

Understanding the Patient Experience With Sodium Oxybate Therapy for Narcolepsy

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INTRODUCTION

Excessive daytime sleepiness (EDS) and disrupted nighttime sleep are 2 of the pentad of symptoms affecting quality of life (QoL) in persons living with narcolepsy.¹ Sodium oxybate (SO), a twice-nightly therapy, has shown effectiveness²; however, SO can present its own challenges to patients as a result of nighttime waking to take the required second dose, including dosing administration errors with immediate-release formulations taken less than 2.5 hours after the first dose.³ By actively listening to the unmet needs of a community, one can glean insights into the disease burden. This is an important step in understanding the efficacy of drugs, dosing regimens, and how patients report these effects on QoL,⁴ to find solutions to reduce clinical and socioeconomic burdens.⁵ Patient-reported outcomes using real-world data can be a valuable resource for gathering patient experiences with rare diseases to increase time- and cost-effectiveness.⁶

METHODS

We developed a customized social listening methodology for analyzing large amounts of social media conversation data united around particular diseases. This analytics engine leverages artificial intelligence based on natural language processing (NLP) techniques. With this approach, a clinical entity recognition tagger used a medical ontology to build a co-occurrence network of concepts and identify relationships between entities (e.g., substances, clinical findings). The deidentified data were used with permission from site administrators. The data sources for the data exploration and survey can be found in the Results section.



DATA EXPLORATION RESULTS

DATA SOURCES

Private Facebook Group and Subreddit r/Narcolepsy

25,018
POSTS
SHARED

229,626
COMMENTS
ELICITED

AUGUST 2021 – OCTOBER 2022
DATE RANGE

FIGURE 1. CHALLENGES WITH SECOND DOSE

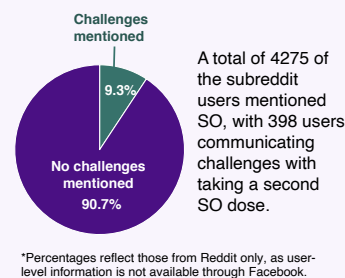


FIGURE 2. CO-OCCURRENCE NETWORK



The network connected the second dose of SO with physical issues such as nausea, headaches, dizziness, and hunger, as well as mental health issues such as anxiety, panic, and depression. These connections should be investigated in further studies.

CONCLUSIONS

Patients often seek avenues for communication using social media regarding their experiences surrounding therapies and treatments. In this study, social media sources and the survey results independently reported that there are issues related to taking the second dose of SO. The required second SO dose is reported to disrupt the daily lives of these patients and their caregivers/care partners. Patients report physical, emotional, and mental health challenges when second doses are missed, when doses are taken more than 4 hours after the first dose, and when the doses are taken less than 2.5 hours apart, as well as injuries during waking to take the second dose. The use of social media sources and surveys presents a unique, time- and cost-effective opportunity to gain insights and interrogate data which may prove valuable to patients and their caregivers, physicians, researchers, and pharmaceutical developers.

SURVEY RESULTS

DATA SOURCES

3 Private Facebook Groups and Discord Servers Patients: 85 Caregivers/Care Partners: 2

Sex Assigned at Birth
Female: 64
Male: 19
Intersex: 1
Prefer not to answer: 1

Diagnoses
Type 1 narcolepsy: 44
Type 2 narcolepsy: 39
Unsure: 2

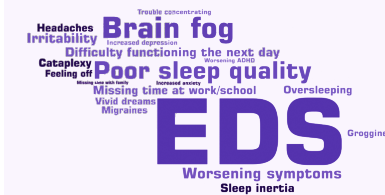
MEDICATIONS

Currently taking Xyrem: 19
Previously taken Xyrem: 34

Currently taking Xywav: 45
Previously taken Xywav: 11

OCTOBER 2022 – NOVEMBER 2022
DATE RANGE

FIGURE 3. IMPACTS OF MISSING SECOND DOSE



"I feel like I'm on a rollercoaster, which then impacts my mental health. There has to be a better way to dose this!"

- Community member



TABLE 1. FREQUENCY OF MISSING SECOND DOSE (n = 64)

Frequency	%
A few times a week	17
Once a week	20
Once a month	28
Every 6 months	25
Once a year	5
Less than once a year	5

Missing the second dose was reported by approximately 75% of the patients surveyed. Of that group, 65% shared that this happens at least monthly.

TABLE 3. FREQUENCY OF DOSING TOO OFTEN (n = 18)

Frequency	%
A few times a week	6
Once a week	11
Once a month	22
Every 6 months	11
Once a year	28
Less than once a year	22

Too-frequent dosing (<2.5 hours after the first dose) was another issue reported by 21% of those surveyed. For 39% of that group, this happens at least once a month.

TABLE 2. FREQUENCY OF DELAYED DOSING (n = 27)

Frequency	%
A few times a week	7
Once a week	7
Once a month	19
Every 6 months	22
Once a year	19
Less than once a year	26

Delayed dosing (>4 hours after the first dose) was another issue reported by 59% of those surveyed. Of that group, 74% shared that this happens at least once a month.

TABLE 4. FREQUENCY OF INJURIES REPORTED (n = 27)

Frequency	%
A few times a week	7
Once a week	7
Once a month	19
Every 6 months	22
Once a year	19
Less than once a year	26

Thirty-two (32%) of respondents reported suffering injuries when waking to take a second dose of SO therapy. Of that group, one-third said this occurs at least once a month.

TABLE 5. BELIEF THAT SODIUM OXYBATE IS SAFER AS A SINGLE DOSE (N = 87)

Response	%
Strongly agree	46
Agree	30
Neither agree nor disagree	11
Disagree	6
Strongly disagree	7

Seventy-six percent (76%) of respondents strongly agreed or agreed that a single bedtime dose of SO would be safer than would a twice-nightly regimen.

Abstract

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Narcolepsy is a chronic sleep disorder defined by excessive daytime sleepiness, impaired rapid eye movement sleep, disrupted nighttime sleep with frequent waking, and several molecular biomarkers; it may also be accompanied by cataplexy. Narcolepsy has no cure and affects both men and women. The purpose of this research was to harness the power of natural language processing (NLP) with social listening to better understand patient experiences in the narcolepsy community with taking sodium oxybate (SO) therapy. Using a proprietary analytics engine that incorporates artificial intelligence and NLP to quickly analyze conversations, we analyzed 25,018 posts/comments which occurred from August 2011 to October 2022 and contributed by 15,280 participants in 2 narcolepsy communities: the Reddit thread r/Narcolepsy and a private Facebook group. A clinical entity recognition tagger leveraging medicine ontology was used to build the co-occurrence network and identify relationships between entities. We filtered conversations that mentioned (1) second dosage (e.g., second dose, 2nd) and (2) SO (e.g., Xyrem, SO) to build a unique co-occurrence network for all conversations discussing second doses of SO. Patient experiences with SO were then documented by surveying and interviewing community members and analyzing the stories and experiences they shared on social media. A total of 4275 of the subreddit users mentioned SO, with 398 (9.31%) users communicating challenges with taking a second SO dose. The co-occurrence network revealed that the second SO dose was co-mentioned with physical conditions (e.g., nausea, headache) and mental conditions (e.g., anxiety, depression, eating disorder). A group of 87 users from the private Facebook group was then surveyed (n = 85 patients, n = 2 caregivers). Missing the second dose was reported by 75% of patients (65% at least monthly). The most common reported impacts of missing doses were poor sleep quality, increased daytime sleepiness, work/school absences, and brain fog affecting next-day functioning. Regarding whether they suffered injuries resulting from waking to take a second dose of SO therapy, 32% responded yes (one-third at least once a month). Injuries ranged from bumps/bruises, falls, and black eyes to pulled muscles, wounds needing stitches, and concussions. Delayed dosing (>4 hours after) was another issue reported by 59% (74% at least once a month). Impacts of this delayed dosing included grogginess/brain fog, headache, and oversleeping, leading to school/work tardiness and missed responsibilities. Patients reported adverse effects with SO therapy, including mental health issues (especially depression), racing heart, muscle spasms, acid reflux, bedwetting, and eating problems. Seventy-six percent of the respondents strongly agreed or agreed that a single bedtime dose of SO would be safer. There is converging evidence from both the social media and survey results that show that the need to take the second dose of SO is associated with various sleep-related issues and disruption for people with narcolepsy and their caregivers. Daily functioning, physical and mental health, injuries, and quality of life were affected. These impacts are present both for missed second doses and doses taken more than 4 hours after the first dose.

Disclosures and Limitations

The data obtained are limited to those from respondents with the means, interest, and ability to participate. Honest representation by participants of their diagnosis, illness, symptoms, and disease progression is an assumption. The analysis does not account for the context in which a term is mentioned; for example, the mention of a symptom might be in the context of its absence. The researchers who prepared this report are not doctors, are not providing medical advice, and are reporting only what was mentioned in the online conversations.

Acknowledgments

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