What is the role of YouTube™ as a source of information on trichotillomania?

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ABSTRACT

Objective: YouTube™ is a very popular video site worldwide and is increasingly being used to access health information. The content in these videos is often incomprehensible and worse, contains inaccurate and incomplete information. This article aims to evaluate the reliability and usefulness of information about TTM available to patients on YouTube™.

Material and Method: This study has a cross-sectional design. 51 videos were reviewed. Global quality score (GQS), modified DISCERN and trichotillomania Youtube score (TTMYS) were used for the quality analysis of the videos. Video duration(sec), time since upload (months), Number of views/comments/likes/dislikes were analyzed.

Results: The majority of the videos (31.4%) were uploaded by physicians, and the least by hospitals (3.9%). The mean GQS score was 2.06±1.363, the modified DISCERN score was

2.06±1.348, and the TTMYS score was 8.45±3.126. The GQS scores 1-2 (low quality), 3 (moderate quality), and 4-5 (high quality) were 68.6%, 11.8%, and 19.6%, respectively. The vast majority of videos were rated as low quality.

Conclusion: The TTM related video content rewieved was largely inadequate. Information about the disease and treatment options were insufficient. It is necessary to either take a primary role in uploading high-quality videos or establish supervisory mechanisms for the security and accuracy of information.

Keywords: Trichotillomania information, Youtube video, quality

INTRODUCTION

Trichotillomania (TTM) is an impulse control disorder characterized by recurrent hair or eyebrow plucking that causes hair loss. It is often a chronic disease and difficult to treat. Although large-scale epidemiological studies are not available, smaller studies estimate that TTM affects 1-3.5% of adolescents and adults. The largest prevalence study to date, involving 2534 students, determined a lifetime prevalence of 0.6% (1).

It was described by the French dermatologist François Henri Hallopeau in 1889 (2). It was first classified as an impulse control disorder in the DSM-3 in 1987 and recorded as a mental health disorder. DSM-4 diagnostic criteria for TTM have difficulties in diagnosis and treatment, so the classification was changed in DSM-5. In DSM-5, TTM is included in the obsessive-compulsive disorder (OCD), excoriation disorder, body dysmorphic disorder, hoarding disorder, and obsessive-compulsive and related disorders section (3). TTM is four times more common in women than men (1,4).

TTM is often accompanied by diseases such as anxiety disorder, depression, skin picking disorder, and addiction. Individuals diagnosed with TTM tend to avoid social environments because they are ashamed of their appearance and fear being judged by their environment. This causes them to spend more time on social media and the internet (5).

Today, many people use online systems to get information about health (6). YouTube™ (http://www.youtube.com) is the most used visual information source in the world after Google in this sense. Undoubtedly, the fact that Youtube is free and easily accessible has a great role in its popularity (7). However, the content in these videos is often incomprehensible and, worse, contains inaccurate and incomplete information (8).

It has become an important source of visual information for patients, medical students, and even residents (9). Since the Internet allows anyone to upload content and is not subject to any regulation, it may contain misleading or false information (8). The fact that patients often turn

to platforms such as YouTube™ to get information about their problems may lead to misdirection of patients and deterioration of the physician-patient relationship. For this reason, the quality and security of information in online systems are very important (9, 10).

To investigate the effectiveness of YouTube videos in patient education, the content, and reliability of YouTube videos on topics as diverse as rheumatoid arthritis, heart surgery decision, COVID-19 Vaccination During Pregnancy were examined (11-13).

The importance of this research is the evaluation of videos on YouTube to develop correct attitudes about TTM and its treatment. To the best of our knowledge, there is no study in the literature evaluating the quality of YouTube videos as a source of information for TTM patients. This article aims to evaluate the reliability and usefulness of information about TTM available to patients on YouTube™.

MATERIAL AND METHOD

This study has a cross-sectional design. Ethics committee approval was not obtained as there was no human or animal participation in the study, and the videos were public. The study according to the World Medical Association Declaration of Helsinki, as no patient data or materials were used and all videos used for the study are available on a public social media website (YouTube).

Video Search On Youtube™

Videos were searched with the keywords "Trichotillomania" and "Hair Pulling Disorder" on https://www.youtube.com/ on October 21, 2021. The top 200 videos were listed by relevance (the default option on YouTube™). Only English videos were included. Videos with advertisements (4), duplicate videos (7), non-English videos (11), irrelevant videos (121), and videos without audio narration (6) were excluded (**Figure**).
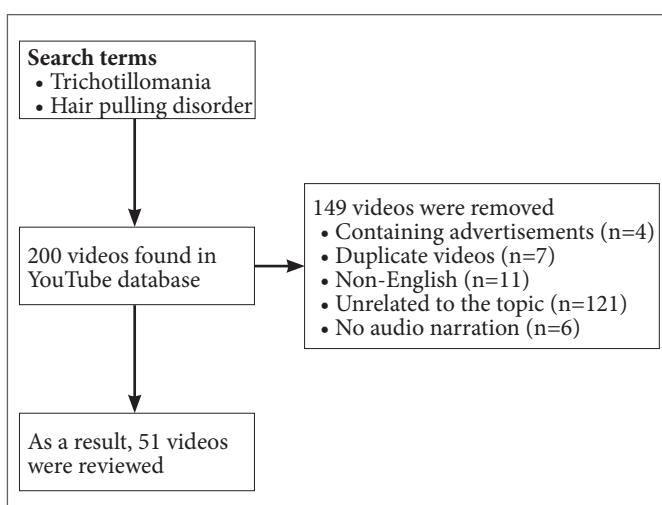
Figure. Working Flow

Video Features

Views, total video duration, total comments, total "likes" and "dislikes", time since upload date (months), video quality (pixels), and upload source were recorded. The upload source was categorized as physician, hospital, TV program, patient, psychologist, and independent user.

Video Quality Analysis

Video contents were evaluated by 2 independent mental health specialists (psychiatrists) (MA, PAA). A consensus was reached among the raters for the items that differed. Global Quality Score (GQS) and modified DISCERN were used for the quality analysis of the videos. GQS is a scoring system that evaluates the information level of the content using a 1 to 5 scoring system.

DISCERN was prepared by a group of experts from England to evaluate the appropriateness of treatment options in the texts. It evaluates the quality of the publication in 16 questions. The first 8 questions assess the credibility of the publication, the following questions examine specific details about treatment options, and the last question inquiries average quality. Each question is scaled from 1 to 5 points from No to Yes. If the answer is 'Absolutely Yes', 5 points are given; if 'Absolutely No', 1 point is given. The criteria evaluated in scoring are given in Table 2. A score of 63-75 is categorized as excellent, 51-62 as good, 39-50 as fair, 27-38 as poor, and 16-26 as very poor. The modified DISCERN score is calculated by dividing the obtained score by 16 and calculating the score per question. The score ranges from 0 to 5 points, with higher scores indicating greater reliability (14, 15).

There is no video scoring system for the evaluation of Trichotillomania videos. In this study, we evaluated all videos according to whether they contain information about diagnostic criteria (according to DSM-5), general treatment, medical treatment, therapies, alternative treatments, patient image, comorbidity, stressor, genetics, age, and differential diagnosis. Scoring was done by giving 1 point if it contains information and 0 points if it does not. The video that answered all questions received 12 points, and the video that did not answer any questions received 0 points. We named this scoring system TTM YouTube™ score (TTMYS).

Statistical Analysis

Statistical Package for the Social Sciences 22 (IBM, Armonk, NY, USA) was used for data analysis. The Shapiro-Wilk test was used to test the normality of the data. Mean, standard deviation, frequency, minimum, and maximum were used as descriptive statistics. The Kruskal-Wallis test was used to determine statistically significant differences of an independent variable between more than 2 groups. For pairwise comparisons, the Dunn- Bonferroni Post-Hoc method was used, followed by a Kruskal-Wallis test. Spearman test was performed for correlation analysis.

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Inter-rater agreement was evaluated with the kappa coefficient. Results were considered significant at 95% confidence interval and P<0.05.

RESULTS

A total of 51 videos were analyzed. The features of the videos are given in **Table 1, Table 2 and Table 3**. The majority of the videos (31.4%) were uploaded by doctors, patients (23.5%), TV programs (17.6%), Independent (17.6%), Psychologists (5.9%), at least by hospitals (3.9%). According to the content analysis of the videos with TTM YouTube™ score (TTMYS), DSM-5 17.6%, general treatment 74.5%, medical treatment 33.3%, treatment 41.2%, alternative treatment 29.4%, using patient image 27.5%, talking about comorbidity 27.5%, talking about stressors 51.0%, genetic structure 7.8%, gender difference 21.6%, giving age information 25.5%, talking about differential diagnosis 25.5% rate was observed.

Table 1. Content analysis of videos		
	n	%
DSM-5	9	17.6
General treatment	38	74.5
Medical treatment	17	33.3
Therapy	21	41.2
Alternative treatment	15	29.4
Using patient image	14	27.5
Talking about comorbidity	14	27.5
Talking about stressors	26	51.0
Genetic pattern	4	7.8
Gender difference	11	21.6
Giving age information	13	25.5
Talking about differential diagnosis	13	25.5

Table 2. Features of the videos	
	Mean (Min - Max)
Video duration (sec)	797.76 (57-5229)
Time since upload (months)	38.37 (1-97)
Number of views	57160.51 (11-1145982)
Average number of views per month	2330.08 (1-71624)
Number of comments	185.31 (0-1400)
Number of likes	1240.69 (0-31000)
Number of dislikes	22.63 (0-259)
GQS score	2.06 (1-5)
DISCERN score	2.06 (1-5)
TTMYS score	8.45 (2-12)
Min: minimum, max: maximum, GQS: Global Quality Scale; TTMYS: Trichotillomania YouTube™ score	

Data were not normally distributed. The mean GQS score was 2.06±1.363, the modified DISCERN score was 2.06±1.348, and the TTMYS score was 8.45±3.126. The GQS scores 1-2 (low quality), 3 (moderate quality), and 4-5 (high quality) were 68.6%, 11.8%, and 19.6%, respectively. The vast majority of videos were rated as low quality. According to GQS, 50% of high-quality videos came from TV programs. Again, according to the GQS system, 34% of the low-quality videos were those uploaded by patients. The Cohen kappa score was calculated as 0.883 for the GQS and 0.912 for the total DISCERN score. There was a significant correlation between DISCERN, GQS, and TTMYS scores. No correlation was detected in other parameters examined.

For GQS, post-hoc analysis determined a statistically significant difference between hospital-patient (hospital>patient p=0.02), hospital-independent (hospital>independent p=0.039), TV program-patient (TV program>patient p=0.005), and TV program-independent (TV program>independent p=0.022) groups.

For DISCERN, a statistically significant difference was observed between TV program-patient (TV program>patient p=0.003), and TV program-independent (TV program>independent p=0.028) groups.

For TTMYS, a statistically significant difference was observed between hospital- patient (hospital<patient p=0.037), TV program-patient (TV program patient p=0.013), and TV program-independent (TV program independent p=0.038) groups.

DISCUSSION

We found that most of the videos were uploaded by physicians. Unfortunately according to all three scoring systems, we found that the content and quality of the videos were insufficient.

YouTube™ includes studies in the field of psychiatry such as obsessive-compulsive disorder, generalized anxiety disorder, and Electroconvulsive therapy (ECT) (16-18). This study aims to evaluate the content and quality of YouTube™ videos as a source of information for TTM patients. To the best of our knowledge, there is no other study evaluating YouTube™ content as a patient

Table 3. Video quality ratings by the video source							
Scoring systems	Physician (n=16)	Hospital (n=2)	Tv Program (n=9)	Patient (n=12)	Psychologist (n=3)	Independent (n=9)	p value
GQS	2.31 (1-5)	4.00 (4-4)	3.00 (1-5)	1.08 (1-2)	3.00 (1-5)	1.22(1-3)	0.001
DISCERN	2.31 (1-4)	3.50 (3-4)	3.11 (1-5)	1.08 (1-2)	2.67 (1-4)	1.33 (1-4)	0.001
TTMYS	7.81 (2-12)	4.00 (3-5)	6.33 (3-12)	10.50 (7-12)	7.33 (5-12)	10.33 (5-12)	0.001
Video duration	352.88 (87-1267)	232.50 (140-325)	2249.11 (94-5229)	710.58 (123-1810)	567.00 (57-1357)	456.11(69-1999)	0.001
Kruskal-Wallis test is presented as median (min-max). GAS: Global Quality Scale; Trichotillomania YouTube™ Score (TTMYS)							

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information source about TTM. Most of the videos share information about the treatment. Most of them were low-quality videos. A significant portion of the videos was uploaded by physicians, but the quality of these videos was also low. The TTMYS system demonstrated that the videos mostly talked about treatment and the presence of stressor factors. We think that it is very reasonable to talk about these two situations. Because the treatment part is an unknown, complex, and attraction-grabbing situation, while talking about well-defined stressors can also create the impression that the subject is known and dominated by the uploader.

GQS, DISCERN, and TTMYS systems showed a high correlation in video quality evaluation. According to the GQS scores, 68% of the videos were of low quality and had poor content. Previous studies evaluating YouTube™ content and quality as a source of information on various diseases have also found similar results (19). In a 2015 study by Macleod et al. (20), no video scored full marks from existing scoring systems. It was determined that more than half of the YouTube™ videos giving information about gallstones contained false information (21). In a study examining rheumatoid arthritis content, they found that about one- third of the videos contained misleading, false and unfounded information (11). The monthly average number of views per video was 2330.08±10028.161. In total, the videos we reviewed were watched 2,915,186 times. This shows how powerful YouTube™ is in data transfer.

Some studies have determined that videos with high-quality scores are longer videos (22, 23). Our findings are also compatible with the literature (p=0.001). The average duration of the videos we reviewed was 797.76±1173.545 seconds. However, when the video duration is too long, people may get bored, distracted, etc. Therefore, we think that this finding should be confirmed with larger samples. There is no study showing the ideal length of a good informational video. It is also possible for some videos to be extended, as those who make videos for YouTube™ can receive advertisements when they upload videos over 10 minutes. This emerges to be a confounding factor. Of all videos analyzed, 35.2% were longer than 10 minutes.

Our study was limited to analyzing only English-language videos on YouTube™. YouTube™ content changes from moment to moment over time. Besides, our study was limited to a direct YouTube™ search. We did not review videos on websites that contain health information other than YouTube™. Also, we examined the YouTube™ search engine with two limited titles (Trichotillomania and Hair Pulling Disorder). We did not take information about trichobezoar formation as a criterion in the contents. The videos were analyzed by two professional mental health professionals with knowledge of the literature on TTM, hence naturally biased physicians. It would have been more realistic to get the opinion of the public on this issue.

CONCLUSION

TTM patients are known to use YouTube™ to obtain information. There is no effective application to measure the quality and reliability of the information on YouTube™. Therefore, it is necessary to critically analyze the quality of YouTube™ videos. Physicians and academic institutions should be aware of the interest in this search for knowledge. It is necessary to either take a primary role in uploading high-quality, reliable videos or establish supervisory mechanisms for the security and accuracy of information.

ETHICAL DECLARATIONS

Ethics Committee Approval: This study has a cross-sectional design. Ethics committee approval was not obtained as there was no human or animal participation in the study, and the videos were public. The study according to the World Medical Association Declaration of Helsinki, as no patient data or materials were used and all videos used for the study are available on a public social media website (YouTube).

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