

Investigating the Role of YouTube in Disseminating Information on Mycosis Fungoides: The Most Common Skin Lymphoma and Eczema Mimicker

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Abstract

Aim: Mycosis fungoides (MF) is the most prevalent cutaneous lymphoma. It is often detected late and can resemble a variety of dermatologic illnesses. Early diagnosis and understanding of the disease are essential, knowledge is accessible through the internet and various social media channels such as YouTube, a popular and easily accessible platform for sharing video information on various topics. This study aimed to analyze the information content of YouTube regarding MF.

Materials and Methods: Separate searches on YouTube were conducted using the keywords “MF,” “cutaneous lymphoma,” and “Sézary syndrome,” resulting in 101 videos included in our study. We utilized the DISCERN scale, the Journal of the American Medical Association (JAMA) scale, and the Global Quality Scale (GQS) to assess the content, reliability, and quality of the video information.

Results: Seventy-six videos (75.2%) contained evidence-based material, while 25 (24.8%) did not. Professional health institutions/foundations were the most common video uploaders (n = 42, 41.6%), followed by medical journals (n = 10, 9.9%). All videos received a mean DISCERN Score of 42.76 (indicating moderate quality), a mean JAMA score of 2.10 (indicating moderate reliability and accuracy), and a mean GQS score of 2.51 (indicating low to medium quality).

Conclusion: Unlike many diseases everyone can comment on, those who upload videos about MF are professionals on this subject, so most of the videos on YouTube about MF are evidence-based and of moderate quality. Dermatologists, who play a crucial role in diagnosing and treating this condition, should share more of their knowledge on YouTube.

Keywords: YouTube, mycosis fungoides, video

INTRODUCTION

The most prevalent cutaneous T-cell lymphoma is mycosis fungoides (MF). It appears clinically as inflammatory erythematous plaques or patches, with epidermotropism typical of its early-stage histology. However, various atypical MF genres have recently been identified in the literature as both clinical and histological, and they can resemble any

dermatological skin condition.¹ Unfortunately, there is often a delay between the first symptom and the initial diagnosis of MF. A multicenter study (n = 430, 29 centers, 15 countries) discovered that the diagnosis was made on average 36 months later than expected.² As a result, diagnosing MF, understanding its various symptoms, and raising patient awareness are critical.

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The stage and severity of the disease determines MF treatment. Non-aggressive treatment options such as topical therapy and ultraviolet A irradiation are recommended in the early stages. Allogeneic stem cell transplantation may be beneficial in advanced-stage patients. Although traditional systemic and single-agent therapies are feasible, recurrences are inevitable. Various monoclonal antibodies are also used in the treatment of some patients.³

Social media use is increasing drastically in the modern day. YouTube is one of the most widely recognized video publishing networks. This platform is increasingly becoming the primary source of learning and teaching material.⁴ YouTube is a popular social networking platform with visual and audio features that appeal to individuals of all ages. It can spread information and influence public opinion.⁵ However, there is also the risk of incorrectly disseminating health-related information.⁴ In addition, the anonymity of video access improves accessibility to medical information.⁶

So far, no study has investigated MF videos on YouTube. Therefore, in this cross-sectional study, we aimed to evaluate the content, reliability, and quality of MF-related information presented in YouTube videos using the Global Quality Scale (GQS),⁷ the Journal of the American Medical Association (JAMA) Benchmark criteria,⁸ and DISCERN scale.⁹

MATERIALS AND METHODS

On May 8, 2023, we conducted three separate YouTube searches using the terms MF, cutaneous lymphoma, and Sézary syndrome. Before entering each search term, we cleared YouTube's existing browsing data was wiped. We then scanned the 100 most viewed videos from each query result, sorted by the YouTube search filter. However, there were only 57 videos in the Sézary syndrome search, resulting in a total of 257 videos being reviewed for the study. Of these, 156 were excluded because they were not in English, were the same video, or because they were unrelated to the subject. Consequently, 101 videos were included in the final stage (Figure 1).

The duration, upload date, type of uploader, country of upload, number of views, number of subscribers of the uploader, number of likes/dislikes, and comments were all recorded for each video included in the study. Additionally, video interaction was calculated using the interaction index (IR): $(\text{Number of likes} - \text{number of dislikes}) / \text{total number of views} \times 100\%$.¹⁰

The videos were then manually assessed by two dermatologists, who were unaware of each other's ratings. A board-certified dermatologist reviewed any inconsistencies or

differences in video categorization. We also note information such as whether the videos were evidence-based, provided and promoted medical prescription therapies, critiqued consultation with healthcare providers, and encouraged the search for a medical expert. Furthermore, the video content type (MF disease definition, symptoms, diagnosis, causes, risk factors, treatments, medications used in treatment, prognostic variables, and follow-up) was documented. The quality and reliability of the health information in all videos were evaluated by two independent dermatologists using content assessment methods, the JAMA criteria, and the DISCERN scale, as well as the educational value using the GQS. According to the average DISCERN score assessment, video uploader types were split into five groups: group 1 (very poor: 16-26 points), group 2 (poor: 27-38 points), group 3 (moderate: 39-50 points), group 4 (good: 51-62 points), and group 5 (excellent: 63-75 points).

This study did not involve any human or animal participants; no ethics committee approval was required, as the study analyzed publicly available data.

Statistical analysis

For statistical analysis, SPSS version 29.0 was employed. Descriptive analyses for both categorical and numerical variables were carried out, Pearson's chi-square test was used for categorical data, and the Kolmogorov-Smirnov test was performed to determine the normality of the distribution. The Kruskal-Wallis test was used to assess whether there was a significant difference in mean scores of views, likes, dislikes, number of comments, and IR between groups 1-5. As there was no normal distribution, the difference between

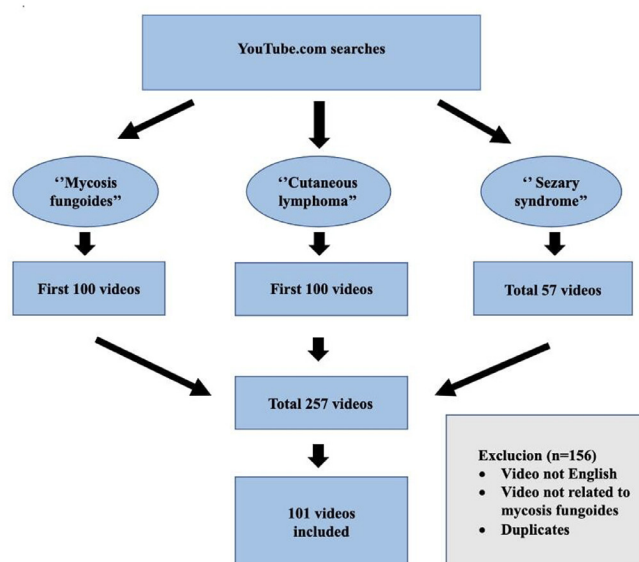


Figure 1. Video selection process about mycosis fungoides for YouTube searches

the average DISCERN, JAMA, and GQS scores of the video uploaders was examined using the Kruskal-Wallis test. The Cohen kappa test was used to assess inter-rater reliability, and a P value of 0.05 was utilized for all statistical tests to determine statistically significant differences.

RESULTS

In the study, 101 videos were evaluated and categorized: 23.8% were uploaded by healthcare providers, while 76.2% were uploaded by non-healthcare providers. 75.2% of the videos contained evidence-based material, while 24.8% did not. The most frequent video uploader was a professional health organization/foundation ($n = 42$, 41.6%), followed by a medical journal ($n = 10$, 9.9%). Table 1 lists all the characteristics of YouTube videos about MF.

The United States of America uploaded, with professional health organizations/foundations and medical journals uploading about half of them. Each of the videos obtained a mean DISCERN score of 42.76 (moderate quality), a mean JAMA score of 2.10 (moderate reliability and accuracy), and a mean GQS score of 2.51 (low-moderate quality) (Table 1). The Cohen kappa was used to estimate interrater reliability, and it revealed an almost perfect correlation for DISCERN (0.88), JAMA (0.83), and substantial agreement for GQS (0.68).

Group 1 had the most significant views out of the five groups (Table 1). However, the groups had no statistically significant difference between the groups ($P = 0.35$). The average number of video likes and IRs in group 1 was statistically significant differences ($P = 0.016$ and $P = 0.019$, respectively). The video time in group 1 was the least (6.22), and the longest (45.79), and it was statistically significant ($P < 0.001$) (Table 2).

Among video uploaders, the professional organization/foundation (52.07) and dermatologist (52.00) categories had the highest DISCERN scores, while the patient (26.75) and non-profit personal channels (26.89), had the lowest. This distinction between groups was also statistically significant ($P < 0.001$) (Table 3). Moreover, the highest JAMA scores were given to professional health organizations/foundations (2.69) and universities (2.67). In contrast, the lowest scores were reported in non-profit personal channels (0.67) and patients (0.75), with a statistically significant difference between video uploaders ($P = 0.001$). Furthermore, dermatologists (3.33) and professional health organizations/foundations (3.24) had the highest GQS scores, while patients (1.25) and pharmaceutical companies (1.33) had the lowest. There was a statistically significant difference in scores between video uploaders ($P = 0.005$) (Table 3).

Table 1. Features of the YouTube videos regarding mycosis fungoides

Video loading time	
Soonest	15.05.2007
Latest	04.04.2023
Uploaded place	
United States of America	71 (70.3%)
United Kingdom	13 (12.9%)
India	5 (5.0%)
Pakistan	3 (3.0%)
Australia	3 (3.0%)
New Zealand	2 (2.0%)
France	2 (2.0%)
Japan	1 (1.0%)
Nigeria	1 (1.0%)
Uploader	
Healthcare provider	24 (23.8%)
Non-healthcare provider	77 (76.2%)
Kind of uploader	
Professional health organization/foundation	42 (41.6%)
Medical journal	10 (9.9%)
Individual, non-medical, without making a profit	9 (8.9%)
Pathologist	8 (7.9%)
Dermatologist	6 (5.9%)
Natural source of healing channel (no financial interest)	6 (5.9%)
Patient	4 (4%)
Private company/hospital/lab	4 (4%)
Pharmaceutical company	3 (3%)
University	3 (3%)
Doctor (not an expert)	3 (3%)
Non-governmental organization	1 (1%)
Individual, non-medical, making a profit	1 (1%)
Hematologist	1 (1%)
Video views	6.536±15.513
DISCERN score	
JAMA score	42.76±16.51
GQS score	2.10±1.10
Video feedback	2.51±1.44
Likes	59.44±172.37
Dislikes	-
Comments	6.89±20.74
Interaction ratio	1.03±1.28
Commentary status of videos	
Closed for comments	36 (35.6%)
Open for comments	65 (64.4%)
Content of videos	
Evidence-based	76 (75.2%)
Not based on evidence	25 (24.8%)
GQS: Global Quality Scale, JAMA: Journal of the American Medical Association	

Table 2. Video source and features of groups separated according to DISCERN classification						
	Group 1, (n = 16) (15.8%)	Group 2, (n = 33) (32.7%)	Group 3, (n = 21) (20.8%)	Group 4, (n = 12) (11.9%)	Group 5, (n = 19) (18.8%)	P*
Professional health organization/foundation	3	11	7	4	17	
Medical journal	1	-	5	4	-	
Individual:non-medical, without making a profit	4	4	1	-	-	
Natural source of healing channel (no financial interest)	2	2	1	1	-	
Dermatologist	-	1	2	1	2	
Pathologist	-	7	-	1	-	
Doctor (not an expert)	1	-	2	-	-	
Private company/hospital/lab	1	2	1	-	-	
Pharmaceutical company	1	2	-	-	-	
Patient	2	2	-	-	-	
University	-	1	1	1	-	
Non-governmental organization	-	-	1	-	-	
Individual, non-medical, making a profit	1	-	-	-	-	
Hematologist	-	1	-	-	-	
Video time (min.) Mean ± SD	6.22±6.9	8.23±13.1	13.31±17.2	15.03±20.1	45.79±18.1	< 0.001
Video view Mean ± SD	11,475±25,585	4,593±7,510	5,360±12,515	11,137±27,069	4,146±4,375	0.35
Video comment Mean ± SD	10.38±27.01	5.21±9.73	11.14±32.64	7.83±24.05	1.58±3.15	0.13
Video like Mean ± SD	96.00±243.7	54.94±121.16	86.90±264.74	37.25±98.69	20.11±39.54	0.016
IR Mean ± SD	1.45±1.73	1.33±1.48	0.93±0.95	0.65±0.70	0.48±0.85	0.019
Closed for comments						
Yes	3	7	7	6	13	
No	13	26	14	6	6	

*Kruskal-Wallis test, IR: Interaction index, SD: Standard deviation, min.: Minute

Table 3. Evaluation results of video content by video uploaders			
	DISCERN Mean ± SD (min.-max.)	JAMA Mean ± SD (min.-max.)	GQS Mean ± SD (min.-max.)
Professional health organization/foundation, (n = 42)	52.07±17.23 (19-75)	2.69±1.02 (1-4)	3.24±1.60 (1-5)
Medical journal, (n = 10)	45.10±10.11 (24-58)	2.40±0.69 (1-3)	2.40±0.84 (1-4)
Individual, non-medical, without making a profit, (n = 9)	26.89±8.25 (17-43)	0.67±0.50 (0-1)	1.33±0.70 (1-3)
Natural source of healing (no financial interest), (n = 6)	34.50±11.64 (25-54)	1.17±0.75 (0-2)	2.00±0.89 (1-3)
Dermatologist, (n = 6)	52.00±13.7 (35-69)	2.50±0.54 (2-3)	3.33±1.50 (2-5)
Pathologist, (n = 8)	34.13±7.90 (27-52)	2.00±1.00 (1-3)	1.88±0.99(1-4)
Doctor (not an expert), (n = 3)	37.33±14.36 (21-48)	1.67±0.57 (1-2)	2.33±1.15 (1-3)
Private company/hospital/lab, (n = 4)	30.25±10.65 (18-44)	1.25±0.95 (0-2)	1.75±0.95 (1-3)
Pharmaceutical company, (n = 3)	28.00±3.00 (25-31)	2.00±1.00 (1-3)	1.33±0.57 (1-2)
Patient, (n = 4)	26.75±5.62 (21-34)	0.75±0.50 (0-1)	1.25±0.50 (1-2)
University, (n = 3)	43.67±7.50 (36-51)	2.67±0.57 (2-3)	2.67±0.57 (2-3)
P*	< 0.001	< 0.001	0.005

*Kruskal-Wallis test, SD: Standard deviation, min.: Minimum, max.: Maximum, JAMA: Journal of the American Medical Association, GQS: Global Quality Scale

DISCUSSION

This study aimed to investigate the suitability of videos as information sources for MF. As a result of the research, the mean DISCERN score for all videos was computed as 42.76 on the DISCERN scale, which is the primary assessment method for determining the information quality of the videos, and it was determined that they were of medium quality. The mean JAMA score was 2.10 (medium reliability), and the GQS score was 2.51 (low-medium quality); both were similar to the overall DISCERN video quality evaluation result. The outcome is relatively high when compared to the findings of many research studies. For example, in a recent study analyzing morphea information on YouTube using DISCERN in dermatology, the average DISCERN score was 32.2 (poor quality).¹¹

In another study regarding YouTube eczema treatment information, the mean DISCERN score was 34.6 (poor quality).¹² Salah et al.'s¹³ 2022 study, which assessed the quality of YouTube vitiligo information using the DISCERN, GQS, and Accuracy in Digital-Health Instrument scales found that 57% of the videos were of very poor quality and 33% were found to be of poor quality according to the DISCERN scoring system. In contrast, our study found that the mean of all videos was of medium quality, with around 50% being good quality. However, there were also videos with excellent scores in our study. Since MF is a rare skin lymphoma, unlike various diseases such as eczema and acne, this explains why videos on this subject are mainly published by physicians such as dermatologists or hematologists and professional associations. Thus, the content's quality and reliability are higher than that of others, which our study also supports.

The mean DISCERN and GQS scores were of moderate quality, and the JAMA mean score was of low reliability in a study that investigated the usefulness of basal cell carcinoma YouTube videos using DISCERN (modified German version), JAMA, and GQS.¹⁴ In another study, Instagram, one of the social media platforms associated with psoriasis in society, was investigated as a psoriasis information source, and the average DISCERN score was 28.8 (poor quality), emphasizing that Instagram contains lower quality information than other social media platforms, such as YouTube.¹⁵ According to a study exploring 80 videos regarding alopecia areata and androgenic alopecia on TikTok and YouTube, most TikTok video uploaders were female patients who expressed their experiences. Furthermore, healthcare providers had a statistically significant higher DISCERN score on YouTube than patients. Their videos were of high quality according to the DISCERN scoring of healthcare providers, but there was no statistically significant difference observed in the study regarding TikTok.¹⁶

YouTube is more favorable than TikTok for providing information because there are no time limits on YouTube videos, and viewing videos does not require a subscription. However, the popularity and usage of the TikTok platform have grown recently, leading us to believe that the tendency of experts to share knowledge from YouTube will shift in favor of TikTok as infrastructure improvements, such as video time extension and the growth in the number of users from all segments of society and ages, continue. Today, almost no profession exists that does not use social media, as not using it is almost synonymous with invisibility. Another striking point revealed in the results of our study is the low number of videos uploaded by patients. MF is a disease most commonly seen in middle-aged individuals, with a male-to-female ratio of 2:1, and about 75% of cases are diagnosed after age 50.^{17,18} The low use of social media/YouTube in this age range and MF being an infrequent condition may have contributed to this predicament.

Most videos on YouTube about MF contain evidence-based information; however, since MF is a mimicking disease that can easily be confused with common diseases such as eczema, it is often diagnosed late. To help combat this, we believe it would be highly beneficial if dermatologists produced videos to raise awareness of early-stage diagnosis, as video sharing sites have become a popular and valuable way to spread information.

In our study, we also observed that although the videos in group 1 had the lowest DISCERN score, they had the shortest duration, the most likes, and the highest IR, which was statistically significant. This finding indicates that information quality is not the sole factor for reaching a broad audience. Competition on social media platforms such as YouTube is fierce, making garnering high views, and interactions challenging. Health professionals aiming to reach a large audience through their videos should focus on aspects such as high-quality sounds and images, short durations, and eye-catching covering photos and titles. These components capture viewers' attention, boost views, likes, and interactions, and increase the likelihood of a video being promoted on YouTube, ultimately reaching more users.

Study Limitations

Limitations of our study include the YouTube algorithm differs from person to person, the features YouTube utilizes to rank the most watched videos are unknown, and only English language videos were included.

CONCLUSION

We suggest that dermatologists, who have an essential role in the diagnosis and treatment of MF, should be included

in the channels of non-profit professional organizations or medical publications in order to provide accurate information to the public, even if they do not have their own YouTube channels. This will accelerate the advancement of professional organizations currently striving for public knowledge and increase the quality of their content. In conclusion, increasing the volume of content in direct proportion to its quality will ensure that the correct information is more likely to be seen in the YouTube algorithm.

Ethics

Ethics Committee Approval: Not applicable.

Informed Consent: Not applicable.

Footnotes

Authorship Contributions

Surgical and Medical Practices: D.M., G.I.K., S.P.K., Concept: D.M., G.I.K., S.P.K., Design: D.M., G.I.K., S.P.K., Data Collection or Processing: D.M., G.I.K., S.P.K., Analysis or Interpretation: D.M., G.I.K., S.P.K., Literature Search: D.M., G.I.K., S.P.K., Writing: D.M., G.I.K., S.P.K.

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