Understanding Pain and Its Impact on Mental Health in Fabry Disease Using Real-World Evidence From Social Media

Maria Picone, Maurice Flurie, Enming Zhang, Monica Converse, Rachelle Cook, Wei Li, E. Robert Wassman, Christopher DeFelice | TREND Community, Philadelphia, Pennsylvania, United States
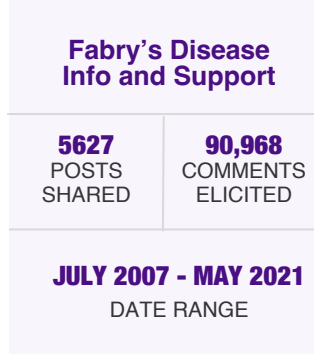
INTRODUCTION

Individuals living with Fabry disease (FD) are at an increased risk for poor mental health (MH) outcomes[1]; however, the relationship between MH and other disease-specific challenges is not well defined. Pain crises and the frequent pain symptoms associated with FD can negatively affect health-related quality of life in persons living with this disease.[2] The aim of the current study was to explore the MH impacts of FD and to explore symptoms in pain conversations to gather real-world evidence from social media.
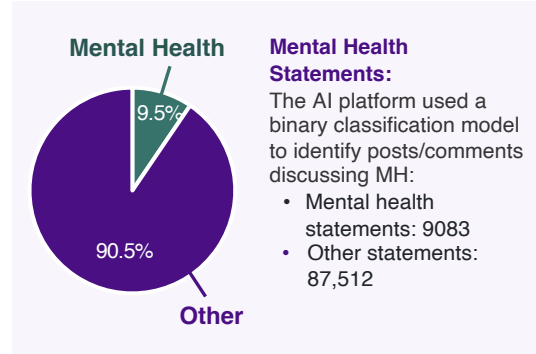
METHODS

An artificial intelligence (AI) platform leveraged a variety of natural language processing techniques to identify prevalent terms, concepts, and topics across a private Facebook group, Fabry's Disease Info and Support, from 2007 to 2021. Using machine learning and a custom analytics engine, we developed a rapid, customized social listening methodology to analyze large amounts of social media conversation data from groups united around particular diseases.
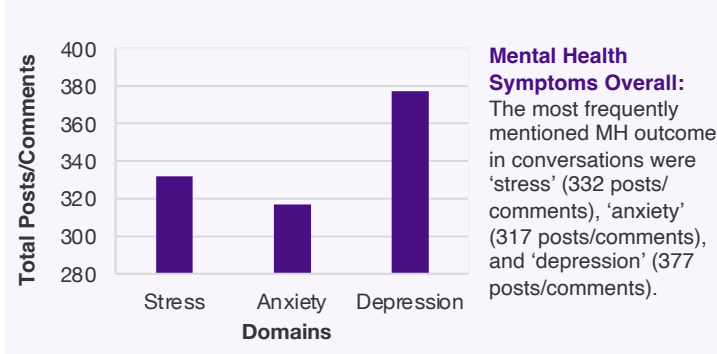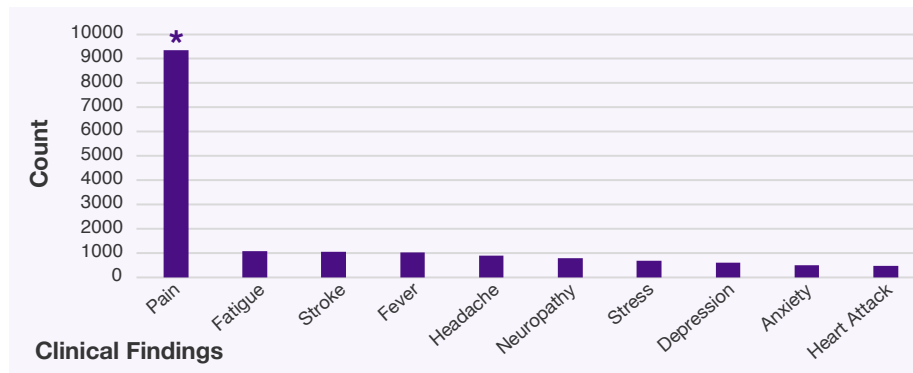
RESULTS

DATA SOURCE TOTALS

Fabry's Disease Info and Support

5627	90,968
POSTS SHARED	COMMENTS ELICITED

JULY 2007 - MAY 2021
DATE RANGE

PERCENTAGE OF CONVERSATIONS

Mental Health 9.5%
Other 90.5%

Mental Health Statements: The AI platform used a binary classification model to identify posts/comments discussing MH:
- Mental health statements: 9083
- Other statements: 87,512

MENTAL HEALTH DOMAINS

Mental Health Symptoms Overall: The most frequently mentioned MH outcomes in conversations were 'stress' (332 posts/comments), 'anxiety' (317 posts/comments), and 'depression' (377 posts/comments).

MENTIONS

Top Symptoms Overall: The platform then extracted the 10 most frequent clinical findings from the data (e.g., 'pain', 'stroke').

Predicting Mental Health: We then fit 3 logistic regression models, with 1 for each MH outcome. Symptom mention predicted an MH outcome mention (e.g., stress mentioned or not). "Pain" was a significant predictor ($P < .001$) in all 3 models, with all adjusted odds ratios between 2.3 and 3.3 (95% CI, 2.03-3.9), suggesting that posts/comments mentioning "pain" are approximately 2 to 3 times more likely to mention a mental health outcome.

*Term use was significantly ($P < .001$) associated with mentions of depression, anxiety, and stress.

TOPIC: CBD

108 Posts/Comments
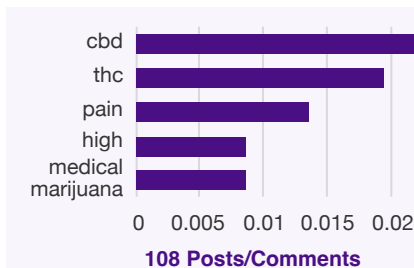
TOPIC: NARCOTICS

60 Posts/Comments
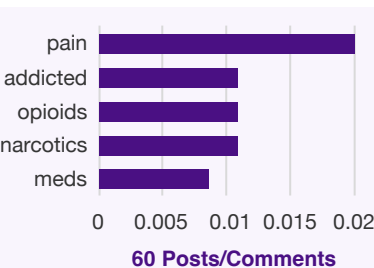
Topic Model: We performed topic modeling on all MH discussions to understand prevalent themes across conversations. The topic model is empowered with the state-of-art transformer language embedding models combined with dimension reduction and clustering algorithms. The model revealed several pain-related topics, 2 of which are related to management (e.g., CBD, narcotics).

CONCLUSIONS

Our analyses evaluated the possible impact on the MH of FD and the possible symptoms that may heighten these impacts.
- These results demonstrate the connection between the physical symptoms of FD and negative MH impacts.
- Specifically in the data, we see the strongest relationship between the symptom of *pain* and MH.
- In addition, we see CBD and THC as management approaches of how individuals in this space may be treating their *pain*.
- Future work should comprehensively explore these relationships so clinicians, caregivers, and patients can better understand and manage MH in the context of chronic disease.
- This approach can be used with other diseases to inform clinicians of patients' experiences to fully address the needs of a community.

Abstract

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It is imperative to understand the patient experience to fully address individual community members' needs. A proprietary artificial intelligence (AI) analytics engine was used to identify prevalent concepts in social media data using natural language processing (NLP). The engine was applied to an online community of caregivers and patients discussing their experiences with Fabry disease. Individuals living with Fabry disease are at an increased risk for poor mental health outcomes; however, the relationship between mental health and other disease-specific challenges is not well defined. The objective of the current study was to characterize mental health impacts of Fabry disease and explore symptoms that might exacerbate these impacts. Data included those from a private Facebook group, Fabry's Disease Info and Support, which contained 96,595 posts/comments from 2007 to 2021. The AI platform used a classification model to identify posts/comments discussing mental health (9083 posts/comments [9.4% of total]). The most frequent mental health outcomes in conversations were stress (383 posts/comments), anxiety (256 posts/comments), and depression (249 posts/comments). The platform then extracted the 10 most frequent symptoms from the data (e.g., pain, stroke). We then fit 3 logistic regression models; 1 for each mental health outcome with symptom mentions predicted a mental health outcome mention (e.g., stress mentioned or not). "Pain" was a significant predictor ($P < .001$) in all 3 models, with all adjusted odds ratios between 2.3 and 3.3 (95% CIs [2.03-3.9]); this suggests that post/comments mentioning "pain" are approximately 2 to 3 times more likely to mention a mental health outcome. Topic modeling then revealed 'pain' topics related to experiences (e.g., neuropathy) and management (e.g., CBD). These results demonstrate the relationship between physical symptoms of a disease and negative mental health impacts. Future work ought to comprehensively explore these relationships so clinicians, caregivers, and patients can better understand and manage mental health in the context of chronic disease.

Disclosures and Limitations

The data are limited to those obtained from individuals with the means, interest, and ability to participate. Honest representation by participants of their diagnosis, illness, symptoms, and disease progression is an assumption. The analysis does not account for the context in which a term is mentioned; for example, the mention of a symptom might be in the context of its absence. The researchers who prepared this report are not doctors, are not providing medical advice, and are reporting only what was mentioned in the online conversations.

Acknowledgments

References

1. Müller MJ. Neuropsychiatric and psychosocial aspects of Fabry disease. In: Mehta A, Beck M, Sunder-Plassmann G, eds. *Fabry Disease: Perspectives From 5 Years of FOS*. Oxford PharmaGenesis; 2006.

2. Körver S, Geurtsen GJ, Hollak CEM, et al. Depressive symptoms in Fabry disease: the importance of coping, subjective health perception and pain. *Orphanet J Rare Dis*. 2020;15(1):28. doi:10.1186/s13023-020-1307-y

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