

Complementary and Alternative Medicine for Hidradenitis Suppurativa Discussed on TikTok: A Cross-Sectional Analysis

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ABSTRACT

Background: Hidradenitis suppurativa (HS) is a painful, chronic inflammatory skin disease that negatively affects patient quality of life, and conventional treatments are variably effective. As a result, patients often turn to complementary and alternative medicine (CAM) for pain relief. Social media enables HS patients to share treatment recommendations. TikTok is a popular social media platform, but little is known about the HS treatments discussed in TikTok videos.

Objective: To evaluate the content and quality of information on TikTok regarding CAM HS therapies.

Methods: A cross-sectional analysis was conducted by performing a search in TikTok using the terms #hidradenitissuppurativa, #hswarrior, #naturalremedy, #complementarymedicine, #alternativemedicine, and #HStreatment. Two independent reviewers evaluated video quality using the DISCERN and AVA instruments. Linear regressions compared the engagement, DISCERN, and AVA scores among different uploader types.

Results: In total, 91 TikTok videos were analyzed. Videos were uploaded by non-physicians (82.4%), dermatologists (6.6%), and private companies (11.0%). The average DISCERN and AVA scores were 36.2 and 1.6, respectively (poor quality). Common CAM therapies were natural salves, turmeric, Epsom salts, elimination diets, and zinc supplements. Physician-uploaded videos were of significantly higher quality than videos by other uploader types, with an average DISCERN and AVA score of 44.3 ($P<0.009$) and 2.6 ($P<0.001$), respectively (fair quality).

Conclusion: TikTok videos were poor quality (low DISCERN and AVA scores); physician-uploaded videos were fair quality. Dermatologists can improve video quality by adequately discussing the supporting evidence, mechanisms of action, and remaining questions for HS treatments.

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INTRODUCTION

Hidradenitis suppurativa (HS) is a painful, chronic inflammatory skin disease that negatively impacts quality of life.¹⁻⁶ Conventional HS therapies are variably effective,² and patients often turn to complementary and alternative medicine (CAM) for relief.⁶

Most evidence supporting CAM therapies is anecdotal.³ Social media enables HS patients to share treatment recommendations with one another.^{1,7-10} TikTok is a popular social media platform, but little is known about the HS treatments discussed in TikTok videos.¹¹ This study aims to evaluate the content and quality of information shared on TikTok regarding CAM therapies for HS to better understand patient experiences and facilitate physician-patient discussions.

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MATERIALS AND METHODS

A cross-sectional analysis was conducted by performing a search in TikTok using the terms #hidradenitissuppurativa, #hswarrior, #naturalremedy, #complementarymedicine, #alternativemedicine, and #HStreatment. The top 60 videos discussing CAM HS treatments and the top 31 videos discussing conventional HS treatments were included. Videos were analyzed if they discussed HS treatment, and if they contained audio and/or text that could be analyzed for content quality. Videos were excluded if they did not meet these requirements.

For each video, descriptive characteristics, including uploader type (physician, non-physician, or private company) and viewer engagement score were collected.

TABLE 1.

Descriptive Characteristics of TikTok Videos Discussing HS Treatment Options								
	No. of Videos (%)	Mean No. of Likes	Mean No. of Comments	Mean No. of Views	Mean No. of Favorites	Mean Engagement Score (SEM)	Mean Discern Score (SEM)	Mean AVA Score (SEM)
Uploader Type								
Non-physician	75 (82.4)	2502.7	68.4	92,190.8	285.7	0.03 (0.003)	35.9 (0.8)	1.6 (0.1)
Physician	6 (6.6)	47764.0	635.2	1,117,700.0	9188.7	0.03 (0.01)	44.3 (2.9)	2.6 (0.2)
Private Company	10 (11.0)	3575	18.7	20,475.5	71.3	0.02 (0.01)	33.1 (3.6)	1.4 (0.3)
Gender								
Female	78 (85.7)	4793.5	85.6	138085.0	696.0	0.03 (0.002)	35.6 (0.8)	1.6 (0.1)
Male	8 (8.8)	12169.9	300.4	352562.5	2795.6	0.04 (0.01)	40.8 (3.1)	2.3 (0.3)
N/A or Unknown	5 (5.5)	1647.0	13.5	58123.0	413.0	0.03 (0.01)	40.6 (7.9)	1.8 (0.6)
Video Category								
Information/how-to	18 (19.8)	16662.3	231.8	401741.2	3405.4	0.03 (0.004)	40.9 (2.0)	2.1 (0.2)
Information/how-to and personal anecdote	7 (7.7)	1183.1	38.9	37736.6	257.7	0.03 (0.01)	37.6 (2.6)	1.7 (0.2)
Information/how-to and product advertisement	2 (2.2)	173.5	3.0	30314.0	4.0	0.01 (0.01)	34.5 (6.0)	1.5 (0.5)
Personal anecdote	49 (53.9)	3222.4	87.3	115666.2	307.6	0.03 (0.003)	35.5 (1.1)	1.6 (0.1)
Personal anecdote and product advertisement	6 (6.6)	415.0	19.5	21038.3	75.7	0.03 (0.01)	35.1 (2.0)	1.3 (0.2)
Product advertisement	9 (9.9)	991.4	31.8	52807.0	187.7	0.02 (0.002)	30.1 (1.6)	0.9 (0.2)

HS, hidradenitis suppurativa; SEM, standard error of the mean; AVA, Armstrong Viewer Assessment

Two independent reviewers evaluated video quality using the Armstrong Viewer Assessment (AVA) and the validated DISCERN instrument.^{12,13} Possible DISCERN scores range from 16-26 (very poor), 27-38 (poor), 39-50 (fair), 51-62 (good), and 63-75 (excellent).¹² AVA scores range from 0 (very poor) to 4 (very good).¹³

Linear regressions were conducted to compare engagement, DISCERN, and AVA scores among different uploader types. Three linear regressions were performed to compare one uploader type to the other uploader types combined (eg, physician-uploaded videos were compared to videos uploaded by non-physicians and private companies combined).

RESULTS

Overall, 91 TikTok videos were analyzed. Most videos (82.4%) were uploaded by non-physicians, 6.6% by dermatologists, and 11.0% by private companies (Table 1). The average DISCERN and AVA scores were 36.2 and 1.6, respectively (poor quality). Lower scores signify worse quality, while higher scores signify better quality. The most mentioned HS treatments and CAM therapies are listed in Tables 2 and 3, respectively. Common CAM therapies were natural salves, turmeric, Epsom salts, elimination diets, and zinc supplements (Table 3).

Compared to videos uploaded by physicians and private companies, non-physician videos did not differ in viewer engagement ($P=0.548$) or quality (DISCERN score: $P=0.547$,

TABLE 2.

Most Common Treatments for HS Mentioned in TikTok Videos Overall	
Treatment Type	% of Videos Mentioned
CAM skincare recommendations	34.1%
Dietary changes	25.3%
Hibiclens solution	18.7%
Topical antibiotics	15.4%
Biologic medications	12.1%
Vitamins, supplements	11.0%
Advice on wound care	11.0%
Oral antibiotics	9.9%
Epsom salt baths	7.7%
Topical benzoyl peroxide	5.5%
Surgery	5.5%
Topical analgesics	5.5%

HS, hidradenitis suppurativa; CAM, complementary and alternative medicine

AVA score: $P=0.293$; Table 4). Compared to videos uploaded by non-physicians and private companies, physician-uploaded videos did not differ in viewer engagement ($P=0.550$); video quality was significantly higher with an average DISCERN and AVA score of 44.3 ($P<0.009$) and 2.6 ($P<0.001$), respectively (fair quality) (Tables 1, 5). Compared to physicians and non-physicians, private company videos did not differ in viewer engagement ($P=0.227$) or quality (DISCERN score: $P=0.193$, AVA score: $P=0.211$; Table 6).

TABLE 3.

Most Common Specific CAM Treatments for HS Mentioned in TikTok Videos	
Treatment Type	% of Videos Mentioned
Beeswax and propolis salve	9.9%
Turmeric	8.8%
Epsom salt baths	7.7%
Autoimmune elimination protocol diet	6.6%
Zinc supplements	4.4%
Apple cider vinegar	3.3%
Exfoliation	3.3%
Tea tree oil	3.3%
Vitamin E oil	3.3%
Topical products with unknown ingredients	3.3%
Castile soap	3.3%

CAM, complementary and alternative medicine; HS, hidradenitis suppurativa

DISCUSSION

HS is a painful, chronic disease, and patients often turn to CAM therapies for relief.⁵ This study is among the first to investigate CAM HS treatments discussed on TikTok. The most common CAM HS treatments included beeswax and propolis salves, turmeric, Epsom salt baths, elimination diets, and zinc supplements.

While these CAM therapies lack strong evidence supporting their efficacy for treating HS, they may have therapeutic benefits.¹⁴⁻¹⁷ For example, propolis and beeswax possess anti-inflammatory and antimicrobial properties.¹⁵ Magnesium in Epsom salts may regulate keratinocyte proliferation, and zinc has been found to promote wound healing in cases of mild-moderate HS.^{14,18} Turmeric possesses anti-inflammatory and immune-regulatory effects.^{16,17} Elimination diets may balance

TABLE 4.

Linear Regression Comparing Viewer Engagement and Quality of Videos Posted by Non-Physicians Compared to Physicians and Private Companies			
		b-Coefficient (95% CI)	P-value*
Engagement Score	Physicians and Private Companies	(Ref)	--
	Non-physicians	0.003 (-0.008-0.015)	0.548
DISCERN score	Physicians and Private Companies	(Ref)	--
	Non-physicians	-1.3 (-5.7 – 3.0)	0.547
Armstrong Viewer Assessment Score	Physicians and Private Companies	(Ref)	--
	Non-physicians	-0.2 (-0.6 – 0.2)	0.293

*Statistical significance was determined at *P*<0.05.

TABLE 5.

Linear Regression Comparing Viewer Engagement and Quality of Videos Posted by Physicians Compared to Non-Physicians and Private Companies			
		b-Coefficient (95% CI)	P-value*
Engagement Score	Non-physicians and Private Companies	(Ref)	--
	Physicians	0.005 (-0.012 – 0.023)	0.550
DISCERN score	Non-physicians and Private Companies	(Ref)	--
	Physicians	8.7 (2.2 – 15.1)	0.009
Armstrong Viewer Assessment Score	Non-physicians and Private Companies	(Ref)	--
	Physicians	1.02 (0.42 – 1.62)	0.001

*Statistical significance was determined at *P*<0.05.

TABLE 6.

Linear Regression Comparing Viewer Engagement and Quality of Videos Posted by Private Companies Compared to Physicians and Non-Physicians			
		b-Coefficient (95% CI)	P-value*
Engagement Score	Physicians and non-physicians	(Ref)	--
	Private Companies	-0.01 (-0.02 – 0.01)	0.227
DISCERN score	Physicians and non-physicians	(Ref)	--
	Private Companies	-3.5 (-8.8 – 1.8)	0.193
Armstrong Viewer Assessment Score	Physicians and non-physicians	(Ref)	--
	Private Companies	-0.3 (-0.8 – 0.2)	0.211

*Statistical significance was determined at *P*<0.05.

the gut microbiome and decrease inflammation by removing dietary triggers.¹⁷

Overall, the TikTok videos were poor in quality (low DISCERN and AVA scores); videos did not explain the treatment mechanism of action, risks associated with treatment, supporting evidence, or treatment alternatives. While physician-uploaded videos were significantly higher quality than other uploader types, their average quality was only fair because they did not consistently discuss how treatments worked, provide supporting evidence, or refer to remaining gaps in knowledge. Because most video uploaders were non-physicians, great potential exists for dermatologists to use TikTok to discuss HS.¹¹ They can utilize this opportunity well by creating videos that adequately discuss the supporting evidence, mechanisms of action, and remaining questions for HS treatments.

DISCLOSURES

Authors HP, PK, KL, DY, MYH, EK, and RA have no conflicts of interest to declare. AWA has served as a research investigator, scientific advisor, or speaker to AbbVie, Amgen, Almirall, Arcutis, ASLAN, Beiersdorf, BI, BMS, EPI, Incyte, Leo, UCB, Janssen, Lilly, Mindera, Nimbus, Novartis, Ortho, Sun, Dermavant, Dermira, Sanofi, Takeda, Organon, Regeneron, Pfizer and Ventyx." No other changes are required to the other authors' disclosures.

REFERENCES

1. Yesantharao LV, Suresh R, Lerman SF, et al. Hidradenitis suppurativa reddit support group: finding new meaning in social media during the covid-19 pandemic. *J Burn Care Res.* 2023;44(2):373-380. doi:10.1093/jbcr/irac183
2. Scala E, Cacciapuoli S, Garzorz-Stark N, et al. Hidradenitis suppurativa: where we are and where we are going. *Cells.* 2021;10(8). doi:10.3390/cells10082094
3. Macklis PC, Tyler K, Kaffenberger J, et al. Lifestyle modifications associated with symptom improvement in hidradenitis suppurativa patients. *Arch Dermatol Res.* Apr 2022;314(3):293-300. doi:10.1007/s00403-021-02233-y
4. Price KN, Collier EK, Grogan T, et al. Physician perspectives on complementary and alternative medicine in hidradenitis suppurativa. *Dermatol Ther.* 2021;34(2)
5. Price KN, Thompson AM, Rizvi O, et al. Complementary and alternative medicine use in patients with hidradenitis suppurativa. *JAMA.* 2020;156(3):345-348. doi:10.1001/jamadermatol.2019.4595
6. Kearney N, Byrne N, Kirby B, et al. Complementary and alternative medicine use in hidradenitis suppurativa. *Br J Dermatol.* 2020;182(2):484-485. doi:10.1111/bjd.18426
7. Golbari NM, Porter ML, Kimball AB. Online communications among hidradenitis suppurativa patients reflect community needs. *J Am Acad Dermatol.* 2019;80(6):1760-1762. doi:10.1016/j.jaad.2018.08.031
8. Fisher S, Jehassi A, Ziv M. Hidradenitis suppurativa on Facebook: thematic and content analyses of patient support group. *Arch Dermatol Res.* 2020;312(6):421-426. doi:10.1007/s00403-019-02027-3
9. Lukac D, Pagani K, Yi J, et al. Consulting 'Dr YouTube': a content analysis of YouTube® videos related to hidradenitis suppurativa treatments. *Clin Exp Dermatol.* 2022;47(3)doi:10.1111/ced.15017
10. Li W, Ma JE, Chan AA, et al. Hidradenitis suppurativa through the lens of YouTube: A cross-sectional analysis. *J Am Acad Dermatol.* 2021;84(5):1398-1399. doi:10.1016/j.jaad.2020.05.148

11. Szeto MD, Mamo A, Afrin A, et al. Social Media in dermatology and an overview of popular social media platforms. *Curr Dermatol Rep.* 2021;10(4):97-104. doi:10.1007/s13671-021-00343-4
12. Charnock D, Shepperd S, Needham G, et al. DISCERN: an instrument for judging the quality of written consumer health information on treatment choices. *J Epidemiol Community Health.* 1999;53(2):105-111. doi:10.1136/jech.53.2.105
13. Chen AY, Azizi B, Borba AJ, et al. Rosacea videos on social media: A comparison of accuracy, quality, and viewer engagement. *Dermatol Online J.* 2021;27(2):13030/qt55c0g9wz. doi:10.5070/d3272052381
14. Polefka TG, Bianchini RJ, Shapiro S. Interaction of mineral salts with the skin: a literature survey. *Int J Cosmet Sci.* 2012;34(5):416-23. doi:10.1111/j.1468-2494.2012.00731.x
15. Kurek-Gorecka A, Gorecki M, Rzepecka-Stojko A, et al. Bee products in dermatology and skin care. *Molecules.* 2020;25(3):556. doi:10.3390/molecules25030556
16. Zhang HA, Kitts DD. Turmeric and its bioactive constituents trigger cell signaling mechanisms that protect against diabetes and cardiovascular diseases. *Mol Cell Biochem.* 2021;476(10):3785-3814. doi:10.1007/s11010-021-04201-6
17. Silfvast-Kaiser A, Youssef R, Paek SY. Diet in hidradenitis suppurativa: a review of published and lay literature. *Int J Dermatol.* 2019;58(11):1225-1230. doi:10.1111/ijd.14465
18. Molinelli E, Brisigotti V, Campanati A, et al. Efficacy of oral zinc and nicotinamide as maintenance therapy for mild/moderate hidradenitis suppurativa: A controlled retrospective clinical study. *J Am Acad Dermatol.* 2020;83(2):665-667. doi:10.1016/j.jaad.2020.04.092

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