

Major Depressive Disorder Patient Voice: AI-Assisted Insights from Inspire's Online Health Community Platform

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Background

- Major depressive disorder (MDD) is a common and serious mood disorder marked by persistent low mood, loss of interest or pleasure, and symptoms, significantly impairing daily functioning [1].
- MDD is a highly prevalent disease in the US general population, with a 20% lifetime prevalence among adults [2].
- This study aimed to increase understanding of clinical and patient-centered unmet needs among patients with MDD and their caregivers from Inspire's online health community.

Methods

Data Source

- Inspire is the world's largest online health community, patient engagement and real-world data platform, supporting over 3,000 disease states and including over 3 million registered members and 10 million annual visitors.
- Data was sourced from user-generated content (UGC) in key Inspire Communities, including Mental Health America, iFred Anxiety and Depression OR any members who have MDD-related content on Inspire's platform.
- Members' UGC, including posts, discussion, and comments were analyzed.

Study Design

- User-generated content (UGC) was analyzed using topic modeling, chained large language models (LLM) with constrained prompts, and iterative feedback from researchers. (Figure 1)
- BERTopic was used to perform topic modelling, with subsequent manual review by the research team to identify topics and documents related to MDD. Chained OpenAI gpt-4o-mini and gpt-4-turbo with constrained prompts were applied against MDD-related documents to answer research questions. (Figure 1)
- For the symptom frequency sub-analysis, a convenience sampling approach was employed.

Results

Study Population

- The study utilized real-world, user generated content drawn exclusively from the Inspire.com online health community. A total of 132,405 posts authored by 42,833 unique members were analyzed. Posts spanned a defined 16-year period, from April 2, 2008, through July 2, 2024, representing diverse perspectives from individuals engaged in peer-to-peer health discussions. (Figure 2)
- The dataset reflects organically generated patient and caregiver expressions within a large, condition-focused online community.

Figure 1: Overview of Methodology

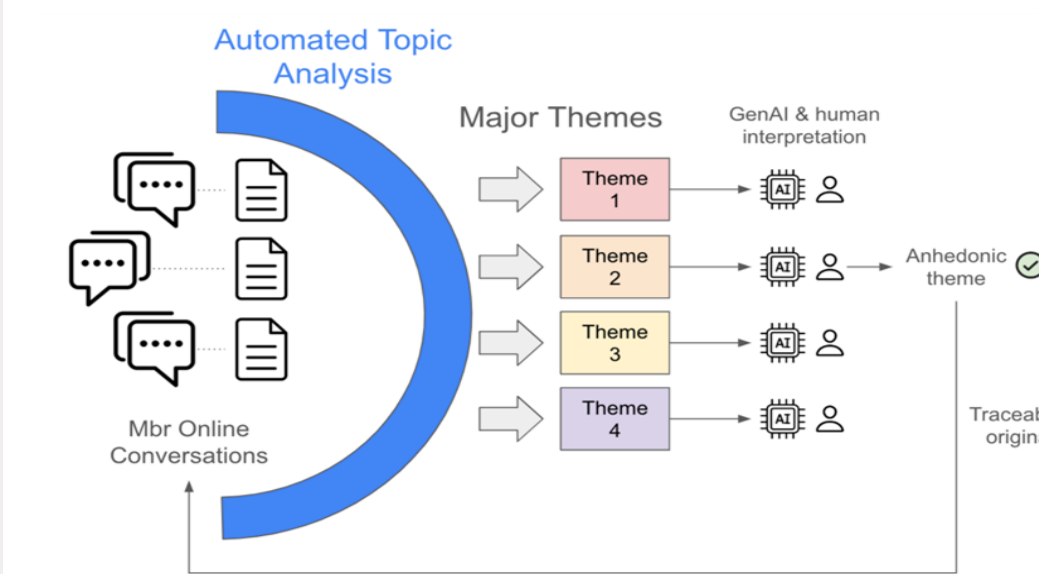
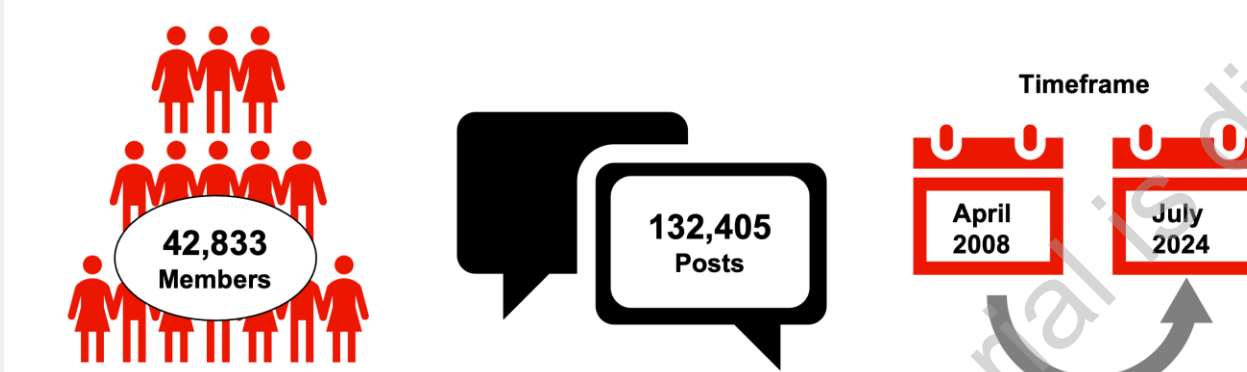


Figure 2: Study Population



Overview of Key UGC Themes (Figure 3)

- The need for comprehensive mental health support was prominent (5,255 posts) with emphasis on emotional, informational, and crisis management resources.
 - Members emphasize the role of empathy and understanding in supporting individuals with mental health conditions, highlight the need for medication adherence to prevent symptom exacerbation and potential crises, and address strategies for handling suicidal ideation or self-harm.
- Discussion of depressive symptoms, management strategies, and recovery narratives, including persistent low mood, loss of motivation, anhedonia, and insomnia and other sleep disturbances comprised 4,325 posts.
 - The most frequently discussed MDD symptoms include persistent low mood, thoughts of guilt or worthlessness, and fatigue or loss of energy. (Table 1)
 - Members frequently mention that their current medications are not sufficiently alleviating their symptoms, leading to ongoing struggles with depression and anxiety.
- Relationship difficulties, including family, romantic, and social challenges, as well as isolation, appeared in 3,918 posts.
 - Posts within this theme discuss emotional struggles in relationships, with many individuals reporting feelings of unworthiness, abandonment, and being unloved, as well as trust issues, concerns about infidelity, and commitment fears contributing to heightened anxiety and depressive thoughts.

Figure 3: Key Depression-Related UGC Themes

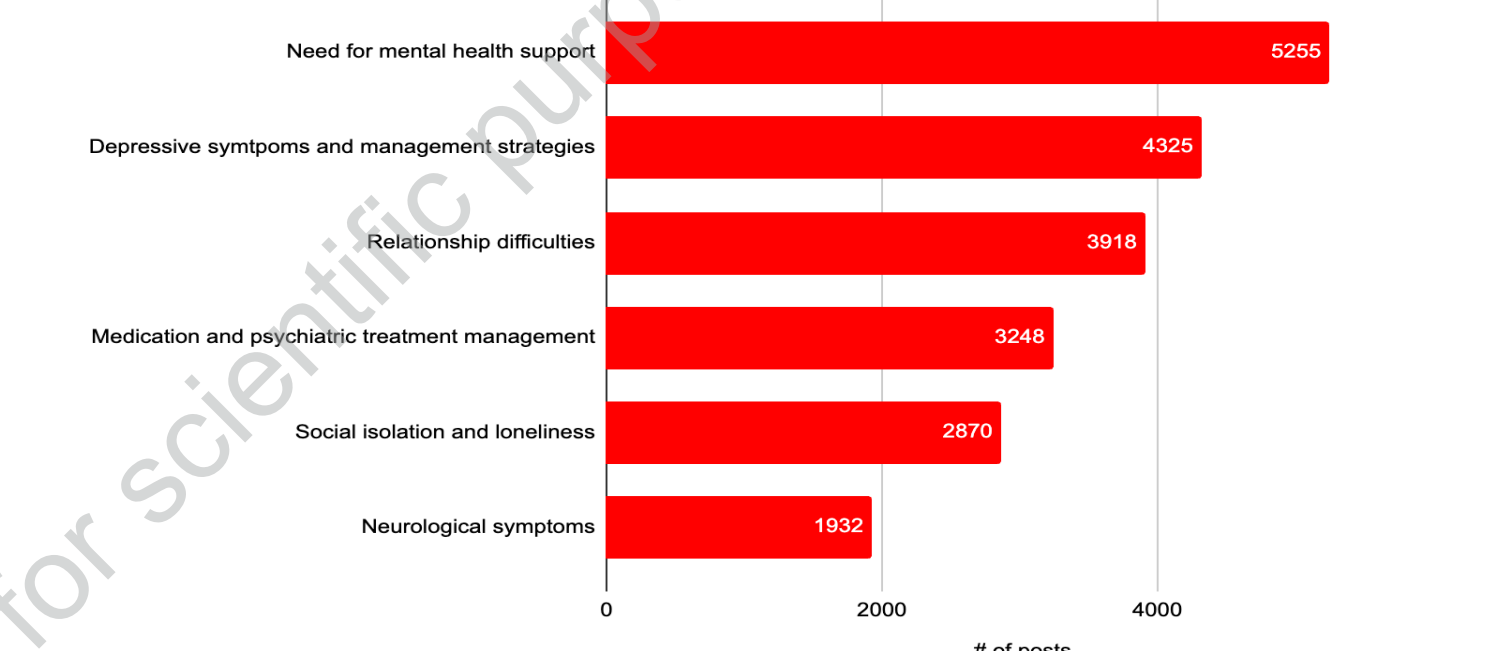
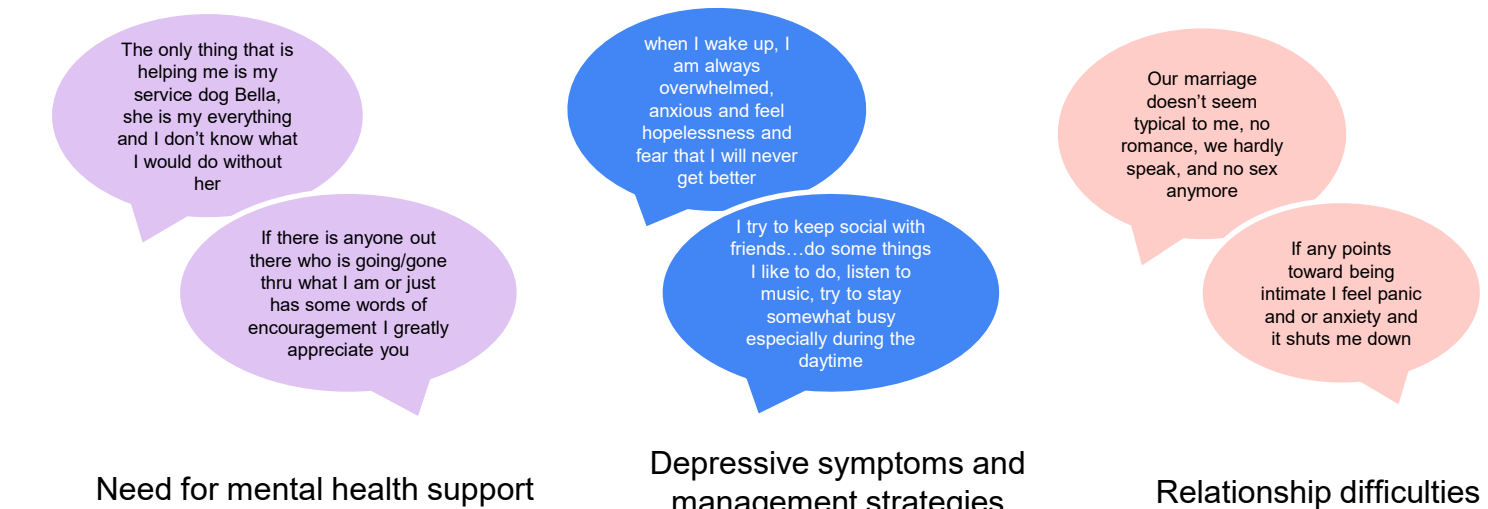


Figure 4: Examples of UGC Representing Key Themes



- Medication and psychiatric treatment management, including issues with efficacy, side effects, and treatment-resistant depression, emerged in 3,248 posts.
 - Members report differing levels of effectiveness of antidepressant medication, often requiring trial and error to identify the most suitable medication and dosage level to obtain the most optimal results. Concerns about side effects and medication interactions are discussed, along with a need for close monitoring by healthcare providers.
- Social isolation and loneliness were expressed in 2,870 posts, with many valuing community support.
 - Many express struggle with forming and maintaining friendships, leading to feelings of isolation and loneliness despite a desire for deeper, more supportive connections. The COVID-19 pandemic intensified these feelings by limiting social interactions and exacerbating pre-existing mental health challenges.
- Neurological symptoms, and interplay between physical and mental health were discussed in 1,932 posts, reflecting MDD's broad and interconnected burden.
 - Discussions highlight a potential link between psychological states, such as stress or anxiety, and neurological events like seizures. Additionally, chronic conditions including autoimmune disorders or chronic pain are also noted to exacerbate depressive symptoms

Table 1: Depressive Symptom-Related Discussions Based On Convenience Sample from Mental Health America Community

Depressive Symptom	# of Posts (%)	Examples
Persistent low mood	18,733 (40.6%)	"I've been depressed my entire life, at least as long as I can remember, but I've never felt as empty as I do right now."
Thoughts of guilt or worthlessness	12,316 (26.7%)	"I have cerebral palsy and scoliosis i also struggle w anxiety/depression i feel worthless all the time i feel like im not good enough for anything or anybody"
Fatigue or loss of energy	7,643 (16.6%)	"I have not been able to wash my clothes, change my bed linens, keep up with most of the daily chores at all" "my depression has drained my energy I don't want to do anything anymore."
Suicidal thoughts or ideation	6,520 (14.1%)	"I contemplate suicide all the time for the fear of the shame on myself"
Difficulty concentrating or making decisions	4,811 (10.4%)	"I feel sleepy and unable to concentrate, organize, listen, etc, even on days I've slept better " "People in general grow tired of my indecisiveness so I don't talk too much about it until the time gets closer"
Sleep disturbances	3,866 (8.4%)	"one of my worst and most bothersome symptoms is my lack of sleep" "I lie in bed for hours and hours and just can't shut my brain off"
Psychomotor agitation or retardation	1,801 (3.9%)	"I can't seem to stop feeling nervous, depress, and having suicidal thoughts" "I have brain fog so that makes it hard to do things"
Changes in appetite or weight	1,454 (3.2%)	"I have put on so much weight in the last 9 years... Nothing I do seems to help..."
Loss of interest or pleasure	1,173 (2.4%)	"I have lost the desire to do anything at all." "I used to love watching my favorite shows, but now I just can't seem to enjoy them anymore."

Key takeaway



Patient-centric unmet needs among patients with MDD and caregivers can be extracted and synthesized leveraging unique data sources from online health communities, expedited with LLM and generative AI.

Conclusions



Web-based peer-to-peer support communities can provide MDD patients with a safe forum to engage in meaningful and frank discussion around their experience with the disease, including strategies for coping and management of depressive symptoms.



AI-enabled insights from online patient communities like Inspire.com offer a complementary method to further understand the lived experiences of patients in their own words.



Providers should adopt a holistic and patient-centered approach to address unmet needs related to clinical, emotional, social and treatment related challenges in patients with MDD.

Strengths and Limitations

Strengths

- The study analyzed 132,405 posts from 42,883 users, providing a substantial sample size that enhances the reliability and richness of qualitative insights derived from people living with Major Depressive Disorder (MDD) and their caregivers.
- Use of user-generated content (UGC) from a peer-led health community (Inspire.com) captures authentic, patient-centered experiences, including topics often underreported in clinical settings, such as loneliness, interpersonal challenges, and holistic symptom burden.
- The application of topic modeling and chained large language models enabled the structured analysis of unstructured text data, allowing scalable and nuanced identification of key themes relevant to MDD.

Limitations

- Insights are limited to users who actively post on an online health community, possibly skewing results toward individuals with greater digital literacy, higher illness burden, or unique engagement patterns not representative of the broader MDD population.
- Diagnoses and symptom descriptions are self-reported and unverified, which may introduce inaccuracy or variability compared to structured clinical assessments.
- Posts may lack context on critical variables such as treatment history, socioeconomic status, or clinical severity, limiting the ability to stratify findings or generalize to subpopulations.

Acknowledgments

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Disclosures

JF and VK are employees of Inspire. BC is a former employee of Inspire. HK and TD are employees of Johnson & Johnson.

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