

Can YouTube be used as a source of information for swallowing disorders in individuals with dementia?

YouTube, demansı olan bireylerde yutma bozuklukları için bir bilgi kaynağı olarak kullanılabilir mi?

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ABSTRACT

Objectives: This study aimed to examine YouTube video content as a general source of information about dysphagia in individuals with dementia.

Materials and Methods: In this study, videos about dysphagia in individuals with dementia uploaded to the YouTube platform on June 4, 2023, were analyzed using the keywords “swallowing in dementia,” “swallowing disorders in dementia,” and “dysphagia in dementia.” Modified DISCERN was used to assess the reliability of the videos, the Global Quality Scale to assess their quality, the Journal of American Medical Association (JAMA) benchmark criteria to assess their transparency, and the Video Power Index to calculate their popularity. Twenty-four videos uploaded between October 21, 2009, and October 31, 2022 were included in the final content analysis.

Results: Speech and language therapists/pathologists (SLPs) uploaded 54.17% of the videos, 37.50% were uploaded by non-SLP health workers, and 8.33% were uploaded by other individuals. Global Quality Scale scores were positively correlated with JAMA and video duration and negatively correlated with the number of days elapsed. There was a statistically significant difference in the duration, number of views, number of likes, comments, and JAMA mean scores among video sources (SLP vs. non-SLP health workers; $p<0.05$).

Conclusion: The number of videos about swallowing and swallowing disorders in individuals with dementia on YouTube is low; popularity does not reflect high quality, reliability, or competence. Therefore, health professionals working in this field, such as speech-language pathologists, neurologists, and otolaryngologists, should increase the number of informative and guiding videos and ensure that videos that are considered accurate are communicated to the patient and caregiver/relative.

Keywords: Alzheimer, dementia, dysphagia, swallowing disorders, YouTube.

ÖZ

Amaç: Bu çalışmada, demanslı bireylerde disfaji hakkında genel bir bilgi kaynağı olarak YouTube video içeriği incelendi.

Gereç ve Yöntemler: Bu çalışmada, 4 Haziran 2023 tarihinde YouTube platformuna yüklenen demanslı bireylerde yutma güçlüğü ile ilgili videolar, “demansta yutma”, “demansta yutma bozuklukları” ve “demansta yutma güçlüğü” anahtar kelimeleri kullanılarak analiz edildi. Videoların güvenilirliğini değerlendirmek için modifiye DISCERN, kalitelerini değerlendirmek için Global Kalite Ölçeği, şeffaflıklarını değerlendirmek için Journal of American Medical Association (JAMA) kıyaslama kriterleri ve popülerliklerini hesaplamak için Video Güç Endeksi kullanıldı. Nihai içerik analizine 21 Ekim 2009 ile 31 Ekim 2022 tarihleri arasında yüklenen 24 video dahil edildi.

Bulgular: Videoların %54.17’si dil ve konuşma terapistleri/patologları (DKT) tarafından, %37.50’si DKT olmayan sağlık çalışanları tarafından ve %8.33’ü diğer kişiler tarafından yüklenmiştir. Global Kalite Ölçeği; JAMA ve video süresi ile pozitif korelasyon gösterirken, geçen gün sayısı ile negatif korelasyon gösterdi. Video kaynakları (DKT’lere karşı DKT olmayan sağlık çalışanları) arasında süre, görüntüleme sayısı, beğeni sayısı, yorum sayısı ve JAMA ortalama skorlarında istatistiksel olarak anlamlı bir fark bulundu ($p<0.05$).

Sonuç: YouTube’da demanslı bireylerde yutma ve yutma bozuklukları ile ilgili video sayısı düşüktür; popülerliğin yüksek kalite, güvenilirlik veya yeterliliği yansıtmadığı görülmüştür. Bu nedenle, dil ve konuşma terapistleri, nörologlar ve kulak burun boğaz uzmanları gibi bu alanda çalışan sağlık profesyonelleri, bilgilendirici ve yol gösterici videoların sayısını artırmalı ve doğru olduğu düşünülen videoların hasta ve bakıcı/yakınına önerilmesini sağlamalıdır.

Anahtar sözcükler: Alzheimer, demans, disfaji, yutma bozuklukları, YouTube.

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Dementia is a syndrome that affects memory, cognitive abilities, and behavior, significantly impairing a person's ability to perform activities of daily living. Diagnostic criteria require significant impairment in at least one cognitive domain, such as memory, executive functions, language, recognition (agnosia), or visuospatial functions.^[1] The incidence of dementia, which represents a series of neurodegenerative pathologies, is rapidly increasing worldwide.^[1,2] Approximately 5 to 8% of the population over 60 years of age has dementia, and dementia is the fifth leading cause of death worldwide.^[3] Furthermore, cortical or subcortical lesions, the severity of which may differ between dementia types, may cause dysphagia by affecting the neural control of swallowing.^[4,5] Dysphagia can lead to decreased appetite, weight loss, dehydration, malnutrition, fear of eating, decreased quality of life, recurrent lung infections, aspiration, and pneumonia.^[6,7] Studies show that dysphagia increases the length of hospitalization and the economic burden of patients with dementia and causes poor clinical outcomes.^[6,8]

With the loss of function, people with dementia may become more dependent and prone to depression. Depression is associated with a loss of appetite, which can trigger a vicious cycle that leads to further dehydration, malnutrition, and weight loss.^[9] This situation creates worry and anxiety for people with dementia and their caregivers. YouTube is the most easily accessible source of information for finding solutions to many problems.

YouTube is a popular website used worldwide and offers a variety of information and news. The use of YouTube as an online source of information has increased among all age groups.^[10] Viewers can easily and conveniently watch various videos for free through YouTube.^[11] They are increasingly turning to video resources to get a second opinion, seek support, and increase their personal knowledge about the disease.^[12] However, the reliability of available videos is variable, and the content lacks quality control and review by experts.^[13] To our knowledge, no study has examined YouTube as a source of information about swallowing disorders in people with dementia. Therefore, it is necessary to examine the quality and accuracy of YouTube videos that can be used as a source of information about dysphagia by relatives or caregivers of individuals with dementia and identify any deficiencies. Hence, this study aimed to examine and analyze YouTube video content as a general source of information about dysphagia in individuals with dementia.

MATERIALS AND METHODS

Video selection

In this study, videos about dysphagia in individuals with dementia uploaded to the YouTube platform on June 4, 2023, were analyzed using the keywords “swallowing in dementia,” “swallowing disorders in dementia,” and “dysphagia in dementia.” A new YouTube account was created to ensure data reliability, and search history and cookies were deleted.

The sample included videos from the first two pages of YouTube results for each search term, with 20 videos per page, following the methodology of other content analysis studies.^[14] Additionally, a second page of search results was included to increase the sample size, as most users tend not to go beyond the first page of internet search results.^[15] In the first phase, a total of 120 videos (40 for each keyword) were recorded for content analysis. From this initial sample, 40 repetitive videos were excluded, resulting in a final sample of 80 videos. Subsequently, videos that did not meet specific criteria, such as being in English (n=2), related to other speech and language disorders (n=7), longer than 60 min (n=2), or lacking relevant content (n=41), were excluded. Twenty-four videos uploaded between October 21, 2009, and October 31, 2022 were included in the final content analysis.

Assessment scales and assessment procedures

The modified DISCERN (mDISCERN) was used to assess the reliability of the videos, the Global Quality Scale (GQS) to assess their quality, the Journal of American Medical Association (JAMA) benchmark criteria to assess their transparency, and the Video Power Index (VPI) to calculate their popularity. The mDISCERN, GQS, and JAMA criteria assessment parameters were scored by two different speech and language therapists. Based on the different opinions of the researchers, the average of the scores was calculated. The source of the analyzed videos was divided into three groups: speech and language therapists/pathologists (SLP), non-SLP health workers, and other non-SLP individuals.

Singh et al.^[16] developed the mDISCERN by focusing on five questions that address the areas of clarity, reliability, bias/balance, provision of additional sources of information, and uncertainty. A score of ≥ 3 is considered good reliability, and scores < 3 is considered poor reliability.

Bernard et al.^[17] developed the GQS to assess the quality of internet-based resources. On this scale, scores range from 1 to 5. A score of 1 indicates that the quality

of the video is low and not useful for patients, while a score of 5 indicates that the video is of high quality and useful for patients. The scores are categorized as follows: 1-2, low quality; 3, medium quality; 4-5, high video quality.^[17,18]

Silberg et al.^[19] developed the JAMA criteria scale to assess the transparency of video sources and publication information. This scale consists of four items and is

scored according to positive answers. A score of 0-1 indicates that the data in the video source is insufficient; 2-3 points indicate that the video source has partially sufficient data; and 4 points indicate that the data in the video source is completely sufficient.

Erdem and Karaca^[20] created the VPI scale to gauge the popularity of videos. In the calculation of VPI, factors such as the time since the video was uploaded to

Table 1
Characteristics of the videos

Video features	Mean±SD	Min-Max
Duration (min)	20.8±21.9	1.4-59.6
Number of views	12,182.9±21,473.8	14-71,000.0
Number of likes	136.7±219.2	0-726
Number of dislikes	0.00±0.00	0-0
Number of comments	11.5±23.4	0-84
Time elapsed after video upload (year)	4.5±3.6	0.6-13
GQS	3.2±0.9	1-4
JAMA	2.2±1.6	0-4
mDISCERN	3.0±1.1	1-5
VPI	3,836.8±10,421.3	0.27-50,365.0

SD: Standard deviation; GQS: Global Quality Scale; JAMA: Journal of American Medical Association; mDISCERN: Modified DISCERN; VPI: Video Power Index.

Table 2
Pearson correlations between the characteristics of the videos

	Duration (min)	Number of views	Number of likes	Number of comments	Passing time	GQS	JAMA	mDISCERN	VPI
Duration (min)	1								
Number of views	-0.228 (p=0.283)	1							
Number of likes	-0.285 (p=0.177)	0.805* (p<0.001)	1						
Number of comments	-0.127 (p=0.556)	0.571* (p=0.004)	0.840* (p<0.001)	1					
Passing time	-0.479* (p=0.018)	0.392 (p=0.058)	0.110 (p=0.610)	0.052 (p=0.809)	1				
GQS	0.623* (p=0.001)	-0.152 (p=0.478)	-0.178 (p=0.405)	0.0182 (p=0.933)	-0.52* (p=0.009)	1			
JAMA	0.753* (p<0.001)	-0.398 (p=0.054)	-0.4 (p=0.053)	-0.132 (p=0.539)	-0.464* (p=0.023)	0.683* (p<0.001)	1		
mDISCERN	0.506* (p=0.012)	-0.325 (p=0.121)	-0.333 (p=0.112)	-0.164 (p=0.444)	-0.47* (p=0.021)	0.825* (p<0.001)	0.747* (p<0.001)	1	
VPI	-0.309 (p=0.142)	0.681* (p<0.001)	0.456* (p=0.025)	0.0195 (p=0.928)	0.608* (p=0.002)	-0.352 (p=0.095)	-0.472* (p=0.020)	-0.324 (p=0.123)	1

GQS: Global Quality Scale; JAMA: Journal of American Medical Association; mDISCERN: Modified DISCERN; VPI: Video Power Index; * p<0.05.

Video source	GQS				mDISCERN				JAMA			
	High quality		Medium quality		Low quality		Good reliability		Poor reliability		Completely sufficient	
	n	%	n	%	n	%	n	%	n	%	n	%
SLP line percentage (n=13)	7	53.85	5	38.46	1	7.69	11	84.62	2	15.38	7	53.85
Non-SLP health workers line percentage (n=9)	1	11.11	5	55.56	3	33.33	5	55.56	4	44.44	0	0
Other individuals line percentage (n=2)	1	50	0	0	1	50	1	50	1	50	0	0
Line percentage (n=24)	9	37.50	10	41.67	5	20.83	17	20.83	7	29.17	8	33.33
GQS: Global Quality Scale; mDISCERN: Modified DISCERN; JAMA: Journal of American Medical Association; SLP: Speech and language therapists/pathologists; VPI: Video Power Index.												
											9	37.50

YouTube and the number of likes, dislikes, and views are taken into account. The combination of these factors is used to determine how popular the video is.

Statistical analysis

Data were analyzed using IBM SPSS version 22.0 (IBM Corp., Armonk, NY, USA). Global Quality Scale, mDISCERN, JAMA, and VPI scores, time since upload, number of views, number of likes, number of dislikes, and comments were descriptively calculated as mean scores and standard deviation values. The Pearson correlation test was used to determine the relationships between quality, reliability, accuracy, and other video parameters. A *p*-value <0.05 was considered statistically significant.

RESULTS

The mean GQS score was 3.2 ± 0.9 , the mean JAMA score was 2.2 ± 1.6 , the mean VPI score was $3,836.8 \pm 10,421.3$, and the mean mDISCERN score was 3.0 ± 1.1 (Table 1). As the number of dislikes was 0 for all videos, the view rate of the videos equaled the VPI.

There was a negative correlation between the number of days since the video was uploaded and the video length. Global Quality Scale was positively correlated with JAMA score and video duration and negatively correlated with the number of days elapsed. Global Quality Scale, JAMA, and mDISCERN scores were moderately or highly positively correlated with each other ($r=0.683-0.825$). A weakly negative ($r=0.472$, $p=0.020$) statistically significant correlation was observed between JAMA and VPI values (Table 2).

Speech and language therapists/pathologists uploaded 54.17% of the videos, 37.50% were uploaded by non-SLP health workers, and 8.33% by other individuals. When the quality of the videos was evaluated according to the source, 53.85% of the videos uploaded by SLPs were of high quality. Moreover, only the videos uploaded by SLPs were found to be sufficient (53.85%). It was found that 66.57% of the videos uploaded by other healthcare personnel and 66.57% of the videos uploaded by other individuals were insufficient (Table 3).

There was a statistically significant difference in the duration, number of views, number of likes, comments, and JAMA mean scores among video sources (SLP *vs.* non-SLP health workers; $p<0.05$). Although the duration and JAMA mean scores of the videos uploaded by SLPs were statistically significantly higher than the non-SLP health workers group, the number of views, likes, and comments were statistically significantly lower ($p<0.05$). The mean scores of all scales and video

Table 4
Comparison of video characteristics by video source

	SLP	Non-SLP health workers	Other individuals
	Mean±SD	Mean±SD	Mean±SD
Duration* (min)	32.78±22.48	7.04±10.08	4.35±2.57
Number of views*	1,206.85±2,303.67	27,633.33±29,131.04	14,000.00±5,656.85
Number of likes*	16.00±32.49	279.78±277.44	277.50±252.44
Number of comments*	1.15±3.58	22.11±33.43	31.00±18.39
Passing time	3.27±2.47	6.22±4.55	4.50±3.54
GQS	3.54±0.78	2.67±0.87	3.00±1.41
JAMA*	3.15±1.21	1.11±1.05	0.50±0.71
mDISCERN	3.54±0.97	2.56±0.88	2.00±1.41
VPI	169.89±452.23	9,222.76±16,041.65	3,434.96±732.02

SLP: Speech and language therapists/pathologists; SD: Standard deviation; GQS: Global Quality Scale; JAMA: Journal of American Medical Association; mDISCERN: Modified DISCERN; VPI: Video Power Index; * p<0.05.

features according to the source of the videos are shown in Table 4.

DISCUSSION

In this study, videos about dysphagia in individuals with dementia on YouTube were analyzed as an information source. The quality, reliability, popularity, and adequacy of the videos were determined by their general characteristics, such as the duration of viewing and the number of likes. There were 24 videos that met the criteria. This showed that there are few sources of information on dysphagia, which reduces the quality of life and independence of people with dementia and increases the mortality and morbidity rate. The number of videos on YouTube should be increased to inform people with dementia, their caregivers, and their families and to be an easily referenced source of information for other health professionals. Considering the scarcity of studies on dysphagia in dementia, we think that the interest of healthcare professionals, particularly SLPs, neurologists, and otolaryngologists, should be increased, which may increase the number of uploaded videos.

Although there are only 24 videos that meet our criteria in this field, we believe that the number of likes, views, and comments is low. Accordingly, the mean VPI was 3,836.8±10,421.3. This result shows that despite the low number of videos, the public is not paying enough attention to this area. This may be because many dementia caregivers or family members do not know about dysphagia in dementia or focus more on the cognitive or physical problems of the person

with dementia and ignore swallowing disorders. We also believe it might be useful to upload this content as separate videos of 5-10 min at most to make it easier for people to watch and to streamline and increase viewing. Videos that are too long can be boring for these people and can also make it difficult for them to maintain their attention, causing them to miss the message.

In studies on videos on the internet, scales recommended to be used for the evaluation of written scientific materials, such as JAMA and mDISCERN, have been used, and it is recommended to develop appropriate methodology and scales for the evaluation of visual publications such as videos.^[21] Therefore, we used VPI, JAMA, GQS and mDISCERN in our study. The mean scores of GQS, JAMA, and mDISCERN for all videos were found to be 3.2±0.9, 2.2±1.6, and 3.0±1.1, respectively. Furthermore, 41.67% of all videos were of medium quality, 70.83% were reliable, and 33.3% were partially adequate. These results indicate that the overall quality of the videos on dysphagia in individuals with dementia is moderate, most of the videos are reliable, and the adequacy of the information is partially adequate. This may be due to the fact that 54.17% of the videos were uploaded by health personnel or other people other than SLPs since both the quality, reliability, and adequacy of the videos uploaded by SLPs were higher than the others.

While 7.69% of the videos uploaded by SLPs were of low quality, 33.33% of the videos uploaded by other healthcare personnel and 50% of the videos uploaded by other people were of low quality. In YouTube studies, the quality of videos can vary significantly according to their subject matter.^[22,23] There is a study using YouTube

as a source of patient information on dysphagia exercises and compensation maneuvers and a study examining the quality, reliability, and accuracy of videos uploaded to YouTube on dysphagia exercises and management in pediatric populations.^[23] According to the GQS, 9.8% (n=5), 35.3% (n=18), and 54.9% (n=28) of the videos were of low quality, medium quality, and high quality, respectively, and this study found about half of the videos useful.^[23] However, in our study, 37.5% of the videos were of good quality, 41.67% were of moderate quality, and 20.83% were of low quality. The reason why our GQS values were lower compared to this study may be that the knowledge on the cause of dementia, swallowing disorders, and dementia itself belongs to specialized fields, and many people have less knowledge on these subjects. However, the results may change when it comes to more general issues.

In terms of the adequacy of the videos, only 29.17% were found to be fully adequate, according to JAMA scores. Therefore, SLPs and other health professionals should thoroughly review previous literature before creating their videos and base their videos on verified and accurate facts, while non-health professionals should consult with medical professionals who have sufficient knowledge on the subject.

In our study, it was found that there was a negative relationship between popularity and validity, adequacy, and quality; however, there was a statistically significant relationship only between the decrease in popularity level and the level of adequacy. Therefore, patients should not trust YouTube videos unconditionally, and it is important that the information be checked at least once by therapists or physicians. Similar situations have been found in some YouTube studies.^[10,24] This has shown that widely viewed and popular videos do not always reflect the quality, reliability, and adequacy of information. Therefore, it was suggested that it may be better for clinicians to recommend the appropriate video for patients, caregivers, and their families to watch. In addition, in our study, videos uploaded by SLPs were found to have fewer likes, comments, and views compared to other healthcare professionals and other individuals despite being of higher quality, reliable, and sufficient in terms of information compared to other videos. In addition to the similar possible reasons above, one reason for this finding may be that the duration of videos uploaded by SLPs is much longer than those uploaded by other individuals, and people may not want to watch the videos for this reason. However, in our study, it was observed that as the duration of the video increased, its quality, reliability, and competence significantly

increased. This may be related to people's desire to increase the information content they want to convey through their education. Therefore, care should be taken to strike a balance between the duration of the message to be shared to make it clearer, shorter, and more informative.

The main limitation of our study was that the data used in it was obtained over a specific and limited time. As it is known, the data in YouTube videos can change instantly. The assessment of the quality of YouTube videos is subjective and may be different for each study due to the lack of objective criteria. The last limitation is that the keyword search language and video content were in English.

In conclusion, the number of videos on swallowing and swallowing disorders in individuals with dementia on YouTube was very low. In addition, the duration, quality, reliability, and adequacy of videos uploaded by SLPs were higher. However, popularity does not reflect high quality, reliability, and competence. On the contrary, popularity decreased as the quality level increased in this study. Therefore, health professionals working in this field, such as speech-language pathologists, neurologists, and otolaryngologists, should increase the number of informative and guiding videos and ensure that videos that are considered to be accurate are communicated to the patient and the caregiver/relative. This YouTube search conducted on dementia and swallowing disorders emphasizes the need for more research and information sharing. The production and dissemination of more content in this area can provide better support to individuals with dementia and swallowing difficulties.

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

Author Contributions:

Conceptualization, data curation, formal analysis, methodology, writing: M.M.P., C.Y.; Review and editing: M.M.P.

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