Research Letter

A Cross-Sectional Analysis of the Quality and Inclusivity of Central Centrifugal Cicatricial Alopecia Content on TikTok

Angela Anaeme[1], BS; Amanda Zhu[1], BA; Albertina Lee[1], BA; Caroline Mann[2], MD

[1]Washington University School of Medicine, Washington University in St. Louis, Saint Louis, MO, United States
[2]Division of Dermatology, John T. Milliken Department of Medicine, Washington University in St. Louis, Saint Louis, MO, United States

Corresponding Author:

Angela Anaeme, BS
Washington University School of Medicine
Washington University in St. Louis
660 S Euclid Ave
Saint Louis, MO 63110
United States
Phone: 1 314-362-5000
Email: a.anaeme@wustl.edu

Abstract

In this cross-sectional analysis of TikTok content related to central centrifugal cicatricial alopecia (CCCA), physician-created videos demonstrated significantly higher QUEST (Quality Evaluation Scoring Tool) scores than nonphysician content, while discussion of racial disparities and skin-of-color considerations in CCCA were limited across all creators on the platform.

JMIR Dermatol 2026;9:e102828; doi: 10.2196/102828

Keywords: central centrifugal cicatricial alopecia; hair loss; social media; health literacy; TikTok; skin color; inclusivity; medical influencer; health information; QUEST score; Quality Evaluation Scoring Tool

Introduction

Social media plays an undeniable role in the dissemination of health information and accessibility of medical information. This role has become increasingly prominent in dermatology, with one cross-sectional study finding 82.4% of dermatology patients used social media to gain medical information about their concerns before seeking care [1]. However, accessibility of online health resources remains unequal. For instance, among African Americans, higher socioeconomic status is associated with significantly greater technology access, which is in turn associated with reduced health care disparities [2,3]. These disparities are particularly relevant as patients increasingly seek out health information online before receiving care. Online dermatologic content may serve as a bridge, influencing whether patients recognize concerning symptoms, seek professional evaluation, and understand treatment options. Therefore, characterizing the quality of this information is important for identifying gaps that could contribute to delayed or misinformed care.

Central centrifugal cicatricial alopecia (CCCA) is a form of scarring alopecia characterized by progressive, tender, and permanent hair loss at the crown of the scalp [4]. CCCA disproportionately affects Black women, with estimates reaching up to 15% of this population [4]. Notably, the very community that CCCA impacts most often has been consistently shown to also experience technology inequity, defined as limited access to telehealth, electronic health records, and virtual technologies [2]. Given both the disproportionate burden of CCCA among Black women and documented disparities in access to digital health resources among African American communities, understanding how CCCA is represented on widely used social media platforms is critical. Here, we conduct a cross-sectional analysis of CCCA content on TikTok to assess markers of information quality, as well as discussion of racial disparities relevant to CCCA, including the disproportionate burden among Black women and inequities in disease recognition, diagnosis, and care.

Methods

Search and Evaluation

On May 5, 2026, we conducted a TikTok query to identify videos pertaining to CCCA using search terms “central centrifugal cicatricial alopecia,” “CCCA,” “scarring

alopecia," "hot comb alopecia," and "crown hair loss." All searches were conducted while logged out of TikTok to minimize account-specific algorithmic influences on search results. Exclusion criteria included non-English posts, duplicates, and videos that did not explicitly discuss CCCA.

Videos were assessed using QUEST (Quality Evaluation Scoring Tool), a validated questionnaire for appraising the quality of online health information content [5]. QUEST evaluates 6 domains of online health information: authorship, attribution, conflict of interest, currency, complementarity, and tone. Two independent reviewers rated each video, and a subset of 50 videos were rated by both reviewers to calculate interrater reliability.

Additionally, videos were binarily scored for whether they included discussion of skin of color disparities in CCCA. Videos received a score of 1 if disparity-related content was discussed and a 0 if no such content was presented. Given differences in creator perspectives and credentials, qualifying discussion was not restricted to a single predefined disparity and could reflect either clinical or lived experiences. Examples included recognition of CCCA's disproportionate prevalence among Black women, delayed accurate diagnosis or treatment of hair loss in Black women, historical misclassification of the disease, or patient-described experiences of inequity related to CCCA care [6-8].

Ethical Considerations

This research did not involve human participants or animals; therefore, ethical approval from an institutional review board was not required.

Results

A total of 111 videos were identified (Table 1), which accrued a total of 181,700 views, 103,290 likes, 8074 comments, and 31,353 saves. The mean overall QUEST score was 6.15. Cohen κ across all individual QUEST items was 0.80, indicating substantial interrater reliability. Patients comprised the largest creator group (n=52, 46.8%), followed by trichologists (n=28, 25.2%) and dermatologists (n=16, 14.4%). Hairstylists, nurses, entrepreneurs, and businesses represented smaller proportions of included videos. Overall, most CCCA-related TikTok content came from nonphysician creators.

Table 1. Overview of the statistics related to CCCA content on TikTok.

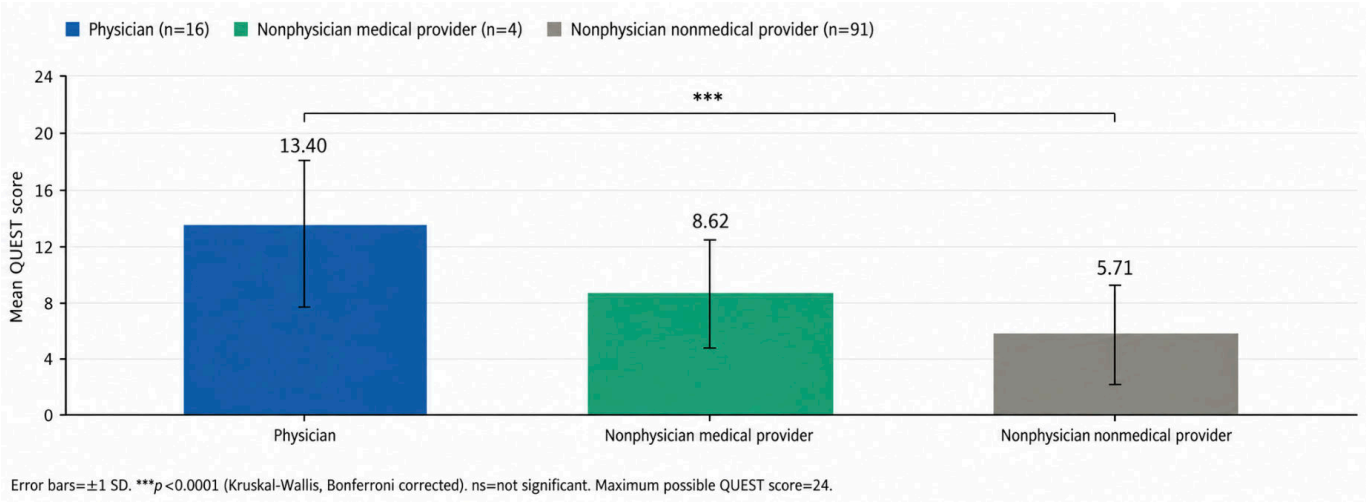
Content variables	Videos, n/111 (%)	Number of views, mean	Number of likes, mean	Number of comments, mean	QUEST[a] score, mean
Creator type					
Physician	16 (14.4)	45,951	848.5	55.1	13.40[b]
Nonphysician	4 (3.6)	7084	266.8	26.5	8.62[b]
Private company	91 (82.0)	53,058	993.3	79.2	5.71[b]
Creator specialization					
Dermatologist	16 (14.4)	43,424	802.3	52.3	12.72
Trichologist	28 (25.2)	40,258	1096.4	93.8	4.61
Patient	52 (46.8)	68,202	1006.8	78.4	6.69
Hairstylist	6 (5.4)	19,116	823.7	62.3	5.00
Nurse (RN[c])	2 (1.8)	3570	252.0	39.5	12.75
Nurse (NP[d])	1 (0.9)	17,300	465.0	25.0	4.50
Entrepreneur	4 (3.6)	10,444	475.2	25.2	2.50
Hair care company	1 (0.9)	1824	602.0	37.0	3.00
Business	1 (0.9)	146	4.0	0	4.00
Creator gender					
Female	103 (92.8)	52,264	967.6	75.3	6.39
Male	8 (7.2)	21,023	575.5	48.8	12.38
Video type					
Educational content	39 (35.1)	29,668	770.5	51.0	8.62
Treatment advice	6 (5.4)	39,956	747.8	62.7	9.58
Personal experience	43 (38.7)	76,261	1097.9	85.9	6.66
Promotional content/advertisement	13 (11.7)	48,383	1430.4	136.8	2.31
Other	10 (9.01)	22,329	404.2	35.2	5.38

[a]QUEST: Quality Evaluation Scoring Tool.
[b]SD for the mean QUEST score was 5.99 for physicians, 4.13 for nonphysicians, and 3.72 for private company creators. SDs reported only for means used in formal comparisons.

[c]RN: registered nurse.
[d]NP: nurse practitioner.

Content created by physicians demonstrated significantly higher QUEST scores compared to nonphysician creators (mean 13.40, SD 5.99 vs mean 5.71, SD 3.72; Kruskal-Wallis H=20.25; P<.0001; Figure 1). Dermatologists and registered nurses received the highest QUEST scores overall, while promotional and advertisement-based videos demonstrated the lowest QUEST scores. Educational and treatment-focused videos generally scored higher than personal experience or promotional content. Patient-generated videos comprised a substantial proportion of analyzed content and frequently demonstrated high engagement metrics despite lower mean QUEST scores compared to physician-generated educational videos. Notably, out of all 111 videos, only 31 (28%) discussed racial disparities, skin of color considerations, or the disproportionate burden of CCCA among Black women.

Figure 1. Association between creator credentials and QUEST (Quality Evaluation Scoring Tool) scores.



Discussion

These findings suggest that TikTok serves as a highly engaged but variably reliable source of information about CCCA. Physician-created content was associated with statistically significantly higher QUEST scores but represented a minority of videos. In contrast, lower-scoring anecdotal content frequently achieved high engagement, demonstrating that popularity does not necessarily correspond with QUEST-assessed marker of information quality. Increased dermatologist participation in social media discussions surrounding CCCA may improve access to evidence-based, culturally inclusive educational content for populations disproportionately affected by this condition. Importantly, differences in QUEST scores should be interpreted in the context of creator intent. For instance, patient creators may use TikTok primarily to share lived experiences with CCCA rather than to provide formal health education, whereas physician creators may be more likely to produce explicitly educational content. Additionally, QUEST was validated for written online health information, and its authorship and attribution domains may favor credentialed creators by rewarding stated qualifications and citations, which are less applicable to patient videos. Thus, higher QUEST scores should not be interpreted as directly indicating greater factual accuracy or overall content quality.

This study is limited by its cross-sectional design, the rapidly evolving nature of TikTok content, and inability to assess the direct impact of videos on patient care-seeking behaviors and health care outcomes. Additionally, although QUEST is a validated instrument for evaluating online health information, it was not developed specifically for short-form video and may not fully capture the purpose or value of patient-generated content. Additional limitations include reliance on publicly presented creator credentials, which could not be independently verified, and potential variability in TikTok search results, despite conducting searches while logged out to minimize algorithmic influence.

In summary, our findings illustrate substantial variability in QUEST-assessed markers of information quality among CCCA TikTok content and highlight the need for greater physician engagement in social media patient education initiatives.

Funding

The authors declared no financial support was received for this work.

Conflicts of Interest

None declared.

References

1. 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. Nov 2020;33(6):e14098. [doi: 10.1111/dth.14098] [Medline: 32725746]
2. Curtis ME, Clingan SE, Guo H, Zhu Y, Mooney LJ, Hser YI. Disparities in digital access among American rural and urban households and implications for telemedicine-based services. J Rural Health. Jun 2022;38(3):512-518. [doi: 10.1111/jrh.12614] [Medline: 34355427]
3. Larnyo E, Tettegah S, Nutakor JA, Addai-Dansoh S, Arboh F. Technology access, use, socioeconomic status, and healthcare disparities among African Americans in the US. Front Public Health. May 28, 2025;13:1547189. [doi: 10.3389/fpubh.2025.1547189] [Medline: 40503485]
4. Aguh C, McMichael A. Central centrifugal cicatricial alopecia. JAMA Dermatol. Sep 1, 2020;156(9):1036. [doi: 10.1001/jamadermatol.2020.1859] [Medline: 32745206]
5. Robillard JM, Jun JH, Lai JA, Feng TL. The QUEST for quality online health information: validation of a short quantitative tool. BMC Med Inform Decis Mak. Oct 19, 2018;18(1):87. [doi: 10.1186/s12911-018-0668-9] [Medline: 30340488]
6. Balazic E, Axler E, Nwankwo C, et al. Minimizing bias in alopecia diagnosis in skin of color patients. J Drugs Dermatol. Jul 1, 2023;22(7):703-705. [doi: 10.36849/JDD.7117] [Medline: 37410034]
7. George EA, Matthews C, Roche FC, Taylor SC. Beyond the hot comb: updates in epidemiology, pathogenesis, and treatment of central centrifugal cicatricial alopecia from 2011 to 2021. Am J Clin Dermatol. Jan 2023;24(1):81-88. [doi: 10.1007/s40257-022-00740-w] [Medline: 36399228]
8. Sperling LC, Darling TN. Central centrifugal cicatricial alopecia: a common but under-recognized and under-treated disease finally comes of age. J Cutan Pathol. Feb 2022;49(2):204-206. [doi: 10.1111/cup.14164] [Medline: 34743373]

Abbreviations

CCCA: central centrifugal cicatricial alopecia
QUEST: Quality Evaluation Scoring Tool

Edited by Michael Kirchberger; peer-reviewed by Anthony Gilding, Nicole James; submitted 28.May.2026; final revised version received 01.Oct.2026; accepted 13.Oct.2026; published 16.Nov.2026

Please cite as:
Anaeme A, Zhu A, Lee A, Mann C
A Cross-Sectional Analysis of the Quality and Inclusivity of Central Centrifugal Cicatricial Alopecia Content on TikTok
JMIR Dermatol 2026;9:e102828
URL: https://derma.jmir.org/2026/1/e102828
doi: 10.2196/102828

© Angela Anaeme, Amanda Zhu, Albertina Lee, Caroline Mann. Originally published in JMIR Dermatology (http://derma.jmir.org), 16.Nov.2026. This is an open-access article distributed under the terms of the Creative Commons Attribution License (https://creativecommons.org/licenses/by/4.0/), which permits unrestricted use, distribution, and reproduction in any medium, provided the original work, first published in JMIR Dermatology, is properly cited. The complete bibliographic information, a link to the original publication on http://derma.jmir.org, as well as this copyright and license information must be included.