

# Amplifying Voices in Sjögren’s and Lupus Communities Through Social Listening: Real-World Evidence From Their Sleep Experiences

Enming Zhang,<sup>1</sup> Monica Converse,<sup>1</sup> Matthew Horsnell,<sup>1</sup> Anne Marie Morse,<sup>2</sup> Chiara Baldini,<sup>3</sup> Jennifer Gudeman,<sup>4</sup> Frederik Ascencion,<sup>5</sup> Veronica Moore,<sup>6</sup> Juliana Angelim Neves,<sup>7</sup> Rorey Smith,<sup>1</sup> E. Robert Wassman,<sup>1</sup> Christopher DeFelice,<sup>1</sup> Maria Picone<sup>1</sup>

<sup>1</sup>TREND Community, Philadelphia, PA, USA; <sup>2</sup>Geisinger Commonwealth School of Medicine, Geisinger Medical Center, Janet Weis Children’s Hospital, Danville, PA, USA; <sup>3</sup>Department of Clinical and Experimental Medicine, Rheumatology Unit, University of Pisa, Pisa, Italy; <sup>4</sup>Avadel Pharmaceuticals plc, Chesterfield, MO, USA; <sup>5</sup>PWN4PWN, Tampa, FL, USA; <sup>6</sup>Horizon Therapeutics plc, Deerfield, IL, USA; <sup>7</sup>Brazilian Association of Narcolepsy and Idiopathic Hypersomnia, Brazil



## BACKGROUND

Sjögren’s and lupus are chronic autoimmune diseases with shared symptoms such as joint pain, skin rashes, fatigue, and decreased sleep quality. Sleep disorders have been identified in both communities and are linked to disease progression.<sup>1-4</sup> However, clinical guidelines and screening approaches lack a standard assessment for sleep disorders in these populations. Unrecognized sleep disorders can lead to impaired quality of life (QoL) and a proinflammatory state, compromising optimal disease management.<sup>5</sup> The goal of this study was to characterize sleep symptoms through social listening in the Sjögren’s and lupus communities to improve our understanding and pave the way for effective sleep education, recognition, and management strategies for these individuals.

## METHODS

We enhanced a proprietary analytical engine that uses natural language processing (NLP) with a clinical entity recognition (CER) model. The CER model was fine-tuned using social media text to better identify clinical terms by leveraging pretrained language models.<sup>6</sup> After clinical terms were identified from the 2 communities, we applied the normalized pointwise mutual information (NPMI) scores to evaluate correlations between pairs of clinical terms that appeared. NPMI scores ranged from -1 to 1, with 1 indicating a strong positive correlation and -1 reflecting a strong negative correlation. This approach allowed us to find clinical terms that are closely linked to sleep issues, which are defined here as any conditions or disturbances that adversely affect sleep quality or duration.



## RESULTS

FIGURE 1. DATA SOURCE

Sjögren’s		Lupus	
4531 USERS	52,690 POSTS & COMMENTS	15,391 USERS	212,060 POSTS & COMMENTS
OCT 2012 - APRIL 2023		JUNE 2010 - APRIL 2023	

FIGURE 2. TOP SLEEP ISSUES IN SJÖGREN’S AND LUPUS COMMUNITIES

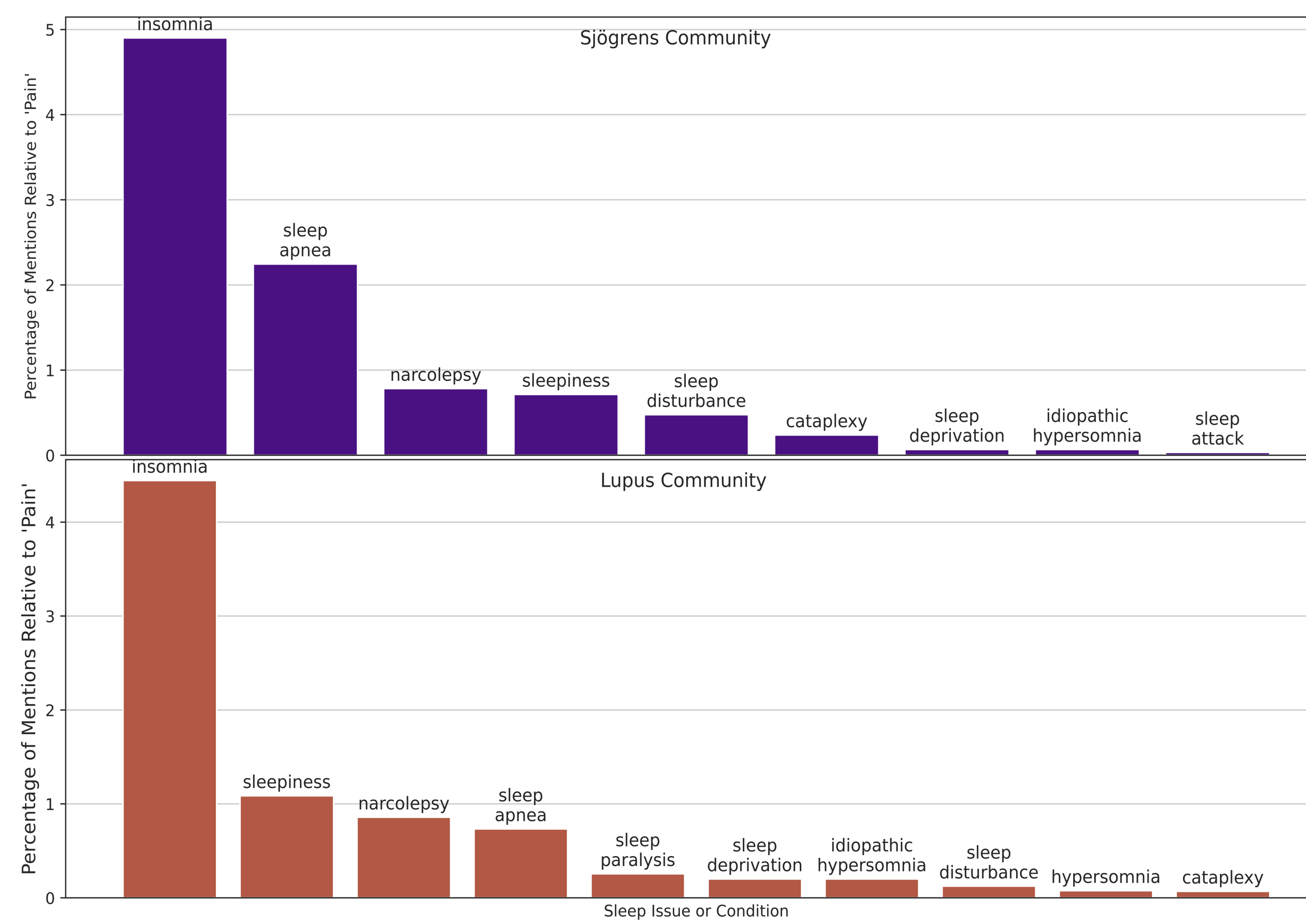


Figure 2 demonstrates the most frequently discussed sleep-related issues and conditions within the Sjögren’s and lupus communities, normalized by mentions of “pain”—the symptom mentioned the most in both communities. Insomnia distinctly emerged as a primary concern for both groups. In the Sjögren’s community, other issues, such as sleep apnea, narcolepsy, sleepiness, disturbances, and cataplexy, were also among top concerns. The lupus community, while also experiencing insomnia, had a broader range of sleep conditions and disturbances. Sleepiness, narcolepsy, sleep apnea, sleep paralysis, and idiopathic hypersomnia were all areas of concern noted for the lupus community.

FIGURE 3. TERM PAIRS BY CO-OCCURRENCE AND NPMI SCORE FOR SJÖGREN’S

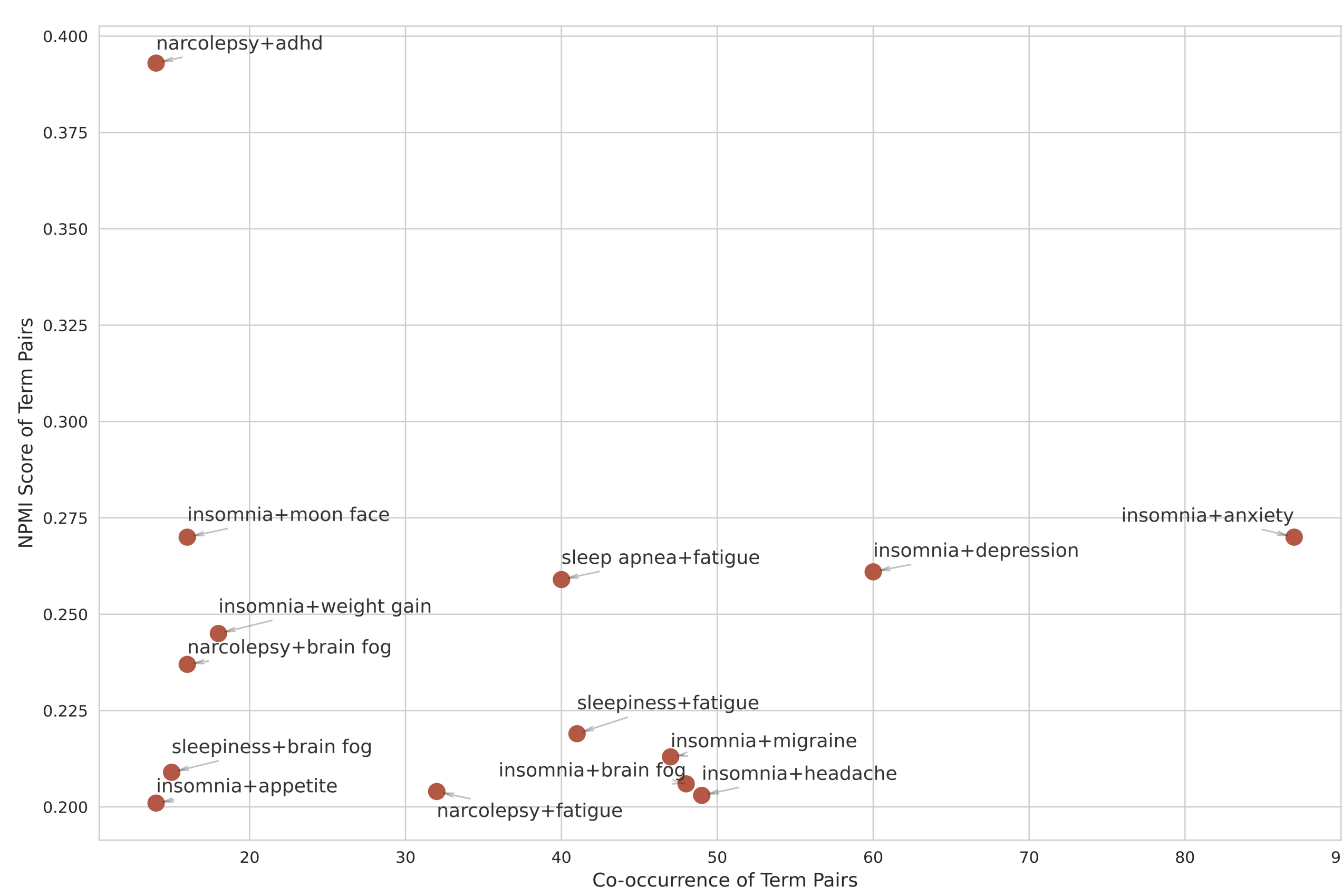
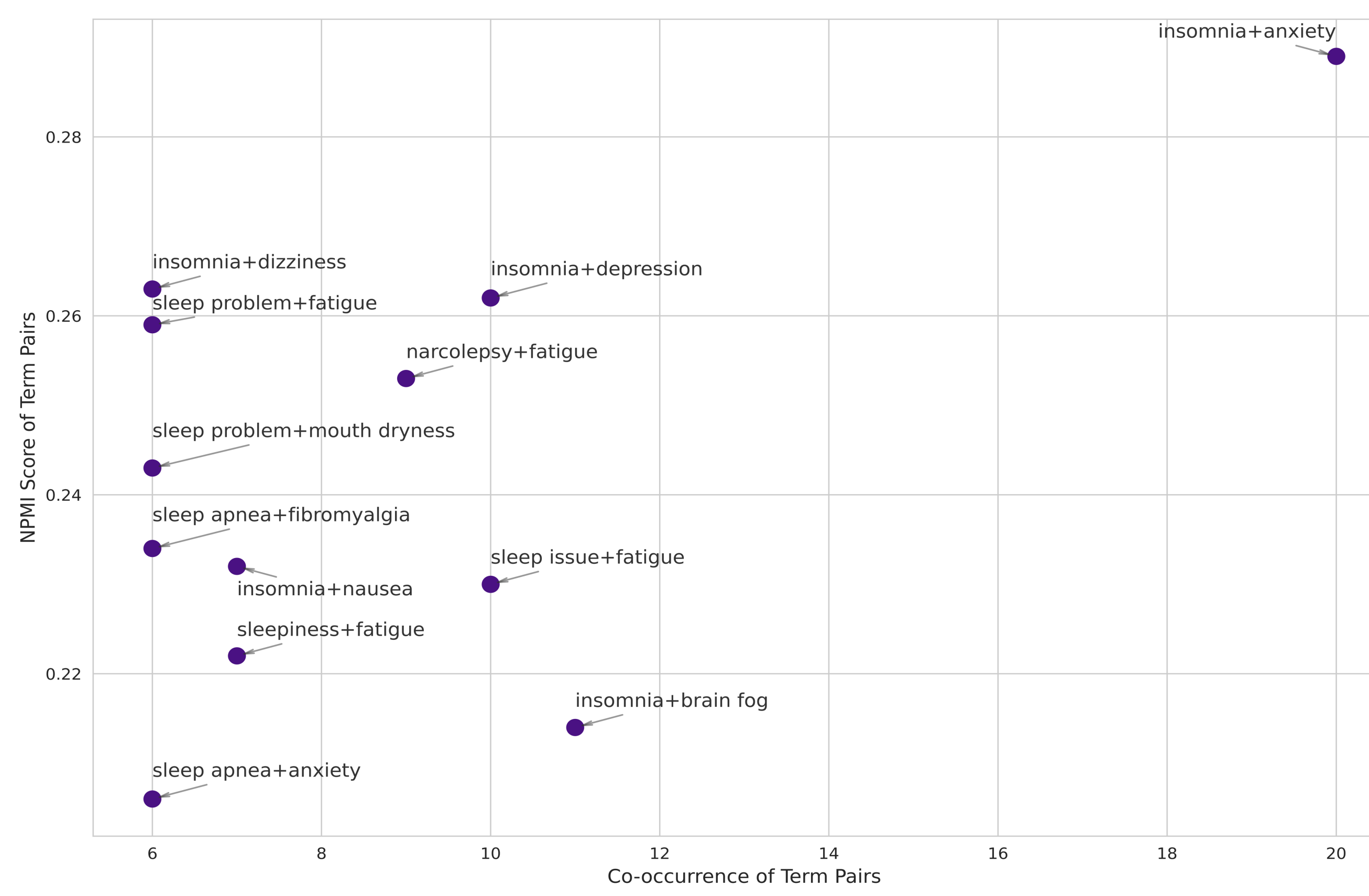


FIGURE 4. TERM PAIRS BY CO-OCCURRENCE AND NPMI SCORE FOR LUPUS

Figures 3 and 4 illustrate the positive correlations between various sleep issues and associated physical and mental health symptoms in these communities. The x-axis quantifies co-mentions—how often a sleep issue and a symptom appear together—while the y-axis shows NPMI scores to gauge the strength of correlation. Figure 3 reveals that ‘insomnia’ is associated with symptoms such as ‘anxiety’, ‘dizziness’, and ‘depression’ for the Sjögren’s community. Figure 4 shows a broader connection spectrum for the lupus community. ‘Insomnia’ here was associated with a variety of symptoms ranging from ‘moon face’, ‘anxiety’, and ‘depression’ to ‘weight gain’, ‘migraine’, ‘brain fog’, and ‘headache’.



## CONCLUSION

Data analysis revealed that insomnia, sleepiness, sleep apnea, and narcolepsy emerged as sleep issues in both the Sjögren’s and lupus communities. The NPMI scores underscored the links between sleep issues and other symptoms, which may imply a unique correlation between these relationships in the discussions for each community. The findings helped increase our understanding of these sleep issues from the perspective of patients living with these chronic conditions. This is pivotal for the optimal management of these disorders, as this information may not arise in the clinical setting during patient-clinician conversations. Addressing these sleep issues can improve QoL for individuals living with Sjögren’s and lupus. Moreover, this study revealed the potential of social media to provide cost-effective, real-world data to inform clinical practices and pharmaceutical companies about populations’ unmet needs and to catalyze further research for rheumatic diseases.

## FUTURE DIRECTIONS

Future research should aim to further examine the factors underlying sleep issues and their subsequent impact on patients with Sjögren’s and lupus. The use of social listening data and advanced NLP techniques will facilitate a deeper understanding of patient narratives, shedding light on the intricate dynamics. By integrating findings from structured medical research with these patient-driven narratives, we will be better positioned to develop more patient-focused therapeutic interventions, leading to improved outcomes for those living with these rheumatic diseases.

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<sup>1</sup>TREND Community, Philadelphia, PA, USA

<sup>2</sup>Geisinger Commonwealth School of Medicine, Geisinger Medical Center, Janet Weis Children's Hospital, Danville, PA, USA

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## Introduction

Sjögrens and lupus are chronic autoimmune diseases that share symptoms such as joint pain, skin rashes, fatigue, and poor sleep quality. Clinical screenings and guidelines used in these communities lack a standard evaluation for sleep disorders. Unrecognized sleep disorders contribute to impaired quality of life and a proinflammatory state which can compromise optimal disease management. Characterizing these sleep symptoms through social listening may improve the understanding and ultimate development of effective sleep education, recognition, and management strategies for individuals with these disorders.

## Materials and Methods

Data were collected from 10 public subreddits: 9 subreddits were for lupus (including systemic lupus erythematosus, discoid lupus erythematosus), containing 212,060 posts/comments from 2010 to 2023; and 1 subreddit was for Sjögrens, containing 52,690 posts/comments from 2012 to 2023. We used an analytical engine leveraging natural language processing techniques and features a clinical entity recognition model designed to extract clinical terms from social media text. After extracting all clinical terms from the data, we computed normalized pointwise mutual information (NPMI) scores, which range from -1 to 1 for negative to positive correlations, for pairs of medical terms. These scores helped us identify any clinical findings correlated with sleep issues, defined as any conditions or disturbances that adversely affect sleep quality or duration.

## Results

The top sleep issues reported in the Sjögrens community were insomnia (144 mentions), sleep apnea (66), narcolepsy (23), sleepiness (21), sleep disturbances (14), and cataplexy (7). In the lupus community, the top sleep issues reported were insomnia (642 mentions), sleepiness (157), narcolepsy (124), sleep apnea (106), sleep paralysis (37), sleep deprivation (29), idiopathic hypersomnia (29), sleep disturbance (18), hypersomnia (11), and cataplexy (10). In Sjögrens, the NPMI scores highlighted the correlation of 'insomnia' with 'anxiety', 'dizziness', 'depression', 'weakness', 'nausea', and 'brain fog'; NPMI scores were 0.289 down to 0.213;

'sleep apnea' was correlated with 'fibromyalgia' and 'anxiety'. For the lupus community, 'insomnia' was correlated with 'moon face', 'anxiety', 'depression', 'weight gain', 'migraine', 'brain fog', and 'headache'; NPMI scores were 0.27 down to 0.203; 'sleep apnea' was correlated with 'fatigue', with an NPMI score of 0.259.

### **Conclusions**

The results showed that insomnia, sleepiness, sleep apnea, and narcolepsy are commonly reported sleep issues among individuals living with Sjögrens and lupus, highlighting the complexity of sleep-related burdens. NPMI scores emphasized the numerous connections between sleep issues and other symptoms. These findings further underscore the need to better understand this relationship as a mitigating factor in the optimal management of these disorders. Addressing sleep issues will improve quality of life for those living with Sjögrens and lupus. This study also demonstrates the potential of social media to provide real-world evidence to inform clinical practices, monitor change, and drive research for those living with rheumatic diseases.

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### **Disclosures**

**Enming Zhang, Monica Converse, Matthew Horsnell** and **E. Robert Wassman** are employees of and own stock options with TREND Community; their clients are pharmaceutical and biotechnology companies including, but not limited to, Horizon Therapeutics, Chiesi Global Rare Disease, Novartis, Harmony Biosciences, and Avadel. **Rorey Smith** and **Frederik Ascencion** have no conflicts of interest to disclose. **Anne Marie Morse** is a consultant for Avadel, Harmony Biosciences and Jazz Pharmaceuticals; has served on advisory boards and speakers bureaus for Avadel and Jazz Pharmaceuticals; has received grant funding from the National Institutes of Health/National Institute of Mental Health; has served as an advisor for Epilog, Neura Health, and the American Sleep Apnea Association; and was a REST-ON site principal investigator for Avadel Pharmaceuticals. **Chiara Baldini** has served on speakers bureaus for GSK, Sanofi, Novartis. Pain instructor for GSK, Sanofi. Consultant for Sanofi, GSK and grant/research support from GSK, Viela, Novartis. **Veronica Moore** is an employee of and own stock options with Horizon Therapeutics, plc. **Jennifer Gudeman** is an employee and owns stock options with Avadel. **Juliana Angelim Neves** is a speaker at Project Sleep's Rising Voices of Narcolepsy and a member of ABRANHI. **Christopher DeFelice** and **Maria Picone** are owners of and own stock options with TREND Community; their clients are pharmaceutical and biotechnology companies including, but not limited to, Horizon Therapeutics, Chiesi Global Rare Disease, Novartis, Harmony Biosciences, and Avadel.

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