

Assessment of TikTok content on hidradenitis suppurativa: A qualitative and quantitative analysis

O que o TikTok realmente sabe sobre hidradenite supurativa? Uma análise qualitativa e quantitativa do conteúdo na rede social

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Dear Editor,

Hidradenitis suppurativa (HS) is a chronic, inflammatory dermatosis with profound psychosocial impact, often accompanied by pain, stigma, and depression^{1,2}. The dissemination of health information through social media has expanded public access to medical knowledge, but the rapid and unfiltered spread of content also raises concerns regarding misinformation. TikTok, one of the fastest-growing social media platforms globally, has emerged as an important source of health-related information for younger audiences³⁻⁵. Given the vulnerability of patients seeking guidance online, a critical evaluation of HS-related content on TikTok is warranted. Motivated by this need, we conducted a qualitative and quantitative analysis of the most widely viewed TikTok videos related to HS to assess both content accuracy and audience engagement.

We performed a cross-sectional observational study in May 2025, using the search terms “hidradenite,” “hidradenite supurativa,” “hidradenitis,” and “hidradenitis suppurativa.” For each term, the 20 most-liked videos were collected, minimizing algorithm-driven selection bias. After removal of duplicates and irrelevant videos, 42 unique clips were included for analysis. Two independent reviewers assessed engagement metrics, content accuracy, and creator profile. Accuracy was evaluated through a pre-defined checklist addressing etiology,

diagnosis, and treatment. Engagement was calculated by summing likes, comments, saves, and shares divided by the creator’s total follower count.

The 42 selected videos amassed 3.77 million likes, 56,196 comments, and 338,775 shares. Most videos were in English (69.0%) and were produced predominantly by patients or influencers (40.5%). Dermatologists accounted for 23.8% of the content. Two main narrative styles emerged: personal accounts (n = 23) and educational explanations (n = 20). While most videos conveyed at least some accurate information (90.5%), key topics were frequently omitted. Only 11.9% specified that HS is not contagious, 7.1% mentioned known triggers, such as obesity and smoking, and just 2.4% disputed the myth that HS is related to poor hygiene.

A striking finding was the “engagement paradox”: low-credibility sources – those containing no correct information according to our predefined criteria – achieved disproportionately higher engagement (418.04%) compared with dermatologists (7.88%), despite the latter demonstrating 100% accuracy. This suggests that accuracy alone does not predict reach on TikTok and that emotionally charged or sensationalized content may be preferentially amplified.

TikTok’s expansion to over two billion monthly active users worldwide, with nearly 80% of its audience aged 18-34, underscores its influence as an emerging

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health-information ecosystem⁶. Brazil ranks among the countries with the highest number of users, and an estimated 40% of young adults now report preferring TikTok over Google for information searches⁶. Although our analysis demonstrates that accurate content is present on the platform, its visibility remains limited when compared with low-accuracy posts. The predominance of high-engagement misinformation highlights a potentially harmful dynamic: the platform's algorithm may inadvertently magnify misleading content, particularly which is emotionally salient, while suppressing medically reliable information.

Our findings align with prior research showing that misinformation about HS circulates widely on social networks, contributing to diagnostic delays, patient confusion, and stigma^{4,5}. Importantly, the presence of correct but incomplete information may also reinforce misconceptions, such as the false association with hygiene or the neglect of modifiable risk factors. While social media offers unique opportunities to increase awareness of under-recognized diseases and shorten diagnostic timelines⁷, its unchecked influence demands active participation from healthcare professionals.

This study has limitations, including its cross-sectional design and relatively small sample size. TikTok's dynamic nature also means that trending content may shift rapidly, and engagement metrics can evolve over time. Nevertheless, the results provide a valuable snapshot of current HS-related discourse on one of the world's most influential platforms.

In conclusion, although most TikTok videos on HS contain at least partially correct information, significant knowledge gaps and high-engagement misinformation persist. Dermatologists and scientific societies should consider adopting proactive digital strategies, producing visually appealing and accessible content, and collaborating with credible influencers to expand the reach of evidence-based messages. Strengthening HS education on social media is essential to improving patient

outcomes, reducing stigma, and promoting accurate public understanding.

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Conflicts of interest

None.

Ethical considerations

Protection of human subjects and animals. The authors declare that no experiments on humans or animals were performed for this research.

Confidentiality, informed consent, and ethical approval. This study does not involve personal patient data, medical records, or biological samples, and does not require ethical approval. SAGER guidelines do not apply.

Declaration on the use of artificial intelligence (AI). The authors declare that no generative artificial intelligence was used in the writing or creation of the content of this manuscript.

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