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Insights Into the Burden and Unmet Needs of Patients With Hereditary Angioedema: A Retrospective Social Media Listening Study

Julia Braverman[1], Quazi Ataher[1], Darcy Ellis[1], Simona Gavata-Steiger[1], Angeline Babitha[2], Revanth Muthu[2]

[1]CSL Behring, King of Prussia, PA, USA; [2]CapeStart Inc., Cambridge, MA, USA.

CONCLUSIONS

- **Despite the availability of treatments for hereditary angioedema (HAE), unmet needs still exist and patients living with HAE experience substantial disease burden**
- **Real-life experiences gathered via social media can support HAE management optimization**

BACKGROUND

- HAE is a rare genetic disorder that causes recurrent, unpredictable, debilitating, and potentially life-threatening angioedema attacks, which substantially impair quality of life[1–3]
- Despite the availability of modern HAE treatments, patients continue to experience a high burden of disease and have unmet needs[4]
- Understanding the experiences of patients living with HAE and the patient journey is critical for optimizing HAE management
- Social media platforms provide outlets for patient communities to freely find, exchange, and discuss health information[5–7] and are therefore recognized as a valuable method used to capture the patient voice and better understand patients' lived experiences and unmet needs

OBJECTIVE

- This social media listening study was conducted to identify and characterize the experiences, burdens, and unmet needs of patients living with HAE

METHODS: RETROSPECTIVE SOCIAL MEDIA LISTENING STUDY

Determine search strategy

Iterative, keyword-based search:

- Predefined search terms
- English language keywords
- Data collection range: Jan 2018–Oct 2023

Manual data collection

Social media platforms used:

- X (formerly known as Twitter)
- Facebook
- Reddit
- Quora
- YouTube
- Patient forums

Data screening and extraction

Subject matter experts:

- Remove duplicates
- Anonymize data
- Determine relevancy
- Extract and categorize according to themes

In-depth data analysis

Quantitative and qualitative analysis:

- By identified subcategory topics and themes

RESULTS: DISEASE BURDEN AND TREATMENT NEEDS WERE COMMON TOPICS

- HAE topics considered relevant for the analysis included **burdens**,* **unmet needs**,* medications, symptoms, triggers, side effects, and misdiagnoses
- Posts discussing disease awareness, news, studies, or other diseases and were excluded from the analysis

6012 total HAE-related posts identified†

→ **892 relevant posts included in the analysis**

→ **1004 individual patients living with HAE**

86% of posts were written by patients, 10% by family/friends

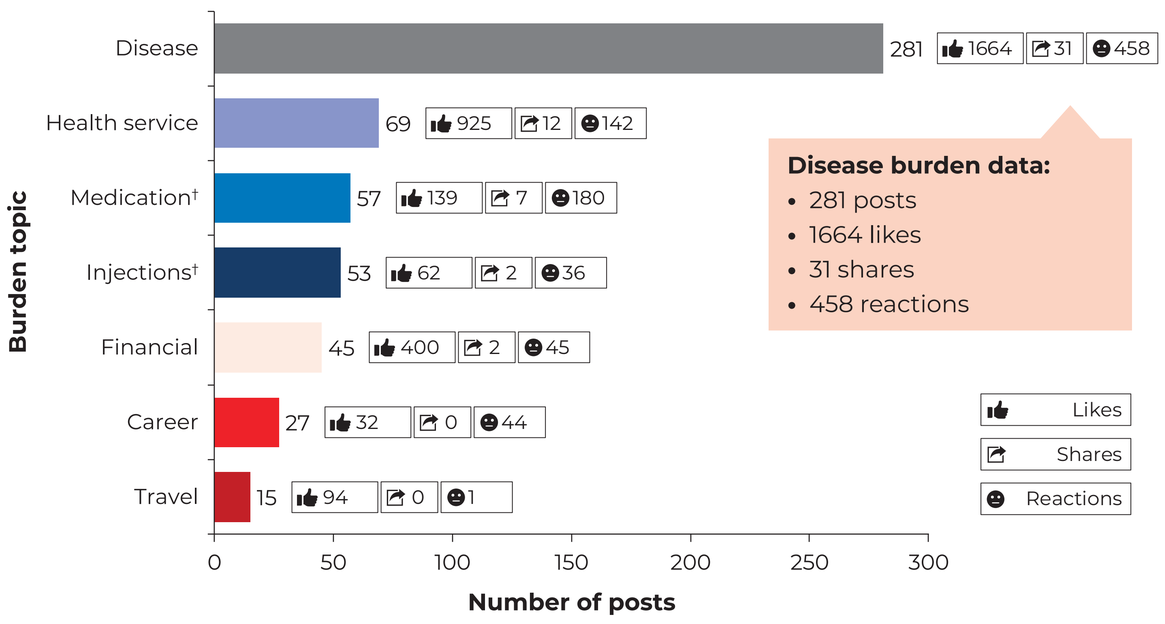
57% of posts were published in 2023, 15% in 2022

56% of posts originated from Facebook, 22% from X (Twitter)

*Predetermined theme of interest; †All posts were available in the public domain.

The most commonly discussed burden was disease burden

Burden topic, by number of posts (total 459/892 posts)*



Disease burden data:
- 281 posts
- 1664 likes
- 31 shares
- 458 reactions

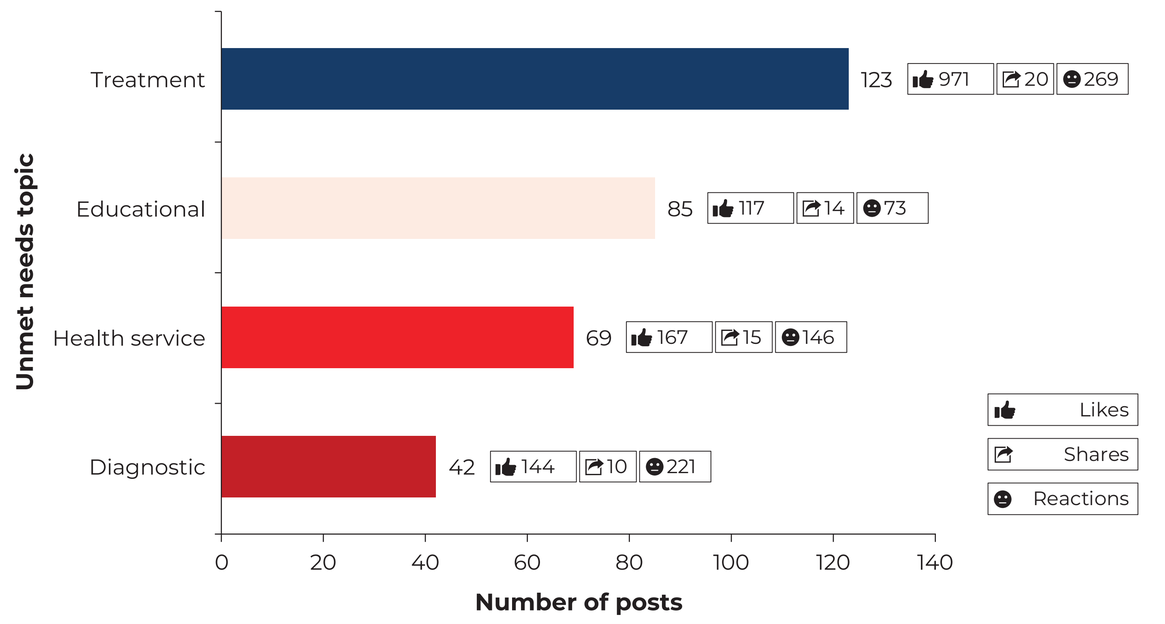
Common themes discussed in disease burden posts:
- Persistent swelling
- Painful HAE attacks
- Frequent HAE attacks

These symptoms led to **hospital admissions, social rejection, insomnia**, and **general discomfort**, impairing patients' QoL

*A single post may discuss more than one topic; †Injection burden related to the process of administration of treatment, whereas medication burden related to the intricacy of controlling HAE symptoms and adverse experiences with medication.
HAE, hereditary angioedema; QoL, quality of life.

The most commonly discussed unmet need was treatment need

Unmet needs topic, by number of posts (total 270/892 posts)*



Common themes discussed in treatment needs posts:
- Insurance denials
- Unavailability of medications
- High treatment costs
- Questions about alternative treatments
- Uncertainty about where to find the right medications

Treatment needs data:
- 123 posts
- 971 likes
- 20 shares
- 269 reactions

*A single post may discuss more than one topic.

Quotes from patients online

"Extremely painful events with significant vomiting"

"I learned to navigate life with painful, disfiguring swelling"

"I can't eat anymore because it became too painful"

"The hospital told me not to come back because they didn't know what to do for me"

"I'm scared they [employers] won't hire me officially unless they find a way to cover some of the cost"

References
1. Craig TJ et al. *Lancet* 2023;401:1079–1090; 2. Bork K et al. *Allergy Asthma Clin Immunol* 2021;17:40; 3. Maurer M et al. *Allergy* 2022;77:1961–1990; 4. Banerji A et al. *Ann Allergy Asthma* 2020;124:600–607; 5. Kline E et al. *Health Expectations* 2023;26:1524–1535; 6. Faust G et al. *JMIR Cancer* 2022;8:e34073; 7. Peric Z et al. *JMIR Cancer* 2023;9:e42905.

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