

What does YouTube® say about schizophrenia: Is it a reliable source of information?

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ABSTRACT

Purpose: The quantitative and qualitative characteristics of YouTube® videos on schizophrenia were examined. The quality of the information provided by the videos, which videos are watched the most, whether there is a relationship between the popularity and quality of the videos was evaluated.

Methods and Materials: A search was performed on YouTube® on using the keyword "schizophrenia". The duration of the videos, the number of views, the number of like-dislike, the contents of the videos were recorded. To assess the popularity of the videos, view ratio, like ratio and the video power index (VPI) were used. The quality of information was assessed with DISCERN, Global Quality Scale (GQS) and YouTube Schizophrenia-Specific Score (Y-SSS).

Results: Most of the videos were of low quality. 20% of the videos were fair and above according to DISCERN, 12.9% of the videos were fair and above according to Y-SSS. View ratio, like ratio and VPI of the videos categorized in patient/their relatives were the higher than the other categories. Although, the GQS, DISCERN and Y-SSS scores were lower than the others. The only predictive for like ratio was view ratio.

Conclusion: Most of the videos about schizophrenia were personal experiences videos, and these were the most watched ones. Unfortunately, the quality of these videos was low. This may cause the development of wrong attitudes about the disease and its treatment. Also, incorrect information may contribute to the stigma surrounding the disorder. There is a need for mental health professionals to be more visible and to present qualified information in videos.

Keywords: Schizophrenia, mental disorder, internet, YouTube, patient education

YouTube Şizofreni hastalığı için ne söylüyor: Güvenilir bir bilgi kaynağı mı?

ÖZET

Amaç: Şizofreni ile ilgili YouTube® videolarının nicel ve nitel özellikleri incelenmiştir. Videoların sağladığı bilgilerin kalitesi, en çok hangi videoların izlendiği, videoların popülerliği ile kalitesi arasında bir ilişki olup olmadığı değerlendirilmiştir.

Yöntem: YouTube®'da "şizofreni" anahtar kelimesi kullanılarak bir arama yapıldı. Videoların süreleri, izlenme sayıları, beğenilme-beğenilmeme sayıları, videoların içerikleri kaydedildi. Videoların popülerliğini değerlendirmek için görüntülenme oranı, beğeni oranı ve video güç indeksi (VGI) kullanıldı. Bilgi kalitesi DISCERN, Global Quality Scale (GQS) ve YouTube Şizofreniye Özgü Skor (Y-ŞÖS) ile değerlendirildi.

Bulgular: Videoların çoğu düşük kalitedeydi. DISCERN'e göre videoların %20'si orta ve üzeri, Y-ŞÖS'ye göre videoların %12.9'u orta ve üzeriydi. Hasta/yakınları kategorisine giren videoların izlenme oranı, beğeni oranı ve VGI'si diğer kategorilere göre daha yüksekti. Bu videoların GQS, DISCERN ve Y-ŞÖS puanları ise diğer kategorilerden olanlardan daha düşüktü. Beğeni oranı için tek yordayıcı görüntülenme oranıydı.

Sonuç: Şizofreni ile ilgili videoların çoğu kişisel deneyim videolarıydı ve bunlar en çok izlenenlerdi. Ne yazık ki, bu videoların kalitesi düşüktü. Bu durum hastalık ve tedavisi hakkında yanlış tutumların gelişmesine neden olabilir. Ayrıca, yanlış bilgi hastalığı çevreleyen damgalamaya katkıda bulunabilir. Ruh sağlığı profesyonellerinin YouTube videolarında daha görünür olmalarına ve nitelikli bilgileri videolarda sunmalarına ihtiyaç vardır.

Anahtar Kelimeler: Şizofreni, ruhsal bozukluk, internet, YouTube, hasta eğitimi

Schizophrenia is a chronic mental disorder that affects approximately 1% of the world population (1). There is a large literature on schizophrenia. However, it is not known to what extent this data is included in the constantly growing internet resources used to provide information about the disease. Many studies show that the internet is increasingly used by people to get information about health (2,3). It may be beneficial for individuals to obtain high-quality and reliable information on the epidemiology, etiology, symptoms and treatment of the disease from the internet in order to affect their attitudes in the process of disease and treatment. In the case of schizophrenia, this detailed information can make an important contribution to understanding of the schizophrenia of both the patients and the society, and in improving the negative attitudes towards the patients and the disease.

YouTube® (<http://www.youtube.com>) is one of the most popular social networking sites for sharing video content and has become a great resource for health information and its use is increasing day by day (4). There is no application that checks the accuracy of the health information in the videos uploaded to YouTube®. Researchers from different specialties investigated to what extent diseases in their field provide reliable data to people in YouTube® videos (5-7).

The evaluation of the information about mental disorders obtained on the internet has a special importance. Non-professionals, who do not have sufficient knowledge and experience in the field of mental health, can present scientifically unproven data to individuals as treatment. As in the diagnosis and treatment of other diseases, diagnosis and treatment of mental disorders must be applied by professionals trained in this field in line with scientific data and ethical principles. These non-ethical practices related to psychological problems may prevent patients from accessing treatment or cause negative attitudes towards patients.

Previously, Nour et al. conducted a study on YouTube® to analyze the accuracy of psychosis depictions in diagnosing schizophrenia and to evaluate the usefulness of these videos as educational tools to teach medical students to recognize the clinical features of schizophrenia (8). Athanasopoulou et al. investigated attitudes towards schizophrenia and schizophrenia patients in YouTube® videos (9). In another study, YouTube® videos on psychosocial interventions in schizophrenia were evaluated. According

to our current knowledge, there is no study about what kind of videos they come across when a user searches for the word “schizophrenia” on YouTube®, and how reliable information they contain about the disease. In our study, it was aimed to determine who is included in the videos about schizophrenia on YouTube® and the level of sufficiency-quality of the information about the disease. In addition, which videos are watched the most, whether there is a relationship between the popularity and quality of the videos was investigated in our study.

MATERIAL AND METHODS

Search Strategy

This study was exempt from ethical approval of the study institution because it involved the use of public access data only.

A search was performed on YouTube® (<http://www.youtube.com>) on March 18, 2021 using the keyword “schizophrenia”. In order to prevent past searches from affecting the current search, a search was made with a new browser that was not used before. Standard YouTube® filters were used to display all videos by relevance. Since users are generally assumed to not go beyond the first five pages in any search, it was seen in previous studies that 100 videos (20 videos / page × 5 pages) were searched for each keyword (10,11). On the other hand, we analyzed a total of 200 videos in the first 10 pages, thinking that a larger video evaluation would give a more accurate result. A document containing URLs and headers of all 200 videos was recorded for browsing and backup. The following videos were excluded: non-English (n: 18), soundless (n: 2), less than a minute (n: 1), the number of views is unknown because it was uploaded live (n: 1). There was no duplicate video or using the word schizophrenia outside of illness (metaphorical uses such as TV series and movie titles). A total of 178 videos were evaluated in our study. All videos were independently viewed by two experienced psychiatrists to increase reliability (GA, ACK). Statistical analysis was done by taking the average of the scores of the two researchers.

Video Evaluation

The duration of the videos (minutes), the time since upload (days), the number of views, the number of like-dislike, the contents of the videos were recorded. To assess the popularity of the videos, view ratio ($\frac{\text{number of view}}{\text{since upload time}}$),

like ratio $\left(\frac{\text{like}}{\text{like} + \text{dislike}} \times 100 \right)$ and the video power index

(VPI: $\frac{\text{like ratio} \times \text{view ratio}}{100}$) were used. The quality of in-

formation was assessed with three measurement tools.

DISCERN

It consists of three sections including 16 questions, and a higher score indicated better quality. The first eight questions are related to reliability and source of information about treatment choices. The next seven questions focus on the specific details of the treatments. The last question consists of the overall quality. Each question is rated on a 5-point scale (13). Videos were grouped into excellent (63–75 points), good (51–62 points), fair (39–50 points), poor (27–38 points), and very poor (16–26 points) quality according to the DISCERN. GQS has previously been used in many studies to determine the quality of YouTube videos for other diseases (11,14).

Global Quality Scale (GQS)

GQS is a scoring system defined by Bernard et al. and was used to assess a video in terms of its instructive aspects for patients. It based on a scale of one to five, which was used to assess the overall quality of all selected videos. While a score of one point indicates the poorest quality, a score of five points indicates the excellent quality. It allows to evaluate the video quality, streaming and the ease of use of the information presented in online videos (15). GQS has previously been used in many studies to determine the quality of YouTube videos for other diseases (10,12).

YouTube Schizophrenia-Specific Score (Y-SSS)

The YouTube Schizophrenia-Specific Score has been developed by the researchers since there is no specific measurement tool for determining the quality of the videos about schizophrenia on YouTube®. A score system has been developed based on the scales used to determine the quality of YouTube® videos of other diseases (10,11). In this scoring system, which includes a total of 13 questions, the following evaluations about the disease are included: diagnosis (question 1-2), epidemiology (question 3-4-5), etiology (question 6-7), symptoms (question 8-9-10) treatment (question 11-12) and prognosis (question 13). Each question was given 0 points if the relevant information was not included in the video, 1 point if there was missing information, and 2 points if full information was given. Video quality is grouped according to the total score as very poor (0-5), Poor (6-10), Fair (11-15), Good

(16-20), Excellent (21-26). The questions used in the scoring system are in Table 1.

Table 1: YouTube Schizophrenia Specific Score (Y-SSS)	
Diagnosis	
Q1.	Psychiatric interviews in diagnostic evaluation
Q2.	Differential diagnosis information
Epidemiology	
Q3.	The age range of the disease
Q4.	Gender differences
Q5.	Knowledge about prevalence
Etiology	
Q6.	Biological risk factors
Q7.	Psychosocial risk factors
Symptoms	
Q8.	Delusions or hallucinations
Q9.	Disorganized speech/behaviors
Q10.	Negative/cognitive symptoms
Treatment	
Q11.	Pharmacological treatment
Q12.	Non-pharmacological treatment
Prognosis	
Q13.	Information on the course of the disease (eg. chronicity)

Y-SSS questions the quality of knowledge on different areas of Schizophrenia. However, if there is no information about that field in the video, a low score can be obtained from the questionnaire. Therefore, the correlation between Y-SSS and GQS was also evaluated in our study.

Statistical Analysis

SPSS for Windows version 22.0 package program was used for statistical analysis. Kolmogorov Smirnov test was used to check the compliance of variables to normal distribution. The relationship between categorical variables was tested using chi-square analysis. For the variables showed normal distribution, student-t test was used in two independent group comparisons. The Spearman correlation test was used to analyze the relationships between quantitative variables. In comparing three independent groups, if the variants' distribution is not homogeneous (Levene's $p < .05$), Welch statistics were used. The Kruskal Wallis H test was used for comparing three independent groups of scales that did not show normal distribution. In cases where there was a significant difference between the groups, two-group comparisons were made, and Bonferroni correction was applied to determine which groups the difference was between them. Stepwise multiple linear regression analysis was performed to determine like ratio of videos, $p < 0.05$ was considered statistically significant.

RESULTS

A total of 178 videos were evaluated in our study. The median duration of the videos was 7.75 minutes (min: 1, max: 108.50, IQR: 9.60), the median time since upload was 730.0 days (min: 38, max: 23304, IQR: 1625.0). Like ratio was median 97.3 (IQR: 3.45) and view ratio was median 44.05 (IQR: 215.5). The number of views of the most watched video was 12,716,737 and the number of views of the videos was median 34,422 (IQR: 122994).

According to the DISCERN score, four (2.2%) videos were excellent, eight (4.5%) were good, 24 (13.5%) were fair, 86 (48.3%) were poor, and 56 (31.5%) were very poor. YSSS showed that 5(2.8%) videos were excellent, 6 (3.4%) videos were good, 12 (6.7%) were fair, 29 (16.3%) were poor, and 126 (70.8%) were very poor. There were 29 (16.2%) videos with a GQS score of three or more.

The videos were divided into five categories according to their content. Videos that convey information and experience about the disease involving patients and their relatives constituted 41.0% (n: 73) of all videos. Psychologists or psychiatrists were present in 23% (n: 41) of the videos. 12.9% (n: 23) of them were videos with other health professionals (internal scientists, nurses, family physicians etc.) informing about the disease. Course videos prepared for a purpose such as academic/professional exams or medical faculty internship exam preparation were 11.2% (n: 20). Lastly, 11.8% (n: 21) were anonymous videos prepared as public spots about the disease in the "medical-related" category. The features of the videos according to their fields are given in Table 2.

When the video durations were examined according to the video categories, there was a significant difference between the groups (p: 0.027, χ^2 : 10.995). In the post hoc tests conducted to find out where this difference originated, it was determined that the videos involving psychiatrists/psychologists were longer than the medical-related group (p: 0.015, χ^2 : 43.879).

When VPI was analyzed according to video categories, there was a significant difference between the groups (p< 0.001, χ^2 : 30.371). In post hoc analyzes, VPI of the videos with patients/their relatives were significantly higher than psychiatrists/psychologists (p< 0.001, χ^2 : 41.961), education (p: 0.012, χ^2 : 41.654), other healthcare professionals (p< 0.001, χ^2 : 50.993).

When the view ratio of the videos was examined by categories, there was a significant difference between the groups (p< 0.001, χ^2 : 28.895). View ratio of videos involving patients/their relatives were significantly higher than education (p: 0.018, χ^2 : 40.653), psychiatrists/psychologists (p<0.001, χ^2 : 41.119) and other healthcare professionals (p< 0.001, χ^2 : 50.362).

There was a significant difference between the groups when the like ratio of the videos were analyzed by categories (p: 0.001, χ^2 : 18.594). Like ratio of patients/their relatives were significantly higher than psychiatrists/psychologists (p: 0.001, χ^2 : 38.269) and education (p: 0.043, χ^2 : 36.632).

When GQS scores were examined according to video categories, there was a significant difference between groups (p <0.001, χ^2 : 31.015). GQS scores of the videos with the patients/their relatives were significantly lower than the other groups (psychiatrists / psychologists; p <0.001, χ^2 : -36.048), (medical-related videos; p: 0.001, χ^2 : -42.495), (education; p: 0.008, χ^2 : -36.528), (other healthcare professionals; p: 0.034, χ^2 : -30.242).

When the Y-SSS scores were examined according to the video categories, there was a significant difference between the groups (p <0.001, χ^2 : 32.159). The Y-SSS scores of the patients/their relatives were significantly lower than other categories (psychiatrist/psychologist; p: 0.001, χ^2 : -39.953), (other healthcare professionals; p: 0.008, χ^2 : -40.796), (medical-related; p <0.001, χ^2 : - 56.157).

When DISCERN scores were examined according to video categories, there was a significant difference between the groups (p <0.001, χ^2 : 41.631). DISCERN scores of patients/their relatives were significantly lower than psychiatrists/psychologists (p <0.001 χ^2 : -59.336), medical-related (p: 0.002, χ^2 : -47.421) and education (p: 0.012, χ^2 : -42.197).

There was no difference between Y-SSS, GQS and DISCERN scores given by the two viewers (Y-SSS: z: - 0.513, p: 0.608; GQS: z: - 0.577, p: 0.564, DISCERN: z: - 1.387, p: 0.166). The Y-SSS used to evaluate quality and developed by researchers was found to be good reliability (α :**0.912**). Internal consistency and inter-rater reliability for quality scores are given in Table 3.

Table 2: Comparison of VPI, Quality and Quantitative Features of Videos According to Video Content

	Patient/their relatives n:73	Psychologist/psychiatrist n:41	Other healthcare professionals n:23	Education n:20	Medical-related n:21	TOTAL	Statistical value*
Duration (minutes), (Median,IQR)	8.33 (IQR:8.21)	10.45 (IQR:26.29)	6.85 (IQR:10.50)	5.92 (IQR:10.19)	5.40 (IQR:3.82)	7.75 (IQR:9.60)	p<0.027 x ² :10.995
Like ratio (Median,IQR)	98.58 (IQR:2.45)	95.98 (IQR:3.62)	97.02 (IQR:4.35)	96.59 (IQR:4.32)	97.38 (IQR:4.28)	97.30 (IQR:3.50)	p<0.001 x ² :18.594
View ratio (Median,IQR)	98.81 (IQR:601.12)	14.59 (IQR:74.51)	13.62 (IQR:32.60)	26.33 (IQR:57.73)	62.27 (IQR:269.85)	44.05 (IQR:215.50)	p<0.001 x ² :28.895
VPI (Median,IQR)	103.08 (IQR:607.30)	13.90 (IQR:72.01)	12.80 (IQR:32.11)	25.73 (IQR:49.88)	46.32 (IQR:284.1)	43.00 (IQR:211.40)	p<0.001 x ² :30.371
Y-SSS (Median,IQR)	1.00 (IQR:2.50)	4.00 (IQR:8.00)	4.00 (IQR:8.00)	3.50 (IQR:10.00)	6.00 (IQR:6.25)	4.40 (IQR:5.40)	p<0.001 x ² :32.159
GQS (Median,IQR)	1.00 (IQR:0.00)	1.00 (IQR:1.75)	1.00 (IQR:1.00)	1.25 (IQR:2.00)	2.00 (IQR:2.00)	1.00 (IQR:1.00)	p<0.001 x ² :31.015
DISCERN (Median,IQR)	26.00 (IQR:7.00)	34.00 (IQR:21.50)	29.00 (IQR:3.00)	31.00 (IQR:5.75)	33.00 (IQR:12.75)	29.00 (IQR:10.10)	p<0.001 x ² :41.631

Y-SSS: YouTube Schizophrenia Specific Score; GQS: Global Quality Scale; VPI: Video Power Index; IQR: Interquartile Range

*: The Kruskal Wallis H test is used

Table 3. Internal Consistency and Inter-rater Reliability for Quality Scores

	Global Quality Scale	DISCERN	YouTube Schizophrenia-Specific Score
κ	0.967	0.941	0.948
α	N/A	0.894	0.912

κ : Kappa α : Cronbach's alpha

In the Stepwise regression analysis (independent variables: duration, video categories, view ratio, GQS, DISCERN, Y-SSS) performed to predict the like ratio of videos, view ratio was found to be only a predictor (F = 10,677, Adjusted R2: 0.053, p < 0.001).

A positive correlation was found between the video's durations and DISCERN (p < 0.01, r: 0.497), YSSS (p < 0.01, r: 0.439) and GQS scores (p < 0.01, r: 0.425) in Spearman correlation analysis. There was also a statistically significant positive correlation between GQS and DISCERN, GQS and YSSS, YSSS and DISCERN scores. Correlation of quantitative values of videos with quality scores is given in Table 4.

Table 4: Correlation of Quantitative Values of Videos with Quality Scores

		Duration	DISCERN	Y-SSS	GQS	VPI	Like ratio	View ratio
Duration	r†	1	,497**	,439**	,425**	-,023	,012	-,022
	r		1	,678**	,682**	,029	,040	,020
DISCERN	r			1	,918**	,016	,055	,003
	r				1	,006	,045	-,008
Y-SSS	r					1	-,212**	,992**
	r						1	-,241**
GQS	r							1
	r							
VPI	r							
	r							
Like ratio	r							
	r							
View ratio	r							
	r							

†: correlation coefficient, in Spearman correlation analysis

*: Correlation is significant at the 0.05 level (2-tailed) **: Correlation is significant at the 0.01 level (2-tailed)

Y-SSS: YouTube Schizophrenia Specific Score; GQS: Global Quality Scale; VPI: Video Power Index

DISCUSSION

The main findings of our study:

- a. The data presented by most of the videos on schizophrenia was inadequate.
- b. View ratio, like ratio and VPI of videos categorized in patient/their relatives were the higher than the other categories.
- c. The GQS, DISCERN and Y-SSS scores of the videos categorized in patient/their relatives were lower than the other categories.
- d. There was no correlation between the duration of the videos and like ratio/view ratio.
- e. There was a positive correlation between the GQS, DISCERN, Y-SSS scores and the duration of videos.
- f. Features about video quality were not a predictor for like ratio, the only predictive was view ratio.

Most previous studies to determine the quality of YouTube® videos for different medical illnesses or conditions have reported that the videos provide insufficient information on the subject (11,12,16). Celik et al. reported that 84% of the videos were poor or very poor in their study on Rotator Cuff Repair (11). Gray et al. evaluated YouTube® videos about plastic surgeries and reported that the video content was insufficient, and the video quality was low. They also warned the audience that they should question the information they acquired (17). In our study, it was found that most of the videos were insufficient to provide information about schizophrenia. When these videos are used as a source of information about the disease, it is possible to obtain false information about the disease by generalizing personal experiences. This can cause negative attitudes about the disease and negatively affect treatment processes.

The source of the video is an important issue. Previous studies have found that the quality of videos uploaded by physicians is higher (11,12). In a study in which videos about atopic eczema were evaluated, it was reported that the majority of the videos consisted of personal experiences, only 32% of which consisted of dermatologists or scientists (14). In the same study, 11% of the videos according to DISCERN and 13% according to GQS were evaluated as “useful or very useful”. Professionals have been

advised to be more visible on health information. In our study, videos containing the experiences of patients/their relatives constituted 41% of the total videos. However, these videos were the lowest quality videos on all three of the GQS, DISCERN and Y-SSS scores. Our study also supports the view that the quality of information decreases as the video resources other than professionals on the subject increase and personal experiences are shared more.

To determine the popularity of videos for users, view ratio, like ratio and VPI are used (12,18). In previous studies, it has been reported that the most viewed and powerful videos are generally patient-experience videos. In our study, the videos with the highest viewing rates, liking rates and VPI were the videos of the patients / their relatives. This makes us think that while watching videos, people expect to learn what people with the same disease experience rather than learning medical information about the disease. Professional videos with medical information about the disease may not be sufficiently understood by patients and therefore may not be of interest.

It has been reported that video durations might be related to view ratio and VPI (11,16). In our study, no relationship was found between video durations and VPI, view ratio. Videos that convey personal experiences in the form of a story seem to attract the attention of viewers, albeit long. It has been reported that the higher the video quality, the longer the video duration (19,20). In our study, a positive correlation was found between GQS, DISCERN and Y-SSS scores and video duration. The need for a longer time to explain the disease-related information such as diagnosis, epidemiology, treatment options and prognosis, therefore, a positive correlation between video quality and duration is expected.

Our study should be evaluated with some limitations. First, Y-SSS is designed by researchers similar to those previously developed for other diseases. Its internal consistency is very high, and it showed excellent correlation with GQS and DISCERN. However, it needs to be validated with further studies. Secondly, information is changing rapidly in digital environments, and our study was conducted using video data obtained at a point-by-point date. After a certain period of time, similar searches can be done again to watch the changes and make better suggestions about the conscious use of YouTube® videos. Finally, in our study, unlike many other studies, a wider page scan was made, and more videos were evaluated. Nevertheless, not

all YouTube® videos about schizophrenia have been examined, and this is a limitation.

CONCLUSION

Most of the videos about schizophrenia on YouTube were personal experiences videos, and these were the most watched ones. Unfortunately, the quality of these videos was low. This may cause the development of wrong attitudes about the disease and its treatment. Also incorrect information may contribute to the stigma surrounding the disorder. There is a need for mental health professionals to be more visible and to present qualified information about the disease in YouTube® videos.

DECLARATIONS

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Disclosure of Interest

The authors declare that they have no competing interest.

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Ethics Committee Approval

This study was exempt from ethical approval of the study institution because it involved the use of public access data only.

Data-sharing Statement

The data that support the findings of this study are available from the corresponding author upon reasonable request.

Author Contributions

Concept – A.C.K., H.K. G.A.; Design – A.C.K., H.K., Y.H.; Supervision – Y.H.; Resources – A.C.K, G.A.; Materials – H.K., A.C.K.; Data Collection and Processing - A.C.K., H.K.; Analysis and/or Interpretation – A.C.K, Y.H.; Literature Review – A.C.K.; Writing – A.C.K., H.K.; Critical Review - A.C.K., H.K., G.A., Y.H.

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