invited by email to complete an anonymous, 47-question online survey on topics including questions on symptoms, treatment regimens, challenges, and desired treatment outcomes
  - The survey included a variety of question/response formats, including Yes/No, ranking, and multiple-choice selection (with selection of ≥1 option allowed)
  - For the "most troubling symptoms" question, respondents selected ≥1 option from a 19-symptom list of patient-friendly terms (definitions were not provided)
- This study qualified for institutional review board (IRB) exemption

ONLINE FOCUS GROUP DISCUSSIONS

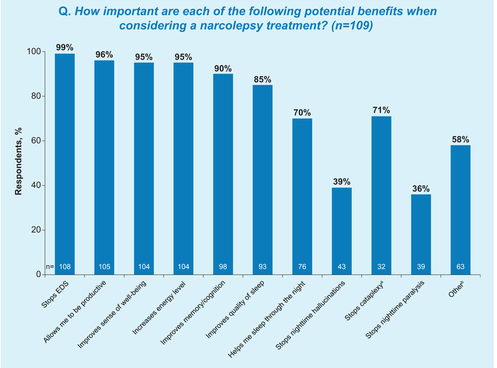
- Separately, PWN were invited to participate in 1 of 2 small online focus group discussion panels
  - 1 discussion including ER-OXB–experienced PWN was held in July 2025
  - 1 discussion including oxybate-naive PWN was held in September 2025
- Both discussion panels were led by a facilitator and conducted using a structured guide informed by findings from previous studies and themes that emerged from earlier discussions
  - Illustrative patient quotes were selected based on relevance to the discussion topic

RESULTS

ONLINE SURVEY

- Of 109 respondents, the majority were female (78%; n=85) and aged ≥50 years (62%; n=68); 41% (n=45) had NT1, 40% had narcolepsy type 2 (NT2; n=44), and narcolepsy type was unknown for 18% (n=20) of respondents
- 97% (n=106) of respondents indicated narcolepsy had a "great deal" or "a lot" of impact on their daily life
  - 93% (42/45) of individuals with NT1 and 100% (44/44) of those with NT2 indicated narcolepsy had "a great deal" or "a lot" of impact
- Symptoms reported as most troubling included EDS (90%), fatigue (84%), nighttime sleep disturbances (81%), and cognitive/memory problems (80%)
  - Nighttime sleep disturbances included poor-quality sleep (67%), disrupted/fragmented sleep (62%), insomnia (40%), or frequent awakenings (40%)
  - Cataplexy was reported as the most troubling symptom among 64% (29/45) of respondents with NT1
- The most important reported potential treatment benefits were stopping EDS (99%), allowing productivity (96%), improving well-being (95%), increasing energy level (95%), and improving memory/cognition (90%; **Figure 1**)

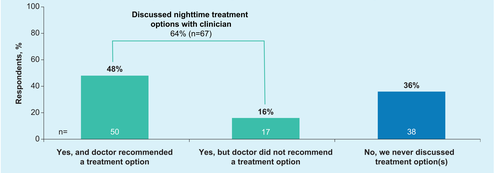
FIGURE 1: Desired Treatment Endpoints



Proportions rating each desired treatment endpoint as "extremely" or "very" important are shown.
ADHD, attention-deficit/hyperactivity disorder; EDS, excessive daytime sleepiness; NT1, narcolepsy type 1.
*Stops cataplexy was "extremely" or "very" important in 71% (32/45) of respondents with NT1 and in 39% (43/109) patients overall.
†Other included improve my mood, reduce depression, reduce brain fog, improve concentration, help so I can drive, improve ADHD, decrease daytime hallucinations, reduce restless leg syndrome, and lose weight.

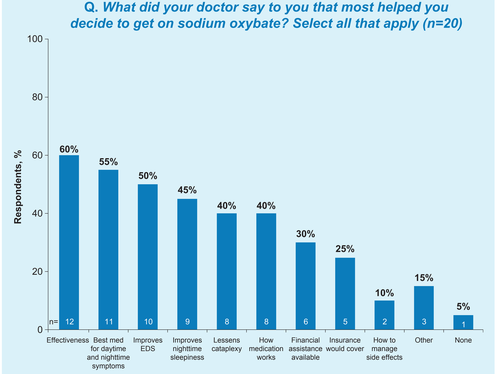
- Most respondents desired treatments that improved sleep quality (85%) and helped them sleep through the night (70%); over a third of respondents desired treatments that stopped REM-related phenomena (36%-39%) (**Figure 1**)
  - However, only 64% had discussed nighttime treatment options with their clinician (**Figure 2**)

FIGURE 2: Experience Discussing Treatment Options With Clinicians



- Recommendations for nighttime treatment options were more common for respondents seeing a sleep specialist (54%) compared with those seeing a generalist (41%)
- Oxybates were the most frequent clinician-recommended nighttime treatment (69%), followed by melatonin (12%), zolpidem (8%), and sertraline (4%)
- Among respondents currently taking oxybates, their decision to start taking oxybates was most frequently influenced by hearing from their clinician about the effectiveness of oxybates (60% [12/20]) and that oxybates are the best medications for treating both daytime and nighttime symptoms (55% [11/20]; **Figure 3**)

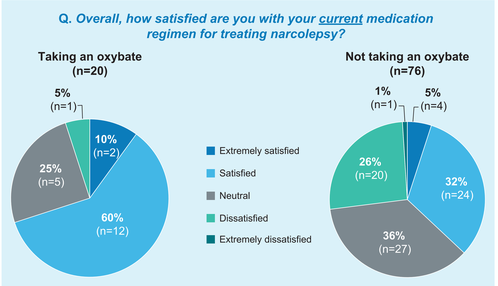
FIGURE 3: What Clinicians Said About Sodium Oxybate



EDS, excessive daytime sleepiness.

- Respondents taking oxybates were twice as likely to be satisfied or extremely satisfied with their current treatment regimen vs those not taking oxybates (70% [14/20] vs 37% [28/76]; **Figure 4**)

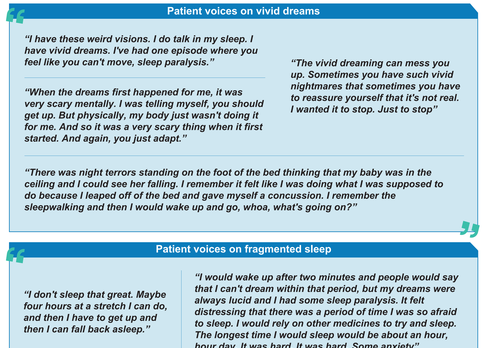
FIGURE 4: Satisfaction With Current Treatment Regimen



ONLINE FOCUS GROUP DISCUSSIONS

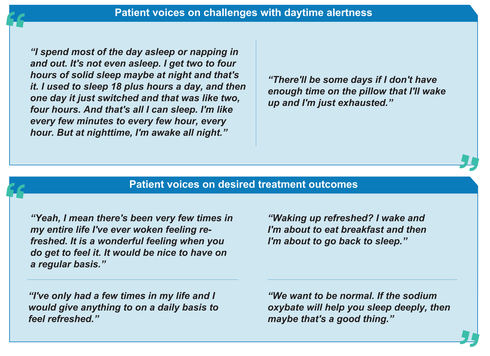
- The small, separately conducted focus group discussions (ER-OXB–experienced, n=3; oxybate-naive, n=5) qualitatively illustrate the survey results and the nighttime symptom burden experienced by PWN (ie, vivid dreams and fragmented sleep; **Figure 5**)

FIGURE 5: Patient Discussions on Nighttime Symptom Burden



- Oxybate-naive PWN described challenges with daytime alertness following poor nighttime sleep and desired a treatment that would allow them to wake refreshed (**Figure 6**)

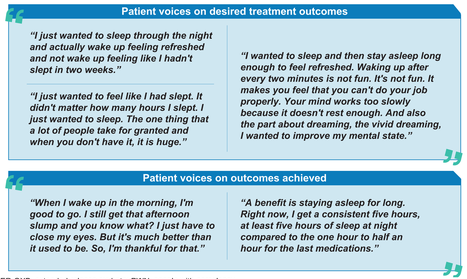
FIGURE 6: Challenges and Desired Treatment Outcomes in Oxybate-Naive PWN



PWN, people with narcolepsy.

- ER-OXB–experienced PWN desired a treatment that would allow them to sleep through the night and wake refreshed (**Figure 7**)

FIGURE 7: Desired Treatment Outcomes in ER-OXB–Experienced PWN



ER-OXB, extended-release oxybate; PWN, people with narcolepsy.

STUDY LIMITATIONS

- These data were collected exclusively from survey responses; participants who are MyNarcolepsyTeam members and their responses may not be reflective of the broader population of PWN
  - NT1 and NT2 diagnoses were reported by one half and one third of participants, respectively; NT1 may have been overrepresented in this study in comparison with real-world estimates
- Additional limitations include the observational design, potential for recall and self-reported biases, and small sample size
  - Results were consistent between the survey data and discussion panels; however, the small number of patients in focus group discussions may not be representative of the broader narcolepsy treatment population

CONCLUSIONS

- Nighttime symptoms, including disturbed/disrupted nocturnal sleep, insomnia, and REM-related phenomena, are common narcolepsy features and have a negative impact on the daily lives of PWN
  - PWN seek relief from both daytime and nighttime symptoms of narcolepsy
- Although the experiences and needs of PWN extend beyond daytime sleepiness, more than one-third of respondents had not discussed nighttime treatment options with their clinician
  - Greater understanding of both daytime and nighttime symptoms experienced by PWN may help clinicians better support, educate, and treat their patients

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DISCLOSURES

LEO has served on advisory boards for Avadel Pharmaceuticals, Harmony Biosciences, and Jazz Pharmaceuticals.

ML has served as a consultant, speaker, and/or has received consulting fees for participation on advisory boards for Avadel Pharmaceuticals, Harmony Biosciences, Jazz Pharmaceuticals, Takeda Pharmaceutical Co., and Axsome Therapeutics and is Sleep Medicine Advanced Practice Provider (SMAPP) President and Founder.

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 the National Institutes of Health, UCB Pharmaceuticals, Jazz Pharmaceuticals, ResMed Foundation, Coverys Community Healthcare Foundation, Harmony Biosciences, and Geisinger Health Plan; is the Chief Executive Officer of DAMM Good Sleep, LLC; and serves as an advisor for Neura Health, OpenEvidence, Pulse Infoframe, Catnap, and FloraWorks.

BS is an employee of MyHealthTeam (now part of Swoop), which received funding from Avadel Pharmaceuticals to conduct the research.

MH has served as a consultant to Avadel Pharmaceuticals and has received compensation or honoraria from Alkermes, Inc., Axsome Therapeutics, Centessa Pharmaceuticals, and Harmony Biosciences.

DL and **SK** were participants in a MyNarcolepsyTeam discussion group.

JG was an employee of Avadel Pharmaceuticals and is a consultant to Alkermes, Inc.

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