

Analysis of YouTube videos as a source of information for reliability and effectiveness of cannabidiol oil in treatment of epilepsy



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ABSTRACT

Objective: Cannabidiol (CBD) oil has been used for the treatment of refractory epilepsy for a long time. In this study, we aimed to investigate the quality and reliability of YouTube videos pertaining to the use of CBD oil in the treatment of epilepsy.

Methods: A total of 100 videos were reviewed. Evaluation of the videos were performed by two experienced neurologists at the same time, but in different settings in order to prevent bias. Videos' image type, video content, video length, upload date, daily view count, comment and like counts, qualification of uploaders, DISCERN, and GQS scores were recorded.

Results: The videos were found to be uploaded by physicians (46%), health channels (33%), TV channels (7%), patients (2%), and other persons (12%). The mean DISCERN score was found as 3.71 ± 1.17 and the mean GQS score was found as 3.21 ± 1.05 in all videos. According to the DISCERN scale, the videos uploaded by doctors were scored as 3.82 ± 1.02 and the videos uploaded by non-doctors as 3.07 ± 1.12 ($p < 0.001$). According to the GQS scale, the videos uploaded by doctors were scored as 3.51 ± 1.02 and the videos uploaded by non-doctors as 3.01 ± 1.17 ($p < 0.001$).

Conclusion: Thirty-two (32%) videos were poor, 43 (43%) videos were moderate, and only 25 (25%) videos were good in terms of quality and reliability. YouTube videos related to health issues need to be audited strictly before they can become publicly accessible.

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1. Introduction

Epilepsy is one of the most common neurological diseases characterized by focal or generalized seizures [1]. According to the World Health Organization (WHO), epilepsy affects more than 50 million people worldwide [2]. Quality of life (QoL) is significantly influenced in patients who experience seizures because of the side effects of antiseizure drugs, social consequences, and comorbidities [3,4]. Therefore, seeking new treatment modalities remains a major difficulty for both physicians and patients. Cannabidiol (CBD) is one of the major ingredients of the *Cannabis sativa*. Several studies have described the anticonvulsant effects of cannabis with controversial results [5]. *Cannabis sativa* has been used to treat epilepsy for centuries [6]. While on the one hand studies are continuing to elicit the efficacy of CBD oil in the treatment of epilepsy, on

the other hand, patients and relatives are searching for new sources of information to find out a remedy for their problem.

Patients obtain information for their health-related problems via the Internet, which is one of today's largest sources of information, before seeking medical health from professionals. Visual content is more attractive than audio text and written sources [7]. More than 80% of Internet users search for healthcare information via online platforms on the Internet and 75% of these patients report that their decision for treatment is based on the information they have obtained in this way [8].

YouTube (YouTube, LLC, San Bruno, CA, USA) is a rapidly growing online video platform with nearly-two billion views every day [9,10]. Every single day more than 1 billion YouTube videos are watched and there are 2.3 billion YouTube users as of 07/03/2022 and more than 500 hours of YouTube videos are uploaded per minute (Available at: <https://www.omnicore-agency.com/youtube-statistics/>). YouTube has the potential of improving the relationship between patients and physicians. On the other hand, the YouTube platform permits users to produce any medical content, and to post this content without any obligation for verification, leading to the potential for spreading

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misleading information to millions of people free of charge [11]. Every-one can upload video content to YouTube without being subjected to any audit or supervision on any topic. This has prompted researchers to question the quality and reliability of health-related information on YouTube [12–14]. The number of studies related to healthcare information on YouTube in every field of medicine is gradually increasing. There were 2,351 studies on Pubmed related to healthcare-related YouTube videos as of 03/08/2022. The objective of this study was to investigate the quality and reliability of YouTube videos pertaining to the use of CBD oil in the treatment of epilepsy.

2. Material and methods

This analysis study was conducted by two experienced independent neurologists on 03–04 August 2022. Searching terms were determined as “CBD oil + epilepsy”, and “Cannabidiol + epilepsy” by consensus. From the filter function of YouTube, the videos were sorted by relevance option. Studies have reported that YouTube users mostly view results from the first several pages [15]. Exclusion criteria included non-English videos, ads, duplicate videos, and those lasting more than one hour. After these videos were excluded, the most relevant 100 videos were included in the study. The links to these videos were entered into the Microsoft Excel program (Fig. 1).

The videos were viewed by the two experienced neurologists (14 and 16 years of experience) at the same time, but in different settings in order to prevent bias. Videos’ length, image type (real, animation, presentation), qualification of the uploaders, video contents, comment and like counts, daily view count, upload date, and time since uploading were recorded and subjected to the analysis. Video uploaders were classified as physicians, patients, tv channels, health channels, and other persons, while video contents were classified as general information, treatment, education, and

patient experience. The accuracy of the videos was evaluated by the two experienced neurologists. The videos were divided into two groups those uploaded by medical doctors and the videos uploaded by non-doctors. The reliability of the examined videos was determined objectively using the DISCERN tool and the quality using the Global Quality Scale (GQS).

2.1. DISCERN scale

DISCERN was described by Oxford University in 1999 for the first time as a tool for assessing the reliability of consumer health information on treatment options [16]. The original version consisted of 16 items. The modified DISCERN scale is a five-question tool adapted by Singh et al. in 2015 from the original 16-question DISCERN tool [17]. The modified DISCERN tool consisted of 5 criteria with each being scored between 0 and 5 (Fig. 2). A DISCERN score < 3 indicates poor reliability, a DISCERN score = 3 moderate reliability and a DISCERN score > 3 good reliability.

2.2. Global Quality Scale (GQS)

The Global Quality Scale (GQS) was developed by Bernard et al. to identify the quality of health-related online material [18]. Global Quality Scale has 5 questions about the flow, ease of use, and quality of the information in the reviewed videos using a 5-point Likert scale. Global Quality Scale items are given in Fig. 3.

Ethical considerations

Ethics approval was not deemed necessary, because no humans or animals were included in this study. Permission from YouTube was not required since all data used in this study were available publicly. The study was conducted in line with the Declaration of Helsinki revised in 2013.

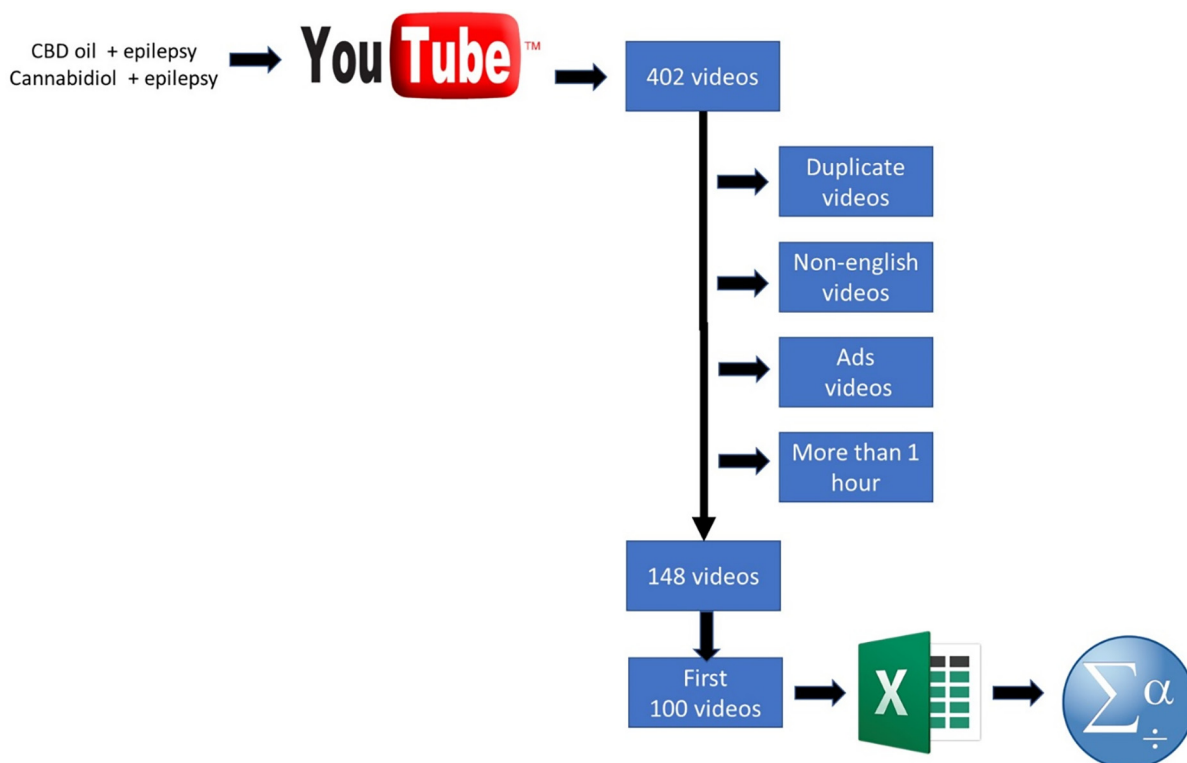


Fig. 1. Flowchart of video exclusion and inclusion.

1. Is the aim of the video clear and understandable?
2. Are reliable sources of information used?
3. Is the information presented balanced and unbiased?
4. Are additional sources of information listed for patient reference?
5. Are areas of controversy/uncertainty mentioned?

Fig. 2. DISCERN Scale.

1. Poor quality, poor flow of the video, most
2. Generally poor quality, poor flow, some information given but many important topics missing, of very limited use to patients.
3. Moderate quality, suboptimal flow, some information is adequately discussed but other information inadequately discussed, somewhat useful for patients.
4. Good quality, good flow, most of the relevant information is listed, but some topics not covered, useful for patients.
5. Excellent quality and flow, very useful for patients

Fig. 3. Questions of the GQS scale.

2.3. Statistical analysis

Statistical analysis of the data obtained in this study was performed utilizing the SPSS version 25.0 (SPSS, Statistical Package for Social Science, IBM Inc., Chicago, IL, USA) program. The normal distribution of the variables was tested using the Kolmogorov-Smirnov method. An independent t-test was used to compare the continuous variables between the groups. Categorical data were analyzed using the Chi-square test. Numerical variables are expressed as mean ± standard deviation and categorical variables as frequency (n, %). Cronbach alpha coefficients were used to identify the consistency between the two researchers. The significance level was set at $p < 0.05$.

3. Results

A total of 100 YouTube videos related to the use of CBD oil in the treatment of epilepsy were included in the study. Total video length was found as 18.41 hours, total view count as 15,249,751, total comment count as 5,584, and total like count as 42,470. In the present study, the average video length was found as 10.61 ± 12.50 minutes, the mean comment count was 55.84 ± 108.96 , and the mean like count was 424.70 ± 905.17 . The distribution of image types is shown in Fig. 4.

When video contents were analyzed, general information was found in 54 (54 %) videos, treatment in 41 (41 %) videos, education in 4 (4 %) videos, and patient experience in 1 video (Fig. 5).

■ REAL ■ ANIMATION ■ PRESENTATION

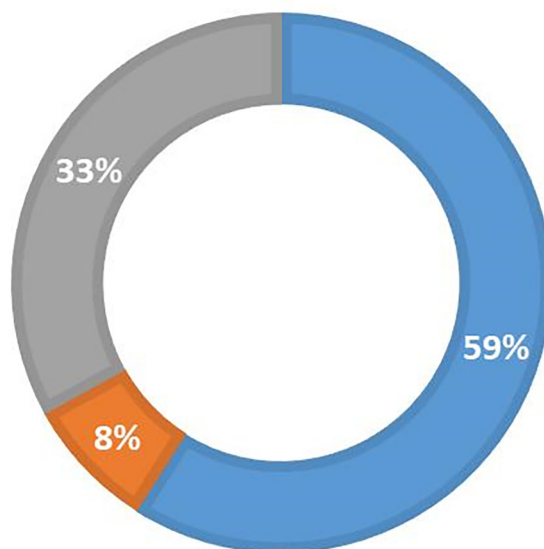


Fig. 4. Type of the video images.

■ GENERAL INFORMATION ■ TREATMENT ■ EDUCATION ■ PATIENT EXPERIENCE

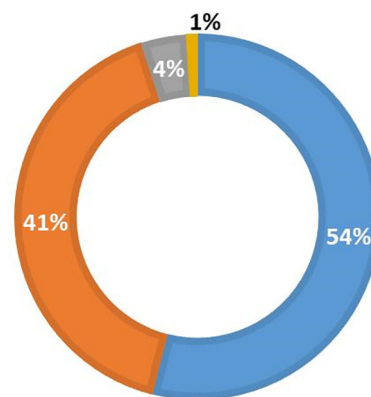


Fig. 5. Contents of the reviewed videos.

The videos were found to be uploaded by physicians (46 %), health channels (33 %), TV channels (7 %), patients (2 %), and other persons (12 %).

Of all videos, 46 (46 %) were uploaded by doctors and 54 (54 %) by non-doctors. The average length was found as 10.61 ± 12.50 min in all videos. The mean video length was found as 10.58 ± 12.62 minutes in the videos uploaded by doctors and 10.61 ± 12.50 in the videos uploaded by non-doctors. No significant difference was found between the videos uploaded by physicians and those uploaded by non-physicians in terms of video length ($p = 0.600$). The mean comment count was found as 72 ± 131.42 in the videos uploaded by physicians and 42.07 ± 84.223 in those uploaded by non-physicians. The mean comment was significantly higher in the videos uploaded by doctors ($p = 0.033$). The average like count was found as 327.30 ± 626.42 in the videos uploaded by doctors and 507.07 ± 1087.22 in those uploaded by non-doctors. No

significant difference was found between the video groups in terms of the mean like count ($p = 0.065$). The basic features of the reviewed videos are presented in Table 1.

The reliability of the videos was evaluated with DISCERN scale and the quality of the videos with the GQS scale. The average DISCERN score was 3.71 ± 1.17 and the average GQS score was 3.21 ± 1.05 in all videos.

According to the DISCERN scale, the videos uploaded by doctors were scored as 3.82 ± 1.02 and the videos uploaded by non-doctors as 3.07 ± 1.12 ($p < 0.001$). According to the GQS scale, the videos uploaded by doctors were scored as 3.51 ± 1.02 and the videos uploaded by non-doctors as 3.01 ± 1.17 ($p < 0.001$). Accordingly, 32 (32 %) videos were poor, 43 (43 %) videos were moderate and 25 (25 %) videos were good in reliability and quality.

The agreement between the two researchers was evaluated using Cronbach α coefficients. Accordingly, an excellent agreement was found between the two researchers in DISCERN and GQS scores (Table 2).

4. Discussion

In the present study, we investigated the quality and reliability of YouTube videos related to the use of CBD oil in the treatment of epilepsy. In the literature, there are studies investigating the reliability and quality of YouTube videos on epilepsy and sudden unexpected death in epilepsy (SUDEP) [19,20]. However, no study was found to investigate the use of CBD oil in the treatment of epilepsy seizures.

Video length differs widely among YouTube studies depending on the topic of interest. In our study, the mean length of the videos was found as 10.61 ± 12.50 minutes. In a study by Onder et al. investigating the quality of YouTube videos on psoriatic arthritis, the mean video length was found as 5 minutes [8]. In a study by Salman et al. examining YouTube videos on female urinary incontinence, the average video length was found as 8.2 ± 10.8 minutes [21]. In a YouTube analysis study by Fode et al. on erectile dysfunction, the average video duration was reported as 4.09 minutes [22].

In our study, 46 % of the videos were uploaded directly by physicians and 54 % by non-physicians. In another study by Duran et al. on YouTube videos related to testicular cancer, 22.4 % of the videos were found to be uploaded by doctors [23]. In a study by Gorrepati et al., 31 % of videos were uploaded by physicians/healthcare professionals [24]. In a systematic assessment of You-

Tube videos by Crutchfield et al., 30.3 % of the videos were uploaded by physicians [25]. In another study by Rayi et al. investigating information about sudden unexpected death in epilepsy (SUDEP) available on YouTube, 51.3 % of the videos were uploaded by individual users and 40.7 % by activist groups [19]. A higher rate of videos uploaded by physicians in our study might result from the fact that our topic of the search was more complex and needs to be interpreted by experts. In this study, there was no significant difference between the videos uploaded by doctors and those uploaded by non-doctors in terms of the comment and like counts and the mean video length.

In our study, we determined the reliability of the YouTube videos through the DISCERN scale. The mean DISCERN score was found as 3.71 ± 1.17 for all videos, 3.82 ± 1.02 in the videos uploaded by doctors, and 3.07 ± 1.12 in the videos uploaded by non-doctors. There was a significant difference in the DISCERN scores between the uploaders ($p < 0.001$). In a study by Onder et al. investigating YouTube as a source of health-related information on gout, the average DISCERN score was reported as 4 for the videos uploaded by doctors and 2 for the videos uploaded by independent users [26]. In another study by Zengin et al. investigating the quality of YouTube videos on musculoskeletal ultrasound, the median DISCERN value (3.66) was found to be significantly higher in the YouTube videos presented by healthcare experts [27]. In another study by Cakmak et al. investigating the reliability and quality of youtube contents pertaining to pancreatic cancer, the mean DISCERN score was reported as 3.47 ± 0.99 [28]. In a study by Szmuda et al. investigating the reliability and quality of YouTube videos on narcolepsy, the mean quality of narcolepsy related-videos was found to be poor and the authors concluded that better educational content about narcolepsy should be uploaded by healthcare professionals [29].

In our study, we measured the quality of YouTube videos using the GQS score. The mean GQS score of all videos was 3.21 ± 1.05 . According to the GQS scale, the videos uploaded by doctors were scored as 3.51 ± 1.02 and the videos uploaded by non-doctors as 3.01 ± 1.17 ($p < 0.001$). In another study by Chang et al. the average GQS score was reported as 2.3 ± 1.1 [30]. In the study by Cakmak et al. the average GQS score was 3.21 ± 0.94 [30]. It is seen that our DISCERN and GQS scores were in the range reported in the relevant literature.

In our study, 25 % of the YouTube videos were good in reliability and quality. Similarly, in a study by Chang et al. investigating YouTube videos on Epidural Steroid Injection, only 22 % of the videos contained information with high reliability, and these were produced by hospitals or physicians [30]. In another study by Wong et al. evaluating epilepsy-related videos on YouTube, 51 % of the videos were evaluated as accurate, while 9 % were inaccurate [20]. Finally, an excellent agreement was found between the two researchers in terms of the DISCERN and GQS scores.

We think that CBD oil therapy is a promising treatment method in the future for specific types of epilepsy, especially in pediatric multidrug-resistant epilepsies, and it is extremely important to reach physicians through channels such as YouTube in order for this treatment method to become possible a choice in epilepsy in adults. Our results showed that neurologists should be encouraged to upload accurate video contents that will increase viewer engagement and the number of views in general to disseminate information about CBD in epilepsy.

4.1. Study limitations

This study has some limitations. First, only 100 videos were analyzed. However, YouTube users prefer to view and make comments on the videos on the first pages of search results. Second, we included only English videos. Finally, we made a snapshot

Table 1
Basic characteristics of the videos.

Feature	Daily View Mean \pm SD	Comment Mean \pm SD	Like Mean \pm SD
Image Type			
Real (n = 59)	27.09 \pm 55.68	73.59 \pm 124.32	570.59 \pm 943.10
Presentation (n = 33)	16.74 \pm 31.85	35.67 \pm 84.20	251.67 \pm 903.27
Animation (n = 8)	28.75 \pm 41.17	8.13 \pm 16.40	62.50 \pm 133.10
Uploaders			
Physicians (n = 46)	30.88 \pm 62.92	72.00 \pm 131.42	327.30 \pm 626.79
Health Channels (n = 33)	21.26 \pm 32.44	54.48 \pm 102.71	722.33 \pm 1318.52
TV shows (n = 7)	7.86 \pm 6.94	18.86 \pm 21.41	110.86 \pm 110.26
Patients (n = 2)	5.33 \pm 0.95	9.00 \pm 9.90	62.00 \pm 29.70
Others (n = 12)	16.08 \pm 28.33	27.00 \pm 44.49	223.08 \pm 516.08
Video Content			
General Information (n = 54)	25.22 \pm 56.71	68.35 \pm 138.91	443.61 \pm 1001.18
Treatment (n = 41)	17.42 \pm 25.25	42.00 \pm 53.16	408.51 \pm 801.01
Education (n = 4)	74.93 \pm 77.70	42.25 \pm 81.17	431.25 \pm 845.84
Patient experience (n = 1)	5	2	41

Table 2
Agreement between the neurologists.

	Mean ± SD	p	r	Cronbach α
DISCERN score 1	3.81 ± 0.95	p < 0.01	0.858	0.882
DISCERN score 2	3.61 ± 1.13			
GQS score 1	3.18 ± 1.07	p < 0.01	0.889	0.911
GQS score 2	3.25 ± 1.03			

assessment, while YouTube has a dynamic structure. However, this is the first study in the literature on the use of CBD oil in the treatment of epilepsy and attracts attention to this controversial issue.

5. Conclusion

This study demonstrated that a significant portion of YouTube videos pertaining to the use of CBD oil in the treatment of epilepsy was uploaded by doctors. However, only 25 % of the videos were of good quality. There were numerous misleading videos on this subject. It is important to reach physicians through channels such as YouTube in order for this treatment method to become possible a choice for epilepsy in adults. Health-related YouTube videos need to be audited in a similar way to peer review strictly before they can become publicly accessible.

Data Availability

Data used in this study can be provided on reasonable request.

Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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References

[1] Gloss D, Vickrey B. Cannabinoids for epilepsy. *Cochrane Database Syst Rev* 2014;2014(3):CD009270.
 [2] Fisher RS, Boas WVE, Blume W, Elger C, Genton P, Lee P, et al. Epileptic seizures and epilepsy: definitions proposed by the International League Against Epilepsy (ILAE) and the International Bureau for Epilepsy (IBE). *Epilepsia* 2005;46(4):470–2.
 [3] Silvestro S, Mammana S, Cavalli E, Bramanti P, Mazzon E. Use of Cannabidiol in the Treatment of Epilepsy: Efficacy and Security in Clinical Trials. *Molecules* 2019;24(8):1459.
 [4] Mazurkiewicz-Beldzińska M, Zawadzka M. Use of cannabidiol in the treatment of epilepsy. *Neurol Neurochir Pol* 2022;56(1):14–20.
 [5] Szaflarski JP, Martina BE. Cannabis, cannabidiol, and epilepsy: from receptors to clinical response. *Epilepsy Behav* 2014;41:277–82.
 [6] Devinsky O, Cilio MR, Cross H, Fernandez-Ruiz J, French J, Hill C, et al. Cannabidiol: pharmacology and potential therapeutic role in epilepsy and other neuropsychiatric disorders. *Epilepsia* 2014;55(6):791–802.

[7] Freeman B, Chapman S. Is, “YouTube” telling or selling you something? Tobacco content on the YouTube video-sharing website. *Tob Control* 2007;16(3):207–10.
 [8] Onder ME, Zengin O. Quality of healthcare information on YouTube: psoriatic arthritis [published online ahead of print, 2021 Sep 1]. *Qualität von Gesundheitsinformationen auf YouTube: Psoriasisarthritis* [published online ahead of print, 2021 Sep 1]. *Z Rheumatol* 2021;1–8.
 [9] Aydın E, Yılmaz E. YouTube as a Source of Information on Echocardiography: Content and Quality Analysis. *Acta Cardiol Sin* 2021;37(5):534–41.
 [10] Snelson C. YouTube across the disciplines: a review of the literature. *J Online Learn Teach* 2011;7:159–69.
 [11] Guler MA, Aydın EO. Development and validation of a tool for evaluating YouTube-based medical videos [published online ahead of print, 2021 Nov 25]. *Ir J Med Sci* 2021:1–6.
 [12] Cakmak G. Evaluation of Scientific Quality of YouTube Video Content Related to Umbilical Hernia. *Cureus* 2021;13(4):e14675.
 [13] Cetin A. Evaluation of YouTube Video Content Related to the Management of Hypoglycemia. *Cureus* 2021;13(1):e12525.
 [14] Andan C, Aydın MF. Evaluation of the Reliability and Quality of YouTube Videos on Ovarian Cysts. *Cureus* 2022;14(3):e22739.
 [15] Kocyigit BF, Akaltun MS, Sahin AR. YouTube as a source of information on COVID19 and rheumatic disease link. *Clin Rheumatol* 2020;39(7):2049–205.
 [16] Charnock D, Shepperd S, Needham G, Gann R. DISCERN: an instrument for judging the quality of written consumer health information on treatment choices. *J Epidemiol Community Health* 1999;53(2):105–11.
 [17] Singh AG, Singh S, Singh PP. YouTube for information on rheumatoid arthritis - a wakeup call? *J Rheumatol* 2012;39(5):899–903.
 [18] Bernard A, Langille M, Hughes S, Rose C, Leddin D, Veldhuyzen van Zanten S. A systematic review of patient inflammatory bowel disease information resources on the World Wide Web. *Am J Gastroenterol* 2007;102(9):2070–7.
 [19] Rayi A, Borad SJ, Kemper SE, Malhotra K. What information about sudden unexpected death in epilepsy (SUDEP) is available on YouTube? *Epilepsy Behav* 2019;93:125–8.
 [20] Wong VS, Stevenson M, Selwa L. The presentation of seizures and epilepsy in YouTube videos. *Epilepsy Behav* 2013;27(1):247–50.
 [21] Salman MY, Bayar G. Evaluation of quality and reliability of YouTube videos on female urinary incontinence. *J Gynecol Obstet Hum Reprod* 2021;50(10):102200.
 [22] Fode M, Nolsøe AB, Jacobsen FM, Russo GI, Østergren PB, Jensen CFS, et al. Quality of Information in YouTube Videos on Erectile Dysfunction. *Sex Med* 2020;8(3):408–13.
 [23] Duran MB, Kizilkcan Y. Quality analysis of testicular cancer videos on YouTube. *Andrologia* 2021;53(8):e14118.
 [24] Gorrepati PL, Smith GP. DISCERN scores of YouTube information on eczema treatments. *J Am Acad Dermatol* 2021;85(5):1354–5.
 [25] Crutchfield CR, Frank JS, Anderson MJ, Trofa DP, Lynch TS. A Systematic Assessment of YouTube Content on Femoroacetabular Impingement: An Updated Review. *Orthop J Sports Med* 2021;9(6):23259671211016340.
 [26] Onder ME, Zengin O. YouTube as a source of information on gout: a quality analysis. *Rheumatol Int* 2021;41(7):1321–8.
 [27] Zengin O, Onder ME. Educational quality of YouTube videos on musculoskeletal ultrasound. *Clin Rheumatol* 2021 Oct;40(10):4243–51.
 [28] Cakmak G, Mantoglu B. Reliability and Quality of YouTube Contents Pertaining to Pancreatic Cancer. *Cureus* 2021;13(3):e14085.
 [29] Szmuda T, Özdemir C, Fedorow K, Ali S, Słoniowski P. YouTube as a source of information for narcolepsy: A content-quality and optimization analysis. *J Sleep Res*. 2021;30(2):e13053.
 [30] Chang MC, Park D. YouTube as a Source of Information on Epidural Steroid Injection. *J Pain Res* 2021;14:1353–7.