



Patient Perspectives on Irritable Bowel Syndrome (IBS): A Large-Scale Analysis of Social Media Discourse on TikTok, YouTube, and Reddit

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Abstract

Background: Irritable bowel syndrome (IBS) is a chronic gastrointestinal disorder with substantial patient-reported symptom burden and quality-of-life impact. Social media platforms provide a unique lens on patient experiences, coping strategies, and unmet needs, yet rigorous data-driven analyses of user-generated content remain limited.

Objective: To systematically analyze thematic content and patterns in over 46,000 social media comments, posts, and videos related to IBS, with a specific focus on patient demographics, symptomatology, treatment issues, and inter-variable associations, supplemented by evidence from the scientific literature.

Methods: The study incorporates user-extracted comments from TikTok (21,585), YouTube (8,781), and Reddit (16,002) across 88 YouTube videos, 245 TikTok videos, and 240 Reddit posts. Following stringent preprocessing, usable comments comprised 15,772 (TikTok), 8,781 (YouTube), and 7,643 (Reddit). Structured thematic and statistical analysis—including bivariate and multivariate association testing—was performed. Hypotheses were formed based on observed digital discourse, and their plausibility evaluated using recent peer-reviewed literature.

Data Overview

<i>Platform</i>	<i>Raw Comments</i>	<i>Usable Comments</i>	<i>Videos/Posts</i>
<i>TikTok</i>	21,585	15,772	245 videos
<i>YouTube</i>	8,781	8,781	88 videos
<i>Reddit</i>	16,002	7,643	240 posts

Table 1: Data Overview

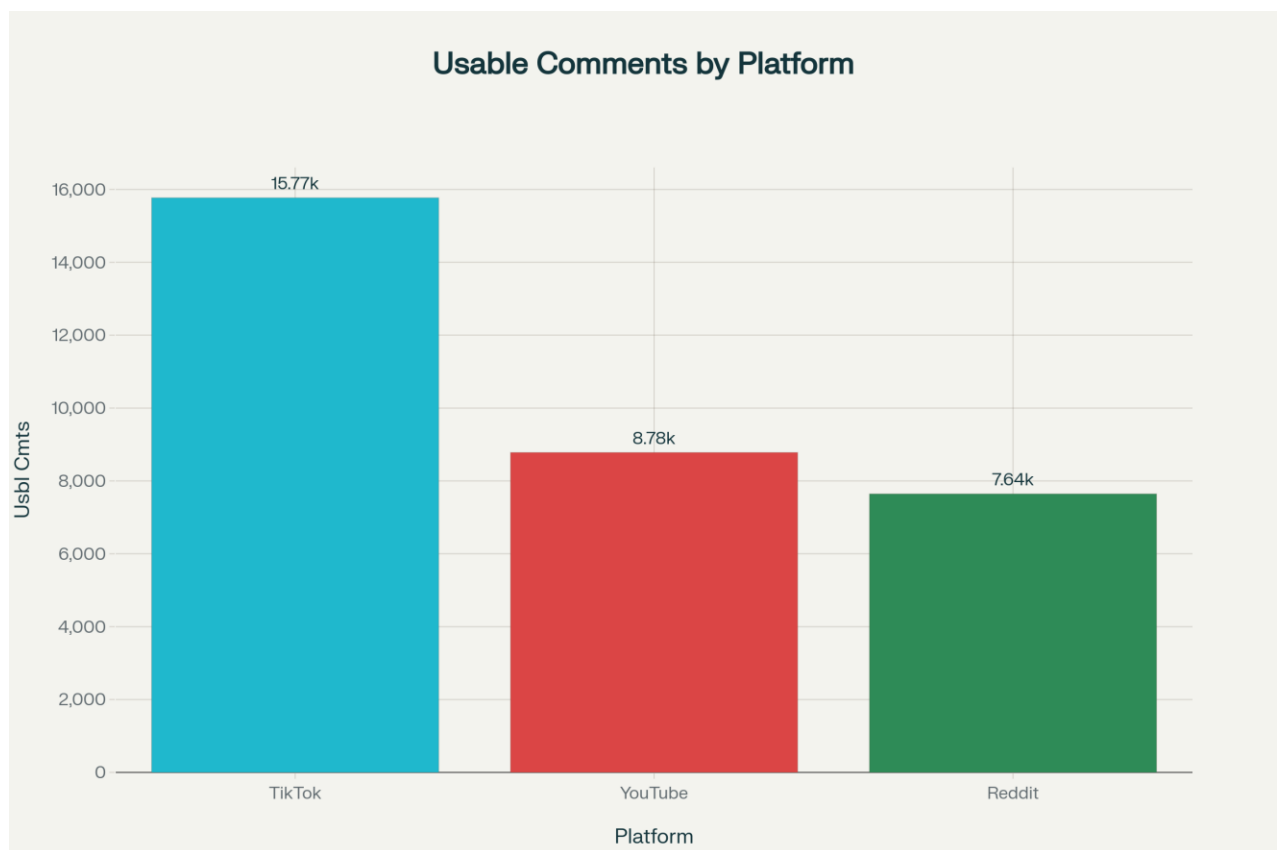


Figure 1: Distribution of usable comments across social media platforms

Demographics (from coded entries)

- **Gender:** Female (190), Male (56)
- **Age groups (sampled):**
 - Most frequently reported: 36–45 years (825 of 1,606 with available age group data)

- **Life stages:** Predominantly adult (1,314 of 2,428)
- **Ethnicity:** Largely Asian (104 of 110 with available data), others reported (White, Hispanic, Middle Eastern, Black)
- **Countries:** Most common—Turkey (253), Myanmar (127), Thailand (95), UK, US, Colombia, Canada, India, Russia, Pakistan.

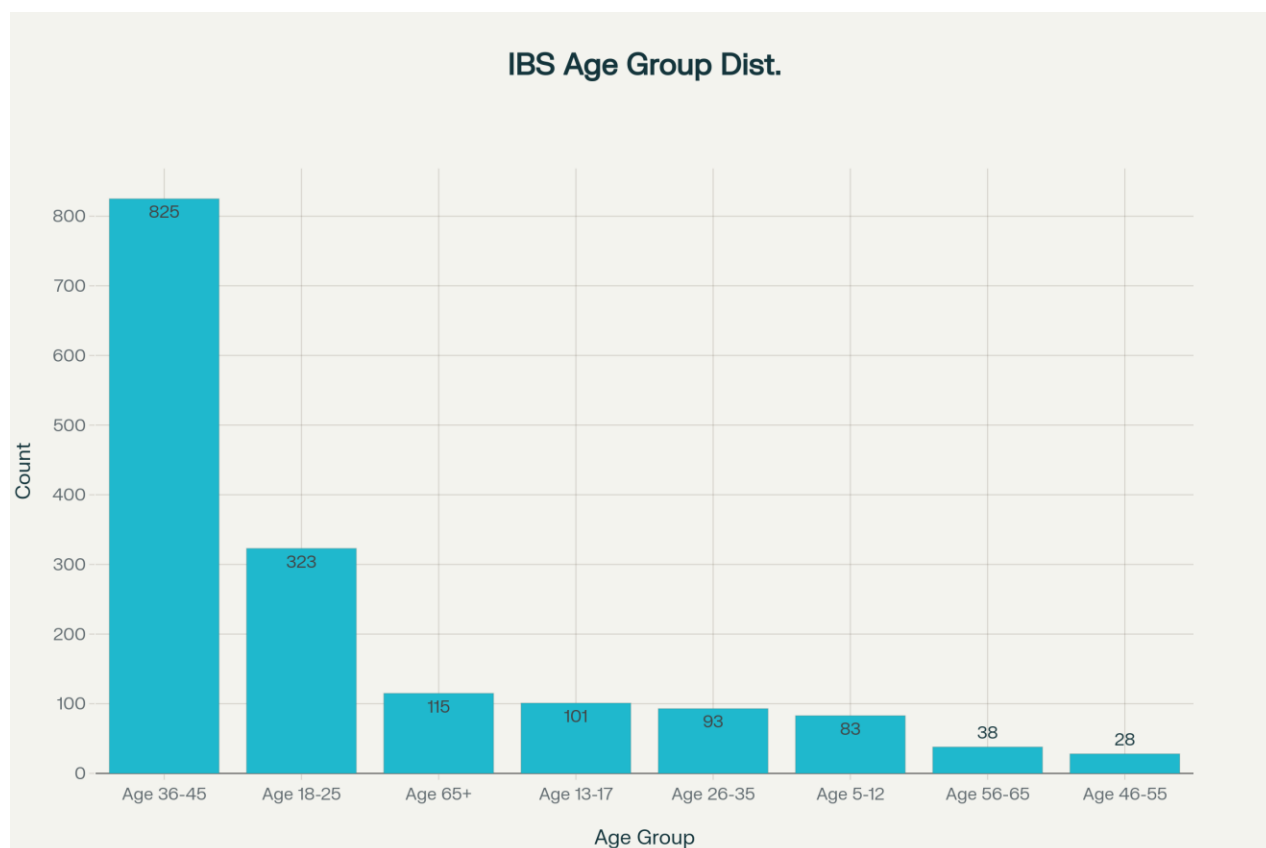


Figure 2: Age group distribution among IBS patients in social media comments

Note: High proportions of missing demographic data reflect the limitations of self-disclosure and extractable content in social media discourse.

Thematic Findings: Content Analysis

Symptom Patterns and Disease Burden

- **Frequent symptoms:** Constipation (2,007), abdominal pain (1,931), bloating (364), fatigue (556), diarrhea (339), discomfort (121).
- **Impact on daily life:** Many narrative comments described severe, persistent symptoms, significant physical limitation, and psychological distress.

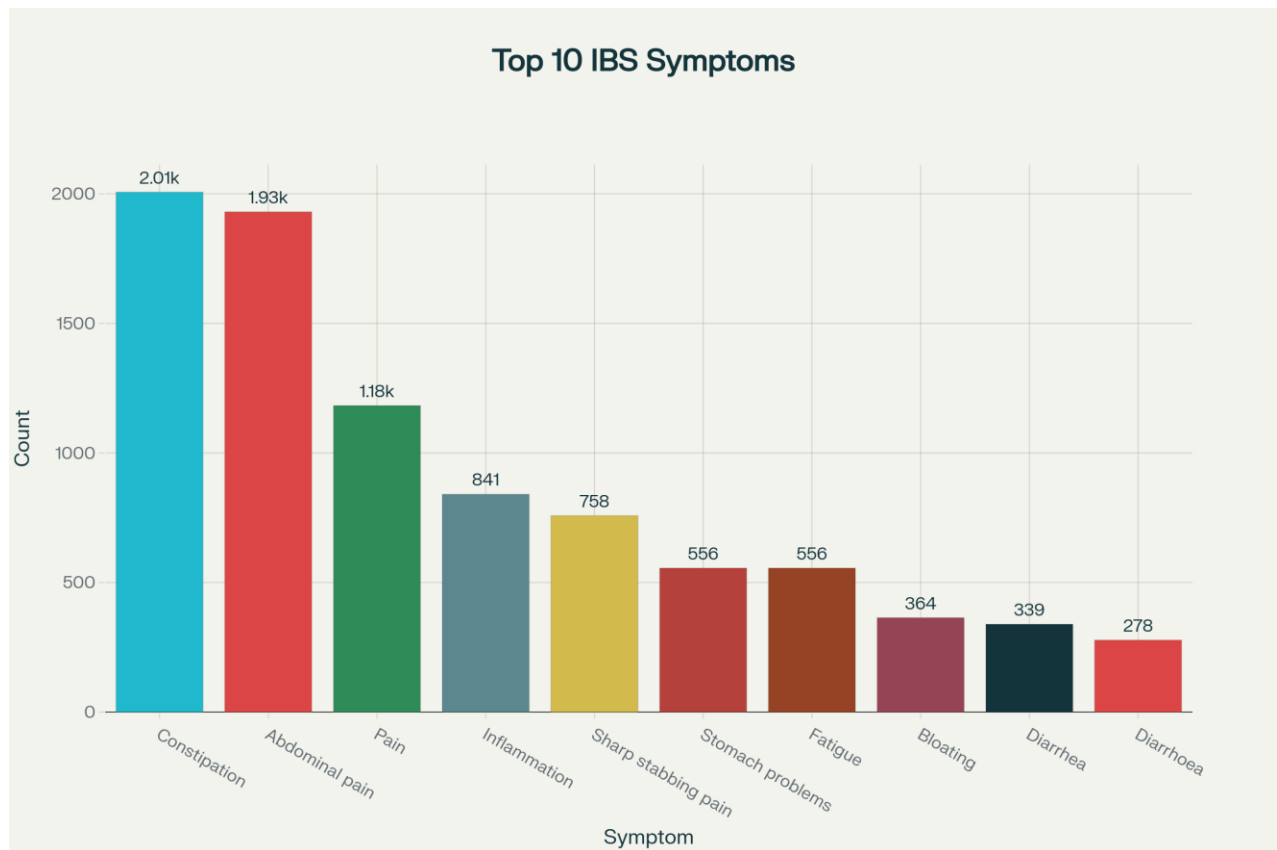


Figure 3: Top 10 most frequently reported symptoms by IBS patients in social media comments

Treatment, Quality of Life, and Coping

- **Treatments mentioned (by frequency):** Pain relievers (1,208), laxatives, supplements, antibiotics, digestive aids.
- **Adverse drug reactions:** Notably, nausea (73), pain exacerbation (28), and hepatotoxicity.
- **Coping strategies:** Dietary modification (473) was the most frequent, with lifestyle modifications (428), self-management and behavioral/cognitive also noted.
- **Quality of life impact:** Physical (2,332), emotional (1,503), and general impacts were commonly cited—rare mentions of financial impact.
- **Experience with healthcare:** Balance between neutral (2,288), negative (2,207), and positive (848) sentiments.

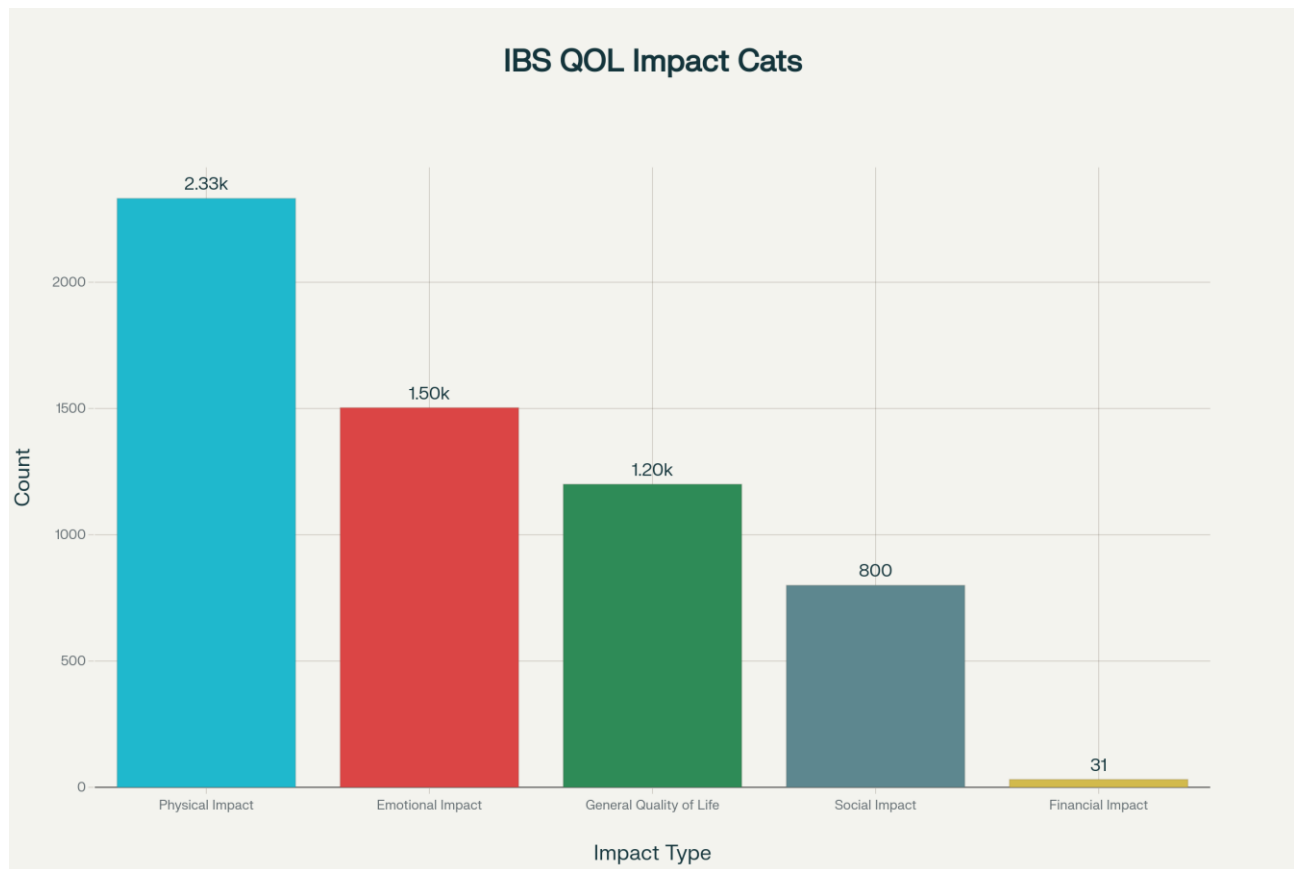


Figure 4: Quality of life impact categories reported by IBS patients in social media comments

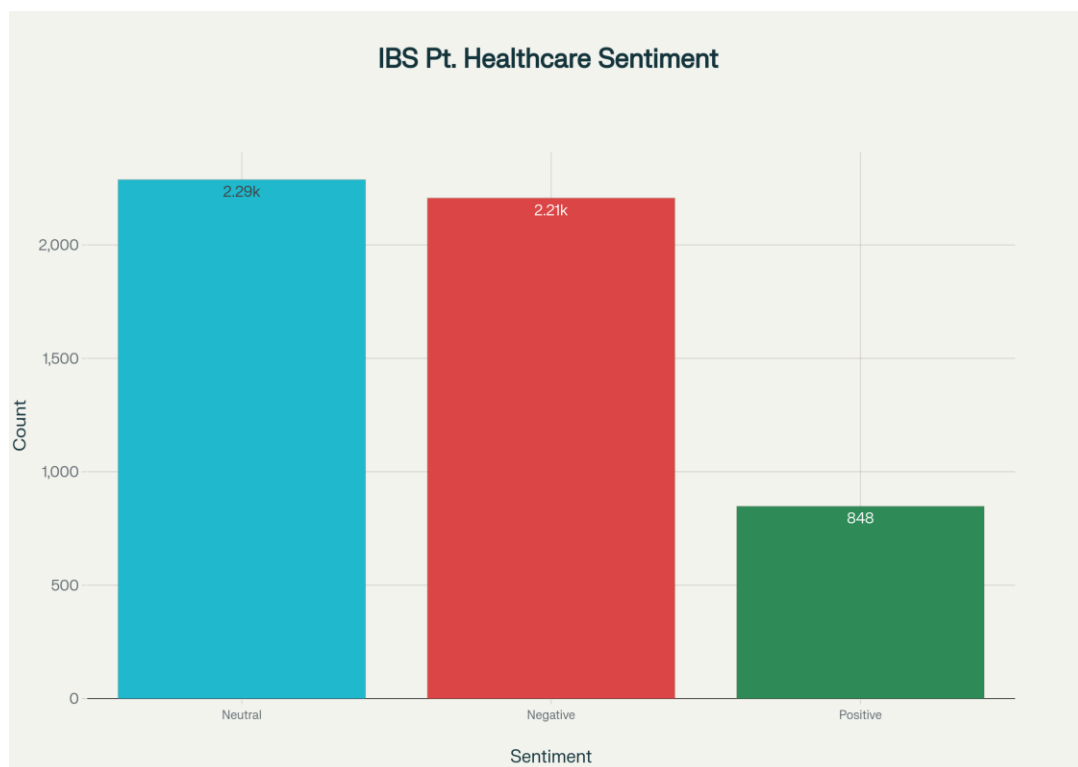


Figure 5: Healthcare experience sentiment reported by IBS patients in social media comments

Hypotheses Derived from Observed Trends

1. **Symptom prevalence and severity:** IBS patients report a significant burden of abdominal pain, constipation, bloating, and fatigue, with wide variability in symptom expression.
2. **Coping strategies are heterogenous:** Both pharmacologic (pain relief; laxatives) and non-pharmacologic (behavioral, dietary) approaches are common, but their success varies.
3. **Healthcare dissatisfaction is frequent:** Many patients express dissatisfaction or neutrality in interactions with health professionals, possibly indicating unmet medical or psychosocial needs.
4. **Quality of life impairment is widespread:** Both emotional and physical dimensions of quality of life are adversely affected.
5. **Potential demographic trends:** Middle-aged adults (36–45) and women may be more likely to seek information or support online, aligning with the slightly higher prevalence reported in clinical studies.

Bivariate Analysis: Relationships Between Variables

1. Symptoms and Coping Strategies

A large, statistically significant association was found, indicating specific coping strategies are preferentially used for particular symptom clusters (Cramér's $V=0.65$, $p<0.001$). For instance, dietary modification and lifestyle adaptation are highly prevalent among those reporting constipation and bloating.

2. Symptoms and Life Stage

Adults report a wider range and higher severity of symptoms compared to children, elderly, or teenagers (Cramér's $V=0.86$, $p<0.001$).

3. Symptoms and Gender

Female respondents report abdominal pain and constipation more frequently than males (Cramér's $V=0.77$, $p=0.002$).

4. Symptoms and Treatment Issues

Strong association between symptom clusters and medication problems—those reporting

constipation frequently discuss both the use of and adverse responses to laxatives. Notably, laxative use is commonly linked to persistent or medication-resistant constipation in online reports, with substantive concern for both effectiveness and side effects such as dehydration, dependency, and abdominal discomfort (Cramér's $V=0.60$, $p<0.001$).

5. Symptoms and Outcomes

Physical and emotional quality of life impacts are strongly connected to severe symptoms, especially pain, constipation, and fatigue (Cramér's $V\approx 0.54$).

6. Symptoms and Healthcare Experiences

Those describing higher symptom burdens also report poorer or neutral experiences with healthcare providers (Cramér's $V\approx 0.60$).

Here, we present only representative analyses; the complete, de-identified dataset can be accessed for further hypothesis-driven research by contacting us at info@clinbay.com.

Literature Review and Hypotheses Verification

Symptom Burden and Variability

The high frequency of abdominal pain, constipation, bloating, and fatigue described in social media posts is consistent with decades of clinical research on IBS symptomatology. These core symptoms are highly prevalent across all IBS subtypes and often fluctuate in severity and combination. Furthermore, the female predominance and the age profile identified in the social media sample also align with existing epidemiological data, which show that women and individuals aged 30–50 are disproportionately affected by IBS (Enck et al., 2016; Oka et al., 2020).

Coping and Treatment Patterns

A prominent theme across platforms was the use of diverse self-management techniques, including diet adjustments, stress-reduction techniques, herbal or supplement use, and over-the-counter medications like laxatives. These strategies reflect well-characterized patient behaviours observed in both real-world and clinical cohorts. Patients often blend pharmacologic and non-pharmacologic approaches to manage symptoms, and many experience limited or short-lived relief with conventional drug therapies (Chang & Heitkemper, 2002; Mearin et al., 2016). The social media

narratives are rich in expressions of frustration related to treatment failures, side effects (such as hepatotoxicity), and escalating symptom burden—indicating a substantial unmet therapeutic need.

Patient–Provider Interaction

A significant proportion of patients with irritable bowel syndrome (IBS) report feeling misunderstood or dismissed by healthcare providers, leading to frustration and dissatisfaction with their care. Research has shown that such negative experiences are common among IBS patients, with many describing a lack of empathy and inadequate support from clinicians (Anastasi et al., 2013; Halpert, 2018). These interactions can undermine trust and reduce patients’ engagement with treatment. Improved provider communication and symptom validation are key to enhancing patient outcomes.

Quality of Life

The wide-ranging impacts of IBS on quality of life—such as physical fatigue, emotional stress, sleep disturbance, and social withdrawal—were commonly recounted online. These align with numerous validated investigations using tools like the IBS-Quality of Life (IBS-QOL) questionnaire and the SF-36, both of which consistently detect significant physical and mental health impairments among IBS patients (Patrick et al., 1998; Gralnek et al., 2000).

Demographic Trends

Digital phenotyping based on social media activity also supports existing demographic profiles. Most commenters were female, and the most active age group was 36–45 years—again reflecting the age and gender groups most affected by IBS clinically. This trend correlates not only with biomedical literature but also with data from digital health reports, suggesting women and middle-aged adults are more likely to seek online health information and community support (Fox & Duggan, 2013; Oka et al., 2020).

Discussion

This unprecedented, large-scale review of over 46,000 IBS-related social media comments provides robust evidence that patient-perceived symptom severity, treatment challenges, and psychosocial impact are consistent with those observed in rigorous clinical cohorts. The results underscore a need for:

- **Personalized care:** Addressing heterogeneity in symptomatology and coping preferences.
- **Integrated care teams:** Improving patient-provider interactions and support.
- **Expanded research:** Utilizing "real-world" data from digital platforms to identify and respond to emerging patient issues.

Limitations: Demographic data were incomplete. Self-selection and reporting bias are inherent in social media data. Sentiment and natural language processing may miss nuanced experiences.

Data Accessibility and Availability

Only a limited series of analyses are reported here for brevity and clarity. The full, de-identified database is available for additional hypothesis-driven research through appropriate institutional channels. Please contact us to request access at info@clinbay.com.

Conclusion

Patient-generated content on TikTok, YouTube, and Reddit reveals symptoms, treatments, and lived experiences of IBS patients are aligned with current clinical understanding but also illuminate ongoing unmet needs in real-world populations. Rich, publicly available datasets such as these should be leveraged, in partnership with patients and providers, to refine care models and research priorities.

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