

Evolution of Patient-Reported Burden and Unmet Needs in Hereditary Angioedema: A Comparative Social Media Listening Analysis

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CONCLUSIONS

- HAE patient discussions continue to reflect substantial disease burden and unmet needs despite treatment advances.
- Nearly two years after the prior analysis, disease burden and diagnostic and educational gaps persist or have increased, while injection and career-related burdens show some improvement, underscoring gaps between innovation and real-world patient experience.

BACKGROUND

- Hereditary angioedema (HAE) is a rare inherited disorder marked by recurrent, painful, and potentially life-threatening angioedema attacks involving subcutaneous and submucosal tissues.¹
- HAE significantly impacts patients' daily functioning, leading to reduced productivity, missed work or school, and substantial psychological burden, including anxiety and depression.²
- Recent therapeutic advances have expanded prophylactic and on-demand treatment options; however, patients may still experience treatment access barriers and persistent unmet needs.³
- Understanding patient perspectives is essential to capture lived experiences, treatment journeys, and preferences in HAE management, with social media listening offering valuable real-world insights from patient-shared discussions that are often not captured in traditional clinical studies.⁴⁻⁵
- A prior social media listening study (2018–2023) identified significant patient-reported burden and unmet needs in HAE, supporting the need for continued monitoring of evolving patient perspectives.

OBJECTIVE

To assess the evolving patient-reported burden and unmet needs in hereditary angioedema using social media listening, by updating previously reported data (January 2018–October 2023) with findings from a recent period (November 2023–October 2025) and evaluate the impact of recent therapeutic advances on patient experience.

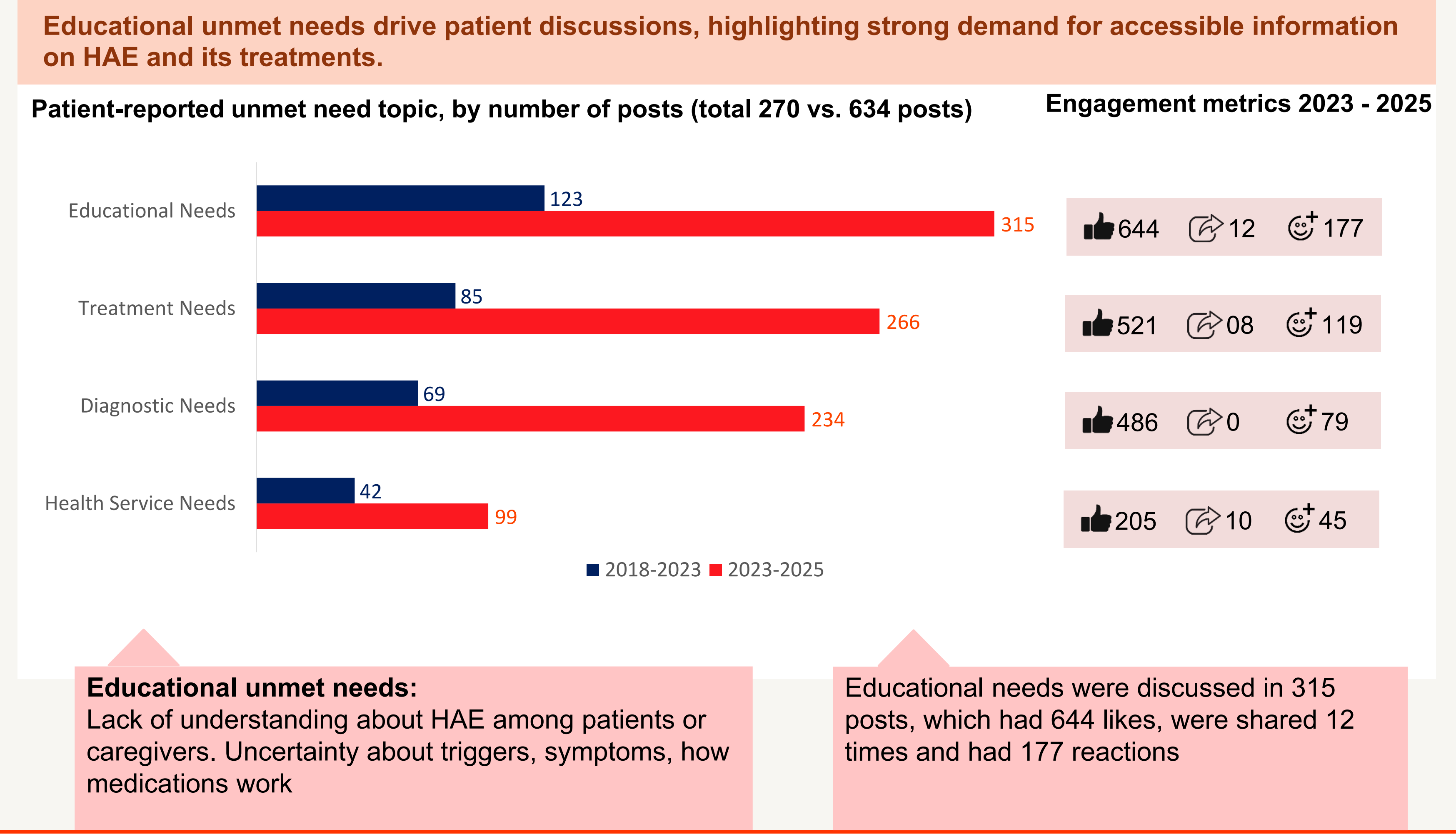
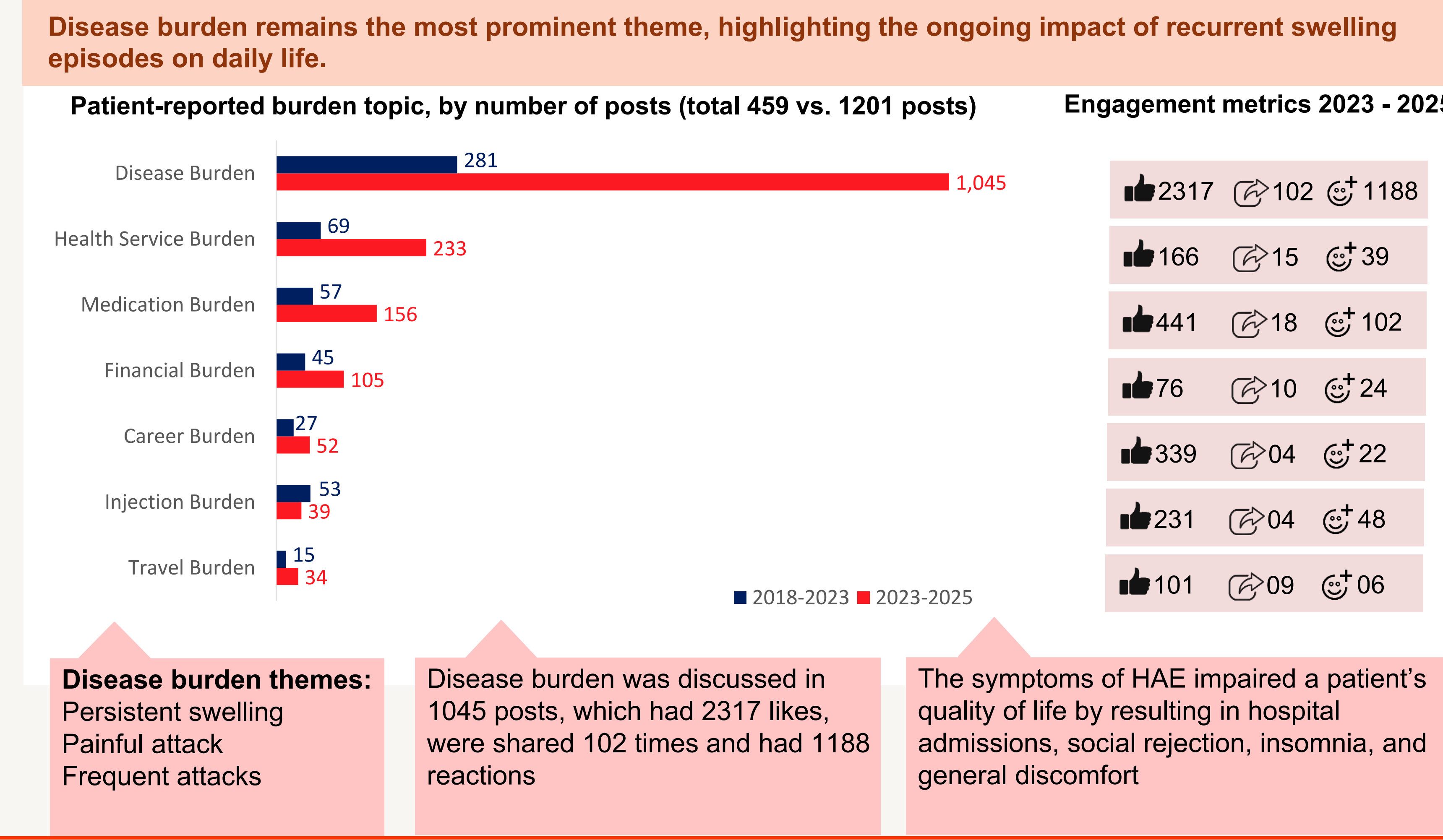
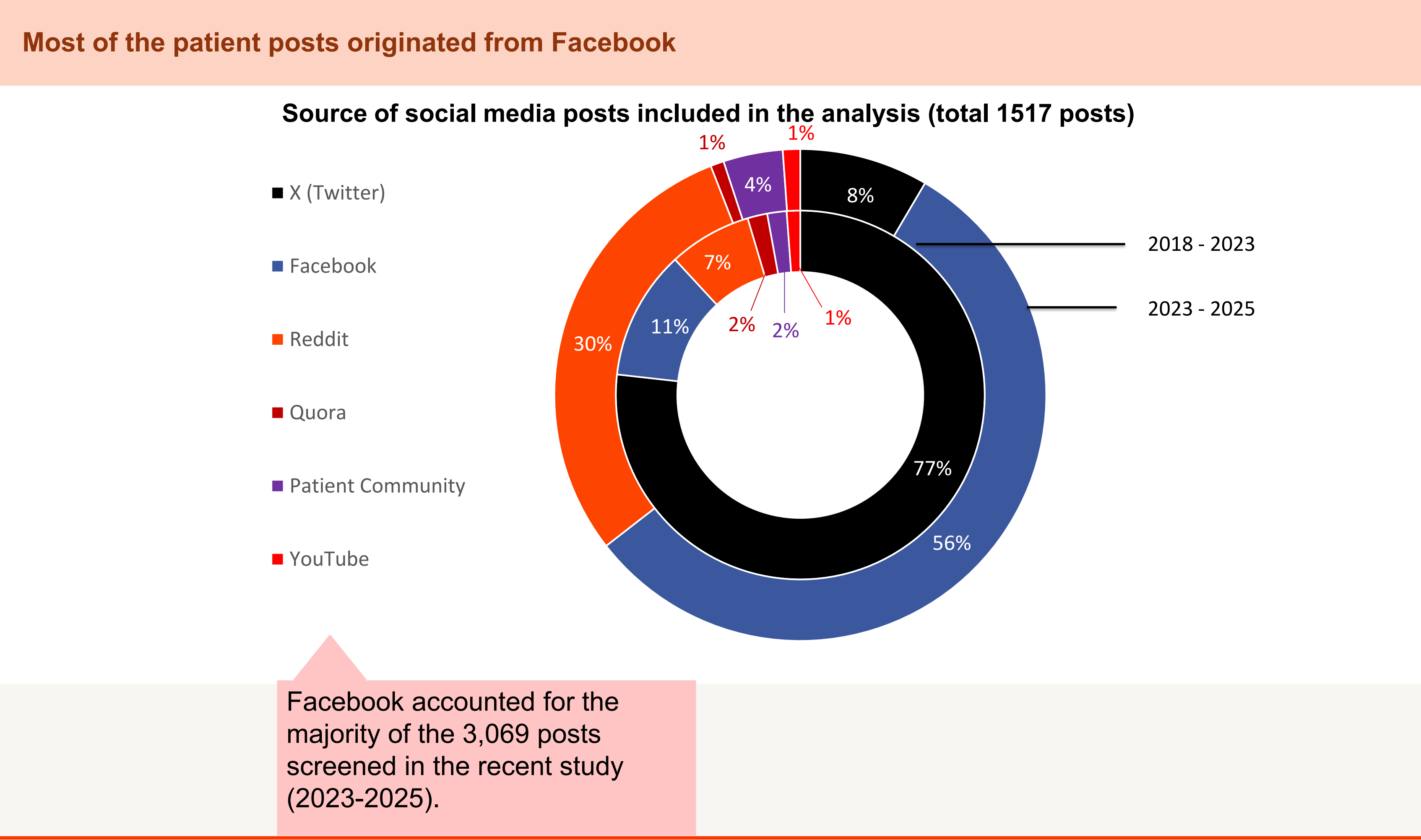
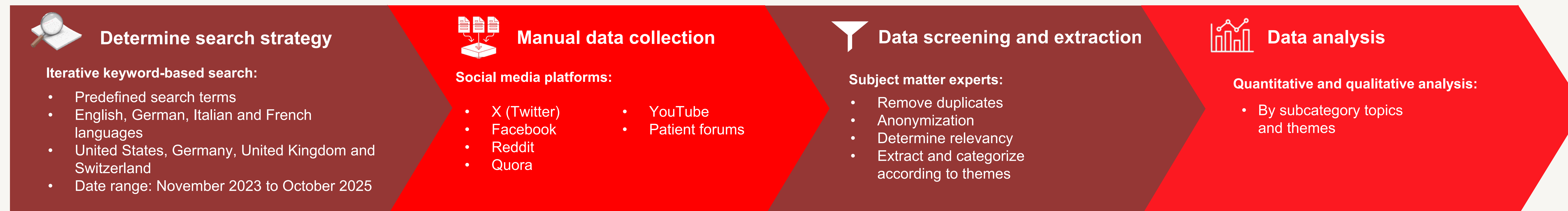
Jan 2018 – Oct 2023 (5.8 years)		Nov 2023 – Oct 2025 (2 years)	
892	Total HAE patient posts analyzed	1517	Total HAE patient posts analyzed
86%	Posted by patients, 10% posted by family/friends	90%	Posted by patients, 8% posted by family/friends
508	Posts identified from 2023, 130 posts from 2022	949	Posts identified from 2025, 395 posts from 2024

METHODS

- Publicly available HAE-related posts were identified using predefined keywords across social media platforms and patient forums.
- Screening: Anonymized posts were reviewed for relevance based on predefined criteria (HAE-related burden, treatment, or unmet needs); irrelevant content and posts with missing/unverifiable timestamps were excluded.
- Labelling: Posts were coded using a structured framework capturing patient-reported burden, unmet needs, treatment experience, symptoms, triggers, and misdiagnosis.
- Analysis: Subject matter experts validated tagging, and labelled data were analyzed descriptively to identify key themes and trends.

RESULTS

- Of 3,069 posts collected, 1,517 (49%) were relevant to HAE. Among these, 1,201 (79%) reported patient burden, predominantly disease-related (87%). Other burdens included health-service (19%), medication (13%), financial (9%), career-related (4%), and injection-related (3%).
- Unmet needs appeared in 42% (634/1,517) of posts. Educational gaps were most common (50%), followed by treatment-related needs (42%), driven by access, cost, and dissatisfaction. Diagnostic unmet needs were reported in 37%, and health service gaps in 16%. Other discussions included medications, symptoms, triggers, side effects, and misdiagnosis; posts on awareness, news, studies, or other diseases were excluded.
- Compared with the prior six-year analysis, both proportion and volume of posts increased for disease burden and unmet needs, indicating higher engagement. Proportions increased for disease burden (61% to 87%) and diagnostic (26% to 37%) and educational unmet needs (46% to 50%), while injection (12% to 3%) and career burden (6% to 4%) declined. Trends should be interpreted considering differences in timeframe, sample size, and platform shift from Twitter to Facebook.



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