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Evaluation of YouTube Videos as a Source of Information about Dementia Care

Demans Hastalarının Bakımı Konusunda Bilgi Kaynağı Olarak Youtube Videolarının Değerlendirilmesi

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ABSTRACT

Aim: Digital platforms such as YouTube are popular sources of health-related information. Although there are studies evaluating the quality of different online medical content, studies focusing on the quality of dementia-related content are limited. This study aimed to investigate the quality of YouTube videos related to dementia patient care.
Material and Methods: Using the term "Dementia care" on the YouTube platform, 100 English videos that met the inclusion criteria were identified and analyzed. In addition to video popularity measurements, to evaluate content quality, the global quality scale (GQS), modified DISCERN scale, Journal of the American Medical Association (JAMA) quality scale, and the patient education materials assessment tool for audio/visual materials (PEMAT-A/V) are used.
Results: It was observed that most of the videos were uploaded by non-academic health institutions (36%) and health professionals (23%). When the content of the videos was evaluated, it was determined that general care strategies were the most common content with 52%. Scores indicating high levels of reliability and accuracy were determined on all applied content quality scales. Videos sourced from academic healthcare institutions were found to have the highest scores on content quality scales. In correlation analyses, video metrics such as duration, view ratio, number of comments, and video power index values were positively correlated with content quality scores.
Conclusion: Videos about dementia patient care on YouTube generally exhibit high popularity and content quality. Individuals seeking information about dementia care on online platforms should be directed to videos uploaded by healthcare institutions.
Keywords: Dementia; dementia care; YouTube.

ÖZ

Amaç: YouTube gibi dijital platformlar sağlıkla ilgili bilgiler için popüler kaynaklardır. Farklı çevrimiçi tıbbi içeriklerin kalitesinin değerlendirildiği çalışmalar yapılmış olsa da, demansla ilgili içeriklerin kalitesine odaklanan çalışmalar sınırlıdır. Bu çalışmanın amacı, demanslı hasta bakımıyla ilişkili YouTube videolarının kalitesini değerlendirmektir.
Gereç ve Yöntemler: YouTube platformunda "Dementia care" terimi kullanılarak, dahil etme kriterlerini karşılayan 100 İngilizce video belirlendi ve analiz edildi. Video popülerlik ölçümlerinin yanı sıra, içerik kalitesini değerlendirmek için, küresel kalite ölçeği (global quality scale, GQS), modifiye DISCERN skalası, Journal of the American Medical Association (JAMA) kalite ölçeği ve işitsel/görsel materyaller için hasta eğitim materyalleri değerlendirme aracı (patient education materials evaluation tool for audio/visual, PEMAT-A/V) kullanılmıştır.
Bulgular: Videoların büyük çoğunluğunun akademik olmayan sağlık kuruluşları (%36) ve sağlık profesyonelleri (%23) tarafından yüklendiği görülmüştür. Videoların içeriği değerlendirildiğinde, genel bakım stratejilerinin %52 ile en yaygın içerik olduğu tespit edilmiştir. Uygulanan içerik kalitesi ölçeklerinin tümünde yüksek güvenilirlik ve doğruluk düzeylerine işaret eden skorlar saptanmıştır. Akademik sağlık kurumları kaynaklı videoların, içerik kalitesi ölçeklerinde en yüksek puanlara sahip olduğu görülmüştür. Korelasyon analizlerinde, süre, görüntüleme oranı, yorum sayısı ve video güç indeksi değerleri gibi video metrikleri, içerik kalitesi skorlarıyla pozitif yönde korelasyon göstermiştir.
Sonuç: YouTube platformunda yer alan demanslı hasta bakımıyla ilgili videolar, genel olarak yüksek popülerlik ve içerik kalitesi sergilemektedir. Çevrimiçi platformlarda demans bakımı hakkında bilgi arayan bireylerin, sağlık kuruluşları tarafından yüklenen videolara yönlendirilmeleri uygun olacaktır.
Anahtar kelimeler: Demans; demans bakımı; YouTube.

INTRODUCTION

The prevalence of dementia is increasing as the global population ages. Presently, over 55 million people worldwide are living with dementia, and around 10 million new cases are diagnosed each year. Dementia is recognized as one of the leading causes of disability and dependency among older adults worldwide (1,2). Dementia syndromes, particularly Alzheimer's disease, which accounts for 60-70% of dementia cases, pose numerous practical challenges for patients, families, healthcare providers, and healthcare systems. Following a dementia diagnosis, patients and their families require practical information and guidance to manage the condition effectively. They seek information on various topics, including maintaining daily living activities, ensuring home safety, financial planning, engaging with formal support services and care teams, guardianship, and legal matters (2,3). Patients' relatives and caregivers increasingly utilize digital platforms to gather information on these topics (4).

Addressing these issues effectively can improve disease management and enhance patient, family, and caregiver experience (5,6).

In recent years, the internet and social media platforms have become prevalent resources offering numerous opportunities to access health information, among other topics. Video-sharing platforms are often preferred by users over traditional websites for obtaining health information (7). YouTube, the leading video-sharing platform, ranks as the second most visited website globally, following Google, according to data from November 2023 (https://www.statista.com/statistics/1201889/most-visited-websites-worldwide-unique-visits). In this regard, YouTube is among the most frequently utilized sources for health-related information (7,8-11). Similar to other health topics, YouTube offers a wide range of medical content related to dementia care and support for patients and their families. This content includes information on different aspects of the disease, evaluation of treatment options, and offering psychosocial support (11-16). Additionally, YouTube offers substantial convenience for healthcare professionals and institutions in achieving their objectives, such as reaching their target audience and providing education. However, there are concerns regarding the potential negative impacts of health-related content. The primary issue is the risk of the uncontrolled spread of misleading or false information, which can lead to significant challenges within the healthcare system for both patients and healthcare professionals (7,8). Therefore, it is essential to verify the reliability, accuracy, and quality of the information obtained and ensure access to reliable content. Numerous studies in the literature have been conducted for this purpose, presenting scales and methods to evaluate the quality of medical content on online platforms (8,9,11,17-22). While some of these studies concentrate on dementia-related content, none specifically examine videos related to dementia care (12-16,20).

This study aimed to assess and evaluate the reliability, accuracy, understandability, applicability, and popularity of dementia care-related videos on YouTube, focusing specifically on their suitability as a source of information for patients seeking such content.

MATERIAL AND METHODS

Since the study did not involve human subjects, approval from a clinical research ethics committee was not required. This decision is consistent with practices observed in similar previous studies. In determining our methods, we adhered to recommendations from previous studies and literature reviews that evaluated the quality of medical content on online platforms (11,19,22).

Video Search

The video search was conducted on January 10, 2024, using the keyword 'dementia care' on the YouTube platform. To ensure unbiased results, all cookies and search history were cleared. To replicate the experience of an ordinary user, the default selection was set to "relevance-based ranking." Given that research indicates individuals typically explore only the initial search results, approximately 60-200 videos, our study focused on analyzing the top 100 most relevant videos. We included only English-language videos and excluded duplicates, videos shorter than 60 seconds or longer than 60 minutes, scientific meeting recordings, medical lectures, videos with audio issues, and irrelevant content as stated in previous literature (9,11). URLs for the 100 videos meeting the inclusion criteria were saved for further analysis. Two neurologists independently reviewed all videos, and any differing evaluations were re-examined and finalized.

Video Analytics

Information such as the title, country of origin, video source, days since publication, image quality, video duration (in seconds), and total number of views, comments, likes, and dislikes up to the search date were recorded. The video power index (VPI), which measures the popularity and impact of video content, was computed using the formula VPI= (like ratio × view ratio) / 100. The view ratio was calculated by dividing the number of views by the number of days since publication (view ratio= total views / days since publication). The like ratio was calculated as like ratio= (number of likes × 100) / (number of likes + number of dislikes). To evaluate the quality of video content, the global quality scale (GQS), modified DISCERN score, the Journal of the American Medical Association (JAMA) benchmark score, and patient education materials assessment tool audio/visual (PEMAT-A/V) were utilized (11,19,23,24).

The global quality scale (GQS) is a widely used scale designed to assess the overall quality of content on a spectrum from poor to excellent. This five-point Likert scale considers key elements such as content flow, information quality, and ease of use. A higher score on the scale indicates better quality and utility. Scores of 1 or 2 suggest low educational quality, 3 indicate intermediate quality, while scores of 4 or 5 indicate high educational quality (11,19,24).

The modified DISCERN tool consists of five questions that assess content for its reliability, clarity, and impartiality. Each question receives a score of either 1 or 0, indicating whether the content meets the established criteria. The total score from these questions determines the overall quality, with higher scores suggesting increased reliability and less bias in the information provided (11,19,24).

JAMA benchmark criteria assess the quality of online health information based on authorship, accurate citation

of sources, currency of information, and disclosure of conflicts of interest. Each criterion earns one point, with a maximum score of four points indicating the highest level of reliability and accuracy (11,19,24,25).

The PEMAT-A/V assesses the quality and clarity of patient education materials, including videos and multimedia presentations. Its goal is to ensure that health information is communicated effectively to patients in a clear and actionable manner, using straightforward language. The assessment consists of 12 items for the understandability domain and five items for the actionability domain. The overall score is reported as a percentage (26).

Statistical Analyses

IBM SPSS v.20 (Armonk, NY: IBM Corp. Released 2011) package program was used for statistical analyses. The distribution of normality was assessed by using the Shapiro-Wilk test. Descriptive statistics regarding the numeric data were presented as mean±standard deviation and median, minimum-maximum. Comparisons of video quality scores among different publishers and video types were performed by the Kruskal-Wallis test. Correlations between quality scores and video analytics were evaluated via Spearman's correlation test. A two-tailed p-value of <0.05 was considered statistically significant.

RESULTS

We watched the first 162 videos from the search results and selected 100 videos that met the inclusion criteria. The total duration of the 100 videos was approximately 703 minutes (around 42.232 seconds), with a median duration of 272 (range, 65-2024) seconds. The total number of views was 2 982 054, with a median of 13879 views. Upon analyzing the country of origin, most (80%, n=80) of the videos were from the United States of America. Videos from the United Kingdom accounted for 11% (n=11), and 9% (n=9) were from other countries. Regarding video sources, non-academic healthcare systems contributed the most content with 36 (36%) videos, followed by healthcare professionals with 23 (23%) videos, academic health organizations (where authors were affiliated with a university or research group) with 22 (22%) videos, and TV/educational websites with 19 (19%) videos. Of the videos, 90 (90%) featured high-definition (≥720p) image quality. The others were in standard definition (480p) with 6 (6%) and low definition (≤360p) with 4 (4%) videos. Regarding the content of the videos, the most prevalent topic was general care strategies featured in 52% (n=52) of the videos. Behavioral problems were addressed in 21% (n=21) of the videos, while 18% (n=18) focused on care centers, and 9% (n=9) discussed social and financial support systems. The median GQS score, which assesses the educational quality of the videos, was 4 (range, 1-5), indicating high quality. The median score on the modified DISCERN scale was 4 (range, 2-4), suggesting high reliability, and the median JAMA benchmark score of the videos was 4 (range, 1-5), indicating high quality. The median PEMAT-A/V scores were 80% (range, 38-100) for understandability and 66% (range, 0-100) for actionability. Video descriptive features and analytics were summarized in Table 1.

We found that VPI, which measures the popularity and impact of video content, varied by video source. Videos from academic sources had statistically significantly higher VPI scores compared to those from non-academic and TV/educational websites (p<0.001, and p=0.023, respectively). Furthermore, videos sourced from healthcare professionals had significantly higher VPI scores than those from non-academic sources (p=0.008).

In evaluating content quality by the source of videos, we observed differences in content quality scales (Table 2). Videos from academic health organizations had higher GQS scores compared to those from non-academic health organizations and TV/educational websites (p=0.001, and p=0.005, respectively). Modified DISCERN scores were significantly higher in videos sourced from academic health organizations than in those from non-academic health organizations (p=0.008). When comparing video sources in terms of JAMA scores, videos from academic health organizations had significantly higher scores than those from TV/educational websites (p=0.045). For PEMAT A/V understandability scores, videos from healthcare professionals scored significantly higher than those from TV/educational websites and non-academic health organizations (p=0.025, and p=0.010, respectively). Differences were also observed in PEMAT A/V actionability scores across video sources. Videos from academic health organizations had significantly higher scores than those from non-academic health organizations and TV/educational websites (both p<0.001). Additionally, videos from healthcare professionals had significantly higher PEMAT A/V actionability scores than those from non-academic health organizations (p=0.013).

Correlation analyses revealed positive correlations between video analytics, such as video duration, view ratio, number of comments, VPI, and content quality scales, including GQS, modified DISCERN, JAMA, and PEMAT A/V scores (Table 3).

DISCUSSION

In this study, we assessed the quality and usefulness of YouTube videos as sources of information on dementia care, focusing on the 100 most relevant videos. Our findings indicate that these videos generally exhibit high content quality and reliability scores when evaluated using the GQS, DISCERN, JAMA, and PEMAT A/V scales. Furthermore, we observed significant variations in content quality based on the source of the videos. Videos from academic health institutions consistently received the highest scores across the VPI, GQS, modified DISCERN, JAMA, and PEMAT A/V assessment tools. Correlation analyses revealed that video analytics metrics, such as video duration, view ratio, number of comments, and VPI values, were positively correlated with accuracy and reliability in the content quality scales.

To the best of our knowledge, this study is the first to specifically examine the utility of online platforms as resources for dementia care information. However, there are some studies in the literature that evaluate online content discussing dementia.

For instance, Lam and Woo (16) found that YouTube effectively adapted educational videos on dementia for the elderly over three years, demonstrating its value in reaching diverse age groups. Similarly, YouTube has been identified as an increasingly popular platform for delivering culturally sensitive dementia education to Chinese

Americans (15). Another study comparing YouTube to talk-based educational workshops on dementia highlighted YouTube's utility in providing dementia-related information to Chinese Americans (14). In these three studies, analyses were conducted only on video metrics, and the lack of use of content quality assessment scales limits the reliability of the results. Despite these insights, these studies lacked content quality assessments.

Table 1. Video descriptive and analytics

	Mean±SD	Median	IQR	Min-Max
Duration (second)	422.32±41.95	272	167-513.25	65-2024
Number of views	108715.29±31096.43	13879	3577-74797	22-2313299
Time since publication (day)	2473.72±468.07	2064.5	966.5-3044	1-45301
Number of likes	1516.75±424.05	229.5	20.75-977.5	1-24444
Academic health organization	1897.36±3250.10	1150	78-1917	13-15084
Non-academic healthcare systems	984.33±4059.05	88	11-457	1-24444
Healthcare professional	1931.43±4291.74	568	291-988	8-15843
TV/educational website	1582.84±5573.39	87	8-301	1-24443
Number of dislikes	54.67±19.38	3	0-17	0-1254
Number of comments	90.64±26.77	10.5	0-68.25	0-1496
View ratio	46.96±10.68	14.32	2.38-45.13	0.1-816.84
Like ratio	97.34±0.76	98.68	96.79-100	25-100
VPI	45.53±10.22	13.98	2.37-43.91	0.09-776.98
GQS	3.94±0.09	4	3-5	1-5
Modified DISCERN	3.44±0.06	4	3-4	2-4
JAMA	3.68±0.06	4	3-4	1-5
PEMAT A/V 1	72.04±1.66	80	60-80	38-100
PEMAT A/V 2	56.04±2.96	66	33-66	0-100

VPI: video power index, GQS: global quality scale, JAMA: Journal of the American Medical Association, PEMAT-A/V: patient education materials assessment tool audio/visual, 1: understandability, 2: actionability, SD: standard deviation, IQR: interquartile range (25^{th}-75^{th} percentile)

Table 2. Analyses of content quality by video sources

	Academic Health Organization (AC)	Non-Academic Healthcare Systems (Non-AC)	Healthcare Professional (HP)	TV/Educational Website (TV)	p
	Mean±SD Median (IQR) [min-max]	Mean±SD Median (IQR) [min-max]	Mean±SD Median (IQR) [min-max]	Mean±SD Median (IQR) [min-max]	
GQS	4.55±0.15 5 (4-5) [3-5]	3.64±0.13 4 (3-4) [2-5]	4.13±0.17 4 (4-5) [2-5]	3.58±0.23 4 (3-4) [1-5]	**<0.001**
DISCERN	3.77±0.11 4 (4-4) [2-4]	3.22±0.11 3 (3-4) [2-4]	3.61±0.13 4 (3-4) [2-4]	3.26±0.16 3 (3-4) [2-4]	**0.004**
JAMA	3.91±0.06 4 (4-4) [3-4]	3.64±0.11 4 (3-4) [1-4]	3.83±0.14 4 (3-4) [2-5]	3.32±0.20 4 (3-4) [1-4]	**0.042**
PEMAT A/V 1	78.41±2.40 80 (80-80) [50-100]	67.92±2.68 73 (55-80) [40-100]	78.78±3.33 80 (75-90) [40-100]	64.32±4.34 70 (40-80) [38-90]	**0.001**
PEMAT A/V 2	82.38±5.36 100 (66-100) [33-100]	40.48±4.26 33 (33-66) [0-100]	63.26±4.15 66 (66-66) [33-100]	41.25±5.63 33 (33-66) [0-66]	**<0.001**
VPI	81.47±25.12 54.3 (7.9-90.6) [1.9-521.2]	14.31±3.41 4.8 (1.3-15.8) [0-79.1]	50.09±14.35 27.5 (13.2-58.6) [1-263.7]	57.52±40.40 6.6 (0.7-28.6) [0.1-776.9]	**<0.001**

GQS: global quality scale, JAMA: Journal of the American Medical Association, PEMAT-A/V: patient education materials assessment tool audio/visual, 1: understandability, 2: actionability, VPI: video power index, SD: standard deviation, IQR: interquartile range (25^{th}-75^{th} percentile), post hoc test results of groups; GQS: AC vs Non-AC: p=0.001, AC vs TV: p=0.005; Modified DISCERN: AC vs Non-AC: p=0.008; JAMA: AC vs TV: p=0.045; PEMAT A/V 1: Non-AC vs HP: p=0.010, HP vs TV: p=0.025; PEMAT A/V 2: AC vs Non-AC: p<0.001, AC vs TV: p<0.001, Non-AC vs HP: p=0.013; VPI: AC vs Non-AC: p<0.001, AC vs TV: p=0.023, Non-AC vs HP: p=0.008

Table 3. Correlation coefficients between content quality scores and video analytics

	GQS		DISCERN		JAMA		PEMAT-A/V 1		PEMAT-A/V 2	
	r_s	p	r_s	p	r_s	p	r_s	p	r_s	p
VPI	0.430	**<0.001**	0.309	**0.002**	0.269	**0.007**	0.413	**<0.001**	0.535	**<0.001**
Video duration	0.399	**<0.001**	0.392	**<0.001**	0.448	**<0.001**	0.428	**<0.001**	0.292	**0.005**
View ratio	0.434	**<0.001**	0.315	**0.001**	0.272	**0.006**	0.419	**<0.001**	0.536	**<0.001**
Number of comments	0.480	**<0.001**	0.475	**<0.001**	0.421	**<0.001**	0.520	**<0.001**	0.624	**<0.001**
Image quality	-0.154	0.126	-0.139	0.167	0.041	0.686	-0.177	0.078	-0.153	0.148

GQS: global quality scale, JAMA: Journal of the American Medical Association, PEMAT-A/V: patient education materials assessment tool audio/visual, 1: understandability, 2: actionability, VPI: video power index, r_s: Spearman's rho

Tang et al. (27) analyzed YouTube video content related to Alzheimer's disease, considering video metrics, content, audience participation, and speaker features. However, they did not assess content quality.

Recent research by Bizpınar et al. (12) evaluated YouTube videos as a source of information on mild cognitive impairment (MCI), revealing that 96% of the videos fell into the useful/very useful category based on content quality scales. Similarly, a study on informational videos about Alzheimer's disease found that English-language videos generally scored high on content quality scales (20). These findings align with our study's results, which also utilized similar quality scales to evaluate the content quality of dementia care videos. Notably, our study observed a higher ratio of videos with useful content quality compared to studies examining videos on various medical topics (18,28-31). The high content quality of dementia care videos in our study can be attributed to their predominantly healthcare professional and academic center origins. Existing literature supports the notion that videos involving healthcare professionals tend to meet higher standards of quality and reliability (7,12,24,32).

Our results regarding the high content quality of dementia care-related videos highlight the potential of YouTube as a useful and adequate information acquisition tool for patients and their relatives.

In our study, we found a positive correlation between video analytics —including video duration, view ratio, number of comments, and VPI— and content quality scale scores. This aligns with findings from other studies (2,27,32,33). While our findings suggest that viewers tend to select videos with higher educational and content quality regarding dementia care, it's important to note that video popularity doesn't always equate to video reliability or quality. Metrics like the GQS, modified DISCERN, JAMA, and PEMAT A/V scores assess specific content quality elements such as accuracy, reliability, understandability, and actionability. In contrast, VPI reflects the perceived value of the video content. Supporting our view, some studies on medical content have indicated that videos popular among viewers may lack content quality (7,28,30,34). We recommend creating a video format that takes into account the standards set by content quality scales to increase the view ratio of informative content about dementia by the target audience.

Online platforms, particularly video-sharing sites like YouTube, have created extensive avenues for patients and their families to access information about various aspects of diseases, evaluate treatment options, and receive psychosocial support (22,24). However, the uncontrolled nature of the sources and content on these platforms can lead to inaccuracies and unreliability, potentially negating the positive effects and misguiding patients and their families (7,8,24). Therefore, monitoring the quality and reliability of health-related content is crucial. Standardizing these evaluations can be achieved using appropriate content quality assessment scales. The most commonly utilized scales for this purpose in the literature include GQS, Modified DISCERN, and JAMA (7,8,24). We also used the PEMAT A/V scale in addition to other scales. Despite the increasing availability and use of audiovisual educational materials such as videos, scales specifically developed to evaluate these materials are limited. PEMAT A/V is superior to other quality assessment tools in its ability to reliably evaluate audiovisual materials. PEMAT is also the first tool to measure actionability, an increasingly emphasized goal of patient education materials. The use of PEMAT A/V is an important advantage, therefore increasing the reliability of the results of our study (26). It is worth noting that the actionability scores of the videos analyzed in our study were relatively lower compared to the understandability scores. Developing video content with enhanced actionability will further elevate the educational quality of videos related to dementia care.

Our study has several limitations that warrant consideration. Firstly, we focused only on the videos in English-language, which may limit the applicability of our findings to non-English-speaking audiences. Secondly, relying on a single keyword for video selection, although aimed at identifying the most relevant videos, could be viewed as a limiting factor. Lastly, our focus solely on videos from YouTube, excluding content from other websites or social media platforms, may not capture the full spectrum of available information on dementia care across online platforms.

CONCLUSION

This study is the first to specifically analyze YouTube videos focusing on dementia care, highlighting the platform's potential as a valuable and accurate resource for the public seeking information on dementia patient care. Given the ease of accessing healthcare information online and the challenges physicians face in controlling misinformation, educational videos on platforms like YouTube must be uploaded by academics and healthcare professionals to ensure the dissemination of reliable content. Also, to enhance viewership and educational quality, we recommend creating video formats that adhere to established content quality standards. Future research should focus on identifying gaps in the realm of online healthcare education materials and on customizing content to effectively address the specific needs of the target audience.

Ethics Committee Approval: Since our study was not an experimental study including human or animal subject, ethics committee approval was not required.

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