Social Listening in Gout: Impact of Proactive vs. Reactive Management on Self-Reported Emotional States

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ABSTRACT

Introduction: This study aimed to characterize patient-reported outcomes from social media conversations in the gout community. The impact of management strategy differences on the community's emotional states was explored.

Methods: We analyzed two social media sources using a variety of natural language processing techniques. We isolated conversations with a high probability of discussing disease management (score > 0.99). These conversations were stratified by management type: proactive or reactive. The polarity (positivity/negativity) of language and emotions conveyed in statements shared by community members was assessed by management type.

Results: Among the statements related to management, reactive management (e.g., urgent care) was mentioned in 0.5% of statements, and proactive management (e.g., primary care) was mentioned in 0.6% of statements. Reactive management statements had a significantly larger proportion of negative words (59%) than did proactive management statements (44%); "fear" occurred more frequently with reactive statements, whereas "trust" predominated in proactive statements. Allopurinol was the most common medication in proactive management statements, whereas reactive management had significantly higher counts of prednisone/steroid mentions.

Conclusions: A unique aspect of examining gout-related social media conversations is the ability to better understand the intersection of clinical management and emotional impacts in the gout community. The effect of social media statements was significantly stratified by management type for gout community members, where proactive management statements were characterized by more positive language than reactive management statements. These results suggest that proactive disease management may

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result in more positive mental and emotional experiences in patients with gout.

Keywords: Disease management; Emotions; Gout; Mental health; Social listening

Key Summary Points

Why carry out this study?

Literature in recent years has highlighted the negative impacts of gout on mental health and quality of life. Yet, the specific factors that alter mental and emotional health are not fully understood.

Social media listening was used to explore differences in gout community perspectives on disease management.

What was learned from the study?

Gout community members tended to use more positive language when describing proactive experiences (e.g., treating underlying disease causes) than when describing reactive experiences (e.g., treating symptoms as they arise) with gout management.

These findings reveal that patients may experience reduced mental and emotional distress when gout is monitored and managed using a proactive, long-term approach and suggest that patients may benefit from education on adherence to such an approach.

INTRODUCTION

Gout is a chronic disease affecting more than 9.2 million adults, or approximately 4% of the population in the United States alone [1]. Gout is caused by hyperuricemia with resultant monosodium urate crystal deposition and development of tophi in peripheral joints and soft tissues [2]. This disease has substantial impacts on physical function, with persons living with gout experiencing severe pain and distress from arthritic flares [2], multiple types of disabilities [3, 4], and increased occurrence of systemic comorbidities, including hypertension [5–7], chronic kidney disease [5, 7–9], and cardiovascular disease [5, 8, 10, 11]. Additional impacts include decreased work productivity [12], increased health care costs [12], and decreased quality of life (QoL) [13–15]. The physical distress of gout particularly affects QoL, especially with increased frequency of attacks and intensity of pain during and between attacks [14, 15]. More recently, the association between gout and negative mental health (e.g., anxiety, depression) and its effects on QoL for patients has come to light. A recent meta-analysis identified associations between depression and anxiety with gout, with a call for more research focusing on mental health outcomes in patients following a gout diagnosis [16].

Growing evidence strongly supports a genetic component in hyperuricemia and gout pathogenesis [17–21], but gout is still predominantly viewed as a "lifestyle" disease [22, 23]. The perception that poor dietary and lifestyle choices are the primary causes of gout deepens the social stigma surrounding the disease and heavily contributes to poor medical management and negative patient experiences in the health care setting [22–24], as well as overall reduced QoL [13, 15, 25]. A recent study [22] compared rheumatologists' perceptions of disease contributors in patients with gout vs. rheumatoid arthritis (RA). Rheumatologists perceived patient behavior, diet, body mass index, and treatment nonadherence to be significantly greater contributing factors in gout management than in RA management. Rheumatologists perceived their patients with gout as being largely responsible for their condition, less compliant with medications, and less likely to benefit from therapies. Further, rheumatologists did not think differently about their patients with controlled and uncontrolled gout, suggesting a gout-specific bias that is independent of disease severity [22].

Pain is the most predominant and severely debilitating gout symptom, and it has been shown that patient perception of greater pain

severity during and between flares is directly associated with increased stigma; it is thus patients who are the most disabled by gout-related pain who are likely to experience greater stigma and subsequent impact on their psychological well-being [24, 26]. Therapies exist that can mitigate painful flares and the resultant mental and emotional impacts; however, various factors can reduce patient adherence to interventions.

Maintaining serum urate levels below 6 mg/dl reduces the occurrence of acute gout flares. Although oral urate-lowering therapies (ULTs) are effective in most gout cases, they are widely underdosed due to a variety of factors. At the patient level, poor compliance can result from shame around having gout and from inadequate education surrounding the cause of gout [22–24]. At the provider level, physicians are not always consistent in their adherence to current guidelines and management approaches [27, 28], particularly with regard to adjustments to interventions when treatment goals are not met (i.e., clinical inertia) [29, 30]. This undertreatment of gout can lead to uncontrolled disease that is refractory to oral ULTs. As a result, patients with gout often seek ambulatory facilities when in pain with flares, which may cause additional negative emotional responses and dissatisfaction with their care.

Proactive management refers to outpatient-delivered care aimed at addressing the underlying cause of a disease to reduce or fully eliminate the need for symptomatic management in the context of a long-term, preventative treatment plan. In contrast, *reactive* management refers to urgent or emergency care in response to concerning/bothersome symptoms after they present. Suboptimal management of gout leads to both emotional and physical distress [14–16].

The objective of the current study was to characterize aspects of the gout experience, as discussed in posts and comments on social media, which might reveal different emotional and mental states. Specifically, we sought to understand how different approaches to gout management (i.e., reactive vs. proactive management) could facilitate different mental and emotional health outcomes.

Listening to, understanding, and interpreting the patient experience are essential aspects of effectively addressing the needs of individuals within a particular community. In recent years, social media platforms dedicated to specific disease communities have offered an outlet for those living with a particular condition to seek out resources and express their personal experiences. Social media listening (SML) has been used to analyze these real-world data to amplify patient voices and understand the impact of the disease on their daily lives [31]. Previous SML studies have offered insights into various aspects of the disease experience, including the diagnostic process, treatment perceptions, and impacts on QoL [31–34], which are not easily captured using traditional approaches. Natural language processing (NLP) is a subfield of artificial intelligence (AI) focused on understanding human language. Here, we employed an NLP analytics engine to identify prevalent terms and concepts in social media data. A priority in selecting social media communities for this study was capturing a large and diverse range of perspectives. To this end, two active social media communities were selected from two of the largest social media networks used today: Facebook and Reddit. Both outlets are used by billions of people from around the world, with millions of groups dedicated to specific topics (these topic-centered communities are called *Facebook groups* and *subreddits*, respectively). The engine was applied to self-reported Facebook and Reddit conversations on gout to hear about and report experiences directly from patients with gout and their communities.

METHODS

Overview

The goal of the current study was to compare general sentiment and emotional language associated with reactive vs. proactive management of gout. A proprietary NLP engine and open-source methodologies were applied to self-reported social media posts on gout to directly examine the experiences of patients with gout

and those of their communities. This methodology identifies prevalent concepts and terms using NLP [35].

Data Sources

Data were obtained from two social media sources: a private Facebook group, The Gout Support Group of America (13,860 members), which contained 12,986 posts/comments gathered from 2021 to 2022; and a public subreddit, r/gout (9416 members), which included 107,231 submissions/replies over more than 10 years (2011–2022). More than 120,000 total posts, comments, submissions, and replies were included in the analyses.

Data Processing

All social media statements were submitted to a proprietary machine learning engine designed to identify statements discussing disease management as well as the most frequently used terms and overarching concepts (e.g., clinical findings, medications, practitioners, health care settings), based on the number of conversations surrounding each concept. This engine leverages neural classifiers trained on social media posts and comments annotated with whether individual statements (i.e., sentences) referenced disease management. Each statement is assigned a score between 0 and 1, with 1 representing the highest possible probability that a statement discusses management. Conversations with a high probability of discussing management were extracted to identify prevalent topics for gout management. A cutoff score of 0.99 was implemented to ensure that the included statements had a high probability of pertaining to disease management.

Disease management statements were then subject to term-based filtering using the Unified Medical Language System meta-thesaurus [36] to isolate statements related to reactive or proactive management. Statements were identified by filtering for English meta-thesaurus concepts associated with reactive (e.g., "walk-in clinic", "urgent care") and proactive (e.g.,

"primary health care", "primary care provider") sites of care and health care professionals.

Sentiment Measures

Sentiment—a measure of how emotionally positive or negative a body of text is—was measured via continuous and discrete outcomes. Continuous sentiment, or polarity, was evaluated for all statements in reactive management and proactive management groups. Polarity refers to how positive or negative language tends to be in any given text (e.g., positive: "I liked the food"; negative: "service was terrible"). Using TextBlob, a Python package used to process and analyze text data [37], all statements were scored from -1 (most negative) to $+1$ (most positive) to evaluate language polarity by management type. TextBlob relies on a lexicon-based approach to tag word-, sentence-, and paragraph-level text with a continuous sentiment score. This approach provides a score based on all words in a sample of text, which provides a general measure of sentiment for the entire sample and reduces the impact of individual words in scoring. Discrete sentiment was assessed to characterize the proportion of positive and negative words, as well as other emotional affects (e.g., "anger", "anticipation", "disgust", "fear", "joy", "sadness", "surprise", "trust") by management type. Analyses employed a bag-of-words approach, which involved extracting relevant text features (e.g., open class words: nouns, adjectives, verbs) and removing uninformative text, such as function words (e.g., "the", "is"), punctuation, and single-letter words. This word-level approach was implemented for a focused analysis on individual words that may be driving conversation by management type. Words were assigned to emotion-based categories using the NRCLex database, a database of more than 27,000 words from the National Research Council Canada and NLTK WordNet Synonyms [38]. A custom filter was then applied to remove word affects that artificially impact medical-based social media text, such as "urgent" in "urgent care" and "care" in "primary care doctor."

Statistical Analysis

Polarities were compared between management types using a Welch's two-sample t test with effect size determined by Cohen's d. Discrete sentiment was compared between management types using a Pearson χ^2 test. Subsequent comparisons of proportions by group (e.g., emotion categories, substances) used a Pearson χ^2 test with Yate continuity correction. Post hoc analysis implemented Bonferroni correction for multiple comparisons. All statistical analyses were implemented in R [39]. Statistical significance was defined as $P < 0.05$.

This study was conducted with an exemption granted under 45 CFR § 46.104(d)(2) by the Western Institutional Review Board. The data in this study come from both publicly (Reddit) and privately (Facebook) accessible sources. TREND Community has established trusted partnerships with specific Facebook groups that have graciously granted TREND Community access to their data, which are essential for the research we are presenting aimed at enhancing public understanding of the subject. This collaborative agreement entails the establishment of formal procedures wherein TREND Community is entrusted with the responsibility of ensuring data stewardship, which includes incorporating privacy safeguards. It is important to note that there was no retention of any data that include private usernames or unique identifiers regarding the private Facebook group. Deidentification measures were employed prior to data analysis. Furthermore, this study does not present any individual patient data that would necessitate consent. This study was performed in accordance with the Helsinki Declaration of 1964 and its later amendments.

RESULTS

The NLP engine revealed prevalent concepts including sites of management and treatments (e.g., allopurinol). Approximately 25% of all statements had a high probability of discussing management. Out of all management-related statements, approximately 1 in 200 (0.5%)

referenced reactive management, and 1 in 150 (0.6%) referenced proactive management. Specifically, these filtering procedures identified 520 statements from 470 posts for reactive management and 654 statements from 586 posts for proactive management.

Polarity by Management Type

We numerically evaluated the general sentiment of language by management type for all statements in the reactive management and proactive management groups. Figure 1 shows the mean polarities for reactive and proactive management statements. A Welch's two-sample t test indicated significant differences in polarity [$t(995.3) = 11.36$, $P < 0.001$, $d = -0.69$]. Proactive management statements had a significantly more positive mean polarity than did reactive management statements (mean [SD], 0.19 [0.21] vs. 0.03 [0.26], respectively; $P < 0.001$).

Emotional Contrasts by Management Type

To better understand the language associated with each management type and the emotional affect, we examined the proportions of positive vs. negative words by management type. Figure 2 shows the positive-to-negative word proportions for proactive vs. reactive management. Pearson χ^2 test revealed significant differences in positive vs. negative word counts between management types ($\chi^2 = 33.0$, $df = 1$, $P < 0.001$). Reactive care statements had a
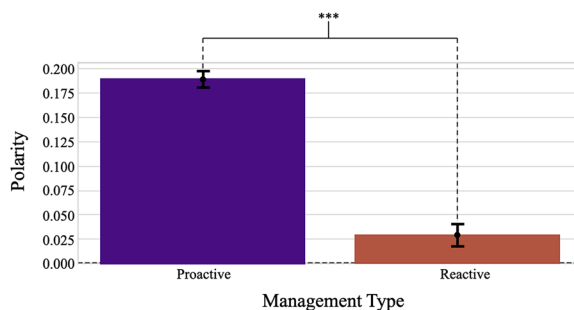
Fig. 1 Mean polarity scores of proactive and reactive management statements. *Error bars* represent SEM. ***$P < .001$ (Welch's two-sample t test)

significantly larger proportion of negative words than proactive care statements (59 vs. 44%, respectively).

Figure 3 and Table 1 show word counts and proportions per emotional state category. Pearson χ^2 test with Yate's correction for continuity showed significant differences in emotion category counts between management types ($\chi^2 = 95.9$, $df = 7$, $P < 0.001$). Proactive statements were higher in generally positive categories ("trust" and "joy"), whereas reactive statements included higher negative categories ("anger", "fear", and "sadness"). Top "trust" words in proactive care included "specialist", "finally", and "advise". Top "fear" words in reactive care included "pain", "bad", and "attack". Top "sadness" words in reactive care included "pain", "shot", and "worse".

Medication Contrasts by Management Type

We evaluated the most prevalent medications by management type and compared raw counts for the top 5 medication entities in each group. Pearson χ^2 test indicated significant differences in counts between management types ($\chi^2 = 73.3$, $df = 4$, $P < 0.001$). Medication entities were significantly different between proactive and reactive management statements, with "allopurinol" appearing significantly more often in proactive management statements and "prednisone/steroids" appearing more often in reactive statements (both $P < 0.001$; Table 2, Fig. 4).
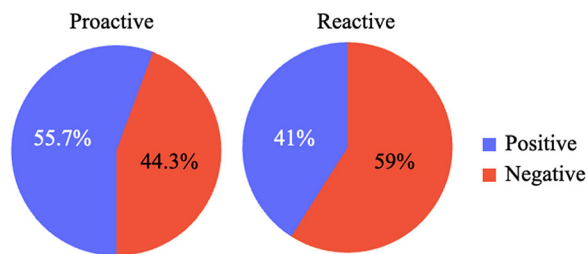
Fig. 2 Proportions of positive and negative words contained in management type statements. Proactive management statements had 516 positive words and 411 negative words; reactive management statements had 279 positive words and 401 negative words
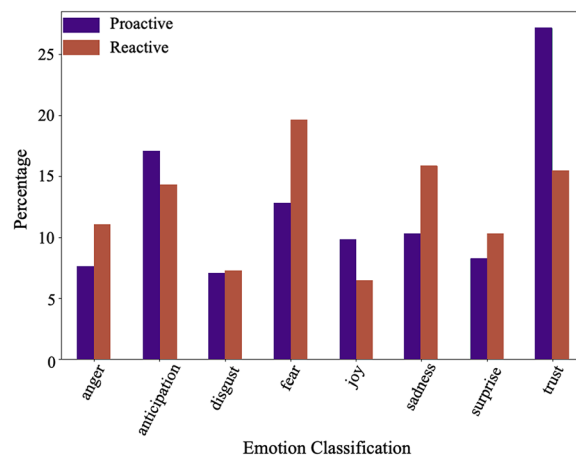
Fig. 3 Proportions of emotions conveyed in proactive and reactive management statements

Table 1 Emotional states conveyed in gout social media posts/comments

Emotion category	Proactive management word count[a] ($n = 1345$)	Reactive management word count[a] ($n = 1182$)
Anger	102*	130*
Anticipation	230	169
Disgust	95	86
Fear	172***	232***
Joy	132*	76*
Sadness	138***	187***
Surprise	111	120
Trust	365***	182***

[a]* = $P < .05$. *** = $P < .001$ in Pearson χ^2 post hoc analysis with Bonferroni correction

DISCUSSION

Although it is established that there is an association between negative mental health outcomes and gout, the circumstances behind this association are not yet fully understood and remain an unmet need in the gout community. Characterizing such experiences across hundreds of individuals is typically a sizable

challenge using traditional approaches (e.g., surveys, interviews) and in clinical discussions with patients with gout. Here, the interrogation of real-world, self-reported experiences in gout-related social media conversations represents a novel contribution regarding the intersection of disease management and emotional states in individuals affected by gout.

Overall, the relative frequencies of conversations were similar for reactive management (0.5%) and proactive management (0.6%). In these conversations, significant differences were observed between management type in general sentiment (positivity vs. negativity), emotional content, and medication mentions. Overall, more positive language was observed in proactive management statements, as supported by a significantly higher (more positive) polarity than reactive care statements. At the individual word level, reactive care statements had a significantly larger proportion of negative words than did proactive management statements. Top negative emotion words in reactive conversations included "pain", "attack", "shot", and adjectives such as "bad" and "worse". Reactive

Table 2 Medications mentioned in gout social media posts/comments

Substance	Proactive management word count[a] (n = 180)	Reactive management word count[a] (n = 239)
Prednisone/steroids[b]	51***	126***
Colchicine	38	49
Indomethacin	7	27
Other nsaids[c]	19	24
Allopurinol	65***	13***

nsaid nonsteroidal anti-inflammatory drug

[a]*** = $P < 0.001$ in Pearson χ^2 post hoc analysis with Bonferroni correction

[b]Prednisone/steroids reflects counts for "prednisone", "steroid", and "steroids"

[c]Other nsaids includes "nsaid", "nsaids", "Advil", "naproxen", and "ibuprofen" counts
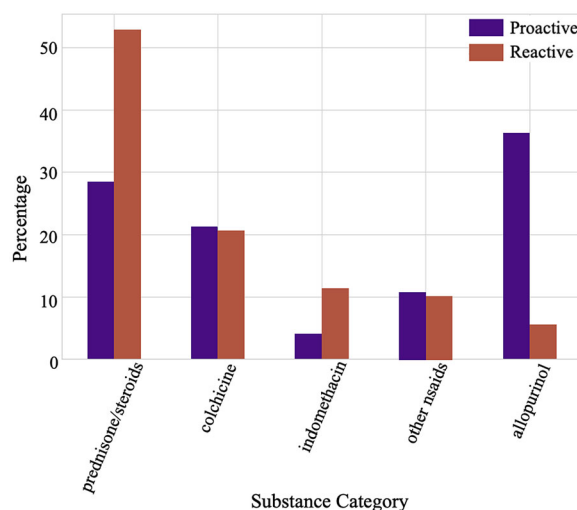
Fig. 4 Proportion of proactive and reactive statements that mention gout-related medications

conversations were also more likely to mention therapies associated with gout flares, including steroids, colchicine, and nonsteroidal anti-inflammatory drugs (NSAIDs). These findings suggest that decision-making in reactive scenarios is motivated by negative experiences, where painful flares drive individuals to manage their condition. This is in opposition to proactive management conversations, where top positive terms included words like "advise" and "specialist". Here, dialogue between patients and physicians appears to be a key element in the management strategy.

The reactive management approach may result in a greater loss of work time and, often, subsequent urgent care or emergency department visits with resulting increased costs to the health care system [12]. Our analysis suggests that "fear" is associated with gout in the reactive care setting, where patients are generally prescribed anti-inflammatory therapies or opioids. These treatments will abate the inflammatory flares and associated pain; however, they do not impact the overall urate burden and therefore do not change the overall course of the disease.

Proactive management with ULT represents the most effective way to improve disease burden and clinical outcomes in gout [20], and discussions about ULT use should take place between affected individuals and trusted

primary care or specialist clinicians in the out-patient—that is, proactive—setting.

Limitations

It is important to note that proactive and reactive statements may not be fully mutually exclusive samples. One of the concepts used to capture proactive care conversations included mentions of primary care providers (PCPs). It is possible that some conversations regarding PCPs include medical intervention that more directly aligns with a reactive approach, as some PCPs adhere to a "treat-the-symptom" approach in managing gout. Given the negativity associated with reactive management in the current study, the contrast in sentiment between the proactive and reactive statements could be further exaggerated with entirely distinct samples. Nevertheless, significant differences in sentiment and emotions were revealed between proactive and reactive management types where each sample was characterized by a unique lexical profile. Future work should explore differences in rheumatologist-focused experiences with reactive experiences in gout.

This is one of the first SML studies to explore mental and emotional experiences related to gout management. As such, these novel findings are likely best interpreted within the context of emerging literature on the topic. Although this study evaluated a considerable number of statements to understand community perspectives, how well these findings apply to the general population is not easily ascertained. Facebook and Reddit comprise international membership across a range of racial and ethnic backgrounds; however, it is difficult to appraise the degree to which specific and/or underrepresented populations are represented in the current study. As a strength, using SML allows researchers to understand patient perspectives that are completely voluntary. Moreover, the minimum requirements for participation using SML are a computer and internet access. While this is a substantial barrier for some individuals, this methodology eliminates patient travel requirements and avoids study burden, survey fatigue, and other

barriers that typically exist with conventional methods.

CONCLUSIONS

Proactive treatment of the root cause of gout (hyperuricemia) appears to positively impact mood. It is likely that an alternative reactive approach which downplays the reality of gout as a chronic condition could contribute to the increased levels of stress, anxiety, and depression known to affect individuals with gout [14–16] and the negative emotional states observed in this study. This, in turn, can increase the sense of frustration, helplessness, and loss of trust in the doctor-patient relationship. In contrast, proactive management can, in addition to better pain control, result in reduced negative mental states and empower patients with increased confidence and trust in the health care system. Driving more gout care to proactive settings could result in less-reactive flare-associated patterns of care with broad impacts on their overall emotional state as well as comorbidities and perceived stigma.

This approach to investigating self-reported social media data could open valuable opportunities for researchers and clinicians to analyze disease-specific trends, gain a better understanding of patient experiences in near real time, and evaluate which interventions are most likely to be successful. This information can be used to improve QoL for patients with gout and other chronic diseases and reduce their overall burden of illness.

ACKNOWLEDGEMENTS

Declarations

usernames or unique identifiers regarding the private Facebook group. Deidentification measures were employed prior to data analysis. Furthermore, this study does not present any individual patient data that would necessitate consent. This study was performed in accordance with the Helsinki Declaration of 1964 and its later amendments.

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