

Evaluating lichen sclerosus content on TikTok by content creators: a cross-sectional analysis

Keywords: lichen sclerosus, social media, TikTok, vulvar dermatology, vulvar lichen sclerosus

Introduction

Vulvar lichen sclerosus (VLS) is a chronic inflammatory dermatosis affecting an estimated 1 in 900 girls and can impact women's self-image, sexual well-being, and quality of life.^{1,2} VLS is often underdiagnosed and undertreated due to underreported symptoms and recognition.³ TikTok has been used to increase VLS awareness. Notably, 82% of dermatology patients use the internet or social media for medical information,⁴ which can impact patient-physician relationships. This project sought to assess the quality of TikTok videos on VLS.

Materials and Methods

In May 2023, the following terms were entered into TikTok's search algorithm: "lichen sclerosus," "lichen sclerosis," "lichen sclerosus treatment," and "lichen sclerosus symptoms." The top 50 videos for each term (200 total) were reviewed, and 91 videos met the inclusion criteria. Information on video characteristics and creators was collected. Video quality was evaluated by a VLS expert and two medical students, using DISCERN,⁵ a validated 16-item questionnaire that assesses consumer health information quality based on criteria such as references and has been widely used to evaluate audio/visual (A/V) health information,⁶ and Patient Education Materials Assessment Tool (PEMAT) A/V,⁷ a validated tool that assesses understandability and actionability of A/V materials. Statistical analyses were performed using ANOVA, the Tukey honestly significant difference post hoc, and *t* test.

Results

ANOVA analyses revealed a significant effect of content creators on DISCERN and PEMAT scores: DISCERN, $F(4, 34) = 3.701$ and $P = .013$; PEMAT Total, $F(4, 86) = 4.181$ and $P = .004$; PEMAT understandability, $F(4, 86) = 5.169$ and $P < .001$; and PEMAT actionability, $F(4, 86) = 3.140$ and $P = .018$ scores. Tukey honestly significant difference post hoc tests revealed significant differences in mean DISCERN scores ($M_D = 8.05$ and $P = .039$), mean PEMAT total scores ($M_D = 22.82$ and $P = .005$), and mean PEMAT understandability scores ($M_D = 19.05$ and $P < .001$) between physicians and patients as content creators. Descriptive statistics for video

characteristics and creators are found in Table 1. Two-sided *t* tests revealed significantly higher DISCERN and PEMAT understandability and actionability scores among physicians versus nonphysicians and healthcare versus nonhealthcare content creators (Table 2).

Discussion

VLS is stigmatized, and those affected may be uncomfortable sharing symptoms with their healthcare team. Thus, patients may initially turn to social media and other online sources to gather disease information. On TikTok, healthcare professionals were more likely to review disease etiology, physical exam findings/symptomatology, and treatment with topical steroids, while nonhealthcare creators focused on disease experience, lifestyle impact, and home remedies. Of the videos evaluated in this study, nonhealthcare content creators generate the most videos, views, likes, comments, and shares on TikTok. However, based on DISCERN and PEMAT A/V scores, healthcare creators produced higher quality health information by acknowledging relevant sources and discussing treatment benefits, risks, and other actionable items more often than nonhealthcare creators (Table 2). These findings demonstrate a need for more healthcare professional-created educational videos about VLS. We urge experts to establish scientific standards and create more accurate and accessible materials to make social media platforms more effective resources for patients and foster a stronger therapeutic alliance between patients and their healthcare providers. Limitations include the sample size, focus on one platform, and the cross-sectional design, given social media's rapid turnover.

What is known about this subject in regard to women and their families?

- Vulvar lichen sclerosus is a debilitating disease that is often undertreated due to underreported symptoms and recognition. Many women and their families turn to the internet or social media to obtain medical information; however, not all information found on these platforms is evidence-based.

What is new from this article as messages for women and their families?

- Most of the information that women and their families may find about vulvar lichen sclerosus on TikTok is created by nonhealthcare individuals and is of lower quality health information. Additionally, these nonhealthcare content creators utilize relevant sources and discuss treatment benefits, risks, and other actionable items less often than healthcare creators.

Copyright © 2025 The Authors. Published by Wolters Kluwer Health, Inc. on behalf of Women's Dermatologic Society. This is an open-access article distributed under the terms of the Creative Commons Attribution-Non Commercial-No Derivatives License 4.0 (CCBY-NC-ND), where it is permissible to download and share the work provided it is properly cited. The work cannot be changed in any way or used commercially without permission from the journal.

International Journal of Women's Dermatology (2025) 11:e198

Received: 12 June 2024; Accepted: 3 January 2025

Published online 6 February 2025

DOI: 10.1097/JW9.0000000000000198

Table 1**Overview of VLS video characteristics, creators, and content on TikTok**

Average views by creator type	Number of views
Patient	62,077
Physician	91,709
Other content creator	92,300
Other healthcare professional ^a	11,281
Company	4,606
Average likes by creator type	Number of likes
Patient	4,687
Physician	1,133
Other content creator	2,039
Other healthcare professional	169
Company	95
Average comments by creator type	Number of comments
Patient	81,687
Physician	78
Other content creator	48
Other healthcare professional	25
Company	8
Average shares by creator type	Number of shares
Patient	86
Physician	50
Other content creator	43
Other healthcare professional	16
Company	9
Creator type	% (number) of videos
Patient	40% (36)
Physician	27% (25)
Other content creator	18% (16)
Other healthcare professional	9% (8)
Company	7% (6)
Physician specialty	% (number) of videos
Dermatology	32% (8)
OBGYN	40% (10)
GP/IM	16% (4)
Uro-Gyn	12% (3)
Video discussion	% (number) of videos
Personal experience	37% (34)
Educational LS content	55% (50)
Treatment advertising	9% (8)
Treatment/management	47% (43)
Disease etiology	42% (38)
Diagnosis	62% (56)
Impact on lifestyle	38% (35)
Physical exam/symptoms	69% (63)
Treatments discussed	% (number) of videos
Topical steroids	55% (28)
Nontopical steroids	24% (12)
Laser	10% (5)
Surgery	6% (3)
Hormone modification	10% (5)
Other treatment	27% (14)
Site mentioned	% (number) of videos
Vulva	53% (48)
Genitals	18% (16)
Extragenital	4% (4)
Anus	1% (1)
Pelvis	1% (1)
N/A	30% (27)

GP/IM, general practitioner/internal medicine; LS, lichen sclerosis; OBGYN, obstetrician-gynecologist; Uro-Gyn, urogynecologist; VLS, vulvar lichen sclerosis.

^aOther healthcare professionals included pelvic floor physical therapists, nurses, functional medicine practitioners, and sexual and reproductive health accounts.

Conflicts of interest

The authors declare no conflicts of interest.

Funding

None.

Table 2**Average TikTok DISCERN and PEMAT scores by creator type**

	Mean	T test (2-sided P) ^a
DISCERN score		
Physician	36.13	<.001
Nonphysician ^b	27.66	
Healthcare ^c	34.63	.002
Nonhealthcare ^d	27.28	
PEMAT total score		
Physician	63.27	.004
Nonphysician	47.83	
Healthcare	63.57	<.001
Nonhealthcare	45.53	
PEMAT understandability score		
Physician	67.62	.003
Nonphysician	54.45	
Healthcare	66.99	<.001
Nonhealthcare	52.99	
PEMAT actionability score		
Physician	54.67	.040
Nonphysician	35.29	
Healthcare	57.07	.003
Nonhealthcare	31.25	

PEMAT, Patient Education Materials Assessment Tool.

^aThe t test with equal variances assumed.

^bPhysician vs nonphysician (patient, other content creator, other healthcare professional, and company).

^cHealthcare (physicians and other healthcare professionals) vs

^dnonhealthcare (patient, other content creators, and company).

Study approval

N/A

Author contributions

MJE: Participated in research design, writing of the paper, performance of the research, and data analysis. JKB: Participated in research design, writing of the paper, performance of the research, and data analysis. CNK: Participated in research design, writing of the paper, performance of the research, and data analysis.

References

- Powell J, Wojnarowska F. Childhood vulvar lichen sclerosis: an increasingly common problem. *J Am Acad Dermatol* 2001;44:803–6.
- Morrel B, Ten Kate-Booij MJ, van Dijk C, et al. Outcome measures in adult vulvar lichen sclerosis: a systematic review. *J Low Genit Tract Dis* 2024;28:282–94.
- Melnick LE, Steuer AB, Bieber AK, Wong PW, Pomeranz MK. Lichen sclerosis among women in the United States. *Int J Womens Dermatol* 2020;6:260–2.
- Gantenbein L, Navarini AA, Maul LV, Brandt O, Mueller SM. Internet and social media use in dermatology patients: search behavior and impact on patient-physician relationship. *Dermatol Ther* 2020;33:e14098.
- Charnock D, Shepperd S, Needham G, Discern GR. An instrument for judging the quality of written consumer health information on treatment choices. *J Epidemiol Community Health* 1999;53:105–11.
- Xue X, Yang X, Xu W, Liu G, Xie Y, Ji Z. TikTok as an information hodgepodge: evaluation of the quality and reliability of genitourinary cancers related content. *Front Oncol* 2022;12:789956.
- Shoemaker SJ, Wolf MS, Brach C. Development of the Patient Education Materials Assessment Tool (PEMAT): a new measure of understandability and actionability for print and audiovisual patient information. *Patient Educ Couns* 2014;96:395–403.

Maria J. Etcheverry, BS^{a,*}

Jordan K. Bui, BS^a

Christina N. Kraus, MD^b

^a Georgetown University School of Medicine, Washington, District of Columbia

^b Department of Dermatology, University of California, Irvine, Irvine, California

* Corresponding author.

E-mail address: mje67@georgetown.edu (M.J. Etcheverry)