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You are the content you consume: Level of informative content of the most commonly viewed dysphagia videos on YouTube

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Abstract

Individuals experiencing dysphagia frequently search for information to discover the cause or best management of their dysphagia from the internet due to delays in in-person service or lack of regional specialists. However, online information is frequently unregulated and could be inaccurate, thus potentially endangering patients. This study aimed to investigate and evaluate the content quality of the top 25 videos related to dysphagia on the video streaming website YouTube (www.YouTube.com). YouTube was searched using the key term 'dysphagia' with the top 25 viewed videos transcribed. The videos were scored using a 10-point scoring system to determine their content quality by awarding points for each domain covered, then categorised as either strong, moderate or poor. The characteristics of each video were recorded and descriptive statistical analysis tests performed. 52% (n= 13) of the videos analysed were scored to have poor content quality, with only 20% of the videos rated as strong quality. The content rated as poor quality had the largest total number of views (2,025,299), suggesting that an individual who searches YouTube using the search term "dysphagia", is likely to view a video of poor content quality. This study highlights that the dysphagia health information most commonly viewed on YouTube, is predominantly of poor content quality. YouTube offers a valuable opportunity for health professionals to share evidence-based, high quality health information on a variety of topics with the public. Hence, the quality of available information should be addressed to mitigate the spread of misinformation.

Introduction

Dysphagia is the medical term that describes difficulty swallowing.[1,2] Swallowing plays an important role in providing adequate nutrition and hydration and enables an individual to enjoy food and drink which can be an integral part of most social occasions and quality of life.[3] Therefore, management should be prompt, and to facilitate patient education and self-management, patients must receive accurate and evidence-based information on their condition.[3] Searching for health information online is one of the first steps for many patients due to barriers to seeking in-person care such as financial or geographical reasons.[4] Unlike in-person care, information online is freely accessible from anywhere at any time. It is therefore understandable why patients turn to the internet for health information. Those experiencing dysphagia may also search for information from the internet, especially as dysphagia is typically considered to be a secondary symptom of many varied conditions such as neurological disorders, cancer, and infection, as opposed to a condition in its own right, thus making it difficult for the patient to know which healthcare professional to seek in-person care from specifically. YouTube is a free video-sharing website with more than 100 million videos watched every day, making it the second most popular website globally.[5] Although there are over 70,000 websites which circulate health information, YouTube is a popular website for this purpose and YouTube videos tend to fall high on the Google search list, increasing the chances of clicking into YouTube videos rather than those from another website.[6,7]

Unfortunately, the quality of health information available online varies greatly.[8,9] It can be difficult for patients to distinguish what information is from a reliable, evidence-based source and what information is uninformative, misleading, or even possibly harmful. Furthermore, anyone can create a YouTube account, leading to the potential for those who are not medically qualified to post healthcare information. As such, this may promote unscientific treatments which can prey on patient vulnerabilities.[10] Accurate health information that is accessible would aid the healthcare system in disseminating reliable information to help patients self-manage their health conditions. This is particularly important in conditions like dysphagia which has been associated with increased length of stay in hospital, an increased chance of readmission and increased costs to health care.[11] Almost half of those searching for health information online reported that their findings influenced treatment decisions.[12] As such, internet information may affect a person's decision on whether they decide to visit a doctor or not, and this can have possible negative impacts such as a delay in diagnosis or beginning the treatment process. Therefore, health professionals must be aware of the information available online. The importance of valid and reliable online health information has been highlighted recently during the coronavirus disease 2019 (COVID-19) pandemic. Recently, public health organizations and technology companies have taken efforts to mitigate the spread of misinformation; for example, Google's SOS alert intervention prioritizes the World Health Organization and other trusted sources at the top of search results.[13,14] However, despite this, a recent study reported that more than a quarter of the most viewed YouTube videos on the topic of COVID-19 still contained misleading information.[15] As patients are now often turning to the internet for health information, especially since the pandemic, it is important to investigate what quality of information is available online. Although there have been studies addressing the quality of health information on YouTube for different conditions, there has been no published research on dysphagia information available on YouTube. Hence, this study aimed to appraise the level of informative content in the 25 most viewed dysphagia videos on YouTube.

Method

Ethical approval was not required for this cross-sectional study study as data collected was freely available on the internet. Information was gathered from www.YouTube.com using the search term "dysphagia" and the filter feature to select the 25 videos with the highest views. The search term "dysphagia" was chosen here as on google searching "swallowing difficulties", results returned all relate to the term "dysphagia", and information seekers are directed towards resources using the term "dysphagia".

DESCRIPTIVE INFORMATION REGARDING EACH VIDEO

Each video's name, uniform resource locator (URL), run time, views, likes, dislikes, and date uploaded were recorded. Next, the top five comments for each of the 25 most viewed videos were recorded. Subsequently, videos were viewed, transcribed, and coded for content information. The presentation quality was scored using a one to three point system adapted from Meade et al.[9] Video quality was rated as 3 (good) if the video had clear visuals and text with some professional graphics or effects, 2 (fair) for regular video quality and average text clarity home videos, or 1 (poor) if the visuals were difficult to understand or blurry. Audio quality was rated as 3 (good) if there was no difficulty understanding spoken words or music, 2 (fair) if the speech was difficult to understand or the video had distracting audio or background sounds, or 1 (poor) if the video had unclear audio or no audio.[18] The Viewing Rating was calculated by dividing the number of views by the number of days since upload and multiplied by 100. Rating views of videos which scored in the strong, moderate and poor quality of content categories were compared to investigate if there was a significant difference. Finally, the top five comments were analysed qualitatively.

ANALYSIS OF VIDEO SOURCES

Videos were categorised by determining who created the video and for what purpose. The following categories were used: education, personal experience, commercial/corporate, and professional/clinical).

CRITICAL APPRAISAL OF INFORMATIVE CONTENT ACCURACY

This was coded and scored using a scoring system developed based on a dysphagia fact sheet and adapted from Meade et al.[9,17] A random selection of 10% of videos were re-coded by a second researcher, with results cross checked to ensure accuracy. No disagreements in coding occurred, but a third researcher was available to mediate disputes if required. Videos were scored based on the level of informative content of each video, which was determined by how many domains were included in its video. The informative content domains considered were: modified diet, exercise, surgery, tube feeding, oral care, role of the speech and language therapist, X-ray/video fluoroscopy, and selling a product. 0-3 factors present meant no/inadequate information (poor level of informative content), 4-7 factors meant adequate information (moderate level of informative content), and 8-10 factors meant excellent and comprehensive level of information (strong level of informative content). Each video could receive a maximum of ten points.

Results

DESCRIPTIVE INFORMATION REGARDING EACH VIDEO: PRESENTATION QUALITY

The visual quality of 52% (n=13) of videos were rated as good, with 40% (n=10) fair visual quality, and 8% (n=2) poor visual quality. 48% (n=12) of the videos were rated to have good audio quality, 36% (n=9) fair audio quality, and 16% (n=4) poor audio quality.

DESCRIPTIVE INFORMATION REGARDING EACH VIDEO: FEEDBACK FROM USERS

There were 22 videos which had comments posted by viewers. Of these, 82% (n=18) received a positive response and no negative com-

Table 1: Feedback from users

Feedback From Users	Education (n=14)	Professional (n=3)	Personal experience (n=3)	Commercial (n=2)	Total (n=22)
Positive response	11 (79%)	3 (100%)	2 (67%)	2(100%)	(18 (82%)
Negative response	1 (7%)	0 (0%)	0 (0%)	0 (0%)	1 (5%)
Relates personal experience to video.	11 (79%)	3 (100%)	3 (100%)	2 (100%)	19 (86%)
Asks for advice	8 (57%)	2 (67%)	0 (0%)	1 (50%)	11 (50%)
Question's over the accuracy of the video's content	5 (36%)	1 (33%)	1 (33%)	1 (50%)	8 (36%)
Mean number of views	101714	85644	310863	61658	140216
Mean number of likes	377	279	1115	240	503
Mean number of dislikes	27	17	87	18	37

Table 2: The number of videos for each domain by source category

Domains	Education n=16 (64%)	Professional /Clinical n=4 (16%)	Personal Experience n=3 (12%)	Commercial /Corporate n=2 (8%)	Total n=25 (100%)
Anatomy and physiology of the swallowing process	11 (69%)	3 (75%)	0 (0%)	1 (50%)	15 (60%)
What dysphagia is	10(63%)	2 (50%)	0 (0%)	2 (100%)	14 (56%)
Prevalence	5 (31%)	2 (50%)	1 (33%)	1 (50%)	9 (36%)
Causes of dysphagia	8 (50%)	2 (50%)	1 (33%)	1 (50%)	12 (48%)
Conditions typically associated with dysphagia	7 (44%)	2 (50%)	1 (33%)	1 (50%)	11 (44%)
Potential secondary health complications of dysphagia	7 (44%)	3 (75%)	1 (33%)	1 (50%)	12 (48%)
Potential secondary quality of life complications of dysphagia	0 (0%)	1 (25%)	1 (33%)	0 (0%)	2 (8%)
Where a person can seek treatment for dysphagia	4 (25%)	1 (25%)	2 (66%)	1 (50%)	8 (32%)
The typical assessment process	5 (31%)	2 (50%)	0 (0%)	0 (0%)	9 (36%)
The typical treatment process	9 (56%)	3 (75%)	1 (33%)	2 (100%)	15 (60%)

Table 3: Additional video content by source category

Content category	Education n (%)	Professional n (%)	Personal experience n (%)	Commercial n (%)	Total n (%)
Mentions modified diet	5 (31)	2 (50)	1 (33)	2 (100)	10 (40)
Mentions exercise	6 (38)	1 (25)	2 (66)	0 (0)	9 (36)
Mentions surgery	1 (6)	1 (25)	1 (33)	0 (0)	3 (12)
Mentions tube feeding	4 (16)	2 (50)	2 (66)	0 (0)	8 (32)
Selling a product	0 (0)	1 (25)	0 (0)	2 (100)	3 (12)
Mentions oral care	2 (13)	1 (25)	0 (0)	0 (0)	3 (12)
Mentions role of speech and language therapist	2 (13)	1 (25)	1 (33)	0 (0)	4 (16)
Mentions X-ray/ video fluoroscopy	8 (50)	3 (75)	0 (0)	0 (0)	11 (44)

Table 4: Descriptive information regarding included videos

Content creator	Number of videos (n)	Mean length (mins)	Median length (mins)	Range of length (mins)	Total (mins)
Educational/University	16	7.90	7.00	1.02-32.56	126.55
Clinical	4	15.37	10.89	3.45-47.1	61.50
Personal Experience/Lay person	3	6.51	2.30	2.14-15.01	19.54
Corporate	2	6.14	6.14	3.16-9.12	12.28

ments were found on any of the videos. Commenters discussed their personal dysphagia experiences on 86% of occasions. Half of the videos had people asking for advice. There were comments regarding the accuracy of the content in the video for 36% of the videos (Table 1).

DESCRIPTIVE INFORMATION REGARDING EACH VIDEO – ANALYSIS OF VIDEO TOPICS

Table 2 describes the breadth of information covered within included videos. Table 3 displays the additional content found in the videos with respect to their source categories.

LEVELS OF INFORMATIVE CONTENT

Overall, 52% of videos scored within the poor informative content range, 28% in the moderate content range, and 20% in the strong content range. More than half (53%) of educational videos had a poor level of informative content. Half of professional videos were scored as poor content with the other half were scored as strong content. No personal experience videos had strong informative content, with 67% of the videos having poor informative content and 33% having moderate content scoring. Of the two commercial videos, one was given a poor content scoring and the other given a moderate content scoring (Table 4).

The poor content quality range had the highest mean viewing rating of 6.8, followed by the strong content quality range with 4.8 and then by the moderate content quality range with 4.6.

Discussion

This study investigated the level of informative content of videos relating to dysphagia on YouTube. The findings suggested that an individual who searches YouTube using the term "dysphagia" is likely to access variable informative content. These results build on the existing evidence of previous studies that address the poor content of health information on YouTube.[9,19] The content quality range of poorly scored videos had the highest viewing rating mean of 6.8. This suggests that dysphagia information being consumed by the public is of variable informative content. This is supported by previous studies that have found that the quality of information within YouTube health videos is largely deficient in credibility.[9] Although this study was small in scale and narrow in focus (i.e. investigating only the term "dysphagia"), preliminary findings here may indicate the need for more rigorous content control checks on uploaded YouTube videos which aim to educate or advise on health matters. This is especially important in the provision of health information, given the potentially vulnerable nature of information-seeking patients who may not necessarily have high levels of health literacy.

Dysphagia impacts an individual's ability to enjoy food and drink which can be an integral part of most social occasions. Thus, the psychological impact of dysphagia should be acknowledged. The comments section of analysed videos provided a medium where viewers discussed their own personal experience with dysphagia and how dysphagia negatively impacted their quality of life. It was found through analysing the comments that 86% of the videos had commenters discussing their own personal experience of dysphagia and 50% of videos had commenters looking for advice on their condition. This indicates that individuals may be using YouTube as a platform to seek and ask for advice on their own condition, as suggested in previous research into the use of social media as a support system for those living with chronic health conditions.[9] For 36% of the videos, commenters raised questions over the accuracy of the content of the video in question. This indicates that the information being presented may not be clear and well explained. It is long known that health literacy levels among patients are often overestimated by health professionals, leading to a mismatch in information provided and information understood, which can often erode the quality of health professional-patient relationships. This can lead to the patient seeking further accessible information on internet sites such as YouTube, which may be particularly concerning with respect to the group in question here. For example, due to the underlying aetiology of dysphagia often being neurological, communication deficits such as aphasia may be more likely to co-exist. This can lead to difficulties in accessing, understanding, and critiquing health information. As such, while the information that they access via YouTube may in fact be more accessible than that provided via traditional medical consultations, these patients may not be able to critique the information as required, leading to them engaging with potentially inaccurate and/or unsafe medical practice, with possible negative implications for patient wellbeing and outcomes

Finally, the top 25 viewed videos on YouTube under the search term "dysphagia" were posted between the years 2010–2018 with the mean year of videos posted being in the year 2012. Speech and language therapy is a relatively new profession, with evidence-based medicine only becoming commonplace in recent years, and funding for large scale, replicable, studies remaining rare. Therefore, there is a lack of investment in continuous rigorous research in this area. In addition to these issues, there is also an ever-shortening accepted

knowledge cycle and an advent of open science which has brought rapid scientific advances in all areas of medicine. This suggests that the information that people with dysphagia are freely accessing may not only be inaccurate, but where it is accurate, may be outdated. This puts this cohort further at risk of potential harm from internet information, highlighting their unique vulnerabilities as compared to previously studied cohorts.

Further research is required to determine how evidence-based health information can be delivered successfully to individuals on online platforms in an accessible manner. It is recommended that policies are introduced to protect those searching for health information online from accessing harmful and poor content quality videos. Putting in place a verification system for video uploaders may help to ensure better quality content is available to allow viewers. Issues relating to the reliability and quality of online health information have recently attracted more attention due to the recent COVID-19 pandemic. Professional and government bodies worked to mitigate the spread of false health information online regarding COVID-19. A similar approach should be taken towards all health-based information available online. This would have the result of improving the overall outcomes for patients with dysphagia.[20]

Limitations

A limitation of this study is that the videos were scored based on whether they mentioned a certain amount of specific information. This was because a standardised, validated scoring system for videos containing health information does not currently exist and the author was required to devise one from existing literature. There are therefore potential limitations in this non-standardised scoring system which must be acknowledged. For example, a video may provide in-depth and accurate information on one specific topic but score poorly as it did not mention a range of topics. In addition, the term dysphagia may not be familiar to lay people and therefore patients may be using different search terms. Additionally, potentially informative videos could have been missed by the author and searching other key terms such as "swallowing problems" would have widened the search. However, this was not possible with the timing or funding constraints of this study.

Conclusion

This study has highlighted that YouTube videos sharing dysphagia health guidance often provide variable information. Therefore, patients may potentially view suboptimal health information and make decisions about their health based on this information. It is important that health professionals are aware of misinformation being accessed by patients to ensure that they can address and correct any false health information received. Providing adequate education is essential for health professionals to support patients to understand the management plans. Patients should be directed to credible sources to access additional health information by health professionals. YouTube offers a valuable opportunity for health professionals to share evidence-based, high quality health information on a variety of topics to the public. Videos can act as a practical tool that can support patients by modelling dysphagia compensatory strategies, while also promoting adherence to rehabilitation. Accurate and informative dysphagia videos can also assist other health professionals in improving their overall understanding and knowledge of dysphagia. As a result, this opportunity should be taken to help mitigate the spread of misinformation and improve the knowledge of all individuals about dysphagia.

References

1. Namasivayam AM, Steele CM. Malnutrition and dysphagia in long-term care: a systematic review. J Nutr Gerontol Geriatr. 2015 Jan 2;34(1):1-21.

2. Ghannouchi I, Speyer R, Doma K, Cordier R, Verin E. Swallowing function and chronic respiratory diseases: systematic review. Respir Med. 2016 Aug 1;117:54-64.

3. Karkos PD, Papouliakos S, Karkos CD, Theochari EG. Current evaluation of the dysphagic patient. Hippokratia. 2009 Jul;13(3):141.

4. Taber JM, Leyva B, Persoskie A. Why do people avoid medical care? A qualitative study using national data. J Gen Intern Med. 2015 Mar;30(3):290-7.

5. Cheng X, Dale C, Liu J. Statistics and social network of YouTube videos. In 2008 16th International Workshop on Quality of Service 2008 Jun 2 (pp. 229-238). IEEE.

6. Alexa Youtube.com Traffic Statistics. 2020. Available from: https://www.alexa.com/siteinfo/youtube.com. Accessed 12 November 2021.

7. Kim J. The institutionalization of YouTube: From user-generated content to professionally generated content. Media, Cult Soc. 2012 Jan;34(1):53-67.

8. Huang QR. Creating informed consumers and achieving shared decision making. Aust Fam Physician. 2003 May;32(5).

9. Meade MJ, Sooriakumaran P, Dreyer CW. Orthodontic retention and retainers: Quality of information provided by dental professionals on YouTube. Am J Orthod Dentofacial Orthop. 2020 Aug 1;158(2):229-36.

10. Tonsaker T, Bartlett G, Trpkov C. Health information on the Internet: gold mine or minefield?. Can Fam Physician. 2014 May 1;60(5):407-8.

11. Attrill S, White S, Murray J, Hammond S, Doeltgen S. Impact of oropharyngeal dysphagia on healthcare cost and length of stay in hospital: a systematic review. BMC Health Serv Res. 2018 Dec;18(1):1-8.

12. Pew Internet and American Life Project. The online health care revolution: How the Web helps Americans take better care of themselves. 2020. Available: http://www.pewinternet.org. Accessed 12 March 2020.

13. Budd J, Miller BS, Manning EM, Lampos V, Zhuang M, Edelstein M, Rees G, Emery VC, Stevens MM, Keegan N, Short MJ. Digital technologies in the public-health response to COVID-19. Nat Med. 2020 Aug;26(8):1183-92.

14. Limaye RJ, Sauer M, Ali J, Bernstein J, Wahl B, Barnhill A, Labrique A. Building trust while influencing

online COVID-19 content in the social media world. Lancet Digit Health. 2020 Jun 1;2(6):e277-8

15. Li HO, Bailey A, Huynh D, Chan J. YouTube as a source of information on COVID-19: a pandemic of misinformation? BMJ Glob Health. 2020 May; 5 (5): e002604. doi: 10.1136/bmjgh-2020-002604.

16. Stemler S. An overview of content analysis. Practical assessment, research, and evaluation. 2000;7(1):17. NIDCD (2010) Fact Sheet Voice, Speech, and Language Dysphagia. Available from: https://www.nidcd.nih.gov/sites/default/files/Documents/health/voice/NIDCD-Dysphagia.pdf. Accessed 12 August 2020.

17. Sorensen JA, Pusz MD, Brietzke SE. YouTube as an information source for pediatric adenotonsillectomy and ear tube surgery. Int J Pediatr Otorhinolaryngol. 2014 Jan 1;78(1):65-70.

18. Basch CH, Yin J, Walker ND, De Leon AJ, Fung IH. TMJ online: Investigating temporomandibular disorders as "TMJ" on YouTube. J Oral Rehabil. 2018 Jan;45(1):34-40.

19. Ilott I, Bennett B, Gerrish K, Pownall S, Jones A, Garth A. Evaluating a novel approach to enhancing dysphagia management: workplace-based, blended e-learning. Jf Clin Nurs. 2014 May;23(9-10):1354-64.

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