

THE EMOTIONAL IMPACT OF GOUT: SHAME AND GUILT

February 2025



Gout is a form of arthritis that occurs when too much uric acid builds up in the joints. Symptoms most commonly present in the large toe, but can be present in other joints, and include a sudden onset of severe pain, redness, and swelling. Gout attacks often happen at night, as the body's temperature lowers, allowing uric acid to more quickly crystallize in the joints to cause the onset of an attack. With proper treatment, gout and its painful attacks can be successfully managed.¹

TREND is a community-powered digital analytics company that turns the conversations of rare and chronic disease communities into actionable insights that spark broader understanding and therapeutic progress. Our analytics engine, Krystie™, enables TREND to identify conversations prevalent in social media. After isolating conversations within domains of interest such as disease burden, management, and mental health, TREND leverages a variety of analytical techniques to characterize the language and emotions associated with patient experiences and perspectives.

The aim of this research is to gain a deeper understanding on the impact of gout and the emotions of shame and guilt with an added focus on sexual dysfunction. We have been partnering with the Gout Support Group of America (GSGA) for this important work.

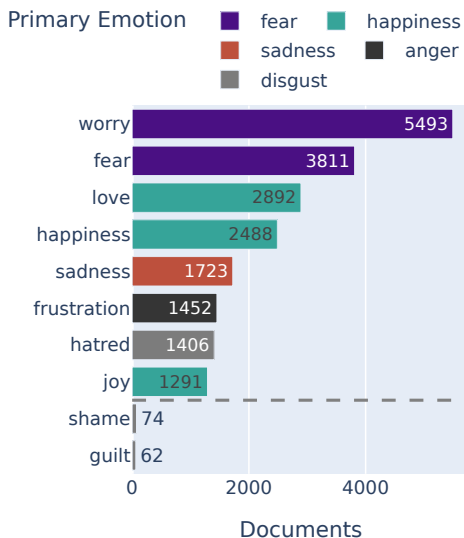
DATA SOURCES

GROUPS: Gout Support Group of America (private Facebook group), r/gout (public subreddit)

POSTS ANALYZED: 20,053	COMMENTS ANALYZED: 328,600	AVERAGE ENGAGEMENT: 14.8 comments per post	TIME RANGE: 2011 – 2025
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EMOTIONS: SHAME & GUILT

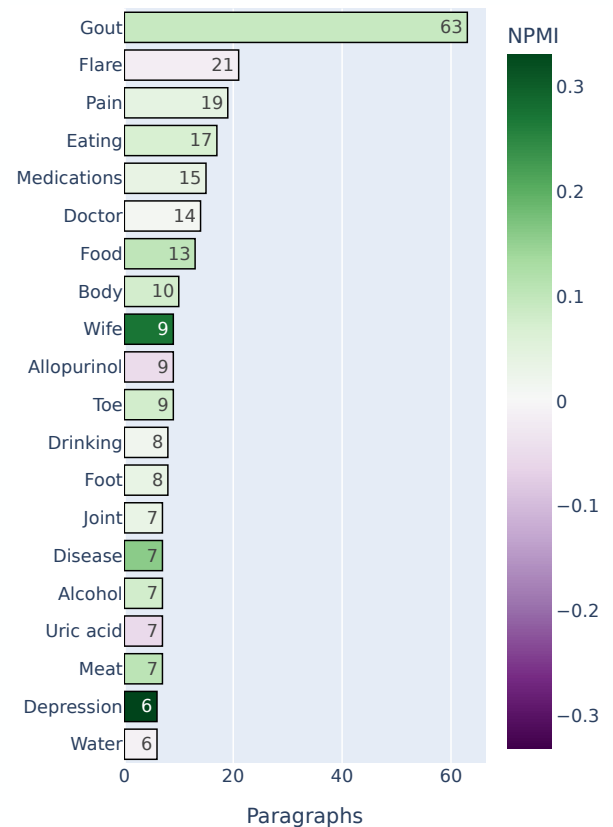
- Krystie™ recognizes mentions of emotion words (e.g., “I’m worried about...”) and categorizes each into one of Paul Eckman’s six primary emotions: *fear*, *happiness*, *sadness*, *surprise*, *anger*, and *disgust*.
- Mentions of **shame** and **guilt**, each under the primary emotion **disgust**, were identified. Their frequency is shown below, alongside the frequencies of the 8 most common emotions.
- Overall, **worry** and **fear** are most frequently mentioned. **Shame** and **guilt** are not mentioned very frequently. Each appears in only ~0.02% of documents*.



*("Documents" means posts and comments.)

CHARACTERIZING SHAME & GUILT MENTIONS

- To highlight the nature of the conversations mentioning **shame** and **guilt**, the 138 paragraphs that mention either were looked at for further analysis.
- The 20 most commonly occurring clinical concepts are shown to the right, along with the normalized pointwise mutual information (NPMI)** between **shame/guilt** and the clinical concept.
- Of those concepts co-occurring at least 6 times with **shame/guilt**, the most highly associated are **'Depression'**, **'Wife'**, and **'Disease'**, showing the seriousness and interpersonal nature of the shame and guilt that patients experience related to living with gout.



- In addition to the clinical concepts, TREND looked at the non-clinical language associated with mentions of **shame/guilt**[^]. Associated words/phrases included **“embarrassed”**, **“image”**, **“feelings”**, **“appearance”**, **“alcoholics”**, **“rich man disease”**, **“mental health”**, and **“living hell”**, illustrating a variety of possible causes of shame and guilt.

**NPMI is a value between -1 and 1 that measures association between concept mentions, with 1 signifying complete cooccurrence, -1 never occurring together, and 0 independence.

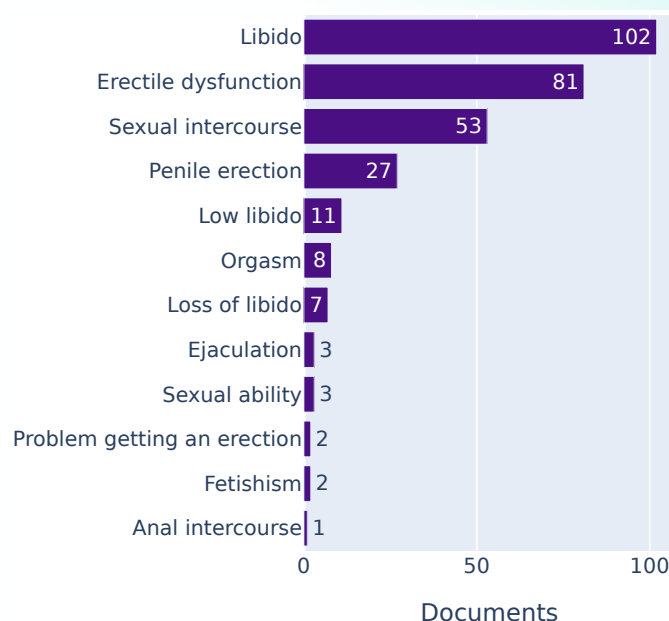
[^]Term frequency – Inverse document frequency (TF-IDF) was used to identify the non-clinical language associated with shame/guilt.

¹Gout Support Group of America website: <https://goutsupportgroup.org/about/>

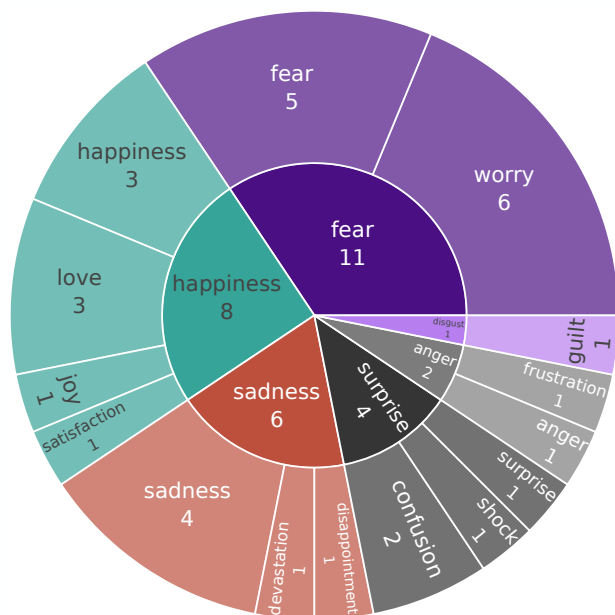
SEX AND SEXUAL DYSFUNCTION

- Next, TREND identified all mentions of concepts relating to sexual intercourse and/or sexual dysfunction#.
- Overall, 252 documents (~0.07%) mentioned at least one sex concept. When grouping by online community, the proportions were ~0.02% for GSGA and ~0.10% for r/gout, a statistically significant difference.
- The concepts identified and their frequency are shown to the right. **'Libido'** was the most common, followed by **'Erectile dysfunction'** and **'Sexual intercourse'**.
- Non-clinical language associated with mentions of a sex concept, again identified using TF-IDF, included **"febu"**, **"testosterone"**, **"hair (loss)"**, **"(rare) side effect"**, **"performance"**, **"desire"**, and **"taking febuxostat"**.

#A combination of Krystie's clinical span recognition capability and phrase similarity searching were used to identify the concept mentions.



SEX AND SEXUAL DYSFUNCTION AND EMOTIONS



- The distribution of emotion words found by Krystie within paragraphs that discuss sex and/or sexual dysfunction is shown to the left. Note that the counts are small, so this distribution should be taken with a grain of salt.
- Mentions of **fear** and **worry** alongside a sex concept were mostly in relation to possible side effects of Allopurinol, especially decreased libido and erectile dysfunction.
- Only a single mention of a sex concept occurred with **guilt**, and none occurred with **shame**. In the one cooccurrence, the author lists all the ways in which their body has been affected by their chronic gout and years of treatment, including erectile dysfunction, how they feel like a burden, and feel guilt for not being alone.

CONCLUSION

Neither the emotions of *guilt* and *shame*, nor sexual activity and sexual dysfunction, are mentioned frequently in the online gout communities Gout Support Group of America and r/gout. Moreover, mentions of any sex-related concept were five times less frequent in the former than in the latter. This could reflect a difference in the experiences of the user bases of these groups, or, more likely, is a consequence of the added anonymity of reddit compared to Facebook. An anonymous survey may yield more insights going forward.

Though infrequent, mentions of guilt and shame were characterized by their association with clinical and non-clinical language, such as mentions of mental health, depression, one's appearance, wives, and gout as a "rich mans disease". This illustrates that the guilt and shame, when experienced, is both severe and interpersonal.

Most discussion of sexual activity and sexual dysfunction involves libido or erectile dysfunction. These discussions are associated with the medication Febuxostat and "side effects", as well as desire and performance. Only one paragraph contains a mention of *guilt* and a sexual concept (ED), suggesting feelings of guilt and shame aren't discussed frequently with sexual issues in the gout community.