

Real-World Symptoms and Impacts of Narcolepsy and Idiopathic Hypersomnia: Qualitative Results Using Social Media Listening Methods

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Introduction

- Narcolepsy and idiopathic hypersomnia (IH) are chronic neurologic disorders characterized by excessive daytime sleepiness (EDS) and a range of other debilitating symptoms¹⁻³
 - Individuals with narcolepsy and IH may experience different types of sleep abnormalities; individuals with narcolepsy more often experience hypnagogic/hypnopompic hallucinations, sleep paralysis, and fragmented nighttime sleep, with cataplexy in narcolepsy type 1, while those with IH more often experience prolonged nighttime sleep, long and unrefreshing naps, and sleep inertia with difficulty waking⁴⁻⁶
- Both conditions are also associated with cognitive impairment and fatigue, which may contribute substantially to overall disease burden^{5,6}
- Although the disease burden associated with narcolepsy and IH has been documented, qualitative research remains limited, with most evidence relying on quantitative studies⁷⁻⁹

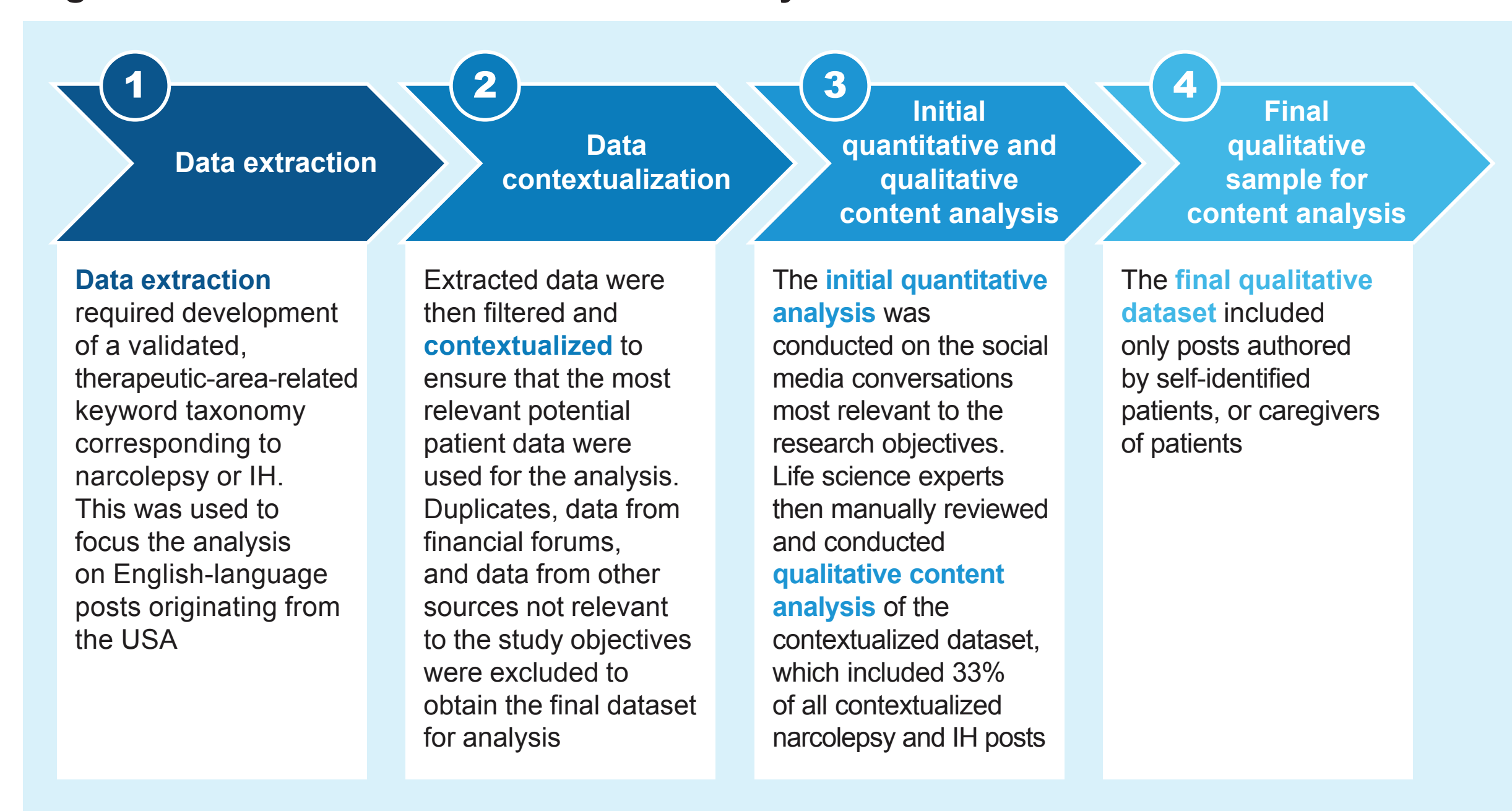
Objective

- This study used social media listening methods to collect real-world data to characterize symptoms and their impacts in narcolepsy and IH

Methods

- This study was a retrospective, observational mixed-methods analysis of posts by US patients with narcolepsy or IH and their caregivers that took place between March 2022 and February 2025. This study utilized artificial intelligence-based analysis and quantitative and qualitative content analysis of publicly available social media channels that included:
 - X (formerly Twitter)
 - Instagram
 - Tumblr
 - Facebook
 - Reddit
 - YouTube
- Additional sources included publicly available blogs, patient discussion forums, and patient advocacy websites
- Topics of interest included gathering information on the most commonly reported symptoms and their impacts on patients
- Searches were primarily performed in English; however, a few Spanish words used in the context of English were included in the data extraction
- Social media listening involved 4 sequential steps to determine the final data sample for qualitative content analysis (Figure 1)

Figure 1: Flow of data extraction and analysis



- All posts mentioning narcolepsy or IH symptoms and impacts were included in the initial quantitative and qualitative analyses, regardless of whether the user(s) self-identified as a patient with narcolepsy or IH or a caregiver. Details on inclusion and exclusion criteria are provided in Table 1

Table 1: Final qualitative analysis inclusion and exclusion criteria

Final qualitative analysis sample	
Inclusion criteria	
Patients	
• Those who have used language in at least 1 online post or in their user bio that indicates they have been diagnosed with narcolepsy or IH (eg, "was diagnosed with narcolepsy/IH," or "I have narcolepsy/IH")	
Caregivers	
• Those who have used language in at least 1 online post or in their user bio that indicates they are related to, friends with, or provide care to someone who has been diagnosed with narcolepsy or IH (eg, "my mother was diagnosed with narcolepsy/IH," or "my daughter is suffering from narcolepsy/IH")	
Exclusion criteria	
Nonspecific posts from:	<ul style="list-style-type: none"> News organizations Journalists Unspecified website and social media users Unspecified nonpatient and noncaregiver users Healthcare providers

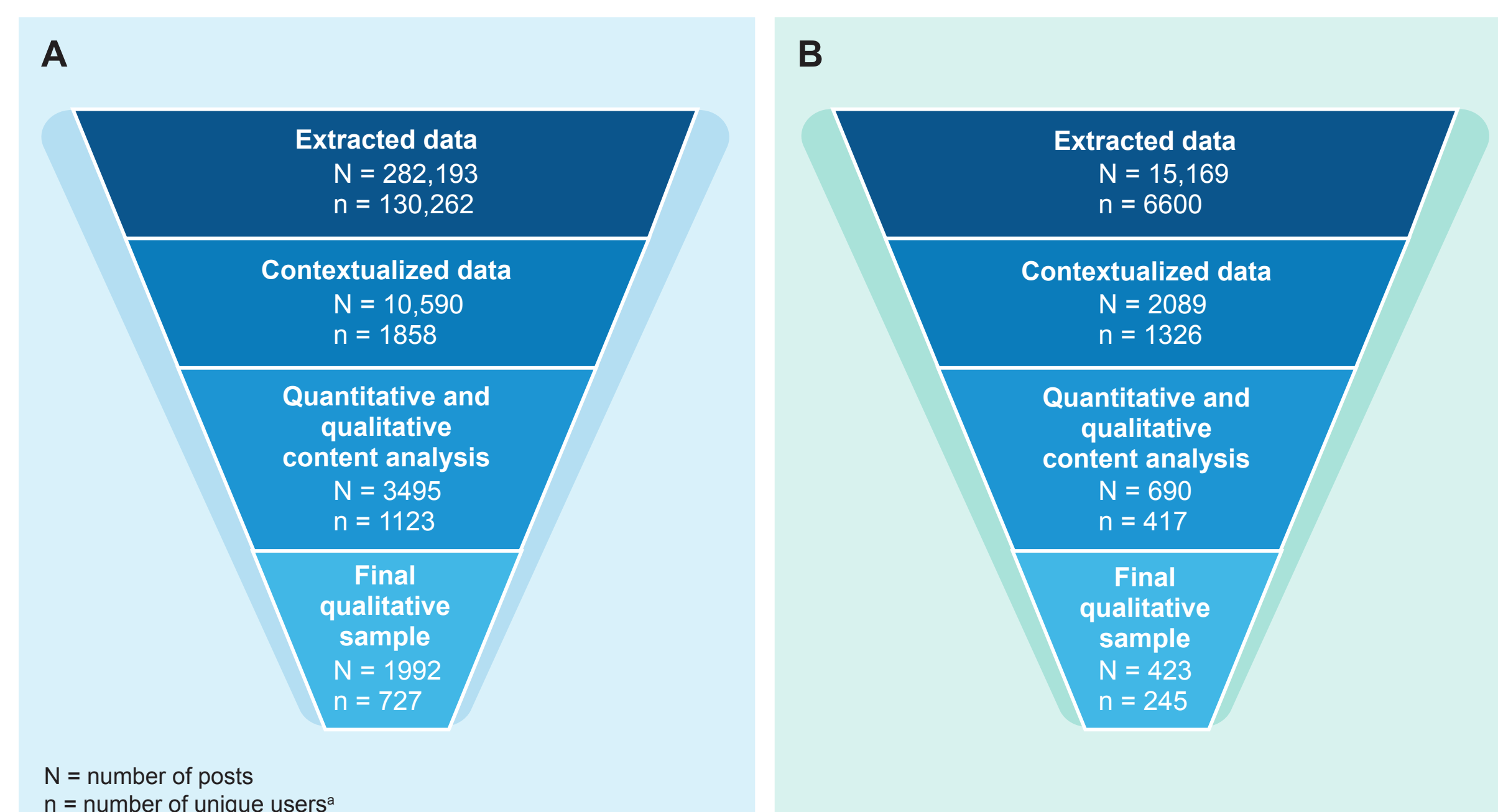
Study outcomes

- Outcomes of social media listening included:
 - Most commonly discussed symptoms and patient perception of the impact of these symptoms on their quality of life
 - Patient perceptions of the current unmet needs and impact of these gaps in their treatment journey

Results

- Nearly 2000 narcolepsy posts (over 700 unique users) and over 400 IH posts (nearly 250 unique users) were included in the final qualitative sample (Figure 2)

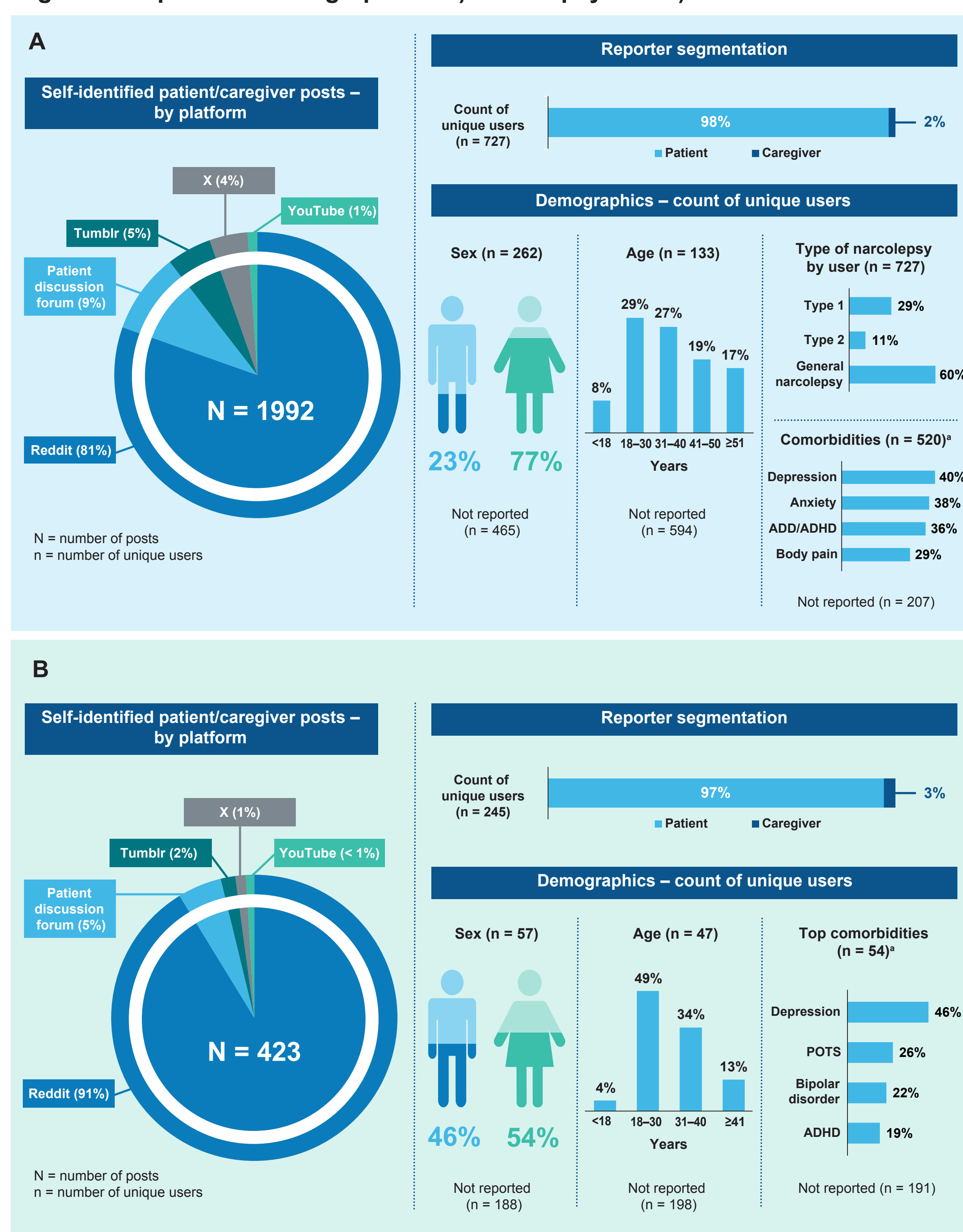
Figure 2: Datasets for social media listening analyses for A) narcolepsy and B) IH



*Unique users were unique individuals within each platform (eg, within Facebook or Reddit); it is possible that the same individual posted across multiple platforms. IH, idiopathic hypersomnia.

- For the narcolepsy community, 81% of posts were extracted from Reddit, and most were posted by females and users aged 40 years and younger (Figure 3A)
- For the IH community, 91% of posts were extracted from Reddit and were posted by nearly equal proportions of males and females, with the majority between the ages of 18 and 40 years (Figure 3B)

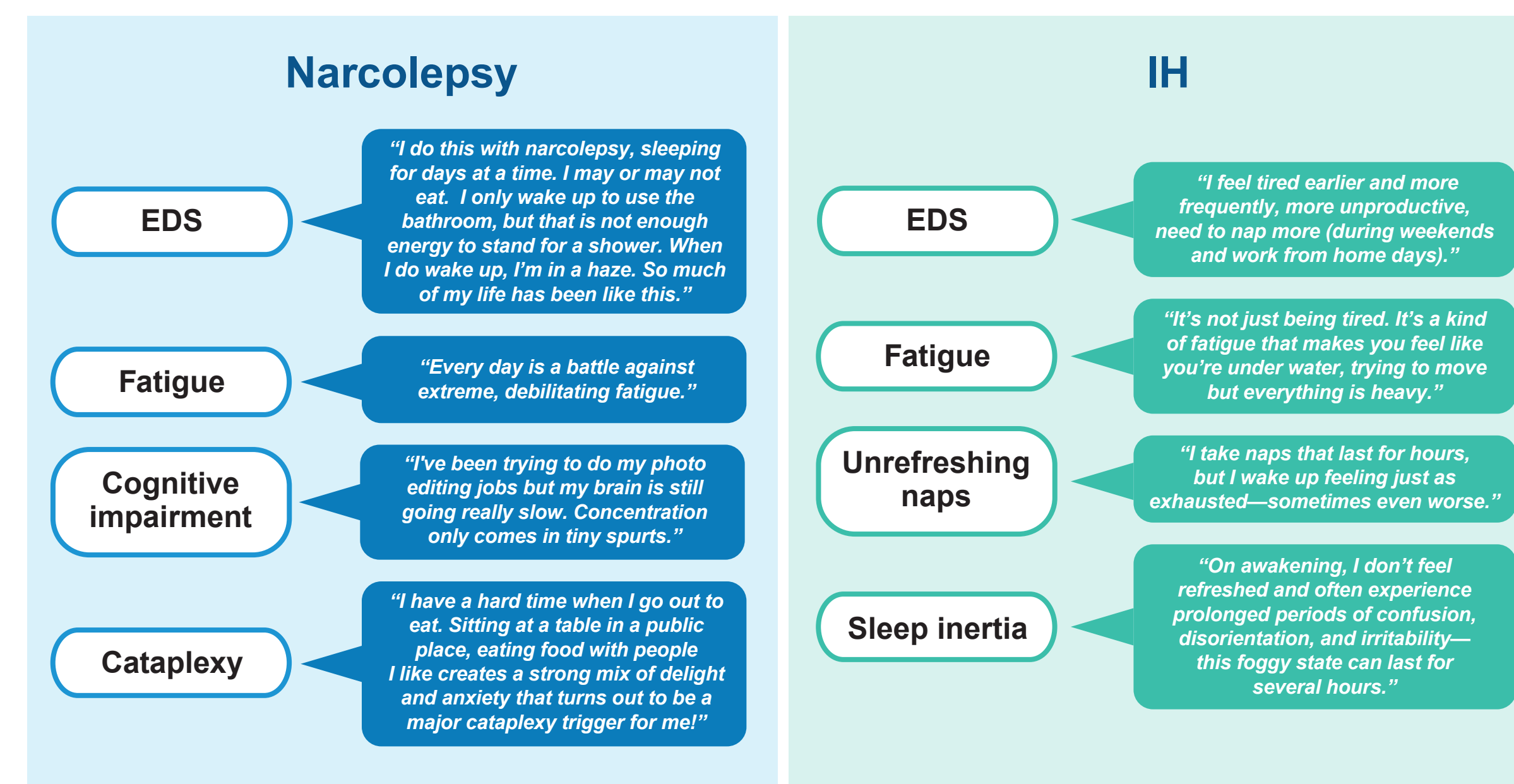
Figure 3: Population demographics: A) narcolepsy and B) IH



*A single user may be included in multiple comorbidity categories. ADD, attention-deficit disorder; ADHD, attention-deficit hyperactivity disorder; IH, idiopathic hypersomnia; PTSD, postural orthostatic tachycardia syndrome.

- In narcolepsy community posts (N = 1992), the most frequently mentioned symptoms included EDS (N = 456), fatigue (N = 400), cognitive impairment (N = 374), cataplexy (N = 373), hallucinations/nightmares/vivid dreams (N = 175), sleep attacks (N = 168), sleep paralysis (N = 128), fragmented sleep (N = 112), and automatic behavior (N = 90) (Figure 4A)
- In IH community posts (N = 423), the most frequently mentioned symptoms included EDS (N = 145), fatigue (N = 102), unrefreshing naps (N = 89), sleep inertia (N = 78), cognitive impairment (N = 63), nightmares/hallucinations (N = 10), changes in mood (N = 4), and headaches (N = 3) (Figure 4B)
- For both the narcolepsy and IH community posts, multiple symptoms were mentioned in 1 conversation, hence sum of values of individual symptom mentions is greater than the number of posts assessed

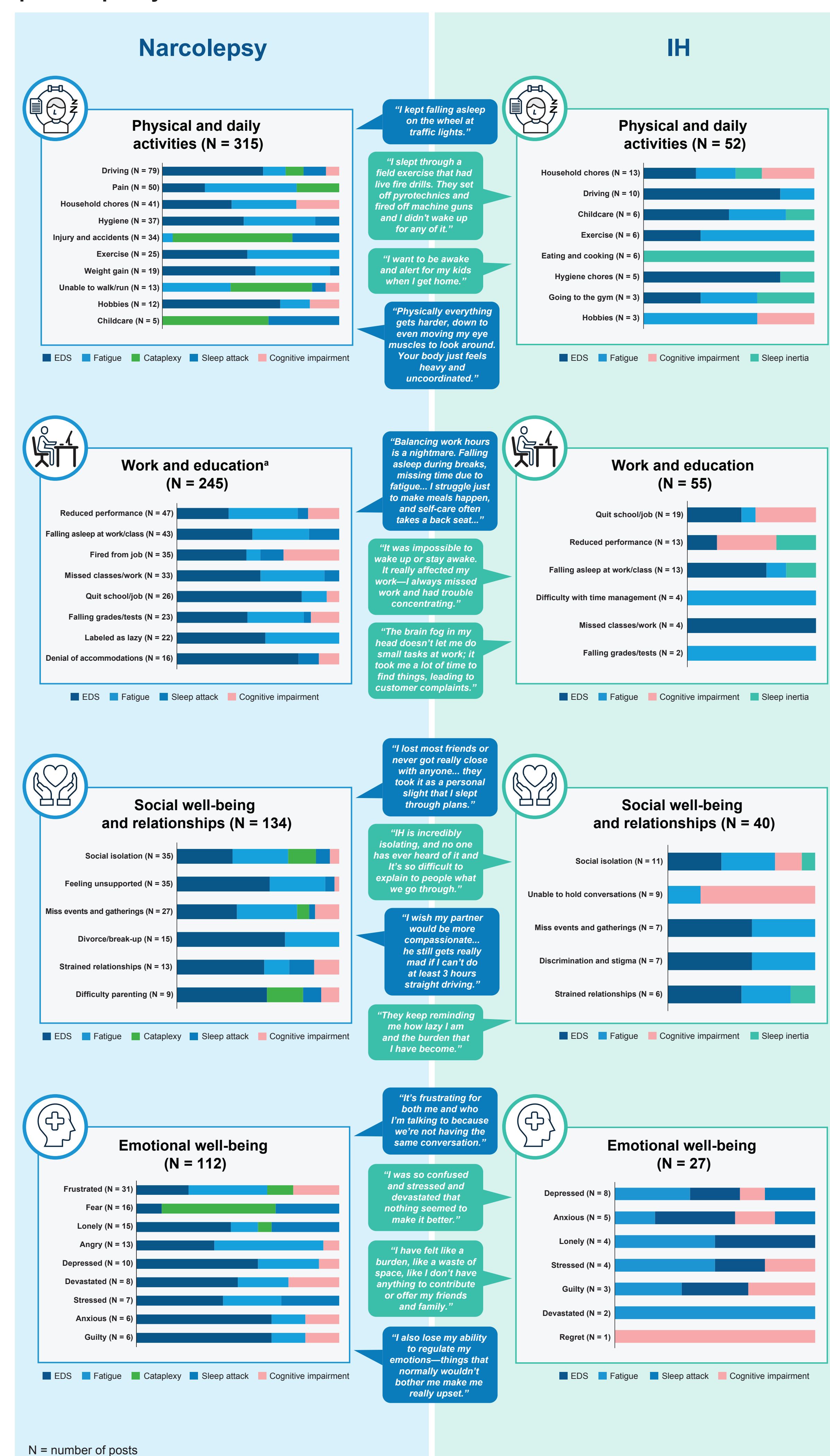
Figure 4: Illustrative patient quotes: Most frequently reported narcolepsy and IH symptoms



EDS, excessive daytime sleepiness; IH, idiopathic hypersomnia.

- Both the narcolepsy and IH communities highlighted marked impacts on patient quality of life, emphasizing considerable impact on physical and daily activities, work and education, social well-being and relationships, and emotional well-being
 - The degree to which specific symptoms (eg, EDS, fatigue, cognitive impairment) impact different aspects of quality of life is shown in Figure 5

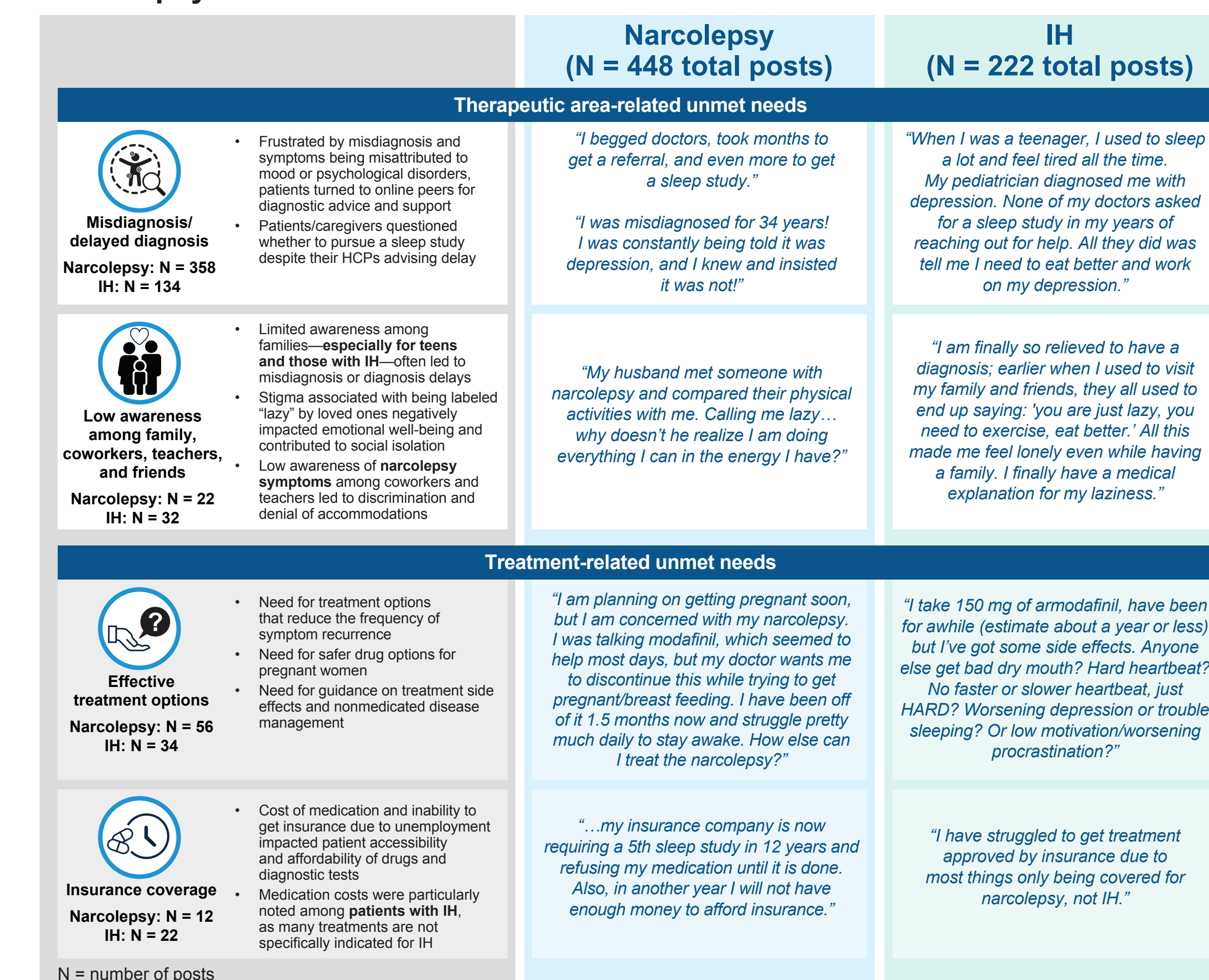
Figure 5: Patient and caregiver perceptions of the impact of narcolepsy or IH on patient quality of life



*Cataplexy was not described as having a direct impact on work and education. EDS, excessive daytime sleepiness; IH, idiopathic hypersomnia.

- In online posts about patients' unmet needs, patients and caregivers frequently discussed misdiagnosis and delayed diagnosis (Figure 6)

Figure 6: Patient and caregiver perception of unmet needs among patients with narcolepsy or IH



HCP, healthcare provider; IH, idiopathic hypersomnia.

Limitations

- Confirmation of diagnosis was not possible, since inclusion of users was based on self-disclosed information
- Only those who shared their demographic and clinical information online had aggregate demographics reported, which represented a small number of individuals compared with the overall dataset. As a result, clinically meaningful insights were not extracted
- Social media users may skew toward being younger, more digitally literate, and more vocal, potentially limiting representativeness. This study population skewed younger, which may have resulted in selection bias
- Findings of this study may not represent those of the larger patient and caregiver populations. For example, individuals who appear to have had their perspectives reflected in this study include those who were dissatisfied with treatment outcomes, experienced fear of stigmatization, juggled multiple life responsibilities, and/or managed burdensome symptoms as well as comorbidities. It is possible that these patients and caregivers felt more comfortable discussing their experience in online forums, where they can remain anonymous
- The volume of social media conversations about IH captured by this study was relatively low. However, the final qualitative sample was large enough for a robust analysis that identified patterns in the patient and caregiver experience with IH

Conclusions

- Reddit was the most frequently used public platform for online conversations for both the narcolepsy and IH communities, serving as a hub for sharing and seeking information about symptoms, diagnosis, treatment, and overall disease management
- The narcolepsy community tended to use the generic term "narcolepsy" when discussing their symptoms rather than mentioning NT1 or NT2
- EDS, fatigue, and cognitive impairment were the most frequently mentioned symptoms across both communities, with cataplexy and sleep inertia highlighted in the narcolepsy and IH communities, respectively. These symptoms were also identified as among the most disruptive, negatively affecting patients' daily functioning, work, education, social relationships, and emotional well-being
- The majority of patients in the narcolepsy and IH community expressed frustration with considerable delays in diagnosis, or misdiagnosis, due to limited awareness of the conditions within their families and among healthcare providers. Low disease awareness, especially for those with IH, negatively impacted their emotional well-being, highlighting a critical need for better education and early diagnostic support
- Patients in the IH community expressed frustration with the limited effectiveness of current treatments, experience of side effects, and the lack of insurance coverage for medications that were not specifically for IH
- Overall, there is a need for additional and accessible treatment options that are effective at addressing common and bothersome symptoms of narcolepsy and IH, alongside a desire for increased awareness of these conditions among physicians, family members, and friends across both communities
- Social media listening studies that include a qualitative component can make important and substantial contributions to patient experience research, particularly in rare conditions, such as narcolepsy and IH

References

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Disclosures

MJD is an employee and shareholder of Alkermes, Inc. DA, KJ, MS, NYA, and KM are employees of IQVIA Patient Centered Solutions.



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