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Real-world patient journey and unmet needs of people with hidradenitis suppurativa: social media research in China

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**Real-world patient journey and unmet needs of people with hidradenitis
suppurativa: social media research in China**

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Wenbo Bu received consulting fees from Novartis for his contributions to the development of research.

Li Yi has no conflict of interest to disclose.

Mei Go is an employee of Novartis.

Ivette Alarcon is an employee of Novartis and holds company stock.

Amit Garg is an advisor for AbbVie, Almirall, Bluefin Biomedicine, Boehringer Ingelheim, Immunitas Therapeutics, Incyte, Insmed, Navigator Medicines, Novartis, Oruka Therapeutics, Otsuka Pharmaceutical, Pfizer, Priovant, Sun Pharma, Takeda, UCB, and Zura Bio.

Patient consent: Not applicable.

Ethics statement

This study was based exclusively on the analysis of publicly available, anonymized social media content and did not involve any direct interaction with individuals or the

collection of identifiable personal data. No studies involving human participants were conducted by the authors. In line with established guidance for research using publicly accessible digital data, formal institutional ethics committee approval was, therefore, not required.

All data processing activities in China strictly comply with the legal framework centered on the Personal Information Protection Law, the Data Security Law, and the Cybersecurity Law. Approval was obtained from Novartis safety registry 1P1R, the governing body that holds oversight on the use of social media by Novartis (DE016220). All relevant local and global laws affecting and relating to the use of social media were aligned with and as reflected in Novartis processes, were followed in the conduct of the study.

Data availability statement

The data underlying this article will be shared at reasonable request to the corresponding author.

Declaration of generative AI and AI-assisted technologies in the manuscript preparation: No AI tools were used in the preparation of this manuscript

Meeting presentation: The results presented in this manuscript have not been published previously in whole or in part, except in abstract form at the European Academy of Dermatology and Venereology Congress, Paris, France, 17–20 September 2025. These results were also presented at the American Academy of Dermatology Congress, Denver, Colorado, United States, 27–31 March 2026.

69 **Author contribution statement**

70 All authors were involved in the conception and design of the study or analysis and
71 interpretation of data, drafting of the manuscript or revising it critically, and reading
72 and approving the final manuscript.

73 **Key words** (2-6 article key words): disease burden, hidradenitis suppurativa, pain,
74 patient journey, quality of life, China

75 Supplementary Material: <https://data.mendeley.com/datasets/4xtf67dgm9/1>

To the Editor: Hidradenitis suppurativa (HS) is a chronic, inflammatory skin disease that substantially impairs patients' quality of life (QoL).¹ In 2023, HS was classified as a rare disease in China,² enabling policy initiatives to enhance public awareness, diagnosis, and treatment access.³ Social media research (SMR) is increasingly used to gain insights into patient experiences and generate real-world data beyond clinical settings.⁴ The objective of this study was to understand key discussion topics, patient journey, symptoms, impact of HS on QoL, and unmet needs through assessment of social media posts in China. A post was categorized as containing QoL-related themes if it included clear indications of negative impact on daily life, such as:

- Physical discomfort (e.g., pain, mobility limitations)
- Emotional or psychological distress (e.g., frustration, embarrassment, anxiety)
- Disruption to daily activities, work, or social interactions, etc.

Duplicates were removed during data filtering. Each post was treated as an independent observation and served as the unit of analysis. This retrospective study (Sep 2022-Sep 2024) analyzed HS-related posts in Mandarin and English across social networking platforms and Online Diagnostics, focusing on HS-specific terms (**Mendeley supplementary Fig 1, Mendeley supplementary Table 1**). Detailed insights were generated against each metric (demographics, QoL impact, patient journey stages, key concerns, and unmet needs) to help answer the research questions (**Mendeley supplementary appendix**).

A total of 14,739 mentions of HS were captured across platforms, with WeChat (46%), Weibo (19%), and Xiaohongshu (18%) being most used. Of these, 1410 patient-centric posts were identified; 1016 relevant posts were coded for

insights (**Mendeley supplementary Fig 2**). Most posts were from people with HS, with males and females having a similar share of conversations where gender was identifiable.

The most frequently discussed topics included patient journey (n=874), QoL impact (n=559), and affected body parts (n=385). QoL impact was identified in 559 posts (**Fig 1**); emotional challenges were most frequently reported (86%; 483/559) followed by physical (56%; 315/559) and functional challenges (11%; 62/559). Social issues (3%; 17/559) and financial concerns (1%; 8/559) were also mentioned. Posts describing consultations (n=43) most commonly mentioned persistent pain (n=21) and pus (n=15).

Among treatment-related posts (n=694) surgery (n=329) was most mentioned, followed by antibiotics (n=133) and traditional Chinese medicine (n=116). Most common reason for treatment discontinuation (n=77) was inefficacy, followed by side effects. Drivers of current treatment were based on doctor's recommendation and efficacy, while barriers included ineffective treatment and side effects. Lack of effective, sustained treatment was identified as a substantial unmet need (**Fig 2**). In China, no biologic therapies were approved for HS during the study period, which may have influenced the treatment patterns observed in the posts.

The results of this SMR analysis reveal frequent discussion of disease burden, QoL-related challenges, and unmet needs in HS-related social media posts from China. These data indicate a need for improved awareness, timely diagnosis, and access to effective and sustained treatments to reduce the substantial burden of living with HS in China, including most bothersome symptoms (pain/pus).

Figure legends**Fig. 1.** Impact on quality of life

QoL, quality of life.

The total may be more than 100% due to multiple themes mentioned in a post.

Fig 2. Unmet needs emphasized by HCPs

HCP, healthcare professional; HS, hidradenitis suppurativa.

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Abbreviations

HS, hidradenitis suppurativa; QoL, quality of life; SMR, social media research; TCM, traditional Chinese medicine

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Emotional challenges:**n=483 (86%)**

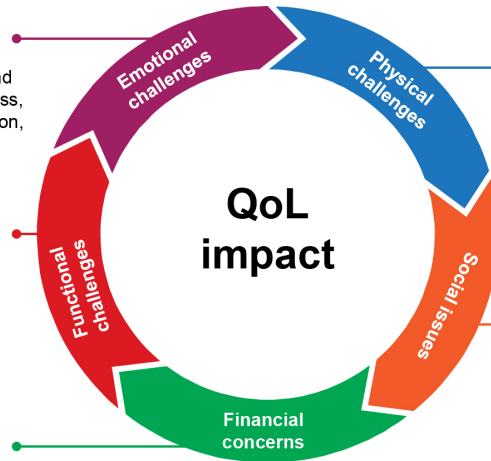
Ineffective treatment, visible symptoms, and recurring flare-ups caused emotional distress, including feelings of helplessness, frustration, and sadness.

Functional challenges:**n=62 (11%)**

Pain and physical limitations prevented patients from performing basic tasks and maintaining independence.

Financial concerns:**n=8 (1%)**

High treatment costs and lost income created financial burdens and stress.

**Physical challenges:****n=315 (56%)**

Chronic pain, abscesses, and scarring severely limited patients' mobility and daily functioning.

Social issues:**n=17 (3%)**

Stigma and misunderstanding led to social isolation and strained relationships.

Unmet needs (n=42)

