Original Investigation
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YouTube as a source of information on Merkel cell carcinoma

Merkel hücreli karsinomda bilgi kaynağı olarak YouTube

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Abstract

Background and Design: To evaluate the content and reliability of Merkel cell carcinoma videos on YouTube, the most frequently used video-sharing platform to access information.
Materials and Methods: In this descriptive study, videos about Merkel cell carcinoma were searched on www.youtube.com using the term "Merkel cell carcinoma", and 100 videos were analyzed using the Global Quality scale (GQS) and modified DISCERN tool.
Results: The majority of the videos were related to treatment (72%), diagnosis (36%), and pathogenesis (19%). 81% of the videos were rated as useful and 19% as misleading. The GQS and DISCERN scores of the useful videos were statistically significantly higher than those of the misleading videos.
Conclusion: The importance of YouTube, which contains both useful and misleading videos about health for public health, is increasing. Since Merkel cell carcinoma is a rare cancer, we found that the majority of the videos on this subject were uploaded by experts, and their rate of usefulness was high. In the selection of videos on health-related topics, the videos posted by experts (such as medical journals, doctors, and universities) should be prioritized, and YouTube should not be the only source of information since it has no supervisory mechanism.
Keywords: Merkel cell carcinoma, YouTube, Global Quality scale, modified DISCERN tool

Öz

Amaç: En sık kullandığımız video paylaşım platformu olan YouTube'daki Merkel hücreli karsinom videolarının içerik ve güvenilirliğini değerlendirmektir.
Gereç ve Yöntem: Tanımlayıcı tipteki çalışmamızda Merkel hücreli karsinomla ilgili videoları www.youtube.com platformunda "Merkel hücreli karsinom" terimini kullanarak taradık ve The Global Quality scale (GQS) ve The modified DISCERN tool (DS) kullanarak 100 videoyu inceledik.
Bulgular: Video içerikleri tedavi (%72), tanı (%36) ve patogenez (%19) ile ilgiliydi. Videoların %81'i yararlı ve %19'u yanıltıcı olarak değerlendirildi. Yararlı videoların GQS ve modifiye DISCERN skorları yanıltıcı videolardan istatistiksel açıdan anlamlı olarak yüksekti.
Sonuç: YouTube erişim, kullanım ve video yükleme açısından herkese açık bir platformdur. Halk sağlığında giderek önemi artmaktadır. Sağlıkla ilgili yararlı ve yanıltıcı videolar bulunmaktadır. Merkel hücreli karsinom nadir görülen kanser olması sebebiyle konunun uzmanı kişiler tarafından yayınlanan videolar çoğunlukta ve yararlılık yüzdesi yüksek saptanmıştır. Sağlıkla ilgili bilgi edinmek istendiğinde konunun uzmanı kişilerin yayınladığı videolar seçilmeli ve denetleyici mekanizması olmadığı için tek bilgi kaynağı olarak görülmemelidir.
Anahtar Kelimeler: Merkel hücreli karsinom, YouTube, Global Quality Skala, modifiye DISCERN tool

Introduction

Merkel cell carcinoma is a rare aggressive skin malignancy of neuroendocrine origin[1]. The incidence of Merkel cell carcinoma is 0.1 (per 100,000 person-years) in the 40-44 age group, increasing exponentially with age to 9.8 over 85 years. It appears as a rapidly growing, solitary, asymptomatic lesion on sun-exposed areas, such as the head, neck, and extremities. The treatment of Merkel cell carcinoma varies

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according to the stage of the disease, with surgery, radiotherapy, and systemic therapy having an important place[2]. Among systemic treatment options, cytotoxic chemotherapy has low efficacy, and in recent years, higher response rates have been achieved with immunotherapy[3,4].

The internet has an important place in people's lives and has become the most frequently used source to obtain information. Individuals refer to the internet to access information in every field, and they increasingly use the internet to obtain health-related information[5]. YouTube is a popular platform that allows internet users to upload and watch videos. It contains many health-related videos. According to the Health Information National Trends Survey data, there has been a significant increase in internet use to access health-related information, with recent research revealing that eight of 10 internet users access health information online. However, due to the absence of a mechanism that controls video content, videos uploaded on YouTube can be misleading for users[5]. The content of these videos is important in terms of public health. In the literature, there are studies evaluating YouTube videos in many types of cancer (such as laryngeal, lung, breast cancer and hepatocellular carcinoma), but no such study was found on Merkel cell carcinoma[6-9]. Therefore, this study aimed to evaluate the content and reliability of the top 100 videos about Merkel cell carcinoma on YouTube.

Materials and Methods

In this descriptive study, videos about Merkel cell carcinoma were searched on www.youtube.com on July 1, 2022, using the term "Merkel cell carcinoma". Cookies and browsing history were cleared before each search to ensure results would not be affected by previous searches. The results were ordered by relevance. Since internet searchers rarely display over 10 results[7], it was assumed that examining 100 videos would provide sufficient information.

The top 100 videos were ordered and recorded. The videos were watched, and parameters such as video length, number of likes, number of comments, number of views, and video upload date were recorded. The videos were recorded in a file, and the information quality and reliability scores were scored by the rater. Interrater reliability was also calculated. The number of daily views and number of daily likes were calculated according to the time from the upload date to the evaluation date.

Measuring Tools

The Global Quality scale (GQS) was used to evaluate the quality of the videos posted on the YouTube platform. Designed by Bernard et al.[10], GQS is a five-point scale that measures the flow, quality, and usefulness of a video. In this scale, 4 or 5 points are considered to indicate good quality, 3 points moderate quality, and 1 or 2 points poor quality.

The modified DISCERN tool was used to evaluate the reliability of the videos. The DISCERN scale consists of five questions, with 1 point given for each "yes" answer. The total score ranges from 0 to 5. Videos that score above 3 points are considered to have high quality and contain useful information for the patient, those scoring 3 points have moderate quality and require additional sources of information, and those rated below 3 have poor quality and should not be used by patients.

The videos were evaluated in terms of quality and reliability according to the upload source (doctor, news agency, etc.) and the target audience (healthcare professional, patient, etc.). In addition, the videos were considered misleading if they contained false information and useful if they did not contain false information.

Statistical Analysis

The Statistical Package for the Social Sciences (SPSS) v. 25.0 software package was used for the statistical analysis of the data. Categorical measurements were summarized as numbers and percentages, and continuous measurements as median and minimum-maximum values. The Shapiro-Wilk test was used to determine whether the parameters in the study showed a normal distribution. The chi-square and Fisher's exact tests were used to compare categorical data. The Mann-Whitney U test was conducted to analyze the differences between the groups. The statistical significance level was taken as 0.05 in all tests.

Results

Of the videos about Merkel cell carcinoma, 72% were related to treatment, 36% diagnosis, 19% pathogenesis, and 16% risk factors. The content of the remaining videos is presented in Table 1. Some videos had more than one content feature (Table 1).

When the videos were grouped as useful and misleading, the two groups were found to have similar characteristics in terms of video length (min), number of views, number of views/day, number of likes, number of likes/day, and number of comments. The useful videos had significantly higher GQS and DISCERN scores compared to the misleading videos. The videos were aimed at healthcare professionals, followed by patients. The majority of the videos were narrated by a medical journal, organization, or doctor. The USA and the United Kingdom were the top countries in terms of upload source. The detailed data are shown in Tables 2 and 3.

Discussion

When patients cannot obtain sufficient information about their disease during clinical visits, they refer to other information sources, such as the internet. In a study conducted with cancer patients in the USA, 44% of the patients used the internet to learn about their diseases. However, online platforms may present medical information that is inaccurate, misleading, or not updated according to new evidence. Most patients are unaware of evidence-based medicine or its importance for patient management, and as a result, they may not know that most information available on the internet does not reflect

Table 1. Distribution of video content, n (%)

Video content*	n	%
Treatment	72	72.0
Diagnosis	36	36.0
Pathogenies	19	19.0
Risk factors	16	16.0
Pathology	1	1.0
Complication	1	1.0
Nutrition	1	1.0
COVID-19	1	1.0

*Some videos covered more than one topic, n: number, %: percentage

Table 2. Detailed characteristics of YouTube videos according to their content and usefulness

	Total (n=100)	Useful (n=81)	Misleading (n=19)	p value
Variables				
Video length (min)	2.63 (0.57-127.0)	2.61 (0.57-127.0)	2.63 (0.68-48.47)	0.641
Views	368.5 (13-17000)	399 (17-17000)	326 (13-3094)	0.660
Views/day	11.5 (0.22-400)	13.0 (0.77-333.33)	6.66 (0.22-400)	0.176
Likes	3 (0-314)	3 (0-314)	3 (0-43)	0.461
Likes/day	0.08 (0.00-11.67)	0.10 (0.00-8.72)	0.05 (0.00-11.67)	0.127
Comments	0.08 (0-11.67)	0.1 (0-8.72)	0.05 (0-11.67)	0.915
Quality and reliability scores				
GQS	4 (1-5)	5 (3-5)	2 (1-3)	**<0.001**
DISCERN	4 (1-5)	5 (3-5)	2 (1-3)	**<0.001**

Median (minimum-maximum), GQS: Global Quality scale

Table 3. The target audience, source and countries of the videos

	Total (n=100)	Useful (n=81)	Misleading (n=19)
Target audience			
Healthcare professionals	58 (58.0%)	54 (93.1%)	4 (6.9%)
Patient	26 (26.0%)	11 (42.3%)	15 (57.7%)
Both	16 (16.0%)	16 (100%)	0 (0%)
Video source			
Unknown	1 (1.0%)	0 (0%)	1 (100%)
Doctor	17 (17.0%)	15 (88.2%)	2 (11.8%)
News agency	6 (6.0%)	3 (50%)	3 (50%)
Patient & doctor	1 (1.0%)	1 (100%)	0 (0%)
Medical journal	43 (43.0%)	40 (93.0%)	3 (7.0%)
Organization	21 (21.0%)	14 (66.7%)	7 (33.3%)
University	11 (11.0%)	8 (72.7%)	3 (27.3%)
Country			
USA	64 (64.0%)	55 (85.9%)	9 (14.1%)
Australia	2 (2.0%)	2 (100%)	0 (0%)
United Kingdom	20 (20.0%)	17 (85.0%)	3 (15.0%)
Canada	3 (3.0%)	2 (66.7%)	1 (33.3%)
Pakistan	2 (2.0%)	2 (100%)	0 (0%)
Unclear	4 (4.0%)	1 (25.0%)	3 (75.0%)
Other	5 (5.0%) (Germany, India, Mexico, Egypt, and Türkiye)	2 (40.0%) (Germany and Mexico)	3 (60.0%) (India, Egypt, and Türkiye)

Data presented as number (%, percentage)

best clinical practice[10]. Videos on YouTube do not undergo a review process and are not regularly updated; therefore, they may contain insufficient or incorrect information[11]. For these reasons, it is important to analyze the information on the internet. In a study by Meteran et al.[7] evaluating YouTube videos on lung cancer, 62% of the videos were useful and 6% misleading. The misleading videos were more popular than the useful videos in terms of views and likes. In another YouTube study on colorectal cancer, 54% of the videos were useful and 46% misleading. It was observed that almost half of the videos in the useful category (47.3%) had been uploaded by academic sources, while most videos in the misleading group (46%) had been uploaded by for-profit companies, private hospitals, and medical advertisements[12]. In another study, most of the information in bladder cancer videos was of moderate to low quality. The majority of the videos were uploaded by hospitals/clinics, foundations/advocacy groups, and health/wellness channels, and 57% were narrated by a doctor[13]. YouTube videos as a source of information on basal cell carcinoma study showed the mean assessment scores were: DISCERN, 3.3; GQS, 3.8; understandability, 70.8%; and actionability, 45.9%. These values showed the videos were of medium to good quality and had good understandability,

low actionability, and poor reliability. The quality of videos provided by health professionals was significantly higher than that of videos provided by laypersons[14].

In the current study, YouTube videos on Merkel cell carcinoma were examined, and 81% were evaluated as useful and 19% as misleading. The GQS and DISCERN scores of the useful videos were statistically significantly higher than those of the misleading videos ($p<0.001$). Forty of the useful videos had been uploaded by medical journals, 15 by doctors, 14 by organizations, and eight by universities. The rare nature of Merkel cell carcinoma may have contributed to the increased usefulness of the videos since they were mostly prepared by professionals with special training concerning this disease. According to the literature data, of the YouTube videos on radiotherapy in lung cancer, 61% were uploaded from the USA, 14% from the UK, 6% from Australia, and 5% from Canada and India[15]. In the current study, 64% of the videos were uploaded from the USA (85.9% useful), 20% from the United Kingdom (85% useful), and 16% from Australia, Canada, Pakistan and other countries. In videos on prostate cancer, the aim was to provide general information in 78%, information related to treatment in 51%, and information related to prostate-specific antigen and routine screening in 26%[16]. Signs/detection constituted the topic that was most covered by treatment-related videos on bladder cancer, and most videos targeted the public[13]. In melanoma, YouTube videos showed that content analysis assessed six areas, as follows: general information, risk factors, prevention, diagnosis, treatment, and prognosis[17]. In this study, 72% of the videos on Merkel cell carcinoma concerned treatment, 36% diagnosis, 19% pathogenesis, and 16% risk factors. Most videos related to treatment can be attributed to low response rates of cytotoxic chemotherapy but the superior response rate and survival with immunotherapy[3,4]. The useful and misleading videos were similar in terms of video length (minimum), views, views/day, likes, likes/day, and comments. The target audience was healthcare professionals in 58% of the videos, patients in 26%, and both healthcare professionals and patients in 16%. The majority of the videos targeting healthcare professionals (93.1%), 42.3% of those targeting patients, and all the videos targeting both groups were determined to be useful.

Study Limitations

Although this study is the first to examine the content and reliability of YouTube videos on Merkel cell carcinoma, it has the limitation of the videos being evaluated by a single rater.

Conclusion

YouTube is a platform that has no restrictions in terms of access, use, and video upload. Besides accurate information, it also contains misleading information. It is important to ensure such platforms support public health in a positive way. Although the usefulness and misleading percentages of the videos published on various subjects differ, the usefulness percentage of the YouTube videos on Merkel cell carcinoma was high in the current study. In the selection of videos on health-related topics, those published by experts (such as medical journals, doctors, and universities) should be prioritized, and YouTube should not be the only source of information.

Ethics

Ethics Committee Approval: Considering that YouTube is a free public platform, and the study did not include any participants, ethics committee approval was not required.

Informed Consent: Informed consent approval was not required.

Peer-review: Externally and internally peer reviewed.

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