

(PB3376) TREATMENTS FOR IMMUNE THROMBOCYTOPENIA (ITP) PLACE A BURDEN ON PATIENTS AND IMPACT QUALITY OF LIFE (QOL): INSIGHTS FROM A SOCIAL MEDIA LISTENING EXERCISE

Topic: 32. Platelet disorders

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Background:

ITP substantially impairs patients' QoL. Current ITP therapies rarely lead to durable responses after discontinuation and therefore typically require longterm treatment, creating a further QoL burden for patients. This burden may not be captured in healthcare professional (HCP)–patient interactions. Social media listening can provide patients' and caregivers' unprompted insights and perspectives on the impact of, and treatments for, ITP.

Aims:

To report data from a social media listening exercise in ITP to highlight possible unmet needs from a patient and caregiver perspective.

Methods:

Sprinklr, a social media listening tool, was used to extract, curate and analyze publicly available, open patient, caregiver and HCP conversations regarding ITP. Data were generated by searching key terms between March 2021 and February 2023 in the USA, UK, Germany, Australia and Japan. Channels covered included, but were not limited to, Facebook, X/Twitter, Instagram, Reddit, YouTube and various forums.

Results:

A total of 16,610 conversations related to ITP were identified; approximately 59% were related to COVID-19 and vaccine-induced ITP and were excluded. After removing noise content, 1085 potentially relevant patient/caregiver conversations were identified; the majority (90%) were from patients. More than 70% of patients discussing their personal experience had long-term, chronic ITP and 70% of the patient posts were by females.

Treatment experience was the main theme of conversation among patients and caregivers(**Table**). Positive sentiments regarding treatment included efficacy and lack of side effects. Negative sentiments included side effects (particularly for steroids), loss of efficacy after long-term use and lack of response. Analysis of conversations highlighted that patients measured treatment efficacy in terms of being able to achieve and sustain remission or maintain a platelet count in the normal range. Patients also expressed concerns about losing a response or developing tolerance to treatment. Patients who achieved remission after first-line or rescue treatment focused positively on efficacy while tolerating side effects. Patients with chronic ITP and experience in multiple treatment lines highlighted that their response to first-line treatment was not sustained; these patients hoped for a curative therapy.

When discussing the emotional impact of ITP, patients expressed anxiety regarding the uncertain efficacy of treatments for ITP. The unpredictable and relapsing nature of ITP also led to patients feeling frustrated and losing hope. ITP symptoms such as bleeding and easy bruising and side effects from treatment have severe physical impact on patients. Patients reported

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Abstract Book Citations: Authors, Title, HemaSphere, 2024;8:(S1):pages.

low platelet counts and current treatment caused fatigue and exhaustion.

Patients also felt that awareness of ITP was low among non-specialist HCPs, and that their treatment preference and opinion, particularly regarding side effects, was often disregarded by HCPs, who were more concerned about raising platelet levels. Interacting with a supportive HCP improved patients' emotional wellbeing.

Summary/Conclusion:

Our social media listening exercise revealed an abundance of information and networking options for patients with ITP on social media and suggests that patients want to achieve durable responses and avoid long-term medication. The impact of ITP treatment on QoL was emphasized, with patient conversations indicating an unmet need in ITP for new treatment options that improve QoL. Our analysis also highlights the increasing importance of listening to patients' perspectives when making treatment decisions for ITP.

Table. Top four patient and caregiver themes of conversation, and topics within each theme (n=446¹)

| Theme of conversation | Percentage of conversations | Topics within each theme | Number of conversations | Insights |
|-----------------------|-----------------------------|---------------------------------|-------------------------|--|
| Treatment experience | 30 | Listing previous treatment | 50 | <ul style="list-style-type: none"> Patients expressed concerns about losing a response or developing tolerance to treatment Patients compared the efficacy and safety of first-line treatments such as steroids or IVIg with second-line treatments such as TPO-RAs or rituximab |
| | | Efficacy | 39 | |
| | | Side effects | 32 | |
| | | Cost/insurance | 5 | |
| | | Drug interaction | 5 | |
| Quality of life | 9 | Treatment dose | 2 | <ul style="list-style-type: none"> Patient discussions were primarily around ITP and its treatment impacting their emotional wellbeing Patients reported concerns about treatment efficacy and anxiety about being on the correct treatment Splenectomy impacted patients' physical wellbeing |
| | | Emotional | 24 | |
| | | Physical | 17 | |
| | | Functional | 10 | |
| | | Social | 8 | |
| Pregnancy and ITP | 7 | Financial | 2 | <ul style="list-style-type: none"> Female patients at various stages of pregnancy talked about risk during pregnancy and discussed ITP treatment from the early weeks of pregnancy to delivery |
| | | Risk during pregnancy | 16 | |
| | | Epidural access | 9 | |
| | | ITP treatment during pregnancy | 5 | |
| | | Induction | 2 | |
| HCP interaction | 6 | Treatment discussion | 8 | <ul style="list-style-type: none"> Patients highlighted concerns about low awareness of ITP among first responders, ER doctors and GPs Patients discussed the issue of misdiagnosis and delayed diagnosis |
| | | Hematologist visit experience | 7 | |
| | | Diagnosis discussion | 6 | |
| | | ER visit/interaction with nurse | 4 | |

¹n indicates total number of themes identified; one post may have more than one theme

ER, emergency room; GP, general practitioner; HCP, healthcare professional; ITP, immune thrombocytopenia; IVIg, intravenous immunoglobulin; TPO-RA, thrombopoietin receptor agonist

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