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Original Research

Quality and Reliability of Raynaud's Phenomenon Information on YouTube: A Cross-Sectional Study

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ABSTRACT

Objective: Raynaud's phenomenon, impacting small blood vessels, can be triggered by cold or emotional stress and present as a primary disorder or a symptom of other diseases. Given the growing use of platforms like YouTube for health information, assessing the reliability of Raynaud's phenomenon videos is crucial. This study aimed to assess the quality, reliability, and educational merit of YouTube videos about Raynaud's phenomenon.

Methods: A YouTube search was performed on February 10, 2025, including videos uploaded since 2012. YouTube search utilized keywords like 'Raynaud's phenomenon', 'Raynaud's syndrome', 'Primary Raynaud's disease', 'Secondary Raynaud's disease', 'Primary Raynaud's phenomenon', 'Secondary Raynaud's phenomenon' and 'Raynaud's disease'. The Global Quality Scale (GQS), modified DISCERN, and a usefulness scale were used by two independent raters to assess video content characteristics.

Results: 100 videos underwent evaluation. The GQS assessment revealed 49 high-quality videos (49%), 23 intermediate-quality videos (23%), and 28 low-quality videos (28%). Modified DISCERN and GQS scores showed a strong positive correlation ($r = 0.709$, $p < 0.001$), while popularity measures did not significantly correlate with quality scores. Raynaud's phenomenon information on YouTube is unreliable and inconsistent; videos created by rheumatologists have the highest quality.

Conclusion: Healthcare professionals should direct patients to trustworthy sources, develop evidence-based materials to enhance the quality of online health information, and seek collaboration with other healthcare professionals. The overall quality of Raynaud's phenomenon-related YouTube videos was found to be highly variable, with nearly half rated as high quality, while a significant portion lacked sufficient reliability and educational value.

Keywords: health information, Raynaud's phenomenon, Raynaud's disease, social media, YouTube, quality assessment

INTRODUCTION

Raynaud's phenomenon, a frequent clinical issue, involves a temporary narrowing of blood vessels in the extremities, typically triggered by cold exposure or emotional stress. The manifestation is a three-stage color change in the digits beginning with paleness (white) from vasoconstriction, then cyanosis (blue) from oxygen deprivation, and finally hyperemia (red) during reperfusion [1]. This condition is found in roughly 3–5% of the population, with women being more affected [2].

Raynaud's phenomenon can be categorized as primary (idiopathic) or secondary to an underlying disease, typically connective tissue disorders like systemic sclerosis, systemic lupus erythematosus, or mixed connective tissue disease [3]. Early detection and distinguishing between primary and secondary types is essential for effective treatment and prognosis [4].

The internet has become an important source of health information resource for patients in recent times. Being the second most visited website worldwide, YouTube is a significant platform for health-related content [5]. With over 2 billion logged-in monthly users and more than 1 billion hours of daily video consumption, YouTube presents a substantial opportunity to shape public health knowledge and patient behavior [6].

Platforms like YouTube could potentially enhance patient education and health literacy [7]. In the U.S., online health information is regularly accessed by over 60% of adults, and at least 80% have searched for health topics online [8]. YouTube offers diverse ways to present health information, potentially improving public understanding [9].

Misleading medical information could be disseminated due to insufficient quality control and evaluation of user-generated content. Previous research has examined the quality of internet resources about various rheumatic diseases, including rheumatoid arthritis, spondyloarthritis, systemic lupus erythematosus, and the side effects of biologic therapy [6,10-13]. The quality of this information shows significant variability between poor and moderate.

Hughes et al. [2] linked increased wintertime internet searches for Raynaud's phenomenon to the condition's symptom severity during those months. Furthermore, a systematic review by Devgire et al. [14] on internet-based information for those with Raynaud's phenomenon and systemic sclerosis revealed poor quality and readability. To the best of our knowledge, a thorough analysis of YouTube videos on Raynaud's phenomenon, focusing on quality, reliability, and educational value, is lacking.

Since Raynaud's is a chronic condition severely affecting quality of life, patients usually search for further information beyond clinical visits. YouTube's 24/7 availability and massive collection of health videos could supplement other information sources. However, to ensure patients receive dependable guidance, the information's quality and accuracy require systematic evaluation.

This study aimed to evaluate YouTube videos about Raynaud's phenomenon for quality, reliability, and educational merit. Through analysis of video quality, content accuracy, and informational relevance, we provide healthcare providers with insights to guide patient recommendations of appropriate online resources regarding Raynaud's phenomenon.

Main Points

- The quality of YouTube videos on Raynaud's phenomenon is highly variable, with nearly one-third rated as low quality, raising concerns about the accuracy of online health content available to patients.
- Videos uploaded by rheumatologists had significantly higher quality and reliability scores, emphasizing the need for expert involvement in online health education.
- There was no correlation between video popularity (views, likes) and content quality, indicating that patients may be more exposed to popular but potentially misleading information.
- Videos covering both causes and treatment of Raynaud's phenomenon received higher quality ratings, highlighting the value of comprehensive and balanced content in patient education.
- Educational videos featuring visual presentations and focusing on rheumatologic aspects performed better, suggesting that format and professional relevance contribute significantly to viewer benefit.

MATERIALS AND METHODS

Search Procedure

On February 10, 2025, a systematic YouTube search was performed using "Raynaud's phenomenon," "Raynaud's syndrome," and "Raynaud's disease" as keywords. Incognito mode in Google Chrome was employed during the search to minimize the effect of prior search history and customized algorithms. The browsing history had been deleted when the search was conducted. To imitate typical viewer searches, YouTube utilized its default relevance algorithm.

Our evaluation of the first 180 YouTube videos on Raynaud's phenomenon was based on the observation that most viewers only explore the top search results, as done in previous studies [6,7,15]. The chosen videos were added to a playlist for further review. A total of 100 videos remained for final analysis after applying exclusion criteria. The following videos were excluded: duplicates (n=46), non-English videos (n=34), irrelevant videos, videos exceeding one hour, and advertisements.

Data Collection

Two independent reviewers collected the following data for each video included:

1. Basic metrics: URL, title, upload date, duration (minutes), and upload source
2. Engagement metrics: number of views, likes, dislikes, and comments
3. Time-adjusted metrics: views per day, likes per day, and comments per day (calculated by dividing the total count by the number of days since upload)
4. This content addresses the epidemiology, pathogenesis, clinical features, diagnosis, and treatment of Raynaud's phenomenon.

Five groups were used to categorize the video sources:

1. Rheumatologists: Board-certified rheumatology specialists or clinics.
2. Nurses: Videos uploaded by registered nurses or nursing educators.
3. Other healthcare branches: Other healthcare fields: videos produced by healthcare professionals from fields outside of rheumatology, such as dermatology, internal medicine, cardiology, or primary care. For instance, videos that discuss Raynaud's phenomenon from a dermatological perspective (e.g., skin discoloration), or general practitioners discussing cold intolerance without detailed rheumatologic context, were grouped in this category.
4. Healthcare organizations: Videos from medical associations, universities, hospitals, or academic institutions.
5. Independent users: Non-professional individuals, patients, or anonymous accounts without verifiable healthcare affiliation.

The target audience of each video was determined based on language and content. Videos were classified as patient-oriented, professional-oriented, or general audience, depending on complexity and intended communication. The source of video was categorized into five groups based on the uploader's identity and affiliation as outlined above.

Quality and Reliability Assessment

Video quality and reliability were assessed using three validated tools.

1. The Global Quality Scale (GQS): A five-point scale assessed patient video quality, flow, and usefulness [16]. Better quality is indicated by higher scores. The videos were rated on a scale of 1-5 points, with 4-5 points representing high quality, 3 points representing medium quality, and 1-2 points representing low quality.
2. The modified DISCERN tool: Adapted from the original DISCERN questionnaire [17], this five-question instrument evaluates clarity, reliability of information, presence of bias, availability of additional sources, and handling of uncertainties. Each question receives 1 point for a "yes" answer and 0 points for a "no" answer, up to a maximum of 5 points.

Usefulness Assessment

Videos were independently assessed by two rheumatologists (F.A. and B.O.) and categorized into one of four mutually exclusive groups based on their usefulness:

1. Useful information: Videos providing accurate and informative content about Raynaud's phenomenon such as systemic sclerosis, systemic lupus erythematosus, and mixed connective tissue disease. For example, videos that explain digital ulcers, vascular involvement, or the differentiation between primary and secondary Raynaud's phenomenon within the context of autoimmune diseases were classified under this category
2. Misleading information: Videos containing inaccurate or incomplete information about Raynaud's phenomenon
3. Useful patient opinion: Videos depicting personal experiences or perspectives that could educate other patients

4. Misleading patient opinion: Videos depicting patient experiences that were either ineffective as educational tools or contained incorrect opinions

To be deemed useful, videos needed scientifically accurate information, adhering to guidelines set by professional organizations, including the American College of Rheumatology and European League Against Rheumatism. Disagreements between evaluators were resolved by a third reviewer (B.K.), who acted as an arbitrator.

Video Popularity Analysis

Video popularity was assessed using the Video Power Index (VPI): [(like ratio × view ratio)/100], where like ratio = [likes/(likes + dislikes)] × 100 and view ratio = views per day [18]. Unlike simple view counts, this metric provides a more comprehensive evaluation of a video's reach and audience engagement.

Statistical Analysis

Data analysis was conducted using SPSS 26.0 (IBM Corp., Armonk, NY, USA). The Shapiro-Wilk test determined data normality. Continuous variables were presented as mean ±standard deviation (SD) or median (minimum-maximum) and categorical variables as frequencies and percentages.

Non-normally distributed data was analyzed using the Mann-Whitney U-test (two groups) and the Kruskal-Wallis test (multiple groups). Following a Kruskal-Wallis test, post-hoc pairwise comparisons were performed using Dunn's test, with Bonferroni correction. The correlations for continuous variables were analyzed with Spearman's rank correlation. Categorical variables were analyzed using Fischer's exact test. Cohen's kappa coefficient measured inter-rater agreement. Statistical significance was set at $p < 0.05$.

Ethical Considerations

No ethics committee approval was needed for this study; it only involved publicly available YouTube videos, and no human or animal subjects were included.

RESULTS

Of 180 screened YouTube videos, 100 met the inclusion criteria and were analyzed. Video durations had a median of 5.0 minutes (0.3-59.2). Views, likes, and dislikes had median values of 8095 (41–394.000), 119 ((1-17.000), and 1 (0-270), respectively. Table 1 provides a summary of the general video characteristics.

Video Quality Assessment

The GQS assessment revealed that video quality percentages were: excellent (25%), good (28%), moderate (20%), poor (15%), and very poor (12%). The median GQS score was 4 (1-5). A summary of video characteristics categorized by GQS is shown in Table 2.

Video scores from DISCERN showed 14% at 5, 29% at 4, 21% at 3, 24% at 2, and 12% at 1. DISCERN scores had a median of 3 (1-5). Inter-rater agreement for GQS and modified DISCERN scores was calculated using Cohen's kappa coefficient and demonstrated substantial agreement ($\kappa = 0.72$ for GQS, $\kappa = 0.69$ for DISCERN).

A strong positive correlation was found between the GQS and DISCERN score ($r = 0.814$, $p<0.001$). VPI scores showed no significant correlation with DISCERN ($p = 0.818$) or GQS scores ($p = 0.411$).

Of the 100 videos reviewed, rheumatologists uploaded 22%, nurses 8%, other healthcare professionals 44%, individual users 10%, and healthcare organizations 16%. Rheumatologists' videos had significantly higher quality scores (median GQS = 4.6) than videos from other sources ($p<0.001$). Similarly, rheumatologist-uploaded videos scored higher on DISCERN (median 4.1) than videos from other sources ($p<0.003$). A comparison of video characteristics from different sources is presented in Table 3.

The video content was divided as follows: causes (30%), treatment (9%), both (55%), and general information (6%). A significant difference in GQS (median 4.4) and DISCERN (median 4.0) scores was observed between videos covering both causes and treatment and those focusing on single topics ($p < 0.001$).

The presence of rheumatic content significantly improved video quality scores ($p < 0.001$), affecting 59% of videos. Likewise, videos incorporating presentations (78%) exhibited superior quality to those without ($p<0.001$).

Quantitative video variable correlations are displayed in Table 4. Likes and views, likes and VPI, and views and VPI showed strong positive correlations ($r = 0.843$, 0.969, and 0.939 respectively, all $p<0.001$).

Table 1. The main characteristics of the analyzed videos (n=100)

Variables	Median	Range (Min-Max)
Video duration (minutes)	5.01	0.10-59.19
Number of views	8095.0	41-394.000
Number of likes	119.5	1-17.000
Number of dislikes	1.0	0-270
Video Power Index (VPI)	6927.0	0-17.170.000
Modified DISCERN score	3	1-5
Global Quality Scale (GQS)	4	1-5

Table 2. Video characteristics by GQS categories

Characteristic	Very Poor (n=12)	Poor (n=15)	Moderate (n=20)	Good (n=28)	Excellent (n=25)	p-value
DISCERN score (median)	1.0 (1-1)	2.0 (2-2)	3.0 (2-3)	4.0 (3-4)	5.0 (5-5)	**<0.001***
Duration (min) (median)	0.5 (0.1-13.5)	2.0 (0.1-58.9)	2.8 (1.0-18.3)	8.1 (3.0-59.0)	10.4 (1.5-59.2)	**<0.001***
Views (median)	10950 (749-111000)	8090 (41-135000)	8395 (71-153000)	10000 (166-105000)	7200 (799-394000)	**0.890**
Likes (median)	89 (1-1400)	57 (1-2100)	77 (1-4100)	126 (2-1700)	140 (4-17000)	**0.620**
Dislikes (median)	5 (0-29)	15 (0-92)	22 (0-270)	9 (0-54)	5 (0-47)	**0.729**
VPI (median)	3944 (78-1176000)	1134 (0-594000)	5533 (1-6273000)	12184 (3-1785000)	11060 (32-17170000)	**0.818**

*Statistically significant ($p < 0.05$)

Table 3. Comparison of video characteristics by source

Characteristic	Rheumatologists (n=22)	Nurses (n=8)	Other healthcare (n=44)	Individual (n=10)	Health organization (n=16)	p-value
DISCERN score (median)	4 (3-5)	4 (1-5)	3 (1-5)	2 (1-4)	3 (1-5)	0.003*
GQS (median)	5 (3-5)	4 (1-5)	3 (1-5)	2 (1-4)	3 (1-5)	<0.001*
Duration (min) (median)	8.8 (1.5-59.0)	7.1 (0.2-12.4)	3.9 (0.1-58.9)	4.1 (0.1-18.3)	4.3 (1.0-49.0)	0.029*
Views (median)	6650 (96-394,000)	15844 (119-38000)	8395 (41-153000)	12600 (71-118000)	3500 (87-61,000)	0.312
Likes (median)	66 (2-17,000)	521 (5-1600)	147 (1-4100)	120 (1-4200)	16 (2-340)	0.023*
Dislikes (median)	6 (0-47)	7 (0-22)	2 (0-270)	8 (0-45)	4 (0-13)	0.850
VPI (median)	5489 (2-17170000)	128064 (6-352000)	12234 (0-6273000)	7407 (1-4956000)	549 (2-207400)	0.093

*Statistically significant ($p < 0.05$)

Table 4. Correlation analysis of the quantitative variables of videos

Variable		Likes	Dislikes	Views	Duration	VPI
Likes	r p	1.000	0.568** ***< 0.001***	0.843** ***< 0.001***	0.100 0.322	0.969** ***< 0.001***
Dislikes	r p	0.568** ***< 0.001***	1.000	0.679** ***< 0.001***	0.023 0.822	0.647** ***< 0.001***
Views	r p	0.843** ***< 0.001***	0.679** ***< 0.001***	1.000	-0.045 0.658	0.939** ***< 0.001***
Duration	r p	0.100 0.322	0.023 0.822	-0.045 0.658	1.000	0.047 0.643
VPI	r p	0.969** ***< 0.001***	0.647** ***< 0.001***	0.939** ***< 0.001***	0.047 0.643	1.000

**Correlation is significant at the 0.001 level (2-tailed)

Of the 100 videos analyzed, 74.8% targeted patients and 25.2% targeted healthcare professionals. Videos were categorized based on their usefulness: 84.7% provided useful information, 8.5% shared useful patient opinions, and 6.8% contained potentially misleading patient opinions. Notably, all videos (100%) uploaded by healthcare professionals contained useful information, while 44.4% of videos uploaded by independent users contained misleading information (data not shown).

DISCUSSION

This study assesses the quality, reliability, content, and educational value of YouTube videos about Raynaud's phenomenon, making the current study significant. Our findings highlight key insights into YouTube health information quality, yet also reveal cause for concern.

High-quality videos comprised 49% and low-quality videos 28% of our study sample; these findings mirror those of similar YouTube studies on other rheumatic diseases. High-quality video proportions differed across studies of arthritic diseases, with rheumatoid arthritis showing similar quality [11], spondyloarthritis showing 47% high-quality videos [12], and systemic lupus erythematosus displaying 31% [13]. While Raynaud's phenomenon videos demonstrate a relatively high-quality profile, enhancing health video content, particularly on highly accessible platforms such as YouTube, is vital, necessitating support for its creators.

Our findings of a strong positive correlation between GQS and modified DISCERN scores ($r=0.814$, $p<0.001$) are consistent with Cüzdan and Türk's [15] results ($r=0.72$) on musculoskeletal ultrasound videos, supporting our assessment tools' reliability. The consistency in video quality scales necessitates correlating certain evaluations for quality improvement.

Knowledge and proper equipment are crucial for anyone uploading videos on YouTube. High-quality videos from field experts enhance social media. Videos by rheumatology experts received significantly better quality ratings (median GQS 4.6) in the present study. This result aligns with other studies. Likewise, Zengin and Onder [6] showed that physician-created gout videos were of better quality. Nevertheless, our study showed a lower rate of rheumatologist-generated videos (22%) than found in studies of other specialties. In a study by Kocyigit and Akyol [7], specialist physicians appeared in 31% of videos about the COVID-19 vaccine and rheumatic disease. This discovery implies rheumatologists ought to increase their social media involvement in educating patients. High-quality videos from experts are especially important in winter, when, as reported by Hughes [2], searches for Raynaud's increase.

The absence of a correlation ($p = 0.411$, VPI and GQS) between quality and popularity in our study highlights a typical problem with social media. In a similar vein, study by Coskun et al. [9] on familial Mediterranean fever videos revealed no significant relationship between quality and viewership. Video viewers seem to favor popular content, this suggests. The risk of exposure to low-quality yet popular videos rises for patients exhibiting symptoms such as Raynaud's phenomenon.

Medical content distribution is skewed by YouTube's algorithm, which prioritizes popularity over accuracy. Producing quality content and raising its profile are both important considerations for healthcare professionals.

The current study highlights the value of comprehensive educational videos by showing that those covering both cause and treatment received higher quality ratings. Devgire et al. [14] found in their systematic review that online Raynaud's phenomenon and systemic sclerosis information lacks quality and require improvement. Better health videos use science to explain causes, propose solutions, and demonstrate control mechanisms.

The 59% higher performance of videos focusing on rheumatic content suggests that explaining Raynaud's systemic connections enhances understanding. Our findings agree with the scientific understanding highlighted by Wigley and Flavahan [4] regarding the importance of differentiating primary and secondary Raynaud's phenomenon.

YouTube's importance in patient education is clear, given that more than 60% of adults use the internet for health information, according to Frost and Massagli [8]. Findings from Madathil et al.'s [5] systematic review reinforce YouTube's growing use as a source of health information.

Multimedia educational materials, as shown by our study's 78% result, are superior to traditional text-based resources. Our findings corroborate Bernard et al.'s [16] review; they found that multimedia content improves the educational impact of online patient resources.

Limitations

This study has certain limitations. The analysis initially focused on videos in English, possibly misrepresenting the reliability of content in other languages. Search results could differ depending on the user's location and search history because of algorithmic personalization and regional content differences, which could introduce selection bias. Additionally, the study assessed the educational value and reliability of the videos, but did not measure their effects on viewer behavior, health literacy, or decision-making. Future research that incorporates participant feedback or behavioral outcome measures would be beneficial in this context. Third, the study reflects a snapshot of the YouTube platform as of February 2025. Because online content is dynamic and changing quickly, video quality and availability could change over time, which may affect our findings' generalizability.

CONCLUSIONS

The quality of YouTube videos about Raynaud's phenomenon is inconsistent. Rheumatologists and other health professionals produce the highest-quality content; popularity is unrelated to quality. A more active social media presence, especially on platforms like YouTube, is important for health professionals. Published videos need to be comprehensive, watchable, and scientifically rigorous to effectively reach the target audience. In addition to creating engaging and evidence-based content, healthcare professionals should collaborate with digital platforms to improve the visibility and accessibility of reliable health information. Safe and accurate social media information for patients necessitates expert evaluation of content published on these platforms. Following these years, more inclusive and constructive research in this field is evidently necessary.

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