

An insight into the patient's perspective of ulcerative colitis flares via analysis of online public forum posts: key triggers and symptoms of flares

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Introduction

Relapse of disease, or flare, in patients with UC can have a significantly negative physical and psychological impact on patients' lives, affecting work and life choices.¹ Preventing flares is a key goal of any UC treatment. Predicting flares in patients with UC remains challenging, with limited analyses of themes in patient conversations related to flare onset

Objective

To identify the most frequent patient-discussed themes and topics, and patient-reported triggers and symptoms of UC flares, which could highlight potential interventions to improve outcomes, using AI text analytics and natural language processing of online data sets

Methods

Online posts written by patients with UC on eight public forums in six countries between January 01, 2019, and February 14, 2021, were reviewed using Netbase Quid™ AI text analytics and natural language-processing software

Forums included HealingWell (USA), Crohn's Forum (USA), Patient (UK), Educainflamatoria (Spain), Crohn Club Forum (Italy), Deutsche Morbus Crohn/Colitis ulcerosa Vereinigung e.V. (Germany), Afa Crohn RCH France (France), and Carenity (USA, UK, Spain, Italy, Germany, and France)

Flare-related posts, including pre- and post-flare posts from the same patients, were identified by keywords such as flare, attack, remission, relapse, inflammation, symptoms, cramps, and bloody stool

Once identified, all flare-related posts were analyzed and mapped semantically to uncover the most prevalent conversational themes and topics (subsets of themes)

Each post was represented by a node, and topics/themes by clusters of nodes. Connections represented similar language used across the posts. Centrally located nodes represented core concepts, while peripheral clusters represented niche concepts not representative of the larger landscape

Topics were also ranked using five quantitative metrics:

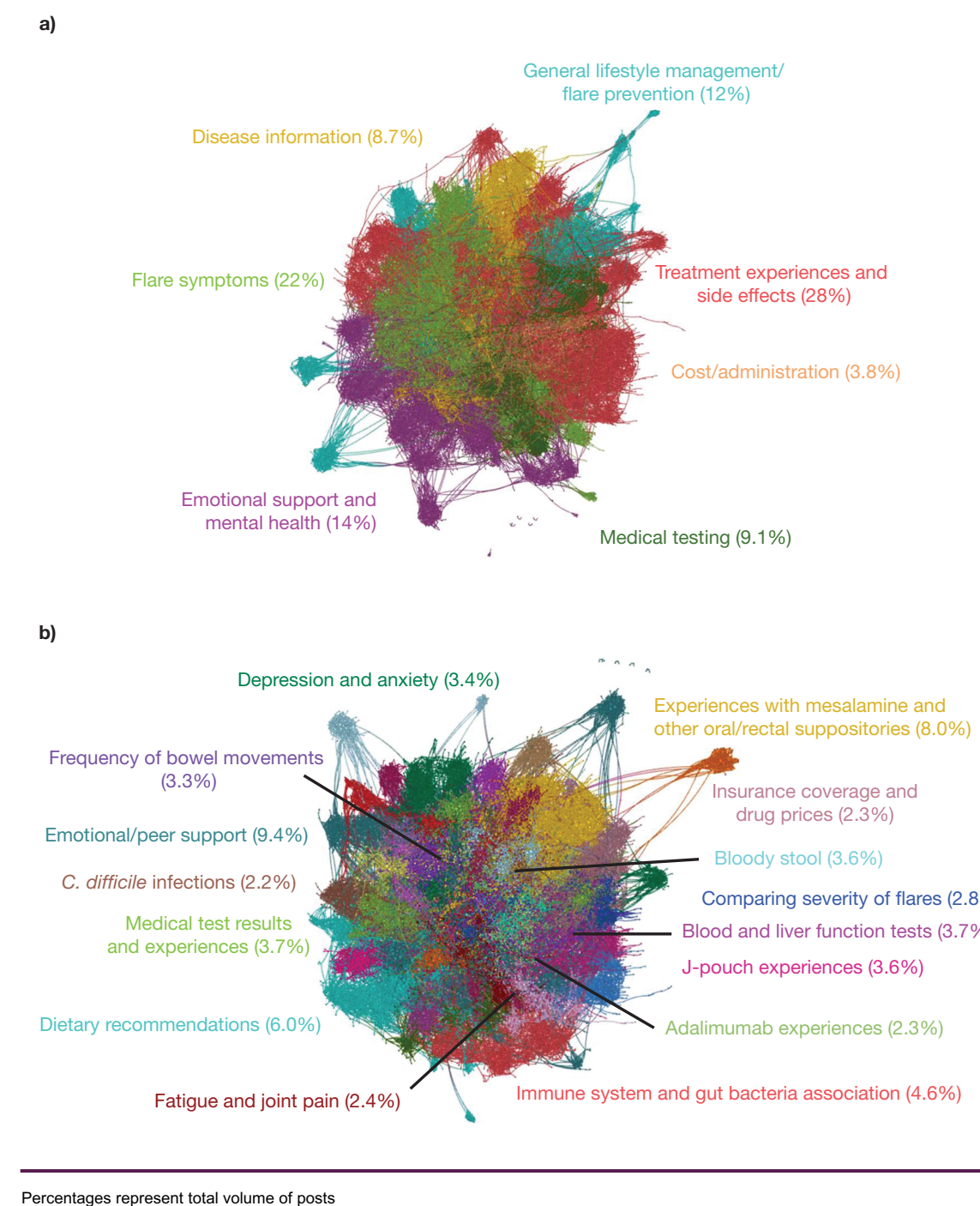
- Total volume of posts within a topic (volume; 40%)
- General attitude of words within a post of a topic (negative sentiment; 15%)
- Degree to which language within a topic overlapped other topics (betweenness centrality; 15%)
- Number of unique authors per topic (unique authors; 20%)
- Average date of the posts within a topic (recency; 10%)

Results

Patient perceptions of flares – discussion themes and topics

- Of >27,000 patient posts in the selected online patient forums on UC, 12,900 were identified as flare-related
- The most frequently discussed theme (Figure 1a) and topic (Figure 1b) in flare-related posts were treatment experiences and side effects, and emotional/peer support, respectively
- In flare-related posts, eight of the top 12 ranked topics had moderate to very high negative sentiment scores (Figure 2)

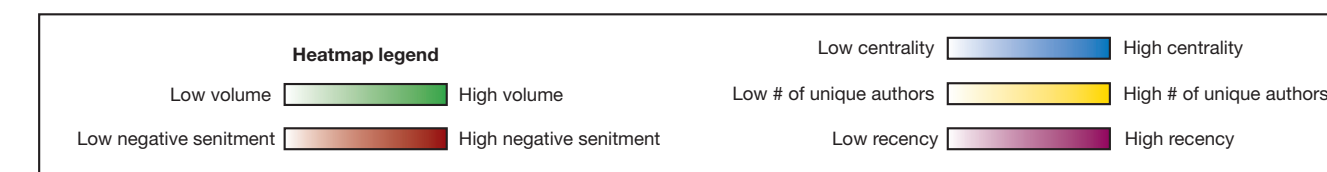
Figure 1. The most frequently discussed flare-related a) themes and b) topics based on total volume of posts



Percentages represent total volume of posts

Figure 2. The top 12 ranked flare-related topics discussed by patients with UC based on five quantitative metrics

Discussion topic (in decreasing order of rank)	Total volume	Negative sentiment	Betweenness centrality	Unique authors	Recency
1 Emotional/peer support	High	Low	Moderate	High	Low
2 Experience with mesalamine (oral and rectal suppositories)	High	Moderate	Moderate	Moderate	Moderate
3 Dietary recommendations	High	Moderate	Low	Moderate	High
4 Immune system and gut bacteria association	Moderate	Moderate	Low	Low	Low
5 Bloody stool	Moderate	Moderate	Moderate	Low	Low
6 Depression and anxiety	Moderate	Very high	Low	Very low	Very low
7 Comparing severity of flares	Low	Low	High	Low	Moderate
8 Fatigue and joint pain	Low	Very high	Moderate	Very low	Moderate
9 Frequency of bowel movements	Low	Moderate	Moderate	Low	Very low
10 Blood and liver function tests	Moderate	Low	Very low	Low	Low
11 Medical test results and experiences	Moderate	Very low	Low	Low	Low
12 Severe abdominal pain	Very low	High	High	Very low	Low



Limitations

- Limitations of this study include its subjective nature — data were taken from the patients' perspectives only, with no objective measure of whether patients were experiencing flares according to standard clinical assessments
- Confirmation that posts were made by patients with UC was not obtained
- The lack of longitudinal data is a further limitation; said data could be useful in elucidating whether there were any patterns in the order, length, and/or severity of symptoms
- These discussions were made by patients who perceived themselves to be undergoing or recovering from a flare; therefore, these data do not provide estimations of the perceptions of the general population of patients with UC, including those with mild disease or in long-term remission
- The sample is also biased towards patients who are comfortable sharing their experiences on online public forums, who may not be representative of all patients with UC

Conclusions

- These results suggest that patients posting in online forums frequently discuss negative aspects of UC
- Frequently discussed patient-perceived triggers and/or symptoms of UC flares, such as diet, and stress and anxiety, are not always captured using traditional clinical disease activity measures^{2,3}
- The results of this analysis suggest that physicians should consider a more holistic approach to UC monitoring and management

Patient-perceived triggers and symptoms of UC flares

- Stress and/or anxiety were frequently identified as both triggers for, and symptoms of, flares (Table)
- Patients often traced their symptoms back to a stressful event, such as a divorce, death, or work/school issue
- Initial symptoms of flares (eg, blood in stool/passing blood, diarrhea and loose stool, stool frequency) were often not distinguished from other symptoms

Table. Based on total volume of posts, frequently discussed flare triggers include stress and anxiety, and diet, with blood in the stool being the most frequently discussed flare indicator

Order	Flare triggers (% of posts) N=1,161	Initial flare symptoms (% of posts) N=645
1	Stress and anxiety (38%)	Blood in stool/passing blood (58%)
2	Diet (28%)	Diarrhea and loose stool (19%)
3	Smoking cessation (9%)	Stool frequency (19%)
4	Antibiotics (9%)	Mucus in stool/passing mucus (17%)
5	Bacterial or viral infection (7%) ^a	Pain and cramping (14%)
6	NSAID usage (6%)	Fatigue (7%)

Flare triggers and initial symptoms were identified and ordered by the total volume of posts

^aPatients who identified bacterial/viral infections as a flare trigger had uniquely low confidence and were unsure about infections being the cause of their triggers

Abbreviations

AI, artificial intelligence; C, difficile; Clostridium difficile; NSAID, non-steroidal anti-inflammatory drug; UC, ulcerative colitis.

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Acknowledgments

This study was sponsored by Pfizer. The authors would like to acknowledge the contribution of Erin Kim, a former employee of Netbase Quid™, who aided in the analysis of the data. Medical writing support, under the direction of the authors, was provided by Sarah Leneghan, PhD, CMC Connect, a division of IPG Health Medical Communications, and was funded by Pfizer, New York, NY, USA, in accordance with Good Publication Practice (GPP 2022) guidelines.⁴

Disclosure of interests

DT Rubin has received consultancy fees from Pfizer Inc. J Torres has been an advisory board member for Pfizer Inc. I Dotan has received consulting fees, grant/research support, and honorarium from Pfizer Inc. LT Xu is an employee of Netbase Quid™, which was a paid contractor to Pfizer Inc in connection with the development of this manuscript and related analyses. I Modesto, JC Woolcott, and S Gardiner are employees and stockholders of Pfizer Inc. BE Sands has received personal fees and nonfinancial support from Pfizer Inc.