Is YouTube a Reliable Source of Medical Information About Hemophilia?

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ABSTRACT

Objective: YouTube videos have an important role in public health. This study aimed to assess the content, quality, and reliability of hemophilia videos on the YouTube platform.

Methods: The keywords, namely, hemophilia, hemophilia factor, hemophilia inhibitors, and hemophilia treatment were used to identify videos on YouTube. The Global Quality Scale and the modified DISCERN questionnaire were used to assess the quality and reliability of videos, respectively. The videos were compared based on their quality and uploaders (physician, healthcare organization, company, patient, and independent users).

Results: A total of 140 videos were reviewed for the study. There were 65 high, 51 moderate, and 24 low-quality videos. The physicians uploaded more videos and high-quality videos than others, with a few videos uploaded by patients and healthcare organizations. The like ratio was different for high-quality videos ($P < .05$), other video characteristics were similar ($P > .05$). The median Global Quality Scale and DISCERN scores of all videos were the same (3 points) and DISCERN scores increased with improved video quality ($P < .05$).

Various significant differences were found in video characteristics between uploader groups ($P < .05$). The Global Quality Scale score of pysicians was significantly different when compared to other groups ($P < .05$). The DISCERN scores of physician videos were different compared to the patient and independent users-sourced videos ($P = .006$ and $P = .001$) and DISCERN scores of patient videos were also different from those of healthcare organization videos ($P = .004$).

Conclusion: YouTube can be considered as a good source of information on hemophilia for people with hemophilia and may improve their self-management skills.

Keywords: Hemophilia, internet, e-health, health care quality, YouTube

Introduction

Hemophilia is a chronic blood disorder which is inherited as an X-linked recessive trait and is characterized by deficient production of coagulation factors. The factor deficiencies (factor VIII and IX) cause the 2 major types of hemophilia (Type A and B).[1] Hemophilia A affects 1 in 10 000 births and about 160 000 people around the world have hemophilia A.[2] The percentage of clotting factor activity in the blood determines the disease severity. Depending on the severity level, hemophilia is classified based on clotting factor activity (CFA) as mild (CFA >%5), moderate (CFA: 1%-5%), and severe (CFA <1%).[3] Hemophilia A accounts for 85% of all hemophilia cases and bleeding symptoms occur spontaneously or after a trauma.[4] While both hemophilia A and B display a similar clinic course, hemophilia B is less common accounting for 15% of the cases.[5] Lifelong pharmacological therapy is required to alleviate disease symptoms, to prevent complications, and treat the condition.[6]

However, the anti-factor VIII development via pharmacological therapy is a primary complication and inhibits factor activity, and this condition increases the severity of hemophilia A and complicates the procedure of management.[7]

There are many guidelines available for the diagnosis and treatment of hemophilia that provide useful guidance to clinicians.[1,8] Behind the guidelines, the internet is becoming a popular source of health information. The patients and health people are using to reach any kind

of information about diseases and their symptom in the internet.[9] Hemophilia is a chronic condition that requires education for affected patients on an ongoing basis to help them cope with challenges in daily activities throughout their lives.[8,10] These patients continue to have lifelong access to education and health services. In this process, the internet can be an easy tool to get information about disease management, medical treatment or their side effects, and diagnosis. Therefore, social media platforms, especially YouTube, can be the preferred information source.

YouTube is a largest media-sharing platform and 1 billion users can share 300 hours of new videos per minute and is increasingly used to access information on health.[11,12] This popularity lead to some concerns about the content, quality, and accuracy of the videos featured in this media platform.[13] In previous studies, it has been stated that while helpful information can be provided by some YouTube videos, others can present misleading, heterogeneous, or contradictory information.[13-15] In particular, there are limited measures in place to regulate the content of the videos and verify their scientific accuracy and quality during and after uploading videos.[15] On the other hand, there are several studies that searched the accuracy, characteristics, and reliability of YouTube videos on diseases, surgeries, medical care, but no studies have focused on videos presenting information on hemophilia.[16-21] Therefore, the present study aimed to assess the characteristics and reliability of hemophilia videos in YouTube media platform.

Methods

Search Process
For this descriptive study, YouTube was searched for videos on June 13, 2021, using the keywords "hemophilia," "hemophilia factor," "hemophilia inhibitors," and "hemophilia treatment." Queries were performed separately for each keyword to identify videos in English on YouTube (www.youtube.com). For each keyword, 60 most viewed

videos were analyzed. This selection criterion is based on previous studies that indicate that people do not watch beyond the first listed videos from a media server.[17,22] About 240 videos were selected for the study. Videos that failed to play, videos that were repetitive, irrelevant, and in another language, and videos with poor image and sound quality were excluded. Ultimately, 140 videos were analyzed in the study. Also, the videos were compared based on quality and source groups. Videos were categorized into high, moderate, and poor quality groups. Video uploaders were divided into 5 categories: (1) physicians, (2) healthcare organizations (HO), (3) medical companies, (4) patients, and (5) independent users (IU) (Figure 1).

The reliability and quality of the videos were graded by 2 independent investigators (TG, SA).[23,24] Videos with an inconsistency between the scores of the 2 independent researchers were detected. These videos were evaluated by a third researcher (SU) without their knowledge of previous scores, and a final decision was made. Interobserver reliability was calculated for DISCERN and Global Quality Scale (GQS) scores and summarized with interclass correlation estimates.

Review
The characteristics of videos (number of views, duration, days since upload, view ratio, number of likes and dislikes, and like ratio) were recorded. The view ratio was calculated with the following formula: number of views/day. The like ratio was calculated with the following formula: likes $\times$ 100/(likes + dislikes).

Video Quality
The quality of videos was assessed with the GQS. This scale is an instrument designed for content quality evaluation for online resources. The scores range from 1 (minimum score) and 5 (maximum score) points on a Likert scale. Investigators use the GQS and graded the quality and usefulness of the videos. The 4 or 5 points indicate that the video has a high quality, a moderate quality video is assigned a score of 3, and a score of 1 or 2 denotes poor quality.[25]
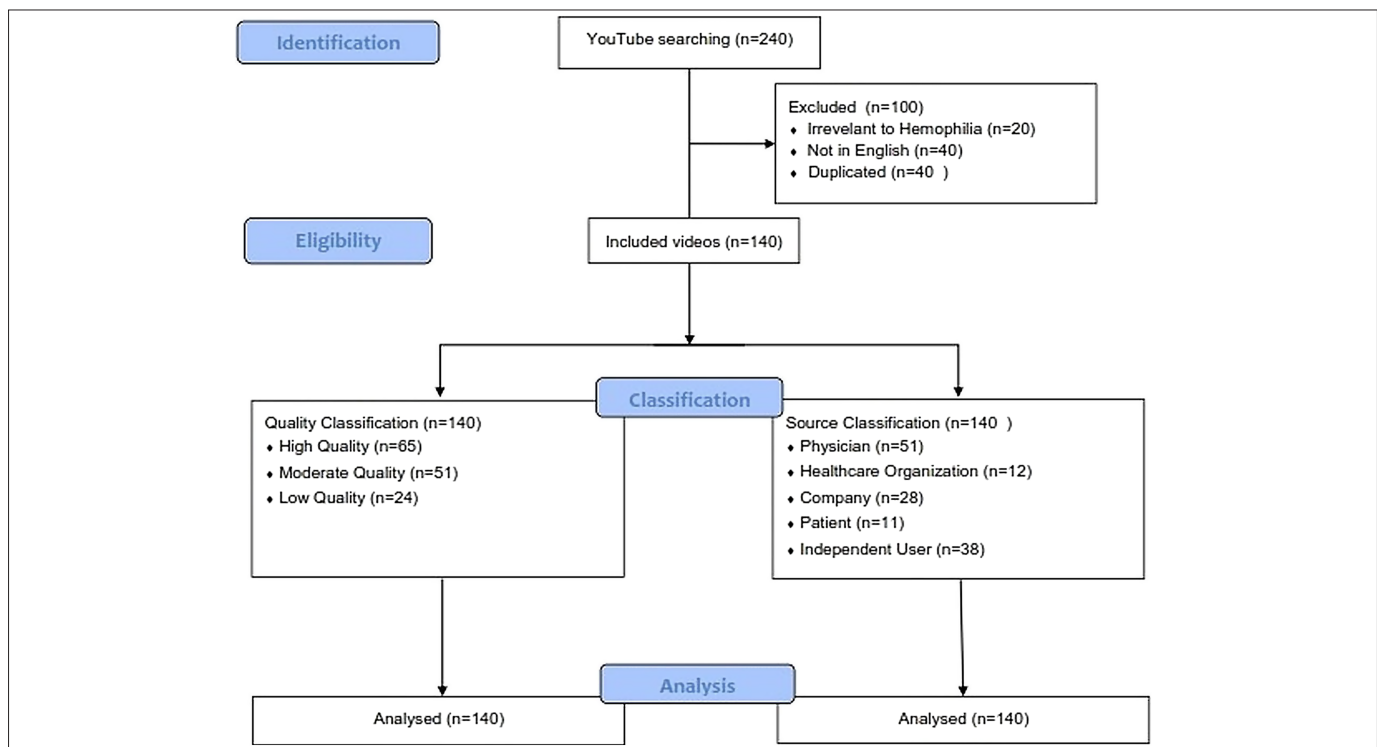
Figure 1. Flowchart selection of YouTube videos for the analyses.

Table 1. Video Characteristics

	Median	Min-Max
Video duration (seconds)	436	43-9083
Days since upload	1446	60-5258
Views	9292.5	187-314 9847
Daily views	6.09	0-2485
Likes	63	0-25 000
Dislikes	3	0-1400
Comments	2	0-1593
Like ratio	1356.82	0-9600
GQS (score)	3	1-5
DISCERN (score)	3	1-5

GQS, Global Quality Scale; min, minimum; max, maximum.

Reliability of Videos

The reliability of information delivered by YouTube videos was evaluated using the modified DISCERN validation tool. This instrument created by Charnock et al[26] includes 5-item questions. The question is answered by a yes or no. Each yes answer gets a score of 1 and the maximum score is 5 points (Table 1). Higher scores indicate greater reliability.

Statistical Analysis

The normality of data was analyzed with the Shapiro–Wilk test. The data were expressed as median (min-max) for continuous variables and number (n) and percentage (%) for categorical variables. The data were analyzed using a non-parametric Kruskal–Wallis test and Pearson's Chi-square test. The post hoc pairwise comparisons (Dunn correction) were applied to see where the differences were raising from. The Cohen's Kappa coefficient of agreement was used to measure the degree of agreement of reviewed video between two investigators. The Statistical Package for Social Science version 22.0 (IBM Corp. Armonk, NY, USA) was used for analysis. A *P*-value of <.05 was considered significant.

Results

A total of 240 videos were reviewed in the current study. Among these, 42 non-English language videos, 37 repetitive videos, 20 videos with irrelevant content, and 1 video that failed to play were excluded. The remaining of 140 videos were assessed in this study. Inter-observer agreement was 0.81 and 0.87 for DISCERN and GQS score, respectively. The DISCERN, GQS, and characteristics of video are presented in Table 1.

Hemophilia videos were most commonly uploaded by physicians and patients and HO uploaded the lowest number of videos. It was found that physicians uploaded the highest quality videos and no poor quality videos were uploaded by HO. The data on video quality and comparisons among uploaders are presented in Table 2.

Table 2. Video Quality Assessment According to the Global Quality Scale by Source Group

Source	Poor Quality (n = 24)	Moderate Quality (n = 51)	High Quality (n = 65)	Total (n = 140)
Physician	4 (7.8)	11 (21.6)	36 (70.6)	51
Healthcare organization	0	7 (58.3)	5 (41.7)	12
Company	4 (14.3)	11 (39.3)	13 (46.4)	28
Patient	4 (36.4)	5 (45.5)	2 (18.2)	11
Independent user	12 (31.6)	17 (44.7)	9 (23.7)	38

Table 3. Comparison of the Video Characteristics Based on Quality

	Poor Quality (n = 24)	Moderate Quality (n = 51)	High Quality (n = 65)	*P*
	Median (min-max)	Median (min-max)	Median (min-max)	
Video duration (sec)	302.5 (257-5225)	380 (46-9083)	577 (76-5865)	.146
Days since upload	1125.5 (257-4844)	1719 (60-5258)	1364 (87-3995)	.150
Views	6328.5 (187-323 938)	7940 (228-867 165)	10181 (192-3149 847)	.851
Daily views	5.56 (0-230)	5.68 (0-2485)	6.93 (0-852)	.494
Likes	41.5 (0-7600)	46 (0-25 000)	104 (0-18 000)	.396
Dislikes	3.5 (0-202)	3 (0-417)	3 (0-1400)	.824
Comments	2.5 (0-144)	2 (0-1593)	4 (0-563)	.286
Like ratio	848.33 (0-7000)	950 (0-5995.2)	**2188.55 (0-9600)**	**.039**
DISCERN (score)	**2 (1-3)**	**3 (1-4)**	**4 (2-5)**	**< .001**

Min; minimum, max; maximum.
Bold values indicate *P* < .05, Kruskal–Wallis test results

Comparing the videos on the basis of their quality, a significant difference was found among the videos with respect to like ratio and DISCERN scores (*P* < .05). High-quality videos showed a higher like ratio. Higher DISCERN scores were observed in parallel with increased video quality (*P* < .05) (Table 3).

The duration of the physician-sourced videos was significantly higher than those uploaded by companies and IU (*P* = .002, *P* = .008) but similar to those uploaded by HO and patients (*P* > .05). The videos generated by patients and HO were uploaded before the videos generated by companies, physicians, and IU (*P* = .001, *P* = .003, and *P* = .001). The number of views on companies videos was higher than the other 4 groups (*P* < .05). The number of daily views of physicians and companies videos was found to be higher than HO, patients, and IU (*P* = .006, *P* = .019, and *P* = .028). The number of likes and dislikes of HO videos was found to be the lowest (*P* < .05). The GQS score of videos uploaded by physicians was higher than other source groups (*P* < .05). The DISCERN scores were found similar between physicians and HO videos (*P* > .05), while the scores for videos of physicians were significantly higher than those videos by uploaded patients and IU (*P* = .006 and *P* = .001) (Table 4).

Discussion

In the present study examining the quality and content of YouTube videos on hemophilia, higher numbers of views, likes, and dislikes were found for the videos uploaded by physicians and companies. Physicians uploaded a greater number of videos and the video quality was also high. The reliability of the videos generated by physicians and HO was better.

Since hemophilia is a chronic condition that requires attention, close relationships with healthcare professionals may mean improved quality of life and better disease management for the patients. It is very important for patients with hemophilia to take an active role in managing their own care over time, and to do this, they need to learn about hemophilia. When hemophilia patients start self-infusions, they should be adequately informed and encouraged to help them improve their self-management skills. Videos on hemophilia may be well-suited for these purposes and can be preferred as a relatively easy tool to educate the patients. Globally, YouTube is the most frequently used video-sharing site. The number of views is the major indicator of the

Table 4. The Comparison of the Video Characteristics by Uploader Source

	Physician	Healthcare organization	Company	Patient	Independent user	P
Video duration (seconds)	1059 (81-5865)	778 (66-9083)	247 (93-2751)[φ]	285 (102-3536)	364 (43-2733)[φ]	.004
Days since upload	1202 (60-3995)[†]	1898.5 (238-5258)	1427.5 (330-4356)[†]	2390 (1672-4230)	1244 (349-4844)[†]	.012
Views	7991 (192-512 569)	1321 (277-15206)[β]	22824.5 (439-3 149 847)	10371 (588-19910)	5398 (187-1 640 698)	.039
Daily views	6.12 (0-154)	1.4 (0-28)[Λ]	20 (0-852)	3.46 (0-12)[Λ]	5.8 (0-2485)[Λ]	.001
Likes	63 (0-6400)	14 (0-192)[ψ]	194.5 (0-18 000)	69 (4-216)	42.5 (0-25 000)[ψ]	.007
Dislikes	3 (0-114)	0.5 (0-5)[x]	6.5 (6.5-1400)	3 (0-6)	3 (0-594)	.031
Comments	4 (0-218)	0 (0-5)	5.5 (0-366)	7 (0-52)	1.5 (0-1593)	.077
Like ratio	1733.33 (0-8900)	650 (0-9600)	2084.29 (0-4666.67)	3020 (0-3800)	822.22 (0-7000)	.069
GQS (score)	4 (2-5)	3 (3-4)	3 (1-5)	3 (2-4)	3 (1-5)	< .001
DISCERN (score)	4 (2-5)	3 (2-4)	3 (1-5)	2 (2-3)[a,b]	2.5 (1-4)[a]	< .001

sec, second; min, minimum; max, maximum.
Bold values indicate *P* < .05, Kruskal–Wallis test results.
Significant difference on Kruskal–Wallis test and post hoc pairwise (Dunn correction) comparisons.
[φ]Company and independent users < physician; [†]physician, company, independent users < patient; [β]healthcare organization < company; [Λ]healthcare organization, patient and independent users < company; [ψ]healthcare organization and independent users < company; [x]healthcare organization < company; [b]other groups < physician; [a]patient and independent users < physician; [b]patient < healthcare organization.

popularity of the videos displayed on YouTube. Looking at the number of views for videos on chronic diseases, it was 403 144 for "rheumatoid arthritis," 6969 for "ankylosing spondylitis," and 2074 for "dialysis" videos.[25,27,28] Although the number of views for the hemophilia videos reviewed in the current study was not as high as that of rheumatoid arthritis videos, it was higher than that of videos on other chronic conditions. The number of views for the hemophilia videos was the same as that of systemic lupus erythematosus videos.[29] This suggests that hemophilia videos reach a large audience and that YouTube is used often as a source of information on hemophilia. This also indicates the need to check whether the videos provide correct or incorrect information to individuals. Accordingly, quality assessment of the educational content of the hemophilia videos using the GQS score showed a higher mean GQS score compared to that of the most frequently viewed "rheumatoid arthritis" videos.[27] The content quality of a video may be affected by the characteristics of its uploader; consistently, physician videos showed a higher GQS score compared to other groups in our study.[30] The fact that physicians are the most important stakeholder of the treatment process in congenital chronic diseases such as hemophilia, the continuation of the patient–physician relationship throughout life, and their experience about hemophilia could be reasons that physicians may have uploaded higher-quality videos. The reliability of the hemophilia videos as demonstrated by the DISCERN scores was higher compared to the videos on "Sjögren's syndrome" and "diabetes and oral health."[24,31] We believed that hemophilia has more prominent symptoms and more specific findings than rheumatic or systemic diseases may have affected the reliability of the uploaded videos.

Concerning the quality of information delivered by the hemophilia videos, there were many videos with high content quality and very few videos with poor content quality. Moreover, physicians and medical companies were found to upload better quality videos and HO did not upload any poor quality videos. Previous studies have reported different categories of uploaders and variations in video quality. It is known that physicians, academicians, and professional organizations share high-quality videos on self-administration of subcutaneous injection.[30] Physicians have also uploaded high-quality videos on kyphosis and fibromyalgia.[32,33] In line with the literature, it was found that high-quality videos were uploaded by physicians and low-quality videos were uploaded by independent users in the present study.[18,24] In addition, the finding of higher DISCERN scores with increased video quality and the high like ratio for high-quality videos reflecting positive viewer feedback suggest that quality information was accessed by

viewers. This result is consistent with the data from a recent study on the reliability of sarcopenia videos.[22]

YouTube is a dynamic online platform and viewers provide feedback by clicking on the like or dislike button or leaving comments about the videos. Among the video characteristics, likes, dislikes, and comments are not directly correlated with the content reliability and accuracy of a video and might give a false impression. As such, the popularity of a video does not mean that it provides helpful information or too many negative comments do not indicate that a video is useless. Singh et al[27] reported that these video characteristics do not have a significant association with content and accuracy. On the other hand, high numbers of views, likes, dislikes, and longer duration have been reported for useful videos.[34,35] In the current study, hemophilia videos had similar quality and characteristics except for the like ratio which was greater for high-quality videos. This finding represents a major difference from previous studies and may be of importance.

Video duration, days since upload, number of dislikes, like ratio, views, daily views, and GQS and DISCERN scores differed among video uploader groups. Physician-sourced videos were longer but patient videos were older with a greater number of days since upload. In addition, the reliability and quality of the physician videos were higher compared to those uploaded by other groups. Longer video duration may reflect the wider scope of the information delivered by the video. Our results showed a correlation between the length of the videos generated by physicians and HO and the GQS and DISCERN scores, that is, the quality and reliability of the video were higher for longer videos, and this is consistent with previous reports.[22,36] The high quality and content reliability of physician videos may be related to their professional knowledge and experience.[18] However, lengthy videos may bore the audience and viewers can lose their interest.[37] In the current study, the shortest videos were those uploaded by companies and numbers of views, likes, dislikes, and daily views were higher for these videos. Although these user activity metrics do not reflect the reliability or usefulness of the information contained in a video, they may give a sense of what the viewer's thought about the video and it can be considered that the videos with higher numbers of views, likes, and dislikes are preferred by the viewers. To promote their business, companies produce attention-grabbing videos with rich visual content and professional shots or videos with similar characteristics to those shared on social media platforms, which may explain the popularity of company videos. Physicians might consider developing strategies to reach a

wider audience and increase the visibility of their videos. From a different perspective, the general audience believes that the most viewed videos are more reliable due to YouTube's new algorithm.[38] Healthcare professionals should create videos that contain accurate information and find ways to keep viewers engaged.

Study Limitations

A number of limitations should be noted for this study. The subjective scales used for the study might have been affected by personal opinions of the individual raters. However, former studies have also used these criteria because there is no specific quantitative method defined for this purpose. Another important consideration is the date the videos were evaluated. YouTube is a gigantic platform with a large number of new videos shared on a daily basis and video characteristics may change over time. Therefore, future studies should take this into account and compare the same videos at 2 different time points.

Conclusion

Hundreds of thousands of videos are uploaded to YouTube each day and viewers provide feedback. While these feedback do not necessarily reflect the quality of the videos, most of the videos sourced by physicians and healthcare organizations can be considered as reliable and of high quality. YouTube can be regarded as a good source of information on hemophilia for people with hemophilia and may improve their self-management skills.

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