YouTube videos regarding idiopathic intracranial hypertension have inadequate information

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Abstract

Objective: Previous studies have found that videos on the internet and YouTube® contain misleading information on medical topics; however, an assessment of the quality of material regarding idiopathic intracranial hypertension (IIH) is lacking. *Methods:* The YouTube® video library was analyzed by using the keywords 'idiopathic intracranial hypertension' and 'pseudotumor cerebri'. The video source, duration of the video, and the number of likes, dislikes, and views were recorded. The video power index (VPI) and view ratio were used to define video popularity. The quality of the information was evaluated using the DISCERN score and a specific usefulness score. *Results:* A total of 129 videos were identified for analysis. DISCERN scores indicated that nine (7%) videos were excellent, 27 (21%) were good, 20 (15%) were fair, 36 (28%) were poor, and 37 (29%) were very poor with respect to medical information. The source of the video was academic (a university-affiliated source) in 10 (8%) videos, a physician in 32 (24%), a patient in 76 (59%), and by a commercial entity in 11 (9%) videos. DISCERN and usefulness scores were significantly higher in the videos uploaded by academics than the others (P < 0.001). VPI, view ratio and number of likes did not differ significantly by source. *Conclusion:* The information for IIH provided on YouTube® is generally of low quality. Only academic-authored videos provided information of sufficient quality.

Keywords: Internet, information, idiopathic intracranial hypertension, pseudotumor cerebri, Youtube

INTRODUCTION

YouTube® is one of the most frequently used online platforms worldwide for medical information.[1] Almost every minute, a new video that can exceed 2 billion views per day is uploaded to YouTube®, and recent surveys have been reported that 80% of internet users access medical information using online platforms.[2] Patient satisfaction is expected to be correlated with beneficial information, but previous studies have concluded that online platforms may contain misleading and inappropriate information.[3-9] The latter may affect the decision-making process of the treatment and cause negative effects on the patient-physician relationship.[10]

Idiopathic intracranial hypertension (IIH), also known as pseudotumor cerebri, is a serious neurological disease characterized by elevated intracranial pressure of unknown etiology.[11] Obese women of childbearing age are mostly affected. Although headaches, vomiting, nausea, papilledema, and visual obscurations are the main symptoms and signs of IIH, the clinical findings may vary.[12,13] Acetazolamide is the preferred treatment; however, surgical intervention may be considered in patients who have fulminant IIH and are medically refractory.[14,15]

The content on YouTube® is not peer-reviewed, and the quality of information on IIH remains to be evaluated. The aim of this study, therefore, was to assess the quality of the information of the videos regarding IIH on YouTube®.

METHODS

The YouTube® video library was independently analyzed by two neurologists on January 24, 2021 using two keywords: (1) idiopathic intracranial hypertension and (2) pseudotumour cerebri. Duplicate videos, non-English-language videos, silent videos, and videos with less than 1,000 views were excluded.[3]

The following data of each video were recorded: (1) video source, (2) time since upload (days), (3) duration in minutes, (4) number of views, (5)

number of likes and dislikes. Five categories were identified based on the video source: (1) academic (author/s affiliated with a university), (2) physician (author/s not affiliated with a university), (3) patient (patient testimonials), and (4) commercial (videos associated with a website or TV channel not authored by physicians)

The quality of information was assessed using a previously described usefulness score with a modification for IIH.[4] The videos were classified as 'very useful', 'useful' or 'not useful' (Table 1). The quality of information was also evaluated using the DISCERN questionnaire.[16,17] The DISCERN questionnaire has three sections comprising 16 questions, and a higher score indicates better quality. The first eight questions relate to reliability and the next seven questions evaluate specific details of treatment. The last question addresses the overall quality of the publication. Videos were categorised as excellent quality (63–75 points), good quality (51–62 points), fair quality (39–50 points), poor quality (27–38 points), and very poor quality (16–26 points) according to the DISCERN scoring system. (Table 2)

The popularity of the videos was assessed using the video power index (VPI) and view ratio. The VPI was calculated using the formula [like ratio x view ratio/100].[5] The view ratio was calculated using the results of [number of views/ time since upload (days)]. The study did not require the approval of an ethics committee as the data are publicly available.

Statistical analysis

Statistical analysis was performed using SPSS version 12 (SPSS Inc, Chicago, IL). Categorical data were reported as frequencies while continuous data were reported as means, medians and standard deviations. Comparison of quantitative variables was performed with a Kruskal-Wallis test using Dunn-Bonferroni post-hoc analysis for non-normally distributed variables. For each score, an interclass correlation coefficient (the ICC) followed by the 95% confidence interval (CI) was reported. A p-value of 0.05 was used as the cut-off for establishing statistical significance.

RESULTS

A total of 129 videos were included in this study. Detailed data are presented in Table 3.

The ICC for the usefulness score was 0.91 and the ICC for the DISCERN score was 0.89, with good and excellent reliability respectively.

According to the usefulness score, 68 (53%) videos were not useful, 42 (32%) were useful, and 19 (15%) were very useful.

DISCERN scores indicated that nine (7%) videos were excellent, 27 (21%) were good, 20 (15%) were fair, 36 (28%) were poor, and 37

Table 1: Usefulness Score

Video has mentioned the main signs/symptoms of IIH
1. Headache
2. Visual disturbance (Blurred vision, diplopia, visual obscuration)
Video has mentioned the main clinical findings of IIH
3. Papilledema
4. Visual field defect
5. Other cranial nerve involvement (6th and 7th nerves)
Video has mentioned the diagnosis of IIH
6. Neuroimaging
7. CSF findings
Video has mentioned the treatment of IIH
8. Modifications of the risk factors
9. Medical treatment
10. Surgical treatment

Not mentioned: 0; mentioned briefly:0,5; mentioned in detail :1

(1-5) not useful, (6-8) useful, (9-10) very useful
IHH: Idiopathic Intracranial Hypertension
CSF: cerebrospinal fluid

Table 2: DISCERN Questionnaire[16,17]

Number	Question	Question Rating				
		No		**Partially**		**Yes**
Section 1	**IS THE PUBLICATION RELIABLE**					
1	Are the aims clear?	1	2	3	4	5
2	Does it achieve its aims?	1	2	3	4	5
3	Is it relevant?	1	2	3	4	5
4	Is it clear what sources of information were used to compile the publication (other than the author or producer)?	1	2	3	4	5
5	Is it clear when the information used or reported in the publication was produced?	1	2	3	4	5
6	Is it balanced and unbiased?	1	2	3	4	5
7	Does it provide details of additional sources of support and information?	1	2	3	4	5
8	Does it refer to areas of uncertainty?	1	2	3	4	5
Section 2	**HOW GOOD IS QUALITY OF INFORMATION REGARDING TREATMENT CHOICES?**					
9	Does it describe how each treatment works?	1	2	3	4	5
10	Does it describe the benefits of each treatment?	1	2	3	4	5
11	Does it describe the risks of each treatment?	1	2	3	4	5
12	Does it describe what would happen if no treatment is used?	1	2	3	4	5
13	Does it describe how the treatment choices affect overall quality of life?	1	2	3	4	5
14	Is it clear that there may be more than 1 possible treatment choice?	1	2	3	4	5
15	Does it provide support for shared decision making?	1	2	3	4	5
Section 3	**OVERALL RATING OF THE PUBLICATION**					
16	Based on the answers to all of these questions, rate the overall quality of the publication as a source of information about treatment choices		1-2-3 Low Moderate			4-5 High

Table 3: Characteristics of analyzed YouTube videos

N=129	Mean	Minimum	Maximum	Standard deviation
Usefulness Score	4.91	1	10	2.6
DISCERN	36.4	8	64	16.7
VPI	5.31	1.02	39.71	6.48
Time since upload (days)	1938.3	153	4383	1099
Duration (minutes)	9.4	0.3	64	11.8
Views	9084	1022	119000	14399
Likes	108.06	1	825	140.6
Dislikes	3.47	0	31	5.75
View ratio	5.3	0.3	40.7	6.8

VPI: video power index

Table 4: Comparison of video sources and scores

	Academic (N =10)	Physician (N =32)	Patient (N =76)	Commercial (N = 11)	P value
Usefulness score	9.5 (7-10; 2)	5 (1-10; 5)	4 (1-10; 3)	2 (2-9; 2)	< 0.001
DISCERN	59 (52-64; 6)	40 (10-64; 33)	35 (8-63; 23)	25 (15-58; 17)	< 0.001
VPI	4.05 (1.31-37.6;16.7)	3.61 (1.04-39.71; 5.56)	2.81 (1.02- 24.04; 3.7)	1.7 (1.1- 12.15; 3.16)	0.22
View ratio	4.1 (1-39.3; 17.7)	3.7 (0.5-40.7; 6.6)	3.2 (0.3-24.1;4.4)	1.7 (0.9-12.5; 3.9)	0.4
Duration (minutes)	21.8 (6-64; 51)	4.4 (1-61; 5)	6.4 (0.3-27; 6)	3.1 (0.3- 19; 2)	< 0.001
Likes	52 (15-499;314)	46 (2-825; 88)	60.5 (1-664; 111)	30 (4-566; 32)	0.08

The results are presented as median (min-max; interquartile range)- (Kruskal- Wallis test)
VPI: video power index

(29%) were very poor.

The video source was an academic institution in 10 (8%) videos, a physician in 32 (24%), a patient in 76 (59%), and a commercial entity in 11 (9%) videos. DISCERN and usefulness scores were significantly higher in academic-authored videos than the others (P < 0.001). No difference was found between physician-authored and patient-authored videos (P= 0.15) while commercial videos scored significantly lower than the other sources (P < 0.05). VPI, view ratio, and number of likes did not differ among groups, but the duration of the videos was longer in academic-authored videos than the others (Table 4).

No correlation between popularity scores (VPI and view ratio) and quality (DISCERN and usefulness) scores was noted (P > 0.05). Video duration positively correlated with the quality scores (P < 0.001) as shown in Table 5.

DISCUSSION

The results of this study indicate that the majority of the YouTube® videos did not provide appropriate information on IIH. Our findings also demonstrate that academic-authored videos had the highest quality, and that the popularity of the videos did not correlate with the quality of information they provided.

We found poor or very poor results with respect to the DISCERN score in 72% of videos. The mean DISCERN score was 36.4 points, which represented insufficient quality, consistent with previous studies on other medical conditions. Keelan *et al.*[18] first reported the low quality of the YouTube® videos for immunization, and subsequent studies also demonstrated poor quality scores for different diseases.[19,20] In the study that assessed videos related to disc herniation, the mean DISCERN score was reported as 30.7 (range, 14- 68).[7] In addition to DISCERN scores, some studies have used novel quality scores to assess various medical conditions. Our novel usefulness scoring system for IIH showed excellent ICC scores between two observers. As with the DISCERN score, 53% of the videos were found not to be useful.

While some studies reported patients as the major source for videos on medical conditions, other studies found that videos were mostly uploaded by physicians.[3,6,7,9,21] In the present study, patients (59 %) were found to be the major source of information, while physicians (25%) were the second most common source. The source of the videos has been shown to be an important determinant for adequacy of the information provided.[4] We noted similar results with previous studies in which the quality of the video was largely determined by the source.[6,21]

Table 5: Correlations of quantitative variables and scores

	VPI	DISCERN	Usefulness
View ratio	P<0.001; rho= 0.929	P=0.15; rho = 0.127	P=0.16; rho = 0.124
Duration	P=0.019; rho = 0.206	P<0.001; rho = 0.396	P<0.001; rho = 0.398
Likes	P<0.001; rho = 0.826	P=0.26; rho = 0.099	P=0.22; rho = 0.108
VPI	-	P=0.17; rho = 0.121	P=0.18; rho = 0.119

P value; rho= Spearman's rho; VPI: video power index

Both usefulness and DISCERN scores were significantly higher in academic-authored videos than in the other groups. In addition, videos from physicians had higher quality scores than patient and commercial sources, although even the former also did not provide high quality information. We believe that non-academic physicians may have attempted to gain wide viewership at the expense of the quality of information provided. Videos from patients were most deficient in information despite being the most common source of IIH information.

YouTube® enables enumeration of the number of views and likes or dislikes, which is an indication of the popularity of the hosted videos. Both VPI and view ratio are useful tools for defining the impact of the video by taking into account the number of views and likes.[5] We found no correlation between popularity scores (VPI and view ratio) and quality (DISCERN and usefulness) scores. In a similar study, Cassidy *et al*. found that video quality did not correlate with the number of views or the number of likes/dislikes.[3] However, some other studies have reported a negative correlation between video quality and YouTube® user engagement.[6] Gokcen *et al*. stated that the videos uploaded by physicians might not be understood by YouTube® users.[7] However, our results revealed that academic videos were not less popular compared to videos from other sources. In addition, the duration of the video has been determined as another factor that affects the popularity of the videos. Biggs *et al*. reported that long videos on rhinosinusitis had a low number of views and stated that viewers had more interest in short videos.[19] However, in the present study, the duration of the videos positively correlated with VPI and the quality scores. Erdem *et al*. have also reported no relationship between duration and quality scores.[4] We also found no difference by source in terms of VPI and view ratio despite the academic videos having the longest duration.

This study has some limitations. YouTube and the internet are growing platforms and researchers may obtain different results at a later time. A threshold of 1000 views will have excluded relevant videos which were recently uploaded. We evaluated only videos that were in English. Despite these limitations, this study is the first one that investigates the quality of medical information in videos related to IIH.

In conclusion, information for IIH provided by YouTube® videos is of low quality, even though some of those were authored by physicians. Only academic-authored videos contained information of sufficient quality. The findings of the present study provide a basis for physicians to caution patients on the quality of information on IIH on YouTube.

DISCLOSURE

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