TREND Community
Turning Anecdotes Into Evidence

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Sjögren's Satellite Symposium Summary

From Noise to Knowledge: Combining Social Media Conversation and AI to Reveal Lived Experiences in Sjögren's disease

June 2024

Summary

The vast world of social media involves conversations on many topics, including the challenges of living with rare and chronic illnesses. A unique data source emerges within disease-focused online communities, blending clinical discourse with candid reflections on daily routines and challenges. This report is a summary of a Satellite Symposium sponsored by Amgen that explored the impact of Sjögren's disease on everyday life in a social media community. TREND's analysis investigated the nuanced challenges this condition imposes on the daily lives of its community members. These data were presented and discussed at The 16th International Symposium Sjögren's Disease (ISSjD) Conference on April 25, 2024, in the Netherlands by a diverse group of members, from those living with Sjögren's disease to clinicians, KOLs, industry partners, advocacy leaders, and researchers, in support of the Sjögren's community worldwide.

Background[1,2]

Sjögren's disease is a systemic disease and one of the most prevalent autoimmune conditions affecting an estimated four million Americans and one to two million people worldwide. Sjögren's symptoms are varied and include extensive dryness, fatigue, chronic pain, neuropathy, esophagitis, swollen/painful glands, abnormal liver function, recurrent pulmonary disease, and gastrointestinal motility disorders. Progression of the condition varies among individuals in severity and rate. People living with Sjögren's disease are also at greater risk for lymphoma. Sjögren's occurs alone or comorbidly with lupus, scleroderma, or other autoimmune disorders.

Methods

TREND Community hosted a satellite symposium organized and sponsored by Amgen at The 16th International Symposium Sjögren's Disease (ISSjD) Conference held on April 22-25, 2024, in Egmond Aan Zee Netherlands. The title of the presentation was *"From Noise to Knowledge: Combining social media conversation and AI to reveal lived experiences in Sjögren's disease".* Approximately 36 Sjögren's experts came together to discuss the data and explore new approaches for tackling the condition. The formal panel consisted of Maria Picone, Co-Founder and CEO, TREND Community, Christopher DeFelice, Co-Founder and CTO, TREND Community, Dr. Chiara Baldini, Professor of Rheumatology, University of Pisa, Italy, and Julia Taylor, TREND Ambassador living with Sjögren's and Associate Director, Field Leadership Development, Commercial Coaching Excellence at Amgen.

Data Sources

The data sources used in the analysis included the following groups: reddit/sjögrens. There were 4,790 posts and 79,819 comments from 6,095 authors. These contributions were made between October 2012 and March 2024. Figure 1 shows the posts and comments over this time period and reflects a noticeable increase in activity since 2019.

Figure 1: Data Sources
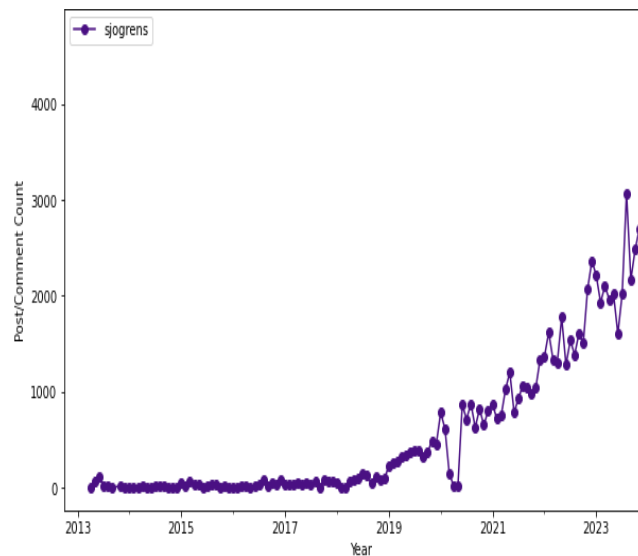
Results

Attributes of Daily Living (ADLs) Data: Overall and Eating and Drinking

TREND's analytics engine, Krystie ™, recognizes and extracts conversations discussing various features, activities, and procedures related to daily living. We can then explore the clinical features of these conversations to begin understanding disease impacts on daily life. Christopher DeFelice presented the data found in Figures 2 and 3 to the audience. To measure the strength of association between an Attribute of Daily Living (ADLs) and clinical concepts, co-occurrence and pointwise mutual information squared (PMI^2) were used. Co-occurrence is the number of conversations that two concepts occurred in together (e.g., "Eating and Drinking" and "Mouth"). PMI^2 is a measure of association utilized in Natural Language Processing (NLP) to determine the relative probability of two concepts occurring together versus independently. Key clinical concepts associated with Eating & Drinking in discussions encompassed issues such as oral dryness, discomfort, and swallowing. Non-clinical language associated with conversations included: sugar, dairy, gluten, and coffee.

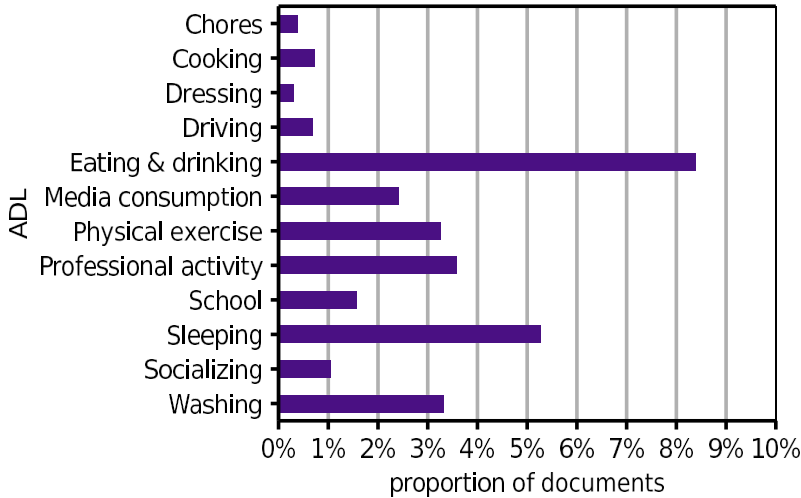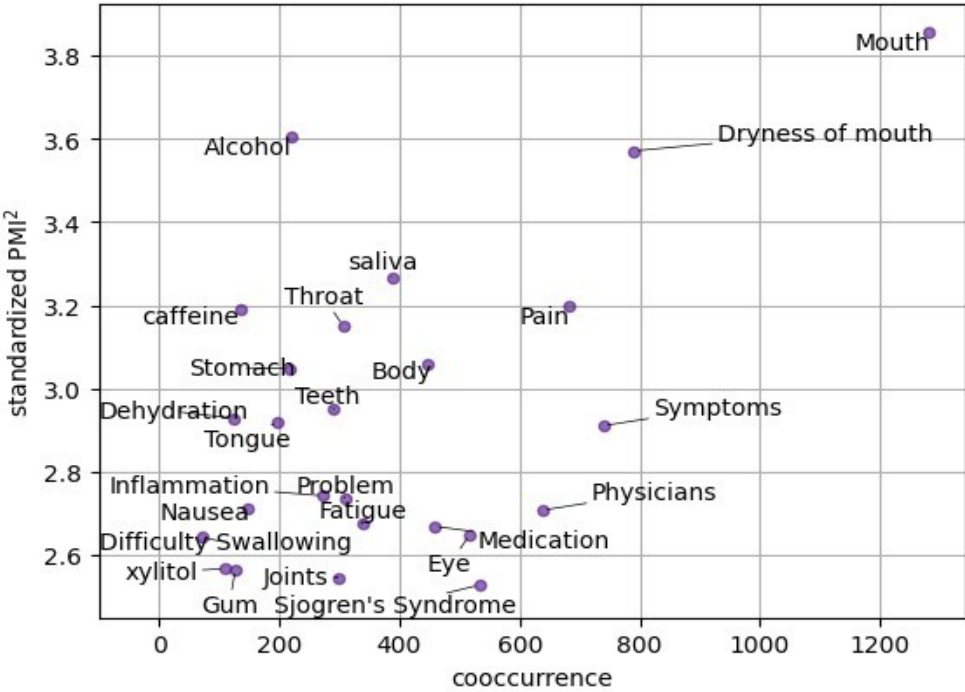**Figure 2: Attributes of Daily Living (ADLs) in Sjögren's disease**

Figure 3: Concept Associations with ADLs: Eating and Drinking

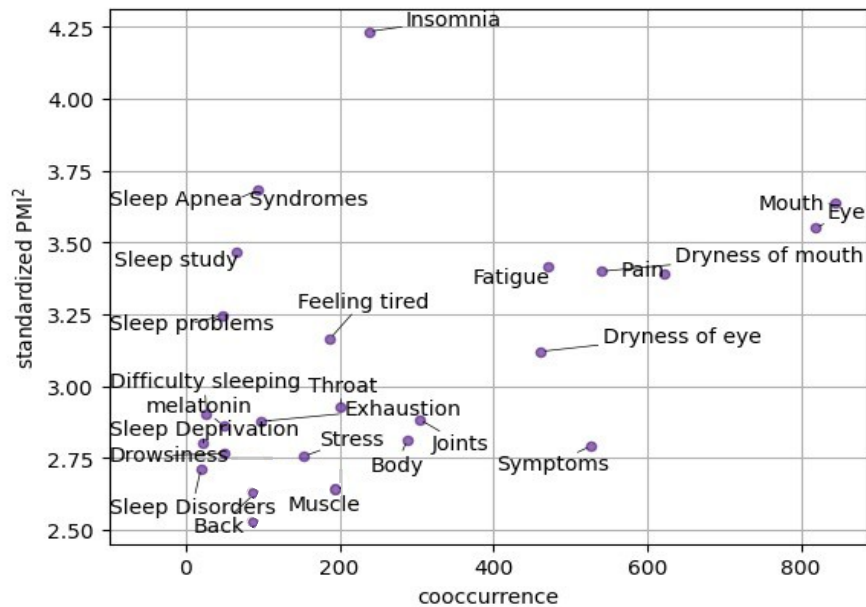## Attributes of Daily Living (ADLs): Overall and Eating and Drinking Discussion

Next, the panelists and audience members discussed the findings. Dr. Baldini shared that, as a doctor, she found this tool and these data valuable because it is a way to improve communications between

patients and doctors. She shared that doctors collect symptoms, but oftentimes don't associate these symptoms with ADLs. This work can help doctors to see what their patients are saying and how they are describing their symptoms so that the doctors can better understand the disease, make new connections between symptoms and ADLs, and ultimately have a better chance of improving ADLs in a patient. One highlighted example is the connection between pain and eating/drinking. To further this point, Julia commented that she wished she had known the impact of eating dairy products on her body since consuming this type of food has led to severe health issues for her. Julia went on to share that in addition to pain, she also experiences dry mouth which requires her to drink ~8L of water a day. One audience member spoke about understanding her pain because she, too, cannot eat or drink anything acidic, alcoholic, or spicy/hot without feeling pain.

Attributes of Daily Living (ADLs) Data: Sleep

Christopher then dove into the ADLs as they pertain to sleep. Key clinical concepts associated with Sleeping in conversations include dryness, pain symptoms, and challenges related to sleep. Non-clinical language associated with conversations include bed, hours, morning, and water. See Figure 4 for additional data.

Figure 4: ADLs and Sleep

Attributes of Daily Living (ADLs): Sleep Discussion

Dr. Baldini felt strongly that looking at conversations around sleep can help doctors understand the patient's ADLs and open up opportunities for new sleep research. Julia expressed that this information will help with anticipating what to look for and will help her doctor identify solutions. Julia explained that as her disease has progressed, sleep isn't just as simple as "going to sleep". Rather, it is a process where she needs to make sure she has her water bottle, lip balm, and eye drops on her nightstand because of the dryness of her eyes and mouth. Julia shared that this can cause her to have anxiety. One audience member shared being with her sister and being asked why she takes so long to get ready for bed. Julia then quipped: "everyone is snoring and I am putting drops in my eyes!" Another participant shared that even when she sleeps well, she is still very tired the rest of the next day which is a concern.

Emotional Impacts

The conversation then focused on the emotional impacts of living with Sjögren's. Christopher highlighted the six primary emotions (*fear*, *happiness*, *anger*, *sadness*, *disgust*, and *surprise*) and their secondary emotions (e.g., 'love' within primary emotion, 'happiness')[3,4] that had been evaluated. *Fear* was most frequent emotion followed by *happiness*. Words most associated with **happiness** posts/comments included: glad (to) hear, thanks, and hope. The words most associated with **fear** included: concerned, symptoms, dryness, years, and pain. Figure 5 displays the emotional impacts.

Figure 5: Emotional Impacts and Sjögren's disease

Emotions in Sjögren's Community: By ADL

Figure 6 provides a view of the six primary emotions and their percentage of mentions in each ADL category. In our high-frequency ADL categories (*Eating & Drinking and Sleeping)* negative emotions (e.g., fear, sadness) represent a larger proportion than positive (e.g., happiness).

Figure 6: Primary Emotions and ADLs
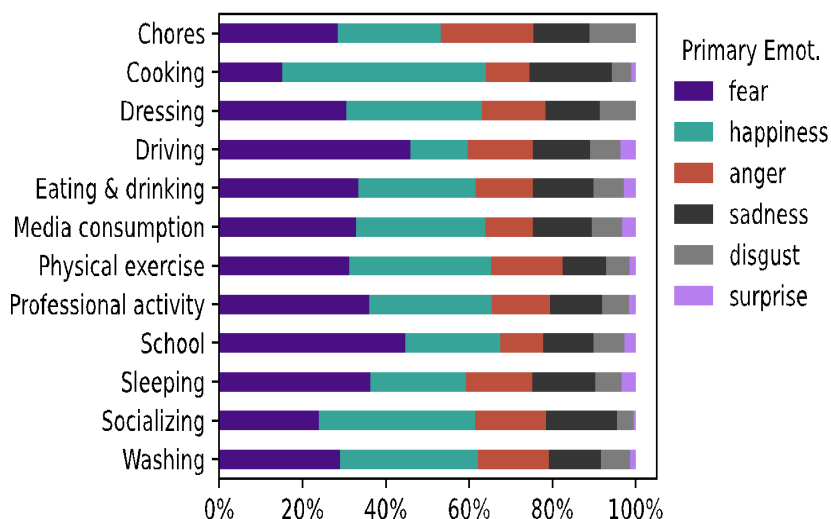
Christopher shared these data and spoke about the prevalence of fear and fear and driving. Dr. Baldini stressed the importance of understanding the emotional weight of questions when developing instruments to best understand the patient experience. Dr. Baldini added: "the fear needs to be weighted and can't be neglected".

One audience member shared thoughts around who is on these social sites; she felt that people go onto these platforms when they don't feel well so that creates fear. She shared an example of people with RA who saw photos of crooked hands; or Sjögren's patients who see people with no teeth and then lymphoma which is scary. In Sweden with Sjögren's patients, one of the community leaders in the audience shared that they realized no one should get a diagnosis and come in and be afraid; so with tips and tricks everyone can support each other versus going online and sharing and creating fear. Another participant reminded the group that there are tips and tricks being shared online and this is helpful. Everyone agreed with an audience member who stated: "How can you live your best life with this disease is what we want to share with [the] patient groups." One person noted that in the United States, there is fear and people being negative and saying 'me too' but there are also people stating things more fully than one would expect them to disclose; this person believes this dynamic is at play because

doctors are not listening or believing them and when things are bad, people spend time trying to be heard.

Julia shared that studying their lived experiences by analyzing social media conversations is a low burden on the community and because it's data this means it can be published and taken more seriously. The previously concerned audience member then shared her opinion that the people speaking are not the people with mild symptoms. Maria then shared a story from a previous community; she spoke of how TREND used social listening data to compile (anonymously) the challenges with a therapy. A survey was fielded where the community members continued to talk about the issues they faced that there were not sharing with their clinicians. All of this research culminated in a letter to the FDA which supported the approval of the new therapy.

Chris reminded the group that fear can mean multiple things; happiness can be coupled with fear such as comments like: "I am grateful for the support because this can be scary." Julia expressed gratitude towards Sjögren's Foundation for its advocacy work and she reiterated that the tips and tricks being shared by the foundation are so valuable as well as when doctors let people know of what worked for others. One person shared that cultural differences will exist too, including access to care, insurance, different forums attract different people and this can create bias. And finally, the President and CEO of Sjögren's Foundation, reminded the audience of the importance of employing a mixed methods approach and remarked that it was a "fantastic tool and everything combined will create a great result."

Conclusion

The Satellite Symposium provided an opportunity to candidly discuss the daily challenges experienced by those living with Sjögren's disease by reviewing patient-driven real-world evidence. The outputs from this event offer a chance to raise awareness about the many implications of these daily burdens (mental, emotional, physical) so healthcare providers, researchers, industry partners, and many other allied stakeholders can address these unmet needs and ease the burden experienced by those living with this condition.

Declarations

Ethical Approval, Consent to Participate and Publish

All panelists provided their written and verbal consent for the contents of the discussions to be collected and transcribed with the purpose of publishing anonymized key insights gathered during the event.

References

1. Sjögren's Foundation Website: https://sjogrens.org/understanding-sjogrens.

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3. Ekman P. Facial expressions of emotion: new findings, new questions. *Psychol Sci* 1992;3:34-8. doi: 10.1111/j.1467-9280.1992.tb00253.

4. Bann EY, Bryson JJ. The conceptualisation of emotion qualia: semantic clustering of emotional tweets. In: Mayor J, Gomez P, editors. Computational Models of Cognitive Processes: World Scientific; 2013. p. 249-63.