

Understanding patient experience through social listening: Impact of pulmonary manifestations on quality of life in patients with Sjögren's disease

Maria Picone¹, Zachary Cline¹, Annie Lau-Kilby², Nishant Gupta³, Christopher DeFelice¹

¹TREND Community, Philadelphia, PA, United States, ²Amgen Inc., Thousand Oaks, CA USA, ³University of Cincinnati, Cincinnati, OH, USA



#P85

Background

Results

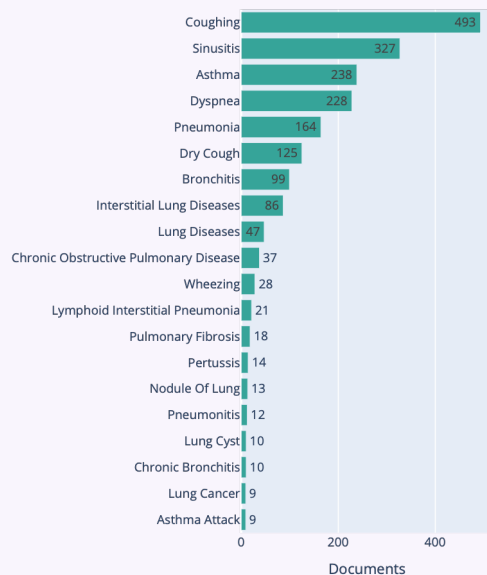
Conclusions

Sjögren's disease primarily affects the exocrine glands, causing dryness symptoms. However, it can also have significant systemic and organ involvement, including pulmonary manifestations. Social media has provided a platform for patients to create community, share their experiences, seek advice, and ask questions. The conversations in these communities present a rich source of insight into the patient experience, which can be tapped by social listening and natural language processing. We applied these methods to better understand the Sjögren's community's experience of pulmonary manifestations, and the impacts of those manifestations on quality of life (QoL).

Methods

110,614 documents (posts/comments) from the r/sjogrens Reddit community, spanning the years 2012-2024, were analyzed. Proprietary models were used to recognize discussion of twelve attributes of daily living (ADLs), extract mentions of clinical concepts, and link the extracted mentions to a lexical knowledge base of medical concepts. Concepts corresponding to pulmonary conditions or symptoms were determined using a combination of the lexical knowledge base's relations and the expertise of a pulmonologist familiar with the topic (NG). The association between discussion of ADLs and pulmonary concepts was measured using squared pointwise mutual information (PMI²) at the paragraph level.

Figure 1: Most Frequently Mentioned Pulmonary Concepts



The most frequently mentioned pulmonary concepts were, in order, *Coughing* (493 documents), *Sinusitis* (327), *Asthma* (238), *Dyspnea* (228), *Pneumonia* (164), *Dry cough* (125), *Bronchitis* (99), and *Interstitial Lung Diseases* (86). For comparison, the most frequently mentioned symptoms were *Pain* (7,669), *Dryness of eye* (6,450), *Dryness of mouth* (5,805), and *Fatigue* (4,428).

Figure 2: Most Frequently Mentioned Symptom/Disease Concepts

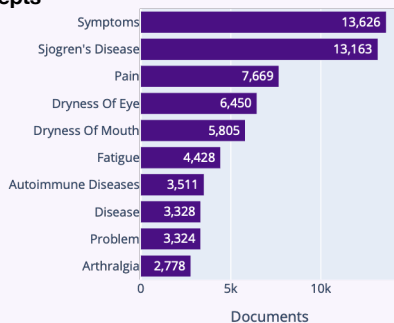
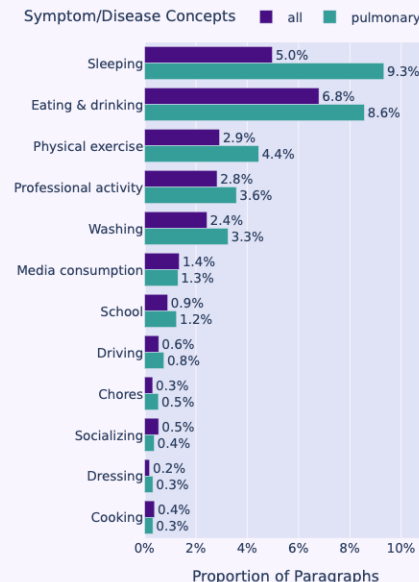
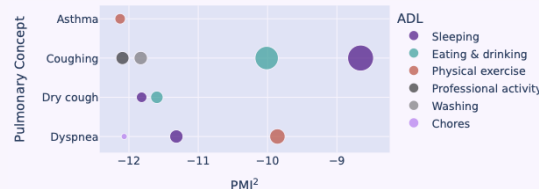


Figure 3: Proportion of Paragraphs Mentioning a Symptom/Disease Concept that also Discuss an ADL, Colored by Which Symptom/Disease Concepts are Included.



Among paragraphs that mention a pulmonary concept, 9.3% discuss the ADL *Sleeping*, compared to a 5.0% baseline among paragraphs that mention any symptom or disease concept. Other ADLs discussed frequently were *Eating & drinking*, *Physical exercise*, and *Professional activity*.

Figure 4: Standardized PMI² and (Co-occurrence Counts) Between Categories and Emotions



Physical exercise–Dyspnea and *Eating & drinking–Coughing* were the next most associated pairs. As measured by PMI², *Sleeping* and *Coughing* were the ADL and pulmonary concept pair that were most highly associated. One paraphrased quotation illustrating this association is, "I haven't had a good night's sleep in a long time due to that unbearable tickle cough."

Pulmonary concepts are mentioned in approximately 5-10% of the instances of the discussion of Sjögren's related symptoms, highlighting the relative importance of pulmonary involvement on the quality of life of people with Sjögren's. The presence of pulmonary symptoms appears to have the highest impact on patients' sleep and ability to exercise. While dyspnea appears to be the primary driver for reduced physical activity, both cough and dyspnea were associated with impaired sleep. These results can help guide clinicians to enquire about the specific symptoms that seem to be driving the quality of life impairment in people with Sjögren's and use that data to guide management.



"If I don't use a numbing lozeng before I eat something acidic or spicy, I end up coughing during the meal."

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Authors: Maria Picone¹, Zachary Cline¹, Annie Lau-Kilby², Nishant Gupta³, Christopher DeFelice¹

Affiliations: ¹TREND Community, Philadelphia, PA, United States, ²Amgen Inc., Rockville, MD, USA, ³University of Cincinnati, Cincinnati, OH, USA

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Rationale:

Sjögren's syndrome primarily affects the exocrine glands, causing dryness symptoms. However, it can also have significant pulmonary manifestations. Social media has provided a platform for patients to create community, share their experiences, seek advice, and ask questions. The conversations in these communities present a rich source of insight into the patient experience, which can be tapped by social listening and natural language processing. We applied these methods to better understand the Sjögren's community's experience of pulmonary manifestations, and the impacts of those manifestations on quality of life (QoL).

Methods:

Proprietary models were used to recognize discussion of twelve attributes of daily living (ADLs), extract mentions of clinical concepts and link the extracted spans to a lexical knowledge base (LKB), from 110,614 documents (posts/comments) on the r/sjogrens Reddit community, spanning the years 2012-2024. Concepts corresponding to pulmonary conditions or symptoms were determined using a combination of the LKB's relations and the expertise of a pulmonologist familiar with the topic (NG). The association between discussion of ADLs and pulmonary concepts was measured using squared pointwise mutual information (PMI²) at the paragraph level.

Results:

The most frequently mentioned pulmonary concepts were "Coughing" (493 documents), "Sinusitis" (327), "Asthma" (238), "Dyspnea" (228), "Pneumonia" (164), "Dry cough" (125), "Bronchitis" (99), and "Interstitial Lung Diseases" (86). For comparison, the most frequently mentioned symptom concepts overall were "Pain" (7,669), "Dryness of eye" (6,450), "Dryness of mouth" (5,805), and "Fatigue" (4,428). Among paragraphs that mention a pulmonary concept, 9.3% discuss the ADL "Sleeping", compared to a 5.0% baseline among paragraphs that mention any symptom or disease concept (Figure). Other ADLs discussed frequently were "Eating & drinking", "Physical exercise", and "Professional activity". The most highly associated ADL-pulmonary concept pairs, as

measured by PMI², were “Sleeping”–“Coughing”, “Physical exercise”–“Dyspnea”, “Eating & drinking”–“Coughing”, and “Sleeping”–“Dyspnea”.

Conclusions:

Pulmonary concepts are mentioned in approximately 5-10% of the instances of the discussion of Sjögren’s related symptoms, highlighting the relative importance of pulmonary involvement on the QoL of patients with Sjögren’s. The presence of pulmonary symptoms appears to have the highest impact on patients’ sleep and ability to exercise. While dyspnea appears to be the primary driver for reduced physical activity, both cough and dyspnea were associated with impaired sleep. These results can help guide clinicians to enquire about the specific symptoms that seem to be driving the QoL impairment in patients with Sjögren’s and use that data to guide management.

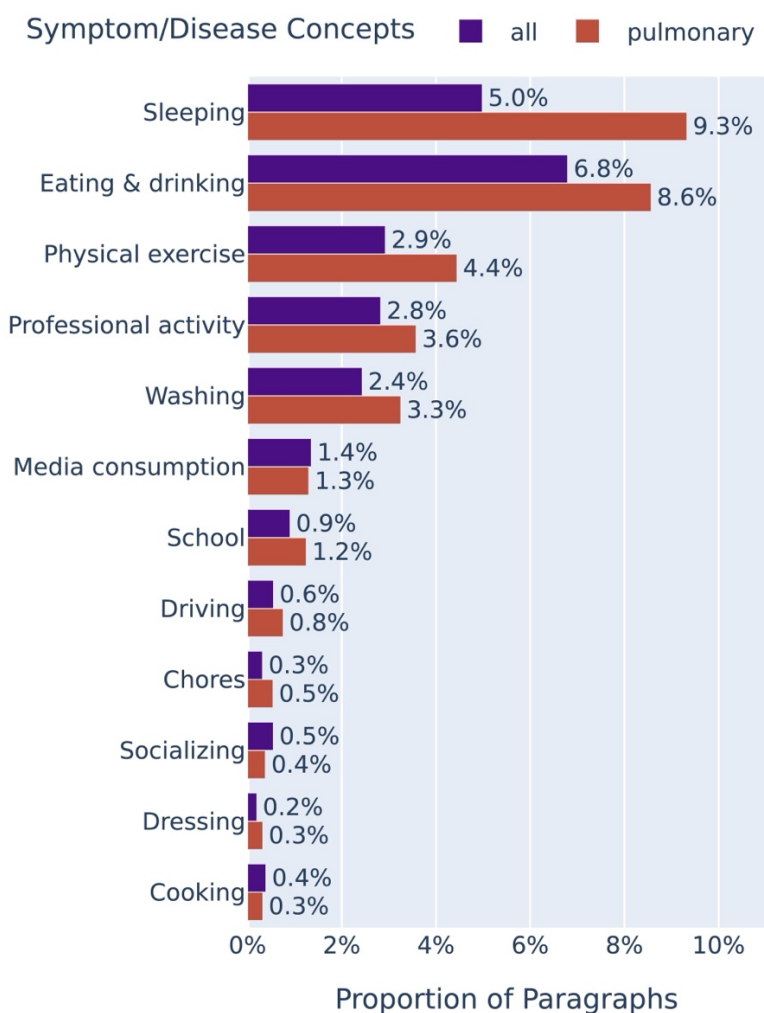


Figure: Frequency of ADL discussion in paragraphs mentioning (a) any symptom/disease concept (b) a pulmonary concept