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EVALUATION OF THE QUALITY AND RELIABILITY OF EXERCISE AND PHYSIOTHERAPY VIDEOS SHARED ON YOUTUBE FOR PATIENTS WITH HEMOPHILIA: A CROSS SECTIONAL STUDY

ORIGINAL ARTICLE

ABSTRACT

Purpose: To evaluate the quality and reliability of shared on YouTube videos pertaining to exercises and physiotherapy in haemophilia.

Methods: The terms "exercise in haemophilia" and ''physiotherapy in hemophilia'' were entered on YouTube, First 300 videos were independently analyzed by two physiotherapists and were classified as reliable or non-reliable. Video demographics were analyzed according to speakers and uploaders of the video. Video Power Index (VPI) was calculated for each video. Modified DISCERN and Global Quality Scores (GQS) were used to assess the reliability and overall quality of the videos.

Results: Eighty-five videos were included and 51.7 % were non-reliable. The median GQS and DISCERN scores of the videos were significantly higher in the reliable group and where the speakers were physician and physiotherapist ($p<0.001$). According to the video source, the GQS and DISCERN scores of the videos shared by haemophilia patients and personal trainers were found to be significantly lower in all pairwise comparisons of other groups ($p<0.001$). Although the VPI was higher in the reliable group, no significant difference was found in all group comparisons ($p=0.185$).

Conclusions: It was determined that most of the exercise and physiotherapy videos shared on YouTube in hemophilia were non-reliable and quite low quality. Although the popularity of the videos shared by Haemophilia Associations/Universities/physician or physiotherapists is not high, their reliability and quality are relatively higher. Considering the difficulties of hemophilic individuals in reaching physiotherapist who maintains their joint health, it may be recommended that musculoskeletal specialist physiotherapists share original, detailed and interesting videos.

Key words: YouTube, Haemophilia, Exercise, Arthropathy, Physiotherapy

HEMOFİLİ HASTALARINA YÖNELİK YOUTUBE'DA PAYLAŞILAN EGZERSİZ VE FİZYOTERAPİ VİDEOLARININ KALİTE VE GÜVENİLİRLİĞİNİN DEĞERLENDİRİLMESİ: KESİTSEL BİR ÇALIŞMA

ARAŞTIRMA MAKALESİ

ÖZ

Amaç: Hemofilide egzersiz ve fizyoterapi ile ilgili YouTube'da paylaşılan videoların kalitesini ve güvenilirliğini değerlendirmek amacıyla yapılmıştır.

Yöntem: "Hemofilide egzersiz" ve "hemofilide fizyoterapi" terimleri YouTube'a girildi, İlk 300 video iki fizyoterapist tarafından bağımsız olarak analiz edildi ve güvenilir veya güvenilmez olarak sınıflandırıldı. Video demografisi, konuşmacılara ve videoyu yükleyenlere göre analiz edildi. Video Güç İndeksi (VGİ) her video için hesaplandı. Videoların güvenilirliğini ve genel kalitesini değerlendirmek için Modifiye DISCERN ve Global Kalite Skoru (GKS) kullanıldı.

Sonuçlar: Seksen beş video dahil edildi ve 51,7 % 'si güvenilir değildi. Videoların medyan GKS ve DISCERN puanları güvenilir grupta ve konuşmacıların hekim ve fizyoterapist olduğu grupta anlamlı olarak daha yüksekti ($p<0,001$). Video kaynağına göre, hemofili hastaları ve kişisel antrenörler tarafından paylaşılan videoların GKS ve DISCERN puanları, diğer grupların tüm ikili karşılaştırmalarında anlamlı derecede düşük bulundu ($p<0,001$). Güvenilir grupta VGİ daha yüksek olmasına rağmen, tüm grup karşılaştırmalarında anlamlı bir fark bulunmadı ($p=0,185$).

Tartışma: Hemofilide YouTube'da paylaşılan egzersiz ve fizyoterapi videolarının çoğunluğunun güvenilir olmadığı ve oldukça düşük kalitede olduğu tespit edildi. Hemofili Dernekleri/Üniversiteler/hekim veya fizyoterapistler tarafından paylaşılan videoların popüleritesi yüksek olmasa da güvenilirliği ve kalitesi nispeten daha yüksektir. Hemofilik bireylerin eklem sağlığını koruyan fizyoterapiste ulaşmada yaşadıkları zorluklar düşünüldüğünde kas iskelet sistemi uzmanı fizyoterapistlerin özgün, detaylı ve ilgi çekici videolar paylaşmaları önerilebilir.

Anahtar Kelimeler: YouTube, Hemofili, Egzersiz, Artropati, Fizyoterapi

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INTRODUCTION

The expected number of patients with haemophilia (PwH) in the world is more than one million and the majority of the severe type (1). Spontaneous recurrent bleeding, especially in the musculoskeletal system, is one of the most important causes of disability and is of serious concern as it affects functioning (2). Exercise therapy in the care of haemophilia is very important because it is non-invasive and easy and inexpensive to administer by the PwH (3).

PwH's traditional habit of consulting a physician or physiotherapist to learn about musculoskeletal problems have turned to online research, especially with the recent pandemic. Of those who relied on internet-based information, 80 % were individuals with chronic disease who accessed health-related information online (4). The internet is today the first source of medical information for patients with concerns about their disease, and they use it to learn more about their disease and search for people who share a similar health problem (5). Many patients believe that health-related information on the internet is equal or even better than the information provided by physicians, and many patients do not report their search results to their physicians (5,6).

YouTube is one of the most widely used platforms that contributes to online access of health-related information by reaching 95 % of all internet users (7). As of January 2022, YouTube has reportedly more than 2 billion logins per month and more than 500 hours of video uploads per minute (8). According to the Global Internet Phenomena Report released in 2019, YouTube is currently responsible for 8.7 % in megabytes of worldwide downstream traffic (9). Since videos shared on this platform have varying quality and reliability, there is a potential risk of spreading misleading information, which can pose a significant challenge in providing optimum healthcare. Previous research showned that YouTube to be a useful and misleading source of information during public health crises, including the H1N1, Ebola and Zika outbreaks (10-12). This situation reveals the necessity of evaluating the quality and accuracy of the video content available on YouTube.

The reliability and quality of YouTube videos for various disease of medical information (13-15) and exercises (16-18) has been evaluated previously. However, to our knowledge, the reliability and quality of YouTube videos regarding exercise and physiotherapy in haemophilia has not been yet investigated. The present study was designed to evaluate the quality and reliability of shared on YouTube videos pertaining to exercises and physiotherapy in haemophilia.

METHODS

Search Strategy and Data Collection

The video-sharing website YouTube was queried in January of 2021 using the keywords '' exercise in haemophilia'' and '' physiotherapy in haemophilia''. More than 90 % of users tended to watch the first pages of the search result. The top 300 videos were sorted by "relevance" due to this situation. The inclusion criteria of the study were as follows; YouTube videos with appropriate titles (including exercise or physiotherapy in hemophilia), both real and animations, videos with a length of 30 sec or longer and English videos. Advertisements, one of the duplicate videos, irrelevant videos and non-English videos were excluded from the study.

Video Characteristics and Scoring System

The videos were independently assessed at different locations simultaneously to avoid bias during assessment by two physiotherapists specializing in haemophilia. In order to evaluate the accuracy of the YouTube videos included in current study, they were examined in two subgroups as reliable and non-reliable information, and the detailed group description were as follows:

Reliable information: If the video contains scientifically correct information about exercise and physiotherapy in haemophilia, such as indications, contraindications and appropriate exercise.

Non-reliable information: If the video contains information that has no scientific value, and also if the video contains untrusted information as well as reliable information, it was classified in this group. While the number of videos containing reliable information was 41, the number of videos containing unreliable information was 44.

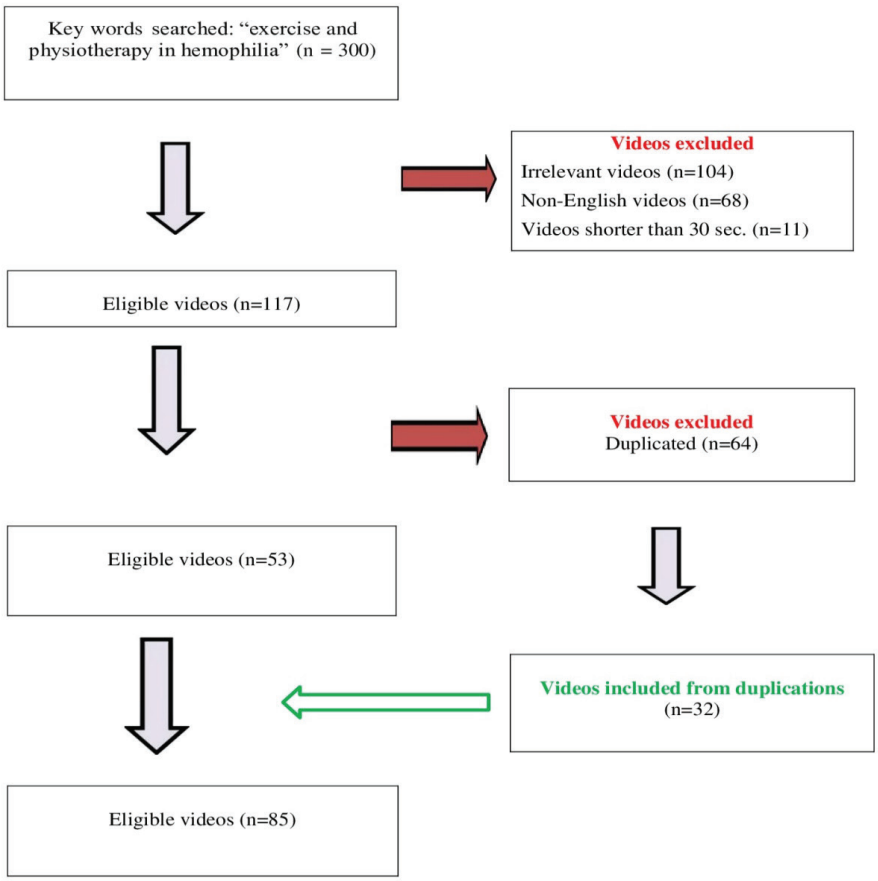

Figure-1. Flow Diagram

This method has already been used in previos studies (13,15,19). For each video, count of view/like/dislike/comment and video length were recorded. The loading times of videos were also recorded to avoid deviating from a video's period on YouTube. Video uploaders were seperated into 4 groups as follows: (1) Haemophilia associations/universities and non-profit physiotherapists/physicians; (2) PwH (patient experience); (3) Health channels/TV programs or non-haemophilia associations and (4) Fitness coach/personal trainer. Participants in the videos were divided into five groups according to who was giving the explanation; (1) physician, (2) physiotherapist, (3) patient, (4) non-health professional and (5) external voice.

Modified DISCERN Tool

DISCERN is a 5-point scale consisting of 15 questions developed to enable patients and information providers to judge the quality of written information about treatment options. We used modified DISCERN tool consisting of 5 questions, used in recent studies, to score the reliability of the information (13,19,20). It is validated tool to evaluate the quality of consumer health-related information. Its scoring is as follows: Reliability (1 point per question if answered yes); 1. Are the explanations given in the video clear and understandable; 2. Are useful reference sources given (publication cited, from valid studies); 3. Is the information in the video balanced and neutral; 4. Are additional sources of information given from which the viewer can benefit; 5. Does the video evaluate areas that are controversial or uncertain.

Global Quality Score (GQS)

GQS is a scale, scored from 1 to 5, to rate the streaming and usability of videos available online on the internet and the overall quality of the video (15,19). Its scoring is as follows: 1. Poor quality, poor flow, most information missing, not helpful for patients; 2. Generally poor, some information given but of limited use to patients; 3. Moderate quality, some important information is adequately

Table 1. Analysis of Video Features By Reliability

	Reliable information n =41	Non-reliable information n =44	p
Views [1]	755 (150-5411)	345.5 (212-1002)	0.228
Likes [1]	10 (1-63)	15.5 (5.5-46)	0.702
Comments [1]	0 (0-2)	3 (0-13)	**0.001****
Video length (minutes) [1]	4.37 (2.55-8.55)	5.69 (2.32-10.85)	0.799
Duration on youtube (months) [1]	23 (9-57)	21.5 (12.5-56)	0.799
Views per month [1]	43.96 (15-137.73)	15.42 (9.4-34.55)	**0.012***
VPI [1]	0.94 (0.18-4.59)	0.51 (0.31-1.15)	0.185
DISCERN [1]	3 (2-4)	0 (0-1)	**<0.001****
GQS [1]	4 (3-5)	0 (0-1)	**<0.001****
Source of upload [2]			**<0.001**** [b]
Haemophilia Associations/ Universities/ non-profit physician or physiotherapist	31 (75.6)	9 (20.5)	
Health channels/TV programs	10 (24.4)	9 (20.5)	
PwH	0 (0)	21 (47.7)	
Fitness coach/Personal Trainer	0 (0)	5 (11.4)	
Speaker [3]			**<0.001**** [b]
Physician	8 (19.5)	0 (0)	
Physiotherapist	20 (48.8)	2 (4.5)	
PwH	4 (9.8)	28 (63.6)	
Non-health professional	1(2.4)	9 (20.5)	
External voice	8 (19.5)	5 (11.4)	

[a] Mann-Whitney U-test, [b] Chi-square test; [1] median (percentile 25-75 %), [2] n (%); VPI : Video Power Index, DISCERN : modified DISCERN score, GQS : Global Quality Score, PwH: Patient with hemophilia; Values of $p < 0.05$ were accepted as significant and marked bold

discussed; 4. Good quality good flow, most relevant information is covered, useful for patients; 5. Excellent quality and excellent flow, very useful for patients

Popularity was assessed by the Video Power Index (VPI). VPI= (likes x 100/(likes+dislikes)) x (views/day)/100 (14,15,21).

Statistical Analysis

The data were analyzed with IBM SPSS 24.0 software (Statistical Package for Social Sciences Inc. Chicago, IL, USA). The Kolmogorov-Smirnov test was used to were calculated normality in the distribution of the sample. Descriptive statictics of the variables (median and percentile 25-75 %) were given. The inter-observer agreement was determined using Cohen's kappa score. Inter-observer reliability was quantified by calculating the intraclass correlation coefficient. Comparisons of two groups that did not show normal distribution were calculated with the Mann-Whitney U Test, and comparisons with more than 2 groups were calculated with the Kruskal-Wallis H Test. Non-parametric post-hoc tests were used in multi-group comparisons in which the difference between groups was determined, and test statistics were tested with Bonferroni correction. Significance level was accepted as $p < 0.05$.

RESULTS

Each keyword was filtered by relevance on YouTube, and the top 150 videos were retrieved in the study. In a total of 300 videos scan, irrelevant videos (n=104). A total of 117 videos were included after the exclusion of irrelevant videos (n=104), non-English videos (n=68), and videos shorter than 30 sec. (n=11). It was determined that 64 of these 117 videos were duplicated. Final analyzes were made on 85 eligible videos by adding 53 videos meeting the criteria to 32 videos, half of which were 64 duplicated videos (Fig-1). Half of 64 duplicate videos (n=32) were analysed. Cohen's kappa coefficient representing inter-rater reliability was calculated as 0.929 for evaluating the reliability of the videos, 0.811 for the GQS score and 0.849 for the modifed DISCERN score. These scores represent excellent agreement between the two researchers for

within the instruments (95 % confidence interval, 0.81–1.00).

The results according to the reliability of the videos included in the study were shown in Table-1. Accordingly, 48.2 % of the videos were defined as reliable, 51.7 % as non-reliable. While the median views per month were significantly higher in reliable group, the number of comments was also lower. There were no significant difference were found between the groups in the VPI, number of views,-likes and dislikes, the length and duration of videos. The modified DISCERN and GQS median scores of the videos were found to be statistically higher in favor of the reliable group (p<0.001). Most of the videos with reliable information were found to be uploaded by haemophilia association/university or non-profit physiotherapist and physician (n=31). Most of the videos containing misleading information have PwH as a speaker (n=28).

While the modified DISCERN and GQS scores were not differ from each other in the videos where the source was PwH and Fitness coach/personal trainer, it was seen that these two source groups were significantly lower in other pairwise comparisons. It was found that the number of video comments in the videos where the source was PwH was significantly higher than the other groups. On the other hand, there was a significant difference in the duration of broadcasting on YouTube in the PwH or TV program group of the video source (Table-2).

Analysis by speakers in the videos found that the PwH and non-health personnel group had significantly lower modified DISCERN and GQS scores in all other group comparisons. There was no difference in these scores in the comparison of these two groups within (PwH and non-health professional) and the remaining 3 groups (physician, physiotherapist and external voice). The number of comments in the videos where the speakers were PwH was found to be higher than the videos where the speakers were healthcare professionals. The video length was found to be significantly lower in the videos where the speaker was external voice compared to the groups where the speaker was a physiotherapist or PwH (Table-3).

DISCUSSION

The results of this study revealed that although the accuracy and quality of the videos in the reliable group were relatively better, they were still quite low. It also revealed that the number of videos that

Table 2. Analysis of Video Properties By Uploader Spource

	Haemophilia Associations/ Universities/ non-profit physician or physiotherapist (n=40)	Health channels/ industry and TV programs (n=19)	PwH (n=21)	Fitness coach/ Personal Trainer (n=5)	p
Views	483.5 (171.5- 1354)	1021 (150-7305)	250 (195-579)	492 (395-1155)	0.166
Likes	7.5 (1.5-42.5)	12 (3-62)	22 (12-43)	52 (32-64)	0.148
Comments	0 (0-1.5)	0 (0-3)	8 (3-29)	10 (7-18)	**<0.001****
Video length (minutes)	4.27 (3.1-.10.6)	4.05 (1.52-7.46)	7.21 (4.02-19.2)	3.5 (3.3-4.48)	0.121
Duration on youtube (months)	23 (8.5-56)	40 (17-107)	18 (9-20)	41 (19-66)	**0.027***
Views per month	21.63 (10.3-93.2)	31.45 (8.16-182.6)	23 (12-34.76)	17.15 (16.73-21.94)	0.956
VPI	0.6 (0.17-3.1)	0.4 (0.17-6.08)	0.76 (0.4-1.15)	0.57 (0.55-0.73)	0.989
DISCERN	2.5 (1.5-3.5)	1 (1-2)	0 (0-0)	0 (0-0)	**<0.001****
GQS	4 (3-5)	2 (1-3)	1 (1-1)	1 (1-1)	**<0.001****

Median (Percentile 25-75 %) , Kruskal-Wallis Test ; Values of p < 0.05 were accepted as significant and marked bold; PwH: Patient with hemophilia, VPI : Video Power Index, GQS : Global Quality Score, DISCERN : modified DISCERN score,

Table 3. Analysis of Video Properties By Speakers

	Physician (n=8)	Physiotherapist (n=22)	PwH (n=32)	Non-health providers (n=10)	External voice (n=13)	p
Views	871 (365.5-1136.5)	358 (128-1130)	327 (195.5-1032)	1088 (395-1768)	1029 (241-7881)	0.334
Likes	10.5 (6.5-20.5)	5 (0-22)	22 (10-63.5)	13.5 (7-32)	18 (5-87)	0.054
Comments	0 (0-0.5)	0 (0-0)	5.5 (1-20.5)	1.5 (0-4)	0 (0-5)	**<0.001****
Video length (minutes)	5.83 (3.03-54.12)	5.85 (3.57-17.09)	5.8 (3.32-14.18)	5.4 (1.52-7.57)	3.03 (1.16-3.3)	**0.021***
Duration on youtube (months)	18.5 (6-31.5)	20 (6-48)	19 (9.5-46)	88 (31-145)	26 (23-65)	**0.003****
Views per month	26.73 (15.03-67.56)	28.97 (9.84-79.32)	21.74 (12.58-44.17)	10.87 (8.16-21.94)	44.73 (9.26)	0.552
VPI	0.89 (0.5-2.25)	0.46 (0-2.64)	0.72 (0.4-147)	0.36 (0.25-0.73)	1.49 (0.3-4.78)	0.352
DISCERN	2.5 (2-4)	3 (2-4)	0 (0-1)	0 (0-1)	2 (1-2)	**<0.001****
GQS	4 (3-4.5)	4.5 (4.5)	1 (1-2)	1 (1-1)	3 (2-4)	**<0.001****

Median (Percentile 25-75 %) , Kruskal-Wallis Test ; Values of $p < 0.05$ were accepted as significant and marked bold; PwH: Patient with hemophilia, VPI : Video Power Index, GQS : Global Quality Score, DISCERN : modified DISCERN score

did not include reliable information (mostly shared by patients) besides the videos that contain reliable information about exercise and physiotherapy in haemophilia is substantial.

YouTube is one of the most popular tools that provides many users access to research on diseases. Considering the current pandemic, the information shared YouTube has become very valuable. To date, many studies have been performed on the reliability and quality of YouTube videos, but these studies have produced conflicting results. A systematic review included 37 studies reported that related health-care videos on YouTube were mostly non-reliable (22). Similarly, some studies evaluated videos on specific health topics on YouTube found that most videos were non-reliable (23-25). The higher number of non-reliable videos in our study was in line with the literature. Contrary to our study, there were studies included more reliable information (26-28). The reliability of the videos can be expected to vary depending on the source of the video and the expertise of the speaker. Patients, health channels and personal trainers share more unreliable information in the field of health. Consistent with the literature in the non-reliable video group, the majority were uploaded by PwH (47.7 %), health channels (20.5 %), and fitness coach/personal trainer (11.4 %). In current study, most of the reliable videos (75.6 %) were uploaded by haemophilia associations/universities or physiotherapist/physician, and most of the speakers (68.3 %) were healthcare professionals. In the study on osteoporosis, it was reported that all of the YouTube videos sourced by universities/professional institutions, and 87 % of the videos published by healthcare professionals contain useful information (27).

The median modified DISCERN and GQS scores were significantly higher in the reliable video group, and these results were in accordance with the results of previous studies (15,19,29). It showed that the accuracy and overall quality of these reliable videos were not sufficient, as the average value of both scores was 3 and 4 out of 5, respectively. The scores of the videos uploaded by the haemophilia society/university or the physiotherapist/physician, showing the reliability and overall quality, are 2.5 and 4, respectively. This situation is consistent with the literature (27). However, in the study claiming to the contrary, it was reported that these scores would not differ according to the video source. The probable reason for this study may be that only 7 out of 59 videos were contain to be misleading information (28). In current study, the videos with the highest reliability and quality are those in which the speakers are physiotherapists. The decline in reliability scores of these videos was due to the vast majority of videos not assessing contoversial or uncertain areas for exercise in haemophilia and

not providing additional sources of information from which the viewer can benefit.

The number of monthly views was significantly higher in reliable group indicates that PwH can distinguish the contents in the long term. The reason for the high number of comments on non-reliable videos (especially videos shared by PwH) may be due to the fact that the videos in the haemophilia association/university were closed to comments and thinks that PwH can understand them better. There were no significant difference between the groups regarding views, likes, video length, duration on YouTube and VPI. This shows that individuals watch both reliable and also non-reliable videos about exercise and physiotherapy in haemophilia at similar rates. It has been emphasized in many other publications that video metrics and popularities were not related to video content (15,27). It has been reported that the popularity of low-quality videos is significantly lower in the classification made by video quality, but we did not make such a classification in our study (14).

In conclusion many YouTube videos, often shared by patients, were encountered that did not contain reliable information about exercise and physiotherapy in haemophilia. YouTube videos shared by Haemophilia Societies/Universities/non-profit physician or physiotherapists where healthcare professionals are speakers have higher reliability and quality, but lower popularity. With increased awareness of this study, haemophilia associations and healthcare professionals involved in haemophilia care should be encouraged to share comprehensive and accurate YouTube video information that is appropriately determined to meet the needs of patients in a way that allows the improvement of haemophilia care. It is also very important that evidence-based reliable and high-quality videos become more popular so that more patients can access them easily.

The main limitation of the present study is that it was a cross-sectional study that captured YouTube videos at a particular moment in time. The most important feature of YouTube is that new videos are constantly being uploaded and video interaction parameters are changing rapidly. It does not include videos uploaded after the search date, and videos included in the search may have been unshared for certain reasons. Our second main limitation is that there is no consensus in the literature on evaluating the reliability and quality of the videos. However, the evaluation parameters used in our study are among the most commonly used methods in previous studies (13,15,19,20). Finally, we analyzed the English videos only available on the YouTube platform. It is the most common health-related platform people use and English is the most dominant language in the world.

Considering the difficulties of hemophilic individuals in reaching physiotherapist who maintains their joint health, it may be recommended that musculoskeletal specialist physiotherapists share original, detailed and interesting videos. Physiotherapists can also suggest reliable and helpful YouTube videos for home-care patients with hemophilia. As a result of a multidisciplinary study with authorized official institutions, including health institutions, hemophilia associations and universities, a guideline hemophilia treatment video can be produced and shared for healthcare professionals we can recommend, making the process more practical and reaching more patients.

Declarations

Conflict of Interest: The authors stated that they had no interests which might be perceived as posing a conflict or bias.

Ethics Approval and Formal Consent: Ethical approval and informed consent were not obtained as publicly accesible YouTube videos were used and no human/animal participants were included in the study.

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