

The Mental Health Impact of Sexual Dysfunction in Sjögren's Disease: A Social Media Approach to Real-World Evidence

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Background: To obtain a comprehensive understanding of the needs of individuals in a particular community, it is essential to actively listen to and interpret the patient experience. A proprietary artificial intelligence (AI) analytics engine was applied to social media conversations from an online community for those living with Sjögren's disease (SjD). Sjögren's disease is an autoimmune disease characterized by inflammation of exocrine glands, most often presenting with dryness of the eyes and mouth (sicca). Some women with SjD also report vaginal dryness and discomfort.¹ Although individuals with SjD have an increased risk for poor mental health outcomes (e.g., anxiety, depression), the unique role of vaginal dryness and the resulting mental health impact are not well understood.

Objectives: The objective of the current study was to identify specific mental health impacts associated with vaginal dryness in SjD. We also aimed to explore common topics shared by community members discussing these symptoms to understand their impact on daily living.

Methods: Data included the public subreddit r/sjogrens, which contained 3779 users and 41,406 posts/comments from October 2012 to March 2022. The proprietary AI engine used for analysis leverages natural language processing techniques to analyze text-based social media data sources. First, the engine used entity recognition to identify the most frequent clinical findings mentioned across all posts/comments. Anxiety and depression were among the most frequently mentioned mental health symptoms in conversations. The engine then extracted the most frequent dryness-related symptoms from the data, which included dry eyes, mouth, throat, and vagina. We then fit 2 logistic regression models where dryness mentions (e.g., 'dry eyes', 'vaginal dryness') predicted mentions of 'anxiety' (model 1) or 'depression' (model 2). For our exploratory analysis, we used a guided topic modeling approach to extract conversations about vaginal dryness. This involved providing a list of seed terms (e.g., 'vaginal dryness', 'vaginal pain') around which the model could converge in identifying word clusters.

Results: In total, topic modeling revealed 563 posts/comments from 345 users regarding vaginal dryness. "Vaginal dryness" was a significant predictor ($P < .001$) in both regression models, with adjusted

odds ratios between 2.2 and 2.8 (95% CI, 1.9-4.2), suggesting that users mentioning vaginal dryness are 2 to 3 times more likely to mention a negative mental health outcome. Our guided topic modeling approach yielded 3 subtopics within the primary vaginal dryness topic. These included conversational topics about 'sexual discomfort', 'lubrication', and 'marital impacts' across 141 users.

Conclusions: These findings suggest that vaginal dryness and sexual dysfunction in SjD are prevalent and associated with specific negative mental health symptoms. Potential daily impacts were illuminated when topic modeling showed conversations centered on physical pain during sex (i.e., dyspareunia) and adverse impacts on marriage/relationships. This social listening approach also revealed management techniques (e.g., lubrication) for individuals experiencing sexual discomfort. Interrogating social media conversations can be invaluable to elucidating patient-reported mental health challenges in rare diseases. It remains unknown how these conversational references to negative mental health symptoms directly translate to specific mental health diagnoses (e.g., anxiety disorder) or treatment challenges in patients with SjD. Future work should comprehensively explore these symptoms so clinicians, caregivers, and patients can better understand and manage mental health in the context of chronic disease.

References:

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