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Clinically Relevant Symptoms of Narcolepsy and Idiopathic Hypersomnia in Patients Initiating Low-Sodium Oxybate: Electronic Health Record Notes Study

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Objective

- To characterize narcolepsy and idiopathic hypersomnia symptomology as recorded in providers' unstructured clinical notes in electronic health records (EHRs) among patients initiating low-sodium oxybate (LXB)

Conclusions

- This analysis of clinician-recorded symptoms identified excessive daytime sleepiness and disrupted nighttime sleep as dominant symptom concepts among patients with narcolepsy and idiopathic hypersomnia initiating LXB, with more than 25 unique terms used to describe some symptom concepts
- Study limitations included inconsistent symptom documentation and a wide variety of terminology in clinical notes (where undocumented symptoms may not reflect true absence and recorded symptoms may not reflect endorsement of that symptom), and, given the qualitative nature, limited generalizability due to use of records containing clinician-reported notes
- Clinical care for patients with narcolepsy or idiopathic hypersomnia involves addressing a multisymptom burden, including complex combinations of daytime and nighttime symptoms
- These results highlight opportunities to explore how people with narcolepsy or idiopathic hypersomnia describe their condition, and how symptoms are recorded by their healthcare providers within the EHR, to better inform treatment decisions and disease management

Reference: 1. American Academy of Sleep Medicine. International Classification of Sleep Disorders – Third Edition, Text Revision. Darien, IL: American Academy of Sleep Medicine; 2023. **2.** Xywav® (calcium, magnesium, potassium, and sodium oxybates) oral solution, CIII [prescribing information]. Palo Alto, CA: Jazz Pharmaceuticals, Inc.

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Disclosures: SC Markt, **M Whalen**, **C Drachenberg**, **S Beaty**, **JK Alexander**, and **C Casstevens** are full-time employees of Jazz Pharmaceuticals who, in the course of this employment, have received stock options exercisable for, and other stock awards of, ordinary shares of Jazz Pharmaceuticals, plc. **RM Fee** and **K Russell** are full-time employees of Optum who were contracted by Jazz Pharmaceuticals to implement the study described in this abstract. **LE Ortiz** has received personal compensation for serving on advisory boards for Avadel, Harmony Biosciences, and Jazz Pharmaceuticals.

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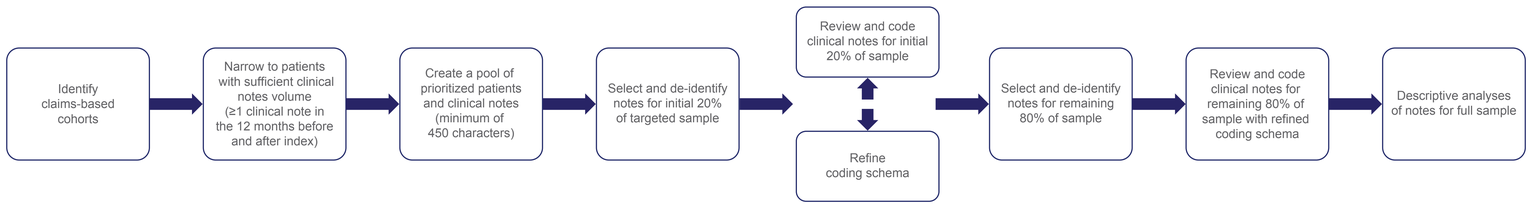
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Introduction

- Excessive daytime sleepiness is a hallmark symptom of both narcolepsy and idiopathic hypersomnia; however, patients also experience a wide range of daytime and nighttime symptoms[1]
- It is important to understand how symptoms are described in real-world clinical practice, including the terminology relevant to patients and healthcare providers, in order to translate research results, inform research endeavors, and guide effective disease management
- Low-sodium oxybate (LXB; Xywav®) is approved by the US Food and Drug Administration for the treatment of cataplexy or excessive daytime sleepiness in patients aged 7 years or older with narcolepsy and for the treatment of idiopathic hypersomnia in adults[2]

Methods

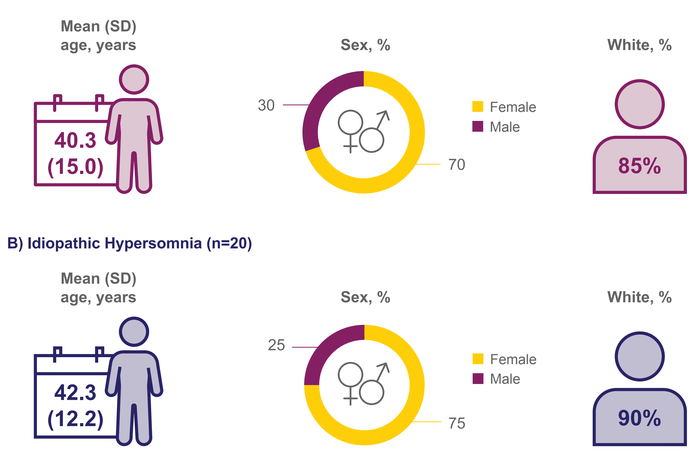
Figure 1. Clinical Notes Selection and Review Process



- This retrospective study used claims from Optum's de-identified Market Clarity Data and linked clinical notes data from Optum's de-identified Electronic Health Records (EHR) Data
- Eligible patients had ≥1 medical claim for narcolepsy (7/21/20–3/21/24) or idiopathic hypersomnia (8/1/21–3/21/24) and ≥1 pharmacy claim for LXB
  - Patients were indexed on the date of their first pharmacy claim for LXB
- From these patients, symptom terms, as recorded by healthcare providers in qualifying clinical notes in Optum EHR Data, were reviewed
- Two researchers independently coded each selected clinical note based on an a priori coding schema of concepts and terms
- Terms not included in the a priori coding schema were identified and coded to capture additional relevant content (open coding)
- Mentions of each term were aggregated within symptom concepts over the study period (6 months preceding and 12 months following LXB initiation), regardless of timing or context (eg, report of symptom, improvement in symptom, or to rule out a symptom), using ATLAS.ti (v24)

Results

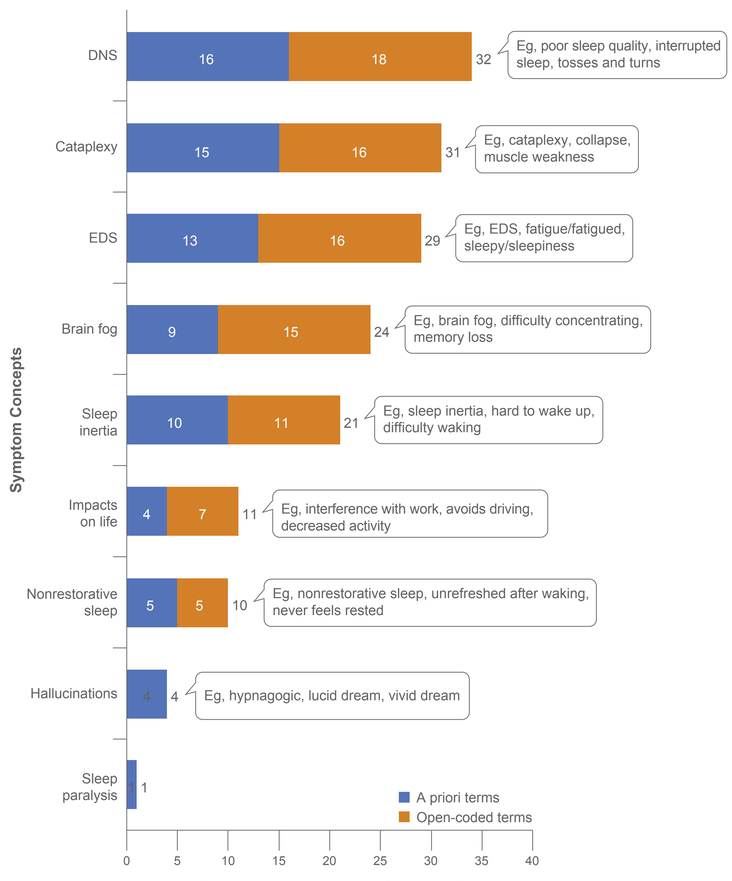
Figure 2. Patient Characteristics



SD, standard deviation.

- Both cohorts were predominantly female and White; the mean (SD) age was 40.3 (15.0) and 42.3 (12.2) years in the narcolepsy and idiopathic hypersomnia cohorts, respectively
- Patients in the narcolepsy cohort had a mean (SD) of 6.6 (1.1) evaluable notes; patients in the idiopathic hypersomnia cohort had a mean (SD) of 6.0 (1.6) evaluable notes

Figure 3. Multiple Terms Were Used to Denote Each Symptom Concept, Independent of Condition

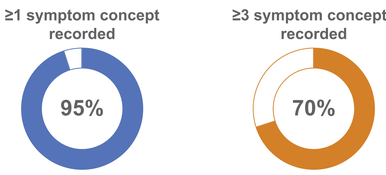


DNS, disrupted nighttime sleep; EDS, excessive daytime sleepiness.

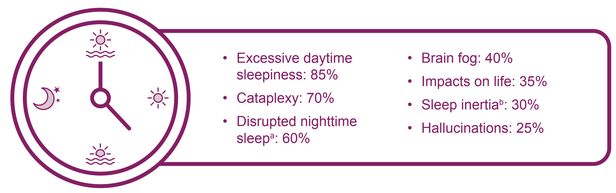
- Multiple terms were used to describe 9 symptom concepts of interest among the narcolepsy and idiopathic hypersomnia cohorts, many of which were not identified a priori

Figure 4. Multiple Symptom Concepts Were Recorded Among Patients With Narcolepsy or Idiopathic Hypersomnia

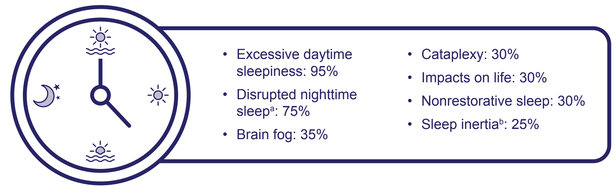
A) In Each Cohort, Most Patients Had ≥3 Symptom Concepts Recorded



B) Most Frequently Recorded Symptom Concepts in the Narcolepsy Cohort (n=20)



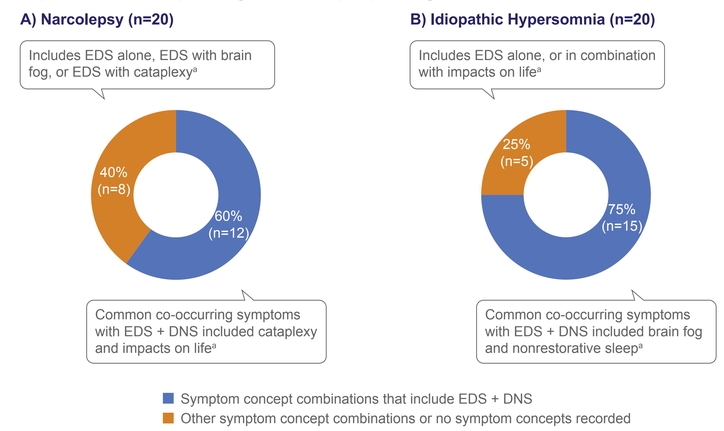
C) Most Frequently Recorded Symptom Concepts in the Idiopathic Hypersomnia Cohort (n=20)



[a]Common terms used to describe the symptom concept "disrupted nighttime sleep" in the narcolepsy cohort included "poor sleep quality," "sleeping difficulty," and "delayed sleep"; common terms used in the idiopathic hypersomnia cohort included "not sleeping well," "tosses and turns," and "wakes up several/multiple times." [b]Common terms used to describe the symptom concept "sleep inertia" in the narcolepsy cohort included "confused/groggy after naps" and "difficulty getting going in the morning"; the most common term used in the idiopathic hypersomnia cohort was "sleep inertia."

- In each cohort, 95.0% of patients had at least 1 symptom concept recorded in notes, and 70.0% had at least 3 symptom concepts recorded
  - Symptom concepts may have been recorded as a report or improvement in that symptom, or in the context of being ruled out
- The most frequently recorded symptom concepts in the narcolepsy cohort were excessive daytime sleepiness, cataplexy, disrupted nighttime sleep, and brain fog
- The most common symptom concepts recorded in the idiopathic hypersomnia cohort included excessive daytime sleepiness, disrupted nighttime sleep, brain fog, and nonrestorative sleep
- The most common term used to describe the symptom concept "cataplexy" in the narcolepsy cohort was "cataplexy"; common terms used in the idiopathic hypersomnia cohort included "paresthesia," "numbness," and "syncopal episode," which may not represent true cataplexy
  - Some of the symptoms recorded for each cohort, such as the relatively low percentage of sleep inertia in idiopathic hypersomnia, differed from anticipated patterns, suggesting that the clinical notes may not capture the breadth or relative importance of patient-reported symptoms[1]

Figure 5. Most Symptom Concept Combinations Included Both Excessive Daytime Sleepiness and Disrupted Nighttime Sleep, Spanning the 24-Hour Period



[a]Not mutually exclusive.
DNS, disrupted nighttime sleep; EDS, excessive daytime sleepiness.

- The most frequent symptom concept combinations included both daytime and nighttime symptoms, such as excessive daytime sleepiness and disrupted nighttime sleep
- Common symptoms co-occurring with both excessive daytime sleepiness and disrupted nighttime sleep included cataplexy and impacts on quality of life in the narcolepsy cohort and brain fog and nonrestorative sleep in the idiopathic hypersomnia cohort